

# *How to involve the public as co-interviewers in research*



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## Introduction

This paper aims to help people decide whether a research study should engage people with lived experience as peer co-interviewers and suggests how this might be done.

The use of language is always problematic. In this guide, the term ‘peer’ is used where others might say patient, client, carer, expert by experience, service user or lay person. ‘Peer interviewers’ are

contrasted with ‘academic interviewers’ as a way of recognising the expertise that comes from lived experience alongside the expertise that comes from scientific training in research methods. But these very terms erroneously imply that there are no scientific traditions of emancipatory research, participatory action research, autoethnography and a host of other scientific endeavours that place life experience at the heart of epistemology and shift the locus of control away from a traditional academic perspective<sup>1</sup>. They also mistakenly suggest that peer interviewers have no academic experience and academics have no personal, lived experience of the health condition or social circumstance under examination.

For some academics<sup>2</sup>, these discussions have led to them blurring the boundaries between the academic researcher and the researched, creating the possibility that the people who are the focus of research may under certain circumstances, themselves become the researcher or co-researcher and even conduct interviews. But it is not this spectrum that concerns us in this paper, but rather the situation where a peer with lived experience works alongside an academic to conduct a data collection interview. So we are concerned with an interview that involves three people, not two.

While peer co-interviewing is the focus of this paper, it is only one component part of a comprehensive approach to the coproduction of health research. Peer interviewing properly sits alongside peer data transcription, analysis and interpretation, and all the other stages in the research journey. The more popular term is ‘peer researcher’, but this paper is restricted in its scope and focuses exclusively on the interview component, despite the fact that it would be tokenistic to share this role without travelling together on the journey of research production both before and after the interview itself.

Some of the other steps on the journey are discussed in a suite of other companion ‘[How To](#)’ guides, one of which is called [How to co-facilitate a focus group](#). As some of the issues involved in co-facilitating focus groups are similar to those involved in peer interviewing, readers interested in either topic should review both these guides. Some of the guides were written by Peter Bates on behalf of the [East Midlands Academic Health Science Network](#) as part of its work on Public Leadership. Additional material has been provided via email<sup>3</sup> and from relevant literature<sup>4</sup>. As readers provide feedback to [peter.bates96@gmail.com](mailto:peter.bates96@gmail.com), further insights will be used to update the paper. Please also let me know if you have made use of this document.

## Competing demands

Peer interviewers occupy a contested area with powerful forces ranged around it. A vigorous lobby of Patient and Public Involvement champions demand that research is coproduced and funds should be withheld from research teams who are lukewarm on this issue<sup>5</sup>. The radical wing remains dissatisfied with anything less than control of the whole process, from selecting the research topic to delivering the outcome. Meanwhile, research ethicists insist that anyone who gets into contact with research participants should be fully qualified to do so; protocols should be approved and rigorously adhered to; and sanctions must be robust to guard against breaches and abuse. Safeguarding sentinels keep watch to ensure that trustworthy provision is made for vulnerable people. Unfortunately, while there is literature that examines the power dynamics of sharing control of the

research process with participants<sup>6</sup>, academic analyses of the triangular relationship between academic researcher, peer researcher and respondent are hard to find.

The agenda of campaigners is no less complex. Some want to prove that peer researchers are equally adept at conducting interviews, and so are pleased to see evidence that shows no differences between the data elicited via their interviews in comparison to the data collected by their academic colleagues. Others hope to see evidence that peers can draw out more personal disclosures or greater significance from their interviews, and so demonstrate an advantage for peer interviewers. Both may be right!

One response is to seek out people who have 'dual qualifications' – professional researchers who happen to live with the health issue that is the focus of the research<sup>7</sup> and so are experts by experience as well as experts by training. It is certainly important that barriers to training are lowered and the current under-representation of disabled people amongst the research workforce is addressed<sup>8</sup>. Some of the issues linked with this career pathway are set out in a companion paper [How to take your lived experience to work](#). In the particular setting of research, the dually qualified researcher must consider how their lived experience influences their research decisions (keeping in mind that complete objectivity is elusive), and vice versa, how their research work may influence their health and wellbeing<sup>9</sup>.

However, this paper is in search of a complementary approach, one that allows experts by experience to add value to the research interview even when they are not academically qualified as researchers. In doing so, it positions lived experience as a valued component alongside academic expertise, releases the expert by experience from the unrealistic requirement of aping the academic, opens the door to involve people with significant impairments, and suggests appropriate safeguards. In so doing, it expressly challenges the expectation from some gatekeepers that peer researchers must undergo vast amounts of training and take on long-term formal appointments with the university before they may be involved in any way. This is not in any way to 'dumb down' the level of expertise needed in robust research processes, but to recognise that academic researchers and peer researchers bring different gifts and contributions to the endeavour.

### **Some of the benefits of involving peer co-interviewers**

In their work on engaging co-interviewers with dementia, Linda Birt and her colleagues<sup>10</sup> summarised the benefits shown in the table below.

<b>Co-researchers</b> <ul style="list-style-type: none"> <li>• Owning research</li> <li>• Contributing to change</li> <li>• Challenging views</li> <li>• Reduced stigma</li> <li>• Reduced isolation</li> </ul>	<b>Academic researchers</b> <ul style="list-style-type: none"> <li>• Improved understanding what it is like to live with the condition</li> <li>• Reduced wariness</li> </ul>
<b>Participants with lived experience<sup>11</sup></b> <ul style="list-style-type: none"> <li>• Feeling more comfortable during data collection</li> <li>• Feeling understood</li> <li>• Reduced stigma</li> </ul>	<b>Research project</b> <ul style="list-style-type: none"> <li>• Improved recruitment</li> <li>• Enriched research</li> <li>• New ways of knowing</li> <li>• Relevance to people living with the condition</li> </ul>

Peer researchers may facilitate privileged access to specific communities that may be less likely to accept an academic researcher<sup>12</sup>, as well as raising the status of peer researchers in their community and deepening the bond between the academic and the peer co-interviewer, which could all strengthen the peer’s contribution to other parts of the study<sup>13</sup>.

Where the only way to gain access to a specific community is to engage peer interviewers, as was the case in Elliott et al’s study of illegal drug users, a judgement has to be made about whether the best option is for the peer researcher to work alone, or to hope that the peer will be accepted as a patron to the academic researcher, thus enabling the kind of two-on-one interview that is the focus of this paper, or even that the peer is relegated to the role of a recruiter who vouches for the academic researcher and then falls away, leaving the academic conducting a one-on-one interview with the participant. Elliott’s academic team found that, where they had delegated the entire interview to the peer interviewer and not attended it themselves, they felt remote and unhelpfully distanced from the participants in contrast to their experience of traditional qualitative research. This problem is, of course, solved by the academic and peer both attending the interview and conducting it together.

A further potential benefit of this arrangement is borrowed from a study<sup>14</sup> of co-trainers working in a Recovery College<sup>15</sup> where classes are delivered by a peer trainer and a ‘practitioner trainer’ working together. The researchers interviewed eight practitioner trainers who were all professionally qualified in either social work, psychology, psychiatry, occupational therapy or psychiatric nursing. Respondents reported that the experience had the potential to be transformative, by which they meant that it:

*“...led practitioner trainers to reassess their expert role and power relations with service users with the potential to alter their approach to service users..”<sup>16</sup>*

Analysis of the interviews revealed three conditions which together created an environment where this experience might fulfil its promise of transformation. First, the collaboration included structured demands – to plan and deliver the session, to hear and process feedback and evaluate their success in relation to delivery and collaboration. Second, the working partnership sometimes grew into a

personal, dynamic relationship where honesty eclipsed formal politeness and professional distance was transcended. Third, transformative relationships acknowledged the uncomfortable aspects of the relationship, such as the inequalities of status and financial remuneration between the practitioner and the peer, while welcoming challenges from one another and also from students in the class. These challenges may occur when group members addressed questions to the practitioner rather than the peer, or when the example of equal working between them was set in contrast to unequal power relationships in other clinical settings. Separate research<sup>17</sup> has found that peer trainers benefit from the partnership too, particularly gaining in self-esteem.

While there is no formal evidence which confirms that these findings apply beyond the Recovery College to 2:1 settings such as interviews or focus groups and other settings, or to dyads made up of a peer and a researcher rather than a peer and a mental health professional, it seems entirely possible that they carry a similar potential for transformation.

### **The interview as dialogue**

Some commentators<sup>18</sup> are conscious of a perceived power held by researchers over those they interview that is manifested when the researcher adopts a highly structured format for the interview, 'keeps their distance' from the respondent by disclosing nothing of themselves, asking all the questions, blocking any questions asked by the respondent, and hiding any information they may have gleaned previously, so that all interviewees receive the same managed experience. In contrast, other researchers aim to make the research interview more like an ordinary conversation between equals in which both parties can ask questions, impart information, offer help and advice, and learn from the other person. The moment when the interviewer becomes aware that they hold information that may benefit the respondent may divide the academic and peer interviewers, if the academic researcher prioritises the purity of the knowledge production and refuses to share the information until after the data collecting is over, perhaps after the final interview is complete, while the peer interviewer may wish to impart the knowledge immediately. Such issues need to be discussed prior to beginning any interviews and built into the research protocol from the outset. Peers can be involved in both structured and unstructured forms, although there are perhaps more opportunities for peers to participate in the more emancipatory, naturalistic approaches.

This distinction between the 'friendly interrogation' of structured or semi-structured interviews on the one hand and the informal dialogue of an unstructured interview on the other does not simply define the category of interview at the outset. Instead, these roles ebb and flow throughout the process, as some topics yield no more than answers to the question that is posed, while others trigger a dialogue in which the interviewee asks the interviewer about their experience or the peer interviewer feels compelled to share a snippet of their own story<sup>19</sup>. For the peer, there is always the danger that telling one's own story, however briefly, shifts the focus from the respondent to the peer and delegitimises the respondent's experiences.

## What is the topic of inquiry?

If the interviewee's story<sup>20</sup> involves vulnerability or shame, or their reputation with other people may be spoilt if it becomes known, then it is quite reasonable for them to be reluctant to entrust these details with anyone at all, and especially with people who they fear may not be entirely trustworthy with such confidences. Both the academic interviewer and the peer interviewer may carry beliefs about the trustworthiness of their own tribe and the reputation for untrustworthiness of the other tribe, and neither of these viewpoints may be held by the respondent, so it is important to explore these matters.

Similar tensions arise when the interviewee or the community they represent is dependent on resources being provided by others. In this situation, people are very unlikely to report negative experiences for fear that their criticism will reach gatekeepers and lead to the withdrawal of support for themselves or their community. If the peer interviewer shares a similar life event, their confident disclosure may create a bond or alternatively cause the interviewee to withdraw for fear that they will lose control of their story.

Similarly, if the person fears that personal information will be used to bribe or threaten them ('if you cooperate, you can have your favourite food'), then they will be reluctant to tell a researcher or anyone else what is important to them.

If the respondent is living in a care setting, the relationship that they have with the healthcare professionals around them will shape their perception of researchers. For example, disclosing information about emotions can be especially difficult where care staff are eager to get to know the people in their care. On the one hand, admitting the existence of negative emotions, such as anger or the wish for revenge, can raise the level of anxiety amongst some care staff, while denying the existence of negative emotions is sometimes read by care staff as a refusal to engage in therapeutic dialogue. While, in theory, the researcher stands apart from these complexities and can establish a clean and new relationship with the care recipient they wish to interview, it is likely that these issues bleed through from one context to another and the independent researcher may well be viewed as just another member of the care team. This presses us to obtain a clear and shared understanding of what will be shared with whom as this will reduce these fears and concerns.

Ideally, service providers will be unaware of who is or is not interviewed for the research so that there is no way in which the interviewee's disclosures to the researchers can affect the service they receive. If this is impossible, other mechanisms will be put in place to ensure that service providers do not have access to the information disclosed during the interview. All these issues should be explored through a prior ethical approval process.

It is into this mix of sensitivities and considerations that the research team must make a decision about who would be best equipped to undertake data collection. The personnel involved, whether staff, peers or a mix, must be driven by the priorities of the research rather than any dogma.

## The peer as question designer

Before the interview itself, the peer could be involved in generating ideas for the pre-prepared interview questions. There is some evidence that this leads to questions being formed in a different way which can change the answers that are elicited, particularly in relation to satisfaction with the service that the person has received<sup>21</sup>, while another study<sup>22</sup> found no significant difference between the information elicited by service user researchers and academic researchers. Topics that are important but have been overlooked by the academic researcher may be added by the peer thus enriching the topic guide, such as emotional responses, quality of life issues and mundane factors<sup>23</sup>.

Potential interview questions could be checked and approved by the academic researcher to ensure that they remain academically and ethically robust (i.e. generate data that can be analysed and avoid bias). One might reduce the power imbalance by allowing the academic researcher power of veto for ethical or methodological reasons, and the peer power of veto for 'service user' reasons. These might include issues based on the user's expertise in discerning whether materials are clearly expressed, harmful, respectful, user-friendly, of value to patients and have the potential to link with community networks and organisations. Of course, the very notion of 'veto' suggests power relationships, while research teams that adopt a coproduction approach will be seeking consensus and equality. We should remember that inequality is often invisible to the conventionally powerful so it is the comparatively powerless who should be asked whether equality has been achieved.

## Managing risk and meeting safeguarding obligations

As soon as the peer enters a face-to-face encounter with people using services, there are potential safeguarding concerns, and the organisation has an obligation to assess and manage risk. If the person is not offered a contract of employment, this can be addressed by registering people on a volunteering database and carrying out a risk assessment and setting in place proportionate selection, training and supervision arrangements<sup>24</sup>. The interview setting may expect all researchers to carry a research passport<sup>25</sup> or a letter of access and perhaps other identification, and sufficient time and tenacity will need to be allocated in advance of the planned interviews in order to acquire these necessary badges of office<sup>26</sup>. Some or all of the following may need to be submitted during the application process for these documents:

- A curriculum vitae
- References
- Occupational health screening certificate
- Good Clinical Practice certificate
- A [Disclosure and Barring Service](#) certificate showing any criminal convictions. Risks should be assessed in the context of the specific activity that is proposed, with mitigating factors set in place where possible, such as avoiding lone working or conducting the interview online or by telephone rather than face to face. If the research topic is connected with experience of the

criminal justice system, it may be a real asset to the interview process to include an interviewer with relevant personal experience.

It is worth noting in passing that these requirements may lead to a situation where peer interviewers require the patronage of an academic colleague (perhaps even a senior academic) to satisfy the requirements of the Research Ethics Committee and the Research and Innovation Department at the sponsoring NHS Trust. For those who aim for 'user-led' research, this is an unacceptably subordinate role which perpetuates and even reinvigorates the unequal relationship between the academic and the peer. Secondly here, the peer interviewer may stumble because they are less experienced in conducting interviews than their academic colleague, and this can affect outcomes and attitudes towards the peer, especially if the problem is attributed to their status as a peer, rather than their inexperience or inadequate provision of training. In one study<sup>27</sup>, the fact that the peer interviewer would always have the academic co-interviewer present when meeting participants was taken as sufficient protection, so the engagement of peer reviewers required no additional ethical approval.

In addition to establishing prior permission to conduct the interview, peer interviewers and their academic counterparts need to consider the risks that may be involved in each specific interview and plan how to respond, such as by cutting short the interview and leaving in order to maintain their own personal safety.

Staff in some environments (secure mental health care settings for example) have the potential to exercise considerable power over the people who use them and can withhold valuable treatment, restrict quality of life or create discomfort in relationships between the person using the service and care staff or other residents. In these settings, the stakes are high and disclosure can feel more hazardous for the person who is comparatively powerless. This may be ameliorated during the consent process by being very clear with both patients and staff about what information the researchers would share with the clinical team and what would be held back. Where a peer researcher is involved, it is important to be clear what their duties are in respect of confidentiality and how this is upheld, especially where there are differences in the sanctions available to manage the conduct of the academic and peer researcher. Confidentiality is always a bounded right, and so all participants need to clarify and agree on the limits to confidentiality and what to do in the event that a risk of harm is detected. That all being said, it may be that the peer researcher has a highly sensitised approach to confidentiality, having been on the receiving end of these processes themselves.

These issues will be all the more acute when a matter comes to light that could trigger feelings of disgust, anger or pity in the peer. In these events, the peer may be sorely tempted to breach confidentiality and may find holding the confidence a painful process, especially if the respondent's disclosure presses on distress in the peer's own life. Support for the peer is crucial in these times<sup>28</sup>. However, we should not assume that professional training insulates professionals from these negative emotions, or that people with lived experience do not demonstrate the highest qualities of understanding, forgiveness and compassion for the frailties of life. There is no doubt that conducting interviews involves substantial emotional labour, whether it engages the interviewer's compassion or more challenging emotions, and so effective support is necessary to minimise emotional harm to



both academic and peer reviewers<sup>29</sup>. Moreover, the most intense emotional response may arise afterwards, rather than in the interview itself<sup>30</sup>.

Traditional person specifications list skills, experience and attitudes under the two headings 'essential' and 'desirable'. A similar approach may help to summarise how each of the issues above is resolved for the peer researcher and working through these matters will help to clarify the role that is expected for each individual piece of research.

Peers who engage in the role of research interviewers will need an understanding of informed consent as well as other elements of the research process. On occasion, they may be required to 'take consent' by satisfying themselves that an interview respondent understands the purpose and process of the research, and is willing to take part, free of any duress or coercion. Research teams that plan to involve peers in taking consent will need to consider the following:

- How the peer will be trained in taking consent. Much of the necessary material is covered in the Good Clinical Practice training.
- The practical arrangements for the interview, and particularly whether the interview is 1:1 or includes an academic and a peer working together to interview the respondent.
- Mechanisms for assuring the quality of the informed consent process, such as listening to an audio recording soon afterwards.
- The time interval between seeking consent and conducting the interview itself, as a gap enables people to actively opt in, while taking consent at the beginning of a dual-purpose meeting can make it difficult to opt out.
- The wording of the consent statement, as people should know if there is a possibility that they may be interviewed by a peer<sup>31</sup>.

## From one interviewer to two

The discussion outlined below adopts a model in which the expert by experience is a co-interviewer, attending the interview alongside the academic researcher. We shall return to an alternative model later, in which the peer researcher is carrying out one-to-one interviews while the academic researcher is elsewhere.

Moving from one interviewer to two interviewers (the researcher and the peer) or even more<sup>32</sup>, can be expected to change what is revealed by the interviewee. The larger 'audience' may increase the person's willingness to speak or inhibit it, as some people prefer to confide in another person when their conversation is private rather than overheard by others. But then, two people may observe and remember a larger total of the person's verbal and non-verbal communication than would be captured by just one person. This is particularly valuable when participants are willing to be interviewed but refuse permission for recording devices to be used<sup>33</sup>, so two interviewers will remember more than one.

The literature reports that the presence of the peer usually facilitates openness on the part of the participant to share their experience, rather than inhibiting it as effective relationships of trust can be established where people have similar life experiences<sup>34</sup>. Talking to someone who has lived

experience creates an empathic connection that participants often find hard to establish with academic researchers, but it can generate insecurity too<sup>35</sup>.

However, the potential inhibitory effect should also be anticipated and adjustments made as necessary. In a more elaborate situation, some interviewees may worry that a 'double act' is being perpetrated as one researcher induces a sense of trust while the other exploits the opportunity. There is even the chance that the 'two to one' situation may feel oppressive to people who are socially anxious or others, such as where perceived threatening or aggressive behaviour is managed by two staff working together, so people may associate the research interview with one of these events, and even if they are told it is for a different purpose, it may feel like restraint. Indeed, the experience of being interviewed may conjure up all kinds of negative associations which may affect the willingness of potential interviewees to participate or their conduct in the interview itself. These matters may need to be considered whilst deciding who is eligible to participate in the research.

Moving from one to two interviewers also has the potential to trigger complex dynamics between the academic and peer researcher. The peer researcher may find that their current skill level is thrown into sharp relief as they compare themselves unfavourably with the academic researcher and find the discrepancy distressing. There may be disagreement about the data or what it means. Perhaps one interviewer picked up on something that the second interviewer missed, or there is an outright disagreement about the importance of something that was said. Increasing the size of the interview team as a whole will make it harder to achieve a consistent approach and add complexity (and possibly richness) to the process of interpreting the interview material. The academic interviewer may be challenged by the peer to improve their practice, such as by starting and finishing on time, building rapport and acknowledging distress during the interview. Even where the peer does not explicitly raise such matters, the presence of a witness may provoke the academic to reform.

Finally here, the introduction of the peer into the interview context with their role as a kind of 'insider', sharing some life experience with the interviewee, sharpens the academic's sense of being an outsider. The implications of this outsider role must be thought through and perhaps negotiated with the peer too<sup>36</sup>.

### **Paying attention to the environment**

The following sections take a layered approach in which the role of the peer is enriched by stages and the implications of this role are explored. As the discussion moves to each new layer, the previous issues are not left behind, but continue to assert their presence and have their effects. So a complex, sedimentary model is built up that reveals the complexity of the approach.

The first of these stages requires consideration of the environment where the interview will be held. This paper assumes that data collection is conducted by interview rather than mere observation, but a range of approaches to this are possible. The traditional private interview room with its closed door, armchairs and telephone creates a climate in which the researchers are perceived as being in charge, and disclosure depends upon the verbal and descriptive skills of the respondent.

In contrast, ethnographic approaches send the researcher out into the places occupied by the interviewee. For example, Di Lorito and colleagues<sup>37</sup> engaged carers of people with dementia as peer interviewers to work with an academic co-interviewer to collect data from respondents with dementia (not the person they cared for) where the interview was conducted in the respondent's home. This setting will be significant in reducing the power imbalance somewhat, as the respondent is host to her/his guests.

A further example of the effect of environment is found in the Go-Along Interview<sup>38</sup> that invites researchers to take an active role in the target setting. Respondents act as tour guides, introducing the researcher to the community setting, explaining how it works and answering questions triggered by the experience<sup>39</sup>. In this approach, the researcher is introduced to the activity and joins in with it alongside the respondent, often carrying an audio recording device as well as using a suitable place in the same setting for a more conventional interview with the person immediately the shared activity is over.

Go along interviews highlight the fact that the physical and social environment in which any interview is conducted will influence the data that is generated. They provide an academically robust way of permitting the respondent to take more control and disclose richer information with less reliance on verbal and descriptive skills, whilst adding many new insights into how the person interacts, engages with activities and is viewed by others. The environment is used to stimulate elucidation of material from the respondent.

### **The peer as a stimulus**

The presence of a second interviewer in the room will provide an opportunity for both researchers to observe how the interviewee interacts with that individual as well as with themselves. This will take place even if the peer is profoundly disabled by their condition, maybe unable to speak or engage actively in running the interview, but they would still add value by the gift of their presence. For some, their humour will disrupt an unhelpful formality and render the interview more homely and chatty, releasing respondents from deferential feelings and helping them to speak the truth. Attention must be taken to ensure that both the peer and the respondent give their consent<sup>40</sup>. There is an equal hazard at the other end of the ability range, in that the interviewee may compare themselves negatively with the skills, status and role of the peer interviewer and leave the interview feeling diminished.

This whole idea is lifted by engaging the peer as an active rather than passive player in the process. For example, Fenge<sup>41</sup> has worked with disabled young people who perform their own poetry to stir and challenge the audience/respondents, using a participative action research approach to frame the whole experience and derive meaning from all stakeholders. Similarly, Turner & Beresford<sup>42</sup> mention user-controlled research that involved singing and drumming workshops. Object elicitation is an approach to interviewing where the respondent is invited to bring a culturally relevant object into the interview and then speak about its significance<sup>43</sup>.

However, there are several considerations to be borne in mind here:

- This may be an entirely unstructured section of the interview, in which there is no attempt to prepare, guide or regulate the content of the interaction between the peer and the interviewee. The academic researcher may wish to simply observe how they interact with one another and gather any data that arises from this. Pressures of time commonly shortens this stage of the interview.
- In some circumstances, the material that arises in this unstructured section may change the interviewee's responses in the more structured section of the interview and so this needs to be factored into the analysis
- The unstructured interaction may take longer than anticipated and restrict the time, energy or concentration available for any other sections of the interview.

### The peer reveals their identity

For some peers, their lived experience is apparent from their appearance or they may be already known to the interviewee. In contrast, peers with a hidden disability have an opportunity to reveal their lived experience, either as a brief declaration, or in a somewhat longer autobiography. In acting ethically, interviewers may be covert and so avoid revealing their identity, but if asked directly, must not lie. Even without further interaction, the presence of a peer on the interview team has the potential to reduce the power imbalance<sup>44</sup> and create a sense of affinity between the research team and the interviewee and may well trigger additional disclosure. This is a key element in the 'outsider-witness' role that is sometimes used in narrative therapy<sup>45</sup>. However, it also carries the risk that the peer will indulge their own need to tell their story by 'opening up too much'<sup>46</sup> and so divert the interview away from the traditional stance in which the focus of attention is on the respondent's story to a new focus on the peer's story.

How close is the lived experience of the peer to that of the respondent? Is experience of cancer sufficient, or does it have to be this particular type of cancer at this particular stage in the lifecourse? What if there is a hierarchy or conflict between subgroups, such as where historic tribal conflicts fracture relationships and external similarities of nationality mask deep mistrust or deference?<sup>47</sup> Sometimes the lived experience of the peer researcher intersects with that of the participant in an unhelpful way that should be avoided – so, to offer an extreme example, a person who has been subject to domestic abuse should not be asked to interview a perpetrator.

The factual parallels between the experience of the peer and the respondent will matter, as will a more ephemeral but important factor, which is the ability of the peer to create a sense that she is a 'kindred spirit' with the person. In passing we might wonder how "kindredness" differs from other roles, such as being a friend, therapist, volunteer, fellow patient, or member of the public with no knowledge of the health condition under investigation. Differences between interviewers may be due to human factors such as emotional warmth rather than biographical factors. The ability to evoke this sense of kindredness can also be misused, as we have seen with the 'Fake Sheikh' who has lured people into making disclosures that they afterwards regret<sup>48</sup>.

There are some considerations to be borne in mind here. Firstly, where the peer and the interviewee already know one another, perhaps because the local community of experts by experience is small and well networked, then this prior connection may ease the process of disclosure in the interview, or inhibit it as the interviewee erects defences that would not be in place with a stranger who will never be seen again<sup>49</sup>. The peer interviewer may also have to navigate moments in the interview when they are asking questions to which they already know the answer – and the interviewee knows that they know. The traditional approach is to remove such examples from the research cohort, but this may disqualify vital data and it would sometimes be better to work with these complexities.

Secondly, the potential to reduce power imbalances will only be realised if the academic and the peer work as a team. The sense of shared identity between the peer interviewer and the participant can be enhanced by matching them on ethnicity, gender and age. The process could have the opposite effect of increasing the power differential if the peer is involved in a tokenistic or patronising way.

Thirdly, the message of equality will also be harder to communicate in settings where there are inherent power imbalances, such as where the interview takes place in a locked facility. In addition to the actual power held by such a setting, its culture may promote an expectation of interrogation, feelings of blame and fears of punishment. There may be raised levels of suspicion about the peer researcher and reluctance to engage with them<sup>50</sup>. Even where the researcher is very clear about their duty of confidentiality, the patient may find it hard to trust them, especially if trust has been broken in the past, or if they believe that the peer researcher's loyalties are aligned elsewhere. The research protocol should include an agreed action plan in the event that such a blame culture was found, as it would be a matter of grave concern that may need to be discussed with management.

Fourthly, we note that even where the information that is provided during an interview may be fairly similar whether the interview is conducted by an academic or peer interviewer, the presence of a peer may influence the number of respondents willing to engage in the interview in the first place<sup>51</sup>.

Fifth, disclosure by the peer interviewer may have a differential impact on different parts of the interview itself. Participants may boost their strengths and play down their weaknesses in order to maintain their dignity when talking with a peer, whilst they feel able to disclose the extent of their problems to a professional<sup>52</sup>. Researchers have found that respondents were more likely to be critical of the service they had received when they were interviewed by a peer researcher who disclosed their status as a service user<sup>53</sup>. These effects were noted in one-to-one interviews, so the presence of an additional academic researcher may cancel them out. In some circumstances, the research team may need to find ways to corroborate the evidence they obtain in the interview.

### **The peer as interpreter**

From time to time, the peer may realise that the academic researcher is not communicating clearly. Perhaps their language is too complex or lacks an everyday illustration that would bring it to life. In

this situation, the peer may augment the academic's questions with focused, simplified, illustrated contributions which elucidate the question but do not add new items of inquiry. Such offers may also be triggered when the peer recognises that the interviewee is bewildered.

In their turn, the interviewee may communicate some of their responses in a particularly coded, incomplete manner, which the researcher could miss, while the peer may spot them simply because of their shared life experience<sup>54</sup>. For example, the interviewee may use 'street language' with which the academic interviewer is unfamiliar or refer to resources and services that they do not know and so the peer can interpret. While some of this material could be decoded by the academic researcher asking a peer afterwards<sup>55</sup>, more of this subtle signalling will contribute to the interview itself if the peer is present in the interview itself and can interpret on the spot.

These issues are not unique to co-interviewing with a peer, but also occur when a language interpreter is present in the interview. Suurmond and colleagues<sup>56</sup> investigated this version of the 2:1 interview and found that while the interpreter could help the process, they also edited information; initiated information-seeking, took over control of the interview, and took over the respondent's role. These researchers suggest ways to eliminate these effects, rather than share power.

### **The peer as sense-maker**

Academics may listen to the interviewee's responses through the lens of their theories, while the peer is more likely to make sense of what they hear by reference to their everyday life experiences, which may be closer to the interviewee's worldview. These complementary approaches to sense-making will enrich the immediate process of interpreting and reacting to each moment of the interview as it unfolds.

While the peer has the advantage of recognising some of the meanings hidden within the interviewee's verbal and non-verbal language, they also bring their own agenda. They may wish to present the interviewee's experiences in a positive light or position their own experience in relation to the interviewee<sup>57</sup>.

However, the peer may have only one viewpoint on the meaning of the responses, and so Chen and Boore<sup>58</sup> suggested that this be checked by reference to an expert panel, while Bergen<sup>59</sup> encourages researchers to clearly describe how the interview was conducted and by whom, so that the role of language interpreters, and, by extension, peers, is made explicit. These issues arise within the interview and continue into the later stages of data processing, aggregation and analysis. Throughout this whole process there is a need for humility and curiosity on the part of both the academic and the peer, so that they both recognise that their viewpoint on the meaning of the interview may not necessarily be right, and alternative interpretations may have value too. This challenges any claims that the peer researcher has special access to absolute truth about the participant's experience by

virtue of their own<sup>60</sup>, or that the academic is the only one with the training to set aside all assumptions and biases in order to draw reliable conclusions.

### **The peer as questioner**

In a structured interview, the peer may ask predetermined questions, rigidly adhering to the script.

It was noted above that the interviewee sometimes responds with incomplete and coded messages and these may be ambiguous and contradictory at both the verbal and non-verbal level. So if the peer is allowed to probe this material by also asking spontaneous questions in a semi-structured interview, they may be able to follow up on these incomplete messages and tease out more detailed meanings. If some of their follow-up questions demonstrate that there is an affinity between the interviewee's partial disclosure and the peer's lived experience, this may lead to the interviewee feeling understood and choosing to disclose additional material that would not have come out if the researcher had been working alone<sup>61</sup>.

It may also be helpful to have additional pastoral support available for interviewees to use afterwards, should the interview process bring distressing thoughts and feelings to the surface and leave them unresolved. Sometimes the worker who would normally provide such pastoral support is themselves the cause of the problem, and so an independent source of support may be needed. The peer may need initial debriefing or ongoing support too, and, of course, it is not just what the respondent says that may cause the peer distress – spending time with someone who is more impaired than oneself can be upsetting, especially where they present a graphic image of one's own future. In one study<sup>62</sup>, the academic and peer interviewer travelled to the respondent's home together to conduct the interview, creating a natural opportunity to brief on the way and debrief on the return journey.

Giving a researcher permission to ask spontaneous questions carries the potential for uncovering vital material, but also the risk that the interview process will be subverted and the data collection compromised. Giving two researchers this freedom multiplies the potential for creative or distracting subthemes to emerge, but also helps to police the process, as each interviewer can monitor the conduct of the other and help to keep the process on track. It would be wise to define roles precisely and in advance and decide whether the trained qualitative researcher should take overall responsibility for the governance of the interview itself and regulate whether the peer is allowed to take the interview off script by adding these spontaneous questions or observations.

### **The peer as interview manager**

It was suggested above that the partnership between the academic and peer researcher allowed both a power of veto. Up to now, the academic researcher has taken entire responsibility for overseeing the process of the interview, monitoring the semi-structured process to ensure that

methodological, technical and ethical concerns are met. While the peer researcher holds some power of veto, ensuring that there is genuine patient benefit in view and that interviewees are treated with dignity throughout the process, this is more limited, and the general oversight of the interview remains with the academic.

Some (but not all) User-Led Organisations may have gone a step further. They have won research contracts and managed research projects in which the peer with lived experience has oversight<sup>63</sup>. Where there is no access to fully-fledged academic researchers (we hasten to notice that the user-led organisation may of course include fully trained academics amongst its number), the commissioner has accepted a lower standard of scientific research rigour, being prepared to trade this in as an exchange for user control<sup>64</sup>. This may be acceptable if useful conclusions can be drawn from these methods, funding is not available for traditional research, or other projects are entirely managed by neophyte researchers. It will help in planning to be clear about exactly what level of research skill is required for these particular interviews.

Most often, such groups have access to academic research expertise. Hybrid arrangements proliferate, such as:

- an academic researcher oversees the development of an interview protocol, which is then administered by peer interviewers working alone
- both the academic researcher and the peer researcher enter the interview room, but the academic sits behind the respondent, so that they are in the line of sight of the peer researcher. Some respondents report that they quickly ‘forget’ the presence of the unseen academic, but anxious respondents or those who struggles with paranoid feelings may find this unsettling.
- peers provide no more than an advance briefing to the academic researchers, alerting them to some of the issues that may arise in the one-to-one interviews with the academic.
- academics take an advisory role rather than exercising managerial leadership of the project, but in so doing, they retain a professional duty of candour and integrity. In this way, they place their skills at the disposal of the peer. Like the accountant on the Board of a charity, the academic would be obliged to notify the funders of their concerns and resign in the event that the project took a path that they considered to be unwise. The same duty to resign and report is, of course, held by the peer in any of these arrangements.

The common characteristic is that all these options empower peers in an attempt to flatten hierarchies and work collaboratively<sup>65</sup>. They also load responsibility on to the peer, increasing what NIHR refer to as ‘power to act’, which triggers additional requirements in terms of checks to ensure ethical practice and competence<sup>66</sup>.



## Training for peer interviewers

It can be seen from the foregoing paragraphs that peer interviewers may work alongside academics without extensive training, if the academic researcher continues to exercise oversight and bring their skills in methodology and ethics to bear on the project. Indeed, the Health Research Authority counsel against burdening people with unnecessary demands:

*Research sites are expected to accept reliable assurances from others in a position to give them. This includes assurances about the... competence, character and indemnification of members of the research team who are not substantively employed at the site, including patients, service users and the public. Decisions about research team members' suitability should not be based on inappropriate HR processes, such as disproportionate training expectations (e.g. Good Clinical Practice or health and safety training for individuals, roles or projects that do not need it), irrelevant occupational health checks (e.g. vaccination history where there is no contact with patients or service users) or duplicative checks of character. (2017, para 9.16d [here](#))*

It is interesting to note that Good Clinical Practice is specifically mentioned as not mandatory for all and may be a useful safeguard for peer interviewers who are conducting 1:1 interviews in the absence of academic colleagues, rather than 2:1 interviews in their presence. Many people who are involved in health research through Patient and Public Involvement activities or user-led research organisations have undergone training, and this is often regarded as a good thing<sup>67</sup>, but the training tends to be measured in days rather than years.

Some people involved in the use of personal narrative as a teaching tool have thought about how to make good use of autobiography, and this may be a useful element of training for peer interviewers.

In addition, some training in listening skills may be helpful. This could help the peer researcher to move beyond the self-referential responses that commonly arise when one hears another person describe an experience that matches one's own. People who know that they have not lived through the same experience may be more curious about the respondent's thoughts and feelings, while the peer may naively assume that an external equivalence is matched by internal similarities<sup>68</sup>. The same problem can arise from the respondent's perspective too, when they assume that the peer understands their experience and so does not need further explanation and elaboration of their viewpoint<sup>69</sup>.

While training in interview skills may help peer researchers to conduct more effective interviews, there are also benefits to training in other phases of the research process. For example, training peer researchers in data analysis will sharpen up their understanding of what constitutes good data and improve their practice in the interview itself<sup>70</sup>. The bullet points below set out the steps taken by one researcher in a blended approach to learning and doing research:

- A general workshop introduces the research process and the role of peer research to interested parties.
- People who are interested then complete the application process

- In the second workshop we design an interview schedule together and train the peers in how to play their part in the interview.
- We then do the interviewing and get the interviews transcribed
- The third workshop begins with an introduction to thematic analysis. We then look at a few transcripts and make a list of themes.
- The academic researchers then go away to analyse the transcripts around the given themes and produce outline findings.
- In the fourth workshop we decide what messages are emerging
- The academics then draft a report around the key messages.

While some training is formative and does not include an assessment which leads to approval or rejection of the candidate, other training programmes do include a summative component where people are required to pass the test before being counted as competent. There is a risk that formal investigations to confirm that Public Contributors are competent will be set aside as researchers prefer to be inclusive and welcome all, which could lead to naïve and potentially incompetent appointments being made<sup>71</sup>.

In addition to training, ongoing coaching and mentoring can be helpful. Indeed, an advantage of co-interviewing is that it creates a very natural opportunity for some mutual reflection and learning, in which each interviewer can question, reassure or even advise the other. As the number of completed interviews increases, each interviewer will gain in confidence and skill, as well as working together more effectively.

## Widening participation

Peer interviewing can involve one or more of the activities set out in the paragraphs above and this range of mechanisms can allow people with definite impairments to participate<sup>72</sup>. So, for example, peer researchers have been used in care homes<sup>73</sup>.

In most cases, peers do not need to hold research qualifications or be drawn from the academic elite and to insist that they should when there is no concomitant need would breach the principle of competence-based recruitment. Finally, it meets the challenge set by the literature, to widen opportunities for participation in research interviewing to a more diverse group of people who represent the range of patient experience. In some cases, a precise fit may be needed between the interviewee's experience and the peer, but in most situations, a broader and more diverse array of peers will be helpful. In the care home work mentioned above, including peers meant that the age profile of the research team moved closer to the demographic profile of the respondents.

Widening participation does not mean that we abandon all requirements for taking up this role. It may be possible to draw some lessons about the right qualities needed from the guidance that has been written to assist in the recruitment and training of peer support workers in mental health services<sup>74</sup> as well as looking at direct advice on recruiting and supporting peer researchers<sup>75</sup>. In addition, guidance on training peer interviewers is available<sup>76</sup>.

Some peer researchers have needed assistance in the room to support them in carrying out the interview task. For example, Miller's team<sup>77</sup> found that some peer interviewers needed a support worker to read out each successive question, perhaps phrase by phrase, which the peer interviewer then repeated. Whether this is achieved by bringing a support worker into the interview room and making it rather crowded, or by the academic interviewer taking on this support role, it will affect the dynamics in ways that Miller's team found prohibitive.

## Reward and Recognition

Research projects need to be fairly costed to include an appropriate budget for involving peer interviewers. People should be offered participation payments<sup>78</sup> or be paid for this work, and example rates are available<sup>79</sup>. When research funding is limited, increasing these budget lines will be at the expense of other kinds of expertise, such as contract researchers.

In addition, sufficient support should be available, providing both emotional support and practical support to shape induction and delivery. Faulkner<sup>80</sup> suggested that these elements should be offered by different people, so that emotional support was provided separately from the demands of delivering the project outputs. Sometimes the material disclosed during research interviews is distressing, while frequent repetition of the peer's own story can produce a degree of emotional blunting that can be harmful to the peer researcher themselves. It is important to be aware of assumptions here, such as the idea that the peer is bound to be vulnerable rather than resilient.

Finally, involving peers may cast light on the workings of the research institution itself. If the organisation is in the habit of exploiting all of its research staff through overwork, lack of pastoral support and indifference, these matters will be detected and challenged by the peer researchers.

## What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online [here](#) from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. The work has been edited many times, and on each occasion a revised version has replaced the earlier material online. This process is still under way, and so this paper may still be lacking crucial concepts, evidence, structure and grammar<sup>81</sup>. As readers continue to provide feedback, further insights will be used to update it, so please contact [peter.bates96@gmail.com](mailto:peter.bates96@gmail.com) with your contributions.

It is one of a suite of over 30 documents available [here](#) that try to open up debate about how in practical terms to empower disabled people and share decision-making in health and social care services – in research, implementation and evaluation.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its

contributors. At least, it can harm those who insist on showing only their 'best side' to the camera, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are gagged by their employer or the workplace culture, silenced lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or by having their material accepted by academic journals.

In contrast, this way of writing can engage people who are not invited to a meeting or asked for their view until the power holders have agreed on the 'right message'. It can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading edge resources. It can stimulate others to write something better than this.

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<sup>1</sup> For a critical discussion of traditional hierarchies of evidence, see Glasby J and Beresford P (2006) Who knows best? Evidence-based practice and the service user contribution *Critical Social Policy* Volume: 26 issue: 1, pages: 268-284. DOI: <https://doi.org/10.1177/0261018306059775>. Patti Lather hopes that these types of research will result in research participants gaining insight and taking action to change the world for the better and so she promotes the term 'catalytic validity'. Such changes would be seen both in research participants and in peer researchers. See <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.474.7140&rep=rep1&type=pdf>

<sup>2</sup> For example, Duckett and Fryer reported a study where people with learning disabilities moved from research participants to co-researchers. In an attempt to retain something of a traditional approach to knowledge production, the learning disabled co-researchers did not appear as co-authors in the article. See Duckett PS and Fryer D (1998) Developing empowering research practices with people who have learning disabilities. *Journal of Community & Applied Social Psychology* 8: 57–65.

<sup>3</sup> The following people have kindly responded to an email inquiry: Graham Bowpitt, Tom Dening, Vanessa Heaslip, Lawrence Jones, Claudio di Lorito, Richard Morriss, Kristian Pollock, Justine Schneider and Louise Thomson. The Hearing BRU planned to involve patients in research (project ref PB-PG-0613-31106, PI Derek Hoare) by training and involving patients to interview patients about their experiences but was unable to do so because of restrictions placed by the sponsor. Steve Gillard and Sarah Gibson at St George's have engaged with peer researchers. Vanessa Pinfold at the McPin Foundation works extensively with peers and is herself a qualified researcher. Patrick Callaghan has worked with peer researchers.

<sup>4</sup> See <http://bjp.rcpsych.org/content/early/2014/03/31/bjp.bp.113.128637.abstract>, also <http://www.biomedcentral.com/1756-0500/7/37>, also Stack, E. and McDonald, K. E. (2014), Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up? *Journal of Policy and Practice in Intellectual Disabilities*, 11: 83–91. doi: 10.1111/jppi.12074, also Helen Kara, (2013) Mental health service user involvement in research: where have we come from, where are we going?, *Journal of Public Mental Health*, Vol. 12 Iss: 3, pp.122 – 135, also <http://bjp.rcpsych.org/content/early/2014/03/31/bjp.bp.113.128637#BIBL>, also <http://bjp.rcpsych.org/content/181/6/468.full.pdf>, also <http://onlinelibrary.wiley.com/doi/10.1002/wps.20086/pdf> also <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/Advanced%20training%20report-April2014.pdf> also [http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014\\_FINAL.pdf](http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014_FINAL.pdf) [http://books.google.co.uk/books?hl=en&lr=&id=oUMbAgAAQBAJ&pgis=1&redir\\_esc=y](http://books.google.co.uk/books?hl=en&lr=&id=oUMbAgAAQBAJ&pgis=1&redir_esc=y). Also Di Lorito, C., Birt, L., Poland, F., Csipke, E., Gove, D., Diaz-Ponce, A., and Orrell, M. (2016) A synthesis of the evidence on peer

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research with potentially vulnerable adults: how this relates to dementia. *International Journal of Geriatric Psychiatry*, doi:[10.1002/gps.4577](https://doi.org/10.1002/gps.4577).

<sup>5</sup> For example, 'there is growing evidence that people with dementia want to participate in research.' Tanner D (2012) Co-research with older people with dementia: experience and reflections. *Journal of Mental Health*. Jun; 21(3): 296-306. Doi: 10.3109/09638237.2011.651658.

<sup>6</sup> See Karnieli-Miller O, Strier R & Pessach L (2008) Power Relations in Qualitative Research. *Qualitative Health Research* Volume: 19 issue: 2, page(s): 279-289. <https://doi.org/10.1177/1049732308329306>.

<sup>7</sup> Well qualified and highly respected researchers who have lived experience of mental health issues include Julie Repper, Diana Rose and Peter Beresford.

<sup>8</sup> Paula Wray notes that the CLAHRC-EM REBOOT study employs a service user consultant as a peer researcher (Matt Rawsthorne) and a lay assessor is also working as a peer researcher in a project linked to the local RDS. Professor Kamlesh Khunti has identified this as an area for further development within CLAHRC-EM.

<sup>9</sup> In the mental health world, peer support for people with lived experience of mental health issues who are conducting user-controlled research is available through the [Survivor Researcher Network](#), and internationally through the [International Association of Service User Academia](#).

<sup>10</sup> Di Lorito, C (2016) op cit. See also <https://blog.esrc.ac.uk/2018/05/22/understanding-dementia-the-value-of-co-research/> See the PRIDE study at <https://www.ucl.ac.uk/psychiatry/pride>.

<sup>11</sup> These benefits were also found by Faulkner, A. and Layzell, S. (2000) *Strategies for living: A report of user-led research into people's strategies for living with mental distress*, London: Mental Health Foundation. Also Rose, D. (2001) *Users' voices: The perspectives of mental health service users on community and hospital care*, London: Sainsbury Centre for Mental Health.

<sup>12</sup> An example of 'privileged access' is this is Elliott et al's study where interviewers who were stable drug users or former users were recruited to interview parents who use illegal drugs but who are not in touch with services. See Elliott E, Watson AJ and Harries U (2002) Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations *Health Expectations*, 5, pp.172–178.

<sup>13</sup> See the report from Lousie Joly on co-interviewing with people who have experience of homelessness. <https://www.nihr.ac.uk/blogs/involving-people-with-experience-of-homelessness-as-peer-interviewers/10360>.

<sup>14</sup> Dalgarno M & Oates J (2019) The crucible of co-production: Case study interviews with Recovery College practitioner trainers *Health Education Journal* Vol. 78(8) 977–987. DOI: 10.1177/0017896919856656.

<sup>15</sup> Perkins R, Meddings S, Williams S et al (2018) *Recovery colleges 10 years on*. Nottingham: ImROC, 2018. Also Meddings S, Byrne D, Barnicoat S, Campbell E, Locks L (2014) *Co-Delivered and Co-Produced: Creating a Recovery College in Partnership*, *Journal of Mental Health Training, Education and Practice*, 9, 16-25

<sup>16</sup> Dalgarno M and Oates J (2018) The meaning of co-production for clinicians: An exploratory case study of Practitioner Trainers in one Recovery College. *Journal of Psychiatric and Mental Health Nursing* 25: 349–357.

<sup>17</sup> Mayer C & McKenzie K (2017) '... it shows that there's no limits': the psychological impact of co-production for experts by experience working in youth mental health. *Health & social care in the community*, 25(3): p. 1181-1189.

<sup>18</sup> See Turner M and Beresford P (2005) *User controlled research: Its meanings and potential – final report*. Shaping our Lives and the Centre for Citizen Participation, Brunel University.

<sup>19</sup> This is eloquently described by Louise Ryan and Anne Golden, Irish migrant researchers collecting data from Irish migrants. Questions about health usually elicited no more than the answer to the specific question, while questions about returning to their country of origin led to questions from the respondent and dialogue that touched on mutual sharing of feelings and futures. Ryan L and Golden L (2006) 'Tick the Box Please': A Reflexive Approach to Doing Quantitative Social Research *Sociology* Volume 40(6): 1191–1200. DOI: 10.1177/0038038506072287.

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<sup>20</sup> See Bates P (2021) [How to honour storytellers](#).

<sup>21</sup> Rose D, Wykes T, Leese M, et al (2003) Patients' perspectives on electroconvulsive therapy: systematic review. *BMJ* 326:1363–1366.

<sup>22</sup> O'Donoghue B et al (2013) Service Users' Perceptions About Their Hospital Admission Elicited by Service User–Researchers or by Clinicians *Psychiatric Services*. <https://doi.org/10.1176/appi.ps.001912012>.

<sup>23</sup> Di Lorito C, Godfrey M, Dunlop M, et al. (2020) Adding to the knowledge on Patient and Public Involvement: Reflections from an experience of co-research with carers of people with dementia. *Health Expectations* 23:690–705. <https://doi.org/10.1111/hex.1304>.

<sup>24</sup> At Nottingham University Hospitals NHS Trust, volunteers must undergo a rigorous approval process that includes two written references, an interview and a DBS check. This is appropriate for people who live locally, volunteer regularly and occupy positions of trust, but may be less workable for peer researchers who will be involved for only a few hours, live far away and are chaperoned throughout their time with the interviewee. As the DBS process emphasises, the process needs to be justified by the context, encourage participation rather than inhibit it, be tailored to the individual and meet 'least restrictive practice' principles consistent with safeguarding obligations.

<sup>25</sup> Laterza V, Evans D, Davies R, Donald C & Rice C (2016) [What's in a "research passport"? A collaborative autoethnography of institutional approvals in public involvement in research](#) *Research Involvement and Engagement* 2:24

<sup>26</sup> In one project, this process took up to 8 months - see Mockford et al (2016) A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges *Research Involvement and Engagement* 2:8. DOI 10.1186/s40900-016-0021-3.

<sup>27</sup> Di Lorito C et al. (2020) op cit.

<sup>28</sup> See Bates P (2021) [How to respond to distress](#).

<sup>29</sup> See Sampson H, Bloor M and Fincham BA (2008) A Price Worth Paying? Considering the 'Cost' of Reflexive Research Methods and the Influence of Feminist Ways of 'Doing' *Sociology* Volume 42(5): 919–933. DOI: 10.1177/0038038508094570.

<sup>30</sup> In one project, peer researchers found that analysing the transcripts was a more emotional experience than conducting the interview. See Hutchinson A & Lovell A (2013) Participatory action research: moving beyond the mental health 'service user' identity. *Journal of Psychiatric and Mental Health Nursing* 20, 641-649.

<sup>31</sup> The following statement is offered for use or amendment. 'Some interviews in this research study may be conducted by members of the Lived Experience Advisory Panel. Such individuals have lived through the issues that we are investigating, either in their own lives or that of a close family member. Whilst they are lay people, they have been trained, are carefully supervised and act under the direction of the Chief Investigator.'

<sup>32</sup> Carole Mockford's interviews sometimes had four people in the room – the respondent, a carer, an academic researcher and a peer researcher. See Mockford et al. A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges *Research Involvement and Engagement* (2016) 2:8. DOI 10.1186/s40900-016-0021-3 and personal communication 12/12/2017.

<sup>33</sup> This was the case in Elliott et al (2002) op cit where drug-misusing participants were reluctant to do anything that may lead to their anonymity being compromised.

<sup>34</sup> See <http://www.peerworker.sgul.ac.uk/>

<sup>35</sup> Bengtsson-Tops A & Svensson B (2010) Mental health users' experiences of being interviewed by another user in a research project. A qualitative study. *Journal of mental health* England: Abingdon.



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<sup>36</sup> See Ryan L, Kofman E and Aaron P (2011) Insiders and outsiders: working with peer researchers in researching Muslim communities *International Journal of Social Research Methodology* Vol. 14, No. 1, January 2011, 49–60.

<sup>37</sup> Di Lorito C et al (2019) *Public Involvement in research: Co-researching with carers of people with dementia in the PrAISED study*, conference poster presented at the Alzheimer Europe Conference 2019, The Hague, Netherlands, 23-25 October 2019.

<sup>38</sup> See Burns R, Gallant KA, Fenton L, White C & Hamilton-Hinch B (2020) The go-along interview: a valuable tool for leisure research, *Leisure Sciences*, 42:1, 51-68, DOI: [10.1080/01490400.2019.1578708](https://doi.org/10.1080/01490400.2019.1578708). The setting is chosen by the person, as they feel included there and they can act as tour guide, explaining what is going on to the newcomer. The researcher can ask questions about what they see. It can happen outside traditional working hours and challenge professional boundaries. Interviews take place before, during and after the shared participation and all three happen on the participation site if possible. Researchers also write reflexive notes and observations immediately after the 3 interviews are complete. It provides more opportunities to shift power in favour of the participant than traditional sit-down interviews. For an adjacent approach, see Kinney P. (2021) Walking Interviews: A Novel Way of Ensuring the Voices of Vulnerable Populations Are Included in Research. In: Borcsa M., Willig C. (eds) *Qualitative Research Methods in Mental Health*. Springer, Cham. [https://doi.org/10.1007/978-3-030-65331-6\\_4](https://doi.org/10.1007/978-3-030-65331-6_4)

<sup>39</sup> The Declutter study will use a complex version of the Go-Along Interview. The researcher will accompany the Professional Declutterer on a visit to the hoarder, join in with conversation at the start before slipping into the background, and maybe even offer a tiny bit of practical help if absolutely necessary. As well as observing during the visit, there may be an opportunity to interview the hoarder afterwards. Personal correspondence with Dr Jennifer Owen, May 2023.

<sup>40</sup> To see a discussion about obtaining consent to participation in research from people who have profound cognitive or communication impairments, see McKeown J, Clarke A, Ingleton C & Repper J (2009) Actively involving people with dementia in qualitative research *Journal of Clinical Nursing* 19, 1935–1943. Doi: [10.1111/j.1365-2702.2009.03136.x](https://doi.org/10.1111/j.1365-2702.2009.03136.x). Also Cameron L, Murphy J (2007) Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*. 35, 2, 113-120.

<sup>41</sup> Fenge LA, Hodges C & Cutts W (2016) Performance Poetry as a Method to Understand Disability *Forum: Qualitative Social Research* 17(2), May 2016, Art. 11. See also Camic P, Harding E, Sullivan M, Grillo A, Mckee-Jackson R, Wilson L, Zimmermann N, Brotherhood E & Crutch S. (2022) Developing Poetry as a Research Methodology with Rarer Forms of Dementia: Four Research Protocols. *The International Journal of Qualitative Methods*. 21. 1-9. [10.1177/16094069221081377](https://doi.org/10.1177/16094069221081377).

<sup>42</sup> Turner M and Beresford P (2005) *User controlled research: Its meanings and potential – final report*. Shaping our Lives and the Centre for Citizen Participation, Brunel University.

<sup>43</sup> Harding, E., Camic, P., Harrison, C.R., Akthar, N., Wilson, J., Stott, J., Rice, H., Herron, D., Mummery, C.J., Crutch, S.J. and (2023), Objects of hope: using object elicitation to open up conversations about hope for people affected by rarer forms of dementia. *Alzheimer's Dement.*, 19: e076209. <https://doi.org/10.1002/alz.076209>.

<sup>44</sup> The shared identity between the researcher and the researched is a key element of what is sometimes called 'survivor research'. See Faulkner A (2004) *The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors*. Policy Press, page 4.

<sup>45</sup> Caldwell, R. & Leaning B (2021) Rosie: Co-production and co-provision. *The Bulletin of the Faculty of People with Intellectual Disabilities* Vol 19 No. 3. The role of the outsider-witness is discussed in Carey M & Russell S (2003) Outsider-witness practices: some answers to commonly asked questions *The International Journal of Narrative Therapy and Community Work*. DCP. Adelaide. Issue 1.

<sup>46</sup> Di Lorito et al (2020) op cit.

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<sup>47</sup> Marlowe reports on an experience of peer research with refugee communities where language and substantial cultural differences bring these issues into sharp relief. Marlowe JM (2015) Conducting post-disaster research with refugee background peer researchers and their communities *Qualitative Social Work* Vol. 14(3) 383–398. DOI: 10.1177/1473325014547252.

<sup>48</sup> See <https://www.youtube.com/watch?v=6fAbQiWTUsA>

<sup>49</sup> See Elliott E, Watson A & Harries U (2002) Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expect* 2002;5:172–8. Also Bryant L & Beckett J. (2006) *The practicality and acceptability of an advocacy service in the emergency department for people attending following self-harm*. Leeds, UK: University of Leeds.

<sup>50</sup> Research Ethics Committees are directed to pay particular attention to situations where a person with lived experience is engaged in recruiting participants, conducting interviews or focus groups or analysing data to ensure that the choice, safety, dignity and wellbeing of research participants is upheld. This may involve training for Public researchers as well as ongoing support and supervision for both Public researchers and study participants. See INVOLVE, Health Research Authority (2016) *Public involvement in research and research ethics committee review*. Downloaded from <https://www.invo.org.uk/posttypepublication/public-involvement-in-research-and-research-ethics-committee-review/> on 7 November 2020.

<sup>51</sup> A study called InvolVe led by Stefan Priebe compared service users and non-service user researchers in a study of people detained under the Mental Health Act. See [here](#) and [here](#). In the latter study, 24% of potential respondents declined to participate in an interview with a service user researcher who disclosed their lived experience, compared with 8% of non-service user researchers.

<sup>52</sup> Davis J.B., Baker R. The impact of self-representation and interviewer bias effects on self-reported heroin use. *British Journal of Addiction*, 1987; 82: 907–912.

<sup>53</sup> Clark CC, Scott EA, Boydell KM, et al (1999) Effects of client interviews on client reported satisfaction with mental health services. *International Journal of Social Psychiatry* 45:1–6, 1999 Also Gillard S, Borschmann R, Turner K, et al (2010) What difference does it make? Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients. *Health Expectations* 13:185–194.

<sup>54</sup> The converse may also occur: researchers may find that insights from their detailed knowledge of the literature and their rigorous training alerts them to aspects of the issue that are missed by the peer.

<sup>55</sup> Di Lorito and colleagues found it important that the academic interviewer and the peer should do some of the encoding of interview themes independently of one another, to ensure that the peer's understanding of the meaning of responses is heard. See Di Lorito et al (2020) op cit.

<sup>56</sup> Suurmond J, Woudstra A, & Essink-Bot M-L (2016) The interpreter as co-interviewer: the role of the interpreter during interviews in cross-language health research. *Journal of Health Services Research & Policy*, 21(3), 172–177. <https://doi.org/10.1177/1355819616632020>.

<sup>57</sup> For a discussion of the complexities of the relationship between the peer and the respondent, see Marlowe JM (2015) Conducting post-disaster research with refugee background peer researchers and their communities *Qualitative Social Work* Vol. 14(3) 383–398. DOI: 10.1177/1473325014547252.

<sup>58</sup> Chen HY & Boore JR (2010). Translation and back-translation in qualitative nursing research: Methodological review. *Journal of Clinical Nursing*, 19, 234–239.

<sup>59</sup> Bergen, N. (2018). Narrative Depictions of Working With Language Interpreters in Cross-Language Qualitative Research. *International Journal of Qualitative Methods*. Volume 17: 1–11. <https://doi.org/10.1177/1609406918812301>.

<sup>60</sup> Researchers have dubbed this idea that lived experience confers unique access to the truth of the participant's experience 'epistemic privilege'.

<sup>61</sup> However, one should not under-estimate the skills of the academic researcher in eliciting a nuanced understanding of the respondent's feelings and thoughts.



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<sup>62</sup> Di Lorito et al (2020) op cit.

<sup>63</sup> It would be interesting to learn how often the NIHR or other major funder of health research awards funds to a principal investigator who has lived experience but without full academic qualifications and experience in scientific research.

<sup>64</sup> For example, the CCQI programme run by the Royal College of Psychiatry engages people who use forensic services in peer reviews of service quality where user-reviewers meet residents in the absence of staff. Also, many Healthwatch organisations and some NHS Trusts engage volunteer patients to conduct one-to-one interviews with current patients and carers in order to audit service quality. Whilst this may be classed as service evaluation rather than health research, many of the risks and issues will be the same.

<sup>65</sup> One of the strengths of the qualitative interview as a research technique is that there is less of a power difference between researcher and respondent than in other forms of data collection.

<sup>66</sup> See <https://sites.google.com/a/nih.ac.uk/dandtda/home/training>.

<sup>67</sup> Some would anticipate that training will have the effect of socialising the person into the culture of academia and somehow 'rubbing off' their validity as an outsider to the research community. See comments on this in Mockford C. et al (2016) A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges *Research Involvement and Engagement* 2:8. DOI 10.1186/s40900-016-0021-3.

<sup>68</sup> See Staley K. There is no paradox with PPI in research. *Journal of medical ethics*. 2013 Mar 1;39(3):186-7. Also Dewar B. Beyond tokenistic involvement of older people in research—a framework for future development and understanding. *J Clin Nurs* 2005;14:48–53.

<sup>69</sup> See Bryant and Becket (2006) op cit, page 108.

<sup>70</sup> Mitchell N, Triska M, Liberatore A, Ashcroft L, Weatherill R & Longnecker N (2017) *Benefits and challenges of incorporating citizen science into university education PLOS One*. Available at <https://doi.org/10.1371/journal.pone.0186285>. Also Stevenson, M., Taylor, B.J. (2017) Involving individuals with dementia as co-researchers in analysis of findings from a qualitative study. *Dementia* Doi: 10.1177/1471301217690904.

<sup>71</sup> Miller E, Cook A, Alexander H, Cooper SA Hubbard G, Morrison J, Petch A (2006) Challenges and Strategies in Collaborative Working with Service User Researchers: Reflections from the Academic Researcher, *Research Policy and Planning* 24 (3): 197-208.

<sup>72</sup> See [Refreshing Perspectives](#) by Revolving Doors (2016). This review explores how peer research has been carried out with different groups facing multiple needs, including prisoners, homeless populations, and people on probation. The review shows that peer research has the potential to break down boundaries by enabling marginalised groups to decide what is important and what questions need to be asked. It explores key concepts such as power dynamics, ethics of peer research, and relationship to social change.

<sup>73</sup> <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8551.2012.00841.x/abstract>

<sup>74</sup> See <http://www.mentalhealthcommission.ca/English/node/18291>

<sup>75</sup> Also Good practice guidance for the recruitment and involvement of service user and carer researchers - [http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014\\_FINAL.pdf](http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014_FINAL.pdf)

<sup>76</sup> See <http://www.invo.org.uk/posttypesource/training-and-support-for-peer-interviewers/>

<sup>77</sup> Miller (2006) op cit.

<sup>78</sup> See [How to make sense of our payments offer](#). One researcher indicated that they provided £20 'love-to-shop' vouchers to peer interviewers for each interview completed or workshop attended. He reported that the DWP seem reasonably OK with this, provided you don't overdo it.

<sup>79</sup> See [How to estimate the costs of public involvement in research](#).

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<sup>80</sup> Faulkner (2004) op cit, page 16.

<sup>81</sup> As a result, the author assumes no responsibility or liability for any errors or omissions in the content of this paper. The information contained is provided on an “as is” basis with no guarantees of completeness, accuracy, usefulness or timeliness. Whilst every reasonable effort has been made to comply with UK legislation, if you believe that the public display of this document or any of its contents breaches copyright please contact [peter.bates96@gmail.com](mailto:peter.bates96@gmail.com) providing details, and public access to the offending work will be removed immediately.