

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



Written by Peter Bates

## Contents

Introduction .....	1
Competing demands.....	2
Some of the benefits of involving peer co-interviewers.....	3
The interview as dialogue .....	4
What is the topic of inquiry?.....	4
The peer as question designer.....	5
Managing risk and meeting safeguarding obligations .....	5
From one interviewer to two.....	7
The peer as a stimulus .....	8
The peer reveals their identity.....	8
The peer as interpreter .....	10
The peer as sense-maker .....	10
The peer as questioner .....	10
The peer as interview manager .....	11
Training for peer interviewers .....	12
Widening participation .....	13
Reward and Recognition.....	14

## 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 real 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.

While peer 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 both before and after the interview itself.

Some of the other steps on the journey are discussed in a suite of nearly 30 companion '[How To](#)' guides, one of which is called [How to co-facilitate a focus group](#). As 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.bates@ndti.org.uk](mailto:peter.bates@ndti.org.uk), 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 analysis 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 peers. 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 their own right. 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** as shown in the table below. In addition, involvement may raise the status of peer researchers in their community and deepen the bond between the academic and the peer co-interviewer, which could strengthen the peer’s contribution to other parts of the study<sup>11</sup>.

<b>Co-researchers</b>	<b>Academic researchers</b>
Owning research	Improved understanding of experience of living with dementia
Contributing to change	Reduced wariness
Challenging views	
Reduced stigma	
Reduced isolation	
<b>Participants with dementia</b>	<b>Research project</b>
Feeling more comfortable during data collection	Improved recruitment
Feeling understood	Enriched research
Reduced stigma	New ways of knowing
	Relevance to people with dementia

## The interview as dialogue

Some commentators<sup>12</sup> wish to reduce the perceived power held by researchers over those they interview. This traditional power is manifested when the researcher '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. **This more emancipatory, naturalistic approach opens opportunities for experts by experience to participate - and may extend the duration of the interview!**

This distinction between 'benevolent interrogation' on the one hand and dialogue 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 impelled to share a snippet of their own story**<sup>13</sup>.

## What is the topic of inquiry?

If the interviewee's story 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. 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 obtain a clear and shared understanding of what will be shared with whom as this will reduce these fears and concerns.

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>14</sup>, while another study<sup>15</sup> found no significant difference between the information elicited by service user researchers and academic researchers.

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 harmful, respectful, user-friendly, of value to patients and have the potential to link with community networks and organisations.

### 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>16</sup>. The interview setting may expect all researchers to carry a research passport<sup>17</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>18</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 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.

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. That 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 life. Support for the peer is crucial in these times. 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 interviewers compassion or more challenging emotions, and so effective support is necessary to minimise emotional harm to both academic and peer reviewers<sup>19</sup>. ~~Moreover, the most intense emotional response may arise afterwards, rather than in the interview itself<sup>20</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.

**Public Contributors** 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 Public Contributors in taking consent will need to consider the following:

- How the Public Contributor 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 Contributor 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 Public Contributor<sup>21</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>22</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.

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>23</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>24</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 participant 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**.

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.

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>25</sup>.

### 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. In such circumstances, attention must be taken to ensure that the person gives their consent to participation<sup>26</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>27</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>28</sup> mention user-controlled research that involved singing and drumming workshops.

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.
- 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 and create a sense of affinity between the research team and the interviewee and may well trigger additional disclosure. However, it also has the potential to 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>29</sup> 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>30</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. 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.**

Secondly, the potential to reduce power imbalances will only be realised if the academic and the peer work as a team. 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. 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>31</sup>.

Fifth, disclosure by the peer interviewer may have a differential impact on different parts of the interview itself. 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>32</sup>. These effects were noted in one-to-one interviews, so the presence of an additional academic researcher **may cancel them out**.

### **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>33</sup>. This could be achieved by asking the peer researcher to listen to an audio recording or watch a video of the interview, but perhaps more of this subtle signalling is conveyed when the speaker and listener are in the same physical space as one another.

### **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>34</sup>.

### **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>35</sup>. **It may 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.** 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.

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>36</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>37</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 struggle with paranoid feelings may find this deeply 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. Like the accountant on the Board of a charity, both academic and peer advisors would be obliged to notify the funders of their concerns and resign in the event that the group took a path that they considered to be unwise.

The common characteristic is that all these options empower peers in an attempt to enhance to flatten hierarchies and work collaboratively<sup>38</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>39</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>40</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.

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>41</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>42</sup>. So, for example, peer researchers have been used in care homes<sup>43</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.

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>44</sup> as well as looking at direct advice on recruiting and supporting peer researchers<sup>45</sup>. In addition, guidance on training peer interviewers is available<sup>46</sup>.

## Reward and Recognition

Research projects need to be fairly costed to include an appropriate budget for involving peer interviewers. **People should be paid for this work**, and example rates are available<sup>47</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, both pastorally and in respect of the induction and supervision of peer interviewers. 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.

---

<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: Tom Denning, 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](http://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 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](https://doi.org/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., Birt, I., Poland, F. et al. (2016) A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia *International Journal of Geriatric Psychiatry*. 31 (1). pp. 58-67. ISSN 1099-1166. 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> 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>12</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>13</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](https://doi.org/10.1177/0038038506072287).

<sup>14</sup> Rose D, Wykes T, Leese M, et al (2003) Patients' perspectives on electroconvulsive therapy: systematic review. *BMJ* 326:1363–1366.

<sup>15</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>16</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>17</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>18</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>19</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>20</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>21</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>22</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>23</sup> See <http://www.peerworker.sgul.ac.uk/>

<sup>24</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.

<sup>25</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>26</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. 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>27</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.

<sup>28</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>29</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>30</sup> See <https://www.youtube.com/watch?v=6fAbQiWTUsA>

<sup>31</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. See

<sup>32</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>33</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>34</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>35</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.

<sup>36</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>37</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>38</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>39</sup> See <https://sites.google.com/a/nih.ac.uk/dandtda/home/training>.

<sup>40</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>41</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*. <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>42</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>43</sup> <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8551.2012.00841.x/abstract>

<sup>44</sup> See <http://www.mentalhealthcommission.ca/English/node/18291>

<sup>45</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>46</sup> See <http://www.invo.org.uk/posttyperesource/training-and-support-for-peer-interviewers/>

<sup>47</sup> See [How to estimate the costs of public involvement in research.](#)