

# Nonsalaried Public Interviewers can collect research data on their own



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## Introduction

In the UK, patients, informal carers and members of the public add value to the processes of selecting, designing and delivering health research and may be offered a ‘Patient and Public Involvement (PPI) payment<sup>1</sup> in recognition of their contribution. This resource paper searches for published examples of health research where such individuals conducted one-to-one data-collection interviews with individual study participants. When acting in this specific role, such Public Contributors are referred to here as Nonsalaried Solo Public Interviewers (NSPIs).

Engaging NSPIs is an unusual choice for academic research teams to make, and this paper explores some of the reasons for their scarcity and seeks out some ways to increase adoption of the approach.

## Finding examples

**Step 1:** On 1 January 2026, Google scholar was alerted to send me a note each time a paper was published which contained a reference to PPIE (Public and Patient Involvement and Engagement). Papers were searched for the term 'interview' and surrounding text reviewed to see whether this paper described the engagement of NSPIs. Interesting material was incorporated into this report. Step 1 continues as Google Scholar continues to notify me of new papers.

**Step 2:** Each paper found in Step 1 that revealed the deployment of NSPIs was used in a further cycle of exploration. The 'citations' button was then utilised to generate a list of more recent papers that referenced the initial paper. The 'search within citations' box was checked and 'NHS "peer researchers"' was added to the search criteria.

**Findings:** To date, 399 papers have been checked, of which 27 show that NSPIs were engaged in the study (publication dates range from 1999 to 2026). Together, these studies appeared to engage 220 NSPIs who conducted 1936 interviews. This shows that the deployment of NSPIs is uncommon but not novel. However, academic reporting of these practices is often vague and difficult to interpret, so some people who appear to be NSPIs may in fact have been employed and salaried rather than being offered a PPI payment, while some interviews may have been chaperoned by an academic or be otherwise ineligible for this resource paper. In other examples, we read that NSPIs were deployed but are not given any numbers<sup>2</sup>. Unreported practices are unlikely to improve.

## NSPIs lack many traditional safeguards

The following paragraphs suggest a journey from the traditional academic way to collect data for research purposes towards the specific role of the NSPI. Each succeeding paragraph strips away another traditional aspect of the usual role of the academic, points to studies that have found a way to engage with NSPIs, and suggests safeguarding practices to protect study respondents, Public Contributors and the research itself. The real world, of course, is not so tidy and individual studies mix and match these options in their own creative ways as we will see in the examples below.

### Contract of employment

Paying attention to equality and diversity means that a proportion of the workforce will have lived experience of the issue being studied by the research team<sup>3</sup>. Public Contributors may serve on selection panels where they help to ensure that the right academic staff are appointed<sup>4</sup>. Once employed, staff shelter under the best of human resource management, including a formal recruitment process, contract of employment, staff policies and procedures, grievance management, supervision and career pathways.

These protections are routinely lacking in many PPIE ecosystems. PPI payments are often calculated at an hourly rate<sup>5</sup> and most academic papers neglect to say whether the expert by experience is employed or not. For example, it would be helpful to know more about the peer interviewers who "were employed through King's Talent Bank or were self-employed and offered PPI payments"<sup>6</sup>, and also whether the seven involvement researchers who conducted 48 individual interviews and were 'paid per hour based on the current starting rate for a research officer'<sup>7</sup> were engaged on a contract of employment.

Employing people is good, but nonsalaried Public Contributors are needed too, as they bring a challenge from outside the research organisation<sup>8</sup>. Serving prisoners, asylum seekers and people with dementia may be unable or unwilling to take on an employment contract; yet they will add value to the research endeavour. Further, an employee's lived experience may be a perfect match with the topic being studied now but is highly unlikely to align so closely with the next topic. Nonsalaried Public Contributors can help the research team draw closer to the lived experience of the people they are investigating.

Some research project teams have found ways to build contractual protections into the PPIE role. Instead of engaging nonsalaried Public Contributors, they have either employed the expert by experience or found a formally constituted community organisation that carries public liability insurance and contracted with that organisation to provide PPIE as a service.

NSPIs should be offered PPI payments for conducting data collection interviews. On rare occasions the PPIE role becomes large enough to justify creating a salaried post rather than relying on the casual nature of PPIE engagement. Indeed, we might argue that there is an onus on the research team to provide job opportunities wherever possible in place of informal offers of a PPI payment.

Creating pathways into salaried positions is not enough. If it is to truly reflect the ethos and expectations inherent in coproduction, the research ecosystem needs to deploy NSPIs. We must find precedents, specify risks, establish real data on their prevalence, invent mitigations and find the courage to bear the risk rather than retreat.

### Education and training

Traditional organisations find comfort in their practice of employing staff who are trained and qualified in research methods. Academic achievement and accredited training help to ensure a level of competence and ethical practice that is vital for getting the job done. Training and competence are underscored by membership of a professional body that holds the power to discipline its members.

Equality of opportunity demands that the workforce of fully qualified research staff includes people with lived experience. Barriers to higher education, recruitment, induction and promotion need to be lowered until the workforce is representative of the wider community. Such staff need to be supported by a work environment that accommodates the needs of disabled employees. Whilst all this is true, and advice is available<sup>9</sup> to support these endeavours, this paper goes further by showing how nonsalaried Public Interviewers are included as data collectors for research purposes.

Some teams have responded by providing brief introductory training, but this is usually very short, unaccredited and lacks summative assessment, so nobody fails. In the UK, many academic researchers are required to complete the *Good Clinical Practice* training course, but this is explicitly noted within authoritative guidance as generally unnecessary for Public Interviewers<sup>10</sup> since training must be relevant to the task.

Repper reported<sup>11</sup> on a training course for carers who were engaged as interviewers on ten sites to collect data for research purposes. Golijani-Moghaddam and colleagues<sup>12</sup> trained three Patient Partners were trained to conduct interviews with study participants and included them in regular team discussions to support reflexivity and consistency. Dewa and team<sup>13</sup> used a three-step process to build skills and confidence in their young co-researchers who were investigating mental health service provision, as follows:

- The academic led the first interview with the co-researcher observing and then they talked to each other about how the interview had gone
- The co-researcher led the second interview with the academic observing. Again, mutual feedback afterwards developed skills and insight
- The co-researcher conducted the third interview alone. , with the researcher in the next room for support if needed, along with a psychiatrist on site and available for back up if required.

Training needs increase if the interview modality is one that demands more sophisticated knowledge and skills. Neither Boutry et al<sup>14</sup>, who intend to use motivational interviewing, nor Phelps et al<sup>15</sup>, who applied Heideggerian Phenomenology to their interviews, engaged NSPIs in the task. NSPIs should be offered PPI payments for any training or other preparation they need prior to conducting data collection interviews. Engaging NSPIs means letting go of the security of professional training and finding an alternative viewpoint in which experiential knowledge is valued alongside formal education. This is more than a philosophical stance, since educational qualifications have a function in the process of selecting staff and regulating workplace conduct, so alternative mechanisms need to be in place to address unethical and incompetent practice amongst NSPIs.

### Coproduce everything else

There are many ways to do PPIE beyond the interview space. Public Contributors can advise on the shape of the research, sit on the panel that selects and appoints academic staff, edit Patient Information, co-author plain language summaries of the findings and speak at dissemination conferences. Closer to the interview, they can carry out a whole range of the activities that surround the interview itself - market the opportunity to become a study participant to community audiences, design the topic guide, act as the respondent in mock interviews to test the topic guide and train academic staff<sup>16</sup>, screen applicants<sup>17</sup>, obtain consent and join in with data analysis<sup>18</sup>. But are NSPIs actually conducting 1:1 data collection interviews?

### Types of data

Interviews enable an investigator to encounter a study respondent and collect data for research purposes. Whilst the simplest approach may appear to invite the respondent to just have a conversation, the level of complexity can be adjusted by using the interview itself to complete a questionnaire, carry out physical or medical tests on the consenting respondent or their environment<sup>19</sup>. Such tests may be more intrusive but also shrink the range of available discretion that risk the interviewer inadvertently superimposing their worldview on the respondent.

Three peer researchers carried out 'check-in' interviews with 15 carers to augment data provided via other research methods<sup>20</sup>. The authors do not clarify which data are collected by NSPIs and which by academics. Gross and colleagues<sup>21</sup> engaged eight Public Contributors and collected data from at least 160 respondents, but it is not clear whether completing the questionnaire together formed the entire content of the data collection interviews or other processes were used.

### Witnesses and whistleblowers

Focus Groups bring together several study respondents, so that the conversation is stimulated by a variety of contributions and viewpoints. As well as enriching the dialogue, the presence of others acts as a safeguard for conduct, since everything is witnessed and can be reported. Academic papers supposedly reporting these practices need to be carefully evaluated, as some researchers<sup>22</sup> use ambiguous terms like 'Focus Group interview', confusing the reader who then does not know how many people are in the room.

NSPIs interview one respondent at a time. For example, seven NSPIs carried out recruitment and follow up interviews with respondents in their first language<sup>23</sup>.

### Colleagues hold each other to account

Some research teams invite a Public Contributor and an academic researcher to cofacilitate an interview with a single study respondent<sup>24</sup> or a Focus Group<sup>25</sup> but this resource paper is relentlessly searching for examples where the NSPI conducts the interview on their own. For example, one PPIE-Partner conducted 15 interviews with working people who live with chronic pain<sup>26</sup>. In these circumstances, the salaried staff member can take responsibility for the event and bear liability on behalf of the nonsalaried Public Contributor. For example, if one of the interviewers presents a leading question which might compromise the data quality, then their colleague can get the interview back on track. When properly set up, personal assistants and translators also provide this protection. As before, it can be difficult to interpret the published account of the research and so the reader is left uncertain about what actually happened<sup>27</sup>.

Commitment to carry out the interview in an ethical and competent manner is also fuelled when NSPIs feel a sense of loyalty to the study itself or to a group. We might imagine that the five NSPIs who carried out 19 interviews considered themselves accountable in this way, since all five were members of the same PPIE group<sup>28</sup> and owed an obligation to their fellow group members.

### Remote media

Interviewing over the internet or a telephone call protects the study respondent since they can obscure elements of their identity and switch off easily, thus terminating the conversation. These media also make it easy to record and archive the call, providing supervisory staff with a record.

There are several examples of studies where NSPIs conducted 1:1 interviews over the telephone, including one study where three patient partners conducted interviews with 15 participants using an interview guide they developed<sup>29</sup> and another where two PPIE co-applicants and one carer completed a total of 17 telephone interviews<sup>30</sup>.

As always, care is needed to accurately understand the detail of what was done, as in the case where a Public Contributor undertook two telephone interviews from her own home, but with an academic researcher 'in attendance for support'<sup>31</sup>.

Online interviews may be conducted via the internet (perhaps using MS Teams or Zoom) and again, NSPIs may lead these with academic colleagues either absent or taking up shadowy roles in the background. In the study by Giles et al<sup>32</sup>, four NSPIs conducted 12 online interviews, with an academic setting up the call, starting the recording, being available should they be needed during the interview and closing it down at the end, so this does not really qualify as a solo interview as we

do not know how much they intervened and even their silent presence will have influenced the process. Elsewhere in this report, there are numerous examples of NSPIs conducting their interviews in person and alone.

## Venue

Dewa and team<sup>33</sup> sited the interview in the office of the service and positioned the academic interviewer in the next room and the psychiatrist in the building, both ready to jump into action should they be needed during the interview. In contrast, four NSPIs arranged to visit the 13 study respondents in their homes and conducted the interview there<sup>34</sup>. In another study, five NSPIs conducted 17 interviews but did not specify the location<sup>35</sup>.

## Fragile interviewer

One of the major reasons for deploying NSPIs is to present an acceptable face to potential respondents, who would otherwise be reluctant to trust their information to the academic researcher. Ethics Committees are likely to insist on additional safeguards where the interviewers are members of a group considered to be fragile and they may go as far as shutting NSPIs out of the interview room. This is a contentious matter, as illustrated by a study of preconception and maternity care<sup>36</sup>, where some of the academic researchers had relevant lived experience, but who may have been seen as less in need of formal care and protection than peer researchers from smaller and more stigmatised groups in society.

Distress Protocols are designed to protect everyone involved in conducting research, but do not routinely include NSPIs, although a solution has been proposed<sup>37</sup>. Lushey and Munro engaged 23 care leavers aged 18-25 to interview 65 care leavers<sup>38</sup>, while eighteen NSPIs aged 16-20 conducted 154 interviews in the Royal Borough of Kensington and Chelsea<sup>39</sup>. Crane and colleagues engaged two peer researchers with experience of homelessness to carry out 49 in-person interviews, although in some of them the peer was “accompanied by a research team member for support”<sup>40</sup>

## Vulnerable respondents and sensitive topics

When respondents are considered to belong to a vulnerable group or the topic under study is deemed delicate or sensitive, the more likely it is that the professional duty of care will be activated to design extra safeguards or, on occasion, shut down the opportunity.

- 4 illicit drug users conducted 52 interviews as they had ‘privileged access’ to this group<sup>41</sup>.
- 10 peers interviewed 201 sex workers<sup>42</sup>.
- 4 NSPIs conducted interviews with PPI group members and also with staff, straddling a significant power gradient<sup>43</sup>.

## Underpinning ideas

Data collection interviews carried out by NSPIs lie at the confluence of several streams of thought in health research. The most significant here are *Patient and Public Involvement and Engagement* (PPIE) which aims to coproduce research with Public Contributors, *Insider Research* which assumes

that respondents form an exclusive community and culture that can only be fully understood by people with membership through lived experience, and *Community-Based Participatory Research* (CBPR) which aims to shift the research out of the university and into the community. A starting point for this paper is therefore to search Google Scholar using the search terms 'CBPR, PPIE' and then follow the leads that arise from papers published in the Open Access press.

It also helps to name approaches that neighbour our topic yet are distinct from it. These include:

- **autoethnography** where researchers have, by accident or design, lived through the experience under scrutiny and then written about it. An early example arose in the USA when Madeleine Z Doty got herself imprisoned so that she could write and subsequently publish a diary of her incarceration<sup>44</sup>.
- Martin et al's research<sup>45</sup> invited women in prison to collect **self-reported data** and these were analysed by the research team. These are, of course, alternatives to one person interviewing another.
- If some study participants are to be interviewed by a NSPI and others by an academic, then each study participant may like to choose, rather than the academic team randomly assigning them.

## Benefits of Nonsalaried Solo Public Interviewers

*"I felt her [NSPI's] warm personality and humour shone through, and this made it very easy to build up a rapport with her quickly and therefore make more effort to contribute. There was careful and gentle questioning, never intrusive, and she encouraged me carefully to think of other things I might have missed. Throughout the interviews I have had with her, I felt I was a real person and not an object of research."*<sup>46</sup>

Potential benefits have been suggested as follows:

- Improving access to seldom engaged groups who consider the peer to be an 'acceptable face' of the research study<sup>47</sup>
- Reducing perceived power over participants compared with academic interviewers<sup>48</sup>
- Gaining trust and rapport<sup>49</sup> which enhances disclosure and so provides fuller and more honest responses from respondents<sup>50</sup>
- More checking of understanding, meaning and significance of what is said<sup>51</sup>.

Clark et al<sup>52</sup> engaged two NSPIs and two staff researchers and then randomly assigned 120 mental health patients between these two groups, finding that patients were more likely to report dissatisfaction with services to the clients. Jorgensen and colleagues compared the data derived from 1:1 interviews conducted by NSPIs with data from 2:1 interviews cofacilitated by a Public Contributor and an academic researcher<sup>53</sup>.

## Why are NSPIs rare?

Multiple factors may be impeding the adoption and deployment of NSPIs, as follows:

- **Yesterday's News.** Some of the innovative work on engagement and support for NSPIs was carried out twenty years ago, and the findings are perhaps not considered applicable to today's managerialist and risk-averse organisational culture.
- **Duty of Care.** Distress Protocols need to be broadened to encompass NSPIs, especially where they are stereotyped as vulnerable. A solution has been proposed<sup>54</sup>.
- **Procedural impediments.** The UK National Health Service has specific concerns about the safety of its patients and therefore regulates access to patients. This system (DBS checks, Letter of Access etc) is not currently designed to ease the process by which approved Public Contributors may meet with patients for data collection purposes. Advice about this complex technical matter is available<sup>55</sup>, much of which is applicable to NSPIs, but these solutions are not well known or implemented.
- **Too informal.** Risks to the organisation are managed through recruitment and human resources management (but NSPIs are not employed), training (but NSPIs are not qualified in research), regulation (but NSPIs are not a regulated profession guided by clear standards) and the procedural systems mentioned above.
- **Weaker versions are available.** Expectations regarding PPIE may be satisfied by recruiting a qualified researcher who also has lived experience rather than engaging nonsalaried persons, forming an advisory group rather than engaging NSPIs, inviting Public Contributors to design the interview topic guide or analyse the data rather than conduct the interview, sending out surveys rather than meeting the study respondent in person, or chaperoning the peer rather than permitting them to collect data on their own.

## How this paper is being written

The investigation that generated this paper is driven by simple curiosity. The work is unfunded and is conducted as a piece of citizen science rather than under the control of any organisation.

Accountability is achieved by following the *Writing in Public* framework<sup>56</sup>. I am grateful to the people<sup>57</sup> who have contributed to this evolving resource but bear responsibility as author for the text appearing here<sup>58</sup>. Please send your suggestions for further improvements.

Weaknesses of the approach taken in this exploration include the lack of prospective ethics oversight from a Research Ethics Committee, which would offer an independent opinion before commencement, the absence of a formal confidentiality and anonymity protocol, and prior informed consent from participants about attribution and how their contributions will be presented. These matters could be repaired if an academic team took up the challenge of investigating the role of NSPIs.

## Appendix: Detailed definition of NSPI

This resource paper has a very precise and narrow focus, as summarised in the table below. We must hastily observe that the practices that are described in the right-hand column are not bad; but simply lie beyond the scope of this resource paper. Further, this paper does not contain much general advice about PPI, qualitative research or interviews, but rather attends to the specific

additional things we need to know that distinguish NSPIs from all other activities of Public Contributors.

In focus	In contrast to...
<b>Citizens</b> – NSPIs enter their role with no prior status as employees and have no formal contract of employment with the research organisation or Service Level Agreement with a partner organisation which would accept formal responsibility for them and hold legal liability if something went wrong.	<ol style="list-style-type: none"> <li>(1) Qualified and salaried researchers who have lived experience.</li> <li>(2) Salaried staff from patient organisations who join the research team, whether they have relevant lived experience or not.</li> <li>(3) People with lived experience who are recognised members of formally constituted user-led or community organisations that hold employer’s liability insurance and other legal protection required by the contracting process.</li> </ol>
<b>Nonsalaried</b> – NSPIs are offered a PPI payment for conducting interviews for the purpose of data collection	People with lived experience who are paid for their activities on the research team through a contract of employment, contract for supply or secondment agreement <sup>59</sup> .
<b>Fragments of time</b> – NSPIs are engaged for brief and nonrecurrent tasks, easing the process of stepping into them or stepping down. This opens access to people who would be otherwise excluded, unable or unwilling to accept a contract of employment.	If the Public Contributor is expected to commit time to the project comparable to that of academic staff (a statistician or medical ethics specialist, for example), then they should be offered a contract of employment rather than PPI payments <sup>60</sup> . Using the PPI Budget to fund such appointments does not satisfy the goal of this paper.
<b>Public Contributors</b> who conduct interviews	Study participants who contribute data for analysis by the research team. This includes occasions when Public Contributors become the subject of investigation and are interviewed, perhaps to inform a report on the process through which PPIE was carried out.
<b>Communication</b> – the interview may be conducted in via any medium, including in-person, video or telephone.	Other data collection formats carried out beyond the interview conversation itself, such as surveys, observations <sup>61</sup> , wearable technology or self-report mechanisms (including patient-reported outcome measurement).
<b>Solo interviewer</b> acting alone	Any data collection activity that puts more than one person into the role of data collector, even if that person (such as an academic researcher) is nonspeaking. For the moment, this also excludes personal assistants and carers supporting the interviewer – this is discussed elsewhere <sup>62</sup> .
<b>Single study respondent</b>	Focus groups <sup>63</sup> or any other activity where the interview respondent is accompanied by others, whether they are study respondents, carers, interpreters or other people using the space.

In focus	In contrast to...
<b>Interview style</b> – any style of interview, ranging from rigidly controlled and directed through semi-structured to open-ended and participant-led interviews where the topics discussed, agenda, timing and data format are selected by the respondent.	An academic who selects a participant-led interview style and remains in role as the data collector has not met the requirement here, which insists that the role of data collector is transferred to a NSPI.
<b>Data collection</b> – interviews are carried out by the Public Contributors to add to the pool of data for analysis.	Commenting on the interview Topic Guide or piloting the interview to check it is robust and suggest improvements <sup>64</sup> . Talking to people to inform them about the study, gain their informed consent, recruit them to the study and screen them for eligibility <sup>65</sup> . Participating in analysis and interpretation of the data which is gleaned from the interview. Participating in an interview panel for the purpose of recruiting, selecting and appointing staff.

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<sup>1</sup> [https://peterbates.org.uk/wp-content/uploads/2017/04/how\\_to\\_make\\_sense\\_of\\_our\\_payments\\_offer.pdf](https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_make_sense_of_our_payments_offer.pdf).

<sup>2</sup> Minkler M, Fadem P, Perry M, Blum K, Moore L & Rogers J (2002) Ethical dilemmas in participatory action research: a case study from the disability community. *Health Education & Behavior*. Feb;29(1):14-29. **Also** Evans D, Bird E, Gibson A, Grier S, Chin TL, Stoddart M, MacGowan A, North Bristol Microbiology Patient Panel, Berry E, Campbell R & Kane N (2018) Extent, quality and impact of patient and public involvement in antimicrobial drug development research: a systematic review. *Health Expectations*. Feb;21(1):75-81. **Also** Eleven Community Researchers reached 240 women, some or all of whom were interviewed – see Meyer MC, Torres S, Cermeño N, MacLean L, Monzón R. Immigrant women implementing participatory research in health promotion. *Western Journal of Nursing Research*. 2003 Nov;25(7):815-34. **Also** unknown members of the Patient’s Council conducted an unknown number of interviews in Taylor J, Dekker S, Jurg D, Skandsen J, Grossman M, Marijnissen AK, Ladel C, Mobasheri A, Larkin J, Weinans H & Kanter-Schlifke I (2021) Making the patient voice heard in a research consortium: experiences from an EU project (IMI-APPROACH). *Research involvement and engagement*. May 10;7(1):24.

<sup>3</sup> Croft and colleagues label this group ‘peer researchers’ – see Croft B, Ostrow L, Italia L, Camp-Bernard A & Jacobs Y (2016) Peer interviewers in mental health services research. *The Journal of Mental Health Training, Education and Practice*. Sep 12;11(4):234-43. **Also** Grundy and team employed a fully qualified academic researcher who also had lived experience – see Grundy A, Keetharuth AD, Barber R, Carlton J, Connell J, Taylor Buck E, Barkham M, Ricketts T, Robotham D, Rose D & Kay J (2019) Public involvement in health outcomes research: lessons learnt from the development of the recovering quality of life (ReQoL) measures. *Health and quality of life outcomes*. Apr 11;17(1):60. **Also** Sometimes specific roles are established that embody the dual qualified contribution of their occupants, such as that held by Diana Rose, Professor of User-led Research at the Institute of Psychiatry, King’s College London. Two such staff conducted twenty 1:1 interviews in Csipke E, Papoulias C, Vitoratou S, Williams P, Rose D & Wykes T (2016) Design in mind: eliciting service user and frontline staff perspectives on psychiatric ward design through participatory methods. *Journal of Mental Health*. Mar 3;25(2):114-21.

<sup>4</sup> <https://peterbates.org.uk/wp-content/uploads/2023/11/Short-How-to-involve-the-public-on-staff-appointment-panels.pdf>. Most citizens interpret the term ‘recruitment’ as the way in which an employee finds a suitable employee, while researchers take it to mean finding eligible and consenting study participants. For more on experts by experience as HR recruitment and selection panellists, see Baxter S, Clowes M, Muir D,

Baird W, Broadway-Parkinson A & Bennett C (2017) Supporting public involvement in interview and other panels: a systematic review. *Health Expectations*. Oct;20(5):807-17.

<sup>5</sup> Bates P (2026) Going cheap on expenses.

<sup>6</sup> Crane M, Joly L, Daly BJ, Daly B, Gage H, Manthorpe J, Cetrano G, Ford C & Williams P (2023) Integration, effectiveness and costs of different models of primary health care provision for people who are homeless: an evaluation study. *Health and social care delivery research*. Oct 6;11(16):1-217.

<sup>7</sup> Ajayi S, Bowyer T, Hicks A, Larsen J, Mailey P, Sayers R & Smith R (2009) *Getting back into the world: Reflections on lived experiences of recovery*. London: Rethink recovery series.

<sup>8</sup> Faulkner's team deployed four 'survivor researchers', two of whom were employed. In total, they carried out 23 one-to-one interviews. The paper is not clear on the precise status of the two who were not employed – whether they were engaged on a zero-hours contract as casual staff or in receipt of PPI payments. Faulkner A, Carr S, Gould D, Khisa C, Hafford-Letchfield T, Cohen R, Megele C, Holley J. 'Dignity and respect': An example of service user leadership and co-production in mental health research. *Health Expectations*. 2021 May;24:10-9.

<sup>9</sup> [https://peterbates.org.uk/wp-content/uploads/2017/04/how\\_to\\_take\\_your\\_lived\\_experience\\_to\\_work.pdf](https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_take_your_lived_experience_to_work.pdf). Also <https://peterbates.org.uk/wp-content/uploads/2022/12/Capability-Adjusted.pdf>.

<sup>10</sup> [UK Policy Framework for Health and Social Care Research](#) paragraph 9.16.

<sup>11</sup> Repper J. (2008) Carers of people with mental health problems. Chapter in Brooker, C. and Repper, J. (Eds) *Mental Health: From Policy to Practice* Edinburgh: Bailliere Tindall.

<sup>12</sup> Golijani-Moghaddam N, Dawson DL, Evangelou N, Turton J, Hawton A, Goodwin E, Law GR, Asghar Z, Roche B, Rowan E, Burge R. Feasibility and acceptability of Strengthening Mental Abilities with Relational Training (SMART) for cognitive difficulties in multiple sclerosis: a randomised controlled trial. *Research Square*.

<sup>13</sup> Dewa LH, Lawrence-Jones A, Crandell C, Jaques J, Pickles K, Lavelle M, Pappa S, Aylin P. Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties. *Health Expectations*. 2021 May;24:134-46.

<sup>14</sup> Boutry C, Hagyar-Donaldson P, Hill A, Mauger F, Mays C, Macauley C, Covington M, Wynn R, Simpson K, Cordrey M & Highton F (2026) Preparation for online psychological therapy for depression in people living with and beyond cancer in East Midlands NHS primary and secondary care services in England: protocol for the PROSPER randomised controlled trial. *BMJ open*. May;16(5):e108442.

<sup>15</sup> Phelps EE, Tutton E, Gould J, Baird L, Achten J & Costa ML (2026) Negotiating research in the Emergency Department: a qualitative study of staff experience of the Distal Radius Acute Fracture Trial CAsT versus SPLint (DRAFT3-CASP) RCT for distal radius fractures. *Bone & Joint Open*. May 19;7(5):667-73.

<sup>16</sup> Taylor and colleagues engaged people 'near to and after release' from prison as Peer Researchers to act as respondents in mock interviews to train academics. See Taylor C, Gill L, Gibson A, Byng R, Quinn C. Engaging "seldom heard" groups in research and intervention development: Offender mental health. *Health Expectations*. 2018 Dec;21(6):1104-10. Also Public Contributors helped to trial the interview schedule in Konioutou M, Evans BA, Chatters R, Fothergill R, Garnsworthy C, Gaze S, Halter M, Mason S, Peconi J, Porter A, Siriwardena AN. Involving older people in a multi-centre randomised trial of a complex intervention in pre-hospital emergency care: implementation of a collaborative model. *Trials*. 2015 Jul 10;16(1):298.

<sup>17</sup> In the study led by Mehay, seven community researchers were trained and supported to conduct recruitment interviews and collect follow-up data in respondent's first language. So here we see a shift away from the full qualitative interview to the lesser task of 'recruitment interview' and possibly a shift away from qualitative interviewing into data collection. Mehay A, Box L, Manning K, Lodder A, Patel TB, Clutterbuck D, Butt J & Watt RG (2026) From tokenism to transformation: lessons from the TOGETHER study for building inclusive and equitable research. *Research Involvement and Engagement*. Mar 30.

<sup>18</sup> Reed et al engaged 35 lay people to conduct data collection interviews (mostly 1:1 interviews) for their research, interview notes were passed back to the individual interviewee for confirmation, and the large numbers created interesting challenges for collaborative data analysis. See Reed J, Pearson P, Douglas B,

Swinburne S & Wilding H (2002) Going home from hospital – an appreciative inquiry study *Health and Social Care in the Community* **10**(1), 36–45. **Also** Golijani-Moghaddam and colleagues (op cit) trained three Patient Partners to conduct feedback interviews with study participants. The Patient Partners were involved in other steps of the research journey too - the interview transcripts were independently coded by researchers, including the trained Patient Partners, with regular team discussions to support reflexivity and consistency.

<sup>19</sup> Edgren et al engaged 41 community members and trained them before they made home visits to 331 families where a child had asthma. They carried out allergy skin-prick testing, maintained atmosphere testing machines, collected survey data and a sample of dust, walked through homes to assess the environment, but did not conduct a traditional interview. Edgren KK, Parker EA, Israel BA, Lewis TC, Salinas MA, Robins TG & Hill YR (2005) Community involvement in the conduct of a health education intervention and research project: Community Action Against Asthma. *Health Promotion Practice*. Jul;6(3):263-9.

<sup>20</sup> Jin H, Green R, Sanders F, Penn A, Moschoyiannis S, Carneiro G, Chen T, Gage H, Touray M & Nicholson C (2026) The Care-Full Study: assessing the feasibility of a mixed-method longitudinal data collection approach for unpaid carers of people with multiple long-term conditions. *NIHR Open Research*. Feb 16;6:14.

<sup>21</sup> Gross O, Garabedian N, Richard C, Citrini M, Sannié T & Gagnayre R (2020) Educational content and challenges encountered when training service user representatives as peer researchers in a mixed study on patient experience of hospital safety. *Research Involvement and Engagement*. Sep 1;6(1):50.

<sup>22</sup> For example, the phrase focus group interview appears in Bourque CJ, Bonanno M, Dumont E, Gaucher N, Lacoste-Julien A, Gomez-Tyo M, Langlet MF & Sultan S (2020) The integration of resource patients in collaborative research: a mixed method assessment of the nesting dolls design. *Patient Education and Counselling*. Sep 1;103(9):1830-8.

<sup>23</sup> Mehay A, Box L, Manning K, Lodder A, Patel TB, Clutterbuck D, Butt J & Watt RG (2026) From tokenism to transformation: lessons from the TOGETHER study for building inclusive and equitable research. *Research Involvement and Engagement*. Mar 30.

<sup>24</sup> <https://peterbates.org.uk/wp-content/uploads/2019/12/How-to-involve-people-as-research-co-interviewers.pdf>. Montgomery et al's study illustrate this as learning disabled peer researchers are paired with academics to conduct 2:1 interviews with respondents, meaning that there are three people present in each interview. Montgomery L, Kelly B, Campbell U, Davidson G, Gibson L, Hughes L, Menham J, McKendry L, Newton LA, Parkinson A & Redmond E (2022) 'Getting our voices heard in research: A review of peer researcher's roles and experiences on a qualitative study of adult safeguarding policy. *Research Involvement and Engagement*. Nov 28;8(1):64.

<sup>25</sup> <https://peterbates.org.uk/wp-content/uploads/2017/04/How-To-co-facilitate-a-focus-group.pdf>.

<sup>26</sup> Blake H, Abbott-Fleming V, Greaves S et al (2025) Five years of patient and public involvement and engagement (PPIE) in the development and evaluation of the Pain-at-Work toolkit to support employees' self-management of chronic pain at work. *Research Involvement & Engagement* **11**, 81. <https://doi.org/10.1186/s40900-025-00757-5>

<sup>27</sup> In the study led by Marent, we can see that peer researchers were recruited and trained, and that seven interviews were conducted by community partners in local languages, perhaps with support from interpreters. It is much harder to be certain whether or not these were 1:1 interviews. See Marent B, Henwood F, Darking M & EmERGE Consortium (2018) Ambivalence in digital health: Co-designing an mHealth platform for HIV care. *Social Science & Medicine*. Oct 1;215:133-41. **Also**, peer interviewers conducted 49 interviews with homeless people, working alone or accompanied by a research team member for support – so we do not know how many solo interviews were undertaken. See Crane et al (2023) op cit.

<sup>28</sup> Morant N, Azam K, Johnson S & Moncrieff J (2018) The least worst option: user experiences of antipsychotic medication and lack of involvement in medication decisions in a UK community sample. *Journal of Mental Health*. Jul 4;27(4):322-8.

- <sup>29</sup> Battista S, Parker J, Ching A, Culley J, Long S, Heard A, Hammond A, Radford K, Holland P, O'Neill T & Walker-Bone K (2025) WORKWELL process evaluation: qualitative data analyses of the participant interviews at 12-and 36-month follow-ups. *Rheumatology Advances in Practice*. 9(2):rkaf034.
- <sup>30</sup> Wilson P, Mathie E, Keenan J, McNeilly E, Goodman C, Howe A, Poland F, Staniszewska S, Kendall S, Munday D & Cowe M (2015) ReseArch with Patient and Public involvement: a RealisT evaluation-the RAPPORT study. *Health services and delivery research*.3(38).
- <sup>31</sup> The following example is ineligible for inclusion in this resource paper. The academic researcher is quoted: "I saw myself primarily as support for the technical equipment and listened to the conversation but did not take part...very occasionally [the PPI contributor] turned to me for clarification but otherwise their interview was a two way conversation." See Mathie E, Wythe H, Munday D, Rhodes G, Vicary P, Millac P & Jones J (2018) Regional working in the East of England: using the UK National Standards for Public Involvement. *Research involvement and engagement*. Dec 6;4(1):48.
- <sup>32</sup> Giles EL, Eskandari F, McGeechan G, Scott S, Lake AA, Teasdale S, Ekers D, Augustine A, Le Sauvage N, Lynch C & Moore H (2024) Food insecurity in adults with severe mental illness living in Northern England: Peer research interview findings. *International Journal of Mental Health Nursing*. Jun;33(3):671-82.
- <sup>33</sup> Dewa LH, Lawrence-Jones A, Crandell C, Jaques J, Pickles K, Lavelle M, Pappa S, Aylin P. Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties. *Health Expectations*. 2021 May;24:134-46.
- <sup>34</sup> Kelly B, McShane T, Davidson G, Pinkerton J, Gilligan E & Webb P (2016) *You only leave once? Transitions and outcomes for care leavers with mental health and/or intellectual disabilities*. Published online at [research.hscni.net/sites/default/files/YOLO Final Report.pdf](https://research.hscni.net/sites/default/files/YOLO%20Final%20Report.pdf).
- <sup>35</sup> Bianchi L, Kelemen M, Shivji AK, Tallant J & Timmons S (2025) The Role of Boundary Spanning in Building Trust: A Place-Based Study on Engaging Hardly Reached Groups in Community Healthcare Settings. *Sociology of Health & Illness*. Jan;47(1):e13870.
- <sup>36</sup> Hanley SJ, McCann S, Lee SI, Schoenaker D, Singh M, Moss N, Nishshanka NM, Vowles Z, Plachcinski R, Nirantharakumar K & Black M. 'It was a bit of a now or never situation': Experiences of preconception care and support for women with multiple long-term health conditions. *Health Expectations*. 2026 Feb;29(1):e70583.
- <sup>37</sup> <https://peterbates.org.uk/wp-content/uploads/2021/06/How-to-respond-to-distress.pdf>.
- <sup>38</sup> Lushey CJ & Munro ER. Participatory peer research methodology: An effective method for obtaining young people's perspectives on transitions from care to adulthood? *Qualitative Social Work*. 2015 Jul;14(4):522-37.
- <sup>39</sup> See RBKC (2018) *Youth Review Engagement Findings*. [rbkc.gov.uk/sites/default/files/media/documents/Youth Review Engagement Findings Report.pdf](https://rbkc.gov.uk/sites/default/files/media/documents/Youth%20Review%20Engagement%20Findings%20Report.pdf). Some might argue that the local authority commissioning this work would have a lower standard of ethical scrutiny compared with a university or NHS organisation, but it is important to remember that they have statutory duties in respect of safeguarding.
- <sup>40</sup> Page 22 of Crane et al (2023) op cit.
- <sup>41</sup> Elliott E, Watson AJ & Harries U. Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expectations*. 2002 Jun;5(2):172-8.
- <sup>42</sup> Benoit C, Jansson M, Millar A & Phillips R (2005) Community-academic research on hard-to-reach populations: Benefits and challenges. *Qualitative health research*. Feb;15(2):263-82. **Also** Benoit C, Millar A. [Dispelling myths and understanding realities: Working conditions, health status, and exiting experiences of sex workers](#).
- <sup>43</sup> Hovén E, Eriksson L, Månsson D'Souza Å, Sörensen J, Hill D, Viklund C, Wettergren L & Lampic C (2020) What makes it work? Exploring experiences of patient research partners and researchers involved in a long-term co-creative research collaboration. *Research involvement and engagement*. Jun 19;6(1):33.
- <sup>44</sup> Doty MZ. *Society's misfits*. Century; 1916.

<sup>45</sup> Martin RE, Murphy K, Hanson D, Hemingway C, Ramsden V, Buxton J, Granger-Brown A, Condello L-L, Buchanan M, Espinoza-Magana N, Edworthy G & Hislop TG (2009) The development of participatory health research among incarcerated women in a Canadian prison. *International Journal of Prisoner Health*, 5(2), 95–107.

<sup>46</sup> Wilson et al (2015) op cit.

<sup>47</sup> Elliott E, Watson AJ & Harries U (2002) op cit.

<sup>48</sup> Lushey & Munro (2015) op cit.

<sup>49</sup> Taylor J, Rahilly T & Hunter H. *Children who go missing from care: A participatory project with young people as peer interviewers*. NSPCC; Quarriers; 2012. **Also** Devotta K, Woodhall-Melnik J, Pedersen C, et al (2016) Enriching qualitative research by engaging peer interviewers: a case study. *Qualitative Research*. 16:661-680.

<sup>50</sup> Croft B, Ostrow L, Italia L, Camp-Bernard A & Jacobs Y (2016) Peer interviewers in mental health services research. *Journal of Mental Health Training, Education and Practice*. 11:234-243. **Also** Fleming J, Goodman Chong H & Skinner A (2009) Experiences of Peer Evaluation of the Leicester Teenage Pregnancy Prevention Strategy. *Children and Society*. 23:279-290.

<sup>51</sup> Thomson J, Lanchin S & Moxon D (2015) *Be real with me: Using peer research to explore the journeys of young people who run away from home or care*. London: The Railway Children.

<sup>52</sup> Clark CC, Scott EA, Boydell KM & Goering P (1999) Effects of client interviewers on client-reported satisfaction with mental health services. *Psychiatric Services*. Jul;50(7):961-3.

<sup>53</sup> Jørgensen CR, Eskildsen NB, Thomsen TG, Nielsen ID & Johnsen AT (2018) The impact of using peer interviewers in a study of patient empowerment amongst people in cancer follow-up. *Health Expectations*. Jun;21(3):620-7.

<sup>54</sup> <https://peterbates.org.uk/wp-content/uploads/2021/06/How-to-respond-to-distress.pdf>.

<sup>55</sup> <https://peterbates.org.uk/wp-content/uploads/2025/01/How-to-get-approval-for-Public-Contributors-to-interview-NHS-patients.pdf>. **Also** Bowness B, Bates P, Chauhan A, Osman Y, Shlovogt T & Lawrence V (2025) Public co-researchers in research: approved in principle, undermined in practice? *Research Involvement and Engagement* 11, 63 (2025). <https://doi.org/10.1186/s40900-025-00708-0>

<sup>56</sup> Bates P (2024) [How-to-write-in-public.pdf \(peterbates.org.uk\)](https://peterbates.org.uk/wp-content/uploads/2024/01/How-to-write-in-public.pdf).

<sup>57</sup> Feedback was gratefully received from nobody yet.

<sup>58</sup> Readers engage with the contents of this paper at their own risk and undertake not to hold the author liable for any injury, loss, or damage arising through reading or acting on its contents. 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@outlook.com](mailto:peter.bates96@outlook.com) providing details, and public access to the offending work will be removed immediately.

<sup>59</sup> Croft and team describe a four-year project that employed people with lived experience as peer researchers. See Croft B, Ostrow L, Italia L, Camp-Bernard A & Jacobs Y (2016) Peer interviewers in mental health services research. *The Journal of Mental Health Training, Education and Practice*. Sep 12;11(4):234-43. **Also** Devotta et al describe a project where they employed 3 people with lived experience of homelessness, drug use or problem gambling who then conducted 30 interviews. Devotta K, Woodhall-Melnik J, Pedersen C, Wendaferew A, Dowbor TP, Guilcher SJ, Hamilton-Wright S, Ferentzy P, Hwang SW & Matheson FI (2016) Enriching qualitative research by engaging peer interviewers: a case study. *Qualitative research*. Dec;16(6):661-80.

<sup>60</sup> Advice on appointing mental health service users to a dedicated post in the research team is provided by Delman J & Lincoln A (2009) Service users as paid researchers. Chapter 10 in *Handbook of service user involvement in mental health research*. Apr 17:139-51.

<sup>61</sup> Edgren et al engaged 41 community members and trained them before they made home visits to 331 families where a child had asthma. They carried out allergy skin-prick testing, maintained atmosphere testing machines, collected survey data and a sample of dust, walked through homes to assess the environment, but

did not conduct a traditional interview. Edgren KK, Parker EA, Israel BA, Lewis TC, Salinas MA, Robins TG, Hill YR. Community involvement in the conduct of a health education intervention and research project: Community Action Against Asthma. *Health Promotion Practice*. 2005 Jul;6(3):263-9.

<sup>62</sup> See [How to involve people as research co-interviewers](#).

<sup>63</sup> Taylor et al use the language of 'interview' and 'peer interviewer', but the study design consisted of Focus Groups where the academic was present but did not take part. Taylor J, Rahilly T, Hunter H, Bradbury-Jones C, Sanford K, Caruthers B. [Children who go missing from care: A participatory project with young people as peer interviewers](#).

<sup>64</sup> Public Contributors piloted the interview in Madden M, Morris S, Ogden M, Lewis D, Stewart D, McCambridge J. Producing co-production: reflections on the development of a complex intervention. *Health Expectations*. 2020 Jun;23(3):659-69.

<sup>65</sup> A community member was trained by research staff to recruit and screen participants – but not conduct the interview itself – in Areán PA, Alvidrez J, Nery R, Estes C, Linkins K. Recruitment and retention of older minorities in mental health services research. *Gerontologist* 2003; 43:36-44. doi:10.1093/geront/43.1.36. The same work is also reported in Areán PA, Gum A, McCulloch CE, Bostrom A, Gallagher-Thompson D, Thompson L. Treatment of depression in low-income older adults. *Psychology and Aging* 2005;20:601-9. doi:10.1037/0882-7974.20.4.601.