Hunting the Snark: Must we abandon all safeguards?

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Contents

Introduction

In a previous paper, *Hunting the Snark: Have Public Contributors collected research data on their own?* I found and reviewed 100 papers that suggested the possibility of deploying Solo Public Interviewers. These are people with lived experience who are not formally qualified as researchers and have no contract of employment, yet conduct one-to one data collection interviews for research purposes on their own. That investigation found over one thousand people who met some or all of these criteria and who had interviewed over 16,000 people.

Despite these large numbers, the practice is extremely rare and there are many reasons for this. One possible explanation is the labyrinthine procedure for granting permission to the Public Interviewer to meet NHS patients, which I have analysed elsewhere. A second, as revealed by the previous *Snark* paper, is that inconsistent terminology and weak reporting has made it difficult to find precedents, which form an essential comfort for pioneers and regulators in academia. A further eight issues are elaborated in the paragraphs below, grouped in two blocks of four. My personal reflections shape these items as well as some of the highlights from the 100 papers examined in this *Snark* review.

SPIs lack traditional governance safeguards

The following paragraphs suggest a journey from the traditional way to engage academics in collecting data for research purposes towards the specific role of the SPI. Each succeeding section strips away another protective element which is held by the academic interviewer, points to studies that have found a way to engage SPIs and, where available, 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 will help to create a workforce where some staff have lived experience relevant to the issue being studied by the research team[1]. Public Contributors may have served on selection panels and so helped to appoint staff who have the right lived and academic experience[2]. Having passed the regular suitability tests (right to work in the UK and criminal background, health and competence) and been offered a contract of employment, we hope that staff shelter under the best of human resource management, including a formal selection process committed to equality of opportunity, decent contract of employment, staff policies and procedures, grievance management, supervision and career pathways. Within this general statement, we note that there are differences in salary, terms and conditions as applied to staff employed on an annual salary, weekly wage or zero-hour contract.

The protections routinely afforded to employees are generally lacking in many PPIE ecosystems. PPI payments are often calculated at an hourly rate set above the national minimum wage[3] but many academic papers neglect to say whether the expert by experience is employed or not[4]. Even where it is stated, we might be curious about the arrangements, especially as definitions vary, with some using the term ‘salaried’ to mean anyone with a contract of employment, while others confine it to positions that enjoy higher pay, looser performance monitoring and better conditions. Some PPI budgets are disbursed through the payroll with PPI funds used to finance the staffing budget, while in the study by Wershler and Ronis[5], three SPIs aged 16-18 who were at risk of homelessness were

'paid' in shopping vouchers and bus tickets for conducting 187 interviews. This also leaves us guessing about the peer interviewers who "were employed through King's Talent Bank[6], those who were "self-employed and offered PPI payments"[7], and the seven involvement researchers who conducted 48 individual interviews and were 'paid per hour based on the current starting rate for a research officer'[8].

Some say that the task of conducting an interview is so vital to the research endeavour that it must always be matched with a contract of employment. From this perspective, SPIs are being exploited and should be offered a job. This paper takes a slightly different view – that there may be circumstances where SPIs are an appropriate response if the role occurs alongside a range of other innovations and reasonable adjustments. Employing people is good, but Public Contributors are needed too, as they bring a challenge from outside the research organisation[9]. Serving prisoners, asylum seekers, people with dementia and others may be unable to accept an employment contract, reluctant to endure the lengthy onboarding process and loath to reset their finances for what might be a very part-time and short-lived job – yet they can still add real 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. Public Contributors can help the research team draw closer to the lived experience of the people they are investigating.

Some research teams have found alternatives to the SPI role that build in contractual protections. Instead of engaging the SPI, they have either employed the expert by experience[10] or found a formally constituted community organisation that carries public liability insurance and contracted with that organisation to provide public voice as a service[11]. Such arrangements may provide better pay, although the details are often mysterious:

> One contributor was part of a peer-led research project, where they would be conducting interviews with research participants and be involved in analysis. *'Contracts were a bit of a nightmare, because I actually don't want to be employed, because I'm medically retired. So I had to, what they had to do was find a workaround where I had some kind of contract with the university, because… I was handling people's data, so I needed the protection of having a contract with the university.'*[12]

SPIs should be offered PPI payments for conducting data collection interviews, although some studies recruit unpaid volunteers to the role[13]. On rare occasions the PPIE role does become 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 SPIs. 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.

Where potential research respondents are under the care of the NHS, the following guidance is pertinent:

> *Researchers with no contractual relationship with the NHS require an honorary research contract only if the planned activities of the researcher involve interacting with individuals in a way that has a direct bearing on the quality of their care, i.e. the researcher could foreseeably directly affect the type, quality or extent of prevention, diagnosis or treatment of*

> *illness or foreseeably cause injury or loss to patients or service users to whom the NHS organisation has a duty of care*[14].

This guidance shows that conducting a data-collection interview should not usually be considered to form an opportunity to 'directly affect the… prevention, diagnosis or treatment or foreseeably cause injury or loss…'. Salaried researchers may be asked for a 'Letter of Access' to permit them to interview NHS patients, and a critique of the current system is available elsewhere[15], along with recommendations for how arrangements can be adapted to suit SPIs.

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 considered 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 diverse employees. Whilst all this is good, and advice is available[16] to support such endeavours, the current paper goes further by showing that SPIs have been included as data collectors in a range of studies.

Some teams have responded by providing brief introductory training to SPIs, 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[17] since training must be relevant to the task.

Repper reported[18] on a training course for carers who were engaged as interviewers on ten sites to collect data for research purposes. Golijani-Moghaddam and colleagues[19] trained three Patient Partners to conduct interviews with study participants and included them in regular team discussions to support reflexivity and consistency. Dewa and team[20] 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[21], who intend to use motivational interviewing, nor Phelps et al[22], who applied Heideggerian Phenomenology to their interviews, engaged SPIs in the task. SPIs should be offered PPI payments for any training or other preparation they need prior to conducting data collection interviews. Engaging SPIs 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 identify and repair unethical and incompetent practice amongst SPIs. A midpoint was taken in a study[23] that trained Community Reporters and collected 23 lived-experience stories. The Community Reporters in this study were undergraduates, an arrangement that engaged several governance mechanisms.

High status interviewer

Salaried academic interviewers carry status and may be perceived as trustworthy. However, one of the major reasons for deploying SPIs is to present an acceptable face to potential respondents who might be reluctant to trust their information to the academic researcher. This shows that status is contextual, as in the example by Scharlach & Sanchez[24] who engaged ten members of a low income Latino community to conduct 210 solo interviews. 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 SPIs out of the interview room. This is a contentious matter, as illustrated by a study of preconception and maternity care[25], where some of the academic researchers had relevant lived experience, but would perhaps have been less likely to trigger stereotypical responses than peer researchers from more stigmatised groups in society.

Distress Protocols are designed to protect everyone involved in conducting research, but do not routinely include SPIs, although a solution has been proposed[26]. Lushey and Munro engaged 23 care leavers aged 18-25 to interview 65 care leavers[27], while eighteen SPIs aged 16-20 conducted 154 interviews in the Royal Borough of Kensington and Chelsea[28]. 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"[29] An unknown number of "former drug users, prostitutes, HIV positive persons, experienced outreach workers, etc." conducted a total of 1,839 interviews across ten European cities[30].

The harms that might be inflicted upon an interviewee by an incompetent interviewer can be mitigated in various ways. An extreme approach is to remove the distinction between interviewer and interviewee entirely by making them one and the same person. This approach is taken in autoethnographic researchers who 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[31]. In a lesser version, a small group of people can be both researcher and researched by interviewing one another, thus removing the need for a separate group of study respondents.

One mitigation would be to raise the level of DBS reporting (i.e. formal disclosure of criminal convictions) in response to perceived risks and vulnerabilities carried by the SPI. Whilst guidance[32] shows that the different levels of check may be applied to different circumstances, care is needed to avoid breaching privacy (GDPR) and legal obligations[33] by asking for unnecessary information, and most SPI arrangements justify no more than a Standard DBS check. This issue is examined in detail elsewhere[34].

These risks have been managed, as in the study by Tavecchio and colleagues[35], where five people with mild intellectual disabilities and severe behavioural problems conducted 23 interviews on their own. Livingston et al employed peer researchers to interview 60 mental health service users who

had been in contact with the Police, managing the risks of disclosure by not reporting the number of SPIs or their names[36] in the resulting publication.

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. Surveillance perhaps found its most extreme expression in the study led by Fields[37], where 74 prisoners were trained and then worked in pairs to interview each other – but oversight from prison officers was never far away. Academic papers supposedly reporting these practices need to be carefully evaluated, as some researchers[38] use ambiguous terms like 'Focus Group interview', leaving the reader uncertain of how many people are in the room and what actually happened[39].

When we start asking about the content of the interview, the problem gets worse. For example, seven SPIs carried out 'recruitment and follow-up' interviews with respondents in their first language[40], but it is unclear whether this was actually harvesting data for the study, or merely warming up the respondent for the main act – a data collection interview with an academic. Such arrangements support the inclusion of diverse research participants but also bring the risk of data being lost in translation and increase the chance that the interviewer and interviewee will already know one another[41].

Some research teams invite a Public Contributor and an academic researcher to cofacilitate an interview with a single study respondent[42] or a Focus Group[43], but bringing additional people into the interview space will affect the data. In such circumstances, the salaried staff member might take responsibility for the event and bear formal liability on behalf of the Public Contributor, but other processes can be at work too. Wexler[44] worked with nine young people who wanted to learn from their elders. In total, they conducted 17 interviews. With permission, other youth from the research team sat in and listened to the one-to-one interview, leaving the elder feeling that their wisdom was valued. Schneider et al[45] brought together 11 people into a series of face-to-face meetings where in turn each member took the role of interviewer and interviewee. As everyone witnessed every interview, this 'interview with audience' gradually evolved into a group interview where a volunteer was interviewed by the group with no-one designated as lead interviewer. Fleming et al[46] cryptically remark that the seven peer evaluators were 'never alone'.

In two-to-one interviews, if the Public Contributor asks a leading question which might compromise the data quality, their academic colleague can get the interview back on track. Equitable collaboration permits this arrangement to be reciprocal, so that the Public Contributor can challenge the academic too. When properly set up, other people in the room (witnesses, family members, personal assistants and translators) hold one another to account.

Where the SPI conducts an interview on their own, alternative protections need to be created. We can see some of the ways this was managed in a study where one PPIE-Partner conducted 15 interviews with working people who live with chronic pain[47]. Commitment to carry out the interview in an ethical and competent manner is fuelled when SPIs feel a sense of loyalty to the study itself or to a group. We might imagine that the five SPIs who carried out 19 interviews considered themselves accountable in this way, since all five were members of the same PPIE group[48] and owed an obligation to their fellow group members.

SPIs are deployed in risky situations

Data collection can be constructed in various different ways, with some options carrying more perceived risk than others. Thus, less structured interviews might be viewed as more risky than highly structured formats, face-to-face interviews are perceived as riskier than those carried out via remote media, interviewing people in their own homes rather than in an office. These options are discussed below.

Semi-structured rather than structured interview

SPIs are often involved in constructing a topic guide which they go on to use in a semi-structured interview format. Such 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 freedom available to the interviewer can be adjusted by structuring the interview itself – asking the interviewee to complete a questionnaire[49], or undergo physical, medical or environmental tests[50]. Such tests may be intrusive but the structure of the encounter can helpfully constrain an unreliable interviewer.

Some of the peer researchers in one study[51] acted as 'finders' by introducing potential interviewees to another researcher, rather than conducting the research themselves, while other peers were SPIs. Three peer researchers carried out 'check-in' interviews with 15 carers to augment data provided via other research methods[52]. The authors do not clarify which data are collected by SPIs and which by academics. Gross and colleagues[53] engaged eight Public Contributors who collected data from 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.

Risks can be mitigated by managing the encounter between researcher and respondent. In Martin et al's research[54], 190 women in prison designed, completed and analysed survey questionnaires but did not conduct face-to-face interviews.

In person rather than 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 that can be inspected at will.

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'[55].

Online interviews may be conducted via the internet (perhaps using MS Teams or Zoom) and again, SPIs may lead these with academic colleagues either absent or taking up shadowy roles in the background. In the study by Giles et al[56], four peer researchers conducted twelve online interviews, with an academic setting up the call, starting the recording, remaining as a supportive but largely silent observer throughout the interview, and closing it down at the end.

Greenwood et al's study[57] involved 22 interviews conducted in person, either by two Public Contributors working alongside each other, or by an SPI supported by an academic. Some risk

mitigation is achieved through recording the call, since its content can then be checked by an independent person.

At home rather than in the office

Dewa and team[58] 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 or immediately after the interview. In contrast, four SPIs arranged to visit the 13 study respondents in their homes and conducted the interview there[59]. Berg et al[60] employed two indigenous co-researchers, who invited interviewees to specify a preferred time and location for the interview. The 37 resulting interviews included one at midnight and another in the co-researchers car. In another study, five SPIs conducted 17 interviews but did not specify the location[61]. Whilst some might view the person's home as a location carrying higher levels of risk, it also places the respondent on home turf where they have the best chance of exercising their personal power.

The interview setting may offer a range of constraints and sanctions for regulating the conduct of a recalcitrant SPI. In the study by Livingston et al[62], five SPIs detained in a secure forensic hospital conducted 45 solo interviews in private with other inpatients and staff. All the SPIs were living within this controlling environment throughout the study and were offered PPI payments rather than being employed. Similarly, in the study by Torre and Fine[63], fifteen women who were serving long prison sentences interviewed 65 other prisoners.

Sensitive rather than safe topics

When respondents are lumped into a group deemed to be vulnerable or the topic under study is judged delicate or sensitive, the 'duty of care' notion may be activated to design extra safeguards or, on occasion, shut down the opportunity. If this happens to a whole category of people, such as where all NHS patients are treated as an amorphous group and subjected to restrictive practices, then this must be regarded as stereotyping and discrimination rather than risk management. Despite these issues, a number of studies have utilised SPIs, including:

- 4 illicit drug users conducted 52 interviews[64] and in another study, one illicit drug user conducted 11 interviews[65]
- 10 peers interviewed 201 sex workers[66].
- 9 peers interviewed 18 people with lived experience of domestic and sexual abuse against women facing multiple disadvantage[67].
- 4 SPIs conducted interviews with PPI group members and also with staff, straddling a significant power gradient[68].

Guidance from the NIHR indicates that suitable insurance, training, risk assessment and management and DBS checks are required for SPIs to mitigate risks:

> *It is essential that researchers check with host institutions that indemnity insurance is in place to cover public co-applicants. Some insurers will cover named public co-applicants under existing policies. Researchers should advise public co-applicants about whether or not this is available, and what the consequences might be if indemnity cover is not in place.*

> *If the public co-applicant's role includes direct contact with study participants (for example, if they will interview participants), the same policies apply as for research staff, including:*
>
> - *risk assessments to ensure the safety of the co-applicant*
> - *implementation of the institutional lone working policy which should be shared with the public co-applicant and followed*
> - *appropriate research governance training (this covers the various principles of good practice, and the requirements and standards when conducting health and social care research)*
> - *for direct, unsupervised contact with children and young people, or with vulnerable adults, they will need a Disclosure and Barring Service (DBS) check – this should be arranged through the host institution or organisation, and the cost covered by the research team.*[69]

This advice unhelpfully conflates the role of Public Co-Applicant[70] and SPI, but we must assume that it covers all SPIs. It is notable that it omits the need to strengthen the voice, choice and control held by the interviewee, even though such actions are important ways to reduce vulnerability. For example, if some study participants are to be interviewed by a SPI and others by an academic, then each individual participant may be permitted to choose their interviewer, rather than the academic team randomly assigning them.

Other possible reasons why SPIs are rare

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

- **Overlooked option.** The lack of clear and explicit reporting means that research teams don't even consider the possibility.
- **Yesterday's News.** Some of the innovative work on engagement and support for SPIs was carried out more than twenty years ago, and the findings may be considered inapplicable in today's managerialist and risk-averse organisational culture. These older examples are less likely to be found in Open Access online libraries and so may have been omitted from this resource paper.
- **Procedural impediments.** The UK National Health Service has specific concerns about the safety of its patients and therefore regulates access to patients. This system (Delegation Log, DBS checks, Letters 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[71], much of which is applicable to SPIs - but solutions are not well known or implemented.
- **Too informal.** Risks to the organisation are managed through recruitment and human resources management (but SPIs are not employed), training (but SPIs are not qualified in research), regulation (but SPIs are not a regulated profession guided by clear standards) and the procedural systems mentioned above.
- **Duty of Care.** Distress Protocols need to be broadened to encompass SPIs, especially where they are stereotyped as vulnerable. A solution has been proposed[72].
- **Weaker versions are available.** Stunted expectations regarding PPIE in data collection interviews may be satisfied by introducing Public Contributors to other aspects of the research production process rather than deploying them as SPIs. This might include:

- seeking advice on research priorities
- including Public Contributors on the panel that selects and appoints academic staff
- employing academic researchers who also have lived experience
- forming a lived experience advisory group to help manage the study
- creating patient-facing information, including the plain language summary of the findings
- Speaking at dissemination conferences and being interviewed by journalists[73].

Public Contributors can also carry out a range of the activities that surround the interview itself:

- market the opportunity to become a study participant to community audiences
- codesign the topic guide
- Collect data through a postal survey or co-facilitated Focus Group rather than interviews
- Ensure an academic researcher is present at all times so that the Public Interviewer is never alone.
- act as the respondent in mock interviews to test the topic guide and train academic staff to conduct the interview in their place[74]
- screen applicants[75]
- obtain consent[76]
- join in with data analysis[77].

Conclusion

Even the most ambitious studies – those that draw close to the goal of deploying Solo Public Interviewers – offer very little detail on how they have done it. A previous investigation examined the process whereby SPIs obtain permission to interview NHS patients, and here I propose a further eight factors which must be addressed. Sadly, there is little to guide us in the academic literature, but some ideas are presented here, mostly gleaned from the descriptions of what study teams actually did.

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[78]. Several people have been approached for comment[79] and I am grateful to those[80] who have responded to my inquiries. This is an evolving resource which I bear responsibility for as author of the text appearing here[81]. 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 SPIs.

[1] 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.

[2] 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.

[3] Bates P (2026) *Going cheap on expenses.*

[4] An exception is Guta et al who discuss the relative merits of employment and honoraria for community peer researchers as well as recruitment and selection, training and management. Guta A, Flicker S & Roche B (2010) *Peer Research in Action II: Management, Support, and Supervision*. Toronto: Wellesley Institute.

[5] Wershler JL & Ronis ST (2015) Psychosocial characteristics and service needs of Canadian suburban male youth at risk for homelessness. *Children and Youth Services Review*. Aug 1;55:29-36.

[6] The King's Talent Bank is an 'easy-to-use online platform gives you exclusive access to a wide range of temporary jobs, with fair pay aligned to King's College London rates, clear pay details and weekly payments—all in one convenient system.' See https://kingstalentbank.com/.

[7] 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.

[8] 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.

[9] 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.

[10] For example, Lynch and colleagues employed five care-experienced young people as Peer Researchers for up to 10 hours per month to support various parts of the research production, including 'shadowing, co-delivering and leading interviews with their supervising Research Fellow', which does not quite add up to the SPI role. Lynch A, Friel S, Munro ER, Sultana M, Hamilton CJ, Kerridge G, Oswick R, Pillay Mitchell T, Alderson H, Harrop C, McGovern R (2025) Developing care experienced young peoples' participation as peer researchers in an inter-disciplinary study: applying the 'Ability-Motivation-Opportunity' framework. *European Journal of Social Work*. Jul 4;28(4):782-97.

[11] For example, Sarah Carr and Associates Ltd is covered by both professional indemnity and public liability insurance to carry out 'mental health and social care research consultancy services including… Qualitative research and surveys… Co-production and patient and public involvement and engagement (PPIE).' **Also** The McPin Foundation is a registered charity and company limited by guarantee which is active in supporting public involvement and works in partnership with research organisations.

[12] Public contributor, Focus Group 2 in Brooks J, Chambers E, Misquitta P, Wharam S & Willcox A (2025) *Battling on all fronts: institutional barriers to public involvement in university research and teaching*. The text does not say who asserted that the Public Contributor needed a contract and why or in respect of which activity.

[13] Havir reported on 67 volunteers who conducted 1,125 telephone interviews - Havir L. An evaluation of older volunteers as telephone interviewers. *Journal of Voluntary Action Research*. 1986 Jul;15(3):45-53. **Also** https://ohs.org.uk/regions/south-east/living-histories-beyond-the-case-notes-listening-to-mental-health-stories/. **Also** Fenge engaged 20 volunteers, some of whom together conducted 30 individual interviews. See Fenge LA (2010) Striving towards inclusive research: An example of participatory action research with older lesbians and gay men. *British Journal of Social Work*. Apr 1;40(3):878-94. **Also** Seven volunteers administered a questionnaire within a 1:1 interview with 45 respondents in Doyle M & Timonen V (2010) Lessons from a community-based participatory research project: Older people's and researchers' reflections. *Research on Aging*. Mar;32(2):244-63.

[14] NIHR (Version 3.0, April 2019) *Research in the NHS – HR Good Practice Resource Pack HR Good Practice: Information for researchers, R&D and HR staff in Higher Education Institutions and the NHS*.

[15] Bates P (2024) *How to get approval for Public Contributors to interview NHS patients for NIHR-funded research*.

[16] 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.

[17] *UK Policy Framework for Health and Social Care Research* paragraph 9.16.

[18] 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.

[19] 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.*

[20] 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.

[21] Boutry C, Hagyari-Donaldson P, Hill A, Mauger F, Mays C, Macauley C, Covington M, Wynn R, Simpson K, Cordrey M & Higton 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.

[22] 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.

[23] Reported in Trowbridge H (2025) 'Changing the world, one story at a time: a methodological approach to curating stories of lived experience' Chapter 5 **in** Liguori A, Rappoport P & Gachago D (eds) *Story Work for a Just Future: Exploring the Plurality of Knowledge and Method within the Digital Storytelling Community*, Smithsonian Scholarly Press, pp. 47-56. (10.5479/si.30758276).

[24] The SPIs 'were paid a nominal stipend for each interview they completed and spent a lot of time building trust. Scharlach AE & Sanchez E (2011) From interviewers to friendly visitors: bridging research and practice to meet the needs of low-income Latino seniors. *Journal of Gerontological Social Work.* Jan 1;54(1):73-91.

[25] In a study of preconception care, the women who provided a lived experience perspective were all high status professionals and respected leaders. See 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.

[26] https://peterbates.org.uk/wp-content/uploads/2021/06/How-to-respond-to-distress.pdf.

[27] 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.

[28] See RBKC (2018) *Youth Review Engagement Findings.* rbkc.gov.uk/sites/default/files/media/documents/Youth Review Engagement Findings Report.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 it is the local authority which holds the lead in meeting statutory duties in respect of safeguarding.

[29] Page 22 of Crane et al (2023) op cit.

[30] March JC, Oviedo-Joekes E, Romero M (2005) Drugs and social exclusion in ten European cities. *European addiction research*. Dec 9;12(1):33-41.

[31] Doty MZ. *Society's misfits*. Century; 1916.

[32] NIHR (2012) *The Research Passport: Algorithm of Research Activity and Pre-Engagement Checks Research in the NHS: HR Good Practice Resource Pack.* Available at Microsoft Word - algorithm_v3.0.doc (myresearchproject.org.uk)

[33] Asking for personal data without justification would breach article 6 of the GDPR, and knowingly asking for a DBS check for a post which is not included in the Exceptions Order 1975 to the Rehabilitation of Offenders Act 1974 constitutes a breach of Part V, section 123 of the Police Act 1997.

[34] Bates P (2024) *How to get approval for Public Contributors to interview NHS patients for NIHR-funded research*. Appendix C provides a critique of current NHS systems.

[35] Tavecchio L, Van der Helm P, Moonen X, Assink M, Stams GJ, Wissink I, Asscher J (2019) Participatory peer research in the treatment of young adults with mild intellectual disabilities and severe behavioral problems. *New Directions for Child and Adolescent Development.* Sep (167):117-31.

[36] Livingston JD, Desmarais SL, Verdun-Jones S, Parent R, Michalak E & Brink J (2014) Perceptions and experiences of people with mental illness regarding their interactions with police. *International journal of law and psychiatry*. Jul 1;37(4):334-40. For a general discussion about authors' anonymity and Public Contributors, see Bates P (2025) Should-I-use-a-pseudonym.pdf.

[37] Fields J, González I, Hentz K, Rhee M & White C (2008) Learning from and with incarcerated women: Emerging lessons from a participatory action study of sexuality education. *Sexuality Research & Social Policy*. Jun;5(2):71-84.

[38] 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.

[39] 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 unclear whether 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.

[40] 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. R*esearch Involvement and Engagement*. Mar 30.

[41] Assumptions about 'professional boundaries' commonly shape the researcher's views about interviewing respondents they know. For a critique, see Bates P, Lymbery M & Emerson E, (2013),Exploring boundary attitude, *The Journal of Adult Protection*, Vol. 15 Iss: 1 pp. 26 – 36

[42] https://peterbates.org.uk/wp-content/uploads/2019/12/How-to-involve-people-as-research-co-interviewers.pdf. In Montgomery et al's study 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. **Also** "We recruited and trained PPI members as co-interviewers for carer interviews. We have always accompanied them to provide support, co-research with them and then conduct a debrief session. They are paid as temporary staff members through the university payroll." Fox C, Hammond SP, Shepstone L, Poland F, Henderson C, Backhouse T, Penhale B, Donell S, Knapp M, Lewins D & MacLullich A (2025) Enhanced recovery pathway for older people with hip fracture and cognitive impairment in acute hospitals: the PERFECTED research programme including an RCT. *Programme Grants for Applied Research*. 2025 Feb 13;13(1). **Also** Twenty two co-researchers conducted 75 interviews, but were almost certainly doing 2:1 rather than 1:1 interviews – see Littlechild R, Tanner D & Hall K (2015) Co-research with older people: perspectives on impact. *Qualitative Social Work.* Jan;14(1):18-35.

[43] https://peterbates.org.uk/wp-content/uploads/2017/04/How-To-co-facilitate-a-focus-group.pdf. Sometimes a mix of methods is used, such as Barnes et al who engaged 12 coresearchers to conduct 30 one--to-one interviews and they involved 59 more people in Focus Groups – see Barnes M, Taylor D & Ward L (2013) Being well enough in old age. *Critical Social Policy*. Aug;33(3):473-93.

[44] Wexler L (2011) Intergenerational dialogue exchange and action: Introducing a community-based participatory approach to connect youth, adults and elders in an Alaskan Native community. *International Journal of Qualitative Methods*. Sep;10(3):248-64.

[45] Schneider B, Scissons H, Arney L, Benson G, Derry J, Lucas K, Misurelli M, Nickerson D, Sunderland M. Communication between people with schizophrenia and their medical professionals: a participatory research project. *Qualitative Health Research.* 2004 Apr;14(4):562-77.

[46] Seven young people conducted 48 interviews in Fleming J, Goodman Chong H & Skinner A (2009) Experiences of peer evaluation of the Leicester teenage pregnancy prevention strategy. *Children & Society*. Jul;23(4):279-90.

[47] 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

[48] 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 Healt*h. Jul 4;27(4):322-8.

[49] In the study by Rhodes et al, an unknown number of 'indigenous fieldworkers' were recruited. They were 'interviewers who were current or former drug users, had established professional experience in the substance misuse field or had privileged access to injecting drug user networks.' This means that some or all of them might have been employed. They 'administered' the interview-based survey' which suggests that they met each respondent and together worked through the questions, perhaps also recording the answers, rather than undertaking office-based administration of the process of issuing and collecting documents. Rhodes T, Platt L, Maximova S, Koshkina E, Latishevskaya N, Hickman M, Renton A, Bobrova N, McDonald T, Parry JV. Prevalence of HIV, hepatitis C and syphilis among injecting drug users in Russia: a multi-city study. *Addiction*. 2006 Feb;101(2):252-66. We learn from Platt et al that all the indigenous fieldworkers were employed by the study team having previously been volunteers or outreach workers in NGOs. They collected data from a total of 3771 respondents across nine studies..

[50] 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.

[51] Taylor et al report that four SPIs conducted 11 interviews. Taylor NJ, Kearney J. Researching hard-to reach populations: Privileged access interviewers and drug using parents. *Sociological Research Online.* 2005 Jul;10(2):55-62.

[52] 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.

[53] 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.

[54] 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.

[55] 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.

[56] Giles EL, Eskandari F, McGeechan G, Scott S, Lake AA, Teasdale S, Ekers D, Augustine A, Le Savauge 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.

[57] Greenwood K, Robertson S, Vogel E, Vella C, Ward T, McGourty A, Sacadura C, Hardy A, Rus-Calafell M, Collett N, Emsley R. The impact of patient and public involvement in the SlowMo study: reflections on peer innovation. *Health Expectations.* 2022 Feb;25(1):191-202.

[58] 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.

[59] 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.

[60] Berg BL, Sañudo F, Hovell M, Sipan C, Kelley N & Blumberg E (2004) The use of indigenous interviewers in a study of Latino men who have sex with men: A research note. *Sexuality and Culture*. Mar;8(1):87-103.

[61] 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.

[62] Livingston J, Nijdam-Jones A, Team PE. Perceptions of treatment planning in a forensic mental health hospital: A qualitative, participatory action research study. *International Journal of Forensic Mental Health*. 2013 Jan;12(1):42-52. "Peer researchers were paid $10 for each team meeting they attended (held 2-4 times per month over 2 years) and $10/hr for participating in data collection, including interviews. The peer researchers were patients involuntarily detained in a forensic mental health hospital, so they were not staff.

Interviews were conducted one-on-one in private offices." (Jamie Livingston, personal correspondence, July 2026).

[63] Torre ME & Fine M (2005) Bar none: Extending affirmative action to higher education in prison. *Journal of Social Issues*. Sep;61(3):569-94.

[64] 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.

[65] "From my recollection the Privileged Access Interviewer was a member of the drug using community and collected the information for my co-author… I think that was the case, otherwise we would have used the term gatekeeper." (personal communication, July 2026). Van Hout MC & Bingham T (2012) "A costly turn on": patterns of use and perceived consequences of mephedrone based head shop products amongst Irish injectors. *International Journal of Drug Policy.* May 1;23(3):188-97.

[66] 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*.

[67] Hailes A, Sterling A, Girling A et al (2018) *Hand in hand: Survivors of Multiple Disadvantage Discuss Service & Support.* Agenda & AVA.

[68] 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.

[69] NIHR (May 2024) *Public co-applicants in research – guidance on roles and responsibilities.*

[70] Bates P & Koon E (2014) *How to engage people as research co-applicants.*

[71] 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. A detailed technical policy analysis is available as Bates P (2024) *How to get approval for Public Contributors to interview NHS patients for NIHR-funded research*.

[72] https://peterbates.org.uk/wp-content/uploads/2021/06/How-to-respond-to-distress.pdf.

[73] Adults with learning disabilities were PPIE members and took part in radio interviews to share the findings of the study with the general public. Kichigina A, Sayers S, Fayter A. Strategic Priorities Fund: Tackling Multimorbidity at Scale and NIHR Artificial Intelligence for MLTC (AIM) Impact Case Studies. *NIHR Open Res.* 2026 Jun 12;6(54):54.

[74] 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 Koniotou 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.

[75] 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.

[76] Interesting to note that in the study by Grayson et al, obtaining informed consent was a task confined to academic interviewers, even when peer researchers were to conduct the interview itself. There were 10 co-researchers, some of whom conducted an unknown number of interviews, and it is not clear if they were one-

to-one. See Grayson T, Hung Tsang Y, Jolly D et al (2013) Include me in: user involvement in research and evaluation. *Mental Health and Social Inclusion*. 17(1): 35-42.

[77] 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 number of interviewers added challenges to the data analysis stage. 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.

[78] Bates P (2024) *How-to-write-in-public.pdf (peterbates.org.uk)*.

[79] Email inquiries have been sent to a number of corresponding authors of relevant papers.

[80] Feedback was gratefully received from Di Levine, Amy Lynch, NIHR Public Partnerships, Yeliz Prior and Mike Slade.

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