Hunting the Snark 1: Have Public Interviewers collected research data on their own?

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1. Introduction

In 1876, Lewis Carroll published *The Hunting of the Snark*, a tale of eccentrics who determinedly apply their own weird logic to an absurd search. The following investigation may turn out to be similarly futile. This paper reviews 100 academic studies that may have deployed Solo Public Interviewers (SPIs), while its two companions, *Hunting the Snark 2: Must we abandon all safeguards?*[1] and *Hunting the Snark 3: Using familiar apparatus*[2] respectively itemise the risks involved and suggest ways to mitigate these risks.

In the UK, patients, informal carers and members of the public add value to the processes of selecting, designing and delivering health research. Such Public Contributors are not quite volunteers nor employees but may be offered a Patient and Public Involvement and Engagement (PPIE)

payment[3] in recognition of their contribution. In this paper, I search for published examples of research where Public Contributors conducted one-to-one data-collection interviews with individual study participants. When acting in this specific role, I call these Public Contributors S*olo Public Interviewers* (SPIs).

Readers will need to look elsewhere for a broad justification and contextualisation of the role of SPIs, but here we briefly note that they stand at the confluence of several streams of thought. The most significant are:

- *Epistemic justice* recognises lived experience as a valid way of knowing
- *Patient and Public Involvement and Engagement* (PPIE) aims to coproduce research with Public Contributors
- *Insider Research* suggests that study respondents form an exclusive community and culture that can only be fully accessed and understood by people with membership through lived experience
- *Community-Based Participatory Research* aims to shift the locus of control of the research out of the university and into the community[4].

To engage SPIs is an unusual choice for a research team to make, and this paper searches for studies where it may have been done. At the very least, this body of work may bring these matters out of the shadows and press research teams to make a conscious decision on who should conduct their one-to-one interviews and improve reporting practices.

2. Benefits of Solo Public Interviewers

> *"I felt her [SPI'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."*[5]

Potential benefits include:

- Improving access to neglected groups who consider the peer to be an acceptable face or privileged access interviewer[6], thereby reducing masking (under-sampling reclusive respondents) and volunteer bias (over-sampling cooperative respondents)
- Reducing perceived power over participants compared with academic interviewers[7]
- Gaining trust and rapport[8], which enhances disclosure and so provides fuller and more honest responses from respondents[9], thereby compensating for the under-reporting of socially undesirable behaviours.
- More checking of understanding, meaning and significance of what is said[10].
- Wider adoption of the recommendations arising from the research, since they are more practical and achievable.

There have been a few attempts to seek evidence in support of these assertions. Clark et al[11] engaged two SPIs 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 SPIs, reproducing earlier findings by Polowczyk et al[12]. Jørgensen and colleagues compared the data derived from one-to-one interviews conducted by SPIs with data from interviews cofacilitated by a Public Contributor and an academic researcher[13].

3. A review of published examples

To begin, I propose a full definition of the SPI role which is set out in Appendix 1. In summary, this paper examines studies that approach or satisfy five conditions:

Two non-modifiable conditions:

- Interviewers have relevant lived experience rather than credentialled academics.
- Data is collected for research purposes via interview

Three modifiable conditions

- Medium – ideally, interviews are face-to-face
- People – ideally, interviews are one-to-one with nobody else in the space
- Money – ideally, peer researchers are offered PPIE payments.

With this in hand, it should be possible to scour the academic press for examples that perfectly match the criteria. Unfortunately, the variety of arrangements and absence of detail in much academic reporting means it is often unclear whether a specific example meets each requirement. Furthermore, the multiple governance issues which are elaborated in *Snark 2* mean that some research teams have quite deliberately moved into orbit around the central idea, achieving stability by balancing the gravitational pull of the SPI concept with a range of opposing forces.

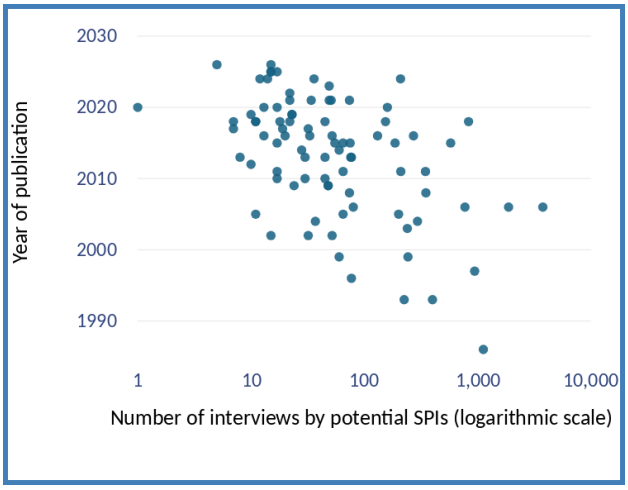
Despite these hindrances, I was able to form a list of 100 papers, each of which is a serious contender for inclusion. Appendix 2 describes my search strategy and the 100 chosen papers are listed at Appendix 3. The findings are frustratingly untidy, tending towards a probabilistic rather than a categorical result, but each paper satisfies enough of the conditions to render it eligible for inclusion in this review.

Riley et al (2024) provides an illustration of how these five conditions can play out. Eight peer researchers met the first non-modifiable condition, as they "all had recent experience of criminal justice contact (e.g. police and probation) and/or other forms of multiple disadvantage, including homelessness, problems with drugs or alcohol and poverty." They met the second non-modifiable condition by carrying out the 209 interviews which formed the evidence base for the paper. Our first modifiable condition concerns the medium of the interview. The report does not state that the interviews were 'face-to-face' or 'in person', but interviewers 'attended services to speak to the people present', so this study is coded as 'in-person' interviews. The second modifiable condition is about the people present in the interview and turns out to be more challenging to classify. We are told that "Revolving Doors staff supported the peer researchers… being present when surveys were being completed in case any issues arose." Despite the possibility that this meant that the staff member was in a neighbouring room, this study was coded as 'three or more people in the interview space'. Finally, the third modifiable condition concerns the financial arrangements for the peer interviewer which are coded as 'not stated' since no information is given at all.

In summary, the Riley et al study reported on eight peer interviewers who conducted 209 face-to-face interviews that were probably chaperoned by a salaried worker and conducted by peers who may have been employed on a short-term contract. Three of the five conditions are fully met, so it is retained in the database. Anyone seeking to explore precedents and arrangements for deploying peer interviewers will have much to learn from this study, as well as from the each of the others.

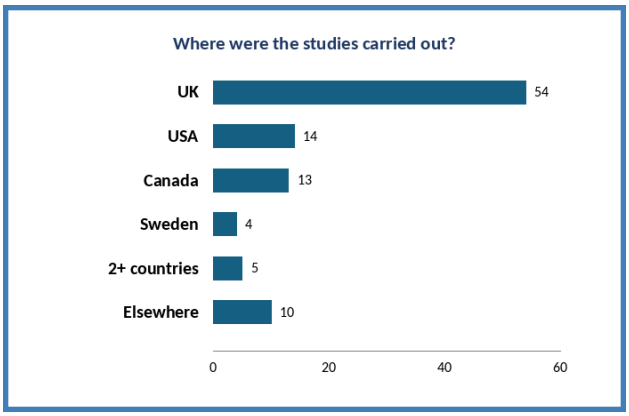
3.1. Publication date

The hundred papers were published between 1971 and 2026. Together, they identify 1,146 peer researchers who conducted 15,678 interviews. Fourteen papers (e.g. Weinberg 1971) omit a count of interviews so do not appear on this scatter graph. Some interviewers were employed; some interviews were carried out over the telephone and some were chaperoned – but the chart suggests that, while the deployment of peer interviewers is uncommon, it has a long history, and the practice continues up to the present day.



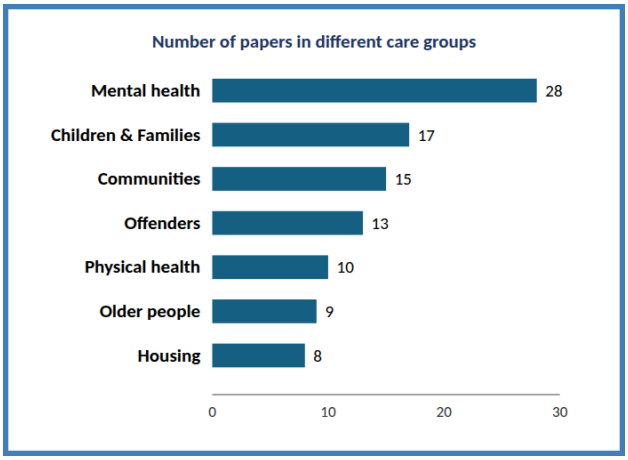
3.2 Location

Fifty-seven of the 100 papers reported work carried out in the UK, with USA and Canada the next largest groups, followed by Sweden. Five studies (March et al 2006, Platt et al 2006, Marent et al 2018, Törrönen et al 2021, Tizaa et al 2024) spanned several countries.



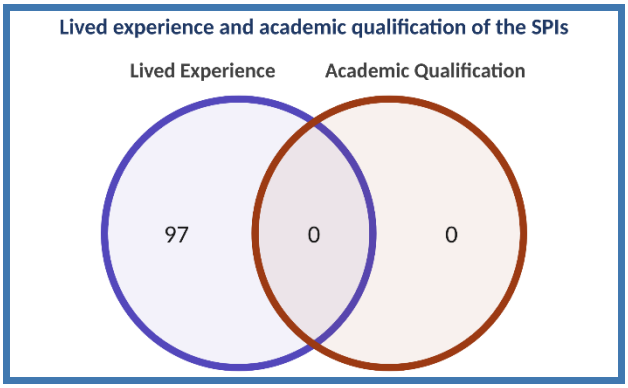
3.3 Care group

Assigning each paper to a single care group makes the spread of studies clear, although it also removes much of the complexity of the actual studies which often straddled several care groups or narrowed their focus to a specific subset, such as illicit drug users who had also experienced contact with justice services. The chart shows that the 100 papers describe work which was distributed across a variety of care groups, with the largest number of research studies focusing on mental health.



The 'Mental Health' category included two papers on learning disability research, the 'Communities' papers included several on specific ethnic or identity-based groups, and the 'Offenders' category included some papers on sex workers or drug users.

3.4 Lived experience



The 100 papers report on studies which engaged interviewers who had lived experience rather than academic qualifications in research methods – our first non-modifiable condition in the definition of Solo Public Interviewers. The attached Venn diagram makes the point. A separate study could examine a different dataset of papers to illuminate research where the interviewers were dually qualified – fully credentialled academics who also had relevant lived experience. In contrast, the interviewers who appear in the Snark papers have lived experience but are not qualified academics.

Three studies have been missed out from the Venn diagram but remain within the sample of 100 papers. They illustrate some of the challenges of forming a classification.

- RBKC[14] engaged 18 young people who then conducted interviews with 154 peers to learn about services for young people. We know that the interviewers were aged 16-20, but we do not know if they had used youth services themselves, or whether their age was a sufficient qualifier. Their age indicated that they would not have had postgraduate qualifications in research methods, but we are given no information about their academic status.
- Marent et al[15] engaged patient community partners to conduct seven interviews with people to learn about HIV. We are not told anything about the interviewer's lived experience of the topic under scrutiny. We can infer that they did not hold academic credentials as the academics provided training, although the duration and syllabus is not given. The partners were accompanied by academics when they facilitated group workshops, but we are not told who was present for the individual interviews.
- James et al[16] describe a situation where "older persons and nurse assistants from a social day care center… cocreate knowledge via interviews" It appears that five care homes each fielded five residents and another three care homes fielded ten residents, all of whom interviewed one resident. Information is provided about the interviewees, but nothing more about the interviewers. Some could have been retired academics or clinicians.

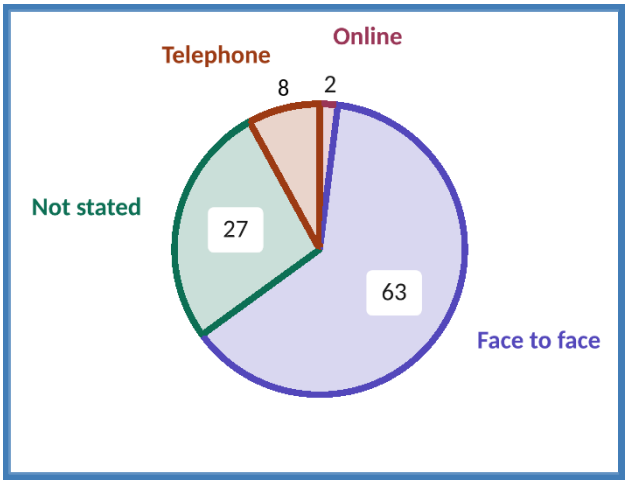
3.5 Data collection by Interview

The second non-modifiable condition which defines this dataset of 100 papers is that they all report on peer researchers who have collected data for research purposes by interview. Other methods, such as wearable technology, self-report by respondents, physical measurement, or postal surveys are perfectly valid data collection methods, but lie beyond the scope of this exploration. Where mixed methods studies appear, the study team may have used other approaches too, but papers in this dataset all collected data via interview.

In addition to these two non-modifiable conditions (that data was collected by peers with lived rather than learned experience and that interviews were the medium for doing so), the three modifiable conditions are explored in the sections below. These comprise the medium of the interview (online, by telephone or face-to-face), the people who were present in the interview, and the money (whether the peer interviewers were unpaid volunteers, offered a PPIE payment or similar, or were hired and paid a wage).

3.6 Interview medium

The 100 papers in our study include 63 where the interview was reported as face-to-face. There are also two studies where the interview was online, eight that were undertaken over the telephone and 27 where no information is provided about the interview medium. Examples include:



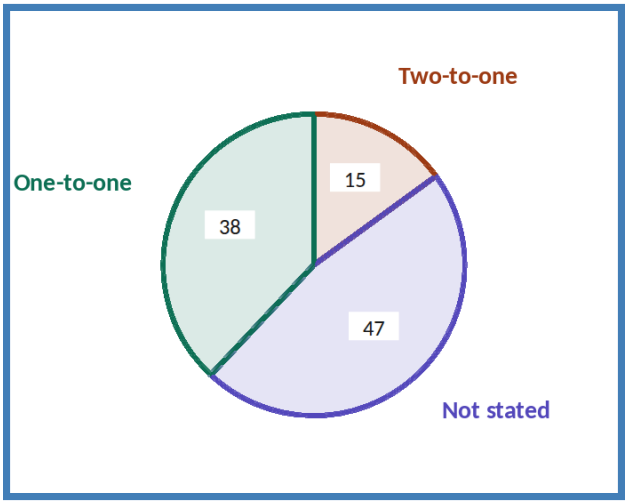
- A study where three patient partners conducted telephone interviews with 15 participants using an interview guide they developed[17]
- A study where six peer interviewers conducted 272 face-to-face interviews[18].

In section 3.9 will return to the 63 studies that used face-to-face interviews.

3.7 People

In our 100 papers, 38 reported that the peer researchers conducted interviews on their own, 15 studies had a third person in the interview space (maybe an academic, interpreter, friend or other person), and almost half of the 100 papers (47) did not state who was present.

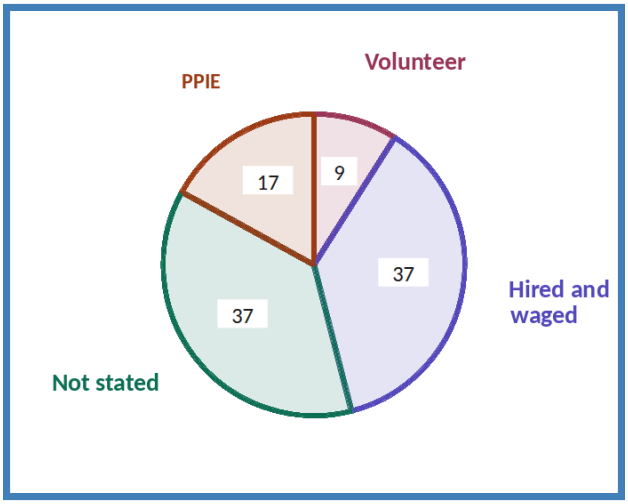
In section 3.9 we will return to the 38 studies that used one-to-one interviews.



3.8 Money

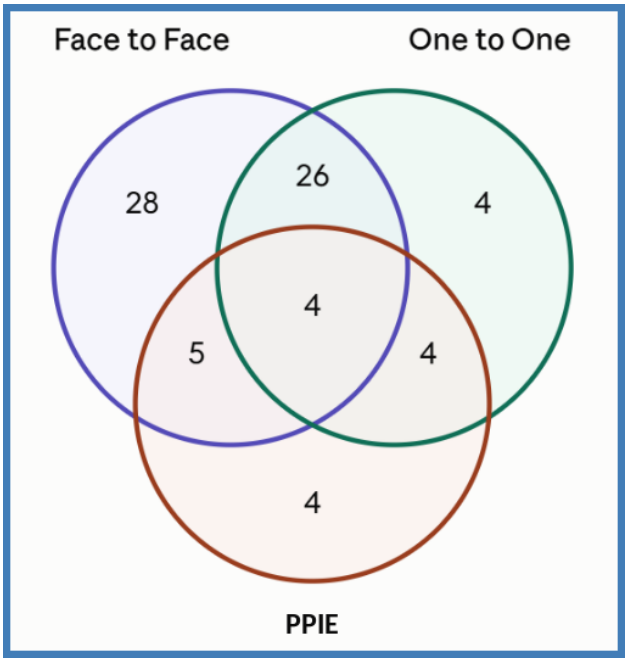
Our 100 papers included 17 that offered PPIE payments or similar ways to recognise and reward the peer interviewer, while in 9 papers they were unpaid volunteers and in 37 studies the peer researchers were hired and waged. Another 37 papers gave no indication of the money offered to peer researchers.

In section 3.9 we shall return to the 17 papers where PPIE or similar payments were utilised.



3.9 Solo Public Interviewers

We have already seen that the two non-modifiable conditions are satisfied by all 100 papers – they all engaged peer researchers with lived experience, and they all conducted interviews to collect data for research purposes. Here, we narrow the focus to look at the 63 studies that used a face-to-face medium for their interviews (see section 3.6), the 38 that kept everyone else out of the interview space so that it was one-to-one (see section 3.7), and the 17 studies where a PPIE or similar payment was offered (see section 3.8).



The Venn diagram shows the relationship between the three modifiable conditions. Headline messages include the following:

- Only four of the 100 papers met all five conditions (two non-modifiable and three modifiable).
- A further 35 papers met four conditions (two non-modifiable and two modifiable criteria)
- A total of 36 papers met three conditions (two non-modifiable and one modifiable condition).
- Twenty-five papers met only the two non-modifiable conditions, and none of the modifiable. This means that these 25 studies deployed peer researchers to conduct interviews, but the published account does not indicate if the interview was face-to-face, one-to-one or acknowledged with an offer of a PPIE payment.

We conclude that all 100 study teams did indeed engage peer interviewers and 75 of them demonstrated some or all of the practices involved in acting as a Solo Public Interviewer. This amounts to a significant precedent which can reassure contemporary research planning teams.

A subsidiary finding concerns the gaps in reporting that have been found. Academic reporting of these practices is often difficult to interpret since:

- There may be a considerable reality/reporting gap, so some of these practices may have been undertaken but simply not written up.
- It is not always clear whether the term 'co-researcher' means that the Public Contributor is on the team or in the interview. To cloud the issue yet further, on occasion, the term 'co-researcher' is used to mean the study participant[19].
- Some of the PPIE budget may have been used to fund contractual staff costs rather than informal PPIE payments.
- Some reports omit a count of the number of peer interviewers or interviewees, voiding any attempt to generate an 'interviews per SPI' ratio[20] or gain a sense of the scale of the work.

Such matters matter – if the study cannot be replicated because information about how it was done is missing, then a tenet of scientific inquiry is breached. Only the bravest researcher would claim that these matters have no impact on the data. Defenders of the status quo might assert that everybody knows that an 'interview' is bound to be in-person and one-to-one unless stated otherwise, and so we should be able to interpret all the papers by reference to these universal norms. But our 100 papers were deliberately selected to explore how peer researchers are getting involved in interviewing, so we should expect more information to be provided on how these practical, and, by implication, governance issues, have been managed. Unreported practices are unlikely to improve.

4. Conclusion

These 100 papers have reported the deployment of over one thousand peer researchers who collected data from over 15,000 respondents. Two thirds of these papers indicated that the peer interviews were face-to-face, one third were solo and unaccompanied, and, in one in six of the studies, the peer interviewer was offered a PPIE payment rather than a wage. There is precedent for the role of Solo Public Interviewer.

In the next paper in this series, *Hunting the Snark 2: Must we abandon all safeguards?* I will consider some of the reasons why research institutions have such difficulty in considering the deployment of Solo Public Interviewers. Finally, the third paper, *Hunting the Snark 3: Using familiar apparatus*, sets out a simple framework that I believe could encourage academic and managerial colleagues to trust Solo Public Interviewers.

5. 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[21]. Several people have been approached for comment[22] and I am grateful to those[23] who have responded to my inquiries. This is an evolving resource which I bear responsibility for as author of the text appearing here[24]. Please send your suggestions for further improvements.

Weaknesses of the approach taken in this exploration include the following:

- There was a lack of prospective oversight from a Research Ethics Committee, which would have offered an independent opinion before commencement,

- No formal confidentiality and anonymity protocol was created for this work
- People who were invited to comment on a draft of this paper were informally asked for their consent regarding attribution and were given an opportunity to amend the manner in which their contribution was presented, but this was not recorded in a formal consent form..

These matters could be repaired if an academic team took up the challenge of investigating the role of SPIs.

6. Appendix 1: Detailed definition of SPI

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 PPIE, qualitative research or interviews, but rather attends to the specific additional things we need to know that distinguish SPIs from all other activities of Public Contributors and all other interviews.

In focus	**In contrast to…**
Solo interviewer acting alone	Any data collection activity that puts more than one person in the space where data is being collected for research purposes, even if that person (such as an academic researcher) is nonspeaking. This excludes security staff, personal assistants, carers, translators and friends as discussed elsewhere[25].
Public – SPIs enter their role as citizens with no continuing status as employees. They 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.	(1) Qualified and salaried researchers who have lived experience. (2) Salaried staff from patient organisations who join the research team, whether they have relevant lived experience or not. (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.
Lived/Living Experience relevant to the health or social issue being studied.	Academic training
Recognition payments – SPIs are offered a PPIE payment for conducting interviews for the purpose of data collection.	(1) 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[26]. (2) People primarily registered as students.

In focus	In contrast to…
Fragments of time – SPIs are engaged for brief and non-recurrent 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 PPIE payments[27]. Using the PPIE Budget to fund such appointments does not satisfy the goal of this paper.
Interviewer – a Public Contributor who conducts the data collection interview for research purposes.	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.
Communication – the interview may be conducted via any medium, including in-person, video or telephone.	Other data collection formats carried out beyond the interview conversation itself, such as surveys, observations[28], wearable technology or self-report mechanisms (including patient-reported outcome measurement).
Single study respondent.	Focus groups[29] or any other activity where the interview respondent is accompanied by others, whether they are study respondents, carers, interpreters, guards or other people using the space.
Interview style – 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 an SPI.
Data collection – interviews are carried out by the SPI to add to the pool of data for analysis.	Public Contributors who (1) Participate in an interview panel for the purpose of recruiting, selecting and appointing staff. (2) Comment on the interview Topic Guide or pilot the interview to check it is robust and suggest improvements[30]. (3) Talk to people to inform them about the study, gain their informed consent, recruit them to the study and screen them for eligibility[31]. (4) Participate in analysis and interpretation of data gleaned from the interview.

7. Appendix 2: Search strategy

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 (Patient and Public Involvement and Engagement). Papers were searched for the term ‘interview’ and surrounding text was reviewed to see whether this paper described the engagement of SPIs or contained any relevant references to other papers

that could be checked. Relevant material was incorporated into this report. The Google Scholar alert was discontinued on 31 July, by which time 676 papers had been reviewed.

Step 2: Some of the papers found in Step 1 that revealed the deployment of SPIs were used in a further cycle of exploration. The 'citations' button was utilised with some of the most relevant papers 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.

Step 3: 67 email inquiries were sent to corresponding authors or academics with an interest in participative research methods to clarify details, seek further examples and locate academics interested in the approach. 16 responses were received.

Step 4: The papers were summarised into an Excel spreadsheet that included columns giving the number of SPIs and the number of people they had interviewed (see elements of this spreadsheet in Appendix 3). Other columns described some of the variables deployed in the Snark papers. The table was then sorted to give priority to the papers that gave the largest number of SPIs and interviewees, and the 100 papers were selected, with PDF or Word copies uploaded to a Dropbox folder.

Step 5: Claude Pro then helped with (i) checking that the 100 papers contained no duplicates, especially those by different authors but reporting on the same interviews; (ii) searching the Dropbox folder to answer some of the questions addressed in the Snark papers, and (iii) presenting the results in charts and tables. At each stage, the output from Claude was checked by hand for errors.

8. Appendix 3: The 100 papers and their contents

First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Ajayi[32]	2009	Getting back into the world: Reflections on lived experiences of recovery (Rethink recovery series: volume 2	1	6	3	2	3	7	48
Barnes[33]	2013	Being well enough in old age	1	4	3	2	1	12	30
Battista[34]	2025	WORKWELL Process Evaluation: Qualitative Data Analyses of the Participant Interviews at 12- and 36-month follow-Ups	1	7	2	2	2	3	15

[1] Location (UK=1, USA=2, Canada=3, Sweden=4, Elsewhere=5)
[2] Client group (Communities =1, Drugs, sex and offenders=2, older people=4, young people and families=5, mental health + LD=6, physical health=7, Housing =8)
[3] Medium of interview (0=Not stated, 1=online, 2=telephone, 3=face to face)
[4] People - who was present? (Not stated=0, Three or more people (e.g. peer interviewer, academic interviewer and interviewee)=1, Just peer interviewer and interviewee=2).
[5] Money – what was the status of the peer interviewer (Not stated=0,Volunteer, perhaps with expenses=1, PPIE or equivalent noncontractual offer of payment or other compensation=2, hired and waged=3).
[6] Number of lived experience interviewers who conducted data collection interviews for the study.
[7] Number of people interviewed by lived experience peers to obtain data for the study.

First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Bengstsson -Tops[35]	2010	Mental health users' experiences of being interviewed by another user in a research project. A qualitative study	4	6	0	0	0		17
Benoit[36]	2005	Community-academic research on hard to-reach populations: benefits and challenges	3	2	0	0	3	10	201
Berg[37]	2004	The use of indigenous interviewers in a study of Latino men who have sex with men: A research note	2	1	3	2	3	2	37
Bianchi[38]	2025	The Role of Boundary Spanning in Building Trust: A Place-Based Study on Engaging Hardly Reached Groups in Community Healthcare Settings	1	1	0	0	0	5	17
Blachnicka -Ciacek[39]	2024	Enhancing benefits for peer researchers: towards a flexible and needs-based approach to participatory research	5	1	3	2	3	8	36
Blake[40]	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	1	7	1	2	2	1	15
Bonham[41]	2004	Consumer-based quality of life assessment: The Maryland ask me! Project	2	6	3	2	3	38	295
Bulutoglu[42]	2021	Discomfort, Dissatisfaction & Disconnect: Exploring local economic perceptions through peer research	1	1	2	0	0	9	51
Burns[43]	2009	Demonstrating the Merits of the Peer Research Process: A Northern Ireland Case Study	1	5	3	2	3	9	24
Burrows[44]	2016	Room to Breathe: A Peer-led health audit on the respiratory health of people experiencing homelessness	1	8	3	2	0	6	272
Chapman[45]	2014	An exploration of the self-advocacy support role through collaborative research: 'There should never be a them and us'	1	6	0	2	0	4	28
Clark[46]	1999	Effects of client interviewers on client-reported satisfaction with mental health services	3	6	3	0	3	4	60
Crane[47]	2023	Integration, Effectiveness and Costs of Different Models of Primary Health Care Provision forPeople Who Are Homeless: An Evaluation Study	1	8	3	2	3	2	49
Crisis[48]	2021	#HealthNow peer research report: Understanding homeless health inequality in Newcastle	1	8	2	0	1	8	49
Croft[49]	2016	Peer interviewers in mental health services research	2	6	3	0	3	9	
Csipke[50]	2016	Design in mind: eliciting service user and frontline staff perspectives on psychiatric ward design through participatory methods	1	6	3	0	3	2	20
Daly Lynn[51]	2021	Partnering with older people as peer researchers	1	4	3	1	1	7	22

First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Dewa[52]	2019	Young adults' perceptions of using wearables, social media and other technologies to detect worsening mental health: a qualitative study	1	6	3	1	2	2	10
Dewa[53]	2020	Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties	1	6	3	2	0	3	1
Dickson[54]	2001	Participatory action research: lessons learned with Aboriginal grandmothers	3	7	3	0	3	2	
Dixon[55]	2015	Corporate Parenting for Young People in Care: Making the difference?	1	5	3	0	0	36	579
Doyle[56]	2010	Lessons from a community-based participatory research project: Older people's and researchers' reflections	5	4	3	0	1	7	45
Edge[57]	2020	Secondary care clinicians and staff have a key role in delivering equivalence of care for prisoners: A qualitative study of prisoners' experiences.	1	2	3	2	0		17
Elliott[58]	2002	Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations.	1	2	0	0	3	4	52
Faulkner[59]	2019	"Dignity and respect": an example of service user leadership and co production in mental health research	1	6	0	0	3	4	23
Fenge[60]	2010	Striving towards inclusive research: An example of participatory action research with older lesbians and gay men	1	4	0	0	1		30
Fields[61]	2008	Learning from and with incarcerated women: Emerging lessons from a participatory action study of sexuality education	2	2	3	2	2	74	74
Fleming[62]	2009	Experiences of Peer Evaluation of the Leicester Teenage Pregnancy Prevention Strategy	1	5	3	1	3	7	48
Flint[63]	2011	Promoting wellness in Alaskan villages: Integrating traditional knowledge and science of wild berries	2	1	0	0	0		65
Fox[64]	2025	Enhanced recovery pathway for older people with hip fracture and cognitive impairment in acute hospitals: the PERFECTED research programme including an RCT	1	5	3	1	3		
Giles[65]	2024	Food insecurity in adults with severe mental illness living inNorthern England: Peer research interview findings	1	6	1	1	3	4	12
Golijani-Moghaddam[66]	2026	Feasibility and acceptability of Strengthening Mental Abilities with Relational Training (SMART) for cognitive difficulties in multiple sclerosis: a randomised controlled trial	1	7	3	2	0	3	

First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Grayson[67]	2013	Include me in: user involvement in research and evaluation	1	6	0	0	3		8
Greenwood[68]	2022	The impact of Patient and Public Involvement in the SlowMo study: Reflections on peer innovation	1	6	0	1	2	5	22
Griffiths[69]	1993	Reaching hidden populations of drug users by privileged access interviewers: methodological and practical issues		2	3	0	2	23	400
Gross[70]	2020	Educational content and challenges encountered when training service user representatives as peer researchers in a mixed study on patient experience of hospital safety	5	7	0	0	2	8	160
Groundswell[71]	2016	An End to Street Homelessness?	1	8	0	2	0	2	52
Hailes[72]	2018	Hand in hand: Survivors of Multiple Disadvantage Discuss Service & Support	1	2	3	0	1	9	18
Hamilton[73]	2011	The effect of disclosure of mental illness by interviewers on reports of discrimination experienced by service users: a randomized study	1	6	2	0	0	19	347
Hancock[74]	2012	Participation of mental health consumers in research: Training addressed and reliability assessed	5	6	3	0	0	5	10
Havir[75]	1986	An evaluation of older volunteers as telephone interviewers		4	2	0	1	67	1125
Holbrook[76]	2006	Surveying a Chicago public housing development: Methodological challenges and lessons learned.	2	8	3	2	3	12	774
Hovén, E[77]	2020	What makes it work? Exploring experiences of patient research partners and researchers involved in a long-term co-creative research collaboration	4	7	2	2	2	4	13
Jacklin[78]	2008	Developing a participatory aboriginal health research project: “Only if it's going to mean something"	3	1	2	0	3	4	350
James[79]	2015	Working together for a meaningful daily life for older persons: A participatory and appreciative action and reflection project—The lessons we learned	4	4	3	1	0	55	55
Jin[80]	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	1	5	2	1	2	3	15
Johnson[81]	2016	A comparison of privileged access interviewing and traditional interviewing methods when studying drug users in treatment	4	2	3	0	3	9	131
Jones[82]	2002	Invisible families: The strengths and needs of black families in which young people have caring responsibilities	1	5	0	0	0	3	32

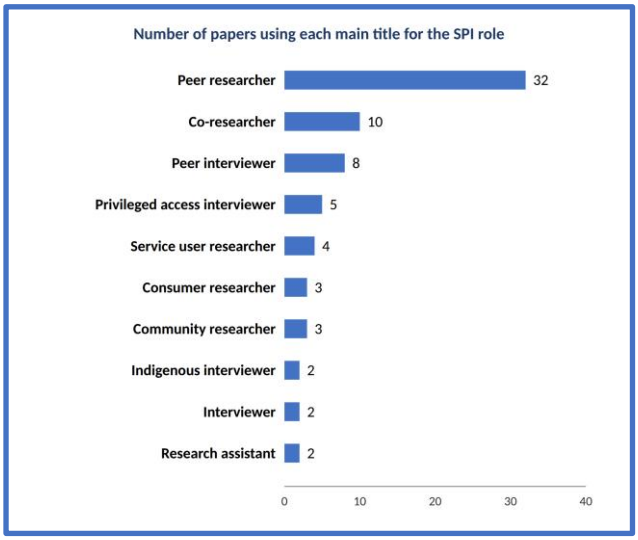
First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Jorgensen[83]	2018	The impact of using peer interviewers in a study of patient empowerment amongst people in cancer follow-up	5	7	0	1	0		11
Keighley[84]	2023	Participatory action research: Developing a collaborative approach to modern slavery research with survivors of exploitation	1	1	3	1	2		
Kelly[85]	2016	You Only Leave Once? Transitions and Outcomes for Care Leavers with Mental Health and/or Intellectual Disabilities	1	5	3	2	0	4	13
Kuebler[86]	1997	The Swiss Hidden Population Study: practical and methodological aspects of data collection by privileged access interviewers	5	2	3	0	3	31	943
Lecomte[87]	1999	Mental health consumers as peer interviewers	2	6	0	0	3	18	243
Levac[88]	2013	Is this for real?' Participatory research, intersectionality, and the development of leader and collective efficacy with young mothers	3	5	3	2	1	11	
Lin[89]	2018	You don't really know people 'till you talk to them	1	4	0	1	0	20	45
Littlechild[90]	2015	Co-research with older people: perspectives on impact	1	4	0	1	0	22	75
Livingston[91]	2014	Perceptions and experiences of people with mental illness regarding their interactions with police	3	6	3	0	3	2	60
Livingston[92]	2013	Perceptions of Treatment Planning in a Forensic Mental Health Hospital: A Qualitative, Participatory Action Research Study	3	6	0	2	0	5	45
London Youth [93]	2018	A space of our own	1	5	3	0	0	5	22
Luchenski[94]	2024	The preventative role of hospitals for people experiencing homelessness in England: a mixed methods study	1	8	3	2	2	1	14
Lushey[95]	2015	Participatory peer research methodology: an effective method for obtaining young people's perspectives on transitions from care to adulthood?	1	5	3	2	3	23	65
Lynch[96]	2025	Developing care experienced young peoples' participation as peer researchers in an inter-disciplinary study: applying the 'Ability-Motivation-Opportunity' framework	1	5	0	1	3	5	
MacKinnon[97]	2021	The political economy of peer research: mapping the possibilities and precarities of paying people for lived experience	3	6	3	1	3	5	34
March[98]	2006	Drugs and social exclusion in ten European cities	1	2	3	0	3		1879
Marent[99]	2018	Ambivalence in digital health: co-designing an mHealth platform for HIV care	1	7	0	0	0		7

First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Mehay[100]	2026	From tokenism to transformation: lessons from the TOGETHER study for building inclusive and equitable research	1	5	3	2	2	7	
Meyer[101]	2003	Immigrant women implementing participatory research in health promotion	3	1	0	0	0	11	240
Milton[102]	2017	Development of a peer-supported, self-management intervention for people following mental health crisis	1	6	0	0	3		32
Morant[103]	2017	The least worst option: user experiences of antipsychotic medication and lack of involvement in medication decisions in a UK community sample	1	6	3	0	0	5	19
Morrell-Bellai[104]	1994	The experience of mental health consumers as researchers	3	6	3	0	3	6	
Norman[105]	2016	Between Two Cultures	1	1	0	0	1	18	33
O'Donoghue[106]	2013	Service users' perceptions about their hospital admission elicited by service user-researchers or by clinicians	5	6	3	2	3	4	77
Platt[107]	2006	Methods to Recruit Hard-to-Reach Groups: Comparing Two Chain Referral Sampling Methods of Recruiting Injecting Drug Users Across Nine Studies in Russia and Estonia	5	2	3	2	3	80	3771
Polowczyk[108]	1993	Comparison of patient and staff surveys of consumer satisfaction	2	6	3	0	0		225
RBKC[109]	2018	Youth Review Engagement findings report	1	5	3	0	0	18	154
Reeve[110]	2002	From Our Perspective: Consumer Researchers Speak About Their Experience in a Community Mental Health Research Project	3	6	3	2	3	3	15
Riley[111]	2024	Building bridges to safer communities and trusted policing: Peer research report	1	2	3	1	0	8	209
Rowe[112]	2006	The effect of involvement in participatory research on parent researchers in a Sure Start programme	1	5	3	2	3	16	80
Salami[113]	2021	Access to mental health for Black youths in Alberta	3	6	3	0	0		
Salway[114]	2015	Researching Health Inequalities With Community Researchers: Practical, Method-ological and Ethical Challenges of an 'Inclusive' Research Approach	1	7	0	0	0	12	
Scharlach[115]	2011	From interviewers to friendly visitors: Bridging research and practice to meet the needs of low-income Latino seniors	2	4	3	0	2	10	210
Simoni[116]	1999	Notes from the field: Training community members toconduct survey interviews: Notes from a study of seropositive women	2	7	3	0	3	17	
St Mungo's[117]	2018	On my own two feet	1	8	3	2	0	10	11
Tavecchio[118]	2019	Participatory peer research in the treatment of young adults with mild ID and severe behavioral problems.	5	6	3	2	0	5	23

First Author	Year	Title	Location[1]	Client group[2]	Medium[3]	People[4]	Money[5]	Interviewers[6]	Interviewees[7]
Taylor[119]	2005	Researching Hard-to Reach Populations: Privileged Access Interviewers and Drug Using Parents	1	2	3	2	0	4	11
Thust[120]	2018	From 'what will the Mayor do about it?' to 'what can we do about it together?'		1	0	2	3	84	833
Tizaa[121]	2024	Lived experience in mental health research in Ghana and Indonesia: What have we learned?	5	6	3	0	0	12	
Torre[122]	2005	Bar none: Extending affirmative action to higher education in prison	2	2	3	2	0	15	65
Törrönen[123]	2021	Ethical reflections on sensitive research with young people living in conditions of vulnerability	1	5	3	0	2	16	74
Varcoe[124]	2013	Help bring back the celebration of life: A community-based participatory study of rural Aboriginal women's maternity experiences and outcomes	3	1	3	0	0	2	76
Villani[125]	2026	A mental health promotion approach to Irish Traveller's mental health: A peer-led research study	5	1	0	2	2	17	5
Weinberg[126]	1971	Community surveys with local talent: A handbook	2	1	3	2	3	52	
Wershler[127]	2015	Psychosocial characteristics and service needs of Canadian suburban male youth at risk for homelessness	3	8	0	0	2	3	187
West[128]	1996	Young people, participatory research and experiences of leaving care	1	5	3	0	0	10	77
Wexler[129]	2011	Intergenerational dialogue exchange and action: Introducing a community-based participatory approach to connect youth, adults and elders in an Alaskan native community	2	1	3	2	0	9	17
Wilson[130]	2015	ReseArch with Patient and Public invOlvement: a RealisT evaluation – the RAPPORT study	1	1	3	2	2	3	17
YWF[131]	2017	A city within a city	1	5	3	2	3	17	7

9. Appendix 4: Terminology

Inconsistent terminology has made it hard to find precedents for the SPI role. Each of the 100 papers listed in Appendix 3 was checked to identify the 'main title' for this role. Where a paper also used other terms in passing, these are captured separately as 'subsidiary titles'.



The search yielded 10 titles which were used by two or more papers, together accounting for 71 of the 100 papers – as shown in the chart. A further 27 titles were preferred in a single paper and appear. Rather than clutter the chart with 27 single-use bars, these one-off main titles have been folded into the combined list of subsidiary titles that follows, alongside other terms that papers mentioned only in passing. Two papers did not use a title clear or consistent enough to classify, and are excluded from both the chart and the list.

The table below shows all 61 titles which were used as the main title in just one paper or were used when discussing earlier studies, offering an alternative label alongside a paper's preferred term, as a term the study team had tried and then set aside. Combined with the 27 single-use main titles above, this adds up to a total of 71 titles (10 in the chart, 61 in the list below) that could be used as search terms in a broader investigation. There may, of course, be yet more terms in use beyond this dataset of 100 papers that could be added to a comprehensive search.

Subsidiary titles		
Advisory committee member	Care-Full Companion	Client interviewer
Co-interviewer	Community interviewer	Community partner
Consultant	Consumer	Consumer employee
Consumer surveyor	Expert by experience	Field worker
Friendly visitor	Indigenous field worker	Indigenous research assistant
Indigenous researcher	Inside researcher	Involvement researcher
Lay health promoter	Lay member	Lay researcher
Lived experience researcher	Local research assistant	Local resident
Older volunteer interviewer	Parent researcher	Participant
Participant-researcher	Participatory researcher	Patient partner
Patient representative	Patient research partner	Patient surveyor
Peer	Peer advocate	Peer evaluator
Peer group interviewer	Peer investigator	Peer research assistant
Peer worker	Peer-youth recruiter	PPI member
PPI representative	PPIE contributor	PPIE member

Subsidiary titles		
PPIE-partner	Prisoner-researcher	Public contributor
Research associate	Researcher labelled with learning difficulties	Self-advocate
Service user interviewer	Service user representative (SUR)	Survivor researcher
User and carer researcher	User interviewer	Volunteer
Volunteer interviewer	Volunteer researcher	Young researcher
Youth researcher		

[1] Bates P (2026) *Hunting the Snark 2: Must we abandon all safeguards?*

[2] Bates P (2026) *Hunting the Snark 3: Using familiar apparatus*.

[3] https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_make_sense_of_our_payments_offer.pdf.

[4] Community Based Participatory Research may utilise approaches such as Community Reporting in place of or in addition to traditional interviews. See the Community Reporter Network. For an example of Community Reporting, see Giorgi Rossi P, Ferrari F, Amarri S, Bassi A, Bonvicini L, Dall'Aglio L, Della Giustina C, Fabbri A, Ferrari A, Ferrari E, Fontana M, Foracchia M, Gallelli T, Ganugi G, Ilari B, Lo Scocco S, Maestri G, Moretti V, Panza C, Pinotti M, Prandini R, Storani S, Street M, Tamelli M, Trowbridge H, Venturelli F, Volta A, Davoli A, Childhood Obesity Prevention Working Group (2020) Describing the Process and Tools Adopted to Cocreate a Smartphone App for Obesity Prevention in Childhood: Mixed Method Study *JMIR Mhealth Uhealth* 2020;8(6):e16165. URL: https://mhealth.jmir.org/2020/6/e16165. DOI: 10.2196/16165.

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[8] 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.

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[10] 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.

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[19] Language is further bent out of shape when a 'conversational' interview is not a process whereby data from both parties is harvested, but rather a one-way unstructured interview. Both examples come from Blodgett AT, Schinke RJ, Smith B, Peltier D & Pheasant C (2011) In indigenous words: Exploring vignettes as a narrative strategy for presenting the research voices of Aboriginal community members. *Qualitative inquiry*. Jul;17(6):522-33.

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

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

[24] 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

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[25] See *How to involve people as research co-interviewers*.

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