

How to get approval for Public Contributors to interview NHS patients for NIHR-funded research



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Section 1: Introduction

In the UK, health research funded by the National Institute of Health Research (NIHR) must be coproduced with people who live with the issue under study. Some of those who bring their personal experience of illness to the research team are not employed or qualified in academic research but receive a small payment in recognition of their contribution. When these Public Contributors collect data via interviews or Focus Groups with research respondents, either alone or alongside a peer or an academic researcher, they may be called Public Interviewers. This role can be distinguished from Public Contributors who participate in study management or advisory groups, who chair those groups, or who undertake collaborative data analysis, since the Public Interviewer is engaging directly with NHS patients for the purpose of data collection.

Meanwhile, each NHS Trust is charged with regulating access to the patients in their care and so must find the balance point between letting anyone in as coproduction partners and locking everyone out for safeguarding reasons. This paper offers a partial explanation of why so few Public Interviewers collect data from NHS patients and suggests how the Research and Development department can find this balance point on behalf of the NHS Trust.

1.1 Summary of findings

Previous investigations¹ suggests that NIHR has a gap between its rhetoric which embraces research coproduction², and reality, where many coproduction practices are uncommon or narrow in application. Where Public Contributors are involved, they tend to be invited to engage in easy ways, while the challenging areas remain unexplored³. Coproduction in which NHS patients are involved throughout the research process may be lagging behind that in social care, education, community development, anthropology and community engaged research, which is why this paper is focused on the NHS.

Detailed accounts of how Public Interviewers contribute to research rarely appear in the academic press⁴ and when they do, they often do not attend to the process by which Public Interviewers obtained approval for their role⁵. Some published reports hint at these arrangements without being explicit. For example, Wadd & Dutton⁶ report the findings of their interviews with people addressing substance misuse through residential rehabilitation. In this study, the research organisation included people with lived experience on an apprentice scheme, but it is not clear whether interviews were conducted by such an apprentice, whether they were salaried or whether the facilities were under the aegis of the NHS. Drafting the text to anonymise⁷ may be a respectful response to sensitivities related to the stigma associated with substance misuse, but it does not help the current investigation.

Plans to engage nonsalaried Public Interviewers in collecting data from NHS patients commonly fail because of procedural complexity and lack of guidance⁸. Previous attempts to bring the problem to the fore in 2007⁹, 2016¹⁰, 2019¹¹ and 2022¹² have not resulted in any improvements and an experienced leader in the field¹³ noted that, while academic staff must navigate their way through similar issues¹⁴, the process is 'significantly more burdensome' for Public Interviewers.

The complexity and uncertainty surrounding the process of gaining approval means that Public Interviewers will be either excluded entirely or obliged to trust their academic guide to lead them by the hand through the labyrinth, reinforcing the powerlessness of the Public Interviewer. Studies designed to collect data across several NHS Trusts will be especially susceptible to delays and confusions, making them even more likely to run aground. These difficulties may drive Principal Investigators to design their study so that it falls outside the NHS research ethics system¹⁵.

1.2 Why is there a procedural vacuum?

Current policies either ignore the role of Public Interviewers or provide confusing and contradictory hints. This may be because:

- The difficulties have not hitherto been drawn to the attention of policymakers and they will be eager to provide a practical way forward as soon as possible.
- The technical challenges are too complex for the busy national policymakers to understand¹⁶, leading to unintended gaps, contradictions and confusions within and between guidance documents.
- Relationships between policymakers and practitioners are suboptimal, closing down feedback and revision of guidance. This may occur because practitioners are overwhelmed or policymakers are remote, inaccessible or unresponsive.

- Policymakers manage their workload by shunting this task on to local Research and Development departments. The unsubstantiated belief that such teams will enjoy the freedoms inherent in local decision making and find innovative solutions provides a convenient rationalisation for the inaction of central policymakers.
- Priority is given to increasing the number of Public Contributors who have any kind of involvement in research, rather than working on removing impediments to the specific role of Public Interviewer¹⁷. Policymakers believe that as the number of generic Public Contributors grows, the voice of would-be Public Interviewers will get louder and push the issue up the priority list. Meanwhile, the risk that frustration will discourage pioneers and slow down innovation is considered negligible.

1.3 Keep the goal in mind

Before turning to an examination of research passports, letters of access and associated processes, it is helpful to check the intended destination. An ideal system will be:

- **Co-produced.** The voice of people with lived experience will be heard and attended to¹⁸ at every stage of research production. This includes involvement in the decision about the mechanism by which suitable Public Interviewers obtain a permit to enter NHS premises and collect data from consenting patients¹⁹.
- **Efficient.** This means that operational processes will be as straightforward and streamlined as possible, agile and responsive to need, with minimum bureaucracy and delays²⁰. The challenges Public Interviewers face in obtaining permission to interview NHS patients raises a question about the relationship between the Research Ethics Committee and the Research and Development team at the NHS Trust. When procedural impediments overturn the favourable decision of the REC they reverse the policy priority of ‘faster study set-up’²¹. Dialogue is needed so that, while each stage of the process is managed by ethically alert and active staff, each with their distinctive focus, the overall process is coherent.
- **Beneficent.** Research will attract a wide range of people and aim to enhance the lives of all stakeholders rather than causing harm. Stakeholders share responsibility for the physical and mental wellbeing of Public Interviewers²². The ULOA guidance (see below) recognises and values the potential advantages of broadening the number of people involved in research. The group named are social care and health staff, with ‘advancing their skills and knowledge’ recognised as a useful consequence of improving the process. Similar benefits will accrue from solving the problems surrounding Public Interviewers and should be recognised as a positive outcome.
- **Brave.** ‘The risk appetite should favour the research taking place’²³. Research-related risks range from experimental surgery and drug trials down to listening to a conversation, so a proportionate approach to mitigations is best.
- **Trusting.** ‘Research sites are expected to accept reliable assurances from others in a position to give them. This includes assurances about ... the competence, character and indemnification of members of the research team who are not substantively employed at the site, including



patients, service users and the public. Decisions about research team members' suitability should not be based on inappropriate... processes.²⁴

At one NHS Trust²⁵, attempts to engage nonsalaried Public Interviewers were eventually abandoned and replaced with the offer of a contract of employment, frustrating the clear intention of the Policy Framework just quoted, which was to permit 'members of the research team who are not substantively employed... including patients, service users and the public' to be involved.

1.4 A simple solution

A simple solution is for the Principal Investigator to write a letter to the Research and Development Department of the NHS Trust like the one shown in Appendix A. Legitimate criteria for approval are discussed below. A successful application would result in the provision of a Letter of Access like the one shown in Appendix B. The name of the Public Interviewer should appear in the Delegation of Responsibilities Log for the study.

The following sections examine this proposal in detail, respond to the numerous challenges that have been mounted to this approach, and set out areas for further development.

Section 2: Potential mechanisms for authorising access

NHS Trusts have a duty to check that the people entering their buildings and making connection with their patients are suitable²⁶. When the host NHS organisation approves the research, a letter of permission is sent to the Principal Investigator including a requirement to notify changes in the research team and any changes in the circumstances of researchers that may impact their suitability to conduct research²⁷. Available mechanisms for granting approval to researchers include:

- Honorary research contract
- Research passport
- Letter of access
- Universal Letter of Assurance
- Approved volunteer with an NHS Trust
- Do nothing.

A system redesign might simplify the system by identifying underpinning themes and reducing the number of different permits on offer. Laterza et al²⁸ note that these processes work best if Public Interviewers behave as if they were professionals, which subverts their fundamental contribution to the research. The paragraphs below offer a brief summary of each option and comment on its suitability for Public Interviewers.

2.1 Honorary Research Contract

While an Honorary Research Contract does not confer employment rights²⁹, it nevertheless provides permission to access consenting NHS patients for research purposes. Precise conditions must be met for an honorary contract to be issued, and circumstances are defined where such a contract must not be issued, so this provides some useful concepts for considering access by Public Interviewers.

An [algorithm](#) explains what counts as a 'regulated activity' and stipulates that an Honorary Research Contract is required where the researcher:

- has access to identifiable patient data derived from health records, tissues or organs with a likely direct bearing on the quality of care; or
- provides healthcare or social care to the person.

Conducting a research interview does not fall within the definition of a regulated activity, available [here](#). From these definitions, it is clear that a research interview does not amount to the delivery of healthcare or social care to the person and will be unlikely to have a direct bearing on the quality of care. To repeat the point, where the research has no direct bearing on the quality of care, then the vicarious liability for the actions of the individual does not fall upon the host NHS organisation and an honorary research contract is not required³⁰. The research policy at Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust acknowledges this distinction by utilising the Honorary Contract system where the person has a direct bearing on the quality of care, and the Letter of Access system where they do not³¹.

The matter is reinforced when exclusions are examined. An honorary research contract must not be issued in any of the following circumstances:

- If the need for a healthcare intervention is revealed during the course of a research interview with a patient³².
- If the researcher is handling identifiable and confidential patient information³³.
- Where the individual conducting the research is not substantively employed by the NHS and the research participants are NHS staff. This is because the NHS organisation's duty of care towards its employees is non-delegable and it will always be liable, regardless of who employs the researcher³⁴.
- Where the research is conducted in an organisation outside the NHS, the NHS organisation should not issue an honorary research contract to the researcher, even if the participants are identified by virtue of their past or present status as NHS patients³⁵.

Despite these pointers, which may add up to a prohibition on the use of Honorary Research Contracts for nonsalaried Public Interviewers, Public Interviewers were required to obtain an honorary research contract in the Repper et al (2007) study, and some NHS Trusts were found at that time that had no system in place for non-employees. Achieving a workaround was onerous and took up to a year, delaying the research and requiring refresher training sessions. Lancashire & South Cumbria NHS Foundation Trust are developing an approach in which nonsalaried Public Contributors will be offered an Honorary Research Contract³⁶.

2.2 Letter of Access

A Letter of Access is generally used to authorise a researcher who is employed by another organisation to enter NHS premises and talk to patients³⁷ for the purposes of the approved research. Where the researcher is employed by an NHS organisation and wishes to conduct research in another, the specific NHS to NHS Letter of Access is used.

A few examples have been found where Public Interviewers have been offered a Letter of Access³⁸. There appears to be no guidance on what information is needed to support such an application³⁹ although a [sample](#) is available which sets out the conditions under which access was granted.

2.3 Research Passport

A research passport is the mechanism for non-NHS staff to obtain an Honorary Research Contract or Letter of Access when they propose to carry out research in the NHS (other applications of the term are available⁴⁰). It permits the researcher to enter NHS premises and engage with the patients who are participating in the research study⁴¹. The process is usually initiated by the research organisation and then processed by the Research and Development department of the NHS Trust which is providing care and treatment to the research participants.

To apply for a Research Passport, a special bundle of papers must be assembled by the applicant and checked by a manager in the Human Resources Department of the research organisation. The Human Resources manager may be unfamiliar with the role of nonsalaried Public Interviewer, even if recognition and reward payments are made via casual payroll claim; and they are unlikely to hold a personnel file in the HR Department for the Public Interviewer. If Human Resources managers are to become involved, they may need training to become familiar with the role and status of the Public Contributor.

Guidance from the [Heath Research Authority](#) and application documents from [IRAS](#) make no reference to the role of Public Contributors⁴². Suggestions for improving the application form have been offered by the author [here](#). Once the application form bears all the necessary signatures, it is considered to be a Research Passport so a separate document is not issued. However, since it does not appear as a distinct option in the decision column of the algorithm discussed in Appendix 3, the research passport may be no more than the process by which one obtains a Letter of Access or Honorary Research Contract (or, by extension, the other permit options)

Laterza et al⁴³ (2016 op cit) found that the following items were required in the cases they reported: A Curriculum Vitae, an occupational health screening certificate, a check of criminal convictions and a certificate showing completion of training in Good Clinical Practice. Individual HR Departments added to this list, including items such as a character reference. These checks are discussed in sections 3 and 4 below.

There are several circumstances in which a research passport is not required, including for 'a student who will be supervised within clinical settings by an NHS employee or HE staff member with an honorary clinical or research contract.'⁴⁴ The student has some similarities with the Public Interviewer in that they have no documentary evidence of competence and so have a named supervisor, but the student has a well-known relationship of accountability with their educational establishment that is more formal than the rather more tenuous connection between the Public Contributor and the institution that engages them.

2.4 Universal Letter of Assurance

The ULOA⁴⁵ provides for situations where employed researchers wish to conduct research in non-NHS settings. Arrangements largely run parallel to the Letter of Access, save from specifying which part of the host organisation stands in place of the NHS R&D team to approve requests.

2.5 Approved volunteer with an NHS Trust

This option has been suggested as a solution⁴⁶ and may set a precedent, smoothing the path for similar requests in the future whilst closing down alternative routes. Associated challenges include:

- Using different mechanisms for the approval of Public Interviewers and academic researchers reinforces the different status of their contributions⁴⁷, while using a single system for both would narrow the gap between them.
- Many research studies work across multiple NHS Trusts so Principal Investigators need to explain the plan to each Trust and seek their separate cooperation. Where the research is being led by a University, this may appear to be a favour granted to an outside organisation.
- Public Investigators need to be registered as volunteers in one Trust and then obtain 'NHS to NHS' authorisation if data collection is to happen at more than one NHS Trust. Where volunteers move from one NHS organisation to another, the second Voluntary Services Manager is required to obtain a reference from the first⁴⁸. Apart from this single comment, there is no known mechanism to facilitate these arrangements, so the Public Interviewer would need to repeat the application process in each place, probably with a face-to-face meeting and possibly by repeating induction processes.
- Individual NHS Trusts may insist that their own volunteers are trained by their own staff prior to starting their volunteer activities. The time investment is justifiable for volunteers who then go on to give considerable time to their role in that NHS Trust but is onerous for those who conduct interviews across several NHS Trusts.
- Guidance is vague on which pre-engagement checks are appropriate for NHS volunteers⁴⁹.
- The legal language used in UK statutory instruments blends rather than separates the language of employment and volunteering, thus "a "volunteer" is a person employed under arrangements to provide their services voluntarily."⁵⁰
- The Voluntary Services Department may be unfamiliar with reward and recognition payments for Public Contributors to research and may prefer to offer reimbursement of expenses only, as paying recognition payments to some and not all volunteers may be considered inequitable and disrupt the whole volunteer labour force.



NHS Trust Volunteer processes can provide a governance framework and conduct a check with the Disclosure and Barring Service, but their expertise is not in research. Their induction process can be tedious and include mandatory training which is less relevant for Public Interviewers⁵¹.

In the 2015 study reported by Garfield et al⁵², peer researchers observed hospital ward rounds and the Research Ethics Committee advised the team to obtain DBS checks and suitable indemnity insurance for the peers. While the academic researchers obtained their permit via the Research Department, the peer researchers were registered as volunteers and were granted permission from the Voluntary Services Manager. Moreover, while the academic researchers were required to undertake pre-engagement checks set by the Research Department's compliance with guidance

issued by the Health Research Authority, the peer researchers were directed to get DBS checks and indemnity insurance by the local Research Ethics Committee. Registration as a hospital volunteer was cumbersome, slow and upsetting, partly as the volunteer department was unfamiliar with the peer researcher's role. As one of the peer researchers put it, “

“It felt a bit like we were being passed from pillar to post, in terms of how we do it. It just took ... a lot of effort and time. I think both for researchers and for the patients. I think it was a big commitment for everybody to try and make it happen. I think we all had to be quite motivated, otherwise it would have been very easy to just say, “You know what? This isn't worth the aggro”.

2.6 Do nothing

The simplest solution is for the Research and Development Department to have no gatekeeping system at all. This can arise in two forms, either permissive or restrictive. In the permissive option, Public Contributors are allowed to fulfil their role with no additional vetting beyond the selection process used by the research team as a whole. In this scenario, the Principal Investigator simply grants their permission and bears overall risk for the project. Where, for example, the Public Interviewer is chaperoned by an employed academic researcher, it is difficult to see what else is necessary and proportionate. This approach has been taken by the team (researchers, Ethics Committee and Research Department) in the 2024 study led by one researcher⁵³ where no requirement was made for the Public Interviewers to obtain a formal permit of any kind, although a standard DBS check⁵⁴ was made (see section 3.3.5 below).

Public Interviewers may be compared with students on placement in the NHS, where guidance is clear that pre-engagement checks need to be made. A memorandum of agreement between the Higher Education Institution and the NHS organisation should be in place for healthcare placements. In this situation, the student will be closely supervised by staff who are clearly covered by NHS indemnity and therefore they do not need an honorary research contract or letter of access⁵⁵.

The more restrictive alternative is to treat the gaps and prohibitions set out in the guidance as amounting to refusal and block Public Interviewers from accessing NHS patients. This can be achieved either by a blatant and outright refusal or by failing to plan for the potential request from candidate Public Interviewers and then starting the search for guidance only when an approach is made. Workload pressures increase the likelihood of this restrictive option occurring by default.

2.7 Summary

Any acceptable taxonomy should offer categories which are mutually exclusive and comprehensively exhaustive, but it is unclear whether this is the case for research permits. As has been shown above, guidance occasionally sets out circumstances in which a particular mechanism may not be used but fails to indicate whether another mechanism should be deployed or the person may continue without further controls. For example, where the researcher has no direct impact on the quality of patient care, an honorary research contract must not be issued, but does that mean that another mechanism should be deployed instead?

None of these six options provide a really satisfactory mechanism for UK Public Interviewers or the other stakeholders in delivering research – Research and Development Departments in the NHS,

research sponsors, universities, representatives of the charitable, voluntary and commercial sector, and infrastructure organisations. Adjustments have not been identified by policymakers and so local Research and Development Teams must work out for themselves how to modify staff systems for nonsalaried Public Interviewers. In doing so, they frequently discover that the underpinning rationale is unclear, and so they cannot be sure why a particular requirement has been made or process selected. Delays ensue as Research and Development Departments become mired in uncertainty, the advice they receive is contradictory, and the favourable opinion given by the Research and Ethics Committee is frustrated. Attempting to conduct research across multiple NHS Trusts amplifies the chaos and stretches out the delays.

Having reviewed all this material, the best option is clear. This is to adopt the Letter of Access, adapting it to ensure that demands upon Public Interviewers are clear and defensible. The Volunteer route is singled out as an unsatisfactory alternative since it reinforces the notion that Public Interviewers are not real researchers, its procedures are disproportionately burdensome, and it does not work for multisite studies.

Section 3: What assurances should be required?

3.1 Introduction

This section of the paper examines the range of assurances that might be sought prior to making the decision about whether to grant the Public Interviewer access to NHS patients. A few are found to be unjustified intrusions, others have no discernible rationale, but some are entirely reasonable responses. This detailed analysis is intended to help Research and Development Departments provide a defensible response to applications and suggest ways in which policymakers could offer a helpful steer. Assurances are grouped into issues related to the role, pre-engagement checks and approaches to mitigate and manage risk.

3.2 Assurances regarding the role

This section provides details of the organisations involved, the research study and the role of the Public Interviewer. It is good practice for volunteer engaging organisation to provide a role description⁵⁶ while employers provide their employees with a job description.

3.2.1 Organisation and study details

Name of project sponsor. The sponsor bears overall responsibility for the research study. There is nowhere on the ULOA form to record the details of the project sponsor.

Organisation that has engaged the Public Interviewer. There is nowhere on the ULOA form to record the contact details of the organisation that has engaged the Public Interviewer.

Electronic staff record number. As Public Interviewers are not employed⁵⁷ this is not appropriate. Is the Public Interviewer registered on another system (such as NHS volunteers or with a database of approved Public Contributors) that can help to avoid duplicative checks? ULOA does not ask for this information.

Title of research project. The Principal Investigator will give the precise title and reference number for the study so that it can be accurately identified.

Project summary. The Principal Investigator can provide a brief summary of the purpose of the research study.

Project duration. The start and end date shows the time period when the Public Interviewer requires access to consenting NHS patients at the study site. Most studies provide some leeway in the end date to allow for delays.

Locations where access is needed. As NHS Trusts have many sites, this section specifies exactly where the Public Interviewer may legitimately carry out their role. Contact information for each site is helpful here.

Outline of the Public Interviewer's research duties for this project. Name the role here as Public Interviewer (local forms may ask for 'job title'). If the role also includes other stages of the research, then Public Contributor may be a more appropriate term.

Role description. A clear role description will specify what is required of the Public Interviewer⁵⁸. Other role and job descriptions may also need to be revised to take account of the Public Interviewer's role. While the role description should clearly show that the Public Interviewer is not employed, it will have some parallels with a Peer Researcher Job Description, and transferring the skills may help Public Interviewers to journey from nonsalaried to salaried positions. Examples are available⁵⁹.

3.2.2 Research method to be used in the study

Some studies involve Public Interviewers by overlapping roles until many of the stakeholders in the research are in fact the same small group⁶⁰. For example, in Dunn's work with care-experienced young people⁶¹, the research respondents and data collection interviewers were the same people – the group of young people was formed, designed the study and collected data by interviewing one another.

Such individuals might be termed 'Respondent Co-researchers' as their narrow role as respondents to the research questions is widened to include many other elements of research production. Thus, in Dunn's study, all respondents were co-researchers. In other mixed methods studies, data from Respondent Co-researchers may be placed alongside data collected from the following sources:

- Data collected from respondents who have no other relationship with the study – such data may be collected by Public Interviewers
- Data collected from Public Interviewers themselves – especially if they reflect on their experiences of coproduction and submit these personal data to the study
- Data collected from academic researchers on the study team - especially if they have lived experience and are reporting on personal responses.

While there are many interesting ethical, methodological and epistemic issues to address when all the research respondents also serve as Public Interviewers, the main focus of this paper is on studies where Public Interviewers are collecting data from persons who do not have other roles in the study itself.

3.2.3 Data collection method

Some options for data collection by a Public Interviewer are listed below in ascending order of risk:

- Remote, chaperoned and recorded contact with respondents (e.g. Public Interviewer and academic researcher working together to conduct an online Focus Group over MS Teams with its 'record' function active throughout the conference)
- Remote unrecorded contact with respondents (e.g. telephone interview)
- Face to face contact with a group of respondents whilst chaperoned by employed co-researcher (e.g. co-facilitating a Focus Group)
- Face to face contact with a group of respondents whilst unchaperoned (e.g. interview a family)
- Unchaperoned face to face contact with an individual respondent.

These options can be elaborated into the typology set out in the table below, where each cell lists the options from low to high risk⁶². Additional items which further reduce risk might be added, such as restricting access to additional data about respondents⁶³, providing additional training or ensuring compliance with policies such as lone working and distress management. In addition, the tasks surrounding the interview or Focus Group itself may affect what is required. For example, if the Public Interviewer is consulting health records, emailing potential respondents to recruit them for the trial, taking consent and writing up extensive notes afterwards, not only will they need a desk, computer, email address and phone provided by the research institution, additional pre-engagement checks may be needed. The following table concentrates on the interview or Focus Group itself rather than these additional roles, which might more properly be assigned to a salaried academic or peer researcher.

Proximity <ul style="list-style-type: none">• Correspondence (e.g. email survey)• Telephone• Online video (see and hear respondents)• Face to face (in the room together)	Co-Facilitators <ul style="list-style-type: none">• Employed academic co-facilitator• Public Interviewer co-facilitator• None (the Public Interviewer works alone)
Observers <ul style="list-style-type: none">• Group interview (respondents witness one another's contributions)• Line of sight (passers-by can see or hear what is happening)• Private meeting (no onlookers)	Recording <ul style="list-style-type: none">• Video record is retained after the event• Audio record retained after the event• Notes are taken during the event.• None

3.2.4 Arrangements for obtaining consent

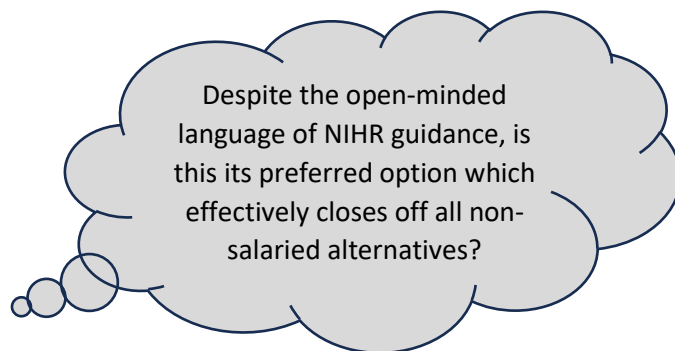
Establishing consent from respondents is a vital precursor to the interview or Focus Group. As it lies outside the data collection process itself, it does not appear in the frameworks above, but may be included in the role description⁶⁴. Ethical concerns surround the act of taking consent as it is vital that research participants are well informed and free to participate or decline⁶⁵. Where an academic researcher works alongside a Public Interviewer to collect data, clarity is needed in the decision about who will take consent and the training and other reassurances required for this role may be

different from those required to co-facilitate the data collection itself⁶⁶. Repper et al 2007 offered respondents a choice of Academic or Public interviewer⁶⁷.

3.2.5 Employment status of the Public Interviewer

Developing pathways into salaried roles for Peer Researchers is a laudable goal⁶⁸, with some research teams engaging nonsalaried Public Interviewers as a first step on that journey⁶⁹, and so the search for an appropriate gatekeeping mechanism for this group continues. Current systems granting permission to engage with NHS patients for the purposes of research assume that the researcher is employed, so the employment status of the Public Interviewer must be clear. The first three employment status options are beyond our remit but are named first and then set aside. They are:

1. Employed on the research team (e.g. full-time Research Assistant) for their academic and research expertise, also bringing relevant lived experience⁷⁰. Posts may be straightforward academic posts (e.g. Research Assistant or Principal Investigator) or may be configured to favour lived experience in the absence of academic training or research experience and perhaps called Peer Researcher⁷¹. Salaried Peer Researchers may have access to academic training in research and obtaining such qualifications may permit them to progress into academic research posts.
2. Employed in an independent organisation (e.g. McPin⁷² or User Voice⁷³) which supplies Public Contributors to the study. The relationship between the independent organisation and the research team may be informal or formalised through a contract for service. Such contractors are not covered by NHS indemnity arrangements unless there are exceptional circumstances and this is not changed by issuing an honorary research contract to them⁷⁴.
3. On application to become a Public Contributor on the study, the person is employed by the research organisation as a member of staff⁷⁵.
4. Not employed as a Public Interviewer but employed in another role (e.g. as an NHS Mental Health Peer Support Worker) and engaged as a Public Interviewer in their own off-duty time⁷⁶.
5. Registered as a formal NHS volunteer with an NHS Trust Volunteer Manager.
6. A non-salaried but recognised member of a formally constituted community organisation, such as a local charity that advocates for patients with a specific condition.
7. Engaged as a Public Contributor and offered reimbursement of expenses and a participation payment, gift or voucher but no further remuneration.



Recent guidance from NIHR⁷⁷ attempts to match employment status with approval mechanism for obtaining permission to carry out research with NHS patients, but unfortunately utilises three contradictory classification systems for employment options and fails to include Public Interviewers

in any of them, as shown in Appendix C. This leaves Research and Development teams and other stakeholders with the task of attempting to discern the general principles embedded in this guidance and then apply them in the context of Public Interviewers.

A contract of employment (as in examples 1-4) alongside policies designed to regulate the organisation's boundaries⁷⁸ may assign some degree of formal responsibility to the employer for the employee's conduct both within and beyond their workplace and working hours. This means that a person who is (i) employed; (ii) engaged elsewhere as a non-salaried Public Contributor; and (iii) behaves inappropriately within their role as a Public Contributor may have to answer for their conduct to their employer⁷⁹. However, the employer's reach is limited, as shown here:

'When NHS employees take part in research as participants outside work, e.g. through professional bodies, their participation is outside the NHS employer's duty of care, even if their participation makes use of knowledge or experience gained as a result of their employment. If a researcher with no contractual relationship with the NHS conducts such research, the research has no impact on the NHS organisation and an honorary research contract should not be issued.'⁸⁰

The intention here may be twofold – to identify a mechanism by which to sanction a Public Contributor who misbehaves (in options 1-4 they might lose their job if they breached confidentiality whilst serving as a Public Contributor), but secondly, to identify an organisation that could be sanctioned if any of its representatives misbehaved (in options 1-4 a claim for compensation could be lodged against the employer by the injured party). While such fears may drive restrictive practices⁸¹, it would be helpful to know if a claim has ever been brought under these circumstances.

In option 6 above, the non-salaried Public Interviewer has a clearly defined relationship with a community organisation which has a formal constitution or articles of association. Under these circumstances, it should be possible to divide responsibilities between the community organisation, the NHS Trust where patients are found, the research organisation and the individual Public Contributor. Doing so would enable a clear allocation of indemnity and insurance responsibilities⁸².

Arrangements for Non-salaried Public Contributors appearing as option 7 above are mentioned by the [UK Policy Framework for Health and Social Care Research](#), paragraph 9.6 which states that

'The research team is the group of people involved in the conduct of a research project. It may include care professionals, academics, patients and service users, members of the public, research professionals, students and/or scientists. Research team members' accountability should be clearly agreed between them and their employer(s) (Or directly with the sponsor⁸³, where this accountability does not arise in the context of their employment, e.g. in the case of research team members who are patients, service users or the public) and documented'.

In line with this, one research manager⁸⁴ made the following comment regarding Public Interviewers, "We would expect the Sponsor to assume accountability" but were unable to show how this worked in practice for Public Interviewers who are not employed.

3.2.6 Delegation of responsibilities

General guidance about researchers indicates that the substantive employer should collect the necessary information and then send a standard confirmation that appropriate checks have been completed to the NHS organisation where the research will be carried out (this is shown in Appendix

A). If local organisations have failed to agree a method of sharing this information between themselves, then the employer has no authority to forward the information, and the responsibility for carrying out pre-engagement checks falls to the NHS organisation hosting the research, and any associated costs may be charged to the employer or research funder⁸⁵. Since so little is known about practice in this whole field, it is impossible to guess how often this process breaks down.

Once engaged, a written Delegation of Responsibilities will set out the relationships between stakeholders without inadvertently creating a contract of employment with the Public Interviewer⁸⁶.

The 'delegation of responsibilities' document should be 'written and agreed in a way that is understood between all concerned, including the service user and carer, with a clear explanation of terms'⁸⁷. Each research study maintains a Delegation of Responsibilities Log⁸⁸ which clearly lists the individuals and duties assigned to them, so this form, or a simplified version of it, should meet requirements. The organisation identified as carrying liability should be notified of the researcher's activities⁸⁹ and the Public Interviewer should be aware of their obligation to report to the study sponsor if they feel unable to discharge their roles and responsibilities⁹⁰.

Recording the duties of the Public Interviewer on the Delegation of Responsibilities Log meets the requirement to 'clearly agree' and 'document' accountability, whilst avoiding the hazard of inadvertently creating an unwanted contract of employment or formal contractor relationship with the Public Interviewer⁹¹. Note in passing that the nonsalaried Public Interviewer needs to make their agreement with the sponsor rather than the Research and Development department, which is expected to accept assurances from the Principal Investigator that their team is suitable⁹².

Asking for a greater specification of responsibility beyond that set out in the Delegation of Responsibilities Log would take our investigation into murky waters. There are at least three ways in which it might be tried, as set out below.

First, a more detailed specification of responsibility might try to describe the delicate relationship between tasks and payments for Public Contributors. In April 2021, NHS England and NHS Improvement published a policy⁹³ and a guide to payments⁹⁴. Despite assurances that it confers no employment rights on Public Contributors, these payments occupy a liminal space between a gift and a wage, as shown in Appendix D. Arrangements have been agreed between NHS England and NHS Improvement, the Department of Work and Pensions and HMRC so are unlikely to have been challenged in an employment tribunal, although it must be asserted that the decision about whether a contract of employment has been formed is a matter for the tribunal and not the paymaster or recipient of a payment. NHS England and NHS Improvement do not require other parts of the NHS to adopt their approach, but few alternatives are available. NIHR continue to accept a variety of payment arrangements for individual studies⁹⁵ and have not attempted to standardise practice.

Second, a more detailed specification of responsibility might try to define or redraw the line between salaried staff, contractors and non-salaried Public Interviewers. It has been suggested⁹⁶ that research teams could approach their local Human Resources Department for advice about whether the Public Interviewer should be established as a paid role rather than be engaged as a non-salaried Public Contributor. Whilst the actual tasks performed by Public Contributors vary in time, commitment, responsibility, and the extent to which they are considered essential functions rather than supernumerary, the decision about which roles should be paid appears arbitrary. There are other roles in public services which bear substantial responsibility but are non-salaried, such as Non-

Executive Director, and as the research may be led by a non-NHS organisation, it is unlikely that this will yield consistent advice acceptable to all stakeholders.

Third, a more detailed specification of responsibility might attempt to pin down obligations in a legal document. A model agreement loaded with legal jargon is available for research teams to use⁹⁷, but it says nothing about Public Contributors. The managerialist mindset that underpins such legal descriptions of accountability is not particularly useful in regulating the behaviour of Public Contributors who favour a relational approach, leading to moral accountability for conduct.

Discarding these complex and over-engineered solutions leaves the simple approach of using the Delegation of Responsibilities Log, augmented with some standard policies which can be reasonably expected to embrace Public Interviewers, such as lone working, confidentiality and so on.

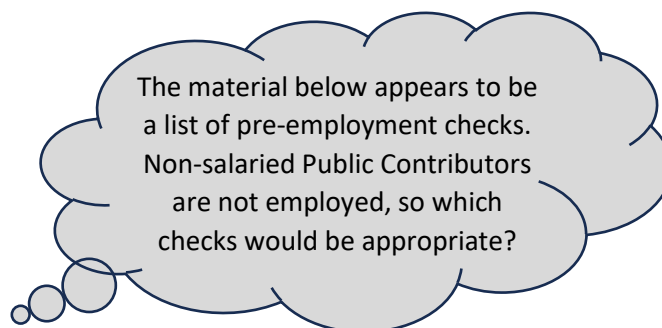
3.3 Pre-engagement checks

Combining the role description and the risk assessment (see below) will prescribe competence-based and proportionate pre-engagement checks of candidate Public Interviewers. The rigour of pre-engagement checks should be proportionate to the precise role undertaken and its associated risks.

The wider use of pre-engagement checks for Public Contributors in many different roles are described elsewhere⁹⁸ along with a suggestion for how they might be proportionately assigned to the specific roles taken up by the Public Contributor, only one of which is data collection. The same threshold of proofs that these checks have been undertaken should be required of staff and Public Contributors, or any differences be justified as fair and proportionate⁹⁹.

Requests for information need to be justifiable and proportionate for both equality and data protection reasons. The equality argument insists that irrelevant material must not be included in a selection decision, especially where protected characteristics are involved¹⁰⁰, so that the outcome is rational, defensible and avoids direct or indirect discrimination. The General Data

Protection Regulation insists that information collected about persons is necessary and purposeful rather than spurious and intrusive¹⁰¹. Organisations need to be able to show why the information is needed¹⁰². Guidance asserts 'Decisions on requirements for pre-engagement checks, induction and training rest with the NHS organisations but should be commensurate with the role of the researcher, type of research and the duty of care'¹⁰³. NHS organisations must therefore decide on which pre-engagement checks to make and be able to offer a reasonable explanation for their decision with no steer beyond this general statement of principle. The result is likely to be a postcode lottery of wildly divergent solutions.



3.3.1 Identity

Common questions about the candidate Public Interviewer include the following:

Full name. The Public Interviewer's name may be recorded, and details confirmed via photo ID, document or official letter with home address)¹⁰⁴. Those asking for home address must be able to explain why they need that information. Principal Investigators may consider supporting the person to use a pseudonym in interactions with others, especially where the topic under study carries stigma or shame in wider society¹⁰⁵.

Date of birth. Asking for this information may help to uniquely identify the person, but there are other ways to achieve this goal, such as home address or mobile phone number. How is the organisation protected against allegations of age discrimination?

Contact telephone number. Arrangements may change at the last minute, so it is helpful for the researcher and the Public Interviewer to be able to contact one another at short notice.

Email address. Some requests specify a work email address in preference to a home email address. Research institutions and NHS organisations may have better security arrangements to prevent email messages being used as a conduit for online viruses. Training can help to ensure that confidential material is not sent electronically via insecure routes.

Next of kin. In the event of a medical emergency, the NHS Trust may wish to retain contact details for the next of kin of the Public Interviewer. The key issue here is proportionality, so if the Trust does not ask this of visiting professionals, bank staff, facilities staff or occasional visitors, then it is hard to see why it might be needed from the Public Interviewer. The Principal Investigator and their team may wish to hold this information, since they have a long term connection with the person.

3.3.2 Nationality and citizenship

Right to work in the UK. As nonsalaried Public Interviewers are not employed¹⁰⁶ this is not appropriate. Public Interviewers who wish to investigate the lives of asylum seekers or those without recourse to public funds must share this life experience and so would be excluded if nonsalaried Public Interviewers were obliged to demonstrate that they had the right to work.

3.3.3 Health and wellbeing

Policy declares that 'Decisions about research team members' suitability should not be based on... irrelevant occupational health checks (e.g. vaccination history where there is no contact with patients or service users).'¹⁰⁷ There is sometimes a need to check the Public Contributor's physical health does not pose a risk to frail hospital patients. The Principal Investigator should assess whether occupational health screening is needed and ensure that it is undertaken where necessary and action taken accordingly¹⁰⁸.

In the study reported by Garfield et al¹⁰⁹, peer researchers who collected their data by observation in hospital wards were obliged by the hospital to attend for an interview with the occupational health department.

3.3.4 Integrity

Policy indicates that 'Decisions about research team members' suitability should not be based on duplicative checks of character.'¹¹⁰ The UK does have a Fit and Proper Person Test¹¹¹, but it applies to

candidate volunteers occupying Board level positions rather than to everyone, so, again, a proportionate approach is best. Indeed, deploying the Fit and Proper Person Test beyond the boardroom would over-inflate its role and overturn the spirit of the intention of the policy. Some organisations do take up references at the end of a selection process in line with guidance from NHS Employers¹¹². Laterza et al (2016, op cit) note that procedures surrounding the uptake of references can reinforce inequalities¹¹³.

3.3.5 Criminal convictions

The ULOA asks the researcher's substantive employer to confirm to the Research and Development department of the NHS Trust that the appropriate level of Disclosure and Barring Service (DBS) check has been undertaken. NIHR guidance published in 2012 indicates that for most Public Interviewers this will be a Standard check (as shown in Appendix C below), although the ULOA inexplicably asks for a check against the barred lists. 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.

Two previously neglected elements - supervision and vulnerability - appear in the 2019 guidance from NIHR which asserts "If the public co-applicant is to have direct, unsupervised contact with children and young people, or with vulnerable adults, they will need a Disclosure and Barring Service check. This should be arranged through the host institution or organisation¹¹⁴, and the cost covered by the research team."¹¹⁵

In a 2022 study¹¹⁶, the Research Department initially tried to apply the Research Passport process but quickly discovered that it was not fit for purpose, so lowered their requirement to a DBS check only, and said they needed to do this because PPI payments were being offered. Since DBS checks should be carried out where required for both salaried positions and volunteer roles and the offer of these gratitude payments to Public Interviewers does not establish a contract of employment, it is hard to see the justification for this decision.

The phrase 'satisfactory check' is taken to mean that those who should be barred can be excluded and those with lesser convictions can be engaged with a satisfactory risk assessment and mitigations plan. Once this is in place, requesting permission is appropriate. Such a plan would balance 'need to know' with confidentiality obligations¹¹⁷ and be constructed in partnership with the person and the Principal Investigator or their delegate. Simply excluding without making a risk management plan amounts to discrimination and risks breaching the principles of GDPR, since information would be gleaned but then not used appropriately. To take the harsh approach of rejecting all offenders, whatever their circumstances, would undermine the principle of offender rehabilitation enshrined in law.

After obtaining the official report from the Disclosure and Barring Service and then designing the risk management plan, both the Public Interviewer and the organisation engaging them are required to confirm that the information about criminal convictions is accurate, up to date and complete.

3.3.6 Skills and experience

In 2019, the NIHR has stated that they, "do not require public co-applicants to complete a standard CV, but they may ask for a summary of any knowledge, skills or experience that is relevant to their

role in the study. This might include: previous or present work (paid or unpaid) with any relevant organisations; links with any relevant groups, committees, networks or organisations; experience of particular health conditions, treatments, use of services - or as a member of a particular community; knowledge and experience of research, including previous research undertaken; knowledge and experience of patient and public involvement, including previous involvement activities; skills from any other roles that are transferable.”¹¹⁸. This guidance applies to Public Interviewers.

Subsequent legislation means that a full employment history is no longer required for volunteers¹¹⁹. Despite this change, NHS Employers have declared that NHS organisations may continue to ask for a full employment history from candidate volunteers should they deem it appropriate¹²⁰. One NHS Trust Volunteer Manager explained “Pre-employment checks are not a “test”... but simply a safeguard and volunteers are expected to carry out those that are “relevant” to the role they are applying for i.e. We do not seek employment history or require qualification or registration.”¹²¹

It is reasonable to ask how such the NHS organisation has honoured the intention of the lawmakers by clarifying the circumstances under which they will not require a full employment history. GDPR also insists that they provide a rationale for their decision to ask for this information and how it will be used.

Asking for a CV suggests that an employment mindset has been adopted in which gatekeepers should start with an assessment of the competences required by the Public Contributor and then match the requirements to those competences. Such competence-based recruitment would insist that spurious and disproportionate eligibility requirements are set aside and equality of opportunity be afforded to all, providing protection against discrimination claims. It is also important to ask who requests a CV and for what purpose. Potential recipients include the Principal Investigator, the Research Ethics Committee, and the Research Department of the NHS Trust. In one case, the CV was requested for the single purpose of seeking information about the employment status of the candidate Public Researcher, breaching the principle of data minimisation set out in the General Data Protection Regulation - that requests for personal data be limited to what is necessary in relation to the purposes for which they are processed¹²². A conventional CV would be unlikely to answer this narrow question very adequately, as well as supplying a large amount of extraneous personal information.

Some forms ask for a professional registration number. Since the Public Interviewer is engaged on the basis of their lived experience rather than professional registration, and there is no official register of experts by experience, this is not a relevant selection criterion.

Section 4: Managing risk

Principle 8 of the UK Policy Framework for Health and Social Care Research makes it clear that a formal, structured risk assessment is not routinely required for research in health or social care¹²³, while other policy guidance advises that a risk assessment of Public Interviewers is undertaken¹²⁴. It is not clear whether these two statements should be thoughtfully integrated or seen as an example of contradictory policy making.

Consideration of risk must be tailored to individual circumstances as a blanket decision applied to all amounts to discrimination. It will be driven by the specific role of the Public Interviewer and any risk management and mitigation plan that has been agreed between the Principal Investigator and the person themselves. Training, supervision and compliance with appropriate policies (see below) will increase confidence that the Public Interviewer is as safe as their employed counterpart.

‘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... and implementation of the institutional lone working policy which should be shared with the public co-applicant and followed.’¹²⁵

Both the Principal Investigator and the Public Interviewer sign to indicate that they understand and will comply with the safeguards that have been set in place. In one example, the Principal Investigator was replaced by another senior figure in the organisation¹²⁶.

4.1 Distress

One potential hazard arising from the role of the Public Interviewer is that someone may be distressed by the interview or Focus Group process or contents. A distress protocol will cover these circumstances and should include the potential for the Public Interviewer becoming distressed or causing distress to others. Advice is available¹²⁷.

4.2 Training

The risk mitigation plan may include training¹²⁸, both prior to commencement as a Public Interviewer and once in the role¹²⁹. The following list of training topics is not exhaustive, but the programme should be ‘appropriate and proportionate’¹³⁰ to the role of the Public Interviewer¹³¹. In some caselaw, mandatory training has been held to be evidence of the existence of a contract of employment¹³².

Good Clinical Practice. “Relevant training might include... Principles of Good Clinical Practice (if a Clinical Trial of Investigational Medicinal Product/CTIMP.” “Relevant training might include... Principles of Good Clinical Practice (if a Clinical Trial of Investigational Medicinal Product/CTIMP.”¹³³ “Decisions about research team members’ suitability should not be based on... disproportionate training expectations (e.g. GCP... for individuals, roles or projects that do not need it).”¹³⁴ “Members of the research team in studies that are not clinical trials of investigational medicinal products are expected to be qualified by education, training or experience but should not be required or expected to undertake GCP training”¹³⁵. Given that the focus of GCP training is CTIMP, Public Interviewers should generally not be asked to undertake GCP training.

Qualitative research methods. “Relevant training might include...record keeping and data integrity... understanding standard operating procedures, (and)... understanding roles and responsibilities”¹³⁶.

Informed Consent. “Relevant training might include... recruitment and/or consent.”¹³⁷ As most members of the public will assume that references to recruitment mean getting a job, rather than finding respondents in a research study, this illustrates the need for accessible language. As discussed above, the Public Interviewer may or may not be taking consent statements from respondents, so training needs to be appropriate for their role.

Information governance. All members of the research team, including Public Interviewers may be asked to sign a confidentiality agreement¹³⁸. “Relevant training might include...patient confidentiality, data protection and information governance.”¹³⁹ In some NHS Trusts, information governance training has become endemic but the principles set out in this paper suggest that Public Interviewers who do not have access to identifiable data derived from health records should be in a lower risk category than those who do. Indeed, if Focus Group respondents are asked to sign a confidentiality statement, the justification for asking more of a Public Contributor needs to be clear.

Safeguarding. “Relevant training might include... reporting of adverse events and incidents... (and) equality and diversity.”¹⁴⁰ This may include separate training on safeguarding adults and safeguarding children.

Health and safety. “Decisions about research team members’ suitability should not be based on inappropriate HR processes, such as disproportionate training expectations (e.g. health and safety training for individuals, roles or projects that do not need it).”¹⁴¹ Despite the above invitation to tailor requirements to context, training in health and safety is elsewhere considered to be a standard requirement¹⁴².

4.3 Supervision

The term supervision can refer to a monthly meeting between a person and their senior where the supervisee is given an opportunity to reflect on their activities in the past month and seek guidance for the next month - or it may mean direct, line of sight observation of the person’s activities in real time. The NIHR algorithm (see Appendix C below) refers to here supervision but does not specify what is meant by it. However, supervision, of one sort or another, is required¹⁴³.

4.4 Lone and out of hours working

NHS organisations will have a policy addressing the risks and mitigations for staff working alone or out of normal office hours, and Public Interviewers may be obliged to read, understand and comply with it.

4.5 Capability management

A further safeguard is achieved by clarifying from the outset what will happen if the Public Contributor fails to comply with the protocol for collecting good data. Potential misdemeanours range from asking leading questions in interviews to fabricating data and abusing respondents. A wish to be kind will properly shape how failure is dealt with, but Public Contributors should know from the outset that they will be stood down if patients or the integrity of the scientific endeavour is put at risk by their conduct. Resnick noted in 2019 that “currently there is no documented evidence of any case of research misconduct involving citizen scientists in human studies.”¹⁴⁴ Some employers are allegedly guilty of ‘failing to fail’ staff who are found incompetent or who misbehave, while the system for standing down underperforming Public Interviewers is simpler and has no built-in impediments such as the right of representation and appeal¹⁴⁵. The lack of such arrangements is perhaps reprehensible, but it does enable unsuitable persons to be quickly discharged from their role if they are found wanting.

4.6 Indemnity cover

In the event of something going wrong during the process of data collection, Public Interviewers must be included in indemnity cover. NHS organisations have a legal duty of quality and a common-law duty of care which includes vicarious liability for harm due to clinical negligence¹⁴⁶.

Appendix A: Sample request for Letter of Access

Enter 'Lived Experience Advisory Panel member' in the Job Title.

Volunteer letter of access: proforma confirmation of pre-engagement checks

For volunteers or freelance researchers who do not have a substantive NHS contract of employment or an honorary clinical contract with an NHS organisation, and who need a letter of access from an NHS organisation hosting their research

CONFIRMATION OF PRE-ENGAGEMENT CHECKS

To: R&D Office / Address of NHS site hosting the research / Researcher's name / Job title / Study title / IRAS project ID / Sponsor / Study end date.

As the Chief Investigator of the above-named research, I can confirm that the above-named researcher is contracted by us to work on the research project. I understand that the responsibility for ensuring that the appropriate pre-engagement checks have been undertaken rests with us. I can confirm that the appropriate pre-engagement checks have been completed, commensurate with her/his job description and proposed research role in your NHS organisation, and in line with NHS employment checks standards.

Name of Chief Investigator / Job Title / Workplace address / Tel / Email.

Appendix B: Sample Letter of Access

Source¹⁴⁷.

Name of research Study / Research Ethics Committee opinion reference / IRAS ID.

We are satisfied that such checks as are necessary have been carried out by the research organisation and that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for them. The research organisation is fully responsible for ensuring such checks as are necessary have been carried out.

This letter confirms your right of access to conduct research through our NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on [date] and ends on [date] unless terminated earlier in accordance with the clauses below.

You are considered to be a legal visitor to our premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through our Trust, you will remain accountable to your research organisation, but you are required to follow the reasonable instructions of the Research Manager in this NHS organisation or those given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by

this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with our policies and procedures, which are available to you upon request and the UK Policy Framework for Health and Social Care Research.

You are required to co-operate with our NHS Trust in discharging its duties under the Health and Safety at Work etc. Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on our premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust Research department prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018 incorporating the General Data Protection Regulation (GDPR). Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Our Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may revoke this letter and terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You MUST stop undertaking any regulated activity immediately.

Your research organisation is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your research organisation

through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

[name] Research Manager, [name and address of NHS Trust where research is to be carried out].

Appendix C: Three classification systems for researchers

Recent guidance from NIHR¹⁴⁸ utilises two contradictory classification systems for researchers in different circumstances and fails to include Public Interviewers, as shown in the table below. Problems with interpreting this guidance may apply to other areas too, such as the references to different kinds of commercial researcher and different kinds of student placements, but that is beyond the remit of this paper.

NIHR (2019) Paragraph 5		Best fit items from NIHR (2019) Table 1
1	Staff with substantive NHS contracts	5. NHS substantive employee
2	Researchers with a substantive university employment and an honorary NHS clinical contract, e.g. clinical academics	2. Substantive HE with honorary clinical NHS contract (clinical academic)
3	Researchers with substantive university employment contracts and no honorary NHS clinical contract	1. HE substantive employee
4	Researchers who are contracted to provide NHS services, e.g. GPs, who may or may not have a substantive university employment contract	6. Independent contractor e.g. GP providing NHS services under contract
5	Researchers with substantive employment contracts with other employers, e.g. social workers	7. Commercial researcher or 8. Commercial researcher under contract to HE (non-commercial activity)
6	University undergraduate or postgraduate students (some of whom may also have substantive NHS employment contracts)	3. HE student on a formal healthcare placement or 4. HE student not on a formal healthcare placement.
7	Researchers in any of the above categories conducting research where the participants are NHS staff	

A third classification system was provided by NIHR¹⁴⁹ back in 2012 and has not been updated. It is intended show the circumstances in which DBS and occupational health checks are required and also indicate which kind of permit is appropriate in each situation. This goes into more detail than the typologies offered above but does not integrate with either of them.

The nearest option for a Public Interviewer is option 6, but see the reflections set out below the table for a critique of this position.

#	Role of researcher	Regulated activity?	DBS level*	Occ Health^	Permit
1	Researcher is a healthcare professional providing healthcare to an adult and/or child.	Yes	4	2	HRC

#	Role of researcher	Regulated activity?	DBS level*	Occ Health^	Permit
2	Researcher provides healthcare to an adult and/or child under the direction or supervision of a healthcare professional	Yes	4	2	HRC
3	Researcher provides personal care to an adult or child. Or Researcher is a social care worker providing social work which is required in connection with any healthcare or social services to an adult who is a client or potential client.	Ye	4	2	HRC
4	Researcher undertakes the following activities unsupervised: teach, train, instruct, care for or supervise children, or provide advice/guidance on wellbeing, or drive a vehicle only for children; with likely direct bearing on the quality of care.	Yes	4	2	HRC
5	Researcher has opportunity for any form of contact with children in the same Children's Hospital (formerly a specified place) but is not providing healthcare or other types of regulated activity and has no direct bearing on the quality of care.	Yes	3	2	LoA
6	Researcher has access to persons in receipt of healthcare services in the course of their normal duties but is not providing healthcare or other types of regulated activity and has no direct bearing on the quality of care ('Access' relates to where individuals will have physical, direct contact with patients e.g. observation, qualitative interviews, focus groups).	No	2	2	LoA
7	Researcher has indirect contact with patients or service users but is not providing healthcare or other types of regulated activity and has no direct bearing on the quality of care (e.g. some types of telephone interview).	No	0	0	LoA
8	Researcher requires access to identifiable patient data derived from health records, tissues or organs with a likely direct bearing on the quality of care	No	0	1	HRC
9	Researcher requires access to identifiable patient data derived from health records, tissues or organs with no direct bearing on the quality of care	No	0	1	HRC
10	Researcher requires access to anonymised patient data derived from health records, tissues or organs only (including by research staff analysing data). Data reviewed in NHS facilities.	No	0	1	LoA
11	Researcher is working on NHS premises (e.g. laboratory) only (no access to identifiable data).	No	0	1	LoA

#	Role of researcher	Regulated activity?	DBS level*	Occ Health^	Permit
12	Researcher requires direct contact with staff only but no access to patients (e.g. staff interviews). Data reviewed in NHS facilities.	No	0	0	LoA
13	Researcher requires access to identifiable staff data only.	No	0	0	LoA
14	Researcher requires access to anonymised staff data only	No	0	0	LoA

* The levels of DBS check shown in the table below are: 0 (no check required), 1 (Basic), 2 (Standard), 3 (Enhanced), 4 (Enhanced with barred lists check).

^ The type of Occupational Health screening required are 0 (no check required), 1 (check required, but only if the researcher is working with tissues or organs in NHS facilities) and 2 (check required if there is direct contact with the respondent).

Reflections on this list

There is no explanation given here as to why some circumstances require an Honorary Research Contract and others a Letter of Access. It may or may not be aligned with the guidance summarised in sections 2.1 and 2.2 above.

#1 in the table above establishes the principle that researchers who are a member of the healthcare team delivering an intervention are in a position of authority and trust, so diligent checks need to be made. #2 widens this to include team members who act under the direction of a qualified healthcare professional on the care team. #3 further widens this to include the provision of social care. The phrase in #3 mentioning ‘potential client’ is problematic, since everyone is potentially a client, so perhaps it suggests that people on a waiting list or subject to assessment are within its range, rather than all citizens.

#3 notes that the provision of personal care to the person is a sensitive matter and needs thorough checks. #1-#3 count as Regulated Activity if they are done just once, while #4 and #5 must be done regularly to fall into the definition of Regulated Activity¹⁵⁰.

#4 refers to roles where training, advice or signposting are provided regularly and this role is ‘unsupervised’. It is not clear whether this means that the worker is entirely unsupervised (#2 refers to ‘under the direction or supervision of a healthcare professional). Few staff working in health or social care would be without professional supervision of any kind. The condition that this will have a ‘likely direct bearing on the quality of care’ is hard to understand. It may be in contrast to a ‘likely direct bearing on the quality of life’ and so be about advice that will impact the delivery of care, such as a Social Prescriber who helps the person find an exercise class instead of the doctor prescribing antidepressants. #4 is about children, but it is not clear whether the reference to wellbeing brings adults into its orbit or not. Moreover, the reference to caring for or supervising children does not take account of care agencies that support adults. Driving is also included but restricted to the vanishingly rare situation where all the passengers are children.

An enhanced DBS check including a check of the Barred Lists must be undertaken for #1-#4 and the guidance indicates that an Honorary Research Contract is the appropriate permit for these options.

#5 makes special arrangements for non-clinical staff working in children's hospitals but makes no reference to children in other kinds of hospital. An enhanced DBS check is required, but not a check of the Barred Lists and a Letter of Access is the appropriate permit.

#6 is hard to interpret, principally because of the phrase 'in the course of their normal duties'. It suggests that the researcher is already known to the respondents, such as a researcher who works in the hospital or other NHS facility and so may have seen or met the respondents before the focus group itself. It may refer to the idea that the researcher has already obtained permission to be on the premises and so does not need an additional permit to enter. However, a standard DBS check is required and the appropriate permit to allow them to conduct their research is a Letter of Access.

#7 introduces the concept of direct and indirect contact. Telephone interviews are included and it might be reasonable to include online video contacts in the same category. No DBS check should be carried out in respect of **#7-#14**.

#8 and #9 distinguish between identifiable and anonymised patient data and the appropriate permit for either of these options is an Honorary Research Contract.

#10 to #14 require a Letter of Access.

#12 treats access to staff respondents differently from access to patient respondents. **#12 to #14** attend to the question of where the data are being worked on.

Questions that can be derived from this typology comprise:

- Is the researcher part of the health or social care team? (see #1)
- Is the researcher providing personal care? (see #3)
- Is the researcher providing regular training or instruction? (see #4)
- Is the researcher caring for or supervising children? (see #4)
- Is the researcher providing regular advice or guidance on wellbeing? (see #4)
- Is the researcher driving a vehicle only for children? (see #4)
- Is the researcher working in a children's hospital? (see #5)
- Does the researcher have access to persons in receipt of healthcare services in the course of their normal duties? (see #6)
- Will the researcher have direct contact with respondents? (see #7)
- Does the researcher require access to identifiable patient data derived from health records? (see #8)
- Are the research respondents all staff of the NHS Trust? (see #12)
- Is the researcher working at an NHS facility? (see #12 – #14)

Appendix D: Recognition payments do not form a contract of employment

In April 2021, NHS England and NHS Improvement published a policy¹⁵¹ and a guide to payments¹⁵² which might help in clarifying how the research team, sponsor and Research & Development Department should together agree and document accountability. The policy applies to PPV partners acting within 'all national and regional teams and across all of our business functions, including hosted organisations such as the clinical senates and strategic clinical networks, commissioning

support units (CSUs), NHS Interim and Management Support and NHS Sustainable Development Unit. It does not apply to other organisations.’ Partners acting in Role 1 receive nothing, Roles 2 and 3 are offered reimbursement of expenses and Role 4 are also offered payments for time. Role 4 payments occupy a liminal space between a gift and a contract of employment as shown below.

Topic	NHS England Role 4 payments look like wages	Policy shows that payments are not indicative of a contract of employment
Choice of language	The term ‘working’ is used.	The role is clearly stated as ‘volunteer’ and not a ‘contract of employment’. It is acknowledged that the role might expand and become an employment or procurement opportunity.
Appointment	Via person specification, role description, application form, references, shortlisting, interview.	Similar to some public appointments.
Output	Made to those who provide ‘strategic and accountable leadership and decision making’. A role description specifies what is expected. Some training is mandatory.	The role is not viewed as evidence of readiness to work. Most of the material in the PPV policy document under the heading ‘Responsibilities of PPV partners’ is about conduct, not output.
Conduct	‘Work to an expected code of conduct’	They are they are not working under the control of the organisation, nor are they subject to its employment policies or procedures or form part of their staff establishment or organisational structure.
Sum involved	The sum is notified in advance and is at least equal to the National Minimum Wage;	Expenses cover home to office costs. Payments are not treated as an hourly rate. The offer of payment can be refused or a smaller amount can be accepted.
Administration	Payments are subject to statutory deductions (tax and National Insurance payments) . Payments are made via the payroll system within two weeks of receipt of the completed claim form.	Recipients are unlikely to have a personnel file in the Human Resources Department

Appendix E: How this paper is being written

Improve this paper

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 other organisation. Accountability is achieved by following the pattern set out in [How-to-write-in-public.pdf](https://peterbates.org.uk/how-to-write-in-public.pdf) (peterbates.org.uk). I am grateful to the people¹⁵³ who have contributed to this evolving resource. Please send me your suggestions for further improvements.

Further work on this topic could involve the following:

Started March 2024. The most recent draft (15 Jan 2025) is at <https://peterbates.org.uk/wp-content/uploads/2025/01/How-to-get-approval-for-Public-Contributors-to-interview-NHS-patients.pdf>. More resources at www.peterbates.org.uk.

- Public Contributors should be invited to co-author a revised version of this paper
- Interested persons should be invited to review this paper and suggest improvements. It is already too long and technical to be shared as a first contact with respondents but note the sensitivities inherent in this approach¹⁵⁴.
- An edited version of this lengthy technical paper could be prepared for publication in the academic press.

Select search terms

While this paper uses the term Public Interviewer, it is not in common use. Simes¹⁵⁵ conducted a systematic review of mental health intervention studies where Public Contributors had acted as data collectors. This included Embase, Medline, PsycEXTRA, PsycINFO and Cochrane and hand searched papers published in *Research Involvement and Engagement* from inception to May 2019 to find reports published in English. Twenty-five papers met her inclusion criteria covering 20 studies where the authors used a total of thirteen terms for the people so engaged, as follows: Co-researcher¹⁵⁶, Consumer academic¹⁵⁷, Lived experience co-facilitator¹⁵⁸, Peer facilitator¹⁵⁹, Peer interviewer¹⁶⁰, Peer researcher¹⁶¹, Peer support worker¹⁶², People with lived experience¹⁶³, Research associate with user experience¹⁶⁴, Service user experience¹⁶⁵, Service user researcher¹⁶⁶, User member¹⁶⁷ and User interviewer¹⁶⁸.

Simes tried a further thirteen search terms without identifying any further papers. This may provide some additional search terms in looking for relevant papers beyond the boundaries of the Simes review.

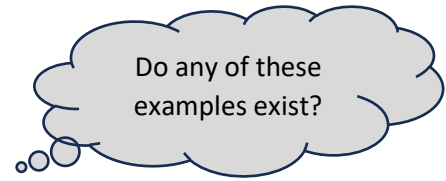
Gather information

Inquiries have been sent to NIHR¹⁶⁹, 109 Principal Investigators, 181 Research Departments in NHS Trusts, 25 infrastructure bodies, 10 individuals, 8 medical charities and 4 training courses for clinician researchers.

A formal literature review could be undertaken by a trained academic to update and broaden that carried out by Simes, including the material found by Bowness¹⁷⁰. Possible search terms include honorary research contract, letter of access, PPI, research passport, as well as the titles for Public Interviewers listed in the section above headed 'Selecting a title for the role'. The literature review might include a search for examples of Public Interviewers engaged outside the NHS: including

- For many years - an historical example is¹⁷¹
- In the USA¹⁷²
- With Public Contributors and research respondents who some might consider a high risk – an example is co-researchers who are young persons¹⁷³
- Where the topic being investigated is sensitive, such as with sex workers¹⁷⁴, people living with HIV/AIDS¹⁷⁵, homeless young people¹⁷⁶ (Couch et al., 2014), lone mothers, or children and people with disabilities¹⁷⁷ (Edwards and Alexander, 2011)
- In a variety of disciplines, such as social work, anthropology and psychology

- With people who use a variety of services, such as psychiatry, learning disability, homelessness, care homes and palliative care
- In hierarchical situations where authority and power affect all relationships, such as prisons
- In small services with high network density where the chances are high that people interact in other roles before, during or after the research is complete.



Develop a process model

The findings from a literature review could be interpreted by taking the following steps:

- Use the taxonomy set out in this paper to organise examples found in the literature. For example, Recollect2, study 3 has been successful in creating opportunities for Public Interviewers who have a contract elsewhere in the NHS to obtain a Letter of Access, while nonsalaried Public Interviewers are having more difficulty obtaining a permit.
- Build a Bayesian 'route probability' chart to inform innovative practice and clarify where routes are appropriately blocked.
- Consider elaborating the taxonomy by adding subdomains and a commentary to each category. For example, a variant where the Public Contributor is employed in another role in the NHS but is taking annual leave for the Public Contributor role may be distinguished from the situation where they are granted permission to undertake it within work time. Co-facilitating a Focus Group may be enriched by setting out a formal statement of the respective duties of the academic researcher and the Public Interviewer.

Learn from failure

Is there any way to review applications for a protocol amendment submitted to the Research Ethics Committees? This might give some indication of the frequency at which plans to engage non-salaried Public Contributors as data collection interviewers have been frustrated¹⁷⁸. Well-written protocols should accommodate iterative approaches in qualitative research without the need for amendments to be submitted to the REC¹⁷⁹. Even further upstream are Chief Investigators and PPI Leads who aspired to involve Public Contributors in this way but quickly abandoned the idea in the face of the difficulties described in this paper. Examples have been found¹⁸⁰ where the research team were forced to abandon aspects of their study because of the bureaucracy involved in gaining approval (rather than for valid ethical reasons), but these examples do not specifically relate to the engagement of Public Interviewers.

- Risk is always considered when carrying out research, Has anyone developed a risk assessment and mitigation plan for Public Interviewers?¹⁸¹
- Material on Public Interviewers may be found by checking out papers that report on the engagement in the adjacent role of Public Analyst¹⁸².

¹ See Lang I, King A, Jenkins G, Boddy K, Khan Z, Liabo K. How common is patient and public involvement (PPI)? Cross-sectional analysis of frequency of PPI reporting in health research papers and associations with methods, funding sources and other factors. *BMJ open*. 2022;12(5):e063356. Also [The 37 Test – Peter Bates](#).

² ‘Patients, service users and the public... are given, and take, the opportunity to participate in health and social care research and get involved in its design, management, conduct and dissemination’. See [UK Policy Framework for Health and Social Care Research - Health Research Authority \(hra.nhs.uk\)](#) paragraph 1.1.. Also ‘Involve the public in research management, regulation, leadership and decision making.’ [UK standards for public involvement](#).

³ Sangill C, Buus N, Hybholt L, Berring LL. Service user's actual involvement in mental health research practices: a scoping review. *International Journal of Mental Health Nursing*. 2019 Aug;28(4):798-815.

⁴ Jones J, Cowe M, Marks S, McAllister T, Mendoza A, Ponniah C, Wythe H, Mathie E. Reporting on patient and public involvement (PPI) in research publications: using the GRIPP2 checklists with lay co-researchers. *Research Involvement and Engagement*. 2021 Dec;7:1-3.

⁵ Bengtsson-Tops, A., & Svensson, B. (2010). Mental health users’ experiences of being interviewed by another user in a research project. A qualitative study. *Journal of Mental Health*, 19(3), 234–242.

<https://doi.org/10.3109/09638230903531084>. A fine example of detailed reporting is provided by Engelaar et al but it does not include Public Interviewers – see Engelaar M, Bos N, van Schelven F, i Sunyer NL, Couespel N, Apolone G, Brunelli C, Caraceni A, Ferrer M, Groenvold M, Kaasa S. Collaborating with cancer patients and informal caregivers in a European study on quality of life: protocol to embed patient and public involvement within the EUonQoL project. *Research Involvement and Engagement*. 2024;10.

⁶ See [FinalReport_0145.pdf](#).

⁷ See [May authors use a pseudonym? – Peter Bates](#).

⁸ Bowness & Bates (in preparation).. Also, a professor responded to this inquiry by admitting ‘I find the NHS ethical processes awful so on the whole tend to steer clear of research in the NHS.’ (personal communication 10/10/2024; identity withheld by the author).

⁹ Repper J, Grant G, Curran M, Nolan M, Hanson E, Keady J (2007) Carers of people with mental health problems as co-researchers: reflections on the partnerships in Carer Assessment project (PICAP). User Participation in Health and social Care Research: Voices, Values and Evaluation. Open University Press, Maidenhead, UK.

¹⁰ Laterza V, Evans, D, Davies R, Donald C & Rice C (2016) What’s in a “research passport”? A collaborative autoethnography of institutional approvals in public involvement in research Laterza et al. *Research Involvement and Engagement* (2016) 2:24. DOI 10.1186/s40900-016-0033-z

¹¹ NHS Research and Development Forum (2019) [Involving Service Users and Carers as Co-Applicants, Project Team Members and Co-researchers in Research Guidelines for Sponsors, Research Managers and Governance Leads..](#)

¹² Blueprint Writing Collective (2022) A Blueprint for Involvement: Reflections of lived experience co-researchers and academic researchers on working collaboratively. *Research Involvement and Engagement*. Dec 5;8(1):68.

¹³ Professor David Evans, quoted in Laterza et al (2016, op cit).

¹⁴ Rush et al reported on the disproportionate administrative burden laid upon studies conducted in Australia – see Rush A, Ling R, Carpenter JE, Carter C, Searles A, Byrne JA (2018). Research governance review of a negligible-risk research project: too much of a good thing? *Research Ethics* Jul;14(3):1-2.. Kearney et al tracked delays in opening 100 research sites across the NHS – see Kearney A, McKay A, Hickey H, Balabanova S, Marson AG, Gamble C, Williamson P (2014) Opening research sites in multicentre clinical trials within the UK: a detailed analysis of delays. *BMJ open*. Sep 1;4(9):e005874.. Wilkinson & Wilkinson suggest that approval systems tend to overlook participatory approaches to research, ask around 80 questions during the IRAS process and take many months to navigate. They also found that IRAS questions about sponsorship and

insurance were especially confusing – see Wilkinson, C., & Wilkinson, S. (2019) The only way is ethics? Applying for National Health Service ethical approval and governance for research with children. *Children's Geographies* 17(4), 480–486. <https://doi.org/10.1080/14733285.2019.1592112>.

¹⁵ Almost all UK citizens are known to the NHS but not all research is reviewed by an NHS Research Ethics Committee. Guidance on which research studies must be reviewed by an NHS Research Ethics Committee is available at [Do I need NHS Ethics approval? \(hra-decisiontools.org.uk\)](https://hra-decisiontools.org.uk). The details vary for each of the four countries of the United Kingdom, suggesting that permit arrangements may vary too. Alternative Research Ethics systems are run for social care research and by universities.

¹⁶ For example, an inquiry to one infrastructure organisation yielded the suggestion that RECs should be approached for advice. While it might be interesting to examine the frequency at which RECs support applications to engage Public Interviewers, this is not the focus of this paper.

¹⁷ For example, HRA (May 2024) [Addressing the barriers to people-centred clinical research](#) makes no reference to Public Interviewers obtaining a research passport, letter of access or honorary contract.

¹⁸ This includes recognising that present arrangements may contribute to the exclusion of racialised groups and others. “...the structures, institutions, people, norms and values that enable research. [Canadian] Participants described these systems as rooted in colonialism and white supremacy that serve as complex determinants of the direction, standards and norms of research.” Plamondon K, Banner D, Cary MA, et al. (2023) Relational practices for meaningful inclusion in health research: results of a deliberative dialogue study. *Health Expectations* 27:e13865. [doi:10.1111/hex.13865](https://doi.org/10.1111/hex.13865). Also “In the [UK] health and care research sector, Black African-, Asian- and Caribbean-heritage patients continue to face systemic barriers to participation.” NIHR (2022) [NIHR Race Equality Framework](#).

¹⁹ “Excellent public involvement is inclusive, values all contributions, ensures people have a meaningful say in what happens and influences outcomes.” NIHR (2022) [Shared commitment to public involvement](#).

²⁰ *Universal Letter of Assurance (ULOA) Guidance: Streamlining researcher access to non-NHS sites out of hospital settings. Version 1.1, 25 May 2022.* <https://www.noclor.nhs.uk/sites/default/files/ULOA%20Guidance.pdf>. Section 1.

²¹ NIHR (April 2019) *RP001 – Good practice: Information for researchers, R&D and HR staff in HEIs and the NHS. Research in the NHS: HR good practice resource pack version 3.0.* Paragraph 2.

²² “Sponsors and research teams have a responsibility to ensure the physical and mental wellbeing of all service users and carers engaged in research teams or as co-researchers.” NHS R&D Forum Service User and Carer Working Group (2019, op cit).

²³ [UK Policy Framework for Health and Social Care Research](#) paragraph 2.1.

²⁴ [UK Policy Framework for Health and Social Care Research](#) paragraph 9.16. Also RP001 op cit, section 5.3 aims to ‘minimise duplication’.

²⁵ This happened at Leeds and York Partnership NHS Foundation Trust (personal communication, Jan 2025).

²⁶ The level of checks varies from almost zero in the case of visitors, through to people who can be seen as acting on behalf of the organisation, such as locum doctors.

²⁷ RP001 op cit, section 5.9.

²⁸ Laterza et al (2016, op cit)

²⁹ Page 3 of NHS Research and Development Forum (2019, op cit).

³⁰ RP001, op cit, section 5.1. It is not clear from this quote whether the term ‘host organisation’ refers to the organisation hosting the research team or the organisation caring for patient respondents.

³¹ As of January 2025, work is still underway on establishing a suitable process for background checks when the Letter of Access approach is used for Public Interviewers. Personal Communication, Jan 2025.

³² See [Honorary research contracts principles and legal requirements \(myresearchproject.org.uk\)](https://myresearchproject.org.uk)

³³ See [Honorary research contracts principles and legal requirements \(myresearchproject.org.uk\)](https://myresearchproject.org.uk)

³⁴ RP001 op cit, section 5.7.

³⁵ RP001 op cit, section 5.8.

³⁶ Personal correspondence, January 2025.

³⁷ This might include 1:1 interviews, 2:1 interviews where an academic researcher and a Public Contributor share the task of conducting the interview, or cofacilitating Focus Groups where more than one patient is providing responses to the research questions. As well as conducting face to face interviews, a Letter of Access may also apply to situations where the researcher is conducting research interviews with NHS patients over the phone.

³⁸ (i) Professor Nicola Thomas at London South Bank University negotiated a Letter of Access for Trust volunteers in 2016 or earlier. In one Trust, the registration process involved classroom training on health and safety and in another Trust online training was required. DBS checks were also carried out. (ii) Nottinghamshire Healthcare NHS Trust provided Letters of Access to Public Contributors for Professor Khalifa's IPS study. (iii) In 2016 or earlier, Paula Wray found that NHS Trusts were unwilling to take on the liability inferred by issuing a research passport but were prepared to offer a Letter of Access.

³⁹ [NHS-to-NHS-confirmation-of-pre-engagement-checks.doc \(live.com\)](https://www.nhs.uk)

⁴⁰ The term 'passport has sometimes been used to refer to a self-disclosure declaration which a person with communication or support needs can hand to a doctor or other professional as a request for personalised care. So, for example, it might say, 'Due to a stammer, I need extra time to answer questions, so please wait for me to speak rather than completing my sentences for me. I may need a longer appointment than usual.' A 'research passport' applies this approach to the encounter between the person and a researcher. See Ashworth M, Crane L, Steward R, Bovis M, Pellicano E. Toward empathetic autism research: Developing an autism-specific research passport. *Autism in Adulthood*. 2021 Sep 1;3(3):280-8.

⁴¹ Jonker L, Cox D, Marshall G. Considerations, clues and challenges: gaining ethical and trust research approval when using the NHS as a research setting. *Radiography*. 2011 Aug 1;17(3):260-4.

⁴² Kate Sonpal, Senior Public Involvement Manager at NIHR INVOLVE indicated on 7/12/2017 that these research passport papers were the most recent and INVOLVE would be addressing this in due course. Unfortunately, INVOLVE was dissolved before the work was carried out.

⁴³ Laterza et al (2016, op cit).

⁴⁴ See [RP_Instructions_V2_0_April_2019.pdf \(myresearchproject.org.uk\)](https://myresearchproject.org.uk)

⁴⁵ *Universal Letter of Assurance (ULOAs) Guidance: Streamlining researcher access to non-NHS sites out of hospital settings. Version 1.1, 25 May 2022.*
<https://www.noclor.nhs.uk/sites/default/files/ULOAs%20Guidance.pdf>.

⁴⁶ For an example see Matheson C & Weightman E (2021) Research and recovery: Can patient participation in research promote recovery for people with complex post-traumatic stress disorder, CPTSD? *Health Expectations*. May. 24:62-9. An inquiry was posted on LinkedIn on 13/08/2024 yielding no further examples. The response to an inquiry submitted to the Health Research Authority in September 2024 indicated that this may be a favoured solution at the HRA, but the response did not address any of the inherent difficulties. Ellie Wildbore, lived experience research ambassador for Sheffield Health and Social Care NHS Foundation Trust, has created two options for Public Interviewers to obtain a research passport, using either (i) registered volunteers or (ii) Band 4 lived experience bank staff. Also, in 2025, RDaSH has a community collaborator process for volunteers such as people involved in PPIE that fall outside of the research passport process. This links into the Trust volunteer process and allows RDaSH to give access and pay expenses. Similarly, at January

2025, Dorset County Hospital NHS Foundation Trust register Public Interviewers as volunteers if they do not have any other relevant status.

⁴⁷ Anyone unsure about whether the status difference is real should suggest to academic researchers employed at the university that their permit be issued by the Voluntary Services Department rather than the Research Department of the NHS Trust.

⁴⁸ NHS Employers (2024) *Employment history and reference checks standard* para 2.4.1. Notice that this process is intended to ensure that the second Voluntary Services Manager carries out checks (taking up references and perhaps making additional checks), slowing the engagement process down, while NHS to NHS authorisation processes for researchers are designed to speed them up.

⁴⁹ The National Association of Voluntary Services Managers is the infrastructure body for NHS Voluntary Services Managers. Its website information on 'What to include in an application form' makes no definitive statement and offers no rationale for the decision that must be taken at local level. It states 'An application form should not ask for unnecessary information... It might include the following: personal details (name, address, postcode... date of birth....), names of referees, Rehabilitation of Offenders declaration...' See www.navsm.co.uk. 'Some NHS Trusts follow poor practices.' (Barry Pridmore, NAVSM Chair, personal communication 09/09/2024.

⁵⁰The Health and Social Care Act 2008 (regulated activities) (Amendment) (NO. 2) regulations 2023, No. 1404.

⁵¹ One NHS Trust required all volunteers to complete seven online training modules and a face-to-face fire safety session. Personal communication from Seonaid Beddows, 19/08/2024. In the example reported by Matheson & Weightman (2021, op cit), no criticisms were mentioned concerning the training delivered by the Volunteer Department at the NHS Trust. Where the induction process requires more hours than the activity itself, volunteers are likely to see the process as not worth it.

⁵² This study engaged peer researchers in data collection via observations of doctors' ward rounds, pharmacists' ward visits and nurses' drug administration at two hospitals rather than utilising interviews or focus groups. The Research Ethics Committee recommended that the academic co-researcher should always be on the ward when the peer researcher was making observations. See Garfield S, Jheeta S, Jacklin A. et al (2015) Patient and public involvement in data collection for health services research: a descriptive study. *Research Involvement and Engagement* 1, 8. <https://doi.org/10.1186/s40900-015-0006-7>.

⁵³ Personal communication 16 and 17/09/2024. The researcher asked for this entry to be anonymous in this guide.

⁵⁴ As the Public Interviewers were engaged in a single, tightly defined role, a standard DBS check was satisfactory in contrast to the enhanced check carried out for salaried researchers who needed authorisation for a range of projects going forward.

⁵⁵ RP001 op cit, section 5.6.

⁵⁶ NHS England (2017) *Recruiting and managing volunteers in NHS providers: a practical guide*. This guidance was published as one response to the Lampard review into matters relating to Jimmy Savile – see [JS Phase 2 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk) and it was partly aimed to reduce local variations in volunteer recruitment mechanisms and pre-engagement checks. Pages 61 and 62 of the practical guide offer an example of a volunteer role description, but it is for an office administration volunteer, not a Public Interviewer.

⁵⁷ See <http://peterbates.org.uk/home/garden-shed/migrants-and-volunteering-in-the-uk/>

⁵⁸ Sam Robertson is designing specific but generic peer research Job Descriptions which will go through the Agenda for Change process - b4 Peer Research Assistant, b5 Peer Researcher and b6 Senior Peer Researcher. Personal communication 19/08/2024. Copies requested. The **Young Foundation Peer Research Network** may be able to offer model job descriptions and advise on the theme of this paper.

⁵⁹ For a recent (2024) example, see <https://peterbates.org.uk/wp-content/uploads/2024/09/Job-Description-for-Peer-Researcher-in-Addictions.docx> and for a general template, see [JD-for-user-researcher.docx \(live.com\)](#) and [rt4aResearchAssistant \(peterbates.org.uk\)](#)

⁶⁰ For an example where participative, arts-based models were used by a small group where it is difficult to separate out the data collectors from the research respondents, see Lee, Caroline (2016) *Research on preparing transition from child and adolescent mental health services (CAMHS): evaluating a creative participatory approach* [83937558.pdf \(core.ac.uk\)](#).

⁶¹ Dunn V, Mellor T. Creative, participatory projects with young people: reflections over five years. *Res All*. 2017;1(2):284–99.

⁶² Notice in passing that this typology is set out from the perspective of risk to organisations. The question of whether NHS patients are at a greater personal risk of abuse from Public Interviewers or Academic staff is a matter beyond the reach of this paper.

⁶³ The research team may collect personal details about respondents in order to test out how representative the findings may be, and this information could be combined with information collected during an interview or Focus Group. Robertson et al (2024 op cit) managed the risk of this by denying Public Interviewers access to the research datasets (personal communication 19/08/2024).

⁶⁴ [Blueprint Writing Collective](#) 2022, op cit. “Co-researchers were required to obtain NHS research passports despite not being responsible for taking consent, having only remote contact with participants and only working under supervision from an experienced academic researcher (holding all governance approvals)”. Also “Some governance departments also seemed to lack understanding of what we were doing within the project and they were clearly not geared up to having young service users as co-researchers.” Researcher quote, p7.

⁶⁵ RP001 op cit section 4 includes a clear reminder that ‘An honorary research contract does not confer the right of access to confidential information for research without explicit consent.’ To reiterate the general principle – the R&D department may grant access to NHS premises, but the patient grants access to their confidential information, so access arrangements do not replace consent arrangements.

⁶⁶ [Blueprint Writing Collective](#) (2022, op cit). The broader picture might include six interdependent elements, as follows; (i) Remove discrimination so that mental health issues are not a barrier to being educated, appointed and promoted as an Academic Researcher. This may include adding lived experience to the list of desirable characteristics in the Person Specification. (ii) Make reasonable adjustments in the workplace so that staff experiencing mental health issues are effectively supported by the right attitudes, behaviours, terms and conditions. (iii) Create new salaried roles for Peer Researchers that value lived experience and require less knowledge and skill in research methods. Find suitable ways to harness their expertise, such as co-facilitating Focus Groups alongside Academic Researchers. This will especially benefit Peer Researchers with intellectual disabilities who would not pass exams in research methods. (iv) Support the development of formally constituted research organisations led by people with lived experience and then commission them to deliver whole research projects or the public involvement aspect of a study. An example is the McPin Foundation. (v) Engage nonsalaried Public Contributors in all aspects of research coproduction, including qualitative data collection, and recognise their contribution through PPIE payments. Apply risk management approaches to shaping their role and obtain research passports as necessary. This will particularly benefit areas like asylum seeker research where Public Contributors are denied access to employment as well as those who want to contribute sporadically rather than make it their fulltime occupation. (vi) Build in-service training and recruitment pathways that enable Peer Researchers and Public Contributors to transition to Academic Researcher posts should they wish to do so.

⁶⁷ In the Repper et al study (2007, op cit.) where data was collected via 1:1 interviews, the REC insisted that respondents be given a choice of interviewer – either academic or lived experience interviewer.

⁶⁸ Sarah Wadd at the University of Bedfordshire and Katie Porter at the University of Southampton have created salaried posts for Lived Experience Researchers. Lynn Laidlaw and Joyce Fox were employed on temporary contracts as peer researchers and conducted 1:1 interviews as part of the study reported at [covid-](#)

[shielding-voices-report.pdf \(versusarthritis.org\)](#). This study was not carried out in the NHS. (Lynn Laidlaw, personal communication 17/09/2024).

⁶⁹ We note that some research teams take an ethical standpoint that Public Interviewers should always be employed on a contract and paid, rather than engaged through Patient and Public Involvement processes and offered recognition payments. If real progress is being made on creating salaried posts for peer researchers, bolstered with robust processes for making reasonable adjustments where necessary, then the need for nonsalaried options is reduced. Ethical use of nonsalaried options will see a proportion of Public Contributors steadily moving into salaried posts.

⁷⁰ It is a good thing when employers make reasonable adjustments to support their employees with protected characteristics and roles in this category can shade from 'no adjustments needed' to tailored roles that focus more strongly on the applicant's lived experience. It is also a good thing when the employer creates roles for nonsalaried Public Interviewers and then builds a pathway so such persons can move into a second role as a salaried Peer Researcher. The distinct contribution of the Public Contributor as outsider to the research organisation remains, and the research community is strengthened when a variety of approaches exist concurrently.

⁷¹ An example of a salaried role where significant adjustments have been made is found in Bruun A, Cresswell A, Jordan L, et al. What are we planning, exactly? The perspectives of people with intellectual disabilities, their carers and professionals on end-of-life care planning: A focus group study. *Palliative Medicine*. 2024;38(6):669-678. doi:[10.1177/02692163241250218](https://doi.org/10.1177/02692163241250218). Bruun and team employed research assistants with intellectual disabilities.

⁷² See, for example, Blueprint Writing Collective (2022, op cit).

⁷³ Simes EF (2021, op cit)

⁷⁴ RP001 op cit, section 5.4 states, 'Where Independent Contractors such as GPs or practice staff undertake research as part of their routine clinical services, their personal professional indemnity arrangements are expected to provide them with adequate cover for that activity. It is the contractor's responsibility to check that the professional indemnity will cover the proposed research or whether additional premiums are required. Where Independent Contractors undertake research on patients outside their routine clinical practice, their personal professional defence arrangements may not extend to cover such research activities. NHS Indemnity arrangements specifically do not extend to Independent Contractors (or their staff) while they are working under contract for services to the NHS. Therefore, issuing an honorary research contract to this group of researchers does not bring them under the ambit of NHS Indemnity arrangements. Independent Contractors may be employed by an NHS organisation under certain circumstances, in which case NHS Indemnity arrangements would apply in the same way as for other NHS staff.' Also NHS R&D Forum (2005) *Indemnity arrangements within primary care – who is responsible for what?*

⁷⁵ Windsor et al (2024) op cit. suggest that a common response in the USA is to offer 'community partner contracts' when engaged in Community Engaged Research. However, it is not clear whether these are contracts with a community organisation or with an individual. Windsor L, Benoit E, Kwan P, Tan K, Richmond A (2024) Protection of participants in community engaged research by institutional review boards: a call for action. *Am J Public Health*. DOI: <https://doi.org/10.2105/AJPH.2024.307592>. Repper et al (2008) employed carers as researchers to study the implementation of carer assessments in social care rather than in the NHS – Repper J, Nolan M, Grant G & Curran M (2008) *Family carers on the margins: Experiences of assessment in mental health* Report to the National Coordinating Centre for NHS Service Delivery and Organisation R&D.

⁷⁶ Robertson et al is an example of focus group cofacilitators being employed elsewhere in the NHS Trust as Peer Support Workers. Both participants and Peer Interviewers engaged in the focus group in their worktime. See Robertson S, Leigh-Phippard H, Robertson D, Thomson A, Casey J, Walsh LJ (2024) What supports the emotional well-being of peer workers in an NHS mental health service? *Mental Health and Social Inclusion*. Jul 5. Personal correspondence, 19/08/2024).

⁷⁷ RP001 op cit.

⁷⁸ Organisational boundary regulation can be applied to many aspects of life including use of social media whilst off duty. See Banghart S, Etter BN, Stoll C (2018) Organisational boundary regulation through social media policies *Management Communication Quarterly*.

⁷⁹ Industrial tribunals in the UK have upheld employer's decision to dismiss staff for their behaviour outside work, even when the matter has not come into the public domain and the employee played no part in it coming to light. See Collins PM (2022) Finding Fault in the Law of Unfair Dismissal: The Insubstantiality of Reasons for Dismissal. *Industrial Law Journal*. Sep; 51(3): 598-625.

⁸⁰ RP001 op cit, section 5.7.

⁸¹ A manuscript describing the difficulties in obtaining approval for Public Interviewers was declined by a journal that specialises in this field. Despite being told that all participants were supportive of the paper, one peer reviewer suggested that publication might trigger a change of heart and litigation against the R&D Department, the University and the journal.

⁸² Minogue V (2020) [Additional legal, ethical and governance considerations when engaging in Community Based Participatory Research \(CBPR\)](#) NHS Research and Development Forum. Page 10 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf> declares that "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." Note that the definition of co-applicant in this guide encompasses Public Contributors who collect data from NHS patients for the study. Page 14 of the same document explains that "Host institutions have a legal and financial responsibility for all co-applicants.... Where appropriate, the host could also provide: indemnity insurance that covers public co-applicants for the duration of the role." More broadly, "NHS bodies owe a duty of care to healthy volunteers or patients.... NHS Indemnity covers negligent harm caused to these people... whenever they are subjects of clinical research aimed at benefiting patients now or in the future, whether as patients or as healthy volunteers." Paragraph 12.3 of [NHS Indemnity \(resolution.nhs.uk\)](#). We can imagine that Public Contributors stand amongst the following list, found on page 3 of the same document; "NHS bodies are vicariously liable for the negligent acts and omissions of their employees and should have arrangements for meeting this liability NHS Indemnity applies where... persons, not employed under a contract of employment and who may or may not be a health care professional, who owe a duty of care to the persons injured. These include locums; medical academic staff with honorary contracts; students; those conducting clinical trials; charitable volunteers; persons undergoing further professional education, training and examinations; students and staff working on income generation projects."

⁸³ [HRA Expectations of Sponsors](#) set out what is required.

⁸⁴ Personal communication, 10/01/2025. The NHS Trust concerned had no experience of this.

⁸⁵ RP001 op cit, section 5.5.

⁸⁶ The absence of a clear framework for the delegation of responsibilities that includes Public Interviewers was identified as long ago as 2018, but there appears to be no sign of progress since then. "Consideration should be given to the different sorts of agreement that exist for service user and carer project team members or co-researchers and the risks and benefits of each type should be assessed. Consideration should be given to whether agreements should be in the form of a personal honorary contract, alongside a separate matrix to make clear the specific roles and responsibilities, or whether this should be more of a collaboration agreement." NHS R&D Forum Service User and Carer Working Group (2019, op cit).

⁸⁷ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

⁸⁸ See [Signature And Delegation Log Template v1-2.docx \(live.com\)](#). As we know from [UK Policy Framework for Health and Social Care Research](#), paragraph 9.6, Public Interviewers are part of the research team, so there is no reason to exclude them from the Delegation of Responsibilities Log.

⁸⁹ RP001 op cit, section 5.1.

⁹⁰ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

⁹¹ It is clear from page 9 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf> that documented roles and responsibilities for the Public Contributor is not the same as a contract of employment. Guidance on NHS Volunteers states “It is important that you do not create the perception, even unintentionally, that a legally binding relationship is being created. The intention to create a legally binding contract may not be something that either party has expressed or even considered. It could simply be implied by the circumstances. You can lay out the general elements of the role, what the expectations are of the volunteer and what the volunteer can expect from the organisation but you should be careful to ensure that you do not create formal obligations – for example by specifying the required number of hours someone should volunteer for. This then appears too similar to an employment contract. You should also not provide any payments to volunteers beyond reimbursement of expenses. Training provided should be relevant to the role as additional benefits could be seen as a perk.” NHS England (September 2017) *Recruiting and managing volunteers in NHS providers: A practical guide*.

⁹² [UK Policy Framework for Health and Social Care Research](#), paragraph 9.6

⁹³ [NHS England Patient and Public Voice Partners Policy](#).

⁹⁴ [B0869 Working-with-patient-and-public-voice-partners-reimbursing-expenses-and-paying-involvement-payments.pdf \(england.nhs.uk\)](#)

⁹⁵ See [How-to-build-an-organising-logic-for-structuring-PPI-payments.pdf \(peterbates.org.uk\)](#).

⁹⁶ Barbara Maloney-Oates, Health Research Authority – personal communication 13/08/2024.

⁹⁷ An example agreement is at <https://www.nihr.ac.uk/documents/partners-and-industry/model-site-agreements/mICRA-template.doc>. Other model agreements may be available.

⁹⁸ [PPI for Bureaucrats – Registration of new public contributors – Peter Bates](#)

⁹⁹ For example, page 10 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf> explains that risk assessment documents for Public Contributors should be similar to those used for academic researchers.

¹⁰⁰ Information about protected characteristics is available at [Protected characteristics | EHRC \(equalityhumanrights.com\)](#)

¹⁰¹ In writing about the Research Passport process, NIHR guidance is clear that the process should use ‘the minimum personally-identifiable information possible’. Moreover, the information should be retained only for the duration of the researcher’s access to the NHS organisation. RP001 op cit, section 6.

¹⁰² “Volunteers should receive an explanation as to why such checks are necessary.” NHS England (September 2017) *Recruiting and managing volunteers in NHS providers: A practical guide*. Page 32.

¹⁰³ RP001 op cit Section 4. Similarly, *Universal Letter of Assurance (ULOAs) Guidance: Streamlining researcher access to non-NHS sites out of hospital settings. Version 1.1, 25 May 2022*. <https://www.noclor.nhs.uk/sites/default/files/ULOAs%20Guidance.pdf>. Section 2 asserts that Pre-engagement checks need to be “appropriate for the proposed research activities”.

¹⁰⁴ NHS England do not give an opinion of whether identity checks are required for NHS volunteers. “Other checks for volunteers may be required by your organisation’s policy. Ensure you identify whether other checks will be required as part of volunteer recruitment. Volunteers should receive an explanation as to why such checks are necessary. Additional checks may include: employment checks (proof of identity, Visa, proof of address) to NHS Employment Check Standard, if appropriate. NHS England (September 2017) *Recruiting and managing volunteers in NHS providers: A practical guide*. Page 32.

¹⁰⁵ See [May authors use a pseudonym? – Peter Bates](#). In summary, in the rare circumstances where security and safety may be compromised by disclosure, there is a case for ensuring that the Principal Investigator has full identity and contact details while others use a pseudonym.

¹⁰⁶ See <http://peterbates.org.uk/home/garden-shed/migrants-and-volunteering-in-the-uk/>

¹⁰⁷ [UK Policy Framework for Health and Social Care Research](#) paragraph 9.16.

¹⁰⁸ Volunteers at an NHS Trust are not routinely subject to screening by the Occupational Health Department unless there are particular reasons to do so, such as when the person who is prescribed sedative medication applies to be a volunteer minibus driver.

¹⁰⁹ Garfield S et al, 2015, op cit.

¹¹⁰ [UK Policy Framework for Health and Social Care Research](#) paragraph 9.16. Also RP001 op cit, section 5.3 aims to 'minimise duplication'.

¹¹¹ The NHS England fit and proper person test framework (the [FPPT framework](#)), launched in August 2023 in response to The Kark review, sets out what is specifically required of organisations to confirm that an individual in a board member position is fit and proper, including the provision and uptake of references.

¹¹² NHS Employers (2024) *Employment history and reference checks standard*.

¹¹³ Laterza et al (2016, op cit) note that Public Contributors who have served in several consecutive roles can easily obtain a reference from a member of the academic team, but (1) this reinforces the power difference between academic staff and Public Contributors, and (2) it favours existing Public Contributors and so forms a disincentive to seek new people.

¹¹⁴ It is not clear here whether the 'host organisation or institution' refers to the NHS Trust where the researcher will conduct the interviews or the research organisation that employs the researcher.

¹¹⁵ Page 15 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf>. This guidance refers to the 'host' organisation but does not make clear if this is the NHS Trust acting as sponsor or the NHS Trust which will welcome researchers onsite to interview their patients. Guidance at [Payment guidance for researchers and professionals | NIHR](#) comments on peer interviews, but stops short of making a clear and unambiguous directive. For example, it says that peer interviewers 'may require' a DBS check.

¹¹⁶ Personal communication, 16 and 17 Sept 2024. The researcher withheld their name.

¹¹⁷ Researchers in the Repper et al (2007 op cit) study were required to have a CRB check. In the Symes (2021, op cit) study, DBS information was shared with the clinical lead but not the NHS Trust Research & Development Departments.

¹¹⁸ Advice is available on the structure and content of a CV for Public Contributors – see NIHR (2019) [Public Co-Applicants in Research – guidance on roles and responsibilities](#), page 6. Laterza et al (2016, op cit) note that some Public Contributors may not know how to present a conventional CV and that HR personnel routinely investigate all gaps in employment, which might be uncomfortable for Public Contributors, especially when it relates to living through stigmatised life experiences. Such gaps may have occurred through the lived experience of the Public Contributor which is the direct reason they are being engaged in the study. It should not be assumed that the Public Contributor is confident and comfortable in disclosing these details to strangers.

¹¹⁹ The Health and Social Care Act 2008 (regulated activities) (Amendment) (NO. 2) regulations 2023, No. 1404 removes the requirement for service providers to obtain a full employment history of health and care volunteers when appointing them for the purposes of carrying out a regulated activity.

¹²⁰ NHS Employers (2024) *Employment history and reference checks standard* para 2.3.2.

¹²¹ Sally Dyson, personal communication 29/08/2024.

¹²² Article 5 of the GDPR.

¹²³ "A formal, structured risk assessment is only expected where identified as essential. The risk: benefit ratio will normally be sufficiently described and considered as part of review processes such as research ethics committee review." HRA (29 March 2023) [UK Policy Framework for Health and Social Care Research](#).

¹²⁴ A risk assessment is required when engaging Public Contributors in data collection interviews – see page 10 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf>.

¹²⁵ Page 10 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf> obliges Public Contributors to follow lone worker policies.

¹²⁶ In the case of the ULOA, a signature is required from a senior figure in the organisation that has engaged the Public Interviewer. This provides an opinion from someone who is removed from the immediate demands of delivering the research project and helps to confirm that arrangements are appropriate.

¹²⁷ For guidance on including Public Interviewers in a distress protocol, see <https://peterbates.org.uk/wp-content/uploads/2021/06/How-to-respond-to-distress.pdf>

¹²⁸ Such as the training material at [User Guide - Peer Research Training \(imperial.ac.uk\)](https://www.imperial.ac.uk/user-guide-peer-research-training)

¹²⁹ “Whereas sponsors are required to ensure their researchers are competent by education, training or experience, enabling service users to become members of project management teams or co-researchers may require a different approach whereby training and support in the roles involved in research study management or methodology are provided during the project itself.” NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹³⁰ [gcp-training-joint-statement.pdf](https://www.invo.org.uk/wp-content/uploads/2019/04/gcp-training-joint-statement.pdf).

¹³¹ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹³² To avoid any suggestion that a contract of employment has been formed, “Training provided should be relevant to the role as additional benefits could be seen as a perk.” NHS England (September 2017) *Recruiting and managing volunteers in NHS providers: A practical guide*. Page 22.

¹³³ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹³⁴ [UK Policy Framework for Health and Social Care Research](https://www.invo.org.uk/wp-content/uploads/2019/04/UK-Policy-Framework-for-Health-and-Social-Care-Research.pdf) paragraph 9.16.

¹³⁵ [gcp-training-joint-statement.pdf](https://www.invo.org.uk/wp-content/uploads/2019/04/gcp-training-joint-statement.pdf).

¹³⁶ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹³⁷ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹³⁸ <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf> Page 10.

¹³⁹ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹⁴⁰ NHS R&D Forum Service User and Carer Working Group (2019, op cit).

¹⁴¹ [UK Policy Framework for Health and Social Care Research](https://www.invo.org.uk/wp-content/uploads/2019/04/UK-Policy-Framework-for-Health-and-Social-Care-Research.pdf) paragraph 9.16.

¹⁴² Page 12 of <https://www.invo.org.uk/wp-content/uploads/2019/04/Co-AppsGuidance2019.pdf> requires Public Contributors to be trained in health and safety.

¹⁴³ RP001 op cit, section 4 insists ‘There should be a system at local level for identification and local managerial control/supervision of all individuals carrying out research in or through the NHS.’

¹⁴⁴ Resnik DB. Citizen Scientists as Human Subjects: Ethical Issues. *Citizen Science: Theory & Practice*. 2019 Jan 1;4(1).

¹⁴⁵ See [How-to-build-an-organising-logic-for-structuring-PPI-payments.pdf \(peterbates.org.uk\)](https://www.invo.org.uk/wp-content/uploads/2019/04/How-to-build-an-organising-logic-for-structuring-PPI-payments.pdf) where section 4 discusses the action taken when the Public Contributor underperforms.

¹⁴⁶ RP001 op cit paragraph 3. See also Department of Health (2005) *Research in the NHS: indemnity arrangements*. Also Department of Health and Universities UK (2004) *Responsibilities, liabilities and risk management in clinical trials of medicines*.

¹⁴⁷ [Example letter of access for uni researchers not requiring honorary research contract_v2_4 March 2019.doc \(live.com\)](#)

¹⁴⁸ RP001, op cit.

¹⁴⁹ 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 \(myresearchproject.org.uk\)](#)

¹⁵⁰ Regulated activity is defined in the Safeguarding Vulnerable Groups Act 2006, as amended (in particular by the Protection of Freedoms Act 2012).

¹⁵¹ [NHS England Patient and Public Voice Partners Policy](#).

¹⁵² [B0869_Working-with-patient-and-public-voice-partners-reimbursing-expenses-and-paying-involvement-payments.pdf \(england.nhs.uk\)](#)

¹⁵³ Responses have been gratefully received from Seonaid Beddows, Bryher Bowness, Heidi Chandler, Peter Eaton-Williams, Chris Gibbs, Paul Hine, Lynn Laidlaw, Vanessa Lawrence, Mark Liddell, Farah Lunat, Barbara Molony-Oates, Katie Porter, Barry Pridmore, Antonino Puglisi, Helen Riding, Joe Shoebridge, Gill Windle and Gemma Winsor. Any remaining errors and omissions in this paper are the sole responsibility of the author. The information is provided in good faith and so readers engage with the contents 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.

¹⁵⁴ See [Dilemmas of writing in public – Peter Bates](#).

¹⁵⁵ Simes published her systematic review in 2021, including 20 mental health intervention studies that engaged Public Interviewers and published their findings in a total of 25 papers in either peer-reviewed or none-peer reviewed journals in English. Simes EF (2021) *Bridging the gap: A mixed methods study exploring the impact of the involvement of researchers with lived experience on a multi-site randomised control trial in the National Probation Service in England and Wales*. Doctoral dissertation, University College London.

¹⁵⁶ Biringer, E., Davidson, L., Sundfjør, B., Ruud, T., & Borg, M. (2017). Service users' expectations of treatment and support at the Community Mental Health Centre in their recovery. *Scand J Caring Sci*, 31, 505-513. doi: 10.1111/scs.12364. Biringer confirmed (i) they did ten 2:1 interviews rather than 5 interviews by Biringer and 5 by Sundfjør; (ii) Sundfjør was employed as a Peer Researcher (personal communication 16/08/2024).

¹⁵⁷ Bocking J, Ewart SB, Happell B, Platania-Phung C, Stanton R & Scholz B (2018) "Here if you need me": exploring peer support to enhance access to physical health care. *Journal of Mental Health*, 27, 329-335. This study used Focus Groups rather than interviews and the lived experience contribution was from Ewart, a presumably dually qualified 'Independent Consumer Academic'.

¹⁵⁸ Fletcher J, Hamilton B, Kinner S et al (2019) Working towards least restrictive environments in acute mental health wards in the context of locked door policy and practice. *International journal of mental health nursing*, 28, 538-550. In this study, forums of up to 10 respondents were co-facilitated by a 'member of the research team, together with a locally-based facilitator with lived experience.' No other details of the selection and approval process are given.

¹⁵⁹ Barber JA, Rosenheck RA, Armstrong M & Resnick SG (2008) Monitoring the dissemination of peer support in the VA Healthcare System. *Community mental health journal*, 44, 433-441.

¹⁶⁰ Siantz E, Henwood B, McGovern N, Greene J & Gilmer T (2019) Peer respites: a qualitative assessment of consumer experience. *Administration Policy in Mental Health Mental Health Services Research*, 46, 10-17. Also Sampogna G, Bakolis I, Robinson E, Corker E, Pinfold V, Thornicroft G & Henderson C (2017) Experience of the Time to Change programme in England as predictor of mental health service users' stigma coping strategies. *Epidemiology Psychiatric Sciences*, 26, 517-525. Also Ridley J & Hunter S (2013) Subjective experiences of compulsory treatment from a qualitative study of early implementation of the Mental Health (Care & Treatment)(Scotland) Act 2003. *Health social care in the community*, 21, 509-518.

¹⁶¹ Stevenson F, Hamilton S, Pinfold V, Walker C, Dare CR, Kaur H., . . . Petersen I. (2016). Decisions about the use of psychotropic medication during pregnancy: a qualitative study. *BMJ open*, 6, e010130. Also Pinfold V, Dare C, Hamilton S, Kaur H, Lambley R, Nicholls V . . . Stevenson F (2019) Anti-psychotic medication decision making during pregnancy: a co-produced research study. *Mental Health Review Journal*. Also Livingston JD, Nijdam-Jones A, & Team P (2013) Perceptions of treatment planning in a forensic mental health hospital: A qualitative, participatory action research study. *International Journal of Forensic Mental Health*, 12, 42-52. Also Livingston JD, Nijdam-Jones A, Lapsley S, Calderwood C & Brink J (2013) Supporting recovery by improving patient engagement in a forensic mental health hospital: Results from a demonstration project. *Journal of the American Psychiatric Nurses Association*, 19, 132-145.

¹⁶² Strudwick G, Clark C, McBride B, Sakal M, & Kalia K. (2017). Thank you for asking: exploring patient perceptions of barcode medication administration identification practices in inpatient mental health settings. *International journal of medical informatics*, 105, 31-37. Also Leung K, Clark C, Sakal M, Friesen M, & Strudwick G (2019) Patient and Family Member Readiness, Needs, and Perceptions of a Mental Health Patient Portal: A Mixed Methods Study. Paper presented at the ITCH.

¹⁶³ Korsbek L, & Tønder ES (2016) Momentum: A smartphone application to support shared decision making for people using mental health services. *Psychiatric Rehabilitation Journal*, 39, 167.

¹⁶⁴ Olsø TM, Gudde CB, Moljord IEO, Evensen GH, Antonsen DØ & Eriksen L (2016) More than just a bed: mental health service users' experiences of self-referral admission. *International journal of mental health systems*, 10, 1-7.

¹⁶⁵ Rise MB, Evensen GH, Moljord IEO, Rø M, Bjørgen D, & Eriksen L (2014) How do patients with severe mental diagnosis cope in everyday life-a qualitative study comparing patients' experiences of self-referral inpatient treatment with treatment as usual? *BMC health services research*, 14, 1-11.

¹⁶⁶ Tew J (2008) Researching in partnership: Reflecting on a collaborative study with mental health service users into the impact of compulsion. *Qualitative Social Work*, 7, 271-287. Also Milton A, Lloyd-Evans B, Fullarton K, Morant N, Paterson B, Hindle D, . . . Johnson S (2017) Development of a peer-supported, self-management intervention for people following mental health crisis. *BMC research notes*, 10, 1-18. Also Hart A, Saunders A & Thomas H (2005) Attuned practice: a service user study of specialist child and adolescent mental health, UK. *Epidemiology Psychiatric Sciences*, 14, 22-31. Also Gillard S, White R, Miller S & Turner K (2015). Open access support groups for people experiencing personality disorders: Do group members' experiences reflect the theoretical foundations of the SUN project? *Psychology Psychotherapy: Theory, Research Practice*, 88, 87-104. Also Gillard S, Simons L, Turner K, Luccock M & Edwards C. (2012). Patient and public involvement in the coproduction of knowledge: reflection on the analysis of qualitative data in a mental health study. *Qualitative Health Research*, 22, 1126-1137. Also Campbell, Shryane, Byrne & Morrison (2011) A mental health promotion approach to reducing discrimination about psychosis in teenagers. *Psychosis*, 3, 41-51. (Get initials)

¹⁶⁷ Barnes, Davis, & Tew J. (2000). Valuing Experience: Users' Experiences of Compulsion under the Mental Health Act 1983. *Mental Health Review Journal*.

¹⁶⁸ Svensson B & Hansson L. Satisfaction with mental health services. A user participation approach. *Nordic journal of psychiatry*. 2006 Jan 1;60(5):365-71.

¹⁶⁹ In 2020, NIHR decommissioned INVOLVE and replaced it with the Centre for Engagement and Dissemination. A search for the CED on the NIHR website on 28/04/2024 was unsuccessful. Jeremy Taylor, Director of Public Voice explained, "CED as an entity has no public profile because NIHR is moving towards presenting itself as a single thing rather than confusing the wider world by showing all the wiring. We present PPIE as a core function of NIHR rather than something hived off to a separate unit. Formally, CED is one of the constituent parts of the NIHR Coordinating Centre described here <https://www.nihr.ac.uk/about-us/who-we-are/our-governance.htm#one>. The work of CED is best represented here [---

Started March 2024. The most recent draft \(15 Jan 2025\) is at <https://peterbates.org.uk/wp-content/uploads/2025/01/How-to-get-approval-for-Public-Contributors-to-interview-NHS-patients.pdf>. More resources at \[www.peterbates.org.uk\]\(http://www.peterbates.org.uk\).](https://www.nihr.ac.uk/about-</p></div><div data-bbox=)

[us/what-we-do/Improving-how-we-work-with-patients-carers-and-the-public.htm](https://www.learningforinvolvement.org.uk/) and here: <https://www.learningforinvolvement.org.uk/>." Both Jeremy and infrastructure@nihr.ac.uk merely pointed to <https://www.learningforinvolvement.org.uk/>.

¹⁷⁰ Bryher Bowness found the following: (1) SUGAR ([Simpson et al, 2014](#)) – honorary contract with the university. (2) [Wright et al \(2006\)](#) honorary contract with each NHS site. (3) [Di Lorito et al \(2020\)](#) – covered in the ethics approval, not seeing patients on their own. In addition, we might check out (4) [Considerations, clues and challenges: Gaining Ethical and Trust research approval when using the NHS as a research setting - ScienceDirect](#), (5) [CoPPer](#) (contact shahid.islam@bthft.nhs.uk); (6) [Young Foundation](#); and (7) [OP79 Optimising patient and public engagement in trials of complex interventions | Journal of Epidemiology & Community Health \(bmj.com\)](#). Also review the examples given at (8) [NIHR Guidance on co-producing a research project \(learningforinvolvement.org.uk\)](#)

¹⁷¹ There may be examples in <https://peterbates.org.uk/wp-content/uploads/2019/12/How-to-involve-people-as-research-co-interviewers.pdf> and <https://peterbates.org.uk/wp-content/uploads/2017/04/How-To-co-facilitate-a-focus-group.pdf>.

¹⁷² Croft B, Ostrow L, Italia L, Camp-Bernard A, Jacobs Y. Peer interviewers in mental health services research. *The Journal of Mental Health Training, Education and Practice*. 2016 Sep 12;11(4):234-43.

¹⁷³ Fløtten KJ, Guerreiro AI, Simonelli I, Solevåg AL, Aujoulat I. Adolescent and young adult patients as co-researchers: a scoping review. *Health Expectations*. 2021 Aug;24(4):1044-55 found the following: (#1) Dunn V (2017) Young people, mental health practitioners and researchers co-produce a Transition Preparation Programme to improve outcomes and experience for young people leaving Child and Adolescent Mental Health Services (CAMHS). *BMC Health Serv Res*. 17(1): 293. (#2) Lincoln AK, Borg R, Delman J. Developing a community-based participatory research model to engage transition age youth using mental health service in research. *Fam Community Health*. 2015; 38(1): 87-97. (#3) van Staa A, Jedeloo S, Latour JM, Trappenburg MJ. Exciting but exhausting: experiences with participatory research with chronically ill adolescents. *Health Expect*. 2010; 13(1): 95-107. (#4) Edwards M, Lawson C, Rahman S, Conley K, Phillips H, Uings R. What does quality healthcare look like to adolescents and young adults? Ask the experts!. *Clin Med (Northfield Il)*. 2016; 16(2): 146-151. (#5) Moules T. 'They wouldn't know how it feels ...': characteristics of quality care from young people's perspectives: a participatory research project. *J Child Health Care*. 2019; 13(4): 322-332. (#6) Kramer JM, Schwartz AE. Development of the pediatric disability inventory-patient reported outcome (PEDI-PRO) measurement conceptual framework and item candidates. *Scand J Occup Ther*. 2018; 25(5): 335-346. (#7) Mitchell K, Durante SE, Pellatt K, Richardson CG, Mathias S, Buxton JA. Naloxone and the Inner City Youth Experience (NICYE): a community-based participatory research study examining young people's perceptions of the BC take home naloxone program. *Harm Reduction J*. 2017; 14(1): 34. (#8) Pullmann MD, Ague S, Johnson T, et al. Defining engagement in adolescent substance abuse treatment. *Am J Community Psychol*. 2013; 52(3-4): 347-358. Also [Blueprint Writing Collective 2022](#), op cit. "Some governance departments also seemed to lack understanding of what we were doing within the project and they were clearly not geared up to having young service users as co-researchers." Researcher quote, p7.

¹⁷⁴ 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.

¹⁷⁵ Greene S, Ahluwalia A, Watson J, Tucker R, Rourke SB, Koornstra J, Sobota M, Monette L, Byers S (2009) Between skepticism and empowerment: the experiences of peer research assistants in HIV/AIDS, housing and homelessness community-based research. *International Journal of Social Research Methodology*. Oct 1;12(4):361-73.

¹⁷⁶ Couch J, Durant B, Hill J (2014) Uncovering marginalised knowledges: Undertaking research with hard-to-reach young people. *International Journal of Multiple Research Approaches*. Apr 1;8(1):15-23.

¹⁷⁷ Edwards R & Alexander C (2011) Researching with peer/community researchers—ambivalences and tensions. *The SAGE handbook of innovation in social research methods*. Mar 11:269-92.

¹⁷⁸ Windsor et al (2024, op cit) note that the emerging nature of community-engaged research clashes with the advance planning required for the Ethics Committee, leading to multiple amendments.

¹⁷⁹ See [UK Policy Framework for Health and Social Care Research](#), paragraph 9.4.

¹⁸⁰ Wilkinson & Wilkinson (2019 op cit). Also Thompson AG, France EF (2010) One stop or full stop? The continuing challenges for researchers despite the new streamlined NHS research governance process. *BMC health services research*. Dec;10:1-8.

¹⁸¹ For an example, see <https://peterbates.org.uk/wp-content/uploads/2023/03/How-to-form-a-risk-register-for-patient-and-public-involvement-in-research.pdf>

¹⁸² Public Contributors who assist with interpreting interview transcripts may need to go through a process to obtain permission to see this confidential information. Grant et al refer to them as Community Analysts – see Grant A, McNamara T, Cooper J, Dvorak S, Dolling A, Ellis R, McIntyre C, Jones S, & Brown A (2024) Analysing Data With Members of a Stigmatised Community: Experiences, Reflections and Recommendations for Best Practice From the Finding the Formula Community Analysis Group. *International Journal of Qualitative Methods*, 23. <https://doi.org/10.1177/16094069241229983>.