Building safe and trustworthy processes to address fraudulent involvement

Guidance for Charities Research Involvement Group and Shared Learning Group members

1. Introduction

Purpose

Almost everyone who gets involved in patient and public involvement (PPI) in research will have the lived experience that the Shared Learning Group (SLG) and Charities Research Involvement Group (CRIG) members are seeking. But in a very small number of cases, this is not the case. The aim of this guidance is to help CRIG SLG members to build and manage a robust involvement process by preventing and addressing involvement which may be deemed to be ineligible or fraudulent.

Underlying principles

We would like you to bear in mind these underlying principles when using this guidance:

1. Almost everyone who wants to take part in PPI activities or research has genuine lived experience to share.
2. We need to balance preventing fraud with not creating too many barriers to taking part in a PPI activity, especially for underserved communities.
3. Supporting involvement processes well is partly about managing risk – and the amount of risk we are prepared to take may vary between both projects and organisations.

Terms used in this guidance

There are many different terms used for people who accidentally or deliberately join activities that they do not have the relevant lived experience for. In this guide we will use the following terms and definitions:

- Patient and public involvement (PPI): when people with lived experience work in partnership with researchers and charities to design or deliver projects or services. Involvement is often described as doing things with or by people, rather than for or to them. This can include (but is not limited to) a range of activities including consultations, surveys, focus groups, advisory panels, user testing, and co-design workshops.
- Ineligible involvement: when someone does not have relevant experience but has joined because they misunderstood the purpose of an activity or who is eligible to take part. For example, it was not clear a particular diagnosis or experience is being sought, or the person is mainly looking for peer support from others in similar circumstances.

  Sometimes there is ambiguity about how experiences or roles are defined, for example, is it possible to say what activities or responsibilities make someone a 'carer'?
- Fraudulent involvement: when someone intentionally mispresents their experiences in order take part in a PPI activity. There are many different reasons for this, but a common one is financial gain if people taking part are offered compensation for their time.

We recognise these terms don't cover every possible reason why someone without the relevant experience might join an activity. Others could include 'bad actors' who are seeking confidential information and people whose genuinely want to help, but whose enthusiasm makes them ignore or overlook eligibility requirements.

Why should we be concerned about ineligible or fraudulent involvement?

Ineligible and fraudulent involvement is a growing issue in academic qualitative research and market/consumer research, as well as charity-led PPI work.[1] Ineligible and fraudulent participants can come from multi-national networks.[2]

Fraudulent involvement has been accelerated by the increase in PPI activities being conducted online (e.g. surveys, Zoom meetings).[3] Large language models, like Chat GPT, have also made it much easier to offer a plausible account of a particular experience.[4]

Some researchers and charities have experienced more sophisticated or coordinated efforts to gain access to compensated involvement activities. For example, bots completing online surveys to claim a voucher.[5]

Strong involvement processes can ensure that:

- People can share their lived experience in ways that are safe and respectful
- Charity funds are spent appropriately
- Insights and/or recommendations reflect the priorities and reality for people with lived experience, enabling future decisions and research to be built on strong foundations
- We build trust and encourage future engagement from people with relevant lived experience
- We build relationships with researchers and promote future collaborations
- The reputation of the charity is enhanced

Fraudulent involvement can undermine all the above. It is unsettling to think about people pretending to have a health condition or lived experience, especially when that experience involves trauma or hardship. However, CRIG members need to recognise this possibility to ensure strong involvement processes and safeguard the people with genuine lived experience who our organisations aim to support.

How to use this guide

This guide was written by five CRIG member charities who have encountered suspected fraudulent and/or ineligible involvement. We hope it will help you to build

[1] Mistry et al (2024) Fraudulent Participation in Online Qualitative Studies: Practical Recommendations on an Emerging Phenomenon https://doi.org/10.1177/10497323241288181
[2] Sharma et al (2024) Navigating the challenges of imposter participants in online qualitative research: lessons learned from a paediatric health services study https://doi.org/10.1186/s12913-024-11166-x
[3] Martino et al (2024) Who can you trust these days?: Dealing with imposter participants during online recruitment and data collection https://journals.sagepub.com/doi/10.1177/14687941231224591
[4] Stafford et al (2024) Participant Use of Artificial Intelligence in Online Focus Groups: An Experiential Account https://doi.org/10.1177/16094069241286417
[5] Bonnamy et at (2024) Survey sabotage: Insights into reducing the risk of fraudulent responses in online surveys doi: 10.1002/ase.70015

strong involvement processes and to develop your own approach to prevent, identify and address potential fraudulent or ineligible involvement – ideally in partnership with people with lived experience. What is an 'appropriate' approach will depend on the community you work with and your organisation's existing policies and processes.

When we suspect or discover possible fraud, it's natural to feel angry, frustrated or upset about the situation. However, it is important that we plan, screen and respond in a calm, impartial and balanced way.

The rest of this guide is divided into three parts:

1. Ensuring strong and safe involvement processes when working with people face-to-face or online
2. Ensuring strong and safe involvement processes when working with people's data (e.g. surveys and online forms)
3. Further reading

2. Ensuring strong and safe involvement processes when working with people face-to-face or online

When working with people face-to-face or online, our starting point should always be to assume good intent and seek to understand someone's situation.

This section takes you through how to build strong processes to prevent, spot and respond to ineligible or fraudulent involvement through the stages of:

- Planning a face-to-face or online activity
- Recruitment
- Running an activity
- Post-activity follow-up

> All examples in this section should be treated as a reason to pause and ask yourself if you should explore further, rather than a reason to remove someone from an activity.

Before you start recruitment

Before you advertise any involvement opportunity, consider if you need any of the following documents. These are often useful before you start an involvement activity but can also be referred back to if you need to have a conversation with someone about whether they are eligible to take part in an activity.

- Terms of Reference, that clearly outlines who is eligible to take part
- Code of Conduct, that sets expectations for behaviour and contributions during meetings
- Consent Form, that confirms someone's understanding of an activity's purpose and their role and that they meet the eligibility criteria

Co-designing these documents with people with lived experience can help make sure they are clear, respectful and reflect what they are willing or able to manage.

If you are compensating people for their time, you could also consider systems that:

- Ensure you can only pay each person once (rather than being able to claim multiple rewards)
- Offer pre-paid cards or vouchers that can only be used in the country people should be living in to be eligible

Advertising involvement opportunities – ensuring the 'right' people sign up

Below we list strategies that may help you to prevent ineligible and/or fraudulent involvement when you advertise involvement opportunities.

> We strongly encourage you to think these through carefully before you introduce them into your involvement recruitment processes, as they may also create barriers for people with genuine experience and make it harder to build rapport and trust. This is particularly a concern when trying to hear from underserved communities and people living in poverty.

- Do not mention compensation for participation/time in the advert for the activity (you could still mention covering expenses incurred for taking part e.g. travel).
- Advertise to closed or trusted sources, e.g. closed mailing lists or support groups that have some sort of check before a member joins, rather than social media and public websites.
- Describe the study and eligibility criteria in slightly broader terms in the advert. Although tricky, try to be clear enough to help people understand if it's relevant to them, without being so detailed that it guides how they respond.
- Explain that you are introducing steps into your recruitment processes to help to make sure everyone who joins has relevant experience for the activity.

Screening interested people

A two-stage sign-up process will help you to ensure that people have the lived experience you are seeking before a group discussion or other involvement activity.

Step one could be an online 'expression of interest' form, with questions about the person and motivation to take part (see section 2 below for more advice on use of online forms).

Step two could be an informal conversation, interview or 'comfort call' before the PPI activity. This conversation can also help you to build a relationship and start to understand what people's needs and preferences are.

Things that could help you identify potential fraud during a two-step process include:

- Repeating questions at stage 1 and 2 and checking for consistency in answers. For example:
    - "What year were your born in?" in the expression of interest form, and "How old are you?" in a follow-up conversation

- (If you are not working with people with memory loss) introducing a gap of at least 1 week between stages 1 and 2, so people who have misrepresented their experience are less likely to remember what they said
- Requesting first part of their postcode, then use it to see if it corresponds to the area the person says they live in
- Asking open/free text questions about experiences and why they want to be involved, and screen for potentially 'thin' or unlikely information. For example:
    - Can you tell us a little bit about how your loved one was diagnosed with dementia?
    - We know that dementia impacts people in very different ways. Could you tell us a little about what living with dementia has been like for your relative and you?
- Asking open questions can also let people share relevant information without providing
    - E.g. 'Do you have any lung conditions?' instead of 'Do you have COPD?'
- Including a simple question that people with genuine experience will be able to answer easily but might not be easy to look up. For example:
    - What is the best advice you've ever received for managing this symptom?
    - What's something your healthcare team didn't tell you about cleft lip and/or palate repair that you only learned from experience?
- Paying attention to communication style that may be putting pressure on you to sign them up quickly e.g. emails that are urgent or forceful in tone

Remember that none of these behaviours on their own are "evidence". There are many possible reasons why people might give brief answers, have an urgent communication style, not knowing something you think they should or forget information. We go into further detail about this on page 8 in "During an involvement activity".

Talking about fraud, ineligible involvement and screening checks

This guide was reviewed by 4 people with lived experience of dementia, infant loss or mental health. We asked for their reactions when learning about fraudulent and ineligible involvement, and how they would feel if a charity said they carry out checks to make sure everyone has relevant experience.

Unsurprisingly, most reviewers expressed concern when they learnt about the issue of fraudulent involvement. However, they felt that when a charity clearly explains what it is doing, and why, to help protect and support genuine participants, it can build trust

and confidence. They suggested it may fit well with any existing communication around data protection policies and confidentiality. At the same time, there is a balance to strike, as talking about the issue too much can make it seem widespread.

"...it makes it sound a more prevalent problem than it actually is."

Most people felt screening checks would be reassuring, but only if they were done respectfully and didn't feel like an interrogation. How they were done may be more important than what was done.

One reviewer felt that checks could make people feel they aren't trusted, depending on how they were carried out.

"I would feel that perhaps they didn't trust me and would wonder if the charity is doubting my honesty. However, I think it depends on how this is expressed by the charity, and the nature of the checks they intend to use."

Help to understand the context and reasoning behind the checks was also felt to be important, as personal questions without explanation are off-putting.

"I think if the context was provided then I would be more comfortable. I am not saying I would like it but would understand the reasoning if it was provided. Often these questions are asked without the context and can come across poorly."

It will always be worth asking yourself if adding screening or checks into your processes will have too much of a negative impact on trust and relationships.

These views do come from a small group of volunteers, and it may be helpful to discuss anything you want to share about fraud or screening checks with the community you are working with.

During an involvement activity

It's possible that some fraudulent participants will end up in PPI activities, no matter how well you try to prevent this or screen them out. Sometimes it may be easier to spot a possible fraudulent participant after comparing their answers and contributions to other participants.

> Both before and during an involvement activity, it is vital not to remove or downplay the contributions of people simply because they do not behave as you expect them to. There are many reasons why people might appear to be fraudulent participants when they are not.

The table below contains examples of things you might observe in an activity that could look like ineligible or fraudulent involvement ('If they' column) and a possible alternative explanation ('They might' column). The first step in each of these scenarios would be to follow-up with the person individually afterwards and have a conversation to explore the situation further.

However, we have also suggested some other strategies you could use to prevent a misunderstanding from happening again in the future ('You could' column).

If they...	**They might...**	You could...
Are very quiet in a discussion or give very short answers	Be feeling unwell, overwhelmed or emotional, and/or have symptoms to manage e.g. brain fog, breathlessness	Ask everyone in advance about any adjustments you could make to support their involvement e.g. regular breaks, emotional support, alternative ways to contribute, access to an interpreter
Give very 'thin' answers or be unwilling to expand on reasons for their statements	Lack confidence in their contributions or ability to communicate	Offer training and guidance to build understanding of research and PPI, explain how to prepare for meetings, give constructive feedback
Talk about unrelated topics or ask irrelevant questions	Not fully grasp their role's scope or the purpose or content of the discussion	Communicate the purpose of an activity and expectations of people taking part verbally and in writing e.g. role descriptions, Terms of Reference and introduction at beginning of a discussion
Appear evasive and reluctant to share any personal information or opinions	Feel uncomfortable with the group dynamics	Foster a safe and welcoming environment e.g. share a Code of Conduct to set ground rules about behaviour and communication, give verbal reminders that all contributions are valuable, facilitate discussion to prevent a minority of people dominating, use one-to-one or small group discussions for particularly sensitive topics
Keeping camera turned off and/or only using chat function to contribute	Feel uncomfortable being on camera, be in a public place where it can be hard to fully participate, not have access to the necessary digital equipment or set-up	Ask everyone to have camera and microphone on for introductions only (warn in advance and encourage people to let you know if this will be difficult). Ask people to only join if they are in a private space where no-one can overhear the conversation or their contributions

Give confusing or seemingly 'wrong' information	Misunderstand the questions due to jargon, cultural differences, language barriers or literacy. Memory problems or brain fog may also be a contributing factor	Use clear, jargon-free language in all written and verbal communication – aiming for something an 11-year-old could understand Explore communication needs as part of the sign-up process to see if additional support or a different way of sharing experiences is needed
Appear to be using AI large language models for written feedback	Be short for time, or lack confidence in their ability to communicate in English	Offer tips for appropriate use of AI, or offer opportunities to give feedback verbally

Some other behaviours or actions that may require some further exploration include:

- Declining to confirm relevant details of a particular condition, symptom or experience e.g. referring to self as a carer, but not a 'carer of someone with dementia'
- Using language that is different to how people normally talk about their experiences – this might be language that is more formal. For example, Google or an AI chatbot might refer to a "short acting beta agonist treatment" for asthma, whereas people with asthma might call it a "blue" or "reliever" inhaler
- Providing information that seems highly unlikely e.g. being diagnosed with age-related macular degeneration at 21
- Inconsistencies in what you're told about their diagnosis, symptoms, treatment (if you are involving people with fluctuating memory or capacity this may not be unexpected)
- Being available at any time for meetings, despite telling you they work or have caring responsibilities
- Providing a completely different name on bank account for payment, without any explanation
- Being quick to ask questions about payment and compensation

Asking a few relevant questions should make it relatively straightforward to spot people who are not eligible to take part in an involvement activity. It may be harder to identify people who are deliberating misrepresenting their experiences.

Where there is doubt about a person's authenticity, further contact will be needed to find out more. In the words of one of our lived experience reviewers: *"Display at all steps of the process total professionalism combined with copious amounts of knowledge and empathy"*

Responding to suspected fraud

It is important to act quickly when you suspect potential fraud. This will help to prevent harm to genuine participants and protect the integrity of your recommendations and insights. Agreeing your possible responses and actions in advance of the involvement activity will help this. The table below is designed to help you work through the key considerations when planning a group or activity, so that you are ready to deal with potential fraud should it arise.

> Remember to seek advice from your organisation's designated safeguarding lead if you have concerns about the safety of anyone taking part in an involvement activity.

Question	Answer
Who in my organisation needs to be informed if I suspect ineligible or fraudulent involvement?	*For example:* • *Head of Research* • *Volunteering Manager* • *Safeguarding Lead*
What are the circumstances that would make me stop a one-to-one meeting or remove someone from a group discussion?	*For example:* • *Their comments are insensitive to others' experiences or risk the emotional safety of other participants* • *They are breaching the Code of Conduct* • *The information shared by others must be kept confidential* • *It will be clear to other participants that this person is not who they say they are* • *If I don't stop them now it will make refusing payment harder*
When will I wait for the interview/meeting to be completed before acting?	*For example:* • *When information being discussed is not confidential* • *When people are not being disruptive to the group*
When will I remove their contributions from the write up and how will this be documented? E.g. 'You said, we did' form, focus group or survey analysis, meeting transcripts	*For example:* • *When it refers to a specific experience or condition I do not believe they have*

In what circumstances will I withhold payment, and do I need to check with anyone else in my organisation before doing so?	*For example:* • *When I have three concrete examples of things they have said that I can point to* • *If I have the slightest suspicion of fraud*
When will I remove someone from mailing lists or involvement networks?	*For example:* • *Always when I suspect fraud* • *Only if I have had to remove them from an interview or group*
Is it appropriate for this person to access other services, support groups or online forums?	*For example:* • *Automatic removal* • *Discuss individual cases with Director of Services and Head of Legal*
When and how will I inform other participants of the suspected fraud, and when will this be kept confidential?	*For example:* • *Every time* • *Only if the person was present in group discussion* • *Only if the person was a member of a recurring Panel/meeting*

When answering these questions consider:

- The level of risk to other people who are involved
- Your organisation's internal policies e.g. volunteering (including process for removing volunteers from their role), complaints, safeguarding, payment
- The participant's access to other services or support through your organisation
- The level of reputational risk to your organisation, including if someone who is removed from an activity may talk publicly about this experience

Managing wider safeguarding risks

A final consideration is to reduce the risk of harm to people with genuine experience, if someone misrepresenting their experience ends up in a group. This could include:

- Not sharing participants' email addresses or telephone numbers
- Encouraging people to keep themselves safe online e.g. advice not to share personal information without checking first, how to report suspicious messages
- Not sharing the recording of an involvement activity with anyone about whom you have cause for concern

- Offering an individual discussion to someone you have some concerns about, instead of inviting them to take part in a group discussion or online forum
- Making them aware who they can speak to (confidentially) with if they have any concerns
- Involving the Designated Safeguarding Lead where you have concerns for the safety or welfare of any parties involved.

3. Working with data to ensure strong involvement processes

If you run an online survey or use online sign-up forms, you will want to ensure that the information you collect is accurate and 'clean'. Different checks can be carried out on online sign-up forms and survey responses to identify any possible causes for concern.

In any covering email or text, be clear that you will be working to ensure that people have the relevant lived experience for the task. For example, you could say something like "We carry out checks to ensure data integrity and that all people taking part are eligible".

As already stated, you should not remove someone's data or choose not to invite them to an activity simply because there is a potential cause for concern in their response. If you have contact information and appropriate consents, try to follow-up with the respondent and explore if there a reason for a discrepancy.

If you cannot follow-up with individuals, you can still separate data from people you are not sure about and compare to what others are saying. You can then report on any differences when making recommendations or decisions.

Check	What to look for	Examples
IP address	Geolocation / VPN	IP address is in a country is outside of the UK/area your charity or research project is operating in IP address identified as something that is designed to hide your location e.g. Virtual Private Network (VPN), Proxy, The Onion Router (TOR) or Data Centre Host (DCH) Note: there are some legitimate reasons for IP differences e.g. workplace uses a VPN, filling out survey when on holiday
	Risk score (including ISP)	Scamalytics flags high risk IP address. Scamalytics uses a combination of fraud scoring, proxy detection, geolocation tracking and blacklists to assess the risk associated with an IP address.

		Note: Fraud/rise score calculated from community reporting, so not a guarantee that low scores mean lack of fraud if IP not commonly used
	Repetition	IP address repeated throughout, or those in very similar range (e.g. 123.456.789.90 repeated, or 123.456.789.88 also in responses) Note: possible legitimate reasons for repetition include people in same house completing survey, so compare with other information collected e.g. name, postcode
Survey start and finish times	Survey completion time	If the survey completion time is very short, this could indicate responses being guessed or not genuinely considered Another way to check is to see if the survey finish time is unreasonably close to start time
	Number of responses at same time	There are multiple responses with very similar start/finish or completion times. This could indicate automated responses, or someone completing the form multiple times in quick succession
Email address	Domain / validity	An online tool, e.g. hunter.io, indicates the email domain is not valid, or the email address is not active. Email addresses are repeated for multiple responses Note: fraudulent respondents will use valid, active accounts e.g. Gmail
	Pattern matching	There is a pattern of similar email address formats across suspicious responses, or that match previously seen suspicious email addresses e.g. pattern of [surnamefirstname12@gmail.com]
Postcode / given location	Valid postcode	Postcode does not match area they say they are in e.g. N5Y matches to London in Ontario, Canada rather than London in UK
	Comparing different data about location	City/town and postcode fields do not match-up Information from other questions, e.g. hospital where care was received, does not roughly match postcode of where they live

	IP geolocation matching	If respondent is not using a VPN, the IP does not match up with the given location information (see caveats above!)
Phone number validity	Valid phone number	UK number does not have correct area code (+44) or length (11 digits) Same phone number is repeated throughout different responses If a landline number is given, but does not match with location from other fields e.g. postcode
	Is phone number a VOIP?	An unusual mobile number format (e.g. starting with a number in 40s or 50s) or an 020 London landline, might mean they are using an anonymous Voice Over IP (VOIP) phone number Online tools (e.g. IPQS) can check for VOIP numbers Note: like VPNs, these can be legitimately used, so this needs to be considered as part of wider checks
Referral source patterns	Referral source (e.g., X)	Referral source is common between a range of suspicious responses. This will only work if surveys are setup to use a different collector URL for each platform / route (e.g. X, Facebook, Instagram, email etc).
Email correspondence	Speed and frequency of reply	Very quick responses to emails related to the survey, including bunches of emails from respondents flagged in survey checks who seem to have filled out the survey at similar times / places
	Short, impersonal or copy and pasted messages	Messages focussed on moving the participation process forward, e.g. signing up to first available focus group, often copy and paste without any greeting or other content, bunch of similar types of responses
	Emails from addresses not in survey responses	Emails asking to take part in second stage not having completed survey in first stage of work with no explanatory message as to why survey was not completed

4. Other useful articles and resources

NIHR and Health and Care Research Wales Guidance for Recognising and Addressing Ineligible Public Involvement in Health and Care research

Paphitis, Le Boutillier and Gallagher (2025) Imposter / Fraudulent Participants in Qualitative Research and PPIE: Methodological, Ethical and Practical Challenges Online Flipbook [presentation slides]

Sage Methodspace Webinar (2022) Avoid survey fraud: The REAL Framework [recording]

Social Research Association (2023) Ingenuine participants in health and social care research - challenges and solutions [blog]

UX Psychology (2025) When Research Participants Aren't Who They Say They Are [blog]

Mistry et al (2024) Fraudulent Participation in Online Qualitative Studies: Practical Recommendations on an Emerging Phenomenon4

Sage Journals (2022) Letter to the Editor: A possible threat to data integrity for online qualitative autism research

Lawlor, Thomas and Drahota (2021) Suspicious and fraudulent online survey participation: Introducing the REAL framework

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