

## Guidance for Recognising and Addressing Ineligible Public Involvement in Health and Care research.

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## Introduction

Involvement of people and communities in health and care research is important, expected, and possible in all types of health and social care research. Excellent public involvement is integral to the design and conduct of health and social care research and it has been shown to improve its quality and impact.

Most of the time, involvement in health and care research is a positive and productive experience for all involved, but sometimes issues can be experienced. Occasionally, these issues have the potential to undermine the benefits of involvement. Ineligible public involvement (see definition below) is one of those issues. It can lead to sub-optimal or ineffective involvement, damage trust in public involvement for researchers, and compromise the integrity of research.

This guidance document has been asked for by research teams, public involvement leads and public contributors, who have encountered ineligible involvement. This guidance has been created by Health and Care Research Wales and is endorsed by the National Institute for Health and Care Research (NIHR), Chief Scientist Office and Health and Social Care Northern Ireland.

The guidance provides some examples of how you might notice potential ineligible involvement, and how you might address it. It also provides some tips for how you can better safeguard against the risk of ineligible involvement in the first place.

## What do we mean by ineligible public involvement?

Ineligible public involvement is when individuals get involved in shaping, delivering, or making use of research but their lived experience, knowledge or skills do not match the requirements for this involvement (eligibility requirements).

Eligibility requirements for involvement are put in place to help ensure that the involvement will be effective and meaningful for all parties, making the best possible contribution to the quality, relevance, and impact of research. Eligibility requirements can vary according to the nature of the research and the resources (time/money) that are available to facilitate the involvement. They might include things like having lived experience of a particular condition, so that the research can be shaped by an understanding of how the condition affects those who live with it and or their carers. They might include being able to use a computer for video calls, so that effective involvement can take place online.

Ineligible involvement can arise for various reasons, which we will refer to as misunderstanding or misrepresentation for the purposes of recognising the differences and deciding on appropriate action.

Misunderstanding means that an individual pursues involvement or becomes involved because the eligibility requirements weren't made clear or weren't understood properly. For example, where there was not an effective process to enable parties to understand what was required or expected in advance. Or, when communication about this was ineffective, for example, due to a language barrier or learning disability.

Misrepresentation arises when an individual pursues involvement or becomes involved, having misrepresented their suitability. For example, stating or that they have lived experience of a particular condition when they do not, failing to disclose that they do not, or evading questions/opportunities to make this clear. This might be motivated by personal benefit. For example, the offer of a financial incentive (e.g. voucher) to become involved.

It is important not to pre-judge the reasons for ineligible involvement, whether this is due to misunderstanding or misrepresentation. In all cases, the situation needs to be handled in a sensitive, equitable and respectful way. When not handled in this way, it can lead to confrontation or emotional distress and unnecessary escalation, which results in negative consequences for those involved, the wider team or the research.

### How to recognise potential ineligible involvement

Research teams and public contributors have reported that they have sometimes noticed early indications of potential ineligible public involvement, as described below. These are sometimes evident at the engagement/onboarding phase, or arise during the involvement activities. It is important to note that even if any, or all of these, are present, it should not be assumed that the individual is ineligible. Other explanations should be fully explored in the first instance, sensitively and with an open mind.

- Void screen' dial-In: Individuals who decline to meet, or constantly avoid meeting, face to face online/in person at the engagement/onboarding phase. Or, who consistently dial into meetings thereafter but never participate. There can be other reasons for this behaviour. For example, needing reasonable adjustments to be able to participate, chairing that is not including everyone, confidence issues or a medical explanation.
- Inconsistencies in the information individuals provide about themselves. This could present as marked differences in their use of language, the skills, or experiences they describe on an expression of interest form, compared with what is said in a meeting. It is important to be aware that being unwilling or unable to describe experience of a condition or disability where this is legitimate eligibility requirement. There can be other reasons for this behaviour. For example, medical experiences can carry a degree of trauma and care and unwillingness to expand on details can be a sign of that trauma. Care must be taken when asking for specific lived experience perspectives.
- Using language (especially in writing) that is overly "text book", and/or not personal to the individual when describing their experiences, For example, this might suggest that someone is not speaking from their own experience, but rather using information that is readily available online/via AI tools. On the other hand, someone may not speak English as a first language and use tools to help them be understood. People with experience of ill health often seek more information, including published research to understand the detail of their condition.
- Claiming involvement payments, expenses, or other incentives, for activities in which it is clear they have not attended/participated in. People may experience cognitive impairment and make an honest mistake. Sometimes communication about the terms of payment are not effective or misunderstood.
- Disinterest: This could be shown through a lack of participation in discussions, not completing assigned tasks, or frequent absences from meetings. There could be legitimate reasons for this behaviour – e.g. a need for support/health reasons, digital literacy, or connectivity issues.
- Reluctance to provide bank details for transfer of involvement payments, and or a strong stated preference for E-Voucher incentives to join involvement activities. It is worth noting that people who claim benefits may be afraid to have their benefits cut, and refugees or homeless people– for example- often find it difficult to open a bank account due to the identification requirements.

## How to address potential ineligible involvement?

It is important to act promptly when you notice potential signs of ineligible involvement.

Your approach might be different depending on the stage at which the issue comes to light, and considering the relationships which have been formed. Your approach should be guided by any agreed role descriptions or specifications you have in place with the individual/s, any relevant organisational policies, or processes (e.g.: for volunteering, equality diversity and inclusion, conflict resolution), and or established involvement policies/processes that you have in place.

Dealing with suspected ineligible involvement requires a careful approach that prioritises sensitivity and transparency. Here are some tips from others who have identified and addressed ineligibility issues.

### Assume genuine involvement first

Always first assume that the involvement is genuine but is experiencing problems. Reach out to the individual (wherever possible, face to face, either online or in person) to establish the reasons for this and how you can support them. For examples, if someone didn't contribute to a workshop, suggest to organise a separate call so that you can support them and the individual has the opportunity to share their views.

### Remain impartial

In any discussions, remain neutral in tone and concentrate on factually describing the behaviours, actions or non-actions noticed, and the effect that this is having on the involvement. Encourage the individual to engage and offer their perspective on what is happening and why, using open questions. Summarise the key points at the end of the meeting, including next steps and any actions for either party and the timeframe in which they will be completed. It may, or may not, be possible to establish whether involvement is eligible at this point.

### In the event that involvement is ineligible through misrepresentation

If it is clearly established that involvement is ineligible through misrepresentation, and this has been discussed with the individual/s (usually face to face), it is advised to terminate the involvement, providing a summary of what you discussed and the reason for the decision to remove them from involvement, in writing. Consider the lessons learned for future involvement, and whether there any actions you can take to guard against future issues.

### In the event that involvement is ineligible through misunderstanding

If it is clearly established that involvement is ineligible due to misunderstanding, and this has been discussed with the individual/s (usually face to face), it is important to acknowledge any communication or understanding issues that have led to the situation, avoid implying blame, and to consider and apply lessons learned for future involvement. It is advised to terminate the involvement, providing a summary of what you discussed and the reasons to remove them from involvement, in writing. Consider providing support or advice to the individual to help them find other suitable involvement opportunities if they want this.

### Collaboration

If it is clearly established that the involvement is eligible, it is important to understand the reasons behind the issues experienced, and to seek to address these in a collaborative way with the individual

concerned. This should be done in line with any existing relevant organisational policies or processes. It is advised to confirm any agreements in writing. You may wish to refer to another relevant guidance document, such as Health and Care Research Wales, [Problem solving procedures](#). Where additional support needs are identified, e.g. difficulties with contributing to a group due to disability, consider whether adjustments could be made, such as enabling them to contribute independently after the group on a one-to-one basis.

### Safeguarding against ineligible involvement

The best way to safeguard against ineligible involvement is through thorough and effective processes of engagement and onboarding, coupled with ongoing open and honest communication (including face to face). This will make sure that the right people are involved/remain involved for the right reasons and that everyone has a shared understanding, and can fulfil the mutual expectations of, proposed involvement. Key areas to consider are set out below:

1. Defining the role:

It is important that the nature, scope, timeframe, and requirements of any involvement role are clear upfront, for all parties, and mutually discussed to confirm the understanding of all parties during engagement and onboarding processes. It is recommended to have a role description, and person specification (including expected behaviours) in place from the outset. Eligibility requirements and an expectation agreement for the involvement should be clear as part of this. All requirements should be proportionate to the involvement, and any potential implications they might have for equality diversity and inclusion should be considered.

2. Alternative incentives

Consider whether alternative approaches to incentivisation or payment can help you to reduce the risk of ineligible involvement. Alternatives. For example, offering physical vouchers posted to a home address, instead of online vouchers, can deter those who are ineligible because they live outside the UK becoming involved. If you require involvement payments to be made by bank transfer to a UK bank account, or via a constituted community group or charity, this can help to mitigate risks.

Remember, the primary objective is to establish a fair and inclusive environment for all eligible involvement. Handling these situations with sensitivity and respect can help uphold yours, your organisations, and your funders trustworthiness and credibility.

3. Effective engagement and onboarding processes:

It is important to ensure that any engagement process allows for a thorough yet proportionate assessment and verification of candidate suitability against the requirements, involving those who have the best knowledge and experience to do this. It is recommended to have a clear selection process, with criteria linking to the eligibility criteria, in place. A selection process could involve a face-to-face element, either online or in-person. For example, you might combine an online expression of involvement interest form reviewed by a public involvement lead, with a call or face-to-face meeting (in person or online) between the individual and a researcher who would be well enough informed about an individual's experience of a condition to ask the right questions and clarify their suitability. For one off public involvement opportunities, it is noted that there might not be time in the recruitment plan for a phone call or face to face interaction first.

During onboarding, it is recommended to formally clarify mutual expectations, access needs and necessary adjustment, and to put in place induction activities which enable those involved, researchers and or involvement leads to get to know each other better. It should be considered whether reasonable adjustments need to be made to facilitate communication and understanding, aligned to relevant organisational/funder equality, diversity, and inclusion policies.

#### 4. Ongoing investment in relationships and good communication

It is widely recognised that effective involvement is underpinned by successful relationships and this is helped by ongoing honest and open communication which helps to instil trust. This requires ongoing investment of time and should always be a two/multi way process. It is recommended that there is an agreement between all parties about the nature, frequency and type of ongoing communication, and that this is regularly reviewed to ensure it meets the needs of all parties.

Open and regular communication and opportunity for feedback helps to better understand the true motivations and concerns of individuals involved in research and if individuals are being appropriately supported. It provides a platform for individuals to voice any concerns, preventing potential misunderstandings, conflicts or escalation of issues. It also promotes active engagement, leading to a stronger commitment to the group's success.. Effective communication is a two-way street - it is as important to listen and respond to feedback as it is to provide information. For additional information about fostering effective communication with the public, refer to the [UK standards for Public Involvement](#).

#### 5. Up to date policies and processes covering the involvement journey.

Maintaining up-to-date policies and processes that outline the involvement journey is essential to prevent ineligible involvement. The guidelines should include a clear framework for all stakeholders to follow. Regularly reviewing and updating these policies will enable organisations to adapt to changing situations, anticipate risks, and enforce controls against issues like conflicts of interest, fraud, or ineligible involvement. Clear and updated policies also enhance transparency, accountability, and consistency, which builds trust and reduces the chances of misunderstandings or misconduct.

#### 6. Regular training and workshops for staff and public contributors

Regular training and workshops on effective communication and conflict resolution are particularly crucial in managing various situations within any environment. This training provides staff and public contributors with the necessary tools and techniques to navigate complex interpersonal dynamics, resolve conflicts amicably, and communicate effectively.

Effective communication skills are essential for building strong relationships, enhancing teamwork, and ensuring clarity in conveying ideas and information. Likewise, conflict resolution skills empower individuals to address disagreements constructively, find mutually beneficial solutions, and maintain a positive work environment.

For comprehensive and up-to-date training and guidance on public involvement, consider visiting the [Learning for Involvement](#) website. This platform is dedicated to enhancing learning and development for public involvement in health and social care research, providing insights into its significance and how to effectively implement it.

The rise in online involvement in recent years has brought numerous advantages. However, it can also create new avenues for ineligible public involvement. To prevent this, various additional measures should be explored.

- **Targeted Recruitment:** By targeting online advertisements to specific groups, organisations, and skills, we can reach the desired involvement audience more effectively. Working cooperatively with community groups or community leaders can help you to reach a more diverse and eligible audience. You might decide not to advertise any financial incentives on social media.
- **Recording IP Addresses, if possible:** Utilising online screening questionnaires that record IP addresses can help prevent multiple responses from the same IP address. When an expression of interest is submitted, you can determine the geographical location of the respondent.

## Conclusion

Maintaining the credibility of public involvement activities and research studies requires proactive steps to identify and address ineligible involvement. The initial step involves recognising and investigating signs of ineligible involvement. Addressing ineligible involvement once it is happened needs to be handled sensitively, without prior judgement of motives, and proper investigation should take place before involvement is terminated. It is important to avoid mistaking ineligible involvement with other issues that may be getting in the way of effective involvement, and to deal with these appropriately. Finally, there are many ways to increase safeguards against the risk of ineligible involvement, ranging from ensuring that the right policies and processes are in place, and ensuring that good practice is followed in advertising and selecting for involvement.

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