

**Patient and Public Involvement trauma
informed guidance for organisations
and healthcare professionals**

Introduction

People who have utilised health services are often invited to offer their expertise through research, service evaluation, giving patient experience talks or other forms of feedback. This is often referred to as Patient and Public Involvement (PPI). This guidance is intended for healthcare professionals, staff who work in patient experience roles, healthcare organisations, researchers and any others who interact with service users and their relatives who are giving insight and feedback through a PPI process.

This document offers guidance on how to work with patient and public involvement partners in a way that is both psychologically and trauma informed. It is split into key phases for any patient and public involvement activity. Throughout the phases the key underlying messages are the importance of choice and collaboration and creating emotional safety, which all need to be embedded throughout the process of the PPI activity.

This guidance has evolved from the lead author's observations when contributing to PPI activities, and the recognition that more needs to be done to create a safe psychological environment to enable people to feel comfortable when contributing and to be involved without harm.

Introduction to Patient and Public Involvement (PPI)

People who use healthcare services have a valuable perspective on their care and treatment. Their relatives, friends and partner may also have important perspectives to share. Patient and public involvement (PPI) has taken place in healthcare for at least twenty years, and it has evolved and become more embedded over that time. However, there is still work to do for it to be a respected contribution in all areas of health and social care, and to ensure that diverse voices (people from a wide range of ethnicities, ages, socioeconomic backgrounds and genders) are heard.

Organisations, specialities, or charities can find that it is very powerful to hear directly from those who use, or have experience of, their services. This important contribution can help inform services in many ways, including influencing service development, improving patient safety and helping healthcare professionals to understand what it is like to utilise their services.

PPI opportunities can vary, for example speaking at a conference, helping research as an advisor, sharing experiences with a hospital board etc. People can have different motivations for wanting to contribute as a PPI partner. They may feel that talking about their experiences contributes to the healthcare organisation and helps services to develop and improve. If their experience was a distressing one, they may feel that they want to help make changes for service users so that other people don't have the same experience. Sometimes contributing as a PPI partner can help to 'make sense' of a health crisis for an individual, such as having cancer or having a critical illness. In rare circumstances people may wish to be involved for negative reasons, such as directing their anger towards healthcare staff.

About psychological trauma and how people who have experienced such trauma might feel

Lasting effects of psychological trauma results from exposure to an incident or series of events that may be perceived as or are life threatening and are often emotionally disturbing with lasting adverse effects on the individual's functioning and mental, physical, social, emotional, and/or spiritual well-being. For many who would not fit criteria for formal diagnosis of post traumatic stress disorder (PTSD), the events may not be perceived as life threatening, but may be laden with personal, psychological and/or spiritual threat to self. The source of the trauma can come from different sources, for example, physical, sexual, emotional etc. Such events may include war, natural disasters, accidents, physical or sexual violence, or childhood abuse and neglect, but could also be a direct result of serious medical events or treatments. People can be exposed to trauma at all ages, but it has a higher impact when it occurs in childhood because of the impact on the developing brain.

Recalling such events can be emotionally painful and may overwhelm the person's coping resources. Others may experience post traumatic growth and new adaptive ways of coping from their experiences. Sadness, grief, and 'reliving' of the event through flashbacks or upsetting dreams or memories are normal responses in the days or weeks following a traumatic event. Approximately two out of ten people will have lasting impacts from a single traumatic event- which may include adjustment difficulties, depression and anxiety - and this figure is likely to be higher for certain traumatic experiences and for when an individual has had a series of traumatic events. About 3% of the population in the United Kingdom meet the criteria for a diagnosis of post traumatic stress disorder. The impact can also depend on the support that is given during and after the traumatic event(s) and what opportunities the individual has had to psychologically integrate and understand the impact of the trauma. Events that involve deliberate harm or interpersonal trauma are more likely to result in psychological trauma.

Working in a trauma-informed way means considering that anybody could have experienced psychological trauma and seeking to not 'retraumatise' in our behaviours or interactions with them. This means healthcare professionals should avoid where possible triggering (start off or invoke) memories of traumatic events or acting in similar ways that remind people of their experiences. For example, healthcare staff may act in ways that may be experienced as inconsiderate or minimising of people's experiences, which may trigger memories of a critical childhood. However, when working with a PPI partner the person's full background and experiences cannot always be known (and it may not be safe or appropriate to ask that it is shared) so it is important to create environments that minimise the potential harm to everyone involved. The United Kingdom Government Office for Health Improvement and Disparities has issued a document called [Working definition of trauma-informed practice](#), which is interim guidance for practitioners working in the health and social care sector. It has identified key principles of trauma informed practice, which are safety, trust, choice, collaboration, empowerment and cultural consideration.

Why PPI should be Trauma-Informed

Many people have experienced psychological adversity, often referred to as psychological trauma, as children, as adults, or in connection with healthcare experiences. This means that sometimes

recounting experiences or contributing to research as a PPI partner or talking with healthcare professionals, can be distressing and can trigger memories from the original experience. It is important that those working with PPI partners are aware of this and take steps to ensure that those engaging are supported and protected.

Research ethics committees carefully consider the needs of people who are participating in research, but currently this remit does not extend to patient and public involvement partners. This means it is particularly important for people who interact with PPI partners to be trauma informed.

A trauma informed approach to working with people reduces the risk that any elements of the PPI activity could trigger memories of previous traumatic experiences, whether these are directly related to the person's healthcare experience, or their wider life. Some people when triggered will have an acute emotional response, which may include experiencing flashbacks or upsetting memories, distress or anger, and this has the potential to break down the trusting relationship that is essential in the patient and public involvement. Others may have a stronger and longer lasting response that could have consequences for their wellbeing and can risk re-traumatisation or new trauma.

How to Be Trauma Informed in PPI activity

It is important to build trust with those who have offered to help with a PPI activity - to create a sense of safety so that they can let you know what they would like to do and would prefer not to do. It is important that assumptions aren't made that because they have volunteered for an PPI activity that they want to share all elements of their experience. Allow the person to set the pace and the limits with this.

Awareness by people engaging with PPI partners

Having a basic knowledge, an understanding and awareness of trauma is important. Knowing that many people may have experienced trauma means that all PPI activity needs to be planned and carried out with this in mind to ensure that PPI partners have a positive experience. It is important to remember the important trauma informed principles (safety, trust, choice, collaboration, empowerment and cultural consideration) at all stages of PPI activity, including at the planning stage.

if you would like to know more about trauma in this context, there is a section at the end of this document for sources of information and training.

Preparation

Preparation and planning are essential to help contribute towards a positive experience for PPI partners.

- First, think about what you want to achieve from PPI input and how this feedback will be meaningfully used. The most meaningful PPI often comes from when PPI partners are an integral part of the project such as being involved at the design stage and then throughout the project, rather than only as an occasional source of information and expertise.
- Think about any benefits this activity might bring to partners and any potential risks to them from that involvement.
- Incorporate [principles of good patient public involvement](#) into your preparation including focusing on how to hear diverse voices and what barriers could be in the way of participation. There is more information the National Institute for Health & Care Research (NIHR) webinar [How to incorporate Equality, Diversity and Inclusion in PPI](#).
- Think about how you will recruit PPI partners.
- It is possible that PPI partners might have an ongoing or possible future treatment need in the service they are advising as a PPI partner. Consider if this has any implications for staff or for the PPI partner and discuss how this might be managed with sensitivity.
- Consider how the contributions of PPI partner will be recognised in any outputs.
- Once your preparation is complete, if you have service users or family members that you have worked with before, ask for feedback from them about your PPI plans. You could discuss your plans with a colleague who is experienced with working with PPI or a clinical psychologist who is trained in psychological trauma.
- Brief colleagues who will be working with PPI partners to ensure their approach will be trauma informed.
- People should be offered to be paid for their time. This is one way of demonstrating that their time is valued. More information about this can be found on NIHR's website [Payment guidance for researchers and professionals](#). For in person meetings, reasonable travel expenses should be covered, and refreshments provided. For online meetings, a payment should be offered for data connection. People must be made aware that the payment for their time (whether paid by bank transfer or voucher) is regarded as income and, as such, maybe liable for tax or affect benefits payments. They can find out more from the NIHR's [Payment guidance for members of the public considering involvement in research](#).
- Finalise your PPI plan.

Recruitment

- It may be that you know of PPI partners that you have worked with in the past and you could ask them if they are interested in this activity which you are planning. It can be helpful to build a longer-term connection with PPI partners to build up trust and safety.
- You may want to do 'open recruitment' by advertising, such as putting up posters or advertising on research PPI websites, asking people if they'd like to know more.
- Whether open recruitment or inviting PPI partners that you know, provide very clear information about the activity, such as what they are being invited to take part in, when and where it is, what it will entail and what the payment is etc. Such information and clarity are essential as it helps to establish boundaries, which contribute to psychological safety. A formal agreement of some kind, clarifying what is required from each party can be helpful in establishing boundaries which contribute to safety.

- If it is an open recruitment process, produce an easy-to-understand role description, and if appropriate include what skills or knowledge you would want people to have. Keep these simple as involvement can be an opportunity for people to learn and develop new skills.
- Have a chat with people who are interested in helping with this activity and see who has skills and knowledge closest to your role description. Be careful not to pressure people to participate and allow time for questions.
- If you are engaging with someone with lived experience from a specific healthcare experience, such as a critical illness, you may want to ask them if they feel enough time has passed since that experience – at least one year might be recommended.
- If you need to turn down someone's offer of help with a PPI activity, do it with kindness and sensitivity. Offer alternative ways to be involved if possible, such as helping with other activities or if they would like to be contacted in the future about other PPI opportunities.

Preparation with PPI partners

- It is important to prepare PPI partners for their involvement. For example, explain what they can expect during the PPI activities and any logistics that it would be helpful for them to know, such as where a meeting will be held, offering technical support if the meeting is online etc.
- It is important to ask them what their motivation, expectations and aims are from involvement. For example, some people might want to add it to a CV or need a reference or want to help improve care for other people. It can be helpful to be aware when the motivation has arisen from a traumatic healthcare experience.
- Discuss the role. This clarity is important as it's important that PPI partners understand what the role is, so they have realistic expectations of it. Tell them they do not have to do anything that they are uncomfortable with. For example, if they are a patient or relative representative in a research management meeting, there is no expectation or need for them to recount their own experiences in detail.

Dr Caroline Bruce, Head of Programme: Transforming Psychological Trauma, NHS Education for Scotland comments about how essential it is to offer this choice:

'It is important that PPI participants are involved in choosing how and when they participate – some may prefer 1:1 interviews, some may work best in focus groups, some may prefer to write responses. Some may be happy to attend meetings, some may prefer to meet with the chair first, or to make written submission. The principles of choice, ideally, should be written in at this initial stage. I think it is important to make sure as much as possible that we are flexing to the impact of trauma on people, and the ways that this can affect their preferences for participation, rather than taking the approach that best suits for our own purposes. Otherwise, we risk excluding people with a lot of expertise to give.'

- Remember that it can feel uncomfortable when unfamiliar with projects or settings (such as contributing to a formal meeting) and this can risk the feeling of a power imbalance for

PPI partner, which can contribute to feeling unsafe. Therefore, offer them their **choice** of ways of contributing – for example, by written contribution, by individual recorded interview, or by participating at the meeting or event itself.

- Provide training if this will help PPI partners undertake their role and build their confidence in participating, for example a basic introduction to research or about the project they are taking part in. Offer to pay PPI partners for their time if training is undertaken.
- Allow time for people to ask questions about what the activity involves. Let them know it's fine for them to change their mind at any time if they prefer not to be involved.
- Let them know who their main contact is and when they can be contacted (for example, during office hours, which days of the week etc).
- Provide contact numbers of charities or other organisations in case PPI partners need professional support during their involvement (for example, if participation has stirred up bad memories).
- Depending on what PPI activity is being proposed, people may be touching on their healthcare experiences, or they may be recounting in more detail about what happened to them in a healthcare setting. Either activity can be triggering. Prepare people that it can be hard to touch on these topics and to talk over difficult experiences, and what they may feel like afterwards. Let them know it's fine to stop talking, take a break or move onto a topic that feels safer to them, if that helps them.
- As part of the preparation, ask them if there are any topics that should be avoided, or topics that are likely to be more emotive for them and they may need more support with sharing them (if they want to and if it's appropriate to the PPI role). Ensure they know they can stop involvement at any time without consequence.
- An important part of preparation with PPI partners is that they know the questions that are being addressed and the scope of the project they are involved in, so that if they share information that is not relevant for their role and/or the activity (but that may be very precious to the person themselves) they understand why they may be stopped or that that information may not be used.
- Discuss what support they can access or have in place already if they feel upset after participating. Offer time to follow up and debrief after any PPI activity if wanted.
- Ask if they have any additional needs or accessibility requirements to help them participate in this PPI activity.

Support during PPI activity

There are different types of PPI activity, and they need different approaches to ensure that PPI partners are supported. Here are some suggestions for face-to-face and online meetings:

Face to face focus group

- It is recommended that two facilitators work with a focus group.
- These facilitators need to have some knowledge about how focus group members may respond if distressed, and how to manage this. For example, if there is a shift in how people usually seem, if the person becomes visibly distressed, angry, or shows signs of agitation through words or physical tension.

- Ideally both facilitators will have introduced themselves to the PPI partners beforehand. If not, then information has been sent to PPI partners beforehand (including photos of the facilitators) so they know who will be running the meeting and who to contact if they have questions before taking part.
- PPI partners need to know that if they find the meeting difficult, they can let the facilitator know, take a break or leave if they want to. If they leave, the second facilitator can go with them to see if they are ok. A breakout room is recommended if someone can accompany them.
- Introduce everyone in the room and what their role is at the start of the group.
- Circulate some draft ground rules before the meeting and have a ground rules discussion at the start of the meeting and ask PPI partners to add ones that are important to them. This helps to create a safe space for those taking part. These could include not to take or post photos or other comments on social media, that everything said stays confidential etc. Remind people of these ground rules at the end of the session and during and at the end of the project if it is a longer term one.
- Be aware that focus groups can be particularly triggering as PPI partners will be hearing other people's experiences too, so this will need consideration in the planning stage and for support afterwards.

Sharing a healthcare experience through an organised talk

These talks can happen in different settings, such as to the executive board of a healthcare trust, or at a healthcare conference.

- Remember that recounting difficult experiences can be especially triggering. This will need consideration in the planning and support afterwards.
- It is essential to have a preparatory meeting with the PPI partner. Give them the opportunity to chat through their key themes or points they want to raise in their healthcare talk. Suggest that they might want to think if there are any particularly emotive points and that it's ok if they prefer not to mention these during the talk if it will be distressing for them.
- If the talk is being given to a hospital executive board, the speaker may be part of a longer meeting where they do not attend the entire session. This may feel daunting and/or unsafe to go into the room when everyone is already there. It is important that adjustments are made, for example, see if the speaker can go in just after a break and have the chance to become familiar with the room before everyone else comes in. Ask everyone in the room to introduce themselves to the speaker.
- Give the people different options for how this talk might be given – they can give it in person, they can read it, someone else could read it for them or it could be pre-recorded. If pre-recorded, arrange for assistance with the recording process.
- Accompany the person out of the meeting afterwards and offer to spend some time with them to see if they are ok.
- Please be aware that audience feedback through the scoring of sessions at conferences may not be appropriate for PPI talks.

Research oversight committees (such as Trial Steering Committees, Trial Management Groups or Data Monitoring and Ethics Committees)

- Explain the role of a PPI committee member and provide introductory training or meeting to help PPI partners learn about this role and the research.
- Acknowledge that it can feel strange for PPI partners to hear the medical topic which they have lived experience of, talked about in such a business like way, for example for someone with cancer to hear a scientific discussion about the illness.
- Brief the chair of the meeting about the role of the PPI partners and what could contribute to a trauma informed approach when working with them, such as creating a comfortable atmosphere where all members can ask questions and that any specialist terms or acronyms are explained. A short plain English glossary of research terms can also be useful, which PPI partners could add to.
- Ensure all committee members and other attendees introduce themselves at the start of the meeting.

Online meetings

There are additional points to consider if the meeting is online, rather than being held in person.

- For some people, an online meeting may feel a more comfortable environment, as they are in their own space, and they may be familiar with online meetings.
- For others, this may be the first time they have taken part in an online meeting, and it could feel very unfamiliar. Sometimes, when things are unfamiliar, people feel less safe, and this could be triggering for them.
- If it is possible to be flexible, ask PPI partners if they would prefer the meeting to be online or face to face.
- Offer a test meeting, to enable PPI partners to try out the online meeting platform, and to help them with key aspects such as how to mute and unmute, how to turn the camera on, how to access the chat, how to change the view of meeting participants etc.
- Let them know it is ok to turn their camera off or leave the meeting if they are finding it difficult.
- Offer a contact number so they can have technical support during the meeting if they need it.
- Offer the contact details of someone, such as a mental health first aider or another member of the team, who PPI partners can call if they are upset and need to leave the meeting. Be clear that this is not specialist support, but someone who will listen to them if they are upset. Let them know the times that they are available (which may be just during the meeting).

Support after the PPI activity

- For people affected by trauma who are being invited to speak publicly about their experiences, the onus is on those organising this activity to protect PPI partners and mitigate the impact of this activity.

- For any PPI activity, have a named person who they can contact if they have any concerns or comments. Offer to hold a debrief meeting with them if they have questions or if they would like the opportunity to talk over the activity and how they felt.
- Ask if the PPI partners have any training needs or other support which would be helpful to them to help them take part in subsequent activities (if more are planned).
- For all PPI activities, build in the option of a feedback mechanism, so that after each meeting and at the end of the PPI project, PPI partners can say what they felt went well, any concerns they have or other feedback that they would like to give.
- Remind people of the further support available if needed - for example, contact numbers for any local mental health support etc.

Reflection after the PPI activity

- Think over, and discuss with colleagues, about what you felt went well about the PPI activity and what could have been improved.
- Ask for feedback from those involved including PPI partners and staff.
- Incorporate the feedback from PPI partners and colleagues into planning the next session or future PPI work.
- If there are long gaps between meetings, keep in contact with the PPI partners in between meetings, if they would like that, keeping them up to date with the progress of the project. This helps people feel included and valued.
- Let PPI partners know about the impact of their involvement and any publications or outputs that the project produced.
- If possible, offer the opportunity to comment on further stages of the project (if PPI involvement had only been for a specific part of the project) or see if they would like to be involved in dissemination activities.
- If it is appropriate to offer that people's names could be included in any output, ask for permission from PPI partners before publishing their names. Explain that this is optional, and their name does not need to be included if they do not want it to be.

Note about professionals working with PPI partners

This guidance has been about PPI partner psychological safety. However, professionals may also have experienced trauma through their work or in their personal life. It is important for professionals to recognise, where possible, when past traumatic experiences may have an impact on their professional role. If they feel comfortable to do so, they may wish to disclose to their manager if there are situations or topics that may trigger upsetting past traumatic experiences. Being in work situations that might be triggering is not always easily avoided, so appropriate support and opportunities for clinical reflection (including from psychologists with training in psychological trauma) are important, as well as access to work based occupational health and employee wellbeing services.

Safeguarding

It may be that while working with PPI partners, you hear something that concerns you, which could be a potential safeguarding concern. Ahead of the PPI process you should be aware of your organisation's local safeguarding policy. It is important, as with any other interaction with service

users, that you follow your duty of care. This duty of care, confidentiality, and the need to broaden confidentiality if there are any concerns for safety should be outlined with PPI partners at the start of any PPI activity.

Summary

In summary, it is important to be considerate, trauma informed and plan thoroughly for all PPI activities, considering the psychological and emotional needs of PPI partners.

Dr Caroline Bruce, Head of Programme: Transforming Psychological Trauma, NHS Education for Scotland comments about trauma informed PPI participation:

'It is important to highlight that involvement is not simply an activity – like a meeting or focus group. It is also what happens afterwards as a result of that activity, and what changes come about. This is one of the key features of trauma informed involvement, that at a minimum participants are well versed in the aims of the work they are involved in, what it is trying to achieve and, if they wish, can stay involved in the progress, either by being updated, or being actively involved in the process of making change. If we simply ask people to come into a meeting or a focus group, share their experiences and then go away again without any further contact or seeing any change, then it risks mimicking the disempowerment and coercion of traumatic relationships'.

Thank you for your interest in trauma informed patient and public involvement. These tips could help to enable service users and their families have a more positive experience of the PPI activity and increase professional confidence when engaging with PPI partners.

Resources

- United Kingdom Government Office for Health Improvement and Disparities '[Working definition of trauma-informed practice](#)'.
- [Trauma informed co-production guidance](#) West Yorkshire Health & Care Partnership.
- Adverse Childhood Experiences Hub Wales [toolkit](#) to support people, organisations, sectors and systems to develop their own ACE and trauma-informed approach.
- [Public resources](#) International Society for Traumatic Stress Studies.
- [Information about Post-traumatic stress disorder](#) (PTSD) Royal College of Psychiatrists.
- [Trauma-informed practice toolkit](#) Scottish Government.
- [Recommendations for education and training of psychologists when working with psychological trauma](#) The British Psychological Society.
- [United Kingdom Standards for Public Involvement in Research](#) The UK Public Involvement Standards Development Partnership.
- [Resources for patient and public involvement](#) National Institute for Health & Care Research.

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