Mentimeter

What role do you have in the public involvement space?

129 responses

14

91

Mentimeter

What comes to mind when you think about 'emotions' in public involvement?

351 responses

6

99

Mentimeter

What challenges have you experienced around emotions in public involvement?

- Not enough time
- Knowing how much to share
- Often a highly negative environment
- Conflicting emotions created a challenge
- Unexpected triggers
- Lack of appropriate support to signpost to
- Challenges working online - no space to follow up after
- Unresolved blame

10 66

Mentimeter

What challenges have you experienced around emotions in public involvement?

it usually comes up unexpectedly, hence, the element of surprise and then not enough time to address it properly

One person triggering another

environment too formal

anger at a particular individual providing care and support

Working with survivors of domestic violence and abuse (DVA) - our discussion was not meant to be about their personal stories, but individuals kept referring to them, which may have distressed others

Not feeling heard

How to support charity PPI staff in talking about their own emotions when supporting PPI contributors/networks

People being angry about negative experiences they have had with health services

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Mentimeter

What challenges have you experienced around emotions in public involvement?

Not knowing whether people are feeling unsafe when they get upset

Supporting researchers who have had minimal experience working with emotions/lived expereince

Difficult to manage when occurring remotely (e.g. on Teams)

Upsetting or offending fellow public contributors

Triggering and realising others pain

Knowing how to respond

More a lack of emotion for me. People not wanting to be emotionally involved.

people getting upset and sharing very personal, traumatic experiences out of the blue

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Mentimeter

What challenges have you experienced around emotions in public involvement?

- Wanting to broaden or narrow the focus of the discussion
- Not enough time to talk about emotions
- psychologically unsafe environments
- Conflict among group members
- Emotional experiences not directly related to topic and how to deal with it
- People being upset by what others say
- How to support both researchers or people with lived experience?
- Different sharing styles in group settings

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Mentimeter

What challenges have you experienced around emotions in public involvement?

sensitive topics, stressful life events /changes during the time working together

Trust acquisition

Need for planning, funding and time for aftercare. For everyone

Knowing when to move forward with our 'agenda' and when to take a break to allow the space for emotions

Feeling dismissed when the emotion is uncomfortable for others, even though the experience is very relevant and important to the discussion.

Surprising emotional response when revisiting memories from a long time ago

sometimes its interpersonal emotions that impact the facilitator not the emotions related to the activity

Researchers who struggle when they encounter anger about Cate or word choices

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Mentimeter

What challenges have you experienced around emotions in public involvement?

knowing how much time to spend on processing/understanding this response. Mindful/ worry about this affects others in the group

Not enough time

Managing expectations and frustration. Understanding that research can't change things immediately

As a staff member, not having space to share emotions afterwards, including linked with lived experience

Anger related to previous experiences of individuals can negatively impact rest of group

Researchers finding it difficult when patients get visually upset

Frustration when the work isn't valued

Managing anger negative experiences of services

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Mentimeter

What challenges have you experienced around emotions in public involvement?

Balancing the difference in contributors in the room - variance of needs and digesting and decompressing

Lack of acknowledgement of the emotional impact on researchers/facilitators

Personal experiences of poor NHS treatment

Different cultural perspectives

Lacking shared empathy when voice becomes the lead rather than enabling others to speak and share

Balancing everyone's expectations, needs, bringing the conversation back.

Time to support people after events meetings

PPI becomes therapy

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Mentimeter

What challenges have you experienced around emotions in public involvement?

I can express emotions differently than what's typically expected, and as a result, I am often misunderstood or even outcast.

Need for training and code of conduct/ethics to support PPI practice (I have formal training - seen others struggle without it)

Supprting but not being a support worker

Picking up the emotions when on zoom calls

Frustration at not seeing people as having intersectionality e.g. assuming a person is only one thing which is often related to how they look and sound.

Need to feel valued - not always acknowledged

It's difficult to know whether the person needs support outside the online meeting

death of a PPI group member

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What challenges have you experienced around emotions in public involvement?

Distress caused by other public contributors

Ensuring PPI feel heard and safe, and signposted to additional support if needed

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Mentimeter

What is the one thing you think your organisation should hear?

Valuing contributions

Experiential knowledge is emotional - don't treat it as a 'thing'

The need for emotional support for both researchers and public partners

Effective training or skills and experience should be supported for facilitators

Emotions happen and need planning for

Need to value facilitation skills and reflective practice

Support colleagues

all researchers (experienced and new) need support and resources in place to support them with emotionally challenging research (all types of experiences and health conditions)

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36

Mentimeter

What is the one thing you think your organisation should hear?

Humans are messy, complex and wonderful!!!!

Don't assume that somebody with lived experience is too vulnerable to be part of things

Valuing contributions but also creating space for dignity and respect

Don't make assumptions about anything, ask people what they need and allow them to be who they are and not who you want them to be.

Emotions are welcome here

Anticipate and prepare

Support your public involvement staff. Many of us are on lower pay grades than academics and are doing a lot of emotionally heavy work, with no formal supervision or support structures.

Valuing contributions
Peer support

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36

Mentimeter

What is the one thing you think your organisation should hear?

we have too much power in how we select our PPIE contributors (suited to our needs)

That PPI workers also need emotional support from time to time within their roles.

Need for funding to support ongoing public involvement groups and allow relationships & trust to develop over time

The need for supporting charity PPI staff to process the emotional work of PPI

PPI should not be a tick-box exercise

Allow time and resource

Emotions are part of what we do but let's support people to share them in safe ways

Training considerations for researchers to deal with the emotions

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36

Mentimeter

What is the one thing you think your organisation should hear?

Training is needed -so that we can support PPI advisers/participants and ourselves more mindfully and professionally

Researchers need training and support to cope with and respond to emotional contributions appropriately

Value facilitation skills and make them required for somebody to be involved in PPI

Recognition and support for researchers/PPI staff and public contributors in recognition of the emotional burden of PPIE

Recognition of the complexity of PPI, and training for facilitators. Support for researchers, PPI contributors and facilitators

Always value contributors as individuals with different needs and experiences. Do not make assumptions about a person's value to a project based on their characteristics.

Peer support is powerful

Time and flexibility is needed to support public contributers involvement..even more so around sensitive topics, where, for example, one on one followup maybe required.

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Mentimeter

What is the one thing you think your organisation should hear?

Stop focussing on the money - and think longer-term and what will provide benefit for society

Develop and provide co-training for researchers and PPI on collaboration skills - including how to express and process emotions - at the beginning of any project

Value of support for PPI staff and researchers undertaking PPI to enable emotion to be expressed by public members - and to express their own, at least in some space

Training for researchers to deal with the emotional aspects

Emotions come from experience and have equal importance in research

Some people won't be able to show their emotions due to trauma and may feel guilty if you focus too much on saying its ok to be emotional. Be clear its ok to show emotions and ok to not.

Need to properly resource - facilitation training, multiple members of the team (especially where emotional responses might be expected) to support the meeting, planning for broad range of responses

Preparation, training, understanding - safe place to talk and listen

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Mentimeter

What is the one thing you think your organisation should hear?

I don't have an organisation. I'm a public contributor. Pleased so many found the session fantastic; it didn't relate to my experience at all. I review plain English summaries, (run out of space)etc

creative approaches help people open up

We are not therapists or friends - we are professional researchers - thought and care needed to address that and still be compassionate and open/approachable.

Training on skilled facilitating

If you are a health care professional who works in an environment where emotions have to be contained for good reason, this is different to the sphere in which other people operate

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36