Trauma-Informed Patient Involvement

MediPaCe
Turning Involvement into Action

Quick Reference

Explaining the approach

Trauma-informed patient involvement is a relation-based approach that recognises how patients and caregivers may bring experiences of physical, emotional, medical, or life-related trauma into engagement activities. Unlike standard patient engagement approaches, which may assume participants feel safe and able to contribute, trauma-informed co-production starts from the understanding that involvement itself can risk harm if not handled sensitively. This is particularly important for people from marginalised groups, who may also experience additional minority stress and trauma linked to discrimination or exclusion. It therefore focuses on building trust, safety, choice, and collaboration, ensuring that people with lived experience are supported to contribute meaningfully without being re-traumatised.

What are you risking by not doing it? V/S What will you gain?

Reinforcing power imbalances and deepening inequity

Retraumatising patients and tokenising them

Increasing selection bias and attrition

Better-designed treatments and services

Improving trust/reputation of your organisation

Increased community agency, uptake and impact

Recommended Actions

Pre-Engagement

- Collaborate with people with lived experience of trauma for the development of involvement activity/engagement
- Staff members must be trained to recognise trauma and the varied ways it can present, as well its impacts. They must recognise conscious and unconscious biases.

During Conversation

- Patient participants have ongoing support throughout the engagement or co-production activity and after if required.
- Seek feedback from participants on how to improve the research process.
- Embed staff support too in recognition that researchers may be adversely affected by the research process.

Post Conversation

- Listen actively, take flexible breaks and build in time for supportive conversations within sessions throughout the project.
- Be transparent about power differences and name them as issues arise, acknowledging that some cannot be overcome.
- There should be no expectation towards the patients to share their life story or a certain amount of experiences.
- Staff must be able to signpost to services/resources for additional support if needed.

Expected Benefits

A trauma-informed involvement approach can build trust, increase participation, and improve the quality and relevance of research. By offering choice, flexibility, support and fair recognition of emotional labour, it helps participants feel safer and more in control while reducing the risk of re-traumatisation. This enables people—particularly those from marginalised or trauma-affected communities—to contribute more honestly and meaningfully, leading to more representative evidence, better-designed treatments and services, and stronger long-term trust in research and healthcare systems.

Questions or Further Discussion

If you would like to discuss how a deeper understanding of trauma-informed framework can be successfully implemented to better patient involvement and gain more insight and actionable outcomes from each activity within your organisation, please reach out for further discussion:

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