

Responses submitted by participants during the session 'Involving people with lived experience in your QI project'

27 April 2023





### What can a person in a lived experience role add to Project Teams?

Firsthand understanding of client needs/wants...improve our services....help us to learn lessons and do better for others. Feedback on areas requiring change. Tailor services to fit population need

Can tell us the impact of long waiting times on their mental health. Can share their expectations of the service

What it's like to be referred to our service and to go through the assessment process

They will support in the co-design of ideas for change

The experience of a client, what did they want help with, what did they get, what do they think could be improved

Personal experience of the system and services; removes assumptions and guess work; brings level of understanding to staff of what it feels like to be a service user

Knowledge is power

The human side to processes and systems we have in place

Avoiding sweeping statements, judgmental attitudes and exposing shortcomings in service

Individual frustrations with the system

The good, the bad and the ugly

We already have a service user in our team, here with us today!





### What can a person in a lived experience role add to Project Teams?

Ensuring quality and meaningful interventions are provided from our services

Gives valuable multiple perspectives

Able to have the knowledge and experience of using the service and what barriers they have come against or positive outcomes and steps of their journey

What they want, ground us

Experience of closed doors

Remind us what it's like to try access services

Their own unique experience and perspective

The real journey of a patient's journey through the system

Stops you acting on assumptions alone

Knowledge, experience, insight

Experience of using the service

Ensuring quality and meaningful interventions are provided from our services

No production like co-production

Making patients feel less judged and like they're not alone in their experiences

Diversity of thought

Concrete examples of things they have experienced in the service that did not work





### What can a person in a lived experience role add to Project Teams?

Enables a dialogue between patient and service provision to build a happy middle where service provision for clinical need meets patient sentiment about that provision

Puts the patient experience at the forefront

Help us to focus on what's important for service user experience

Service user adds a perspective that is outside the system and it's helpful to remove the jargon

Shaping services from a user of services perspective

Can give us ideas of how we can improve the service for them

Their lived experience of the service and what went well

Personal experience and examples of what might have improved their care

To make sure the team think in a patient focused way

Keep us in touch with reality

Fist hand experience, real life

Communication flaws in the system

Communication methods, levels of communication

Insight into the impact of patients

Keep us in touch with reality





# What are the issues, attitudes and behaviours that would get in the way of achieving all those benefits?

Thinking it will be too traumatic for the service user, they won't be able to cope

Disrespectful, patronising, lots of jargon, treated like a number

Assuming treatment received, place treatment/support was provided

Tell them how busy we are

Inaccessible jargon, tokenistic.
Selection of unrepresentative
experts by experience. Avoiding
disruption. Lack of pre-meeting
support. Not opening up agenda.
Not providing practical support

Assuming peer support worker represents all patients

Limit access to materials and meetings

Recruit them but don't invite to any meetings and then let them know the outcome....or not!

Having hierarchy

Speak to a few/limited number of people

Dismissive of their opinions

Tokenistic attitude





## What are the issues, attitudes and behaviours that would get in the way of achieving all those benefits?

Authoritative, not being responded to or listened to

Judgements and assumptions

Use lots of acronyms

Don't feedback outcomes

Unhelpful language - I am the professional

Mute them in meetings

Forget to inform meetings are rearranged

Talk over them

They will slow down the process

They will question the service too

Not being heard

Not following through

much

Using abbreviations

Don't pay expenses

Weaponized incompetence

Their ideas don't count

Refuse to pay travel expenses





