

Paul Binfield

Head of People Participation

Beyond Patient Experience
Rhetoric into Reality

We care

We respect

We are inclusive

Welcome to our Workshop

Agenda,

- 11.15 – 11.45
 - PRIDE, what can patients get from being involved
 - How did we react to the findings
 - What is our next plan
- 11.45 – 12.25: Your work
- 12.25 – 12.40: Report out
- 12.40 – 12.45: End of session, Paul

We care

We respect

We are inclusive

PRIDE Research Project

Adrian Curwen, Jane Fernandes, Racheal Howison, Paul Binfield,
Winnie Chow and Domenico Giacco

2017

We care

We respect

We are inclusive

The PRIDE Project

- PRIDE = Participation; Recovery; Involvement; Development; Experience.
- Funded by the Centre for Public Engagement, Queen Mary University of London, based at East London Foundation Trust.

PRIDE Qualitative Study Research Findings

Why did participants join People Participation activities?

To give back to the service

“I felt a sort of passion in wanting to help improve things. I felt sort of like a need to pay back some of the really great sort of professionals I met across the years who’d helped me out”.

To influence changes for the better within services

“I think the move towards greater patient engagement, if you like, with their own treatment and the way that they are dealt with by the NHS, I think participation is a huge step towards that...”.

“I’ve had quite a few staff remark to me that I’ve changed their attitude of service users and service user involvement in peer support and that sort of thing. So I think I’ve changed some attitude there”.

Curiosity

“So really it was the PPL lead... and she came along and, I’m not even sure how it happened, but I got involved and I started enjoying it. It was hard at first, especially talking to many people. Very scary and very shaky, but she kind of made it a lot better. She’s really good at her job. She really looked after me, you know, and I feel there’s been progress since I first started.”

Social aspect – meeting like-minded people

“I come to the meetings and I look forward to coming... because it’s a change from that routine of hanging around with people (and) doing things that are not going to help them in their mental state.”

PRIDE Qualitative Study Research Findings

Why did participants join People Participation activities? (cont.)

Social aspect – meeting like-minded people (cont.)

“I needed to be involved in getting to know some other people.”

Having structure to their day and keeping occupied

“People Participation has turned my life around in the last 2 years I have been doing it. It gives me something to do. It involves me in aspects of other people’s illnesses, understanding other people’s illnesses.”

“I feel that I am happy...mental state as well because I feel more happier when doing participation.”

What were the benefits and experiences (positive or negative) for recovery by being involved in People Participation?

Sharing experiences with like minded people

“Be able to express my views, meet like-minded people who have gone through the same thing.”

“You get to connect with people and it’s so lovely when people come up to you and say “I love coming here because you are here as well” and, you know, that sort of thing. Just to be you.”

PRIDE Qualitative Study Research Findings

What were the benefits and experiences (positive or negative) for recovery by being involved in People Participation? (cont.)

Improvement in self-confidence and motivation

“I have learnt how to... be more assertive, be more confident, be more not confrontational...”

“My self-worth is probably the biggest improvement.”

“It helped me achieve a sense of well-being, it’s educated me, it’s made me more self-aware, it’s helped me just become a person that could, a normal person, normal as in the sense that like a person that can be in the community and have a mental health problem but still carry on and live a normal life...”

Better understanding of services

“How do I relate to services, it’s more of a positive thing...”

“When going inside the service that I did stay in it was kind of nice to see the day-to-day running so I guess that kind of give me another dimension to what I knew about that service...”

“It’s changed my views of services in ELFT and it’s changed my view that services are changing towards a more patient focused and listening more to the service users. I think, I mean in the past with psychiatric services, there wasn’t such a focus on recovery. It was more a focus on containment”

PRIDE Qualitative Study Research Findings

What were the benefits and experiences (positive or negative) for recovery by being involved in People Participation? (cont.)

Facing and overcoming fears, independence

"It is always good to learn about things that you actually fear."

"One of my things is the fear of... being discharged and being left on your own. But now I don't fear that because I know there's always access to everything, you know, and if you are having problems, you talk."

Sense of achievement, feeling valued

"You are important actually... You do learn if you're given a question your answer is important."

"So it opens doors. You meet people you normally wouldn't have met. You know, when you give yourself to something, it is not about rising to this or being big at this or doing, earning x amount of money. For me it was, you know, just one step at a time and I enjoy it now."

Giving back feels good

"I've always felt the value in everything I've done."

PRIDE Qualitative Study Research Findings

What were the benefits and experiences (positive or negative) for recovery by being involved in People Participation? (cont.)

Giving back feels good

“It’s helped with my recovery greatly. Sort of helping other people and feeling productive and putting a positive end to a negative set of experiences. It’s all, sort of, been great.”

Having a voice and improving services

“It made me more empowered because I was sitting on panels and I was having a say of who comes in and who doesn’t come in”

“Getting involved... taking part, having a say, being listened to, being educated...”

Better coping mechanisms

“I ain’t had drugs, drunk alcohol for 17 years, I haven’t smoked cigarettes for 12 years... it’s made me more self-aware of how you can end up back in hospital again or in trouble with the law if you don’t do things that are positive rather than negative.”

PRIDE Qualitative Study Research Findings

What were the benefits and experiences (positive or negative) for recovery by being involved in People Participation? (cont.)

Better coping mechanisms

“It’s helped me because it’s made me think about what are the good things in life and what are the bad things in life and what’s going to keep me well and safe and keep me from going back to hospital again.”

What skills were refreshed or gained by taking part in PP activities?

Listening skills/interpersonal skills

“I’ve learnt so much from going to the meetings, you know, talking and listening to other people, so I’ve learnt a lot, and I’ve got sort of self-respect and my say back, which I didn’t have before”

General communication skills.

“It trains you to develop your skills set. That was very attractive to me.”

PRIDE Qualitative Study Research Findings

What skills were refreshed or gained by taking part in People Participation activities?

Public speaking skills - giving training to staff

“I think being able to express yourself, especially when I do talks with new nurses or new social therapists, they really want to hear the service user’s view and see the other side. Not just the things they are trained in. Not just the things that are passed down, but the service user’s view is the reality. The fact that I was a patient made my views more important.”

“I’ve had quite a few staff remark to me that I’ve changed their attitude of service users and service user involvement in peer support and that sort of thing. So I think I’ve changed some attitude there.”

Creative skills (poetry)

Avoiding conflict/ dealing better with conflict

PRIDE Qualitative Study Research Findings

What were the participants' experience of the support provided?

Trust/Availability

"Yes, she has been really good. I've needed to lean on her quite a bit. Especially when writing any script or doing any talk, the fact that she's there makes it much easier. I can get all the information that I need and she really supports me. She does a wonderful job. She has great qualities, you know. So I wouldn't be able to do the stuff I've done without her."

"Our People Participation Lead is probably the best one and I wouldn't want anyone else. I can talk to her about anything. She is down to earth, human. She's a lovely lady and I can go to her whenever I like."

Being a companion

Facing fears - pushing personal boundaries

"I set myself boundaries because I guess we all live in our own safety nets when you have mental illness. She actually makes me go to the edge and sometimes over. And when I do that, I feel, you know, like, 'wow, I'm so glad I did that. Can I do that? I can really do that' you know."

Keeping updated on training, events and opportunities

Support with personal issues

PRIDE Qualitative Study Research Findings

What were the participants' experience of the support provided? (cont.)

Genuinely caring – seeing service users as people and not just a job

“People Participation Leads should be on ward rounds. You can talk to People Participation Leads about things you wouldn't talk to a doctor about.”

What aspects of this initiative could be improved/suggestions for improvement?

More involvement from young people

Change in staff attitudes – especially on interview panels not seeing service user involvement as valid

Better financial incentive

Better payment system – getting paid on time, less form filling

Financial recognition of travel time involved for service users from Luton and Beds who attend events in London, recognition of childcare issues and that some service users are parents

Moving-on support system like careers advice

Having a People Participation web page with info on events, training, different mental health conditions, common medication side-effects, sign-posting to other support services, etc

Does not need improving!

PRIDE Qualitative Study Research Findings

What aspects of this initiative could be improved/suggestions for improvement? (cont.)

“Whoever is listening to this, just know one thing – People Participation has pulled me out of a very big hole which is now filled with cement and I don’t go back there now... I’m moving forward. I feel like a human being now, not an animal.”

“As far as this Trust is concerned, we seem to have pretty well nailed People Participation, I think. I don’t know where we stand nationally in terms of participation, but we are damn good at it and I think we could teach those other Trusts.”

We care

We respect

We are inclusive

- 11.45 – 12.25:
 - What are you doing now?
 - How can you turn the wealth of knowledge of patient experience into meaningful action and outcome?
 - What can you do differently
 - How to begin
 - What can be a plan for a small test of change next week?