# Developing holistic physical health support with people living with severe mental illness (WHOLE-SMI)

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## Our approach to public involvement and community engagement (PICE)

- The WHOLE-SMI project explores how best we can deliver physical health support to people living with severe mental illness (SMI) in the North East of England.
- We want to contextualise an established intervention, PRIMROSE, with and for people living with SMI in our region.
- We've involved people with lived experience throughout; as project partners, peer researchers, through a community advisory group, as well as through expert by experience workshops. They may be carers or family members of someone with SMI, or have SMI themselves.
- In essence, our approach aligns with the principles of 'nothing about us without us' and seeking local expertise for shaping local services.
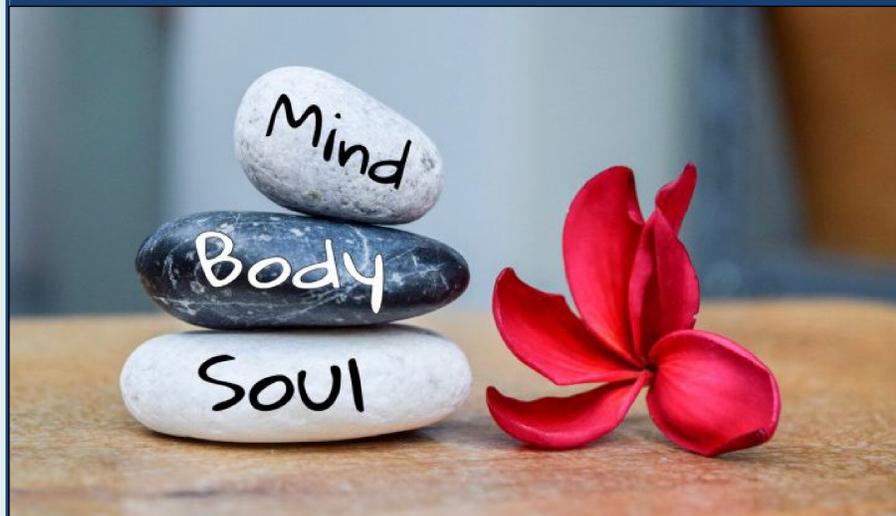


## What does 'holistic health' mean to us?

- Our involvement work so far has helped the team to think about what holistic health can mean, and why it matters.

**"Looking at getting rid of the symptom is not holistic. It's about looking at the causes and working on those too".**

**"I've had some good examples of holistic care and it's changed my life, literally changed my life".**

- Recovery Colleges and peer support are valued, offering experience: "not just what someone read in a book".
- Staff consistency and insight are key in holistic patient-centred approaches. Need to consider the whole person, their trauma, environment, and history, not just an illness/diagnosis.
- Communication and accessing physical health support beyond medication can be challenging: "It can feel like the odds are stacked against you".

## Our Community Advisory Group

**What we did?**

- Linked up with CNTW's Involvement Bank; this provided guidelines and one gateway for recruiting.
- Used engaging visual resources in physical support spaces in the community (e.g., recovery colleges).
- Recruited 11 people living with SMI from across the region, meeting quarterly to advise the project team.

This group is diverse in terms of age, location, health, and wider experiences (e.g., childcare responsibilities; employment).
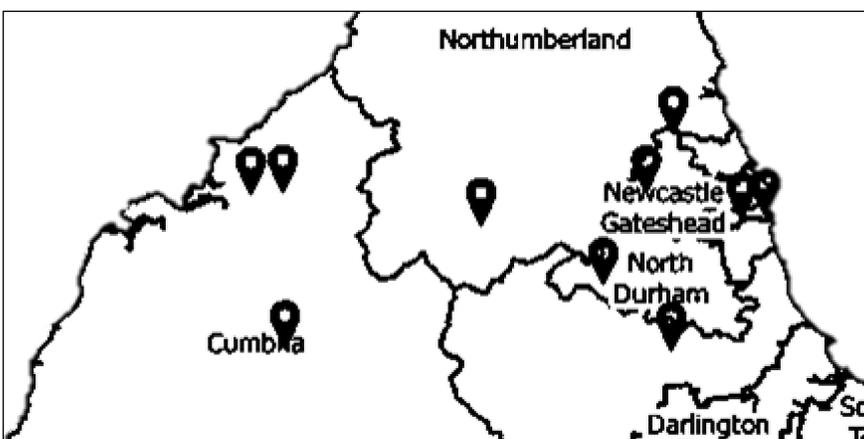


**Example learning so far:**

- To adopt inclusive definitions of severe mental illness. A reliance on diagnostic categories excludes some who are and doesn't capture those who may or between diagnoses.
- Online options are important for those with travel or mobility restrictions, and health and social anxieties. Support for digital access is needed.
- To widen recruitment channels; the National Survivor User Network and Carer networks have been useful.

## Involving Peer Researchers

**What we did?**

- Formal collaboration with The McPin Foundation who support the involvement of people with lived experience in mental health research.
- Open recruitment of two paid peer researchers with lived experience of SMI, based in the North of England, working a day a week each on the project.
- Peer researchers are engaged in co-design of the research, data collection, and in project management meetings.
- McPin involvement on all research staff recruitment panels.

**Example learning so far:**

- Mentoring and support from a senior McPin researcher has been vital – "John has great experience and has been a good support, particularly about technical issues, as I am a bit of a technophobe!" - Sue
- Peer researchers have been great advocates for the project and of involvement generally: "research shapes the future – it teaches us new things & helps us to adapt and evolve" – Keith; "Able to use my lived experience to help make a difference & empower others" – Sue.
- Researchers have altered the language we use (e.g., "experts by experience, as you are the expert in own life"), as well as developed their own research, presentation, networking and dissemination skills.

## What next – future plans for PICE?

- Diversify the spaces and places we hold engagement activities, working with recovery colleges.
- Become more accessible for those who may be digitally or methodically excluded (e.g., working with ResearchAbility to reach those with learning disabilities).
- Need to think creatively about how to pay for engagement when individuals cannot accept money/vouchers.
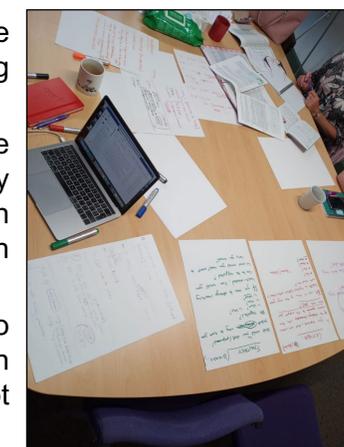
**Scan me to access our peer researchers' blog on their hopes for the research**