

Experts by Experience in Mental Health Research –

Tips from a #MentalHealthResearchMatters webinar

“It’s important that we do research that **matters to us**. It’s important we **shape the research questions**, that we do the **right research**, so that we do **good research** and so that we do **relevant research** and influence policy and practices”

Gordon

What is lived experience involvement in mental health research?

Lived experience in research can take many different forms as people actively use their experiences to shape mental health research.

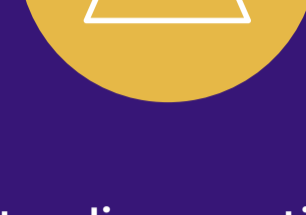
Lived experience involvement in research can look like (but isn’t limited to):



Leading research - known as survivor-led or peer-led studies



Steering or advisory groups



Attending meetings and discussions



Working with academics



Reviewing funding applications



Working with researchers equally on research projects



Planning projects, writing projects, co-author with researchers



Creating guides/materials

“Without lived experience, research isn’t as **real or relevant**... It gives a **voice and power** to those the research will affect in the future. It’s really important we are addressing what is happening to **real people right now**”

G

Co-production

Sometimes research is carried out using an approach known as **co-production**. Here, academics and people with lived experience have an equal say in how research is designed and carried out.

Tips for co-production:



Build strong relationships

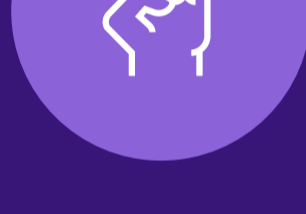


Respect boundaries



Be flexible in the process

Why get involved?



Empowering



Using experience for good



Meaning and purpose



Gain skills



Make research relevant



Get rewarded

“This has given me courage. I’ve met people who have had similar experiences to mine and have felt a sense of **community and connection**, and a safe space to turn our lemons into lemonade.”

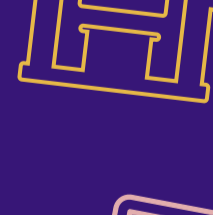
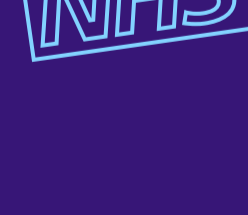
Catherine F

Tips before you begin:

- 1 Start small and find opportunities that suit you. You don’t need to lead a study the first time you do this (unless you want to!)
- 2 Be aware of what you are comfortable sharing with others. There’s no need to share everything about your mental health story. Your viewpoints and expertise are more than that!
- 3 There are times when research can be quite stressful and overwhelming. Be honest with yourself when you need to take a step back, or extra help or support. Good research teams will be understanding of this.
- 4 It may be nerve-wracking joining a research project for the first time, but it is definitely rewarding!

How/where to get involved

Contact your local NHS Trust



Sign up to the **McPin Foundation involvement network**, **NSUN bulletin**, **SRN (Survivor Researcher Network)** and other mental health charity opportunity listings



Check out **PeopleInResearch.org**



Take a look on Twitter for terms like **#LivedExperience** **#MentalHealthResearch** **#LEAPS** (lived experience advisory panels) **#YAGS** (youth advisory groups) **#CoProduction**



“There are quite a lot of ways to get involved with mental health research, especially for people from minority backgrounds, as I feel we are not heard enough within research.”

Yasmin

“I would recommend this to anybody who is interested in lived experience research work. It’s a great way to re-frame your experiences.”

Isla

This infographic was created in collaboration with the Experts by Experience from the Mental Health Research Matters steering group.

#MentalHealthResearchMatters