Lived Experience Network for Scholars

Support network for academic mental health and addiction researchers with lived experience

LENS
LIVED EXPERIENCE NETWORK FOR SCHOLARS

MENTAL HEALTH RESEARCH
DEVELOP YOUR CAREER • CHANGE LIVES

If you like, you can introduce yourself in the chat box

Overview of our meeting

13:00-14:00

- Introducing our new network – Ruth Naughton-Doe and Ruth Knight

- Managing disclosure - Tanya Mackay McPin Foundation

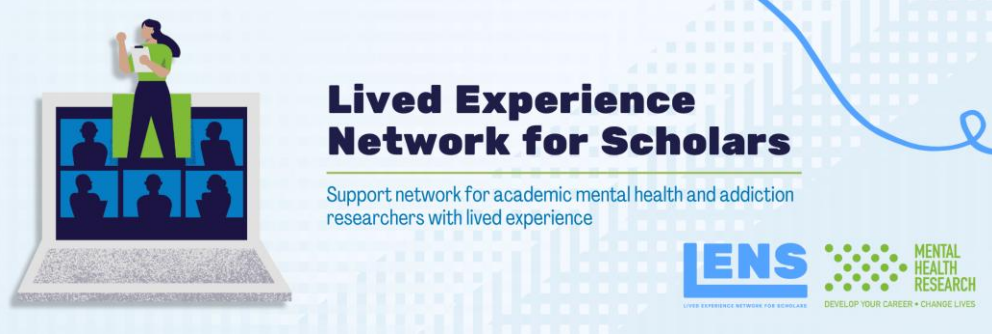- Keeping our network an inclusive and safe space

14:00-14:30 Open Space

- General reflection and chatting

- Ideas for topics/training future meetings

- Future of the network

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LIVED EXPERIENCE NETWORK FOR SCHOLARS

Why this network, and why now?

- We know that many academic researchers researching mental health and/or addiction have lived experience of mental ill health and/or addiction

- We know that researchers want more support

- The growing requirement to involve people with lived experience in mental health research (good!) means growing tensions

- There are other networks out there, but our network aims to fill a gap for support

MENTAL
HEALTH
RESEARCH

DEVELOP YOUR CAREER • CHANGE LIVES

Lived Experience Network for Scholars

Support network for academic mental health and addiction researchers with lived experience

LENS · MENTAL HEALTH RESEARCH

About our network

- The network aims to provide support and community for academic mental health researchers with lived experience.

- The network will be open to any academic mental health and/or addiction researchers who have lived experience. There will be no pressure to disclose this experience.

- The network is especially relevant to early career researchers but also will benefit academics at all stages of their research careers to build their resilience and capacity as lived-experience researchers.

- We hope the network will encourage academic researchers to feel better supported and connected and thus more likely to remain in working in the field.

Why I wanted this network: the support I wish I had.

Questions I struggled with

- To disclose to colleagues, or not to disclose?

- How to disclose, and to whom?

- Disclosure with research participants… why/why not?

- Fears about bias/reflexivity/how to mitigate these

- Managing the mental health impacts of fixed-term contracts

How did I get here?

- Feeling on the seesaw of lived experience and academia

- Map-less

- Not wanting to have to cleave off a part of me

- Not knowing the best way forward

- Community and discussion

What is next?

Quarterly meetings

Meeting in person in September

We will ask you what you want these meetings to focus on

Opportunities for more training/speakers- please suggest

A website will be built

We will work together on a paper

The McPin Foundation
We are a mental health research charity that champions *expertise from experience* in research

OUR GOAL – to improve mental health and wellbeing in communities everywhere. By improving quality of research

Three main areas:
Research and evaluation
Patient & Public Involvement
Influencing activities – policy and campaign work

Tanya Mackay
Head of Research and Involvement

Ways of working

Describing roles?

Expert by Experience · Lived experience Researcher · Survivor Researcher · Consumer Researcher · Co-researcher · Peer Researcher · Service User Researcher · Mad Studies Academic/ Scholar
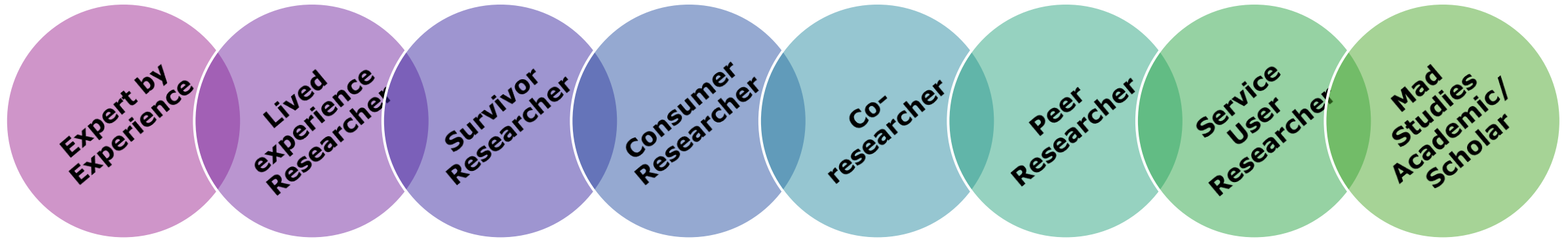
Ways of working

Respect one another

Feel free to ask **questions**

Take **breaks** when you need them

We'll speak **one at a time** – and can use the chat

No one is expected to share any **personal information** that they do not want to

Stories stay – learning leaves

Any others you would like to add?

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Disclosure

Tanya Mackay

Disclosure

- Explicit disclosure

- Implied (through association)

- Disclosure is ….

  o Often context specific

  o Mostly small parts are shared

  o Views may change over time

- Requires support and a culture of team inclusivity

WORKING TOGETHER TO CHANGE MENTAL HEALTH CARE

Meet some of our team

Our team includes researchers who also have personal experience of using mental health services. They work with us because:

"I'm excited by the PARTNERS approach of collaborative support for people with on-going mental health needs: it seeks to help us in our recovery in ways a focus on medication alone does not."

John

Related blogs

12th Apr 2021 Blog

Achille Crawford
McPin Researcher

Black Thrive: Researching the impacts of Covid-19 on Black people in Lambeth

2nd May 2023 Blog

Peer research • Research methods

The 3 types of lived experience researcher & how to support them

A PhD student shares how her work into lived experience research ended up creating a framework that can lead to better research supervision and support.

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Disclosure, why?

- **Epistemic justice approach** recognising the expertise and ownership of the knowledge of those typically marginalised or oppressed.

- Can reduce power imbalances (but not always!)

- Builds trust, rapport, engagement, which can in turn enhance data quality

- Reflexivity/positionality

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When using their lived experience people can face challenges around stigma and discrimination.

Discrimination against people with mental health issues across society persists and many also experience **anticipated discrimination** (also known as self-stigma). The research profession is not immune to these problems

76% Judgements of others

65% Negative impact on future career

47% Digital visibility and online trolling

41% Anxiety related to sharing

- Some people may choose not to be explicit about their personal experiences in public or in published work, and that they may have many reasons for doing so. Others are comfortable being open about their experiences and using them as a way of challenging prejudice.

- People may choose to be explicit in one setting, and not in another. An individual researcher's preferences for using lived experience may also change over time.

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Our principles on using lived experience continue to evolve

Based on our experience we have developed organisational principles for using lived experience in our work:

- On some projects we explicitly use a peer research methodology and people working on these have **job descriptions have the title of peer researcher.** People can choose what label they use and how much they disclose.

- In some projects it is an important aspect of the work that the researcher have a close or relevant lived experience to the topic being researched.

How people draw on their LE will differ – it does not always involve an open disclosure for example:

- Considering a venue for other people with LE of trauma

- Using a measure/interviewing in a way that accounts for a certain type of LE/using language that is accessible to people with similar LE.

- Using own networks to support recruitment
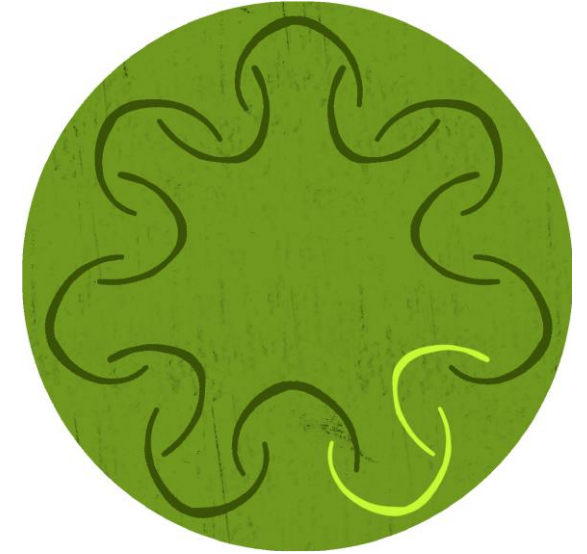
Disclosure decisions
How do you decide?

- It's up to you
  - Think & talk about it
  - In each context
- What's good for you?
- Do you want to or feel ready to share?
- Impacts for other people?
- What's useful for the support and practical understanding you need around work?

If you decide to disclose.....

Lived Experience: Sharing and listening safety

- Do you feel you have supports if needed (personal/work?)

- How is your wellbeing? (comfort with sharing can change when wellbeing changes)

- Content warnings. People who have experienced difficult or traumatic events should be able to make an informed decision about whether to view/hear sensitive content. This does not mean silencing a story – but giving space for each other's lived experience needs!
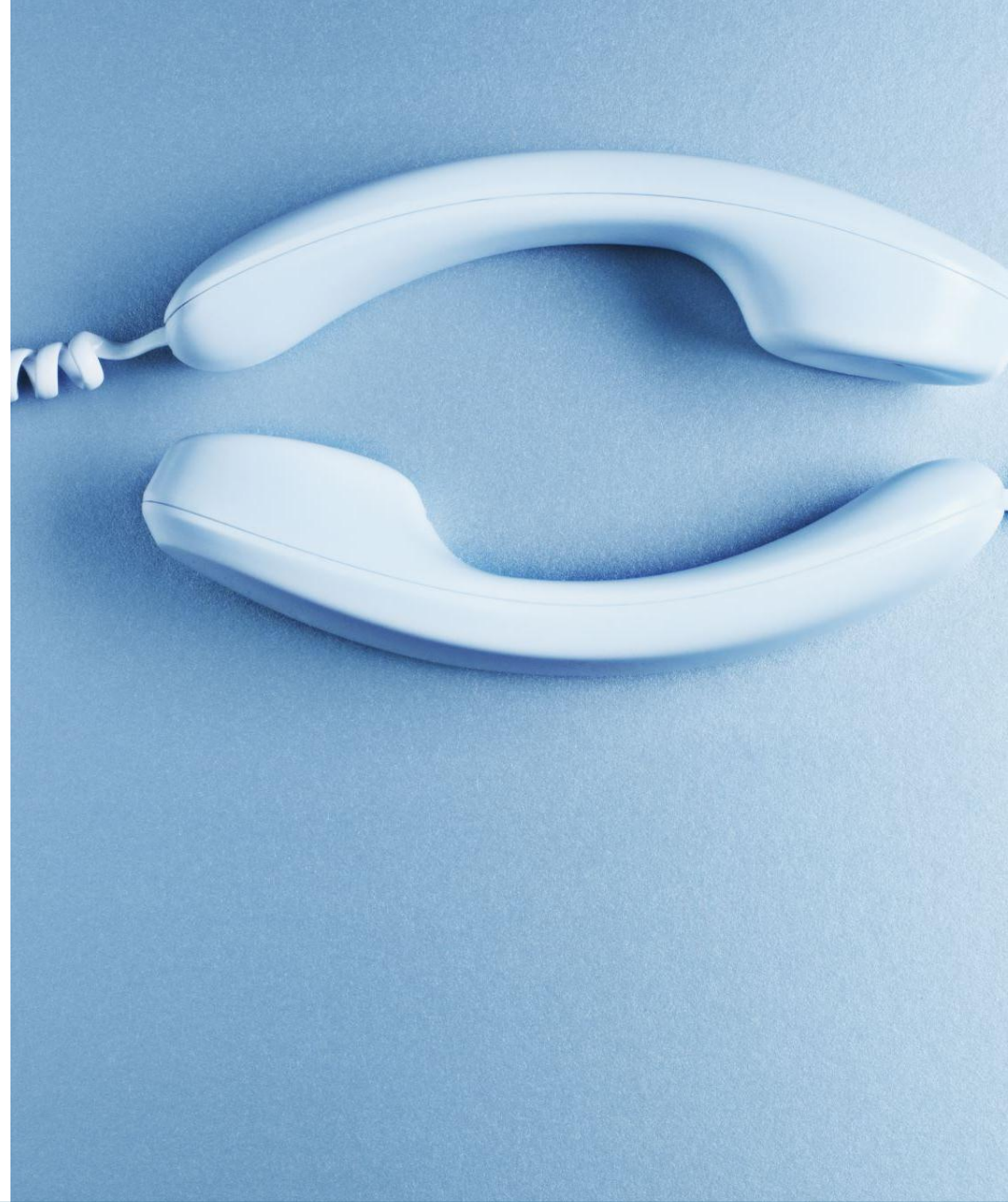
Lived Experience: Sharing and listening safety

- Respect the privacy of others. Avoid naming others in your life, co-workers or participants, even close family, who have lived experiences or experience intersect with yours.

- If someone tells you they aren't ready to hear, that's okay. This might mean they have their own experiences that would be impacted or are not feeling up to it.

- Think about your environment. Who can hear this conversation?

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Discussion

Someone in one of the projects you are working on asks you directly

So what's your diagnosis? How might you respond to...

1. A PPI member
2. A colleague
3. An external partner/research funder

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Staying Connected With McPin

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The McPin Foundation

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IG: @mcpinypnetwork

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Scan for socials, involvement opportunities and resources

Feedback form

https://forms.gle/WBYe9F1XzHoSnJuQ9