

MHIN PPI reflections for Sharing Success Stories



Jason Grant-Rowles, Lucy Gallagher & Amy Allard-Dunbar



The MHIN PPI Workstream

- Our role in MHIN:
 - To ensure PPI was part of the central governance
 - To provide support to our partners on embedding lived experience across the program in their implementation journeys
- Involvement and Inclusion Guidance:
 - Structures of Involvement
 - Meaningful involvement checklist
 - Snakes and Ladders of Involvement



Reflections from Jason

- In January 2022, I received an email from a colleague in Sussex about an involvement opportunity with MHIN.
- The South London ARC hosts the ARC National Priority Programme for Mental Health, and they are looking for public members, with lived experience of mental health challenges, to be on their Public Advisory Board.

My involvement in numbers

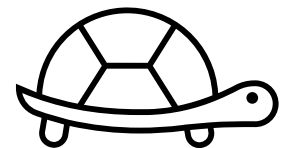
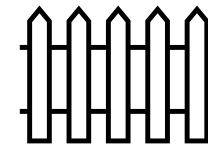
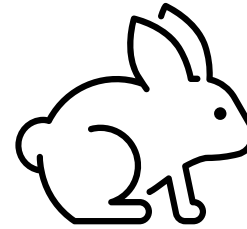
- After reading through the application information, applying, interviewing, and being appointed:
- Over 1,050 emails
- Around 55 meetings
- A total of 180 hours
- Most importantly working with a committed group of people who have drawn on their experiences to improve the programme.

Reflections on impact

- Advisory board
- PPI workstream
- Project 1
- Project 3
- PPI Lead
- Coordination
- Sheffield

Lucy's journey

- Joined the MHIN in October 2021
- Involvement and Inclusion Strategy
- Imposter syndrome
- Overcoming hurdles
- Building trust, resilience and confidence
- Steadfast PPI support
- Reflections on PPI in Implementation Science paper
- PPI celebration event



Some final thoughts

Recent shifts in global research priorities have meant that there has never been a more important time to:

- Create a culture of kindness and trust where lived experiences can be shared without fear of judgement
- Acknowledge the voices that aren't in the room and engage the systemically disadvantaged communities

By doing so, we can:

- Increase the likelihood that the research we do will benefit the communities that will be most impacted by our work
- Help address health disparities

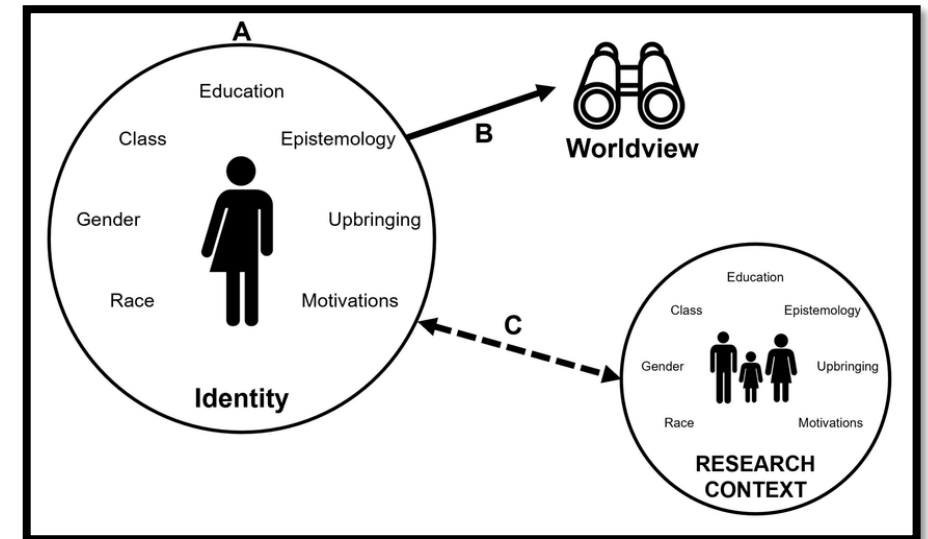


The Peer Researchers Journey

- Amy Joined MHIN in April 2023
- Involvement in P1 as peer researcher
- Peer researcher vs Research Assistant
- Navigating as an activist scholar and lived experience researcher
- CEDI
- Involvement in Workstream evaluations
- PPIE Across the Programme.

Learnings and Moving Forward

- Integrating CEDI & PPI + Allyship
 - The Global context of Research
- Trainings
- Support
 - Early Career and Lived experience
- Researcher Reflexivity and positionality
- Moving towards co-production
 - Innovative Approaches



MENTAL HEALTH IMPLEMENTATION NETWORK'S PUBLIC & PATIENT INVOLVEMENT - A CELEBRATION

MHIN PPI Celebration Event
February 2025 at The Circle, Sheffield

JASON
Woohoo!
THE PPI TEAM HAVE BEEN EXCELLENT!
AMY
Welcome!
THANK YOU for your leadership!
Jason & the team

BEYOND TICKING BOXES
It felt a bit tokenistic at first
Moving to embed the voice of lived experience across services for influence & IMPACT
What do you think of the words & images in this flier?
DO WE REALLY NEED A PPI GROUP?!

BUILT IN TO ALL BUDGETS
AN EQUAL VOICE FROM THE START!
Always learning from the communities you serve

CO-PRODUCTION
Simple Words / Shukran / WELCOMING / Jargon Buzzer / DIGITAL / SPOKEN languages / ANTI-RACIST from the GROUND UP ↑ / cultural awareness / lightning reports

START WITH FUNDING
THE ADVISORY BOARD DEVELOPED OVER TIME FROM DOMINANT VIEWS, TO A STRONGER VOICE & INFLUENCE FOR PPI
Who is involved, where & how?
Who gets to make the decisions? Who vetas?
How open are researchers to sharing power?
Who is being empowered through this?
How is privilege working in this context?

PROMOTING A MORE HOLISTIC VIEW & APPROACH
Real lives can be messy
DEVELOPING A FRAMEWORK THAT IMPROVES ACCESS & OUTCOMES FOR RACIALISED COMMUNITIES
feedback mechanisms

HUMAN CONNECTION
Building trust
Our group has years of experience! Working with Black-led organisations & other VCSEs

INCLUSION CANNOT BE RUSHED!
You just take our ideas & stories & disappear!
ORGANIC OVER MANDATORY A PARTNER

Power
I'm hungry mum
Thinking about people's whole lives rather than oversimplifying & failing to provide support
If you hadn't come out to us, we would not have participated
Taking care with people & their organisations

EVALUATION CRITERIA:
 UPSKILLING
 CONFIDENCE BUILDING
 RESEARCH METHODS & LEADERSHIP
 EVALUATION

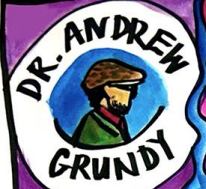
Lightning reports @penmendonca

Artwork: Dr Penelope Mendonça

LIVED EXPERIENCE RESEARCH NEEDS:

A PIPELINE

- a career trajectory
- from consultation to collaboration
- to user-led & user-controlled



TRAINING

The grounding to influence design & process



for patient & public involvement researchers

SUPPORT

Structures & systems that understand personal (& financial) needs.

THESE STORIES & PERSPECTIVES ARE HAVING A NEGATIVE IMPACT ON ME

WHAT DOES THIS MEAN?

Being a carer can be exhausting

I wonder when my expenses will be paid?

This is getting difficult for me

I wonder when I am due another pay rise!

Research can make you feel Raw

Moving towards shared dialogue & mutual challenge supported by leadership & infrastructure

EFFECTIVE COMMUNICATION

flexible, active communication

Recognise our work

Time, resource, & time funding for this is essential

Check-ins & check-outs



Simon

TRUST

SHARING YOUR STORY

Think about how we are valuing PPI

I feel better, had a great service



better than last time

Showing evidence of impact

Experts by experience is expertise

Don't just leave it to the PPI lead, or one PPI group

The added value of being face2face

FUTURE DIRECTIONS

We should be creating a culture of kindness

Promoting importance of lived experience

IN STRATEGY
IN FUNDING

OPENING RESEARCH UP TO PEOPLE WHO HAVE LIVED THE TOPIC IS EVERYONE'S BUSINESS!

COMMUNICATE THAT YOU CARE, THAT THIS MATTERS

MHIN PPI Celebration Event February 2025 at The Circle, Sheffield

Artwork: Dr Penelope Mendonça

