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SAFE RESEARCH PARTNERSHIP WITH PEOPLE WITH LIVED AND LIVING EXPERIENCE

Reflective Guide for People with Lived and Living Experience Partnering in Research

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This guide will help people with lived and living experience feel ready and supported when engaging in co-design or participatory research. It aims to build confidence and provide clarity on roles, expectations, and ways to protect emotional safety.

Partnering with people with lived and living experience in research is important as it increases the relevance of research priorities and outcomes and enhances the quality of knowledge translation.

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1. PREPARING FOR THE CO-DESIGN PROCESS

Know the co-design process: Co-design can sometimes be unclear, so ensure that the team defines what co-design means in the context of this project. Understand when you will be involved, what will be expected of you, and when your contributions will be most valuable.

Understand your role: Ask the research team to clarify your role within the project. What are your responsibilities, and how will your lived experience drive the research? What is the research trying to achieve, how does it align with your values, and how will your perspective influence the outcomes?

Ask yourself, is this project right for you: Take the time to get to know the values, behaviours and motivations of the other researchers, and assess whether they align with your principles and ethical stance.

For more information about the origins of co-design, read page 7 of CMHDARN's Co-design Kickstarter.

DOWNLOAD RESOURCE

2. NAVIGATING POWER DYNAMICS

Preparing for discomfort: Understand that stigma may be associated with being an LE partner, particularly in academic or institutional settings. While your contributions might not always be fully recognised or valued due to stigma, it is important to remain confident in your expertise. It is crucial to call out such lack of recognition as inappropriate and use these moments as opportunities for collective learning with the team. You may also encounter challenging assumptions or views from other researchers about the research topic or participants; use this as an opportunity to critically reflect with the team where these assumptions stem from and use it as a shared learning opportunity. Remember, combating institutional stigma is a collective responsibility and not solely the burden of LE researchers.

Acknowledge the power imbalance: Understand that a power dynamic between conventional researchers and those with lived experience may exist. Acknowledge that this is common and that your perspective is just as valuable and important, even without formal qualifications.

Be mindful of group dynamics: If you are the only LE partner in a team, it can feel isolating or tokenistic. Ask for a group dynamic that includes multiple LE partners to help balance power dynamics and promote enhanced collaboration and inclusivity.

Look out for yourself: If you feel uncomfortable with how you are being treated, or how your contributions are considered, it is important to voice your concerns to someone you feel safe talking to. It is okay to ask questions or to seek clarification if you don't understand something, and it's important to feel validated for your contributions. Familiarise yourself with the organisation's complaints and escalation processes.

Seek support: If you feel uncomfortable or overwhelmed, reach out for support. This could be from the research team, a mentor, or someone who has experience in similar roles.

3. PROTECTING YOUR EMOTIONAL AND PSYCHOLOGICAL SAFETY

Understand your boundaries: Establish boundaries around the emotional and operational aspects of the work. It is important to remain faithful to maintaining a work/life balance and practicing the right to disconnect from professional obligations. If you need a break or if something is challenging, it's okay to step back. You can always rejoin when you feel ready.

Debrief and reflect: After each session or meeting, take time to reflect on your experience. This could include journaling, reflective writing, mind mapping, artistic expression, or voice/video recording to capture and reflect on your thoughts and feelings, process the experience, and track any concerns or questions that arise. Debriefing with fellow peers is also an important way of unpacking shared experiences.

Support structures: Ensure that the research team has a plan for offering debriefing or emotional support, should you want this.

Ask for flexible arrangements: If you need any accommodations (e.g., flexible hours or a later start time), request them. The research team should be willing to work with you to ensure that you can participate in a way that respects your needs.

4. CONTRIBUTING TO A POSITIVE CO-DESIGN EXPERIENCE

Be open but assertive: Feel free to share your lived experience and ideas, but also be clear about your boundaries. You don't have to share everything or expose personal experiences that you are uncomfortable with in order to validate or defend your opinions. A useful guide on safe storytelling here

Help establish a democracy of idea sharing: Everyone should have equal opportunity to express their thoughts, opinions and suggestions to ensure a diversity of perspectives are considered and integrated.

Build trust: Take the time to get to know the other team members, whether they are from academia or have other lived experiences. Building trust can help support safe collaboration with the whole team.

Voice your concerns and queries: If something feels off or you don't understand a part of the process, ask questions. You don't need to preface your questions by saying "this might be a stupid question"—your perspective is valid.

"If I'm not clear on what this means, it won't be clear to others"

5. CLOSURE OF RESEARCH

Expectations of research impact: Change can take time. Translation of research into policy and practice can be slow, but don't let this dishearten or stop you from undertaking future research opportunities – every bit of work counts.

Recognition is a right: Make sure that your contribution is acknowledged, whether it's through credit on publications or recognition in meetings or privately – this is up to you. Ask the research team to explicitly acknowledge the value of lived experience in the project's outputs.

Dissemination of research findings: You may feel pressured or obligated to hold the responsibility of disseminating the research findings back to the LE community. Explore with the team whether this is a role you are happy to take on, or whether there is someone else better suited for this task – your LE 'label' should not automatically dictate roles and responsibilities, these should be decided collaboratively with the team as a whole.

Moving forward: Once the project is finished, this may open the door to future opportunities such as sharing your findings at a conference, developing 'translational research resources' such as short guides or workshops based on your findings, or starting new research projects


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