# **Key Points and Highlights from Inclusive Involvement - Community of Practice meeting**

# **29th April 28th 1-2.15pm on Microsoft Teams**

# **Learning from Lived Experience Involvement: MINDS study, with Sarah Rae.**

**Elspeth Mathie** from the University of Hertfordshire led the session, focusing on inclusive involvement in research.

The meeting aimed to discuss challenges, learnings, and success stories related to inclusive involvement in research with diverse and underserved groups.

**Sarah Rae** shared her experience of co-leading the **Mind Study**, which aims to improve discharge planning and outcomes for adults transitioning from inpatient settings to the community. Sarah emphasized the complexity of co-production and expressed scepticism about achieving authentic co-production. The Mind Study involved a lived experience advisory group (LEAG) that influenced various aspects of the research, including pilot interviews, ethics applications, and co-design workshops.

**Key Learnings and Reflections**

* **Pre-Grant Involvement**: Sarah highlighted the importance of obtaining funding for meaningful pre-grant involvement to ensure diverse perspectives are included from the start.
* **Inclusivity and Diversity**: Greater consideration for inclusivity and diversity in recruiting team members was identified as a key area for improvement.
* **Building Trust**: Facilitating early building of trust among LEAG members through informal activities like coffee mornings and WhatsApp chats was suggested.
* **Impact Log**: Regularly reviewing a co-designed impact log to capture both researchers' and LEAG members' perspectives on impact was recommended.

**Evaluation and Feedback**

* A co-production survey was circulated to LEAG members after each meeting to evaluate how well co-production was working.
* The survey results were generally positive, indicating that LEAG members felt their voices were heard and valued.
* A copy of the questionnaire is attached with these notes

**Recommendations**

* **Support from the Start**: Building support for everyone from the start and appreciating each other's expertise.
* **Infrastructure and Governance**: NIHR should build infrastructure and governance to support PPI in practical ways and ensure researchers are rewarded for doing PPI.
* **Regular Review**: Regularly reviewing co-production throughout the project and establishing a shared vision from the start.

**Discussion and Questions**

The community of practice discussed the differences between co-production and typical patient public involvement (PPI). Participants shared their experiences and reflections on co-production, including challenges and strategies for involving people with little or no research experience in complex projects.

The meeting concluded with a call for more pre-grant funding to support inclusive involvement and a recognition of the need for continuous learning and adaptation in co-production practices.