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### Considerations and strategies for incorporating lived experience in mental health research

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# Considerations and Strategies for Incorporating Lived Experience in Mental Health Research

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### Introduction

- Incorporating lived experience in mental health research deserves special focus due to the unique stigma faced by those with lived experience and the unique gap between the experience and expression of mental health struggle.
- Too often this inclusion looks like tokenism.<sup>3</sup>
- Goals should be to produce practical benefits, mutual relationships, as well as personal and social change.
- Research Advisory Council (RAC) is our attempt to incorporate lived experience; this poster displays our accomplishments and hopes for future implementation in our lab and elsewhere.

### Methods

- RAC members were recruited by Dr. Woodberry's research team and by the Maine Behavioral Healthcare Peer Services Department.
- RAC meetings occurred once a month in person or by video and were attended by up to nine members.

### Results and Discussion

- Benefits abound. One RAC member pointed out the impact that social and environmental factors might have on answers to typical psychosis screening questions about paranoia. Another, in an effort to educate the team about barriers to the efficacy of Peer Support, recalled their own worries about stigma when first receiving services through the PIER program. As a group, the RAC examined language used in common psychosis screeners and suggested changes meant to eliminate biased or harmful language. The same screeners were then aggregated and examined for the questions most likely to pick out and eliminate experiences that might resemble psychosis but require a different intervention, or none at all.
- Having a road map doesn't mean this is easy. Our participation in a multi-site PCORI trial demonstrated the difficulties of avoiding tokenism and eliciting meaningful feedback early enough to make a difference.
- We continue to improve our communication with members of the RAC about the nature of their contributions, prioritizing transparency and avoiding tokenism.





Take a picture to download the full poster

More people with schizophrenia struggle with fatigue than with hallucinations or delusions. So, why does all the research focus on hallucinations and delusions?

# Fig. 1 Roles for Lived Experience in Research<sup>2</sup>

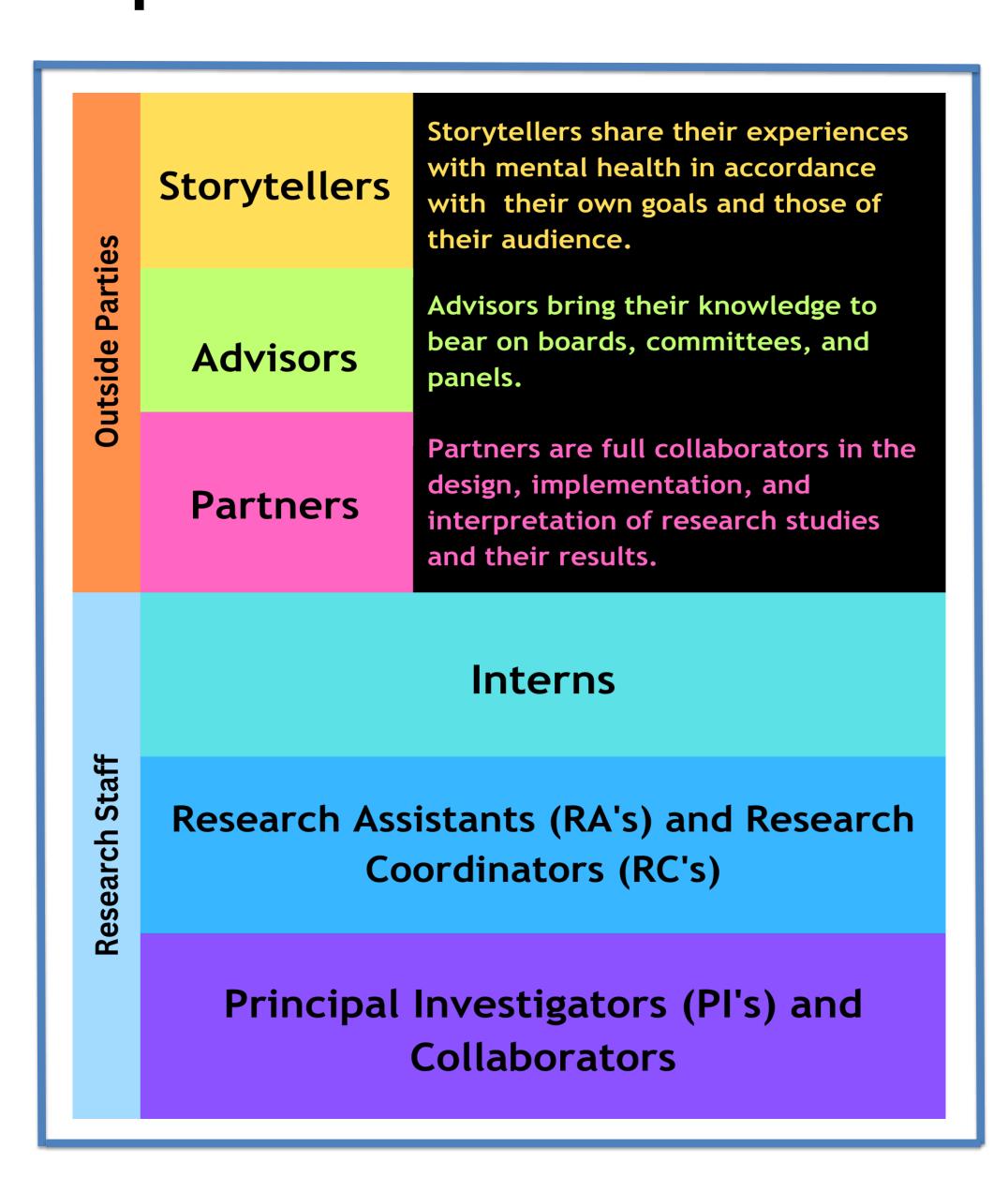
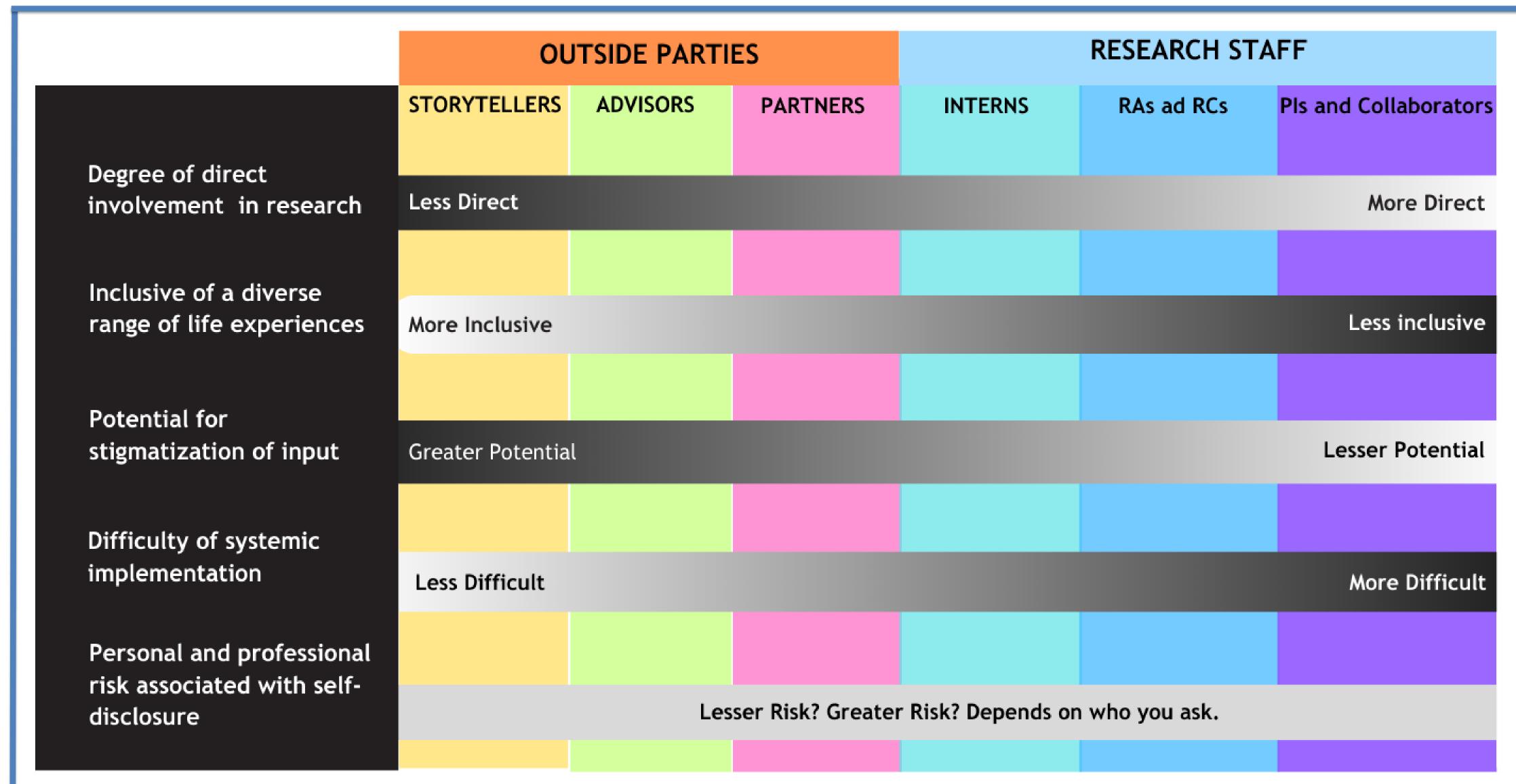


Fig. 2 Considerations for Effective Implementation: Our Opinions



## Fig. 3 Inclusion Strategies and Examples

### **STORYTELLERS** RESEARCH STAFF **PARTNERS ADVISORS** Partners can guide inquiry, do Storytellers' narratives can Advisors can offer feedback With more influence over the direction Potential inform qualitative research, advocacy work, cultivate that research takes, staff are in a on research questions, illuminate differing surveys, and papers; share connections to community, and position to lead by example by owning Contributions experiences of marginalized knowledge of unintended their own lived experience, holding space provide trainings to clinicians. At the state and national level communities, and add harms and consequences of for a wide range of voices, shaping office and lab culture, and securing funding for context and perspective for treatment; and suggest partners may help develop questions for further study. projects that center lived experience. future researchers. resources such as white papers position papers, and policy Between 45-75 percent percent of Maine Health's Peer Services The Woodberry lab analyzed The RAC examined psychosis Examples mental health professionals have lived interviews with participants screening tools in the hope of Department provided council of experience,⁴ but there is a perception, making them more accurate research into barriers to the in the PIER program for particularly within psychiatry, that efficacy of Peer Support and less stigmatizing. information about barriers disclosure could compromise neutrality Services to care in rural areas. or erode trust. We have found, by contrast, that speaking openly about our Potential future partners mental health experiences cultivates an One member offered helpful Each semester, Elias travels feedback on the limitations include the Consumer Council of environment of mutuality and increased to Bowdoin for a Maine and the Wildflower of the SEE ME study, which trust, in which our work's intersection presentation to an abnormal looked at psychosis-specific Alliance of Western with and impact on those with lived psychology class. referrals from PCPs. experience is at the forefront. Massachusetts.

### This project would not have been possible without the generous support of the Judy Glickman Lauder Foundation

# Fig. 4 What Does it Really Look Like?

### Willingness to Teach

- Understanding that stakeholders will have varying levels of comfort and familiarity with the clinical and research worlds.
- Taking the time to simplify or reword certain ideas and concepts.
- Scaffolding stakeholders' understanding in order to introduce more complicated concepts over time.
- Being as transparent as possible when describing how input and stories will be used in the research.

### Willingness to Learn

- Understanding that stakeholders may bring knowledge not traditionally valued in academic spaces.
- Making efforts to avoid confirmation bias.
- Being ready for one's assumptions to be challenged; and being willing to sit with that discomfort.
- Taking the time to build relationships that involve mutual trust.

### Acknowledgment of Self-Disclosure as Meaningful, Effortful Work

- Paying people.
- Treating them as members of your team.
- Not disclosing identities without permission.
- Considering equitable recruitment techniques.

