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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.³
- 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.

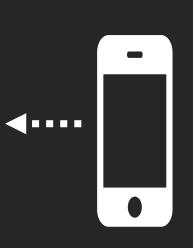
Methods

- 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.¹ So, why does all the research focus on hallucinations and delusions?

Roles for Lived Fig.1 **Experience in Research²**

es	Storytellers	Storytellers share their experiences with mental health in accordance with their own goals and those of their audience.
Outside Parties	Advisors	Advisors bring their knowledge to bear on boards, committees, and panels.
Out	Partners	Partners are full collaborators in the design, implementation, and interpretation of research studies
		and their results.
		Interns
Research Staff		

Inclusion Strategies and Examples Fig.3

	STORYTELLERS	ADVISORS
Potential Contributions	Storytellers' narratives can inform qualitative research, illuminate differing experiences of marginalized communities, and add context and perspective for future researchers.	Advisors can offer feed on research questions, surveys, and papers; sh knowledge of unintende harms and consequence treatment; and suggest questions for further st
Examples	The Woodberry lab analyzed interviews with participants in the PIER program for information about barriers to care in rural areas.	The RAC examined psyc screening tools in the h making them more acco and less stigmatizing.
	Each semester, Elias travels to Bowdoin for a presentation to an abnormal psychology class.	One member offered he feedback on the limitat of the SEE ME study, wi looked at psychosis-spe referrals from PCPs.

Considerations for Effective Implementation: Fig.2 **Our Opinions**

	OUTSIDE PARTIES		
	STORYTELLERS	ADVISORS	PARTNER
Degree of direct involvement in research	Less Direct		
Inclusive of a diverse			
range of life experiences	More Inclusive		
Potential for			
stigmatization of input	Greater Potentia	ι	
Difficulty of systemic			
implementation	Less Difficult		
Personal and professional risk associated with self-			
disclosure		Les	ser Risk? Gre

dback es of tudy

/chosis nope o curate

PARTNERS

Partners can guide inquiry, do advocacy work, cultivate connections to community, and provide trainings to clinicians. At the state and national level. partners may help develop resources such as white papers position papers, and policy models.

Maine Health's Peer Services Department provided council of research into barriers to the efficacy of Peer Support Services

Potential future partners include the Consumer Council of Maine and the Wildflower Alliance of Western Massachusetts.

RESEARCH STAFF

With more influence over the direction that research takes, staff are in a position to lead by example by owning their own lived experience, holding space for a wide range of voices, shaping office and lab culture, and securing funding for projects that center lived experience.

Between 45-75 percent percent of mental health professionals have lived experience,⁴ but there is a perception, particularly within psychiatry, that disclosure could compromise neutrality or erode trust.³ We have found, by contrast, that speaking openly about our mental health experiences cultivates an environment of mutuality and increased trust, in which our work's intersection with and impact on those with lived experience is at the forefront.

	RESEARCH STAFF					
S	INTERNS	RAs ad RCs	PIs and Collaborators			
			More Direct			
			Less inclusive			
			Lesser Potential			
			More Difficult			
eater Risk? Depends on who you ask.						

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.

