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## MaineHealth Knowledge Connection

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Costas T. Lambrew Research Retreat 2023

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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.

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

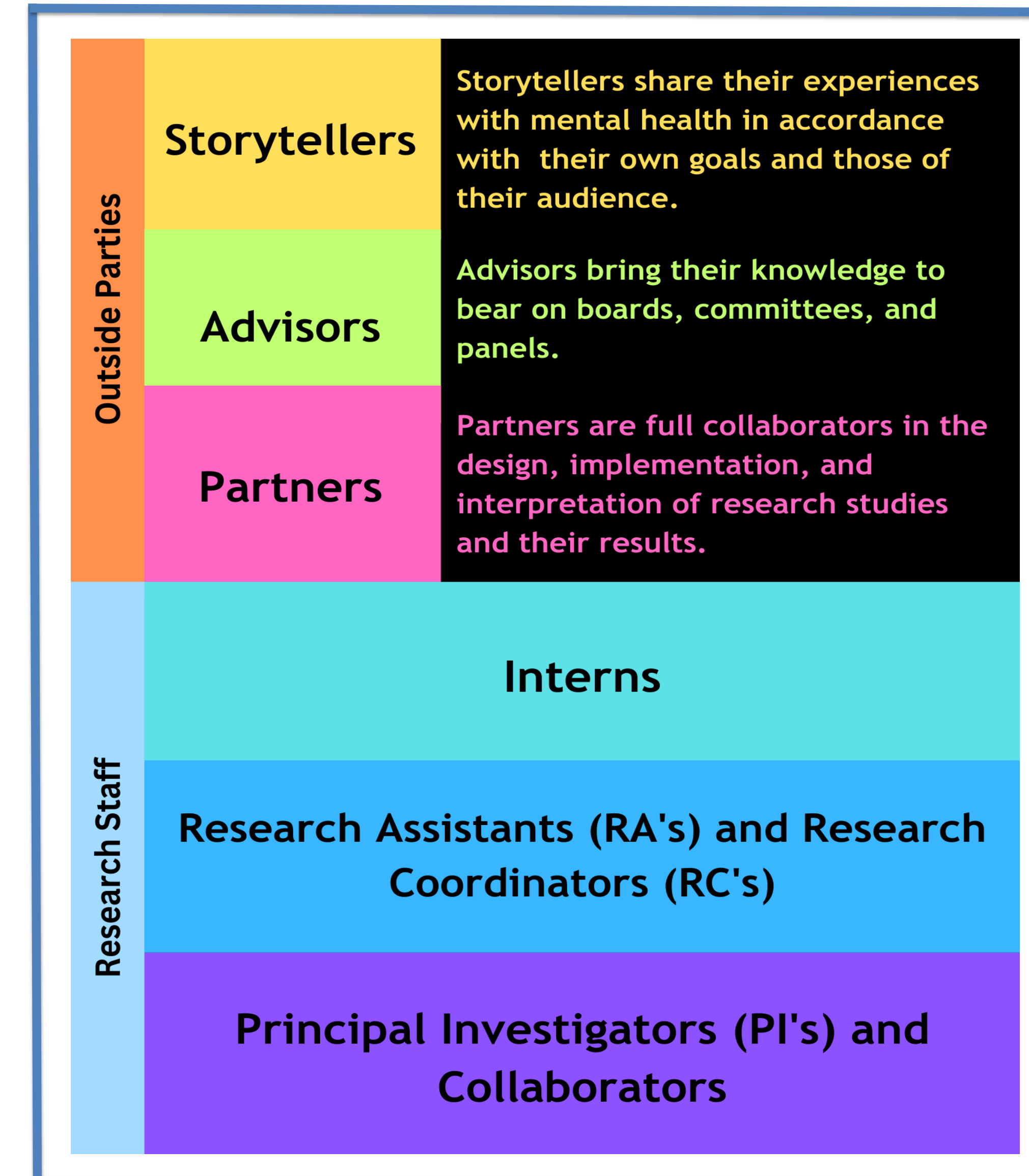


Fig.2 Considerations for Effective Implementation: Our Opinions

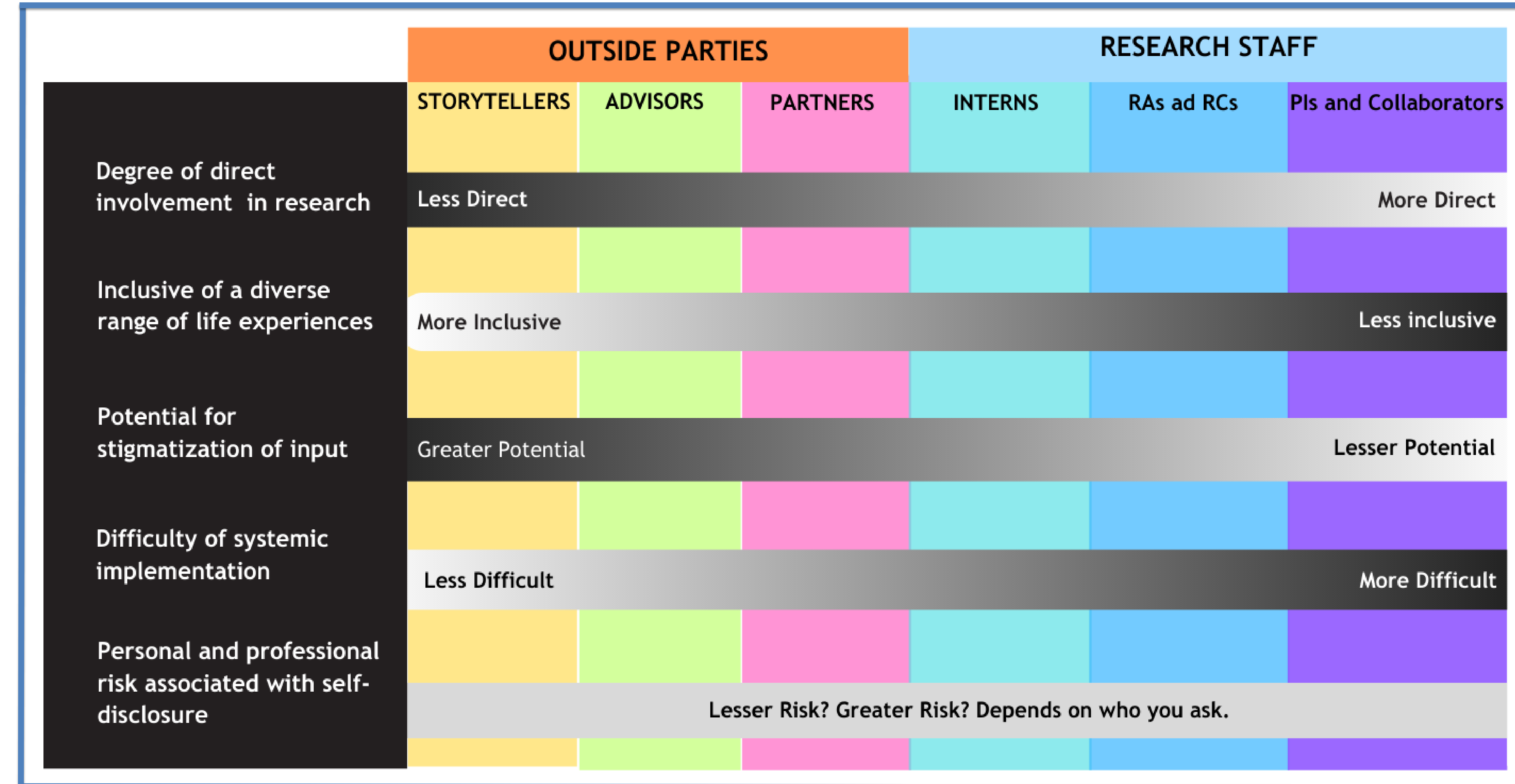


Fig.3 Inclusion Strategies and Examples

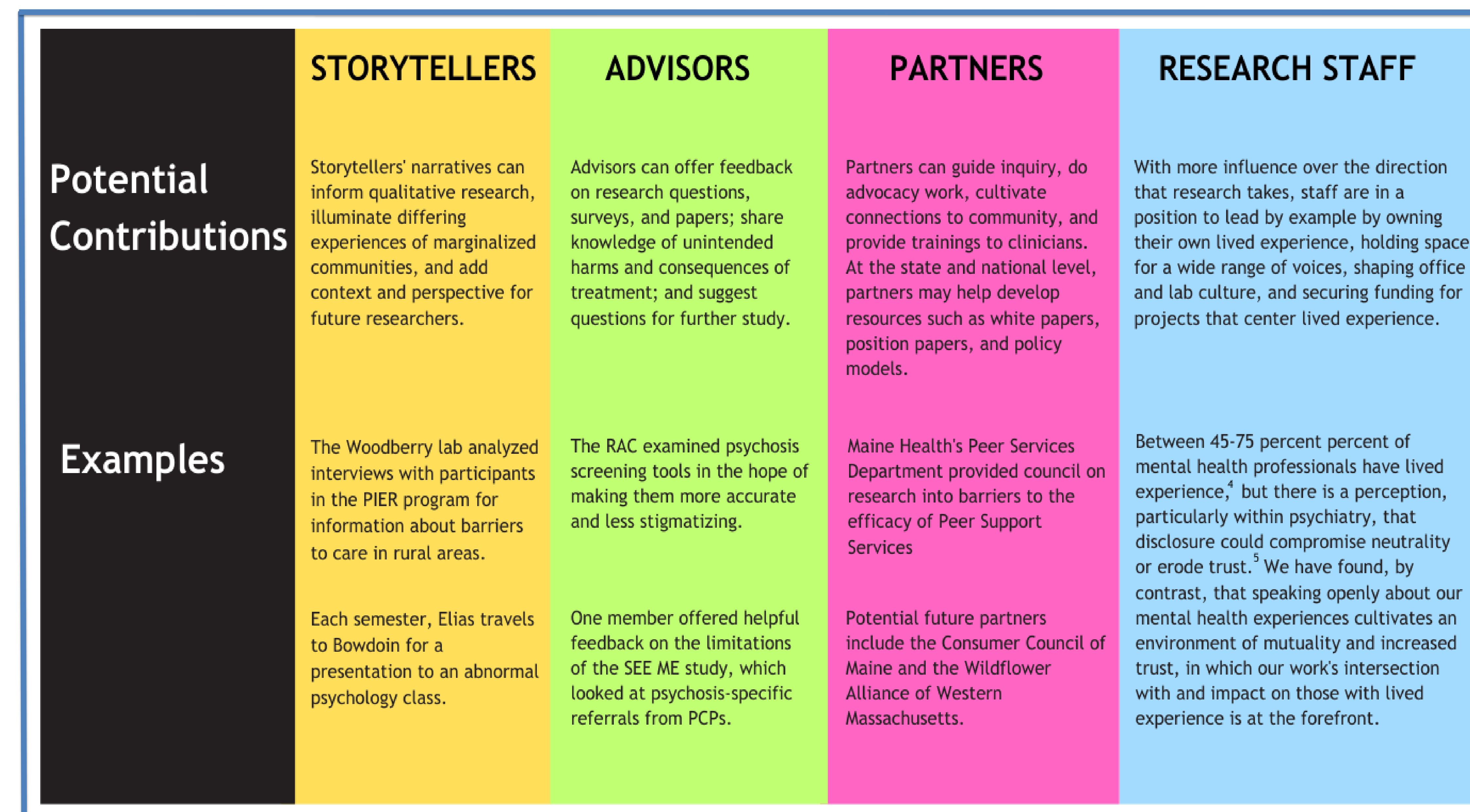
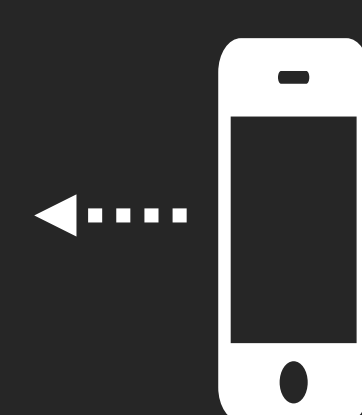
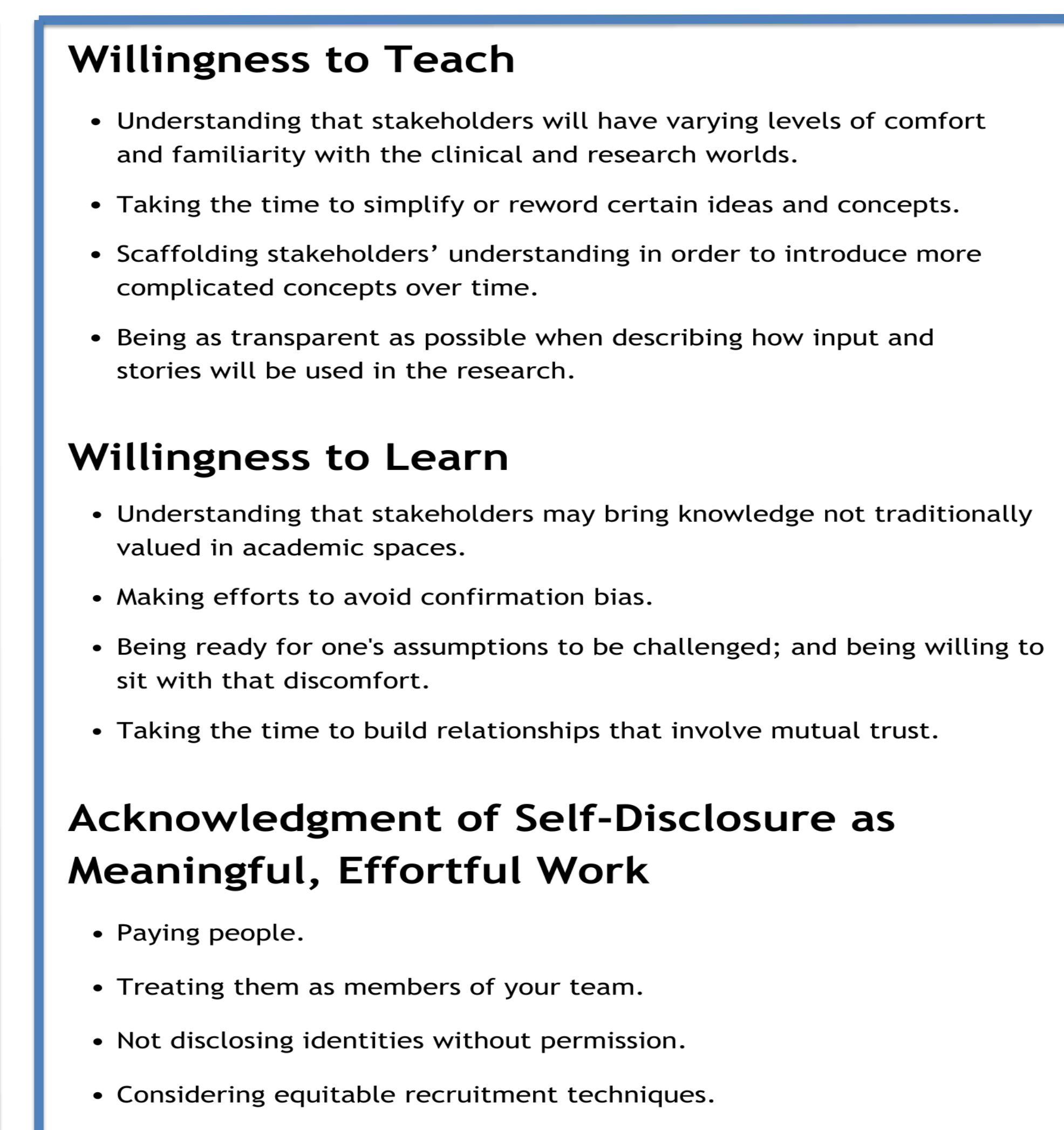


Fig.4 What Does it Really Look Like?



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