

Lessons learned to advance person-centered outcomes research and virtual engagement with underrepresented populations: Engaging adults with serious mental illness

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Background

- **People with serious mental illness** (SMI: bipolar disorder, schizophrenia, and major depression), especially those who are older adults, Latino/a, or in congregate housing:
 - **Face barriers** to participating in research and are often excluded from clinical trials¹
 - **Die 15-30 years earlier** than the general population²⁻⁴
 - Experience higher rates of **cancer mortality** than the general population²⁻⁴
 - Have **higher rates of COVID-19** infection and are at greater risk for adverse outcomes¹⁰
- **Telehealth:**
 - Has **the potential to promote access** to care for underserved populations⁵
 - Has become **widespread** during the pandemic⁶
 - Poses unique challenges to people with serious mental illness (especially for those who are older adults, Latino/a, or in congregate housing) who encounter structural **obstacles accessing telehealth**⁷
 - May **widen health inequities** without targeted outreach to marginalized populations⁸

Specific Aims

- Produce **stakeholder-generated interventions** that can be adapted for underserved populations
- Elucidate **barriers/facilitators** to telehealth
- **Build capacity** for person-centered outcomes research
- **Generate strategies** to increase access to research and telehealth

Methods

- To **amplify stakeholder's voices**, researchers:
 - Conducted recorded semi-structured qualitative **key informant interviews** and **listening sessions**
 - Engaged **60** diverse stakeholders in **2 months**
 - **Coded transcripts** with Rapid and Rigorous Qualitative Data Analysis (RaDaR)
- To generate stakeholder-recommended strategies to **advance equity** in telehealth researchers:
 - Formed a **Community of Practice (CoP)**, defined as a: 1) **community** of people (e.g., people with a history of SMI, older adults, Latino/a adults, clinicians, caregivers, researchers, advocates), who 2) share a **domain** (e.g., a shared passion for advancing health equity for people with serious mental illness), and 3) engage in **practice** to advance their shared mission and learn together (e.g., building capacity for person-centered outcomes research and generating strategies to increase access to research and telehealth)⁹
 - Convened **10 CoP virtual sessions** with diverse stakeholders
 - Utilized **community-based participatory research** principles
- To evaluate **acceptability:**
 - Organizers assessed CoP members **experiences of partnership**

Results

Figure 1. RaDaR-Coded Interview and Listening Session Key Themes



Figure 2. CoP-Recommended Strategies to Advance Equity in Telehealth

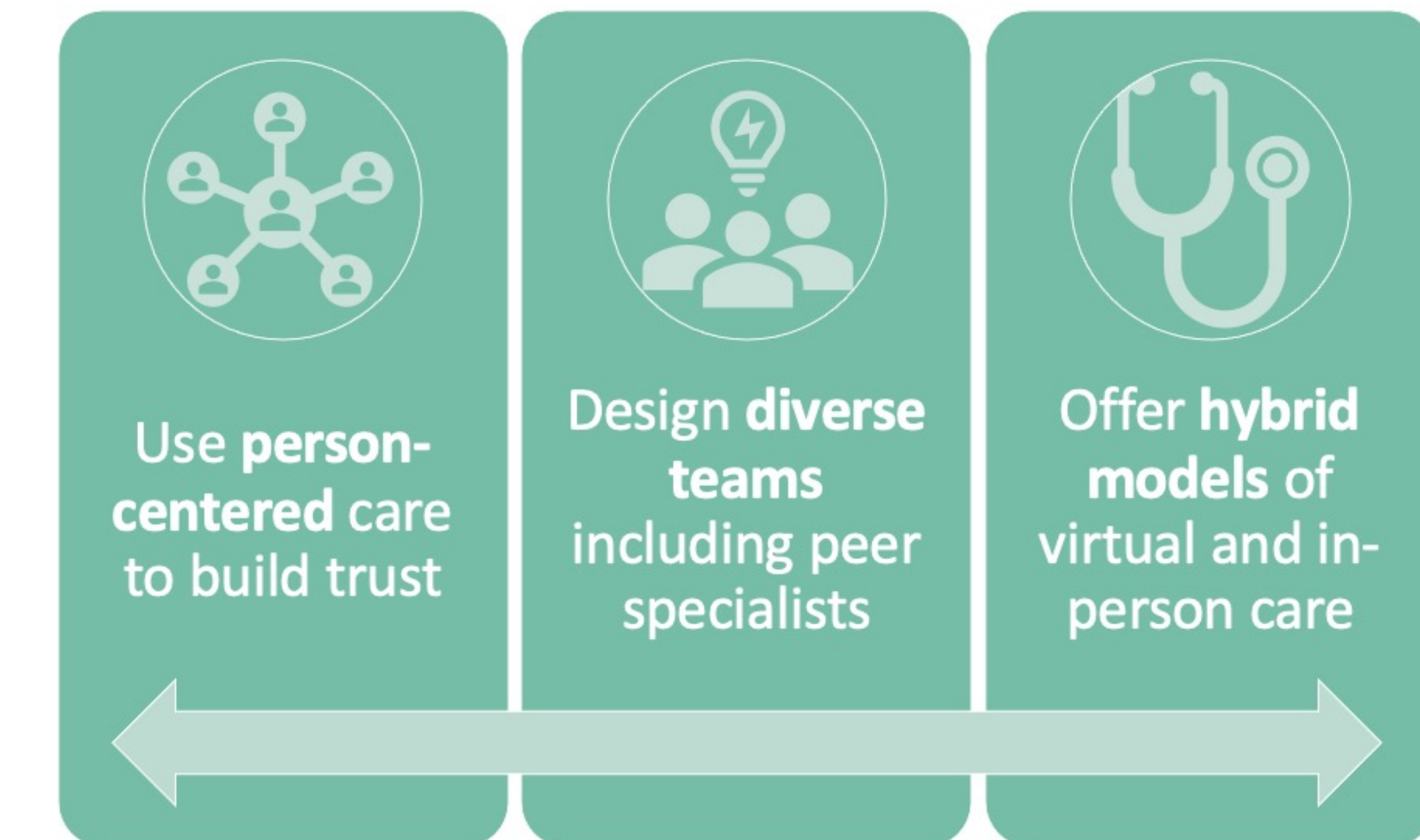


Figure 3. CoP Members' Experiences of Research Partnership

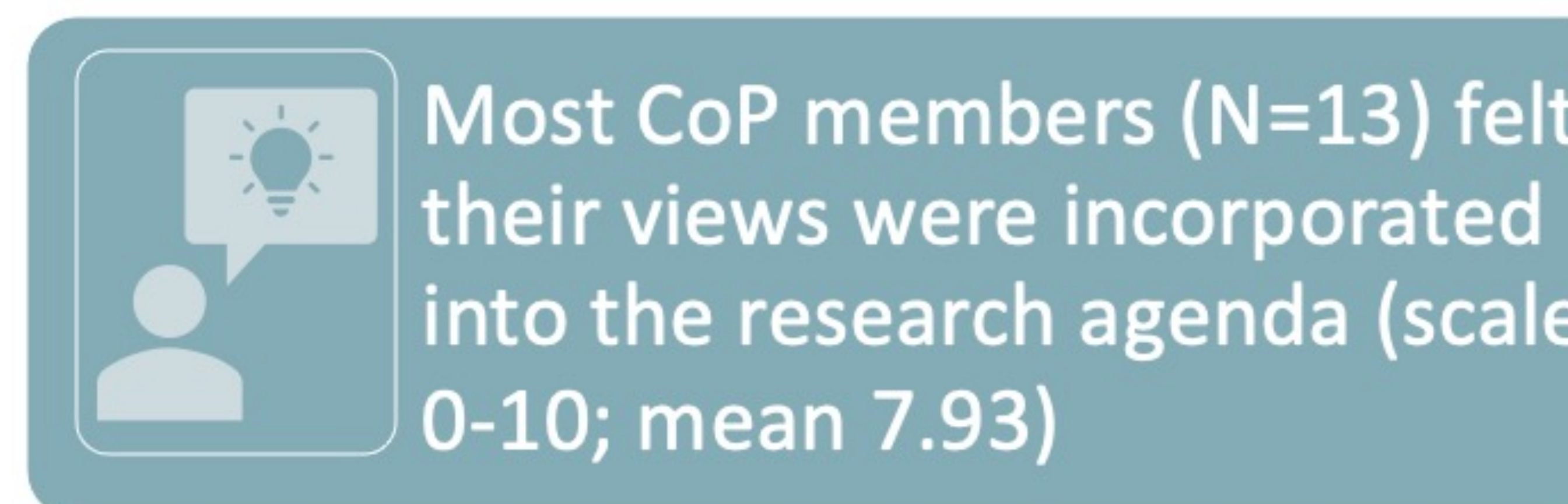


Figure 4. CoP Members' Desire to Stay Involved with the Group's Research



Conclusions

Person-centered approaches and co-design are promising approaches for stakeholder engagement to:

- Inform telehealth interventions** for adults with SMI
- Adapt approaches** with an equity lens

Citations

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