Eugene Washington PCORI Engagement Award Program

Engagement Awardee Lunch and Learn: Mental Health and COVID-19

August 9, 2021

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Agenda

Introduction

Awardee Presentations

- Tiffany Haynes, PhD, RN

  - University of Arkansas for Medical Sciences

- Kelly Irwin, MD, MPH

  - Massachusetts General Hospital

Q&A

Wrap-Up

Housekeeping

- This webinar is available to the public and is being recorded.

- The slides and webinar recording will be made available on PCORI's website following the webinar.

- Attendees are in listen-only mode.

- To learn more about the awardees presenting in this webinar and their Eugene Washington PCORI Engagement Award projects, click here: [Engagement Awardee Lunch and Learn: Mental Health and COVID-19](#)

Welcome
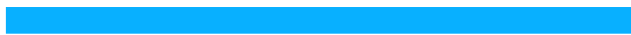
# Eugene Washington PCORI Engagement Award Program Background

- Support projects to build a community of patients and other stakeholders equipped to participate as partners in patient-centered outcomes research/comparative clinical effectiveness research (PCOR/CER), as well as serve as channels to disseminate PCORI-funded study results

- Funding for projects and conferences, NOT research

Develop Community Skilled in PCOR → **Engage Community in Research Processes** → **Involve Community in Dissemination**

Building a National Network for PCOR

- Approximately $124 million awarded since 2014, creating an expansive network of individuals, communities, and organizations interested in and able to participate in PCOR/CER
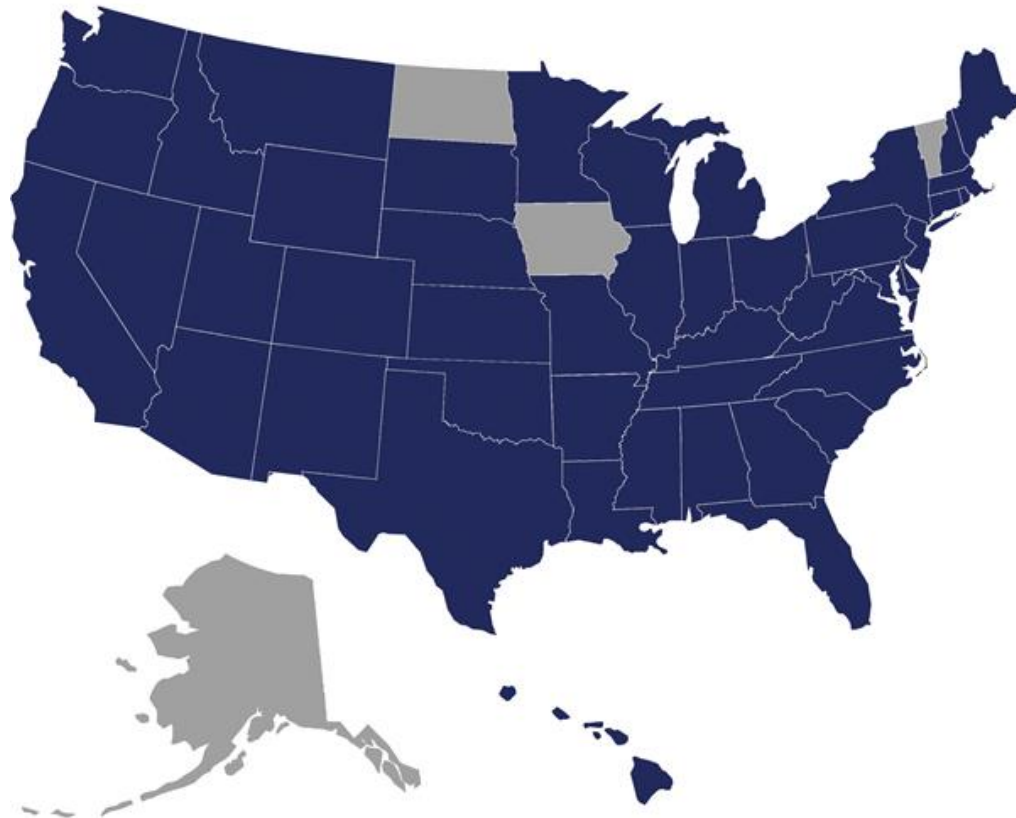
Learning Objectives

- Identify methods to build capacity for engaging populations at high risk of mental health disorders in PCOR/CER in the context of the COVID-19 pandemic

- Learn how to overcome COVID-19 challenges related to PCOR engagement

- Describe the impact of COVID-19 on the mental health of high-risk populations and older adults with serious mental illness

The Impact of COVID-19 on the Mental Health of High-Risk Populations

Engagement Award

Tiffany Haynes, PhD, Project Lead

University of Arkansas for Medical Sciences
Fay W. Boozman College of Public Health

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Acknowledgement and Disclaimer

Our Team

Community and Academic Team

- Tiffany Haynes, PhD- Project Lead

- Keneshia Bryant-Moore, PhD

- Nickolas Zaller, PhD

- George Pro, PhD

- Leta Anthony

- Khiela Holmes, PhD

- Ruby Welch

- Ellen Hutchins

COVID-19 and Mental Health

COVID-19 and Mental Health

During the pandemic, Americans reported increases in poor sleep, substance use, and eating changes.

- In 2019, **11%** of American adults reported symptoms of anxiety or depression

- In 2020, **41%** of American adults reported symptoms of anxiety or depression

Implications of COVID-19 for Mental Health and Substance Use KFF

https://www.kff.org/coronavirus-covid-19/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use

COVID-19 and Mental Health

- Everyone is experiencing stress related to COVID-19; however, some groups are more likely to experience psychological distress related to COVID-19

  - Individuals living with mental health conditions

  - Formerly incarcerated individuals

  - Frontline and essential workers

Project Objectives

1. Facilitate an inclusive dialogue with patients, healthcare providers, and other stakeholders to set and address research priorities related to the COVID-19 pandemic impact on the mental health of populations at greatest risk.

2. Disseminate project outcomes via the Addressing Mental Health Needs Related to COVID-19 Summit, local/national presentations, and publications.

3. Establish a COVID-19 Emotional Wellness Task Force to formalize a PCOR/CER research agenda

The long-term objective is to support those at greatest risk of experiencing a mental health crisis due to the pandemic and other public health crises.

Engagement in the Midst of COVID-19

Engagement Activities

1. **Research Generating Sessions**
   - Engaged individuals with lived experience
   - Identify common stressors associated with COVID-19 and practices that are helpful in reducing psychological distress associated with COVID-19
   - Identify next steps to address COVID-19 related psychological distress

2. **Stakeholder Sessions**
   - Engaged relevant stakeholders including healthcare providers, family members, activists, employers, employee support leaders, and state/local policy makers
   - Reviewed results of research generating sessions
   - Ranked priorities based on importance, feasibility, and acceptability

3. **Impact of COVID-19 on High-Risk Populations Symposium**
   - Engaged broader stakeholders
   - Developed research agenda

Engagement Activities
Opportunities and Challenges

Virtual Engagement

- Opportunities:
  - Ability to engage stakeholders from around the state
  - Provides scheduling flexibility

- Challenges:
  - Technological literacy
  - Sustained engagement via virtual platforms
  - Engaging populations without internet access

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Engagement Activities
Lessons Learned

- Virtual Engagement Challenges:
  - Technological Literacy
    - Provided lay-friendly Zoom guides
    - Provided one-on-one training with project staff

  - Sustained Engagement via virtual platforms
    - Provided reminder calls, texts, and emails
    - Provided intro orientation about what to expect
    - Encouraged use of cameras during sessions

  - Engaging populations without internet access
    - Allowed phone access to sessions

Priorities for Addressing Mental Health Needs in the Context of COVID-19

Research Generating Sessions

- Common impacts of COVID-19
  - Increased stress
  - Increased anxiety
  - Changes in mood and irritability
- Impacts for individuals living with mental health conditions
  - Worsening of symptoms
- Impacts for formerly incarcerated individuals
  - Concerns about COVID-19 spread within criminal justice settings
  - Policy barriers to re-entry for those recently released
  - Limited communication between family members and those currently incarcerated
- Impacts for frontline and essential workers
  - Anxiety about spreading COVID-19 to family
  - Longer hours without increased pay
  - Low morale

Stakeholder Sessions

Individuals Living with Mental Health Conditions

- **Recommendation 1**: <u>Raising awareness about mental health</u>

- **Recommendation 2**: Additional mental health services for low-income residents

- **Recommendation 3:** Integration of mental health services

- **Recommendation 4:** Addressing social stressors

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Formerly Incarcerated Individuals

- **Recommendation 1**: <u>Improving communication between individuals currently incarcerated and family members</u>

- **Recommendation 2**: Build a village: Increase community support for families with loved ones who are incarcerated and for individuals trying to re-enter their community

- **Recommendation 3:** Provide more mental health services within correctional settings

Stakeholder Sessions

Frontline and Essential Workers

- **Recommendation 1**: Raising awareness about mental health among employers

- **Recommendation 2**: Additional mental health services

- **Recommendation 3:** Create a supportive work environment

The Impact of COVID-19 on the Mental Health of Special Populations Symposium
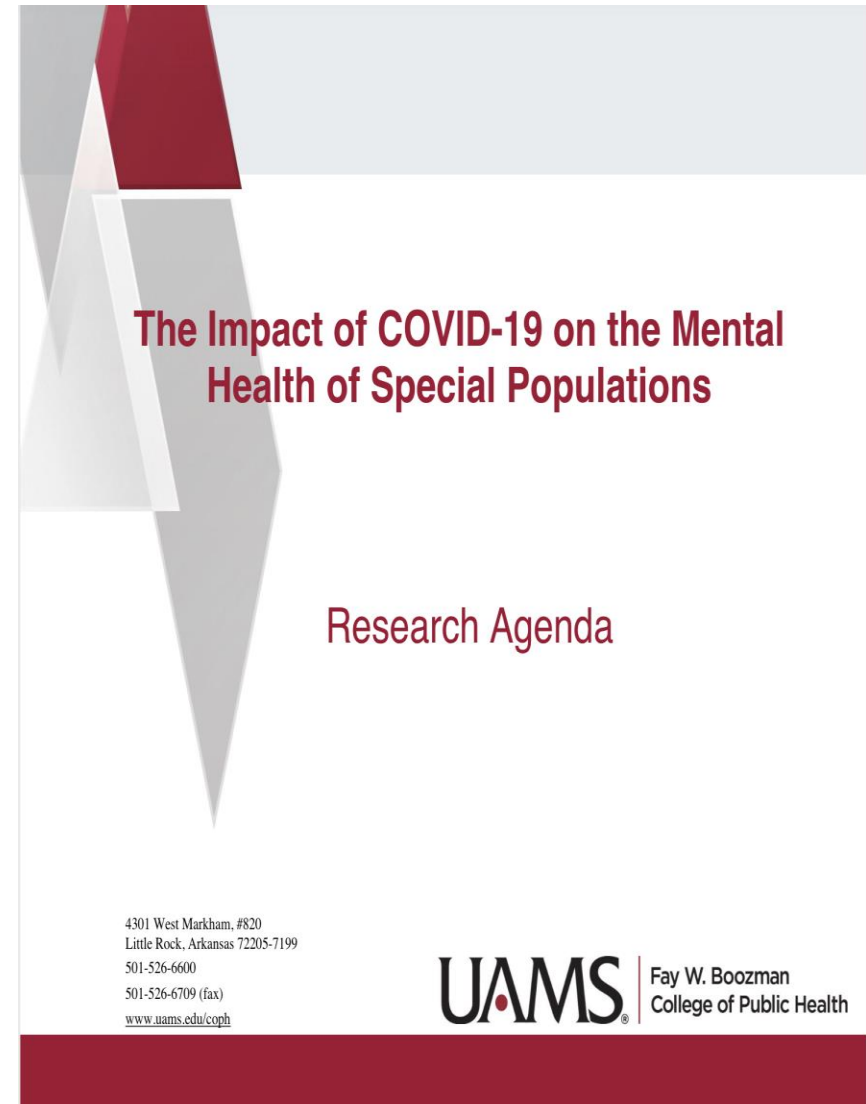
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Virtual Symposium

- One-day symposium

- Disseminate results of research generating sessions and stakeholder sessions

- Breakout sessions to generate discussions on research agenda

- Opportunities to remain engaged in the conversation

Next Steps

Next Steps

Research Agenda

- **Effective Programs/Strategies**
  - Which programs are most effective in building resilience or improving emotional wellness?
  - Which strategies are most effective in decreasing stigma and raising mental health awareness?

- **Effective Implementation Strategies**
  - Which strategies are best for increasing intervention uptake?

- **Promising Policy Options**
  - What policies are most effective in to support emotional wellness?

The Impact of COVID-19 on the Mental Health of Special Populations

Research Agenda

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Next Steps

Emotional Wellness Task Force

- **Sustained Stakeholder Engagement**
  - Quarterly Meetings
  - Email Newsletter

- **Implementing Research Agenda**
  - Moving from recommendations to action

Contact Information

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Acknowledgement and Disclaimer

- This project was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award MGH EAIN-00130.

- The statements presented in this presentation are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.

During the pandemic, we have witnessed escalating mental health needs, gaps in care, and sometimes feel helpless

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Resident of skilled nursing: "I see more bodies coming in than going out. It's just a matter of time."

Older adult: "I'm scared to go to the hospital, and I'm scared to stay home."

Social worker: "I'm always on alert. I worry about my patients dying alone. I worry that my patients with mental illness are falling through the cracks. I worry about my family's safety."

Navigator: "Not everyone has a smartphone. Or a consistent phone number. Or a family member."

Caregiver: "People get lonely in group homes, too."

Psychiatrist: "I worry about the people we can't reach. I feel like a failure all the time."

CALL TO ACTION:

Who Aren't We Reaching?

Impact of Systemic Racism and Mental Health Discrimination

What Changes Can Be Sustained?

The Need

Multi-level challenges experienced by patients, caregivers, clinicians, and administrators at the intersection of serious mental illness and cancer

Lessons Learned

Strategies to promote research participation and engagement in care during the pandemic

Call to Action

Research gaps, inadequate clinical services, need for structural and systems-level change

Who aren't we reaching?
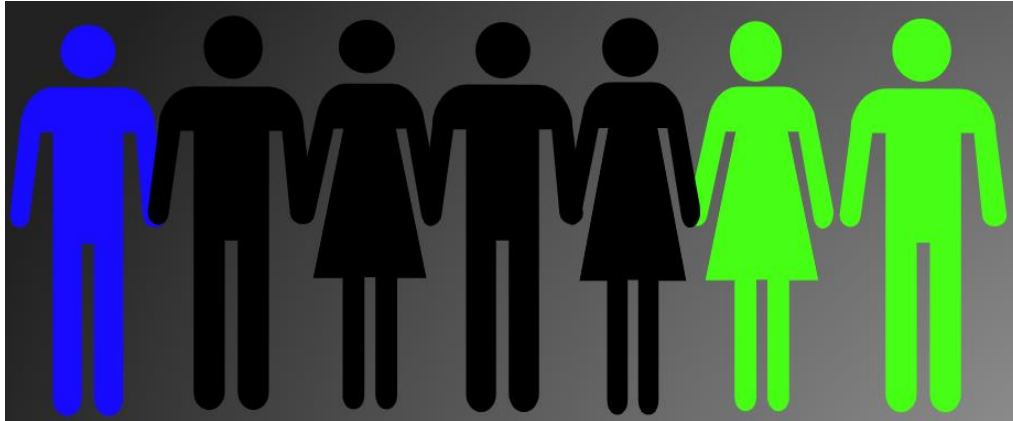
1 in 7: No consistent phone

4 in 7: Phone only

2 in 7: Can access virtual visit

Isolation: Decreased in-home services and caregiver support

Under-resourced, hard-hit settings: Skilled nursing, mental health system, shelter, prison

Compounded inequities: Poverty, health literacy, immigration status, language, racism, discrimination due to mental illness

Many individuals with serious mental illness lack access to default strategies to access virtual care

Patient Portal (MyChart) Status by Serious Mental Illness Diagnosis

Major Depressive Disorder — Active N: 12,852/21,420

Bipolar Disorder — Active N: 940/1,852

Schizophrenia Spectrum — Active N: 1,372/4,092

Legend: Active, Inactive
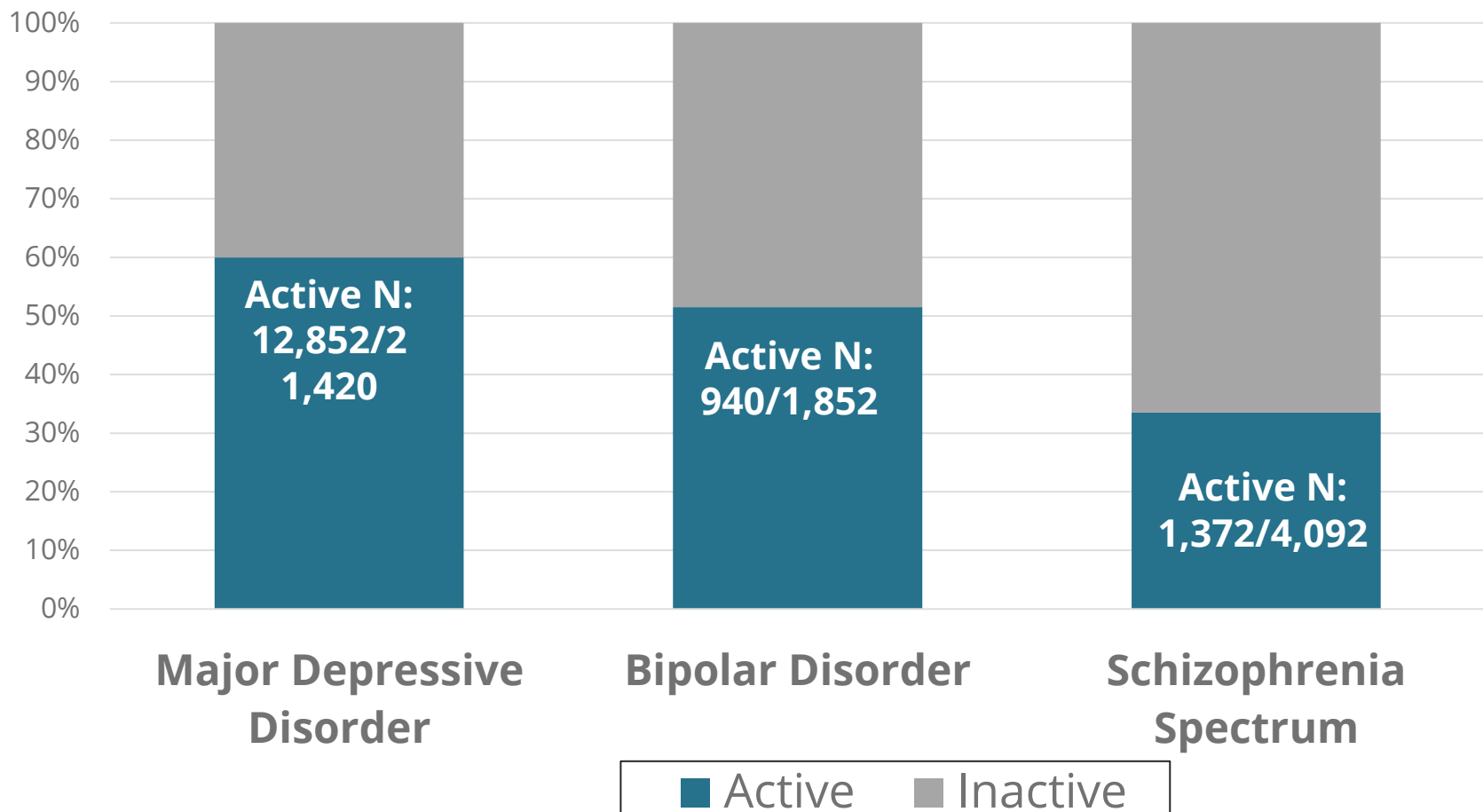
We apply a population-based, person-centered, team-based approach to clinical care, research design, and coalition building

Clinical Model: Proactive identification, person-centered, team-based care

Research: Adapting trial procedures to ensure access to research during the pandemic, extending reach to Latino/as, older adults, and individuals in congregate settings guided by our stakeholder board

Education, advocacy, and community partnership: The Engage Initiative

How do we meet people where they are during the pandemic?

What was lost?

- Home and community-based visits
- Seeing patients in person in the clinic or hospital to consent to trials
- Caregiver accompaniment to visits

What was gained?

- More comfort asking why not, decreased regulatory barriers
- Increased access to telehealth, decreased geographic barriers

Key questions:

- How do we build trust?
- Can this research trial continue?
- How do we reach our population? And keep them engaged?
- How do we partner with overburdened clinicians?
- When is in-person care necessary?

Project Overview

Aim 1
- Identify barriers and facilitators to engagement and technology use

Aim 2
- Build capacity to conduct PCOR that can be adapted to other populations

Aim 3
- Capture emerging research questions
- Create a shared agenda for PCOR
- Developing & disseminate a virtual engagement toolkit

Aim 1: Identify barriers and facilitators to engagement and technology use

Listening Sessions and Key Informant Interviews

- Older adults

- Peer specialists

- Spanish language session

Engage partners early and often to recruit diverse participants

- Small group virtual format

- Spanish language session

Aim 1: Identifying barriers and facilitators to engagement and technology use

Key Barriers

- Access to technology: Network and device
- Comfort with/knowledge of technology
- Stigma about mental health services and not knowing how to use new technologies
- Lack of trust
- Challenge of privacy and worry about documentation status

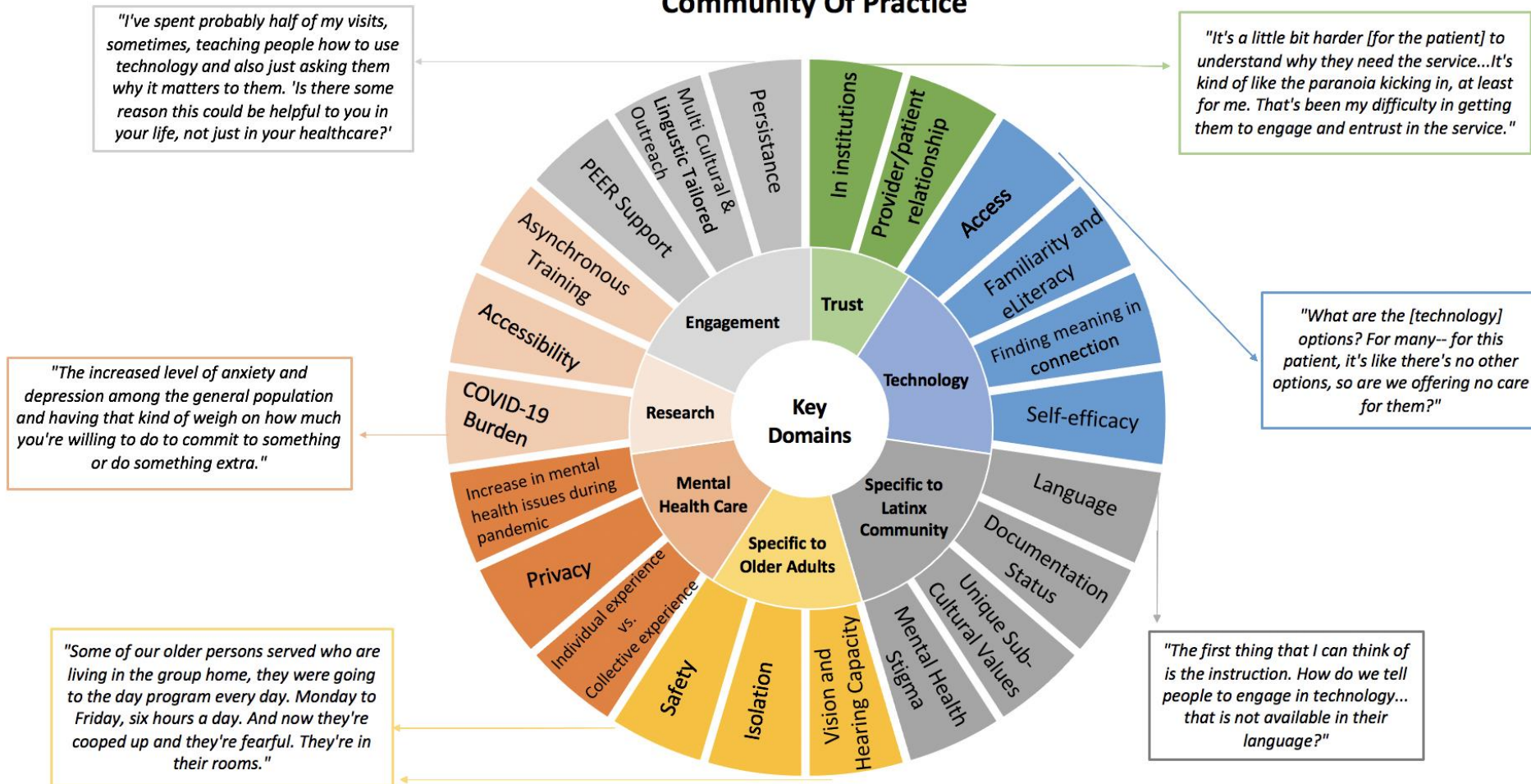# Aim 1: Identifying barriers and facilitators to engagement and technology use

Key Facilitators

- Flexibility and creative thinking
  - Ask about preferences
  - Call for hybrid models

- Use of digital navigators, peer specialists, and community health workers to build trust and capacity to access and use technology

- Untapped community resources and call to bridge clinical care settings and community

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Community Of Practice

"I've spent probably half of my visits, sometimes, teaching people how to use technology and also just asking them why it matters to them. 'Is there some reason this could be helpful to you in your life, not just in your healthcare?'"

"It's a little bit harder [for the patient] to understand why they need the service...It's kind of like the paranoia kicking in, at least for me. That's been my difficulty in getting them to engage and entrust in the service."

"The increased level of anxiety and depression among the general population and having that kind of weigh on how much you're willing to do to commit to something or do something extra."

"What are the [technology] options? For many-- for this patient, it's like there's no other options, so are we offering no care for them?"

"Some of our older persons served who are living in the group home, they were going to the day program every day. Monday to Friday, six hours a day. And now they're cooped up and they're fearful. They're in their rooms."

"The first thing that I can think of is the instruction. How do we tell people to engage in technology... that is not available in their language?"

Wheel labels: Community Of Practice — Persistance, In institutions, Provider/patient relationship, Access, Familiarity and eLiteracy, Finding meaning in connection, Self-efficacy, Language, Documentation Status, Unique Sub-Cultural Values, Mental Health Stigma, Vision and Hearing Capacity, Isolation, Safety, Individual experience vs. Collective experience, Privacy, Increase in mental health issues during pandemic, COVID-19 Burden, Accessibility, Asynchronous Training, PEER Support, Multi Cultural & Lingustic Tailored Outreach, Trust, Engagement, Research, Mental Health Care, Specific to Older Adults, Specific to Latinx Community, Technology, Key Domains

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What is a Community of Practice?

"A group of people who share a passion about something they do and get better at it by doing it together." [1]
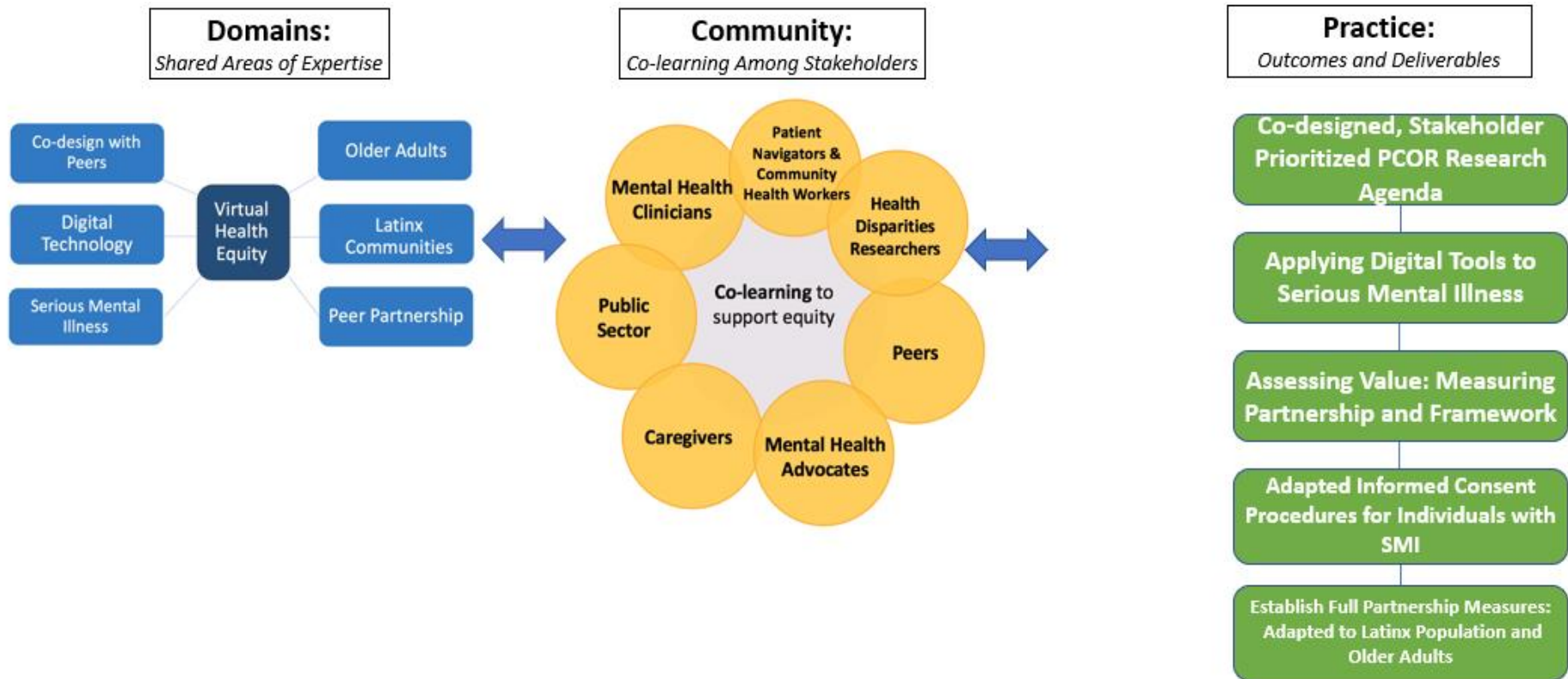
1. **Domain — What do we care about?**
2. **Community — Who are we?**
3. **Practice — What we do together to advance our shared mission?**

1. Wenger, Etienne, McDermott, Richard, Snyder, William M. Cultivating Communities of Practice. Harvard Business School Press. Boston, MA. 2002.

Aim 2: Building capacity to conduct PCOR that can be adapted to other populations

We established a Community of Practice to Advance Health Equity for Older Adults with Serious Mental Illness during COVID-19

Domains:
Shared Areas of Expertise

- Co-design with Peers
- Digital Technology
- Serious Mental Illness
- Virtual Health Equity
- Older Adults
- Latinx Communities
- Peer Partnership

Community:
Co-learning Among Stakeholders

Co-learning to support equity

- Mental Health Clinicians
- Patient Navigators & Community Health Workers
- Health Disparities Researchers
- Peers
- Mental Health Advocates
- Caregivers
- Public Sector

Practice:
Outcomes and Deliverables

- Co-designed, Stakeholder Prioritized PCOR Research Agenda
- Applying Digital Tools to Serious Mental Illness
- Assessing Value: Measuring Partnership and Framework
- Adapted Informed Consent Procedures for Individuals with SMI
- Establish Full Partnership Measures: Adapted to Latinx Population and Older Adults

Working Summit
Increasing Engagement and Access to Virtual Care and Research for Older Adults with Serious Mental Illness

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1. **Building Partnerships with Latino/a Communities (Conducted in Spanish)**
   - Co-Leaders: Danny Jimenez, Gaby Cabezas

2. **Improving Access to Mental Health Care**
   - Co-Leaders: Ben Macri, Celeste Peay

3. **Developing Trust & Engagement**
   - Co-Leaders: Amy Corveleyn, Shukriyah Brown

4. **Partnering Creatively with Older Adults**
   - Co-Leaders: Ruthanne Switzer, Diana Hanan

5. **Increasing Reach & Sustainability of Virtual Care & Digital Tools**
   - Co-Leaders: Robert Walker, Karen Fortuna

Thank you for joining us and sharing your perspective:

What frustrates you most?

What has worked well?

Going forward, what matters most?

What two action steps do you recommend?

What do we need to find out together?

Who isn't in the room?

Take home lessons for engagement in care and research

- Address patient and caregiver priorities first

- Assess access to technology and preferences for use and offer multiple modalities

- Build capacity to use technology and develop strategies to sustain the workforce needed

- Start with the why: Underscore need to learn together to develop new solutions to problems that matter to community members

- Build teams: Call for creative persistence and coalition building

"There's really no such thing as the 'voiceless.' There are only the deliberately silenced, or the preferably unheard." – Arundhati Roy, 2005

ENGAGE
TOGETHER WE WILL ENSURE THAT MENTAL HEALTH IS NEVER A BARRIER TO CANCER CARE

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Engage Initiative

Q&A and Wrap-Up

- Feel free to ask questions by typing into the Questions pane on the Control Panel.

- Recording and slides will be posted on the event page after the webinar.

Contact Information

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Thank You!