

FINAL SESSION: WRAP-UP & NEXT STEPS

June 23rd, 2021

***Nothing about us without us:
Building patient-centered research capacity in a
consortium of LGBTQIA+ health centers***

Patient Centered Outcomes Research Institute (PCORI)
Community Engagement Convening Project



LONG-TERM OBJECTIVES

1. Creation of a **strategic plan and vision** for equity-driven research integration, implementation, and dissemination both within and across health centers.
2. Development of an **action plan** designed to enhance research infrastructure CHC collaborative partners by drawing on each partner's strengths.
3. Identification of **strategies to enhance capacity** for research at the organizational and health systems levels designed to: a) improve care; b) ensure sustainability; and c) increase representation of LGBTQIA+ identified researchers.

OVERALL GOAL FOR WRAP-UP

The primary objective is to **report back** some ideas, themes, & action steps that have emerged over the past week together, and to **explain** the next steps post-convening.

WRAP-UP & NEXT STEPS

1. Present some bullets on information that emerged during each session.
2. Discuss next steps for post-convening.
3. Share something that you will take away from the convening and/or some hope for our future collaboration.

SESSION 1: Shared Research Priorities

- **Mental Health, LGBTQIA+ Competence in Healthcare, & Best Practices in Gender-Affirming Healthcare** were ranked as your **Top 3** research priorities.
- Research should focus on the **whole person** by **identifying factors** that contribute to **overall health & wellness**, rather than treatment.
- Research should focus on **solutions to & strategies** that **address** and **mitigate access** to care issues, not continue to document disparities.
- Research must **define & operationalize LGBTQIA+ competence & gender-affirming care** before we can create and test best practices.

SESSION 2: Building Research Capacity

- **Top 3 goals:** 1) increasing health center's capacity to generate research that "solves problems", 2) enhancing the ability to generate "home-grown" research studies; 3) improving integration of research into clinical care.
- Research must be non-coercive, inclusive of patients, providers, & researchers, and enhance both patients lives and the care given.
- Identify & enact shared collective power to demand/advocate for, develop, conduct, and disseminate meaningful, patient-centered/driven research.

SESSION 2: Building Research Capacity

- What is needed to begin accomplish these goals:
 - Identify models for research integration & creating actions steps for beginning this process.
 - Creating a collective partnership between health centers to share resources and support.
 - Developing overall mission & rationale for why an integrated research program is important and what it will contribute to both your organizational goals & the community.
 - Setting shared standards for research collaboration both within and across each health center.

SESSION 3: Increasing LGBTQIA+ Inclusion & Engagement

- Making Research Inclusive & Non-stigmatizing
 - Inclusion of community at all stages in the process.
 - Creating an 'elements of style' guide to improve overall language used in recruitment materials, study protocols, consent forms, surveys, interview guides.
 - Developing a cohort study that enabled people to connect with one another at different stages of the trans journey.

SESSION 3: Increasing LGBTQIA+ Inclusion

- **Actively Providing Ongoing Clear Communication about Study Purpose, Design, and Potential Impact.**
 - Open engagement session for patients to hear about research underway, in planning, completed. Complete with compensation and meals.
 - Creating research champions within the health center to bridge the gap between patients, providers & researchers.

SESSION 3: Increasing LGBTQIA+ Inclusion

- **Ensuring That The People Doing Research Are Members Of The LGBTQIA+ Community.**
 - Valuing lived experience over academic qualifications for job roles.
 - Actively reviewing hiring and training practices to ensure that they are equitable and do not include unnecessary requirements for hiring & that job responsibilities and support set people up for success.
 - Creating co-lead research investigator positions Shared role and expertise between community & researchers.
 - Even if researchers are LGBTQIA+ identified – ensuring that the research is responsive and includes the community the study is about.

Patient Only Session

- Patients have untapped power and experience navigating a fractured health care system and getting services that everyone needs more information on.
- Research generates information that is useful and allows patients to have control over their healthcare and health decision-making.
- What is the point of community advisory boards if patients do not have any equal say or power to make change.
- Need to create opportunities to broaden patient impact – for example, create research advisory committee where patients review research study ideas and proposals before they are implemented.

SHORT-TERM NEXT STEPS

1. Produce a written report based on each convening session & discussion; including a sustainability plan with actions steps toward accomplishing the identified agenda.
2. Identify a team of folks to review & provide feedback on report.
3. Send out convening evaluation.
4. Send contact information list out to begin to form connections & develop collaborative working groups.
5. Organize & facilitate a virtual town hall to happen in August to disseminate content from the convening and solicit additional stakeholder engagement in next steps.

PARTING THOUGHTS

What is something that you will take away from the convening and/or some hope for our collaboration in the future.

THANK YOU