SESSION #1

IDENTIFYING SHARED RESEARCH PRIORITIES
among health centers and stakeholder groups

June 21st 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

REMINDER OF CONVENING NORMS (IN A ZOOM REALITY)

1. **Please start your video and mute your audio**. For a good conversation, we want your presence, but not your background noise ☺.

2. Please make sure that you **Zoom name** is what you want to be called, and includes your **pronouns**. Also include your health center!

3. **Use the hand-raise feature (located in the participant bar) if you'd like to speak.** The facilitator can see the order in which people have raised hands, and will call on you accordingly.

4. **Use the comment bar for quick clarifications or questions**. Other participants can help clarify for you, without breaking the flow of the conversation.
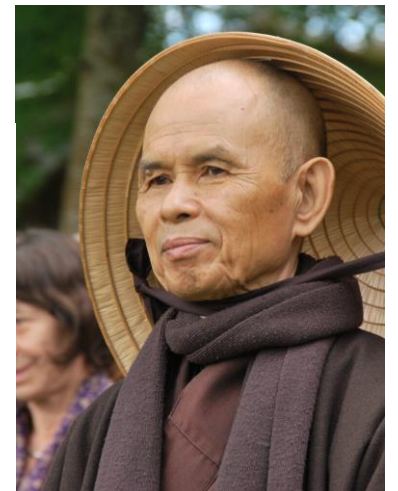
CONVENING NORMS (IN A ZOOM REALITY)

5. **Please be aware of dynamics in your own participation style that might limit the participation of others.** Think about when to "step forward" and when to "step back." Our goal is to make space for many voices and perspectives and ensure that participation is as equitable as possible.

6. **Consider hiding your self-view.**

7. **Try releasing yourself from the need to multi-task.**

Live in the actual moment.

Only this actual moment is life.

-- Thích Nhất Hạnh

OVERALL GOAL FOR SESSION #1

The primary objective of this session is to build consensus on **high-priority research topics** that can acts as a strategic "blueprint" for developing short-term and long-term collaborative research projects.

SESSION #1 OBJECTIVES

1. Review information from listening sessions about the **research priorities and research goals** elicited from different stakeholder groups

2. Discuss six **potential high-priority research topics** for future shared work to advance and support patient-centered LGBTQIA+ health equity

3. **Build consensus** on the 2 or 3 highest priority research topics for future collaborative efforts.

4. Identify 1 or 2 **specific action steps** that would help us move forward in each priority area in the short- and long-term

WHAT IS PATIENT-CENTERED OUTCOMES RESEARCH (PCOR)?

- PCOR refocuses research on the things that **matter most to patients**

- Stakeholders partner with researchers at **every stage** of the research process

- Research results have a **direct real-world impact** on how patients and those who care for them make decisions about their healthcare.

HOW IS PCOR DIFFERENT FROM "TRADITIONAL" HEALTHCARE RESEARCH?

- Based on the premise that healthcare research requires an **active partnership** with the people who will be using the findings to make decisions.

- Active stakeholder partnership allows for research to be driven by **questions that are important to patients, caregivers, clinicians, and healthcare administrators.**

- Research findings represent **useful and trustworthy information th**at help patients, families, clinicians, and healthcare administrators make key healthcare decisions that impact the way healthcare is provided and utilized.

WHAT DOES IT MEAN FOR RESEARCH TO FOCUS ON HEALTH EQUITY?

- Health equity research goes beyond merely "documenting" disparities to:
    a) identify mechanisms that perpetuate inequity; and
    b) develop strategies to overcome inequity.

- Health equity research considers the impact of interventions, programs, and policies on equitable access. It doesn't matter if a new intervention "works" if it won't be accessible to all patients, especially the most under-served.

GOALS OF RESEARCH AT LGBTQIA+ HEALTH CENTERS

Research Goals	% rating this goal in the top 5
1. Provide evidence for **best clinical practice** in LGBTQ health	52%
2. Help health center **advocate** for better health care policies and practice for LGBTQ communities	41%
3. **Evaluate the effectiveness** of health center's services to increase positive health outcomes for patients	37%
4. Address the **health issues** that matter most to our patients	35%
5. Identify **gaps** in services at health center	28%

TOP TEN HEALTH CONCERNS FOR PATIENTS (N=250)

	% rated as **very important**	% rated as very important or important
1. Access to LGBTQ competent provider	71%	93%
2. Access to health insurance	68%	89%
3. Mental Health (Depression, anxiety, suicide)	62%	94%
4. Access to gender-affirming hormones and/or surgery	50%	63%
5. Fitness & nutrition	46%	96%
6. Sexual health (incl. STI's, HIV)	42%	82%
7. Cardiovascular health	35%	86%
8. Violence &/or harassment	34%	78%
9. Cancer	32%	82%
10. Reproductive health &/or Family planning	28%	67%

MOST IMPORTANT RESEARCH TOPICS -- PATIENTS AND STAFF

Research Topics	% rated in Top 3	
	Patients (n = 250)	Staff (n = 105
1. Mental Health (Depression, anxiety, suicide)	47%	1 (44%)
2. Access to LGBTQ competent provider	36%	3 (31%)
3. Access to gender-affirming hormones and/or surgery	34%	2 (38%)
4. Access to health insurance	26%	6 (14%)
5. Health impacts of discrimination	23%	6 (14%)
6. Cardiovascular health	22%	6 (14%)
7. Fitness & nutrition	18%	7 (5%)
8. Sexual health (e.g., STI's, HIV)	18%	5 (24%)
9. Substance use (alcohol & drugs)	16%	4 (30%)

POTENTIAL HIGH PRIORITY RESEARCH TOPICS

1. Mental Health (and mind-body connection)

2. Access to/definition of/health impacts of LGBTQIA+ competence in health care

3. Best practices in gender-affirming health care

4. Access to health insurance

5. Health impacts of discrimination

6. Weight/body image/fitness and nutrition (with a connection to cardiovascular health)

TENSIONS/QUESTIONS FOR RESEARCH PRIORITIES

- How do communities better understand and communicate about what is already known (about competent care, about the negative effects of discrimination) and do meaningful work without re-inventing the wheel?

- How do we evaluate whether existing guidelines for LGBTQIA+ competence are sufficiently "evidence-based" or research driven?

- What is the goal of research on trauma and discrimination beyond documenting negative effects? How will these data be used? How can we conduct research without re-stigmatizing individuals?

- How can research best advance advocacy or service goals? Can research in support of an advocacy agenda remain "unbiased" and does that matter?

GROUP DISCUSSION

> Which of these six research topics are the **top priority** for you and your health center?

> What **aspects** of the topic that you chose are most important and why?

Please raise your hand and we can get things started!

High Priority Research Topics from Listening Sessions

1. Mental Health
2. LGBTQIA+ competence in health care
3. Best practices in gender-affirming health care
4. Access to health insurance
5. Health impacts of discrimination
6. Weight/body image/fitness and nutrition

GROUP POLL

Based on our group discussion, which of these six research topics are the **top priority** for you and your health center? (Pick up to three!)

AGENDA FOR BREAKOUT GROUPS

1. Go deeper into what we really "mean" by this topic
- What aspects of this topic are most important to you? What questions do you have about it?
- What do you think is most important to know, focus on, or find out about?

2. Making sure we build on work that is already being done
- Has any activity already been done or is any work currently taking place at your health center in this area?
- What resources or infrastructure are already in place at your health center that could be brought to bear related to this topic (working groups, trainings, meetings, etc)?

3. Identifying next steps
- What specific action steps can we take to advance research in this area within or across our five health centers?
- What stakeholders (internal and external) most need to be involved?
- What should we do next?

EXTRA SLIDES

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3. **Build consensus** on the 2 or 3 highest priority research topics for future collaborative efforts.

4. Identify 1 or 2 **specific action steps** that would help us move forward in each priority area in the short- and long-term

QUESTIONS TO GUIDE LIVE SESSION

1. Which of these six research topics are the top priority for you and your health center?

2. What aspects of the topic that you chose are most important and why?

3. Based on the answers to #1 and #2 above, how can we define a set of 2 or 3 shared research priorities?

4. What specific action step could we take to advance research in each priority area immediately after the convening?