

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



OVERALL GOAL FOR SESSION #1

The primary objective of this session is to build consensus on **high-priority research topics** that can act 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

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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** that 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.

PATIENT STAKEHOLDERS (N = 250)

Age	
18- 29	102 (43%)
30-49	102 (43%)
50 plus	36 (15%)
Race/Ethnicity (census categories)	
American Indian or Alaskan Native	6 (3%)
Asian	23 (10%)
Black or African American	45 (19%)
Hispanic or Latino/a/x	52 (22%)
White Non-Hispanic	90 (38%)
Multiracial	48 (20%)

Gender Identity	
Cisgender Man	63 (26%)
Transgender man or non-binary transmasculine	73 (30%)
Transgender woman or non-binary transfeminine	62 (26%)
Cisgender Woman	42 (18%)
Agender	3 (1%)
Sexual Identity	
Queer	61 (25%)
Gay	61 (25%)
Heterosexual	31 (13%)
Bisexual	24 (10%)
Pansexual	22 (9%)
Lesbian	12 (5%)
Asexual	11 (5%)
Other	18 (8%)

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%

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TOP TEN HEALTH CONCERNS BY GENDER IDENTITY

	TM/TMNB (n = 78)	TW/TFNB (n = 66)	CisM (n = 64)	CisW (n = 42)
Access to LGBTQ competent provider	2 (93%)	1 (98%)	2 (94%)	6 (81%)
Access to health insurance	3 (91%)	2 (97%)	7 (81%)	4 (88%)
Mental Health (Depression, anxiety, suicide)	1 (97%)	3 (94%)	3 (92%)	3 (90%)
Access to gender-affirming hormones and/or surgery	3 (91%)	3 (94%)	10 (19%)	9 (31%)
Fitness & nutrition	1 (97%)	3 (94%)	1 (98%)	2 (92%)
Sexual health (incl. STI's, HIV)	4 (89%)	6 (76%)	6 (83%)	7 (79%)
Cardiovascular health	6 (81%)	4 (86%)	4 (86%)	1 (95%)
Violence &/or harassment	5 (83%)	5 (82%)	8 (70%)	8 (74%)
Cancer	7 (80%)	5 (82%)	5 (84%)	5 (83%)
Reproductive health &/or Family planning	8 (79%)	7 (65%)	9 (41%)	4 (88%)

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%)

TOP RESEARCH TOPICS BY STAFF STAKEHOLDER GROUP

	Direct Patient Care (n = 78)	Administration Management (n = 26)	Patient Care & Management (n = 13)	Research (n = 18)
1. Mental Health	(45%)	(46%)	(46%)	(50%)
2. Access to LGBTQ competent provider	(33%)	(35%)	(23%)	(28%)
3. Access to gender-affirming care	(38%)	(31%)	(39%)	(44%)
4. Access to health insurance	(17%)	(8%)	(23%)	(11%)
5. Health impacts of discrimination	(12%)	(11%)	(15%)	(28%)
6. Cardiovascular health	(7%)	(23%)	(23%)	(11%)
7. Fitness & nutrition	(7%)	(7%)	(8%)	(0%)
8. Sexual health (e.g., STI's, HIV)	(17%)	(42%)	(15%)	(39%)
9. Substance use	(29%)	(27%)	(23%)	(44%)

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%

GOALS OF RESEARCH AT LGBTQIA+ HEALTH CENTERS

(staff stakeholder open-ended responses)

I would like to know what our patient's see as continuing barriers to accessing care within the clinic itself. Is there anything in the clinic that is causing them to feel like they are having difficulty accessing their care? How can we provide solutions?

Reasons why people stay in care with us; what keeps people from engaging more; what patients wish we did differently.

I would like to know what our patients need from us. Maybe they have urgent needs that are on their minds.

I want to be able to say that multidisciplinary, holistic and community approaches improve x, y, z health indicators. But to do this, I think we need to improve accessibility of services...

What types of collaborate care or integrated care work best for the specific populations?

#1 MENTAL HEALTH – COMMENTS & CONSIDERATIONS

- 50% of patient stakeholders wrote-in a research topic related to mental health, social support, and/or stress and coping -- PTSD, trauma, mental health, family issues, anxiety, depression, relationship issues, & stress were commonly used terms.
- Patients talked about mental health in the context of greater mind-body connection and overall wellness
- Several patients stated that they would like more information on strategies for managing stress, treatment options for PTSD and trauma, and alternative/non-pharmaceutical approaches for depression.

#2 LGBTQIA+ COMPETENCE – COMMENTS & CONSIDERATIONS

- Stakeholders of all types were interested in research on the health impacts of LGBTQIA+ centered care, including on physical health, emotional health, and health care access/engagement
- Patients were particularly interested in research on the impact of provider bias on treatment outcomes
- Stakeholders mentioned the difficulty of defining or operationalizing “competent” “non-stigmatizing” and “affirming” behavior at the level of health center staff, health center programs and policies, and the broader health center environment

#3 GENDER-AFFIRMING CARE— COMMENTS & CONSIDERATIONS

- Stakeholders were most interested in research on the long-term effects of hormones and other gender-affirming interventions on physical, emotional, and social health
- There was a desire to identify more individualized best practices for specific patient groups, and an argument that these health centers are best positioned to do this work.
- Patients highlighted the need for more studies that include or are specific to BIPOC TGNBGD persons and their experiences of HRT & gender-affirming surgery.
- Patients highlighted the need for research on medical transition options for non-binary individuals and health outcomes for non-binary individuals overall, as well as the use of HRT with intersex patients.

#4 HEALTH INSURANCE— COMMENTS & CONSIDERATIONS

- Stakeholders of all types talked about the role of insurance coverage in limiting access to care
- Research was described as an advocacy tool and as a potential avenue for providing free care to under-insured patients
- Staff stakeholders identified a need for greater patient education about health insurance and how health care is paid for, including picking the appropriate coverage, & what is a covered benefit and why.

#5 DISCRIMINATION – COMMENTS & CONSIDERATIONS

- 23% of patient stakeholders identified research topic aimed at understanding the health impact of discrimination.
- Patient responses addressed the critical need for research on the health impact of racism for BIPOC LGBTQIA+ individuals, in particular queer women of color, and black trans and non-binary individuals.
- Additional responses included examining fatphobia in health care, ableism and the lack of accessibility in LGBTQIA+ health care for persons with disabilities, the impact of transphobia on overall well-being, and the health impact of intersectional systemic oppression.

#6 WEIGHT/FITNESS – COMMENTS & CONSIDERATIONS

- 15% of all patient stakeholders identified research topics related to eating disorders, body image, &/or weight management.
- Topics ranged from obesity, weight gain or loss, sugar addiction, access to healthy foods and/or exercise, body dysmorphia, body image, understanding diet/relationship with food, weight gain & stress related eating, &/or managing eating disorders.

POTENTIAL HIGH PRIORITY RESEARCH TOPICS

1. Mental Health
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 (violence & harassment)
6. Weight/body image/fitness and nutrition (with a connection to cardiovascular health)

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?