SESSION #3

INCREASING LGBTQIA+ STAKEHOLDER INCLUSION & ENGAGEMENT in research

June 22nd, 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.

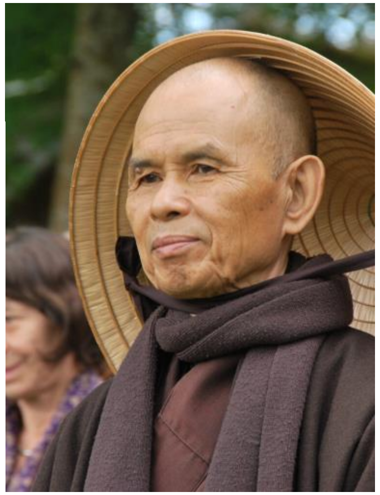
6. **Consider hiding your self-view.**

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 #3

The primary objective of this session is to identify specific **strategies for increasing LGBTQIA+ stakeholder inclusion and engagement** at all levels of the research process.

SESSION #3 OBJECTIVES

1. Review information from listening sessions about **who is** and **is not** included **research** and **potential strategies** to for **increasing stakeholder** inclusion and engagement in research within and across each health center.

2. Discuss three **potential areas of focus** for future shared work to enhance LGBTQIA+ stakeholder inclusion and engagement in research.

3. Identify 1 or 2 **specific action steps** that would help us move forward toward each of these goals in the short- and long-term.

WHAT DO WE MEAN WHEN WE SAY INCLUSION & ENGAGEMENT IN RESEARCH?

Inclusion means **actively engaging** a **diverse group** of LGBTQIA+ **patients and other healthcare stakeholders** as **equitable partners** in the research process - where each person is **welcomed and valued** for **their** lived experience and expertise.

WHAT DO WE MEAN WHEN WE SAY INCLUSION & ENGAGEMENT IN RESEARCH?

Engagement in research is the **meaningful involvement** of LGBTQIA+ patients, clinicians, and other healthcare stakeholders throughout the **entire research process** – from planning the study, to conducting the study, to disseminating study results and helping translate research in policy & practice.

WHY INCLUSION & ENGAGEMENT MATTERS IN RESEARCH?

LGBTQIA+ patient and other healthcare stakeholder inclusion & engagement makes research more **patient centered**, **useful**, and **trustworthy**, and will ultimately lead to **greater use** and **uptake** of **research results** by patients and the broader healthcare community.

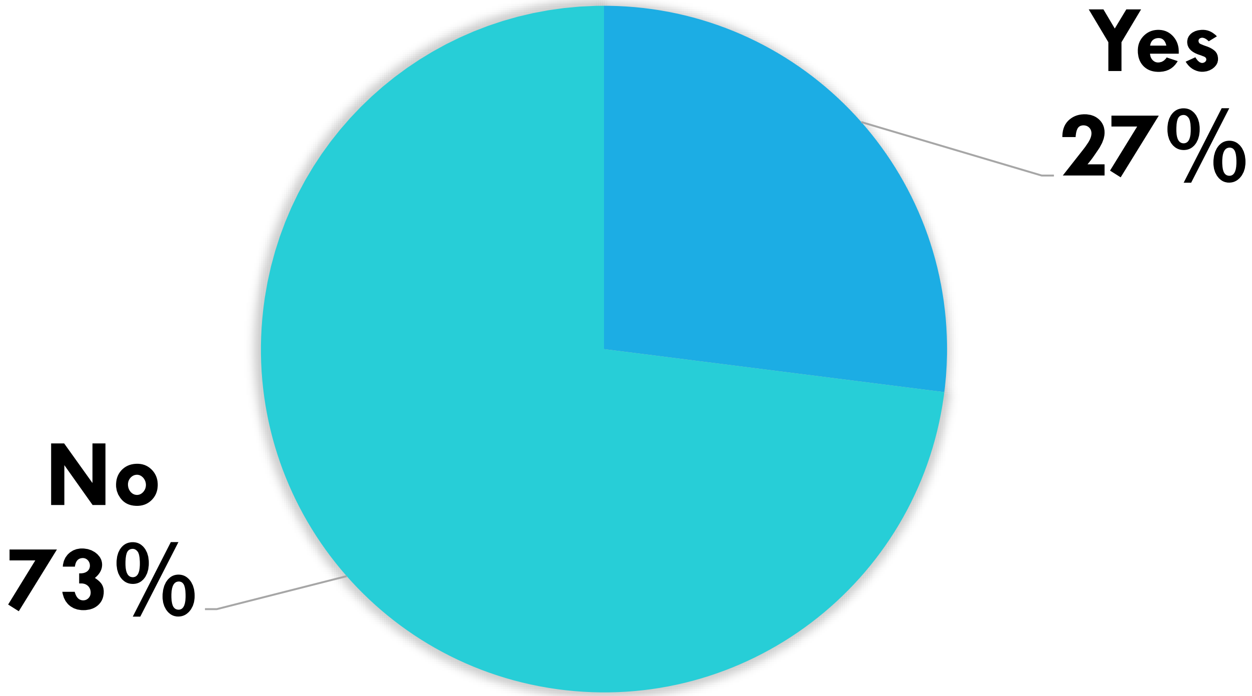
WHOSE VOICES ARE BEING LEFT OUT OF RESEARCH? AND WHY?

Stakeholders repeatedly discussed how LGBTQIA+ persons with multiple and intersecting identities and health care needs are systematically left out of LGBTQIA+ health research, including BIPOC LGBTQIA+ communities, disabled persons, persons with mental health issues, elder communities, houseless/homeless LGBTQIA+ individuals, low-income individuals, and immigrant communities.

WHOSE VOICES ARE BEING LEFT OUT OF RESEARCH? AND WHY?

1. The people being ignored/not included in LGBTQIA+ health research are the very communities who have the least access to and engagement in consistent health care.
2. Funding priorities for LGBTQIA+ health care, which are most often driven by research create inherent health disparities.

HAVE YOU EVER PARTICIPATED IN RESEARCH AT YOUR HEALTH CENTER? (N=250)



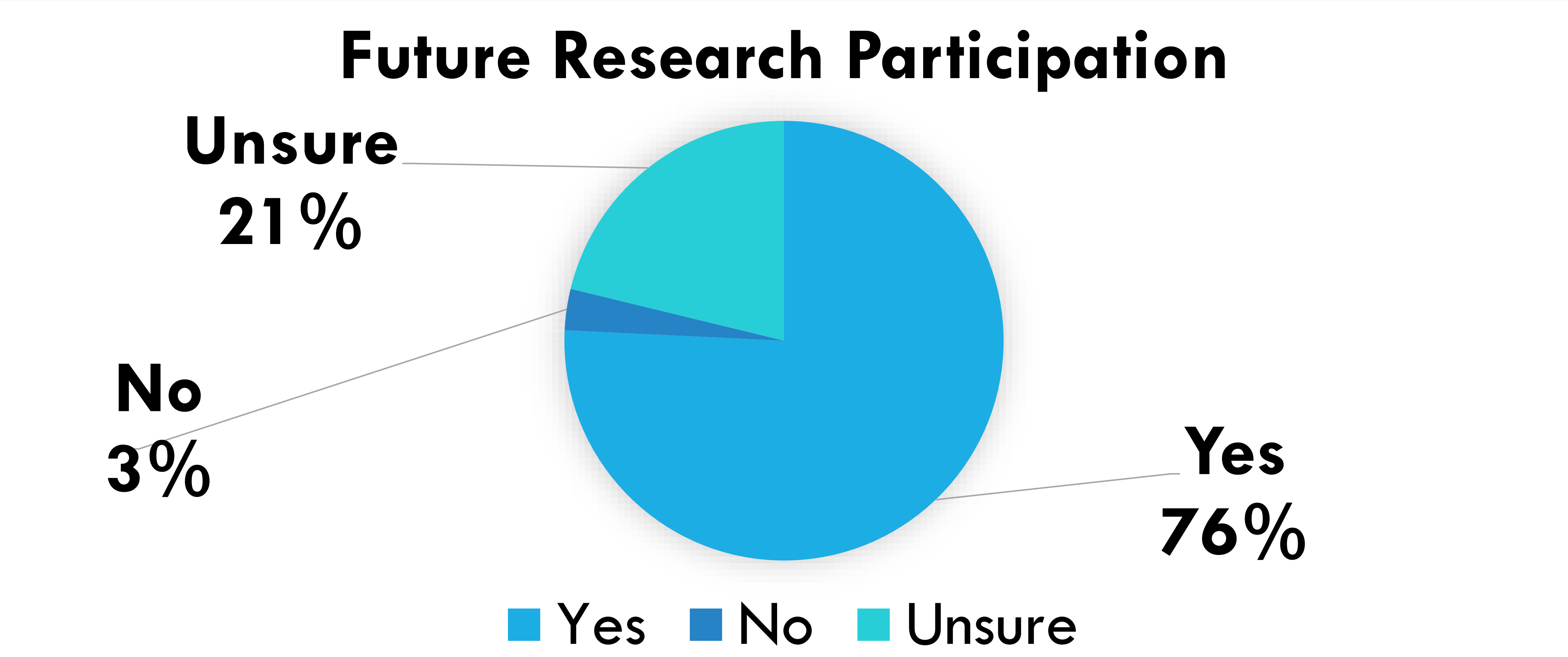
WHY ARE PATIENTS PARTICIPATING IN RESEARCH?

TOP 3 REASONS

- To help my community
- I like participating in research because I learn new things
- To help end the HIV epidemic

To **develop strategies** for increasing inclusion and engagement it is important to understand patient’s motivation for participating in research.

WOULD YOU BE WILLING TO PARTICIPATE IN FUTURE RESEARCH? (N=183; 73%)



WHAT WOULD MAKE YOU MORE WILLING TO PARTICIPATE IN FUTURE RESEARCH?

Being compensated > $20 for my time

Being able to attend a study info session

Making sure that the people doing the research are also LGBTQIA+

Being a part of a research advisory committee that decides the studies/topics that will happen at my health center

BREAKOUT GROUPS – CHOOSE YOUR ADVENTURE

- We will present three areas for increasing/addressing inclusion and diversity that came out of the listening sessions
    1. Making research inclusive and non-stigmatizing
    2. Improving communication about research purpose and impact
    3. Ensuring that those doing research are members of the LGBTQIA+ community
- We have a series of questions about each one that we'd like to discuss in small groups
- Choose which one you would like to discuss! We will then come together to report back!

AREA #1: Making Research Inclusive & Non-stigmatizing

1. What are our standards for equitable compensation?
2. What tangible actions “de-stigmatize” the research process?
3. How do we do research on stigma without re-traumatizing?
4. How do we increase diversity and inclusion in all its manifestations (not just by age/race/gender)?
5. What are the non-tangible aspects of the research process that will increase accessibility?

AREA #2: Actively Providing Ongoing Clear Communication About Study Purpose, Design, And Potential Impact

1. What structures or formats can be created and/or used to actively communicate and engage with patient and healthcare stakeholders about both ongoing and potential research studies?
2. How can we improve the quality of recruitment materials?
3. What are our standards for “ report-back” of study findings and at what intervals should this happen (e.g., not waiting until the study is over)?
4. How do we facilitate real time feedback, questions, and complaints from study participants & health center staff?

AREA #3: Ensuring That The People Doing Research Are Members Of The LGBTQIA+ Community

1. What standards of LGBTQIA+ inclusion are required in order to conduct research at your health center?
2. What support, resources, and infrastructures are needed to facilitate research engagement by LGBTQIA+ health center staff?
3. What workforce development role can LGBTQIA+ health centers play in developing entry-level and mid-level research jobs for LGBTQIA+ individuals?
4. How do we guard against the pitfalls of “me-search” – meaning an assumption by LGBTQIA+ researchers that their OWN experiences or perspectives are representative of the larger community?