

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



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. **Build consensus** on the 2 or 3 most important goals for future collaborative efforts.
4. Identify 1 or 2 **specific action steps** that would help us move forward toward each of these goals in the short- and long-term.

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.

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.

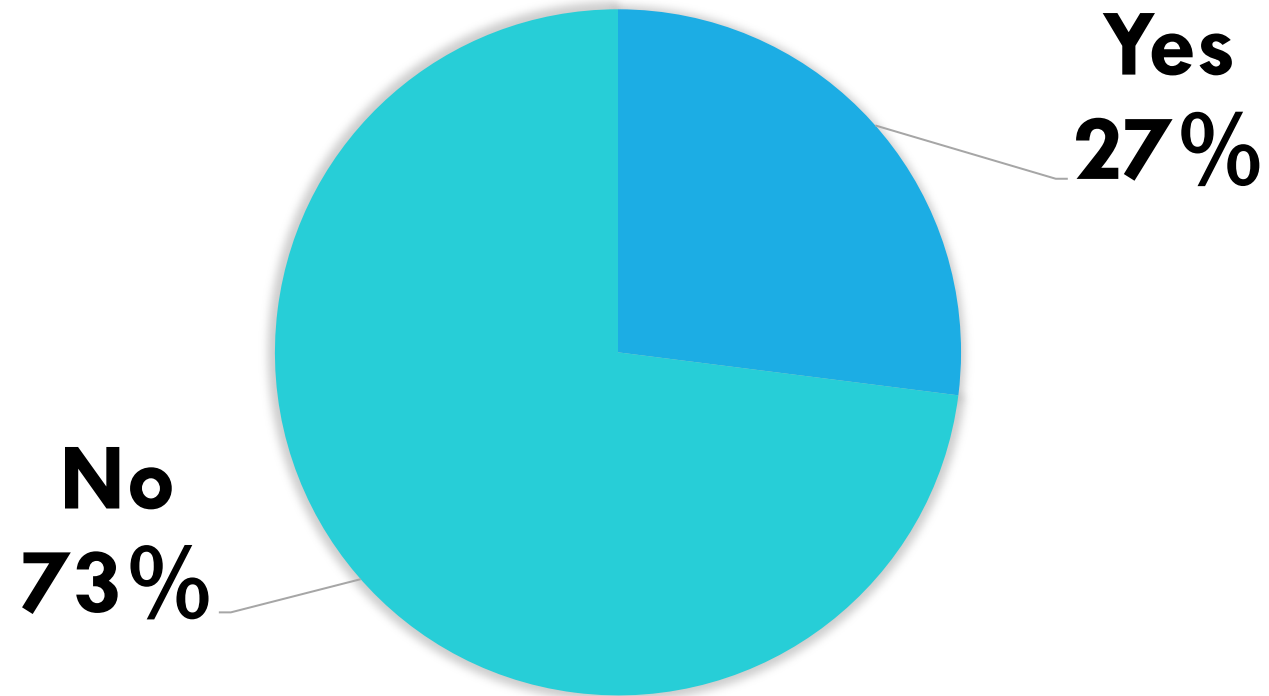
WHAT DO WE MEAN WHEN WE SAY INCLUSION & ENGAGEMENT IN RESEARCH?

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 influences research** to be 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.

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



WHO IS PARTICIPATING IN RESEARCH?

- Patient stakeholders who have participated in research were more likely to:
 - 40 years of age and older
 - Black, White, & Multiracial patient stakeholders;
 - Assigned male at birth;
 - Cis man or transgender woman;
 - Bisexual, heterosexual, or gay;
 - Have a high school diploma, an annual income of \$40,000 or more, or currently have a job.

WHY ARE PATIENTS PARTICIPATING IN RESEARCH?

TOP 3 REASONS

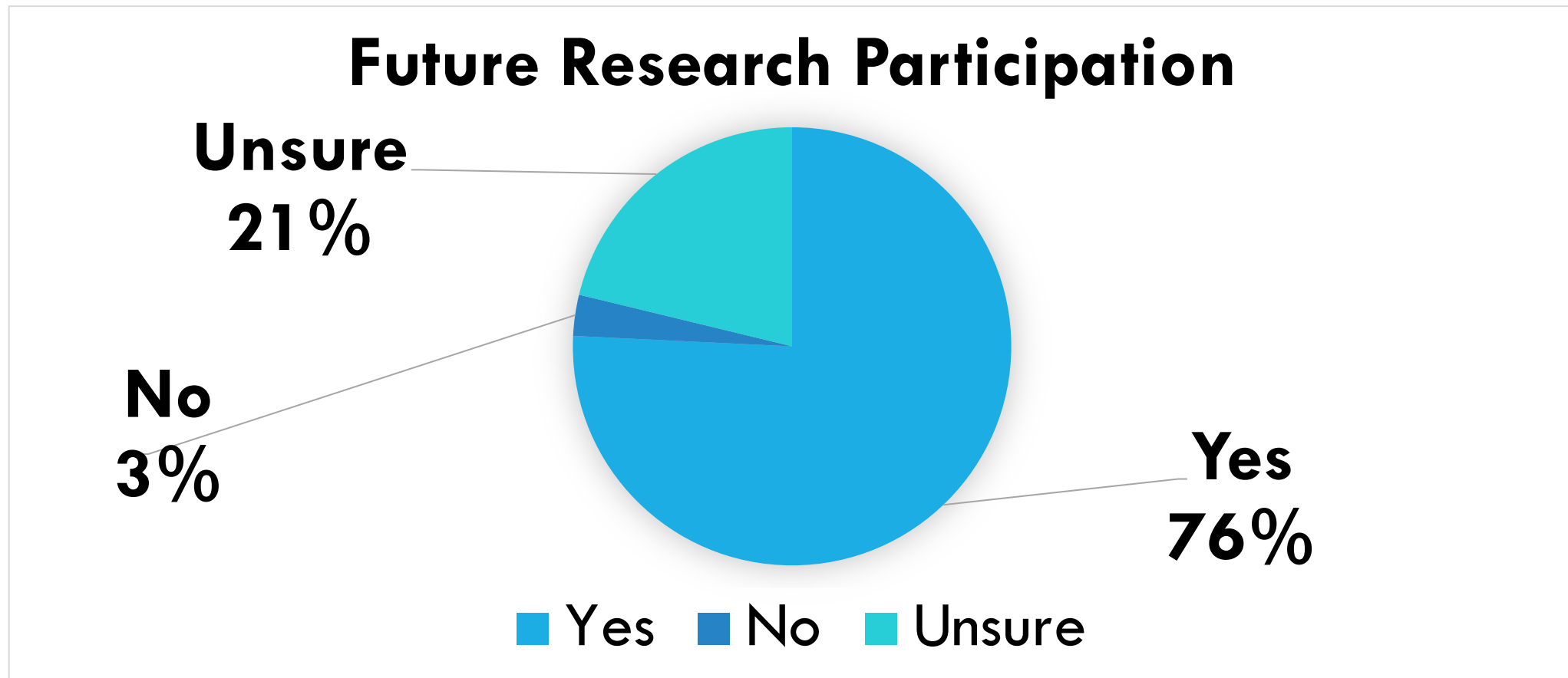
- To help my community
- I like participating in research because I learn new things
- To help end the HIV epidemic

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

WHO ISN'T PARTICIPATING IN RESEARCH? (N=183; 73%)

- Patient stakeholders who had not participated in research were more likely to be:
 - Under the age of 40;
 - Latinx, American Indian, or Asian;
 - Assigned female at birth or intersex;
 - Cis woman, transgender man, or non-binary
 - Asexual, lesbian, pansexual, or queer;
 - Have attended some college or more, an annual income of <\$40,000 or currently do not have a job.

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



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 person, persons with mental health issues, elder communities, houseless/homeless LGBTQIA+ individuals, low-income individuals, and immigrant communities.

“Any community that is viewed as “not at risk for HIV or STIs”.

Communities that are **historically disenfranchised** are not represented (**POC, disabled folks, trans folks, etc**) by research **because** they are **rarely in positions to make decisions**, mostly, white, cis, able-bodied researchers with terminal degrees (regardless of research experience) get to decide to not listen to community advisory boards (which are bullshit forms of academic theater). **Older LGBTQ folks** - most projects and interventions are geared towards young LGBTQ people, as it's more palatable to funders to provide grants for prevention. Many researchers give up on older LGBTQ folks because they do not want to invest the time in them or their needs. **Any community that is not popular to study, due to the fact that 1) funders do not want to include 2) have no benefit to a specific political/policy agenda.”** - Dual Role, Patient Care/Management

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.

“Black and brown communities, especially poor and houseless communities. These patients have the least access to care already and because of federal and state funding guidelines, I feel we sacrifice these patients in order to grow bigger and better and serve more patients at a higher socio-economic level. We need to start breaking down barriers for these patients that come from lack of documentation, lack of access to basic health and hygiene needs, and access to supportive care coordination for other basic needs like food and housing stability. I feel that without access to these supports, our LGBTQ patients in these populations are mostly ignored and never have a chance to access the care we are offering.” – Patient Care Staff

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.

“Communities affected by poverty and racism tend to not be fully invested in or alleviated of oppression by the non-profit industry, in part because the non-profit industry is inherently reliant on catering to systems of capitalism and white supremacy for sustained funding. Research is usually supported by top-down funding and thus must somehow appeal to those with the funding, often by excluding or ignoring more marginalized communities. Within these systems, research that is community-led is hard to undertake.” - Patient Care Staff

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

HOW DO WE INCREASE PATIENT INCLUSION & ENGAGEMENT IN RESEARCH?

- 1. Actively engage and provide equitable compensation for patient stakeholder participation at all levels of the research process.**

STRATEGY #1: ACTIVELY ENGAGE AND PROVIDE EQUITABLE COMPENSATION

“Bring in patients when first approached by researchers.”

“Involving patients in a research advisory process or brainstorming research topics among patients.”

“Have community input about what gets prioritized for research.”

“Include us in a follow-up process and give participants' voices a place in the final outcomes in a way we approve of.”

STRATEGY #1: ACTIVELY ENGAGE AND PROVIDE EQUITABLE COMPENSATION

“Offer large amounts of money, because not all of us can participate in service, even online surveys like this. I have the privilege of taking a day off from work today, not everybody has that privilege. \$25 is barely enough to compensate me for the mental energy I am putting into this. People should be getting paid \$50-\$60 for a half hour of stuff that is potentially triggering”.

HOW DO WE INCREASE PATIENT REPRESENTATION & PARTICIPATION IN RESEARCH?

1. Actively engage and provide equitable compensation for patient stakeholder participation at all levels of the research process.
- 2. Provide detailed and ongoing information about the study purpose, benefits, risks, expectations for participation & findings.**

STRATEGY #2: PROVIDE DETAILED AND ONGOING INFORMATION ABOUT THE STUDY

“I want to know how can it (research) help the LGBT community? How will it affect its participants? Are we gonna be updated of the research results?.”

“The affects the research would have on my health? current research done? affects on my personal time?”

STRATEGY #2: PROVIDE DETAILED AND ONGOING INFORMATION ABOUT THE STUDY

“Explain the purpose of the study, what is the intended reasoning for the study and what are the pros & cons regarding how the study will impact the community.”

“Make it very clear how patients can participate.”

“updates on how the research is going and the findings.”

HOW DO WE INCREASE PATIENT REPRESENTATION & PARTICIPATION IN RESEARCH?

1. Actively engage and provide equitable compensation for patient stakeholder participation at all levels of the research process.
2. Provide detailed and ongoing information about the study purpose, benefits, risks, expectations for participation & findings.
3. **Make research inclusive & non-stigmatizing.**

STRATEGY #3: MAKE IT INCLUSIVE & NON-STIGMATIZING

“Make sure to listen and keep an open mind as most people who are LGBTQ have faced some sort of discrimination and or danger in the past that will make them less likely to talk openly about what is most important to their well-being therefore taking a no wrong answers approach will result in more accurate data.”

STRATEGY #3: MAKE IT INCLUSIVE & NON-STIGMATIZING

“Making sure that the things being discussed aren’t stereotypes or uncomfortable for people to answer.”

“Listening to all ideas without bias and not be dismissive when mental illness or housing are a concern.”

“Whatever it is they want to research should be tied to actual care, empathy, and just general respect.”

STRATEGY #3: MAKE IT INCLUSIVE & NON-STIGMATIZING

“Actually get a diverse group: black, latinx, API, native, of various housing and income statuses who are trans and nonbinary and queer. Ask us open ended questions, too, not just what you are trying to study. Think discovery, not so much reductive.”

HOW DO WE INCREASE PATIENT REPRESENTATION & PARTICIPATION IN RESEARCH?

1. Actively engage and provide equitable compensation for patient stakeholder participation at all levels of the research process.
2. Provide detailed and ongoing information about the study purpose, benefits, risks, expectations for participation & findings.
3. Make research inclusive & non-stigmatizing.
4. **Make sure the people doing the research are LGBTQIA+.**

STRATEGY #4: LGBTQIA+ RESEARCHERS

“Do not accept research that is not led BY the affected community.”

“Making sure that the researchers are LGBTQ+ competent.”

“Value input rather than just use the community to appear supportive.”

STRATEGY #4: LGBTQIA+ RESEARCHERS

“Language and gendering of both framing and especially results of the study matter a lot.”

“Our cis counterparts who will probably be leading the study shouldn't treat us like aliens.”

AREAS OF FOCUS & QUESTIONS TO GUIDE LIVE SESSIONS — AREA #1

Making research inclusive & non-stigmatizing

1. What are our standards for equitable compensation?
2. How do we increase diversity and inclusion in all its manifestations (not just by age/race/gender)?
3. What are the non-tangible aspects of the research process that will increase accessibility?

AREAS OF FOCUS & QUESTIONS TO GUIDE LIVE SESSIONS – 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?

AREAS OF FOCUS & QUESTIONS TO GUIDE LIVE SESSIONS – AREA #2

Actively providing ongoing clear communication about study purpose, design, and potential impact

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?

AREAS OF FOCUS & QUESTIONS TO GUIDE LIVE SESSIONS — 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?

AREAS OF FOCUS & QUESTIONS TO GUIDE LIVE SESSIONS – AREA #3

Ensuring that the people doing research are members of the LGBTQIA+ community

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?