SESSION #2

BUILDING RESEARCH CAPACITY
within and among LGBTQIA+ health centers

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)
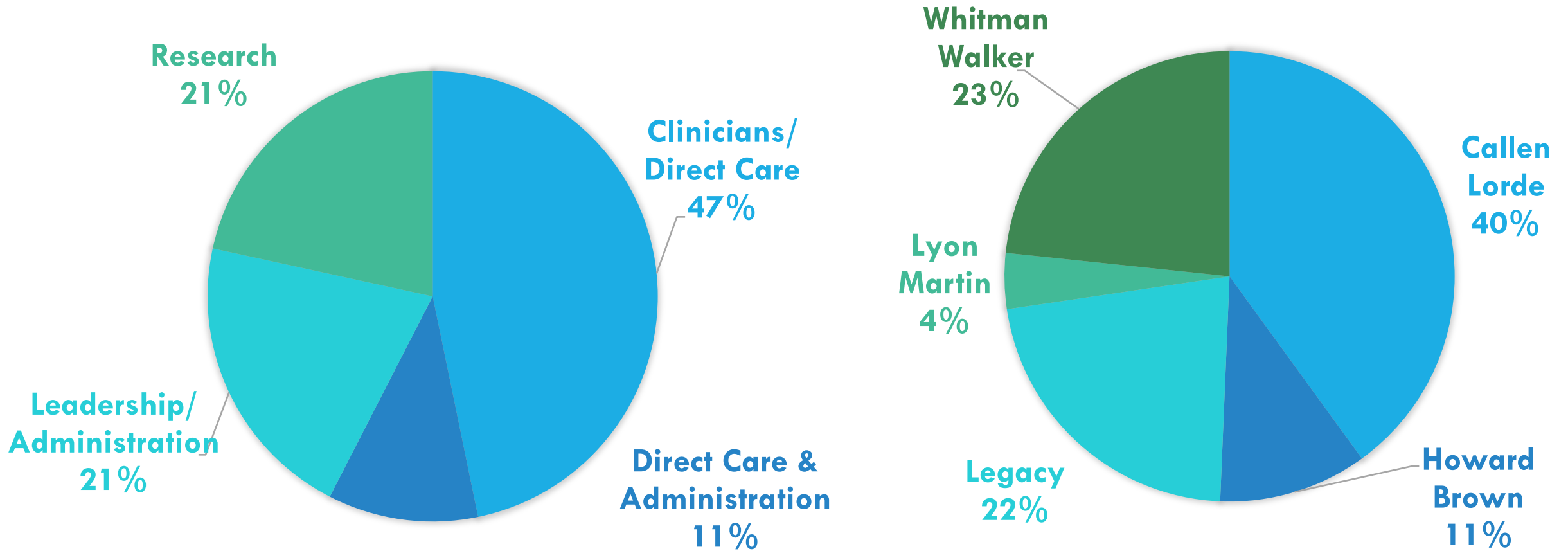Community Engagement Convening Project

OVERALL GOAL FOR SESSION #2

The primary objective of this session is to identify specific **resources and infrastructure needs** that are most important in helping health centers engage more fully in patient-centered research.
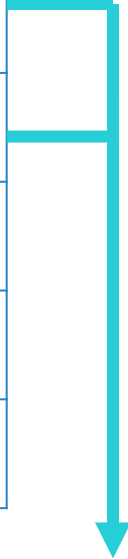
SESSION #2 OBJECTIVES

1. Review information from listening sessions about the **strengths and challenges** of doing patient-centered research

2. Discuss six **potential areas of focus** for future shared work to enhance research capacity

3. **Build consensus** on the 2 or 3 most important research capacity 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

LISTENING SESSION DATA ON HEALTH CENTER SYSTEMS AND INFRASTRUCTURE (N = 139)

Research 21%

Clinicians/ Direct Care 47%

Leadership/ Administration 21%

Direct Care & Administration 11%

Whitman Walker 23%

Callen Lorde 40%

Lyon Martin 4%

Howard Brown 11%

Legacy 22%

From your perspective, how important is research to the overall mission and work of your health center?

Extremely important	51%
Very important	29%
Moderately important	12%
Slightly important	2%
Not at all important	6%

80% of stakeholders said that **research is extremely or very important** to the overall mission and work of their health center.

WHY IS RESEARCH IMPORTANT TO YOUR HEALTH CENTER?

"Research informs how clinicians' practice; research also historically has been performed by populations that are more privileged and hold more power on those less privileged with less power. We have the ability to change that."
— *Patient Care Staff*

I had chosen extremely important due to the lack of representation in BIPOC LGBT communities. Many studies do not represent the people we serve...I believe in order to create better services and understanding of our patients, we must know more about our patients, beyond sensationalizing their experience with documented evidence that continues to speak and elevate the areas to focus.
— *Patient Care Staff*

"Having research embedded in a FQHC is a way to help patients believe in the science that is being done- if they know the providers involved, they are more likely to trust it."
— *Dual Role (Management & Patient Care)*

"Patient centered care must be informed by research specific to the needs of our patient population."
— *Senior Management*

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%

STRENGTH #1 -- **YOUR PATIENTS**

- Staff stakeholders across each health center identified the diversity of patients as an important facilitator to conducting PCOR within their health center.

- Staff identified the importance of serving marginalized patient groups that are often underrepresented in research.

"We have a huge sample size with patients of various conditions and socioeconomic status, and we are able to reach the LGBTQ+ community members who are homeless."

- Patient Care

"We work with underserved and underrepresented groups who often do not show up in many traditional research projects, so I know we are able to conduct research most places are not able to do."

- Senior Management

"We have access to communities that are traditionally underrepresented."

— Research Staff

Our patient population is diverse. So our findings will not be based on a homogeneous group of people.

- Program Coordinator

STRENGTH #2 -- COMMUNITY TRUST

- Community trust was also identified as an important facilitator and strength for conducting research at each CHC.

- Staff emphasized the importance of how providing care to diverse patient groups for several decades has allowed them to build credibility and connections to the very communities for whom research is most needed.

"History in community means people trust us, we have the opportunity to do research in a more trauma informed way among people that other centers don't have rapport with."

Patient Care & Management (dual role)

"We have a very strong relationship with our patients and the transgender community, and we would be able to do research that involves patients in every step of the process and is based on trust and knowledge-sharing (rather than being exploitative and for academic prestige) by making sure we (and our patients) are part of the decision-making process for what studies should be conducted, as well as how to best conduct them."

-Patient Care Staff

STRENGTH #3 – **YOUR STAFF**

- Health center staff was identified as a strength to conducting ethical, sensitive, and community-centered research.

- Representation of LGBTQIA+ communities among staff was consistently highlighted as an important factor to developing and conducting research.

- Having a non-judgmental and respectful rapport with patients was identified as a potential facilitator to research participation.

"We tend to have a respectful, nonjudgmental rapport with our patients. Hopefully, patients who participate in research will give honest answers because they feel that it is safe to do so."

- Patient Care Staff

"We have a large number of staff members who are part of the LGBTQ community and therefore are more sensitive to the impacts and consequences of research on vulnerable populations."

- Senior Management

"Better to have queer folks run studies on queer populations" - Administration

STRENGTH #4 – **PROXIMITY TO PRACTICE**

- Stakeholders consistently highlighted the unique opportunity to lead research that develops, tests, and disseminates an evidence-base for best practice by using research to highlight the work that is already going on in each health center.

- Stakeholders also identified that a strength of having research within a health center was its potential to improve patient outcomes and have the data to better understand what specific factors contributed to this improvement.

"We have specific practices, knowledge and experiences that are highly valuable to wider LGBTQ and research communities. Research is a great way to strengthen these partially informal goods and be able to disseminate them widely."

- Patient Care Staff

"There are not a lot of clinics working with the LGBTQ community and this community in particular historically has many challenges and reservations in accessing healthcare which leads to poor outcomes. We need to do research here so we can share our knowledge with other clinics, schools, etc."

– Support Staff

"Research in our clinic has led to positive health outcomes for our patients." – Senior Management

BARRIER #1 – LIMITED RESOURCES

- Limited or a lack of resources within an FQHC was consistently identified as a barrier to conducting research.

- Not having the time to integrate research into existing staff workloads, money, limited data systems, & lack of physical space were all identified as barriers to conducting research.

"Research seems like a luxury, if there's any time and resources left."

— Support Staff

"Our health center often has limited resources and/or has to work within larger systems that are often times outdated and unable to meet the needs of our populations."

— Senior Management

BARRIER # 2 – WORK & TIME PRESSURES

- Stakeholders stated that they are overworked and already have limited time to provide care to their patients.

"The federal community health center system (of which we're a part) is woefully underfunded and built around volume-of-care models, making it difficult to integrate research into our work."

- Dual Role, Management & Patient Care

We are often overworked and tired. I think we need to set time apart for research for whoever is involved."

– Direct Care Staff

Folks in other departments may not prioritize assisting with research because they are so busy doing other things, tired, as well as just managing their personal struggles outside of work.

– Support Staff

BARRIER #3 – LIMITED COMMUNICATION

- Stakeholders stated that study visibility, outreach & communication, including study updates & dissemination of findings was lacking within the centers that currently have active research programs.

"One challenge is that other teams outside of the provider team do not know that as an agency we conduct research. In part because we do not have a robust promotional team that works to market and advertise our research program".

— Research Staff

"Our research department does not advertise or publish their work to our (health center's) community."

- Direct Patient Care Staff

"Dissemination is challenging following the completion of research. If a report back happens it is very rare."

— Research Staff

BARRIER #3 – LIMITED COMMUNICATION (cont.)

- Stakeholders discussed wanting ongoing and consistent communication about studies and expressed that this could possibly help with staff buy-in and clear up confusion about ongoing studies.

"Challenges to research at our center, staff buy-in & visibility. There needs to be more outreach to all staff on a consistent level. This includes dissemination of study updates and publications on a regular basis."

— Direct Care Staff

"We also have multiple research programs that seem to overlap, and I've been confused about which is which. This puts me as a staff member at a disadvantage in talking to patients about it."

- Support Staff

"Would love to see more visibility around studies that are going on at all times."

- Senior Management

BARRIER #4 - LACK OF RESEARCH INTEGRATION

- Staff stated that research often conflicted with the priorities of patient care, indicating that research priorities are often set within research departments with little to no engagement of clinic staff.

- Staff indicated that the lack of integration between research and the overall clinic has led to a disconnect between research and clinical care.

"Research can be a little bit disconnected from the general clinical care provided at our health center. In the past, when there was supposed to be integration, there was still a large degree of separation because the staff members and leadership of the research program were not invested in integration"
— Senior Management

"The research department operates in a very siloed culture and is not transparent to folks outside that department. Need more focus on social science and public health research. Need to develop the capacity for program evaluation which we currently lack."
— Management

"Priorities are (until this survey) set only within the research department and react to funding, even though funding does not cover all time/cost. Appreciate this opportunity for community participation in setting priorities. Would like to see more collaboration between research and care teams."

"Research often doesn't coordinate care with other direct patient services (e.g., navigation, nursing)."
— Direct Patient Care

SUMMARY OF STRENGTHS AND CHALLENGES

Strengths

➢ Diversity of health centers' patient population

➢ Level of trust in the community for the health center

➢ Representation of LGBTQIA+ communities among staff

➢ Staff's ethical, community-centered, non-judgmental and respectful rapport with patients

➢ Co-location of research within a health center and proximity of practice to both answer research questions and put research findings into action

Challenges

➢ Limited resources (money, physical space) in an FQHC setting

➢ Time pressure which prevents integration of research into workloads

➢ Limited data systems and capacity

➢ Lack of communication about existing research to clinical staff

➢ Limited dissemination of research findings

➢ Potential conflict between research goals and priorities of patient care

➢ Lack of coordination or integration of research and patient care agendas

POTENTIAL AREAS OF FOCUS TO BUILD CAPACITY

1. Developing a **standardized system for evaluating outside research collaboration requests** and upholding standards for outside partnership.

2. Developing more formalized **structures and process for dissemination of research findings** to health center staff, patients, and the broader community.

3. Enhancing **data capacity** within the health center (including data collection, extraction, and/or analysis)

4. Developing more formalized structures and process to **improve integration of research into clinical care** and/or communication between research and practice.

5. Increasing the health center's capacity to **generate research that "solves problems"** in the health center and/or focuses on program evaluation goals

6. Enhancing the ability to generate "home-grown" research studies with **health center staff as Principal Investigators** (as opposed to collaborators)

QUESTIONS TO GUIDE LIVE SESSION

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

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

3. What would moving forward in this area mean to you – what would you like see included in any project or initiative about it?

4. What specific action steps do you think your health center would need to take to move forward in this area?