SESSION #2

BUILDING RESEARCH CAPACITYwithin 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



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 #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

- 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

CORE STRENGTHS IDENTIFIED IN LISTENING SESSIONS

- 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

KEY CHALLENGES IDENTIFIED IN LISTENING SESSIONS

- 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

SUMMARY OF STRENGTHS AND CHALLENGES

Strengths

- Diversity of health centers' patient population
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Challenges

- Limited resources (money, physical space) in an FQHC setting
- Time pressure which prevents integration of research into workloads
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- Lack of communication about existing research to clinical staff
- Limited dissemination of research findings
- Potential conflict between research goals and priorities of patient care
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As we go through these, feel free to jot down a couple of notes about:

- a) the parts of each that are most relevant for your health center;
- b) how high a priority you feel it is for your health center (on a scale from 1 (not at all important) to 5 (extremely important)

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

Do health centers want unified "standards" for collaborative research?

- Principles for equitable budgeting
- Standards for partnership in research agenda and methods
- Requirements for local patient engagement and input (that can make change!)
- Standards for compensation
- Investment in dissemination
- Plans for sustained practice change

- 2. Developing more formalized structures and process for dissemination of research findings to health center staff, patients, and the broader community.
 - Development of standards or guidelines that can be used by each health center
 - Individual or shared structures for dissemination, e.g., town-hall meetings, newsletter, website, other?
 - Processes for presenting preliminary "nimble" -- findings
 - Regular research-related updates at staff meetings or other health center meetings
 - Research presence or report-back at regular events

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

- Grants or other funding for dedicated staff to work with EMR
- Development of new tools or reports to monitor and provide regular feedback about service delivery or patient outcomes
- Training or professional development to enhance analytic capacity of data managers
- Development of a cross-health center data base or cohort study

- 4. Developing more formalized structures and process to improve integration of research into clinical care and/or communication between research and practice.
 - Creation of a cross-health center working group to identify and discuss different models for research/practice integration and the strengths and weaknesses of each
 - Development of shared standards for the parameters of research/practice integration (e.g., development of research protocols in the context of care demands; prioritizing patients over participants, planning for sustainability)
 - Development of policies or protocols for enhancing research-practice communication about study development, recruitment, and implementation
 - How do we get over the "silos" that people talk about?

- 5. Increasing the health center's capacity to **generate research that "solves problems"** in the health center and/or focuses on program evaluation goals
 - Creation of inter- or intra-health center working group on specific program evaluation needs or research questions
 - Development of technical assistance program/collaborative that could help translate these questions into data that could be extracted from EMR or other ongoing work
 - Identification of avenues for pilot funding for small-scale program focused research and evaluation projects
 - Development of a technical assistance network that could support analysis and translation into lessons for practice

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

- Training and professional development opportunities for staff in health center
- Development of a mentorship network that could link established Pls (vetted!) with health center collaborators
- Training sessions on identifying grant opportunities, grant writing, research design
- Development of a technical assistance network that could support research development

INITIAL TEMPERATURE CHECK

Which of these six capacity areas are your top priority?

- 1. System for evaluating outside research collaboration requests
- 2. Structures and process for dissemination of research findings
- 3. Enhancing data capacity
- 4. Improve integration of research into clinical care
- 5. Increasing the health center's capacity to generate research that "solves problems"
- 6. Enhancing the ability to generate "home-grown" research studies

GROUP DISCUSSION

Why did you pick the one that you picked?

What would you like to see happen in this area?

- 1. System for evaluating outside research collaboration requests
- 2. Structures and process for dissemination of research findings
- 3. Enhancing data capacity
- 4. Improve integration of research into clinical care
- 5. Increasing the health center's capacity to generate research that "solves problems"
- 6. Enhancing the ability to generate "home-grown" research studies

GROUP POLL

Based on our group discussion, which of these six capacity areas 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?

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?