GOOD MORNING!
EAT BREAKFAST & GET COMFORTABLE!
ANDIE BAKER (ANY PRONOUNS)
Four Corners Project Lead &
Vice President of the Center for Education, Research & Advocacy

NAT ROSS (THEY/ THEM/ THEIRS)
Four Corners Project Coordinator &
Education & Research Associate
HOUSEKEEPING ITEMS

- Name tags and pronoun buttons
- Reminder to turn phone on silent/vibrate
- Gender neutral bathrooms down the hall
- Consent form for pictures in welcome folder
- Lunch at 12:30 PM
- Help yourself to snacks and refreshments throughout the day
2-Year Project: October 1st, 2018 – September 30, 2020

- Awarded the Eugene Washington Capacity-Building Grant through the Patient Centered Outcomes Research Institute
  - “In PCORI-funded research, patients and other healthcare stakeholders are equitable partners—as opposed to research subjects—who leverage their lived experience and expertise to influence research to be more patient centered, relevant, and useful. Their early and continued involvement throughout a study can lead to greater use and uptake of research results by patients and stakeholders within the healthcare community.”

1. Form the TGNC Health Research Advisory Network
2. Host 8 Focus Groups across the Nation
TGNC HEALTH RESEARCH ADVISORY NETWORK

Grant Structure:

- Total of Five Meetings (2 In-Person, 3 Web-Meeting)
  - Meetings 2, 3, 4: Half-Day Web-Meetings
    - Approximately every few months; exact schedule TBD
  - 5th Meeting (In-Person): Anticipated for April 2020

- Each meeting will include:
  - Training session/workshop aimed at building knowledge/capacity around patient-centered outcomes research (PCOR) and community-based participatory research (CBPR)
  - Pre-Post Session Evaluations

- ???

- Center for Education, Research & Advocacy
  - A Division of Howard Brown Health
TGNC HEALTH RESEARCH ADVISORY NETWORK

Grant Objectives:

- Establish Network operating procedures and rules
- Identify patient-centered research priorities
  - Disseminate findings to community
  - Publish in Transgender Health/present at conferences
- Establish formal continuation plan for Network
  - Includes identifying community members to serve as Co-Investigators future research proposals
PROJECT OVERVIEW
OCTOBER 1ST, 2018 – SEPTEMBER 30, 2020

1. Host focus groups to identify community priorities
   - Center TGNC community & voices

2. Form TGNC Research Advisory Network
   - Equal partnership of community members, researchers, & clinicians

Support patient-led research
- Network pursues PCOR funding with community members as COIs

Disseminate meaningful health information to community
- Publish patient-centered research priorities

Findings inform Network priorities
OUR FACILITATOR OF THE DAY

Introducing…

Jen Brown
Director & Co-Founder of the Alliance for Research in Chicagoland Communities (ARCC) in Northwestern University’s Center for Community Health
<table>
<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>9:05 AM</td>
<td>Site by Site Sharing &amp; Introductions</td>
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<tr>
<td>10:05 AM</td>
<td>Pre-Session Evaluation</td>
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<tr>
<td>10:15 AM</td>
<td>Community-Engaged Research Training and Activities</td>
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<tr>
<td>11:45 AM</td>
<td>Break Out Session 1: By Four Corners Network Member Role</td>
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<tr>
<td>12:30 PM</td>
<td>Lunch</td>
</tr>
<tr>
<td>1:15 PM</td>
<td>Group Discussion: Partnership Structure for Four Corners Network</td>
</tr>
<tr>
<td>2:15 PM</td>
<td>Group Discussion: Four Corners Focus Group Script Review</td>
</tr>
<tr>
<td>3:00 PM</td>
<td>Break Out Session 2: By Four Corners Participating Sites</td>
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<tr>
<td>3:45 PM</td>
<td>Post-Session Evaluation</td>
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<tr>
<td>4:00 PM</td>
<td>Closing Activity</td>
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<tr>
<td>4:20 PM</td>
<td>Closing Remarks &amp; Stipend Distribution</td>
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</table>
GROUND RULES

- Be present
- Step up, Step Back
- Honor diversity of opinions/experiences
- “Community Garden”
- Have fun
- ?
SITE SHARING PREPARATION

- Introductions
  - Name, Pronouns, Network Role

- Provide a brief description of your FQHC and city

- Tell us about noteworthy TGNC research, programming, services, etc.

- Describe your local TGNC community
SESSION I PRE-EVALUATION
Ensuring Research Benefits Communities:
The role of community-engaged research

Four Corners:
TGNC Health Research Advisory Network
April 2019
• What is research?

• What do you think of when you think of research?
Research is

- **Having a question** and seeking evidence to answer
- **Plan to seek answers**: systematically use predefined set of procedures to answer
- **Intensively seek answers**: gather info/collection evidence to answer
- **Analyze the evidence** and **draw conclusions** to answer - produce new knowledge
- Produces findings not determined in advance & applicable beyond immediate boundaries of study
Research ideology vs community experience

Research ..
- Is good
- Benefits society
- Identifies most important health topics for improvement
- Interventions establish most effective approaches
- Interventions help to reduce disparities
- Researchers carefully weigh cost & benefits

Community experience of research
- Most benefits research team
- Community benefit isn’t primary concern of research enterprise
- Researchers most concerned with short term deliverables (enrollment, study aims, publication)
- Driven by researcher priorities, not community priorities
- Influx of research grant resources isn’t sustainable long-term
- Research may harm community—more vulnerable the community, more likely research-related harm
Why would universities want to engage communities in research?

- Current approaches aren’t working - gap/time between research & practice
- Need perspective/input researchers don’t have
- $ Money $/Required to
- Communities demanding it
- Enlightened self-interest
How do communities think about getting involved with research?

• Mission match?
• State of the art practice?
• Real world realities: Time/cost/capacity?
• Tension between research & service
• Implementation sustainability? ‘Helicopter Research’
• Mistrust/Ethical concerns/Lack of respect- researcher understanding?
Community-Engaged Research

- Bidirectional exchange of expertise between academics (scientific experts) & communities (local, cultural, practice experts) that aims to increase the value of research for improving health & health equity

- Broad spectrum: minimal to equal partnership in all aspects
Community-engaged research

Orientation to research: changes role of researcher & researched: **Who makes the decisions? Who has the power?**

**Key Principles**
- Address local priorities
- Build on community strengths & resources
- Mutual respect of values. Power sharing & flexibility.
- Results that mobilize & catalyze change. Disseminate findings to all partners
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<thead>
<tr>
<th></th>
<th>Not engaged</th>
<th>Engaged</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research question</strong></td>
<td>Researcher generated/initiated</td>
<td>Collaboratively generated/designed</td>
</tr>
<tr>
<td><strong>Decision-making</strong></td>
<td>Scientist in complete control</td>
<td>Shared governance/ ownership</td>
</tr>
<tr>
<td><strong>Resources</strong></td>
<td>Limited sharing</td>
<td>Shared</td>
</tr>
<tr>
<td><strong>End point</strong></td>
<td>When data are analyzed</td>
<td>Makes sure what is learned is used</td>
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Spectrum

Inform

Consult

Involve

Collaborate

Empower

We will keep you informed
We will consider your input and give feedback about how it informed our decisions
We will ensure that your input is considered among the choices we implement
We will work together and incorporate your views as much as possible
We will implement what you decide
Community-Based Participatory Research (CBPR)

A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change...”

~W K Kellogg Community Health Scholars Program
• **Patient Centered Outcomes Research (PCOR):** Bringing together all stakeholders in healthcare enterprise to set research priorities, with patients at the center. *Meaningful involvement of patients & other stakeholders in all steps of research process.*

• **Practice-based research (PBR)-** primary care clinicians & practices working with researchers to answer community-based healthcare questions & translate findings into practice
Reflection BEFORE & during engagement

Research & engagement status quo?

- Current involvement, history
- Support (leadership, board, frontline staff, clients)?
- Value & use in decision-making?
- Priorities/agenda?
- Who decides on participation? Who gives input?
- Capacity
Reflection BEFORE & during engagement

How will it benefit community/clients/organization?

How will it add to research success/ outcomes? Researcher’s scholarship?
How is research benefiting the community partner?

- Is it providing a needed service for their clients? Is it sustainable to their CBO?
- Will it raise capacity of CBO staff and community?
- Will the research be valuable to CBO practice/operations?
- Will researchers better understand CBO/community/clients?
- Is research bringing resources/funding to the CBO?
Reflection BEFORE & during engagement
Who is “The Community”? Who represents the community?

Stakeholders impacted by the research/topic

Stakeholders who have power to make change based on findings
Reflection BEFORE & during engagement

Most experiencing inequities

Individual community contact vs organizational engagement

Faculty engagement vs institutional engagement
Reflection BEFORE & during engagement

Reflection BEFORE & during engagement
Engagement in Research Phases

- Find partners/form team
- Develop research question(s)
- Plan study
- Conduct research
- Analyze data
- Share findings
- Take action
Proposed domains and elements of stakeholder impact

Post Research/Translation
- Formulating next research questions
- Impact on community researched
- Participant follow-up

Dissemination/Translation
- Cultural relevance and appropriate language of message delivery/materials
- Co-authorship
- Appropriate audiences

Analysis
- Alternative interpretation of results
- Attention to factors not accounted for in the literature
- Context for relevance to patients/stakeholders

Pre-Research/Proposal Development
- Idea/topic generation
- Setting research priorities
- Relevance/Purpose

Ethics
- Infrastructure
  - Time/Cost/Compensation for stakeholders
  - Structure for shared decision making
  - Sharing of funds

Engagement
- Research Design
  - Define population
  - Cultural appropriateness
  - Research methodologies

Quality Improvement
- Implementation
  - Best approaches to recruitment and retention of research participants
  - Best approaches to data collection
  - Setting and environment for implementation

Boyer et al. A Tool to Assess Stakeholder Engagement in Research, April 2015
The Continuum of Community (Stakeholder) Engagement in Research

- **Patient/Community-Driven Research:** Stakeholders serve as Principal Investigator (PI) or Co-PI and are leading the research.
- **Research Team Members:** Stakeholders are integral members of the research team and participate in key activities.
- **Advisory and Governance:** Stakeholders serve on boards, councils and committees that provide oversight and/or guidance.
- **Focus groups, semi-structured interviews, nominal groups techniques, Community Engagement Studios:** Stakeholders serve specific, time-limited roles.
- **Surveys, online polling, listening sessions:** Broader community of stakeholders provides brief input.

Number of **Stakeholders**

Extent of Engagement

Ongoing Involvement

Wilkins CH et al. 2015
How are communities/clients impacted by research?

• How are they involved in the proposed research?
• Does budget reflect clinic/clients contributions? (CAB/patient support, dissemination, indirect costs for space)
• Does it minimize disruption of clinic workflow/ client service?
• How will findings be shared with communities/ clients?
What resources does it take to conduct engaged research?

- Funding
- Engagement skills/research skills
- Community/academic knowledge
- Policies/procedures/infrastructure
- Time
- Support of leadership/community
Institutional & Systemic Capacity for Engaged Research

- Academic Institution/Health Institution
- Funders
- Academic journals
- Public agencies/policy makers
Challenges

• Trust & respect (or lack of), power differentials
• Relationship building process
• Time-consuming/Effort
• Compromise/conflict
• Isms
• Community research not always understood/supported by community or university leaders- pay for colleagues’ errors
• Services vs research
• Ethical issues unique to engaged research
Getting Started

- Take time to get to know each other
- Decide if & how you want to work together
- Who is missing from the table?
- Keep working on & paying attention to trust & healthy relationships
- Talk about how you want your partnership to work
- Plan for disagreements
- Set up partnership structures & process to support you
National Resources

NIH CTSA
National Institutes of Health Clinical & Translational Science Awards

Community-Campus Partnerships for Health
Promoting Health Equity and Social Justice

www.ccphealth.org

Journal

Patient Centered Outcomes Research Institute:
www.pcori.org

Community-Based Public Health Caucus
Alliance for Research in Chicagoland Communities

Celebrating 11 years of engagement and action

Mission: to catalyze and support meaningful community and academic engagement across the research spectrum to improve health and health equity
ARCC STEERING COMMITTEE

Health & Medicine Policy Research Group

Government Agencies: Chicago Department Of Public Health, Chicago Public Schools

Northwestern Faculty & Academic Staff: Inger Burnett-Zeigler PhD, Rebecca Carl MD, Tara Gill PhD, Gail Huber PT PhD, Prakash Jayabalan MD PhD, Lisa Kuhns PhD, Holly Manprisio MPH, Matt O’Brien MD, Siobhan Phillips PhD MPH, J.D. Smith PhD, Theresa Sukal-Moulton, DPT, PhD, Shaan Trotter MS, Sarah Welch MPH
Strategic Focus Areas

Commitment to Culture of Engagement
Capacity for Engaged Research
Support for Research Conduct
Actionable Research Findings
ARCC Resources

- [www.ARCConline.net](http://www.ARCConline.net) and [ARCC@northwestern.edu](mailto:ARCC@northwestern.edu)

- [www.ARCCresources.net](http://www.ARCCresources.net)

- Monthly Resources & Opportunities [listing](#)

- April 18 IPHAM seminar- live stream available
BREAK OUT SESSION 1: BY NETWORK ROLE

- Clinicians, Community Members, Researchers

- What are you excited about? nervous about?
- What do you wish others knew about your role/perspective? What do you wish you knew about others role/perspectives?
- What does it look for you to feel most respected/heard?
BREAK OUT BY NETWORK ROLE: REPORT OUT

- Please share....
  - At least 1 note about assets/resources/strengths
  - At least one note about resources/things you’re seeking
LUNCH
LET'S TALK ABOUT PREP
GROUND RULES & PARTNERSHIP STRUCTURE

- Getting to know each other
- Decided to work together
- Who is missing from table?
- Partnership process
  - Ground rules for Four Corners?
  - What will help to deepen & sustain Four Corners relationships?
  - Communication styles/modes?
  - Decision making process?
  - Possible disagreements? Ways to address?
PARTNERSHIP STRUCTURE & PROCESS

- Roles & Responsibilities
- Leadership
- Documented agreement
FUTURE MEETINGS & TRAINING

- Things you want to learn
- Things you want to teach
- Resources you want to share
FOUR CORNERS FOCUS GROUPS

- **Primary goal:** Explore community strengths, priorities, barriers/facilitators to research, preferred ways to receive TGNC health and/or research information

- 8 focus groups total (2 per city)
  - Scheduled between May and June of 2019
  - 8-10 TGNC identified participants per group
  - Approximately 60 minutes per group
  - Includes food, a participation stipend, and a community-building activity
FOCUS GROUP SCRIPT REVIEW

Four Main Topics:

1. Understanding community strengths, resiliency, and health
2. Identifying community health priorities
3. Community engagement in research and research priorities
4. Meaningful ways to disseminate TGNC research/health findings

- Findings to be reviewed as group at future meeting
BREAK OUT SESSION 2: BY SITE

**LA LGBT Center, Whitman-Walker Health, Howard Brown Health, Legacy Community Health**

- How will you communicate with other folks in your local partnership about what you learned today?
- Any unique ground rules for your site?
- Any logistics to discuss for your site (e.g. communication preferences?)
- Local next steps?
SESSION 1 TRAINING POST-TEST
CLOSING ACTIVITY
DON'T FORGET TO TURN IN YOUR PRE-AND POST TESTS & PICK-UP YOUR PARTICIPATION STIPEND!