Enhancing Community Health Center PCORI Engagement (EnCoRE)

This work was partially supported through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (NCHR 1000-30-10-10 EA-0001).

With support from:

\( N^2 \) PBRN

funded by:
Enhancing Community Health Center PCORI Engagement (EnCoRE)

Session 3: Community Engagement for Selecting and Designing Interventions for Testing

Presenters:
Rosy Chang Weir, PhD
Director of Research
Association of Asian Pacific Community Health Organizations (AAPCHO)

Michelle Jester, MA
Research Manager
National Association of Community Health Centers (NACHC)
Project Partners

Clinical Directors Network (CDN)  
New York, NY

Jonathan N. Tobin, PhD  JNTobin@CDNetwork.org

National Association of Community Health Centers (NACHC)  
Washington D.C.

Michelle Proser, MPP  MProser@NACHC.org
Michelle Jester, MA  MJester@NACHC.org

The Association of Asian Pacific Community Health Organizations (AAPCHO) Oakland, CA

Rosy Chang Weir, PhD  rcweir@aapcho.org

Access Community Health Network  
Chicago, IL

Danielle Lazar, Danielle.Lazar@accesscommunityhealth.net

Institute for Community Health (ICH) a Harvard Affiliated Institute  
Cambridge, MA

Shalini, A. Tendulkar, ScM, ScD  stendulkar@challiance.org
Leah Zallman  lzallman@challiance.org

The South Carolina Primary Health Care Association (SCPHCA)  
Columbia, South Carolina

Vicki Young, PhD  vickiy@scphca.org
Goal:
To adapt, enhance, and implement an existing year long training curriculum designed to educate and engage Health Center teams including patients, clinical and administrative staff in Patient Centered Outcomes Research (PCOR).

Objectives:
• Build infrastructure to strengthen the patient-centered comparative effectiveness research (CER) capacity of Health Centers as they develop or expand their own research infrastructure and engage in PCOR/CER
• Develop, implement, and disseminate an innovative online training, which will be targeted to and accessible at no cost to all Health Centers and other primary care practices. Content will prepare Health Center patients, staff, and researchers in the conduct of community-led PCOR
• Evaluate, refine, and disseminate training resources to Health Centers and other primary care practices nationally
Session 3: Community Engagement in Research

December 16, 2014
Michelle Jester, Research Manager, National Association of Community Health Centers
Rosy Chang Weir, Director of Research, Association of Asian Pacific Community Health Organizations (AAPCHO)
Training Goals

• Understand community engagement and the difference between patient engagement and community engagement

• Learn methods and models of community engagement

• Identify potential barriers to community engagement in research to complete a community engagement plan

• Understand potential selection bias in community engagement

• Update on projects and feedback on EnCoRE
Presenters

Michelle Jester, MA
Research Manager,
NACHC

Rosy Chang Weir, PhD
Director of Research,
AAPCHO
WHAT IS COMMUNITY ENGAGED RESEARCH?

http://www.umassmed.edu/ccts/funding/
Definition of Community Engagement

• A process that works collaboratively and equitably with community members to address issues and catalyze change that affect the well-being of those community members. (Fawcett et al., 1995).
## Difference Between Patient Engagement and Community Engagement

<table>
<thead>
<tr>
<th>Community Engaged Research</th>
<th>Patient Engaged Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Important to break down barriers to participating in research</td>
<td>Important to identify research topics of interest to patients</td>
</tr>
<tr>
<td>Builds knowledge and trust of research process and project</td>
<td>Empowers patients to be more active in their health care</td>
</tr>
<tr>
<td>Narrows health disparities and improves population health</td>
<td>Improves patient health outcomes</td>
</tr>
</tbody>
</table>

“The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”


“A process that “helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options...”


Both can lead to more long-term and sustainable interventions and improvements because patients and members of the community are involved and invested in the process and outcomes.
Benefits of Community Engagement

- Community involvement helps ensure:
  - Research is relevant and culturally appropriate
  - Higher participation and ownership
  - Community feels empowered
  - Research will result in action
  - More sustainable partnerships
  - Knowledge flows bi-directionally
  - Have mediums for dissemination
  - Research is relevant and culturally appropriate
  - Higher participation and ownership
  - Community feels empowered
  - Research will result in action
  - More sustainable partnerships
  - Knowledge flows bi-directionally
  - Have mediums for dissemination
How Does Community Engagement Apply to PCORI Proposals?

• Need to demonstrate past success in community building and how you engaged communities to achieve shared goals

• Community engagement particularly important for PCORI’s Pipeline to Proposal Program
PCORI Pipeline to Proposal Program

• Funding opportunity for organizations/individuals who are not usual candidates for research funding

• Designed to build capacity and infrastructure, develop research partnerships, and ensure underserved populations are engaged

• Goal: To support development of partnerships between organizations over a few years so that they can create high quality PCORI research proposals and projects

• Proposals are accepted for Tier 1 and Tier 3 only
PCORI Pipeline to Proposal

Tier 1
- $15,000
- 9 months
- Build relationship, develop infrastructure, communicate

Tier 2
- $25,000
- 12 months
- Mature partnerships, define research questions and priorities

Tier 3
- $50,000
- 12 months
- Develop PCORI proposal

Apply for PCORI Funding Announcement
PCORI Pipeline to Proposal Deadlines

• Letter of Intent: December 23, 2014

• Questions: January 25, 2015

• Application Deadline: February 16, 2015

• Announcement of Awardees: March 2015

• Start: May 1, 2015
COMMUNITY ENGAGEMENT METHODS
Role of a Health Center in a Research Community

• Knows the community so can help define research community and identify research champions

• Holds trust of the community so can be the bridge between community and researchers

• Shares information with the community throughout the research process

**Persons consulted by the researchers are at the periphery of the community.**

**Researchers retain total control of the project. There is community involvement, but it is passive.**

**Community leaders are asked not only for endorsement of the project, but for guidance in hiring community residents to serve as interviewers, outreach workers, etc.**

**Community members are first among equals in defining the research agenda.**
Engagement Methods

Methods of involving the community from the beginning

• Engage through CHC consumer board members
• Engage community champions who will attend regular quality meetings and listen to their input on health issues
• Develop Community Advisory Boards and involve patients in improving their health; Implement positive change based on input.
• Partner with community organizations, advocacy groups
• Educate community members at community events, health center newsletters, etc about opportunities to engage in their own healthcare decisions at the CHC
Engaging Community Members in a Chinese Diabetes Care Intervention at a CHC

- Development of project: focus groups/interviews regarding needs for diabetes care at local clinic and community
- Developed intervention for Chinese diabetic limited English proficient patients
- Community Advisory Group
  - 10 members (patients, family members, local providers)
  - Met every 2 months throughout project
  - Guided the study team to make changes in participant recruitment, instrument and protocol design, interview and focus group implementation, intervention protocols, data analysis, reports, and dissemination.
  - Community members received $50 stipends for each meeting
  - Reminder calls in language. Multiple translators used during meetings.
  - Culturally appropriate materials, food, and education to accommodate requests.
CHALLENGES TO ENGAGING THE COMMUNITY IN RESEARCH

http://mindthegap.smarthealthmessaging.com/
Challenges and Solutions to Patient Engagement

Challenges

• Partner does not seem to understand us, our unique context, or our patients
• Community members may not feel comfortable or prepared to be involved in research
• Time commitments and communication barriers
• Unclear and/or unrealistic expectations and roles
• Lack of knowledge, respect, and/or appropriate compensation
• Different goals between community and researchers (peer review)

Solutions

• Refer partners to “What Academics Need to Know about Community Health Centers” (http://bit.ly/1o2iWac)
• Provide training and educational opportunities (www.CDNetwork.org/NACHC)
• Delivery of interventions in community settings and by organizations trusted by stakeholders
• Have MOUs/MOAs
• Compensation for participation is included in budget
• Develop shared goals
QUESTIONS AND DISCUSSION OF SECOND HOMEWORK ASSIGNMENT
Questions on Community and Patient Engagement

• Progress update on engaging patients

• What has your experience been engaging communities in research?

• What do you see as some of the key challenges and some of the key facilitators to engaging the community in research? How would you overcome or use them?

• How would you begin engaging your community? Your board?
### Sample CHC Patient Engagement Plan

<table>
<thead>
<tr>
<th>Planning the study</th>
<th>Conducting the study</th>
<th>Disseminating study results</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient partner: Consumer Advisory Board (C.A.B)</td>
<td>• Stakeholders would inform us of what they would like to find out regarding the study question</td>
<td>• Stakeholders will assist in identifying useful publications, editing and conference spaces</td>
</tr>
<tr>
<td>• Present study idea at CAB board meeting</td>
<td>• Collaborate on study design, provide necessary tools</td>
<td>• Stakeholders will describe pertinent information</td>
</tr>
<tr>
<td>• Questionnaires for feedback</td>
<td>• Patients will inform us what they would like the care coordinator to do</td>
<td>• Community presentation of findings</td>
</tr>
<tr>
<td>• Invite them to share what are the best ways to assess usefulness of Care Coordination</td>
<td></td>
<td>• Patients will review presentations to determine appropriate language</td>
</tr>
<tr>
<td>• Patient partners sit in on study planning sessions and provide feedback</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Sample CHC Patient Engagement Plan**

<table>
<thead>
<tr>
<th>Reciprocal Relationships</th>
<th>Co-learning</th>
<th>Partnership</th>
<th>Trust, Transparency, Honesty</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patients, stakeholders, and key personnel will determine what is best to share with the community</td>
<td>• Regular meetings: stakeholders and patient partners know each stage of the research process</td>
<td>• Utilize C.A.B meeting location to minimize burden of traveling</td>
<td>• Monthly meetings: discuss status updates, concerns, progress</td>
</tr>
<tr>
<td>• Patients will have final say in the community presentation language</td>
<td>• Each group can inform the other about study expectations, discuss patients concerns</td>
<td>• Schedule meetings before or after their regular board meeting for convenience</td>
<td>• Bi-weekly conference calls with key community members and stakeholders</td>
</tr>
<tr>
<td>• Head patient partner and lead stakeholder will help research personnel draft all pertinent documents</td>
<td></td>
<td>• Incentives for food and transportation will be included in the budget</td>
<td>• Emails as needed for additional means of contact</td>
</tr>
<tr>
<td>• Stakeholders will help edit documents and create abstracts, posters, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
STUDY DESIGN AND SELECTION BIAS
What is Research (Study) Design?

• Research design can be thought of as the *structure* of research -- it is the "glue" that holds all of the elements in a research project together.

• A research study contains a:
  • Pre-program measurement or observation
  • Intervention or treatment
  • Post-program measurement or observation
Questions Asked in Research Study

• Is the difference between the pre and post measurement due to the intervention? Why or why not?

• If there was a change in the program participants, can we assume that similar results will also occur in another group? Why or why not?
Participants

• Intervention group
  • Those who receive the intervention

• Groups used to compare
  • Control group - those who do not receive the intervention; have been randomly assigned to group
  • Comparison group - those who do not receive the intervention; have not been randomly assigned to group

IN HEALTH CARE STUDIES, THE CONTROL OR COMPARISON GROUP RECEIVES USUAL STANDARD OF CARE
Hierarchy of Possible PCORI Designs (from least control to most control)

- **Quasi-experimental** (defined by comparison of intact groups, those not randomized...comparison groups)

- **Experimental** (defined by comparison after randomization...control groups)
Determining design

Classical research hierarchy:
- Case study
- Case series
- Cohort studies
- Non-randomized intervention trials
- Randomized controlled trials
Different designs for different questions

- Cross Sectional Study
  - Assess relationships at one point in time
- Longitudinal Study
  - Assess relationships at more than one point in time

- Qualitative Research
  - Verbal, non-numeric data - focus groups, interviews
  - Descriptive and exploratory – Generate hypotheses
- Quantitative Research
  - Numeric data – surveys, EMR data
  - Focused and conclusive - Test hypotheses
Threats to What We Think We Know

- Internal Validity
- Bias
- Chance
- Association
- Causation
- Confounding
- Generalizability

Source: Harvard Community Catalyst. Building Primary Care Research Infrastructure at Your Community Health Center. Module 1: Research and QI
## Validity (External & Internal)

<table>
<thead>
<tr>
<th>Technical Term</th>
<th>Meaning</th>
<th>Example</th>
<th>Technique to Maximize</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Validity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Truth”</td>
<td>Are we measuring what we intend to measure in the study, or is what we see actually caused by something other than the intervention?</td>
<td>Research could not determine if a diabetes education program improved health because it did not account for the availability of new medication [not valid]</td>
<td>Choose previously validated tool</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Blind the process/observer</td>
</tr>
<tr>
<td><strong>Reliability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Consistency”</td>
<td>Are we measuring the impact and other needed data in the same way every time?</td>
<td>Diabetes intervention used scale to measure weight. A patient who is 200 pounds steps on the scale 5 times and it measures 150 pounds each time. [reliable, but not valid]</td>
<td>Repeat the measurement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Pilot test and refine the measurement tool</td>
</tr>
</tbody>
</table>
QUESTIONS AND DISCUSSION
Questions for Discussion

• Study Design and Selection Bias
  • What do you think are some of the potential sources of selection bias with your study? How can you avoid these selection biases?

• Feedback on overall EnCoRE Project
  • How can we make this more helpful, relevant, and comprehensive to meet your needs?
Get a Head Start on Your Homework

• Let’s think through each project...
  • What are your questions?
  • What design should you use?
  • What would be your key variables you want to see change in?
  • What resources do you need?
  • What is your health center capacity to conduct?
  • Who are the partners and what skills do they bring?
Next Webinar

- Measurement, Measurement Error, and Descriptive Statistics
- Tuesday, January 20th
- 3:30 – 5:00 pm EST
Thank You!

Michelle Jester, MA
Research Manager,
National Association of Community Health Centers
T: (202) 331-4609
E: mjester@nachc.org

Rosy Chang Weir, PhD
Director of Research,
Association of Asian Pacific Community Health Organizations (AAPCHO)
T: (510) 272-9536  x107
E: rcweir@aapcho.org