Enhancing Community Health Center PCORI Engagement (EnCoRE)

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

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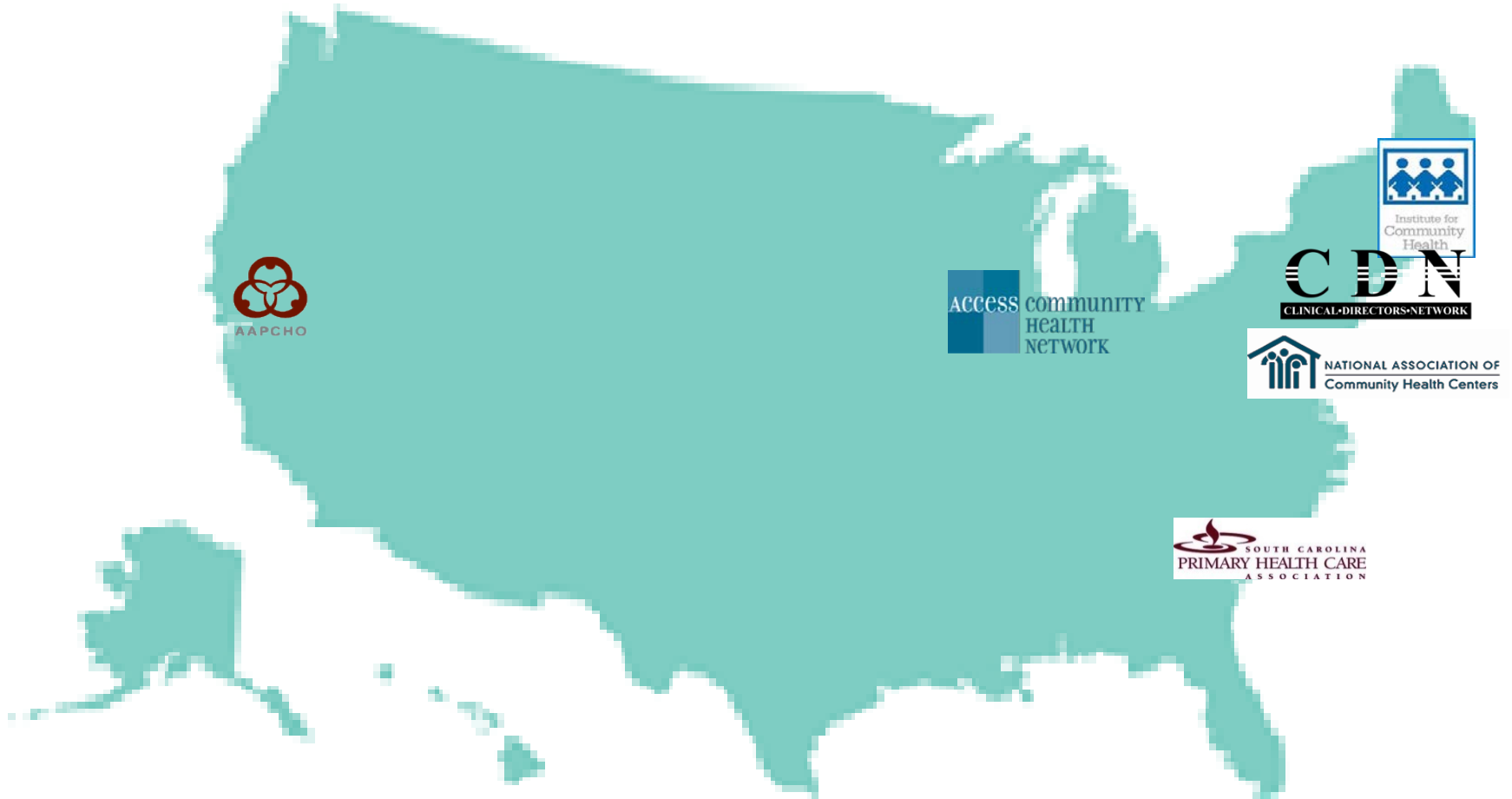

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EnCoRE

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

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WHAT IS COMMUNITY ENGAGED RESEARCH?

- 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

Community Engaged Research	Patient Engaged Research
Important to break down barriers to participating in research	Important to identify research topics of interest to patients
Builds knowledge and trust of research process and project	Empowers patients to be more active in their health care
Narrows health disparities and improves population health	Improves patient health outcomes
"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." Centers for Disease Control and Prevention. Principles of community engagement (1st ed.). Atlanta (GA): CDC/ATSDR Committee on Community Engagement; 1997.	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…" Patient-Centered Outcomes Research Institute Board of Governors March 2012 Meeting Notes. Accessed January 10, 2014 from http://www.pcori.org/research-we-support/pcor/.

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

Research will result in action

Have mediums for dissemination

Community feels empowered

More sustainable partnerships

Knowledge flows bi-directionally

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

- 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

CDN CLINICAL·DIRECTORS·NETWORK

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

NATIONAL ASSOCIATION OF Community Health Centers

AAPCHO

SOUTH CAROLINA PRIMARY HEALTH CARE ASSOCIATION

access community HEALTH NETWORK

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
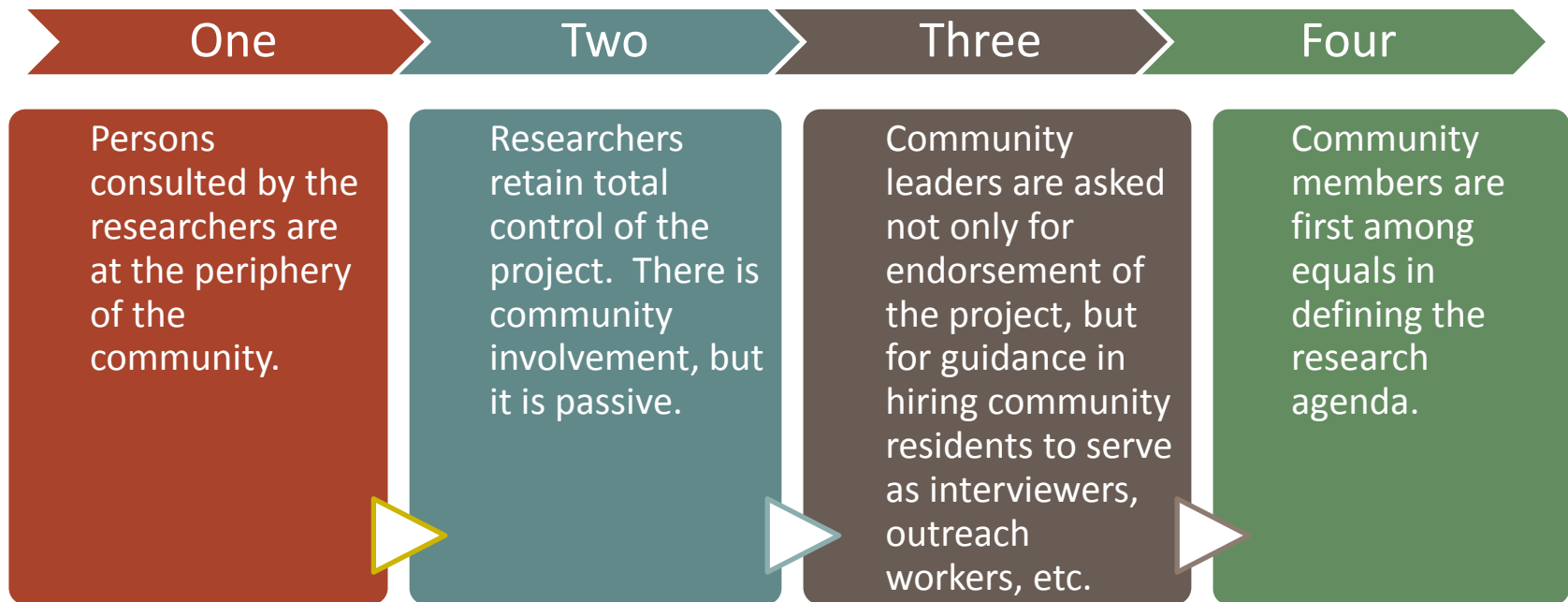
- Start: May 1, 2015

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

Various Levels of Community Engagement

One	Two	Three	Four
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.

1. Hatch J, Moss N, Saran A et al. Community research: Partnership in Black communities. *American Journal of Preventive Medicine.* 1993 Nov-Dec;9(6 Suppl):27-31; discussion 32-34.

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

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
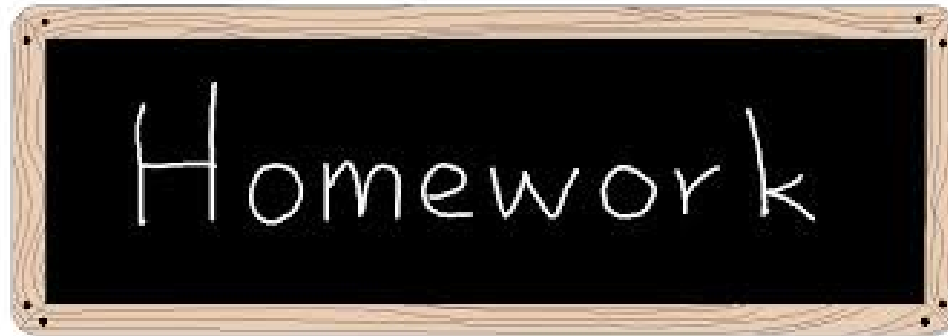
QUESTIONS AND DISCUSSION OF SECOND HOMEWORK ASSIGNMENT

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

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

Sample CHC Patient Engagement Plan

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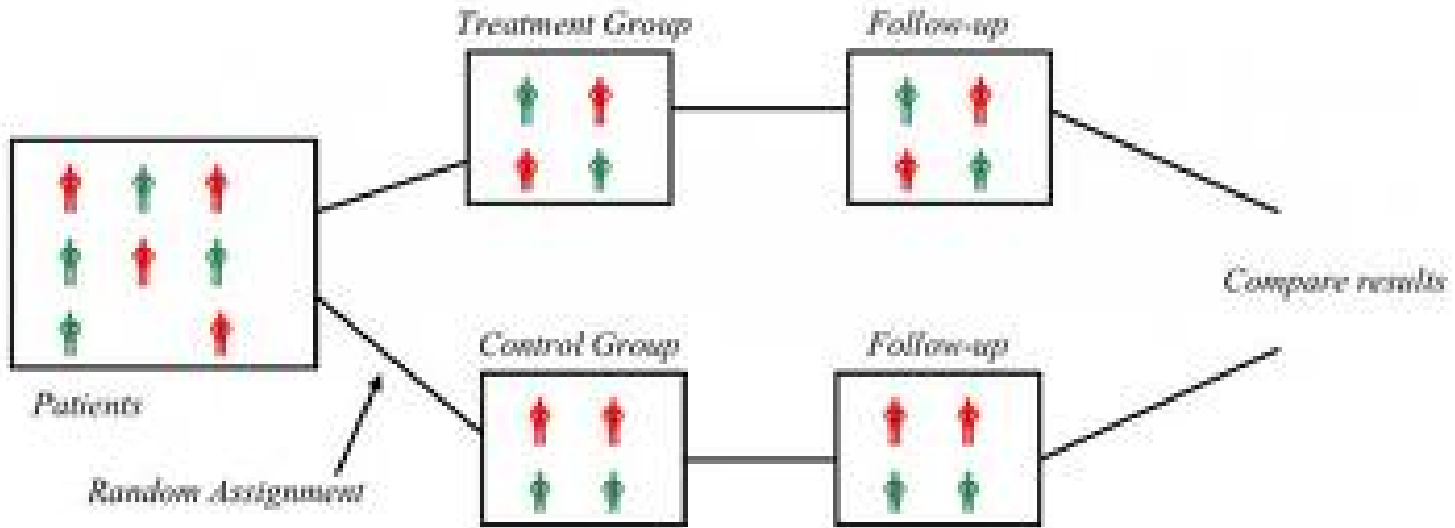
STUDY DESIGN AND SELECTION BIAS

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

- 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?

- **Intervention group**
  - Those who receive the intervention

- **Groups used to compare**
  - <u>Control group</u> - those who do not receive the intervention; <u>have</u> been randomly assigned to group
  - <u>Comparison group</u> - those who do not receive the intervention; <u>have not</u> been randomly assigned to group

IN HEALTH CARE STUDIES, THE CONTROL OR COMPARISON GROUP RECEIVES USUAL STANDARD OF CARE

- **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:

Advancing Rigor

  Case study

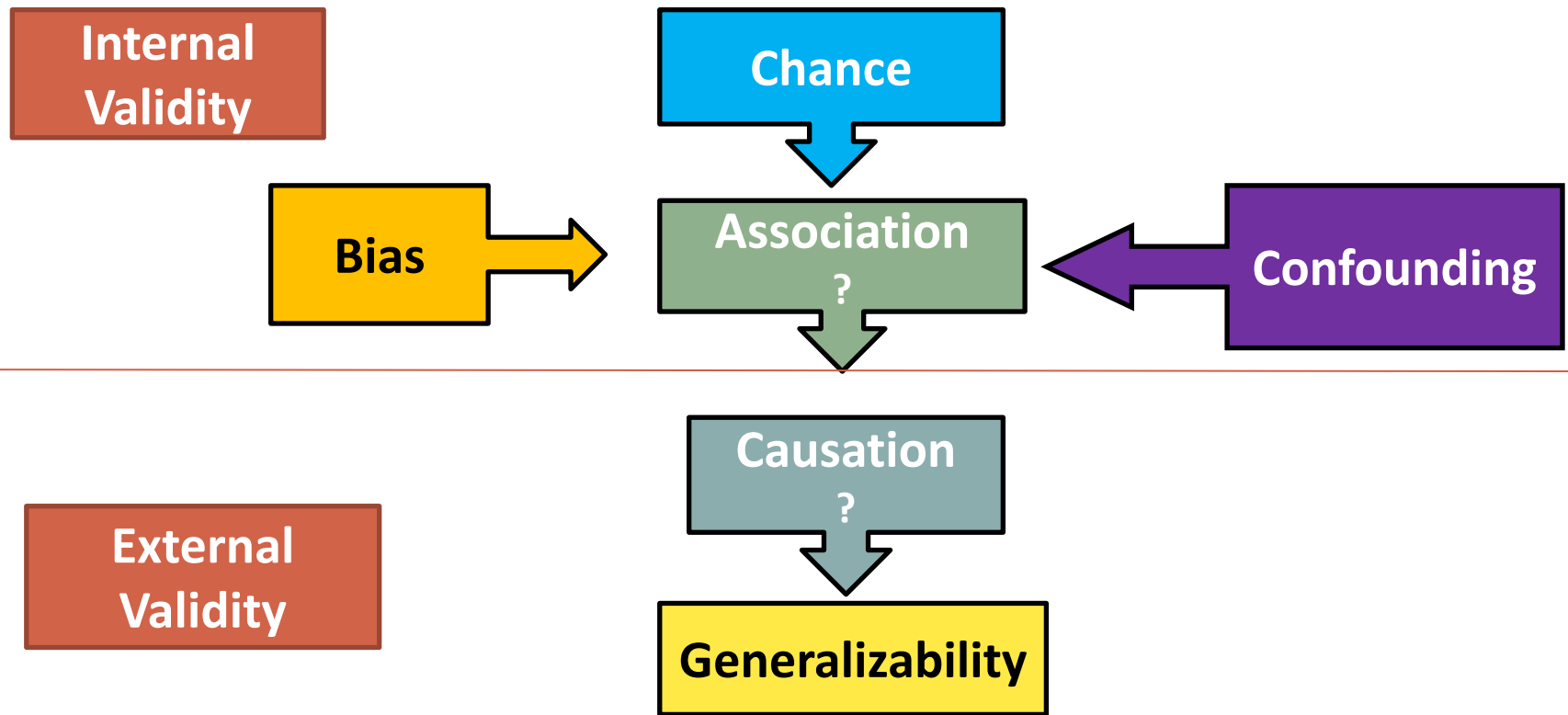 Case series

  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

Chance

Bias

Association ?

Confounding

External Validity

Causation ?

Generalizability

Source: Harvard Community Catalyst. Building Primary Care Research Infrastructure at Your Community Health Center. Module 1: Research and QI

Validity (External & Internal)

Technical Term	Meaning	Example	Technique to Maximize
Validity **"Truth"**	Are we measuring what we intend to measure in the study, or is what we see actually caused by something other than the intervention?	Research could not determine if a diabetes education program improved health because it did not account for the availability of new medication [not valid]	Choose previously validated tool Blind the process/observer
Reliability **"Consistency"**	Are we measuring the impact and other needed data in the same way every time?	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]	Repeat the measurement Pilot test and refine the measurement tool

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?

- 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

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