Introduction
Partners in Research Community Scholars Training

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University of Minnesota
West Side
Community Health Services
Agenda

- Introduce ourselves and our health interests
- Training course overview
- Community-based Participatory Action Research
- Choosing a research topic
- Representing your community
- Assignment
- Evaluation
Introduce “Partners in Research”

- Partners in Research is funded by NIH a grant number R03DA0266632-01
- “Partners in Research” Project
  - Community Scholars Training
  - Academic Faculty Training
  - Matching community and academy partners
  - Creating research projects
  - Submitting projects for funding
  - Informed consent to participate
Introduction and Health Interests

- What is your name and affiliation?
- What areas of health interest you?
- And why?
Community Scholars Training

- **Overall goal:**
  - Increase the ability of Latino, Hmong, and Somali community members to partner with academic researchers in community-based participatory action research.
Training Objectives

• By training end, the participants will be able to:

• *Knowledge:*
  1. Describe advantages of Community-based Participatory Action Research (CBPAR).
  2. Describe basic research processes (question, design and analyses).
  3. Describe strategies for effective CBPAR partnerships.
Skills:
1. Perform and analyze individual interviews.
2. Read quantitative data tables.
3. Write letter of intent for grant.
4. Advocate for community as partner with academic researchers.
5. Implement communication and negotiation skills to overcome potential barriers to developing strong partnerships.
Training Objectives Cont.

- **Attitudes:**
  1. Be excited about the potential of CBPAR to improve health of communities.
  2. Be willing to hold self and partners accountable for success of partnerships.
Training Schedule

- Introduction
- Basics of Research, Part 1
- Basics of Research, Part 2
- Ethics in Research
- Community Collaboration in Research, Part 1
- Community Collaboration in Research, Part 2
Establish rules/ expectations

• What rules/ expectations of behavior for this group?
CBPAR - Definitions

• Community-based
• Participatory
• Action
• Research
• Other acronyms: CBR, CBPR, PAR, CPR
• Examples: Review handouts
Barbara Israel - Definition

- “CBPR is a partnership approach to research that equitably involves all participants in all aspects of the research process where each person shares his/her expertise in order to enhance knowledge and to develop interventions that will benefit the whole community.”

- Israel et al 1998.
Research Steps

- Health concerns identified
- Instruments designed and data collected
- Study designed and funding sought
- Intervention designed and implemented
- Participants recruited and retained
- Data analyzed and findings interpreted
- Findings written/disseminated
- Findings translated into action

Partners in Research
## Degrees of Community Engagement in Research

<table>
<thead>
<tr>
<th>No community engagement</th>
<th>Community placed research</th>
<th>Collaboration with community, but researcher driven</th>
<th>CBPR or CBPAR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary data analysis, or basic science</td>
<td>Recruitment from community organization</td>
<td>Community sponsor on researcher defined project</td>
<td>Community involved in all aspects of research</td>
</tr>
</tbody>
</table>

Task Force on Community Research (2009). University of Minnesota
The Spectrum of Research

**Researcher Driven**
- Researchers select research topics, questions, & methods
- Power and decision making are in researchers’ hands
- Researchers are the experts
- Primary goal is knowledge production for its own sake

**Participatory**
- Communities & researchers decide about topics, questions, & methods
- Power and decision making are shared equally
- Communities/researchers are experts and co-learners
- Primary goals are improved health, empowerment & capacity building

Task Force on Community Research (2009). University of Minnesota
Barbara Israel- Key Principles

- Recognizes community as a unit of identity.
- Builds on strengths & resources within the community.
- Facilitates collaborative, equitable partnership in all research phases and involves an empowering and power-sharing process that attends to social inequities.
- Promotes co-learning and capacity building.
- Integrates and achieves a balance between research and action for mutual benefit of all partners.
- Emphasizes public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease.
- Involves systems development through cyclical and iterative process.
- Disseminates findings to all partners and involves all partners in the dissemination process.

Israel et al, 2008
Budd Hall - Seven Characteristics

- The "problem" originates within the community or workplace.
- The research goal is to fundamentally improve the lives of those involved, through structural transformation.
- The people in the community or workplace are involved in controlling the entire research process.
- The focus of PAR is on oppressed groups whose issues include inaccessibility, colonization, marginalization, exploitation, racism, sexism, cultural disaffection, etc.
- Participatory research plays a role in enabling by strengthening people’s awareness of their own capabilities.
- The people themselves are researchers, as are those involved who have specialized research training.
- The researchers with specialized training may be outsiders to the community, but are committed learners in a process that leads to militancy (fighting for change) rather than detachment.
CBPAR is NOT a research project.

“It is a social change project of which the research is one piece.

As such, it has three goals:
Learn relevant knowledge/skills,
Develop relationships of solidarity,
Engage in action that wins victories and builds self-sufficiency.

Doing research is not, in itself, a goal.

Research is only a method to achieve these broader goals.”

Randy Stoecker, 2007
Roles of Community Members

- What ideas do you have about the role of community members in CBPAR?
Roles of Community Members

- Advocate for community’s interests, desires, and priorities.
- Participate in research decisions and processes.
- Be attentive to CBPAR research ethics from the community perspective.
- Identify capacities in community that will be strengthened through research project.
- Advocate for application of research findings (service/ or policy/ or further research).
- Identify appropriate venues to share findings with broader community and community stakeholders.
Research Steps

1. Health concerns identified
2. Study designed and funding sought
3. Participants recruited and retained
4. Instruments designed and data collected
5. Intervention designed and implemented
6. Data analyzed and findings interpreted
7. Findings written/disseminated
8. Findings translated into action
Choosing a Research Topic

- Is your area of health interest important in your community?
- Is it a health disparity?
- What do you already know and don’t know about the topic that could be important?
- How would that information improve the health of your community?
- How can research help your community improve its health in this area?
- How could partnering with an academic health researcher render information that could be useful?
Representing Your Community

- What community/communities do you belong to?
- How can you represent your community/communities?
Assignments

- Consider health disparity area
- Read chapter by Barbara Israel and colleagues (optional) (Israel et al, 2008)
Evaluation

1. What did you learn today?
2. What do you want to learn more about?
3. What went well?
4. What didn’t go well?
5. What suggestions do you have for improvements?
Session 2
Partners in Research Community Scholars Training: Research Basics

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University of Minnesota
Academic Health Center
Driven to Discover™

West Side
Community Health Services
Agenda

- Discussion: Community representation
- Developing a research topic
- Research paradigms/ Models: Quantitative and qualitative
- In-depth interviewing
- Assignment
- Evaluation
Objectives

- Will be able to:
  - Describe basic research elements so can be familiar with research processes.
  - Compare/contrast qualitative and quantitative research approaches.
  - Interview key informants about chosen health topic.
1. What communities do you belong to?

Discussion: Community Representation

2. How can you represent your community or communities?

- What can you do to increase your ability to represent community in research?
- How can you connect with and advocate for the diversity in your community?
- Or do you just represent one sub-group in the community?
Developing a Research Topic

- Identify health topic: dependent variable
- Identify associated influences/ contributors: independent variables
- Explore each independent variable in depth
- Link independent variables with dependent variable by an explanatory hypothesis

- Independent variable
  - Independent variable
  - Independent variable
  - Dependent variable
Identify an Issue (DV)

- What is the issue?
- Why is it important?
- Who is affected by it?
- Why is this serious enough to research?
- How can you find/collect the information?
- Where can you find/collect the information?
- What could be the benefits of research?
- What could be the problems from research?

Participatory Action Research Curriculum for Empowering Youth; National Teen Action Research Center of the Institute for Community Research [2000]
Identify the Influences (IV)

- What influences the health topic? (IV)
- Who is affected by these influences?
- When might this occur in someone’s life?
- Where might this occur?
- Why is this important?
- How might the IV affect the DV?
Explore the influences (IV)

- Who would have information about these?
- What kind of information do you want to collect?
- How can you collect the information?
- Where can you collect the information?
- When is the best time to collect the information?
- Why is it important to gather this information?
Imagine Possible Actions

- Who might be interested in the information?
- What actions can you take on this information?
- How can we use this information to make changes?
- When is the best time to take these actions?
- Where can you take these actions?
- Why should we and others care about making changes?
Research Paradigms/ Models

- Quantitative Research Paradigm/ Model
- Qualitative Research Paradigm/ Model

Which model you chose depends upon:
- your overall goal in gathering the data
- what research questions you want to ask and
- what research methods you want to use.
## Comparing Quant & Qual

<table>
<thead>
<tr>
<th></th>
<th>QUANTITATIVE</th>
<th>QUALITATIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dominant Disciplines</td>
<td>Epidemiology</td>
<td>Anthropology</td>
</tr>
<tr>
<td></td>
<td>Basic Science</td>
<td></td>
</tr>
<tr>
<td>Theory</td>
<td>Positivistic</td>
<td>Relativistic</td>
</tr>
<tr>
<td></td>
<td>Objective reality</td>
<td>Subjective reality</td>
</tr>
<tr>
<td>Model of Reasoning</td>
<td>Linear</td>
<td>Iterative (recursive)</td>
</tr>
<tr>
<td></td>
<td>Reductionistic</td>
<td>Holistic</td>
</tr>
<tr>
<td></td>
<td>Deductive</td>
<td>Inductive</td>
</tr>
<tr>
<td>Unit of Study</td>
<td>Measurable phenomena</td>
<td>Experienced reality</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>Mathematical</td>
<td>Naturalistic</td>
</tr>
<tr>
<td></td>
<td>Numbers</td>
<td>Words and stories</td>
</tr>
</tbody>
</table>

|Partners in Research|
## Research Intent

<table>
<thead>
<tr>
<th>QUANTITATIVE</th>
<th>QUALITATIVE</th>
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</thead>
<tbody>
<tr>
<td><strong>Overall Goal</strong></td>
<td><strong>Interpretation</strong></td>
</tr>
<tr>
<td>Discovery</td>
<td>“This is what the earth means to us”</td>
</tr>
<tr>
<td>“We found the earth”</td>
<td></td>
</tr>
<tr>
<td><strong>Describe (numbers)</strong></td>
<td><strong>Describe (words/ stories)</strong></td>
</tr>
<tr>
<td>Explain</td>
<td>Explain</td>
</tr>
<tr>
<td><strong>Predict</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Discover universal truths</strong></td>
<td><strong>Discover local truths</strong></td>
</tr>
<tr>
<td><strong>Generalizations</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Theory testing</strong></td>
<td><strong>Theory generating</strong></td>
</tr>
<tr>
<td><strong>Theory testing</strong></td>
<td><strong>Theory testing</strong></td>
</tr>
<tr>
<td><strong>Test causal hypotheses</strong></td>
<td><strong>Discover experiences</strong></td>
</tr>
<tr>
<td><strong>Evaluate interventions</strong></td>
<td><strong>Discover meaning</strong></td>
</tr>
<tr>
<td><strong>Evaluate interventions</strong></td>
<td></td>
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</tbody>
</table>
## Research Questions

<table>
<thead>
<tr>
<th>Identification</th>
<th>QUANTITATIVE</th>
<th>QUALITATIVE</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>What is this?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Who is that?</td>
</tr>
<tr>
<td>Description</td>
<td>How many?</td>
<td>What is the nature of the phenomena?</td>
</tr>
<tr>
<td></td>
<td>How much?</td>
<td>What variations exist?</td>
</tr>
<tr>
<td></td>
<td>How often?</td>
<td>What does this mean?</td>
</tr>
<tr>
<td></td>
<td>What size?</td>
<td></td>
</tr>
<tr>
<td>Explanations</td>
<td>Does X relate to Y, Z?</td>
<td>What is happening?</td>
</tr>
<tr>
<td>Associations</td>
<td></td>
<td>What patterns exist?</td>
</tr>
<tr>
<td></td>
<td>Why did it happen?</td>
<td>How are things similar/ different?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How did it happen?</td>
</tr>
<tr>
<td>Explanations</td>
<td>Does X cause Y?</td>
<td></td>
</tr>
<tr>
<td>Predictions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation</td>
<td>What difference did program make?</td>
<td>What difference did program make?</td>
</tr>
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</tbody>
</table>
## Comparing Partners in Research

<table>
<thead>
<tr>
<th></th>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of Data Collection</td>
<td>Measurements, Questionnaires</td>
<td>Participant Observation, Long Interviews, Focus Groups</td>
</tr>
<tr>
<td>Sample Size</td>
<td>Generally large</td>
<td>Generally small</td>
</tr>
<tr>
<td>Sampling Strategy</td>
<td>Based on statistical power analyses, Based on randomization</td>
<td>Search for information rich cases &amp; continue until “saturation”, Purposeful Snowballing</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>Statistical</td>
<td>Interpretive</td>
</tr>
<tr>
<td>Generalizeability</td>
<td>High</td>
<td>Often low</td>
</tr>
<tr>
<td>Strengths</td>
<td>Easier to analyze and generalize to larger number of persons</td>
<td>In-depth understandings, unexpected insights</td>
</tr>
</tbody>
</table>
## Comparing Partners in Research

<table>
<thead>
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<th>QUANTITATIVE</th>
<th>QUALITATIVE</th>
</tr>
</thead>
</table>
| **Validity (goodness)** | Face Validity  
Content validity  
Construct validity               | Contextually based on completeness, plausibility, illustrativeness  
Multiple methods/ triangulation of data                                                                 |
| **Reliability  
(trustworthiness)**     | Statistically determined                                                      | Researcher, participant and process dependent                                                     |
| **Role of Researcher**       | Objective bystander – outside of the process                                  | Research instrument – part of the process                                                         |
| **Reflexivity**               | Non-existent                                                                  | Instrumental/ essential                                                                          |
| **Strengths**                 | Easier to analyze and generalize to larger number of persons                  | In-depth understandings, unexpected insights                                                      |
Can Combine: “Mixed Methods”

- Added value and understanding from different “ways of knowing.”
- Iterative approach where results from each method support use of the next method.
  - **Examples:**
    - Explore then count
    - Count then explain
    - Explore, then count, then explain
- Production of multiple “truths” or “realities.”
- Triangulation of methods for comparison of results.
- Involvement and buy-in from community.
Quantitative Methods

METHODS:
1. Measurements: biological, physical, psychological
2. Standardized instruments
3. Questionnaires/ surveys
4. Observation with standardized tool
Qualitative Methods

1. Participant Observation
2. Observation with mapping
3. In-depth interviews
   (open or unstructured and semi-structured)
4. Focus Groups
5. Elicitation techniques: pile-sorts/ body maps
6. Case studies: 1 or series
7. Open-ended questions on surveys
Examples

- Health disparity topic:
- If quantitative approach:
  Questions:
  Methods:
- If qualitative approach:
  Questions:
  Methods:
Qualitative Interviews

- Open-ended or unstructured
- Semi-structured
- Focus group
Interview Skills

- Listen
- Use probes
- Focus the interview
- Take notes
- Tape record
Interview Exercise

- Demonstration: Unstructured and semi-structured
- Create list of questions you want to ask community members about your chosen topic.
- Review with peer and then revise.
Assignments

• Conduct 1-3 interviews with “key informants” about your area of interest.
• Take notes (leave wide right margin) and bring to class.
• Consider an overall research approach to your chosen health disparity area.
Evaluation

• 1. What did you learn today?

• 2. What do you want to learn more about?

• 3. What went well?

• 4. What didn’t go well?

• 5. What suggestions do you have for improvements?
Session 3
Partners in Research Community Scholars Training: Research Basics cont.

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Agenda

- Quantitative research design and analyses
- Qualitative research design and analyses
- Share experiences with interviews
- Analyze interviews
- Discuss research project
- Assignment
- Evaluation
Objectives

- Will be able to:
- Describe basic research elements so can be familiar with research processes.
- Analyze quantitative survey data.
- Analyze qualitative interviews.
Quantitative Research Design

1. Define the research question
2. Formulate research hypothesis
3. Make operational definitions
4. Design research instruments
5. Gather data
6. Analyze data
7. Draw conclusions
8. Publish findings
9. Generate more questions and repeat linear research model
METHODS:
1. Measurements: biological, physical, psychological
2. Standardized instruments
3. Questionnaires/surveys
4. Observation with standardized tool

ANALYSES: Statistical analyses
1. Descriptive statistics of sample
2. Inferential statistics from sample to population
Data Analyses: Quantitative

- Statistical analyses
- Computer programs
- Role of statisticians
- Degrees of significant relationships, associations, causations
Example of Quantitative Study using CBPAR

Goals
Methods
Instruments
Findings
Qualitative Research Cycle

Identify area of concern

Explore area of concern

Collect Data

Analyze Data

Verify Triangulate

Reformulate Refine

Write conclusions
1. Participant observation
2. Observation with mapping
3. In-depth interviews (open or unstructured and semi-structured)
4. Focus groups
5. Elicitation techniques: pile-sorts/body maps
6. Case studies: 1 or series
7. Open-ended questions on surveys
Analysis Styles

Crabtree B & Miller W
Doing Qualitative Research
1st edition
Thematic analysis of interviews

- Consider each statement and assign a word that describes that statement. These words are “codes”.
- Re-code the entire interview.
- What major codes, which reflect major ideas?
- Can you combine major codes/ ideas into themes?
Follow-up questions

- What are main ideas?
- What are new ideas? What new questions arise?
- How gather more data to confirm/ refute?
- Interview same or new people? How choose?
- Would other people have same interpretations?
- How get other people’s interpretations?
- How put this information into action?
Work on research projects

- Research topic: Dependent Variable
- Contributing influences: Independent variables
- How investigate independent variables?
- Qualitative or qualitative paradigm?
- Research questions? Research methods?
Assignments

- Conduct analyses on key informant interviews.
Evaluation

1. What did you learn today?

2. What do you want to learn more about?

3. What went well?

4. What didn’t go well?

5. What suggestions do you have for improvements?
Session 4
Partners in Research Community Scholars Training: Ethics in Research

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Academic Health Center
Driven to Discover

West Side
Community Health Services
Agenda

- Discuss research projects with leaders
- Research Ethics
  Background
  Informed Consent
  Community participation
- Evaluation
- Assignments
Objectives

- Will be able to:
- Describe major historical tenets of research ethics.
- Describe 3 major components of research ethics.
- Apply community ethical considerations to phases of research.
Work on research projects

- Research topic: Dependent Variable
- Contributing influences: Independent variables
- Did in-depth interviews help identify more independent variables?
- How investigate independent variables?
- Qualitative or qualitative paradigm?
- Research questions? Research methods?
Research Abuses and Subsequent Research Codes

- Nuremberg Nazi Doctors Trial 1946
- Nuremberg Code 1947
  - Codes of ethics about research
  - Need informed consent without coercion
  - Requirements regarding scientific merit/design
- Declaration of Helsinki 1964
  - Distinguished between non-therapeutic and therapeutic research.
  - Encouraged that participants benefited from results
  - Stressed written consent forms
  - Has been revised/updated
Research Abuses and Subsequent Research Codes

- Tuskegee Syphilis Study 1932-1973
  1. National Research Act 1974
     Institutional Review Boards - IRBs
  2. Nat’l Commission Protection of Human Subjects in Biomedical and Behavioral Research
     a. Belmont Report 1979
     b. “Common Rule” 1991
Research Abuses and Subsequent Research Codes

- Human Radiation Experiments 1944-1974
  1. ACHRE Report 1995
  Informed consent may not overstate benefits and may not minimize risks, especially quality of life.

- Human Gene Therapy at U of Penn 1999
  Jesse Gelsinger died
  AAMC and AUA published guidelines
  Informed consent/ study design/ protection Disclosure of conflicts of interest
• 3 Ethical Principles:
  Respect for Persons
  Beneficence
  Justice

• Principles are applied in study design and informed consent process.
Belmont Report: Respect for Persons

• Two aspects, applied in informed consent:
  1. People must be treated as autonomous agents:
      Are unique and free. Have value and dignity. 
      Have the right and capacity to decide. Have the right to informed consent.
  
  2. People with diminished autonomy are entitled to special protection.
      People with diminished decision making capacity – vulnerable populations (difficult to make truly informed and voluntary choice): prisoners, children, subordinates, non-literate, non-English speakers, those involved in illegal activities. 
      Others: Hospitalized, institutionalized, pregnant women.
Belmont Report: Respect for Persons

- Informed Consent
  1. Information:
     Why, what, how, who, risks/benefits, etc
  2. Comprehension:
     People must be able to understand the information; presentation and form must fit the participants. Participants must be able to ask questions
  3. Voluntariness:
     Must be free of coercion or undue influence.

- Community representation can ensure respect for persons in the informed consent process.
Belmont Report: Beneficence

- Use kindness and charity towards participants.
- Protect social, physical, and mental well-being.
- Do not harm research participants.
- Maximize possible benefits and Minimize possible harms.
- Researchers need to inform assessment of risks/benefits, which considers risks/benefits to society as well as to individuals.
- Community representation can ensure beneficence.
Risks/ benefits must apply fairly to all people. Can’t include people because of ease. Can’t exclude people because of challenge. Must try to include all types of people in research (age, gender, ethnicity, etc). If exclude, need to defend rationale.

• Benefits be available to wide range of people.
• Special protection to vulnerable people.
• Community representation can ensure community participation is justified.
Belmont Report: Federal Regulations

- Review of Research by IRBs - Institutional Review Board
- Informed Consent of Subjects
- Institutional Assurances of Compliance
- Scientific Misconduct: Misconduct in science means fabrication, falsification, plagiarism or other practices that seriously deviate from common practices... does not include error or honest differences of interpretations or judgments of data.
Research Institutions have to review, via IRB:

- Ethical review of research protocol and informed consent in order to protect rights, safety and welfare of research subjects. Investigators are responsible for subjects’ safety:
  - Respect subjects dignity and autonomy
  - Protect subjects from harm by minimizing risks and maximizing benefits
  - Ensure that benefits/ burdens are shared fairly.

- Scientific Peer Review. The study design must state the scientific objectives, the research methods, security measures and all human subject issues.

- Administrative Review of Proposals, Grants, Contracts
What is Informed Consent?

“Consent given by a competent individual who has received the necessary information, has adequately understood the information, and .....has arrived at a decision without being subject to coercion, undue influence, or inducement, or intimidation.”

- CIOMS - Council of International Organization of Medical Sciences
Informed Consent Requirements

- Introduction
- Purpose of study
- Description of study procedures
- Potential risks or discomforts
- Potential benefits
- Alternatives
- Costs/Compensation
- Confidentiality
- Voluntary participation
- Contact persons
Risks and Benefits

- **Risks:**
  Any anticipated or foreseeable risks
  Physical, social, psychological risks
  Likelihood, severity, duration

- **Benefits:**
  Reasonably expected
  Not exaggerated
  Duration
Creating Informed Consent Documents

- Use appropriate language
- Use appropriate reading level
- Create verbal consent process
- Illustrate with appropriate images
- Perform translation and back-translation
- Pilot-test
Informed Consent Process

- Recruitment
  - Advertisements
  - Wide range of subjects: including women, minorities, non-English speakers, all ages
- Verbal instructions
- Written materials
- Question/answer sessions
- Agreement documented by signature
Informed Consent Context

- WHO?
  Investigators or trained designees? Power relationship with subject?
- WHERE?
  Private, comfortable?
- WHEN?
  Sufficient time between explanation and consent?
- HOW?
  Read? Explain?
IRB Informed Consent Application

- Range of types of human subjects review
- Exempt from Review
  - Educational research on teaching techniques
  - Educational research without identifiers
  - Existing data (documents, specimens) without identifiers
- Minimal Risk
- Greater than Minimal Risk
HIPPA Authorization

- Individually identifiable health information = protected health information

- Personal identified information: Names, birthdates, addresses, SSN, etc.

- Personal health information: Medical history, PE results, lab results, etc.
Conflicts of Interest

Researchers must declare their conflicts of financial interest to IRBs, to audiences:

- Financial
  - Stock, royalties
  - Funding, gifts, consultation fees
  - Honoraria, recruitment incentives

- This is a concern because
  - Subject safety may be compromised
  - Knowledge may be biased towards financial rewards

- Other conflicts are not declared:
  - Time commitments
  - Reputation/ Ego/ Fame/ Success
Community-based Research

Assumptions:
1. Community is authority in its own situations, strengths, needs, and potential solutions.
2. Researchers may have cultural biases that unduly influence the research topic, data collection, and interpretation of results.

With community partners, may be able to better address:
- Appropriate topic
- Confidentiality
- Methods
- Implications of results for community
- Dissemination practices
Application: Ethics of CBPAR

- Background
- Research methods
- Research participants
- Recruitment
- Risks/ benefits
- Privacy/ confidentiality
- Compensation
- Conflicts of interest
- Informed consent process
Assignments

- Read handout on ethical considerations of community-based research
- Read examples of community agreements
- Consider ethical implications for your research projects
- Take on-line course (optional)
Evaluation

1. What did you learn today?

2. What do you want to learn more about?

3. What went well?

4. What didn’t go well?

5. What suggestions do you have for improvements?
Session 5
Partners in Research Community Scholars Training: Challenges in CBPAR Partnerships

MICHELE ALLEN, MD MS
KATHIE CULHANE-PERA, MD MA
KATHLEEN THIEDE CALL, PHD
SHANNON PERGAMENT, MPH MSW
Objectives

- At the end of the session, participants will be able to:
- Describe 4 major challenges to community-research partnership.
- Describe how communicating can help address these challenges.
- Utilize active listening skills in partnership development.
- Conduct a literature search on internet.
Agenda

- Challenges to Community-Academic Research Partnerships
- Exercise: Improve communication
- Literature Searches
- Evaluation
- Assignments
What experiences--positive and negative--have you had with researchers?
CBPR Scenario

- Divide into groups of 2-3.
- Read through the CBPR scenario.
- Make a list of all the problems that lead to the failure of the collaboration.
Key Challenges in CBPR Partnerships

- Trust
- Power Differences
- Decision Making
- Conflict
Challenges to Developing...

**Trust**

- Bad experiences with researchers or community
- Historical and recent injustices & racism in research
- Lack of understanding of other partner’s priorities
- Differing levels of commitment to the project
- Actions are not consistent with words

Challenges of...

**Power Differences**

- Discrimination: Racism, Sexism, Ageism, etc.
- Control of resources
- Lack of respect for expertise of all partners

Challenges to Dealing With...

Decision Making

- Partners have different goals, values, priorities
- Clashing organizational cultures
- Lack of clear process for making decisions

Challenges Leading to...

**Conflict**

- Contrasting goals, values, priorities
- Clashing organizational cultures
- Budget difficulties or resource allocation
- Power imbalances
CBPR Scenario

- Categorize the list of problems from the scenario into:
  - Challenges to developing trust
  - Challenges of power differences
  - Challenges dealing with decision making
  - Challenges leading to conflict
Good Communication can help address each of these challenges
How would you define “Communication”?
Communication Model

Sender → Noise → Receiver

Jennifer Warren, Ph.D.
What Sometimes Makes Communication Difficult?

Differences in:

- Languages (proficiency and literacy)
- Communication styles (verbal/non-verbal)
- Appropriate topics
- Styles of dealing with conflicts
- Assumptions/expectations
Bases of Communication

- **Speaker**
  - Speak clearly and loud enough to be heard.
  - Eye contact.
  - Be aware of feelings. Does body language match your spoken word?
  - Know your message.

- **Message**
  - Must be clear.
  - Direct and to the point.

- **Listener**
  - Eye contact.
  - Listen actively.
  - Repeat back the message you heard.
  - Ask for clarification.

University of Minnesota Extension
Active Listening

Listening isn’t always easy. It requires:

- **Concentration:** Minimize distractions. Tell the person if it is a bad time.

- **Patience:** Let the other person tell you what you need to hear. If you’re not sure you understood, ask him/her to explain.

- **Empathy:** Put yourself in the speaker’s place.
Active Listening Exercise

- Two person partnership.
- First person has 90 seconds to talk about:
  - “A place of peace for me is...” or
  - “A highpoint of this week has been....” or
  - “Some strong feelings I’ve been having about work lately...”

- Second person cannot talk until time is up.
- Second person paraphrases, restates content, and reflects feelings. You don’t have to be a tape-recorder, just say back what hits you: “So, I heard you saying...”

- First person give feedback about how it felt being heard.
- Now switch.
Reflection

- What parts of this were comfortable or uncomfortable for you?
- Is this type of listening common in your cultural tradition?
- How might this sort of listening be helpful with a research partner?
Literature Searches

- Enter search terms
- Use AND NOT OR.
- Read abstracts. Consider if you want the entire article.
- See related articles.
Assignments

- Conduct a literature search.
- Read articles about your research topic.
- Read articles about community responses to your research topic.
Evaluation

1. What did you learn today?
2. What do you want to learn more about?
3. What went well?
4. What didn’t go well?
5. What suggestions do you have for improvements?
Session 6
Partners in Research Community Scholars Training: Challenges in CBPAR Partnerships cont.

MICHELE ALLEN, MD MS
KATHIE CULHANE-PERA, MD MA
KATHLEEN THIEDE CALL, PHD
SHANNON PERGAMENT, MPH MSW
Objectives

- By end of session be able to:
- Describe strategies to deal with difficulties in community-academic partnerships.
- Write a memorandum of understanding (written agreement).
Agenda

- Reasons for Community-Academic Partnership
- Scenario: Brainstorming strategies for dealing with difficulties
- Communication: strategies for dealing with difficulties
- Written Agreements
- Research Projects: Literature Searches/ Partners
- Evaluation/ Assignments
Why Do Community and Academic Partners Do CBPAR?

- Why might community partners want to become involved in CBPAR partnerships?
- Why might academic partners want to become involved in CBPAR partnerships?
What are Community and Academic Partners’ Expertise?

- Community partner expertise:

- Academic partner expertise:
Exercise: Navigating Through Difficult Decisions

- Re-read scenario.
- Discuss potential strategies for successfully dealing with each challenge.
Communication Model

Jennifer Warren, Ph.D.
What Sometimes Makes Communication Difficult?

Differences in:

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- Communication styles (verbal/non-verbal)
- Appropriate topics
- Styles of dealing with conflicts
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Jennifer Warren, Ph.D.
# Bases of Communication

## Speaker
- Speak clearly and loud enough to be heard.
- Eye contact.
- Be aware of feelings. Does body language match your spoken word?
- Know your message.

## Message
- Must be clear.
- Direct and to the point.

## Listener
- Eye contact.
- Listen actively.
- Repeat back the message you heard.
- Ask for clarification.

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Extension, University of Minnesota
How Can Good Communication Build Trust?

- Start conversations about partnership as early as possible.
- Discuss openly any prior negative experiences with research partnerships.
- Clearly identify priorities of each partner (and their organization).
- Clearly identify goals of project.

Strategies for Building Trust

- Be open and honest but tactful.
- Be open to learning from each other.
- Build relationships with people.
- Assume good intentions.
- Listen well.

How Can Good Communication Help With Decision Making?

- Clearly establishing a process for making decisions can prevent problems/conflict.
- Consider and talk about whether empowering one partner to make certain decisions makes sense.

Types of Decision Making

- **Autocratic** – one person decided without input from others
- **Consensus** – allows entire group to be heard and participate. Tries to get the group to agree, but does not require that everyone wholeheartedly agrees - “70% rule”
- **Democratic** – straw polling, voting, delegation
- **Consultation** - co-leaders decide after gaining input from others

Strategies for Improved Decision Making

- Decide together about how to make decisions.
- Make sure everyone has the same understanding of how to make decisions.
- Talk openly when making decisions.
- Be aware of one’s assumptions.

• Acknowledge and talk openly about socially defined power differentials.
  ○ Race/ethnicity: white privilege
  ○ Class: economic privilege
  ○ Education: academic privilege
  ○ Gender: male privilege

• Talk early about financial arrangements and control of resources.
Strategies For Addressing Power Inequities

- Acknowledge and value the expertise and skills of all partners.
- Emphasize needs identified by community.
- Share control of meetings/agendas.
- Have transparent decision making.
- Make partners co-PIs.
How Can Good Communication Help Prevent Conflict?

- Establish positive communication strategies early in the beginning of the partnership.
- Understand that different people have different ways of doing and thinking about things.
- Talk about & resolve differences as they arise.
How Can Good Communication Help Resolve Conflict?

- Assume there is a good reason for the conflict.
- Assume everyone has the right to bring up their feelings.
- Identify the most likely cause of the conflict.
- Work together to find solutions using a problem-solving approach.

Strategies for Preventing/ Resolving Conflict

- Be open and honest.
- Respectfully present one’s viewpoint.
- Respectfully listen to others’ viewpoints.
- Write agreements: Memorandum of Understanding
Written Agreements

- Agreements between researchers and community members/organizations can be written before research starts, to guide partnership during research project.
- Participation
- Ownership
- Dissemination
- Examples: see handouts
Exercise: Navigating Through Difficult Decisions

- What additional strategies would you suggest or pursue to prevent or address these conflicts?
- What agreements could the partnership adopt which could help guide the decision making?
- Who should have the final say?
- What are partners’ potential self-interests?
Final Thoughts on Steps to Successful Collaborations

- Establish good communication early!
- Find a committed academic partner.
- Outline common goals, roles, privileges, and rules of engagement.
- Make financial agreements clear.
- Time, time, time.
Assignments

• Read handouts on examples of “memorandum of understanding.”
• Consider MOU for your research project.
• Consider contacting community organizations about partnering with them.
• Continue to work on research project.
Evaluation

1. What did you learn today?

2. What do you want to learn more about?

3. What went well?

4. What didn’t go well? What suggestions do you have for improvements?