09. Essential elements of design: Partnerships, funding and evaluation

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Essential Elements of Design: Partnerships, Funding, & Evaluation

Community-Engaged Research: Exploring the Unique Community-Academic Relationship
September 26, 2011
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E. Desmond Lee Professor of Racial & Ethnic Diversity
Washington University in St. Louis
Definition of Community-Engaged Research (CEnR)

A process of inclusive participation in research in which academic researchers and community stakeholders act in concert to create a productive working and learning environment that extends from before a research project begins to after its completion.

NIH Office of the Director, Council of Public Representatives
Community & Academic Partnerships & Research Projects

Partnership begins

Project #1
What’s the problem? → What is the cause?

Project #2
What is a solution? → How do we do it?

Project #3

Project #4
Did it work?
Categories of Community-Academic Research

- Community-Placed Research
- Community-Based Research
- Community-Engaged Research

Degree of community participation
Benefits of Community & Academic Partnerships
## Research Process Through Two Lens: The Best of Both Worlds

<table>
<thead>
<tr>
<th>Step</th>
<th>Community Perspective</th>
<th>Research Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Formulating question &amp; hypotheses</strong></td>
<td>Matches life experiences of community members</td>
<td>Testable by science</td>
</tr>
<tr>
<td><strong>Obtaining background info.</strong></td>
<td>Community voices; experiential knowledge</td>
<td>Professional literature</td>
</tr>
<tr>
<td><strong>Methods</strong></td>
<td>• those who know</td>
<td>• objectively obtained to achieve statistical power</td>
</tr>
<tr>
<td></td>
<td>• meaningful to community</td>
<td>• psychometrically sound</td>
</tr>
<tr>
<td></td>
<td>• culturally appropriate</td>
<td>• scientifically rigorous</td>
</tr>
<tr>
<td></td>
<td>• statistically appropriate</td>
<td>• statistical methods</td>
</tr>
<tr>
<td><strong>Evaluating results</strong></td>
<td>Clinically significant</td>
<td>Statistically significant</td>
</tr>
<tr>
<td><strong>Drawing conclusions</strong></td>
<td>Relate to life experiences</td>
<td>Relate to original hypotheses</td>
</tr>
<tr>
<td><strong>Disseminating results</strong></td>
<td>Lay media; community presentations</td>
<td>Scientific journals</td>
</tr>
</tbody>
</table>
Goal = Balance Between Community & Academic Perspectives

Community Reality

Gives faith that findings are translatable

Academic Rigor

Gives faith that findings are real
Academic Conceptual Schemes or Models

- Elements in linear form or progression
- Time implied from left to right
- Focus on cause and effect
Community Conceptual Schemes or Models

Native American Medicine Wheel

The goal is to communicate, negotiate, and find a balance between the two perspectives.
Establishing Community & Academic Partnerships
Engaging Communities

Determine research questions

Define partner appropriate to the question or goal

Explore existing partnerships
Create new partnerships

Focus groups

Town hall meetings

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Who Initiates the Partnership

The ideal is for ideas to originate in communities
Yet, many projects would not occur without the initiative of an academic researcher

It is important for:

• projects to be high on the agendas of communities
• researchers to have the skills & knowledge to ensure that partnerships are balanced & fair
so that projects lead to sustainable change
How Can Academics Get the Interest of Individuals & Organizations?

- work through existing partnerships with structured groups & broach topic
- create partnerships with those who have an interest by virtue of their health status & history
- put out “calls” using established community channels (newsletters, AM radio, announcements in churches, community group meetings, etc.)
- convey complex material in understandable terms (without oversimplifying it)
Focus Groups

Research discussion groups conducted by a facilitator or facilitators and designed to create a free-flowing exchange/conversation about one or more issues related to a general topic

Usually 10-12 persons
Focus Groups

Advantages
• Interviews can be conducted & data analyzed in a relatively short time
• Interview schedule can be flexible; possible to probe & clarify

Disadvantages
• Recruiting can be difficult
• Responses may not be completely independent of one another
Community Advisory Boards

Groups of community stakeholders representing key constituencies that meet regularly to provide community perspectives, help set research agendas, review research, and advise on issues that arise throughout the research process.
Community-Advisory Boards

• usually 9-15 persons
• should be those who will evaluate the process and issues fairly and critically
• must meet regularly face-to-face
• need a system of achieving rapid feedback at other times
• should be compensated for time
• should represent the stakeholders of focus re age, gender, religion, SES
Coalitions/Collaborations/Partnerships

- Longer-term entities
- May span research projects
- Heightens sustainability
- Increase odds of policy change
- Take time to develop

Metropolitan Chicago Breast Cancer Coalition

Illinois Reducing Breast Cancer Disparity Act (PL95-1045)
Helping to Ensure that Community & Academic Partnerships are Equitable
Topics & Modes of Communication

1. Define as a group what you mean by “equitable partnership” & what it would look like if worked

2. Develop Memoranda of Understanding (MOUs)
   • Document each partner’s roles in concrete terms, including compensation & milestones for achievement
   • Lay out the decision making process
   • Outline expectations for meeting & communication between face-to-face meetings

3. Decide on a process for resolving (inevitable) conflict, including when resolution cannot be achieved internally
Cultural Responsibilities of Community and Academic Partners*

**Community Partner**
- Recognize good will & try to excuse well-meaning errors
- Collaborate when collaboration entails parity
- Insist on evoking power & sustainable change an outcome of partnership
- Learn about the culture of your partner community

**Academic Partner**
- Look for & recognize bias when you see it; challenge & educate your colleagues
- Recognize your privilege-how you may have gotten to “third base”
- Ask for help when you need it
- Learn about the culture of your partner community

*Adapted from Campbell, J.C. et al. (2003).
Funding Community & Academic Partnerships
How do We Locate and Secure Funding?

Local opportunities

• courses on CEnR grant preparation for community stakeholders through CTSAs & other sources
• funding opportunities through CTSAs (e.g., Harvard Catalyst)
• other local opportunities (e.g., Community/University Health Research Partnerships [St. Louis University, Washington University, BJC HealthCare & the St. Louis Regional Health Commission]; California Breast Cancer Research Program Community Research Collaboration awards)
How do We Locate and Secure Funding?

Federal Opportunities

1. Special Emphasis Panels at NIH’s Center for Scientific Review (CSR)
   - Community-Level Health Promotion
   - Health Disparities and Equal Promotion
   - Community Influences on Health Behavior

2. R01, R03, R21, P30 mechanisms
   - NIH
   - CDC
   - AHRQ
CEnR Proposals Fail to Survive the Review Process for Two Main Reasons

- Community partnerships are strong, but not written about systematically and scientifically
- Strong scientific projects, but fail to demonstrate community engagement
Evaluating Community & Academic Partnerships
There is ample evidence that the work of building & maintaining an effective partnership is as important as the work to address the health problem of focus

<table>
<thead>
<tr>
<th>Stage</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td></td>
</tr>
<tr>
<td>Implementation</td>
<td>Formative; process</td>
</tr>
<tr>
<td>Completion</td>
<td>Summative; outcome; impact</td>
</tr>
<tr>
<td>Implementation &amp; reporting</td>
<td></td>
</tr>
<tr>
<td>Evaluation Stage</td>
<td>Types of Evaluation Questions</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Planning</td>
<td>What is the prevalence of the problem?</td>
</tr>
<tr>
<td>Implementation</td>
<td>How many individuals are participating? What are the changes in performance? How many/what resources are used during implementation?</td>
</tr>
<tr>
<td>Outcome</td>
<td>Is there a change in quality of life? Is there a change in biological &amp; health measures? Is there a difference between those who are involved in the intervention &amp; those who are not?</td>
</tr>
</tbody>
</table>
Elements for Process Evaluation

1. Leadership
2. Community & academic investigators
3. Staff
4. Committees
   - Appropriateness of function(s)
   - Appropriateness of structure (e.g., membership)
5. Internal documents (e.g., meeting minutes)
6. Partnership agreements
   - MOUs
   - Subawards
# Approaches to Evaluation

<table>
<thead>
<tr>
<th>Approach</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traditional</td>
<td>Conducted by outside expert with input from partners</td>
</tr>
<tr>
<td>Participatory</td>
<td>Involves key stakeholders in evaluation using multiple methods, perhaps with outside expert as facilitator</td>
</tr>
<tr>
<td>Empowerment</td>
<td>Transfers evaluation from an external evaluator to stakeholders; steps include identifying strengths &amp; weaknesses, establishing goals, &amp; developing strategies</td>
</tr>
</tbody>
</table>
Case Example

The St. Louis Komen Project
The St. Louis Komen Project

CRnR project with four community and one academic partner with the purpose of understanding how gaps in the provision of services of women in North St. Louis contribute to the African-American and white disparity in breast cancer mortality.
Identify shortfalls or gaps in the breast cancer treatment of African-American women living in North St. Louis City that will help to explain their disproportionate rates of breast cancer mortality compared to white women, with an ultimate goal of remedying these shortfalls or gaps.
Problem Scheme

Quality of Inter- and intra-organizational referrals (e.g., community clinics to hospitals)

Completion of prescribed breast cancer treatment

African-American & white breast cancer mortality disparity

Black women 37% higher

Incidence

Mortality

African-American and White Breast Cancer Mortality, Missouri and US

Historical Trends (1975-2007)

Mortality, Breast Female, All Ages

Deaths per 100,000 resident population

Year of Death


Missouri White (incl Hisp)
United States White (incl Hisp)
Missouri Black (incl Hisp)
United States Black (incl Hisp)

Source: Death data provided by the National Vital Statistics System public use data file. Death rates calculated by the National Cancer Institute using SEER*Stat. Death rates (deaths per 100,000 population per year) are age-adjusted to the 2000 US standard population (19 age groups: <1, 1-4, 5-9, ..., 80-84, 85+). Population counts for denominators are based on Census populations as modified by NCI. The US populations included with the data release have been adjusted for the population shifts due to hurricanes Katrina and Rita for 62 counties and parishes in Alabama, Mississippi, Louisiana, and Texas. The 1969-2007 US Population Data File is used with mortality data.
Racial Polarization by Zip Code, St. Louis City, 2007

Source: The City of St. Louis Department of Health
## Breast Cancer Mortality by Zip Code, St. Louis

<table>
<thead>
<tr>
<th>Zip Code</th>
<th>Cancer</th>
<th>Map Quartile</th>
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<tbody>
<tr>
<td>63101**</td>
<td>472.3</td>
<td>4</td>
</tr>
<tr>
<td>63113</td>
<td>349.9</td>
<td>4</td>
</tr>
<tr>
<td>63106</td>
<td>336.4</td>
<td>4</td>
</tr>
<tr>
<td>63115</td>
<td>280.2</td>
<td>3</td>
</tr>
<tr>
<td>63107</td>
<td>268.2</td>
<td>3</td>
</tr>
<tr>
<td>63147</td>
<td>265.2</td>
<td>3</td>
</tr>
<tr>
<td>63104</td>
<td>256.8</td>
<td>2</td>
</tr>
<tr>
<td>63120</td>
<td>255.7</td>
<td>2</td>
</tr>
<tr>
<td>63118</td>
<td>253.7</td>
<td>2</td>
</tr>
<tr>
<td>63111</td>
<td>242.6</td>
<td>2</td>
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<tr>
<td>63112</td>
<td>228.4</td>
<td>2</td>
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<tr>
<td>63108</td>
<td>211.8</td>
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<tr>
<td>63116</td>
<td>208.4</td>
<td>1</td>
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<tr>
<td>63110</td>
<td>205.0</td>
<td>1</td>
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<tr>
<td>63109</td>
<td>204.5</td>
<td>1</td>
</tr>
<tr>
<td>63139</td>
<td>187.4</td>
<td>1</td>
</tr>
<tr>
<td>63103</td>
<td>178.8</td>
<td>1</td>
</tr>
<tr>
<td>63102**</td>
<td>153.7</td>
<td>1</td>
</tr>
</tbody>
</table>

**small population interpret with caution
## Community & Academic Partners

<table>
<thead>
<tr>
<th>Partners</th>
<th>Principal Investigator</th>
<th>Partner Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betty Jean Kerr</td>
<td>Betty Jean Kerr</td>
<td></td>
</tr>
<tr>
<td>People’s Health Clinic</td>
<td>People’s Health Clinic</td>
<td></td>
</tr>
<tr>
<td>Dwayne Butler, CEO</td>
<td>Dwayne Butler, CEO</td>
<td>Provider</td>
</tr>
<tr>
<td>Christian Hospital</td>
<td>Ron McMillan, President</td>
<td>Provider</td>
</tr>
<tr>
<td>Women’s Wellness Unit</td>
<td>Women’s Wellness Unit</td>
<td></td>
</tr>
<tr>
<td>SL Effort for AIDS</td>
<td>SL Effort for AIDS</td>
<td></td>
</tr>
<tr>
<td>Cheryl Oliver, CEO</td>
<td>Cheryl Oliver, CEO</td>
<td>Organizational</td>
</tr>
<tr>
<td>Committed Caring Faith Communities</td>
<td>Committed Caring Faith Communities</td>
<td></td>
</tr>
<tr>
<td>Rev. Isaac McCullough, President</td>
<td>Rev. Isaac McCullough, President</td>
<td>Organizational</td>
</tr>
<tr>
<td>Washington University</td>
<td>Washington University</td>
<td></td>
</tr>
<tr>
<td>Sarah Gehlert, PhD</td>
<td>Sarah Gehlert, PhD</td>
<td>Academic</td>
</tr>
</tbody>
</table>
Specific Aims

1. Use Missouri Cancer Registry, provider partner data, & outreach to identify women diagnosed with breast cancer living in seven zip codes of North SI, & determine where they were treated
2. Interview African-American women living in the zip codes to determine their breast cancer treatment histories in their own voices
3. Increase trust among residents through a drop in center at 3335 North Union Boulevard, town hall meetings, training in research, & community presentations
The St. Louis Komen Project

Partner Equity

- Monthly partnership meetings that rotate among partners’ offices
- Carefully written Memoranda of Understanding
- Written plan for resolving conflict

Funding

- Each project task delineated & “costed out”
- Partners chose tasks
- Funding for tasks goes to responsible partner

Evaluation

- Evaluation plan with milestones and deadlines
- Progress discussed at monthly meetings