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Essential elements of design: Partnerships, funding and evaluation

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Essential Elements of Design: Partnerships, Funding, & Evaluation



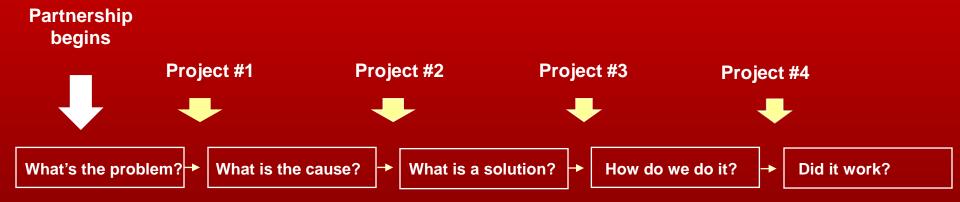
Community-Engaged Research: Exploring the Unique
Community-Academic Relationship
September 26, 2011
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Washington University in St. Louis



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

Community & Academic Partnerships & Research Projects



Categories of Community-Academic Research



Benefits of Community & Academic Partnerships

Research Process Through Two Lens: The Best of Both Worlds

Step	Community Perspective	Research Perspective
Formulating question & hypotheses	Matches life experiences of community members	Testable by science
Obtaining background info.	Community voices; experiential knowledge	Professional literature
Methods sample measures data collection analysis	those who knowmeaningful to communityculturally appropriate	 objectively obtained to achieve statistical power psychometrically sound scientifically rigorous statistical methods
Evaluating results	Clinically significant	Statistically significant
Drawing conclusions	Relate to life experiences	Relate to original hypotheses
Disseminating results	Lay media; community presentations	Scientific journals

Goal = Balance Between Community & Academic Perspectives

Community Reality

Academic Rigor

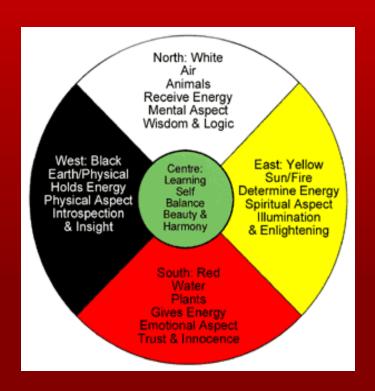
Gives faith that finds are translatable



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

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)

Mechanisms of Community Engagement

Focus groups Community-advisory boards



Collaborations/Coalitions/Partnerships

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

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

Stages & Type of Evaluation

Stage	Туре
Planning	
Implementation	Formative; process
Completion	Summative; outcome; impact
Implementation & reporting	

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

Evaluation Questions by Stage of Partnership

	Types of Evaluation Questions	
Evaluation Stage	Quantitative	Qualitative
Planning	What is the prevalence of the problem?	What are the values of the stakeholders? What are the expectations and goals of participants?
Implementation	How many individuals are participating? What are the changes in performance? How many/what resources are used during implementation?	How are participants experiencing the change? How does the program change the way individuals relate to or feel about each other? To what extent is the intervention culturally or contextually valid?
Outcome	Is there a change in quality of life? Is there a change in biological & health measures? Is there a difference between those who are involved in the intervention & those who are not?	How has the culture changed? What themes underscore the participant's experience? What metaphors describe the change? What are the participant's personal stories? Were their unanticipated benefits?

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

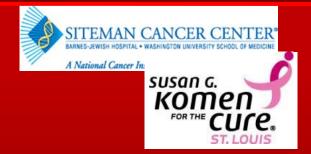
Approaches to Evaluation

Approach	Description
Traditional	Conducted by outside expert with input from partners
Participatory	Involves key stakeholders in evaluation using multiple methods, perhaps with outside expert as facilitator
Empowerment	Transfers evaluation from an external evaluator to stakeholders; steps include identifying strengths & weaknesses, establishing goals, & developing strategies

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

Overarching Mission

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 intraorganizational referrals (e.g., community clinics to hospitals)



Completion of prescribed breast cancer treatment

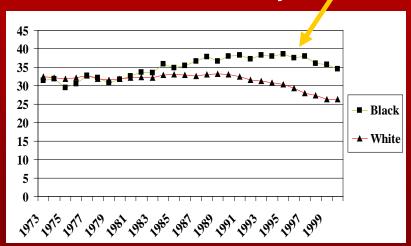


Black and White Age-Adjusted Breast Cancer Statistics, 1975-2000

Black women 37% higher

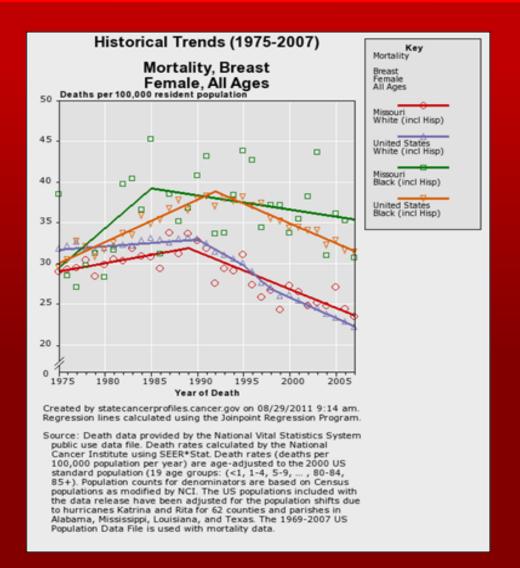
Incidence

Mortality

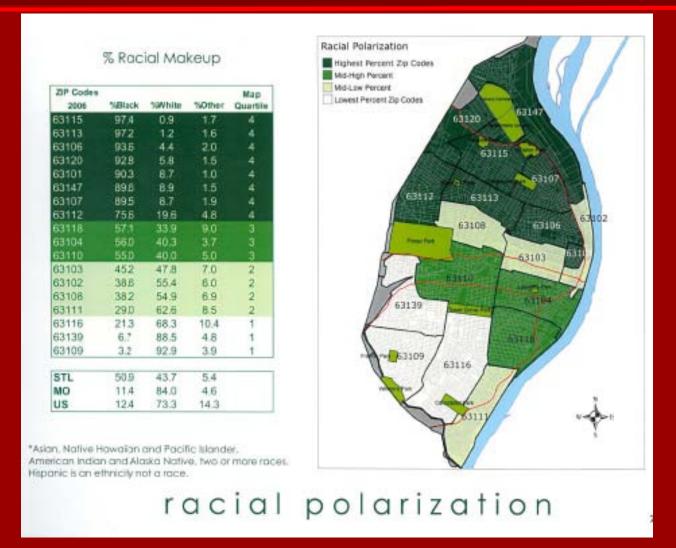


SEER Cancer Statistics Review, 1975-2000

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



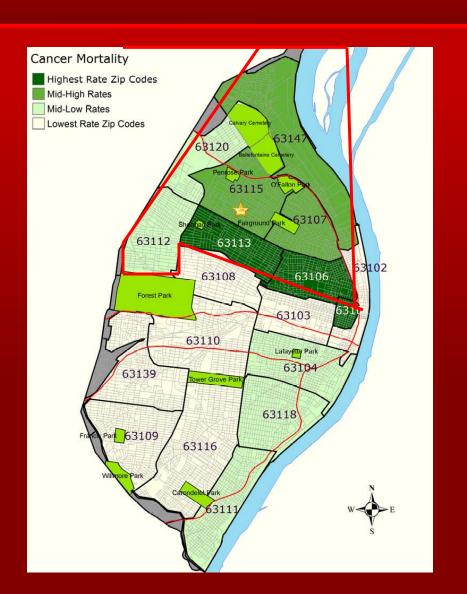
Racial Polarization by Zip Code, St. Louis City, 2007



Breast Cancer Mortality by Zip Code, St., Louis

Deaths/100,000 Population		
Zip Code	Cancer	Map Quartile
63101** 63113 63106	472.3 349.9 336.4	4 4 4
63115 63107 63147	280.2 268.2 265.2	
		2 2 2 2 2
63108 63116 63110 63109 63139 63103 63102**	211.8 208.4 205.0 204.5 187.4 178.8 153.7	1 1 1 1 1
	63101** 63113 63106 63115 63107 63147 63104 63120 63118 63111 63112 63108 63116 63110 63109 63139	Zip Code Cancer 63101** 472.3 63113 349.9 63106 336.4 63115 280.2 63107 268.2 63147 265.2 63147 256.8 63120 255.7 63118 253.7 63111 242.6 63108 211.8 63116 208.4 63109 204.5 63139 187.4 63103 178.8

^{**}small population interpret with caution



Community & Academic Partners

Partners	Principal Investigator	Partner Type
Betty Jean Kerr People's Health Clinic	Dwayne Butler, CEO	Provider
Christian Hospital	Ron McMillan, President	Provider
Women's Wellness Unit SL Effort for AIDS	Cheryl Oliver, CEO	Organizational
Committed Caring Faith Communities	Rev. Isaac McCullough, President	Organizational
Washington University	Sarah Gehlert, PhD	Academic

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

