



Approaches to Community-Engaged Collaborative Research to Achieve Health Equity

Deborah Parra-Medina, MPH, PhD

Professor, Mexican American and Latina/o Studies

Director, Latino Research Initiative



The University of Texas at Austin

Latino Research Initiative

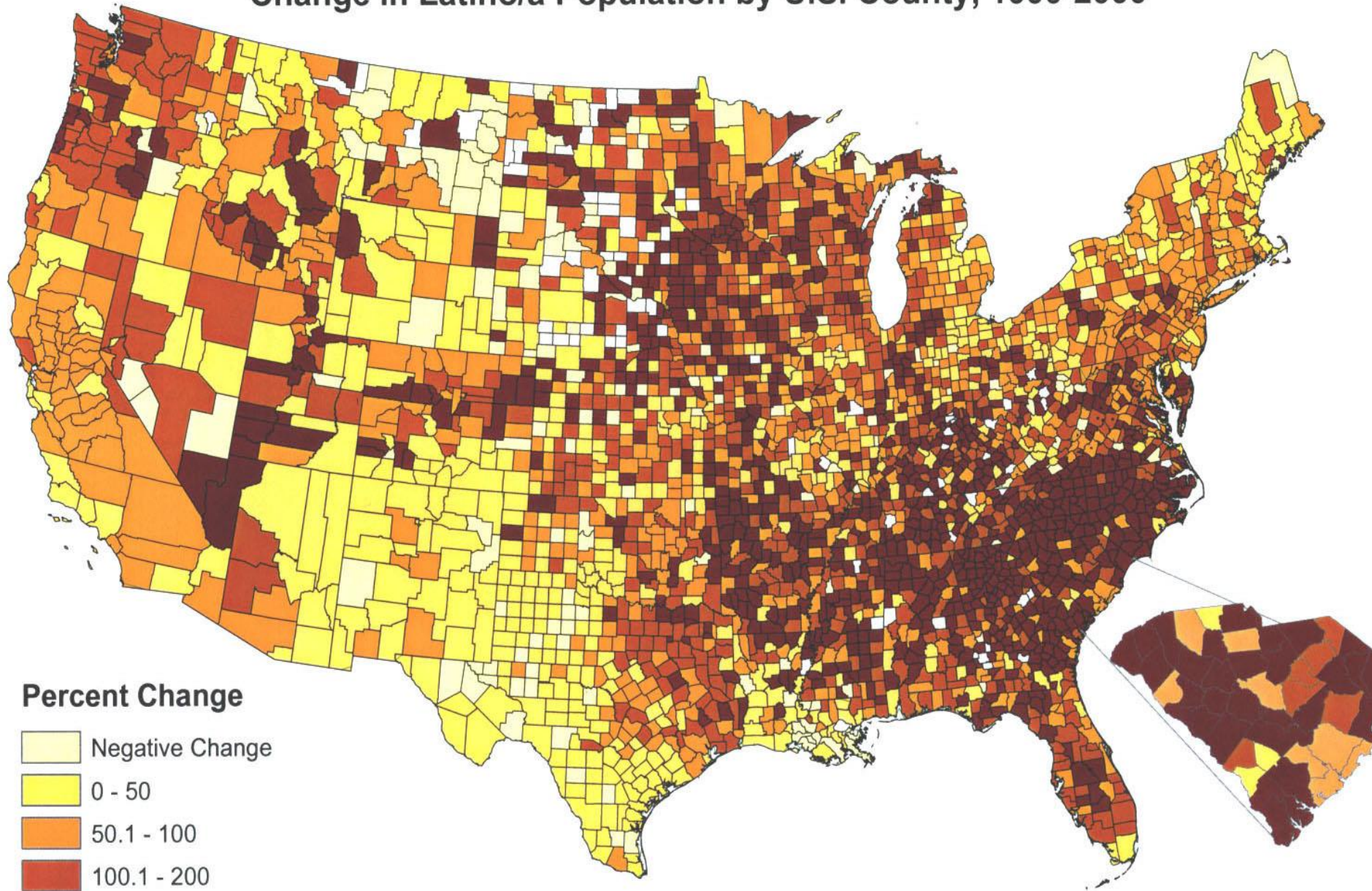
College of Liberal Arts



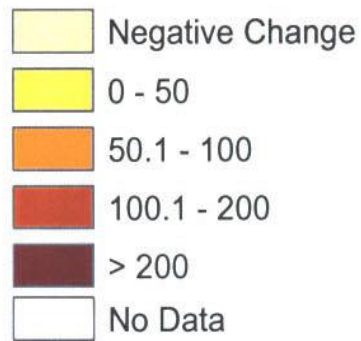
Outline

- Historical Context
- Community mobilization and priority setting
- Health Equity and CBPR
- Example of Community Engaged Research
- Lessons Learned

Change in Latino/a Population by U.S. County, 1990-2000



Percent Change



Prepared by Katie Freer at the University of South Carolina
Department of Geography on April 8, 2003, using data from the US Census Bureau.



Community Partnered Research





The Processes

Community Mobilization

Partnership Formation

Community Outreach

Collaborative Research



SC Governor's Ad-hoc committee

- Identify barriers to delivery of services to non-English speaking Hispanic/Latino population in SC and advise the Governor
- Staffed by Commission of Minority Affairs and Office of the Governor
- 5 subcommittees
 - Education
 - Health Care
 - Public Safety (emergency preparedness, police and emergency services, legal system)
 - Human rights (workers rights, civil rights, housing)
 - Immigration/Transportation/Fraud



Community Partnered Research



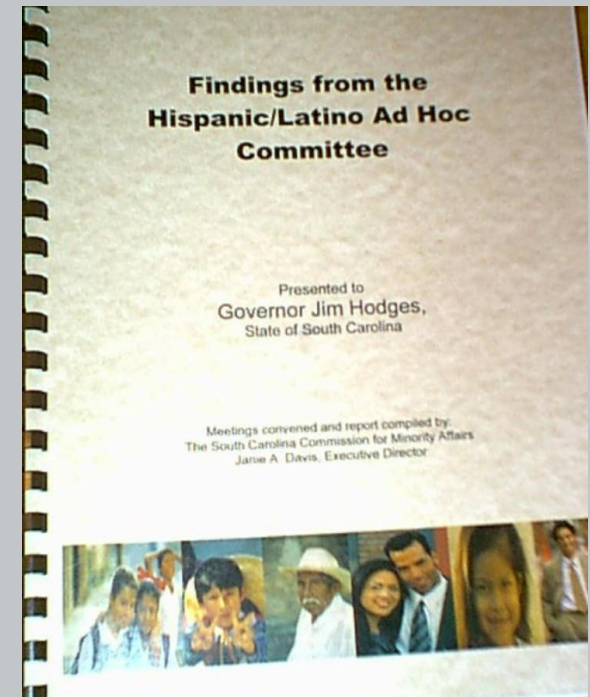
Health Care Sub-Committee

- **Health Priorities**

- Language and communication barriers
- Cultural competency
- Access to care barriers
- Lack of data for planning & surveillance
- Immigration and social issues

- **Overarching systemic issues**

- Cut across a wide range health concerns
- must be addressed in order to ensure culturally and linguistically appropriate, quality healthcare.





Coalition Model

- Voluntary membership of
 - Individuals
 - Organizations
 - Agencies
- Share common interest or focus
- Collaborate and share resources to achieve goals



Levels of Engagement



Adapted From: Hashagen 2002 and Sydney Department of Planning 2003.



Types of Partnerships

| Organization | Definition | Structure |
|--------------------|--|---|
| Partnership | An organizational form in which member agencies or individuals possess equal power over decision-making | Can include any of the structure below |
| Network | The set of linkages among people or organizations. Network structure may have effects on the behavior of the members | Organizationally loose and very flexible. Perhaps an initial step towards other structures |
| Coalition | An organization of individuals representing diverse organizations, functions, or constituencies who agree to work together in order to achieve common goal | Additional structural strength and longevity with some effects on each organization's actions. Perhaps a limited time period. |
| Collaborative | A more enduring and highly structured organization of diverse groups working together to achieve multiple goals over time. | A well organized, differentiated structure with great longevity |



Community Partnered Research





Hispanic/Latino Health Coalition

- Mission
 - Provide **coordinated leadership** in advocating for equal access to quality health care
- Objectives
 - To **improve communication** among health care service providers, state agencies, and the Hispanic/Latino community.
 - To **reduce organizational, systemic, and cultural barriers** to health care.
 - To **promote “best practices”** and cultural competency by agencies and organizations across South Carolina.
 - To **foster collaborative efforts** and partnerships around specific issues of concern to the Hispanic/Latino population in South Carolina.
 - To **serve as a liaison and advisor to public and private agencies** and organizations.



Meanwhile.....

- South Carolina Breast and Cervical Cancer Early Detection Program
 - member of the coalition
 - invites coalition to participate in strategic planning
 - ↑ # uninsured age- and income-eligible Latinas in their free breast and cervical cancer screening program
 - ↑ % of women screened who had not received a Pap smear in 5 or more years
- Call for pilot projects
 - Key concepts
 - Access to cancer screening and care
 - Doctor/Patient Communication
 - Health disparities
 - Cervical cancer**
 - Community based organizations and Research organization Partnerships
 - Community-based Participatory research (CBPR)



Health Disparities

“... a particular type of health difference that is closely linked with economic, social, or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic -status, gender, age, or mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”

Healthy People 2020

HealthyPeople.gov. Disparities [cited 2012 Nov 20] Available from:
URL:<http://www.healthypeople.gov/2020/about/disparitiesAbout.aspx>.



Health Equity

- Health equity is the principle underlying a commitment to reduce—and, ultimately, eliminate—disparities in health and in its determinants.
- Pursuing health equity means striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions.
- Health disparities are the metric we use to measure progress toward achieving health equity.



Definition of CBPR

- “ Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.”

W.K. Kellogg Foundation, 2001

- “Scientific inquiry conducted in communities in which community members, persons affected by condition or issue under study and other key stakeholders in the community’s health have the opportunity to be full participants in each phase of the work – conception, design, conduct, analysis, interpretation, conclusions and communication of results.”

Federal Interagency Working Group on CBPR, 2003

CBPR: What it is and isn't.

- CBPR is an orientation to research/values
 - changes the role of researcher and researched
 - work “with” rather than “on” communities
- CBPR is not a method or set of methods
 - Typically thought of as qualitative
 - Fewer epidemiologic examples, but increasing
- CBPR is an applied approach
 - Goal is to influence change in community health, norms, systems, programs, policies



Common Problems for Communities

- “Traditional” research approaches have failed to solve complex health disparities.
- Research does not addresses their locally identified needs
- Poor methodology that in turn is a waste of resources
- Research data and findings are not given back
- Communities feel:
 - “over-researched”/ tired of being “guinea pigs”
 - coerced to participate in research
 - researched upon rather than partners in the process
 - lied to or misled
- Insensitivity to community concerns or issues
- Benefits to community are minimal or nonexistent



Principles of CBPR

- Participatory - community shares power (decision-making) with the research team
- Cooperative - community members and researchers engage in a joint process mutual ownership of the process and products
- Co-learning & reciprocal transfer of expertise - researchers and community members learn from each other
- Empowering – Community members learn new skills, increase self-determination and capacity
- Seeks balance between research and action
- Building on existing community strengths and assets



Project Goal

- The goal of this community-based participatory research project was to:
 - build health partnerships and community capacity to address cervical cancer prevention and early detection for Latinas in South Carolina



Partnership Formation

- Partners
 - Universities
 - Latino Community Based Organizations
 - Cancer Support Agencies
 - Health Care Providers
- Multidisciplinary Research Team
 - Public Health, Health Administration, Nursing, Social Work, Women's Studies

Partners in Action



- Getting to know each other
 - bringing in other partners
- Brainstorming about access to preventive cancer services in SC
- Identifying gaps in knowledge
- Developing a research plan
 - To identify Hispanic women's needs
 - To assess provider cultural competency



Community Partnered Research





Aims

- Conduct formative research to explore attitudes and behaviors around cervical cancer prevention and detection
- Determine extent to which cervical cancer prevention programs are able to provide culturally competent services to Hispanics



Participatory Research Processes

- Focus group recruitment
- Focus group data analysis
- Survey development
- Survey distribution and administration
- Survey data analysis
- Dissemination of results



Perceptions and Experiences of women:

Focus groups



Focus Groups

- 4 groups (x 2 mtgs)
- 38 women
- Church setting
- Audio taped, transcribed
- Analyses





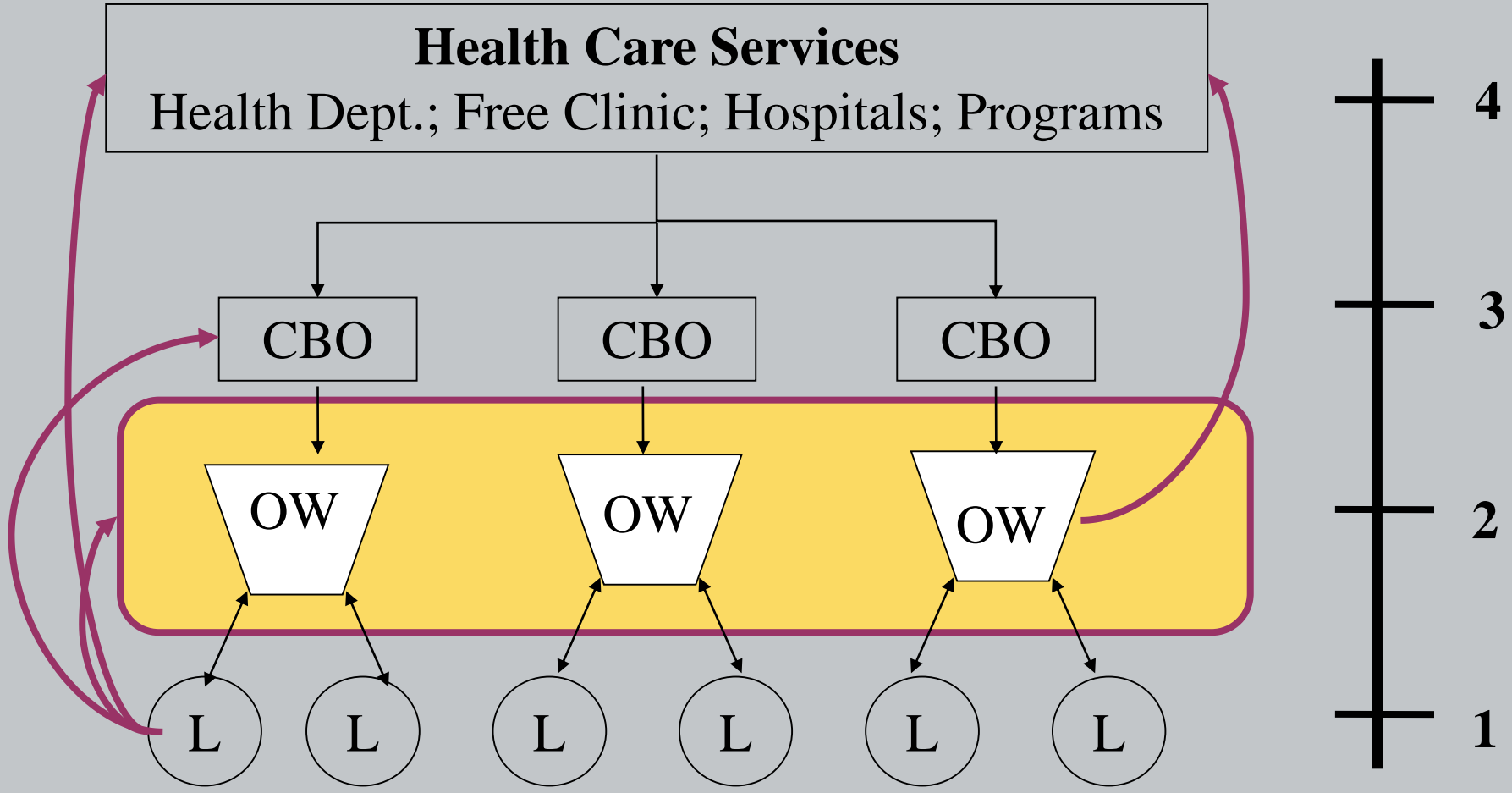
Focus Group Outcomes

- Cancer knowledge & risk perception
 - hygiene
 - if an infection is not treated then cancer
 - do not personalize risk
- Access to care
 - acute or pregnancy-related care
 - role of informal networks
- Health care system experiences
 - perceive “second-rate” treatment
 - barriers: language, transportation, costs



Health Information Network

Levels





Acess to Cultural and Linguistically Appropriate Services:

Surveys



Cultural Competence Surveys

- Developed 2 Self-administered, paper-pencil surveys
 - Partners identified and recruited sites
 - Developed sampling and obtained appropriate approvals
 - Distributed by partner reps to clinical and support staff at Women's Health Service sites
- University Partner
 - Obtained IRB approval
 - Facilitated survey development
 - Received complete surveys by mail
 - Cleaned and managed data
 - Produced data reports



Cultural Competency Surveys

Settings (N=14):

BCCEDP Providers 42%

County Health Departments 47%

Community Health Centers 11%

Provider type:

Clinical service providers 60%

Administrative support staff 40%



Provider Perceptions and Knowledge of Hispanic Clients

- Regular contact with Hispanic clients
- Primarily young female clients
- Reproductive health and chronic disease
- Recognize language barrier
 - Other aspects of cultural competency not recognized



Community Partnered Research





Translating Research Evidence to Practice

- What are the 3 most important messages?
- Who needs to receive this information?
- How should this information be delivered?
- Who should deliver it?
- What else do we need to know?





Prioritizing audiences and messages

- Providers need to understand
 - Expectations of Hispanic women
 - Importance of knowing who their clients are
 - The CLAS Guidelines/implications of Title VI
 - Know what language access resources and services are available
- How to reach them
 - Partners give presentations to their staff
 - Identify Hispanic physicians and nurses as spokespersons
 - Presentations at professional meetings & conferences
 - Articles on CLAS in newsletters for SCNA, SCMA, others



Prioritizing audiences and messages

- Local Hispanic communities need to understand
 - US health care system and how to access it
 - patient rights and responsibilities, and
 - health issues (health 101 series)
 - US Health Care System 101 – how to access health care services and what to expect
 - Women's Health 101- a class for women only that addresses women's health issues
- How to reach them
 - ESL classes
 - Worksites
 - Churches
 - Store-owners



Strategies

- strategies to address barriers to access and promoting CC cancer screening among local Latinas:
 - Address language barriers by providing trained interpreters or Spanish-speaking staff.
 - Improve provider-patient relationships and trust through cultural education and training.
 - Provide linguistically and culturally appropriate information about availability, accessibility, costs, and benefits of services.
 - Bring information and services to the local Latino community and use lay informants to mobilize the community



Partnership Outcomes

- SCH/LHC developed and is **providing cultural competency training** throughout the state to various audiences.
- SC BCCEDP identified areas of the state with the capacity to serve Latinos. They hired **bilingual outreach workers**.
- DHEC now has all **paperwork, forms, and materials available in Spanish**, has **qualified bilingual staff and interpreters** and they contract with HABLA for phone interpretations and translations.
- SC Hispanic Outreach completed a three month contract with SC BCCEDP to outreach to Hispanic community statewide they continue to **work with four promotoras to conduct outreach**.
- University received funding to **develop and evaluate the US Healthcare 101**



CBPR

C. helps identify key issues

C. helps with study design, budget, proposal

C. gives guidance re recruitment and retention

C. helps with measures development and testing

C. helps guide intervention development

C. helps with data interpretation and publications

→ Increased motivation to participate

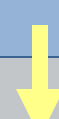
→ Increased acceptability and “buy-in”

→ Enhanced recruitment and retention

→ Increased reliability and validity

→ Greater relevance & likelihood for success

→ Enhanced potential for translation and dissemination



Health Concerns Identified

Study Designed and Funding Sought

Participants recruited and retention systems implemented

Measurement instruments designed and data collected

Intervention designed and implemented

Data analyzed and interpreted
Translation of findings



Issues selected from Epid. data

Design: science and feasibility
Budget: research expenses

Recruitment and Retention based on science and “best guesses”

Measures adopted or adapted from other studies, psychometric testing

Intervention designed by researchers based on literature and theory

Researchers report findings from analysis and publish in peer review journals

Traditional Research Approach



Community-Engaged Research: Lessons Learned



Advantages of Research Partnerships

- **Assessment of Needs and Resources:**
 - Process creates linkages and bridges to community resources
- **Setting Priorities:**
 - Consideration of multiple perspectives
 - Input, review, and critique of project content, approaches, and cultural appropriateness



Advantages of Research Partnerships

- **Planning and implementing research**
 - Partnerships key to recruiting and enrolling participants in the research
- **Evaluating and providing feedback**
 - Community partners took ownership of findings



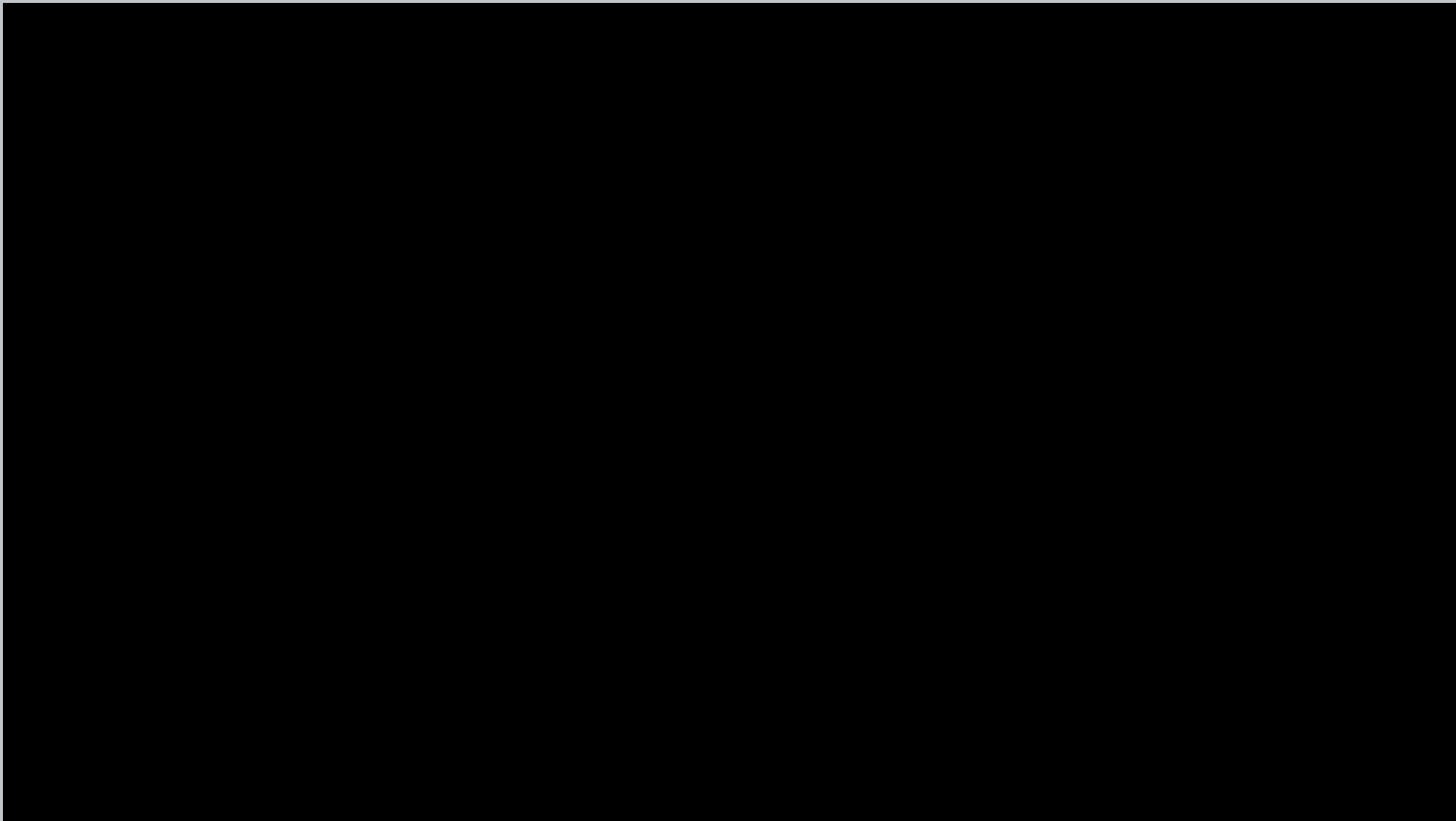
Challenges of Research Partnerships

- Maintaining continuous and open communication
- Maintaining continuity through organizational and personnel transitions among partners
- Sustaining community engagement throughout the research process
- Competing priorities and turf issues
- Resistance to the notion of randomization



Advantages of CBPR

- Skills and knowledge acquired can be applied to future issues
- Sharing of resources and findings with community
- Leads to tangible outcomes (action)
- Has the potential to build greater trust and respect between researchers and communities





Conclusion

Commitment and investment over time have contributed to productive campus-community partnerships, resulting in participatory research with sustainable outcomes for the community.



Acknowledgement

- *The project is supported by Grant No. 5 U01 CA86117- from the National Institutes of Health*



Thank you



Source: Greenvilleonline.com, 11 August 2005

Copyright 2005