

Case Study of an Unsustainable Community-Academic Partnership:

Toward Core Standards for the Structure of Emerging Participatory Research



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US Department of Health and Human Services (HHS)

'Action Plan to Reduce Racial and Ethnic Disparities'

- ✚ Calls for a *comprehensive community-driven approach*
- ✚ Consistent Healthy People 2020 objectives
- ✚ 2011 National Stakeholder Strategy for Achieving Health Equity



Community Driven Development

A Global Example

- ✦ Underpinning is partnership between communities in developing nations & financial institutions: World Bank
- ✦ Objective is to drive efforts for socio-political, economic and health reform
- ✦ Later instituted in nations affected by natural disasters or wars

The World Bank. Community-driven Development. worldbank.org/en/topic/communitydrivendevelopment.

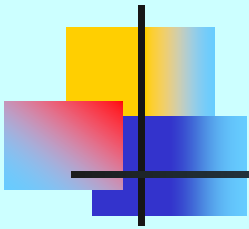


Community-based Participatory Research

A National Example

- ✦ Underpinning is partnership between underserved communities & academic institutions
- ✦ Objective is to drive community-based efforts to end health disparities
- ✦ Guided by nine Participatory Research Principals

Wallerstein NB, Duran B. Using community-based participatory research to address **health disparities**. *Health Promot Pract.* 2006;7(3):312-323



Core Participatory Research Principles

Edicts & Ethics of Participatory Research

Characterize Participatory Research as:

- ✦ A shared process
- ✦ Equal community and academic contribution in all respects
- ✦ Promoting mutual learning
- ✦ Benefiting local capacity building
- ✦ Empowering community-level social change

Israel B, Schulz AJ, Parker EA, Becker AB Community-based Participatory Research: **Policy Recommendations** for Promoting a Partnership Approach in Health Research Education for Health 2001;14(2):182-197



Literature on Participatory Research

What is Known?

- + Many success stories are reported
- + Research enterprises with long standing partnerships
- + Ethical & Racism Issues
- + Conflicts & Conflict Resolution

Seifer S. Building and sustaining community-institutional partnerships for prevention research: findings from a national collaborative. *J Urban Health*. 2006;83(6):989-1003



Literature on Participatory Research

What is Not Known?

Paucity of Reports:

- + How to develop new PR partnerships between smaller institutions
- + Without prior community-based research experience
- + PR partnerships that were unsustainable and why
- + Guidance for developing PR Organizational Structure (PROS)



Participatory Research Organizational Structure (PROS)

A collaborative research approach that is designed to **ensure and establish structures for participation** by communities affected by the issue being studied.

Agency for Healthcare Research & Quality

Throughout the process of establishing a CBPR partnership, it is equally important to devote time and resources to **developing an effective organizational structure** that will provide support to the partnership.

University of Washington's Examining Community-Institutional Partnerships for Prevention Research Group

How is PROS Defined?



Definition of PROS

The relatively unchanging attributes related to a PR partnership's capacity to implement community-centered research for achieving research goals.

Based on definitions of organizational structure provided by:

- ✚ National Quality Measures Clearinghouse: 'Selecting structure measures for clinical quality assessment'
- ✚ Donebedian paradigm's definition of structure in health care quality measurement
- ✚ Organizational structure business models



The 6 Domains of PROS

- ✦ Memorandum of Understanding (MOU) Directional
- ✦ Policy Environment
- ✦ Human Resources & Dedicated Effort
- ✦ Community & Academic Research Capacity Resource related
- ✦ Expertise & Experience
- ✦ Funding Sources



Policy Environment

- ✦ Influenced by parent organizational structure & MOU
- ✦ Defines contributions and disbursement of resources by partners
- ✦ Influences how resource related domains interact and function
- ✦ Defines partnership capacity and needs



How may emerging PR partnerships develop sound PROS?

Answer: Identify a set of core standards for PROS

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Calderón JL, Norris KC, Hardigan PC, Calderón LA, Hays RD. Ethnicity &
Disease 2015;20(2):

Objective: Propose a set of core standards for PROS



PR Parent Organization Structures

Community Partner

- + Non-profit
- + Hispanic Social Services
- + Gov't & Philanthropy
- + Executive Officers & B. of D.
- + Community-based Outreach
- + Service Outcomes Oriented
- + Recruitment Experience
- + No PR Experience

Academic Partner

- + Non-profit
- + Hispanic Serving Institution
- + Tuition & Pharma Grants
- + Academic Hierarchy
- + Limited Outreach
- + Academic Outcomes Oriented
- + Pharma Research Experience
- + No PR Experience



Participatory Research Roles

Community Partner

- ✦ Subcontracted
- ✦ Project Administration
- ✦ Administrative Staff
- ✦ Implementation Space
- ✦ Project Implementation-Admin
- ✦ Participant Recruitment
- ✦ Data Collection
- ✦ 55% of Grant Funding

Academic Partner

- ✦ Institution of Record
- ✦ Research Administration
- ✦ Research & Clinical Faculty
- ✦ Clinical Equip & Supplies
- ✦ Project Implementation -Clinical
- ✦ Participant Follow-up
- ✦ Data Manage & Analysis
- ✦ 45% Grant Funding



Summary of Research Events

- ✦ Type II Diabetes identified by community partner as primary health concern
- ✦ 2 year \$225K study funded by CMS
- ✦ Randomized controlled trial: Immigrant Latinos in South Florida with T2D
- ✦ Multi-educational and training intervention
- ✦ Outcome Measures: Hemoglobin A1c, BP, BMI, Lipids, Alb/Cr ratio



Summary of Research Events

- ✦ All staff and faculty except one were native Spanish speakers
- ✦ Research requires no-cost extension
- ✦ Partnership ends before research completed



Positive Participatory Research Outcomes

- ✦ Intervention shown efficacious for improving HgbA1c, BMI
- ✦ Published as a pilot study
- ✦ Preliminary data for next grant
- ✦ PR Education Program (PREP)
- ✦ PREP Training Model manuscript in preparation

SO WHAT REALLY HAPPENED??



Methods

- ✦ Challenges to research and sustaining partnerships point to conflict-related issues
- ✦ Hypothesis: Parent organization conflict resulted in partnership demise
- ✦ Retrospectively explored instances of potential conflict and actual conflict
- ✦ Related to six domains of PR organizational structure
- ✦ Community monthly reports, academic quarterly, continuation and final reports
- ✦ Research related meetings and communications with senior administrators
- ✦ Neutral and factual observation was used as the approach to data gathering



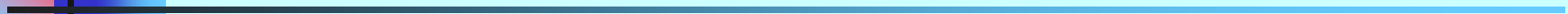
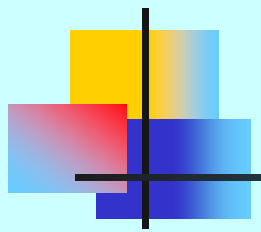
Potential Conflicts

- ✦ Arise by any action or decisions that may negatively impact the PR process and/or cause disagreement or discord
- ✦ Potential conflicts may be disambiguated by mediation within the partnership before they become actual conflicts
- ✦ Disambiguation is the process mediation within the partnership
- ✦ Actual conflict requires conflict resolution
- ✦ Actual conflict usually requires third party mediation



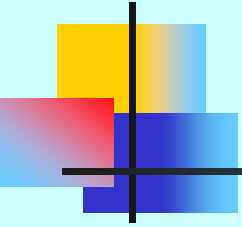
Conceptual Framework

The Donabedian Model for assessing quality of health care provides the conceptual framework for retrospectively exploring the PR partnership by three levels of assessment: structure, process and outcome



Case Study Results

Table 1



Core Standards for the Organizational Structure of New and Emerging PR Partnerships

Table 2