
Community-Based Participatory Research

Perspectives from an academic & non-profit institution

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CBPR Perspectives from an academic & non-profit institution

Agenda

Non-profit perspective (Isles, Inc.)

- Isles Overview
- Definitions for Community Based Participatory Research
- Isles' Principles
- Isles' research examples
- Benefits and Challenges

University perspective

- Definitions of CBPR
- Clarifying expectations
- The GLO project
- CBPR web-based resources

**Fostering more self-reliant families
in healthy, sustainable communities**



REAL ESTATE DEVELOPMENT
*Housing
Community improvements*



COMMUNITY PLANNING
*Neighborhood planning
Research
Leadership development
Public policy*



**FINANCIAL
SELF-RELIANCE**
*Financial literacy
Homeownership
Savings accounts
Micro-business*



YOUTHBUILD INSTITUTE
*Education
Job training
Life skills*



**CENTER FOR ENERGY &
ENVIRONMENTAL TRAINING**
*Workforce readiness
Green job training
& placement*



**ENVIRONMENT &
COMMUNITY HEALTH**
*Gardens, parks and trees
Healthy homes
Environmental cleanup
Community health*

isles
Fostering Self-Reliance

www.isles.org
609.341.4700

Why Research?

- To gain knowledge to improve Isles systems and programs.
 - To share knowledge with other communities and organizations.
 - To partner with communities and other organizations to address concerns.
 - To implement strategies that are uncovered by the research experience.
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- Agency/Academic Research Partnerships
 - Community-Based Participatory Research
 - In-house research projects

What is CBPR?

- CBPR is an approach to how research is conducted
 - CBPR is *not* a specific method or research design
 - CBPR can involve qualitative and quantitative methods and multiple research designs

CBPR vs. Agency/Academic Research Partnerships

- Community-based participatory research is a partnership approach to research that:
 - equitably involves community members, organizational representatives, and researchers in all aspects of the research process;
 - enables all partners to contribute their expertise with shared responsibility and ownership;
 - enhances understanding of a given phenomenon; and
 - integrates the knowledge gained with interventions to improve the health and well-being of community members

Some Definitions that Put It All Together

- Continuous, self-renewing efforts by residents and professionals to engage in collective actions aimed at problem solving initiatives to make life in the community better. This work improves lives and equity and creates new relationships, assets, standards, and expectations of life in the community.

Angela Glover Blackwell, J.D., PolicyLink

- Community-based participatory research is a "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, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities."

WK Kellogg Foundation Community Health Scholars Program

Isles Research Principles

- Research built on strengths.
- Expect equity in all aspects of the research process.
- Facilitation of co-learning and capacity.
- Disseminates of results.
- Respect and recognition.
- Research must have relevance.
- Balance between research and action.

Isles CBRP Research Example

- Trenton Spirit Walk--a project that motivates residents to walk more for good health
 - Community advisory committee involved in conceptualization and implementation of project
 - includes community members and other stakeholders in a position to affect outcome of project.
 - Committee involved in ongoing measurement of project's outputs and outcomes
 - Committee meets regularly to respond to measurements, both formal and informal, to guide project
 - Engages local partners to enhance project outcomes

Isles Agency/Academic Research Partnership

- Community Gardening Program– enables local residents to grow their own food, improve family nutrition, build community, improve open space and increase opportunities to exercise
 - Undertaken in partnership with the University of Pennsylvania urban studies and public health faculty
 - Survey questions prepared by faculty---broader research goals about impacts of community gardening as well as interest in helping community.
 - Utilizes student researchers & survey administrators
 - Collection of published data---demographic, crime, property values
 - Findings will be shared with the community
 - Adjustments will made to the program with community input based on findings.

Benefits of Using a CBPR Approach

- Can enhance relevance and use of data
- Can enhance quality and validity of research
- Can strengthen intervention design and implementation
 - Recruitment
 - Retention
- Knowledge gained and interventions can benefit the community
Provides resources for communities involved
- Joins partners with diverse expertise to address complex public health problems
- Increases trust and bridges cultural gaps between partners
- Has potential to translate research findings to guide development of further interventions and policy change

Challenges of Using a CBPR Approach

- Establishing and maintaining trust
- Developing agreed upon goals and objectives
- Significant time required to develop positive relationships and jointly carry out tasks
- Seeking balance between task and process/research and action
- Working together amidst ethnic, cultural, social class and organizational differences
- Following agreed-upon CBPR principles in practice (e.g., open communication, consensus decision-making)
- Working toward fair distribution of resources and benefits
- Questions of scientific quality of the research
- Competing institutional demands and risks

Community Based Participatory Research: An Academic Perspective

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Universities' definitions of CBPR

- Varied definitions / expectations
- The Rat Study
- “Outreach Component”
- “Action Research”
- “Program Evaluation”
- “Service-Learning”
- “Translational research-recruitment”
- “Community Engaged Research”

Guiding Principles for Community-Engaged Research

- Long-Term engagement
- Mutual benefit
- Mutual respect
- Shared findings
- Enhanced community capacity
- Shared responsibility
- Evidence-based
- **Collaborative from start to finish ***
- **Responsive to community priorities and perspectives ***

* These guidelines apply specifically to Community-Based Participatory research.

Defining Community

- “Classic”: The affected community
- Community based organizations (CBO)
- Health interest (local/national)
- Environmental groups
- Government
- “Not academic”
- Coalitions

Community-Based ('choosing' partners)

- Who represents “the community”
 - Multiple organizations
 - Conflicting organizations
 - No organizations
 - Residents vs. representatives
- Single v. multiple partners
- Legitimacy/credibility
- Capacity (existing and created)

Participatory

- Ideal: “involvement at all stages”
- Challenges:
 - Timing
 - Research funding
 - Narrow expertise/capacity
- Clarify constraints and roles
- “True” CBPR requires long-term partnership (multiple researchers)

Participatory roles

- Planning Team/partnership
- Advisory Council (stipended?)
- Paid staff
- Assistance with recruitment
- Incentives for participation
- Capacity building

Research

- “Generalizable Knowledge”
- Institutional Review Board (IRB)/ Human Subjects Review Board (HSRB) challenges
- Funders – quality control, commitment to product, timelines
- Products – papers, presentations
- Researchers’ goals/incentives
- Community’s goals/incentives

Types of Research

- Exploratory/Hypothesis generating
- (Quasi) Experimental (Hypothesis-testing)
(randomized controlled)
- Descriptive (Surveillance, Epidemiological
Ethnographic, Observation)
- Program Evaluation
- Policy (Process, analysis, evaluation)

This is a test:

Collaboration between communities and researchers is....*

Fun	T	F
Time-consuming	T	F
Frustrating	T	F
Personally rewarding	T	F
Easy	T	F
A tool for better research	T	F

***www.ccph.info (presentation by James Krieger, Seattle-King County Healthy Homes project)**

Questions for Academic-University research partnerships

- What does the community get?
- What does the researcher get?
- Principles for collaboration
- “Plan B”
- What is the Big Picture (institutional context, history, future plans)

Partnering to produce change through
information:
Get the Lead Out (GLO)

Origins of GLO

- Survey of School 17 kids showed 41% had elevated blood lead levels
- Community Health Center initiated GLO as primary prevention program
- Grant from Rochester Area Community Foundation for \$25,000 to fund 100 risk assessments



41% of your neighborhood's kids are lead poisoned...
What's a community doctor to do?

GLO Goals

- Assess the homes of 100 OSCHC patients under three years old
- Educate family about reducing hazards
- Encourage property owner to fix hazards
- Learn from this project's experience

Partners

- Action for a Better Community
- City of Rochester
- Orchard Street Community Health Center
- Healthy Homes Associates, Inc.
- Jay and Orchard Street Neighborhood Association
- Monroe County Department of Public Health
- University of Rochester

University of Rochester Role

- Community Outreach and Education program received \$25,000 pilot grant
- Recruited and supervised medical students
- Managed program evaluation/data
- Grantwriting
- “Steered” evolving partnership
- “Lessons learned” (programs/policy)

GLO Process

- Contact family through physician
- Conduct Lead Inspection and Risk Assessment
- Educate Family
- Support/encourage property owner
- Collect and analyze data

Risk Assessment

- EPA certified risk assessor
- Dust wipes, soil samples, XRF
- Risk Assessment sent to parents and property owners
- Later, CBO staff trained to take dust wipes/visual



Home Visits-Parent Survey



- Survey to get background information on the home and child
- Originally by med students, later by CBO staff

Analysis/evaluation

- “Case studies” of typical/challenging cases
- Analyze data from parent visits (changes)
- Collect information from city, county, and property owners re: lead hazard reduction
- Track policy changes
- Communicate lessons learned to Coalition to Prevent Lead Poisoning, community groups, City and County

Measuring impacts on people

- Changes in how house is used
- Over a third reported changed cleaning practices
- Contact with landlord to address hazards
- Raised awareness of lead hazards
- Look for lead safety when moving

Information about hazards= power to avoid hazards



Child next to old window



Old window

Impacts on Places

- Reports from follow up visits show some voluntary repairs (painting)
- Some owners applied to city's HUD lead hazard reduction grant program (number unknown)
- 15 properties made lead safe by County HUD grant program, "leveraged" 11 more

GLO-ing Success!



Crib next to new window



Tenant next to new window

Impacts on Policies

- GLO showed that there was no effective law against lead-unsafe housing
- Helped build case for local lead law
- Law passed in December 2005; implemented July 2006

University's Role in GLO

- Input on/support of other neighborhoods' plans (Day of Caring, SWAN)
- “Lessons learned” for feedback on policy proposals (City Code, County pilot testing DSS housing)
- “Spinoff studies” (primary prevention; Lead Check Swabs by medical students)
- Interaction with national lead community (listserve, meetings, etc.)

GLO's role in University

- HANYS nomination
- AAMC 2004 Community Service Award
- Visible community involvement in lead issue (June 2004 Lead Summit)
- Opportunity for public health/policy experiences for students
- Model for community partnership

The GLO Project:



Making our neighborhood lead safe for children –
one house at a time.

A few CBPR Resources

- Center for Community Health:

www.urmc.rochester.edu/communityhealth/

- CEAL-UNC Collaborative:

www.ceal.org/index.php

- Community-Campus Partnerships for Health:

www.ccph.info/