

Quantitative Methods in Participatory Research: Being Sensitive to Issues of Scientific Validity, Community Protection and the Academic Community Relationship

CU Expo 2013 Presenters:

Ann C. Macaulay, Jon Salsberg, Sarena Seifer

Participatory Research at McGill (PRAM)

Department of Family Medicine, McGill University, Montréal, Canada.

© 2013 PRAM



Member of the Anisnabe Kekendazone-NEAHR
Network Environment for Aboriginal Health Research

Participatory Research at McGill

<http://pram.mcgill.ca>



Presentation Outline

- Working definition of participatory research
- History behind developing this presentation
- Results of realist review on the benefits of participatory research for teams focusing on health interventions
- Examples of quantitative research taken from three projects retained by the realist review

Participatory Research (PR)

“Systematic enquiry,

with the collaboration of those affected by the issue being studied,

for the purpose of education and taking action or effecting social change.”

- Undertake the research
- Within the partnership
- To make a difference

The Royal Society of Canada- Study of Participatory Research in Health Promotion. 1995 Green LW, George MA, Daniel M, Frankish CJ, Herbert CP, Bowie WR, O'Neill M.

Definition used by CDC and Institute of Medicine

Using quantitative designs in participatory research

- Participatory Research at McGill (PRAM) promotes PR as an approach to research and not a research methodology
- Therefore PR uses qualitative, quantitative and mixed methods as appropriate to answer the research question(s)

Origin of the topic

- Invited paper from a journal that usually publishes only qualitative research
- Journal wanted to emphasise that PR uses all research methods (which also addresses the issue of those who conflate participatory with qualitative research)
- We used three projects retained in our recent realist review of the benefits of PR

Recent Realist review on benefits of Participatory Research

- 7167 citations pulled from the literature



- 594 full-text articles retained using an identification tool



- 83 partnerships (sets of full-text articles) retained for appraisal using selection tool



- 23 partnerships (276 articles) retained for synthesis

J Jagosh, P Pluye, AC Macaulay, J Salsberg, J Henderson, E Sirett, PL Bush, R Seller, G Wong, T Greenhalgh, M Cargo, CP Herbert, SD Seifer, LW Green. Assessing the Outcomes of Participatory Research: Protocol for Identifying, Selecting and Appraising the Literature for Realist Review. *Implementation Science* 2011;6(24).

Note on selection...

Selection: 591 full-text papers

- 508 papers excluded using a selection tool

- Selection tool (7 questions):

- (a) Is the research health related?

- **(b) Does participation occur in these three areas:**

- partners are involved in identifying or setting the research questions;

- partners are involved in setting the methodology or collecting or analysing the data or interpreting the results;

- partners are involved in dissemination or implementation of the research findings

- (c) Is the setting community-based, organizational, or other? (describe)

- (d) Is there a description of empirical research? (some description of methods, data collection and analysis? Specify the methodology)

- (e) Are there PR-related process or outcome results mentioned?

- (f) Is there a description of the PR process or context (or is there a reference to the process/context in a cited companion paper?)

Results

1:

PR generates culturally and logistically appropriate research characteristics related to :

1.1 Shaping the scope and direction of research

1.2 Developing program and research protocols

1.3 Implementing of programs

1.4 Collecting, analysing and interpreting research data

1.5 Disseminating research findings

Results

2:

PR generates recruitment capacity:

2.1 community members to the advisory board

2.2 community members for implementation (e.g.,
for lay health worker programs)

2.3 community members as recipients of
programs

Results

3:

PR expands the personal and professional development of:

3.1 the community partners

3.2 the academic research partners

Results

4:

PR often results in productive conflict between the co-governing stakeholders during decision-making processes, resulting in:

4.1 positive outcomes for subsequent program planning

4.2 negative outcomes for subsequent program planning

Results

5:

Partnership Synergy accumulates in cases of repeated successful outcomes in partnering, thus increasing the quality of outputs and outcomes over time

6:

PR accumulates capacity to sustain project goals beyond funded timeframes and during gaps in external funding

Results

7:

PR generates systemic changes and new unanticipated projects and activity

Quantitative design in PR projects

All 23 projects retained for review had used quantitative data collection at some point in their partnerships

- 15 also used qualitative and/or mixed methods

Following examples come from 3 retained projects

Community's role

- Governance
 - Identifying new knowledge or action needed
 - In discussions with researchers what methods are appropriate to answer the above
- Maximising benefits and minimising harms
 - Assuring details of data collection, analysis and reporting are culturally appropriate and safe
 - Combining scientific rigour with community relevance
- Interpretation of results
- Implementation and dissemination of findings

Kahnawake Schools Diabetes Prevention Project (KSDPP)

Repeated cross sectional quantitative data collection 1994-2002 from Grades 1-6 (anthropometric measurements, food and physical activity frequency, screen time, physical fitness)

CAB role in decision making to

- Mohawk RN undertook the anthropometric measurements
- children measured in light clothing to reduce embarrassment
- reduced number of skin fold thicknesses to reduce embarrassment
- dropped hip- waist ratio measurements to reduce embarrassment
-

Kahnawake Schools Diabetes Prevention Project (KSDPP)

CAB role in decision making to

- anonymised data aggregated from 2 elementary schools (i.e. no comparison of children from different schools)
- CAB allowed comparison of snacking data for children of healthy and obese weights provided the interventions remained the same for all children (i.e. did NOT discriminate re weight)

“Which partner is the primary owner of KSDPP at the present time?”

- Repeated cross sectional data from all team members at 18 mths, 5 yrs, 10 yrs seeking input on levels of influence in different domains (intervention, research, ethics etc)
- Linear trend: KSDPP staff as **the primary owner** at 18 mths, to joint staff - Community Advisory Board (CAB) ownership at 5 years, to CAB perceived as primary owner at 10 years.
 - Academic researchers never perceived as the primary owner
- Assessed levels of governance, and also demonstrated that long term funding is needed to build community capacity

Cargo M, Delormier T, Lévesque L, McComber AM, Macaulay AC. Community capacity as an "inside job": evolution of perceived ownership within a university-aboriginal community partnership . American Journal of Health Promotion 2011;26(2):96-100

Planning Randomised Control and Quasi-Experimental Trials using a PR approach

Issues

- whether or not to have a control group
- if yes, how to recruit participants to the intervention and control groups
- how to balance external validity granted by control group design with ethics and relational considerations of having some community participants not receive the intervention.

Project Bridge

1997 Project initiated with a mandate to plan an intervention for HIV/AIDS and substance abuse prevention. The partnership was comprised academic researchers, a HIV prevention organization and a church organization.

1997-2000 monthly meetings

2000 academic proposed RCT intervention (a) cognitive-behavioural substance abuse prevention program, (b) Afro-centric program based on arts, media, communication, music, and physical activity strategies, (c) an abstinence-focussed curriculum; and (d) a faith-based component

Project Bridge

- Community members were very concerned how to identify the comparison group while ensuring that some adolescents not be ‘objectified’ in the process.
- After months of ongoing dialogue, a comparison group from a neighbouring faith-based ministry was identified and participants were given incentives for their participation.
- Additionally, this ministry’s staff and volunteers were offered training to fully implement Project BRIDGE in their setting at a later time.

Project Bridge

« Church members shifted their views about the value of comparison groups over time with the realization that the comparison group would substantiate changes they were seeing and, thus, enable the team to attract future funding and to serve larger numbers of young people »

Marcus M.T, T. Walker, J. M. Swint, B. P. Smith, C. Brown, N. Busen, T. Edwards, P. Liehr, W. C. Taylor et D. Williams. (). Community-based participatory research to prevent substance abuse and HIV/AIDS in African-American adolescents.

Journal of Interprofessional Care 2004;8(4): 347-359

The East Harlem Diabetes Center for Excellence,

Partnership initiated in 1997

1997 - 2006 coalition conducted events to raise awareness for diabetes prevention and 2 community needs assessment surveys.

2007 community based RCT to test the efficacy of a peer-led weight reduction program for African American adults

At that time “Team included 33 leaders of community-based health and social service organizations, religious institutions, seniors and tenants organizations, as well as local activists”

The East Harlem Diabetes Center for Excellence,

The coalition had to negotiate differing views on control group randomization.

- Community leaders wanted to recruit from community organisations (concerned that strict inclusion criteria would appear negative to community at large)
- Researchers wanted to recruit from the community at large (to avoid bias of those belonging to organisations)

East Harlem cont'd

After lengthy discussions researchers realised potential damage to partnership and decided

« researchers were pleased to adopt community leaders' recommendations, and these leaders moved from being reluctant to recommend potential participants to enthusiastically offering to recruit participants »

Horowitz, C. R., A. Arniella, S. James, N. A. Bickell. Using community-based participatory research to reduce health disparities in East and Central Harlem. Mt Sinai J Med 2004;71(6):368-74

Using Quantitative Research in CBPR

Our review synthesis suggests that tensions over data collection, research design and subsequent modifications to methods are more significant for academic-community partnerships that use quantitative methods, including planning randomized control trials (RCTs) and quasi-experimental studies, than for partnerships that use qualitative methods solely.

Quantitative Methods in Participatory Research: Being sensitive to issues of scientific validity, community safety, and the academic-community relationship.

Macaulay AC, Jagosh J, Pluye P, Bush P, Salsberg J.

Nouvelles pratiques sociales 2013 (in press)

Synergy Building

Pre-context

Synergy typically builds over time

Context: mistrust
Mechanism: respect
Outcome: new trust, synergy

Context: new trust, synergy
Mechanism: humility, respect
Outcome: innovation, new synergy; new resources

Context: new infrastructure
Mechanism: continued mutual respect, caring
Outcome: spin off projects; systemic change

TIME



Commentary:

AC Macaulay, J Jagosh, R Seller, J Henderson, M Cargo, T Greenhalgh, G Wong, J Salsberg, LW Green, C Herbert, P Pluye. Benefits of Participatory Research: A Rationale For a Realist Review. Global Health Promotion. 18(2) June. 2011

Protocol:

J Jagosh, P Pluye, AC Macaulay, J Salsberg, J Henderson, E Sirett, PL Bush, R Seller, G Wong, T Greenhalgh, M Cargo, CP Herbert, SD Seifer, LW Green. Assessing the Outcomes of Participatory Research: Protocol for Identifying, Selecting and Appraising the Literature for Realist Review. Implementation Science, 6(24). 2011

Findings:

Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, Sirett E, Wong G, Cargo M, Herbert CP, Seifer SD, Green LW, Greenhalgh T. Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice. Milbank Quarterly, 90(2). 2012

AC Macaulay, J Jagosh, Pluye Pluye, PL. Bush and J Salsberg. "Quantitative Methods in Participatory Research: Being sensitive to issues of scientific validity, community safety, and the academic-community relationship." La Revue Nouvelles Pratiques Sociales. 2013 (In press)

Methodology:

Jagosh et al. (under review) – methodological reflection paper (Research Synthesis Methods)

<http://pram.mcgill.ca>

Thank You!