Unexpected and Unintended Outcomes of Community-Based Participatory Research:

Findings from a Realist Review of What Works, for Whom, and in What Circumstances

CU Expo 2013 Presenters:

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Project Partnership:

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Presentation Outline

- Working definition of participatory research;
- Origins of our research question and partnership
- Describe the problem we sought to address using realist review;
- Briefly explain the logic and key ingredients of realist review;
  - What does realist evaluation purport to solve?
  - Why critical realism?
  - Context, Mechanisms and Outcomes – in the realist evaluation
  - Demi-Regularities
- Briefly discuss our identification, selection, and appraisal strategy;
- Our 7 key findings
  - Particularly, Finding #7: PR Generates Unintended and Unexpected Outcomes

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

Origin of the Research Question?

A participatory approach to assessing the participatory approach…

One partner has to ask the other to dance!

- The question was ours (the academic researchers)

- Who might be interested in this study…?

We identified 4 sectors:

- ## public health policy actors
  - 1 federal and 1 regional public health agency (Public Health Agency of Canada and Peel Region Public Health, Ontario)

- ## research funding agencies
  - 1 federal and 1 provincial research funder (CHSRF and FRSQ)
    [CIHR was interested but could not be involved because of conflict of interest - they were the funder]

- ## community-engaged advocacy organisations
  - 1 community-university health research organisation
    (Community-Campus Partnerships For Health)

- ## university or hospital IRBs/REBs
  - 1 institutional review board (McGill University Faculty of Medicine IRB)

Research Questions:

- What benefits, if any, can be observed from the collaborative steering of health research by academic researchers and 1) those affect by the issues under study and/or 2) those who would apply research results?

- How are these benefits conceptualized?

- How do variations of program <u>context and mechanisms</u> influence the <u>process and outcomes</u> of health research or interventions?

What have been the barriers to assessing PR?

- Despite purported benefits of PR, there are not enough completed studies with evaluated, reported outcomes

- The one previous systematic review of PR, by the Agency for HealthCare Research and Quality in 2004, was unable to demonstrate that a PR approach improved research and health outcomes.
  - AHRQ did not appraise studies for quality of the partnership, therefore could not link PR to research outcomes

Why Realist Review?

it is… *"A synthesis for the unsynthesizable."*

traditional systematic reviews do not deal well with heterogeneity of…

- design and methodology
- interventions
- outcome measures
- contexts
- population
- etc…

What Realist Review Does

- Avoids these problems through a focus on…

- Identifying <u>mechanisms</u>, the <u>contexts</u> in which they are (or are not) activated, and the <u>outcomes</u> to which they lead

- Categorizing and building these Context-Mechanism-Outcome clusters into <u>Demi-Regularities</u>
  - Not *laws*, but *things that tend to happen*

- Bringing to bear middle-range theory to help understand the patterns of these demi-regularities

- Ultimately <u>building or testing a theoretical model</u> of how a program works

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 (*in press*). <u>Global Health Promotion. 18(2) June.</u> 2011

Critical Realism:

- Critical realism (Bhaskar 1975) views reality as <u>ultimately objective</u>
- yet our ability to approach, perceive and derive meaning from it is <u>continuously constructed</u> and situated by the <u>contexts</u> in which we exist.
- Critical realism is often viewed as a <u>mid-way point</u> on the continuum between positivism and constructivism.
- Taking a critical realist perspective allows one to come to terms with a <u>wide range of data</u>, including both positivist experimental evidence as well as rich contextual (qualitative) understanding of meaning
- While critical realism assumes that <u>objective reality does exist</u> outside the perceiver and may in fact be investigated, the objects of investigation have <u>internal mechanisms that produce particular outcomes</u> within situated contexts

Realist Logic:

Realism: a philosophical stance concerning the fallibility of knowledge

"What causes something to happen has nothing to do with the number of times we observe it happening" (Sayer, 2000 p. 14).

Not: "does it work or not?"

But rather, "what works, for whom, and in what circumstances?"

Realist Logic:

You cannot understand a how mechanism leads to an outcome outside of its context

Thus...

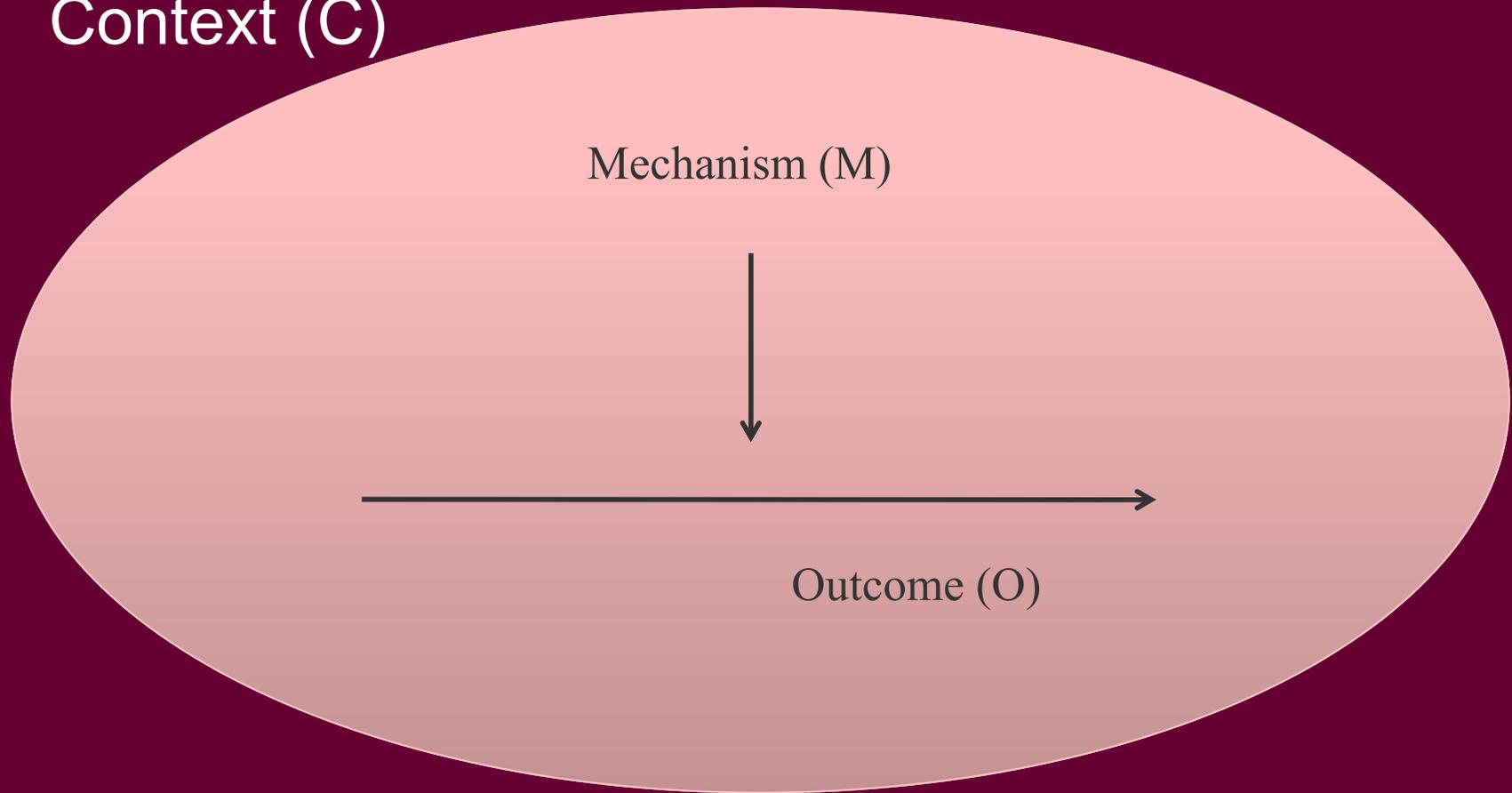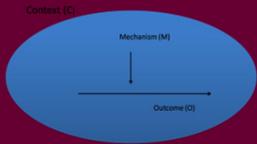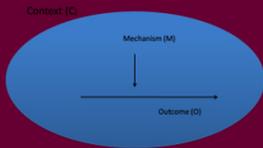# Ingredients in Realist Synthesis:

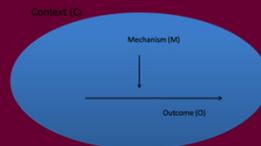Context (C)

Mechanism (M)

Outcome (O)

Figure 1: Basic components of realist causal explanation

Pawson R, & Tilley N. 1997 [2003]. *Realistic Evaluation*. Thousand Oaks, CA: Sage Publications.

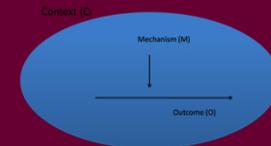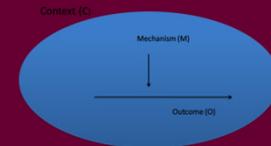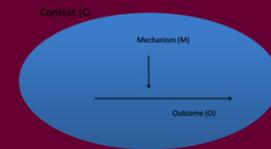**Demi-regularities** = What we expect to find in a semi-predictable manner

Demi-regularity 1

Demi-regularity 2
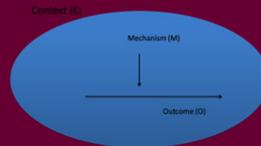
Demi-regularity 3

An example of CMO configuring

- CONTEXT: the Vietnamese Community Health Promotion Partnership (VCHPP) has been in existence for 15 years before the planning of the current intervention. It was already a known and trusted source of health information and it's members were from the community. Additionally, VCHPP staff members came from the community and thus were effective in establishing contacts with community organizations. This capacity led to appropriate choices when research requirements and community priorities conflicted and eased the transfer of decision-making power to the coalition. (Nguyen; p. 50; pa 2)

- MECHANISM: community <u>trusted</u> the VCHPP due to its previous work and members' insider status.

- OUTCOME: community agrees to participate in the research; researchers respond to needs of community. For example, during survey development, researchers were sensitive to community concerns to balance the need between asking more questions for research purposes and the need to limit respondent burden." (Nguyen; p. 50; pa 2--p. 40; pa 2 mentions trust)

- ## CMO: Preexisting relationships and experiences lead to active and relevant partnerships

Tung T. Nguyen, Stephen J. McPhee, Ngoc Bui-Tong, Thien-Nhien Luong, Tuyet Ha-Iaconis, Thoa Nguyen,Ching Wong, Ky Q. Lai, Hy Lam. Community-Based Participatory Research Increases Cervical Cancer Screening among Vietnamese-Americans. Journal of Health Care for the Poor and Underserved; 2006, 17: 31–54.

Identification, Selection, and Appraisal of the literature

- Realist Review is a qualitative appraisal, typically requires small sample of cases for in-depth analysis
- "Hand-picking" and snowball sampling techniques are accepted sampling strategies in realist review

- We decided to take a more formal ("systematic") approach to sampling, using a formal identification-selection-appraisal process and a two-person standard review style coding system

Identification, Selection, and Appraisal

- 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,

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?)

Findings…

Demi-regularities:
(semi-predictable outcomes of participatory processes)

Demi-regularity 1:

PR generates culturally and logistically appropriate research characteristics related <u>to</u> :

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

Demi-regularities:
(semi-predictable outcomes of participatory processes)

Demi-regularity 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

Demi-regularities:
(semi-predictable outcomes of participatory processes)

Demi-regularity 3:

PR expands the personal and professional development of:

    3.1 the community partners

    3.2 the academic research partners

Demi-regularities:
(semi-predictable outcomes of participatory processes)

Demi-regularity 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

Demi-regularities:
(semi-predictable outcomes of participatory processes)

Demi-regularity #5:

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

Demi-regularity #6:

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

Demi-regularities:
(semi-predictable outcomes of participatory processes)

Demi-regularity #7:

PR generates systemic changes and new unanticipated projects and activity

- *Unintended and unexpected outcomes*

Unintended or Unexpected Outcomes:

Building toward equitable co-governance

increases then accumulates synergy which leads to unexpected/unintended outcomes.

- This is not saying that there is not conflict and relational challenges in building the partnership, but generally speaking when conflict is successfully resolved over time and the partnership gains long-term sustainability, we observe the accrual of unexpected/unintended outcomes

# Context-Mechanism-Outcome configuration of 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
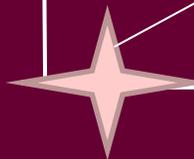
Unintended or Unexpected Outcomes:

Types of Unintended outcomes:

- Policy change
- Capacity building
- New projects
- New academic directions
- New community agencies or programs
- Use of PR products by unanticipated end-users
- …?

Challenges:

- Locating documenting and understanding these outcomes
- Short-term, medium-term, long-term outcomes
- Within the community/setting/project vs. Outside/other settings

Unintended or Unexpected Outcomes:

Unintended outcomes *might not be unexpected*

- Seasoned PR coalition members may expect that spontaneous ideas for new spin-off projects will arise when multi-stakeholders converge around a research topic of interest.

- However these may be unintended in the sense that they are apart from the original interest or goals of the partnership.

Example:

Messengers For Health Partnership

Originally dedicated to increasing breast and cervical cancer awareness.

As the profile and positive reputation of the partnership grew within the community, the men in the community approach the partnership to see if they could support them in planning an intervention for men's health issues.

Unintended or Unexpected Outcomes:

Unintended outcomes may also be understood in terms of

how synergy is built to address the same issue, but in different ways over time.

I.e., PR synergy leads to project design changes to address contextual needs

Example:

The East Harlem Diabetes project began their partnership with the idea to focus on diabetes prevention in the community (there was a change of direction at the start of the partnership which led to a focus on diabetes).

It did not intend at the outset to conduct a community RCT. Instead, they started with creating a number of needs assessment surveys, a community health day and grant funding proposals.

It was through the partnership building, productive conflict and negotiation, mutual respect, etc., that the partnership achieved the kind of synergy within the community to successfully launch an RCT for a weight loss program.

Unintended or Unexpected Outcomes:

A strength of the PR approach is in fact the way it creates conditions which lead to unintended outcomes.

Example:

- Some partnerships have the luxury of having funding at the outset that is not tied to a particular mandate, design or intervention.

- E.g., Seattle Partners for Health Communities.

- The Seattle partnership was able to be more creative and open to possibilities and to allow the research focus to emerge through on-going dialogue.

- Members of that partnership said that it was actually too much freedom, that it would have been easier in a way, to have a focus from the start.

- In a case like this one, you could say that all outcomes are in a sense unexpected, although intended.

Example:

- Other partnerships begin with a very clear and focused mandate.

- So the unintended outcomes can be unrelated spin-off projects, or else new ideas to tackle the same issue.

Example:

Mental Health (Ken Wells and Loretta Jones)

- Success led to policy change at Robert Wood Johnson clinical scholars program (approx 2006)
  - all trainees now trained in CBPR

Example:

Vietnamese Reach for Health Initiative

- Their CAB managed to convince one of the county supervisors to do a Vietnamese needs assessment survey from the Public Health Department.

  - then the Public health department had to offer surveys to other ethnic communities too

- Improved health delivery services to be more culturally competent for the population.

Example:

The Kahnawake Schools Diabetes Prevention Project (KSDPP)

- Capacity building:
    - intervention worker became council member
    - Several community members chose academic paths
- Creation of an academic centre (PRAM)
- McGill Family Medicine Graduate Programs (MSc and PhD) now require PR course as a core competency
- KSDPP CoRE to other Indigenous and non-Indigenous projects – including CIHR
- Lawson Foundation switched their funding to require CBPR

Example:

- CPBR Creates inter-organisational cohesion - brings community organisations together

- Brings researchers from different universities within the same city/region to work together:

  "The community agency becomes a central organization that is able to help researchers coordinate their research to create a more seamless network of research that isn't duplicating or being inefficient.   …they help to establish this pattern so it's complementary rather than competitive."

Unintended or Unexpected Outcomes:

Challenges:

- Locating documenting and understanding these outcomes
- Short-term, medium-term, long-term outcomes
- Within the community/setting/project vs. Outside/other settings

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!