

Uncovering the Benefits of Participatory Research:

Implications for Public Health Research and Practice

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Acknowledgments:

This session is adapted from previously developed workshops on Realist Review methodology, and the **collaborative process of a multi-disciplinary team of researchers and decision makers**

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Funding Acknowledgements:

Supported by a Canadian Institutes of Health Research KT-Synthesis Grant (# KRS-91805), a CIHR Postdoctoral fellowship, and funding from Participatory Research at McGill (PRAM), and the Department of Family Medicine, McGill University.

Content of this Presentation

Part one: Conceptualizing Participatory Research (PR) and identifying barriers to assessment

Part two: Describing the realist review methodology we used to assess PR outcomes

Part three: Reporting on the findings

Part four: Concluding with a few thoughts on the design requirements of PR assessment

Part one:

Conceptualizing Participatory Research and its Assessment Challenges

Participatory Research is:

“Systematic enquiry,

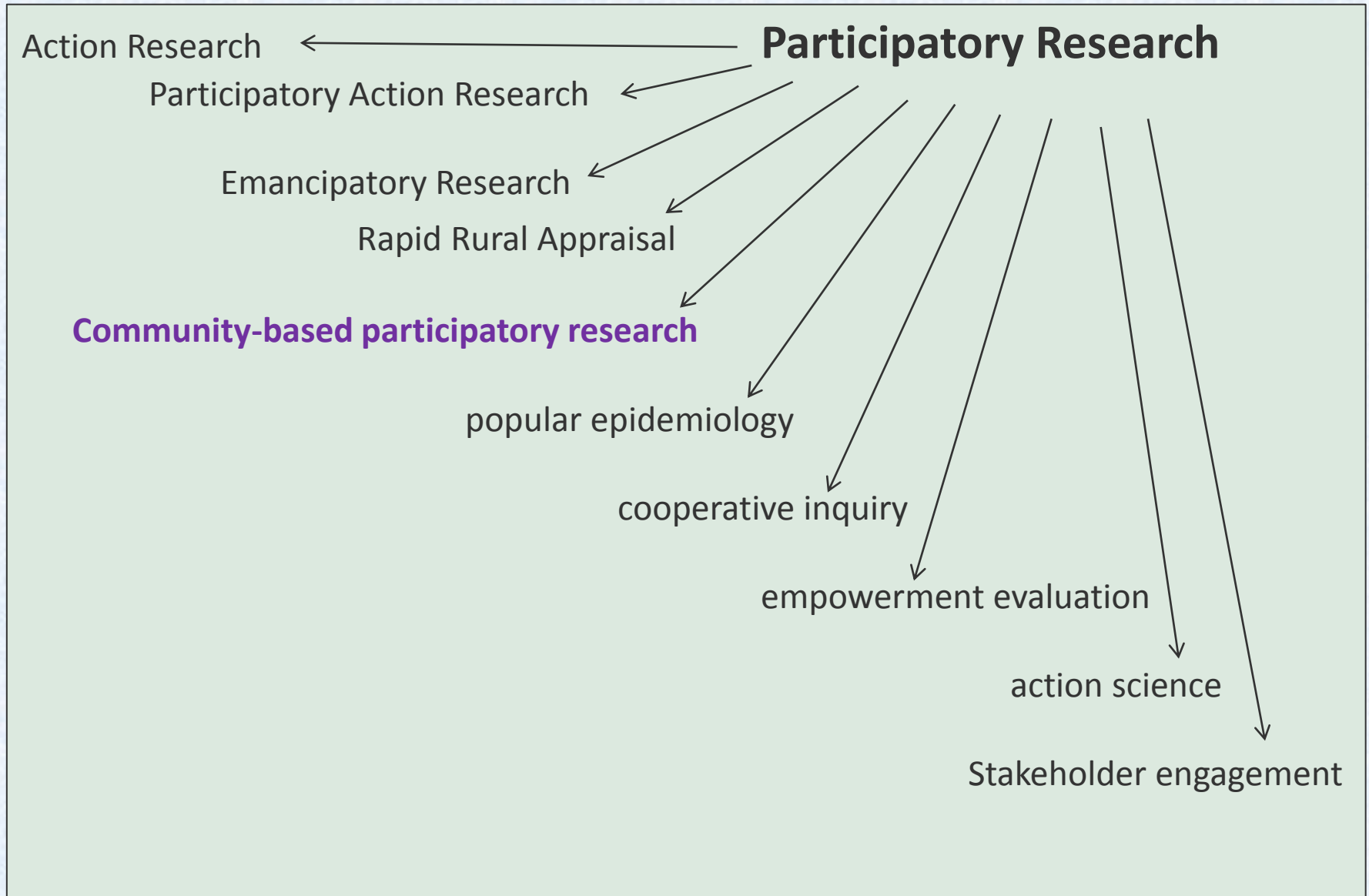
with the collaboration of those affected by the issue being studied,

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

-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.

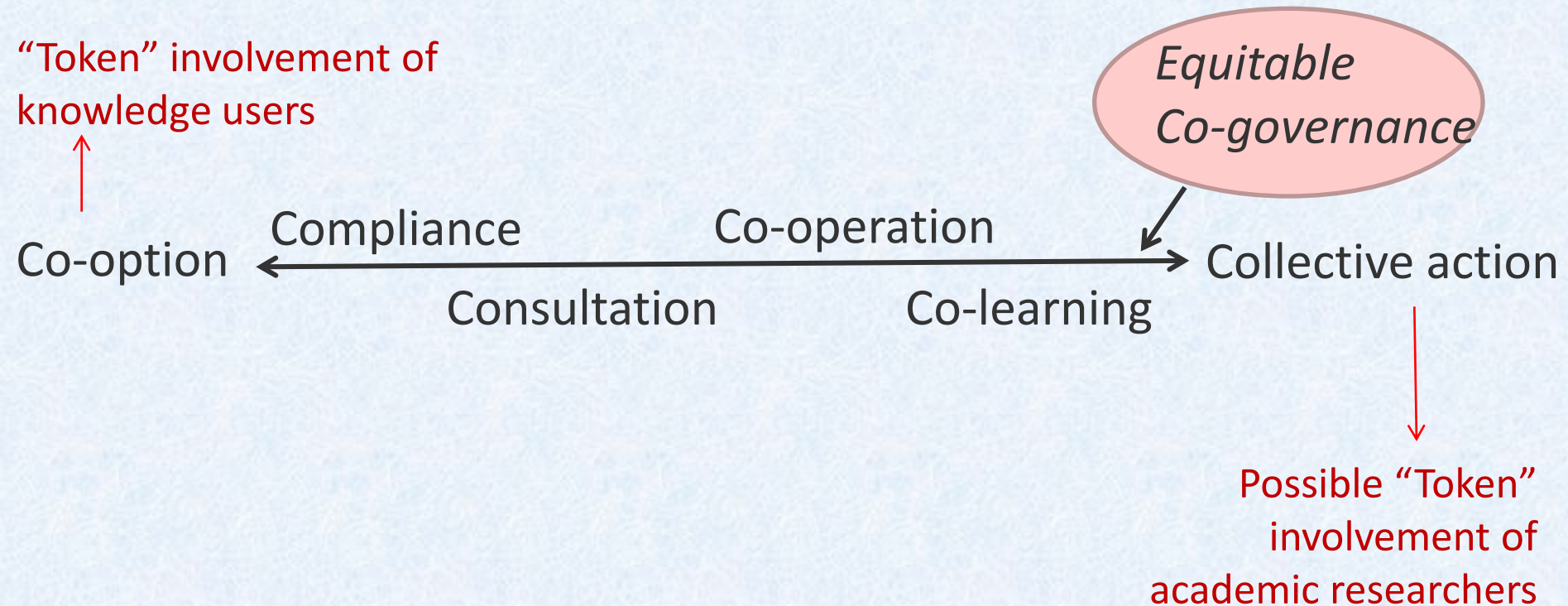
Definition used by CDC and Institute of Medicine

Participatory Research is an Umbrella Term:



Spectrum of Participation:

(Cornwall 2008)

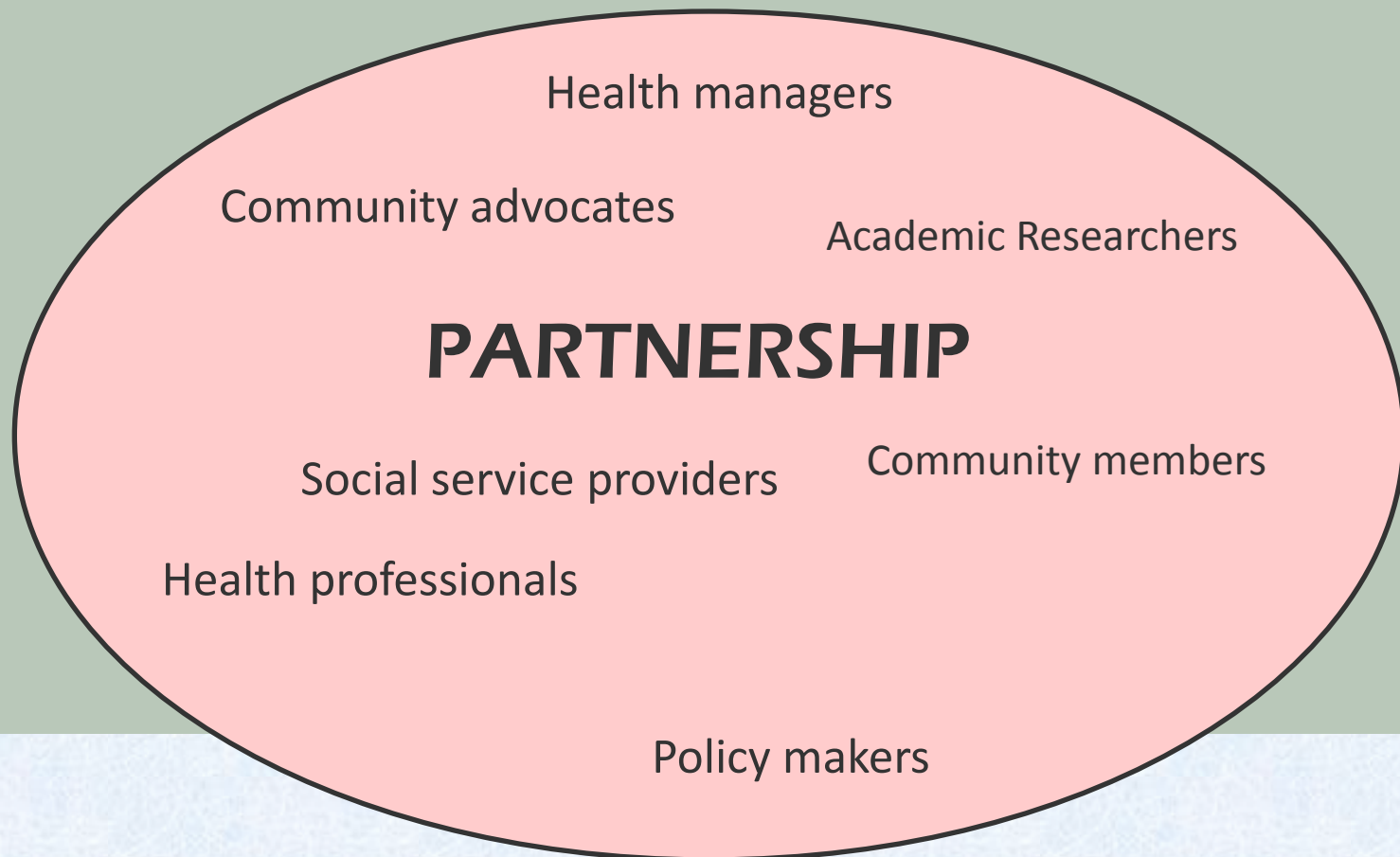


Cornwall, A (2008) Unpacking "Participation" Models, Meanings and Practices. *Community Development Journal*; 43(3): 269–283.

What our review examined:

The collaborative construction of research by:

*academic researchers +
people who are affected by, or use the research findings*



Research Questions:

1. What benefits, if any, can be observed from the collaborative steering of health research by academic researchers and those affected by the issues under study and/or who would apply research results?
2. How can benefits be conceptualized?
3. How do variations in context and mechanism influence the outcomes of participatory health research?

Part two: applying Realist Review methodology to PR assessment



Defining Realist Review:

An interpretive, theory-driven approach to synthesizing evidence from qualitative, quantitative and mixed-methods research:

...typically used for the assessment of complex evidence for policy implementation, programmes, services and interventions.

Realist Logic:

Not: “does it work?”

But rather, “what works, for whom, in what circumstances,
and how?”

(Pawson 2006)

Components of Realist Analysis:

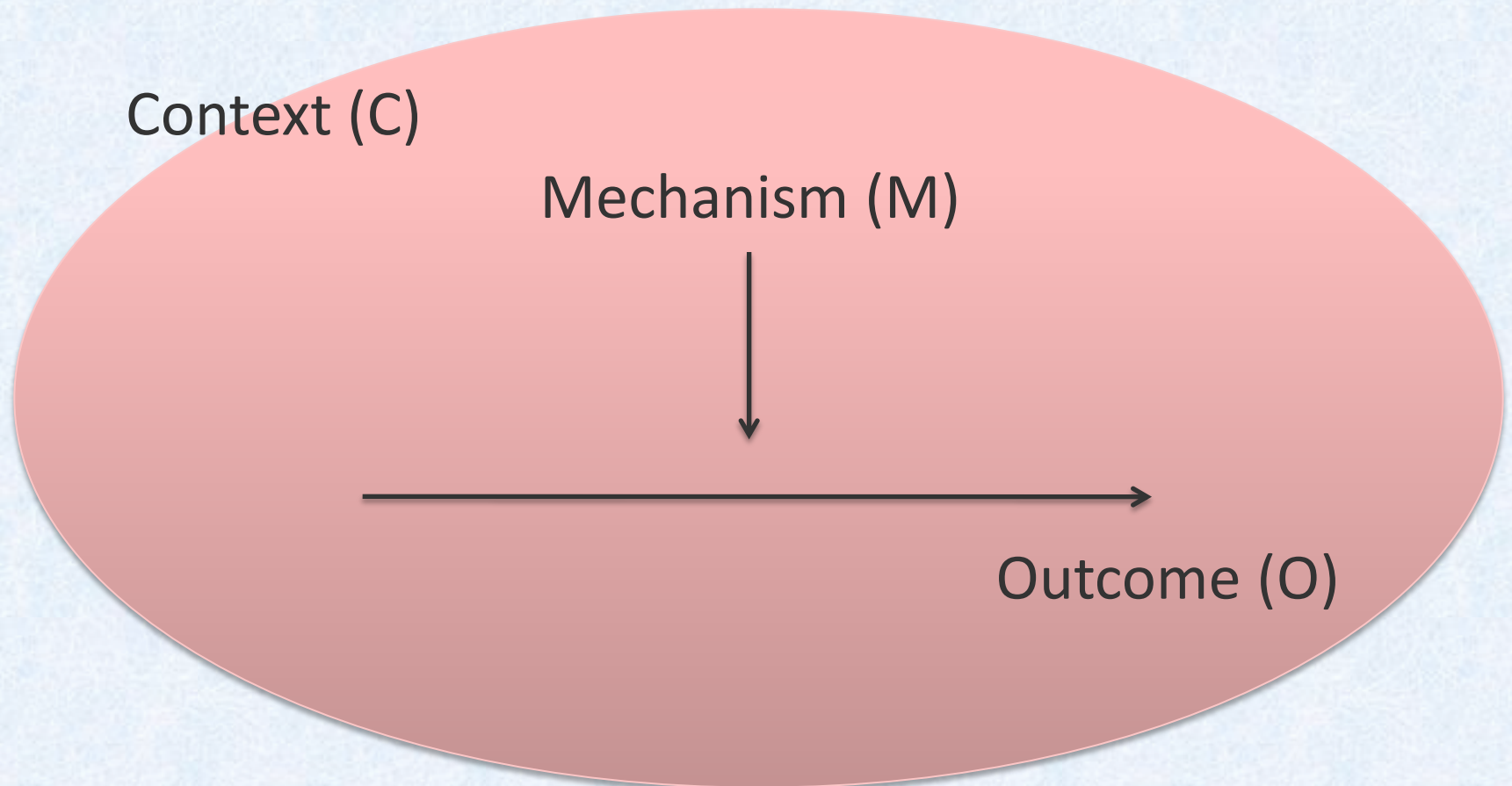
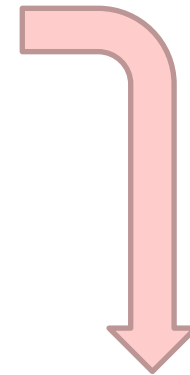
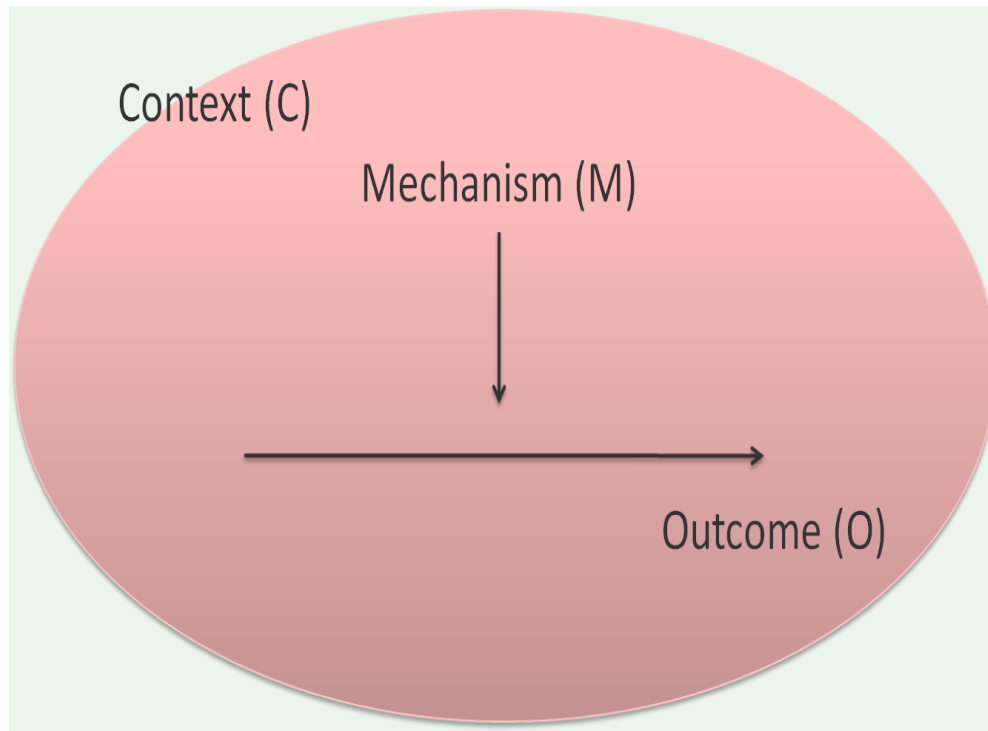
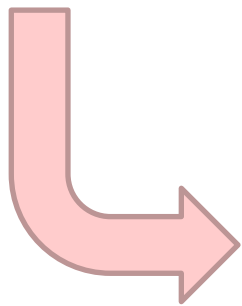


Figure 1: Basic components of realist causal explanation

Pattern of Work for Realist Review

Identify Candidate
Middle-Range Theory(ies)



Evidence-informed
Middle-Range Theory

Context-Mechanism-Outcome Defined:

- Context: any element of the physical or social environment including resources offered;
- Mechanism: the reaction or response of participants to resources offered, given contextual conditions
- Outcome: all impacts (planned or otherwise)

Review Stages:

1. Librarian-guided literature search
2. Identification
3. Selection
4. Appraisal
5. Synthesis

Stages 2-4 involved iteratively developed tools. Two reviewers independently assessed the literature and a third person arbitrator was there to help resolve disputed cases

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

Criteria for retaining literature:

- a) Had to be about health research
- b) Had to be in a community-based setting
- c) Had to report on an 'intervention'
- d) Participation had to be demonstrated as 'equitable co-governance': stakeholders involved across all stages of the research

Synthesis Procedure

1. Sets of papers were read in chronological order;
2. Passages were then annotated and extracted when they described how the collaborative process led to an outcome (of any kind);
3. Themes were generated from these CMO configurations;
4. Partnerships were then mapped visually
5. New CMO configurations were created from that process;
6. CMO configurations were then re-sorted according to demi-regularities;
7. On-going refinement of CMO configurations;
8. The use of partnership synergy theory used to facilitate 'higher-level' conceptualizing of the evidence;

Partnership Mapping:

(1997)
East Harlem
Diabetes Centre
for Excellence
Established

CMO3: Building social capital with Coalition Members
 C: local physicians in connection to community and low understanding of community wide challenges
 M: set on coalition committees organized community events, volunteered to give community lectures on diabetes prevention, collaborated on survey design, which indicated that community members have good understanding of diabetes prevention but low self-efficacy
 O: transfer of survey results directly into their clinical practices; shift in perspective - began to see patients living in a chronic community struggling with limited individual and community resources

Coalition formed:
(Physicians, nurses, nutritionists, health educators, community members, health services and policy leaders)

Kind focus on improving clinical performance for diabetes prevention

Tension: focus did not resonate with members.

CMO 4: Adjustment in Power Dynamic and Focus
 C: new group dynamics; high level of mistrust amongst disparate group of coalition members; leaders suggested a research direction that did not resonate with the coalition members
 M: partners allowed to see the "big picture" they agreed to remain on board if the direction of research moved away from patient healthcare satisfaction to community and individual disease self management
 O: Renewed interest in present increased feeling of ease and safety

Community events held to raise community awareness re: Diabetes

change in direction of research away from clinical service to community prevention

CMO4: Impact of Survey on Collaboration
 C: local knowledge of diabetes self-care measurements was lacking
 M: collaboration of coalition members on a survey to investigate present knowledge and behaviors concerning diabetes management
 O: Experts who of coalition working on the survey project built community infrastructure. Community services local partial ownership of survey injected new grant money into the neighborhood; outreach workers learned the basics of diabetes care; health center staff learned how to collect/analyze data to improve services; other members disseminated lessons learned to local politicians, religious, political, and hospital leaders; partners gained appreciation for using rigorously collected local data for addressing problems and obtaining new funding

(1998) Second survey conducted to study availability of recommended diabetes prevention foods at local grocery stores

CMO 5: RPT augmenting uptake of research findings
 C: increased social networking and social capital due to the success of previous coalition approaches to group business and public activities
 M: Discontinued 2nd survey test kit with local clinicians and community groups as interactive sessions
 O: direct uptake of research findings; physicians were suggested to use options above their difficulty finding diabetes self-care options; food and encouraged them to shop at grocery stores that carry diabetes prevention foods; nutrition centers from established coalitions; nutritionists, grocery store owners and distributors and other food stakeholders in the community

Applied for new funding for EXPORT grant to promote disease self-management; new board established;

CMO 6: Existing social capital from previous PR cases the establishment of a new board and creates more social capital
 C: social capital already exist from previous PR related activities
 M: Leaders carefully selected an interdisciplinary board of reps from community-based and local service organizations
 O: some community leaders who agreed to participate as a liaison other than an opportunity, came to appreciate the complexity of planning and implementing a large-scale research project; some researchers viewed the board as an obligation rather than opportunity; learned the depth and breadth of existing local programs to target racial and ethnic disparities, and the extent of board members' experience in issues relating to the local community's health thus increasing social capital

Large RCT - PROJECT HEAL (peer-led weight's program) Ongoing

CMO 6: Collaboration facilitates recruitment into peer-led, community-based course on weight loss
 C: increased social capital and capacity created by previous activities of the Centre for East Harlem Diabetes Prevention
 M: existing social networks used to recruit participants; church leader coalition members were involved in the logistics of recruitment; Peer-based approach used community members who already had the trust of their neighbours as teachers
 O: recruitment success of pilot project HEAL enhanced by existing PR interventions

CMO 7: Conflict between approaches to recruitment and requirements of RCT randomization
 C: previous trust and social cohesion built on experience; feedback had previous experience negotiating between competing interests; Members have an appreciation of difference perspectives from previous collaboration experiences
 M: board members (city) who transitioned to community organizations and recruited participants to project HEAL from those organizations; Researchers were concerned that lack of randomization of participants would jeopardize research goals of RCT; Community members were concerned that the same parameters for inclusion in the randomized trial would exclude many community members, thereby disrupting local ecosystem and mission of the program and decreasing potential to disseminate and sustain the program in the future
 O: all parties came to an agreement; researchers were pleased about community leaders' recommendations as these leaders viewed their being reluctant to recommend potential participants enthusiastically offering to recruit and engage

PROJECT HEAL: pilot study for peer-led weight reduction community trial

Part three: Results



Middle-Range Theory: Partnership Synergy

Defined as:

“Combining the perspectives, resources, and skills of a group of people to “create something new and valuable together—a whole that is greater than the sum of its individual parts.”

Lasker, Weiss, and Miller (2001, p184)

Results

Finding #1:

PR generates culturally and logistically appropriate research in relation to :

- 1.1 Shaping the scope and direction of research
- 1.2 Developing program and research protocols
- 1.3 Implementing programs
- 1.4 Interpreting and disseminating research findings

Results

Finding # 2:

PR generates recruitment capacity:

2.1 community members to the advisory board

2.2 community members for implementation
(specifically for lay health worker programs)

2.3 community members as recipients of
programs

Results

Finding #3:

PR expands the personal and professional development of:

3.1 the community partners

3.2 the academic research partners

Results

Finding #4:

PR 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

Finding #5:

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

Finding #6

Partnership synergy accumulates the capacity to sustain project goals beyond funded timeframes and during gaps in external funding

Results

Finding #7:

PR generates systemic changes and new unanticipated projects and activity

CMO Example

CONTEXT:

Most Lowell Cambodians are from rural Cambodia and thus had little educational opportunity because of the closing of schools by the Khmer Rouge, resulting in very low literacy levels in their own language, Khmer, and in English;

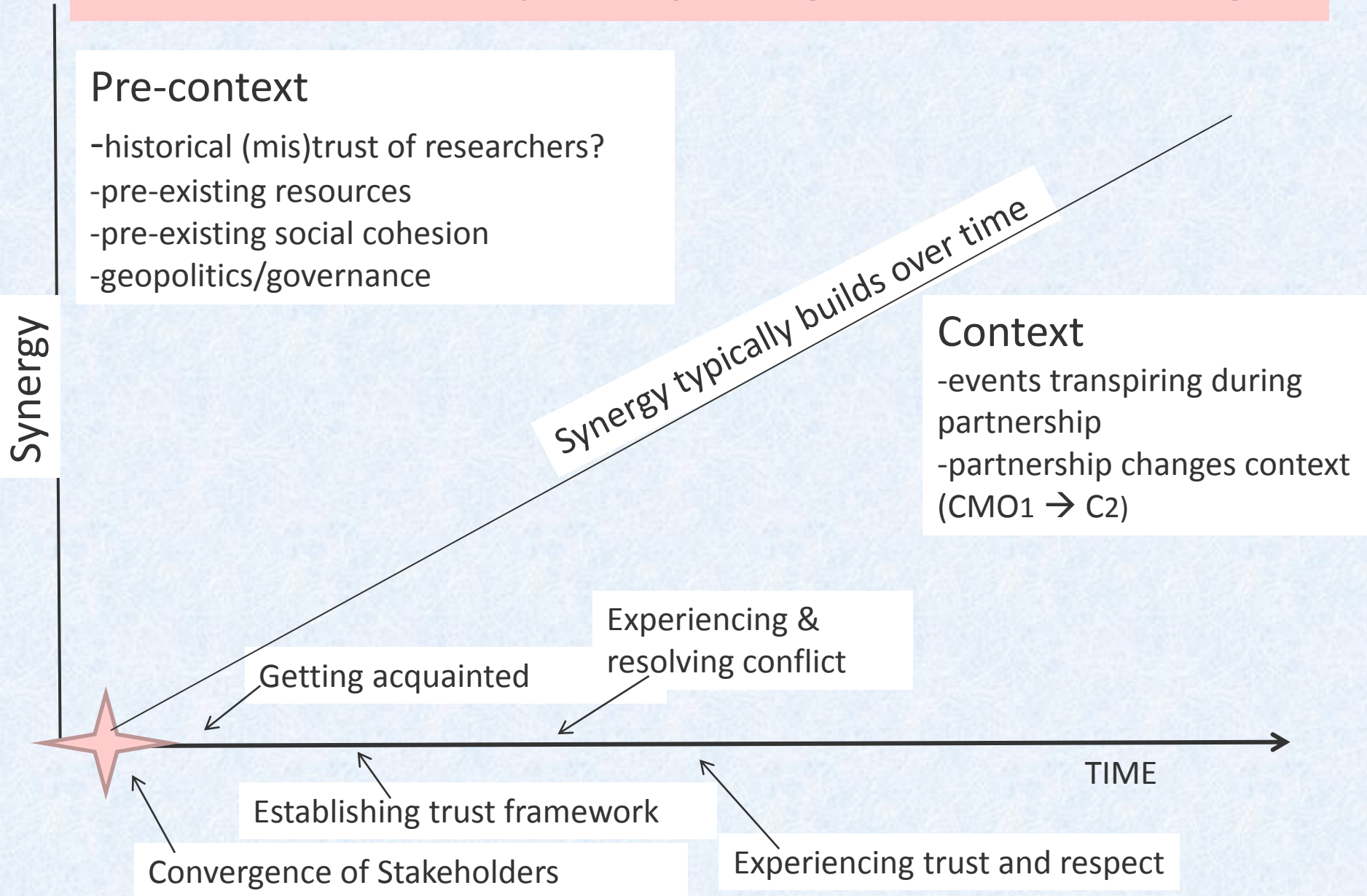
MECHANISM:

Academic and community coalition members valued the coalition's "insider" knowledge and considered the effect of these historical traumas on community uptake of the intervention;

OUTCOME:

A more culturally sensitive intervention strategy was created which involved personal outreach, development of audiotapes to replace brochures, and extensive use of weekly radio and cable TV shows.

Process and Impact of Long-term Partnering



Experiencing and Resolving Conflict

- What is the focus of research?
- What methods should be used?
- How to tailor scientific methods to community needs?
- Who owns the data?
- Accept or challenge associated institutional restrictions
- Address concern over potential stigma from research evidence

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



Publications

- Macaulay et al. (2011) – paper describing the rationale for using realist review (Global Health Promotion)
- Jagosh et al. (2011) – protocol paper describing our search terms, identification, selection, appraisal and synthesis processes (Implementation Science)

Publications continued

- Jagosh et al. (2012) – findings paper (Milbank quarterly)
- Macaulay et al. (in press - 2014) – findings paper #2 on collaborative conduct of quantitative research and randomized control trials (Nouvelles Pratiques Sociales)
- Jagosh et al. (2013) – methodological reflection paper (Research Synthesis Methods)