# Creating an evidence base for community engagement

Can community-based peer support promote health literacy and reduce inequalities? A realist review.

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Advisory Network: Over 120 people representing clients and workers in breastfeeding, diabetes, healthy living, HIV/safer sex, smoking cessation

NIHR Journal of Public Health Research (in press)

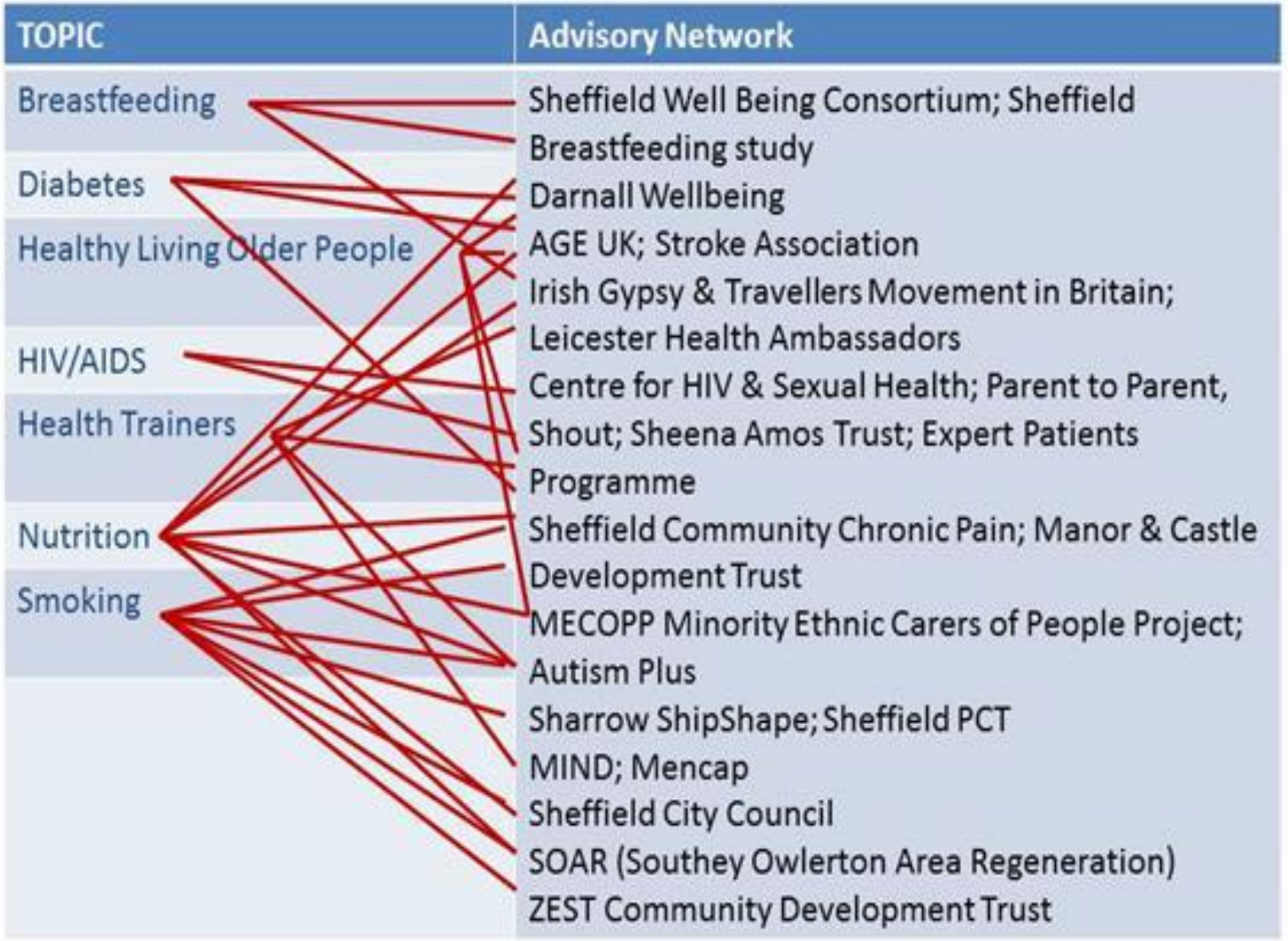
# Community-based versus community-level interventions

- A community-level intervention is an intervention organized to modify the entire community through community organization and activation, as distinct from interventions that are simply community-based, which may attempt to modify individual health behaviors such as smoking, diet or physical activity (Patrick & Wickizer, 1995:52).
- Confusion between the terms in the literature
- ‘Conceptual insecurity’ affects findings of aggregative systematic reviews

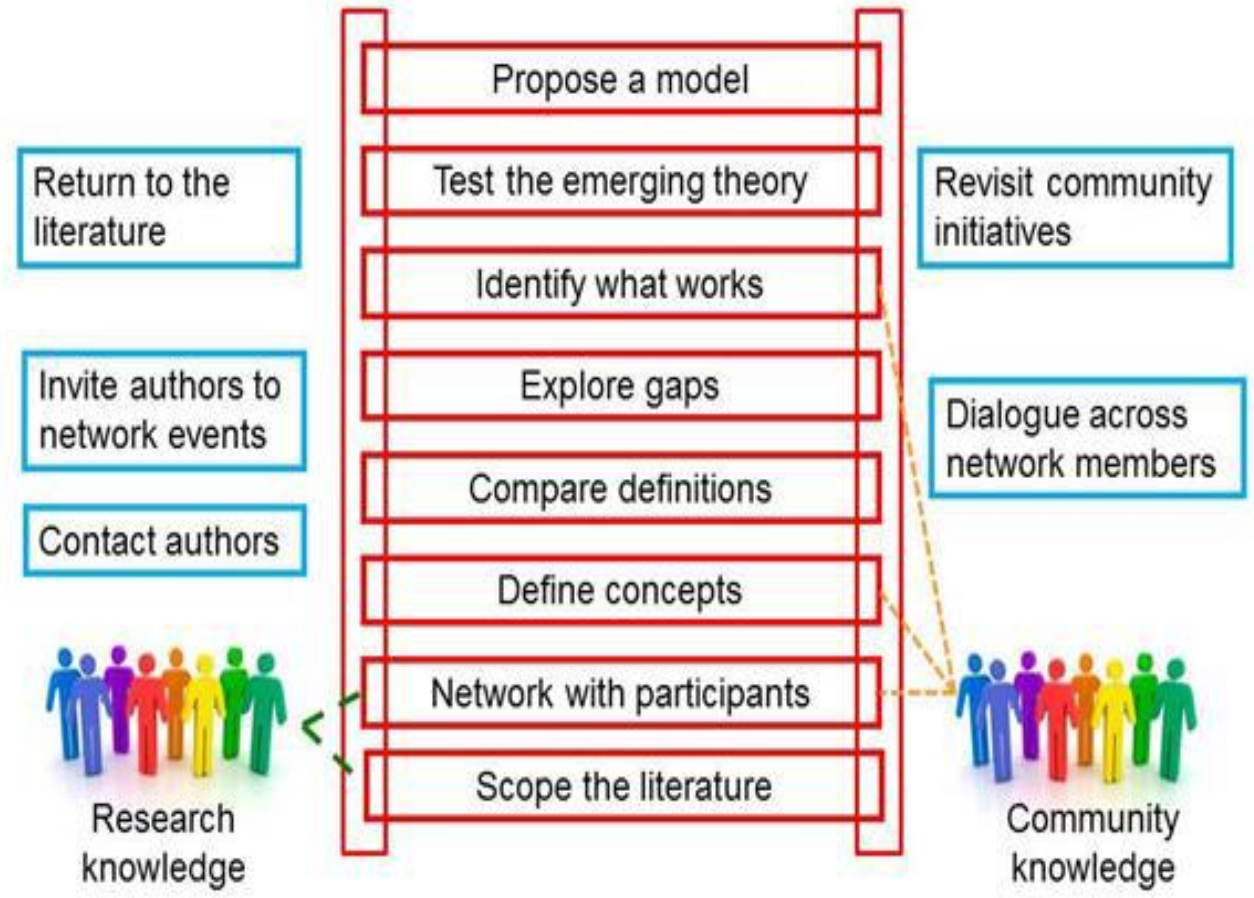
# Challenges for primary research

1. Funding for trials dominates: do we really know enough about the process to experimentally test hypotheses?
   - Whose hypotheses are represented?
2. Equitable partnerships: Researchers and communities need time to develop relationships in order to co-design interventions
3. Process of co-design needs to be researched alongside outcomes (Lomas 1998)

# Our Advisory Network



# Engaging people in defining essential components of peer support



# Components of peer support

- The Advisory Network described core components as:
  - *Establishing a connection; sharing a bit about yourself
    - Finding common ground
    - Active listening to get a picture of the entire situation: Problems, challenges, social networks
    - Finding out what the client or patient needs
    - Providing encourage for clients to reflect on what they would like to be able to do (aspirations)
    - Looking at what the client is currently capable of doing
    - Setting small and realistic goals
    - Reviewing progress; affirming frustrations; celebrating achievements; dealing with setbacks (affirmational and emotional support)
  - ** Showing people how to do things and going places with them (practical support; developing capabilities)
  - **Offering information opportunistically, on an as needed basis
- Outcomes: Increased confidence, motivation and capability – a p re-cursor for achieving longer term health outcomes
- Although these components are rarely part of the research design, they are offered as explanation in the Discussion section of research papers

*Similar characteristics are only a starting point – and not always needed. Skills in building relationships are crucial and can overcome different backgrounds

** Missing from the health literature (Dennis, 2003)

# Does peer support increase capability?

- Research does not use a capability framework
- We developed on and tried to apply it
- Extracting data was challenging due to poor reporting

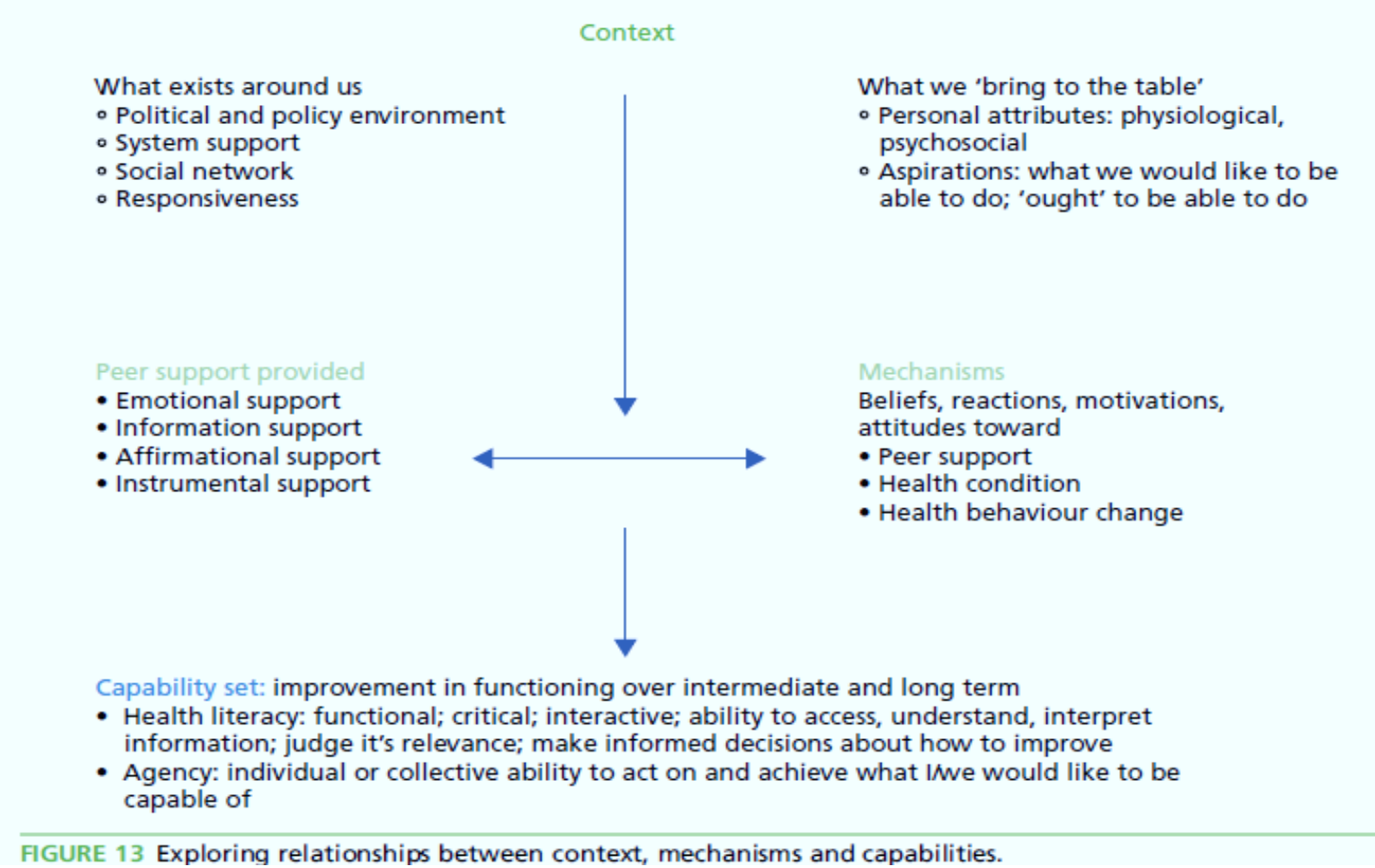



FIGURE 13 Exploring relationships between context, mechanisms and capabilities.

# Two epistemological stances in community-based interventions

| Intervention characteristics | Authoritarian approach | Negotiated approach |
|---|---|---|
| Model | Risk | Assets based; capabilities |
| Phenomenon of interest | Individual behaviour – dyadic relationships | Social networks – 'strength of weak ties' |
| Valued outcomes | Health outcomes – long term | 'Non-health', social or wellbeing outcomes – shorter term |
| Level of engagement | At informing or consultation level | Spanning all levels – selected according to project needs, community attitudes and context |

# Does epistemological stance influence the effectiveness of engagement?

When interventions replaced negatives with positives at any stage, the trajectory of the intervention changed

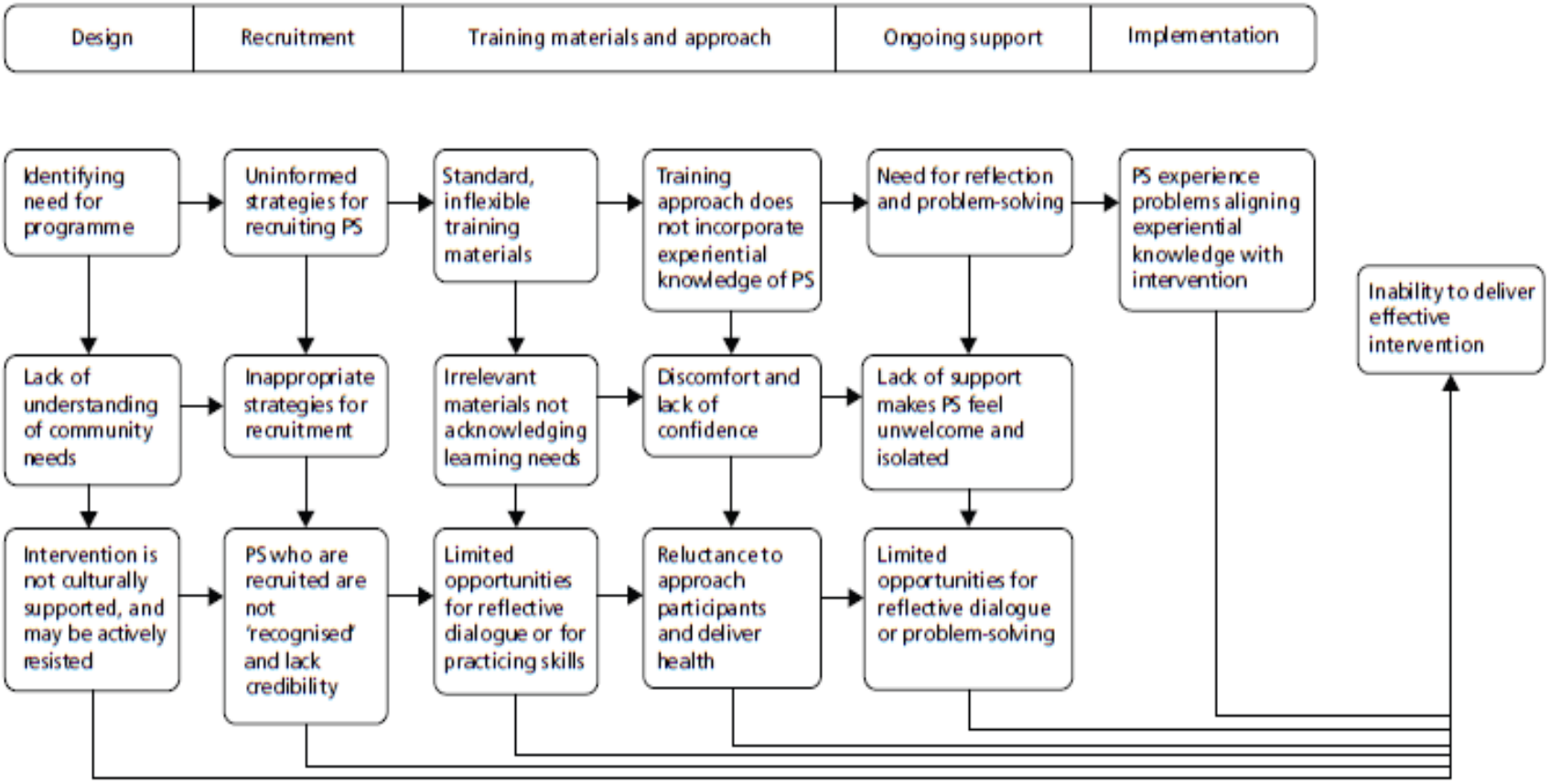
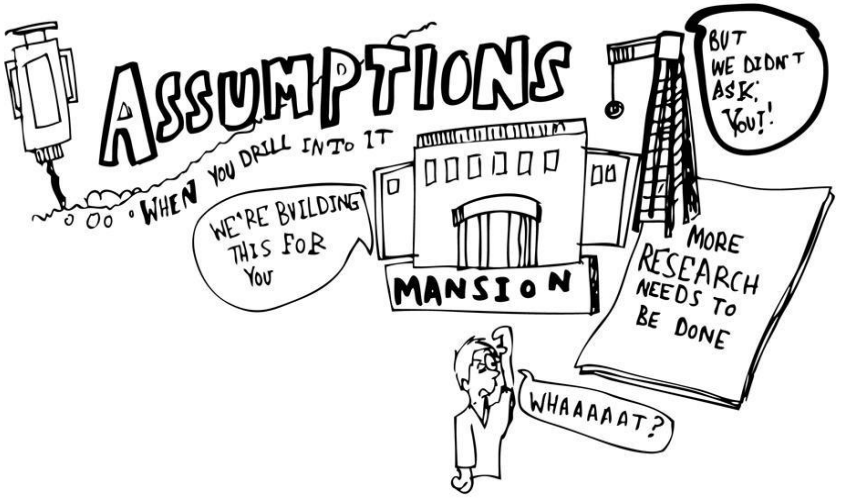



FIGURE 23 Alternative and recursive causal strands that affected outcomes.

# Empirically tested versus culturally supported interventions

- Implementation fidelity
  - Where communities are not engaged in design and delivery, tailoring of the intervention may occur in practice
  - Tailoring is rarely included in evaluations
- Should communities be defined as geographical place, health topic/condition, or a set of resources and relationships?
  - The review indicated that interaction between resources and relationships is the 'active ingredient'

"My analogy of it is that it's almost that you've got a group of academics if you like sort of sat in one place building this brilliant mansion.



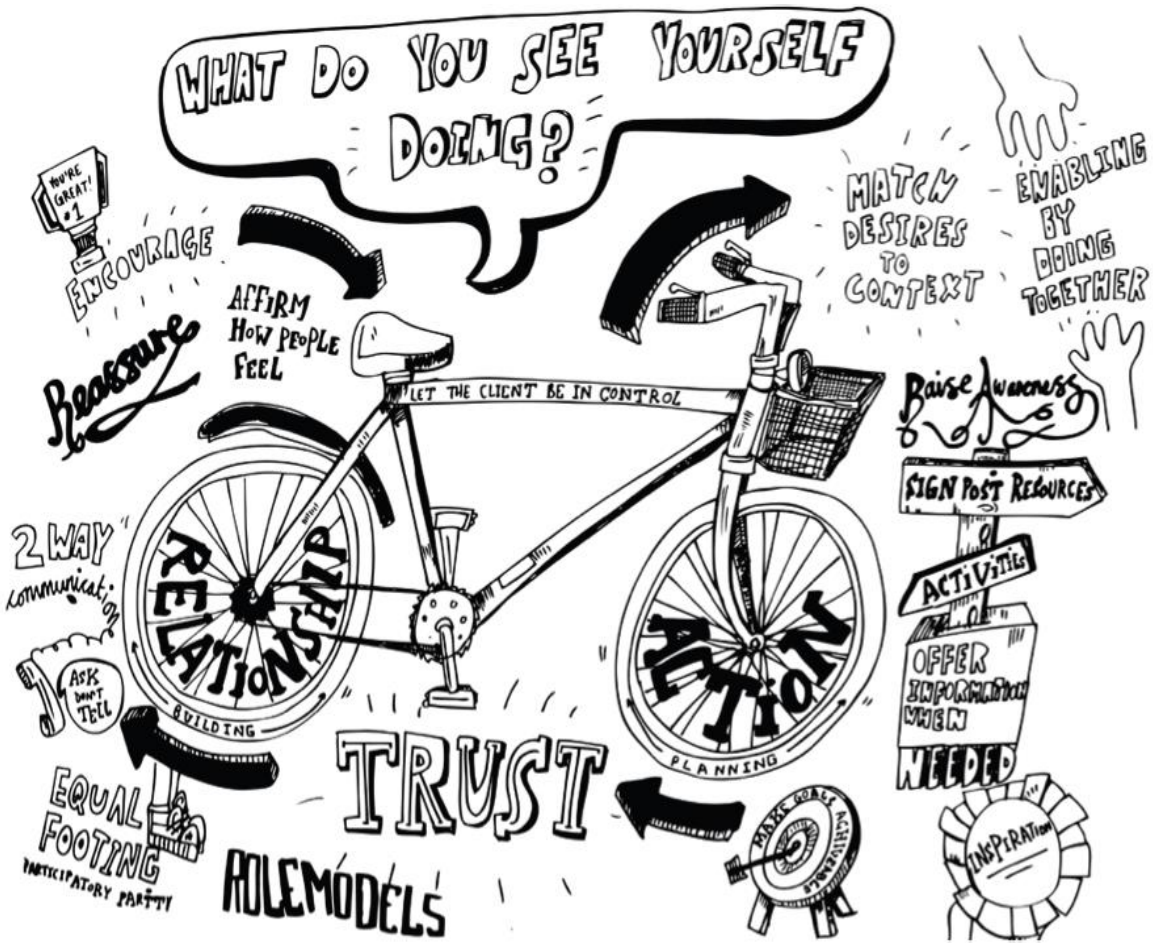

But they're not talking to the people who it's there for, who are the concrete. So they've put their mansion on some sand and it sinks." (AN11)

# A community engagement model?

"The engagement process is based on the same key principles of good practice no matter what the topic."

We don't need yet another model – we just need to focus on evaluating the process."

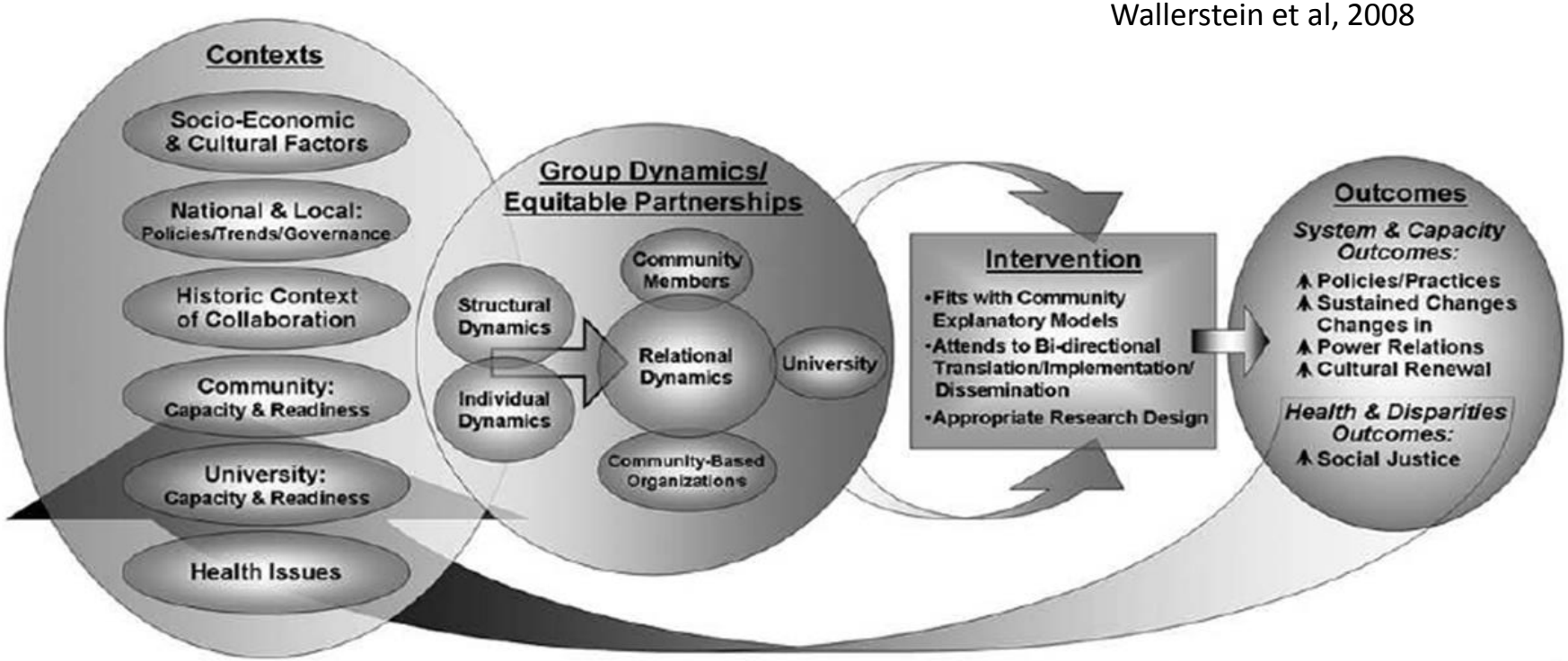
(Advisory Network client and advocate)




Artwork: Sarah Smizz

# Effectiveness needs to focus on the process of engagement

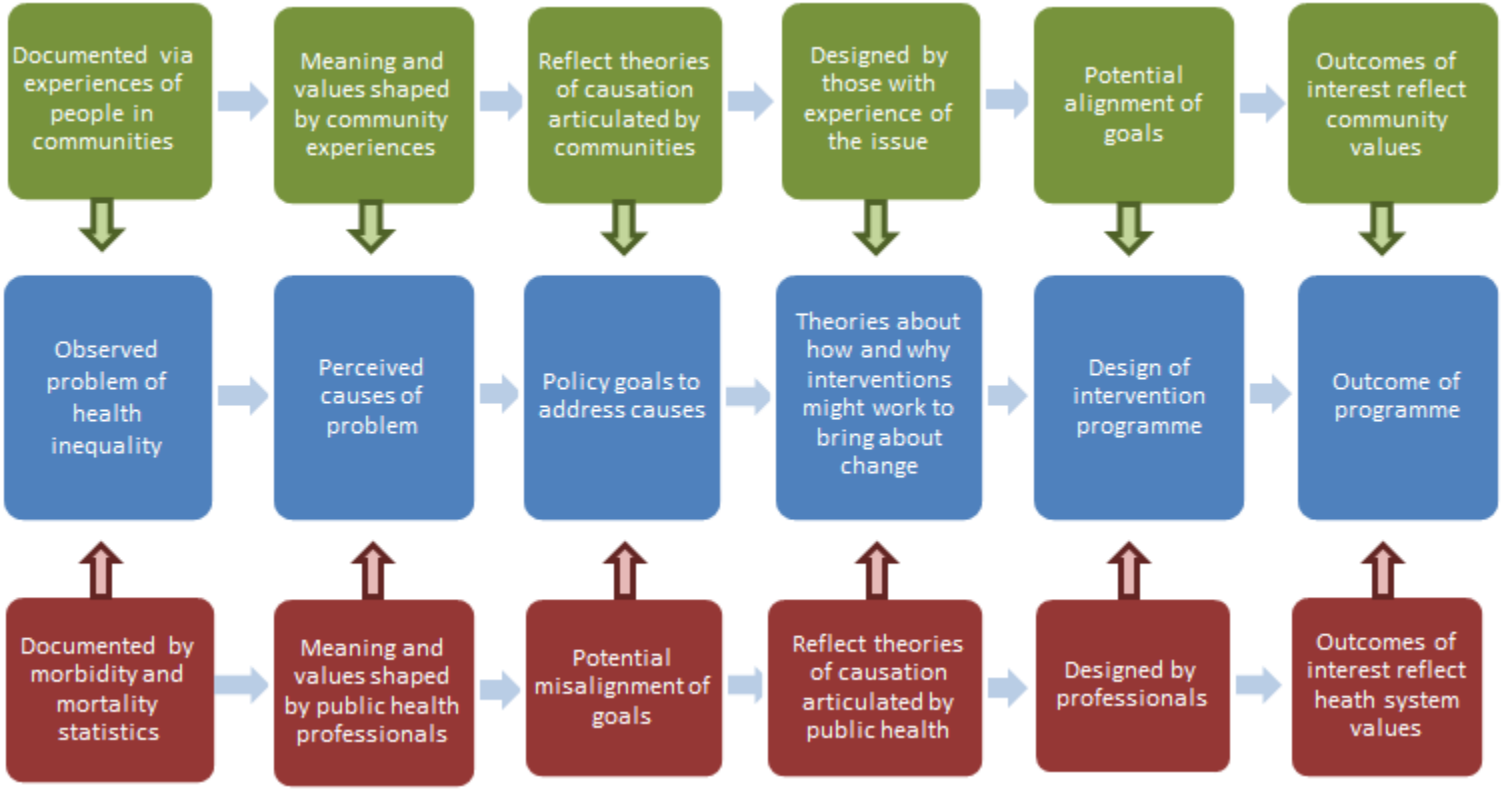
Wallerstein et al, 2008




| Contexts: | Group Dynamics | | CBPR System & Capacity Outcomes: |
|---|---|---|---|
| •Socio-Economic, Cultural & Environmental Factors<br>•National/Local Policies, Trends & Political Governance<br>•Historical Context of Collaboration:<br>• Trust/Mistrust<br>•Community: Capacity & Readiness<br>•University: Capacity & Readiness<br>•Perceived Severity/Salience of Health Issues | **Structural Dynamics:**<br>• Diversity<br>• Complexity<br>• Formal Agreements<br>• Real Power/Resource Sharing<br>• Alignment with CBPR Principles<br>• Length of Time in Partnership<br><br>**Individual Dynamics:**<br>• Core Values/Cultural Identities<br>• Cultural Humility<br>• Individual Beliefs<br>• Community Reputation of PI | **Relational Dynamics:**<br>• Congruence of Core Values<br>• Dialogue/Mutual Learning<br>• Leadership/Stewardship<br>• Influence/Power Dynamics<br>• Flexibility<br>• Self & Collective Reflection<br>• Participatory Decision Making & Negotiation<br>• Integration of Community Beliefs to Group Process | • Changes in Power Relations<br>• Changes in Practices & Policies<br>• Sustained Changes in Conditions which Enable Health<br>• Cultural Revitalization & Renewal<br>• Empowerment<br>• Community & University Reflection<br>• Culturally-Based & Sustainable Interventions<br><br>**Health Outcomes:**<br>• Overcoming Disparities |

FIGURE 21.1 *Conceptual Logic Model of Community-Based Participatory Research: Processes to Outcomes*

# Have these perspectives been successfully combined…any examples?



# Next steps:
# Reviewing the impact of epistemological stance in diabetes research

- Does a CBPR approach produce more appropriate interventions?
- Involving people in diabetes research: A realist review
  - RQ1: How have patients been involved in setting priorities, designing and conducting research on diabetes interventions?
  - RQ2: What are the main characteristics of the process that appears to explain the relative success or failure of patient involvement?
  - RQ3: How has patient involvement (or lack of involvement) influenced the successful implementation of diabetes interventions?

Harris, Graue et al. Funded by Norwegian Research Council

# A continuum of possible responses for diabetes management

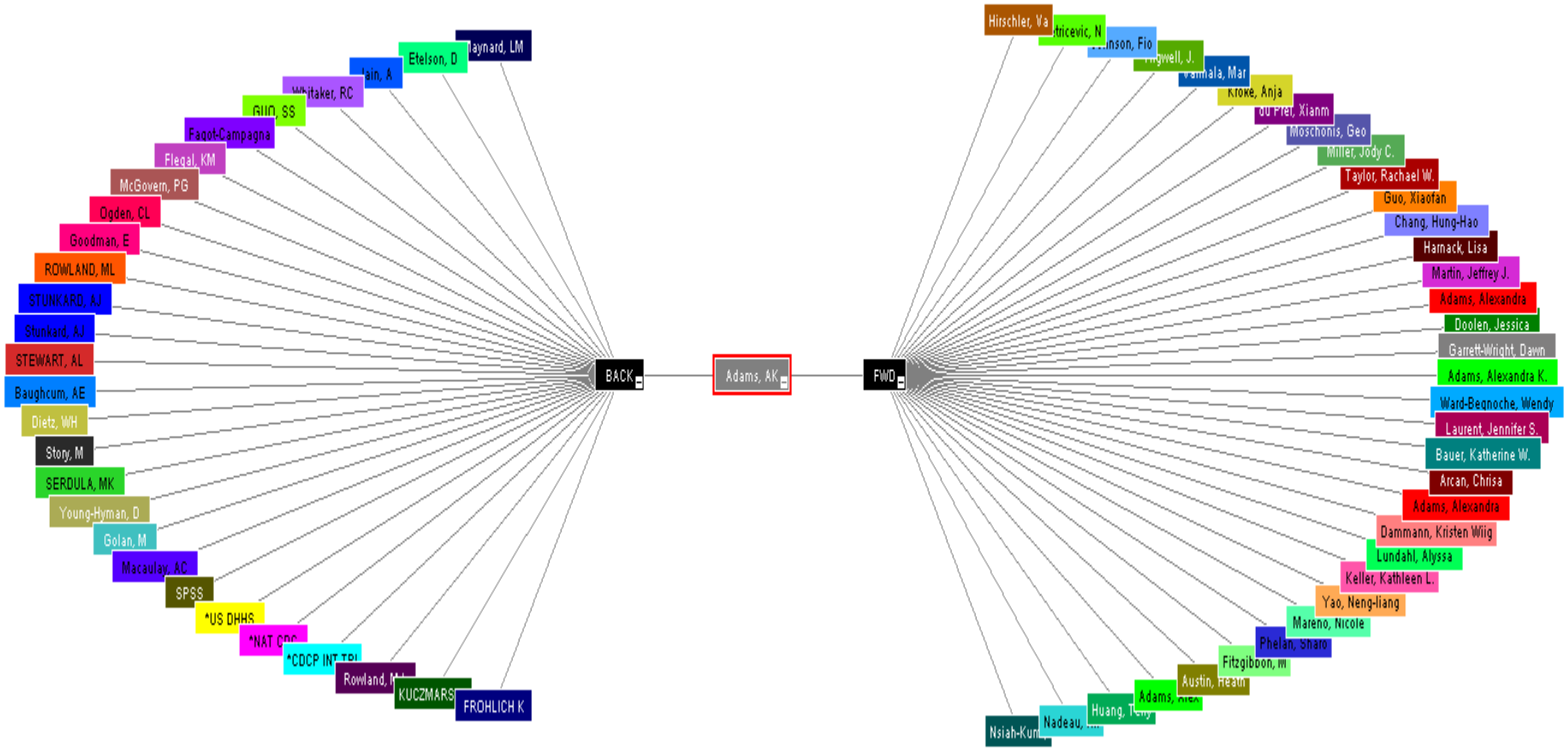
| Points on intervention continuum | Target |
|---|---|
| Rescue e.g. admission to A&E for hypoglycaemia | Sick individuals |
| Routine medical are e.g. blood glucose monitoring | Positively screened individuals |
| Increase accessible health care e.g. reduce barriers of cost, location, equity | Potentially sick individuals |
| Traditional public health e.g. modify risk behaviour via lifestyle modification programmes; modify physical environments | Worried individuals |
| Family and support services e.g. home visitors, social support | Needy individuals and families |
| Social cohesion – preserve and advance social structures that allow exchange of views and values and engender trust e.g subsidised clubs for cooking, community health walks | Community structure |

(Modified from Lomas, 1998)

# How does engagement in design and delivery of interventions evolve?

- CLUSTER searching: an approach to sifting through citations for those that are:
  - Research involving members of the same team, which informed the current programme
  - Part of the same programme
  - Theories cited by the papers, which were used to inform the development and implementation of the programme

# Citation mapping (using Adams 2005 as the index study)



# Cluster analysis

- Map theory development by
  - Initial theory (may be taken from elsewhere or developed specifically for the programme)
  - Evolution of theory, informed by the evaluation of how and why the programme is working (or not working)
  - Compare with original theory for the programme, related theories (that may be from different disciplines)
  - Select relevant theories, or concepts from theories, to produce a mid-range theory

# Successful involvement: Principles and steps

- The principles used in co-creating diabetes interventions are:
  - Based on a mutually respectful partnership between researchers and community
  - Equitably involves all partners in all phases of research
  - Builds on knowledge, strengths, and resources within the community
  - Involves a cyclical and iterative process
  - Educates both researchers and communities
  - Results in action based on results obtained from the research
- The Steps needed to co-create research :

1. Determine mutual concerns and research priorities
2. Define the problem and collect background data
3. Do a pilot project
4. Return results to the community and assess response
5. Find funding and do the project
6. Return results to community and collaboratively interpret data
7. Assess health outcomes and recycle through process

(Adams, 2004 – based on McCaulay, 1999)

| Authors Year | Stage of research by involvement |
|---|---|
| Adams, Miller-Korth 2007 | Facilitating authentic academic and community health research partnerships? Contextual barriers and facilitators for PSUE in research |
| Adams et al 2004a | Learning to work together: Contextual barriers and facilitators for developing academic and community research partnerships in research |
| 2004 Adams A, Prince R, Webert H. | Community feedback on appropriateness and acceptability of possible intervention components |
| 2005 Adams AK, Quinn RA, Prince RJ. | Low recognition of childhood overweight and disease risk among Native-American caregivers: Baseline data |
| LaRowe 2010 | Dietary intakes and physical activity among preschool-aged children before a family-based healthy lifestyle intervention: Baseline data |
| Adams A, Harvey H, Brown D. 2008 | Constructs of health and environment inform child obesity prevention in American Indian communities. |
| 2010 Adams, A | Understanding community and family barriers and supports to physical activity in American Indian Children |
| 2007 LaRowe | Development and piloting of a culturally appropriate, home-based nutrition and physical activity curriculum for Wisconsin American Indian Families |
| 2012 Adams AK, LaRowe TL, Cronin KA, Prince RJ | The Healthy Children, Strong Families Intervention: Design and Community Participation: Priority setting, design, piloting, implementation. |