



REAL 2 participatory health research realist review: emerging insights from scoping GPP Evaluation Webinar 27th June 2024

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REAL²
Participatory Research
Realist Review

Outline

- Background to REAL2
- Issues emerging from scoping literature and consultations
- Implications for evaluation of GPP

Background to the REAL 2 project

Realist review of participatory research in health, drawing on insights from mental health, climate change and infectious disease

8 months scoping phase to focus a Realist review on a key area(s) of participatory research

Previous REAL realist review of community engagement showed

‘working relationships’ between researchers and communities across differences of wealth, culture and power get research done but are ethically problematic – **relational dynamics are key**

Follow up review REAL2 exploring limits and potential of greater community involvement in research by looking at participatory research literature

https://media.tghn.org/medialibrary/2023/05/Real2_Introductory_brief.pdf



REAL2 realist review



24 months from February 2024



Finalise review question



Develop initial explanations – realist ‘programme theories’



Systematic searches of literature



Iterative analysis, development of explanations and further searches



Draw on advisory inputs



Refine programme theories/explanatory accounts



Share findings in various formats

REAL2 review team

Team:

- Core team:** Robin Vincent, Sassy Molyneux, Geoff Wong and Helene- Mari van der Westhuizen, Becky Wolfe (communications), Eli Harris (information specialist)
- Advisors:** Janet Harris, Rene Loewenson, Gill Black
- Advisory group:** Dorcas Kamuya, Mike Powell, and others (depending on focus of review)

Scoping the participatory research literature

Participatory research described as:

Community Based Participatory Research (CBPR),
Community Engaged Research (CEnR)
Participatory Action Research (PAR), Systemic
Action Research (SAR), Popular Education,
Participatory Research (PR), Indigenous research

**‘where people affected by the issue being
studied are involved throughout the research
process’**

(International Collaboration for Participatory Health Research ICPHR 2018)



Men in Gender & Participatory Research in Ghana
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Scoping the participatory research literature

Participatory approaches described as:

Co-production, public and patient involvement, community engagement, co-design, human-centred design, participatory approaches in international development

Where tools or techniques support participation at one or more stages of a research or design process

REAL findings on **double edged nature of relational dynamics of engagement**

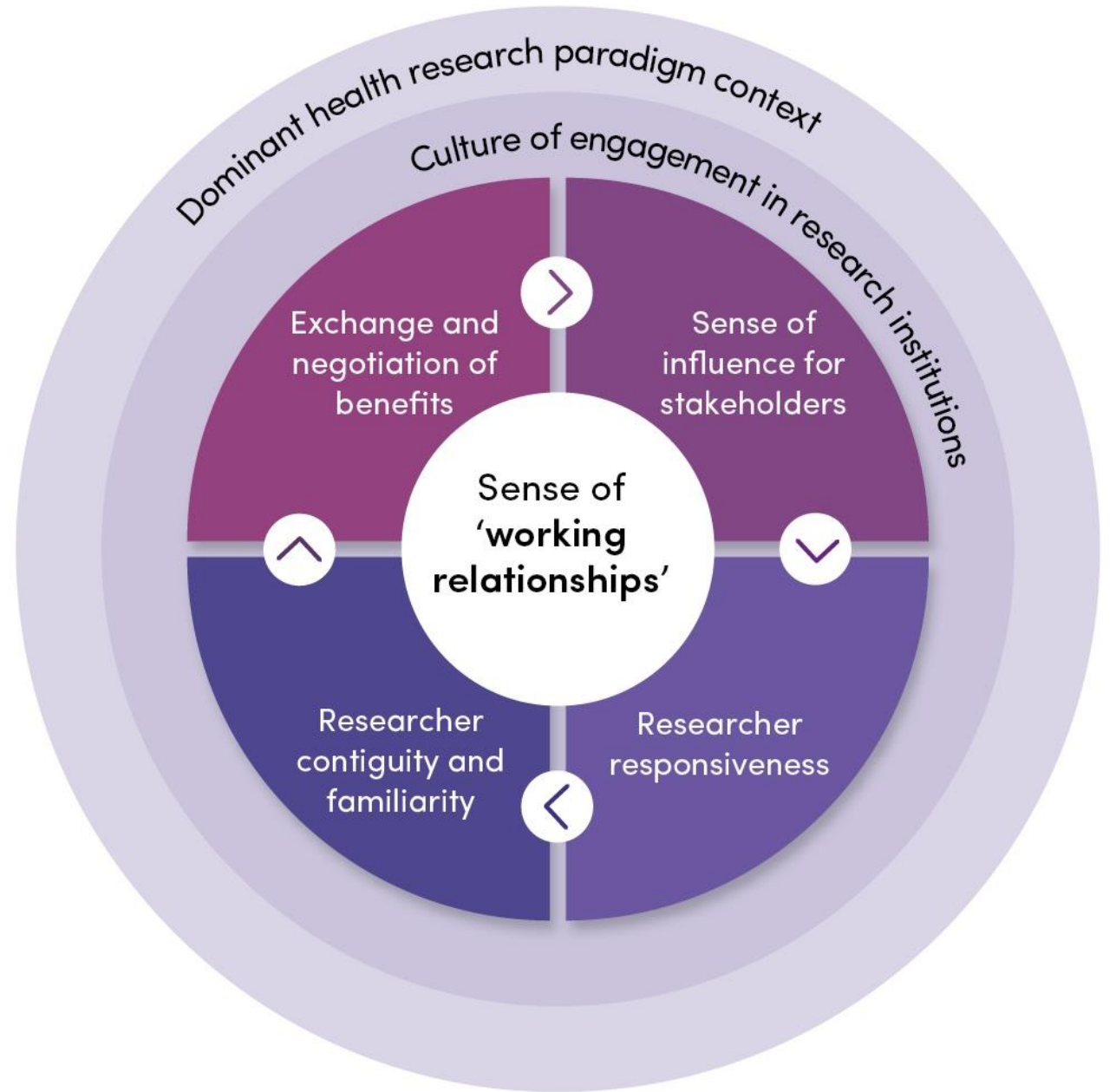
Established 'working relationships' across difference **tend to reproduce the dominant health research paradigm**

OR

Potentially challenge the paradigm with relational dynamics of collaborative partnership and greater stakeholder influence



<https://mesh.tghn.org/programme-hubs/real/>



Good participatory practice guidance

- Attempt to be more explicit and consistent about participation (GPP, CIOMS, others)
- What if **terms of participation decided outside of the research process**
- Insights from participatory research

Emerging issues –key dimensions of participatory research

	Power/control	Co-optation	Knowledge generation
Macro National, regional, international	Contribution to understanding and promoting human well-being and flourishing and addressing marginalisation processes impacting on wellbeing	Research legitimising or challenging status quo (commercial curative technologies) OR in service of wider health, well-being and flourishing	Research supporting social justice movements and action, understandings of human flourishing and balanced relations with the world, ‘conviviality’ and building body of knowledge and practice/tradition
Meso Institution, programme	Co-governance and deliberation around research Role of brokers and intermediaries across partners and stakeholders	Combining PR with dominant research methods – benefits costs ‘Emancipatory’ research of social movements versus instrumental participation and PPI Influence of horizontal versus vertical health approaches and paradigm	Participatory research methods across the research cycle – consistent with knowledge democracy . Principle of ‘no delegation’ Impact of local knowledge on institutions and social practice Use of interdisciplinary methods
Micro Project – stakeholder groups	Facilitation and group process – power in interactions and spaces of participation Building ‘power within’ and collective consciousness and confidence for change	Working with diversity in meaning-making and action Social determinants of health as focus enabling change	How research processes work with experiential knowledge, action and reflection on action and processes of collective validation and abstraction from diverse knowledges

REAL 2 initial programme theory

CONTEXTS

Existing **organisations or networks** with interest & motivation to host inquiry process

Researchers/ actors ready to take on facilitatory role in a different scientific process

Resources and spaces to conduct inquiry process

Culture of independent action and belief

'Levers' for support of **participatory process** and receptiveness to action and results

MECHANISMS

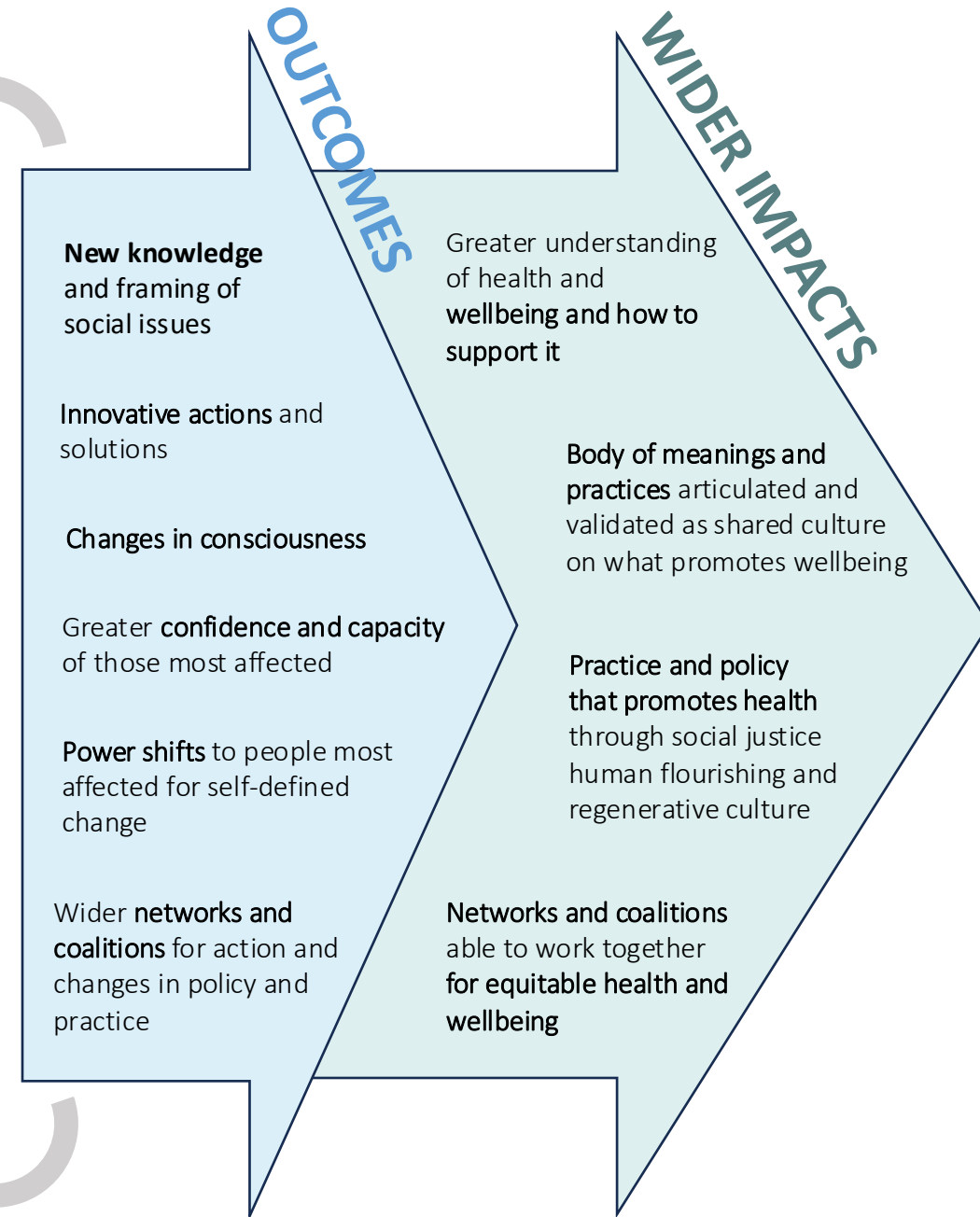
Facilitation/creation of safe spaces for sharing and validating experiences

Co-governance of research and related process of deliberation shifts power to define the research priorities and process

Collective analysis of experience and cycles of action and reflection reframes issue and reveals new priorities & opportunities for action

Dedicated time together builds familiarity and relationships and readiness to share ideas and experiences

Experience and action of most affected starting point for collective analysis to better understand social issues



REAL2 review questions

1. When, why and **in what contexts** and with whom do researchers seek to use a participatory research approaches to conduct health research?
2. Through **which mechanisms** does participatory research produce **outcomes** at a range of levels (micro, meso, macro)? What are the key **facilitating or inhibiting or contexts**?

Search terms to draw out data on **power shifting process** (including role of safe spaces and co-governance), the role of **lived experience**, and **impacts** of participatory research including **local action** and wider social change and **changes in policy and practice**.

Issues emerging from scoping

1. The benefits and challenges of **power sharing/shifting** at a range of different levels in the research process and the risks of co-optation
2. **'lived experience'** and rigorous knowledge generation – **broadening notions of objectivity and validity** (complementarity of participatory research and biomedical research)
3. The challenge of **linking local inquiry and action to broader changes** in social life, policy and practice



1. Benefits and challenges of power shifts

Need an integrated framework for analysis of power

- Better understand the processes and spaces of participation, aspects of knowledge generation and different kinds of power and different mechanisms involved at each level
- More explicit attention to ‘power within’ – aspects of confidence and capacity
- More attention to the way power marginalises some experiences from research

What mitigates co-optation in research process

- including co-governance
- capacity to participate (or not be excluded)
- equitable facilitation
- transparent role of intermediaries

How do research processes relate to wider contexts and relationships

- governance, resource flows, values

2. 'lived experience' and rigorous knowledge generation

Broader participation in knowledge generation process

- not only expert researchers – principle of '**no delegation**'

Widen notions of objectivity and rationality (reframing 'science')

- to include practical and embodied knowledge
- evaluative focus on wellbeing and flourishing, not only 'instrumental' rationality

Importance of diverse experiences

- Complexity and systems theories stress need for range of perspectives and recognise complex and social character of 'health'
- Learning from patient experience literature

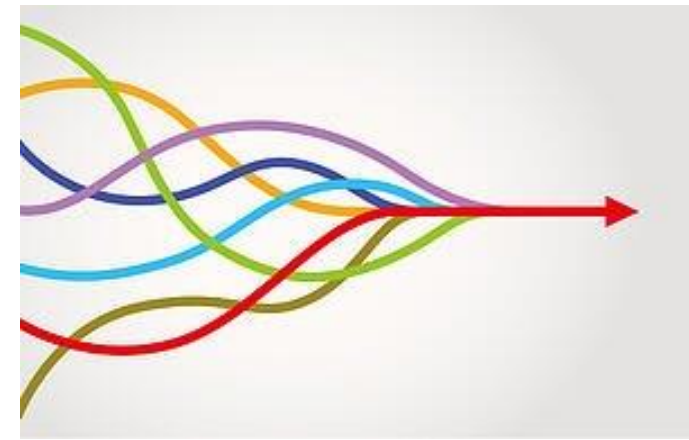
Consistent approach to knowledge, action and being

- ontological design of environmental & indigenous movements
- principles of 'regenerative cultures', ethic of care



Women participating in an exercise called "Daily activity clock" in Teanoba Ghana. Photo by/ Nafisa Ferdous (CCAFS)

3. Linking local inquiry and action to broader change



How research processes explicitly address links to policy and practice

- Equity context for research and inquiry and consistency of relations and process across scales
- Different types of research may more or less foster the relationships and networks that support policy change
- Need for longer term funding and sustainable support for participatory initiatives with marginalized people

influence of different understandings of Health

- ‘Vertical’ control, disease focus and commodified approach
- ‘Horizontal’ approach more consistent with local agency and wellbeing, social determinants of health

Understandings and actions across places

- ‘learning infrastructure’ in participatory research, different approach to ‘scale’
- Understanding ‘Knowledge mobilization’

How meanings and action generated from local practice do or don’t lead to wider social changes

- role of institutions and wider social structures in enabling or constraining changes
- Better understanding of the generation of meaning and action in social movements
- The role of prevailing culture and dominant ideologies accommodating diverse experiences and perspectives

THANKS!

<https://mesh.tghn.org/programme-hubs/real2-participatory-research-realist-review/>

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Issues emerging from scoping – conceptual resources

1. The benefits and challenges of **power sharing/shifting** at a range of different levels in the research process

spaces and practices of participation and power, mitigating co-option, co-governance, facilitation

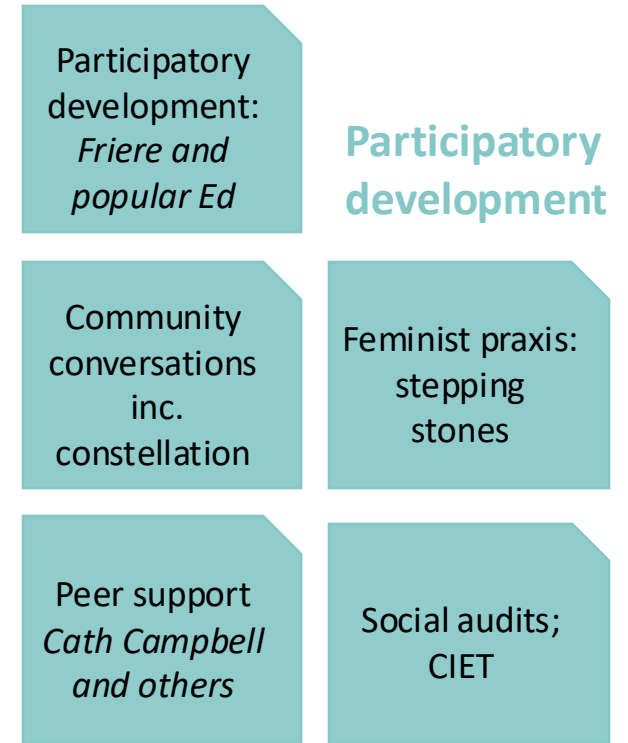
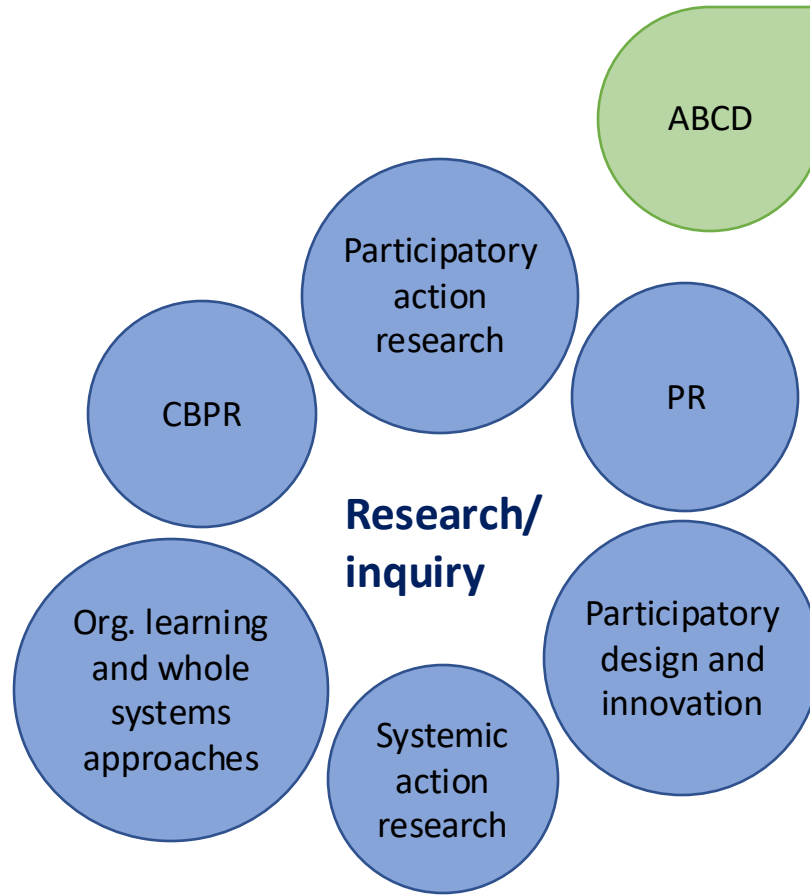
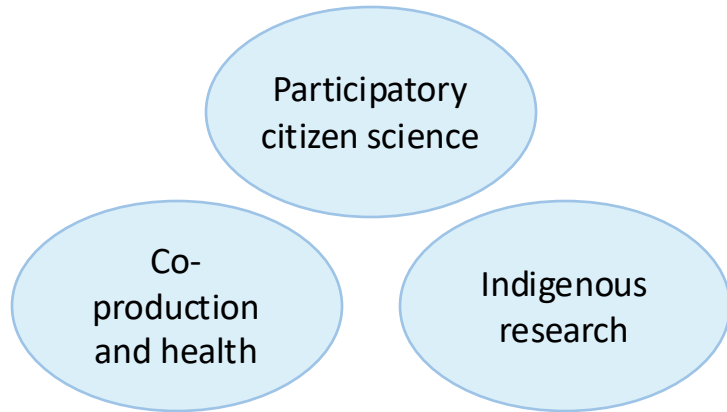
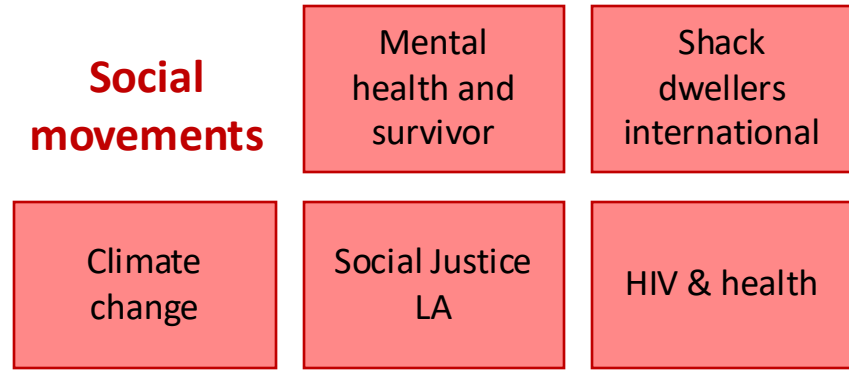
2. **'lived experience'** and rigorous knowledge generation – **broadening notions of objectivity and validity** (complementarity of participatory research and biomedical research)

wider participation in research, broader understandings of objectivity and validity, 'epistemic justice', social cognition, embodiment and emotions, diversity of perspectives in 'systems', 'ontological design', role of values

3. The challenge of **linking local inquiry and action to broader changes** in social life, policy and practice

social movements and social change, knowledge mobilization, anthropology of policy, influence of health paradigm, learning infrastructure in participatory research

Figure 1 - Mapping literature



Conceptual resources

