

‘Taking relationships seriously’: a realist review of community engagement with malaria research

A group of approximately ten people, including men and women, are sitting in a circle on the ground in a rural, dusty outdoor setting. They appear to be engaged in a community meeting or discussion. Some individuals are holding papers or books. In the background, several bicycles are parked in a row. The overall atmosphere is one of active participation and community engagement.

Mesh Webinar, May 2022

Robin Vincent, Sassy Molyneux, Dorcas Kamuya for REAL team

Supported by Wellcome grant 210505/Z/18/Z

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Overview

- Introduction and rationale for the REAL review
- Review process and realist logic of analysis
- Findings
- Implications and recommendations

Significant investment in community engagement in health research

Wide range of assumptions about the value of CE

- Improves the ethics of research
- Facilitates the successful execution of research
- Improves the impact/outcomes of research

Funders and implementation partners support CE

Eg - Wellcome Trust, Gates Foundation, DFID, World Bank, NIH, CDC

lack of a robust evidence base, but empirical research suggested that these assumptions have some validity

Persistent challenges for improving community engagement

- High degree of **variability** in CE:
 - Language/concepts; goals; guidance; practice
- Engagement typically emphasizes **activities/interventions**, rather than the nature of the interactions/relationships, underlying mechanisms and outcomes :
 - E.g., Community Advisory Boards (CABs); formative research
- Engagement activities are **complex social interventions**; dynamic multi-stakeholder processes
 - understanding relationships, context and culture is vital



Rationale for a Realist Review



Literature Review



- Need greater understanding of how engagement actually works
- Realist review good for:
 - Examining complex interventions
 - Dynamic, multi-stakeholder processes
 - Understanding relationships and cultural influences on context
 - Avoiding hierarchical views of evidence
- Realist review notable **successes in related areas** of community development and public health (Harris et al 2015, Wong, Pawson, Owen 2011)
- In Realist terms - 'programme theory': focus on **Context – Mechanism - Outcome** relationships in community engagement

Convergence of interest in realist review

Sassy Molyneux
and colleagues
KEMRI, Kenya

Cumulative work on CE relational ethics and empirical ethics

(S Molyneux, D Kamuya, V Marsh, Al Davies, N Mumba)

Jim Lavery and Emma Richardson

Body of work on CE in Global health

Previous systematic review of CE found **98,618** papers, 'insufficient conceptual architecture to pare down logically' (Richardson et al 2020)

Robin Vincent

Expertise in **Complexity sensitive evaluation** including realist evaluation

Evaluation advisor to Wellcome supported **international community of practice on CE** (OUCRU, MORU, KEMRI, MLWT, AHRI)

Geoff Wong

Global leader in **Realist Review**

Currently advising/
Supporting 8 reviews mainly in UK health and care settings



Wellcome funding for review (with support from KEMRI-Wellcome Trust and Emory University)

Full team recruited January 2019:

- Sassy Molyneux P.I. (KEMRI/Oxford Centre for Tropical Medicine)., Robin Vincent co-PI (independent), Jim Lavery (Emory University), Emma Richardson (St Michaels Hospital Toronto), Geoff Wong (Nuffield Dept of PHC), Bipin Adhikari (Independent and MORU), Claire Duddy (Nuffield Dept of PHC)

Content expert advisors – 10 scholar practitioners

- Mary Chambers, Phaik Yeong Cheah, Alun Davies, Kate Gooding, Dorcas Kamuya, Vicky Marsh, Noni Mumba, Deborah Nyirenda and Paulina Tindana

Advisory Group

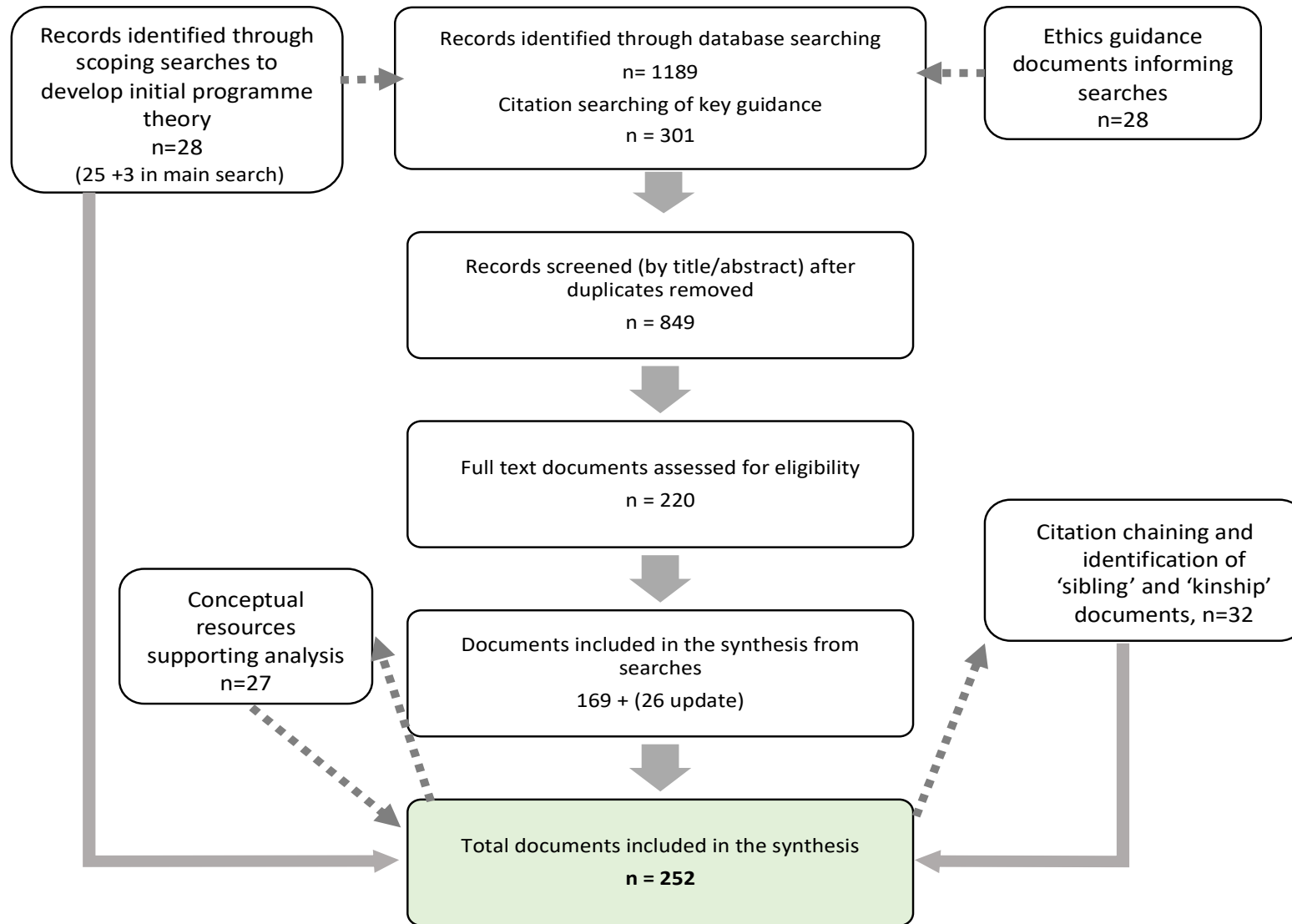
- Kevin Marsh (Malaria, Global Health), Mike Parker (Global bioethics), Geoff Wong (Realist review methods), Georgia Bladon (Wellcome) Janet Harris (community participation)



Realist review process

- Make **programme theory explicit** ('candidate' theory(s) from literature and practitioners' insights)
- **Focus the review** to make it manageable (focus on malaria research)
- Examine whether the understanding – captured in the 'programme theory' – is **supported by the evidence**
- **Systematic searches** of published literature
- **Refinement of programme theory** in dialogue with the evidence
- **Iterative** process - analysis refines programme theory - additional searches - further analysis – refinement
- Protocol paper for Review: <https://wellcomeopenresearch.org/articles/4-87/v1>

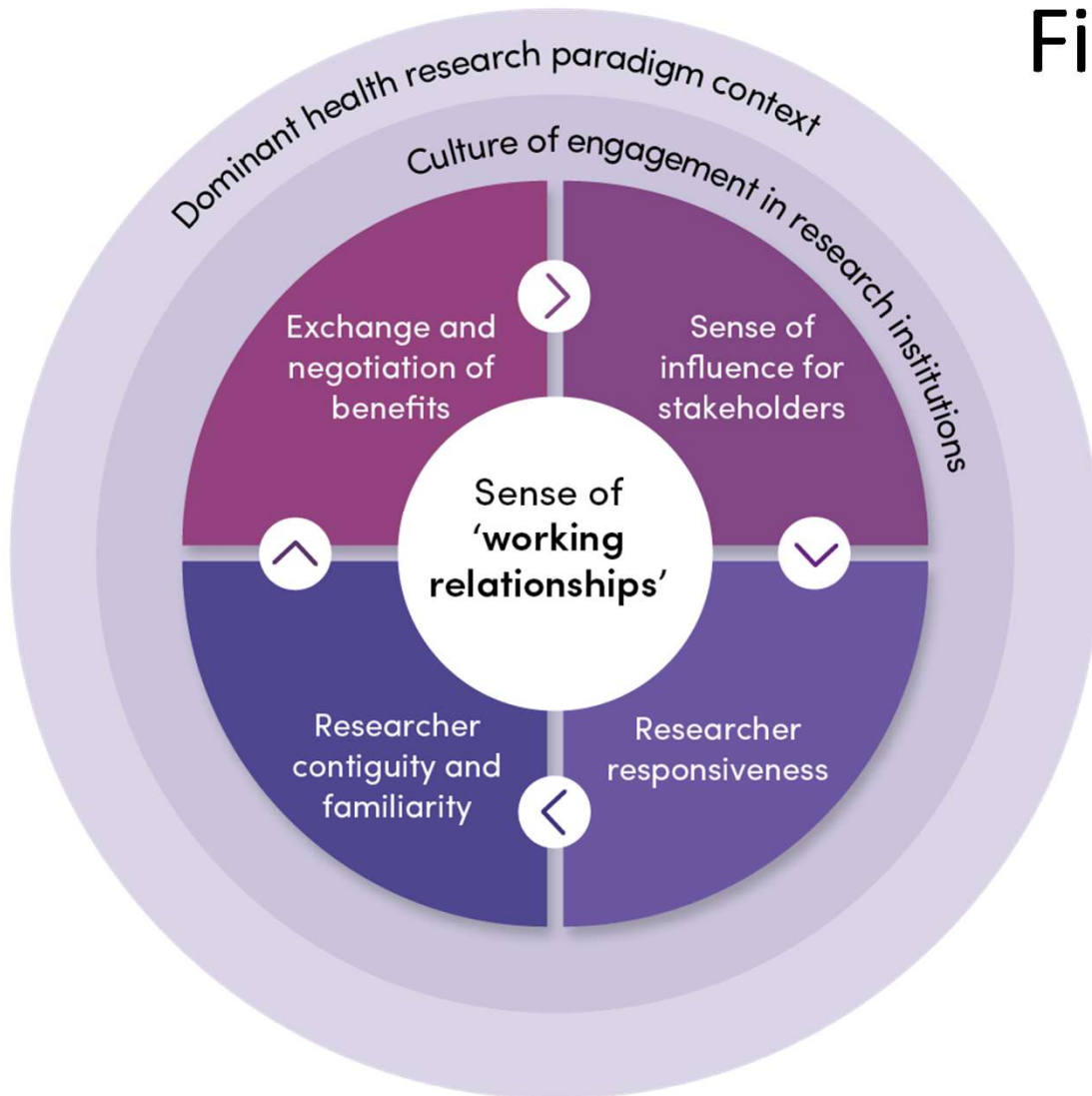
Search process



Findings - characteristics of literature

- **Descriptive**, limited detail of context and outcomes
- **CE often not main** focus of paper
- Conflation of **aspirational commentary** and documentation of actual practice
- **A-theoretical** – very little explicit account of how CE was expected/understood to work
- **Borrowings from theory on ‘behavior change’** and ‘social marketing’ from international development and health interventions
- **Significant body of qualitative work** invaluable for understanding causal dynamics and contextual influences

Findings



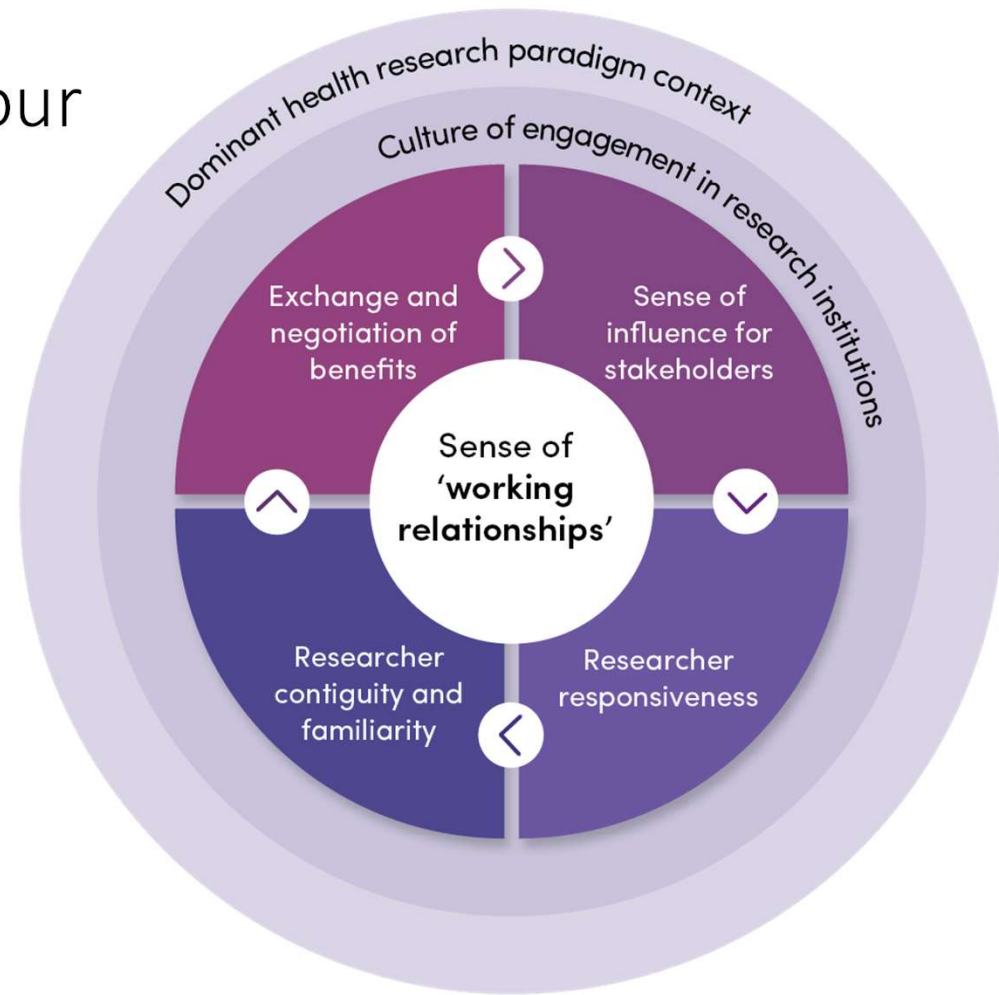
Realist logic of analysis of selected literature identified

- 4 mutually reinforcing relational dynamics of CE
- Influences of more immediate context
- Influence of global health research paradigm

1. 'working relationships' – four interlinked dynamics

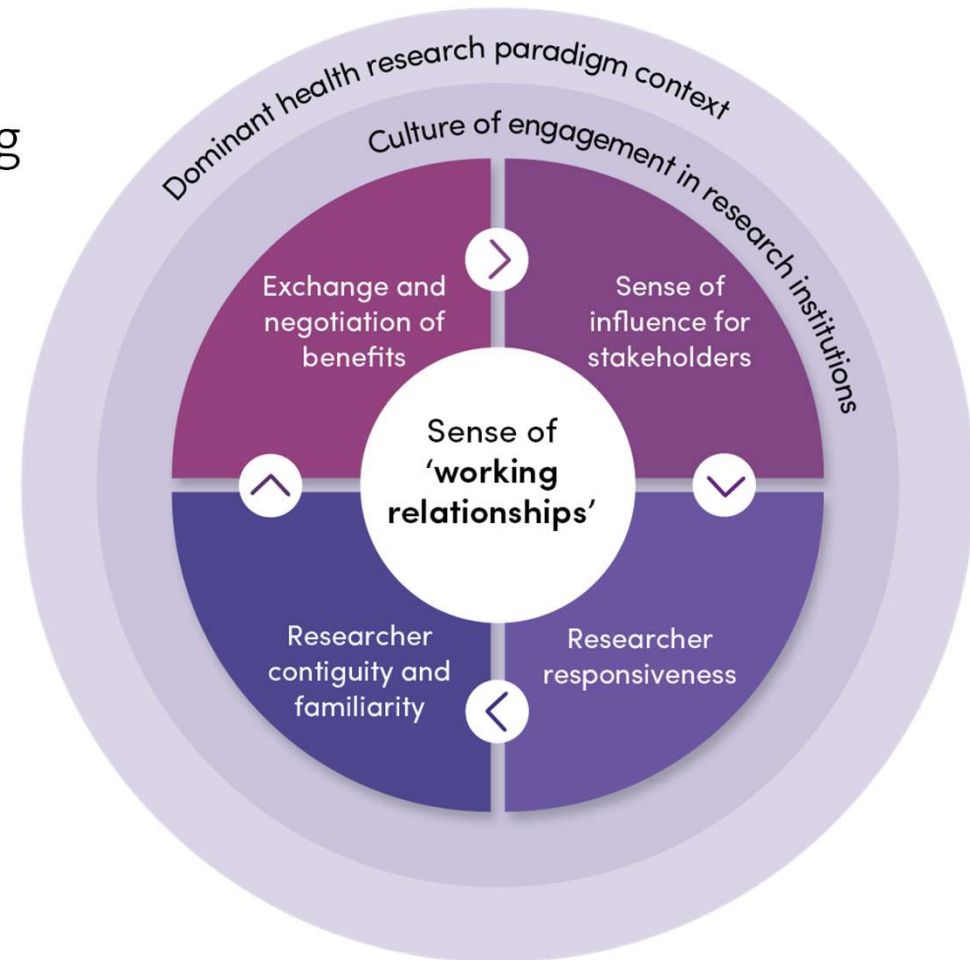
Importance of **access to health care** accompanying research participation

Contribute to **greater acceptance of research** and participation



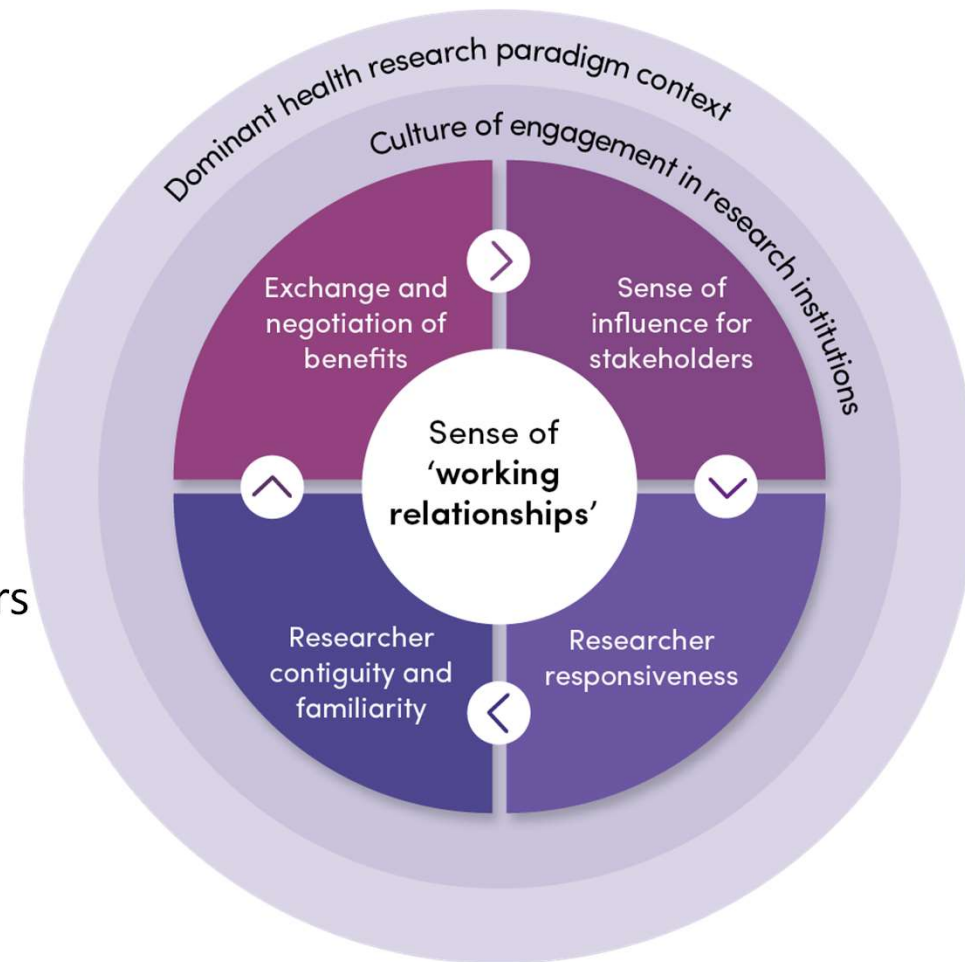
2. Culture of and commitment to CE in research institutions a facilitating influence

- Senior research staff and institution leadership and 'culture' of engagement
- Dedicated roles for engagement
- Supportive supervision of research fieldworkers and engagement staff
- Social science and other expert input into engagement strategies
- Reflection and evaluation of engagement informing research management
- Supportive funders



3. Characteristics of global health research paradigm a challenge

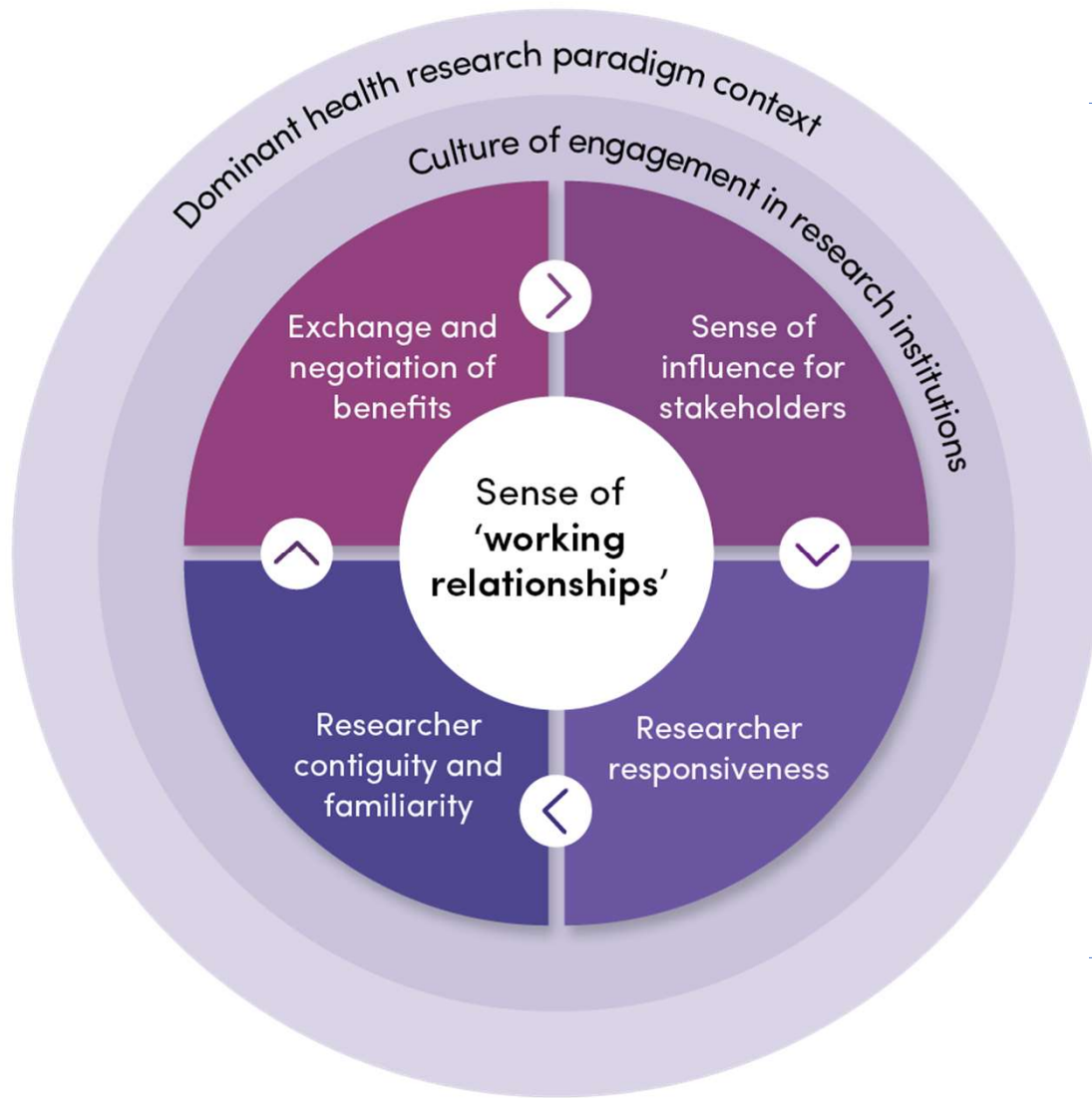
- Setting of research linked to colonial administration and vertical health campaigns
- Differences of wealth, power and culture, between researchers and research stakeholders
- External funding and control of research priorities and design
- Research ethics focus on individual choice and autonomy and 'consent' obscuring wider influences on decision-making



Conclusions

- CE more about developing **working relationships than any particular technique**, tool or method
- CE strategies need to be informed by an **understanding of the relational dynamics** of engagement and influences of context
- Developing working relationships across difference tends to 'accommodate' **and reproduce the dominant paradigm**
- The very relationships that help get research done **rest on ethically problematic aspects** of global health research
- The analysis hints at an **alternative dynamic of 'collaborative partnership'** not systematically explored in the current review





Reproduce the dominant health paradigm *or challenge it*

Recommendations

- Health research should maximise **opportunities to strengthen health services and systems**
- Support **engagement at inception** phases of research and flexibility in funding
- **Institutional support** for frontline research and engagement staff and 'programme-wide' engagement
- **Broader ethical and political focus** for CE
- **Extend the review** to include collaborative partnerships and participatory approaches



Recommendations



- Focus CE on **building relationships**, including beyond particular research studies and over the longer term
- Better planning and evaluation of CE with more explicit **‘theory of change’**
- Clarity in the **scope for stakeholder input**
- Ensuring **listening and responding** to stakeholder concerns as well as **‘accurate’** information

Review outputs

- **Full paper** in Wellcome Open (submitted)
- **Commentary paper** (in preparation)
- **Briefing paper** for funders and research institutions
- **Briefing paper** for engagement practitioners and researchers
- **Animation** of review findings
- Materials **hosted on Mesh** Community Engagement Hub:
<https://mesh.tghn.org/programme-hubs/real/>
- Dissemination through networks, webinars, meetings

Taking relationships seriously

Building the evidence base for community engagement in health research



REAL BRIEFING FOR RESEARCH INSTITUTIONS & FUNDERS | 2021

Summary

Community Engagement (CE) is a critical aspect of health research because of its potential to make research more ethical, relevant, and well implemented. Many research programmes now aim to incorporate CE activities at all stages of their work and CE is often a requirement in research funding applications, from biomedical trials in low and middle-income countries (LMICs) to 'public and patient' involvement in health research in the North. However, there is a lack of conceptual clarity around how engagement works, and with this, potential disregard for the complexities, context and ethical issues that shape engagement, especially within health research.

A recent review provides new clarity about how CE works in practice, highlighting its importance in facilitating precarious 'working relationships' between researchers and local research stakeholders, rooted in interactions around research and exchange of research related benefits. It is these provisional relationships, rather than any particular engagement activities or technical interventions, that lead to greater acceptance and participation in the research. The

review identifies challenges in forming and sustaining such relationships including differences of wealth and power, compounded by the broader context where research is often externally funded and controlled. The review highlights issues of power and representation that have long been a concern in public health and research but given new impetus by the recent debates on decolonising global health.

Funders and research institutions have a responsibility to consider the ethical issues that arise from working in environments shaped by wealth and power differences, and to seek to challenge, rather than reproduce, existing inequalities in researcher-participant relationships. Given the importance for local research stakeholders of the access to health care that often accompanies research participation, more explicit attention to how the infrastructure of health research can strengthen health systems is one way of addressing this ethical responsibility. There is also a need for further review and research looking more closely at participatory research methods that embed stakeholder input within the research process, to better understand the dynamics and limits of greater stakeholder decision-making in research.



Navigating the complexity of Community Engagement with health research

REAL BRIEFING FOR COMMUNITY ENGAGEMENT LEADS & RESEARCHERS | 2021

Summary

Community engagement (CE) is increasingly recognised as an essential component for improving health research where high-quality, ethical research can contribute to greater understanding of health issues and to designing contextually appropriate responses. Whilst CE approaches and activities have proliferated, there is a lack of conceptual clarity around how

highlighting its importance in developing long term 'working relationships' between frontline researchers, engagement staff and local populations. It is these provisional relationships, built through a range of formal and informal interactions, that lead to greater acceptance and participation in the research.

The review identifies challenges in forming and sustaining such relationships including differences

With thanks

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Acknowledging our:

REAL team: Robin Vincent, Sassy Molyneux, Bipin Adhikari, Jim Lavery, Geoff Wong, Claire Duddy, Emma Richardson

Content experts: Vicki Marsh, Dorcas Kamuya, Al Davies, Noni Mumba, Mary Chambers, Phaikyeong Cheah, Kate Gooding, Deborah Niryenda, Paulina Tindana

Advisory Group: Kevin Marsh, Mike Parker, Georgia Bladon, Janet Harris

Photographs: Panos Pictures and KEMRI

