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Enhanced or hindered research benefits? A realist review of community engagement and participatory research practices for non-communicable disease prevention in low- and middle-income countries

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ABSTRACT

Introduction Community engagement and participatory research are widely used and considered important for ethical health research and interventions. Based on calls to unpack their complexity and observed biases in their favour, we conducted a realist review with a focus on non-communicable disease prevention. The aim was to generate an understanding of how and why engagement or participatory practices enhance or hinder the benefits of non-communicable disease research and interventions in low- and middle-income countries.

Methods We retroductively formulated theories based on existing literature and realist interviews. After initial searches, preliminary theories and a search strategy were developed. We searched three databases and screened records with a focus on theoretical and empirical relevance. Insights about contexts, strategies, mechanisms and outcomes were extracted and synthesised into six theories. Five realist interviews were conducted to complement literature-based theorising. The final synthesis included 17 quality-appraised articles describing 15 studies.

Results We developed six theories explaining how community engagement or participatory research practices either enhance or hinder the benefits of non-communicable disease research or interventions. Benefit-enhancing mechanisms include community members' agency being realised, a shared understanding of the benefits of health promotion, communities feeling empowered, and community members feeling solidarity and unity. Benefit-hindering mechanisms include community members' agency remaining unrealised and participation being driven by financial motives or reputational expectations.

Conclusion Our review challenges assumptions about community engagement and participatory research being solely beneficial in the context of non-communicable disease prevention in low- and middle-income countries. We present both helpful and harmful pathways through which health and research outcomes are affected. Our practical recommendations relate to maximising benefits and minimising harm by addressing institutional inflexibility and researcher capabilities, managing expectations on research, promoting solidarity in solving public health challenges and sharing decision-making power.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Ethical considerations and democratic principles are in favour of community engagement and participatory research approaches at all stages of health research or interventions.
- ⇒ These practices are typically assumed to be beneficial, but in research contexts characterised by power inequalities, as is typical in global health, it is important to critically assess whether, how, why and for whom engagement or participatory approaches are beneficial or burdensome.
- ⇒ Taking a theory-informed approach to evidence synthesis, realist reviews help to generate a more comprehensive understanding of community engagement.

WHAT THIS STUDY ADDS

- ⇒ Our review builds on existing realist syntheses of health topics and engagement or participatory research by similarly emphasising the importance of social dynamics and offers new insights about how research teams and institutions can promote, or may be hindering, successful engagement.
- ⇒ By complementing our realist literature synthesis with realist interviews, we were able to uncover practical and institutional elements that are not always included in publications, and as such provide more realistic recommendations for engaged or participatory health research and interventions.

INTRODUCTION

Community engagement involves building and maintaining relationships between

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The theories developed in our review highlight both deliberate actions (eg, researcher humility and responsiveness) and institutional factors (eg, inability to accommodate community preferences regarding health research or interventions) that can enhance or hinder the benefits of community engagement and participatory research.

⇒ Institutional support and flexibility to accommodate community preferences, as well as training and incentives for researchers to conduct more engaged or participatory research, would help ensure more beneficial research and intervention outcomes.

research actors and intended beneficiaries.[1] Participatory research similarly invites contributions to the research process itself (eg, formulating research questions, interpreting findings), as opposed to merely treating participants as data sources.[2,3] The literature on community, public, patient or stakeholder engagement with health services, research and interventions is vast, but it has been noted that traditional methods for evaluating and synthesising the impacts or effectiveness of community engagement fall short of understanding the complex dynamics at play.[4–6] For example, the authors of an umbrella review of community engagement for communicable disease control in low- and middle-income countries (LMICs) noted that quantitative summaries and meta-analyses were difficult to produce due to heterogeneity of existing evidence, opting for a narrative approach instead, exploring mechanisms of effect with the help of qualitative methods.[7] In addition to complexity and heterogeneity, our rationale for adopting a realist approach to this topic was also informed by the relative paucity of evidence on the relationship between community engagement and non-communicable disease (NCD) prevention in particular, as the combination of empirical evidence and theorising in realist reviews can help to fill in some of the gaps in the evidence base.[8,9]

Realist methodologies have thus been recommended for unpacking community engagement, and they have already been applied in the context of engagement with malaria trials, maternal and newborn health, healthcare services and mental health interventions.[2,5,6,10–13] Realist methodologies are informed by realist philosophy of science and adopt theory-driven approaches to examine the interplay between contextual factors and mechanisms of change in producing outcomes.[14] These methodologies can draw on primary data, as is done in realist

Table 1 Key terminology

Term	Meaning in the context of this review
Realist review	An approach to evidence synthesis that draws on iterative cycles of theorising and evidence review. The aim is to produce explanations of how, why, for whom and under what circumstances community engagement or participatory research work or do not work.[20]
Abductive thinking or reasoning	A form of creative ('hunch-driven') thinking or reasoning that allows researchers to imagine how a phenomenon might work, therefore, generating new interpretations to be further examined and tested.[21,50,51]
Retroduction	Theorising and testing of interpretations obtained through abductive thinking or inferred from literature to refine explanations of phenomena.[21,50,51]
Context (C)	The local circumstances (eg, individual, organisational and environmental features), history and dynamics that can activate or disactivate mechanisms.[8,16,52] This is not the same as 'setting' or 'context' in a generic sense of providing background information, and only captures those aspects of the context that have a bearing on mechanisms and outcomes.
Strategy (S)	Strategies refer to actions by researchers or research institutions as opposed to community circumstances. This term stems from implementation science, where implementation strategies capture the 'how to' of ensuring evidence-based interventions are adopted or sustained in practice.[53] Strategies are not necessarily intentional or well defined and can be ad hoc in nature. Since many strategies are organisational features or similar, they could be labelled as Context (C) instead of S, but we use separate constructs to distinguish the role of researchers and research institutions from community circumstances.
Mechanism (M)	An underlying entity that produces specific outcomes in specific contexts. Mechanisms are a combination of resources (eg, components of an intervention) and responses (eg, the perceptions of participants) highlighting the importance of examining how interventions or strategies are received as opposed to centring how they were intended.[8,16]
Outcome (O)	Potential or actual outcome (change) achieved by the combination of specific contexts, strategies and mechanisms.[8,16]
Context–strategy–mechanism–outcome (CSMO) configuration	CSMO configurations are representations of a causal relationship between contexts, strategies and mechanisms that lead to specific outcomes.[8,33] Realist studies more typically use the triad CMO, but we have included S to the configuration to highlight strategies and actions by research teams or institutions in contrast with community context.

evaluation,[15] or secondary data, as is typically done with published literature in realist reviews.[16] Realist reviews are used to synthesise evidence on complex social interventions or programmes based on realist principles and are thus suitable for unpacking community engagement. The community engagement literature has also been criticised for a positive a priori bias,[17] assuming beneficial impacts of engagement, and overlooking coercive elements or other threats to research ethics.[18 19] Since realist evidence synthesis embraces more creative forms of abductive reasoning and retroductive theorising,[20] it offers opportunities to explore both positive and negative causal pathways.[21]

We undertook a realist review in response to the relative paucity in considerations of how community engagement or participatory approaches work in the context of NCD research and interventions in LMICs. We recognise that diversity between and within countries makes income-classification problematic, especially considering current, welcome discourse around the topic,[22–24] but we chose to retain the scope defined in our protocol.[20] However, this calls for contextual considerations, well afforded by realist approaches.

Our review includes the 2013–2020 period stipulated in the WHO's Global Action Plan for the prevention and management of NCDs, which emphasised the importance of involving communities in addressing NCDs.[25] The 2030 Agenda for Sustainable Development similarly highlights the role of engaging communities in reducing premature mortality from NCDs by one-third by 2030.[26]

The aim of the realist review was to generate an understanding of how community engagement enhances or hinders the benefits of NCD research and interventions in LMIC settings.[17] The specific objectives were as follows:

1. To review existing theoretical and empirical literature across disciplines and settings to understand how, why, for whom and under what circumstances community engagement and participatory research approaches work or do not work.
2. To inform, and formulate recommendations for, future research and interventions with a focus on drawing lessons for ethical, community-centred NCD prevention research and health promotion in LMIC settings.

METHODS

We followed the process outlined in our review protocol,[20] drawing on the principles developed by Pawson *et al*[15 16] and Wong *et al*.[27 28] The review comprised of iterative cycles of literature searches, screening, data extraction, theorising and feedback from stakeholders through realist interviews,[29] all broadly falling under the umbrella of retroduction (see table 1 and online supplemental file 1).[9 30]

Study selection was guided by the criteria of relevance, richness and rigour.[9] SK carried out initial searches and screening with a focus on 'relevance' (ie, the content of each article that corresponded with our research question, particularly relating to NCD prevention, prioritising descriptions of community-based interventions over national level policies or healthcare settings), while PT contributed to more advanced selection, focused on 'richness' (ie, contribution of studies to theorising in terms of easily identifiable potential theories, as well as rich detail about exact forms of community engagement or participatory approaches and related outcomes) through critical review and discussions with SK. The search and screening process is described in figure 1 and online

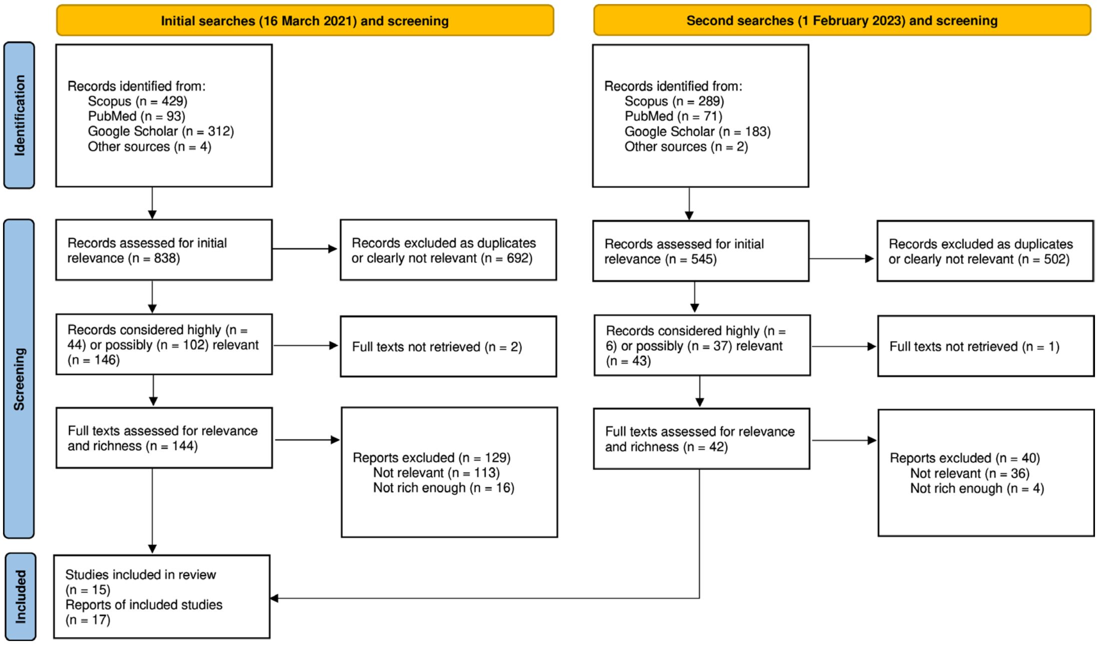

Figure 1 Search and screening process.

supplemental file 2. CED and DN appraised selected studies in duplicate with SK using study design-specific Critical Appraisal Skills Programme checklists[31] to assess 'rigour' (ie, the trustworthiness of sources as indicated by fulfilment of checklist criteria). Other aspects of rigour, namely coherence of the developing theory, were considered throughout the synthesis process. No grey literature was included as no such sources fulfilling the criteria of relevance and richness were identified.

SK coded and extracted data using MAXQDA software. Using the realist Context-Strategy-Mechanism-Outcome (CSMO, see table 1) configuration heuristic tool, our analysis involved coding for configurations of contexts (C), strategies (S), mechanisms (M) and outcomes (O), and other combinations of these (eg, CO).[32] We provide explanations of these realist constructs in table 1. To produce pragmatic insights about deliberate efforts by research teams or shortcomings in research organisations, we introduced the construct 'S' for 'strategies', capturing actions from the perspective of researchers or practitioners.[33] For example, a responsive research team could be seen as both a contextual factor and a deliberate component, but to highlight the active role of researchers in contrast with the experiences of communities, it is labelled S instead of included under C.

BA and FCM advised the coding, data extraction and theorising phases, and helped SK develop the synthesis. With guidance from FCM and another external advisor, EB and SK developed realist-informed interview guides for each literature-based theory and conducted a pilot interview with CED. All three agreed on a theory-informed sampling strategy guided by participants' expected ability to comment on specific aspects of the synthesis and theory development, such as hypothesised elements or counterintuitive findings.[29 34] SK invited participants and conducted realist interviews with five individuals: three researchers, one community activist and one representative of local government with experience of research encounters. The researchers contributed virtually, while the other two participants were interviewed in person in South Africa. Participants received a gift voucher valued at ZAR100 (approximately 5GBP). Transport costs were reimbursed, and refreshments provided in the case of in-person interviews. All participants were asked different questions about the preliminary theories achieved through the realist synthesis of published literature. The goal of this process was to challenge, support and/or build on the emerging theories, rather than saturate the findings or be representative of all possible perspectives on the topic of interest.[29 34] Patients were not involved in this study.

SK subsequently revised the literature-based theories and carried out final searches (see figure 1). The output described here consists of synthesised CSMO configurations of how, why, for whom and under what circumstances NCD-focused community engagement and participatory research approaches work or do not work.[17]

Patient and public involvement

We consulted research and community stakeholders through the aforementioned realist interviews and engaged research stakeholders in the development of our research question and review design.[20] We have shared our results with the contributing stakeholders and will disseminate findings primarily through research networks as our recommendations centre on improving researcher practices and institutional frameworks. Patients and the wider public were not involved in this study.

RESULTS

In total, 17 articles describing 15 different studies from LMICs were included in the realist review. Key characteristics of each study are summarised in table 2.

Following the literature-based realist synthesis and stakeholder consultations using realist interviews, we retroduced six theories about NCD-focused community engagement and participatory research. We have divided these into theories that enhance benefits of interventions or research (theories 1–4), and those that hinder such benefits (theories 5 and 6). Figures 2–7 demonstrate how each theory captures the causal relationships between contexts, strategies, mechanisms and outcomes. These synthesised theories are connected to specific contextual factors, but not exclusively tied to a single setting or intervention, capturing variation across settings. We introduce each theory through 'If—Then' statements,[35 36] which verbally summarise the configurations visually presented in figures 2–7.

Theories of enhanced intervention or research benefits

Community members' agency to contribute meaningfully is realised

If a community with preferences for research or an intervention (C) works with research teams that consider and welcome their views (S), *then* research or interventions that better suit the community's needs will be implemented (O) *because* community members' agency to influence research or interventions is realised (M).

The first mechanism represents a power dynamic in which the views expressed by communities and stakeholders influence the research or intervention in question, resulting in concrete changes (figure 2). Depending on the timing of engagement, an existing intervention may end up being further tailored to a specific community's preferences (O), or a study's design may be informed by community priorities from the start (O).

> This study used Photovoice as a research tool to identify and include a community in research-agenda setting and to better understand community perceptions regarding community health issues and strengths in Kuc, Uganda. (…) The community identified issue of alcohol-use disorders will be the topic in the long-term

Table 2 Key characteristics of included studies

Study reference	Country	Community engagement or participatory research approach	NCD focus
Balagopal *et al*, 2012[54]	India	Community-based participatory intervention	Diabetes
Bradley and Puoane, 2007[55]	South Africa	Participatory action research	Hypertension, diabetes
Caperon *et al*, 2021[56]	El Salvador	Social mobilisation	General
Catley *et al*, 2020[57]	South Africa	Community advisory boards	Diabetes
Dowhaniuk *et al*, 2021[37]	Uganda	Community-based participatory research, photovoice	Alcohol-use disorders
Egid *et al*, 2021[58]	Multi-country	Multiple	Not specific to NCDs
Gonsalves *et al*, 2019[59]	India	Co-design	Mental health
Mathews *et al*, 2018[60]	India	Community-based participatory intervention	Diabetes
Mohan *et al*, 2006[40]	India	Community empowerment	General
Morrison and Arjyal, 2021[38]	Nepal	Cocreated art-based community engagement	Diabetes
Morrison *et al*, 2019a, Morrison *et al*, 2019b, Fottrell *et al*, 2019[39 41 61]	Bangladesh	Participatory Learning and Action groups	Diabetes
Mosavel *et al*, 2005[62]	South Africa	Community-based participatory research	Cancer
Mosavel *et al*, 2011[42]	South Africa	Community researchers	Cancer
Mutiso *et al*, 2018[63]	Kenya	Interactive dialogue	Mental health
Pazoki *et al*, 2007[64]	Iran	Community-based participatory research	Cardiovascular diseases

NCD, non-communicable disease.

> CBPR [community-based participatory research] inspired project. The project goal is the development, implementation, and evaluation of a community-driven public health program that builds on community strengths to address alcohol-use disorders (…)
>
> [I]f public health is to maintain sensitivity to local realities, including local perspectives in research and practice, bottom-up agenda setting is a must to ensure health issues of community importance are addressed.[37] p.19-20

For this mechanism to be activated, contextual factors such as specific community concerns or health needs (C) are required, and the corresponding welcoming of views by the research team, captured by the construct strategy (S). Under such circumstances,

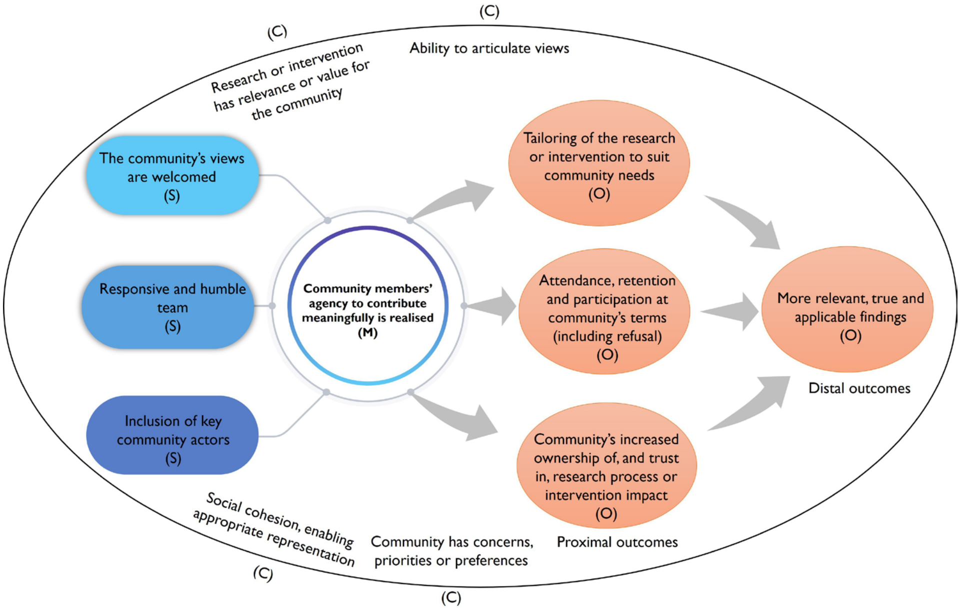

Figure 2 Theory 1.

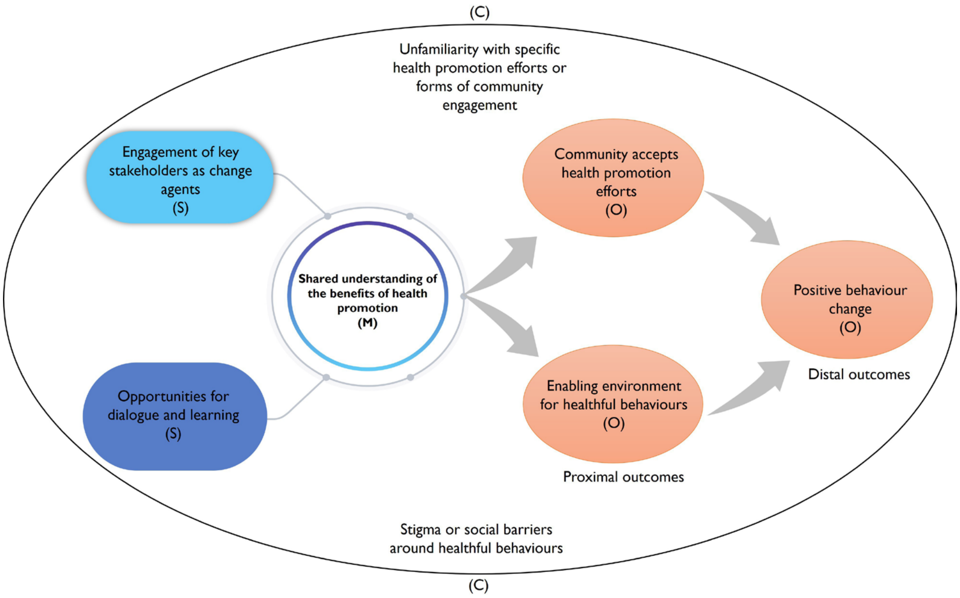

Figure 3 Theory 2.

there is likely going to be increased acceptability and relevance of the research or intervention (O) through the community's agency to contribute meaningfully being realised (M).

The responsiveness of research teams (S) was expressed in a realist interview (RI) as researchers being open to changing their views, and welcoming rather than shutting down community views:

> I'm a researcher, I've got my framework, my way of thinking, but I'm open to be corrected. And maybe this is just a kind of power thing that [community stakeholders] want to feel like they have an equal power, space, a relationship with you in the engagement process. (…) Sometimes, as researchers, we tend to, probably without realising it, shut out the environment that allows people to actually talk. (RI1, researcher)

On the context side, the conditions required for communities to have the power to influence research mainly consist of views about, and relevance of, the research or intervention for communities. Otherwise, there would be no obvious reason for community members to realise their agency in this way. We also surmised, based on experiences on the research team, that a degree of health literacy and community cohesion, or some level of trust in community representatives to express views to the researchers, are also required.

While such contextual conditions can be expected to enable community engagement or participatory processes, the relevance of power dynamics of both what are imagined to constitute 'communities', and those between communities and researchers, cannot

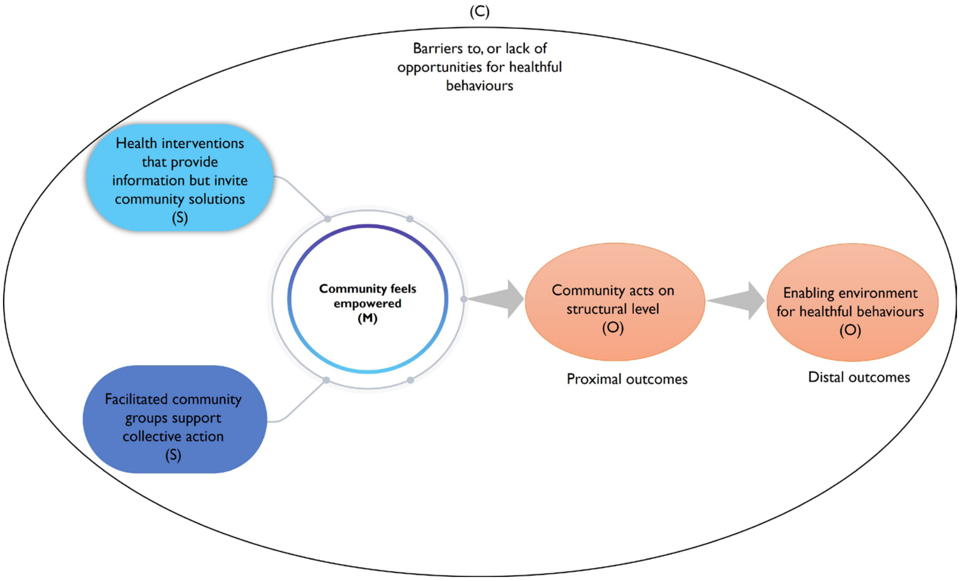

Figure 4 Theory 3.

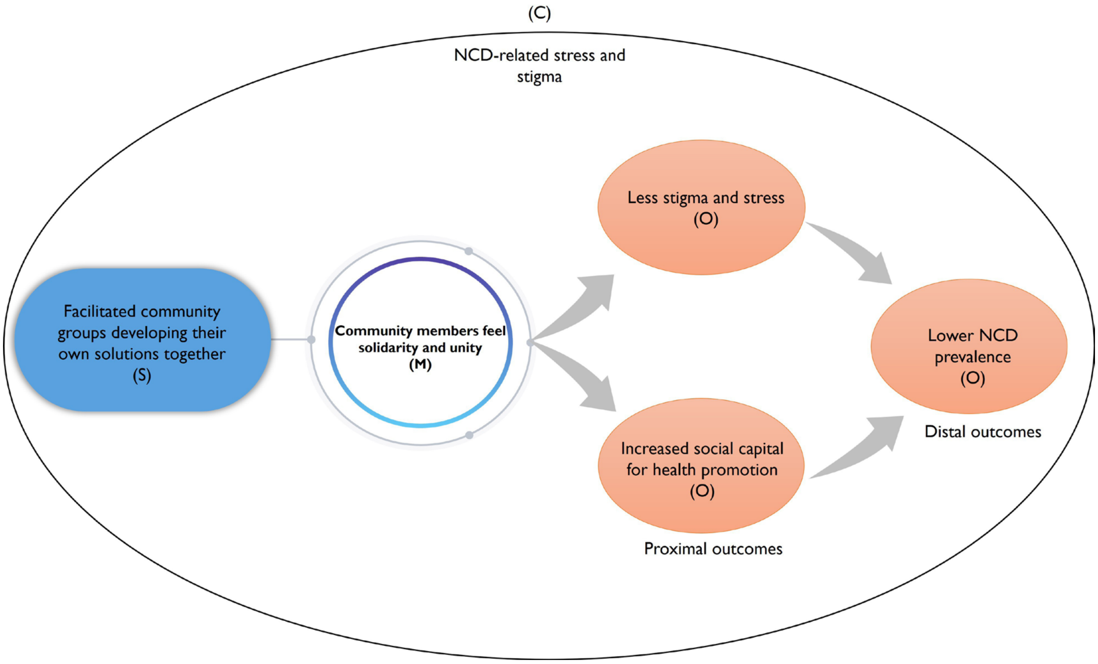

Figure 5 Theory 4.

be overlooked. As one of the interviewed researchers expressed, trust and power also enable dissent, widening the scope of research outcomes to also include refusal, or participation on communities' own terms:

> Both in terms of participants and an advisory board that would speak for a broader community, if they don't have space to voice their dissent, how kind of quote unquote empowered are they? To me, not hearing dissent is a failure. (…) If you have really high rates of consent in a study, beyond a certain point it's not a good thing. To me, it suggests that people don't have enough of a sense of power. Like, not everyone should want to participate in research. (…) Part of the role of a community engagement officer is to try to increase consent to encourage people to agree to participate. And that creates a really dicey tension, right? (RI4, researcher)

On the more positive side of outcomes, realist interviews illustrated the generally optimistic expectations of community engagement and participatory research. These include both more ethical research

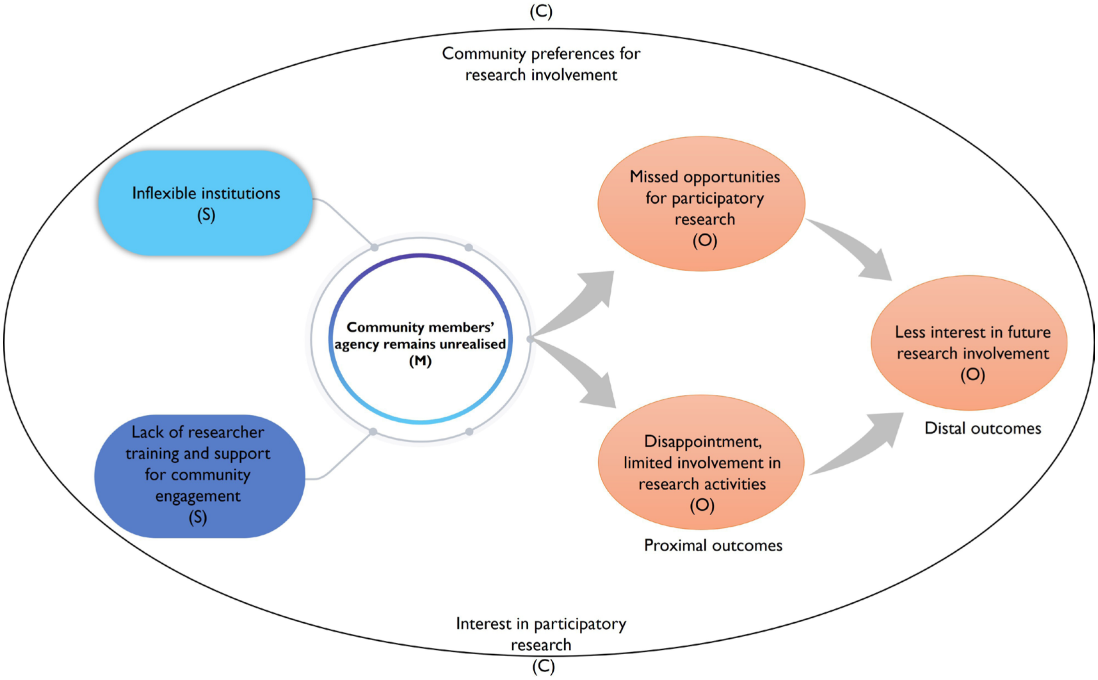

Figure 6 Theory 5.

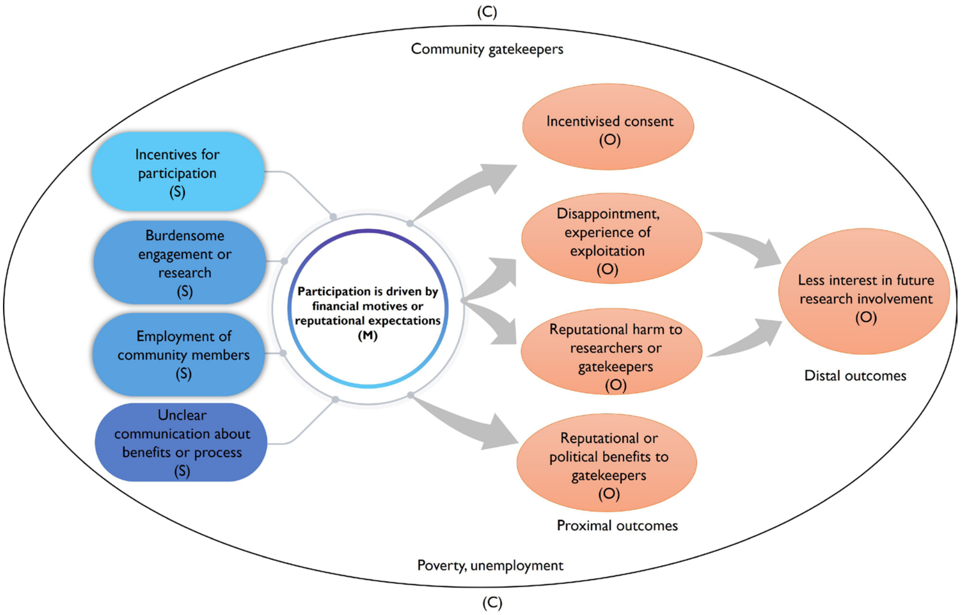

Figure 7 Theory 6.

conduct, and better research output, as expressed by RI4:

> I think that it's not just that research that is collaborative, or research that is more engaged with communities, is more just or more ethical, that's definitely part of it. (…) I mean, maybe that would be enough on its own. But it's also that the findings are more true, more relevant, more applicable to people's real lives. So it's both better research and it's more just. (RI4, researcher)

Shared understanding of the benefits of health promotion

If a community is unfamiliar with certain forms of health promotion (C), *but* community engagement provides opportunities for dialogue and learning (S), *then* the community accepts health promotion efforts (O) *because* there is a shared understanding of the purpose and benefits of the activities (M).

The second theory (figure 3) describes a shared understanding of health promotion (M) as the causal link required for desired health outcomes or behaviours (O). In communities where health-related activities (eg, women exercising in public) are stigmatised (C), strategies such as opportunities for dialogue and engagement of key stakeholders as change agents (S) can activate the mechanism of a shared understanding when it comes to health promotion efforts (M).

Included studies described stigma around both having NCDs, which were sometimes believed to be contagious, and in engaging in healthful behaviours such as physical activity, as it implied the presence of illness. For women, there were also gendered barriers to being physically active in public, as well as getting involved in health promotion efforts. These barriers were typically about women's safety and reputations under patriarchal norms. In a study from Nepal, there was also specific gendered stigma or shame around women's involvement in health promotion efforts as part of an art-based participatory approach (C):

> Some community drama audiences felt that artists were acting inappropriately and feared their behaviour would erode social norms. (…) But as a group, [the artists'] fear of social shame was less, and interactions with crowds afterwards led to increased understanding about why the women were performing and were effective in promoting dialogue about how to prevent and control diabetes.[38] p.24

As expressed in a realist interview, researchers can help alleviate stigma and address health issues through creating forums for health-related discussions to take place (S):

> We were asked about fertility and diabetes, whether it was possible to get pregnant if you had diabetes. (…) So much stigma in marriage and diabetes. So yeah, to create forums where people can ask all these questions (…) that's what you do as a researcher is, you make linkages and you facilitate. That's my participatory action research. It's the role of the researchers, really, to facilitate, bringing all these people together to address the problem. If you're committed to creating a space for conversation, then anything can happen. (RI3, researcher)

If the mechanism of a shared understanding (M) is activated, outcomes such as a more enabling environment for healthful behaviours (O), and consequently positive behaviour change (O), can be achieved.

Community feels empowered

If there are barriers to healthful behaviours (C), *but* facilitated community groups support collective action (S), *then* the community can take structural action (O) *because* they feel empowered (M).

The focus of NCD research or interventions is often on individual behaviours, but some included studies explored the role communities play in addressing upstream, structural dimensions that research or interventions alone could not reach. Our synthesis, therefore, captured some examples of participatory health interventions (S) under conditions of structural barriers to healthful behaviours (C) (eg, social norms hindering women's physical activity) and limited opportunities to pursue healthful behaviours (C) (eg, lack of sports facilities or health screening) fostering community empowerment (M) that can lead to action on a structural level (O), such as building sports facilities, organising access to health screening or collectively challenging restrictive gendered norms (figure 4).

Authors reporting on a diabetes prevention trial in Bangladesh summarised the mixed outcomes of community action as follows:

> Community actions addressed lack of awareness about diabetes, gendered barriers to physical activity and lack of access to blood glucose testing. The interaction between the individual, household, and community contexts amplified change, and yet there was limited engagement with macro level, or 'state', barriers to healthy behaviour.[39] p.1

In one study from India, community action resulted in the building of a new park to improve local opportunities for physical activity:

> Having been empowered with knowledge about the importance of NCD and preventive steps that can be taken, community members felt the need to increase their level of physical activity. However, the most important limitation was finding a place for exercise. After several meetings, a colony committee decided to construct a park. They mobilized resources from the local municipal authorities, philanthropists, and from residents in and around the colony (…). A beautiful park was constructed in 2002 with a walkers' lane (…). Today, the park is used not only by the residents of this colony but also by neighbouring colonies. (…) Treating the community as a partner can result in the community taking action leading to potential health benefits. By altering the social environment and changing the attitudes of people, it is possible to stimulate the community to get most interested in preventive health.[40] p. 860-862

While participants in realist interviews disliked the patronising undertones of the concept of 'empowerment', they refined our theorised interpretations by discussing how participatory approaches can stimulate collective action and support communities to realise their own power in creating change.

> The crucial step is that we can come in and say, 'yeah, we can tell you about diabetes, but actually, you know, you have the answers'. (…) In getting people together, and in making them knowledgeable, they become empowered, like, I hate that word [laughs]. But you know, they're like 'Yeah, I know how I can prevent diabetes, I can tell other people, like, I'm knowledgeable' you know, and then in doing so, you sort of provoke people to take action. (RI3, researcher)

Community members feel solidarity and unity

If there is NCD-related stress and stigma (C), for which facilitated community groups develop their own solutions (S), *then* stigma and stress are reduced (O) *because* community members feel solidarity and unity (M).

Solidarity was a hypothesised mechanism proposed by authors reporting on a participatory learning and action (PLA) approach to diabetes prevention in Bangladesh:

> Furthermore, the removal of stigma about diabetes, the increased solidarity among villagers, and the sharing of information and ideas might have reduced stress levels in the population, which might have contributed to the PLA intervention effect.[41] p.211

In this way, solidarity resulting from the participatory approach was seen to enhance intervention benefits. As the CSMO configuration in figure 5 illustrates, PLA groups (S) can seemingly counteract challenging contextual conditions such as NCD stigma and related stress (C). By welcoming collective action based on communities' own expertise regarding their own problems and corresponding solutions (S), the PLA groups contribute to solidarity and unity (M), making outcomes such as reduced stigma, stress and NCD prevalence (O) possible, and enabling increased social capital for health promotion (O). The participatory and empowering nature of the group approach, therefore, involves addressing NCDs such as diabetes as shared challenges, rather than individual, stigmatised problems. More generally, community-based participatory approaches can generate solidarity through collective problem-solving:

> It's about communities coming together and feeling like they're addressing something together in solidarity with each other. (RI3, researcher)

However, it is easy and risky for researchers pursuing community engagement to make assumptions about social cohesion and harmonious collective action:

> Often, what research does is constitute a community or imagine a community that maybe doesn't see itself as a community. And then you (…) say, 'Okay, now, claim power and act' and the people who have been brought together as research participants because of some shared condition, right? Maybe they share a health condition, or maybe they are within the boundaries of a kind of study geographic area and are meant to act as a collective. And in fact, that's quite a complicated thing. (RI4, researcher)

We, therefore, acknowledge that solidarity and unity are highly complex and may constitute an idealised mechanism. Nevertheless, we found this theory useful for exploring approaches to enhance intervention or research benefits through less direct mechanisms than typical intervention components (eg, behaviour change communication).

Theories of hindered intervention or research benefits

Community members' agency remains unrealised

If community members are interested in contributing to research in specific ways (C), *but* the research institutions are inflexible (S), *then* there are missed opportunities for participatory research (O) *because* the community members' agency is not realised (M).

The mechanism of unrealised agency represents a negative or inverse pathway of the first theory. It is presented separately to highlight factors that can hinder the benefits of community engagement or participatory research approaches. When instead of having the power to influence interventions or research, communities' agency is not realised (M), the contextual factors and outcomes look different (figure 6). Institutional barriers (S) are often the strategies associated with the mechanism of unrealised agency being activated, and community interest or preferences being overlooked. This can include scenarios like ethics boards not accommodating participants' preferred involvement, or researchers not having the necessary skills, support or interest in engagement. Outcomes of these pathways may include limited future involvement in research and missed opportunities for engaged or participatory research (O).

In one published example, South African community researchers who produced reflective journals during their research involvement could not pursue named co-authorship or acknowledgement according to their preferences. The authors reported their limited institutional review board (IRB) approval as the reason:

> When we collected the journals, some of the community researchers expressed that they would prefer their real names used in any publications emanating from their journal entries because they wanted the "world to know about them and help their community." Our IRB approval did not, however, allow for this contingency; hence, all community researcher names and other clearly identifying information have been removed from, or replaced in, the data presented in this paper. [42] p.5

In addition to the phenomenon of institutions being inflexible when it comes to participants' or communities' specific preferences for engagement and research, the extent to which researchers are trained, supported or encouraged came up as factors complicating community engagement or participatory research:

> No one is taught these things, you just have to be so intuitive and read the room (RI1, researcher).

When it comes to more transformative, non-hierarchical and community-led practices, the institutional dimension came up both in interviews, discussions with colleagues and through the author team's own experiences.

> And there are so many structural barriers in most academic institutions to doing work that is genuinely collaborative and participatory, where you as the researcher don't position [yourself] as the quote unquote expert researcher, don't position yourself at the front and centre. Those are the things that I think are necessary to do genuinely participatory (…) work that transforms engagement from more like top-down knowledge dissemination to something that is genuinely collaborative. And I, unfortunately, don't think that many academic institutions allow for the kind of flexibility that's needed to do that work. (…) You might get a job, but you probably won't get promoted very fast and very far, unfortunately. (RI4, researcher)

Participation is driven by financial motives or reputational expectations

If a community experiencing poverty and unemployment (C) gets involved in research with unclear communication about research benefits and processes (S), *then* community members will feel disappointed and exploited (O) *because* their participation is driven by financial motives or reputational expectations (M).

The underlying democratic principles of community engagement and participatory research make it tempting to assume that such principles are the primary motive for individuals' or communities' involvement in research. However, monetary expectations or hopes of employment come up frequently in the literature, particularly in settings with high levels of poverty, inequality and unemployment (C), as exemplified in an article about community researchers conducting participatory cervical cancer research in South Africa:

> In poor communities, where unemployment is rife, it is not unusual for community members to volunteer their services or agree to participate in research in the hope that job opportunities would arise from this participation. Four of the six community researchers' initial journal entries confirm the view that their participation was motivated by paid employment possibilities. The scarcity of jobs in the region and their inability to secure employment elsewhere were the primary motivators for them to agree to become community researchers.[42] p. 147

As an interview participant working in local government pointed out, the risks of paying people to participate may compromise participants' voluntary consent, but the solution cannot be not paying participants.

> Then it loses what you wanted to do, because this person, not to say he wanted to be part of this, but for the sake of money. You understand? (…) Sometimes you can make the study and call them, you take them there, they come back without [pause] nothing. Then what will happen? You understand? That would be BAD! [big emphasis] Maybe at [name of research site] you take a long day, sitting there hungry, what he's gonna eat? Doesn't work. But if you give him something that will motivate that person, I don't think it's that bad, no, it's a good thing to do. (RI5, local government)

Some financial expectations naturally concern the typical minimum standards of health research, such as transport remuneration. However, the line between such standards and financial 'motivation' is fraught with ethical tension.

The realist interviews provided further insights about how expectations may also be affected or have implications for key stakeholders or gatekeepers of research, such as local political actors. Indeed, beyond financial motivation, we also heard examples of expectations related to status or reputation influencing relationships between communities and research (figure 7). Gatekeepers such as community leaders or politicians may use financial expectations of potential research participants for their political gains, in terms of endorsing research from which community members can gain something, thus benefiting reputationally from being seen to secure their community such opportunities. Conversely, research without clear benefits or incentives may cause reputational harm to local leaders who are seen as bringing the study to the community.

In both scenarios, the relationship between research institutions and communities is potentially harmed since it may either become characterised as compromised research ethics or undue inducement (O) when people do not consent voluntarily but because of expected financial gains (M), or it may lead to lower participation (O) and reputational damage to gatekeepers (O) when the financial gains do not meet expectations (M). A key consideration here is whether expectations are realistic or based on incomplete or misunderstood information, or perhaps stem from previous research encounters.

> If they see [community gatekeepers] recruiting for something which does not have that benefit, ne? People will turn against them to say they're the one who's benefiting from this. (RI5, local government)

> People enter into the studies, because umm mostly, they want something to benefit something. Especially money, or whatever voucher that they give.(…) They've got needs, you know? (…) Besides, the level of unemployment, unemployment in our country is skyrocket high. (RI2, community activist)

In terms of expectations, a researcher also warned of community stakeholders and gatekeepers having expectations based on their own agendas, and a disconnect being created when expectations were not expressed:

> They'll talk to you about representing the community's voice. But when it comes to what's available as benefits, they're looking out for themselves. So that disconnect is one that I find creates expectations that cannot be met, simply because expectations are never communicated. (RI1, researcher)

Overall, financial motives and reputational expectations have the potential to both enhance or hinder benefits of research and interventions, but our review findings tended to point to the risks, including communication challenges and resulting expectations.

DISCUSSION

The aim of our realist review was to generate an understanding of how community engagement enhances or hinders the benefits of NCD research and interventions in LMIC settings. We developed six synthesised theories built around mechanisms found across studies that capture whether community engagement enhances or hinders the benefits of interventions to facilitate NCD-related research, prevention and health promotion. The mechanisms we uncovered, and associated recommendations, are summarised in table 3.

The first four mechanisms predominantly enhance, and the last two predominantly hinder, intervention and research benefits. We further set out to understand how, why, for whom and under what circumstances community engagement and participatory research approaches work or do not work. In terms of the 'how', 'why' and 'under what circumstances', our review captured some of the power dynamics and institutional factors involved in both facilitating or blocking beneficial outcomes. Through employing a multimethod realist approach to evidence synthesis, we were able to go beyond idealised notions of community engagement or participatory approaches, and thus challenge the positive a priori bias.[17] The consideration of 'for whom' is of particular relevance for academic institutions, as our review highlights the role of inflexible, unprepared or uninterested research actors in activating negative mechanisms around community engagement and participatory research.

Our review findings are both similar and different to previous realist syntheses on related topics. In a realist review of community engagement with malaria trials, Vincent *et al*[12] identified what they term 'working relationships', such as influence and responsiveness and encounters with research teams, that align with some of our NCD-focused theorising. However, we have further highlighted the element of power by considering whether community members' agency to contribute meaningfully is realised or not. This reflects our attempts to tease out concrete actions by research teams, which in this case involves humility and power-sharing[43] through welcoming and subsequently incorporating community views. We have also described power dynamics as being broader than unidirectional and always oppressive in favour of researchers, and were thus able to consider the agency of communities through outcomes such as refusal.[18]

A realist synthesis of community-based participatory research in North America reported on longer-term outcomes of successful community–academia partnerships. These included cultural shifts in attitudes towards cancer,[44] resembling the mechanism we uncovered around community action on a structural level. In the North American review, such beneficial outcomes seemed to be facilitated by trust building and maintenance in the partnerships.[44] We similarly reasoned throughout the realist review process that trust plays an important, often implicit role in producing both positive

Table 3 Review findings and associated recommendations

Uncovered mechanism	Recommendations
Community members' agency to contribute meaningfully is realised	Power sharing should be pursued where feasible, welcoming views from as early as possible where the research agenda or intervention focus can still be adjusted.
Shared understanding of the benefits of health promotion	Research or intervention teams should support affected communities in reaching a shared understanding about divisive or stigmatising aspects of health promotion.
Community feels empowered	Research teams should foster a sense of 'empowerment' in affected communities with evidence and be available to answer health-related questions and concerns, while emphasising the communities' own expertise and agency in solving problems affecting them.
Community members feel solidarity and unity	Public health issues should be presented as shared challenges to be addressed together, while avoiding assumptions about 'communities' defined by researchers already being cohesive or harmonious entities. Consider partnering with existing groups and self-identifying communities where relevant and possible.
Community members' agency remains unrealised	Research teams should be realistic and transparent about what can be accommodated, pursuing institutional flexibility where possible (eg, more senior researchers with authority/tenure have more scope to create change).
Participation is driven by financial motives or reputational expectations	Research teams should manage expectations as much as possible, perhaps through cultivating partnerships or relationships where non-academic actors can understand the realities and constraints (eg, reasons for targeting of studies, scope of funding or ethical approval) of academic research. The likely risk of undue inducement needs to be taken particularly seriously whenever engaging with communities experiencing, or with a long history of, structural inequality or any form of oppression. While the rationale for engaging and doing research with disadvantaged communities is typically related to the potential beneficial impact of the research, it cannot be assumed that well-intended research or engagement is never harmful or exploitative.

and negative outcomes of engagement and participatory research, but it was often too broad or vague to capture in configurations.[12]

Jagosh *et al*[44] observed that their focus on partnership dynamics and synergies contrasted with the pressure within academic public health to demonstrate and quantify impact.[45] Our findings around the lack of institutional preparedness, flexibility or support for more equitable or non-hierarchical engagement echo their observations from high-income countries, and these tendencies clearly hinder health researchers from moving beyond tokenistic or unidirectional community engagement or participatory research practices.[43] An important consideration arising from our review is also whether it is advisable to go ahead with certain research projects, community engagement activities or health interventions if it is recognised that financial motives or reputational expectations may significantly undermine research ethics and the risk of undue inducement is high or difficult to mitigate.[19]

In our protocol, we asked whether NCDs are any different from other health topics when it comes to community engagement and participatory research.[20] However, the mechanisms we uncovered relate more to social dynamics than a specific health theme, and can thus potentially inform health research beyond NCDs. This is supported by the degree of similarities between our theorising and the findings of another recent LMIC-focused realist review,[13] which specifically examined communication in community engagement, but in the context of maternal and newborn health as opposed to NCDs. In particular, our findings around the positive outcomes of community engagement or participatory research where community members' agency is realised resemble the other LMIC review's programme theories of 'actively involved', 'acceptable' and 'value/benefit'.[13] Our review highlights the power dynamics between researchers and communities more, whereas the communication-focused review provides insights about trust and the power health workers hold in communities.[13] These two realist reviews together suggest that as long as the thematic focus of health research or interventions is relevant to communities they intend to benefit, the health topic is not as critical for successful community engagement in LMICs as the practices and strategies, including communication, of research teams.

It is, nevertheless, important to note that there are unique and context-specific aspects of NCD research and interventions, and these do need to guide the approaches taken to community engagement. For example, NCD-related stigma or stress may not be relevant or be similarly expressed across settings, but researchers need to be mindful of the nuances of lived experience and cultural dimensions (eg, gendered barriers to healthful behaviours) when it comes to NCDs.[46–49]

The theoretically targeted realist interviews are a strength of this review. Merely basing the synthesis on published accounts would have limited our ability to uncover and explore negative causal pathways, as there is likely a form of publication bias or self-censorship against the more problematic dynamics and experiences of research–community relationships. We, therefore, recommend exploring realist interviews, focus group discussions or other ways of capturing nuanced accounts of events to complement literature syntheses.[29 34] Our small number of realist interviews introduced numerous and interesting avenues for potential subreviews (eg, the power of refusal), and so we must reiterate the limitation already acknowledged in our review protocol: 'A realist review cannot produce an exhaustive account of all contexts, mechanisms and outcomes of potential relevance to non-communicable disease prevention'.[20] Nevertheless, a strength of our realist review is that it provides a basis for future case studies and realist evaluations, which can delve deeper into specific topics and mechanisms uncovered by our review.

CONCLUSION

Our realist review of community engagement and participatory research for NCD prevention in LMICs uncovered six mechanisms that either enhance or hinder the benefits of interventions and research. Our theorising challenges assumptions about engagement and participatory practices, considering both helpful and harmful pathways through which health and research outcomes are affected. Our practical recommendations relate to maximising benefits and minimising harm by, for example, addressing institutional inflexibility and researcher capabilities, managing expectations on research, promoting solidarity in solving public health challenges and sharing decision-making power.

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