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# The ethics and politics of community engagement in global health research

## Introduction

Community engagement is an increasingly common component of scientific research, policy-making, ethical review, and technology design. Drawing on a growing consensus about the importance of community representation and participation for ethical research, a number of research institutions and funding bodies now promote, or even mandate, community engagement. Many researchers have also taken these normative expectations to heart, integrating diverse community engagement activities into their research practices. The increasing interest in and emphasis on community engagement can also be seen in the explosion of published articles over the last 30 years describing engagement activities across a wide variety of research areas. These include, to name only a small selection of a vast and growing literature: pandemic prevention and malaria control (e.g. Garrett, Vawter, Prehn, et al., 2009), genetics and genomics (e.g. Felt & Fochler, 2010), nanotechnology (e.g. Delgado, Kjølberg, & Wickson, 2010), patient advocacy (e.g. Rabeharisoa, Moreira, & Akrich, 2014), mental health (e.g. Campbell & Cornish, 2010), HIV prevention (e.g. Koen, Essack, Slack, et al., 2013), and biobanks (e.g. Papaioannou, 2011). It could be said that the ethos of community engagement and participation has become something of a zeitgeist in scientific research in recent decades.

Effective community engagement is increasingly understood by its proponents and practitioners to be essential for ensuring both instrumental objectives and moral ideals of scientific research. This is particularly the case when research is conducted across cultural, structural, or economic differences. Due to its historical origins and the nature of the research endeavour, global health research is often characterised by significant differences, and geographic distances, between researchers and those under study. Global health research projects and programmes are often initiated and led by researchers based in the Global North, where human capital and financial resources are concentrated, but rely heavily on the active participation of local researchers, practitioners, and participants in the Global South, where most 'global' health research and intervention is focused. The diversity of actors involved in large-scale transnational research collaborations and the broader 'background conditions' of global inequality and injustice that frame the field (King, Kolopack, Merritt, & Lavery, 2014) have led some researchers, funders, and policy-makers to conclude that community engagement is nothing less than a moral imperative (e.g. Nuffield Council on Bioethics, 2002; Emanuel, Wendler, Killen, & Grady, 2004).

It has been suggested that engagement has the potential to redress past harms; dissolve long-standing mistrust and suspicion; minimise the risk of further exploitation; compensate for or resolve existing differences in power, privilege, and positionality; allow for marginalised voices and experiences to be represented in the production of scientific knowledge; and ensure that research is relevant and impactful. To this end, its proponents suggest, engagement activities must aim to create meaningful partnerships between researchers and those who inhabit the social or physical spaces where research is being conducted (Israel, Schulz, Edith, & Becker, 1998). Through effective partnerships, proponents, and practitioners hope to move beyond interpersonal and structural inequalities and to foster genuine dialogue between researchers and study communities. Once partnerships are established, it is argued, ongoing dialogue and collaboration ensures that community members play an active role in shaping study design and implementation, thereby improving the quality of scientific research and

ensuring its impact for marginalised communities and populations (MacQueen, Bhan, Frohlich, Holzer, & Sugarman, 2015).

Despite explicit objectives related to socially responsible knowledge production, inclusivity, and empowerment, practices of community engagement in global health research are not inherently democratising. As will be explored below, community engagement programmes can serve a wide variety of ends. Engagement activities can be used for purely instrumental goals – to gain community ‘buy-in’, to increase consent and study enrolment, or to ensure smooth research operations – rather than to achieve broader transformations in the politics and power dynamics of research. Further, despite the inclusive promises of community engagement, engagement practices can be exploitative or can serve to exclude already marginalised members of a community (Gbadegesin & Wendler, 2006). Instead of redressing ethical concerns around research, engagement activities can introduce new ethical and social challenges (Molyneux et al., 2016).

Rather than taking community engagement as a given, the papers in this special issue highlight how processes of community engagement are shaped by particular local histories and social and political dynamics, and by the complex social relations between different actors involved in global public health research. By interrogating the everyday politics and practices of a wide variety of engagement activities across diverse contexts, the special issue critically explores the social, political, and ethical dimensions of community engagement in global health research, policy-making, and practice. To this end, the contributors analyse the complex interactions between research organisations, governmental institutions, civil society actors, social movements, and interest groups that are involved in the conduct of community engagement. Further, by drawing out the conceptual underpinnings of community engagement and the contextual backgrounds that inform its conduct, contributions highlight how these relationships are shaped and reshaped by the particular economic, social, technological, bioethical, and developmental demands, pressures, and interests of biomedical research in diverse low-income settings. By including contributions from critical scholars as well as engagement practitioners, the special issue draws together a set of papers that move between these spaces and approach the problem of ‘engagement’ from divergent perspectives, interrogating and expanding standard narratives of community engagement. Through this perspective, the collection also offers unique insights on broader issues of representation, power, and justice in global health.

## **Understanding the origins of community engagement**

Despite the increasing emphasis on the importance of community engagement and participation in global health, relatively little attention has been paid to the origins of engagement and participation within global health. While community engagement in global health has had its own particular history and trajectory, many of its central ideologies, assumptions, motivations, and practices are linked to the broader histories and dynamics of what has sometimes referred to as the ‘participatory turn’ in scientific research. The ‘participatory turn’ has focused on interrogating and shifting the relationship between researchers and researched, ‘expert’ and ‘non-expert’, and between ‘science’ and ‘society’<sup>1</sup> more broadly. While there is not sufficient space for an exhaustive review of the literature, we offer here a brief reading of the historical origins and underlying logics and assumptions of community engagement and participation across three interrelated fields: global and public health, international development, and science and technology studies (STS).

## **Promoting participation in health and development**

As many historians of medicine have pointed out, the uneven distribution of power in the production of biomedical knowledge and the practice of biomedicine is not a new phenomenon, but has been a dominant feature of public health and medical research and intervention since the beginnings of modern biomedicine (e.g. Tilley, 2011). A concern with the involvement of local ‘communities’ and an emphasis on ‘community-based’ approaches to health promotion and service delivery first emerged

in the 1960s as part of a broader commitment to strengthening primary health care systems health services in newly independent states (Cueto, 2004). The intent of the primary health care movement was to deliver locally appropriate health services that were universally accessible. This commitment was formalised in the language of 'community participation' in the 1978 Declaration of Alma-Ata (WHO, 1978).

Following a broader shift towards neoliberal paradigms in health and development in the 1980s, new global health collaborations began to replace state-focused, international health programmes (Brown, Cueto, & Fee, 2006). These new structures have also given rise to new governmental forms that have been instantiated through moral economies of responsabilisation and 'community ownership'. Despite increasing emphasis on community participation, recent social scientific literature has highlighted how historically rooted social dynamics and structural inequalities have continued to shape the conduct of health research in the Global South. Scholars have highlighted the social, political, ethical, and technical complexities of large-scale, transnational collaborations and explored the cross-regional relations that emerge between researchers, participants, and study communities in such spaces (e.g. Fairhead, Leach, & Small, 2006; Kelly, MacGregor, & Montgomery, 2017; Lavery et al., 2010; Molyneux & Geissler 2008; Montgomery & Pool, 2016; Montgomery, Sariola, Kingori, & Engel, 2017; Reynolds, Cousins, Newell, & Imrie, 2013; Tindana et al., 2015).

A somewhat similar process has unfolded in the field of international development, where community participation has increasingly become a central element of development programmes. Similar to the stated goals of community engagement in public health and medicine, participatory approaches in international development were intended to break the structural and social boundaries created by legacies of colonialism, racialised hierarchies, and inequalities and to allow for marginalised voices to be heard. The 1999 World Bank *Voices of the Poor* report, for example, explicitly aimed to place personal narratives of suffering at the heart of anti-poverty debates (Naraya, Patel, Schafft, Rademacher, & Koch-Schulte, 2000).

To involve communities in the conception and conduct of development interventions, development researchers and practitioners have deployed a variety of tools, perhaps most notably the methodology of Participatory Rural Appraisal (PRA) (Chambers, 1981). The approach has been widely used in international development programmes across Africa and Asia (e.g. Mukherjee, 1993). Moving beyond PRA, the model of community-based participatory research has aimed to involve communities more explicitly in the full process of knowledge production (Wallerstein, Duran, Oetzel, & Minkler, 2003). These approaches intend to bring the 'subjects' of development programmes into the process of defining the focus, procedures, and outcomes of interventions. Rather than simply being seen as subjects of research, local communities are understood to hold crucial social and technical knowledge that development practitioners should learn from to ensure that interventions are effective and responsive to community needs and interests (Mosavel, Simon, van Stade, et al., 2005). These approaches to participatory research have been taken up widely in global health research (e.g. Lorway, Thompson, Lazarus, et al., 2013).

A growing number of scholars, however, have critiqued the implementation of participatory approaches in development and global health, arguing that they fail to address underlying structural inequalities that shape relationships between diverse stakeholders in research endeavours (Cooke & Kothari, 2002). David Mosse has argued that participation can be a self-fulfilling strategy, in which those who are already successfully 'engaged' participate in the engagement process and modes of engagement are significantly constrained by existing power dynamics (Mosse, 2005). Cornwall (2010) and others have argued that by the mid-2000s, ideas of 'community' and 'participation' had become empty signifiers – deployed to signal a commitment to local perspectives, but often not carried through in any meaningful way.

### **Expert knowledge and trust in science**

From the 1960s to the 1990s, a growing literature on 'public understanding of science' emphasised the importance of educating 'the public' about scientific developments. Bauer, Allum, and Miller (2007) have described how activities in this paradigm were often framed around 'a deficit model', which assumed that publics lack basic knowledge or understanding of science or scientific facts. The success of involving

publics in this tradition was measured in terms of increases in scientific knowledge, or 'science literacy', amongst specific target groups (Wynne, 2006). Contemporary STS and public health scholars have questioned the underlying assumptions of this model regarding what forms of knowledge count as 'scientific' and how forms of knowledge are transferred.

Critical scholars have also raised concerns regarding the distribution of power in these top-down relations where 'science' is instantiated through the voices of 'experts', while 'society' is understood to be made up of 'non-expert' publics or communities (e.g. Davies, 2013; Gottweis, 2008; Stern & Green, 2008). Several authors have argued that such top-down approaches can cause harm, and pointed to the potentially transformative power of including lay publics in scientific knowledge production (Carlisle & Cropper, 2009; Ui, Heng, Yatsuya, et al., 2010). Critical scholars have brought attention to the everyday processes of knowledge production and power relations that play out in the design and conduct of science and the creation of policy (e.g. Hyysalo, Jensen, & Oudshoorn, 2016; Jasanoff, 2003; Leach, Scoones, & Wynne, 2005).

A few key moments of public crisis have reinforced the scholarly critique, shaken public trust in scientific knowledge and led to significant changes in science policies relevant to participation. In the UK, the mass burning of livestock due to foot and mouth disease in the 1990s resulted in a major 'crisis of trust' between government researchers, policy-makers, and 'lay' publics (UK House of Lords, 2000). Critical scholars argued that the crisis was caused by a failure of scientific institutions to take people's concerns and understandings seriously, treating them rather as passive recipients of knowledge (e.g. Jasanoff, 2003). To redress such concerns, they suggested, knowledge production and scientific policy-making must be democratised by involving publics in the design of research and policy, ensuring greater accountability, and redefining expertise and ownership. In 2000, in response to the crisis, the British House of Lords published a report entitled *Science and Society in 2000*, mandating community engagement and participation as an essential component of all research and science policy in the UK (UK House of Lords, 2000). Following on this advance a number of major research bodies (including the Royal Society and the Wellcome Trust) began to shift funding to community engagement activities. Similarly, public institutions in the UK began to encourage community participation in governance of research, design, and science policy.

In some contexts, social movements have managed to enact changes in priorities and practices of scientific research, representing an alternative, bottom-up model of 'science' and 'society' relations. The contest around scientific knowledge production and governmental funding in the early years of the HIV epidemic in the US is a notable example. In response to a relative lack of scientific and governmental attention to the 'gay men's health crisis' unfolding in the early 1980s, activist groups publicly demanded increases in funding and shifts in scientific priorities to better understand this new disease and develop treatments (Epstein, 1996). As innovative medical treatments were successfully developed and the HIV epidemic expanded worldwide, social movements began to focus on the question of access to anti-retroviral treatment. In South Africa, where the epidemic was causing a significant mortality and where no treatment was available, the Treatment Action Campaign carried out a successful campaign to demand access to ART in the public health care system (Heywood, 2009). In both contexts, in addition to demands for medical care, people living with HIV called on scientists and policy-makers to recognise the necessity of including their voices and perspectives in HIV research, policy, and programmes. More broadly, patient activist groups formed around a number of different health conditions have increasingly demanded a 'seat at the table' (Stern & Green, 2008) and an opportunity to be part of scientific knowledge processes and policy-making, embracing a motto of 'nothing about us without us'. In response to these demands and to broader ethical concerns, ethical guidelines have increasingly emphasised the importance of community engagement in global health and clinical trials research (e.g. Council for International Organizations of Medical Sciences (CIOMS), 2016; Nuffield Council on Bioethics, 2002).

The combination of ethical and policy mandates, increased levels of funding, recognition of the positive effects of engagement on the feasibility and quality of research, and continued demands from social movements and civil society actors for recognition and involvement have made community engagement an increasingly important component of global health research. At the same time, after nearly 40 years of scholarly research and implementation of community engagement and participation

programmes in many contexts, some scholars have suggested that the field is undergoing a 'reflexive turn' (Chilvers, 2012). This turn is characterised by a growing awareness on the part of (some) engagement practitioners and researchers that, despite their lofty ideals, engagement activities have too often reproduced old models of top-down knowledge production and dissemination, privileged particular voices to the exclusion of others, and served to consolidate existing social inequalities. To take up these concerns and to seek new, transformative ways of engaging, the special issue brings together a diverse set of perspectives on the possibilities, promises, and pitfalls of community engagement in global health research.

## Exploring the ethics and politics of community engagement

The special issue emerges from a workshop which took place at the University of Oxford in September 2016. The aim of the workshop was to foster knowledge exchange between divergent actors working in and on community engagement, ranging from engagement practitioners and applied researchers to critical scholars. We focused in particular on facilitating knowledge translation from engagement practitioners and researchers based in the Global South. For many participants, their roles moved between practitioner, researcher, advocate, and activist. In addition to their different professional roles, workshop participants came from 21 countries and represented more than a dozen disciplinary backgrounds. Drawing together this diverse group of participants and authors fostered a rich, ongoing conversation that interrogated and moved beyond standard narratives of community engagement in global health.

To explore political, historical, and social tensions in the practice of engagement in global health research, the workshop, and the resulting papers have opened up a series of questions across multiple registers:

- (1) First, engagement practitioners and critical research have addressed the descriptive realities of engagement: What counts as community engagement in global health research? Who are the players involved and what are their relationships like? Who is included and excluded from engagement activities? What makes engagement 'effective'? What are the challenges and tensions that emerge in everyday practices of engagement?
- (2) Second, they have explored a set of broader normative questions: What constitutes ethical and just global health research, and how does engagement contribute to achieving this? What are the arguments for and against engagement? What exactly about engagement makes research more 'ethical'?
- (3) Finally, authors have focused on the social and political contexts that shape (and are shaped by) engagement activities and global health research: How do engagement activities and global health research intersect with existing structures of power, local social relationships, and broader structural forces? What kinds of encounters and relationships are produced through these activities, and how do they (re)shape everyday social life? How do local historical specificities shape how the objectives of engagement are perceived and achieved?

The papers included in this collection represent a selection of the papers circulated for the workshop itself, and are informed by the rich discussions that took place amongst participants.

## Defining and refining the terms of engagement

The papers in the special issue demonstrate that the diverse (intended or unintended) effects of community engagement activities are determined in part by the various ways in which the concept of 'community engagement' itself is defined and enacted.

Firstly, the seemingly simple concept of 'community' is deployed in diverse ways in different social and political contexts, signalling intersecting ideas of power, belonging, and participation. The term has been widely used by researchers, development practitioners, anti-globalisation activists, and state



and corporate actors, amongst others, to encode quite different understandings of and commitments to collective dynamics. The term is conceptualised very differently in diverse engagement programmes and everyday practices in global health. In some cases, communities are brought together simply as a result of physical proximity, by inhabiting a particular place, bounded by specific geographic, juridical, or bureaucratic borders. In other instances, communities are defined through a shared identity – such as sexual orientation or gender identity – that is of relevance to the engagement effort in some way. Alternatively, people involved in ‘community engagement’ activities may have had nothing in common except for a shared disease diagnosis or increased risk of contracting a specific disease. Or, in other instances, ‘communities’ may be constituted temporarily or fleetingly, as those who are brought together for a particular research activity or engagement event. These different understandings of the term can have important effects, particularly when definitions are imposed externally.

Similarly, the aims and practices of engagement are defined in multiple, differing, and sometimes overlapping ways. In many instances, engagement is conceived of as part of the ethical operations of a research institution and is thus conceptualised and practiced in order to satisfy the requirements of ethics board and others by ensuring ‘community consent’ or ‘community representation’ in research operations and decision-making. At other times, it is understood to be primarily a strategy for researchers and health practitioners to deliver scientific knowledge to communities through educational programmes and events. In other cases, engagement activities aim explicitly to shift or ‘democratise’ the process of knowledge production itself through bringing collectives together to shape research agendas, design and carry out research, and share their own insights. These forms of engagement can be linked more explicitly with activist agendas, aiming for structural transformations and social change. The various modes of ‘engagement’ also signal the diversity of individuals involved as engagement ‘practitioners’.

### ***Power and social relations***

While several papers offer ‘case studies’ from one country setting, most focus on transnational research programmes or projects that involve funders, researchers, or other stakeholders from different locations, thus embedding them within the ‘global health research’ establishment. In this complex space, the papers in the collection highlight the importance of questions of power, positionality, authority, and privilege in the practice of community engagement.

Drawing on qualitative research with two community advisory boards (CABs) in Zambia, Simwinda, Porter, and Bond (2018) offer a critical exploration of the role of community advisory boards (CABs) in ensuring accountability between researchers and ‘communities’ in medical research. They describe how unequal power relations between researchers and CAB members and a lack of accountability on the part of researchers themselves produced powerful contradictions between stated goals and everyday operations of CABs (Simwinda et al., 2018). Relatedly, Aggett (2018) explores the quality and depth of involvement of researchers themselves in two participatory arts projects in Nepal. The author, an engagement practitioner herself, highlights how key contextual factors created ‘logistical and attitudinal obstacles’ to the genuine involvement of researchers in community engagement, including discomfort with creative methodologies, institutional and disciplinary hierarchies and priorities, and ambiguity from funders regarding the value of engagement.

### ***Interrogating the ends of engagement***

The papers and broader conversations in the workshop and beyond highlight what might simplistically be seen as a set of arguments for and against community engagement. Some have focused on the positive attributes or potential of engagement work: as furthering normative ideals of democratisation; shifting the ownership of science and redefining expertise; empowering individuals and addressing vulnerability; furthering normative ideals of democratisation; or promoting social justice. Van der Elst and colleagues (2018), for instance, describe a dialogue-based approach to addressing homophobic stigma amongst religious leaders in Kenya. In a context of extremely high rates of stigma towards sexual

minorities, they argue, community engagement activities served not only to mobilise stakeholders around a public health research agenda, but also became sites for conflict resolution, trust building, sensitisation, and the sharing of different ontological and moral frameworks and perceptions (van der Elst et al., 2018). Implicit in their account is also a broader set of questions related to trust in scientific knowledge, colonial power relations, and competing moral and ethical frameworks.

Also working with a group of participants who often experience high rates of stigma and discrimination, Versfeld and colleagues (2018) reflect on the successes, limitations, and lessons learned from processes of community inclusion in a multi-city harm reduction service provision project for people who inject drugs in South Africa. They suggest that for many participants, active engagements through regular community advisory group meetings and 'consistent empathic responses' from the project team contributed to 'the (re)generation of a sense of a right to exist, comment on, and shape the world they live in' (Versfeld, Scheibe, Shelly, & Wildschut, 2018, p. 331). The authors point out that these impacts went well beyond the bounded, measurable aims of the public health intervention, speaking to the broader transformative potential of community engagement.

Others have offered more critical perspectives, exploring the ways that engagement work could be top-down and prescriptive; impose a form of governance or a political ideology; serve as 'window dressing' or a way of masking unequal power structures; potentially cause stigma, risk, or other unintended consequences; or produce or amplify experiences of inclusion and exclusion. Oldenhof and Wehrns (2018), for instance, describe how engagement activities for older people in a Dutch healthcare research programme produced new forms of exclusion for frail older people who lacked existing social, cultural, and symbolic capital. Further, despite their relative privilege, those who were included in engagement activities still expressed difficulties with effective participation in the evaluation and design of research. While focusing on a population who would generally be outside the gaze of 'global' health, the article offers important insights for global health research in its detailed analysis of everyday processes of inclusion and exclusion in community engagement work.

Competing arguments for and against community engagement, however, were not understood to be mutually exclusive. The papers and conversations highlighted how the same project could often move between different registers simultaneously. Despite concerns about the ways in which some engagement projects were rolled out, participants mostly agreed that engagement work was still essential to ethical and just global health research. However, they suggested that assessing when and how engagement should be done ought to be weighed against broader, contextual needs, and objectives.

### ***Community engagement and scientific knowledge production***

Several articles in the special issue take up the tension between engagement as a set of practices intended to support and facilitate scientific research and engagement as an approach to transforming the production of scientific knowledge itself. The articles offer quite different accounts of how communities might be engaged, or engage themselves, in the process of scientific research. The paper by Biruk and Trapence (2018), written collaboratively by an American medical anthropologist and a Malawian researcher and activist working in an LGBTI rights organisation, argues for a broadening of the term 'research' itself to encompass activities often partitioned outside of the process of knowledge production through the use of language of 'engagement'. Once research comes to be understood in this more inclusive way, they suggest, it becomes possible to see other forms of risk and potential harm faced by LGBTI-identified volunteers working in this context. Through this perspective, the authors suggest, engagement must be understood

not merely as strategy for improving ethics or enhancing research but as ambivalent process of building trust and suspicion and bringing benefits and harms to communities, many of which are invisible if we think only within normative bounded frames for engagement and ethics (Biruk & Trapence, 2018, p. 341).

Rather than focusing on scientists or practitioners engaging communities in the production or dissemination of research, Datta (2018) explores how 'communities' themselves engage with and interpret



research. Datta describes how patients and their families share and evaluate disease-specific evidence related to experimental stem cell therapies on Facebook, in a sense removing scientists and clinicians from this process. Within these 'online communities', users combine scientific and experiential forms of evidence to produce more 'user-centred' form of science and 'user-to-user' engagement, motivated in part by an innate distrust in particular institutions and individuals involved in the production of scientific knowledge (Datta, 2018).

Drawing on ethnographic research in a series of oncology clinical trials in Cuba, Graber (2018) explores the meaning and practice of 'community engagement' in a political and social context where conventional notions of community engagement in global health research do not apply. Instead of a discrete set of activities designed to establish the legitimacy and efficiency of transnational research projects, the oncology trials implicitly engage communities and ensure that technological innovations are adapted to their needs by bringing cancer therapeutic innovations to primary health care (PHC) professionals, who already work in close relation to patients, relatives, and neighbourhoods (Graber, 2018). Community engagement in this context is thus embedded within the architecture and professional ethos of the PHC system itself. The paper encourages us to think beyond frameworks focused on discrete groups of 'stakeholders', and rather to see the diverse actors involved in global health research as embedded within shifting configurations of citizenship, medical practice, health research, and the nation state.

Reflecting on her own experiences of implementing a menstruation-related critical health project in South Africa, the commentary by Paphatis (2018) asks if engaged research practices can address underlying concerns with epistemic injustice in global health research. While highlighting some important successes of the engaged research process, she points out that many of her colleagues, the institution, and the project funders did not deem the more participatory forms of knowledge generation and dissemination as valid, valuable, or legitimate 'academically' (Paphatis, 2018). Instead, the project's more standard academic outputs, produced *without* active collaboration, remained the key metric of success. As a result, the project failed, in her assessment, to shift underlying power dynamics. To more effectively address epistemic injustice, Paphatis argues, requires researchers to challenge and transform their own ideas, practices, and power relations.

## **Next steps, lessons, and implications for policy and practice**

The initial workshop on which this special issue is based was conceived in response to a shared sense that the work of community engagement is too often an invisible form of labour in academic research – vital for its success, but taken for granted and not deemed as scientific (and thus, in many cases, not published). Relatedly, for many involved in the workshop and special issue, the ability to participate in the conversation, to think critically about the practices of engagement, and to write up and eventually publish their work required ongoing negotiations around institutional politics, competing priorities, and the practical demands on their work. For some participants, practical and political challenges unfortunately meant they were eventually unable to complete or publish their papers.

Despite these challenges, this collection of papers serves to highlight many of the key insights and themes of the broader collective process. The papers also push conversations around engagement and participation beyond their conventional framings to raise more radical questions about knowledge, power, expertise, authority, representation, inclusivity, and ethics. As several of our authors and participants highlighted, it is at times far too easy for radical, transformative politics to be depoliticised through their reification into structured sets of tools and interventions. The papers show that the belief in the emancipatory potential of participation doesn't always sit comfortably with the tools available to do community engagement and emphasise the need for more creative and inclusive modes of engagement.

Drawing on insights from the papers, broader conversations, and our own research in diverse sites of knowledge production in global health, we close by offering an initial set of recommendations for more transformative, inclusive, and meaningful community engagement in global health research:

(1) *Explore the messiness of engagement in the everyday and acknowledge the possibility for engagement to be both 'good' and 'bad'*

As described above, assessments of the impact and importance of community engagement can fall into two categories – either engagement is seen to be empowering, democratising, and deconstructing or it is critiqued for being instrumental, tokenistic, and depoliticising. The papers in this special issue have demonstrated, however, that the risks and benefits of community engagement are unpredictable, contextual, and relational: both ends of this dichotomy can co-exist within a single engagement project. This makes it difficult to standardise engagement and transfer the same models across geographic and social contexts.

This complexity does not mean, however, that those involved in engagement can release themselves from critical interrogation or self-reflexive duty. For engagement to be conducted effectively and ethically, it is vital to ask critical questions about the shifting everyday challenges of implementing engagement in diverse economic, social, political, and institutional contexts. By drawing attention to the importance of everyday experiences as a way of illuminating such problems, engaged and socially conscious research can illuminate the unequal structures of knowledge production and power that continue to dominate global health research. Such critical thinking can produce importance knowledge on the labour that goes into making global health research and engagement happen, and can suggest new, transformative modalities of community engagement in global health.

(2) *Ensure effective engagement across the knowledge production process*

A key issue in the understanding and implementation of engagement in global health is that engagement is too often compartmentalised, or restricted to one part of the research process. Engagement rarely starts at the point of defining issues and shaping questions and extends through publication, dissemination, and policy-making. While we acknowledge that fully participatory research is not necessarily possible in all cases, implementing community engagement at only one moment of the knowledge production process is unlikely to achieve the kinds of emancipatory and transformative goals envisioned by its stronger proponents. The role of community engagement and participation must rather be thought throughout the knowledge production process. In particular, we would encourage research groups and collaborations, funders, and journals to consider how engaged, participatory research might carry through more effectively to academic publishing and authorship practices.

(3) *Develop and support training and skills building for community members and researchers*

To work towards the transformative potential of community engagement and ensure that it causes no harm, it is necessary to develop the capacity of community members, practitioners, policy-makers, and academics to engage and participate in collective, transformative research partnerships. This training should entail not only the transfer of information about existing tools for engagement, but should also aim to encourage new and innovative approaches to knowledge production and implementation and to confront existing injustices and inequalities within the conduct of global health research. By enabling more effective community-led research, such programme could help to illuminate structural problems and provide spaces for young people and other vulnerable and excluded groups to contribute directly and meaningfully towards changing their community.

(4) *Promote transformative partnerships and collaborations*

Much of the language around the importance of community engagement focuses on the values of building partnerships and collaborations. However, a key challenge to reframing North–South collaborations and promoting partnerships within the Global South remains the power imbalance created by the heavy reliance on Northern donors, who are thereby able to powerfully shape the terms of research projects and partnerships. Promoting partnerships without interrogating the terms of such arrangements can be counterproductive, creating new structures that (intentionally or unintentionally) exploit or disempower researchers and community partners in the Global South. Effective partnerships must explicitly acknowledge and aim to redress historically shaped structures of inequality in North–South collaborations. To do so will often require 'unequal' partnerships, where *more* opportunities and

support are offered to some partners than others in order to redress existing inequalities. Further, partnerships should also entail a re-centring of research as a transformative social practice through embedding it in the local context, with leadership by and accountability to people living in the place the research is happening. These new modes of partnership and collaboration must privilege voices that have been historically underrepresented and undervalued and focus centrally on questions of epistemic and social justice.

#### (5) *Create incentive structures within research that encourage and reward genuine engagement*

While an increasing number of funders encourage and fund engagement work and many research institutions have developed formal engagement programmes, there remain few incentives that encourage researchers to prioritise engagement and participatory research in their own professional lives. The current system of academic assessment and reward makes it challenging for many researchers to carry out the necessarily complex and time-consuming work of collaborative, participatory research and community engagement. Funding bodies and academic institutions should be aware of the (perhaps unintentional) roles they can play in discouraging engagement by rewarding particular forms of academic achievement (notably first/sole authorship of peer-reviewed journal articles), while undervaluing other kinds of contribution to knowledge production and dissemination. We would encourage institutional actors to re-evaluate and reframe their systems of assessment and reward to recognise the importance of participatory, collaborative research, and knowledge sharing.

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## Note

1. We use this pairing as a shorthand, with full awareness that, as Franklin (1995) amongst others has argued, 'science' and 'society' are not distinct entities. For our purposes here, 'science' and 'society' are used as analytical concepts that allow us to examine particular processes of knowledge production and the diverse people and groups involved in.

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