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TARGET ARTICLE

Solidarity and Community Engagement in Global Health Research

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ABSTRACT

Community engagement (CE) is gaining prominence in global health research. A number of ethical goals–spanning the instrumental, intrinsic, and transformative–have been ascribed to CE in global health research. This paper draws attention to an additional transformative value that CE is not typically linked to but that seems very relevant: *solidarity*. Both are concerned with building relationships and connecting parties that are distant from one another. This paper first argues that furthering solidarity should be recognized as another ethical goal for CE in global health research. It contends that, over time, CE can build the bases of solidaristic relationships—moral imagination, recognition, understanding, empathy—between researchers and community members. Applying concepts from existing accounts of solidarity, the paper develops preliminary ideas about who should be engaged and how to advance solidarity. The proposed approach is compared to current CE practice in global health research. Finally, the paper briefly considers how solidaristic CE could affect how global health research is performed.

KEYWORDS

Community engagement; ethics; global health; research; solidarity

INTRODUCTION

Community engagement (CE) is gaining prominence in global health research. Here, global health research refers to research addressing health problems worldwide, including those of the most disadvantaged, who live primarily (but not exclusively) in low- and middle-income countries. CE has long been promoted as a core element of participatory health research. Growing consensus about the importance of community representation and participation for ethical research means research institutions, international research ethics guidelines, and funding bodies now promote, or even mandate, CE as an important component of "traditional" non-participatory health research (Council for International Organizations of Medical Sciences 2016: Participants in the Community Engagement & Consent Workshop 2013; Reynolds and Sariola 2018).

Yet many questions remain about the value or contribution of CE in global health research (Lavery 2018). A lack of consensus currently exists regarding CE's ethical goals and approaches for performing it, reflecting high amounts of variability in how CE is defined,

designed and applied in global health research (Reynolds and Sariola 2018; MacQueen et al. 2015). A number of ethical goals—spanning the instrumental, intrinsic, and transformative—have been ascribed to CE in global health research. Engagement activities can be used for purely instrumental goals—to gain community 'buy-in', to increase study enrollment, or to ensure smooth research operations (Reynolds and Sariola 2018; MacQueen et al. 2015). Engagement can secure more intrinsic goals like showing respect or ensuring a sense of inclusion (Participants in the Community Engagement & Consent Workshop 2013). It also has "the potential to redress past harms; compensate for or resolve existing differences in power, privilege, and positionality; allow for marginalized voices and experiences to be represented in the production of scientific knowledge; and ensure that research is relevant and impactful" (Reynolds and Sariola 2018, 257; Versfeld et al. 2018; Gichuru et al. 2018). These transformative goals link CE's value to advancing social justice and knowledge democracy. So far, no consensus exists on whether the ethical goals of CE in global health research

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should span the intrinsic, instrumental and transformative or whether the same ethical goals should apply in different types of global health research (e.g. genomics, clinical, health systems).

In global health research practice, a platform of CE activities is often undertaken for particular projects or as part of research institutions' CE programs. These activities may include communities coming into research institutions (e.g. visits, exhibitions, student placements) and institution staff going out to be with communities (e.g. participatory training, science cafes, drama, school visits). Activities can be continuous (e.g. community advisory boards) or one-off initiatives (e.g. public meetings in communities) (Participants in the Community Engagement & Consent Workshop 2013). Chosen activities reflect overlapping or distinct ethical goals, which can encompass the instrumental, intrinsic, and/or transformative.

What ethical goals are ascribed to CE then have important implications for its practice. How CE in global health research should be performed to achieve *transformative* ethical goals of social justice and knowledge democracy is beginning to be described. Key features of these CE approaches include: engaging with communities marginalized by social institutions and norms, co-design or consultation with communities throughout research projects, and explicitly acknowledging and aiming to redress structural inequalities in North–South research collaborations (Oswald, Gaventa, and Leach 2016; Reynolds and Sariola 2018; Pratt and de Vries 2018; Paphitis 2018). The latter will often "require 'unequal' partnerships, where *more* opportunities and support are offered to some partners than others in order to redress existing inequalities" (Reynolds and Sariola 2018, 265–266).

This paper draws attention to an additional transformative value that CE is not typically linked to but that seems very relevant: *solidarity*. Solidarity is increasingly being explored in bioethics and calls for assisting others regarded as similar (fellow community members, co-nationals, distant others) to meet their needs (Gould 2018). The relationship between CE and solidarity has yet to be investigated in-depth.

The omission is important to address. The concept of solidarity can make a substantial contribution to the moral imagination of bioethics, teaching us to see in new ways (Jennings 2015). The field of bioethics endeavors to shape reasons for obeying norms and rules in an open, diverse society and answers questions such as, Why should I care? Why should I help? Why should I engage with communities in global health research? Solidarity as a value/concept acknowledges our equal vulnerability, self-insufficiency, and interdependence (Tosam et al. 2018). It inherently leads us

to view our actions and the rights, well-being, health, and dignity of others as interconnected (Jennings 2015). The concept of CE in global health research is intuitively related to the value of solidarity. Both are concerned with building relationships and connecting parties that are distant from one another. Global health researchers often live very far away from the communities with whom they perform studies. This encompasses both researchers from high-income countries and researchers from LMICs, who frequently live in cities quite a distance from the host communities of their studies. Solidarity is thus an especially pertinent lens to apply to CE in global health research.

This paper's first aim is to make a case that furthering solidarity should be recognized as another ethical goal for CE in global health research. It begins by introducing several accounts of solidarity that have recently been described in the bioethics literature and highlighting the various bases and features of solidarity they identify. It next argues that a potential contribution of CE in global health research is to develop solidaristic relationships between researchers and community members. The bases of solidarity—moral imagination, recognition, understanding, empathy—can be built by CE over time. Recognizing this ethical goal adds to our understanding of why to perform CE and adds new dimensions to conceptions of CE's transformative potential. Yet for CE to further solidarity, its practice must be oriented in a particular way.

This paper's second aim is to consider what promoting solidarity means for engagement practice in global health research generally. It considers how CE should be undertaken to develop solidaristic relationships, discussing who should be engaged and how to advance that goal, and compares that approach to current CE practice. To illustrate what aspects of the proposed approach might look like in practice, the paper uses examples from the extensive CE experience of two of its authors. These examples are not offered as cases of best practice but rather to provide readers with a clearer idea of what solidaristic CE could look like. The paper's third aim is to briefly consider what solidaristic CE could mean for global health research practice. Finally, objections to the arguments presented in the paper are articulated and defended against.

While the paper discusses the community advisory board (CAB) model frequently, we emphasize that the ideas presented apply to CE generally and that many CE mechanisms exist beyond the CAB model. It is beyond the paper's scope to consider whether the ethical goal of solidarity should apply to CE in all types of global health research or how the account developed here could be specified for different types of studies, but the value of exploring such questions in

the future is recognized. It is also beyond scope to consider whether solidaristic relationships ground particular duties between research institutions, researchers, and community members.

ACCOUNTS OF SOLIDARITY IN BIOETHICS

The concept of solidarity has recently come to greater prominence in the bioethics literature. In 2012 and 2018, the journal *Bioethics* had special issues focused on solidarity. Several accounts of solidarity have been proposed by ethics scholars. In 2012, Barbara Prainsack and Alena Buyx published a substantive piece of work on the concept and application of solidarity within bioethics. Following that work, Bruce Jennings and Angus Dawson, Mbih J. Tosam et al., and Carol Gould have each elaborated accounts of solidarity (Jennings and Dawson 2015; Jennings 2015; Jennings 2018; Tosam et al. 2018; Gould 2014; Gould 2018).

Prainsack and Buyx define solidarity as a practice enacted at the interpersonal, communal, and contractual/legal levels. At the first level, solidarity comprises "manifestations of the willingness to carry costs to assist others with whom a person recognizes sameness or similarity in at least one relevant respect" (2012, 47). Recognition of similarity means seeing one's own potential or actual fate in the fate of another. It can entail seeing shared characteristics or circumstances or, perhaps, even interdependence between one's fate and that of another, though the latter is not explicitly mentioned by Prainsack and Buyx. The second level concerns: "manifestations of a collective commitment to carry costs to assist others who are all linked by means of a shared situation or cause" (2012, 48). Particular solidaristic practices at the individual level become institutionalized and shared by members of a group or community; they solidify into social norms. At the third level, these commitments of carrying costs to assist others are further institutionalized beyond social norms into contractual or legal norms. An example given of 'tier 3 solidarity' is legal arrangements underpinning publicly funded healthcare systems—collecting taxes from a population to fund the services provided to those in need of healthcare. Prainsack and Buyx (2012) hold that 'higher' levels of solidarity are only possible on the basis of sufficiently strong 'lower' levels.

Thus, their account identifies recognition of sameness and empathy[1] as bases of solidarity. However, the recognition of sameness and sentiments such as empathy are not sufficient to satisfy an understanding of solidarity. Prainsack and Buyx's account further requires action. It demands a willingness to carry costs (relatively small to significant) in order to assist others. Solidaristic actions of assistance are regularly but not exclusively directed toward the most vulnerable (Prainsack and Buyx 2012). They aim to relieve suffering and aid the poor but do not seek to overcome structural injustice[2] (Gould 2018).

Bruce Jennings and Angus Dawson conceptualize the practice of solidarity as moving through a trajectory of relational dimensions: standing up for, standing up with, and standing up as (Dawson and Jennings 2012; Jennings and Dawson 2015; Jennings 2015, 2018). Moving through these dimensions means moving in the direction of greater:

- Mutual recognition: recognition of others' moral standing and of interdependence, i.e. viewing our lives and agency as bound together with the rights, well-being, health, and dignity of others (Jennings and Dawson 2015; Jennings 2018)
- Moral imagination: capacity to project oneself imaginatively into the perspective and viewpoint of another person and ability to understand lifeworlds other than one's own (Jennings and Dawson 2015; Jennings 2018)
- Mutual concern: concern for others and their relational human flourishing; minimally this means that one must give others' interests some non-instrumental weight in his/her practical reasoning (Jennings and Dawson 2015; Jennings 2018)
- Awareness of the structural context of others' freedom of action: understanding the interaction between individual agency and the institutional structures within which that agency takes place (Jennings and Dawson 2015; Jennings 2018)
- Respect for others (Jennings and Dawson 2015)
- Bonds of attachment, empathy and identification (Jennings 2015)

Standing up for assumes the stance of advocacy. It involves assisting, defending, and speaking or acting on behalf of another who is considered disadvantaged (Dawson and Jennings 2012; Jennings 2018). It comprises an "abstract moral commitment to support application of general norms to the life situation of the other without fully embracing the lived reality and

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[1]Empathy, or similar sentiments, may motivate solidaristic practices but are not essential. Solidarity can entail such sentiments as preceding an act of giving but does not have to (Prainsack and Buyx 2012).

[2]Problematic dimensions of contemporary life are identified by Prainsack and Buyx but are treated more as background conditions rather than as structural and institutional features against which solidaristic actions with others need to struggle (Gould 2018).

distinct perspectives of the other" (Jennings and Dawson 2015, 37). This kind of solidarity can advocate for improved treatment or benefits for an oppressed or vulnerable group, but it does not necessarily challenge the underlying structural basis for their subordinate social status (Jennings and Dawson 2015; Jennings 2018). *Standing up with* takes another step in the direction of mutual recognition and moral imagination. It requires deeper engagement with the experience and lifeworld of the other, going beyond recognition of shared humanity to relating to other people in the specificity of their values and identities (Jennings 2015, 2018). Mutuality grows, generating recognition of a shared situation, interdependence, and mutual struggle against injustice. *Standing up as* entails an even stronger degree of identification between agents and recipients of solidaristic support and a deeper understanding of one another's lived experience perceived through the other's distinctive cultural and personal lens (Jennings and Dawson 2015). Solidaristic support entails public action to improve or correct past or present disadvantage or injustice (Dawson and Jennings 2012). Achieving significant gains in health and well-being happens through institutional restructuring (Jennings and Dawson 2015).

Tosam et al. (2018) present an African approach to solidarity rooted in the philosophy of Ubuntu and a conception of persons as interdependent beings. They define solidarity as a reciprocal relationship in which community members acknowledge their similarities, shared vulnerability, and interdependence and stand up for and with others, with the aim of ensuring mutual flourishing, preventing suffering, and reducing health disparities. "Solidarity allows us to see that your condition is actually inextricably related to my condition. This is not merely because your condition might be a threat to me (due, for example, to contagion) but because our health states are interdependent in a far richer way" (Tosam et al. 2018, 247). For example, policies adopted in one country can affect the health of distantly situated others. Cultivating moral imagination is essential to generating reciprocal relationships. It builds individuals' capacity to identify, commiserate and share, which, in turn, fosters the mutual respect, understanding, recognition of shared vulnerability, and empathy required for solidaristic relationships.

Gould (2018) draws on traditional meanings of social movement solidarity to propose that it is centrally a process aimed at overcoming forms of structural injustice (domination and oppression). She argues that dispositions of empathy and deference to the needs and goals of others are important components of solidarity. Ideally, solidarity should embody democratic modes of decision making among participants (Gould 2018).

According to Gould, solidarity also entails a critical analysis of social context and concretely taking action. "Effective action requires understanding the economic and social factors that condition people's life chances and their health … Recognizing how institutions and practices function in ways that assign differential power to various groups in society is essential if justice is to be constructed through solidaristic action" (Gould 2018, 7). That action is generally aimed at alleviating structural injustices but may also include networking to help alleviate suffering.

Gould further distinguishes between two forms of solidarity: networking and unitary. *Networking solidarity* captures relations of support between distantly situated others. It can apply within, as well as across, borders, and democratic decision-making should be characterized by distantly situated others having substantial input into decision-making (Gould 2014, 2018). *Unitary solidarity* captures relations of support within a single group or community. The equal status of group members requires their having an equal say in determining the group's goals and how those goals are carried out. They have equal rights to co-determine common activities for overcoming domination and exploitation (Gould 2014, 2018). Of the two forms of solidarity, networking solidarity may pertain most frequently to the global health research context, which typically involves building relationships between external researchers (foreign or national) with community members.

Ultimately, accounts of solidarity from bioethics identify several bases for solidaristic relationships and features of such relationships. Bases for solidaristic relationships include moral imagination, recognition of shared moral standing and interdependence, empathy, understanding, and respect. Features of solidaristic relationships include deference, deliberative decision-making, social critique, and action. At present, there is no consensus in bioethics about what bases and features are essential to a conception of solidarity. However, areas of convergence amongst accounts may create a stronger case for certain bases and features being important or necessary aspects. The advantage of adopting a convergence approach is that it often leads to solutions that are less likely to be contentious when compared to those developed from a single theory or account (Bailey et al. 2015; Krubiner and Merritt 2017).

SOLIDARITY AS AN ETHICAL GOAL OF CE

Returning to the question, why should researchers engage with communities in global health research, we will argue that furthering solidary is one answer. It comprises an ethical goal of CE in global health research. Accounts of solidarity identify cognitive and motivational bases that give rise to solidaristic relationships: moral imagination, mutual recognition, empathy, understanding, and mutual respect. These bases are constructed through interactions between actors over time; they are established in practice (Gould 2018, 2014). We contend that the bases of solidaristic relationships develop (or can be developed) through CE activities in global health research. CE brings researchers and community members together. It creates structures and mechanisms that establish regular interactions between them, often over lengthy periods. The most prominent mechanism for CE in global health research has been the CAB model, though it is by no means the only approach used (Marsh et al. 2008; Tindana et al. 2007; Participants in the Community Engagement & Consent Workshop 2013). CABs can be set up as part of single projects, and they are also created as part of research institutions wider CE strategies (Marsh et al. 2008).

To show how interactions through CE are likely sufficient to generate solidaristic relationships, the example of the Shoklo Malaria Research Unit (SMRU) Tak Province Border Community Ethics Advisory Board (T-CAB) (2009-present) is presented and discussed. SMRU conducts research with and provides healthcare to refugees, migrant workers, displaced people, and day migrants on the Thai-Myanmar border. The T-CAB consists of roughly twelve to fifteen members (six women and seven men in 2019) and meets every four to six weeks (Kulpijit and Khirikoekkong 2019). Meetings include both formal discussions and presentations and informal interactions over lunches and tea breaks. In addition to these regular meetings, there have been workshops and training sessions that span over a weekend. T-CAB members have included teachers, pastors, social workers, farmers, village chairmen, administrative assistants at local clinics, taxi drivers, cooks, and interpreters. The vast majority are Karen, though other ethnic groups are represented such as the Kachin, Mon, and Burmese (Pratt et al. 2015). Some of the current T-CAB members have served for more than 10 years. At any one time, two researchers serve as T-CAB coordinators; they are present for T-CAB meetings. Other SMRU researchers are also present to share their proposed research projects and the results of completed projects with T-CAB members (Pratt et al. 2015). Thus, the T-CAB model has brought the T-CAB coordinators into very frequent contact with fifteen community members (with some changes in their composition over time) and other SMRU researchers into regular contact with them over a ten-year period. SMRU researchers are largely from high-income countries or Myanmar nationals. The latter are typically not Karen.

Consistent and sustained interactions as part of CE afford researchers and community members the opportunity to build their moral imagination in regards to one another. Over time, they can learn more and more about each other's cultures, views, and daily lives and circumstances. SMRU researchers, for instance, would have learned more about lived reality in Thai-Myanmar border zones and the cultures of the Karen, Kachin, Mon, and Burmese. T-CAB members would have learned more about what T-CAB coordinators and SMRU researchers do as healthcare providers and researchers and about their personal backgrounds. Such experiences make it easier for researchers and community members to understand one another's situations and to see similarities and connections between one another's circumstances. They foster growth in both parties' capacity to project themselves imaginatively into the other's perspective and to see connections between their needs and circumstances (Jennings 2018; Gould 2014).

Over time, the bases of solidaristic relationships can emerge and get stronger through CE interactions in global health research. Early in an engagement relationship, the bases of understanding, recognition, and empathy might develop to the extent that they comprise a sufficient foundation for global health researchers to 'stand for' community members. Gradually, as interactions and relationships deepen, solidaristic relationships where global health researchers 'stand with' community members could be established. Perhaps, even relationships where researchers 'stand as' community members might develop. Where researchers are from the community, this possibly would not demand much or take too long to develop. However, it is probably more common for researchers to grow up outside the communities with whom they work. For researchers from outside a given community, standing as community members would likely demand researchers embed themselves and their work within the community for a very lengthy amount of time (e.g. 25 or more years). Such embedded models of global health research are less common compared

to models where researchers travel in and out of host communities (Costello and Zumla 2000).

IMPLICATIONS FOR CE PRACTICE

Assuming furthering solidarity comprises an ethical goal of CE in at least some forms of global health research, the next matter to explore is how such a goal would orient CE practice. We will argue that it means taking a certain approach to CE in terms of who is engaged and how engagement happens. We will compare that approach to current CE practice in global health research. As previously noted, CE activities can be performed as part of particular projects and/or institutional CE programs. The proposed approach can also be applied to CE at the project or institutional level, though it is beyond the scope of the paper to tease out the specific implications of the approach for each level.

Who is the Focus of Engagement?

To further the value of solidarity, who is engaged in global health research should reflect between whom solidarity is to be established. That means engagement should focus on groups, communities, or populations who experience marginalization, oppression, and suffering; they are the focus of solidaristic action under all four accounts in the bioethics literature. Engagement should *also* focus on researchers because it is about both parties learning about each other and is a two-way process. In the authors' experience, CE practice can frequently focus on community members' engagement with research projects or institutions, while having a lesser or little focus on researchers' engagement with host communities.

If CE should focus on connecting researchers and marginalized communities, it raises the questions of who within the community researchers should engage. Who should represent the community? Who should speak for groups considered to be disadvantaged or marginalized is a key issue explored in political philosophy. A distinction is raised between the representation of ideas and the representation of experience (Phillips 1993; Young 2000). The former means that representatives do not have to share the characteristics of those they are representing as long as they represent their beliefs, views, and preferences. It is a common form of representation in politics in modern democracies. The latter means that representatives mirror the characteristics of those they are representing and share their lived experiences (Phillips 1993).

Similarly, ethicists distinguish between selecting individuals to engage who can speak on behalf of a community and selecting those who are typical members of that community (Kamuya et al. 2013). Individuals who speak on behalf of a particular community are often charismatic and well-known such as leaders or religious elders. Individuals who are typical are often identified based on their characteristics—age, gender, religion, geographic location, or education level—and collectively match the demographics of the community (Kamuya et al. 2013).

The value of solidarity may support engaging with individuals who are representative of community members' experiences. Such representatives will often be best able to give insights into the daily lives and circumstances of community members and thus help researchers better understand the community's situation and develop their moral imagination of what it's like to live in the community. Kamuya et al. (2013, 12) affirm that typical community members "may have greater contact with and awareness of everyday issues and concerns in their communities, including the most vulnerable and marginalized members."

In much CE practice, however, CAB members are selected because they can advise researchers on behalf of their communities as opposed to because they are typical of their communities. This choice can be openly stated or indirectly supported through, for instance, selection criteria for representatives to be literate (Kamuya et al. 2013). In T-CAB, for example, its members are largely community leaders and key workers. They are better off members of a marginalized community (e.g. literate and able to leave work to attend meetings), diverse in certain ways but admittedly not representative of the diversity within their community (Cheah et al. 2010).[3]

Yet there are examples of CE practice where community representatives are sought based on lived experience. At the Kilifi site of the Kenyan Medical Research Institute (KEMRI), a parastatal organization under the Ministry of Health, a network of community representatives has been established who are meant to be 'typical' in their characteristics and place

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[3]Representativeness was "a common concern in the establishment of CABs and reflected in T-CAB experience. The term 'community representative' was heavily discussed among the SMRU working group and the T-CAB members, and it was concluded that it would not have been feasible to have members who were authentically and truly representative of their community. Authenticity implies fair, balanced and accurate representation of the many and varied constituents within a community. In addition, the T-CAB members were not elected representatives, but self-appointed. The T-CAB members are fully aware of this and they themselves agree that they are not true community representatives." (Cheah et al. 2010)

of residence. Data has been collected on their characteristics and compared to those of the community to document how typical they are (Kamuya et al. 2013). Although the data show KEMRI community representatives are well spread out geographically and mirror the community in relation to gender and religion, the most vulnerable and marginalized are underrepresented. Their inclusion remains a challenge that KEMRI researchers are actively seeking to address (Kamuya et al. 2013). Such efforts to engage with the worst-off within Kilifi and gain the full picture of the community's needs and experiences are consistent with accounts of solidarity.

How Should Engagement Happen?

The value of solidarity supports sustained CE approaches that foster the bases of solidaristic relationships and that express features of solidaristic relationships. What this could mean for CE practice in global health research is explored by taking bases and features in the aforementioned accounts of solidarity as a starting point. Specifically, we consider what cultivating bases of solidarity, deference, transnational deliberation, and social critique might entail in CE practice. The aim is to provide an initial picture of what the value of solidarity might require for CE approaches, while recognizing no consensus exists on an account of solidarity in bioethics. Each of the four accounts do not identify all the same features of solidarity, so individually they would not demand everything proposed below. Deference and deliberation, for example, are primarily discussed in Gould's account.

Cultivate Bases of Solidarity

Cultivating bases of solidarity amongst community members and researchers means CE practice ideally involves activities that foster moral imagination, recognition of interdependence, empathy, and greater understanding of one another. Researchers and community representatives should be trained in reflexivity and encouraged to consider each other's situations and the connections/similarities between them. CE should also consist of a sustained series of interactions, especially informal ones, where researchers and community representatives are more likely to share personal information and contextual knowledge with each other. At Kilifi, for example, researcher staff participate in community events (e.g. weddings and funerals) (Participants in the Community Engagement & Consent Workshop 2013). During informal interactions, Novelli (2006) recommends researchers start by

listening to those marginalized by social institutions and norms, trying to understand their struggles, and seeking out alternative knowledge systems beyond modern science.

Beyond informal interactions, embeddedness experiences on both sides are valuable. Embeddedness experiences could consist of community representatives spending time at research institutes; community members working as researchers, CE coordinators, or CE staff; and researchers spending time in the community. They could, for example, join a community group/activity or work with community organizations and contribute their knowledge and skills to further the organization's operations (Novelli 2006). Beyond short-term experiences, greater embeddedness could be achieved by researchers living in a community over the long-term or by sustained schools engagement programs (see https://sep.kemri-wellcome.org/about). Embeddedness promotes deep engagement with the experiences and lifeworld of the other. By gaining understanding of the lived reality and perspectives of one another, individuals are better able to project themselves imaginatively into the viewpoints of the other and to see connections between them (Jennings 2018).

Such an approach would contrast with approaches that focus CE primarily on the business of research, e.g. getting community input on research protocols, ethics applications, etc. The CAB model, for example, often consists of meetings between researchers and community representatives about proposed research projects. While informal interactions happen through CABs, they are not necessarily seen as a core CE activity. Embeddedness experiences also are not a common feature of the CAB model, aside from perhaps short-term experiences designed to enhance CAB members' understanding of research. Embeddedness experiences for researchers are even less common, with the exception of researchers who are from the communities in question.

Express Deference

Deference means that those affected have a major role in specifying what their needs are and how they want to be assisted. Efforts are made to hear from them systematically such as on governance boards (Gould 2018). In the context of global health research, deference might then be expressed by giving community members a substantial role in determining what research is done, specifying the needs and priorities upon which to focus research projects. It could further entail their having a say throughout research projects

and being systematically included on the governance bodies of research projects, consortia, or institutions.

However, this would not necessarily mean community representatives have equal decision-making power to researchers. Gould (2014, 2018) distinguishes between two criteria for determining the scope of democratization: "common activities" and "being affected." The former applies in unitary solidarity and the latter in networking solidarity. When individuals undertake a common activity, they have rights of *equal participation*. They have the right to co-determine the direction and course of the joint activity. When people at a distance are impacted by the decisions of institutions, they have rights of *democratic input* into institutional policies and decisions. Affected peoples have the right to give "substantial" input or "have a say" but not "fully equal rights of robust participation" (Gould 2014, 89).

We would argue that, in global health research, community members are often not partners in the research activity, but they are affected by its conduct and the conduct of external, national, and local research institutions. Their opportunities to fulfill their basic human rights are affected. (Community organizations, however, are often partners in global health research and should be afforded equal participation. Where community members are employed as researchers, they would also have equal rights of participation.) Whether community members receive preventative care and treatment for their illnesses in part depends on what public health interventions and medicines have been developed and whether health systems can deliver them efficiently and affordably. This, in turn, depends on what research has been prioritized and performed. They thus have rights of democratic input in relation to what research is done with their community and how it is performed.[4] This could apply to individual projects and more broadly to external research institutions' policies for global health research and national and local research institutions' research policies.

The right of democratic input entails *equality in choosing representatives*, *having regular representatives*, and *differential participation* (Gould 2014, 90 and 240). What each could demand of CE is briefly considered. First, in relation to choosing community representatives, several models exist in global health research: election by communities, selection by community leaders, and selection by researchers. For example, at KEMRI, a number of community representative candidates are first nominated by local communities. Then around 200 representatives are elected by local communities (groups or villages) at a series of fifteen public meetings across the geographic area served by the Sub-County Hospital, with elections repeated every three years (Kamuya et al. 2013). The right of democratic input would favor these types of election processes because they mean community members get a say in selecting representatives, though the KEMRI model is my no means the only election approach that can be used. The choice is not made for them by others (leaders, researchers). This is also consistent with data from KEMRI, which suggests the public election approach to selection is more acceptable to community members than representatives being identified by community leaders or community-based organizations. All community representatives elected through votes in public meetings were accepted by the public. In contrast, three community representatives nominated by chiefs were rejected on the basis of non-residency and lack of transparency and later replaced with others directly elected by the community (Kamuya et al. 2013).

Having regular representatives supports having formal CE mechanisms such as community representatives on governance boards, steering committees, and/or data access committees. It does not support having ad-hoc CE approaches alone.

Differential participation means affected peoples' participation should correspond to how affected they are by an institution and its policies and activities. Their form of input could vary from consultation to representation in decision-making processes (Gould 2014). This suggests that, in global health research, some community representatives' level of participation should be higher than others and should extend beyond consultation. Those within communities who are more affected by particular research projects will often be identifiable because, in practice, certain aspects of global health research like the broad research topic are typically already set before engagement commences (Pratt and de Vries 2018). While this may not be ideal, as it is inconsistent with the right to deference, it will likely aid in identifying which community representatives should be engaged more deeply in the context of particular research projects. As an example, in a study focusing on maternal and child health, women of childbearing age and men in relationships with them are more affected by the study than older women and single men. Differential

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[4]Where a decision is made with community input to use participatory methods, community members would then likely meet the "common activities" criterion and rights of equal participation should be afforded to them for the remainder of the research project.

participation would then support community representatives in the former two categories being represented in decision-making about what the particular project looks at and how it is performed, whereas it may be sufficient to consult community representatives in the latter two categories.

By contrast, community members are not generally part of global health research agenda setting in current CE practice. They do not typically give input and specify the needs and priorities upon which to focus research projects (Pratt and de Vries 2018). Where community members are engaged in other aspects of global health research projects, their participation is often consultative (Pratt and de Vries 2018). However, some examples exist where community members have been represented in decision-making processes for research institutions' ethics policies (O'Doherty et al. 2012; Marsh et al. 2013; Njue et al 2014). Choosing community representatives via elections is also uncommon (Kamuya et al. 2013), though having regular representatives is increasing, e.g. through the CAB model.

Undertake Deliberative Dialog

Transnational deliberative dialog is a key feature of networking solidarity. It ensures that those affected can provide input into decision-making by the institutions that affect their lives (Gould 2014). In the global health research context, researchers and community members should then undertake deliberative dialogs as part of CE to determine what research is done and how it is done.

Yet rationalist models of deliberative democratic processes have limitations in the transnational context, where historical and current oppressive conditions enter deliberative spaces. Two factors that can prevent cross-border deliberative processes from being effective and exclude participation by actors from LMICs are: (1) systematic misunderstandings due to language and cultural differences and (2) power disparities (Gould 2014). The terms used in discussions will frequently have different meanings for participants from different countries (or even from different parts of the same country), which will likely lead to misunderstandings, misinterpretations, and accentuate disagreements. Participants may lack awareness of the one-sidedness of their interpretation of certain terms and that multiple interpretations exist (Gould 2014). Power disparities pervade North-South relationships. They also pervade relationships within nations and communities, where social norms don't permit open discourses and/or privilege certain voices over others.

They would pervade foreign researchers' relationships with national researchers and community members as well as national researchers' relationships with community members and relationships amongst community members.

Beyond achieving norms of deliberative decision-making[5], deliberations undertaken as part of CE practice should also recognize contextually-relevant factors that prevent participation in transnational deliberative dialogs. As such, there is a need to assess what power disparities exist between those involved in the deliberation and to develop strategies for reducing the impact of those power disparities. Additionally, contested terms and their range of different meanings and uses should be highlighted at the start of and during deliberations by facilitators in order to increase participants' awareness of their various meanings and hopefully reduce potential disagreements due to misunderstandings.

In contrast, "much CE practice seems to focus less on using deliberation to make project decisions and more on gathering information on potential positive and negative aspects of research through nondeliberative processes such as surveys, key informant interviews and seminars" (Pratt and de Vries 2018, 7). Deliberative CE processes have, however, been used to inform institutional ethics policies on biobanking and benefit sharing (O'Doherty et al. 2012; Marsh et al. 2013; Njue et al 2014). At Kilifi, for example, these processes were transnational, involving international researchers, national researchers, local researchers, CE staff, and community members. Strategies to mitigate power disparities included recruiting CE staff from the local community and bringing small groups together (e.g. younger women, village leaders) (Njue et al. 2014).

Undertake a Social Critique

Dawson and Jennings propose that, as solidaristic relationships develop, the more those involved learn about how the other's health and health-related choices relate to the context in which they live and the more they find structural drivers (norms, networks and institutions) are key determinants of health. Solidarity "recalls the structural context of individual freedom of action." Gould (2014) further contends solidarity *requires* becoming socially critical to the ways of exploitation and colonialism and

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[5]Norms of deliberative decision-making include equal opportunities for being heard, especially for marginalised individuals or groups; using reasoning to achieve agreements; responsiveness to the positions and needs of others; and freedom from coercion (Gould 2014; Gutmann and Thompson 2004; Young 2000).

understanding a given context in terms of power differences and inequalities that are generated by political and economic institutions. It entails self-reflexivity about the effects of the structural context in which you operate (Gould 2018).

In the global health research context, this feature of solidarity implies building an understanding of the systemic factors that generate hardships in community members' daily lives and limit their ability to be healthy. Researchers should strive to develop this understanding through their CE interactions and some CE interactions should be purposefully structured to help facilitate its development. Additionally, researchers should seek to gain community representatives and members' insights about the ways legacies of colonialism and exploitation have manifested in global health research in the given community or country. These legacies could be expressed through high-income country researchers' and funders' domination of agenda setting, a lack of benefits accruing to the community post-study, or in other ways (Jentsch and Pilley 2003; Emanuel 2008). It would then be important to develop strategies to minimize identified structural inequalities from manifesting in the current project or institutional practices to the extent researchers and community members have the power to do so.

IMPLICATIONS FOR GLOBAL HEALTH RESEARCH PRACTICE

Taking on such an approach to CE practice and building solidaristic relationships between researchers and community members may have an additional impact on global health research. Over time, solidaristic relationships may generate solidaristic actions on the part of researchers. Two types of action are identified by solidarity accounts: (1) to prevent or alleviate suffering by the vulnerable (Prainsack and Buyx 2012) and (2) to combat structural injustices (oppression, domination) identified through social critique and dialog (Gould 2014, 2018). In global health research, the solidaristic relationships established through CE can motivate researchers to conduct research aimed at generating new knowledge to help alleviate suffering of those considered disadvantaged or to combat structural and institutional injustices. Such research would be highly socially valuable under certain definitions (see Barsdorf and Millum 2017).

An idea of what this type of research could entail is provided by Novelli (2006), who explores what research as solidarity looks like through reflections on his own research practice. He argues that research as solidarity can mean performing studies with community or grassroots organizations while embedding oneself in them over the long-term. In his own research, Novelli's:

> focus changed markedly during this solidarity process and switched to a 4-year ethnographic study of Sintraemcali, a public service union in Colombia that since 1994 had developed a multi-scalar and multi-sectoral strategy to prevent the privatisation of the public services of water, electricity and telecommunications in Colombia's second city of Cali. The participatory research approach necessitated a sustained process of working full time for the union in its human rights department … Working alongside grassroots activists I was able not only to carry out practices of value to my own research process, but also help with the necessary tasks of the movement. In Colombia I worked in a variety of roles as a translator, as a delegation organiser, as an international contact point, which served to make the researcher/research subject relationship far more reciprocal. (Novelli 2006, 278)

In this example, Novelli integrated his research into processes of popular resistance and became part of a social movement. The line between academic and activist was blurred. According to Novelli (2006, 276), "the critical 'scholar' or 'intellectual' does not necessarily reside in the university campus, but also in a range of policy, social movement and NGO environments." Standing up with or as a particular community or group is expressed through this form of research. Its conduct may emerge organically in global health research as solidarity relationships between researchers and community members deepen over time through sustained CE. Other forms of research as solidarity may also emerge.

POSSIBLE OBJECTIONS

Several objections can be anticipated to the arguments presented in favor of adopting solidarity as an ethical goal for CE in global health research and to the preliminary ideas about what doing so means for CE practice. First, just because CE can further solidarity does not mean it should or has to do so. This is potentially true and requires further exploration that is beyond the scope of the paper. This paper identifies an additional or complementary role for CE to assume that it seems well equipped to take on and makes a connection, that is not discussed (to the authors' knowledge) in the bioethics literature, between CE and the value of solidarity. But the paper does not establish a philosophical justification for why CE in

global health research should advance value of solidarity. Future work could seek to do so perhaps using a moral theory of solidarity like Avery Kolers' (2016) or cosmopolitan accounts like Craig Calhoun's (2002) or Gould's.

Second, an objection could be raised that transformative ethical goals do not apply to all types of CE in all types of global health research and, thus, solidarity is not an appropriate ethical goal for many CE initiatives. This is also potentially true and requires more consideration. However, as an initial response, attention is drawn to the work of ethics scholars and policymakers who argue that global health research should help reduce global health inequities (CHRD 1990; Benatar and Singer 2000, 2010; London 2005; WHO Task Force on Research Priorities for Equity in Health & the WHO Equity Team 2005). CE is an ethically essential component of global health research. If global health research should advance transformative values like social justice, then this should be reflected in its CE goals and approach. Additionally, even if we assume all global health research should have transformative CE goals, this does not necessarily mean that CE approaches should be the same for different types of global health research. While the paper develops a general account of solidarity for CE in global health research, it may need to be further specified for various types of studies. What advancing solidarity should look like for CE in biomedical research studies may look somewhat different to what it should look like for CE in public health research studies. CE may also look different where research is conducted alongside clinical care.

Third, it might be argued that if CE must focus on marginalized communities, then global health research must as well. Not all global health research should or can do that exclusively, so making it a requirement of CE could potentially obstruct lots of projects from going forward. In response to this concern, it is affirmed that a solidarity approach to CE does call for connecting researchers with marginalized groups and communities. However, this does not mean all global health research must be performed with such groups and communities. Where global health research is conducted with populations that are not considered to be marginalized within host countries, it is important that CE efforts access the marginalized within the research population as opposed to engaging mainly with better-off segments of the research population. This is something that the KEMRI community representatives network is currently trying to do and

learnings from their example can perhaps be adapted by other research teams.

As the KEMRI example demonstrates, ensuring that the marginalized are amongst those endorsed as community representatives can be difficult. Another potential objection is thus that a solidarity approach to CE asks for substantial changes or additions to CE practice that may not be feasible. Although a range of CE activities are often undertaken as part of global health research projects or institutional CE programs, taking a solidarity approach may entail substantially broadening that set of activities for some projects or programs. Certain aspects of a solidarity approach to CE may also be especially difficult to implement in some contexts. For instance, it may not be feasible to engage marginalized communities without significant time, resources, relationship-building, and capacity development. It may also not be feasible to undertake elections of community representatives. In the T-CAB example, no mechanism existed for formal elections and there were no community structures for the border population (Cheah et al. 2010).

In such cases, there are nonetheless a number of ways to take a solidarity approach to CE forward. One way is to adopt an incremental approach by building on what CE structures exist and moving toward greater alignment with a solidarity approach to CE over the course of a project. Where certain aspects of a solidarity approach are difficult to achieve, researchers and CE staff can look to examples where those aspects have been achieved by other research teams or institutions and adapt them to their own context. In some contexts, however, it may not be possible to achieve certain features of the proposed approach due to structural constraints that cannot be easily altered. What these features and contexts are requires further investigation. Additionally, where a mix of CE activities are undertaken, the number of activities supporting other ethical goals could be reduced to make room for adding several CE activities that promote solidarity. Doing so would achieve a better balance of CE activities across a range of goals. CE activities to promote solidarity could be specifically selected because they promote other ethical goals as well. That way removing certain CE activities might not have a huge impact on achieving other ethical goals.

A related objection is that building researchers' and community members' understanding of each other's lived experience and perspectives takes time and is not essential to getting research done. If required, it will slow research down and drain resources away from research activities. There is inherent tension

between carrying out scientific studies and strengthening solidarity. In response, it is noted that building solidaristic relationships can make for better research—namely, research that is locally grounded and responsive to local issues related to structural injustice. However, the amount of time and resources allocated to CE activities aimed at building moral imagination and recognition should be balanced against other research activities. A solidarity approach would likely support a greater amount of resources being allocated to the former than is typical in current practice, but it would not call for such substantial support that other essential research activities would be stymied. Additionally, funders have responsibilities to ensure that research budgets can support all activities necessary for the ethical conduct of global health research, including CE.

Finally, tensions have been identified to exist amongst CE goals (Participants in the Community Engagement & Consent Workshop 2013). It is possible that the ethical goal of solidarity may conflict with other CE goals and the approaches to CE that they support. For example, it might be suggested that the ethical goal of building project legitimacy would seem to favor specifically engaging with key opinion leaders and influencers rather than typical community members. However, King et al. (2014) state that a project's legitimacy is built largely through deliberation and discussion with *anyone* whose interests stand to be affected by the proposed research. Legitimacy emerges from deliberative processes through which disagreement is acknowledged and addressed (King et al. 2014), which is consistent with a solidarity approach to CE.

Other ethical goals of CE like respect and social justice also call for aspects of CE practice that align with a solidarity approach. According to King et al. (2014) "researchers respect stakeholders by first listening to them to understand their perspectives about the research and how it may affect their interests, and then acting in ways that express that recognition … Given the historical legacy of colonialism and exploitation in many host countries, where the interests of the population were systematically disregarded, listening to, acknowledging, and being responsive to stakeholders acquires great significance." These aspects of demonstrating respect are similar to aspects of a solidarity approach related to cultivating recognition. Accounts of health justice support CE models in global health research with the following features: engaging marginalized groups and communities, ensuring they are represented in agenda-setting and throughout

the research process, and undertaking deliberations structured to minimize the impact of power disparities (Pratt and de Vries 2018). Perhaps this alignment is not entirely unexpected given the close relationship between the values of justice and solidarity. Overall, while this brief assessment suggests the ethical goal of solidarity may not conflict with some of the other ethical goals of CE, more work is needed to explore the matter.

CONCLUSIONS

This paper has taken a first step in exploring the relationship between CE in global health research and solidarity. It argued that CE can serve to further the ethical value of solidarity. Another ethical goal for CE in global health research should thus be to develop solidaristic relationships between community members and researchers.

Applying concepts from four accounts of solidarity in the bioethics literature, the paper then developed preliminary ideas about how CE practice should be oriented to further solidarity. A solidarity approach to CE practice would conceive of CE as a sustained two-way process, focusing on engaging communities in research *and* engaging researchers with the community. Typical community members comprising the diversity of their communities, including those that experience marginalization, oppression, and suffering, would be engaged as representatives. They would be selected or endorsed by the rest of their community rather than solely by community leaders or researchers. Community representatives would have a say in determining what research is done and how it is conducted at the project and/or institutional policy level. Their level of participation could range from consultation to involvement in decision-making. Those more affected by specific research projects or policies would have a deeper level of involvement. Community representatives would be engaged via deliberative processes structured to attend to power disparities and contested terms. Much current CE practice does not have these features.

A solidarity approach to CE would also require activities to build researchers' and community members' understanding of one another and the context in which the other lives. These activities could include informal social activities or embeddedness experiences. As part of these activities, there would be particular emphasis on community members helping researchers better understand the structural injustices that affect community members' health and that have shaped

their past experiences with research. Much current CE practice does not give great prominence to such types of activities. Finally, the paper suggests that, over time, the development of solidaristic relationships between researchers and community members through CE may foment the conduct of solidaristic action: namely, research aimed at generating knowledge to address the structural injustices faced by a given community.

Ultimately, it is hoped that this paper starts a dialog amongst ethicists, researchers, community representatives, CAB members, funders and others about whether CE should advance solidarity and, if so, how CE should be undertaken to do so. The concepts of CE and solidarity are intuitively related and the value of solidarity comprises a rich lens that can inform approaches to CE practice. There are many questions left to explore in relation to this topic. For example, why should solidarity be an ethical goal of CE in global health research? Should and how can the general account of how to advance solidarity be specified for CE in different types of global health research? What can other accounts of solidarity, including those from disciplines outside bioethics, tell us about how to undertake CE? Do various existing CE approaches and activities in global health research generate the bases of solidarity over time and which are the best at doing so? What tensions exist between carrying out scientific research and strengthening solidarity and how can they be addressed? How should researchers achieve political legitimacy to 'enter' communities? How should political challenges to efforts to stand up for and with the most vulnerable groups in a given community be navigated? Future conceptual and empirical bioethics research can help answer these and other questions on the topic.

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REFERENCES

Bailey, T. C., M. W. Merritt, and F. Tediosi. 2015. Investing in justice: Ethics, evidence, and the eradication investment cases for lymphatic filariasis and onchocerciasis. *American Journal of Public Health* 105(4): 629–636.

Barsdorf, N., and J. Millum. 2017. The social value of health research and the worst-off. *Bioethics* 31(2): 105–115.

Benatar, S. R., and P. A. Singer. 2000. A new look at international research ethics. *British Medical Journal* (Clinical Research ed.) 321(7264): 824–826.

Benatar, S. R., and P. A. Singer. 2010. Responsibilities in international research: A new look revisited. *Journal of Medical Ethics* 36(4): 194–197.

Calhoun, C. 2002. Imagining solidarity: Cosmopolitanism, constitutional patriotism, and the public sphere. *Public Culture* 14(1): 147–171.

Cheah, P. Y., K. M. Lwin, L. Phaiphun, et al. 2010. Community engagement on the Thai-Burmese border: Rationale, experience and lessons learnt. *International Health* 2(2): 123–129.

Costello, A., and A. Zumla. 2000. Moving to research partnerships in developing countries. *British Medical Journal* 321(7264): 827–829.

Council for International Organizations of Medical Sciences. 2016. *International ethical guidelines for health-related research involving humans*. Geneva, Switzerland: CIOMS.

Dawson, A., and B. Jennings. 2012. The place of solidarity in public health ethics. *Public Health Reviews* 34(1): 65–79.

Emanuel, E. J. 2008. Benefits to host countries. In *The Oxford textbook of clinical research ethics*, ed. E. J. Emanuel, R. Crouch, C. Grady, R. K. Lie, F. Miller, and D. Wendler. New York: Oxford University Press.

Gichuru, E., B. Kombo, N. Mumba, S. Sariola, E. J. Sanders, and E. M. van der Elst. 2018. Engaging religious leaders to support HIV prevention and care for gays, bisexual men, and other men who have sex with men in coastal Kenya. *Critical Public Health* 28(3): 294–305.

Gould, C. C. 2014. *Interactive democracy: The social roots of global justice*. Cambridge: Cambridge University Press.

Gould, C. C. 2018. Solidarity and the problem of structural injustice in healthcare. *Bioethics* 32(9): 541–552.

Gutmann, A., and D. Thompson. 2004. *Why deliberative democracy?* Princeton: Princeton University Press.

Jennings, B. 2015. Relational liberty revisited: Membership, solidarity and a public health ethics of place. *Public Health Ethics* 8(1): 7–17.

Jennings, B. 2018. Solidarity and care as relational practices. *Bioethics* 32(9): 553–561.

Jennings, B., and A. Dawson. 2015. Solidarity in the moral imagination of bioethics. *The Hastings Center Report* 45(5): 31–38.

Jentsch, B., and C. Pilley. 2003. Research relationships between the South and the North: Cinderella and the ugly sisters? *Social Science and Medicine* 57(10): 1957–1967.

Kamuya, D., V. Marsh, F. K. Kombe, P. W. Geissler, and S. C. Molyneux. 2013. Engaging communities to strengthen research ethics in low-income settings: Selection and perceptions of members of a network of representatives in coastal Kenya. *Developing World Bioethics* 13(1): 10–20.

King, K. F., P. Kolopack, M. Merritt, and J. V. Lavery. 2014. Community engagement and the human infrastructure of global health research. *BMC Medical Ethics* 15: 84.

Kolers, A. 2016. *A moral theory of solidarity*. New York, NY: Oxford University Press.

Krubiner, C. B., and M. W. Merritt. 2017. Which strings attached: Ethical considerations for selecting appropriate conditionalities in conditional cash transfer programmes. *Journal of Medical Ethics* 43(3): 167–176.

Kulpijit, N., and N. Khirikoekkong. 2019. The Tak Province Border Community Ethics Advisory Board (T-CAB). https://mesh.tghn.org/articles/tak-province-border-community-ethics-advisory-board-t-cab

Lavery, J. V. 2018. Building an evidence base for stakeholder engagement. *Science* 361(6402): 554–556.

London, A. J. 2005. Justice and the human development approach to international research. *The Hastings Center Report* 35(1): 24–37.

Marsh, V., F. Kombe, R. Fitzpatrick, T. N. Williams, M. Parker, and S. Molyneux. 2013. Consulting communities on feedback of genetic findings in international health research: Sharing sickle cell disease and carrier information in coastal Kenya. *BMC Medical Ethics* 14:41.

Marsh, V. M., D. Kamuya, Y. Rowa, C. Gikonyo, and S. Molyneux. 2008. Beginning community engagement at a busy biomedical research programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. *Social Science and Medicine* 67(5): 721–733.

MacQueen, K. M., A. Bhan, J. Frohlich, J. Holzer, and J. Sugarman. and the Ethics Working Group of the HIV Prevention Trials Network. 2015. Evaluating community engagement in global health research: The need for metrics. *BMC Medical Ethics* 16:44.

Novelli, M. 2006. Imagining research as solidarity and grassroots globalisation: A response to Appadurai (2001). *Globalisation, Societies and Education* 4(2): 275–286.

Njue, M., F. Kombe, S. Mwalukore, S. Molyneux, and V. Marsh. 2014. What are fair study benefits in international health research? Consulting community members in Kenya. *PLOS One* 9(12): e113112.

O'Doherty, K. C., A. K. Hawkins, and M. M. Burgess. 2012. Involving citizens in the ethics of biobank research: Informing institutional policy through structured public deliberation. *Social Science and Medicine* 75: 1604–1611.

Oswald, K., J. Gaventa, and M. Leach. 2016. Introduction: Interrogating engaged excellence in research. *IDS Bulletin* 47(6): 1–18.

Paphitis, S. A. 2018. The possibility of addressing epistemic injustice through engaged research practice: Reflections on a menstruation related critical health education project in South Africa. *Critical Public Health* 28(3): 363–372.

Participants in the Community Engagement & Consent Workshop. 2013. Consent and community engagement in diverse research contexts. *Journal of Empirical Research on Human Research Ethics* 8(4): 1–18.

Phillips, A. 1993. *Democracy and difference*. University Park: The Pennsylvania State University Press.

Prainsack, B., and A. Buyx. 2012. Solidarity in contemporary bioethics: Towards a new approach. *Bioethics* 26(7): 343–350.

Pratt, B., and J. de Vries. 2018. Community engagement in global health research that advances health equity. *Bioethics* 32(7): 454–463.

Pratt, B., K. M. Lwin, D. Zion, F. Nosten, B. Loff, and P. Y. Cheah. 2015. Exploitation and community engagement: Can CABs successfully assume a role minimising exploitation in international research? *Developing World Bioethics* 15(1): 18–26.

Reynolds, L., and S. Sariola. 2018. The ethics and politics of community engagement in global health research. *Critical Public Health* 28(3): 257–268.

Tindana, P. O., J. A. Singh, C. S. Tracy, et al. 2007. Grand challenges in global health: Community engagement in research in developing countries. *PLOS Medicine* 4(9): e273.

Tosam, M. J., P. C. Chi, N. S. Munung, O. O. M. Oukem-Boyer, and G. B. Tangwa. 2018. Global health inequalities and the need for solidarity: A view from the Global South. *Developing World Bioethics* 18(3): 241–249.

Versfeld, A., A. Scheibe, S. Shelly, and J. Wildschut. 2018. Empathic response and no need for perfection: Reflections on harm reduction engagement in South Africa. *Critical Public Health* 28(3): 329–339.

WHO Task Force on Research Priorities for Equity in Health & the WHO Equity Team. 2005. Priorities for research to take forward the health equity policy agenda. *Bulletin of the World Health Organization* 83:948–953.

Young, I. M. 2000. *Inclusion and democracy*. Oxford: Oxford University Press.