Ethical Issues in Research with Marginalized Groups

Inclusion of Marginalized Groups and Communities in Global Health Research Priority-Setting

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Abstract

Community engagement is gaining prominence in global health research. But community members, especially those from groups and communities that are considered disadvantaged and marginalized, rarely have a say in the agendas and priorities of the research projects that aim to help them. This article explores how to achieve their inclusion in priority-setting for global health research projects. A total of 29 in-depth interviews and one focus group were undertaken with researchers, research ethicists, community engagement practitioners, and community-based organization staff. Thematic analysis identified two core dimensions of inclusion—representation and voice—and what is necessary to realize them with marginalized groups and communities in global health research priority-setting. A set of ethical considerations is proposed to assist researchers and their partners design more inclusive priority-setting processes.

Keywords

priority-setting, health research, disadvantage, inclusion, equity, research ethics, engagement

Introduction

Global health research project agendas are largely set by researchers and their partners (policy makers, health care providers, community organizations, industry) in response to funding calls. As a matter of social justice, global health research projects should help improve the health and well-being of those considered disadvantaged and marginalized and foster their engagement throughout studies, including when setting research topics and formulating research questions (Benatar & Singer, 2010; London, 2005; Pratt & de Vries, 2018). The engagement of groups and communities that are considered disadvantaged and/or marginalized by social institutions and norms can provide a path for making their voices and concerns more audible and visible in agenda-setting. This, in turn, can help address epistemic injustice and generate research topics and questions that are more explicitly focused on improving access and affordability of health care and services for them. The engagement of such groups and communities has been proposed as a core component of equity-oriented health research priority-setting (Pratt, Merritt, & Hyder, 2016).

Yet engagement can often lead to presence without voice and voice without influence. Voices are then excluded from priority-setting, particularly those of marginalized groups and communities who often have the poorest health. Existing evidence confirms that being female, being poor, having little formal education, living with a disability, and/or belonging to certain ethnic groups means community members are listened to less or not at all in health priority-setting (Alderman, Hipgrave, & Jimenez-Soto, 2013; Shayo et al., 2012).

For global health research projects and programs to advance social justice, priority-setting should be designed to achieve the inclusion of disadvantaged and marginalized groups and communities. But how should priority-setting processes be structured to achieve that goal? Although a considerable amount of literature focusing on such groups’ and communities’ inclusion and participation exists in fields like philosophy, health policy, community-based participatory research, and development studies (see Arinstein, 1969; Benhabib, 1996; Cargo & Mercer, 2008; Cornwall, 2004, 2011; Crocker, 2008; Gaventa, 2004; Goulet, 2006; Kapoor, 2002; Mitton, Smith, Peacock, Evoy, & Abelson, 2009; O’Meara, Tsofa, Molyneux, Goodman, & McKenzie, 2011; Richardson, 2002; Rowe & Frewer, 2002; Young, 2000; Wallerstein & Duran, 2006, 2010), it largely does not consider the health research priority-setting context. This article explores how the inclusion of marginalized groups and communities in global health research can be achieved.
Method

This study adopted a grounded theory approach to build an account of power-sharing in global health research priority-setting. In-depth interviews were chosen as the primary method to explore the topic because they allow for the rich details of key informants’ experiences and perspectives to be gathered. A total of 29 semi-structured interviews were conducted with the following types of key informants: Global health researchers who engage communities, including those considered disadvantaged and marginalised, in their studies (13), ethicists (5), community engagement practitioners who work at research institutions (5), staff of CBOs who work with marginalised groups and communities and have been partners in health research projects (4), and researchers with experience in health research priority-setting at national level (2). A focus group was also conducted with nine research ethicists in the United Kingdom. The specific types of key informants were selected because they had experience undertaking community engagement in global health research, experience being engaged by researchers as part of research projects, and/or expertise in the ethics of community engagement or priority-setting in global health research. They, thus, could provide important insights about how to achieve power-sharing with marginalised groups and communities in research priority-setting.

As the project aimed to capture considerations related to power-sharing in global health research, study participants from both high-income countries and low- and middle-income countries were sought in each type of key informant category. Interviewees in the researcher category with a collective breadth of expertise were also sought so as to generate findings that reflect experiences from multiple types of global health research. Although the study initially sought to interview community members who had been or are involved in priority-setting or decision making for global health research projects, recruiting such individuals proved extremely challenging for reasons discussed later in the article. Ultimately, CBO staff were interviewed to provide a more community-informed perspective.

Sampling was initially purposive; potential participants with significant experience undertaking engagement with disadvantaged groups in global health research or expertise in community engagement ethics were identified through B.P’s existing networks. Snowball sampling was then used to identify additional interviewees. This led to two new categories of key informants being identified: Community engagement practitioners and researchers with experience in national health research priority-setting. Recruitment continued until no new information emerged and saturation was achieved.

In total, ten men and nineteen women were interviewed. Twelve interviewees live in Africa, nine in Australia, five in the United Kingdom or Europe, one in the United States, one in Latin America, and one in Asia. Nineteen were employed by universities or research institutions, four by non-governmental organizations, five by CBOs or civil society organizations, and one by a health organization focused on the African region. There was overlap between categories, with many interviewees meeting criteria of two or occasionally three of the categories. Interviewees were assigned to the category where their experience was the strongest fit or the category in which they self-classified. Interviewees in the researcher category ultimately had expertise conducting clinical, health systems, public health, development, and biomedical research.

Following the technique of thick description, interview questions were open-ended (Geertz, 1973) and attempted to draw out interviewees’ experience with and perspectives on community engagement in health research priority-setting. Interviewees were first asked to describe their experience in community engagement and health research, especially with marginalized groups and communities. They were then asked what is important to balance or share power when community members participate in health research priority-setting for projects. These questions were kept general to draw out interviewees’ ideas and then probes were used to further explore their ideas’ meaning. For example, where interviewees discussed concepts related to inclusion (i.e., representation and voice), the following two probes were used:

- In your experience, what’s important to representing diversity and difference when community members participate in health research priority-setting for projects?
In your experience, what’s important to ensuring community members have an equal opportunity to speak and be heard when participating in health research priority-setting for projects?

The interview guide was developed iteratively. The same questions and probes were posed in the focus group discussion. Interviews and the focus group discussion were approximately 30 to 75 min in duration. Ten interviews and the focus group discussion were conducted in person in Australia and the United Kingdom; Nineteen interviews were performed over Skype or the phone.

Interviews and the focus group discussion were transcribed verbatim and thematic analysis was undertaken by two coders in the following five phases: initial coding framework creation, coding, inter-coder reliability and agreement assessment, coding framework modification, and final coding of entire dataset (Campbell, Quincy, Osserman, & Pedersen, 2013; Hruschka et al., 2004). Interview and focus group data were combined for analysis because the same topics and questions were discussed in them. The categories and sub-categories in the initial coding framework were derived inductively and deductively (Ali, Kass, Sewankambo, White, & Hyder, 2014) relying on concepts from the development, ethics, health policy, and philosophy literature on participation and transcripts’ content. The initial coding framework was developed by B.P., with N.E. co-coding three transcripts independently and jointly coming up with a list of codes. The remaining transcripts were then coded by B.P. and that initial list of codes was revised.

Using the initial coding framework, B.P. and N.E. next undertook an iterative process of coding a transcript, assessing inter-coder reliability and agreement, and modifying the coding framework (Hruschka et al., 2004). Once the coding framework was finalized, B.P. applied it to re-code all 30 transcripts using NVivo Version 10. According to Campbell et al. (2013), once high inter-coder agreement is reached, a single person can perform the remaining coding, provided it is the person whose coding generally carried the day during the negotiation process. Ethical approval for the study was obtained from the Melbourne School of Population and Global Health Human Ethics Advisory Group.

### Results

Thematic analysis identified inclusion as a main theme during global health research priority-setting or decision-making, with two core dimensions: representation and voice.

#### Representation

Representation was defined as being present for global health research priority-setting or decision-making, either directly (representing oneself) or indirectly (being represented by others). Interviewees highlighted four aspects of representation in global health research priority-setting or decision-making: Who is represented, by whom, by how many, and via what recruitment strategies.

**Who is represented.** Inviting “relevant” parties to be present when selecting research topics and formulating research questions was strongly emphasized by interviewees. However, their definition of relevance varied with analysis revealing multiple underlying rationales for inviting different parties to the priority-setting table: knowledge, interest, credibility, and comprehensiveness (Table 1).

Disadvantaged and marginalized groups were identified as being relevant to include for four of the five reasons: Knowledge, interest, credibility, and comprehensiveness. For example, a community engagement practitioner stated comprehensiveness meant:

<table>
<thead>
<tr>
<th>Reason for participation</th>
<th>Definition</th>
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<tr>
<td>Knowledge</td>
<td>Having the information or evidence needed to reach a good decision; Having specific expertise or experience that will modify the health research agenda substantially. Entails gathering a diversity of perspectives that can inform research topics and questions.</td>
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<tr>
<td>Interest</td>
<td>Having a stake in the conduct or outcome of health research, or being affected by a project’s research topic. Entails gathering a diversity of affected parties and stakeholders.</td>
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<td>Impact</td>
<td>Having the power to take action and allocate resources to identified research topics and questions; Having the power to change policy and practice in relation to the topic under study.</td>
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<td>Credibility</td>
<td>Presence required for the outputs of health research agenda-setting to have legitimacy.</td>
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<tr>
<td>Comprehensiveness</td>
<td>Presence required to achieve complete or, at least, a wide representation of the community or society’s population. Entails gathering a diversity of social positions, for example, living with disability and not living with disability; male, female, and transgender; formally employed, informally employed, and unemployed; and so on.</td>
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</table>
[Y]ou have to be considerate about the minorities, the marginalised populations, the vulnerable populations, you know in order to be able to incorporate views from all the people who matter in the society . . . you’d want to deliberately reach out to this kind of people and make sure that you talk to them to try to find out their views.

Capacity to generate impact was not identified as a reason to include such groups. That which is relevant depends upon the scope of global health research priority-setting was also discussed by interviewees. In some (rarer) situations, the scope will be completely or relatively open. However, more commonly, parameters exist that narrow what research topics and questions can be set such as funding constraints or the nature of researchers’ expertise. Where the scope of priority-setting is limited to a particular topic, interviewees called for framing relevant parties, including disadvantaged groups, in relation to that topic. This means thinking about who has knowledge, interest, impact, and credibility in relation to that topic. For instance, if a research project focuses on HIV, an interviewee suggested “relevant” disadvantaged groups within the HIV community would likely include men who have sex with men, commercial sex workers, and injecting drug users.

By whom. Where marginalized groups and communities are to be represented in health research priority-setting, selecting channel(s) of representation and representatives with features related to genuineness and legitimacy were highlighted as important by interviewees. Three types of channels were described: (a) single or umbrella organizations representing groups or communities, (b) individuals representing groups or communities, and (c) individuals representing themselves. Where the latter channel is relied upon, interviewees recommended recruiting individuals with lots of different viewpoints from the group or community of focus. Desirable features of individuals and organizations to represent groups or communities were also identified (Table 2). They largely related to being able to genuinely reflect the diversity of needs and interests in the community or group being represented.

Selecting individuals who share lived experience with those they are representing is important but can be challenging to achieve with marginalised groups and communities. Interviewees noted that groups such as migrants, women who experience domestic violence, and those living with disability are often not homogeneous, and this has implications for their representation by individuals:

So you know you talk about a disability community, the only thing that those individuals would have in common with a person living in an informal settlement on the edges of Manila [Philippines] who also has a disability is this label of disability. But they’re, in every aspect of their life they have education and wealth and privilege and, and these other people don’t, and so the concerns that they see as priorities do not necessarily represent the concerns of more disadvantaged people from the same group that’s labelled people with disability. (Researcher)

Another challenge to genuine representation by individuals arises when their responsibilities as a representative increasingly place them at a distance to those they are representing:

[P]eople ended up spending so much time in these invited consultative spaces that they ended up getting drawn away from their communities or from the politics of the street or from their base . . . So the really articulate representatives are getting invited more and more and more and over time just lose their base. (Researcher)

Gradually, this distance may lead them to lose a strong understanding of their group or community’s needs and priorities.

Some interviewees suggested that selecting organizational representatives that meet desired criteria (Table 2) when possible may be preferable, particularly for representing groups and communities that are considered disadvantaged and marginalized. Being part of an organization helps members develop knowledge based on prior engagement with a topic and reflection on it. They have then gained information and developed their views on a topic before being thrown into a priority-setting process. Representatives of organizations formed to take care of the interests of particular marginalised groups may also be better at negotiating for their groups’ interests than individual representatives because their work entails doing so regularly.

By how many. The total number of representatives of disadvantaged and marginalized groups and communities is another important consideration in global health research priority-setting. The aim is to ensure that dominant voices within groups and communities do not dominate priority-setting by force of numbers. Interviewees suggested that it is, therefore, necessary to balance power through slight inequalities in numbers. For example, it could mean having greater numbers of groups whose voices are less heard than groups that are typically heard or having multiple representatives for each marginalised group so that it’s not just one person alone representing the group.

Recruitment. Researchers often encounter significant difficulties recruiting the disadvantaged and marginalized to participate in research activities in general. Interviewees felt that these barriers would apply in the priority-setting context. Identifying such groups and communities requires
an understanding of what comprises disadvantage or marginalization in a particular setting, which researchers, especially those engaging with a group or community for the first time, may lack. Marginalized groups may also be hidden within communities and/or unwilling to be involved in health research priority-setting due to previous negative experiences with researchers. According to a researcher,

you won’t get marginalised groups unless you actively go out there and spend quite a lot of time overcoming those barriers, which are that you are a researcher and we’ve had researchers come through here before and they use us and spit us out.

Suggested strategies for promoting marginalised groups’ successful recruitment to global health research priority-setting included the following: (a) developing researchers’ understanding of disadvantage and marginalisation in the given setting, (b) embedding oneself in the setting, (c) engaging community leaders or key informants to help with recruitment, and (d) undertaking community mapping exercises with key informants. Key informants are very knowledgeable about their community, so they know what the traditional power structures are, who the marginalized groups are, who those groups’ leaders are, and how their members can be engaged. A staff member at a CBO emphasized the role that trust plays in key informants’ capacity to recruit more hidden and marginalized segments of their communities:

The critical part is that those women are trusted by their communities so that’s our buy-in you know. If we just came in off the street no one’s gonna, you know, but because they’re trusted you know whatever these women are kind of not selling to them but offering them they’re gonna be open to.

**Voice**

Voice was defined by interviewees as ensuring individuals have the opportunity to share their views, the freedom to say what they think, and to have their voices influence what research priorities are set. They further highlighted

<table>
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<tr>
<th>Desirable feature of representatives</th>
<th>Individual level</th>
<th>Organizational level</th>
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<tr>
<td>Reflect diversity of experience in the group or community</td>
<td>Individuals beyond leaders and well-off within the group or community are among those selected as representatives; individuals of different ages, genders, and so on. within the group or community are selected.</td>
<td>Membership reflects diversity within the group or community organized around. This means membership includes the marginalized and disadvantaged within that group or community.</td>
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<tr>
<td>Shared identity and experience</td>
<td>Live a similar reality to those they are representing, which enables them to recognize problems on the ground and the needs people have due to those problems; Empathize with those they represent.</td>
<td>NA</td>
</tr>
<tr>
<td>Consultation with members</td>
<td>NA</td>
<td>Has a systemic practice of consulting its members on their needs and priorities.</td>
</tr>
<tr>
<td>Capacity to take others’ perspectives</td>
<td>Able to take perspectives that are not their own and to think from the perspective (views, values, beliefs) of others in their group or community, particularly those who are marginalised; able to reflect on the implications of different research priorities for their broader group or community and how its members will be affected.</td>
<td>NA</td>
</tr>
<tr>
<td>Reliable narrator of experience</td>
<td>Haven’t absorbed stigmatizing messages that profoundly color their understanding of their experience or other people’s experience, for example, adopting victim-blaming discourses of poverty and applying it to others.</td>
<td>NA</td>
</tr>
<tr>
<td>Absence of financial conflicts of interest</td>
<td>Do not have a vested interest in the outcome of priority-setting, for example, a stake in a medical product company; do not volunteer to be representatives for reasons of potential financial gain, for example, employment.</td>
<td>Do not have a vested interest in the outcome of priority-setting, for example, patient organizations funded by pharmaceutical companies.</td>
</tr>
<tr>
<td>Accountability</td>
<td>Relay information given during and outputs from priority-setting process back to group or community they represent.</td>
<td>Relays information given during and outputs from priority-setting process back to their organization’s membership.</td>
</tr>
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*Patient organizations funded by pharmaceutical companies may have a vested interest in global health research priority-setting. In contexts where the company sells products to address particular health problems, patient organizations will then have an interest in getting research prioritized that relates to those problems and/or medical products. In contrast, patient organizations that aren’t funded by pharmaceutical companies are motivated by an interest in wanting to improve the services patients use. In global health research priority-setting, information with “legitimacy” was suggested as being more likely to come from patient organizations not funded by industry.*
five aspects of global health research priority-setting and decision-making as critical to disadvantaged and marginalized groups and communities having voice: Ground rules, space, facilitation, documentation, and synthesis.

**Ground rules.** According to interviewees, ensuring the voices of those considered disadvantaged and marginalized are not silenced calls for adopting certain ground rules during priority-setting. This would include, for example, rules that everyone has an equal right to speak and rules that clearly define how community members’ views and ideas will be used. Without such rules, members of marginalized groups and communities may be less willing to speak and there is a high danger that their views will not be reflected in the resultant research topic and questions set for a research project or program.

**Space.** The physical spaces chosen for global health research priority-setting can promote the voices of the marginalized and disadvantaged being raised. Interviewees emphasized selecting settings that made people feel comfortable and were not imbued with norms or power dynamics that would silence them ex-ante:

> [T]he example I oftentimes use is if you bring a poor woman from India to the World Bank and say “talk,” she may feel intimidated. But if you took the head of the World Bank to, you know, to, to her village and surrounded by a group of local woman, um, around the fire place or in their small hut, that person’s gon’ maybe feel pretty uncomfortable as well. So I think those settings are really really important. (Researcher)

**Facilitation.** Good facilitation is critical because global health research priority-setting spaces are not neutral. Asymmetrical power dynamics exist among group and community members. Suggestions were made for who should facilitate global health research priority-setting and how they should facilitate it to give voice to marginalized groups and communities.

In terms of who should facilitate, interviewees recommended drawing on existing community assets and employing locals who work in the community and are not of too high a status. Such individuals will understand community dynamics, know how to manage them, and be able to establish rapport with participants. This means that facilitators will know who will talk less and whom to encourage to talk more. They are aware of cultural cues and norms that silence people and know strategies for getting those people to share their views. Having facilitators who can speak local languages is also important. A researcher noted that even using the national language for priority-setting might exclude many marginalized groups and communities because they often only speak local languages.

In terms of how facilitation should be performed, interviewees strongly recommended utilizing a “stepped” approach where small groups with some degree of homogeneity or similar characteristics meet first before everyone (or representatives of each small group) comes together as a large group. Such an approach helps mitigate the impact of power disparities between and within groups and communities by giving those who might otherwise be silenced a safe space to express themselves and to reflect on their ideas for research priority-setting before having to present them to a wider audience. It was commonly employed in interviewees’ practice for those reasons:

> What I’ve done in the past say in Papua New Guinea, is get groups of women separate to the men and they kind of just come to a consensus amongst themselves in the first instance and that’s hard, and then they practise putting into words what they wanna say in a way that’s clear and convincing and then get them into the room with the men. And they kind of then know they’ve got each other’s back a little bit as well rather than if someone has to speak up and represent a group when they don’t know, they’re not confident if they actually are representing the group and then they’re nervous that no one else will sort of stand by them, yeah . . . If you’ve never been asked your opinion before it’s not easy to find the words just like that to say what you think you know, yeah so I think those sorts of strategies before bringing people into a mixed setting is an important one. (Researcher)

Such small group work was deemed especially essential before bringing community members, especially those considered disadvantaged and marginalized, into the same priority-setting space as policy makers and health care providers. A researcher stated that

> I don’t think you can just throw in a, a citizen who has no knowledge and has perhaps . . . little education and expect them to hold their own at a table where there are sitting well educated doctors, stakeholders, policy makers, researchers and expect them to actually say very much. Cos I think that’s really unfair.

Without prior small group work, interviewees emphasized that it was highly likely that community members will voice their opinions on what research topics and questions are pertinent less than policy makers and health care providers.

Beyond a stepped approach, engaging marginalized groups and communities in their own ways of speaking was deemed vital. A researcher noted that where priority-setting processes immediately shut down elaborate greetings and storytelling, they suggest such ways of speaking are a waste of time, which is disrespectful, and excludes particular ways of communicating, which can be very disempowering. Assuring and ensuring confidentiality was also considered important, especially when engaging with groups without formal legal status in countries.
**Documentation.** Documentation of what is said in global health research priority-setting can promote the voices of marginalized groups and communities being heard by ensuring their comments and views are accurately written down. Interviewees affirmed that documentation must be done in a particular way to achieve that goal. It should be performed by community members rather than research staff. Its outputs should be made available to participants in local languages and a mechanism to challenge exclusions and omissions should exist. Where discussions occur in local languages, documentation may involve translating what is said into a second language (e.g., the national language, English). Here, participants, including members of marginalized groups and communities, should have to give approval of back translations to confirm the translation matches what was originally said. Ideally, the way documentation is done will be agreed upon by all participants, including marginalized groups and communities, at the start of priority-setting.

**Synthesis.** Using the views expressed by marginalized groups and communities, to construct final global health research topics and questions ensures their voices are heard. That sharing power means their voices are incorporated into the final research priorities was emphasized by interviewees. At a minimum, an ethicist interviewee took the position that, where their voices are not used, there must be transparency as to why that happened.

Yet doing so is not without complexity. Many voices, including opposing ones, will be raised in global health research priority-setting, even among members of the same group or community. This creates a dilemma of whose voices to take forward and whose to drop or community. The answer can reinforce hierarchies of knowledge and result in people not being heard, as demonstrated by an example of a community-based project on adolescent sexual health. That project was run by health professionals at a medical school in a conservative Catholic environment and, as part of its design phase, sought adolescents’ views on their health service needs. According to a researcher, the youths expressed a lot of opinions that were kind of counter to the way that my medical school colleagues thought was sort of what was right or best for them. So they were asking, some of them were asking for a lot more progressive material in the form of sexuality education, they wanted to talk about sort of taboo subject matter, they wanted information about you know safe abortion, they wanted to talk about transgender—so they, so the participatory research brought out these demands but then the demands were completely just like ignored slash squashed by the people running the project... certain of the young people kind of got classified by my colleagues as being like troublemakers because they were kind of saying the things that, not that they faced any sanctions for that but they were just sort of saying oh well their ideas don’t really count because they’re just like bad kids anyway. And the other kids who kind of were more conservative, then they’d say oh yes, yes you know that’s, you know but these were like, these were the kind of kids who were saying exactly what the adults were saying.

Researchers had control over whose voices were used in the project’s design and they selected those that best aligned with their own ideas, which the interviewee noted were consistent with dominant biomedical paradigms. The result was that many of the young people who were engaged felt taken advantage of by the project and that their views were not listened to. The example shows how who decides which voices are used is a key site of power in global health research priority-setting and that their choice can reinforce hierarchies of knowledge even where local knowledge is used. Stratifications exist within local knowledge systems. Some align more closely with dominant Western paradigms than others.

In terms of who ultimately decides which voices are used in global health research priority-setting, a CBO staff member and community engagement practitioner emphasized the importance of taking all proposed research priorities back to marginalized groups or communities and giving them the final say or approval as a way to share power. However, what happens in research practice is typically less inclusive. Interviewees’ descriptions suggested that decision-making is often done by researchers alone. They determine whose knowledge is used and make the final selection of research topics and questions, although they can share decision-making with staff who are also community members.

In terms of how decisions are made about whose knowledge is used, a CBO staff member noted that it was essential to acknowledge the complexity of voice and to make a “political choice” as to whose voices are heard. Here, decision makers must have a good understanding of what reasons they’re basing their decision on and be able to justify that choice. Similarly, an ethicist affirmed that decision makers must provide reasonable rationales about why they give certain interests or voices greater weight than others in global health research priority-setting. Suggestions for such rationales were provided by interviewees based on their own practices and included amplifying unheard voices or voices that will create change, underlying values, legitimacy, and feasibility.

Amplifying unheard voices or voices that will create change was described as a rationale for giving weight to certain viewpoints in priority-setting by CBO staff. This reflected their organizations’ having an advocacy role. It meant they wanted to amplify voices that were otherwise excluded and/or that could change the discourse on a topic if the proposed priorities were the focus of research. It
supported selecting research priorities with the potential to create change for the marginalised group(s) or community(ies) with whom they work. If taken forward, such research topics and questions would generate knowledge that could be translated into an advocacy platform to make policy changes that would benefit that group or community. At the same time, CBO staff wanted to avoid amplifying voices that might reinforce negative stereotypes of the group(s) or community(ies) with whom they work.

Another strategy used at a research institution to decide which voices to amplify was to identify the underlying normative values behind people’s opinions and then assess whether or not there were reasons that made those values difficult to support. For instance, an interviewee described a hypothetical case where certain expectations about the role of women in society were underpinning a particular research topic, whereas another topic strongly took account of the rights of women. In such a case, researchers might well give the latter research topic more weight than the former. Were they to do so, the interviewee emphasized that they would have to draw on views and values held within the community that opposed the former topic. The selection of research topic would then not constitute an imposition of external values on the community.

Other rationales for giving greater weight to certain voices in priority-setting were that their suggested research topics and questions had greater legitimacy or fell into researchers or CBO’s spheres of influence. Legitimacy was linked to information coming from individuals or organizations without significant financial conflicts of interest. Falling into a sphere of influence meant that health research topics and questions were ones that researchers or a CBO could take forward given their current capabilities.

Discussion

This article has explored how global health research priority-setting processes should be designed to achieve the inclusion of disadvantaged and marginalized groups. It identified two core components of inclusion: Representation and giving voice. Interviewees and focus group members highlighted different aspects of these components, which collectively generated rich definitions of what each should comprise in global health research priority-setting. No explicit areas of disagreement arose in the data, although some of the ideas described by interviewees may potentially come into conflict in practice, for example, who should be represented in global health research priority-setting.

The article’s findings strongly align with existing literature on what comprises inclusion and participation in decision making. Work from philosophy, development studies, ethics, and health policy identify being present or represented and achieving qualitative equality as core dimensions of inclusion. Like giving voice, qualitative equality means having an equal opportunity to raise one’s voice and to be heard (Blacksher, Diebel, Forest, Goold, & Abelion, 2012; Cornwall, 2011; Gibson, Martin, & Singer, 2005; Goold, Biddle, Klipp, Hall, & Danis, 2005; Hutchison, Rogers, & Entwistle, 2017; Richardson, 2002; Young, 2000). In addition, ensuring all or a diversity of those affected by a decision are part of the decision-making process is a common definition of inclusion in political philosophy and health policy (Blacksher et al., 2012; Goodin, 2008; Young, 2000). Accounts of health-related decision-making such as the accountability for reasonableness framework apply such a definition (Gruskin & Daniels, 2008). Similarly, selecting who is represented in global health research priority-setting to achieve a diversity of affected parties was one basis for inclusion discussed by interviewees. That affected parties specifically include members of disadvantaged groups and that their participation is required in decision making is also strongly emphasized in the literature (Blacksher et al., 2012; Gruskin & Daniels, 2008; Goulet, 2006; Mitton et al., 2009; O’Doherty, Gauvin, Grogan, & Friedman, 2012; Phillips, 1993; Young, 2000).

This article builds on that existing work by elaborating upon what core dimensions of inclusion (representation and giving voice) mean and how they can be upheld for disadvantaged and marginalized groups in global health research priority-setting. Representation means disadvantaged and marginalized groups participate, through genuine and legitimate representatives, and with slight inequalities in numbers that favor them. Their giving voice entails certain requirements for priority-setting processes’ ground rules, physical setting, facilitation, documentation, and synthesis of research topics and questions. Based on these results, an initial set of ethical considerations is proposed to assist researchers and their partners design more inclusive priority-setting processes for global health research projects and programs (Box 1). The proposed considerations correspond to the four aspects of representation and five aspects of giving voice described in the article.

The article’s findings and proposed considerations largely support or add to existing scholarship in the ethics, health policy, development studies, and community-based participatory research literatures on good practice for meaningful engagement. Work has been done to comprehensively compare the findings of this study with that literature, but it is the focus of a separate paper. Although it is beyond this article’s scope to report the results of that analysis, examples are provided below to demonstrate how the proposed considerations support or add to the existing literature.

When determining who will represent various marginalized groups, ethical considerations include the following: For organizations, do you have evidence that their memberships reflect the group’s diversity and are regularly consulted.
about their health needs and priorities? For individuals, do they collectively reflect the groups’ diversity and share lived experience with those they are representing? The considerations are meant to promote critical reflection on whether chosen organizational and individual representatives are genuine and legitimate. Individual and organizational channels of representation are identified in literature on public deliberation in health (Kahane, Loptson, Herriman, & Hardy, 2013). Interviewees’ descriptions added insights as to what genuine and legitimate representation means for the two channels in research priority-setting. Their insights are consistent with the concept of representation of shared experience rather than representation of ideas (Phillips, 1993; Young, 2000). To promote equal voice, ethical considerations include the following: How will your facilitation approach help equalize power dynamics between community members? That meaningful participation requires addressing power hierarchies in deliberative spaces is described in the literature (Abelson, Giacomini, Lehoux, & Gauvin, 2007; Blacksher, 2013). Both interviewees and the literature identified a stepped approach as a useful facilitation technique for breaking down power disparities in deliberative spaces (Cornwall, 2011; Marsh et al., 2013; O’Doherty et al., 2012).

The existing literature also includes ideas and concepts not described by this study. Those ideas and concepts were drawn upon to inform the proposed considerations. In particular, they identify having a decision-making role as the strongest form of engagement by those considered disadvantaged and marginalized (Arnstein, 1969; Young 1990, 2000). Inclusion in global health research priority-setting arguably entails such individuals participate in making decisions about how the process is set up and what its outputs are (Pratt et al., 2016). Disadvantaged and marginalized groups should help set priority-setting process ground rules, select the spaces used for priority-setting, and choose the final research priorities.

With respect to the latter, a distinction is made between externally driven and internally driven synthesis in the literature (O’Doherty et al., 2012). Internally driven synthesis means that the output of decision making is a ratified collective conclusion. It is an explicit product of deliberation that is endorsed by all participants, whereas externally driven synthesis means that the output of decision making is an inferred product constructed by experts following deliberation. Interviewees commonly described externally driven synthesis processes because that was their experience. Yet internally driven synthesis is likely a stronger option for giving voice to disadvantaged and marginalized groups. It would mean they are involved as decision makers in priority-setting, which is considered a deeper mode of engagement compared with being involved as consultants (Arnstein, 1969). Taking research priorities constructed by researchers back to community members to ratify would also afford them decision-making power, although to a lesser extent.

In light of this existing literature, the concept of inclusion as encompassing having decision-making power has been introduced into the proposed set of ethical considerations in relation to ground rules, space, and synthesis (Box 1). For example, one consideration related to synthesis is, “Will disadvantaged groups be part of deliberations to set the final research topic and questions?” This consideration is meant to promote critical reflection on whether research priorities are to be internally synthesized with marginalized groups.

**Study limitations.** First, although the study sought to interview community members who had been or are involved in priority-setting or decision making for health research projects, recruiting such individuals proved extremely challenging. Difficulty identifying community member interviewees was largely due to how uncommon it is for them to be involved in priority-setting or decision making in health research projects, which numerous interviewees affirmed and often attributed to being due to current research funding models. Yet it is, nonetheless, a key perspective to obtain when exploring how to share power with disadvantaged and marginalized groups during health research priority-setting. Future case study research performed as part of this project will focus on capturing this perspective and incorporating it into the proposed list of considerations. Second, 15 of 29 interviewees were researchers. This, in part, was due to there being three sub-categories of researcher who were recruited. There were, however, many interviewees who met criteria within more than one category (e.g., researcher and ethicist; ethicist and community engagement practitioner). Third, a large proportion of interviewees came from three regions: United Kingdom and Europe, Australia, and Africa. Future research could better acquire perspectives from interviewees from the Americas, Eastern Mediterranean, and Asian regions.

**Best Practices**

The inclusion of disadvantaged and marginalized groups in priority-setting can help global health research advance health equity (Pratt et al., 2016). Yet researchers and their partners need guidance on what is necessary to achieve it. Based on the findings of this article, a set of initial ethical considerations is proposed (Box 1) to assist them promote such groups’ inclusion in priority-setting for global health research projects and programs.

The set of ethical considerations are for use before setting global health research projects and programs’ topics and questions. They are a reflective set of questions for researchers and their partners to discuss and answer collectively. Attending to the considerations and revising the design of priority-setting afterward will help ensure disadvantaged
Box 1. Considerations to Promote the Inclusion of Disadvantaged and Marginalized Groups in Global Health Research Priority-Setting.

**Representation**
- Who are the disadvantaged and marginalized groups within your project or program’s research setting or population?
- Which of these groups will you engage during priority-setting and for what reason(s)?
- Do organizations or individuals exist who can represent those groups?
  - For organizations, do you have evidence that their memberships reflect the group’s diversity and are regularly consulted about their health needs and priorities?
  - For individuals, do they collectively reflect the groups’ diversity and share lived experience with those they are representing?
  - Do any of the selected individuals or organizations have financial conflicts of interest that you think will bias their selection of research priorities?
- Will the number of participants drawn from disadvantaged groups equal or exceed the number drawn from higher status groups in your project or program’s research setting or population? If not, what are your reasons?

**Giving Voice**
- What ground rules will you adopt to protect disadvantaged and marginalized groups from being silenced during priority-setting?
- Will you involve disadvantaged and marginalized groups in developing and approving the ground rules for priority-setting? If not, what are your reasons?
- What spaces exist in the host community that are not imbued with norms that silence disadvantaged and marginalized groups excluding? Can you hold your priority-setting process at one of those spaces?
- Will you involve disadvantaged and marginalized groups in selecting the space for priority-setting? If not, what are your reasons?
- Can you identify a community member to facilitate priority-setting who has a strong understanding of local relationships and hierarchies, who speaks local languages, and is acceptable and trusted by disadvantaged and marginalized groups?
- How will your facilitation approach help equalize power dynamics between community members?
- Who are community members that you can ask to document the priority-setting process?
- How will community members, including disadvantaged groups, be given an opportunity to review the documentation of the priority-setting process?
- Will disadvantaged groups be part of deliberations to set the final research topic and questions?
- If not, how will the research team ensure the voices of the disadvantaged and marginalized groups are used to set research priorities?

and marginalized groups’ knowledge and voices are raised and visible in the resultant research topic and questions. To realize the full potential of these recommendations, the study also indicates that changes to current funding mechanisms are necessary. Grants programs should require and support engagement from the outset of global health research projects.

Although the proposed considerations can usefully inform research practice in their current form, they, nonetheless, comprise a work-in-progress. The article highlights complexities in the meanings of core dimensions of inclusion and dilemmas that arise when trying to uphold them. These complexities and dilemmas raise a multitude of topics for future research.

**Research Agenda**

If who should be present in global health research priority-setting is ideally a diversity of relevant parties via representatives (a position that is itself open to debate), clear definitions of what comprises relevance and selection criteria for representatives are essential. This article has provided some initial suggestions for those definitions and selection criteria, but its findings raise additional matters for investigation. Interviewees identified bases beyond interest (e.g., knowledge, impact, legitimacy) for who might be relevant to include in health research priority-setting. More exploration is needed as to which of these bases makes the most sense to rely upon. Perhaps the goal(s) of health research priority-setting determines which basis or bases should be used. For example, if the goal is to generate research priorities of relevance to disadvantaged groups, selecting participants based on their capacity to provide knowledge about the problems such groups face might be key. If the goal is to generate research that is likely to be used in policy and practice, selecting participants based on impact might be important. Having both goals could mean relying on bases of knowledge and impact to identify participants. Other questions to explore include the following: “Are there additional bases of relevance and criteria for selecting representatives at the individual and organizational levels?” What is necessary or sufficient to be selected as a representative (e.g., meeting some or all criteria identified in this article)?

Dilemmas that arise when seeking to include disadvantaged and marginalized groups in health research priority-setting were also described by interviewees. In terms of achieving genuine representation, questions were raised around the heterogeneity of disadvantaged groups and what this means for representation. When do well-off members of groups labeled as “disadvantaged” comprise genuine representatives of the entire group? In terms of approaches
to facilitation, questions were raised about the fairness of bringing policy makers and members of disadvantaged groups into the same priority-setting space. Under what circumstances (if any) is it fair to do so?

In terms of synthesizing final research priorities, dilemmas around choosing voices and who chooses them were articulated and raised additional questions for exploration. Key questions to answer are: Does disadvantaged and marginalized groups’ inclusion demand the internal synthesis of research priorities? Is it fair that when communities are (rarely) engaged in health research priority-setting, researchers are typically responsible for constructing research topics and questions and then deciding which are the highest priority to act on? When might external synthesis be permissible? If research priorities are externally synthesized, another question to explore is, “What are ‘reasonable’ rationales for amplifying certain voices over others when constructing research priorities?” How to navigate and address these dilemmas should be the focus of future ethics research and can usefully draw upon existing conceptual and empirical literature on inclusion and participation from other disciplines.

Another topic to further explore is whether the nature of global health research matters in specifying what inclusion requires. It has been suggested that certain types of global health research place greater emphasis on researchers and their partners’ engagement with marginalized communities (Council for International Organizations of Medical Sciences, 2017). Should all the considerations identified in Box 1 then apply to all forms of global health research? Should the considerations be further specified for different types of global health research? Although the proposed considerations were informed by the experiences and perspectives of researchers spanning biomedical to applied health research, perhaps nuanced considerations are appropriate for basic and clinical research relative to public health research and health systems research.

Finally, given the funding-related barriers to inclusion of communities in global health research priority-setting, ethics research could usefully explore the obligations of research funders to incentivize engagement in all phases of research. Recent work has started to consider the ethics of research funders’ priority-setting and their design of grants programs (Pierson & Millum, 2018; Pratt & Hyder, 2019). It is suggested that health systems research funders should design grant programs that require and support disadvantaged and marginalized groups and policy makers to share priority-setting with researchers or, at a minimum, be consulted as part of selecting research topics and questions (Pratt & Hyder, 2019). Their grants programs should allow for greater flexibility to pursue research topics identified through engagement processes. Whether funders of other types of global health research share this responsibility has yet to be investigated.

Educational Implications

The growing prominence of community engagement in global health research means research ethics training for the field should include the topic of community engagement. As part of this training, how to include disadvantaged and marginalized groups in the research process, including during priority-setting, should be covered. The set of ethical considerations proposed in this article can inform the content of such training. They can be used to help teach global health researchers and their partners how they can design priority-setting processes to ensure those considered disadvantaged and marginalized are represented and heard.

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Notes

1. In this article, global health research is defined as research addressing health problems worldwide, including those of the most disadvantaged, who live primarily (but not exclusively) in low- and middle-income countries.
2. Disadvantage is defined as experiencing substantial deprivations in core dimensions of well-being such as health, reasoning, self-determination, attachment, personal security, and respect. It is frequently created and entrenched through institutional arrangements and social practices (Powers & Faden, 2006; Wolff & de-Shalit, 2007).
3. The focus on priority-setting is not meant to convey that engagement of disadvantaged and marginalized groups is unnecessary in other phases of research projects and programs.
4. Researchers conducting studies in low- and middle-income countries (LMICs) are either from LMICs or high-income countries (HICs), which may result in their having quite different experiences with community engagement in their work. The project, therefore, sought to interview researchers of three sub-types: Those from HICs who work in LMICs, those from HICs who work in LMICs, and those from LMICs who work in LMICs. Having three sub-categories of researchers led to recruitment of more interviewees in that category.
5. For example, interviewees were initially asked specifically about sharing power in health research priority-setting, but their experience conducting community engagement was often not during the priority-setting phase of projects. The term decision-making was then added to the interview guide to better draw out interviewees' wealth of knowledge and experience.

6. For example, concepts such as channel of representation, space, and synthesis were identified as sub-categories. Each concept has been previously described in the health policy and development studies literatures (see Cornwall, 2004; Gaventa, 2004; Kahane et al., 2013; O’Meara, Tsoka, Molyneux, Goodman, & McKenzie, 2011).

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