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Response to Open Peer Commentaries on "Solidarity and Community Engagement in Global Health Research"

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We would like to thank those who took the time to write open peer commentaries for their thoughtful analysis and contributions on the topic of solidarity and community engagement in global health research. These colleagues have collectively (and helpfully) identified several areas in which the proposed account does not, at present, adequately provide guidance on solidaristic community engagement (CE). These areas comprise future directions for work to strengthen the account and enhance its utility. In our response, we discuss some of these areas, focusing on those that were raised across several commentaries: recognizing the prior foundations needed for solidaristic CE, articulating the purpose of solidaristic CE, better consideration of power dynamics during solidaristic CE, consideration of what harms solidaristic CE can generate for communities, and consideration of the roles of funders and governments to support solidaristic CE.

Jennings (2020) and Jayaram (2020) point out that certain foundations must exist *prior* to undertaking solidaristic CE. They highlight normative, environmental, and collective foundations: a preexisting ethos of solidarity, participatory democracy in politics, funder and government support, and communities that have a strong sense of their interests and who are empowered to demand more for themselves. Jayaram (2020) suggests the latter requires organizations to help communities clarify their interests and values prior to CE. We strongly agree with these scholars' assessment. To achieve power-sharing when

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engaging communities, our own research has shown that personal, relational, environmental, and normative foundations are necessary (Adhikari et al. 2017; Gikonyo et al. 2008; Jao et al. 2015; Participants in the Community Engagement and Consent Workshop, Kilifi, Kenya 2013; Pratt 2019). However, the implications of needing foundations to undertake solidaristic CE effectively requires further exploration. Some questions here include: what foundations are essential, who is responsible for building them, who is responsible for supporting their development, how would the existing global health research enterprise need to change for this to be possible? Their answers should inform an account of solidaristic CE.

Scholz (2020) raises the important question: what is the moral goal of the solidaristic relationship? Upon reflection, we do not think our account addressed this question. Several commentary authors understood our account to say that the purpose of solidaristic CE is to reduce power disparities between researchers and communities and to generate more equitable research collaborations. Daftary and Viens (2020) rightly point out that “CE is built upon a platform that is off-centre from the outset.”

While did not necessarily intend to convey that message, we are persuaded by the idea that the or a moral goal of solidaristic CE relates to reducing power disparities and promoting community empowerment in the research context. How this is grounded in accounts or theories of solidarity and what their application identifies as the specific goals of solidaristic CE bears more consideration. The accounts of solidarity in bioethics that we relied on in our article perhaps do not consider power sufficiently to do this. They affirm that the goal of solidarity is to aid the vulnerable and to reduce structural inequalities. Our paper, therefore, discussed solidaristic CE relationships as potentially generating research that seeks to further those aims. In that view, solidaristic CE can help generate new knowledge to alleviate the suffering of those considered disadvantaged and/or combat structural and institutional injustices. Given our article’s focus on global health research, though perhaps not explicitly stated, we were thinking this meant suffering in relation to health and structural injustices that generate global health disparities. Thus, the goal of solidaristic CE that our account alluded to was more focused on reducing health disparities than power disparities. The commentaries have led us to revisit this and conclude that a wider focus on the power disparities underpinning health disparities is appropriate, and an important area for future analysis.

Yet, Daftary and Viens (2020) argue that solidaristic CE’s capacity to address power disparities in global health research collaborations is limited. They state what is needed to reduce such disparities are research capacity development, health system strengthening, shared decision-making within collaborations, and shared funding. We agree to a some extent with their assessment, but we think that solidaristic CE is likely to be a contributor to reducing such disparities. Thus, it should and can be expected to help address inequities in research collaborations in some capacity. Drawing on Powers and Faden’s (2019) work, perhaps solidaristic CE should help combat power relations that are fundamentally unfair —subordination, exploitation, and social exclusion—in the research context. It could also combat hierarchies of knowledge underlying epistemic and cognitive injustices in global health research. Ultimately, more work on the matter of solidaristic CE’s goals is needed to further strengthen our account.

Staying on the topic of power, Sariola (2020) suggests our account of solidaristic CE needs to better incorporate considerations of power. We strongly agree. While our account does factor in power relations in two ways (mitigating power disparities in deliberations and undertaking a social critique), that is insufficient, particularly if an or the overarching goal of solidaristic CE is to redress power disparities in the research context. Sariola (2020) proposes that one way to better consider power would be to think about who faces the risk of harm and who benefits from solidaristic CE, using an intersectionality lens. Similarly, Sholz (2020), Jayaram (2020), and Daftary and Viens (2020) also draw attention to the fact that solidaristic CE may worsen power disparities, have perverse consequences, and/or cause social harms that exacerbate vulnerabilities or negatively affect those already marginalized by social institutions and norms. The distribution of harms and benefits of solidaristic CE is not covered by our account, but we agree that a robust account should provide guidance on that matter. If the goal of solidarity is to aid the vulnerable and reduce disparities in health and well-being, then surely solidaristic CE should ensure its conduct does not make marginalized groups and communities' situation more precarious and/or widen disparities.

Scholz (2020) further argues that the goal of solidaristic CE should be the equitable sharing of social risk. She defines this as a reciprocal exchange of risks, no person carrying so much risk that s/he is made vulnerable, not creating undue burdens or new vulnerabilities, and not intensifying vulnerability unevenly. We are not sure that we agree this should be the main goal of solidaristic CE, but we agree that solidaristic CE should share risks equitably. Scholz's concept of equitable risk sharing is an interesting and complex one; its nuances should be further fleshed out and would importantly advance accounts of solidaristic CE.

Lander and Dierks (2020) and Jayaram (2020) raise questions for our account's requirements of diversity and deliberation. Our account called for community "representatives" to mirror the characteristics of those they are representing, share their lived experiences, and collectively match the demographics of the community. It supports selecting those who are typical members of their community as community "representatives." Lander and Dierks (2020) say that "CE groups are usually too small to be representative in either sense. Therefore, those planning and conducting CE may prefer to aim to portray only a subset of characteristics and views of the target population, and, instead of focusing on representativeness." As such, they think it would help to have a clearer definition of who ought to participate (Lander and Dierks 2020).

In response, we would clarify that we meant community "representatives" should reflect the range of important views and values within a community. They should collectively hold views and have experiences that (we hope are) are typical of the wider community, rather than be "representative" in terms of "speaking on behalf of" or being representative of the wider community in a formal way. Collectively encompassing the range of important views and values is a better description of our position than our original suggestion that they "match the demographics of the community" and be selected based on demographic characteristics. What those important views and values are would of course vary by community but could be identified by researchers or already be known to them.

As Jayaram (2020) rightly points out, deliberations are ideally about identifying shared interests, modifying initial preferences to find common ground, and reaching consensus. But she proposes that perhaps we should not (always) have equality in deliberations between researchers and communities. Sometimes researchers' voices should be favored and other times communities' voices and preferences, uninfluenced by researchers' interests, should be deferred to. Our account emphasizes the importance of deliberations. However, we agree that demanding equal weight be given to researchers' and community members' inputs in deliberations may not always be warranted. For example, where voices have historically been excluded, privileging them over other voices is perhaps the just course of action. Gould's concept of deference may support this. The question of whether or when the voices of community members and/or researchers should be privileged versus treated equally in deliberations as part of solidaristic CE is a key area to further explore.

Finally, Wright and Sheather (2020) and Jayaram (2020) each argue that funders and governments belong in the ethical picture of solidaristic CE. Our proposed account did not discuss their role and this is another shortcoming. We agree that funders and governments have obligations to promote and support solidaristic CE. Funders are increasingly requiring CE as an essential component of global health research projects and programs. CE can be a funding principle and/or selection criterion (Pratt and Hyder 2018). Yet simply requiring applicants to have a CE strategy and perform CE will not necessarily give rise to solidaristic CE. More nuanced selection criteria are needed if solidaristic CE is to be incentivised. Additionally, grant programs specifically for CE could further support solidaristic CE practice in global health research.

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