Community engagement in global health research that advances health equity

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Abstract: Community engagement is gaining prominence in global health research. So far, a philosophical rationale for why researchers should perform community engagement during such research has not been provided by ethics scholars. Its absence means that conducting community engagement is still often viewed as no more than a ‘good idea’ or ‘good practice’ rather than ethically required. In this paper, we argue that *shared health governance* can establish grounds for requiring the engagement of low and middle-income country (LMIC) community members in global health research, where such research aims to help reduce health disparities. This philosophical basis has important implications for the ethical goals ascribed to engagement and the approach adopted to undertake it. We suggest the ethical goals of engagement in equity-oriented global health research should include: 1) generating research priorities and questions that reflect the key problems disadvantaged groups face in accessing healthcare, services, and broader social determinants of health and 2) promoting research findings’ translation into policy and practice in ways that benefit disadvantaged groups’ health. We propose engagement practice should have the following features: deliberation with LMIC community members to make a range of project decisions, beginning with setting research topics and questions; inclusion of members of disadvantaged groups and those with the power to change policy and practice to benefit them; and structuring deliberations to minimise the impact of power disparities between LMIC community members. Finally, we reflect on how these features differ from those typical of much current community engagement practice in LMICs.

Keywords: community engagement , global health research , justice , health equity , disadvantage , ethics

INTRODUCTION

Global health research collaborations have repeatedly been recognised as a 'powerful tool' to reduce health disparities between and within countries[1] and frequently perform research and research capacity strengthening to advance that aim.[2] In this paper, global health research is defined as research focused on health problems typically (but not exclusively) experienced in low-income countries.

Community engagement (CE) is gaining prominence in global health research, with funders increasingly expecting researchers to conduct it as an integral and often mandatory component of the research process.[3] This is true for a variety of types of health research, including genomics, clinical, implementation, and health systems research. Examples include the UK Department for International Development's Research Programme Consortia scheme, which funds health systems research (amongst other types of research) in low and middle-income countries (LMICs). That grant program requires and supports a yearlong Inception Phase for funded

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[1] Commission on Health Research for Development. (1990). *Health Research: Essential Link to Equity in Development*. Oxford: Commission on Health Research for Development, p. xvii; Ministerial Summit on Health Research. (2004). *The Mexico Statement on Health Research*. Mexico City, Mexico; Global Ministerial Forum on Research for Health. (2008). *Bamako Call to Action on Research for Health*. Bamako, Mali.

[2] Parker, M., & Bull, S. (2009). Ethics in Collaborative Global Health Research Networks. *Clinical Ethics.* 4, 165-68.

[3] MacQueen, K. M., Bhan, A., Frohlich, J., Holzer, J., Sugarman, J., & 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.

consortia during which they must undertake engagement.[4] The second and final round of funding for the H3Africa Consortium, which supports genomics research in Africa, made CE a required component of applications.[5]

Yet there are many remaining questions about the contribution of CE in global health research. So far, a philosophical rationale for why researchers should perform CE as part of global health research has not been provided by ethics scholars.[6] This omission is important for several reasons. Its absence means that, despite growing literature on the value of CE and recent emphasis on it by funders,[7] conducting CE is still often viewed as no more than a 'good idea' or 'good practice', especially where it is not made mandatory by funders. CE does not have the standing of other ethics requirements like, for example, informed consent. A theoretical foundation would

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[4] Department of International Development. (2010). *Managing the Inception Phase of Research Programme Consortia*. London: DFID.

[5] National Institutes of Health. (2016). *Human Heredity and Health in Africa (H3Africa): Research Projects (U01)*. Retrieved March 13, 2017, from http://grants.nih.gov/grants/guide/rfa-files/RFA-RM-16-015.html; National Institutes of Health. (2016). *Human Heredity and Health in Africa (H3 Africa): Collaborative Centers (U54)*. Retrieved March 13, 2017, from http://grants.nih.gov/grants/guide/rfa-files/RFA-RM-16-016.html.

[6] Ethics scholars have proposed a principle of community respect, arguing that communities have moral status and thus deserve respect. Upholding the principle entails acknowledging the heterogeneity of communities and enacting protections such as community consent and consultation (See: Weijer, C., & Emanuel, E.J. (2000) Protecting Communities in Biomedical Research. *Science*. 289(5482), 1142-1144). We note, however, that community consultation does not require shared decision-making or deliberation – concepts which we will introduce and discuss later in this article – and so arguably may introduce a lower standard of involvement than we will propose is necessary for equity-oriented health research.

[7] Woolf, S.H., Zimmerman, E., Haley, A., & Krist, A.H. (2016). Authentic Engagement of Patients and Communities can Transform Research, Practice, and Policy. *Health Affairs*. 35(4), 590-594.

also help to clarify what the ethical goals of engagement should be and to develop a coherent approach to engagement practice and evaluation.

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 collaborative research in LMICs.[8] A number of ethical goals—spanning the normative, procedural, and substantive—have been ascribed to CE in global health research. An overarching normative goal often identified in literature is the protection of communities in research. Substantive goals relate to the identification of non-obvious risks and benefits, minimizing exploitation, ensuring research relevance, minimizing community disruption, and increasing the likelihood that research will generate fair benefits locally. Process goals include ensuring awareness of and respect for cultural differences and (traditional or administrative) community leadership structures.[9] Similarly, there are a number of types of CE employed in practice: co-design, consulting, informing, and sensitising.[10] A wide variety of CE mechanisms are used as well, ranging from information provision, community meetings, lab visits, community advisory boards, theatre interventions,

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[8] MacQueen et al., *op. cit.* note 3.

[9] Ibid; Tindana, P.O., Singh, J.A., Tracy, C.S., Upshur, R.E.G., Daar, A.S., Singer, P.A., Frohlich, J., & Lavery, J.V. (2007). Grand Challenges in Global Health: Community Engagement in Research in Developing Countries. *PLoS Medicine*. 4(9), e273; King, K. F., Kolopack, P., Merritt, M.W., & Lavery, J.V. (2014). Community Engagement and the Human Infrastructure of Global Health Research. *BMC Medical Ethics.* 15, 84.

[10] Oswald, K., Gaventa, J., & Leach, M. (2016). Introduction: Interrogating Engaged Excellence in Research. *IDS Bulletin*. 47(6), 1-18; Marsh, V.M., Kamuya, D., Rowa, Y., Gikonyo, C., & Molyneux, S. (2008). Beginning Community Engagement at a Busy Biomedical Research Programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. *Social Science & Medicine.* 67(5), 721-733; Dickert, N., & Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health*. 95(7), 1123–1127.

and many other activities. These activities may take place only once, continue on for a few months, or even over many years.[11]

This paper focuses on the contribution of CE to global health research that aims to generate new knowledge to help reduce health disparities. Our starting point is the question, where global health research has such an objective, what does this mean for CE? Should engagement be a mandatory component of these collaborations' research? If so, what should its ethical goals be and how should it be performed?

To explore these questions, we draw largely on an existing account of health governance from political philosophy and an ethical framework that was developed (by applying it) to guide the governance of global health research collaborations. That account is called *shared health governance* and it describes the type of governance necessary for joint enterprises to promote health justice, proposing that five components are essential: shared sovereignty, shared resources, furthering the ideals of health justice, mutual collective accountability, and shared responsibility.[12] The ethical framework—hereafter referred to as the research collaboration governance framework—describes what is required for global health research collaborations to uphold those five components.[13] To develop the framework, shared health governance was supplemented by other accounts. In particular, Iris Marion

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[11] 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; Tindana, P., de Vries, J., Campbell, M., Littler, K., Seeley, J., Marshall, P., Troyer, J., Ogundipe, M., Alibu, VP., Yakubu, A., & Parker, M.; as members of the H3A Working Group on Ethics. (2015). Community Engagement Strategies for Genomic Studies in Africa: A Review of the Literature. *BMC Medical Ethics.* 16, 24.

[12] Ruger, J.P. (2011). Shared Health Governance. *American Journal of Bioethics.* 11(7), 32-45; Ruger, J.P. (2012). Global Health Justice and Governance. *American Journal of Bioethics.* 12(12), 35-54.

[13] Pratt, B., & Hyder, A.A. (2016). Governance of Transnational Global Health Research Consortia and Health Equity. *American Journal of Bioethics*. 16(10), 29-45.

Young's work on inclusion in decision-making and David A. Crocker's work linking the capability approach to deliberative decision-making were used to generate more specific guidance for consortia on sharing sovereignty and sharing resources.[14]

Most relevant to this paper, the research collaboration governance framework proposes that *sharing sovereignty* requires collaborations to undertake decision-making in an inclusive and deliberative manner. Deliberation, as described in the framework, needs to involve researchers and laypersons, be led by LMIC partners, and be applied when making a range of decisions, including the formulation of research questions, intervention design, allocation of resources, and agreed standards for collaboration.[15] Deliberation thus proposed bears considerable similarity with what has been called CE. Both require representation of individuals from the host population and aim to solicit critical discussion about research processes in order to advance ethical goals (e.g. promoting health equity, ensuring respect, minimising exploitation). We, therefore, wanted to explore more comprehensively whether shared health governance, and shared sovereignty in particular, could offer a philosophical justification for CE being a necessary component of equity-oriented global health research and, if so, its implications for how CE should be conducted.

Our *first aim* in this paper is to consider whether shared health governance can establish grounds for requiring the engagement of LMIC community members in such research and what this means for the ethical goals of engagement. The philosophical basis and ethical goals ascribed to engagement have important implications for the approach adopted to undertake it.[16] Our *second aim* is then to consider what achieving inclusive and deliberative decision-making means for

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[14] Ibid.

[15] Ibid.

[16] King, Merritt, & Lavery, *op. cit.* note 9; Gradinger, F., Britten, N., Wyatt, K., Froggatt, K., Gibson, A., Jacoby, A., Lobban, F., Mayes, D., Snape, D., Rawcliffe, T., & Popay, J. (2015). Values Associated with Public Involvement in Health and Social Care Research: A Narrative Review. *Health Expectations*. 18(5), 661-675.

engagement practice. The research collaboration governance framework identifies a number of components of such decision-making: breadth, level of participation, deliberation, equal voice, and stage of participation. We explore what upholding each component entails for engagement in equity-oriented global health research. In doing so, we reflect on how these features differ from those typical of much current CE practice in LMICs.

In the paper, our definition of community encompasses both research users such as policymakers and healthcare providers and research beneficiaries such as patients, their families, and other community members, which is perhaps a broader use of the term "community" than is common. However, definitions of community can be based on geography, on special interests or goals, or on shared situations or experiences. As affirmed by participants in the 2013 Community Engagement and Consent Workshop in Kilifi, depending on how communities are defined, any interactions with research stakeholders, such as patients, practitioners, policymakers, the media, and universities, can be considered a form of CE.[17] Similarly, the CIOMS guidelines state that different sectors of society with a stake in the proposed research should be encapsulated in the definition of the 'community' that is affected by that research.[18]

In addition to the term CE, 'citizen engagement' in research and decision-making more broadly is used frequently in the literature. In this paper, we use the terms citizen and citizen engagement only when they are used in the literature we cite. Otherwise, we use the terms community member and CE, but note that our definition of community member strongly overlaps with the term 'citizen', which can also refer to research users and beneficiaries.

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[17] Participants in the Community Engagement and Consent Workshop. (2013). Consent and Community Engagement in Diverse Research Contexts. *Journal of Empirical Research on Human Research Ethics*. 8(4), 1-18.

[18] CIOMS. (2016). *International Ethical Guidelines for Health-related Research Involving Humans*. Geneva: Council for International Organizations of Medical Sciences, pp.25f.

SHOULD ENGAGEMENT OF LMIC COMMUNITY MEMBERS BE ETHICALLY REQUIRED?

We first consider whether shared health governance can establish a normative basis for why LMIC community members should be engaged in equity-oriented global health research. Shared health governance is an account of the type of social cooperation needed to achieve health justice, where health justice is defined as improving the health of those with the worst health globally, bringing them closer to the optimal level of health achieved worldwide.[19] Arguments for *why* shared health governance is required to achieve health justice have be previously made[20] so we do not repeat them here. A basic premise is that multiple societal actors, public and private, engage in a joint enterprise that by collective action succeeds in co-producing the conditions for all to be healthy. For them to do so, shared health governance identifies five components as essential— *shared sovereignty*, shared resources, furthering the ideals of health justice, mutual collective accountability, and shared responsibility based on the specific functions and roles individuals and groups take on in the joint enterprise.[21]

Shared sovereignty specifies who should take part in decision-making about health matters and how the process of decision-making should be undertaken. It has three main components where decision-making relates to LMICs and involves parties from

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[19] Ruger, *op. cit.* note 12; Ruger, J.P. (2009). Global Health Justice. *Public Health Ethics*. 2(3), 261-275. Here, it is acknowledged that philosophers have conceptualised health and social justice in various ways and it continues to be a matter of debate. However, a point of convergence among multiple theories of social justice is that it is a priority and duty of justice to avert and alleviate disadvantage (see Bailey T.C., Merritt, M.W., & Tedioso, F. (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; Wolff, J. & de-Shalit, A. (2007). *Disadvantage*. Oxford, UK: Oxford University Press.)

[20] Ruger, *op. cit.* note 12.

[21] Ruger, *op. cit.* note 12.

high-income countries and LMICs: *inclusion, deliberation,* and *LMIC-leadership*. Deliberative decision-making by a broad range of societal actors, including experts and laypersons, with health-related roles is required.[22] Decision-making power is thus not concentrated in the hands of a small number of experts (health practitioners and policymakers) who dictate policies and procedures with little involvement of lay parties or effort to achieve broad consensus. Decision-making power is not entirely devolved to civil society either. High-income country actors' role is only to assist LMIC actors to make health decisions related to their populations, rather than to make decisions on their behalf. High-income country actors should have a 'supportive and facilitative role' such that LMIC actors become better able to ensure their populations' health on their own.[23]

An emphasis on citizen participation and deliberative decision-making as a means of advancing health justice (and social justice more broadly) is not unique to shared health governance. Empowerment of citizens through democratic processes is a shared aim of most scholars who work on the capabilities approach.[24] In particular, David A. Crocker and Sabine Alkire argue that citizen participation in deliberative decision-making is required by the capability approach because it furthers citizens' agency.[25] Similarly, Iris Marion Young's work identifies participation in deliberative decision-making as a core component of social justice because it is a means of realising individuals' self-determination and self-development. She purports that

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[22] Ruger (2011), *op. cit.* note 12.

[23] Ruger, J.P. (2006). Ethics and Governance of Global Health Inequalities. *Journal of Epidemiology and Community Health*. 60, 998–1002, p. 1001; Ruger, J.P. (2008). Normative Foundations of Global Health Law. *Georgetown Law Journal*. 96, 423–443, p. 433.

[24] Nussbaum, M.C. (2011). *Creating Capabilities*. Cambridge, MA: Harvard University Press.

[25] Crocker, D.A. (2008). *Ethics of Global Development: Agency, Capability, and Deliberative Democracy*. Cambridge: Cambridge University Press; Alkire, S. (2002). *Valuing Freedoms: Sen's Capability Approach and Poverty Reduction*. Oxford: Oxford University Press.

social justice entails having institutional conditions for the realisation of those two values.[26]

Where global health research collaborations are undertaken with the goal of helping reduce health disparities, the research collaboration governance framework proposes that they should uphold the five components of shared health governance, including shared sovereignty. Doing so means these collaborations' governance will promote health justice.[27] But what does upholding shared sovereignty entail for global health research collaborations? Is it achieved when high-income country *and* LMIC researchers (i.e. experts) participate in decision-making? Or is LMIC community members' participation also necessary? Bearing the above description of shared sovereignty in mind, it would seem to call for decision-making in global health research collaborations to include *both* experts and laypersons from LMICs. Pratt and Hyder (2016) propose exactly this; the research collaboration governance framework requires engagement of LMIC community members.[28] Here, we explore in more detail the grounds for why this should be the case.

Shared sovereignty calls for inclusive and deliberative decision-making. Inclusion in decision-making has been defined as encompassing all those whose options for action would be substantially conditioned by the decision under discussion.[29] In the research context, it may be understood to refer to all parties whose options for action are substantially affected by the selection of research priorities, the conduct of research, and/or the translation of the evidence it generates.[30] Three categories of people meet this criterion: research-producers, research-users, and research-beneficiaries.[31] Achieving inclusion in global health research collaborations' decision-making, therefore, means such processes should include not only global health

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[26] Young, I.M. (1990). *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press.

[27] Pratt & Hyder, *op. cit.* note 13.

[28] Ibid.

[29] Young, I.M. (2000). *Inclusion and Democracy*. Oxford: Oxford University Press.

[30] ANONYMOUS

[31] Pratt & Hyder, *op. cit.* note 13.

research producers but also global health research users and beneficiaries within host countries: health policymakers, administrators, providers, and patients served by the health system.[32] LMIC community members should participate in global health research collaborations' decision-making because they are affected by what research is performed in their country.

We further propose that inclusion in decision-making should reflect who has the knowledge and power to improve the health of the worst-off in host countries. That who takes part in global health research collaborations' decision-making is linked to the goal of advancing health justice seems consistent with the account of shared health governance. The engagement of LMIC community members is then required because it can help make the needs of disadvantaged groups (i.e. those groups who are worst-off or badly-off in health terms in host countries) visible in the research priorities and research questions set by global health research collaborations. Engagement of LMIC community members can also promote the use of research findings in policy and practice in ways that benefit the health of disadvantaged groups within host countries. Specifically engaging those with the power to impact the health of disadvantaged groups—health practitioners, policymakers, managers—can promote their use of research findings, supporting changes that can help bring disadvantaged groups closer to an optimal level of health. Thus, LMIC community members' capacity to advance health justice makes ensuring their engagement a necessary aspect of governing global health research collaborations.

This is an important claim because it suggests engagement should be a *mandatory* part of global health research, provided collaborations are serious about reducing health disparities. Supplying a rationale for engaging LMIC community members also helps identify what the *ethical goals* of doing so might be when global health research is conducted with the aforementioned aim. The ethical goals of engagement would include: 1) generating research priorities and questions that reflect the key problems disadvantaged groups face in accessing healthcare, services, and broader social determinants of health and 2) promoting research

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[32] Ibid.

findings' translation into policy and practice in ways that benefit disadvantaged groups' health. (This does not preclude such research having additional ethical goals for engagement that reflect other ethical values.) These goals contrast with most of the normative, procedural, and substantive goals attributed to CE that we briefly outlined in the Introduction. Where CE goals emphasise ensuring research relevance and fair benefits locally, it is not specifically in relation to disadvantaged groups within the research population. The goals are, nonetheless, consistent with the aims of many community-based studies in LMICs such as the Ghana Community-based Health Planning and Services Initiative.[33]

The philosophical rationale and ethical goals ascribed to LMIC community members' engagement have important implications for the approach adopted to undertake it. Our next step is to consider what they might require of engagement practice.

WHAT FEATURES SHOULD ENGAGEMENT OF LMIC COMMUNITY MEMBERS HAVE?

The research collaboration governance framework draws on the work of Jennifer Ruger, Iris Marion Young, David A. Crocker, and Henry Richardson to develop its guidance on what upholding shared sovereignty entails for global health research collaborations. The latter three scholars each describe what achieving inclusion and deliberation comprise in contexts of power disparities.[34] The framework identifies a number of components of decision-making based on their work: breadth, level of participation, deliberation, equal voice, and stage of participation. These components capture not only who is involved in decision-making but also how and when they are involved.[35]

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[33] Nyonator, F.K., Awoonor-Williams, J.K., Phillips, J.F., Jones, T.C., & Miller, R.A. (2005). The Ghana Community-based Health Planning and Services Initiative for Scaling Up Service Delivery Innovation. *Health Policy and Planning*. 20(1), 25-34.

[34] Pratt & Hyder, *op. cit.* note 13.

[35] Ibid.

For each component, we offer a general definition, consider what features of engagement in global health research are necessary to uphold it, and then compare the identified features to those typical of CE practice in LMICs. This is done to provide an initial picture of how engagement of LMIC community members ought to be performed in equity-oriented global health research and how that may contrast with current CE practice. Our understanding of current CE practice draws on the empirical literature describing it and on one of the author's extensive experience with CE in health research in Africa.

Who to engage

Breadth

Inclusion, in part, means achieving a breadth of participants. The research collaboration governance framework proposes that breadth encompasses two main elements: range and mass. *Range* refers to ensuring that participants span a wide spectrum of relevant roles and demographics.[36] In the categories of research users and beneficiaries, relevant roles have been suggested to include patients, carers and families, healthcare providers, health policymakers, health insurers, and health managers.[37] Relevant demographics are individual characteristics likely to give rise to differential understandings of healthcare or health system needs. For instance, amongst patients, relevant demographics might include race, gender, working in the formal or informal sector, having an acute or chronic illness, and living in an urban or rural setting.[38] The framework purports it is essential to include differently situated actors in order to enhance the base of social knowledge used to make decisions. *Mass* refers to achieving similar numbers of participants representing the various roles and demographics. This is to ensure powerful actors do not dominate decision-making by force of numbers.[39]

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[36] Ibid.

[37] ANONYMOUS *op. cit.* note 30.

[38] Ibid.

[39] Pratt & Hyder, *op. cit.* note 13.

Bearing these concepts in mind, perhaps engagement of LMIC community members should focus on including a diversity of patients, carers and families, healthcare providers, health policymakers, health insurers, and health managers from the research population.[40] However, we argue that the aim of furthering health justice calls for a somewhat more targeted approach when selecting LMIC community members to engage. The ethical goals described previously speak to two main reasons for selecting particular LMIC community members to participate in deliberative decision-making: because they either have pertinent knowledge of the health needs of the worst-off or the badly-off within the research population, or because they have the power to change policies and practices that affect the health of the worst-off or badly-off. This would (in part) entail the engagement of a diversity of members of disadvantaged groups within the research population and individuals with health-related roles who routinely interact with them. By specifically including disadvantaged groups (and other LMIC community members who can speak to their needs), priority setting will deliver a more complete account of what global health research is required to meet their needs. This is essential if global health research collaborations are to help advance health justice, as these collaborations' research priorities and questions should focus on improving healthcare and services for disadvantaged groups.[41] Where members of disadvantaged groups are not part of such decision-making processes, it is highly likely that the processes will exclude their perspectives and serve to reinforce the status quo.[42]

Determining which LMIC community members have pertinent knowledge of the health needs of the worst-off or the badly-off means first identifying which groups are 'disadvantaged' *within* the research population. In the research collaboration governance framework, the comparator is against the global optimal level of health and wellbeing. Against this yardstick, many people in LMICs fall into the worst-off or

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[40] We are assuming the research population is set but not necessarily worst-off or badly-off. This reflects what is typical rather than ideal.

[41] Pratt & Hyder, *op. cit.* note 13.

[42] Young, *op. cit*. note 26.

badly-off categories. However, even within a poor, rural setting where access to healthcare and services is under-resourced, there may still be disparities in health and wellbeing that qualify some people as being ‘worst-off’ or ‘badly-off’ as compared to others who are ‘better off’. This may the case for people affected by conditions that are generally under-resourced such as mental health conditions. Where health services for other conditions may be poor, health services for psychiatric illness may be non-existent, meaning that patients suffering from such conditions are arguably worse-off than the general population in that locality. Similarly, people that are stigmatised or marginalized may be worse-off such as (again) psychiatric patients and members of the lesbian, gay, bisexual, transgender and queer (LGBTQ) community. The determination of who falls into the worst-off and badly-off categories within the research population, therefore, requires an internal comparison between individuals within the same local, provincial/district, or national location. The most socially privileged group in that location can serve as the reference group.[43]

The ethical framework requires that members of disadvantaged groups within the research population be specifically included in deliberations to the extent that proposed research is *relevant* to them. Selecting disadvantaged groups for whom the research is relevant will likely be aided by current practice in global health research, where certain aspects like the broad research topic are typically already set when engagement commences (due to researcher expertise, available funding opportunities, etc.). While we note that this may not be ideal from a shared health governance perspective, as it places limits on sharing sovereignty with LMIC community members, it will likely aid in identifying who should be engaged in the context of particular research projects. As an example, a project on maternal and child health in an African country could be based in rural districts where certain

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[43] Braverman, P. (2016). Health Difference, Disparity, Inequality, or Inequity—What Difference Does it Make What we Call it? An Approach to Measuring and Conceptualizing Health Inequalities and Health Equity. In M. Buchbinder, M. Rivkin-Fish, & R.L. Walker (Eds.), *Understanding Health Inequalities and Justice: New Conversations across the Disciplines* (pp. 33-63). Chapel Hill, NC: University of North Carolina Press.

categories of women are more vulnerable and have worse health: disabled women, unwed teenagers, single mothers, and victims of domestic abuse. These disadvantaged groups would likely be most relevant to engage given the topical focus of the research project. Those members who are engaged should span various demographics within the groups because doing so will give rise to differing perspectives on their health needs.

Including those with the power to change policies and practices would require *also* engaging higher-level stakeholders (not just local but also district/provincial/regional and national), potentially encompassing a variety of research user roles and demographics that would depend on the nature of the research project. These could be for instance policymakers that set health priorities and budgets at district/provincial and/or national levels, healthcare providers from primary and/or secondary institutions, individuals responsible for health facility management in urban and/or rural areas, health insurers, and product manufacturers. For example, a project focusing on child health in a particular state within a LMIC could engage with state policymakers during the development of the state's annual health service delivery plan and develop relationships with key media contacts to push childhood undernutrition and poor health up the state's political agenda.[44] Effective research translation can help deliver the conditions (e.g. new medicines, improved health systems) necessary for the worst-off or badly-off to attain an optimal level of health. Who is specifically engaged within this category may likely be an adaptive process, shifting somewhat as the research question becomes more defined and between different phases in the research process.

By contrast, CE activities seem to focus on recruiting individuals for different reasons such as their being either directly involved in or affected by the research project. This means that those engaged are prospective participants or their family members, or that a research project taking place in their community may directly affect them even

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[44] Pratt, B., & Hyder, A.A. (2017). Linking the Governance of Research Consortia to Global Health Justice: A Case Study of Future Health Systems. *Journal of Law, Medicine & Ethics*. 45, 664-681.

if they are unlikely to be enrolled.[45] An example of the latter would be a genomics study, which may reveal something about group genetics that could affect members of the community beyond research participants.[46] CE normally also involves individuals that play an important gatekeeper role (i.e. can provide administrative or actual access to communities) or that are knowledgeable about community culture and processes and can, therefore, help identify or address potential negative implications of the research project on the community. Examples of these latter kinds of roles are traditional or administrative leaders, teachers, nurses, community health workers, and religious leaders. A key distinction with the research collaboration governance framework is then that, while most individuals recruited for CE activities are part of the research population or host community, they are not necessarily members of disadvantaged groups within it or individuals with the power to change policies and practices that affect such groups' health.

Another key distinction is that CE practice typically involves *local* community members rather than community members working at the district/provincial or national levels. Where CE endeavours do involve individuals at district/provincial or national levels, the focus of such involvement seems to be on identifying potentially adverse implications of research projects and ensuring access to communities rather than promoting the use of research findings to improve health policies and practices affecting the worst-off. The *nature* of that involvement is usually minimal and limited to the provision of information and seeking of permission to conduct research in a particular community. Applying the requirements for inclusive decision-making that are found in the research collaboration governance framework then supports engaging a much broader group of LMIC community members—beyond the local level—than have traditionally been involved in CE activities around health research in Africa.

How to engage

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[45] Participants in the Community Engagement & Consent Workshop, *op. cit*. note 11.

[46] Tindana et al., *op. cit*. note 11.

Level of participation

A variety of levels of participation exist, with some more 'active, deliberative, and influential' than others.[47] These range from *lay control* to *shared decision-making* between researchers and LMIC community members to *consultation* of LMIC community members, which may or may not use deliberative processes to gather information. Lay control means citizens are solely responsible for decision-making with (at most) consultative input from experts (researchers or development practitioners). Collaboration involves shared decision-making and two-way communication between experts and citizens. Consultation is characterised by citizens being invited to give their input in various ways but having no assurance that it will be used by those who decide.[48] Whilst the ideal of the research collaboration governance framework is that of shared decision-making between researchers and LMIC community members, CE seems to focus more on promoting consultation that is often not deliberative in nature.[49] Consultation is a less active level of participation because, while LMIC community members' input is collected, researchers retain decision-making power over, for example, setting research questions and intervention design.[50]

That shared health governance emphasises shared decision-making and not lay control, which is often viewed as the highest level of citizen participation, is acknowledged. Future work should explore whether this is unnecessarily restrictive. It may be a significant limitation of relying on that particular theoretical foundation to provide a justification for engagement in global health research.

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[47] Crocker, D.A. (2006). Forward. In D. Goulet (Ed.), *Development Ethics at Work: Explorations-1960-2002* (pp. xiv-xxx). New York, NY: Routledge, p. xxvii.

[48] Arnstein, S. R. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners.* 35(4), 216-224; Rowe, G., & Frewer, L.J. (2002). A Typology of Public Engagement Mechanisms. *Science, Technology, & Human Values*. 30(2), 251-290.

[49] Participants in the Community Engagement & Consent Workshop, *op. cit*. note 11; Tindana et al., *op. cit*. note 11.

[50] Pratt & Hyder, *op. cit.* note 13.

Deliberation

The research collaboration governance framework calls for shared decision-making to be *deliberative*. Young and Richardson characterize deliberative decision-making as a process of discussing problems or claims of need through dialogue with others who test and challenge these proposals.[51] The deliberative public rejects or refines proposals and collectively agrees on those proposals that are supported by the best reasons.[52]

Accordingly, the framework expects researchers and LMIC community members to undertake deliberative processes involving progressive consensus building, where both parties first express their views, concerns, suggestions, or other contributions they wish to make. The group then discusses the advantages and disadvantages of various proposals to ultimately agree on which is/are the best option(s).[53] To achieve such a result, researchers and LMIC community members must be mutually aware of, and responsive to, one another's perspectives and needs, modifying their preferred priorities in light of other participants' proposals.[54] Ideally, deliberation should transform participants' perspectives from an initial ‘narrow and selfregarding’ baseline to a more comprehensive understanding that takes others' needs and interests into account.[55] In this way, deliberation according to the framework is a means to facilitate decision-making based on consensus between researchers and LMIC community members.

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 non-deliberative processes such as surveys,

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[51] Young, *op. cit*. note 26; Richardson, H.S. (2002). *Democratic Autonomy: Public Reasoning About the Ends of Policy*. Oxford: Oxford University Press.

[52] Young, *op. cit*. note 26.

[53] Pratt & Hyder, *op. cit.* note 13.

[54] Richardson, *op. cit*. note 51.

[55] Young, *op. cit*. note 26, p. 112.

key informant interviews, and seminars.[56] Deliberative CE processes have, however, been used to inform institutional ethics policies on biobanking and benefit sharing.[57] Methods applied in these studies may be a rich resource to draw upon to inform practice. Key features include having a day of information provision and an introduction to deliberation prior to commencing deliberations, undertaking both small and large group deliberations, and having a ratification process that achieves closure but documents minority viewpoints.[58]

Equal voice

According to the research collaboration governance framework, an important aspect of deliberation is that it promotes an equal opportunity for all participants to express their views and for all views to be considered equally. In other words, the design of the deliberative process needs to account for existing power dynamics within the group of participants and seek to minimise their effect on deliberation. This ensures that the views expressed in decision-making processes are not solely those of more powerful actors.[59]

To promote equal voice, the framework posits that there is a need to assess power disparities between the different LMIC community members involved in the deliberation, and between them and researchers. Sources of power disparities could

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[56] Participants in the Community Engagement & Consent Workshop, *op. cit*. note 11; Tindana et al., *op. cit*. note 11.

[57] O'Doherty, K.C., Hawkins, A.K., & Burgess, M.M. (2012). Involving Citizens in the Ethics of Biobank Research: Informing Institutional Policy through Structured Public Deliberation. *Social Science & Medicine*. 75, 1604-1611; Marsh, V. et al. (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; Njue, M., Kombe, F., Mwalukore, S., Molyneux, S., & Marsh, V. (2014) What Are Fair Study Benefits in International. Health Research? Consulting Community Members in Kenya. *PLoS ONE.* 9(12), e113112. doi:10.1371/journal.pone. 0113112

[58] O'Doherty et al., *op. cit.* note 57.

[59] Pratt & Hyder, *op. cit.* note 13.

relate to existing ethnic relations in a country or where people reside (rural versus urban). In some cases, they can arise because certain groups are more powerful economically or politically than others or have higher levels of education. For instance, doctors, nurses, and other medical professionals tend to have greater authority than health workers who have not attended or completed education. In addition, power differentials could be caused by existing social or political marginalisation. The second step would be to develop strategies for reducing the impact of these power disparities during engagement. This could involve ensuring that people with less power are over-represented in deliberative forums or that the methods of deliberation favour those with less power (e.g. through choice of venue, language, means of discussion).

Both steps are particularly important given that the two categories of LMIC community members that we have identified as essential to engage (people with pertinent knowledge of the health needs of the worst-off or the badly-off, and people with the power to change policies and practices that affect them) will likely have substantial power disparities between them. Yet the aforementioned strategies may not always be sufficient to address the depth of power inequality between members of disadvantaged groups and those in powerful positions in terms of setting policy and practice. In these cases, it may make sense not to engage both sets of actors in the same deliberative forum and to have separate processes. At times, those with the means to change health policy and practice may even be the same parties responsible for oppressing particular disadvantaged groups. For example, in South Africa, local administrators can be powerful oppressors of the LGBTQ community and their access to health services. Does that mean these local administrators or oppressors in general should not be engaged with at all as part of the research process? This question requires further exploration. At a minimum, it would arguably not be desirable for them to participate in the same deliberative forum as members of LGBTQ community. Another matter to consider then is, where multiple deliberative fora are necessary, how should their outputs be brought together? And who is given the power to determine which outputs are used in decision-making and how they are integrated?

By contrast, CE practices appear to not normally be explicitly designed to recognise or reduce existing power differentials in the engaged community, nor do its practitioners describe how these have been dealt with in practice. In fact, some CE activities – most notably, traditional community meetings such as durbars – specifically draw on existing social hierarchy and traditional leadership structures to start the process of engagement.[60] Where such local structures are characterised by norms where minorities are simply informed and generally do not have a say, consultations or shared decision-making using these structures will likely mean minorities are present but rarely speak.[61] It seems untenable that in those cases, a principle of respect for cultures and community values would justify diluting the criteria for deliberation that we have outlined, but we recognise that showing respect for cultures is important. How to resolve the tension between that principle and our criteria thus merits further investigation.

When to engage

Stage of participation

The stage in decision-making at which LMIC community members begin to participate has particular normative significance. Possible entry points include the initial diagnosis of the problem, identification of possible solutions, selecting a course of action, and evaluation during implementation. The earlier individuals enter the process, the higher is the quality of their participation.[62] The research collaboration

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[60] Tindana, P.O., Rozmovits, L., Boulanger, R.F., Bandewar, S.V., Aborigo, R.A., Hodgson, A.V., Kolopack, P., & Lavery, J.V. (2011). Aligning Community Engagement with Traditional Authority Structures in Global Health Research: A Case Study from Northern Ghana. *American Journal of Public Health*. 101(10), 1857-1867.

[61] Mompati, T., & Prinsen, G. (2011). Ethnicity and Participatory Development Methods in Botswana: Some Participants are to be Seen and not Heard. In A. Cornwall (Ed.), *The Participation Reader* (pp. 224-237). New York, NY: Zed Books.

[62] Goulet, D. (1995). *Development Ethics: A Guide to Theory and Practice.* New York, NY: Apex Press.

governance framework suggests that deliberative decision-making with LMIC community members should take place throughout the research process, from topic solicitation, prioritization, and formulating research questions to intervention design, data collection, data analysis, and dissemination.[63]

The role thus awarded to deliberation with LMIC community members seems to exceed the role that is normally awarded to CE, although various authors argue for the importance of ensuring that CE is effective throughout the research process. Tindana et al. and Emerson et al. have suggested different models for ensuring CE plays a key role in informing governance decisions in the context of research projects involving the secondary use of samples and data.[64] Yet what is critical is that most CE initiatives take place after research priorities and questions are conceptualised. This is a significant difference with the requirements of the research collaboration governance framework, which insists that deliberation with LMIC community members occur as part of selecting research priorities and formulating research questions in order to ensure that research maximally contributes to promoting health equity. In other words, in the context of CE, engagement is serviceable to a pre-defined research project and question, whereas in the research collaboration governance framework, deliberation lies at the heart of project development so that the ultimate project is serviceable to the greater goal of reducing health disparities.

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[63] Pratt & Hyder, *op. cit.* note 13; Mullins, C.D., Abdulhalim, A.M. & Lavalee, D.C. (2012). Continuous Patient Engagement in Comparative Effectiveness Research. *Journal of the American Medical Association.* 307(15), 1587-1588.

[64] Emerson, C.I., Singer, P.A., & Upshur, R.E. (2011). Access and Use of Human Tissues from the Developing World: Ethical Challenges and a Way Forward Using a Tissue Trust. *BMC Medical Ethics*. 12, 1-5; Tindana, P., Molyneux, C., Bull, S., & Parker, M. (2014). Ethical Issues in the Export, Storage and Reuse of Human Biological Samples in Biomedical Research: Perspectives of Key Stakeholders in Ghana and Kenya. *BMC Medical Ethics*. 15, 76.

In this sense, deliberation as described by the research collaboration governance framework may bear more resemblance to ongoing and programmatic CE such as that conducted as part of the Kenya Medical Research Institute (KEMRI)-Wellcome Trust Research Programme in Kilifi.[65] In Kilifi, all health research takes place in the context of a decade-long relationship between a health research centre and a thorough CE program, which focuses more broadly on what issues are pertinent to communities rather than on single identified projects. As such, it is more likely that KEMRI CE activities are a vehicle for identifying new research questions that would otherwise not have been conceived or received attention and, thereby help address hermeneutical deficits.[66]

DISCUSSION

In this paper, we have argued that engagement is a necessary component of global health research that aims to advance health justice. Shared health governance can establish grounds for requiring the engagement of LMIC community members in such research. This philosophical basis has important implications for the ethical goals ascribed to engagement and the approach adopted to undertake it. Initial ideas are presented in relation to both. We suggest the ethical goals of engagement should include: 1) generating research priorities and questions that reflect the key problems disadvantaged groups face in accessing healthcare, services, and broader social determinants of health and 2) promoting research findings' translation into policy and practice in ways that benefit disadvantaged groups' health. We propose that engagement practice should have the following features:

- Inclusion of members of relevant disadvantaged groups and those with the power to change policy and practice to benefit them,

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[65] Marsh et al., *op. cit.* note 10.

[66] Hutchison, K., Rogers, W., & Entwistle, V. (2016). Addressing Deficits and Injustices: The Potential Epistemic Contributions of Patients to Research. *Health Care Analysis*, doi:10.1007/s10728-016-0323-5.

- Shared decision-making with LMIC community members rather than consultation,
- Deliberation with LMIC community members to make a range of project decisions, beginning with topic solicitation and/or prioritization, and
- Structuring deliberations to minimise the impact of power disparities between LMIC community members (and between LMIC community members and researchers).

The nature of the deliberation we describe is resource- and time-intensive and may have the perverse effect of slowing research or preventing otherwise worthwhile studies from being conducted. However, in line with theories of justice that outline the importance of procedural requirements for decision-making[67] and accounts applying such work to the research context,[68] we suggest that the *process* by which health research happens equally contributes to it being just as the *outcomes* it generates. Deliberation of the kind that we describe, in our view, is key to ensuring global health research's potential to promote global health justice. This suggests that whilst the deliberation we describe may indeed slow down or prevent research, it is a necessary component of such research. Changes to the funding and education environments can potentially lessen this impact by making more resources available and developing researchers' capacities to set up and undertake such deliberations. Establishing CE programs similar to the KEMRI model may do so as well.

The features we propose may not commonly be found in or *required* of CE practice in global health research at present. Key international ethics guidelines on CE—UNAIDS *Good participatory practice guidelines for HIV prevention trials* (2011), *Recommendations for community involvement in National Institute of Allergy and Infectious Diseases HIV/AIDS clinical trial research* (2009)—largely do not call for CE to have the four features we identify. Interestingly, the CIOMS *International*

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[67] Young, I.M. (2000). *Inclusion and Democracy*. Oxford: Oxford University Press; Daniels, N. (2008). *Just Health: Meeting Health Needs Fairly*. Cambridge: Cambridge University Press.

[68] Pratt, B., Merritt, M., & Hyder, A.A. (2016). Towards Deep Inclusion for Equity-oriented Health Research Priority-setting: A Working Model. *Social Science & Medicine*. 151, 215-224.

Ethical Guidelines for Health-related Research Involving Humans (2016) do describe CE in terms that are more compatible with what our analysis demonstrates – for instance, those guidelines insist on the involvement of community members as early in the research process as possible and allude to some form of shared decision-making as being essential to the research process. This is encouraging as it may *up the ante* so to speak for CE work in global health research, increasing possibilities for research to make further strides in reducing global health inequity.

The UNAIDS, CIOMS, and National Institute of Allergy and Infectious Diseases (NIAID) guidelines ascribe different ethical goals to CE than those that are proposed in this paper. They identify goals such as building trust and community support for research, showing respect, ensuring the relevance of proposed research to the affected community, ensuring research is culturally appropriate, and sharing information.[69] This may account for the differences between our account of CE practice and their recommendations. In terms of *who* should be represented, the UNAIDS and CIOMS guidelines define stakeholders as people who can 'influence or are affected by the conduct or outcome' of the research project;[70] the NIAID guidelines state that community representatives should include those infected and affected by HIV, service providers, advocates, and other stakeholders.[71] None emphasise the inclusion of disadvantaged and marginalised groups within the HIV community. The UNAIDS and CIOMS guidelines do consider government officials and policymakers to be stakeholders but they are selected based on their being affected by a given trial, rather than their capacity to change policy and practice in

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[69] UNAIDS. (2011). *Good Participatory Practice Guidelines for HIV Prevention Trials.* Geneva: UNAIDS; National Institute of Allergy and Infectious Disease (NIAID). (2009). *Recommendations for Community Involvement in National Institute of Allergy and Infectious Diseases HIV/AIDS Clinical Trial Research*. Retrieved March 13, 2017, from http://www.mtnstopshiv.org/sites/default/files/attachments/CAB_Recommendations_Certified.pdf; CIOMS, *op. cit.* note 18.

[70] UNAIDS, *op. cit.* note 69, p. 14; CIOMS, *op. cit.* note 18.

[71] NIAID, *op. cit.* note 69.

ways that benefit disadvantaged and marginalised groups. (The NIAID guidelines discuss informing political leaders and decision-makers about trials but not consulting them or sharing decision-making with them as part of CE practice.)

In terms of *how* these stakeholders should be involved in HIV trials, none of the guidelines emphasises relying on deliberative processes. The UNAIDS guidelines do suggest that power imbalances ought to be dealt with in an honest, respectful, and transparent way.[72] The CIOMS guidelines note that 'good-quality community engagement helps to ensure that existing community dynamics and power inequities are not allowed to derail the process of ensuring the comprehensive engagement of all relevant community stakeholders.'[73] Like the UNAIDS guidelines, they do not elaborate on how this should be done. The UNAIDS guidelines focus largely on power imbalances between researchers and community members,[74] displaying limited recognition of the importance of addressing power imbalances *within* the community that is engaged. The UNAIDS guidelines also do not explicitly identify a role for CE in articulating the research agenda of HIV prevention trials.

In contrast, the NIAID guidelines do not discuss power disparities but do identify a role for community advisory boards (CABs) in developing the research protocol, implementing the research study, and disseminating research results. They also recommend that CABs set their own scientific research priorities.[75] The CIOMS guidelines require involving communities early on. They further state that 'before a study is initiated, the community from which participants will be recruited should, when feasible, be consulted about their research priorities, preferred trial designs.'[76] However, whilst the two guidelines affirm that CABs and community members should provide input into research questions and design for specific trials, the aim is consultation and contributing information rather than articulating a research question

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[72] UNAIDS, *op. cit.* note 69, pp. 18.

[73] CIOMS, *op. cit.* note 18, p. 26.

[74] Ibid: 20.

[75] NIAID, *op. cit.* note 69.

[76] CIOMS, *op. cit.* note 18, p. 26.

together with researchers. The use of deliberative processes structured to minimise power disparities are not identified as part of this involvement or when setting priorities.

Ultimately, we hope this paper starts a dialogue amongst ethicists, researchers, LMIC community members, and funders about what goals and approaches CE should have where global health research aims to advance health justice, and how they might be achieved in practice. There are many questions left to explore on this topic such as those we raised about whether or not to engage with powerful oppressors, governments, or other authorities who default on their responsibilities to ensure the health and wellbeing of their populations. Other questions include: how should the outputs of separate deliberative fora be combined and by whom and what ethical goals of CE are identified when accounts other than shared health governance are drawn upon as a foundation. Were Iris Marion Young's scholarship to be applied, for example, an ethical goal relating to empowerment and building relations of equality might be identified for CE, which would have important implications for how LMIC community members should be engaged. We think such future conceptual work is essential to further developing ideas around CE in equity-oriented global health research beyond the initial steps taken in this paper.

Empirical bioethics research is also needed. One particular question such work could focus on is how deliberation as we describe it relates to traditional decision making mechanisms and how possible tensions between respecting cultural norms and mitigating power disparities can be resolved in practice. Future work might adopt a more explicit reflective equilibrium approach, using practical examples of CE to further test and develop the ideas we present in this paper and to determine how they apply to different types of research (e.g. genomics, health systems, clinical). Nuances in the proposed CE approach may well be necessary for different types of research.

Finally, in this paper, we have limited our analysis to global health research that aims to reduce global health inequality. This suggests that our analysis – and thus the nature of the deliberation we describe – is limited to research that falls in the 'global health' category. Similarly, it is restricted to research that expressly seeks to reduce health inequality, to the exclusion of research that does not have such an explicit aim. We suggest that further conceptual and empirical work should explore whether and how the ethical goals and features of CE that we describe might apply in global health research that only implicitly seeks to address global health inequalities.