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Deliberation to Promote Shared Sovereignty in Health Research: Four Questions to Clarify Goals, Methods, and Scope

Jantina de Vries,

University of Cape Town

Syntia Nchangwi Munung, and

University of Cape Town

Paulina Tindana

Ghana Health Service

Pratt and Hyder (2016) explore how governance mechanisms can help global health research consortia attain their explicit or underlying equity objectives. One key feature of their model concerns shared sovereignty, which can be achieved through what they call ‘*deliberative decision-making*’, in which a broad range of societal actors with health-related roles are involved in the development of governance structures, identification of research priorities, resource allocation decisions, and agreed standards for collaboration (ibid: 12). Pratt and Hyder identify different key components of deliberation that would lead to shared sovereignty and thus, ultimately, to research that has a chance of reducing global health inequalities. These are, for instance, that research partners in high income countries (HICs) only assist researchers from low and middle income countries (LMICs) in decision-making but do not take a directive role or even have an equal opportunity to share their views. They also suggest that what is important is broad representation of stakeholders, including representatives from disadvantaged groups – and presumably Pratt and Hyder here mean broad representation from people in LMICs, not HICs – as well as the means of involvement.

Our commentary seeks to critically explore the limitations of Pratt and Hyder’s description of both the means and goals of deliberation. We draw on our experience of being involved in various forms of genomics research in Africa, where some methods of deliberation and community involvement have been key to the research process. We then provide some key recommendations on how a legitimate deliberative process can be achieved in global health research.

Our first critique relates to *who is involved* in deliberation and touches on Pratt and Hyder’s desire for ‘broad societal representation of all stakeholders’, including those from more disadvantaged groups. It intersects with a concern about Pratt and Hyder’s recommendation that truly just health research requires a focus on the ‘worst off’ in a country. The critique is this: that in LMICs (as is also true for people in HICs), many people in society are

politically, economically, and socially disenfranchised and badly off, with a health status that is far from the global average, but that there are also invariably groups that are more marginalised or disempowered than others in these societies. What is not clear in Pratt and Hyder's account is when and to which extent research should involve representatives from both those groups – the badly off and the worst off. These groups may sometimes have opposing views or be the actors of marginalisation of other groups. We suspect that what Pratt and Hyder mean – but this would merit clarification – is that what is required is a genuine effort to involve *pertinent* LMIC stakeholder groups who have an interest in a project, and not just all stakeholder groups in a country. For instance, in a project focusing on HIV/AIDS, it would make sense to deliberately seek out representation from the LGBT community but such a project would not necessarily merit from the involvement of, for instance, a marginalised rural minority community with low infection rates of this virus, unless that project is being conducted directly in this community, in which case, the principle of respect would require that they are consulted and involved in the research process.

A second critique relates to the *moral justification* of deliberation, and here we draw on our broad experience with fostering and conducting community engagement in the context of health research broadly, and genomics research specifically (Campbell et al., 2015; P. Tindana et al., 2015; P. O. Tindana et al., 2011). There are parallels with deliberation and community engagement that seem pertinent for a discussion of Pratt and Hyder's work: for instance, both require broad representation of different stakeholders in a target population, both rely on mutual communication about research, and both have the ambition to solicit critical discussion about research processes with the aim of improving these (in the case of community engagement the aim being to make research more ethical, whilst in the case of deliberation as described by Pratt and Hyder to achieve shared sovereignty and promote research collaborations' ability to reduce health inequality). What we would like to highlight here is that although we intuitively strongly support community engagement as a means of ensuring the upkeep of high ethical standards when conducting research (in LMICs), we are also troubled by the absence of a strong philosophical account rooting community engagement in a moral theory – and we wonder if this too is in parallel with Pratt and Hyder's focus on deliberation. Unlike the case of informed consent – which is strongly rooted in a breadth of philosophical work exploring the importance of autonomy in the human moral experience – community engagement often seems to be conducted because it is a 'good idea'. It is possible that in the African research context, a philosophical justification for community engagement can be found in what is called Ubuntu philosophy in South Africa, or 'African moral theory' in other parts of the continent (Metz & Gaie, 2010) – but this work is in its infancy and remains controversial on the African continent.

A third critique relates to the *methodology* of deliberation. There are several research groups that have sought to conduct deliberation of the standard Pratt and Hyder seek to achieve (Burgess, 2014; Longstaff & Burgess, 2010; V. Marsh et al., 2013). But such deliberation is resource and time intensive and limited in scope. For instance, in the examples we know of, deliberation was used to inform the development of a governance framework for biobanks (O'Doherty et al., 2011) or to seek community feedback on the return of individual genetic research results (Marsh, Kombe, Fitzpatrick, Molyneux, & Parker, 2013), but it was not used

to also inform on priority setting, resource allocation decisions, and the other aspects of research collaboration identified by Pratt and Hyder. There is no reason, of course, that the deliberative panels forwarded by Burgess et al. could not also be convened to explore those questions – but this may have implications for panel composition for instance. In our experience with community engagement, we have also been troubled by the absence of methodological discussions, particularly those pertaining to the assessment of effectiveness. There is limited evidence that community engagement makes for more ethical science – partly because we haven't been very effective at outlining measurable objectives and tracing the impact of the work we do. The critical question here relates to evidence that deliberation *makes for better research* – with 'better' meaning either more ethical or more effective at reducing health inequalities.

This brings us to our fourth and final critique, which relates to the *scope* of deliberation. What we think is required is an account of when (at what stage) decision-making should be based on deliberation, and who should be involved when. For instance, although it is fairly straightforward to imagine deliberative processes supporting priority setting, it is more difficult to envisage how broad deliberation would function if it was a central feature of all consortia decision-making – and we are not here talking about deliberation between LMIC and HIC consortia partners, but mostly about deliberative decision-making between other stakeholders in society described by Pratt and Hyder, including for instance the 'worst-off', policy makers, representatives of civil society organisations, and so forth. Clarifying the scope of deliberation is also important considering that the kinds of research collaborations that Pratt and Hyder focus on tend to be really big and involve many stakeholders and research groups in LMICs and HICs. A critical question is how deliberation could meaningfully be fostered across those sites and partners.

We agree with Pratt and Hyder's point about the importance of deliberative decision-making in global health research, as a critical component of ensuring shared sovereignty. Drawing on our experiences of working in international research networks involving researchers from HICs and LMICs, we believe in the need for genuine efforts to be made to incorporate the voices of key stakeholders, including marginalised groups, in the research process with an emphasis that this ought to be done throughout the research process. But we also think that in order for deliberation to have the kind of impact envisaged by Pratt and Hyder, we need to think critically about who is involved in deliberation when, how they are involved, and for what reasons. For deliberative decision making to serve its purpose, it is important these issues are critically evaluated.

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