



Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

Pratt, B

Title:

Constructing citizen engagement in health research priority-setting to attend to dynamics of power and difference

Date:

2019-01-01

Citation:

Pratt, B. (2019). Constructing citizen engagement in health research priority-setting to attend to dynamics of power and difference. *Developing World Bioethics*, 19 (1), pp.45-60. <https://doi.org/10.1111/dewb.12197>.

Persistent Link:

<https://hdl.handle.net/11343/284105>

DR BRIDGET PRATT (Orcid ID : 0000-0002-4934-3560)

Article type : Original Article

Conflict of interest statement: No conflicts declared

**RH [PRATT**

**Constructing citizen engagement in health research priority-setting to attend to dynamics of power and difference**

**Bridget Pratt**

Correspondence

Bridget Pratt, PhD, School of Population and Global Health, University of Melbourne, Carlton, Victoria 3053 Australia.

Email: [bridget.pratt@unimelb.edu.au](mailto:bridget.pratt@unimelb.edu.au)

**Abstract:** Engaging citizens is vital to achieving people-centred health research. This paper aims to put attention to dynamics of power and dynamics of difference back at the centre of citizen engagement in health research priority-setting. Without attention to power and difference, engagement can lead to presence without voice and voice without influence, particularly for disadvantaged and marginalised groups. By analysing six key bodies of literature, the paper first identifies the different components of engagement—who initiates, for what purpose, who participates, and how they participate—and the dimensions of power and dimensions of difference relevant to each of them. For each component of engagement, the ethical considerations relating to those dimensions of power and dimensions of difference are characterised for the research priority-setting context and preliminary guidance on how they might be addressed is provided. An initial framework comprised of a series of questions reflecting these ethical considerations has been developed for use by researchers and citizens when designing engagement processes for research projects. Where researchers and citizens attend to the framework's questions and then revise their priority-setting processes' design to better represent diversity and mitigate power disparities, more *inclusive* citizen engagement is promoted. Disadvantaged and marginalised groups are more likely to be present and heard, which, in turn, will help generate research projects with topics and questions that encompass and more accurately reflect their health needs.

**This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/dewb.12197](https://doi.org/10.1111/dewb.12197)**

This article is protected by copyright. All rights reserved

## KEYWORDS

ethics, justice, research ethics

## 1. INTRODUCTION

Engaging citizens—from policymakers and providers to patients and members of marginalised or disadvantaged groups—is vital to achieving people-centred health research.<sup>1</sup> In health systems research, for example, citizen engagement helps ensure that projects' research questions and intervention design reflect the specific circumstances or problems facing the health system of the host community or country. Their engagement has been identified as an ethical imperative because it is central to respect for persons and will likely improve health outcomes, facilitate the stewardship of resources, enhance prospects for justice, and build public trust.<sup>2</sup> Funders, particularly those of applied health research, increasingly expect researchers to engage with citizens *throughout* the research process in countries worldwide.<sup>3</sup> This entails involving citizens not only in shaping research projects'

---

<sup>1</sup> Woolf SH, Zimmerman E, Haley A, Krist AH. (2016). 'Authentic Engagement of Patients and Communities can Transform Research, Practice, and Policy'. *Health Affairs*, 35(4): 590-594; Sheikh K, George A, Gilson L. (2014). 'People-centred Science: Strengthening the Practice of Health Policy and Systems Research'. *Health Research Policy and Systems*, 12: 19.

<sup>2</sup> Solomon MZ, Gusmano MK, Maschke KJ. (2016). 'The Ethical Imperative and Moral Challenges of Engaging Patients and the Public with Evidence'. *Health Affairs*, 35(4): 583-589; MacQueen KM, Bhan A, Frohlich J, Holzer J, Sugarman J, and the Ethics Working Group of the HIV Prevention Trials Network. (2015). 'Evaluating Community Engagement in Global Health Research: The Need for Metrics'. *BMC Medical Ethics*, 16: 44.

<sup>3</sup> Fleurence R, Selby JV, Odom-Walker K, Hunt G, Meltzer D, Slutsky JR, Yancy C. (2013). 'How the Patient-Centered Outcomes Research Institute is Engaging Patients and Others in Shaping its Research Agenda'. *Health Affairs*, 32(2): 393-400; van Bekkum JE, Hilton S. (2014). 'UK Research Funding Bodies' Views Towards Public Participation in Health-related Research Decisions: An Exploratory Study'. *BMC Health Services Research*, 14: 318; Pratt B, Hyder, AA. (2016). 'Designing research funding schemes to promote global health equity: An exploration of current practice in health systems research'. *Developing World Bioethics*, DOI: 10.1111/dewb.12136.

design, conduct, and dissemination but also in setting their research topics and formulating their research questions.<sup>4</sup>

However, there remains limited guidance on what inclusive and meaningful engagement in health research entails. So far, conceptual frameworks have been developed that identify possible categories of stakeholders to engage and the specific steps in the research process in which to engage them.<sup>5</sup> These frameworks have largely been derived from experiences and observations from engagement practice in research. Good participatory practice guidelines have also been developed for international clinical research focused on HIV/AIDS.<sup>6</sup>

This paper builds on and complements that existing work by characterising the *ethical* considerations to take into account when designing citizen engagement in health research *priority-setting* so that it attends to dynamics of power and dynamics of difference. Without attention to power and difference, engagement can lead to a lack of presence, presence without voice, and voice without influence. Voices are then excluded from priority-setting, particularly those of disadvantaged and marginalised groups who often have the worst health. Existing evidence confirms that being *female*, being *poor*, having *little education*, having a *disability*, and/or belonging to certain *ethnic groups* means citizens are listened to less or not at all in health priority-setting.<sup>7</sup>

---

<sup>4</sup> Woolf et al., *op cit.* note 1.

<sup>5</sup> Concannon TW, Meissner P, Grunbaum JA, et al. (2012). 'A New Taxonomy for Stakeholder Engagement in Patient-centered Outcomes Research'. *Journal of General Internal Medicine*, 27(8): 985-991; Mullins CD, Abdulhalim AM, Lavalee DC. (2012). 'Continuous Patient Engagement in Comparative Effectiveness Research'. *Journal of the American Medical Association*, 307(15): 1587-1588.

<sup>6</sup> United Nations Programme on HIV/AIDS (UNAIDS) and Global Advocacy for HIV Prevention (AVAC). (2011). *Good Participatory Practice Guidelines for Biomedical 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 Trials Research*. Washington D.C.: National Institutes of Health.

<sup>7</sup> Shayo EH, Norheim OF, Mboera L, et al. (2012). 'Challenges to Fair Decision-making Processes in the Context of Health Care Services: A Qualitative Assessment from Tanzania'. *International Journal*

The paper's focus on priority-setting derives from a lack of discussion in the ethics literature around engagement during this key phase of the research process. Existing literature commonly focuses on engagement during research projects' implementation and ethical review.<sup>8</sup> The paper's focus is not meant to imply it is sufficient to include citizens in the priority-setting phase of research alone. Citizen engagement is critical in all phases of research projects.<sup>9</sup>

The exclusion of citizens' voices in priority-setting is ethically problematic because it violates fundamental ethical principles—respect for persons and justice—and obstructs achievement of ethical goals ascribed to citizen engagement in health research. Those goals include: sharing power with citizens, shaping relevant research questions, and creating positive change/action for health (including for disadvantaged groups).<sup>10</sup> Where citizens' voices, and

---

for *Equity in Health*, 11: 30; Alderman KB, Hipgrave D, Jimenez-Soto E. (2013). 'Public Engagement in Health Priority-setting in Low- and Middle-Income Countries: Current Trends and Considerations for Policy'. *PLoS Medicine*, 10(8): e1001495.

<sup>8</sup> Valley A, Shagi C, Kasindi S, Desmond N, Lees S, Chiduo B, Hayes R, Allen C, Ross D, and the Microbicides Development Programme. (2007). 'The Benefits of Participatory Methodologies to Develop Effective Community Dialogue in the Context of a Microbicide Trial Feasibility Study in Mwanza, Tanzania'. *BMC Public Health*, 7: 133; Boga M, Davies A, Kamuya D, et al. (2011). 'Strengthening the Informed Consent Process in International Health Research through Community Engagement: The KEMRI-Wellcome Trust Research Programme Experience'. *PLoS Medicine*, 8(9): e1001089; Sharp RR, Foster MW. (2000). 'Involving Study Populations in the Review of Genetic Research'. *Journal of Law, Medicine, & Ethics*, 28(1): 41-51; King KF, Kolopack P, Merritt MW, Lavery JV. (2014). 'Community Engagement and the Human Infrastructure of Global Health Research'. *BMC Medical Ethics*, 15: 84.

<sup>9</sup> Cargo M, Mercer SL. (2008). 'The Value and Challenges of Participatory Research: Strengthening its Practice'. *Annual Review of Public Health*, 29: 325-350; Wallerstein N, Duran B. (2006). 'Using Community-based Participatory Research to Address Health Disparities'. *Health Promotion Practice*, 7(3): 312-323.

<sup>10</sup> Gradinger F, Britten N, Wyatt K, et al. (2013). 'Values Associated with Public Involvement in Health and Social Care Research: A Narrative Review'. *Health Expectations*, 18: 661-675; Shippee ND,

in particular those of disadvantaged and marginalised groups, aren't heard in priority-setting, such processes are much less likely to generate outputs that reflect or include their health concerns. Where research is less relevant to these groups, it is much less likely to generate knowledge that will improve public health and health care systems for them. Additionally, excluding citizens' voices violates their right to participate in research, which encompasses a right to have input into the research agenda (NHMRC 2017). It is, therefore, vital to design citizen engagement in research priority-setting to attend to dynamics of power and dynamics of difference in order to prevent such outcomes.

In this paper, the concept of engagement is first *deconstructed* in terms of power and difference. This approach reflects the fact that engagement is a concept with discrete components that introduce important ethical considerations.<sup>11</sup> However, deconstruction on its own often runs the risk of depoliticising concepts, turning achieving engagement into a technique that doesn't pay sufficient attention to the power relations inherent in its conduct.<sup>12</sup> To deconstruct engagement, key bodies of literature were, therefore, analysed to identify its components *and* the dynamics of power and dynamics of difference relevant to each of them. These key bodies were: development literature on participation, political philosophy literature on the democracy of difference, health priority-setting literature on participation, public deliberation literature, community-based participatory research (CBPR) literature, and patient/consumer/user/community engagement/involvement in research literature, which included literature on researchers' and citizens' perspectives of engagement.

---

Domecq Garces JP, Prutsky Lopez GJ, et al. (2013). 'Patient and Service User Engagement in Research: A Systematic Review and Synthesized Framework'. *Health Expectations*, 18: 1151-1166; UNAIDS and AVAC, *op cit.* note 6.

<sup>11</sup> Cohen J, Uphoff N. (2011). 'Participation's Place in Rural Development: Seeking Clarity through Specificity', in A. Cornwall (ed.) *The Participation Reader*. New York, NY: Zed Books, p. 34-56; Chambers, R. (2011). 'Managing Local Participation: Rhetoric and Reality', in A. Cornwall (ed.) *The Participation Reader*. New York, NY: Zed Books, p. 165-171.

<sup>12</sup> Hickey S, Mohan G. (2004). 'Towards Participation as Transformation: Critical Themes and Challenges'. In: Hickey S, Mohan G, editors. *Participation from Tyranny to Transformation*. London: Zed Books, p. 2-24; Gaventa J. (2006). 'Finding the Spaces for Change: A Power Analysis', *IDS Bulletin*, 37(6): 23-33.

Literature was identified through key informants' knowledge and handsearching. Key informants familiar with each of the key bodies first identified core authors and works on participation in their fields. The those works and authors' publications were collected. A handsearching technique was then used to review their reference lists in order to identify additional publications. The reference lists of those publications were then reviewed to identify more sources and so on. Conceptual, empirical, and literature review articles and books on citizen participation or engagement in health research or health priority-setting were included, with empirical articles limited to those that used either concepts or frameworks to analyse practice or empirical results to inform concepts or frameworks for engagement. A systematic review of the six bodies of literature was not performed. A timeframe for including articles and books was not set because some seminal work on participation was written many years ago, e.g. Sherry Arnstein's Ladder of Participation. However, much of the identified literature was published from 1990 onwards.

Thematic analysis is a method for identifying and reporting patterns within data.<sup>13</sup> Literature from key informants and handsearching was thematically analysed for components of engagement and concepts relating to power or difference, with categories and sub-categories largely emerging from the data. Literature was collected and analysed until saturation was achieved—namely, no new components of engagement or concepts relating to power or difference were being found.

For each identified component of engagement, the paper explores how relevant dynamics of power and dynamics of difference might shape engagement in health research priority-setting at the *project level*. It characterises the resultant ethical considerations and provides preliminary guidance on how they might be addressed that is consistent with the principles of respect for persons and justice. Finally, an initial ethical framework is proposed that comprises a series of questions reflecting the identified ethical considerations and guidance. It is intended for use by researchers and citizens when constructing citizen engagement for research priority-setting and is meant to help them identify where their processes' design might be improved.

## 2.0 ETHICAL CONSIDERATIONS RELATED TO POWER AND DIFFERENCE

---

<sup>13</sup> Braun V, Clarke V. 2006. Using thematic analysis in psychology. *Qual Res Psychol* 3(2): 77–101.

Four components of *engagement*—who initiates, for what purpose, who participates, and how they participate—were identified through analysis of peer-reviewed publications from the aforementioned six key bodies of literature (Supplemental File 1). Iris Marion Young notes that deep inclusion involves not only who is invited to be present for a decision-making process but also how they are involved: do they have an equal opportunity to share their ideas during the process?<sup>14</sup> Andrea Cornwall further highlights a distinction between being able to raise one's voice and being listened to in decision-making processes.<sup>15</sup> These distinctions are also expressed in work from the health priority-setting, CBPR, and patient/consumer/user/community engagement/involvement in research literatures (Supplemental File 1). Beyond who participates and how the process of participation takes place, other key components of participation are: who initiates it and for what purpose.<sup>16</sup> Participation as freedom is not only the right to participate effectively in a given space but also the right to define and shape that space.<sup>17</sup> These distinctions are expressed in the health priority-setting and development literatures (Supplemental File 1).

For each component of engagement, this section introduces the relevant dynamics of power (e.g. making spaces, framing, knowledge synthesis) and dynamics of difference (e.g. range, channel) and then describes what ethical considerations relating to them apply during priority-setting for research projects. The identified components of engagement and dynamics of power and dynamics of difference were typically discussed in two or more bodies of literature, reflecting interdisciplinary convergence (Supplemental File 1). The dynamics of power relate to the main forms of power described in the participatory development literature—power to, power over, structural power, and discursive power.<sup>18</sup> Attending to such dynamics can promote citizens being present, raising their voices, and/or being heard during priority-setting. Since the meanings of power are diverse and often

---

<sup>14</sup> Young IM. (2000). *Inclusion and Democracy*. Oxford: Oxford University Press.

<sup>15</sup> Cornwall A. (2011). 'Whose Voices? Whose Choices? Reflections on Gender and Participatory Development'. In: Cornwall A, editor. *The Participation Reader*. New York, NY: Zed Books, p. 203-223.

<sup>16</sup> Cohen, Uphoff, *op. cit.* note 11

<sup>17</sup> Gaventa, *op. cit.* note 17

<sup>18</sup> Gaventa, *op. cit.* note 17; Nelson N, Wright S. (1995). *Power and Participatory Development: Theory and Practice*. London: Intermediate Technology Publications.

contentious, the way in which these forms of power are interpreted in this paper is clarified below (Box 1).

The dynamics of difference relate to the presence of diversity. Forms of difference are identified in terms of a diversity of ideas or a diversity of experience and identities, with the latter potentially (but not necessarily) generating the former.<sup>19</sup> Identities are related to individuals' social locations. Social locations can vary by country but typically include different genders, races, sexualities, cultures, and economic classes.<sup>20</sup> Differently situated persons' educational opportunities, access to resources, and political power are conditioned differently by social structures, giving rise to varied perspectives, interests, needs, goals, and knowledge.<sup>21</sup> Attending to dynamics of difference can promote a diversity of ideas and experiences being represented during priority-setting, either directly (representing oneself) or indirectly (being represented by others).

Box 1: Forms of power

Power to refers to the capacity to act, to know, to exercise agency, and to realise the rights of citizenship.<sup>22</sup> It can be experienced individually or collectively; Arendt affirms power is 'the human ability not just to act but to act in concert.'<sup>23</sup> Power to also refers to gaining the sense of self-identity, confidence, and awareness that are pre-conditions for action.<sup>24</sup>

Power over refers to the direct control of one actor over another. The classic definition

---

<sup>19</sup> Phillips A. (1996). 'Dealing with Difference: A Politics of Ideas, or a Politics of Presence?' In: Benhabib S, editor. *Democracy and Difference: Contesting the Boundaries of the Political*. Princeton, NJ: Princeton University Press, p. 139-152.

<sup>20</sup> Young, *op. cit.* note 14.

<sup>21</sup> Young IM. (1996). 'Communication and the Other: Beyond Deliberative Democracy'. In: Benhabib S, editor. *Democracy and Difference: Contesting the Boundaries of the Political*. Princeton, NJ: Princeton University Press, p. 120-136; Young, *op. cit.* note 14.

<sup>22</sup> Gaventa, *op. cit.* note 17.

<sup>23</sup> Arendt H. (1970). *On Violence*. New York: Harcourt Brace & Co, p. 44.

<sup>24</sup> Gaventa, *op. cit.* note 17.

expressed by Robert Dahl is: 'A has power over B to the extent that he can get B to do something that B would not otherwise do.'<sup>25</sup> A and B can be individuals, groups, or organisations. Power over is also exercised where A has control over a particular process or enterprise (e.g. knowledge production, priority-setting).<sup>26</sup>

Structural power refers to institutional practices (formal rules and procedures) and norms that enhance the capacities or possibilities for action of some and limit those of others.<sup>27</sup> It is exercised in decision-making when certain institutional practices and norms affect what issues get on the agenda, privilege the involvement of certain agents over others, and/or privilege the voices of certain agents over others.

Discursive power operates through language and concepts, creating meanings that lead us to think of the world in some ways but not others.<sup>28</sup> Discourse governs by framing and positioning who it is possible to be and what it is possible to do. By influencing how individuals think about the world, this form of power shapes one's beliefs, sense of self, and acceptance of the status quo, defining what is normal and acceptable. It has been described as the 'most insidious form of power': 'A may exercise power over B by getting him to do what he does not want to do, but he also exercises power over him by influencing, shaping, or determining his very wants.'<sup>29</sup>

Attending to ethical considerations related to dynamics of power and dynamics of difference promotes inclusive priority-setting, where hierarchies of privilege and subordination that marginalise the voices of disadvantaged groups are less likely to be reproduced. Communicating the experiences and knowledge derived from different social positions helps to correct the dominance of partial perspectives over the definition of problems and their possible solutions.<sup>30</sup> Drawing out the voices of members of disadvantaged and marginalised

---

<sup>25</sup> Dahl RA. (1957). 'The Concept of Power'. *Behavioral Science*, 2(3): 201-215, p. 202-203.

<sup>26</sup> Nelson, Wright, *op. cit.* note 18.

<sup>27</sup> Haugaard M. (2010). 'Power: A 'Family Resemblance' Concept'. *European Journal of Cultural Studies*, 13(4): 419–438.

<sup>28</sup> Shiffman J. (2014). 'Knowledge, Moral Claims and the Exercise of Power in Global Health'. *International Journal of Health Policy and Management*, 3(6): 297-299.

<sup>29</sup> Lukes S. (1974). *Power, A Radical View*. London: Macmillan, p. 23.

<sup>30</sup> Young, *op. cit.* note 11.

groups advances cognitive and epistemic justice<sup>31</sup>. Participants in priority-setting transform their opinions on what research priorities should be from narrow expressions of self-interest to a more complete account of what research is needed to serve the population as a whole, with particular attention to the disadvantaged.<sup>32</sup> Priority-setting processes are then more likely to deliver outputs that reflect or include disadvantaged groups' health concerns and that maximise the social knowledge generated to identify the complex problems that their impede health and well-being.<sup>33</sup>

## 2.1 Who initiates

### 2.1.1. Making spaces

Participation as freedom is not only the right to participate effectively in a given space but also the right to define and shape that space.<sup>34</sup> The concept of making spaces is widely used in development literature on participation. Andrea Cornwall reminds us that spaces are not neutral; making a space is in itself an act of power. She raises the distinction between 'invited spaces' and 'created spaces.'<sup>35</sup> Invited spaces are those into which people are invited to participate by various kinds of authorities. They are provided or owned by the powerful and often bring together a heterogeneous set of actors with significant differences in status, interests, and accountabilities.<sup>36</sup> Created spaces are those that are claimed by the

---

<sup>31</sup> Santos B. (2014). *Epistemologies of the South: Justice Against Epistemicide*. Boulder, CO:

Paradigm Publishers; Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

<sup>32</sup> Pratt B, Merritt M, Hyder AA. (2016). 'Towards deep inclusion for equity-oriented health research priority-setting: A working model'. *Social Science & Medicine*, 151: 215-224.

<sup>33</sup> Young, *op. cit.* note 11.

<sup>34</sup> Gaventa, *op. cit.* note 17.

<sup>35</sup> Cornwall A. (2004). 'Spaces for Transformation: Reflections on Issues of Power and Difference in Participation in Development', in S. Hickey and G. Mohan (eds.) *Participation from Tyranny to Transformation*. London: Zed Books, p. 75-91.

<sup>36</sup> Gaventa J. (2004). 'Towards Participatory Governance: Assessing Transformative Possibilities', in S. Hickey and G. Mohan (eds.) *Participation from Tyranny to Transformation*. London: Zed Books, p. 25-58; *Ibid.*

less powerful from the power-holders or created more autonomously by them.<sup>37</sup> They are often spaces that emerge organically out of common concerns or identifications experienced by marginalised groups in a society.<sup>38</sup> Cohen and Uphoff and Mitton et al. affirm that it is important to consider who instigates participation: does it come from the grassroots (the people, local leaders), the national centre, or foreign personnel?<sup>39</sup>

The implication of these concepts for citizen engagement in research priority-setting is, first, to recognize that such engagement is typically an invited space in practice, where foreign and/or local researchers invite citizens of the host country to participate in research projects. Two types of power dynamics are then often recreated within such spaces—namely, those of ‘expert’ researchers over ‘lay’ citizens and those of foreign researchers from high-income countries over researchers from low and middle-income countries (LMICs) (where research is conducted in LMICs). *A key ethical consideration when constructing citizen engagement for research priority-setting is then whether the process will be initiated by foreign researchers, local researchers, and/or citizens.* If foreign ‘experts’ are solely responsible, it will establish their *power over* who is included, what the purpose of the engagement exercise is, and how it is framed. They are also more likely to have power within spaces (i.e. during the priority-setting process).<sup>40</sup> Existing unequal power dynamics are much less likely to be recreated where local researchers and citizens initiate or are amongst those who initiate engagement and priority-setting in research projects. This occurs, for example, when a local community-based organisation approaches university researchers about collaborating on a research project.

## 2.2 For what purpose

### 2.2.1 Instrumental versus transformative

Multiple literatures identify two main purposes for participation: instrumental (i.e. as a means to another goal) and transformative (i.e. to generate empowerment) (Supplemental File 1). Participation as a means builds *power to* within existing social structures whereas participation as an ends builds *power to* in ways that are transformative at the micro and/or

---

<sup>37</sup> Cornwall, *op. cit.* note 35.

<sup>38</sup> Gaventa, *op. cit.* note 36

<sup>39</sup> Cohen, Uphoff, *op. cit.* note 11; Mitton C, Smith N, Peacock S, Evoy B, Abelson J. (2009). ‘Public Participation in Health Care Priority Setting: A Scoping Review’. *Health Policy*, 91: 219-228.

<sup>40</sup> Gaventa, *op. cit.* note 17.

macro levels, thereby shifting *power over* decision-making. Micro-level transformations consist of building individuals' knowledge, confidence, relationships, identities, and capacities.<sup>41</sup> These affective and cognitive changes can generate behaviour changes that challenge power dynamics.<sup>42</sup> Macro-level transformations refer to altering the social relations and institutions that shape individuals' capacities and actions.<sup>43</sup>

*The relevant ethical consideration for those engaging citizens in research priority-setting is then whether the exercise will be constructed as instrumental and/or transformative.* In health research, citizen engagement is often discussed as a means to enhance the relevance of research questions and to promote research translation, rather than as transformative.<sup>44</sup> However, where engagement in research priority-setting is constructed solely for instrumental purposes, this limits its capacity to mitigate disparities in *power over* knowledge production. It will fail to empower citizens in ways that support their right to participate in research and is, therefore, not ideal. At a minimum, where the purpose of engagement is solely instrumental, it should be made explicit and justified.

Where citizen engagement in research priority-setting is constructed for instrumental purposes, questions to answer are relevance to whom and sustainability for whom? The answers to these questions will demonstrate in whose interests the research project is likely being performed. They will also have significant implications for who should be invited to participate in priority-setting. The CBPR literature highlights a continuum between the

---

<sup>41</sup> Hickey, Mohan, *op. cit.* note 12; Kitchin R. (2000). The Researched Opinions on Research: Disable People and Disability Research'. *Disability & Society*, 15(1): 25-47.

<sup>42</sup> Oden K, Hernandez, B, Hidalgo MA. (2010). 'Payoffs of Participatory Action Research: Racial and Ethnic Minorities with Disabilities Reflect on their Research Experiences'. *Community Development*, 41(1): 21-31

<sup>43</sup> Hickey, Mohan, *op. cit.* note 12; Kitchin, *op. cit.* note 41.

<sup>44</sup> Ellis LE, Kass NE. (2016). 'How are PCORI-funded Researchers Engaging Patients in Research and What are the Ethical Implications?' *AJOB Empirical Bioethics*, Advanced Access published 28 June 2016, doi.org/10.1080/23294515.2016.1206045; Sheikh et al., *op. cit.* note 1.

‘utilisation-focused ‘Northern tradition’ and the ‘Southern emancipatory tradition.’<sup>45</sup> The former seeks to ‘produce knowledge that addresses the real-world needs of policy and practice decision makers and facilitate its translation into action.’<sup>46</sup> In the Southern tradition, partnerships are formed with disadvantaged and marginalised groups. Research seeks to identify and transform the root causes that produce and reproduce social disparities and hierarchies.<sup>47</sup> Falling on the Southern end of the spectrum may be more likely to help mitigate power disparities.

Where engagement in research priority-setting is constructed as transformative, questions to answer are: who is to be empowered and how? At the micro level, it could entail building LMIC researchers or disadvantaged groups’ capacity to participate more effectively in research priority-setting. This includes strengthening their *power to* understand the agendas and relationships of different stakeholders, to identify research questions, and to use the language of and debate with experts. Empowerment at the micro-level may then serve to facilitate macro-level transformations, gradually shifting *power over* knowledge production away from solely experts and/or foreigners (Nelson and Wright 1995).

### 2.2.2 Framing

Another question to consider is how will the priority-setting exercise be framed? To frame an issue means to select and highlight certain aspects of it and is a key site of power in decision-making. Whoever controls the frame of an issue shapes the outcome of the decision-making process.<sup>48</sup> Kadlec and Friedman distinguish between partisan framing to

---

<sup>45</sup> Cargo, Mercer, *op. cit.* note 9, p. 329-330; Wallerstein, Duran, *op. cit.* note 9; Trickett EJ. (2011).

‘Community-Based Participatory Research as Worldview or Instrumental Strategy: Is It Lost in Translation(al) Research?’ *American Journal of Public Health*, 101(8): 1353–1355.

<sup>46</sup> Cargo, Mercer, *op. cit.* note 9, p. 329.

<sup>47</sup> *Ibid.*

<sup>48</sup> Barisione M. (2012). ‘Framing a Deliberation: Deliberative Democracy and the Challenge of Framing Processes’. *Journal of Public Deliberation*, 8(1): Article 2; Blue G. Dale J. (2016). ‘Framing and Power in Public Deliberation with Climate Change: Critical Reflections on the Role of Deliberative Practitioners’. *Journal of Public Deliberation*, 12(1): Article 2.

persuade and non-partisan framing, where a diverse range of frames for an issue are made explicit at the outset of deliberative decision-making.<sup>49</sup>

In research priority-setting, framing can occur when the topics that can be raised are narrowed from the start, distorting or restricting what and/or whose health needs can be proposed as priorities. This can happen in a number of ways such as framing discussions to focus on the needs of particular groups (decision-makers, the disadvantaged), certain causes of poor health, types of research, certain diseases, and/or donor priorities. If individual-level causes (biological endowments, individual agency) are emphasised as the main drivers of poor health during priority-setting, this may exclude discussion of research topics related to population-level causes (environmental and social determinants).<sup>50</sup> Shayo et al. further note that autonomous priority-setting at the sub-national or national levels can be restricted where participants are required to adhere to particular national or donor priorities.<sup>51</sup> Those initiating priority-setting should, therefore, be reflexive about whether or not their framing is neutral and what frames are being used and why. *Will using the selected frames likely exclude key health needs experienced by the research population or certain groups' health needs from being considered during priority-setting?* If yes, alternative frames should be incorporated to minimise that risk.<sup>52</sup>

## 2.3 Who participates

### 2.3.1 Range

Range refers to ensuring participants span a wide spectrum of relevant roles and axes of difference in a society.<sup>53</sup> In general, relevant citizen roles to include could be: patients,

---

<sup>49</sup> Kadlec A, Friedman W. (2007). 'Deliberative Democracy and the Problem of Power'. *Journal of Public Deliberation*, 3(1): Article 8.

<sup>50</sup> Warr D, Mann R, Kelaher M. (2013). 'A Lot of the Things We Do... People Wouldn't Recognise as Health Promotion'. *Critical Public Health*, 23(1): 95-109.

<sup>51</sup> Shayo et al., *op. cit.* note 7.

<sup>52</sup> Barisione, *op. cit.* note 48.

<sup>53</sup> Crocker DA. (2008). *Ethics of Global Development: Agency, Capability, and Deliberative Democracy*. Cambridge: Cambridge University Press.

families and carers, providers, purchasers, payers, policymakers, and product makers.<sup>54</sup>

Axes of difference are individual characteristics likely to give rise to differential understandings of health or health system needs in the host country. For policymakers and providers, relevant axes of difference could include race; gender; working at the national, district, or local level; and working in the public or private sector.<sup>55</sup> For patients, they could include gender, family status (household head versus household member), level of education, ethnicity or caste, level of income, residence (urban versus rural), employment status (formal versus informal), and type of illness (acute versus chronic).<sup>56</sup>

Which roles and axes of difference citizen participants embody will affect what emerges from the research priority-setting space. For instance, focusing on citizen roles at the local versus national levels may set research priorities from the bottom-up or top-down respectively, which, in turn, may reinforce or counter existing power disparities. *When constructing citizen engagement for research priority-setting, a key ethical consideration is then which citizen roles will be included and along which axes of difference.* Both selections must be identified and justified.

The participatory development literature further emphasises the caveat that simply relying on standard axes of difference may not be appropriate in a given research setting. Dividing populations along externally defined axes of difference may take for granted forms of commonality that fail to reflect how people identify themselves or that match their concerns, connections, and agendas.<sup>57</sup> It is, therefore, important to identify axes of difference that are relevant in a given setting and to ensure that (amongst others) those corresponding to *powerlessness* are represented by citizens who participate in priority-setting. Doing so

---

<sup>54</sup> Cargo, Mercer, *op. cit.* note 9; Concannon et al., *op. cit.* 2012 note 5; Pratt, Merritt, Hyder, *op. cit.* note 32.

<sup>55</sup> Pratt, Merritt, Hyder, *op. cit.* note 32; Viergever RF, Olifson S, Ghaffar A, Terry RF. (2010). 'A Checklist for Health Research Priority Setting: Nine Common Themes of Good Practice'. *Health Research Policy and Systems*, 8: 36.

<sup>56</sup> Cohen, Uphoff 2011, *op. cit.* note 11; Pratt, Merritt, Hyder, *op. cit.* note 32.

<sup>57</sup> Cornwall 2011, *op. cit.* note 15; Cornwall A. (2008). 'Unpacking 'Participation': Models, Meanings and Practices'. *Community Development Journal*, 43(3): 269-283.

requires a dynamic understanding of people's social networks and what characteristics matter in the pursuit of livelihoods in a particular context.<sup>58</sup>

That achieving range specifically entails members of disadvantaged groups participate in decision-making was strongly emphasised in the literature (Supplemental File 1). Goulet's work on participatory development, for example, raises the principle of non-elite participation, which affirms disadvantaged groups should have a key role in deciding matters related to their basic interests like health.<sup>59</sup> Thus, the citizens engaged in research priority-setting should include members of disadvantaged groups.

*Another ethical consideration is then which disadvantaged groups will be included in the process.* As Schrijvers and others rightly affirm, the poor, the vulnerable, and the disadvantaged comprise an extraordinarily heterogeneous category that varies by country.<sup>60</sup> Those conducting engagement processes ought to adopt a definition of what constitutes 'disadvantage' in the country in which they are working, analyse the total heterogeneous context to identify which groups meet that definition (in the country or, where applicable, in the population within it with whom they are working), and make a choice as to which groups to include in priority-setting and why.

### 2.3.2 Channel of participation

Once roles and disadvantaged groups to include are identified, determining by what channel they are to participate is essential (Supplemental File 1). People can participate as individuals speaking for themselves, as individuals speaking for particular roles or groups, or as individuals speaking on behalf of organisations that represent particular roles or groups. For a decision-making process, a single channel or a combination of channels can be relied upon, e.g. having individual citizens as deliberators, representatives of organisations as deliberators, or both.<sup>61</sup>

---

<sup>58</sup> Cornwall 2008, *op. cit.* note 57.

<sup>59</sup> Goulet D. (2006). *Development Ethics at Work: Explorations-1960-2002*. New York, NY: Routledge.

<sup>60</sup> Schrijvers J. (1995). 'Participation and Power: A Transformative Feminist Research Perspective'. In: Nelson N, Wright S, editors. *Power and Participatory Development: Theory and Practice*. London: Intermediate Technology Publications, p. 19-29.

<sup>61</sup> Kahane D, Loptson K, Herriman J, Hardy M. (2013). 'Stakeholder and Citizen Roles

Where a combination of channels is used, existing power dynamics may be reinforced. Representatives of organisations will often have greater *power to act*, to know, and to negotiate than individual citizens because they have more understanding and experience with policy processes.<sup>62</sup> In health research priority-setting, *a key ethical consideration when selecting the channel(s) of participation for citizen role-types and disadvantaged groups is whether it/they will recreate an unequal power dynamic*. This should be avoided wherever possible. For example, relying on individual citizens to represent marginalised groups and organisations to represent doctors or insurers may place the former at a disadvantage.

Where the selected channel for a citizen role-type or disadvantaged group is individual representation, the voices of some are taken to represent others.<sup>63</sup> Authentic representation means that individuals genuinely reflect the needs and interests of a role or group. Comprehensive representation means they reflect its diversity in its entirety.<sup>64</sup> The latter speaks to the fact that those selected to represent certain roles or groups will inevitably represent only certain axes of difference within them. They also may be selected to represent axes of difference that they do not identify with strongly. Individuals typically have multiple identities or intersectional positionalities, with some felt more deeply than others.<sup>65</sup> To assume female solidarity, for example, potentially masks women's agency in the pursuit of interests based on other lines of connectedness and difference.<sup>66</sup> When selecting specific *citizens* to speak on behalf of others with the same role or group affiliation, it is suggested that they authentically represent their role or group, that their multiple identities represent the

---

in Public Deliberation'. *Journal of Public Deliberation*, 9(2), Article 2.

<sup>62</sup> Ibid.

<sup>63</sup> Cornwall, *op. cit.* note 57; Peuravaara K. (2015). 'Reflections on collaborative research: to what extent and on whose terms?' *Scandinavian Journal of Disability Research*, 17(3): 272-283.

<sup>64</sup> Hunter DJ, Kieslich K, Littlejohns P, et al. (2016). 'Public Involvement in Health Priority Setting: Future Challenges for Policy, Research and Society.' *Journal of Health Organization and Management*, 30(5): 796-808.

<sup>65</sup> Phillips, *op. cit.* note 19; Mouffe C. (1996). 'Democracy, Power, and the "Political"'. In: Benhabib S, editor. *Democracy and Difference: Contesting the Boundaries of the Political*. Princeton, NJ: Princeton University Press, p. 245-256.

<sup>66</sup> Cornwall, *op. cit.* note 15.

axes of difference selected to be included in priority-setting, and that they see themselves as representing those dimensions.

Where the selected channel is organisational representation, individuals act on behalf of an organisation focused on a specific issue, group, or interest. Goetz and Gaventa affirm an organisation's authentic representation of a group means (amongst other things) that the group's members participate in the organisation's activities, they are represented in its leadership structure, and that the organisation's accountability mechanisms are responsive to them.<sup>67</sup> When selecting specific *organisations* to speak on behalf of certain roles or disadvantaged groups, it is suggested that they authentically represent the selected roles or disadvantaged groups and have memberships that encompass the selected axes of difference.

### 2.3.3 Mass

Mass refers to the number of participants having each of the selected roles and axes of difference.<sup>68</sup> The aim is to ensure that the powerful do not dominate priority-setting by force of numbers.<sup>69</sup> *The implication for research priority-setting is to, first, identify those who lack power over health decision-making and to then strive to balance or exceed their numbers relative to those who do.* Although the roles and dimensions lacking *power over health decision-making* will vary by setting, it might, for example, entail ensuring similar numbers of those with the following roles—researchers to citizens, policymakers and providers to patients and disadvantaged groups—and those falling along the following axes—foreign to local, national to local, private sector to public sector, men to women. Greater numbers of those along roles and axes of powerlessness relative to those along roles and axes of power would also be encouraged.

## 2.4 How citizens participate

*Deliberative* processes have been proposed as a way to deepen participation in democratic societies.<sup>70</sup> Theories from political philosophy delineate ideal processes for deliberative

---

<sup>67</sup> Goetz AM, Gaventa J. (2001). *Bringing Citizen Voice and Client Focus into Service Delivery*. IDS Working Paper 138. Brighton, UK: Institute of Development Studies.

<sup>68</sup> Crocker, *op. cit.* note 53.

<sup>69</sup> *Ibid.*

<sup>70</sup> Gaventa J. (2002). Exploring Citizenship, Participation and Accountability. *IDS Bulletin*,

decision-making and draw largely on the work of Jürgen Habermas, who identified two main components: the ideal speech situation and communicative rationality.<sup>71</sup> In the ideal speech situation, deliberations are governed by the norm of *equal voice*, which means having an equal opportunity to raise one's voice *and* to be heard.<sup>72</sup>

It might be suggested that ideal models of deliberation could be applied to identify how participants should be involved in health research priority-setting. However, theories of deliberative democracy have been criticised for their failure to take power effects seriously.<sup>73</sup> Where countries exhibit social and economic inequalities, it is likely that 'ideal' deliberative processes will reinforce the status quo, giving effective voice only to stakeholders with considerable power and excluding the perspectives of disadvantaged groups.<sup>74</sup> Ideal approaches to deliberative democracy have, therefore, been adapted to attend to the way power enters deliberative spaces.<sup>75</sup>

Drawing on that work, this paper proposes that the following concepts are pertinent when determining how individuals participate in research priority-setting: stage of participation, level of participation, power dynamics within deliberative spaces, mode of deliberation, and

---

33(2): 1-11; Benhabib S. (1996). 'Towards a Deliberative Model of Democratic Legitimacy'. In: Benhabib S, editor. *Democracy and Difference: Contesting the Boundaries of the Political*. Princeton, NJ: Princeton University Press, p. 67-94; Goold SD, Biddle AK, Klipp G, Hall CN, Danis M. (2005). 'Choosing Healthplans All Together: A Deliberative Exercise for Allocating Limited Health Care Resources'. *Journal of Health Politics, Policy and Law*, 30(4): 563-601.

<sup>71</sup> Gutmann A, Thompson D. (2004). *Why Deliberative Democracy?* Princeton, NJ: Princeton University Press; Kapoor, I. (2002). 'Deliberative Democracy or Agnostic Pluralism? The Relevance of the Habermas-Mouffe Debate for Third World Politics'. *Alternatives: Local, Global, Political*, 27: 459-487.

<sup>72</sup> Cornwall, *op. cit.* note 15; Kapoor, *op. cit.* note 71; Benhabib, *op. cit.* note 70; Young, *op. cit.* note 21; Richardson H. (2002). *Democratic Autonomy: Public Reasoning About the Ends of Policy*. Oxford: Oxford University Press.

<sup>73</sup> Cornwall, A. (2002a). 'Locating Citizen Participation'. *IDS Bulletin*, 33(2): i-x.

<sup>74</sup> Young, *op. cit.* note 14.

<sup>75</sup> Leach M, Scoones I. (2003). *Science and Citizenship in a Global Context*. IDS Working Paper 205. Brighton, UK: Institute of Development Studies.

knowledge synthesis (Supplemental File 1). Each concept affects whether or not equal voice is achieved in contexts of power disparities. Attending to the ethical considerations related to them will promote deliberation in research priority-setting in which power dynamics put fewer constraints on citizens' ability to raise their voices and be heard.

#### 2.4.1 Stage of participation

The stage in decision-making at which individuals begin to participate has particular normative significance. Goulet contends that the earlier 'non-elites' (or other participants) enter the process, the higher is the quality of their participation.<sup>76</sup> Earlier entry is associated with making a greater number of decisions, including those that steer the direction of the rest of the project. Citizens thus have a greater opportunity to raise their voice and be heard.

In health research priority-setting at the project level, several stages of entry can be identified: 1) planning the process, 2) research topic solicitation and prioritization, 3) formulating the research question, and 4) designing the intervention.<sup>77</sup> Those decisions made in the planning stage are especially significant because they determine how the priority-setting process is structured. They include choosing the goals of priority-setting, who is included, how they are included, the mechanism(s) by which priorities are set (e.g. small group work, plenaries), and the ground rules for the process (e.g. how a chair is selected, rules for speaking).<sup>78</sup> *It is then important to consider whether citizens and disadvantaged groups will enter the process early and whether those who typically have power over health decision-making ((foreign) researchers, policymakers) will enter earlier than those who do not.* At what stage in the process will foreign researchers enter compared to local researchers? At what stage will researchers enter compared to citizens? At what stage will citizens with different roles and citizens from disadvantaged groups enter? Mitigating existing power disparities would support the early entry of local researchers and citizens, especially those who typically lack *power over* health decision-making in a given country. For example, it could mean including community-based organisations representing disadvantaged groups are included as part of developing research proposals and grant applications, rather than primarily to help link researchers with communities and to recruit study participants.

---

<sup>76</sup> Goulet D. (1995). *Development Ethics: A Guide to Theory and Practice*. New York, NY: Apex Press.

<sup>77</sup> Mullins, Abdulhalim, Lavallee, *op. cit.* note 5.

<sup>78</sup> Pratt, Merritt, Hyder, *op. cit.* note 32.

#### 2.4.2 Level of participation

Participants' entry point into a decision-making process does not exclusively determine the quality of their participation. Rather, a variety of levels of participation exist, with some more 'active, deliberative, and influential' than others.<sup>79</sup> Sherry Arnstein and others distinguish between lay control, partnership, and consultation.<sup>80</sup> Lay control means citizens are solely responsible for decision-making with (at most) consultative input from experts. Collaboration or partnership involves shared decision-making between experts and citizens.<sup>81</sup> Consultation is characterised by citizens being invited to give their input but having no assurance that it will be used by those who decide.<sup>82</sup> Beyond this, the importance of having a *self-determined* level of participation in the research process is emphasised. Whether citizens with a disability, for example, participate in disability research as leaders, partners, or consultants, it should be determined by them and not others.<sup>83</sup>

---

<sup>79</sup> Crocker DA. (2006). 'Forward', in D. Goulet (ed.) *Development Ethics at Work: Explorations-1960-2002*. New York, NY: Routledge, p. xxvii.

<sup>80</sup> Arnstein SR. (1969). 'A Ladder of Citizen Participation'. *Journal of the American Institute of Planners*, 35(4): 216-224; Hanley B, Bradburn J, Barnes M, et al. (2003). *Involving the Public in NHS, Public Health and Social Care Research: Briefing Notes for Researchers*. 2nd ed. Eastleigh: INVOLVE Support Unit; Shippee et al., *op. cit.* note 10; Oliver SR, Rees RW, Clarke-Jones L, et al. (2008). 'A Multidimensional Conceptual Framework for Analysing Public Involvement in Health Services Research'. *Health Expectations*, 11: 72-84; Cargo, Mercer, *op. cit.* note 9; Mitton et al., *op. cit.* note 39; Rower G, Frewer LJ. (2002). 'A Typology of Public Engagement Mechanisms'. *Science, Technology, & Human Values*, 30(2): 251-290; Church J, Saunders D, Wanke M, Pong R, Spooner C, Dorgan M. (2002). 'Citizen Participation in Health Decision-making: Past Experience and Future Prospects'. *Journal of Public Health Policy*, 23(1): 12-32; Kitchin, *op. cit.* note 41.

<sup>81</sup> Rowe, Frewer, *op. cit.* note 80.

<sup>82</sup> Arnstein, *op. cit.* note 80.

<sup>83</sup> Chappell P, Rule P, Dlamini M, Nkala N. (2014). 'Troubling Power Dynamics: Youth with Disabilities as Co-researchers in Sexuality Research in South Africa'. *Childhood*, 21(3): 385-399; Peuravarra, *op. cit.* note 63; McDonald KE, Kidney CA, Patka M. (2013). "You Need to Let Your Voice be Heard": Research Participants' Views on Research'. *Journal of Intellectual Disability Research*, 57(3): 216-225

In health research priority-setting, *a key ethical consideration is then whether citizens have negotiated or selected their level of participation.* Respect for persons suggests that they should have a say in this matter. *Another ethical consideration is whether decision-making will be limited to (foreign) researchers (i.e. 'experts').* Where decision-making lies solely with foreign researchers, it may reflect an exercise of *structural power*, reinforcing norms that position foreign researchers as experts whose advice ought to be accepted by allegedly information deprived LMIC researchers and citizens.<sup>84</sup> Where decision-making is shared only by researchers, it can reinforce the power of experts over citizens in knowledge production. Mitigating existing power disparities would, thus, support lay control or sharing decision-making with citizens in research priority-setting for projects.

*Another ethical consideration is what level of participation will be afforded to different citizen roles and to different disadvantaged groups.* Do those who participate as decision-makers typically have *power over* health decision-making while those who participate as consultants typically lack such power? Who is cast as decision-makers versus consultants will help determine the extent to which engagement reinforces or challenges traditional power dynamics within research and health decision-making. For example, researchers will potentially reinforce existing power dynamics if they partner with district health teams on a project about maternal health services and consult with community-based organisations representing vulnerable women (e.g. teenage mothers, women who experience domestic violence).

#### *2.4.3 Power dynamics within deliberative spaces*

The ideal of having an equal opportunity to raise one's voice and be listened to is often undermined in deliberative processes because power dynamics constrain citizens' agency.<sup>85</sup> How the forms of power identified in Box 1—power to, power over, structural power, discursive power—can have such an effect is summarised in Supplemental File 2.

*A key ethical consideration is then whether deliberations in research priority-setting will be structured to reduce the potential for power to diminish citizens' agency.* The first step towards promoting equal voice is to identify how forms of power suppress citizens' agency.<sup>86</sup>

---

<sup>84</sup> Shiffman, *op. cit.* note 28.

<sup>85</sup> Richardson, *op. cit.* note 72.

<sup>86</sup> Gibson JL, Martin DK, Singer PA. (2005). 'Priority-setting in Hospitals: Fairness,

The framework provides a set of questions designed to help organisers of citizen engagement in priority-setting do this (Table 1, Section III). The second step is developing and implementing strategies to minimise or reduce the impact of forms of power operating between citizens and between researchers and citizens.<sup>87</sup> Potential strategies described in the literature are summarised in Supplemental File 3. *Another key ethical consideration here is how Western norms of participation might raise tensions with local norms in priority-setting.* If existing decision-making structures are characterised by norms that restrict certain groups' voices, research priority-setting processes that challenge or disrupt such norms (using, for example, the strategies in Supplemental File 3) may have unintended negative consequences.<sup>88</sup>

#### **INSERT [TABLE 1**

##### *2.4.4 Mode of deliberation*

The literature identifies two modes of deliberation: consensus and conflict (Supplemental File 1). In political philosophy, deliberative democracy and agnostic pluralism both seek to deepen democracy but differ as to whether consensus or conflict is the best way to bring it about. Where deliberation is *consensus-seeking*, it is structured to bring about agreement amongst participants on deliberative outputs. Where deliberation is *conflict-seeking*, it is structured to bring opposing points of view to the surface in order to sharpen understanding of difference.<sup>89</sup> Agnostic pluralists contend that all consensuses entail some form of exclusion; coming to a single position can silence, marginalise, and erase differences. They doubt the playing field can be sufficiently levelled for less powerful actors to adequately voice their opinions.<sup>90</sup> Deliberation that is conflict-seeking thus constitutes the best way to ensure that the needs of the less powerful are clearly articulated.<sup>91</sup>

---

Inclusiveness, and the Problem of Institutional Power Differences'. *Social Science & Medicine*, 61(11): 2355-2362.

<sup>87</sup> Ibid.

<sup>88</sup> Mompati T, Prinsen G. (2011). 'Ethnicity and Participatory Development Methods in Botswana: Some Participants are to be Seen and not Heard'. In: Cornwall A, editor. *The Participation Reader*. New York, NY: Zed Books, p. 224-237.

<sup>89</sup> Mitton C, Smith N, Peacock S, Evoy B, Abelson J. (2011). 'Integrating Public Input into Healthcare Priority-setting Decisions'. *Evidence & Policy*, 7(3): 327:343; Weale A. (2016). 'Between Consensus and Contestation', *Journal of Health Organization and Management*, 30(5): 786 – 795.

<sup>90</sup> Kapoor, *op. cit.* note 71.

In health research priority-setting, *an ethical consideration is then whether identified power inequalities are likely to be sufficiently minimised by proposed strategies to promote equal voice. If it is unlikely, should deliberation be structured to be conflict-seeking?* To decide, the risks and benefits of doing so must be considered. Bringing opposing points of view to the surface may have negative consequences for certain marginalised and disadvantaged groups. When the risks are high, an alternative could be to have separate deliberative fora for groups for whom power disparities with other participants cannot be sufficiently minimised.

#### 2.4.5 Knowledge synthesis- Constructing research priorities and questions

The concept of knowledge synthesis reflects awareness that knowledge is socially constructed. Normative constructs such as Habermas' communicative rationality, in contrast, conceal the complex nature of information production.<sup>92</sup> Power dynamics permeate the construction of knowledge in a number of ways. Whose knowledge is used and who controls the integration of that knowledge determine what outputs emerge from decision-making<sup>93</sup> and, in effect, whose voices are heard.

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.<sup>94</sup> The latter gives experts the power to interpret the content of deliberations amongst citizens or amongst themselves and citizens. In research priority-setting, *an ethical consideration is then whether research priorities and questions will be internally or externally synthesised. Where citizens participate in projects as consultants, selected research topics and questions will be the product of external*

---

<sup>91</sup> Mitton et al., *op. cit.* note 89.

<sup>92</sup> White S. (2011). 'Depoliticizing Development: The Uses and Abuses of Participation'. In: Cornwall A, editor. *The Participation Reader*. New York, NY: Zed Books, p. 57-69; Mosse D. (2011). 'The Making and Marketing of Participatory Development'. In: Cornwall A, editor. *The Participation Reader*. New York, NY: Zed Books, p. 182-202

<sup>93</sup> O'Doherty K, Gauvin F-P, Grogan C, Friedman W. (2012). 'Implementing a Public Deliberative Forum'. *Hastings Center Report*, 42(2): 20-23.

<sup>94</sup> *Ibid.*

synthesis by researchers, which reinforces the power of experts over citizens. Shared decision-making entails internally-driven synthesis. Thus, citizens' level of participation can determine whether they are responsible for co-constructing research priorities and questions.

Given that research priorities and questions are constructed, whose knowledge is used to do so bears consideration. Wallerstein and Duran call for relying on both expert and local knowledge in CBPR, stating that integrating these two types of knowledge is a way to equalise power relations between researchers and citizens.<sup>95</sup> Even where local knowledge is used, however, Schrijvers and Kothari suggest that those who synthesise knowledge inevitably will have to make a choice of perspective(s) out of a heterogeneous reality.<sup>96</sup> *Another ethical consideration is then whose local knowledge will be used to set research priorities and questions.* While it is essential that citizens from disadvantaged groups' knowledge be used,<sup>97</sup> even the poor and marginalised are a heterogeneous category.<sup>98</sup> Those who construct research priorities and questions must be explicit about, amongst the powerless and disadvantaged, whose perspectives they have chosen to rely upon and why.

How expert and local knowledge is interpreted by those who synthesise research priorities and questions for projects should also bear scrutiny. Those who share synthesis power will summarise or frame expert and local knowledge in ways that highlight certain problems or certain solutions over others.<sup>99</sup> Constructing research priorities and questions is an act of *discursive power*, as the resultant outputs promote or reinforce thinking about the world in certain ways over others.

*This means another ethical consideration in research priority-setting is how the knowledge being synthesised is interpreted.* It entails assessing whether local knowledge is framed in ways that render it technical or that further the dominance of certain ways of conceptualising

---

<sup>95</sup> Wallerstein, Duran, *op. cit.* note 8.

<sup>96</sup> Schrijvers, *op. cit.* note 60; Kothari, U. (2002). 'Power, Knowledge and Social Control in Participatory Development'. In: Cooke B, Kothari U, editors. *Participation: The New Tyranny?* New York, NY: Zed Books, p. 139-152.

<sup>97</sup> Mitton et al., *op. cit.* note 80.

<sup>98</sup> Schrijvers, *op. cit.* note 96.

<sup>99</sup> Cornwall, *op. cit.* note 15.

health problems. Both may be ethically problematic. The former means information generated from local sources is interpreted in ways that largely ignore the political causes of problems and support implementing technical solutions that fail to address such causes.<sup>100</sup> Questions to consider are: do resultant research questions focus on identifying the technical causes of health problems or testing interventions that primarily focus on building capacity and knowledge? Research priority-setting can also be used to reinforce dominant concepts and narratives for thinking about health that emerge from high-income countries, e.g. science and technology narratives emphasising that health problems will be solved by the application of new high technology solutions. Such narratives shift focus away from addressing the social determinants of health.<sup>101</sup> Questions to consider are: do research questions align with certain dominant 'Western' knowledge paradigms in global health? Or do they disrupt them and 'replac[e] them with new voices of resistance and representation'?<sup>102</sup>

### 3. A PRELIMINARY ETHICAL FRAMEWORK

An initial ethical framework has been developed to assist researchers and citizens attend to dynamics of power and dynamics of difference when designing engagement processes for research priority-setting. It should be used at the start of research projects. The proposed framework comprises a series of questions reflecting the ethical considerations identified throughout this paper (Table 1). It is relevant for use in settings where there is high background inequality, which applies to many countries today, irrespective of income-level. It is intended to help researchers and citizens identify where their engagement processes' design might be improved.

---

<sup>100</sup> Li TM. (2007). *The Will to Improve: Governmentality, Development, and the Practice of Politics*. Durham, NC: Duke University Press.

<sup>101</sup> Shiffman, *op. cit.* note 28; Pratt B, Loff B. (2013). 'Linking international research to global health equity: The limited contribution of bioethics'. *Bioethics*, 27(4): 208-1.

<sup>102</sup> Lunn M, Munford R. (2007). "She Knows Who She Is! But Can She Find Herself in the Analysis?': Feminism, Disability and Research Practice'. *Scandinavian Journal of Disability Research*, 9(2): 65-77, p. 76.

The framework indicates whether affirmative answers to its questions are ethically ideal, preferable, minimally acceptable, or problematic. No one 'ethically problematic' answer makes a priority-setting process unethical. It is, however, suggested that, after using the framework, researchers and citizens modify their engagement processes' design in order to achieve as many 'ethically ideal' or 'ethically preferable' answers as possible and as few (if any) 'ethically problematic' answers.

Where researchers and citizens attend to the framework's questions and then revise their processes' design to better represent diversity and mitigate power disparities, more inclusive citizen engagement is promoted. For example, by using Section III of the framework, researchers and citizens may identify several ways that power dynamics will suppress the voices of disadvantaged groups in their host communities. They may also determine that they do not have strategies to mitigate those power dynamics. In response, they then might develop several such strategies to employ during research priority-setting. Doing so would facilitate disadvantaged groups' raising their voices and being heard because existing social norms and rules would be less likely to suppress them. This, in turn, will help generate research projects with topics and questions that encompass and more accurately reflect the health needs of disadvantaged and marginalised groups. The framework questions can also be asked by funders and ethics review committees when reviewing citizen engagement plans for proposed projects.

When using the framework, it is acknowledged that research teams may find it difficult to reach consensus on answers to framework questions and/or on whether and how to alter the design of priority-setting processes based on their answers. Even so, discussing the framework's questions can, at a minimum, help researchers and citizens identify where priority-setting processes' design may be improved and foment dialogue about doing so. Perhaps changes will not be made in all areas where improvement is possible due to a lack of agreement, but it is likely that some alterations will be made, giving rise to more inclusive processes than would have existed had the framework not been used.

Thus far, the framework's content reflects the conceptual work described in this paper. Next steps include testing that content against the experiences and practices of researchers and citizens, revising the framework, and piloting it with them.

#### 4. CONCLUSIONS

Citizen engagement is increasingly being required during all phases of health research projects, including priority-setting. It is, therefore, vital to identify what is necessary for achieving inclusive and meaningful engagement in the context of dynamics of power and dynamics of difference. Without attention to such dynamics, citizen engagement can lead to presence without voice and voice without influence. Voices are then excluded from research priority-setting, particularly those of disadvantaged and marginalised groups with the worst health.

This paper characterised the ethical considerations relating to power and difference that arise during citizen engagement in research priority-setting at the project level and provided preliminary guidance or suggestions on how they might be addressed in ways that represent diversity or mitigate power disparities. According to that guidance, engagement processes will ideally be initiated by local researchers and citizens or citizens alone; be constructed as instrumental and transformative; and involve local researchers and citizens along axes of powerlessness and disadvantage early on and as decision-makers. The number of participants representing those who typically lack power over health decision-making in a given setting exceeds the number of participants who typically have such power. Deliberations are structured to mitigate different forms of power and their outputs are internally synthesised, using local knowledge from citizens along axes of powerlessness and disadvantage in the given setting.

This paper also developed an ethical framework to assist researchers and citizens attend to such dynamics when designing citizen engagement processes for research priority-setting (Table 1). The proposed framework consists of a series of questions corresponding to the ethical considerations described throughout the paper and indicates whether affirmative answers to its questions are ethically ideal, preferable, minimally acceptable, or problematic. Thus, it can help researchers and citizens identify areas where their engagement processes' design might be improved.

While the paper's articulation of ethical considerations for citizen engagement is a useful starting point, it is a starting point nonetheless. Next steps could include testing the framework against actual practice as part of a reflective equilibrium approach and investigating what ethical considerations arise in relation to another component of citizen engagement that this paper did not address: accountability. Having a right to participate

means citizens have a relationship of accountability with researchers and, perhaps, funders.<sup>103</sup>

Ultimately, inclusive and meaningful citizen engagement in priority-setting requires mitigating power disparities and representing diversity. The proposed ethical framework provides a set of questions that should be asked when designing citizen engagement processes in order to promote their doing so. Its use can help reduce the likelihood of shallow, tokenistic citizen engagement in research priority-setting and deliver projects with research questions that more accurately reflect the health needs of disadvantaged and marginalised groups.

### **Acknowledgements**

The author would like to thank Professor Lynn Gillam (University of Melbourne) and Dr Rosalind McDougall (University of Melbourne) for providing comments and feedback on earlier versions of this paper.

Bridget Pratt is currently supported by an Australian Research Council (ARC) Discovery Early Career Researcher Award (Award No. DE170100414). At the time this research was started, she was supported by an Australian National Health and Medical Research Council (NHMRC) Early Career Sidney Sax Public Health Overseas Fellowship (Award No. 1052346). The contents of this article are solely the responsibility of the author and do not reflect the views of the NHMRC or the ARC.

### **Disclosure Statement**

The author reports no conflicts of interest.

### **AUTHOR BIO**

**Bridget Pratt, PhD**, is a research fellow in the Nossal Institute for Global Health and Centre for Health Equity at the School of Population and Global Health at the University of Melbourne; she is Associate Faculty in the Department of International Health at Johns Hopkins Bloomberg School of Public Health. Her research interests include the ethics of international research and health systems research, with a focus on social and global justice.

INSERT [Supplemental File 1

---

<sup>103</sup> Jones E, Gaventa J. (2001). *Concepts of Citizenship: A Review*. Brighton, UK: Institute of Development Studies; Abelson J, Giacomini M, Lehoux, P, Gauvin F-P. (2007). 'Bringing 'the Public' into Health Technology Assessment and Coverage Policy Decisions: From Principles to Practice'. *Health Policy*, 82: 37–50; Cargo, Mercer, *op. cit.* note 9; Shippee et al., *op. cit.* note 10.

INSERT [Supplemental File 2

INSERT [Supplemental File 3

INSERT [Supplemental File 4

# Author Manuscript

**Table 1: Ethical considerations when designing citizen engagement in health research priority-setting**

<b>I. General considerations</b>	<b>Answers</b>
	(Tick if Yes)
<p>1a. Will the engagement process be initiated by:</p> <ul style="list-style-type: none"> <li>• Local researchers and citizens, or citizens alone***</li> <li>• Foreign researchers, local researchers, and citizens**</li> <li>• Foreign researchers and local researchers*</li> <li>• Foreign researchers<math>\phi</math></li> </ul>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<p>1b. If solely foreign researchers, what is the justification?</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div>	
<p>2a. Will the engagement process be constructed as:</p> <ul style="list-style-type: none"> <li>• Instrumental and transformative***</li> <li>• Instrumental*</li> </ul>	<input type="checkbox"/> <input type="checkbox"/>
<p>2b. If solely for instrumental purposes, what is the justification?</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div>	
<p>3a. As instrumental: To whom will priorities be relevant?</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div>	
<p>3b. Will priority-setting be framed in a non-neutral way that excludes some of their key health needs?<math>\phi</math></p>	<input type="checkbox"/>

4. As transformative: For whom will participation in priority-setting be empowering and how?

5a. Will citizens be included in priority-setting?\*\*\*

5b. Which citizen roles will be included and along which axes of difference? Why?

<u>Citizen Roles</u>	<u>Axes of Difference</u>

<u>Citizen Roles</u>	<u>Axes of Difference</u>

5c. Will the axes of difference for citizens include those corresponding to powerlessness in the given setting?\*\*\*

R1 R2 R3 R4 R5 R6

5d. When will each role be included?

- Planning the process,\*\*\*
- Research topic solicitation and prioritization,\*\*\*
- Formulating the research question,\*\* and/or
- Designing the intervention\*

R1 R2 R3 R4 R5 R6

5e. At what level will each role participate?

- Lay control\*\*\*

<ul style="list-style-type: none"> <li>• Decision-making**</li> <li>• Consultation*</li> </ul>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
5f. Will citizens select their levels of participation*** or freely agree* to them?	<input type="checkbox"/>
6a. Will members of disadvantaged groups be included in priority-setting?***	<input type="checkbox"/>
6b. Which disadvantaged groups will be included in the process and why?	
<div style="position: absolute; top: 50%; left: 50%; transform: translate(-50%, -50%); opacity: 0.1; font-size: 48px; pointer-events: none;">             Manuscript           </div>	
6c. When will each group be included?	G1 G2 G3 G4 G5 G6 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Planning the process,***	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Research topic solicitation and prioritization,***	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Formulating the research question**, and/or	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Designing the intervention*	G1 G2 G3 G4 G5 G6 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
6d. At what level will each group participate?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Lay control***	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Decision-making**	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
• Consultation*	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
7. Will the number of participants representing those who lack power over health decision-making balance** or exceed*** the number of participants representing those who typically have such power?	<input type="checkbox"/>
8. Will the selected channel(s) of participation reinforce an unequal power dynamic?φ	<input type="checkbox"/>
9. Will those who typically have power over health decision-making—(foreign) researchers, policymakers—enter the process earlier than those who do not?φ	<input type="checkbox"/> <input type="checkbox"/>

10. Will decision-making be limited to (foreign) researchers, i.e. “experts”? $\phi$

11. Do citizens who will participate as decision-makers typically have power over health decision-making while those who will participate as consultants typically lack such power? $\phi$

## II. When identifying specific participants

## Answers

(Tick if Yes)

1. Particular citizens to represent selected roles and groups:

a. Are they likely to authentically represent their role or group?<sup>\*\*\*</sup>

b. Do they represent the axes of difference selected to be included in priority-setting?<sup>\*\*\*</sup>

c. Do they see themselves as representing those axes of difference?<sup>\*\*\*</sup>

d. Who will select them?

• Members of their group or community<sup>\*\*\*</sup>

• Local leaders/authorities<sup>\*\*</sup>

• Organisers of the priority-setting process<sup>\*\*</sup>

• Experts (researchers)<sup>\*</sup>

• Other \_\_\_\_\_

2. Particular organisations to represent selected roles and groups:

a. Do organisations exist that authentically represent the selected roles and disadvantaged groups?<sup>\*\*\*</sup>

b. Do their memberships encompass the selected axes of difference?<sup>\*\*\*</sup>

c. Do power disparities exist between selected organisations? $\phi$

d. Who will select individuals to represent organisations in priority-setting?

• Their members<sup>\*\*\*</sup>

• Their leaders<sup>\*\*</sup>

• Organisers of the priority-setting process<sup>\*\*</sup>

• Experts (researchers)<sup>\*</sup>

• Other \_\_\_\_\_

## III. When structuring deliberations to promote equal voice

## Answers

1. In what ways will power suppress citizens' agency in deliberations during priority-setting?

- a. Are certain roles or disadvantaged groups likely to have lower, for example, assertiveness, argumentation skills, negotiation skills, and understanding of research? Which ones?

- b. Are certain roles and axes of difference afforded lower status in a given society and/or in the local space being used for deliberation? Which ones?

- c. Are certain roles likely to use types of speech afforded lower status? Which ones?

- d. Is a lower status afforded to local systems of knowledge by researchers or within health decision-making in the host country?

- e. Will researchers' axes of difference constrain citizens from being heard? Which citizen roles?

- f. Do historical or current relationships of exploitation exist between researchers and citizens in the research setting?
- g. Do norms of donor dependence or Ministry of Health control characterise health decision-making in the country?
- h. Are citizens discursively framed as something other than co-researchers with a right to participate?
2. Will strategies be implemented to counteract the impact of these power dynamics on citizens' agency in the deliberative process?\*\*\*

What are they?

- 
3. Are these strategies likely to sufficiently minimise power inequalities? (If yes, move to Section IV.)
- If not, should deliberation be structured as conflict-seeking?
- What are the risks and benefits of doing so?

**IV. Constructing research priorities and questions**

**Answers**

(Tick if Yes)

1. Will research priorities and questions be internally synthesised\*\*\*? By whom?
- Citizens, including less powerful citizens\*\*\*
  - Researchers and citizens, including members of disadvantaged groups and less powerful citizens\*\*
  - Researchers and citizens\*
  - Researchersφ

If they'll be externally synthesised, what is the justification?

**Consider the questions below during and after priority-setting:**

2. Was local knowledge used to construct research priorities and questions?\*\*\*

If not, why not?

3. Has local knowledge from citizens along axes of powerlessness and disadvantaged groups been used?\*\*\*

If yes, which ones and why?

If not, why not?

4. Are the resultant research priorities and questions rendered technical? Do they reinforce dominant narratives for thinking about health? $\phi$

#### Totals

#### Answers

Number of 'ethically problematic' options selected

/ 9

Number of 'ethically ideal' or 'preferable' options NOT selected (count 1 per question)

---

/ 23

---

**These comprise areas of potential improvement for the priority-setting process.**

**Legend:** \*\*\* = Ideal; \*\* = Ethically preferable; \* = Minimally ethically acceptable;  $\phi$  = Ethically problematic

#### Definitions:

1. **Role** = Roles correspond to types of actors falling within the broader categories of researcher and citizen. Researcher roles include investigators, managers, and implementers. Citizen roles include patients, families and carers, providers, purchasers, payers, policymakers, and product makers.
2. **Axes of difference** = Relevant axes of difference are individual characteristics likely to give rise to differential understandings of needs related to the health system.
3. **Channel** = People can participate in priority-setting through a number of channels: as individuals speaking for themselves, as individuals speaking for particular roles or groups, or as individuals speaking on behalf of organisations that represent particular roles or groups.

4. **Internal synthesis** = 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
5. **External synthesis** = Externally-driven synthesis means that the output of decision-making is an inferred product constructed by experts following deliberation. The latter gives experts the power to interpret the content of deliberations amongst citizens or amongst themselves and citizens
6. **Render technical** = Information generated from citizens is interpreted in ways that largely ignore the political and social causes of problems and, instead, supports implementing technical solutions that fail to address them.

Author Manuscript