



## Towards deep inclusion for equity-oriented health research priority-setting: A working model



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### ARTICLE INFO

#### Article history:

Received 25 February 2015

Received in revised form

12 October 2015

Accepted 11 January 2016

Available online 13 January 2016

#### Keywords:

Priority-setting

Health research

Justice

Health equity

Inclusion

Health systems research

### ABSTRACT

Growing consensus that health research funders should align their investments with national research priorities presupposes that such national priorities exist and are just. Arguably, justice requires national health research priority-setting to promote health equity. Such a position is consistent with recommendations made by the World Health Organization and at global ministerial summits that health research should serve to reduce health inequalities between and within countries. Thus far, no specific requirements for equity-oriented research priority-setting have been described to guide policymakers. As a step towards the explication and defence of such requirements, we propose that *deep inclusion* is a key procedural component of equity-oriented research priority-setting. We offer a model of deep inclusion that was developed by applying concepts from work on deliberative democracy and development ethics. This model consists of three dimensions—breadth, qualitative equality, and high-quality non-elite participation. Deep inclusion is captured not only by *who* is invited to join a decision-making process but also by *how* they are involved and by *when* non-elite stakeholders are involved. To clarify and illustrate the proposed dimensions, we use the sustained example of health systems research. We conclude by reviewing practical challenges to achieving deep inclusion. Despite the existence of barriers to implementation, our model can help policymakers and other stakeholders design more inclusive national health research priority-setting processes and assess these processes' depth of inclusion.

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### 1. Introduction

A growing consensus holds that research funders should align their investments with national health research priorities (*Global Ministerial Summit on Research for Health, 2008* and *Ministerial Summit on Health Research, 2004*). This requirement presupposes that such priorities exist and are just. Yet many low and middle-income countries (LMICs) don't (regularly) set national health research priorities. A systematic review of health research priority-setting in LMICs indicates that a total of 39 national processes were undertaken in English-speaking countries between 1996 and 2014 (*McGregor et al., 2014*). There has also been limited consideration of what constitutes *justice* in setting national health research priorities. Recently, scholars have argued that health

research priority-setting should promote health equity as a matter of justice (*Pratt and Hyder, 2015*). This position is consistent with recommendations made by the World Health Organization (WHO) and at global ministerial summits that health research should serve to reduce health disparities between and within countries (*CHRD, 1990*; *WHO Task Force on HSR, 2005* and *Ministerial Summit on Health Research, 2004*). It is also supported by accounts from philosophy and bioethics that link principles of global health justice to health governance (*Ruger, 2011, 2012* and *Gostin, 2014*). These accounts support global health equity as the goal of governance rather than improving the health of the greatest number worldwide.

In this paper, we adopt a middle-ground position: to achieve health equity is to reduce health inequalities by bringing groups up to at least a *decent level* of health. Philosophers have conceptualised the goal of health equity in various ways and it continues to be controversial. At a minimum, it demands that people reach a basic level of health understood in terms of subsistence or survival (*Shue, 1996*). Beyond this basic level, the sufficiency principle holds that it

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is morally valuable for people to attain the level of health required for a decent life over a “sufficient” life span (such as 75 years) (Powers and Faden, 2006: 62). Egalitarians have argued that health equity entails reducing shortfall inequalities in health status between actual achievement and the *optimal level* (i.e. the highest level of health achieved by a population in terms of morbidity and mortality indicators) (Ruger, 2009 and Ruger, 2010). These accounts emphasise that (some) priority should go to those whose health is substantially below a decent or optimal level of health (Powers and Faden, 2006, Ruger, 2009). Here, health equity is defined as being concerned with health inequalities between *groups* rather than individuals. This understanding is prevalent in health equity research and policy discourse (Asada, 2013).

Just health research priority-setting should promote the health of worst-off groups<sup>1</sup> within countries, i.e. those groups who experience a sizeable (though not necessarily the absolute greatest) gap in their health status relative to a decent level of health. But *how* should such processes be structured to advance health equity? Policymakers need guidance. Yet no specific requirements for equity-oriented health research priority-setting have been identified (Nuyens, 2007).

A comprehensive account of equity-oriented health research priority-setting might include both procedural requirements (how processes ought to be structured and conducted) and substantive requirements (what the resulting decisions ought to be like). In this paper, we focus only on procedural requirements and, in particular, propose *deep inclusion* as a requisite procedural component of priority-setting. We do not take a position here on whether it's necessary to formulate substantive requirements. In their absence, however, inclusive processes may generate outputs that don't strongly promote health equity.

### 1.1. Deliberative democracy

The idea of employing a deliberative process holds promise for equity-oriented research priority-setting. Relevant theories of justice in political philosophy generally call for relying on deliberative processes and norms to achieve fair or just priority-setting (Daniels, 2008; Ruger, 2010 and Young, 2000). These theories delineate ideal processes for deliberative decision-making, where diverse stakeholders discuss problems or claims of need and how to address them. Ideally, all stakeholders voice their ideas and the reasons behind them. They debate the pros and cons of various proposals. Proposals are refined or rejected and stakeholders coalesce around their preferred options (Young, 2000). Deliberation forges novel proposals that a majority of participants can endorse (Crocker, 2008). To achieve such a result, participants must be *mutually aware* of, and responsive to, one another's perspectives and needs, modifying their preferred priorities in light of other participants' proposals (Richardson, 2002). Ideally, deliberation should transform participants' perspectives from an initial “narrow and self-regarding” baseline to a more comprehensive understanding that takes others' needs and interests into account (Young, 2000: 112).

Deliberative processes and norms can be applied in priority-setting for health research. Inherent in existing accounts of deliberative democracy are norms such as inclusion, reciprocity, reasonableness, and publicity (Gutmann and Thompson, 2004, Young, 2000). All are likely to be important to achieving justice in

priority-setting.

### 1.2. Inclusion

Supposing that equity is a core component of justice in health research priority-setting, the norm of *inclusion* is critical. Where countries exhibit major social and economic inequalities within their populations, it's likely that deliberative processes will merely reinforce the status quo, giving effective voice only to stakeholders with considerable power and resources and excluding the perspectives of disadvantaged groups (Young, 2000). Such conditions of inequality occur in many countries worldwide, at all levels of national income. Philosopher Iris Marion Young (2000) has argued that one way to counteract this distorting influence is to deepen democratic inclusion. Processes designed to be deeply inclusive are more likely to produce decisions that reflect the needs and interests of society as a whole (Young, 2000).

Deep inclusion is crucial to equity-oriented health research priority-setting for two reasons. First, it can lead participants to transform their opinions on what national research priorities should be from expressions of self-interest to a more complete account of what research is needed to serve the interests of the population as a whole, with particular attention to the worst-off. Those in structurally privileged positions often take their own experiences and preferences to be typical and uncontroversial, and they have the power to represent their views as general norms. Having to listen and answer to others who speak from different, less privileged perspectives can reveal otherwise unnoticed biases and partialities and lead people to reassess their positions (Young, 2000).

Second, deepening inclusion can enhance the social knowledge base used to set research priorities. Ensuring that people from disadvantaged social groups (e.g. women, the poor) are present and able to voice their opinions means that their needs and perspectives will be expressed and taken into consideration when identifying health research priorities. The priority-setting process will give rise to a fuller account of health sector shortfalls and research needs. Young (2000) argues that such an account can only be generated by pooling the situated knowledge of all social positions.

### 1.3. Achieving inclusion

The main existing account of inclusion in priority-setting requires that a wide range of stakeholders be involved. The well-known and increasingly applied ‘accountability for reasonableness’ (A4R) framework considers inclusion to be a core aspect of its relevance condition and calls for the “inclusion of all affected by a decision, with particular attention to vulnerable groups” in priority-setting (Gruskin and Daniels, 2008: 1576).

A growing body of research assesses health priority-setting processes, primarily using the A4R framework. These assessments have been performed in Canada, Norway, Israel, Peru, Uganda, Tanzania, and Indonesia (Kapiriri et al., 2009; Greenberg et al., 2009; Maluka et al., 2010; Tomlinson et al., 2011; Romero and Quetal, 2014; Zulu et al., 2014 and Tromp et al., 2014). They demonstrate that, in many cases, health priority-setting processes fail to achieve broad stakeholder involvement (Tomlinson et al., 2011; Kapiriri et al., 2009 and Greenberg et al., 2009).

Yet certain countries' experiences implementing A4R suggest that even meeting this standard of inclusion is not sufficient. Health research priority-setting in Panama shows that, while wide participation of stakeholders from health research, health care, and civil society occurred, it was not *balanced*. Of the 65 health care stakeholders, 25 were from the health ministry compared to only one from the Caja del Seguro Social, which provides health care to

<sup>1</sup> In this paper, the terms ‘disadvantaged groups’ or ‘worst-off groups’ are understood to mean groups within countries who are worst-off in terms of their health. To be sure, the very use of such terms, however benignly intended, risks offending those so labelled; the substitution of terms that connote agency and personhood would in itself be more inclusive.

60% of the Panamanian population (Romero and Quetal, 2014). Efforts to implement A4R in health care priority-setting at the district level in Tanzania have produced evidence that

*[m]ore attention needs to be paid to issues of difference and inclusion. It was evident that while priority-setting was meant to be participatory, this was not the case. In practice, most of the district health plans were products of a few members of the CHMT [Council Health Management Team], with private partners and community bodies at best operating as a rubber stamp for decisions taken without their input. (Maluka, 2011: 7829)*

Although private partners and community bodies were part of this priority-setting process, they were *excluded* from decision-making. Shayo et al. (2012) have also found that—even where health priority-setting processes in Tanzania included men and women representing a diverse array of income-levels, education-levels, and ethnicities—being male, having a higher income or education level, and/or being from the main ethnic group in the district-under-study meant that a person was listened to more seriously and had greater influence on the outcome.

These experiences indicate that further exploration of how inequalities are reproduced in priority-setting is necessary to identify requirements for meaningful inclusion. They demonstrate that including a wide range of stakeholders comprises a *shallow* form of inclusion when priority-setting is undertaken in contexts where social and economic disparities are rife. Relying on this form of inclusion will likely be inadequate to generate health research priority-setting outputs that reflect the health care and health system needs of worst-off groups. A model of deep inclusion should be developed for use where research priority-setting is conducted in the context of power inequalities.

As a step towards the explication and defence of procedural requirements for equity-oriented health research priority-setting, we propose an operationally-oriented model of deep inclusion. Deep inclusion comprises three dimensions: breadth (range and mass), qualitative equality, and the involvement of minority and disadvantaged groups, which Denis Goulet (1995, 2006) has termed “non-elite participation” (Fig. 1). The dimension of breadth captures *who* is involved in the priority-setting process while the latter two dimensions focus on *how* and *when* stakeholders can participate. To develop our model, we apply concepts from work on deliberative democracy and development ethics. (Development ethics as a field of study centers on international development and asks critical questions about its value, its declared goals, how it is pursued, and what benefits are gained and what burdens are imposed by it (Goulet, 1996).) We rely significantly on the scholarship of Young and Henry S. Richardson, as they each consider inclusion in contexts of power disparities, and that of Goulet, who has explored the phenomenon of non-elite participation (Young, 2000; Richardson, 2002; Goulet, 1995 and Goulet, 2006).

To clarify and illustrate the three proposed dimensions of deep inclusion, understood as a candidate procedural requirement for equity-oriented health research priority-setting, we use the sustained example of a specific type of health research—*health systems research* (HSR). HSR is the production of new knowledge to improve the performance of health systems (WHO, 2009). It investigates how and why health systems fall short of their goals and it develops interventions to improve their functioning (Gilson, 2012). Interventions evaluated by HSR span a wide range and might include novel delivery mechanisms for existing health services, new methods of creating demand for health services, or community-based health insurance mechanisms.

Our choice of HSR as an example is informed by the suggestion that its priorities should be set independently from those of more



Fig. 1. Proposed components of deep inclusion. **Note:** Component in grey encompasses who is included. Components in black encompass how they are included.

disease-focused health research, using an interpretive approach. This involves a consultative process, convening a range of stakeholders to identify priority research topics and questions under those topics. Criteria for ranking research topics/questions are determined and used to generate a list of priorities that all stakeholders then validate. By contrast, technical disease-driven approaches to research priority-setting such as the Combined Approach Matrix methodology often determine what burden of specific diseases may be averted by developing new drugs and technologies, improving existing drugs and technologies, or extending the uptake of existing interventions. By linking HSR to specific diseases, rather than considering it as a whole, this method serves to systematically deprioritize such research and contributes to the fragmentation of the field (Ranson and Bennett, 2009).

If HSR priorities are better set through a distinct process, then a field-specific model of inclusive priority setting will be useful. A model of deep inclusion for HSR priority-setting is also of particular value because the final results of interpretive processes will depend significantly on the range of stakeholders consulted.

## 2. A working model of deep inclusion for research priority-setting

Young (2000) notes that 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 opportunity to influence the process? Goulet (1995) asks, in addition, *when* are non-elites involved, at what stage(s) of the process do they participate? Bearing these distinctions in mind, we propose that deep inclusion consists of achieving breadth (range and mass), promoting qualitative equality, and promoting high-quality non-elite participation (Fig. 1). Strong performance on all three dimensions is necessary for health research priority-setting to generate outputs that advance health equity. Non-elite participation is particularly critical. We discuss below how to understand each dimension in the context of national HSR priority setting.

## 2.1. Who is included?

Inclusion has been broadly defined as ensuring that all those affected by a decision take part in the decision-making process (Young, 2000; Gruskin and Daniels, 2008 and Goodin, 2008). This definition leaves unclear who ought to be included in a given priority-setting process, as ‘all those affected’ can be interpreted to encompass many people or even an entire population. Young (2000) suggests that ‘affected’ should mean those whose options for action would be substantially conditioned by the decision.

Relying on Young’s definition, in national health research priority-setting, inclusion should encompass all parties whose options for action are substantially conditioned by the development of health research priorities or the translation of the evidence generated by their implementation. Three categories of people meet this criterion: research-producers, research-users, and research-beneficiaries. These categories may be specified differently for different types of health research. Using the example of HSR, inclusion may encompass people in the following categories: health systems researchers, members of the health systems workforce, and patients served by the health system.

New national priorities will affect what evidence is generated and the nature of work performed by health systems researchers. Where the list of priorities includes or excludes certain topics, researchers with expertise in corresponding aspects of the health system (e.g. finance, delivery) will be more or less likely to find support for their projects. HSR priorities substantially condition researchers’ options for action through impact on their employment and funding opportunities. The scope of impact includes all health systems researchers who primarily work in a particular country.

The translation of HSR evidence may produce health system changes that will likely condition options for action among workforce members and patients. Workforce members will be affected by changes in governance and management structures, modes of service delivery, and financing mechanisms. Whether and how patients can meet their health needs will be impacted by health system changes that affect how they access and/or pay for services.

When selecting individuals to provide the patient perspective, it is essential to ensure that members of disadvantaged groups are amongst those chosen. In the context of national HSR, this would specifically refer to those groups who fall substantially below a decent level of health due to their experience of burdens imposed by an unjust health system. Such groups would have lower levels of health insurance coverage and utilisation, inadequate financial protection (as evidenced by higher rates of catastrophic spending), lower levels of health service utilisation, and/or poorer quality care accessible to them relative to other groups in their country. Moreover, their expected contribution to the financing of the health system may far outweigh their ability to pay.<sup>2</sup> We recommend using measures of unequal access, inequitable financing, and poor financial protection as proxy indicators to identify people who are worst-off due to unjust health system performance. Such groups must explicitly be made a part of HSR priority-setting because otherwise their perspectives will likely be excluded from the process.

Aside from their being significantly affected by whatever HSR priorities are set, another reason to involve health systems researchers, workers, and patients in the priority-setting process is that they possess vital knowledge. They are best positioned to

understand what problems are experienced by the health system within a particular country context and what research is needed to address them.

### 2.1.1. Achieving breadth

Making sure that the priority-setting process involves research-producers, research-users, and research-beneficiaries is necessary but not sufficient to achieve inclusion. Young (2000) calls for decision-making processes to draw on the knowledge of *differently situated* actors in order to maximise the social knowledge relied upon to reach decisions. This requires achieving a breadth of participants from all three categories of stakeholders. Breadth encompasses two main elements—*range* and *mass* (Crocker, 2008).

*Range* refers to ensuring that participants span a wide spectrum of relevant roles and dimensions, so that they *collectively* represent the diversity of health research stakeholders. Fig. 2 summarises relevant roles and dimensions of stakeholders in HSR priority-setting. Relevant roles correspond to types of actors falling within the broader categories of research-producer, research-user, and research-beneficiary. Relevant dimensions or demographics are individual characteristics likely to give rise to differential understandings of needs related to the health system or HSR (Fig. 2). To some extent, relevant dimensions vary by the category of stakeholder. Beyond dimensions that vary by category of stakeholder, there are also certain dimensions whose different facets should be present across all categories. For purposes of this paper, we emphasize those dimensions that correspond to Young’s concept of “structural social groups”: those groups for whom social structures (rules, norms, practices) condition their members’ educational opportunities, access to resources, and political power and prestige. Structural social groups can vary by country but typically include different genders, races, and economic classes (Young, 2000: 94).

*Mass* refers to the number of participants belonging to each category and having the various roles and dimensions. In addition to ensuring a full range of participants, it is essential to make sure that research-producers, researcher-users, and researcher-beneficiaries are not disproportionately included relative to one another. It is highly desirable that people who fit any particular dimension or role of a category are not disproportionately included either. For example, participants who are providers should include similar numbers of doctors, nurses, and community health workers, and similar numbers from the public and private sectors. The aim is to make a best effort to achieve a critical mass of various perspectives, including those of disadvantaged groups, and to ensure that certain powerful groups do not dominate the priority-setting process by force of numbers.

## 2.2. How and when are stakeholders included?

### 2.2.1. Promoting qualitative equality

The presence of a breadth of stakeholders is necessary but not sufficient to achieve deep inclusion. People may still lack effective opportunity to express their views and influence others even when they take part in priority-setting processes (Young, 2000). What is needed in addition to breadth is *qualitative equality*, meaning that individuals have a fair or equal chance to influence the priority-setting process (Richardson, 2002, Crocker, 2008). Qualitative equality ensures that the actual views expressed through the priority-setting process are not solely the purview of the powerful, with other actors, including disadvantaged groups, being no more than passive participants. It has three components: an equal right and effective opportunity to express one’s views and interests; an equal right and effective opportunity to question other participants and to respond to their questions; and freedom from domination,

<sup>2</sup> This description of how people might experience an unjust health system draws on leading philosophical accounts of what constitutes a just health system (see Ruger, 2010 and Daniels et al., 2000).

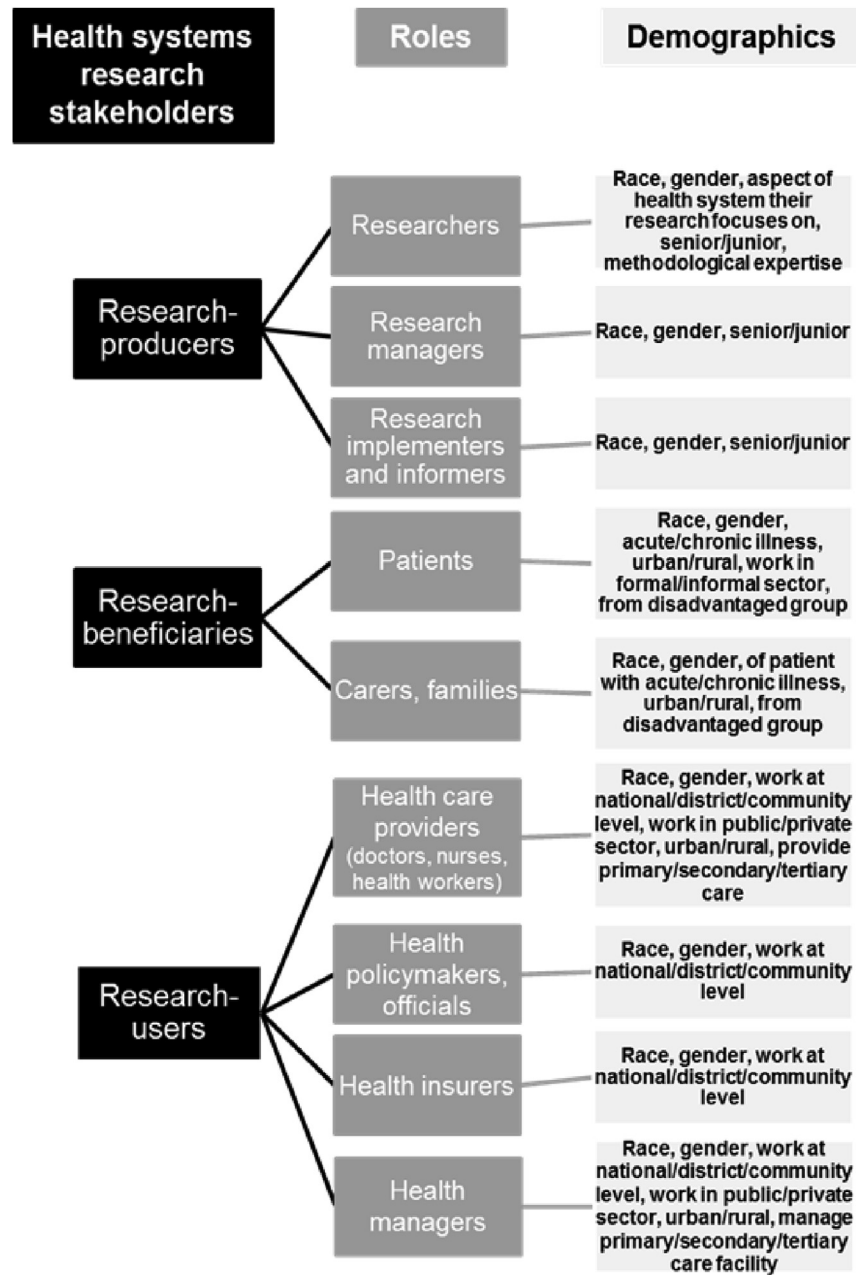


Fig. 2. Achieving a range of stakeholders in HSR priority-setting.

meaning that no one is in a position to coerce certain participants to endorse or accept specific proposals and that people can make their own choices (Young, 2000).

Richardson (2002) acknowledges that achieving complete qualitative equality is unlikely in most situations where power disparities exist. He identifies five conditions, however, that can promote qualitative equality where such disparities exist within countries. Four concern general political and economic circumstances: 1) equal political liberties, 2) equality of citizens before the law, 3) implementation of effective measures to mitigate concentration of economic power in the hands of the few, and 4) a decent minimum of subsistence for all. Meeting these first four conditions falls outside the direct scope of research priority-setting, although countries that meet one or more of them are more likely to attain qualitative equality. Richardson's fifth condition concerns the

structure of the decision-making process of interest; it calls for the process to be *structured* so as to reduce the potential influence of factors that diminish people's chances to participate and affect decision-making equally. In the case of research priority-setting, meeting this condition is a reasonable requirement for equity-oriented processes because it's typically under organisers' control.

The first step towards structuring a research priority-setting process to promote qualitative equality is to identify factors that suppress people's opportunities to participate equally (Gibson et al., 2005). Key (and interrelated) factors identified in the literature include: limited individual capacity for decision-making, aspects of the decision-making context, structural barriers, and norms of discourse (Young, 2000; Gibson et al., 2005 and Shayo et al., 2012). Differences in people's capacity for identifying research priorities can affect their ability to construct a set of

proposed priorities and to question the proposals of others. The priority-setting context may exacerbate the effect of these differences by, for example, enforcing strict timelines for discussion and providing limited information to participants beforehand (Gibson et al., 2005). Top-down processes often concentrate real authority in the hands of a few senior stakeholders. Pressure to conform makes individuals less likely to voice dissenting opinions, particularly if doing so puts them at odds with more senior members of their organisations (Gibson et al., 2005).

Structural barriers such as the low status associated with being female, being poor, having little education, having a disability, or belonging to certain ethnic groups can mean that certain participants are listened to less, with their statements being more easily ignored or dismissed. The validity of their suggestions may be questioned more frequently as well (Shayo et al., 2012). Finally, certain modes of discourse may be given more normative value in particular societies. For example, in many western societies, the conception of proper political communication is often restricted to articulate, dispassionate arguments. These norms devalue rhetoric and narrative styles of expression and privilege those who are better educated and belong to higher income groups (Young, 2000). Valuing other forms of expression can broaden the scope of discussion and influence who is listened to within priority-setting processes. Narrative, in particular, offers a way for disenfranchised groups to assert themselves publicly (Young, 2000).

Promoting qualitative equality also demands developing and implementing strategies to counteract the impact of all these factors on the priority-setting process (Gibson et al., 2005). How to do so remains largely unknown. Within health priority setting, there is little reliable, transferable evidence on effective approaches to public participation and engagement of disadvantaged groups (Alderman et al., 2013). Some authors have suggested “empowerment” strategies such as appropriate education or training to support meaningful participation, extension of time to prepare discussion statements, advance provision of materials with opportunities to ask questions, and rules of order that establish and enforce clear expectations for fair deliberation (Gibson et al., 2005: 2360 and Shayo et al., 2012).

Additional strategies for reducing the impact of structural barriers on qualitative equality in decision-making appear in the literature on citizens' juries and consumer involvement in research. Relying on citizens' juries of lower status stakeholders (e.g. patients and carers or non-physician health providers) as part of the priority-setting process may be one means for promoting an equal opportunity to voice opinions. Evidence from Western Australia shows that these juries can make resource allocation recommendations across areas of health service inequity, so it may be possible for them to propose research priorities (Mooney and Blackwell, 2004). Another option might be to include lower status stakeholders in positions of governance (steering committee members) in order to promote power sharing in priority-setting, as has been done in breast cancer research. These stakeholders must be involved from the planning stage for this strategy to maximize its effect (McCormick et al., 2004). While promising, much more work needs to be done to develop such strategies for research priority-setting, particularly for use in LMICs, and to test them in practice.

### 2.2.2. Depth of non-elite participation

Denis Goulet's work on participatory development explores the principle of non-elite participation in decision-making. This principle affirms the key role of disadvantaged groups in deciding matters related to their basic interests like health as opposed to having others (government officials, development assistance officials) make decisions for them (Goulet, 2006). For national HSR priority-setting, this principle would specifically entail ensuring the

participation of groups who fall substantially below a decent level of health due to their experience of unequal access, inequitable financing, and/or poor financial protection under the existing health system. Goulet further argues that the stage in decision-making at which non-elites begin to participate has particular normative significance (Goulet, 1995). Possible entry points include the initial diagnosis of the problem, identification of possible solutions, selecting a course of action, and evaluation during implementation. Goulet (1995) contends that the earlier non-elites enter the process, the higher is the quality of their participation.

Crocker (2008) expands this account, suggesting that non-elites' entry point into the decision-making process does not *exclusively* determine the quality of their participation. Rather, a variety of modes of participation exist for each entry point, with some more “active, deliberative, and influential” than others (Crocker, 2006: xxvii).

In light of these accounts, we contend that achieving a substantial depth of non-elite participation is essential to an inclusive priority-setting process. Depth of non-elite participation can be understood as a function of the stage at which worst-off groups enter the priority-setting process *and* the mode(s) of their participation. The phases of the priority-setting process are described in Fig. 3, while Fig. 4 shows how the phases of entry and various modes can combine to generate different forms of participation.

In relation to interpretive research priority-setting processes, we highlight three stages or entry points associated with making certain sets of decisions. As shown in Fig. 3, it is possible to involve worst-off groups in planning the priority-setting process (decisions 1–6), identifying research topics and ranking criteria (decisions 7–9), and/or actually setting HSR priorities (decisions 10–11). Those decisions made in the planning stage are especially important because they have significant implications for whether or not a priority-setting process ensures that the voices of worst-off groups are heard. For example, outcomes of planning-stage decisions could be the purposeful selection of poor strategies to promote qualitative equality or to minimally involve disadvantaged groups. At the second stage, participants propose different research topics that they consider to be priorities. Criteria to rank the proposed priorities are selected and their respective weights chosen. For instance, in the Alliance for Health Policy and Systems Research's priority-setting exercise for health systems financing research, ‘answerability’, ‘extent to which relevant research is lacking’ and ‘impact on health and equity’ were the three criteria used to rank priorities, with ‘impact on health and equity’ weighted twice as heavily as the other two criteria (Ranson et al., 2010). In the final stage, participants apply selection criteria and weights to the proposed research topics in order to rank them. Based on those rankings, a final list of priorities is decided.

Drawing on Sherry Arnstein's work (1969) and Crocker's distinctions amongst different modes of participation, we propose the following possible modes for health research priority-setting in order of *decreasing* depth: shared decision-making, proposal-sharing, information-giving, and providing feedback. The latter three modes each constitute distinct activities. Shared decision-making, however, encompasses the other three modes and goes beyond them, demanding that disadvantaged groups are also part of the group of stakeholders responsible for making key choices (e.g. decisions 1–11 in Fig. 3). In proposal-sharing, worst-off groups are not part of this group of stakeholders. Instead, they provide their recommendations or suggestions for what they would decide if they had the power to make certain decisions. For instance, they might share their recommendations for what research topics or questions should be under consideration or for what criteria should be used to select research priorities. Proposal-sharing invites disadvantaged groups to deliberate amongst themselves about

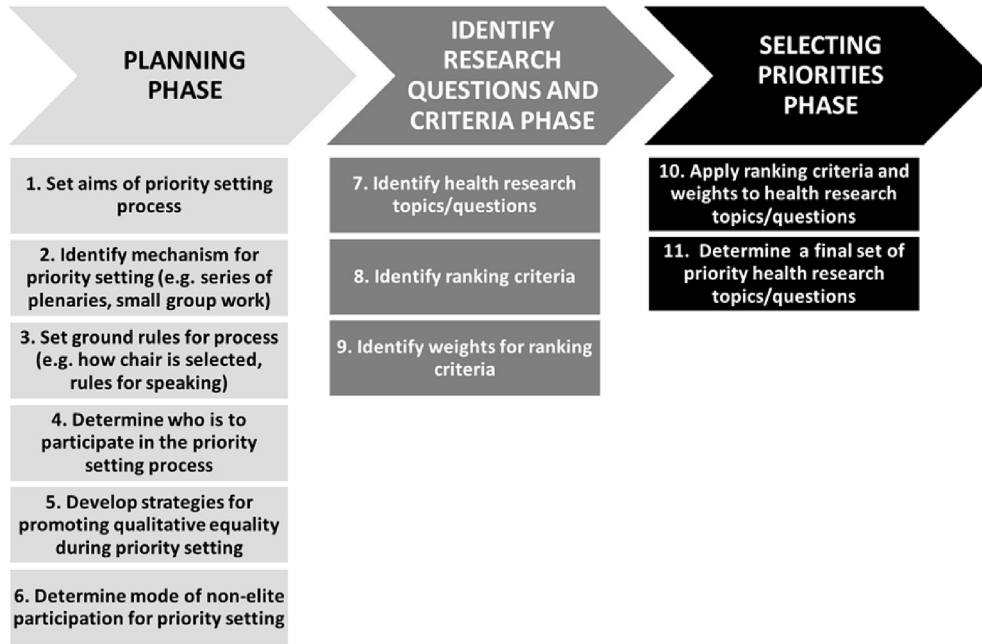


Fig. 3. Phases and decisions made in research priority-setting.

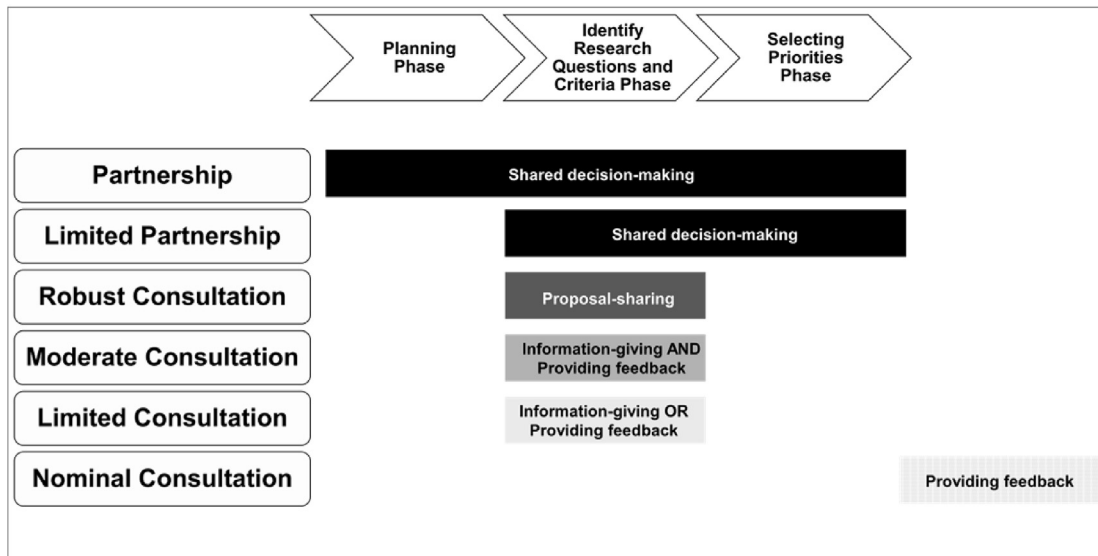


Fig. 4. Forms of non-elite participation in research priority-setting. **Note:** Forms of non-elite participation are listed on the left side of the figure. Phases of participation in research priority-setting are listed at the top of the figure. For each form of participation, a rectangle is used to indicate not only when non-elites take part in the priority-setting process but also the mode(s) by which they take part. Rectangle length indicates when non-elites are involved in the process. Rectangle colour indicates the particular mode(s) that is relied upon. Darker colours correspond to modes of greater depth or quality of involvement.

what proposals to recommend to other stakeholders who, after listening, actually decide upon what research topics to include or what ranking criteria to use.

Where worst-off groups participate by giving information, they are again not amongst the stakeholders who make decisions. They offer information on their health system context and the challenges they face in accessing and paying for health services. Their information may or may not be used by the stakeholders who choose priorities. At most, it may help those stakeholders reformulate their opinions on what research topics and questions to consider.

Finally, providing feedback means that disadvantaged groups share their opinions or preferences on the outputs of the

stakeholder group's decision-making. As an example, where the output is a list of health research topics, worst-off groups can give feedback on what they think are the most relevant and important topics on that list.

While there are many possible combinations of entry points and modes of participation along the continuum from nominal to deep participation, we identify six to provide a sense of the spectrum (Fig. 4). On this spectrum, equity-oriented HSR priority-setting processes should ideally aim to achieve partnership or limited partnership forms of non-elite participation. The most desirable form of non-elite participation—*partnership*—is characterised by shared decision making (Arnstein, 1969) and occurs when worst-off

groups are involved in making all types of decisions as part of the priority-setting process. The next most desirable form of non-elite participation—*limited partnership*—occurs when worst-off groups are involved in deciding research topics, ranking criteria, and weights and then selecting research priorities. They are not involved in the planning stage of the priority-setting process where its aims and ground rules are determined.

Forms of participation as consultation are characterised by the remaining modes of participation, and have the common feature that, while non-elites are invited to give their input in various ways, there is no assurance that it will be used by those who decide the research priorities (Arnstein, 1969). *Robust consultation* occurs when worst-off groups propose research topics and possible ranking criteria, but the final decisions are made by others. *Moderate consultation* takes place when worst-off groups *both* influence the range of research topics under consideration by providing information on the problems they experience within their health system, *and* give their preferences amongst the research topics and ranking criteria proposed by others. This form of participation involves using two modes: information-giving and providing feedback. *Limited consultation* occurs when disadvantaged groups *either* give information on the problems they experience within their health system *or* give feedback on the research topics and ranking criteria proposed by others. This information may or may not be used to set health research priorities. *Nominal consultation* occurs when worst-off groups are informed of the research priorities set by others and asked to give feedback. To give a better sense of how non-elite participation looks in practice, Box 1 describes an example of how participation as robust consultation was achieved for select disadvantaged groups in Tanzania's most recent national research priority-setting process in 2012.

In contrast to Arnstein's (1969) model, we do not conceptualise non-elite participation as a contest between parties wrestling for power. Rather than an adversarial relationship, we envisage a collaborative relationship. In keeping with Young's concept of deep inclusion, the aims of non-elite participation are to break down barriers, share experiences, and build understanding of worst-off groups' health system needs in order to use a broad social knowledge base to set priorities.

### 3. Discussion

Truly just research priority-setting requires deep inclusion because it is essential to advancing health equity. The greater the depth of inclusion that national research priority-setting processes achieve, the more likely they will be to capture the interests and concerns of the worst-off, giving rise to research priorities that effectively help to reduce health inequalities within countries. Policymakers and other participants in national research priority-setting processes need guidance on what benchmarks to aim for and how to assess progress toward achieving deep inclusion in practice. We offer a model of deep inclusion to provide such guidance.

There are significant practical challenges to implementing this model. Robert Goodin (2008) notes the inherent tension between including a diverse set of participants and keeping numbers low enough to facilitate deliberation. He refers to Robert Dahl's (1970: 67–68) calculation that “if an association were to make one decision a day, allow ten hours a day for discussion, and permit each member just ten minutes—rather extreme assumptions ... —then the association could not have more than sixty members.” If, instead, 600 people were included, they would each get one minute to present their preferred health research priorities, the reasons behind them, and their critiques of other participants' proposed priorities. In light of such logistical constraints, in countries with a

large number of relevant roles and dimensions and numerous groups that experience an unjust health system, it may not be possible to fully reflect the existing diversity of relevant stakeholders *and* effectively undertake a deliberative priority-setting process. In such instances, Goodin (2008: 249) suggests that the “sheer fact of diversity” should be represented, noting that

*... a fully representative sample is not strictly necessary. A suitably diverse representative body can instantiate the fact of diversity, reminding us what a diverse society we are, without instantiating all the particulars of that diversity.*

Even priority-setting processes that reflect the sheer fact of diversity can serve to expand the perspectives of those in positions of power and authority and maximise the social knowledge used to set research priorities (Goodin, 2008). Including as many roles-types and dimensions as possible without jeopardizing the deliberative process is an essential component of just health research priority-setting.

Another potential obstacle to undertaking equity-oriented priority-setting is identifying who the relevant non-elites are in a given country; in relation to HSR, the relevant non-elites are the groups that experience unequal access, inequitable financing, and/or poor financial protection. An increasing number of countries conduct assessments of their health care system's performance, although less information is generated in LMICs (Boerma et al., 2009). Where these performance assessments measure equity, they may or may not include in-depth analysis of sub-populations beyond different income-level strata or gender. As a result, data may not exist to identify populations other than the poor, women, the disabled, and perhaps certain rural populations that experience an unjust health system. Under such circumstances, those responsible for organising national HSR priority-setting processes may have to rely on information from a number of (ideally fairly impartial) key informants to better determine which non-elite groups they should invite to participate.

Further challenges are establishing pre-conditions for research beneficiaries' involvement, limited resources, and lack of political will to support inclusive deliberative processes. For research beneficiaries to be adequately involved in priority-setting, time and expertise needs to be devoted to developing trust and their capacity to participate effectively (Tritter and McCallum, 2006). Both can take substantial time and be difficult to achieve. Deliberative processes also tend to consume more time and resources, which may not be available in many LMICs. Even where a country has the resources, the budget allocated to national health research priority-setting by its government may not be sufficient (Ranson and Bennett, 2009). Political considerations may present a further obstacle. Priority-setting is a “value-laden and political” process in which various stakeholders' agendas will typically involve considerations other than achieving inclusion (Kapiriri and Martin, 2007: 159). Who ends up being included and how and when they are included may be driven by political expediency more than considerations of equity.

Finally, it will likely prove challenging to identify the specific factors that drive qualitative inequality in given country contexts, how to combat those factors, and how to achieve deep levels of non-elite participation. A protocol or method for efficiently surveying or determining which factors are relevant would be of immense use and should be developed. Evidence indicates that normative and structural barriers (patriarchy, poverty, low social status) in countries frequently result in outcomes where certain groups, especially the worst-off, aren't able to participate or have their voices heard in health priority-setting (Shayo et al., 2012, Alderman et al., 2013). The question remains: how to mitigate the

impact of such barriers? This paper has suggested some strategies to use, but they have yet to be tested in practice. Evidence is also lacking on how to engage disadvantaged groups to achieve modes of participation like partnership and limited-partnership, especially in countries where civil society has a limited role (Alderman et al., 2013).

#### 4. Conclusion

We have argued that inclusion is a vital component of research priority-setting because it is critical to advancing health equity. We have developed a working model of deep inclusion that stakeholders can use to design and evaluate priority-setting processes. We have also highlighted areas of work that need significant attention to fully put this model into practice. Despite the existence of clear barriers to achieving deep inclusion, our intention is not to discourage stakeholders from trying to achieve breadth, qualitative equality, and high-quality non-elite participation. Instead, they should make their best effort towards attaining each component of deep inclusion and document their experiences for others to learn from them. As affirmed by Lydia Kapiriri and Douglas Martin (2007: 160), a “continuous learning platform” is required to improve priority-setting, as “capturing the experiences of decision makers from multiple contexts can provide an evidence base upon which to build context sensitive improvements.” Descriptions of how health research priority-setting processes were inclusive and how this was achieved should be part of such a learning platform.

#### Ethics approval

Ethical approval for this research was not required because it didn't involve human subjects.

#### Acknowledgements

BP is 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 authors and do not reflect the views of the NHMRC. At the time this manuscript was written, BP was supported by the Berman Institute of Bioethics as a Hecht-Levi fellow. MM is her mentor as part of the Hecht-Levi program. AAH and BP are also supported by the Future Health Systems Initiative, which is funded by the UK Department for International Development.

#### Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2016.01.018>.

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