



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



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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 groups¹ 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

¹ 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.

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