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## Patterns of Public Participation: Opportunity Structures and Mobilization from a Cross-National Perspective

### Abstract

**Purpose:** The paper summarizes data from twelve countries, chosen to exhibit wide variation, on the role and place of public participation in the setting of priorities. It seeks to exhibit cross-national patterns in respect of public participation, linking those differences to institutional features of the countries concerned.

**Design/Methodology/Approach:** The approach is an example of case-orientated qualitative assessment of participation practices. It derives its data from the presentation of country case studies by experts on each system. The country cases are located within the historical development of democracy in each country.

**Findings:** Patterns of participation are widely variable. Participation that is effective through routinized institutional processes appears to be inversely related to contestatory participation that uses political mobilization to challenge the legitimacy of the priority setting process. No system has resolved the conceptual ambiguities that are implicit in the idea of public participation.

**Originality/Value:** The paper draws on a unique collection of country case studies in participatory practice in prioritization, supplementing existing published sources. In showing that contestatory participation plays an important role in a sub-set of these countries it makes an important contribution to the field because it broadens the debate about public participation in priority setting beyond the use of minipublics and the observation of public representatives on decision-making bodies.

**Keywords:** Public participation, priority setting, cross-national comparisons, resource allocation.

**Article Classification:** General review

## Introduction

The purpose of this special issue of the *Journal of Health Organization and Management* is to examine the role that public participation plays in the setting of health care priorities. Our concern is to map the various forms that public participation takes and to evaluate its role in priority setting in respect of important social values, including legitimacy and accountability. As we highlighted in the introductory paper, our focus is on public participation understood in its relation to public policy. We examine participation that is collective rather than individual, excluding consideration of the role of patients in the determination of their individual care. We also focus on participation that is about priorities as a matter of policy in general, even if the participation is triggered by a particular case, for example with an appeal to an administrative body by an individual about a denial of treatment. Because participation must be relevant to the making or changing of policy, participation in pure research on public attitudes, for example replies to questionnaires, is excluded in our analysis, although participation in research that is an element of the policy process, for example patient feedback responses, is a form of participation.

Even with these exclusions, public participation takes a wide variety of forms and terminology varies sometimes extending to involvement and representation (Arnstein, 1969; Conklin *et al.*, 2012: 158-9; Gauvin *et al.*, 2010; Greer, Wismar, Figueras and McKee, 2016: 35-6; Mitton *et al.*, 2009: 223; Rowe and Frewer, 2005; Tritter and McCallum, 2006). In the present context, participation includes public representatives sitting on decision-making bodies, either as elected representatives or as appointed ones. It covers institutionalized relationships of consultation and discussion between policy makers and patient groups or other stakeholders, including stakeholder forums, consultations, partnerships and advisory committees. It may involve the use of minipublics established by policy making bodies or forms of participatory budgeting. Importantly, for our purposes, it also includes what in the Introduction was called ‘contestatory participation’ in the form of court challenges, demonstrations, protests, sit-ins and the like.

What is the relationship between the way in which priority setting is institutionalized, patterns of public participation and the mobilization of the public in decisions on priorities? In this paper, we suggest that there may be an inverse relationship between representational participation that is participation initiated and organized by policy making institutions, which may be thought of as engineered participation (Blaug, 2002), and contestatory participation on the other hand, which is outside the scope of the processes and initiatives defined by

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3 policy makers. This distinction can be regarded as an extended version of Stewart's (2016:  
4 13-14; 127-8) 'invited' and 'uninvited' participation.  
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7 A key analytical concept in this context is that of political opportunity structures. This  
8 concept was developed in the context of explaining cross-national patterns of anti-nuclear  
9 protests in the 1980s (Kitschelt, 1986). The concept highlights the extent to which different  
10 types of institutions and processes create different opportunities for political participation.  
11 To the extent to which a relationship between institutions and opportunity structures holds,  
12 patterns of public participation will depend upon the form of health care organization that a  
13 country possesses, as well as general features of the political and cultural context. For  
14 example, in social insurance systems there is an institutional distinction between local and  
15 central government on the one hand and the social insurance agency on the other. In a tax-  
16 funded system, where local government structures are used to deliver health care, there may  
17 be an opportunity for participation through the electoral process that does not exist in a social  
18 insurance system. Institutions distribute political opportunities.  
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27 Public involvement and participation is also likely to be influenced by the more general  
28 institutional arrangements that are found in different countries. Federal political systems will  
29 induce different forms of organization from unitary systems. The age and extent of  
30 democracy within a country is also likely to have an effect, both through setting the formal  
31 constitutional context within which health care is provided, for example whether the  
32 constitution guarantees a right to health, as well as the patterns of political attitudes and  
33 culture that generally inform behavior within a country. Relationships between health care  
34 participation and these broader contextual variables are neither simple nor straightforward.  
35 The vibrancy of political mobilization in new democracies may be off-set by the weakness of  
36 state institutions in those same societies, resulting in a situation in which active mobilization  
37 encounters ineffective state structure. By contrast, in older democracies, the social contracts  
38 embodied in the relationships between the state and health care professionals, health care  
39 industries and sub-national political actors as part of the process of introducing universal  
40 health care may well substantially constrain the scope and effectiveness of public  
41 participation in the making of policy (compare Marmor and Klein, 2012: 416).  
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53 The paper proceeds as follows: the next section outlines the methods and data for our study  
54 before going on to look in a subsequent section at the health policy contexts for the twelve  
55 countries; the following section describes the political opportunity structures that might  
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3 support public participation or mobilization aimed at influencing the distribution of power in  
4 priority setting; a subsequent section proposes that there is an inverse relationship between  
5 routinized or institutionalized participation on the one hand and contestatory participation, on  
6 the other. We conclude by showing how our empirical analysis addresses some long-standing  
7 conceptual ambiguities in the idea and practice of public participation.  
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## 11 12 13 14 **Methods and Data**

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16 Our primary units of comparison are the national health care systems of countries, which  
17 include Australia, Brazil, China, Colombia, England, Germany, New Zealand, South Africa,  
18 South Korea, Sri Lanka, Thailand, and the USA. The USA is a special case, however.  
19 Although the various institutions of medical care finance (the Veterans Administration,  
20 Medicare, Medicaid and the private insurers) make decisions on priorities, there is no one  
21 national body that evaluates interventions for their value. However, there are two distinct  
22 bodies, the work of which is related to priority setting. One is the Institute for Clinical and  
23 Economic Review (ICER), an independent non-profit body that conducts health technology  
24 assessment. The other is the Patient-Centered Outcomes Research Institute (PCORI),  
25 mandated by Congress to gather research to improve the quality of evidence on the clinical  
26 effectiveness of health care interventions. These two bodies are included, alongside the  
27 country cases, in our analysis.  
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37 Data on the cases comes from reports presented by country experts at the workshop held in  
38 the Brocher Foundation in November 2015 (Littlejohns, Kieslich and Weale, 2016). Slides in  
39 PDF form giving details of those reports are available at: <http://www.ucl.ac.uk/socialvalues>.  
40 These country reports have been supplemented by information derived from secondary  
41 literature and data sources cited in relation to Table 1.  
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46 Although the sample of countries omits some potentially important cases, with no country  
47 from the former Soviet bloc or Arab world included, it does represent a wide range in terms  
48 of geography as well as social and political structure. The countries have not been selected  
49 because they show evidence of public participation initiatives. That is to say, they have not  
50 been selected on the variable of interest (King, Keohane and Verba, 1994: 139-49; Landman,  
51 2000: 44-5). Looking simply at systems chosen for positive public participation risks  
52 observation bias and false inference, particularly in respect of the effects of participation. As  
53 Berry, Portney and Thomson (1993: 73-81) showed when looking at measures to increase  
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3 public participation in US cities, seemingly positive results disappeared when compared to a  
4 control sample in which there were no such measures. More generally, surveys of  
5 participation initiatives are largely restricted to well-established democracies (Conklin *et al.*,  
6 2005 and Mitton *et al.*, 2009), which are likely to have their own distinctive dynamics and  
7 patterns of participation and political mobilization. By including countries outside the group  
8 of well-established democracies, we avoid these sources of potential observation bias.  
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13 A similar bias in many studies is towards participation that is initiated by administrative  
14 actors, either as part of their mandate or as an attempt to reach out to new forms of public  
15 engagement. The effect is to neglect the importance of non-invited forms of participation,  
16 forms that may be as important, if not more important, than invited forms (compare Stewart,  
17 2016: 14). By making the unit of selection the country case, we open our analysis out to the  
18 contestatory forms of participation.  
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### 24 25 26 **Country Contexts**

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29 The twelve countries include a range of political experience, and exemplify the three waves  
30 of democracy (Huntington, 1996). Following the Polity IV data-set we can classify them as  
31 follows (see: <http://www.systemicpeace.org/polity/polity4.htm>). Four (Australia, England,  
32 New Zealand and the USA) are Anglophone first-wave democracies, which achieved  
33 substantial mass enfranchisement by the first part of the twentieth century, building on the  
34 beginnings of democratization from the early part of the nineteenth centuries. Of course,  
35 even in these cases, major developments were needed for the country fully to meet conditions  
36 of democracy, for example in the southern states of the USA before the 1965 Voting Rights  
37 Act. Alongside these four first-wave democracies, there are three second-wave democracies  
38 (Colombia, Germany and Sri Lanka) each with a history of continuous democracy, to varying  
39 degrees, from the middle of the twentieth century to the present. Although Sri Lanka had  
40 universal franchise since the 1930s, it counts as second wave since until 1948 it was a UK  
41 colony. In the case of both Colombia and Sri Lanka their history of democracy is also  
42 marked by extensive civil violence. There are three third-wave democracies (Brazil, South  
43 Korea and South Africa) and two countries without an extended history of democracy,  
44 including Thailand, in which there have been significant periods of military rule, and China,  
45 which is a one-party system.  
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3 These differences in democratic experience do not correlate in any simple way with the  
4 institutionalization of universal health care. Germany was the first country in the world to  
5 institutionalize a form of collectivized provision for health care in 1883 in the Wilhelmine  
6 Empire under Bismarck. Sri Lanka had tax-funded universal health care in the 1930s while it  
7 was still a British colony. The South Korean health insurance scheme was first introduced in  
8 1977 when the country was under military rule and achieved universal health care in 1988  
9 under the last president from a military background. By contrast, the USA did not achieve  
10 anything like universal health care until the 2010 Affordable Care Act. These complex  
11 patterns suggest important issues in the dynamics of political legitimacy. One obvious  
12 hypothesis is that sometimes authoritarian systems seek to enhance a potentially vulnerable  
13 legitimacy through social reforms, including the extension of health care provision.  
14 Conversely, democratic systems, in which there is the freedom of groups and interests to  
15 mobilize may create the conditions in which health care reform can be blocked by political  
16 mobilization, of which the USA is the most obvious example (Marmor and Oberlander, 2011).

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18 The familiar distinction between Bismarck and Beveridge systems of health care financing is  
19 increasingly coming under strain, in part from the influx of tax support in social insurance  
20 systems and in part from moves to provider competition in social insurance markets under the  
21 influence of ideas from new public management (Greer, Wismar and Figueras, 2016, 7-8;  
22 Okma and de Roo, 2009). Nonetheless, in terms of governance, the relative autonomy of  
23 social insurance funds is still a relevant distinguishing institutional characteristic in  
24 classifying countries according to their predominant mode of financing in securing universal  
25 health care. Three of our twelve countries have collective provision that is based on social  
26 insurance systems (Colombia, Germany and South Korea). All the other systems, with the  
27 exception of the USA, use revenue derived from taxation as the predominant instrument to  
28 extend coverage to the majority of those unable to pay for private insurance. The USA stands  
29 out as a highly pluralistic system, with private and occupational coverage, Medicare,  
30 Medicaid, the Veterans' Administration and, since the 2010 Affordable Care Act, mandated  
31 private insurance. Private insurance plays a significant role in all the countries, although to  
32 varying degrees. In some countries, for example South Korea, there is some public regulation  
33 of private insurance cover.

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35 Eight of our twelve countries have formal institutions conducting HTA that have at least  
36 some part in priority setting, including the country with the oldest of such institutions, namely  
37 the Pharmaceutical Benefits Assessment Committee (PBAC) in Australia. China and Sri  
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3 Lanka do not, and neither does South Africa although there are efforts underway to create one.  
4 Again, the USA is a special case. Formally, it does not have an HTA agency. However,  
5 PCORI conducts research on patient-oriented care and an independent body, ICER,  
6 undertakes work on cost-effectiveness. Nevertheless, the absence of a collectivized system of  
7 health service financing and payment means that there is no national agency equivalent to  
8 that found in other countries. Key elements of health care financing and the presence or  
9 otherwise of a HTA agency are summarized for these countries in Table 1, together with  
10 information on forms of public participation.  
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17 **[Table 1 about here.]**  
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## 22 **Opportunity Structures**

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24 Political opportunity structures are important in relation to the political involvement and  
25 mobilization of citizens on matters of public policy. The concept helps highlight the extent to  
26 which institutional structures are open or closed to public participation. For example, some  
27 administrative and constitutional processes permit a right of opposition at the agenda-setting  
28 or formation stage of policy, whereas in other political systems opposition is channelled into  
29 the implementation stage of policy. If we are interested in understanding the forms and  
30 effectiveness of public participation, it is always a pertinent question to ask where public  
31 movements may realistically seek to make their influence felt.  
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38 A number of countries in our sample include provision for the representation of patients, the  
39 public or consumers in the governance of health care, either as part of an HTA process or as  
40 part of the resource allocation process more generally. (For the sake of brevity we shall speak  
41 of ‘public’ representation in the bulk of the paper, returning at the end to the conceptual  
42 complexities implicit in the notion.) In terms of governance, Brazil and Colombia provide  
43 for public representatives on decision-making bodies at various levels of government, Brazil  
44 within the different levels of its federal system (federal, state and local) and Colombia in its  
45 decentralized system. In Brazil, public representatives on the Health Councils, which make  
46 decisions on resource allocation and service provision, are thought of as citizen  
47 representatives, sitting alongside representatives of the government, providers and health  
48 professionals to formulate policy. In England there is a place reserved for lay representatives  
49 in the Clinical Commissioning Groups who have responsibility for commissioning according  
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3 to population needs and are responsible for the finance of much of the care that is provided,  
4 as well as NHS England at various locations in the decision-making structures. In South  
5 Africa, the Community Health Committees are supposed to provide a public voice in relation  
6 to the work of the tier of local government (metropolitan, district or local) that has the  
7 responsibility for providing health services in a locality. By contrast two of the sample,  
8 China and Sri Lanka, have systems of general decision-making that are professionally  
9 dominated, with little or no effective role for organized groups to contribute to governance.  
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15 Although priority setting is implicit in any governance process, HTA agencies occupy a  
16 special place in relation to public involvement and participation. They provide a particular  
17 set of opportunity structures by reference to which participation can take place, both as focal  
18 points and as stimuli. They are focal points because their processes are a tangible point at  
19 which otherwise diffuse forms of resource allocation take place. They are stimuli, because the  
20 decisions that they make, in particular decisions to deny or delist treatments, provide the  
21 impetus for public engagement on the part of patient groups, industry and others. Moreover,  
22 independent or quasi-independent public agencies often have a sense that they are subject to a  
23 legitimacy deficit that can only be remedied through some form of patient or public  
24 involvement. HTA agencies may sometimes be established in the hope that, in rendering  
25 decisions on priorities through methods of technical assessment, they can thereby de-  
26 politicise priority-setting, as in the example of NICE (Klein, 2013: 199-204). Ironically,  
27 however, such bodies often feel the need to secure public involvement in order to render their  
28 decision-making legitimate. For this reason, it is not simply a question of the supply of  
29 political participation from the side of the public; it is also a question of the demand for  
30 political participation on the part of administrative agencies.  
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43 It is well known that the 'public' is defined in different ways both by analysts and by  
44 administrators and policy makers (Conklin *et al.*, 2015: 154; Mitton *et al.*, 2009: 223). It is  
45 no surprise, therefore, to see that different HTA agencies use different principles for public  
46 representation in their processes of decision-making. For example, in Australia the public  
47 representative on PBAC and the Medical Services Advisory Committee (MSAC) are thought  
48 of as consumer representatives. In New Zealand PHARMAC has a consumer advisory panel.  
49 In South Korea, in relation to the HTA agencies, the representatives are drawn from distinct  
50 social groups, including labour and consumer organizations. In Germany the representatives  
51 on the Federal Joint Committee, which receive information from the HTA body IQWiG, are  
52 patient representatives. In the USA PCORI has a governing board that aims to be  
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3 representative of the community at large, and stakeholders propose topics for investigation.  
4 In Colombia, IETS uses open online consultations to reach out to the different stakeholders,  
5 patient organizations and the general public. In Brazil, Conitec provides different  
6 questionnaires for both the general public and health professionals through its official website  
7 in order to promote public consultation.  
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11 Participation can occur at various stages of the decision process for HTA agencies. For  
12 example, in Korea the National Evidence-based Healthcare Collaborating Agency has a topic  
13 solicitation process by which suggestions for research can be submitted by members of the  
14 public, as well as academia and policy makers. In Thailand, patient groups, lay people and  
15 civil society organizations play an important role in making suggestions to the National  
16 Health Security Office, the Universal Coverage Scheme managing authority, as to which  
17 technologies should be evaluated (Mohara *et al.*, 2012). The public can also be involved  
18 through representation on various bodies in HTA agencies, or through participation in  
19 advisory panels. By contrast, public participation in a body like NICE does not have an  
20 agenda-setting role in determining the interventions to be appraised. Those topics are  
21 initially determined by the government through the Department of Health.  
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31 Although a great deal of theoretical and research interest has been shown in minipublics, they  
32 do not feature prominently in the forms of public participation in most countries, either in  
33 relation to general governance or in relation to priority setting (Whitty, 2013). In terms of  
34 their role in the formal policy process, England stands out in its use of minipublics, in  
35 particular the NICE Citizens Council, which comprises thirty members of the public selected  
36 to be broadly representative in demographic terms (Davies, Wetherell and Barnett, 2006;  
37 Littlejohns and Rawlins, 2009), and the NHS England Citizen Assembly. ICER and PCORI  
38 in the USA also use minipublic processes. For example, ICER has used public deliberation  
39 and voting to help determine value in relation to medicines, breaking up the country into a  
40 group for New England, one for the Mid-West and one for California. On these panels, two-  
41 thirds of the participants are physicians and the remainder are patient groups or public  
42 members. The South Korean health insurance agency has responded to the experimental use  
43 of a minipublic on the willingness to pay to expand the drug formulary and set up such a  
44 panel on a more permanent basis. By contrast, in most of our sample minipublics have been  
45 the preserve of researchers, interested in eliciting public preferences for example, or have  
46 been used relatively little, including in quite highly developed systems like Germany. One  
47 hypothesis is that these patterns reflect the balance between professional influence and power  
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3 in a health care system (strong in Sri Lanka, China and Germany), as distinct from other  
4 groups, particularly politicians or managers, in other systems. However, this hypothesis  
5 would require more evidence fully to test its plausibility.  
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### 10 11 **From Opportunities to Mobilization**

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13 There is one particular reason why HTA agencies are likely to be a focal point of  
14 participation, namely their role in denying or limiting access to interventions that may be  
15 widely or intensely demanded by the public, particularly when those interventions are  
16 pharmaceutical products with strong industry backing. Considerations of cost-effectiveness,  
17 alongside other criteria, act as a hurdle to access and sometimes lead to a decision not to  
18 cover or include in the drug formulary medicines for which there is evidence for clinical  
19 effectiveness but not cost-effectiveness. These decisions therefore affect the extent to which  
20 the medical care provided by a system is comprehensive as well as equitable, presenting no  
21 financial barriers to access. Low cost access to an inadequate range of therapies will seem to  
22 the public to be a breach of the principle of universal health care. Moreover, the processes  
23 and chains of reasoning that HTA agencies use to assess cost-effectiveness are typically  
24 esoteric, drawing upon economic and statistical modelling, sampling assumptions and  
25 measures of outcome that only make sense within a particular policy paradigm. Members of  
26 the public, particularly patient groups, may also be sceptical of the feasibility constraints that  
27 cost-effectiveness analysis involves, holding in particular that costs are not a natural given  
28 but something that may be affected by policy decisions as well as accounting conventions. It  
29 is not, therefore, surprising that, in different countries, much participatory activity takes place  
30 around questions about access to pharmaceuticals, perhaps also symbolizing a broader range  
31 of concerns about access to care.  
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45 In England patient groups have mobilized around access to pharmaceuticals that NICE has  
46 judged cost ineffective, including Abiraterone and Herceptin. Herceptin has also been an  
47 issue in New Zealand and Australia. In South Korea, mobilization has occurred around  
48 several new drugs that were not being covered in the national formulary, as well as coverage  
49 in the regulated private insurance system used to cover out-of-pocket expenses, in particular  
50 for Xalkori for lung cancer in 2015, where eventually the mobilized groups pushed the  
51 financial authority to rule in their favor. In Brazil mobilization has taken place over  
52 Fingolimod, following the precedent of mobilization in 1996, which led to free combination  
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3 antiretroviral therapy being offered to all citizens with AIDS. However, although an HTA  
4 agency provides a focal point for mobilization, it is certainly not a necessary condition. In  
5 South Africa, without an HTA agency, patient groups, following the campaigns around AIDS  
6 medicines, have mobilized in the Treatment Action Campaign on such matters as reduction in  
7 drug pricing and the development of needs-based budgeting. Even in the silent system of Sri  
8 Lanka, there has been a move to supply HPV vaccine, though this was professionally led.

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14 In any system it is always possible that there will be contestatory participation taking the  
15 form of protests and campaigns against administrative decision-making. However, we can  
16 distinguish cases where such participation is occasional and supplementary to more  
17 routinized forms of participation from cases where contestatory participation is a major  
18 characteristic of the policy making process. How is the extent and seriousness of  
19 institutionalized participation related to the character of the public participation? Answering  
20 this question depends on making a distinction between public participation in formal  
21 decision-making that is consequential from participation where it is not.

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There is no one test that can simply be applied to determine whether a system treats formal  
public participation seriously and one where it does not. However, as a first cut, one test is to  
distinguish those cases of public participation in which public representatives can influence  
policy agendas, as distinct from those cases where they cannot. Sometimes this can mean  
having formal or quasi-formal agenda-setting responsibilities; sometimes it is a matter of  
sitting as a full member on a decision-making body. For example, with the HITAP process in  
Thailand, the public representatives have a role in proposing or prioritizing topics for analysis.  
In Germany patient representatives sit on the high level body that makes a decision on the  
added benefit of pharmaceuticals that have been evaluated by IQWiG. In England, the  
emergent NHS Citizen invites and facilitates broad, deliberative input to board priorities via  
online and physical forums which are, in turn, mediated by a Citizens' Jury. By contrast, in  
other countries, participation appears to be token. The members of the Community Health  
Councils in South Africa generally fall into this category as do the patient representatives in  
South Korea. In South Africa, community participation is entrenched in various policy  
documents and formalised in the National Health Act which makes provision for the  
establishment of community health committees, hospital boards and local health councils.  
The members of these committees are supposed to ensure community participation in the  
governance of local clinics. While the political climate is in theory supportive of community  
participation, and while there are some Community Health Committees in existence with

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3 public representation, the role of these bodies is poorly defined, ultimately not functioning  
4 optimally with members having little input in decision making but rather playing the role of  
5 pseudo community health workers. Similarly, in Brazil and Colombia lay representation on  
6 Health Councils takes place at the different levels of political organization, but members are  
7 sometimes nominated rather than being independently selected.  
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11 In our sample, there are four countries where contestatory participation is routine: Brazil,  
12 Colombia, South Africa and South Korea. For example, in Colombia and Brazil, there is  
13 extensive use of the courts to challenge the denial of access as a violation of their right to  
14 health. In some cases, patients seek access to medicines to which they would be entitled to by  
15 policy, but that are denied them through failures of implementation. In other cases, patients  
16 seek access to medicines that have not been included or have been explicitly deemed  
17 ineligible for coverage as a result of priority setting (Dittrich *et al.*, 2016). Every year  
18 thousands of patients use this contestatory participation path to highlight failures in the  
19 provision of services or to overturn results of HTA and benefit basket design. Judges usually  
20 rule in favor of the plaintiffs. This phenomenon has escalated to the higher courts that have,  
21 in some cases, mandated reforms be made in order to address the underlying roots of this  
22 avalanche of litigation.  
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32 The constitutional right to health has also been a focal point for mobilization by many  
33 advocacy groups in South Africa. Some have used litigation to empower a social movement,  
34 like in the case of the Treatment Action Campaign (TAC) and Section 27. The former is a  
35 HIV/AIDS civil society organisation and the latter a public interest law centre that uses  
36 research, advocacy and litigation to ensure among others, access to health care. TAC has  
37 campaigned and litigated since 1998 for access to AIDS treatment. Their most significant  
38 success was the 2002 Constitutional Court ruling which held that government must provide  
39 treatment to combat mother to child transmission of HIV. This case enshrined South Africans'  
40 right to access to treatment proven to be a core treatment and medically necessary but noted  
41 that this access may not be available immediately and that the State ought to provide it as  
42 soon as reasonably possible. The TAC has used this same approach of advocacy alongside  
43 litigation to achieve several other outcomes, one of which was reduction in drug pricing.  
44 More recently, a collaborative project, known as Stop Stock Outs, between the TAC, Section  
45 27 and others has focused on using protest, advocacy and litigation to address the issue of  
46 drug stock outs in the country and to force policy makers to prioritize better. Another  
47 organization known as the Rural Health Advocacy project focuses specifically on improved  
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3 access to quality health care services for people living in rural South Africa. This group uses  
4 evidence and advocacy in its aim to influence decision-making in line with rural realities.

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6 These three examples of advocacy organisations have been established independently of the  
7 state and have forced their way into the priority setting process, albeit with varying levels of  
8 success.  
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11 South Africa's broader political context committed to democratic principles provides on the  
12 one hand an enabling environment for public participation, but on the other, protects the state  
13 in its role as the decision-making authority. This context, alongside a legacy of community  
14 mobilization and protest has resulted in citizens increasingly articulating their concerns  
15 outside of government provided channels where their voice is louder. Similarly, in Korea,  
16 resort to street protest is routine since it was the means originally to convert the military  
17 regime to democracy. In 2008, the candlelight protest gathered 50,000 people worrying about  
18 mad cow disease from US beef imports on the street with candles. It symbolized the Koreans'  
19 changing interest in relation to health related issues. In 2010, a group of left-wing activists  
20 including the hospital chapter of one nationwide labor union formed a coalition for free  
21 health. This group is asking for increasing coverage of the National Health Insurance by  
22 allocating more government budget to the health sector. This coalition is still active and  
23 posted "vote against" list of candidates for the general election in 2016 in its website  
24 (<http://medical.jinbo.net/xe/>).  
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36 In some countries, then, contestatory participation is so extensive as almost to be a routine  
37 element of the policy making process. This in turn suggests that we can divide our sample  
38 into two categories in two different dimensions. We can classify public representation by the  
39 extent to which it is either token or has some agenda shaping influence on the one hand, and  
40 we can classify systems by the extent to which constestatory participation is either routine or  
41 not on the other. With two categories in two dimensions we have the four possibilities  
42 illustrated in Table 2.  
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48 **[Table 2 about here.]**  
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53 Table 2 shows a broadly inverse relationship between representatives having some  
54 meaningful power within the system of resource allocation and an absence of contestatory  
55 participation. Although Australia, Germany, New Zealand, Thailand and England have never  
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3 been entirely free of contestation, it is not the routine feature of health policy making that it is  
4 in Brazil, Colombia, South Africa and South Korea. The fact that cell A is empty is  
5 confirmation of some inverse association between significant representation and contestatory  
6 participation. There is no country that gives public representatives a serious role in priority  
7 settings decisions and that is also pervaded by the contests that are seen in the countries in  
8 cell B.  
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13 Three of the four countries in which contestatory participation is a routine part of the policy  
14 making process (cell B) are third-wave democracies, and Colombia has been a second-wave  
15 democracy under strain over decades. The process of democratization in these countries  
16 involved political mobilization on a large scale over a number of years. One important case  
17 in this context is Brazil, where mobilization over health issues was a central part of the more  
18 general community-based democratic movement. However, when the 1990 law  
19 institutionalizing public participation in the Health Councils was being debated, there was a  
20 division of views in the health movement, with significant elements claiming that it was  
21 impossible to be an opponent of the state whilst interacting with it through formalized means  
22 (Dall'Agno Modesta *et al.* 2007: 16). Where oppositional mobilization is a central element in  
23 political contestation, it may be hard to move towards effective forms of more  
24 institutionalized participation.  
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34 However, such an analysis cannot be over-generalized. Thailand lacks a history of  
35 continuous democracy. However, it does have a politics of mass mobilization. In priority  
36 setting, however, it lacks the contestatory style of Brazil, South Africa and South Korea. One  
37 possible explanation is that, following from its experience of dealing with AIDS in the 1980s  
38 when it engaged intensely with patient groups and representatives, Thailand institutionalized  
39 patient involvement in policy making in more than a token way (Rasanathan *et al.* 2012;  
40 Tantivess and Walt, 2008). The case would suggest that it is not the general experience of  
41 democratic politics or mass mobilization for democracy that is important, but the  
42 institutionally specific ways in which public participation is facilitated or inhibited together  
43 with the larger confounding variables of political structure.  
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51 The three interesting off-diagonal cases are in cell D. These exhibit different routes to the  
52 same outcome: public participation with low significance for priority setting but the absence  
53 of contestatory participation. In the case of China the outcome is to be explained by the  
54 general restrictions on freedom of association and political protest. Sri Lanka stands out as a  
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3 particularly interesting null case. The early establishment of universal health coverage in the  
4 1930s together with the inherited system of professional domination seems to have left a  
5 legacy in which a traditional medical domination is still to be found. Finally, in the USA the  
6 absence of a single national priority setting agency means that there is nothing for political  
7 protest to mobilise around. Individual law suits may be common, and they may have class  
8 action effects, but the institutional dynamic is different from one in which a central decision  
9 provides a focal point of protest. None of these three off-diagonal countries has an HTA  
10 agency with the scope and significance of those found in other countries, and none are likely  
11 to have one in the near future.  
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## 21 **Conclusion**

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23 Our comparative review has highlighted some basic issues of theory and organization that  
24 have been identified for some time (Marmor and Klein, 2012, chapter 10), involving the  
25 character of public participation, the accountability of public representatives to the public  
26 they are supposed to represent, the effectiveness of those representatives and the place of  
27 state structures and capacities when considering the role of the public in priority setting.  
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31 Although public participation is often advocated and promoted by activists and policy makers,  
32 there remain conceptual ambiguities as to its character that are seldom, if ever, resolved in the  
33 policy process. Whether we are talking about the public in the formal decision-making  
34 process or a selected sample of citizens in a minipublic, we are always referring to  
35 representatives of the public when we are thinking of public participation. Conditions of  
36 assembly government, in which all citizens come together to determine the conditions of their  
37 common life, do not exist in the modern world outside particular places like some communes  
38 in Switzerland. Moreover, there is often an ambiguity as to what portion of the public public  
39 representatives are supposed to represent and the extent to which they are consulted or  
40 become more actively involved or engaged, so that they become partners in the process.  
41 Sometimes they are characterized as consumers, sometimes as patients and sometimes as  
42 citizens. These distinctions matter in priority setting. If public representatives have a role in  
43 commenting on how health services are delivered, then there is unlikely to be a serious  
44 discrepancy between the roles of patient, consumer and citizen. It is reasonable for citizens  
45 to want consumers of health services to be satisfied with their care, and one of the best ways  
46 of knowing whether they will be satisfied or not is to obtain the views of those patients who  
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3 have had experience of care. By contrast, with resource allocation, there are many built-in  
4 conflicts of interest: among different patient groups, as well as between citizens as consumers  
5 and citizens as tax-payers. If public participation is to be more than a slogan in relation to  
6 priority setting, then those responsible for the design of institutions and practices need to  
7 address the differences in the roles and responsibilities that different forms of public  
8 representation involves.  
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13 Secondly, the use of minipublics prompts a number of questions. The concept of  
14 representation in minipublics is normally a descriptive one. Members of a minipublic are  
15 supposed to be a microcosm of society, partly with the aim of rectifying the imbalance of  
16 voice among different social groups in the broader political and policy making process. The  
17 basis of this descriptive representation is normally demographic. However, it can be argued  
18 that this is only one possible basis of selection, and that equal, if not more, attention should  
19 be given to religious, cultural or social attitudes. After all, in relation to the priority to be  
20 given to IVF or the extent to which personal responsibility should be taken into account,  
21 conviction is likely to be more important than membership of a particular social group. The  
22 issue is partly a practical matter for health service management, but it is also one that carries  
23 wider implications, since it highlights the extent to which administratively sponsored  
24 participation reflects some of the problems of 'engineering democracy' (Blaug, 2002). It  
25 would go too far to say that sponsored or engineered democracy is problematic in and of  
26 itself; public organizations have good reasons for wishing to enhance their engagement with  
27 the public. However, it would also be misleading to say that minipublics can be a substitute  
28 for a vibrant civil society.  
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33 Thirdly, there is a case to be made for saying that presence matters (Phillips, 1995). It is hard  
34 to find evidence that the public's representatives are enormously influential in policy making.  
35 Nonetheless, this is not to say that their presence in decision-making is unimportant, rather  
36 that expectations of their feasible role need to be more finely calibrated. As our case studies  
37 have shown, there are instances where formal representatives do seem to exercise some  
38 agenda-setting power in relation to specific issues, inducing policies that would not otherwise  
39 have occurred, or they have some influence on the way in which issues are constructed and  
40 determined. More generally, it is an open question as to the extent to which their presence in  
41 the decision-making system reconciles the public at large to the decisions that have been  
42 made.  
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3 Fourthly, the cases of contestatory participation highlight the importance of state structures  
4 and administrative capacity in the policy making process. Contestatory participation is  
5 typically prompted by failures of implementation, problems of corruption or a lack of state  
6 capacity to create the conditions of citizenship for all, an issue that is particularly important  
7 when priority setting involves fundamental interests. It grows out of a contrast between  
8 ambitious constitutional promises and poor system performance. Large macro variables like  
9 state structure and capacity ought to influence how policy makers think about how public  
10 participation is best fostered and responded to in the context of an understanding about what  
11 state structures facilitate or inhibit. State structures evolve and are changed over time, but just  
12 as it is easier to create the formal rules of democracy than its effective practice, so it is easy to  
13 borrow forms of public participation without that participation articulating legitimate interests.  
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Table 1

## Financing, HTA and Forms of Public Participation: Key Data

Country	Predominant Basis of Universal Coverage	National HTA Agency with a Key National Priority-Setting Function	Forms of Public Representation
Australia	Medicare scheme funded predominantly from taxation.	Pharmaceutical Benefits Advisory Committee (PBAC) for pharmaceuticals.  Medical Services Advisory Committee (MSAC) for medical devices and.	Consumer representative member on Committee.  Stakeholder input (including patient and public engagement) invited for individual technology assessments.
Brazil	National Health System predominantly funded from taxation.	National Committee for Technology Incorporation (CONITEC).	Participatory Health Councils at local, federal and state level with a mandate for equitable access to healthcare, social participation and social mobilisation.
China	Basic social medical insurance for employees.  Rural cooperative	None.  There are some academic HTA groups/institutions	Expert panels are formed to participate in the process to determine drug reimbursement list.  There is process by which the drug reimbursement list open to consultation,

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	<p>medical insurance for rural residents.</p> <p>Basic social medical insurance for urban residents.</p>	across China.	although it is mainly professionally dominated.
Colombia	<p>Universal Social Health Insurance funded through payroll taxes and general taxation. All citizens have access to the same basket of services.</p>	The Institute for Health Technology Assessment (IETS).	<p>User Associations to monitor health service quality and mediate between insurers/providers/service users.</p> <p>Customer Service Offices to protect and promote quality improvements.</p>
England	<p>National Health Service predominantly funded through general taxation.</p>	National Institute for Health and Care Excellence (NICE).	<p>Patient representatives on appraisal and guidance committees.</p> <p>Citizens Council minipublic, selected on a purposive basis, to advise on general issues.</p>
Germany	<p>Social insurance.</p>	Institute for Quality and Efficiency in Health Care (IQWiG) and the Federal Joint Committee (FJC).	<p>IQWiG working groups allow patient groups to address items on the agenda.</p> <p>Patient representatives on the FJC but without voting rights.</p>
South Korea	<p>Social insurance.</p>	National Evidence-based Healthcare	In the process of setting up a Citizen Committee for Participation to incorporate social value judgements in priority setting is in discussion

		Collaborating Agency (NECA). Health Insurance Review and Assessment Service (HIRA).	
New Zealand	General taxation.	Pharmaceutical Management Agency (PHARMAC).	Consumer Advisory Committee advises on policies, optimal medicine use and funding issues.
South Africa	General taxation for a government provided service used by 68% of the population. 16% of the population use private insurance. 16% of expenditure from out-of-pocket.  Moving towards a National Health Insurance (White Paper on NHI released in 2016).	None, but attempts to create one	Supported and specified in official policy  Some formal structures in place but limited role in decision making advocacy. Litigation and protest more of an impact on priority setting.

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Sri Lanka	General taxation.	None, but has a rapid assessment technique for health care service evaluations.	None.
Thailand	Three tax-based schemes: the Civil Servant Medical Benefit Scheme (CSMBS), Social Security Scheme (SSS) and Universal Coverage Scheme (UCS). The last covers essential care for 75% of the population.	Health Intervention and Technology Assessment Programme (HITAP).	Representatives of patients associations, people networks and civil society organizations alongside academics, health professionals, MOH departments and health product industries are involved in different stages of benefit package development including HTA.
USA	Highly pluralistic, including Medicare , Medicaid , Veterans' Administration and mandated private insurance.	None. Patient-Centered Outcome Research Institute (PCORI) and Institute for Clinical and Economic Review (ICER) conduct relevant research.	PCORI have public comment periods/ an Engagement Plan to shape the nature of research.  ICER has 3 Advisory Boards, one for each of its public deliberation programs: New England Comparative Effectiveness Public Advisory Council (CEPAC); Midwest CEPAC; and the California Technology Assessment Forum (CTAF). Advisory Boards guide topic selection and provide advice on methods to enhance uptake and application of evidence reports to clinical practice and insurance coverage.



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7 *Source:* Case studies presented at Brocher Foundation Workshop, 9-13 November 2015. Also:

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**Table 2**  
**Representation and Contestation in Priority Setting**

		<b>Contestatory Participation Routine</b>	
		<b>Yes</b>	<b>No</b>
<b>Public Representatives Have Agenda Role</b>	<b>Yes</b>	(A)  ----	(C) Australia  Germany  New Zealand  Thailand  UK
	<b>No</b>	(B) Brazil  Colombia  South Africa  South Korea	(D) China  Sri Lanka  USA

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