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Introduction: Priority Setting, Equitable Access and Public Involvement in Health Care

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Introduction: Priority Setting, Equitable Access and Public Involvement in Health Care

Abstract

Purpose: The paper introduces the special issue on improving equitable access to health care through increased public and patient involvement (PPI) in prioritization decisions by discussing the conceptualization, scope and rationales of PPI in priority setting that inform the special issue.

Design/Methodology/Approach: The paper employs a mixed-methods approach in that it provides a literature review and a conceptual discussion of the common themes emerging in the field of PPI and health priority setting.

Findings: The special issue focuses on public participation that is collective in character, in the sense that the participation relates to a social, not personal, decision and is relevant to whole groups of people and not single individuals. It is aimed at influencing a decision on public policy or legal rules. The rationales for public participation can be found in democratic theory, especially as they relate to the social and political values of legitimacy and representation.

Originality/Value: The paper builds on previous definitions of public participation by underlining its collective character. In doing so, it develops the work by Parry, Moyser and Day by arguing that, in light of the empirical evidence presented in this issue, public participatory activities such as protests and demonstrations should no longer be labelled unconventional, but should instead be labelled as 'contestatory participation'. This is to better reflect a situation in which these modes of participation have become more conventional in many parts of the world.

Keywords: Public participation, priority setting, contestatory participation, democratic theory, deliberation

Article Classification: Literature Review and General Review

Introduction

Priority setting in health care is now at the centre of policy and political attention in many parts of the world. More countries move towards attaining universal health care, but many struggle to ensure the sustainability of their health systems under competing demands from patients, a steady increase in medical advances and limited health care budgets. Where trade-offs are inevitable, a process that uses evidence to set priorities is essential. The most visible expression of this central role is to be found in the establishment of health technology assessment (HTA) agencies with the responsibility for determining what counts as value for money in health care and what priority should be given to particular interventions. Although the oldest of such bodies, the Australian Pharmaceutical Benefits Assessment Committee (PBAC) was founded in 1954, many countries have by now established similar bodies, including the National Institute for Health and Care Excellence (NICE) in the United Kingdom (UK) set up in 1999, the Institute for Quality and Efficiency in Health Care (IQWiG) in Germany set up in 2004, the National Evidence-Based Healthcare Collaborating Agency (HIRA) in Korea, the Health Intervention and Technology Assessment Program (HITAP) in Thailand as well as many others (Stafinski et al., 2011). At the 2014 World Health Assembly in Geneva, a resolution was adopted for the incorporation of health intervention and technology assessment to support Universal Health Coverage (UHC).

Priority setting in health care does not simply take place in the setting of health technology assessment agencies, however. Cabinets, government departments, health care agencies and local authorities all have a role in priority setting through their routine decisions on resource and budgetary allocations, decisions on capital spending, price negotiations with manufacturers on pharmaceutical products and medical devices as well as investments in the training of medical and para-medical staff. Courts play a role in adjudicating the extent to which some of these decisions, when contested by plaintiffs, conform to administrative, constitutional or international law. Hospitals and insurance agencies make decisions on which services to provide and to whom. And individual physicians are inevitably involved in making decisions on health priorities when they make treatment decisions with their patients. From boardroom to bedside the determination of priorities is implicit in an organized health care system.

The context of these decisions is one in which governments and insurance funders increasingly are seeking value for money in resource allocation. In high income countries the

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3 choices involved typically revolve around access to expensive therapies, sometimes of
4 marginal advantage but which are thought important by particular groups. Approval and
5 finance of such interventions raise considerable issues of policy choice, particularly in fixed
6 budget systems where any positive decision necessarily involves an opportunity cost, often
7 with direct implications for disadvantaged groups for whom the use of political voice may be
8 harder. In middle and low income countries priority setting is increasingly seen to be central
9 to securing universal access to reasonably comprehensive care of reliable quality (World
10 Health Organization, 2014), but mechanisms for it are less established.

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17 A popular mechanism for priority setting is health technology assessment (HTA). Here, it is
18 important to distinguish between technology assessment as practised by HTA agencies, and
19 the appraisal of assessment outcomes. While HTA is defined as a multidisciplinary
20 undertaking that assesses effects, benefits, and harms of a health technology across a range of
21 issues, including social, economic and ethical issues (see for example WHO, 2016), in
22 practice the remit of HTA agencies is often limited to providing expert evaluations of the
23 benefits and costs of health technologies according the pre-defined decision criteria and
24 health economic methodologies such as cost effectiveness analyses. These processes are
25 largely scientific, technocratic and expert-driven. The results of such processes need to be
26 given meaning in the policy making arena. It is for this reason that the process of HTA
27 assessment and appraisal are distinct from one another: “Assessment is the science that
28 underlies HTA (i.e., the HTA study). Appraisal is the process by which the science is
29 considered at the policy-making level” (Oliver et al., 2004: 4). This distinction reflects the
30 fact that priority setting decisions give rise to contentious distributional conflicts that need to
31 be resolved in the public space that includes avenues for deliberation (Landwehr, 2009).

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Priorities can be set in different ways. The most frequently observed and frequently contested
examples are concerned with decisions about which medicines or interventions to cover for
provision or reimbursement. Controversies around expensive pharmaceuticals are familiar,
but similar controversies can occur in relation to such interventions as renal replacement
therapies. Priority setting also occurs around decisions to disinvest from relatively expensive
interventions in order to release resources for most cost-effective uses, decisions that, for
example, may pitch the priority to be given to urban hospitals against the priority to be given
to rural public health. Priorities are also set, and in low and middle income countries are most
commonly set, by failures to include certain social groups in the financial risk protection that
universal health care allows.

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3 Even in countries in which governments enjoy a high level of political legitimacy, priority
4 decisions in health prompt challenges. Health policy makers or managers cannot assume that
5 they can derive legitimacy for their decisions from the general legitimacy of the political
6 system. Even when the choices meet formal conditions of due process, they can encounter
7 public resistance. In high income countries, such resistance takes the form of campaigners,
8 patient groups and industry contesting the decisions on cost effectiveness or on decisions to
9 deny coverage or reimbursement of particular interventions. In low and middle income
10 countries it may take the form of citizens protesting against the denial of basic services from
11 the government. Where general government legitimacy is low, the stock of political capital
12 that health policy makers can borrow from it in making controversial decisions may well be
13 very low.
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22 In this context, policy makers are exploring the potential for direct public participation to
23 enhance legitimacy in the identification of priorities. New forms of public participation, for
24 example the use of mini-publics like citizens' juries or deliberative polls, are being developed
25 alongside the representation of members of the public in routine decision-making processes.
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27 However, alongside this top-down interest in participation, priority setting has also stimulated
28 bottom-up forms of participation as patient groups, rights activists and others mobilize
29 around the promise of universal health care.
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34 The papers gathered together in this special issue of the *Journal of Health Organization and*
35 *Management* explore the character, modes and implications of public participation in health
36 care priority setting, examining empirically, analytically and normatively the contribution
37 that public participation makes to priority setting and health care equity. These papers derive
38 from a workshop held at the Brocher Foundation in Geneva in November 2015, which
39 brought together scholars and policy makers from twelve different countries to share their
40 experiences and understanding. This Introduction presents an overview of the issues that
41 public participation in priority setting raises.
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50 **Defining Public Participation in Priority Setting**

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53 The term 'public participation' covers a variety of activities and practices, and no one
54 definition is likely to secure universal assent. Our approach has been to follow the lead of
55 Parry, Day and Moyser (1992: 16) in their path-breaking study of political participation in
56 Britain and to define participation in health policy as a form of political participation, where
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3 political participation is defined as ‘taking part in the processes of formulation, passage and
4 implementation of public policies’. On this definition, public participation in priority setting
5 involves individuals or groups taking part in processes of policy making that shape the
6 determination of priorities in health care and the conditions of access of different groups in
7 society. Political participation is thus collectively-orientated and aimed at securing a decision
8 on public policy or legal rules.
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13 Closely related to the conceptualization of political participation is our understanding of what
14 constitutes the ‘political’, which we derive from Lasswell’s definition of politics as involving
15 decisions about who gets what, when and how (Lasswell, 1936). Since priority setting and
16 rationing in health care give rise to political conflicts over distributive consequences of
17 decisions (e.g. Landwehr, 2009), they can be usefully thought of as decisions about who gets
18 what, when and how. Using Lasswell’s definition of politics in this way also underlines one
19 of the normative rationales for public participation, namely that those affected by distributive
20 decisions should be included in decision-making processes whose outcomes affect them.
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28 The definition of ‘public’ lacks consensus (Abelson et al., 2007; Mitton et al., 2009). Does it
29 refer to the general public, to patients, potential patients regarded as consumers or patient
30 groups and associated activists? How do we treat the fact that public participation typically
31 means not participation by the public as a whole but by selected persons, taken to be
32 representative of the whole? These questions are more than just conceptual puzzles for policy
33 analysts; they are also practical questions of public administration when designing or
34 reforming participatory practices. For example, Australia’s PBAC includes a ‘consumer’
35 representative while the Pharmaceutical Management Agency (PHARMAC) in New Zealand
36 has a consumer advisory panel, made up of representatives or advocates of consumers.
37 Patient groups play an important role in Thailand’s HITAP. The German Federal Joint
38 Committee, which makes decisions based on the HTA assessment of IQWiG, allows for
39 patients to take part in discussions and submit petitions (G-BA, 2016). The patient
40 representatives take part in deliberations and propose resolutions, but they do not have voting
41 rights (Kieslich, 2015: 106). Similarly, as part of the Thai process for setting priorities for
42 inclusion in the basic package of universal health coverage, representatives of patient groups
43 can propose items for consideration. Public participation can therefore take a wide variety of
44 forms, with different understanding of ‘the public’ affecting how decision-making is
45 structured.
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3 Public participation in the formal sense also includes institutionalized forms of consultation
4 with the public, for example in cases where draft decisions or determination are put out to
5 stakeholders for comment. Public participation in the making of policy also includes the use
6 of mini-publics, in which selected members of the public come together for the purposes of
7 deliberation in forums established by policy makers, to help shape policy and define choices.
8 For example, NICE's Citizen Council represents a form of public participation in our sense.
9 In all of these forms of public involvement, participation is institutionalized in some way, so
10 that members of the public play a relatively well defined role, working through established
11 procedures, and typically responding to policy agendas and issues that have been set by the
12 administrative or political authorities.
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20 Following Parry, Moyser and Day (1992: 18), we also include in public participation
21 activities that they describe as 'unconventional', that is to say actions that are outside the
22 confines of conventional politics and therefore of the formal policy process. Such activities
23 include demonstrations, political strikes, boycotts, acts of interference with traffic and even
24 instances of physical violence or riot. However, in some health care systems, as the analysis
25 in a later paper shows (Slutsky et al., 2016), these types of activity are far from
26 unconventional; in fact they represent a routine form of public participation in priority setting.
27 They include, for example, street protests and demonstrations that aim to challenge the
28 legitimacy of decisions about access to care or the availability of medicines. We label such
29 participation 'contestatory', rather than 'unconventional' as in Parry, Moyser and Day,
30 because the use of such protests is sometimes routine.
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39 From this point of view, our definition of public participation is meant to be inclusive,
40 covering both its formal, routine and institutionalized forms, on the one hand, and its
41 contestatory forms on the other. However, it is exclusive in that it rules out various forms of
42 involvement that are often considered important from the point of view of those interested in
43 participatory health care. Of these, the most important is the involvement of patients in
44 choices about their own personal care, a form of participation that is typically particular to the
45 person concerned carrying no implications for public policy. It is restricted to what Mitton et
46 al. (2009: 221) call the macro and meso levels of decision-making rather than the clinical
47 level. Thus, when individual patients negotiate with their physician about the choice between
48 surgery or watchful waiting, or a pregnant woman determines the choice between home or
49 hospital delivery, these are forms of participatory involvement excluded from our discussion.
50 Such exclusion is not intended to suggest that such practices are unimportant. Indeed, one of
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3 the principal ways in which health services may be transformed is through the cumulative
4 effect of a large number of individual decisions made by patients. However, the decisions
5 remain individual ones taken from a personal perspective (Dolan et al., 2003), and so are not
6 directed towards the collective determination of public priorities.
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10 It might be argued that this distinction between individual and collective is artificial in those
11 cases of priority setting where public education (both government or non-government
12 sanctioned) can shift personal choices from one form of treatment to another. Moreover, the
13 use of administrative and legal challenges by individuals can have widespread policy
14 implications. For example, in 1997 Mr Soobramoney, who had kidney failure and other co-
15 morbidities, appealed to the Constitutional Court of South Africa for the right to a kidney
16 transplant, even though his medical condition was such that he was not eligible under the
17 transplant guidelines of the treating hospital. His appeal was based on the grounds that failure
18 to secure the transplant would breach his right, under Section 27(3) of the South African
19 Constitution, that 'no one may be refused emergency medical treatment' and Section 11 that
20 stipulates that 'everyone has the right to life'. In the particular case, the court decided that it
21 should not interfere with the existing resource allocation policy of the hospital, ruling that
22 Soobramoney's case was not an emergency (Constitutional Court of South Africa, 1997).
23 However, had it decided to the contrary, there is no doubt that the individual case would have
24 had widespread implications for health care resource allocation in South Africa, potentially
25 requiring many other forms of medical care to be provided. As this example shows, even if an
26 individual appellant is not aiming at a general change in law or policy, there can be cases
27 where court decisions in an individual's case can have general ramifications.
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31 Between individual and collective action there is clearly a continuum of activities and we
32 accept that there is a fine line to be drawn as to when an individual legal challenge is to count
33 as political participation. Sometimes an individual administrative or legal challenge simply
34 affects the individuals involved, as is the case with individual funding requests in the United
35 Kingdom's National Health Service or New Zealand's PHARMAC, where physicians on
36 behalf of their patients request the funding of therapies that are not normally covered by the
37 funders. Such types of challenge do not figure in our analysis, because they are not
38 challenges to the policy but to the way that the policy operates in the individual case. Other
39 legal challenges may have policy relevance, as in the Soobramoney case, even if that is not
40 the intention of the appellant. And yet others may be individually related but are supported by
41 more general political mobilization. If we were to exclude all forms of legal challenge,
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3 particularly legal challenge under constitutional provisions, entirely from the scope of public
4 participation, we should miss an important element of the dynamics of mobilization in a
5 number of countries. Conversely, to exclude the cases of action for purely individual reasons
6 keeps the focus on the collective dimension of public participation.
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10 A second type of participation excluded from our analysis is that involving survey responses
11 and similar attempts to ascertain preferences. Such surveys include patient experience
12 surveys, where the views of those who have used a service are elicited, but also include
13 experimental results and discrete choice experiments. Such experiments “typically involve
14 the presentation of a series of choices in which respondents are asked to choose one of two or
15 more alternative scenarios, each representing a unique combination of specified attributes and
16 levels of the treatment or service, under consideration” (Whitty et al., 2014: 59). An
17 important aspiration of these experiments is to provide a sense of the relative priority to be
18 given to alternatives. Our exclusion of these methods of public participation from our
19 analysis is not because they are unimportant, or because they should be classified as research
20 rather than patient involvement. They are part of the information that flows through a health
21 care system and in that sense are an important component of decision-making on priorities.
22 However, their policy dynamic is different from the forms of participation with which we are
23 concerned, since they are typically the product of administrative processes. In this respect,
24 they fall into a different category from patient and public representatives occupying seats on
25 priority setting bodies or mobilizing in order to secure a change in policy. A similar point can
26 be made about information collected through complaints mechanisms. These may be an
27 important resource for policy makers (although typically they are not given sufficient
28 attention), but they are not in themselves a means by which patients and the public participate
29 in policy making. Similar points can also be made about the use of focus groups, which are
30 often used to assess public reaction to issues, but are not themselves integrated into the public
31 deliberative system.
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47 An important form of public participation that straddles the divide between public
48 deliberative system and individual survey response is the use of mini-publics (e.g. Goodin
49 and Dryzek, 2006; Grönlund et al., 2014; Niemeyer, 2014; Ryan and Smith, 2014; Niemeyer,
50 2011). A mini-public is a group of lay persons selected so as to be descriptively
51 ‘representative’ in some sense of a wider public and asked to deliberate about a policy issue
52 and provide an opinion. They take different forms including citizens’ juries, citizen panels,
53 consumer forums or deliberative polls. Sometimes these approaches aim at consensus, as with
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3 citizens' juries, and sometimes they prompt individual responses to be aggregated, as with
4 deliberative polls. Mini-publics are like surveys in that their function is typically to provide
5 policy makers with information about public preferences and attitudes. However, they are
6 unlike conventional surveys because they ask participants to deliberate about a general policy
7 question, often from the point of view of a citizen rather than a patient, and come to a
8 conclusion on that question. In some cases, as with NICE's Citizens Council, they are closely
9 integrated into the decision-making system. In other cases, they may be ad hoc one-off events.
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15 In summary, then, this special issue focuses on public participation that is collective in
16 character, in the sense that the participation relates to a social, not personal, decision and is
17 relevant to whole groups of people and not single individuals. It can take various forms both
18 formal and institutionalized on the one hand, as with public representatives on decision-
19 making bodies, and informal and contestatory on the other, as with organized demonstrations
20 and protests. It also includes legal challenges, the significance of which go beyond the
21 individual case. The use of mini-publics should also be included, both when they are
22 routinely integrated into decision-making and when they ad hoc and one-off. In identifying
23 these different forms of public participation, we are not supposing that they are mutually
24 exclusive. Indeed, different forms of participation may come into play in relation to the same
25 types of decision, as discussed in the next section.
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37 **The Scope of Public Participation**

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39 Public participation in health policy can affect a wide range of issues. Following Lomas
40 (1997), however, it is possible to identify three broad types of question that can be addressed
41 through public participation: decisions on overall levels of funding; decisions of principle on
42 the type of services to be offered or reimbursed, including the principles used in health
43 technology assessments; and decisions on the eligibility of different types of patients or
44 groups. (Compare also Mitton et al., 2009: 223, who also add questions of monitoring and
45 evaluation.)
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51 *Overall Funding.* Health care spending is popular with citizens in democracies. However,
52 opportunities for public participation on such decisions are typically limited, because they are
53 bound up either with the wider public expenditure process in government or with the
54 processes of determining contributions among the major social partners in social insurance
55 systems. However, it is possible in principle to organize such discussions and one example is
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3 the Deliberative Poll on the future of the UK's National Health Service held on the service's
4 fiftieth anniversary and organized by the Center for Deliberative Polling at the University of
5 Texas, Social & Community Planning Research (SCPR) and Channel 4 (Park et al. 1998;
6 Parkinson 2006). Channel 4 broadcast four episodes about the poll on the weekend of 5–6
7 July 1998. More generally, however, public participation in such matters normally takes
8 place through voting in elections and the competition for support by parties standing for
9 office.
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15 *Principles of Service Coverage.* The most visible forms of priority setting concern which
16 medicines or procedures to provide or reimburse within the scope of public coverage. Which
17 pharmaceuticals over and above the WHO Essential Medicines list should be covered? What
18 should be included in primary health care benefit packages? How far should renal
19 replacement therapy, heart transplants, bariatric surgery or infertility treatment be included?
20 Such decisions cannot be avoided, even if they are only made implicitly, with potentially
21 limited transparency, rather than explicitly. Disinvestment raises similar problems
22 compounded by the fact that, where there are established services, individuals and patient
23 groups will have acquired legitimate expectations in the availability of care.
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31 Obviously, where public representatives sit in an official capacity on decision-making bodies,
32 there is some form of public participation in such choices. However, the number of public
33 members is necessarily limited, and each public member can quickly become an
34 “institutionalized” expert. One of the ways in which policy makers have sought to extend
35 public participation is through the use of mini-publics, which can provide a forum in which
36 the principles of coverage can be debated by an informed lay public.
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41 An illustrative example of public involvement through mini-publics of this sort is the Israeli
42 Health Parliament, which was a meeting established by officials from the Ministry of Health,
43 researchers from Tel Aviv University and members of the Zippori Center for Community
44 Education (Guttman et al., 2008: 180). As part of the exercise there were six meetings held
45 in six regional groups in community centres, and participants were asked their views on
46 issues of equity (whether people should be allowed to pay to ensure their choice of doctor in
47 publicly funded hospitals and whether the requirement of co-payment for medical services
48 and medications provided through the National Health Insurance system should be continued)
49 and rationing (how should ‘life-saving’ treatment be defined and what priority should be
50 given to rare conditions).
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3 In some cases, the discussions can become quite technical, for example the NICE Citizens
4 Council discussed whether the standard time discount rate should be applied to assess the
5 benefits of interventions when those benefits occurred at a relatively distant point in the
6 future (NICE, 2011). Technology assessment can also prompt participation in the form of
7 demonstrations protests and resort to the media. On more than one occasion there have been
8 protests at the offices of NICE over particular decisions that the agency has made.
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13 *Decisions on Eligibility for Services.* One of the ways in which services can be provided in
14 relation to resources is by the denial of services to particular groups of people. Hospitals and
15 clinics in particular localities may be closed or the scope of their services reduced. In relation
16 to health technology assessment, questions can arise about the extent to which particular
17 groups should be eligible or ineligible for services that are generally available. Thus, for
18 instance, the NICE Citizens Council has been asked to examine how far age should be a
19 relevant criterion of assessment (NICE, 2003) or whether self-inflicted diseases should be
20 given lower weight in assessments.
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28 Not all decisions on service provision need concern the availability of resources. Instead they
29 may concern how best to use such resources as are available. For example, in the provision of
30 some services there is a well-known trade-off between accessibility, which suggests small
31 centres of care close to patients, and quality, which suggests concentrating care so that
32 professionals improve their skills through dealing with large numbers. This sort of trade-off
33 ought to take into account a number of considerations, and one of the ways of making a
34 decision is to involve members of the public, or patients, in deliberating on alternative
35 courses of action. Thus, early citizens' juries, financed by the King's Fund, were asked to
36 consider the location of specialist cancer services, where the question of access versus quality
37 typically emerges (McIver, 1998). Decisions on services, particularly decisions to reduce or
38 close services, are often controversial and so it is not surprising that they provoke public
39 participation of the contestatory kind.
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50 **Rationales for Public Participation**

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53 Public participation in all its forms in priority setting is an empirical phenomenon, taking
54 various forms in different health care systems. As far as rationales go, the emerging wisdom
55 is that involving the public can increase the chances of successful policy implementation,
56 manage public expectations, improve public understanding of complex policy problems and
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3 result in a more empowered citizenry (for example Lomas, 1997; Niemeyer, 2011). In light of
4 existing barriers to PPI in priority setting (e.g. Goold et al., 2005) though, ascertaining
5 whether these theoretical expectations translate into empirical actuality remains a challenging
6 issue.
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10 However, public participation also raises issues of social and political values that give rise to
11 its underlying rationales. There are a number of strands of democratic theory that suggest that,
12 if citizens take an active interest in matters of public service, then both instrumental and
13 intrinsic values are served. Properly to evaluate the role of public participation in priority
14 setting, then, requires us to examine the range of possible values that such participation may
15 serve. Two sets of values that are likely to be particularly relevant to questions of priority
16 setting: legitimacy and representation.
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22 *Democratic Legitimacy.* Priority setting in health policy is an obviously important part of
23 public decision-making, and public decisions require legitimation. One minimal notion of
24 legitimacy is purely procedural, based on the principle that decisions are legitimate when they
25 are made in accordance with legal and constitutional rules and conventions. For example,
26 principles of good governance and due process require administrative decisions to be taken
27 after consultation with affected parties. One way of understanding public participation is an
28 extension of the existing obligation of governments to consult in order to enable individuals
29 and groups to forward views and opinions in accordance with their interests.
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36 However, since the rise of deliberative democratic theory in the 1970s and 1980s, theorists
37 have advanced a more demanding standard than purely procedural legitimacy, summarized in
38 Cohen's (1989: 22) claim that political outcomes are legitimate "if and only if they could be
39 the object of free and reasoned agreement among equals". Studies of innovations in public
40 involvement invoke this background of theory (Abelson et al., 2013: 1; Guttman, 2007: 411)
41 as part of the rationale for increasing and improving public deliberation through the use of
42 mini-publics. One central principle in deliberative theory is to move away from the normal
43 pulling and hauling of competing political forces in procedures of policy consultation towards
44 a more collectively-orientated and problem-orientated basis of decision-making.
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53 This concern with the deliberative quality of policy decisions is reinforced by observations on
54 the weakness of conventional competitive party politics and modes of interest-group
55 representation to accommodate adequately the scale of views, needs and equality issues to
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3 which challenging trade-offs in health policy give rise. In a competitive party system there is
4 an incentive for those campaigning to make incompatible promises, for example offering
5 lower taxes or contributions and improved services. In consequence, citizens are rarely
6 confronted by the trade-offs that are required by policy choice. “Public deliberation rests on
7 the democratic principle that important societal decisions—particularly issues involving
8 competing values and complex trade-offs—are best made by policymakers in partnership with
9 an informed public” (American Institutes for Research, 2016).
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15 New methods of public participation through mini-publics are sometimes seen as rectifying
16 the imbalance of financial or human resources between different societal groups. For example,
17 if a proposal is made to exclude an intervention from collective health coverage, then
18 industry and producer groups are likely to be in a better position to make representations in a
19 consultation than individuals. By contrast, if an effort is made to consult citizens through the
20 use of mini-publics, then a more general perspective in terms of social values may be
21 garnered.
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27 However, the literature on deliberative democratic theory also raises complex questions about
28 the extent to which instruments of deliberative democracy such as mini-publics can meet the
29 requirements of legitimacy that are set out by deliberative democratic theorists. For example,
30 Lafont (2015) explores the tensions between the conditions for high-quality deliberative
31 processes, such as the participants being open to change their views and opinions as a result
32 of deliberations, and the normative demand that participation processes be inclusive of the
33 citizenry at large. She argues that “[...] even the most general necessary conditions for
34 deliberation are best satisfied in small-scale face-to-face deliberation” (Lafont, 2015: 46).
35 However, the make-up of such small-scale deliberations does not necessarily satisfy
36 conditions of what constitutes legitimate representation as the representatives in these forums
37 have neither been elected nor selected through democratic processes available to the non-
38 participants who may be affected by the outcomes of deliberative processes (Parkinson,
39 2003). This raises complex questions about whether deliberative processes can, or should, be
40 used as instruments to inform public policy making (Lafont, 2015).
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51 The papers in this special issue underline these complexities. As Hunter et al. (2016)
52 conclude, an underlying theme of the papers is the importance and the challenge of
53 establishing legitimacy in health prioritization. Here, public participation may be thought of
54 as part of the process of legitimation as distinct from contributing to the product of legitimacy.
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3 The latter is a matter for empirical investigation in order to explore whether theories of
4 legitimacy in health care decision-making actually yield more acceptable decisions in the
5 eyes of those affected (see Kieslich and Littlejohns, 2015), whereas the former is a trend, a
6 goal, a demand and a fact in most health care systems, albeit in different forms. The different
7 modes of public participation, be they orientated towards consensus or contestation (Weale,
8 2016), can support the decision-making process by illuminating additional perspectives and
9 arguments that can be considered. Regardless of the form of public participation, behind the
10 question of legitimacy is the important question of representation.

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17 *Better Representation.* Conventional democratic politics, though based on the principle of
18 representation, is biased against various forms of participation. Elected representatives are
19 rarely representative of those whom they represent. If social characteristics (age, class,
20 ethnicity, gender and so on) are related to political opinion, then a skew in the characteristics
21 of elected representatives and public officials, relative to the population at large, runs the risk
22 of neglecting important elements of public opinion. More generally, those who are politically
23 active through parties and interest groups, which in the case of health care will include patient
24 group representatives, are socially unrepresentative of the population at large.

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31 It is partly for this reason that mini-publics have become popular in some discussions around
32 public participation in health care. Mini-publics can be seen as a way of rectifying the
33 imbalance of representation brought about through the selection processes inherent in
34 electoral politics, although there are important caveats on whether this amounts to legitimate
35 representation (e.g. Lafont, 2015; Parkinson, 2003). These caveats relate to the broader
36 literature on how political representation is established and how it incorporates deliberative
37 democratic norms (e.g. Mansbridge, 1999; Mansbridge, 2003; Parkinson, 2003; Pitkin, 1967;
38 Phillips, 1995; Dryzek and Niemeyer, 2008). A large branch of this literature examines how
39 political representatives relate to their constituents (Mansbridge, 2003). Traditional forms of
40 representation are closely aligned with principal-agents models, where the agent (the political
41 representative) represents the principal (the elector) through either a delegate or a trustee
42 model of representation. Under the trustee model agents make decisions as they choose,
43 whereas they follow the principals' instructions directly under the delegate model (Parkinson,
44 2003). These views of representation have been expanded to include more nuanced
45 understandings of representation including, but not limited to, descriptive representation
46 (Pitkin, 1967), surrogate representation (Mansbridge, 2003) and discursive representation
47 (Dryzek and Niemeyer, 2008). While a detailed discussion of these forms of representations
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3 is beyond the scope of this paper, it is important to note the recurring questions in relation to
4 representation. Who and what is represented? How are representatives selected and what is
5 their role (Parkinson, 2003)? How are issues of power played out in deliberative forums?
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9 A related consideration is diversity. Random sampling will enhance the diversity of social
10 characteristics represented in deliberation on public policy, but it will not necessarily capture
11 the views and opinions of small minorities who may not be included in a random sample. In
12 some cases, for example, members of minorities have been purposively included in mini-
13 public events in order to deal with this problem. Any concern with the politics of difference
14 in priority setting will need to find some ways of overcoming the selection effects inherent in
15 the policy process, and mini-publics seem to offer one way around this problem if they
16 incorporate forms of descriptive representation, that is if individuals share characteristics or
17 experiences with particular members of a societal group (Mansbridge, 2003; Pitkin, 1967).
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21 The question of diversity is also important because the price mechanism, which is one
22 familiar way of dealing with diversity, is attenuated in the case of health care. For reasons
23 including information asymmetry between physicians and patients the regulation of the
24 market based on price mechanisms that follow demand and supply fails in the case of health
25 care and it has to be modified or suspended and replaced with a collective alternative (Arrow,
26 1963). However, in restricting the operation of the price mechanism, those providing
27 collectively-based universal health care lose the role of prices as a source of information
28 about strength of patients, consumer and citizen preferences. If citizens are willing to pay for
29 improvements in health care, they may have no way of signalling this fact in a system based
30 upon administratively determined resource allocation. If voice is to stand in for exit in health
31 services, then the question of how representative the voices are becomes important.
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35 The question of the representativeness or otherwise of the voices that are heard in the priority
36 setting process, and the lack of voices that may be missing, has important implications for the
37 justice and fairness of the priorities that are set. An influential account of justice in health
38 care resource allocation stresses the place of 'accountability for reasonableness' (Daniels,
39 1994; Daniels and Sabin, 2008). This approach assumes that disputes about priority setting
40 cannot be resolved consensually, but they can be resolved procedurally. Provided decision-
41 makers are willing to be open and transparent about their reasoning, offering grounds for
42 their judgement that are public, reasonable and revisable, then resource allocation can be
43 regarded as fair by virtue of meeting those procedural conditions. However, if political
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3 participation is unbalanced in representative terms, then the legitimacy of decisions based on
4 procedural norms alone is called into question.
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8 9 **Conclusion**

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11 Public participation in priority setting is both a fact and a challenge. It is a fact because
12 through various formal and contestatory routes it exists and plays a role in the way that
13 decisions are made. It is a challenge because we have relatively little empirical evidence as to
14 how it affects the decisions made, whether it “improves” decisions against some specified
15 desirable criteria, and few attempts to assess the extent to which it conforms to democratic
16 norms. This special issue is an attempt to address these issues through comparative cross-
17 country analysis.
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21 The first paper looks at patterns of public participation, and suggests a dynamic in which
22 token formal inclusion leads to more active contestatory action (Slutsky et al., 2016). In the
23 second paper, Kieslich et al. (2016) examine this dynamic through the analysis of decision-
24 making on interventions for the management of Hepatitis C, which has been a controversial
25 priority setting issue in many countries. In a third paper, Weale (2016) focuses on the
26 implications for democratic theory and argues that given the role of routinized contestation in
27 some priority setting contexts, particularly in Latin America, South Korea and South Africa,
28 we should move away from a focus on Habermas-inspired ideals of consensus through mini-
29 publics to look at ideas of radical democracy associated with Chantal Mouffe. Finally, Hunter
30 et al. (2016) provide an analysis of the findings’ implications for PPI in health priority setting
31 and for the future research agenda.
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