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Democracy, Deliberation and Public Service Reform

Annabelle Lever¹

Is there a role for lay deliberation in the rationing of health care, and in administration more generally? The answer seems to be ‘no’. Once ordinary democratic politics have set the goals and priorities which health care decisions should attain, there seems to be no distinctive role which deliberation by non-experts might serve. Instead, one might think, determining how government objectives might best be achieved, and then actually achieving them, is a matter for experts armed with the best available evidence of the subject area involved, and of management and administrative excellence.²

However, more deliberative and less technocratic views of democratic politics suggest an alternative answer to our question. Lay deliberation, it suggests, has an important role in the administration and execution of government policy, both because these latter inevitably have a political element which needs to reflect democratic norms and values, and because lay people are, themselves, a source of information, even of wisdom, that experts will want to use in fulfilling their professional responsibilities.

Recent debates on the value of lay participation in health care provision can illuminate the strengths and weaknesses of both approaches, as can the experience of the National Institute for Health and Clinical Excellence (NICE). So, I will start by examining two articles which attempt to clarify the role that

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² A recent example of this is the ‘outcome commissioning’ strategy presented and advocated in Cumming *et al.*, 2009.

lay deliberation should have in health care, before turning to the dilemmas for both the technocratic and deliberative views which emerge from the experience of NICE.

Lay participation: What is the point of *citizen* participation?

In a two recent articles, Albert Weale seeks to clarify the point of public consultation on health care (Weale, 2004: 41–51, 2007: 31–43). ‘Like the darling buds of May’, he claims, ‘democratic values appear to be breaking out in the NHS’, chiefly in the form of efforts to ‘consult’ ordinary people about various aspects of health care and health policy. But what, exactly, is the point of public consultation, Weale asks, and how is it to be squared with the accountability of decision-makers for the wise use of scarce public resources?

According to Weale, the main reasons to involve lay people in health care debates is to reflect the views of the public as the users and providers of services to which all are entitled and to which, in principle, all contribute. Doing so may also improve the technical quality of decisions, both because people’s experiences as users of health services is an essential element of any assessment of their quality, but also because the lay public will often have important types of technical experience – experience of planning or organizing transport systems, handling inventories as well as data analysis and option appraisal – which health professionals may lack.

Above all, Weale thinks, such consultation is justified by significant democratic values and concerns with equality, representation, accountability and legitimacy. The NHS is, in effect, a powerful monopoly, and the target for pressure groups of one sort or another. Hence, the perspective of citizens as funders of the NHS is likely to be under-represented compared with the concentrated producer interests involved, as are the more diffuse user interests of citizens who do not fit neatly into the political interest groups centred around particular diseases, or set up to publicize drug companies or their products. Moreover, democracies require those wielding collective power to be able to justify its use openly and, Weale remarks, ‘the ability of decision makers to explain to a consultative forum the rationale of their decision provides some test that a publicity condition has been met’.

Finally, while it would be ‘terribly Panglossian’ to suppose that dialogue always provides consensus – let alone that all agreements are equally attractive – consultation can promote legitimacy even in the absence of consensus, because

it is better 'to have had the opportunity to register a voice in a fair and open process in which you have lost the decision' than simply 'to have had one's voice ignored completely'. So, Weale concludes: 'What is so good about citizen involvement is that it is the expression of a democratic civic culture in the vital interest of health care.' However, he warns that 'existing forms of public consultation ... can never substitute for authoritative decision-making processes. The task therefore is to design public consultation so that it reinforces, rather than undermines, the tasks that decision makers face.' For that, he thinks, 'we need a political theory of consultation.'

I am generally sympathetic to Weale's claims, although I worry that he exaggerates the tension between accountability and representation, and underestimates the many forms these can take (see Lever, 2009; Weale, 2004: 4).³ However, albeit unintentionally, Weale raises a far more troubling issue – namely, how far consultation can be distinguished from deliberation in practice, if consultation is to provide the democratic goods for which it is sought.

Weale carefully uses the language of consultation, rather than deliberation, because deliberation implies that we are pondering a decision that we will make or expect to make. We are thinking about matters as potential decision-makers. By contrast, when we participate as consultants – whether paid or unpaid – we seek to provide advice to others who are authorized to make decisions that we are not, and who, unlike us, will be held responsible for their consequences.

Weale has to insist on this difference, given the importance he attaches to distinguishing representation from accountability, and his justified concern that those responsible for the direction and conduct of public services are publicly identifiable and capable of being held publicly to account for the decisions they made. The problem, however, is a familiar one: that if we are not the ones who are accountable for a decision, we may lack the incentives (as well as the resources) assiduously to study an issue, and to make sound judgements in the face of conflicting evidence.

There is, therefore, a worry about the use of citizen consultations which does not vanish simply because chains of decision-making and accountability are clear, and by-pass lay consultants. We may hope that the members of these groups are public-spirited volunteers, and expect them to recognize that their

³ Initially, Weale seems to be arguing that there is a tension between new forms of democratic deliberation, such as the use of citizen juries, and a 'Westminster Model' of accountability. However, later he refers to a tradition, in political science, of noticing trade-offs between increased representation and accountability, with Proportional Representation as the example, which suggests a broader form of conflict than one peculiar to the UK.

consultations may affect people they know and love in some unspecified future, thereby creating incentives to think clearly and hard about the issues put before them. However, we are unlikely ever to see legal sanctions against citizen consultants who give bad, lazy, self-interested or prejudiced advice. Moreover, consciousness of the sincerity of their beliefs, and of the conscientiousness of their efforts, often insulate people from the full force of the harms they have caused. So, I am sceptical that the sharp distinctions between consultation and deliberation, which Weale favours, either resolve questions about the accountability of lay deliberators within public bodies, or are consistent with the gains to knowledge, equality, representation and legitimacy which he foresees from consultation.

These doubts about Weale's arguments might suggest that there is no legitimate place for lay participation in the administration of health care, because the advantages of consultation come at potentially significant costs to equally fundamental democratic values. But that, I think, would be a mistake. As we will see, Weale's claims about the benefits of citizen participation are borne out by the experience of NICE. In what follows, then, I will briefly describe the nature and history of NICE, before turning to the problems it initially faced, the ways that it tried to solve them, and the significance of NICE's efforts for lay deliberation more generally.

However, before proceeding, I should note that I tend to use the term 'deliberation' where Weale uses 'consultation'. The ability to give good advice requires us imaginatively to take up the perspective of the decision-maker, with the powers and responsibilities involved. So while it is important that lay consultative bodies do not have the same moral or legal responsibilities as those authorized to make binding decisions on our behalf, their activities may, nonetheless – and often will, and should – involve deliberation on evidence supplied by others, rather than offering up their personal opinion or expertise.

NICE and the problem of fair deliberation

NICE was established in April 1999 by the Labour Government, to advise the National Health Service in England and Wales on the clinical effectiveness and cost-effectiveness of health-care technologies, and to produce guidelines for a range of conditions. 'NICE guidance is intended to be authoritative, robust and reliable, underpinned by EBM [evidence based medicine] and legitimated by the involvement of a range of health-care stakeholders' (Quennell, 2003: 39). In

providing that guidance, NICE is guided by three principles: (i) that all guidance should be based on the best available evidence; (ii) that the process of creating that guidance should be as open and transparent as possible; and (iii) that it should be inclusive: 'any stakeholder likely to be affected by its guidance should be part of the development of that guidance, either by being a member of one of the independent advisory bodies, or through participating in open consultations' (Littlejohns, 2009a: 1).

In 2005 NICE was asked to take on responsibility for public health promotion and disease prevention, with the result that it now has four programmes which provide guidance: the technology appraisal programme, the clinical guidelines programme, the interventional procedures programme and the public health guidance programme. NICE clinical guidelines are developed using a systematic methodology by Guideline Development Groups (GDGs) which comprise health care professionals, researchers and patients and carers – at least two of which are lay members recruited by open advertising. The GDGs meet regularly, and assess all the available research on one specific condition, symptom or disease, including qualitative research on patients' views and experiences, as well as quantitative research on the effectiveness of treatment (Thomas, 2009: esp. 20). The findings form the basis of recommendations, with the supporting evidence for them, which then form the basis for consultation with health care professionals, commercial organizations, the NHS, and patients and carers and members of the public. Where necessary, the guidelines are amended, and the results are published and disseminated in a wide variety of formats.

National patient and carer organizations can register as 'stakeholders' for a particular topic, and NICE will actively invite relevant organizations to register as stakeholders, though such invitations are not a requirement for registration (Thomas, 2009: 22). Registration enables organizations to comment on the scope and draft recommendations provided by a GDG, and those comments and the formal response to them by the GDGs are published on the NICE website at the same time as the guidelines themselves.

The same is also true of the Citizens Council – perhaps the most innovative and distinctive part of NICE's commitment to transparency and inclusion in the rationing of health care. The Citizens Council is made up of 30 people, chosen to reflect the attitudes of the general public, rather than those with professional knowledge and experience of health care or the NHS.⁴ It meets twice a year for three days at a time to discuss a particular issue, usually formulated as a

⁴ For details of the way in which Council members are selected see Rawlins, 2009: 75–80.

question, on which NICE would like advice. Meetings involve NICE explaining the question, and the reasons for asking it, as well as experts who present divergent views of the right answer. Members then debate and deliberate, and their conclusions are presented in the form of a non-binding report to the Board. Council members do not have to agree, but the Council is encouraged to lay out the reasons for any disagreements, as well as for the advice that they give. In order to ensure continuity, members of the Council are appointed for three years, with one-third retiring each year. NICE staff have only limited contact with Council members, and their recruitment, as well as the organization and facilitation of meetings, are carried out by an independent body, and an independent academic organization was also commissioned to evaluate the workings of the Council.⁵

Two worries about lay participation

Two related worries about lay participation characterize the literature on NICE. The first is that NICE will ‘capture’ patient groups and the Citizens Council, thereby undermining their ability to provide an independent perspective on health care in the UK. The second worry, expressed by patient groups as well as members of the Citizens Council, was whether their participation had any demonstrable effect on NICE’s decisions. Members of patient groups sometimes complained that ‘we’re always being told how important we are ... and [that] NICE value[s] our input. Yet we’re never told how they value our input, and why they value our input.’ Or as one of Quennell’s respondent says, ‘if a small organisation doesn’t have much resources and comes and says, “What should I do, should I spend £5,000 on this research?”, no one today can say, “Yes, because this will have an effect, an impact” ’ (Quennell, 2003: 43).

So if, on the one hand, commentators worried that NICE would unduly influence, or dominate, the input by patients or the Citizens Council, participants themselves were most aware of the difficulty of determining what NICE wanted, and how their participation was supposed to shape NICE’s guidance.

Patients and carers

The first ten years of NICE suggest that worries about the ‘capture’ of lay participants by NICE can largely be laid to rest, and that NICE’s commitment to its

⁵ The report has been published on the NICE website, and is the subject of Davies *et al.*, 2009: 129–38.

principles of inclusion and transparency are genuine (Davies *et al.*, 2009: 135).⁶ Increasing the role for lay people in health care planning and deliberation seems to have created a 'virtuous circle', whereby NICE has made a positive effort to show how and why it values the participation of patient groups and the Citizens Council, and to explain how lay participation is now embedded both in its procedures and outcomes (Thomas, 2009: 24–5).

Moreover, the important contributions of patient groups to recommendations on psoriasis, kidney dialysis, age-related macular degeneration, cervical cancer and the treatment of HIV-related facial wasting have helped to vindicate the role of patient representatives, despite legitimate concerns about the ways in which patient groups can become conduits for drug company lobbying (see Kelson, 2009: 9–18; Amis, 2009: 37–8; Chambers, 2009: 54–6). Originally, some people thought that NICE appraisals should be insulated from patient pressure for these reasons, whereas others doubted that patients could provide anything other than emotional drama, distraction and anecdotal evidence to a process of appraisal that should be formal, impartial and rigorously scientific (see Milewa and Barry, 2005: 503). But while it is fair to ask patient groups to be open about their funding, the effort to solicit independent testimony from patient groups has been largely vindicated and has, in turn, forced NICE to be more open about the limitations of the clinical evidence and, even, of its own advisers.⁷

The significance of patient involvement for the quality, as well as the legitimacy, of NICE guidelines, then, should not be underestimated. As Fenton *et al.* (2009: 166–9) note, patients' or clinicians' priorities for research very rarely match those of researchers. Whereas the former frequently want to know about the likely results of physical therapy or surgery for given conditions, researchers overwhelmingly study the effects of drugs, and pay little attention to patient interests in access to good information on how to cope with a chronic or disabling condition. Hence, Fenton, Brice and Chalmers contend that 'researchers could do more to address patients' and clinicians' questions. What remains unclear is how, in a research world where perverse incentives often determine what research will be done, the information needs of patients and

⁶ Rawlins, himself, refers to the worry that NICE might 'contaminate' the Council – which is a rather striking choice of words, in Rawlins (2009: 78).

⁷ For example, Emma Chambers notes that 'Five of the six responses [to a consultation on high-dose-rate brachytherapy for cervical cancer] documented the fact that having the procedure was both distressing and painful. This was an aspect of the procedure that was not identified as part of the clinical evidence nor was it commented on by any of the programme's clinical advisors' (Chambers, 2009: 55–6).

clinicians can achieve more prominence.’ NICE efforts to involve patients in the creation of clinical guidelines cannot alone address these perverse incentives – which presumably reflect the political economy of the pharmaceutical industry on the one hand, and of academia on the other – but they are a necessary and desirable step in the process.

The Citizens Council

Evidence of a ‘virtuous circle,’ whereby increased representation increases accountability and transparency, can also be seen with regard to the Citizens Council. Initial concerns by outside observers that the Council would just prove ‘window dressing’ had their counterpart within NICE in doubts about the usefulness, and expense of the Council.⁸ However, concerns that Council members would be unable to cope with the demands made on them, or be unable to step outside their own narrow experience and interests have not been borne out by events, and Council members have been quite ready to probe and discuss the views of professionals even when they have been more timid and uncertain in exploring the differences in their own experiences (Davies *et al.*, 2009: 131, 134).

Still, greater clarity about the place of social value judgements within NICE, and therefore of the Citizens Council, seems desirable for two reasons. The first, is that the picture of the Council’s work presented by NICE can be confusing. For example, Rawlins refers to the Citizens Council as ‘a sounding board to ensure that the views of the taxpayer are also obtained alongside organisations and individuals with a direct and vested interest in a specific guidance topic’ (Rawlins, 2009: 182). But the idea of the Council as a sounding board for tax payer views sits uneasily with current practice within NICE, let alone all the trouble that has been taken to make the Council as representative of UK Citizens as possible, rather than of the population of taxpayers. Moreover, NICE has recently required decision-making committees to demonstrate how they have taken account of the social value judgements generated by the Council, and endorsed by the Board (Pathak-Sen, 2009: 86). This effort to account

⁸ These expenses are not trivial: Council members are paid a per diem attendance allowance, so as to encourage the self-employed and those with families to attend; outside facilitators are used to recruit and run Council meetings, outside evaluators are used to examine proceedings and, at least initially, NICE was helping Council members to make their travel arrangements and find childcare in order to remove as many obstacles to participation as possible. The amount of time, effort, thought and expense that has gone into the Council is really remarkable, reflecting the seriousness with which the Board has treated this experiment in democratic deliberation (see Pathak-Sen, 2009: 82–3).

to Council members for the use of their deliberations would be otiose if the Council were merely a 'sounding board', nor would it be necessary to account for the Council were it not a body into which considerable resources and hopes had been poured.

Whether or not the Council is seen as a sounding board, however, it is notable that the Board draws a sharp distinction between clinical and cost effectiveness when asking the Council to consider the social values which should underpin NICE's work. Yet, social values underpin both, and the Council could, in principle, illuminate the one as well as the other. What we recognize as effective in clinical or financial terms depends fundamentally on our assumptions about how people behave, and how they *ought* to be able to behave, as well as on the way we frame alternatives, and aggregate costs and benefits over a life-time and across individuals. So, it seems odd to suppose that the social value judgements of lay people are critical to the wisdom and legitimacy of judgements on cost effectiveness, but irrelevant to our judgements of clinical effectiveness, or to efforts to combine the two in measures such as QALYs.⁹

However, the main reason to wish that NICE were clearer about the values and aspirations underpinning the Council is that this might improve the quality of Council deliberation itself. Council members appear to have a poor understanding of concepts such as equality or discrimination, which are essential to their work. Deficiencies in this respect appear to have affected at least two reports: the second report on age as a factor in distributing scarce resources, and the seventh report on inequalities in health care. Thus, the view that 'positive discrimination [is] still discrimination' led the Council to reject preferential spending on children, and to reject efforts to target health care resources in order to minimize the very significant effects of social inequality on life expectancy, general health and access to health care in the UK.¹⁰

Equality is a complex and contentious concept, and there is a good deal of uncertainty, even among philosophers, over when, or how far, a commitment to equality requires us to treat people identically (see, for example, Clayton and Williams, 2002; Mackinnon, 1988; Minow, 1990; White, 2007). Nonetheless, it is wrong to say, as Council members do, that 'positive discrimination [is]

⁹ For example, as Littlejohns notes, a substantial majority of Council members thought that NICE should take costs, as well as benefits, into account when recommending measures to improve patient safety. However, they were also clear that QALYs are a poor measure of cost-effectiveness in these cases, because they ignore costs such as litigation, the cost to carers, and costs to those left behind by a death when determining the cost-effectiveness of different safety measures (Littlejohns, 2009b: 104–6).

¹⁰ See Brown, 2009: 128. He is reporting not only his own view of equality, but that of a majority of Council members.

still discrimination' if by 'discrimination' one means 'unjustified differences in treatment'. Whatever the merits of describing discrimination as intrinsically wrongful, it does not follow that the patterns of behaviour and judgement constituting 'positive discrimination' are instances of 'discrimination' so understood. Above all, there is something dishearteningly unreflective in this simplistic condemnation of positive discrimination by a group who were themselves carefully selected in an unusually thorough and expensive effort to counteract the factors that make most deliberative bodies in the UK a talking shop for a bunch of privileged, middle-aged, white men.

Procedure and substance in deliberative democracy

External observers of the Citizens Council shed some light on the obstacles to a more informed analysis of concepts like equality and discrimination by Council members, and bring out the importance of connecting our conception of democratic procedures to an account of democratic values.

'Coming forward to participate as individuals is one thing. Pulling off collective, and specifically deliberative participation ... is another. Although the amount of deliberation that took place in the Citizens Council increased over time and across the meetings observed, the amount remained very small. Over the first two years of the Citizens council, hopes for a high-quality deliberative debate were not met' (Davies *et al.*, 2009: 131).

The problem, surprisingly, was not an inability to challenge the opinions of the professionals, who were presenting their views to the Council. Rather, 'members were far more precarious with their contributions based on "common sense", a "down to earth" or "bigger picture" view' and facilitators clearly struggled both to emphasize that consensus was not necessary for Council reports to be informative, and to help members to articulate their differences of belief.

'One of the most challenging findings from the ethnographic study was an absence of resistance to the ruling point of view and hence of inclusive discussions that might be genuinely oppositional and generative of new ideas. A lack of clarity about the grounds on which citizens could legitimately speak, and pressures to not generate conflict, meant that while differences of class, ethnicity, gender, disability and age were visible to all, these identities were not ... explored with regard to the topic under discussion. This was borne out in a dramatic incident where members dismissed any notion that such discrimination could be positive and strongly affirmed a call for treating everyone "the

same,” at which point the Council burst into applause. Two members sat silent and were clearly baffled by this. A third, who had taken part, noted this and in a later interview mused “were so many of us wrong?” (Davies *et al.*, 2009: 133).

Understandably, Council members ‘rarely felt representative of the gender, ethnicity, sexuality, class and disability groups to which they belonged. And if they did so, they did not feel that they could, with ease, represent distinctive counter-positions that such groups might hold.’¹¹ Moreover, ‘Council members often persuaded each other that personal experience, and the anecdotes that could often bring arguments alive, were somehow not the proper business of the public discourse in which they were engaged’ (Davies *et al.*, 2009: 134), with the result that discussions often resulted in ‘a ready – but potentially misrepresentative – homogenizing of viewpoints and a restatement of the very orthodoxy of thinking that deliberation seeks to disrupt’.

There is no easy solution to these problems, which largely reflect how rarely we get to debate collectively important matters with strangers. Still, some of the difficulties facing Members seem to arise from an inability to connect the ways in which they have been recruited – or the procedural aspects of the Council – with the substantive matters on which they are asked to report. Hence, if NICE could explain the intuitions about representation which it used to constitute the Council, it might be easier for Council members to explore competing conceptions of basic values, such as liberty and equality, and to experiment with different ways of presenting, testing and supporting their views.

For example, when the Council is first presented with a question to answer, some effort should be made to explain why the views of lay people on that question are desirable, what sorts of differences of opinion or experience lay people might be expected to hold; and how far these might be different from those of professionals, or of patients and carers. Greater clarity about such matters might help to free Council Members to explore different positions openly, and to see the value of personal experience – their own, as well as that of other people. In short, NICE needs to be more forthcoming about the

¹¹ It is a common, though understandable, mistake to suppose that the individual members of a descriptively representative body – or a group of people constituted to reflect important socio-political cleavages within a country – must therefore strive to represent ‘their’ group. But this transposes an idea of *functional representation* to bodies whose representative character comes not from what its members *do*, or are *supposed to do*, but from who they *are*. The legitimacy of jurors, as opposed to legislators, does not depend on the idea that they have a *duty* to represent other people. Instead, jurors are meant, themselves, to be *exemplars* of the citizen body, from whom they have been selected. However, given the ways that prejudice and poverty shape living patterns, the formal equality which randomization secures in jury selection may co-exist with predictable, substantial and ethically troubling disparities in the racial, religious and economic composition of jurors (see Lever, 2011: 61–78).

connection it sees between descriptive or mirror representation – at least for the Citizens Council – and the quality of its decisions on rationing.¹²

Descriptive representation might be important to democratic politics for several reasons. Melissa Williams and Iris Marion Young draw attention to the ways that descriptive representation might improve the quality of democratic deliberation, by facilitating the representation of hitherto marginalized or subordinate social groups (Williams, 1998: esp. Chapters 4 and 6; Young, 2000: esp. Chapters 2 and 3). For others, such as Anne Phillips, descriptive representation is a fair test of the extent to which political opportunities are, in fact, equal, as well as an integral element of equal representation.¹³ However, common to all advocates of descriptive representation, or what Phillips describes as a ‘politics of presence’, is the belief that all sections of the citizenry ought, in principle, to be found in positions of power and responsibility roughly in proportion to their numbers.

This is not merely a matter of equality of opportunity – though it is certainly that (Phillips, 1995: 62–4). Rather, it is because the fundamental social and political cleavages, characteristic of modern democracies, have epistemological as well as moral and political consequences. As Young (2000: 144) says, ‘special representation of otherwise excluded social perspectives reveals the partiality and the specificity of the perspectives already politically present’; or as Williams (1998: 193) puts it, since members of privileged groups lack the experience of marginalization, they often lack an understanding of what marginalized groups’ interests are in particular policy areas.

There are, therefore, a variety of important democratic values which appear to be consistent with and, arguably, to illuminate, NICE’s commitment to a deliberative body selected in order to maximize mirror representation, and used to explore the implications of democratic values for the rationing of health care. However, in order for the Council to realize those values more fully, the

¹² Descriptive or Mirror Representation refers to representation that aims to ensure that social distinctions, such as of sex, gender, race, age and class are reflected in a representative body. By contrast, electoral representation tends to result in representative bodies dominated by middle-aged, wealthy white men, although this can be altered by the use of various forms of quotas, as well as by devices such as cumulative voting, which enable voters to select candidates based on a variety of considerations – such as their race or ethnicity *as well as* their views on the economy.

¹³ As Phillips puts it, ‘if there were no obstacles operating to keep certain groups of people out of political life, we would expect positions of political influence to be randomly distributed between the sexes’. That is not what we see. ‘Equal rights to a vote have not proved strong enough to deal with this problem: there must also be equality among those elected to office,’ she concludes (Phillips, 1995: 63, 65). I am assuming that the force of her arguments – and those of Williams and Young – extend beyond the constitution of legislatures to include positions of power and responsibility more generally, such as the Citizens Council.

Board will have to articulate the links it sees between descriptive representation and a deliberative approach to the rationing of health care. In addition, it will, unfortunately, be necessary to accept that, as a country, we are simply not used to deliberating together as citizens, and find this especially difficult when confronted with evidence of the differences of privilege, belief and identity among us.¹⁴

Conclusion: Democracy, lay deliberation and public service reform

- 1 NICE's efforts at citizen participation show that democratic deliberation and participation is costly, in terms of time, energy and money. It is therefore not a 'cheap' solution to the reform of health care or other public services, as some may have hoped, although greater experience organizing democratic consultations and participating in them may in time reduce some of these costs.

Democratic consultation and deliberation are expensive because it is necessary to minimize and, ideally, to remove or neutralize, inequalities of information and status among participants. Removing these may not be necessary to oligarchic, plutocratic or medieval conceptions of consultation, which are fundamentally hierarchical, but they are incompatible with the democratic idea that ordinary people, with no special qualifications, virtues or experience, are entitled to participate in the business of ruling, as well as being ruled. NICE's efforts to ensure the ready availability of information, and to support lay as well as professional participation, are important examples of what democratic consultation and deliberation may involve. Their treatment of patients and carers also reflects the complicated negotiations required to encourage participation while protecting decision-makers from manipulative uses of public pressure.

- 2 Lay participation exposes the need for a political theory of evidence, as part of the political theory of consultation which Weale seeks. Issues of publication bias, the power and influence of the pharmaceutical industry, the nature of accreditation and validation in medicine are specific to the regulation of health care, but are likely, nonetheless, to have their

¹⁴ I suspect that unwillingness actually to debate issues of race, crime and policing is partly to blame for some of the striking biases in favour of black, as opposed to white, defendants revealed in Cheryl Thomas' (2010) research on juries in England. See Lever, (2010, 2011).

counterparts in the political economy of knowledge and authority in other fields.

The experience of NICE suggests that a commitment to democratic deliberation and consultation requires attention to the ways we identify evidence and expertise, and combine qualitative and quantitative evidence. Until recently double blind randomized controlled trials (RCTs) were thought to be the ‘gold standard’ against which all other sorts of evidence was to be measured – and found wanting. However, their limitations are now analysed, not simply by philosophers of science, such as John Worrall, but by clinical pharmacologists like Sir Michael Rawlins, the Chairman of NICE (Rawlin, 2008; Worrall, 2002, 2007). However, even if you reject the idea of evidence hierarchies, as Rawlins does, you still have to decide the relative quality and weight of evidence from different sources, created by different methodologies, the relative merits of which may be hard to determine.

How deliberative bodies ought to approach such problems has largely been overlooked by philosophers and political scientists, but it seems a necessary counterpart to democratic concerns with ‘agenda setting’ and the selection of participants, which have dominated the politics and theory of democratic deliberation thus far (see Moore, 2010). So, further reflection is needed on what is to count as evidence in the justification of collectively-binding decisions, and of how that evidence is to be used and weighed by decision-makers, who are rarely in a position to appraise its epistemological merits for themselves, and will often receive reports of what others have discovered only at second or third hand.

- 3 Finally, the experience of NICE illustrates the desire for, but difficulties in realizing, democratic participation in the governance and reform of our public service. Those difficulties arise not because people are irretrievably selfish, ignorant or lazy – as jeremiads on public mores sometimes suggest. The problem, rather, is that we generally lack experience of democratic deliberation with strangers and consequently are fearful of embarrassing ourselves, offending others and, above all, perhaps, fearful of exposing the fragility of our common ties when faced with evident differences of status, opportunity, identity and loyalty. The experience of NICE suggests that the use of facilitators and outside evaluations may be necessary, not merely helpful, while people learn to cope with these problems.

NICE’s use of lay participation reflects the appeal of deliberative solutions to seemingly administrative problems. But it also highlights

the gulf between the rhetoric of democracy in our society, and the limited experience of democratic deliberation, and limited opportunities for acquiring more, which face most people in practice. The past few decades have been dominated by ideas of politics which have eroded the skills we need for democratic politics, as surely as the skills we need for manufacturing. NICE shows what can be achieved by a commitment to openness, inclusion, transparency and deliberation in the distribution of public resources. It is an example worth pursuing.