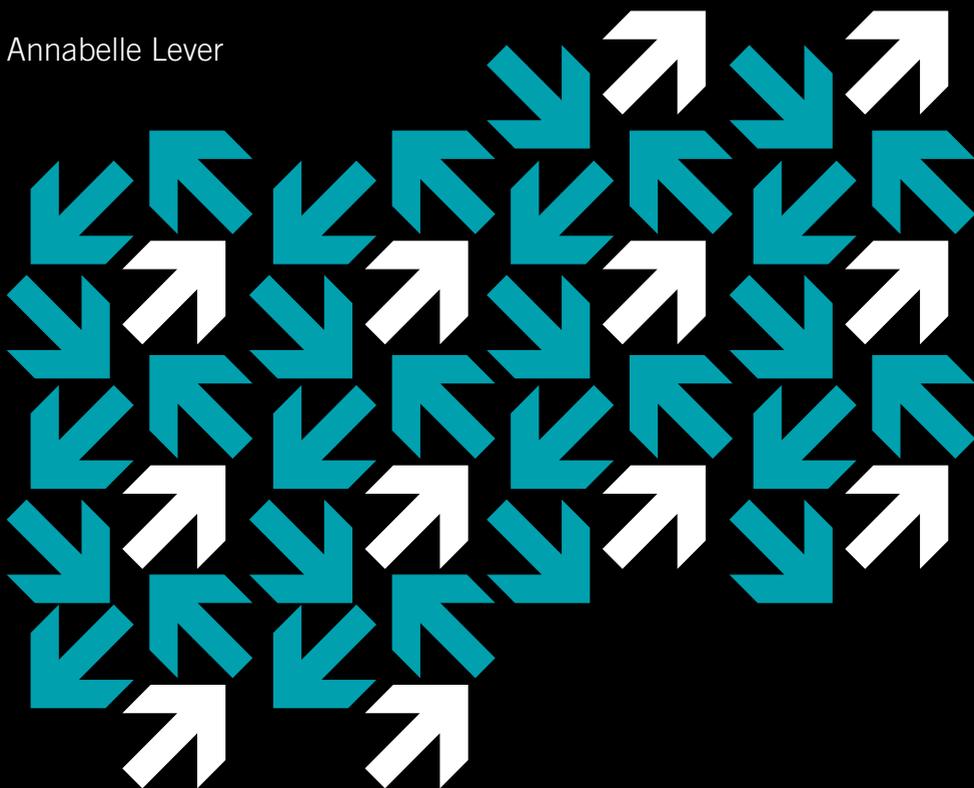


# Democracy, deliberation and public service reform

The case of NICE

Annabelle Lever



**2020 Public Services Trust**  
*at the* RSA

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& SOCIAL  
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# Introduction to this series

The Commission on 2020 Public Services is a major inquiry into how public services should respond to the significant societal challenges of the next decade. The Commission is developing a practical but compelling vision of the priorities for public action to address the emergent challenges facing society in 2020. The Commission has three aims:

- 1** To broaden the terms of the debate about the future of public services in the UK.
- 2** To articulate a positive and long-term vision for public services.
- 3** To build a coalition for change.

This series of essays represents a working partnership between the 2020 Commission and the Economic and Social Research Council (ESRC). As part of our commitment to rigorous, evidence-based research, we jointly commissioned a series of experts to examine the key issues in public services. Two broad themes emerged: one considering future relationships between citizens, state and society; the other exploring the future delivery of public services.

Generous support from the ESRC has allowed the Commission to dig deep into a complex set of issues, and ensure its inquiry represents the best contemporary thinking on public services and society, with a strong evidence base.

Each paper can be read separately, and will also be available as a collected volume in the future. We believe that the research and analysis emerging from this partnership is a rich and significant contribution both to the ongoing national debate on public services and to the Commission's vision for the future. We hope that you enjoy the series, and we invite you to share your own reflections and analysis at [www.2020pst.org](http://www.2020pst.org).

# Foreword

“Big issues need real debate, a big conversation between politicians and the people.”

Tony Blair, 2003

“What we want to do is make sure that all political parties, that the brightest and best brains across Whitehall and the public sector, that voluntary groups, think tanks, trade unions that members of the public are all engaged in the debate.”

George Osborne, 2010

The role of public deliberation in government decision-making is at the centre of our current national debate. In the aftermath of the general election, our new coalition government - itself built on negotiation and compromise - wants to involve the public in some of the most difficult spending decisions for decades. In one recent poll, Ipsos MORI found that 66% of the public would ‘prefer a Prime Minister who mainly acts on the views and opinions of the general public to make decisions’. As the quote from Tony Blair shows, the idea of such a ‘big conversation’ is nothing new; but we have never quite got it right, and the stakes are now higher than ever.

In this enjoyable and challenging paper, Dr Annabelle Lever reminds us that engaging the public in a meaningful way is neither straightforward nor without its own underlying issues. Her analysis of NICE’s experience of lay deliberation over the cost-effectiveness of NHS treatments demonstrates the validity and strength of ‘deliberative solutions to seemingly technical problems’. But it also uncovers challenges. Deliberation and consultation are expensive; they are vulnerable to information asymmetries; and an objective presentation of the evidence being considered is difficult to achieve.

The following pages should be of interest to anyone concerned with the legitimacy and efficacy of health interventions, particularly within a context where

citizen engagement, 'co-production' and utilising informal resources are high on the policy agenda. But Dr Lever's observations also carry a broader relevance, and a sense of real urgency. Her contention is that 'the past few decades have been dominated by ideas (which) ... have eroded the skills we need for democratic politics'. If we are to reverse this worrying trend, extending the role of public deliberation is not just a means to legitimise government decision-making; it is vital to making democracy work.

Henry Kippin

2020 Public Services Trust, July 2010

# 1

## Introduction:

“Statistical models are like bikinis: what they reveal is suggestive, but what they conceal is vital.”

Aaron Levenstein

What is the role of lay deliberation – if any – in health-care rationing, and administration more generally? Two potential answers are suggested by recent debates on the subject. One, which I will call the technocratic answer, suggests that there is no distinctive role for lay participation once ordinary democratic politics has set the goals and priorities which reform should implement. This view suggests that determining how best to achieve those ends, and then actually achieving them, is a matter for experts armed with the best evidence available to them, both of the subject area involved, and of management and administrative excellence.<sup>1</sup>

By contrast, the second – deliberative – view holds that lay deliberation has an important role in the administration and execution of government policy. This is 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 healthcare 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 by Albert Weale, which attempt to clarify the role that lay deliberation should have in healthcare, before turning to the dilemmas for both the technocratic and deliberative views which emerge from the experience of NICE.

# 2

## Lay Participation: Citizens, Patients and Providers

In a couple of recent articles, Professor Albert Weale seeks to clarify the point of public consultation on healthcare.<sup>2</sup> ‘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 healthcare 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?

Weale’s answers are easily summarised. The main reasons to involve lay people in healthcare 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 organising 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 to the concentrated producer interests involved. The same is likely to be true of 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 publicise 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’. And 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. There are a variety of forms of representation, as of accountability, some of which will be mutually supporting, whereas tensions in other cases will be more obvious.<sup>3</sup> This is rather different implying that we must trade off accountability and representation, although the implication in either case is that all good things do *not* go together, and you therefore need to be clear about what forms of accountability, representation and consultation make sense, given your set of policy goals and constraints.

A more troubling question raised by Weale’s analysis, however, is 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 authorised to make decisions that we are not, and who therefore, 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.

In the case of professional consultants, there is often the possibility of holding people legally accountable for the poor quality of their advice. The threat of a bad reputation and loss of valued customers may also provide some incentives to self-control and self-exertion. But it is a familiar feature of public life that these mechanisms are lamentably insufficient to ensure that consultants act responsibly. They also do little to remedy the damage caused by widely-shared, but grievously mistaken assumptions, and personal or professional character flaws.

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 recognise that their 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, the sincerity of our beliefs and the conscientiousness of our efforts – as we all know - 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 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 Weale foresees from consultation.

These doubts might suggest that we should abandon the deliberative model of public service reform for the technocratic one, since they cast uncertainty on our ability to get the advantages of consultation without costs to equally fundamental democratic values. But that, I think, is a mistake. As we will see, Weale's claims about the benefits of citizen participation are borne out by the experience of NICE. Moreover, when we look at that experience, we see something like a 'virtuous

circle' whereby NICE's efforts at promoting lay representation lead to demands for greater accountability by NICE to patient bodies and to the Citizens Council. In response, NICE has increasingly tried to show how its decision-making 'outputs' reflect lay 'inputs' and has experimented with new ways to encourage and support lay participation, and to show why and how it is being used.

Finally, we will see that the difficulties which NICE has encountered in combining lay and professional sources of evidence highlight a problem that dogs nearly every aspect of public service reform: namely, the difficulty of combining and evaluating evidence from different sources. These problems, in essence, concern the difficulty of deliberating well - whether on healthcare or on education; and whether you are a lay member of a consultative body, or an expert or 'professional'. Hence, I conclude by highlighting the need for a political theory of evidence as a part of, rather than a substitute for, the political theory of consultation that Weale advocates.

I will start by briefly describing 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 debates on public service reform. However, before proceeding, I should note that I tend to use the term 'deliberation' for what Weale describes as '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 of those authorised 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.

# 3

## NICE and the Problem of Fair Deliberation

The National Institute for Health and Clinical Excellence (NICE) was established in April 1999 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'.<sup>4</sup> In providing that guidance, NICE is guided by three principles: (1) that all guidance should be based on the best available evidence; (2) that the process of creating that guidance should be as open and transparent as possible; (3) 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'.<sup>5</sup>

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 healthcare 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. The findings form the basis of recommendations, with the supporting

evidence for them, which then form the basis for consultation with healthcare professionals, commercial organisations, 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 organisations can register as ‘stakeholders’ for a particular topic. NICE will actively invite relevant organisations to register as stakeholders, though such invitations are not a requirement for registration.<sup>6</sup> Registration enables organisations 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.<sup>7</sup>

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 healthcare. 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 healthcare or the NHS.<sup>8</sup> It meets twice a year for three days at a time to discuss a particular issue, usually formulated as a 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 organisation and facilitation of meetings, are carried out by an independent body, and an independent academic organisation was also commissioned to evaluate the workings of the Council.<sup>9</sup>

## Two worries about lay participation

Two main worries about lay participation characterise the literature on NICE. The first worry is that NICE will ‘capture’ patient groups and the Citizens Council, thereby undermining their ability to provide an independent perspective on healthcare in the UK. The second worry, expressed by patient groups as well as members of the Citizens Council, was what effect, if any, their participation had on NICE’s deliberations.

Thus, 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...’<sup>10</sup> The problem is most acute for smaller patient groups, who have to decide how best to use very limited resources. As one of Quennell’s respondents 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” ...’ 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 principles of inclusion and transparency are genuine.<sup>11</sup> Increasing the role for lay people in healthcare 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.<sup>12</sup>

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.<sup>13</sup> Originally, some people thought that NICE appraisals should be insulated from patient pressure for this reason, 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.<sup>14</sup> 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 advisors.<sup>15</sup>

The significance of patient involvement for the quality, as well as the legitimacy, of NICE guidelines, then, should not be underestimated. As Fenton, Brice and

Chalmers 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 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.<sup>16</sup>

## 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.<sup>17</sup> 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.<sup>18</sup>

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, as well as puzzling. 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'.<sup>19</sup> But the idea of the Council as a sounding board for taxpayer 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.<sup>20</sup> This effort to *account to* Council members for the use of their deliberations would be otiose if the Council were merely a 'sounding board' for NICE, 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 them both, and the Council could, in principle, illuminate the one as well as the other.

What we recognise as effective in clinical or financial terms depends fundamentally on our assumptions on 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, on the face of it, there is something peculiar about the idea that the social value judgements of a bunch of lay people are critical to the wisdom and legitimacy of our judgements of cost effectiveness, but irrelevant to our judgements of clinical effectiveness, or to the way that the two can be combined in measures like Quality-Adjusted Life Years (QALYs).<sup>21</sup>

There is a second reason for wanting NICE to be clearer about the values and aspirations underpinning the Council – because 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, and 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 healthcare.

Equality is a complex and contentious concept, and there is a good deal of uncertainty, even amongst philosophers, over when, or how far, a commitment to equality requires us to treat people identically.<sup>22</sup> Nonetheless, it is wrong to say that 'positive discrimination [is] still discrimination' if by 'discrimination' one means 'unjustified differences in treatment'. Whatever the merits of describing discrimination as intrinsically wrongful, it would still have to be shown that the pattern of behaviour and judgement that constitutes 'positive discrimination' are instances of 'discrimination' so understood. Above all, there is something

disappointingly unreflective in such a condemnation of positive discrimination by a group who have, themselves, been selected using positive discrimination, in an unusually thorough and expensive effort to counteract the factors that make most deliberative bodies, including legislatures, into a talking shop for relatively wealthy, well-educated and middle-aged white men.<sup>23</sup>

### **Procedure and Substance in Deliberative Democracy**

The comments of outside 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.<sup>24</sup>

‘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’.<sup>25</sup> (p.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...’ (emphasis in original text) and facilitators clearly struggled both to emphasise 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?”. (p. 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’. 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’ (p.134), with the result that discussions often resulted in ‘a ready – but potentially misrepresentative – homogenising 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. In this respect, NICE’s commitment to lay deliberation seems like a praiseworthy effort at ‘reskilling’ the population. 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. If so, explicitly articulating the moral and political assumptions implicit in the choice of procedures for the Council might improve the quality, as well as the quantity, of lay deliberation.

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 and 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 connection it sees between descriptive or mirror representation – at least for the Citizens Council – and the quality of its decisions on rationing.<sup>26</sup>

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.<sup>27</sup> 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.<sup>28</sup> 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.<sup>29</sup> 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 says, “special representation of otherwise excluded social perspectives reveals the partiality and the specificity of the perspectives already politically present”; or as Williams 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.”<sup>30</sup>

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 maximise descriptive representation, and used to explore the implications of democratic values for the rationing of healthcare. However, in order for the Council to realise those values more fully, the Board will have to articulate the links it sees between descriptive representation and a deliberative approach to the rationing of healthcare. And it will, unfortunately, be necessary to accept that, as a country, we are simply not used to deliberating together as citizens, and we find this especially difficult when confronted with evidence of the differences of privilege, belief and identity which can pit us against each other.

NICE can hardly be blamed for the existence of these difficulties, and was clearly right to assume that people from all walks of life are eager to do ‘their bit’, beyond paying obligatory taxes, in order to support their public services. But it is equally clear that most of us simply lack the experience of deliberative decision making with strangers. The experience of NICE’s Citizens Council, therefore, highlights the enormous gap between the rhetoric of democracy, with which we are familiar, and the scant experience and opportunities for democratic participation which have faced most of us in practice.

# 4

## Conclusion: Deliberation and Public Service Reform

- 1.** A study of NICE's efforts at citizen participation make it all too plain that democratic deliberation and participation is costly, in terms of time, energy and money. It is therefore not a 'cheap' solution to public service reform, as some may have hoped, although greater experience organising democratic consultations and participating in them may in time reduce some of these costs. For example, the experience of NICE suggests that demonstrations of accountability, transparency and inclusivity may be necessary to establish and secure trust, although in time less formal and costly arrangements might be sufficient.
- 2.** Democratic consultation and deliberation are expensive because it is necessary to minimise and, ideally, to remove inequalities of information, access and status. Removing these may not be necessary to oligarchic, plutocratic or medieval conceptions of consultation, which are fundamentally hierarchical. However, 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.

3. Lay participation exposes the need for a political theory of evidence, as part of the political theory of consultation, to which Weale referred. 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 healthcare, but are likely, nonetheless, to have their 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. Above all, it draws attention to the need to examine our assumptions about the particular, the anecdotal and the personal.

Until recently double blind randomised 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.<sup>31</sup> 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.

4. Finally, the experience of NICE illustrates the desire for, but difficulties in realising, 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 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.

As we have seen, NICE's use of lay participation illustrates the strength and appeal of deliberative solutions to seemingly technical problems. But it also highlights the gulf between the rhetoric of democracy and most people's lack of experience of, and opportunities for, democratic deliberation in practice. The past few decades have been dominated by ideas of politics which, whether by design or not, 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 generalising.

## Endnotes

- 1 Recent example of this is the 'outcome commissioning' strategy presented and advocated in 'Better Outcomes', written by Lauren M. Cumming, Alastair Dick, Lord Geoffrey Filkin, Gary L. Sturgess available at <http://clients.squareeye.com/uploads/2020/documents/BetterOutcomes.pdf>.
- 2 Albert Weale, 'Democratic Values, Public Consultation and Health Priorities' in A. Oliver (ed.), *Equity in Health and Health Care* (London; The Nuffield Trust, 2004), pp.41-51. (1-902089-93-6) and 'What Is so Good about Citizens' Involvement in Healthcare?' in Edward Andersson, Jonathan Titter and Richard Wilson (eds), *Health Democracy: The Future of Involvement in Health and Social Care* (London: Involve and NHS National Centre for Involvement, 2007), pp. 37-43.
- 3 For a more detailed development of these points, and their implications for democracy and judicial review, see A. Lever, 'Democracy and Judicial Review: Are They Really Compatible?' in *Perspectives on Politics* (vol. 7 no. 4, Dec. 2009) pp. 805-822. Weale, 'Democratic Values' op. cit., p. 4. Initially, it seems that Weale is arguing that there is a tension between new forms of democratic deliberation and politics (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 tradeoffs between wider representation and accountability, with Proportional Representation as the example. This might still implicitly assume only the one model of accountability but seems to imply something more general.
- 4 P. Littlejohns and Rawlins eds. (2009) p. 1.
- 5 Pauline Quennell, 'Getting a Word in Edgeways? Patient Group Participation in the Appraisal Process of NICE' in *Clinical Governance*, (8.1.2003) pp. 39-45, at p. 39.
- 6 Regional or local organisations can register as stakeholders if there is no national organisation representing a particular specialist interest or group of people/ See Virginia Thomas, 'Patient and Carer Involvement in NICE Guidelines', in P. Littlejohns and Rawlins eds., *Patients, the Public and Priorities in Healthcare*, (Radcliffe Publishing, Oxford, 2009) pp. 19-28, esp. p 22.
- 7 Thomas (2009) p. 25.
- 8 For details of the way in which Council members are selected see Michael Rawlins, 'Background to NICE's Citizens Council', in eds. Littlejohns and Rawlins, pp. 75-80.
- 9 The report has been published on the NICE website, and is the subject of C. Davies, M. Wetherell and E. Barnett, 'A Citizens Council in the Making: Dilemmas for Citizens and their Hosts', in eds. Littlejohns and Rawlins, pp. 129-138
- 10 Quennell 2003, p. 43.
- 11 Indeed, one of the problems facing the Citizens Council, as described by an outside evaluator, was that in their eagerness to 'step aside' and not to influence proceedings, NICE's Board were so 'hands-off' that 'the result seemed...less like capture and more like abandonment'. Davies, Wetherell and Barnett, p. 135. Rawlins, himself, refers to the worry that NICE might 'contaminate' the Council – which is a rather striking choice of words. In Rawlins, p. 78.
- 12 For example, NICE now supports the patient-organised support group, Patients Involved in NICE (or PIN), but also runs workshops and training sessions to help patient participants comment effectively on the adequacy of NICE guidelines, and now has formalised procedures for responding to that evidence in the revision of guidelines. In turn, patient and carer groups are taking a role in disseminating and implementing NICE guidance, because patients often have different views from healthcare professionals about the quality of existing care, and the best ways to provide it in line with NICE recommendations. Victoria Thomas discusses support for patient and carer members of the GDGs at pp. 24-5, which is in addition to support for patient and carer groups who wish to make representations to the GDGs.
- 13 The concerns of Prof. Robin Ferner and Sarah McDowell are discussed by Marcia Kelson, 'NICE's Commitment to Patient, Carer and Public Involvement' in eds. Littlejohns and Rawlins, pp. 9 – 18 at p. 13. For the

- significance of patient information in these cases see Lizzie Amis, 'Patient Involvement in NICE Technology Appraisals', in eds. Littlejohn and Rawlins, pp. 29-38, at pp. 37-8 and Emma Chambers, 'Patient Involvement in NICE Interventional Procedures Programme', in eds. Littlejohns and NICE, pp. 51-56, pp. 54-6.
- 14 For the concerns about the emotional and anecdotal aspects of patient testimony see Timothy Milewa and Christine Barry, 'Health Policy and the Politics of Evidence' in *Social Policy and Administration* (39.5 2005) pp. 498-512, at p. 503.
  - 15 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, pp. 55-6.
  - 16 See M. Fenton, A. Brice and I. Chalmers, 'Harvesting and Publishing Patients' Unanswered Questions about the Effects of Treatments', in eds. Littlejohns and Rawlins, pp. 165-180, pp. 166-9. They also note that NICE has now developed a research recommendations database of treatment uncertainties that have emerged from the process of developing their guidelines. 'Not infrequently, we have found that reliable answers to patients' questions already existed but had not been made available to them, thus emphasising the need to improve access to information about "known knowns", as well as to combat 'perverse incentives' for exploring "known unknowns".
  - 17 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 Ela Pathak-Sen, 'Ordinary People, Extraordinary Wisdom', in eds. Littlejohns and Rawlins, pp. 81-88, pp. 82-83.
  - 18 Davies, Wetherell and Barnett, p. 131. Interestingly, 'Council members often persuaded each other than personal experience, and the anecdotes that could often bring arguments alive, were somehow not the proper business for the public discourse in which they were engaged. However, in contrast, anecdotes from experts and hosts tended to be appreciated and positively affirmed for their value'. (134)
  - 19 Michael Rawlins, p. 182.
  - 20 Ela Pathak-Sen, p.86.
  - 21 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. Similar complaints might be made about the use of QALYs more generally and, as Littlejohns makes clear, the Council clearly thought that it is time to review, if not to abandon, its use and to adopt more social, rather than medical, models of illness. Peter Littlejohns, 'The Citizens Council Reports' in eds. Littlejohns and Rawlins, pp. 109-124, at pp. 104-6.
  - 22 See for example, *The Ideal of Equality*, eds. M. Clayton and A. Williams, (Palgrave Macmillan, 2002). Catherine A. Mackinnon, *Feminism Unmodified: Discourses on Life and Law*, (Harvard University Press, 1988); Martha Minow, *Making All the Difference: Inclusion, Exclusion and American Law* (Cornell University Press, 1990).
  - 23 See Brian Brown, 'The View of a Citizens Council Member' in eds. Littlejohns and Rawlins, pp. 125-128, p. 128. He is reporting not only his own view of equality, but that of a majority of Council members. Interestingly, in light of Ronald Dworkin's ideas on the subject, Brown implies that the people he talked to thought

- that children should get preferential treatment and extra spending on healthcare, compared to other people. However, the Council majority decided that this was unjustified, because 'positive discrimination is still discrimination'. Brown says that 'when I discussed that decision with the same people back at home, they were quite sympathetic with the outcome and understood the reasoning behind it'. For 'positive discrimination' and the construction of the Citizens Council see Rawlins pp. 78 – 80.
- 24 In 'The Complexity of Race and Juries' for *The Guardian's* 'Comment is Free', (3/3/2010) I try to show how unacknowledged assumptions about race and crime seem to be affecting jury outcomes in England. However, it is equally apparent that the way in which juries are addressed matters to the quality of jury deliberation. *The Jury Expert*, (21.1. jan. 2009). Perhaps because judgements of fact are principally at issue in jury trials, it is possible that they are less prone to reticence about discussing racial and other differences which seems to have marked the Citizens Council. But it is hard not to wonder whether an unwillingness actually to debate issues of race, crime and policing is not partly to blame for some of the striking biases in favour of black as opposed to white defendants revealed in Cheryl Thomas' research on juries in England. <http://www.guardian.co.uk/commentisfree/libertycentral/2010/mar/03/all-white-juries-race> and <http://www.astcweb.org/public/publication/article.cfm/1/21/1/Ethical-issues-in-racial-profiling>.
- 25 The following quotations are from Davies, Wetherell and Barnett, who conducted the outside review of the Council.
- 26 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.
- 27 Melissa Williams, *Voice, Trust, and Memory: Marginalised Groups and the Failings of Liberal Representation* (Princeton University Press, 1998), 998, especially chapters 4 and 6; Iris Marion Young, *Inclusion and Democracy*, (Oxford University Press, 2000), especially chs. 2 and 3. The following paragraphs draw on my description of the importance of descriptive representation in 'Democracy and Judicial Review', op. cit.
- 28 Anne Phillips, *The Politics of Presence*, (Oxford University Press, 1995), pp. 63 and 65. 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. 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.
- 29 Phillips, 62-4.
- 30 Young p. 144; Williams p. 193. Emphasis is in the original.
- 31 A summary of Sir Michael Rawlin's Harveian Oration to the Royal College of Physicians (oct. 2008), can be found at [http://www.politics.co.uk/opinion-formers/press-releases/royal-college-physicians-sir-michael-rawlins-attacks-traditional-ways-assessing-evidence-\\$1245035\\$365674.htm](http://www.politics.co.uk/opinion-formers/press-releases/royal-college-physicians-sir-michael-rawlins-attacks-traditional-ways-assessing-evidence-$1245035$365674.htm). The full text is available at <http://www.rcplondon.ac.uk/pubs/contents/304df931-2ddc-4a54-894e-e0cdb03e84a5.pdf>. See also John Worrall, 'Why There's No Cause to Randomize' *BJPhis*, 2007 (58.3) 451-488; 'Evidence in Medicine and Evidence-Based medicine', *Philosophy Compass* 2007 and 'What Evidence in Evidence-Based Medicine' *Phil of Science*, Sept. 2002.