

# Who shall live and who shall die? A case study of public engagement in health care planning

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## INTRODUCTION

Who shall live and who shall die? Decision making doesn't get much tougher than this. Spend NHS funds on this treatment and save a handful of lives, or spend it on that treatment and improve quality of life for thousands. Given that rationing is inevitable, who decides? Should it depend on where you live (the postcode lottery) or on national guidelines laid down by the unelected National Institute for Clinical Excellence (the 'faceless bureaucrats')? As the research director at health research partnership Dr Foster Intelligence pointed out recently:

In the well-used lexicon for damning public service there is only one phrase used more often than 'postcode lottery' and that is 'faceless bureaucrat'. The current commissioning of health services is a powerful example of how these twin horrors can be combined to maximum impact.

(Taylor 2007)

Taylor's solution to the dilemma is 'making information about what services are available and what is not available in your area clear and accessible to all' (Taylor 2007). While not in any way disagreeing with that, this paper presents a case study of a third approach: using market research methods to give the public a direct say in healthcare decision making at their local level.

## OVERVIEW OF METHODOLOGY

On 21 November 2006 the Barnet Primary Care Trust ('the trust', or 'the PCT') in north-west London invited a group of 56 local residents to have their say in determining how to allocate some £60 million of public money to 24 health care spending options. In health service terminology, they were being asked to advise on the commissioning of various health interventions. This was real money, and they were real spending options. This was not an academic exercise and the findings have directly influenced the Trust's spending decisions (see the 'Conclusions' section).

Those present, apart from the trust staff and the moderators, were members of Barnet Council's Citizens Panel (representing the general public) and a handful of representatives of patient groups. There was a good mix of participants in terms of ethnic origin, gender and disability. In common with other events involving Citizens Panels, however, the turnout was skewed towards the older age groups, with only two participants being aged under 35, for instance. This could be seen as appropriate, given that older people consume disproportionately more health care

resources than younger people.

The participants were arranged in groups at seven tables, with roughly but not exactly the same number at each table. Barnet Council and the PCT provided a facilitator and a note taker for each table. Each participant was given eight tokens to allocate as they saw fit to the 24 options, each token 'buying' one unit of intervention. Tokens (which were poker chips supplied – rather worryingly! – by the Trust) were used because experience suggests that 'budget-pie methods' work better when respondents are given tokens or points to allocate, rather than money (Mullen 1999), also because all the cash sums underlying the token calculations were estimates, and the Trust did not want these to be misinterpreted as exact monetary values.

Participants had been provided before the event with an estimate of the maximum number of people in the borough who stood to benefit from each option. The reason for this is that there is an upper limit for *productive* expenditure on any particular health intervention. For example, the Primary Care Trust estimated that there are 1,000 patients across Barnet who have epilepsy. Improving services for all these people would cost three tokens. There would be no point in a participant allocating four or more tokens to this service because there was no one to spend the extra resource on. Thus a 'cap' of three tokens was imposed on epilepsy services. We believe that this cap on permitted expenditure played a very important role in the process of reaching spending decisions in respect of each of the 24 health care options. [Appendix 1](#) presents the cost and prevalence data presented to the participants.

Participants were also given information about the estimated cost of the option, expressed in standardised form as the number of people who could be treated for the unit amount represented by one token. This last piece of information was undoubtedly helpful, but not ultimately as important as the cap. On the evening itself the chief executive of the Barnet PCT, the medical director and the director of commissioning gave presentations on the background to the budget, the health of the local population and how services are commissioned, respectively.

There were two important restrictions placed on the participants' freedom of choice. First, the total number of tokens available to each table was less than the number required to provide the optimal resources to each option, so that there had to be some 'winners' and some 'losers' among the options. In other words, the participants had to make priority choices. The second proviso was the cap already described. Both restrictions reflected the reality of the trust's own decision-making process and were introduced as such.

In the first round of preference selection the participants debated what they had heard and the information provided to them in advance, drew on their own experiences and listened to those of other participants, questioned the experts present if they wanted to, and reached some preliminary decisions about their preferences. They expressed their individual preferences by placing half their tokens on the corresponding places on the list of options.

The second and final round of preference selection consisted of a rerun of the first round, but with the proviso that the participants should reflect on the overall balance that had emerged from the previous round before making their final allocation of tokens. The facilitators also challenged the emerging findings to ensure their eventual robustness.

Before giving an outline of the conclusions that this group of people reached, it is worth stepping back a couple of paces to consider some underlying questions that may not always be asked by market and social researchers before they embark on the more familiar task of designing and executing a public participation project.

## **UNDERLYING QUESTIONS**

### **Does the Public Actually Want to get Involved in Spending Decisions?**

There is a sense in which the answer to this question is irrelevant, as the following extract from the Local Government and Public Involvement in Health Bill (2006) makes clear:

1. Each Primary Care Trust must, at such times as the Secretary of State may direct, prepare a report –
  - a. on the consultation it has carried out, or proposes to carry out, before making commissioning decisions, and
  - b. on the influence that the results of consultation have on its commissioning decisions.

Leaving this compulsory element to one side, there is evidence of a growing public desire to get involved in the commissioning process. At the least sophisticated level this shows itself in the regular public outcry about 'postcode lotteries' determining who gets what medication or treatment. At a more considered level, Litva *et al.* (2002) studied public involvement 'in one health authority area in the UK'.<sup>1</sup> They found a strong desire on the part of the public (57 people in eight focus groups) to be involved in health care decision making, both at the system (i.e. PCT) and programme levels, with much less willingness to be involved in taking decisions at the level of an individual patient. The latter phenomenon echoes Lomas's (1997) description of the public as 'reluctant rationers'.

The National Institute for Clinical Excellence itself has a minimum of two patient/carers members on each guideline development group, and makes use of expert patient/carer advisers in formulating the national guidelines (Cowl 2006).

Also, the Health Services Research Collaboration at Bristol University's Department of Social Medicine ran a full-scale Citizens Jury in the city between March and July 2006. This one considered what the research priorities should be for Primary Health and Social Care. The project was set up in response to 'an increasing call for users ... to be involved in research' (Calnan *et al.* 2007). And of course the present case study was commissioned by Barnet PCT in acknowledgement of public interest.

Public involvement should not be taken for granted, however. While 38% of the 200 respondents to a recent survey in Australia said they did want direct involvement in decision making about the provision of 'high cost medications' in public hospitals, a higher proportion did not (Gallego *et al.* 2007). Neither is every Primary Care Trust geared up to engaging the public in the commissioning process (Chisholm *et al.* 2007).

### **Under What Conditions do the Public Want to get Involved?**

There is general agreement that the public have a desire for 'accountable consultation' – consultation with a guarantee that their contribution will be heard and that the decisions made following consultation will be explained.

Public awareness of the opportunities for involvement in the NHS is low, but this does not reflect a lack of willingness to become involved. For those who do get involved, organisational failure to feedback the result of involvement is very discouraging.

(Farrell 2004)

It is not even necessary for the decision to be in line with the public's wishes:

If [the] decision was made on grounds outside the public's expertise that was considered to be acceptable as long as the reasoning behind the decision was explained.

(Litva *et al.* 2002)

Tennant makes the accountability point by emphasising its converse in a study for the King's Fund, as does an experienced patient representative:

The group [of health and social care representatives] felt that consultation processes were often a legitimisation exercise. They felt that if the results of consultation were not

used to influence services, there was no point in carrying them out, and resources should be deployed elsewhere.

(Tennant 2002)

Connect the levers of patient participation to the real machinery of the Health Service, and teach us how to use them, and we will be queuing up to have a go ... show us how participation will bring real change in our own interests. The problem [with patient involvement] at the moment is that none of the alternatives on offer do what they promise ...

(Kramer 2004)

Similarly, 43 participants in a six-focus-group, five-province study in Canada by Abelson *et al.* (2004) expressed a strong desire for 'a clear relationship between the input provided and the decision outcome' as a condition of involvement.

This is not confined to health care alone, but is more generally applicable:

Demand for more participation exists, but it is related to whether or not people believe getting involved can enable them to make a difference.

(Involve 2005)

### **Are the Public Capable of Making Complex Spending Decisions?**

With so much money at stake the question has to be asked whether the public are capable of making sensible decisions on highly technical issues, especially since they already employ highly paid expert staff to take such decisions for them. More generally, are the public capable of dealing with health care rationing issues in a way that is rational and fair? And, if so, is small group discussion the way to do it? Price (2000) took a pessimistic view of this question; Bowie *et al.* (1995) took an optimistic one.

For Wilmot *et al.* (2004) the answer is a qualified 'yes'. They used four focus groups in suburban Derby to study the allocation of donor livers for liver transplants. Their conclusion was that the public are indeed capable of weighing up several complex and conflicting issues when making decisions, and that individuals can change their minds on hearing different points of view. They conclude that:

although rational public deliberation can be achieved, groups, panels and [citizens] juries may need appropriate support in avoiding the premature adoption of apparently clear-cut solutions.

(Wilmot *et al.* 2004)

These authors also mention two particular problem areas: dominance by one individual with very strong views, and a strongly held moralistic stance by a minority.

The Barnet exercise took these findings into account and provided support in the following ways:

- factual material issued before the event
- brief presentations of relevant background information by senior PCT staff at the start of the session
- availability on demand of experts from the PCT to answer questions at the session
- group moderators instructed to challenge all early conclusions as they emerged
- a two-round priority-setting process – the moderators were instructed to use the interval between rounds one and two to sum up any emerging consensus on health care spending

priorities, and then to challenge it.

On the question of dominant individuals, a study of health care decision making in Canada also observed this at work:

deliberative processes can and do change participant views. It also appears that, on average, deliberation is less likely to change more dominant views [e.g. top rankings, highest priorities] but with increased deliberation comes the opportunity for these views to become more rather than less entrenched.

(Abelson *et al.* 2003)

Qualitative researchers will be familiar with this effect, and will know that experienced moderators are the best hope of mitigating it.

The moralistic issue was not addressed directly in the Barnet exercise, although it did surface as one of the decision-making strategies discussed later in this paper.

### **How Best to Involve the Public?**

There are a plethora of techniques for public participation (for a recent round-up, see Involve (2005), many derived from market research. These range from opinion polls through unstructured public meetings to focus groups and advanced deliberative techniques such as citizens juries. The justification for using market research techniques over and above established user groups, voluntary organisations, consumer groups or public meetings is that groups, organisations and meetings can 'disproportionately influence the agenda' (Williams 2006). On the other hand, the established groups are much more likely to be able to engage with decision makers on something approaching equal terms, precisely because they have developed some expertise over a series of encounters. (For more on the trade-off between capacity and representativeness, see May 2006.)

In the Barnet case the decision was taken to combine the two approaches, using both representative members of the public from the Citizens Panel and representatives of interest groups – mostly those concerned with one particular condition or group of conditions.

### **SUMMARY OF RESULTS**

Table 1 shows the aggregated preference scores for each of the 24 health options offered to the participants. In the table the health care options are presented in descending order of preference. These scores can be thought of as the percentage of the available money (roughly £60 million) that the group as a whole would like the PCT to spend on commissioning the different options.

#### **Table 1: Summary of the preferences expressed for different spending options**

What is immediately striking about this table is that all the options attracted some support. There was nothing in the set-up of the event to make this inevitable, and the implication is that the public recognise that the NHS has a wide range of responsibilities.

Table 1 shows that the highest preference score was for funding extensions to GP surgery opening hours. The next preference is more complicated to explain. A literal reading of the wording of the option as presented to the participants is that they were being invited to *save* money rather than *spend* it, by making patients wait longer before surgery for hip replacement. (Other 'save not spend' options were ceasing the community-based maternity delivery service and raising the threshold before surgery for cataracts.)

The table facilitators have, however, confirmed that the participants chose to read the three savings opportunities as if they were in fact spending and not saving options, and the results need to be interpreted in this way. There is a lesson here about mixing spending and saving decisions in the same exercise – perhaps equal numbers of both types of option should have been presented, or spending and saving presented at different times during the event?

The third preference was for reducing average waiting times for hospital treatment, still an important priority in the overall scheme of things, but noticeably less so than the extension of primary care services.

At the other end of the scale, the use of a new drug for a certain form of brain cancer scores very low – perhaps because only a handful of people stood to benefit from what had been described as an uncertain treatment.

Similarly, it is likely that the small number of patients standing to benefit affected the scoring for the very specialist rehabilitation for patients in persistent vegetative states with limited chance of recovery of functions.

The lowest score of all went to varicose vein operations for appearance reasons. The comments on this option make it clear that the public (as represented in this exercise) do not look favourably on 'cosmetic' surgery on the NHS.

It is not just the average score that matters in a consultation of this kind. The variability of the scores is also important, not least because this can be an indicator of the contentiousness of a topic. As a rule of thumb, the more variability there is between table scores for a particular option the less agreement there is about its priority, and hence – potentially at least – the more contentious it is. On this basis, one of the most contentious options is likely to be the extension of GP opening hours, which happens to be the highest preference as well. In terms of using the market research to guide the PCT's communications strategy the message would seem to be 'handle the extension of GP opening hours' with care. (The GPs present on the evening had strong views on the subject as well.)

The other most contentious options are extra funding for NHS dentistry and cataract operations (one of the save not spend options). The least contentious were community physiotherapy, and increasing the take-up of the measles, mumps and rubella (MMR) vaccine.

## **STRATEGIES FOR MAKING RATIONING DECISIONS**

The purpose of this exercise was not just to obtain a quantitative set of preferences for health care commissioning for the next year but also to explore the strategies that the participants used to determine their spending recommendations. We observed that the following strategies (listed in no particular order) were the most often used, either singly or in combination. We also observed that, at any one table of randomly assorted members of the public, more than one strategy could be invoked in respect of the same spending option.

### **The Greatest Good of the Greatest Number**

Spending money on services from which the greater number of people would benefit is a fairly obvious strategy to use when faced with limited resources. Typical comments in support of this strategy were:

- 'if the service benefits lots of people it should be made a priority'
- 'we don't really want to vote for those treatments that help small numbers of people only for a short time'.

However, there was also discussion on whether this was a fair way of deciding, especially if you were the individual who was suffering.

### **Quality and Length of Life**

Health economists use the concept of Quality Adjusted Life Years (QALYs) to 'provide an indication of the benefits gained from a variety of medical procedures in terms of quality [of] life and survival for the patient' (Phillips 1996). QALYs are calculated by multiplying the number of extra years of life expected to follow from a particular health option by the resultant quality of life.

(The quality factor will generally be less than unity, representing a lowering of quality of life – but still preferable to death.)

Our representatives of the general public did not use this terminology, or make the calculations that produce QALYs. Nonetheless they had an intuitive understanding of the principle. Typical comments were:

- '[give priority to] services which provide the most longevity/longer life'
- 'we don't really want to vote for those treatments that help small numbers of people only for a short time'
- 'treat younger people – the good effects will last longer'.

As Phillips says:

It is no use pretending that QALYs are anything but a crude measurement. It is necessary to be aware of their limitations ... [but] the use of QALYs in resource allocation decisions does mean that choices between patient groups competing for medical care are made explicit.

(Phillips 1996)

### **Ineligible Conditions**

Many of the participants had strong views on the eligibility for treatment of certain conditions. Ineligibility comes in two forms, which we can call 'self-inflicted' vs 'act of God'. The former category covers avoidable conditions that are regarded as being self-inflicted – for example, the result of smoking or drinking alcohol, or incautious sexual activity. Some participants were clear that financial responsibility for such conditions lies with the individual and not the NHS, although there was also a less harsh view that responsibility should be shared between the PCT and other organisations – police, schools, council.

In the Barnet case this philosophical issue seems only to have overtly affected the decisions of a minority, but it is something that should perhaps be tackled head-on in future work, particularly as Skitka and Tatlock (1992) found that when this issue arises those allocating resources can get quite angry with the prospective beneficiaries and even want to withhold existing resources from them.

Ineligibility due to 'act of God' covers both cosmetic treatments such as removal of varicose veins if not medically indicated, and also IVF fertility treatment. Neither of these cases is self-inflicted, both treatments are well established technically, and either might be considered important for the psychological health of a particular patient. Nonetheless there was a definite undercurrent of 'these people should just put up with their condition and not expect the NHS to pay'.

### **Prevention is Better than Cure**

As a general rule, the participants considered prevention to be better than cure, and so tended to rate preventative measures quite highly. They also regarded prevention of self-inflicted conditions as being more acceptable than treatment.

### **Personal experience**

The personal experience of participants inevitably influenced their choices, although the moderating effect of being in a group will have toned down the impact of purely first-person considerations in the table scores.

### **Funding from other sources**

Some people felt that funding for some services should come from non-NHS sources. One

example given was smoking cessation, which could be funded by an additional government grant, not taken from the NHS budget. Participants also considered that other organisations, such as the police, schools, the local council – but not, apparently, employers – had a responsibility to spend money on prevention.

### **Possibility of Delaying Treatment**

One factor that seems to have influenced voting was patients' tolerance levels and the severity of their needs. If it was possible to treat a condition with drugs rather than the full treatment on offer, in order to palliate the condition for a while, this would save money by delaying the provision of the full service. (On the other hand, when this approach was presented as an explicit option most participants rejected it. Some evidence of inconsistency here.)

## **THE ROLE OF THE CAP, AND A POSSIBLE MODEL FOR THE DECISION-MAKING PROCESS**

What part did the cap play in the eventual rationing decisions? It is clear that the cap stopped the exercise turning into a simple popularity poll by forcing participants to consider options in addition to their first choice – they were forbidden to throw money at an option simply as a way of registering their strong support for it. Consequently, the use of the cap spreads the available resources across a wide range of options, while still preserving clear priority orders between them.

In terms of how the participants reacted to the cap, the table scores are revealing (see Table 2). One might have expected that the most popular options would also be the ones that reached their caps most often, but this was not the case. There were only two options – more community physiotherapy and increasing take-up of the MMR vaccine – which reached their cap on all seven tables, the caps being set at three and two tokens respectively.

### **Table 2: Allocation of counters by table**

Conversely, three options – reduce the number of hip replacements by delaying treatment, spend 10% more on NHS dentistry, varicose vein removal for cosmetic reasons – did not reach their caps on any of the tables. The caps for these three were set at 12, 10 and 2 tokens respectively.

Statistical investigation failed to show any significant correlation between the total number of tokens allocated to an option, expressed as a percentage of the cap, and its share of the overall budget. This is reassuring, in that it suggests that the participants were influenced more by what they saw as the merits of each option than by a simplistic principle of 'equal misery' (i.e. giving every option the 70% of its cap that would have used up all the available tokens).

There is, however, a significant correlation between the percentage of the cap awarded to an option and the rank order of that option. This is consistent with a strategy of 'on its merits' (although the terms 'deserving and undeserving' are perhaps more commonly used), while simultaneously using the cap as a guide to indicate a range within which to allocate resources. For example, one might feel that a certain option is meritorious according to the guiding principle or strategy one has chosen as being appropriate to the case. However, it may not be felt to be totally meritorious – perhaps only three-quarters so. If the cap is set at 12 then a score of 9 would signal support but not unqualified support. (By the same token, a cap of 8 would need a score of 6 to express the same degree of support.)

The actual pattern of scores in this case study is consistent with this two-stage process of assessment of merit followed by, or possibly combined with, use of the cap as a guide to the permissible range. As a rationing strategy it is characterised by a desire to reward certain options (the meritorious) by being generous relative to the cap, while being reluctant to fund others (the unmeritorious) and hence being parsimonious with the resources, again relative to the cap.

## **CONCLUSIONS**



So what difference did this particular exercise make? Health care decision making is a very complex process, which has to take into account all sorts of influences and considerations, in addition to local preferences. Furthermore, the time gap between consultation and decision can be many months, even a year or more. So it is all the more pleasing to be able to report that at least three of the main outcomes of the November 2006 event have directly influenced the Trust, and that the participants have been informed of this.

First, hip replacements: as a result of the clear message from the public, Barnet PCT has allocated more money to hip replacements.

Second, 'low priority treatments': the public identified a number of treatments as being of low priority for NHS spending – these included IVF and cosmetic surgery for varicose veins; the Trust has decided to make these procedures lower priority than they were before.

Third, and top of the poll in November 2006, GP surgery hours: access to primary health care (of which GP access is but one part, albeit an important one) is a complex issue and very difficult to change in the short term; nonetheless Barnet PCT has taken the public wish on board and has made improving access to primary care a central plank of its forward strategy. Interestingly, national policy is now swinging in this direction as well – which validates the approach taken in Barnet and the confidence we placed in ordinary people's ability to grapple with complex issues.

I believe that this experiment in engaging with the public shows that, if they are given the opportunity, in the form of a carefully designed, structured and facilitated consultation exercise that includes some detailed information about costs, benefits and opportunities, the public are both willing and able to engage with some big health issues, to debate them seriously and to assist the NHS locally in setting spending priorities.

The public recognise that the NHS has a wide range of responsibilities, and while they may find some health care spending options more palatable than others, they seem to accept that all deserve some measure of funding.

Even when the preferences of individuals are aggregated into group scores there remains a lot of variability. There may be less genuine consensus about health care spending priorities than we like to think, or than opinion polls quoting average rankings tend to imply. (Also, some knowledge of the variation about mean preference scores can flag up where the most opposition to spending decisions can be expected. Forewarned is forearmed.)

The public (like health care managers?) use a complex, unpredictable and sophisticated set of strategies to determine spending priorities. These include some with a cost–benefit flavour, but also some that reflect a more moralistic approach, taking personal responsibility into account. Sometimes they are swayed by personal experience (direct or indirect); other times they are influenced by the public health information they have received. They are also perhaps more resistant to emotional appeals than one might have expected.

Complex decision-making processes can sometimes be approximated by a single, simpler heuristic (Gigerenzer *et al.* 1999). In this case we suggest that the public first decide whether a particular intervention is 'meritorious', and then assess its cost-effectiveness. Is this a good way to set priorities in a patient-led NHS embedded in a mature democracy? Perhaps we need another consultation – this time with politicians, clinicians and NHS managers – to find out.

## **APPENDIX 1: PLANNING HEALTH SERVICES IN BARNET**

On the evening you will be working in small groups. We will give you further information at the time on how much each of the health interventions listed below costs, and how many people would benefit from it. Each small group will be asked to discuss this list of treatments, care options and health care areas, and to advise the Primary Care Trust on which are the most important ones to commission for the health benefit of Barnet residents like yourselves. Please note that we have *not* put the options in the table below in order of priority – we do *not* necessarily believe that No. 1 is the most important or that No. 24 is the least important. That is

for you to advise us on.

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#### ENDNOTES

1. The NHS is constantly being reorganised – broadly speaking, what used to be called 'health authorities' are now called Primary Care Trusts.



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