Report on NICE Citizens Council Meeting

8-10 June 2006

Inequalities in Health

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Foreword

The National Institute for Health and Clinical Excellence (NICE) exists to advise clinical and public health professionals on how to achieve the highest attainable standards of care. The Institute and its advisory bodies base their conclusions on the best available evidence. In doing so, however, they also have to make scientific and social value judgments.

The Institute and its advisory bodies are well qualified to make scientific judgments but have no special legitimacy to impose their own social values on the National Health Service (NHS) and its patients. These, NICE believe, should broadly reflect the values of the population who both use the service (as patients) and who ultimately provide it (as taxpayers). NICE has therefore established a Citizens Council, drawn from the population of England and Wales, to help provide advice about the social values that should underpin the Institute's guidance. The Council meets twice a year.

The members of the Council reflect the demographic characteristics of the English and Welsh populations. They serve for three years with one third retiring annually. They do not represent any particular section or group in society; rather they are a cross-section of the population with their own individual experiences, attitudes, preferences and beliefs.

At this three day meeting of the Council, members were asked to consider the issue of health inequalities from NICE's perspective. Specifically, they were asked to decide which of two broad strategies would be more appropriate for NICE to follow:

- whether to issue guidance that concentrates resources on improving the health of the whole population (which may mean improvement for all groups) even if there is a risk of widening the gap between the socio-economic groups;

- or whether or to issue guidance that concentrates resources on trying to improve the health of the most disadvantaged members of our society, thus narrowing the gap between the least and most disadvantaged, even if this has only a modest impact on the health of the population as a whole.

The Council's report will be available for public comment before it is presented to the Institute's Board with a view to incorporating the Council's conclusions into the next edition of NICE's guidance on social value judgments for its advisory bodies.

Once again, the Institute is extremely grateful to the Council for its continuing help in developing NICE's social values.

Professor Sir Michael Rawlins

Chairman

What we were asked to consider
We were asked to decide which of two broad strategies would be more appropriate for NICE to follow.

Option 1
Is it appropriate for NICE to issue guidance that concentrates resources on improving the health of the whole population (which may mean improvement for all groups) even if there is a risk of widening the gap between the socio-economic groups?

Or

Option 2
Is it appropriate for NICE to issue guidance that concentrates resources on trying to improve the health of the most disadvantaged members of our society, thus narrowing the gap between the least and most disadvantaged, even if this has only a modest impact on the health of the population as a whole?

And

For each of these strategies, are there factors that should merit special consideration?

A copy of the full Citizens Council briefing paper can be found in Appendix 1.

The conclusion we reached
We were unable to reach unanimous agreement. In the end 10 of us backed Option 1, while 15 of us favoured Option 2. One of us felt unable to express a firm preference. As will appear, neither preference was unqualified.

Together with evidence from the tracking questionnaires (see Appendix 2), this finding indicates that, despite our many and varied reservations, a majority of the Citizens Council would look with sympathy on NICE strategies intended not only to improve public health for all, but to do so in a way that offers particular benefit to the most disadvantaged.

How we worked
The council met from June 8-10 at the NICE headquarters in London. Twenty six of our 30 members were able to attend the meeting, which began with brief presentations from Professors Sir Mike Rawlins and Mike Kelly. They outlined the causes of ill health, the relationship between peoples' health and the socio-economic group to which they belong, the history of our understanding of this connection, and the reasons for wishing to do something about it. We also heard about the difficulties encountered when attempts are made to persuade people to improve their health by changing their behaviour.

Later in the meeting we listened to presentations from five experts (see meeting programme, Appendix 3) with experience of studying or researching inequalities in health, or of applying programmes of intervention designed to tackle them. We also had presentations from two more experts who described the relationship between health and ethnicity, and health and gender. Another session brought us two case studies of the nature and consequences of inequality; one featured coronary heart disease, the other road traffic accidents in childhood.

At various times we were asked to choose between different schemes for health improvement, or challenged to say what we thought were the most important factors to bear in mind when tackling the question that NICE had set us. Details of these exercises appear below. To record how our opinions developed we completed two tracking questionnaires, the first during the morning of day one, and the second at the beginning of day two.

We were able to question all the experts who spoke to us - and the entire meeting was punctuated with discussions among ourselves held in small groups, or together in plenary session.

Reaching decisions on questions as wide-ranging and multi-faceted as those set by NICE is not an orderly, linear process. Our discussions ranged hither and yon, with many diversions and cul-de-sacs! What follows cannot be an account of *how* we reached our final recommendation; but it may provide the reader with some insights into *why* we reached them.

What we heard, and what we did

First thoughts and questions

Following the introductory presentations by Mike Rawlins and Mike Kelly, some of us raised a few basic questions that would affect the rest of our discussions. For example, the socio-economic group categorisation currently in use - originally devised in 1890 - is based on the occupation of the head of the household: still, typically, a man[1]. How would this affect figures for health inequality related to cervical cancer or some other illness exclusive to women? We were told that in practice this is not usually a problem, partly because men and women tend to marry or cohabit within the same or similar class.

One of us brought up the issue of private medicine: a privilege obviously more available to higher socio-economic groups. Doesn't this play a part in determining the better health of the well off? We heard that it may indeed make some impact, but mostly at the margins. The major differences seem to be shaped by prevention rather than treatment. And here, we were reminded, the middle class are more likely to take advantage of knowledge and resources.

Another of our members raised a still more fundamental issue – one that we would return to many times in the next two days. If, as we had been told, much health inequality derives from unequal access to resources other than medicine and heath care, why pursue a health route in trying to overcome health inequality? Why not simply work for a more equal society? As one of us put it, "I feel that in shifting resources we're not actually tackling the causes of inequality, which are often deep-seated and historical."

[1] **Registrar General's socio-economic groups.**

Socio-economic group (% population)	Description	Examples
I (10.6)	Professional	Doctors, lawyers, accountants
II (22.2)	Intermediate	Managers, teachers, journalists
IIIN (10.5)	Skilled non-manual	Clerks, cashiers, retail staff
IIIM (7.4)	Skilled manual	Plumbers, electricians, bus drivers
IV (9.5)	Partially skilled manual	Security guards, care assistants
V (12.9)	Unskilled	Labourers, cleaners, messengers

In response we learned that some people do indeed view the matter in this light. But it was suggested to us that health systems also have a part to play, and that NICE - with its widened brief to tackle public health - is in a position to make recommendations (albeit non-binding ones) to non-health bodies.

A quite different difficulty was also foreseen: that in advocating the direction of extra and perhaps disproportionate resources to disadvantaged groups NICE might itself be creating a new form of inequality! The ethos of the NHS is, after all, that access to it should be not only free but equally available to all. This disturbing prospect was to re-emerge many times during the next two days.

A practical exercise: *Consequences*

Once we had completed our first tracking survey (for results, see below), the remainder of the first morning was taken up with an exercise, *Consequences*, in which we had to choose between seven different heath promotion programmes competing for the same funds. Each of us received three credits with which to support our choices. The figures in brackets indicate the number of credits we awarded each scheme.

The seven schemes were:

(a) A community health programme to which teachers could refer obese or overweight children. [9]
(b) A drug education programme forming part of the school curriculum. [22]
(c) A TV advertising programme - “Slip, slap, slop” - to promote the use of sunscreens. [0]
(d) A specialist sex education programme for schools delivered before the onset of pupils’ sexual activity, and linked to contraceptive services. [20]
(e) The enquiry by GPs into the smoking habits of the patients, irrespective of the reasons for the consultation. [8]
(f) A training programme for bar staff to help them deal with and prevent under-age and/or excessive drinking. [4]
(g) The provision by local authorities of smoke alarms for council houses. [11]

We felt that the sunscreen project was unlikely to be cost effective, or that it was something for commercial organisations to handle, and therefore not a priority. The clear winners were drug and sex education.

“A lot of children get misinformation from their peers,” said one member speaking in support of the drug program. “My own son’s a heavy drug user,” said another. “We couldn’t get help. We didn’t know how.” Some of us felt that responsibility for drug awareness shouldn’t be left entirely to the schools. “And should we concentrate just on the children, or should we be talking to the parents as well?” One of us who’d had experience of a scheme for providing information to parents suggested that those most in need of information were least likely to attend.

Another felt that showing children the consequences of their actions - perhaps even shocking them - might help. The same could apply to teenage pregnancy which, like drugs, has costs both to individuals and to society. Making it personal would be more effective than simply handing out a leaflet.

Most of us were conscious of the limitations of programmes of this kind – which lead some members to express doubts about their own choices even as they reported them. Speaking, for example, about the effectiveness of such interventions, one member who’d backed the drug project went on to add: “I’m pessimistic about the

impact of this when society is awash with drugs. It's just a sticking plaster." Someone else, though, disagreed: "You teach young children to cross the road safely. It should be the same with drugs – and with sex.". This prompted the further comment that "one lesson a week with a class of kids wouldn't be likely to have much effect".

At this point we were asked to think about targeting. Of the seven programmes, only the last was directed at a specific section of the community. Would the others be more effective if similarly targeted? Several of us thought they would. "Targeting the right groups will increase the success rate." But then the doubts began to re-emerge. Identifying children with obesity may put them at increased risk of bullying and cause them to lose self-esteem. And in the case of drugs, since they're ubiquitous, education about them should anyway be applied universally. On the same topic, another member argued that targeting deprived communities was less likely to be effective in reducing drug use than targeting affluent ones – which may be logical but it not entirely at one with the egalitarian imperative of the NICE questions!

What was the basis of our various choices? Had we been thinking about how to reduce inequality - or had we been judging the competing schemes simply on the basis of which would stand the best chance of success? On a show of hands it turned out that most of us had been backing what we thought would give the best overall results. Only five of us had been motivated by the urge to reduce health inequalities. One of us claimed that of all seven programmes it was the one on sunburn that would be most likely to work. (But even that member hadn't backed it!)

The exercise gave us our first taste of the difficulty of making choices in this area, the contradictions that emerge when you do make them, and the conflict that can exist between creating benefits to all as opposed to benefits for the most needy. That said, anyone taking the results of this exercise as an early hint that most of us would eventually support the first of NICE's two options would have been misled….

<u>More presentations...</u>
The first half of the afternoon was given over to five presentations on the origins and consequences of inequalities in health, and how they might be tackled. It soon became clear that the experts themselves are not in agreement.

Richard Wilkinson of the University of Nottingham summarised his core message like this: "Rather than choosing between raising national standards of health or reducing health inequalities, inequality turns out to be the main driver of national standards". Among rich countries, he said, it's the most unequal that have the worst health. In short, to improve national health standards we have to reduce socio-economic inequality.

He was followed by Richard Cookson of the University of East Anglia who set out to help us think through the consequences of the alternative strategies that NICE was asking us to choose between. He did it with the help of a hypothetical example of two health programmes - both costing the same and both calculated to increase life expectancy – but one of which concentrated on narrowing the life expectancy gap between rich and poor.

In offering us her thoughts on inequality, Sheena Asthana of the University of Plymouth reminded us that, for some, socio-economic inequality is a not undesirable feature of free-market societies. But this, she added, is not consistent with attempts

to reduce health inequalities. We need to face this contradiction, she argued, and to be honest about it.

Health economist Nick Bosanquet of Imperial College, London - who described himself as a “chronic optimist” - was eager to dispute Richard Wilkinson’s analysis of the link between health and inequality. He also offered his own suggestions for the kind of initiatives that NICE should recommend, including an improvement in mental health services. Poor mental health, he commented, leads to poor socio-economic standing.

Finally, David Stout, Chief Executive of Newham Primary Care Trust, brought his experience to bear by describing health and social conditions in his part of East London, and outlining how he and his colleagues were trying to improve them.

In the discussion that followed these presentations some of us expressed surprise at the apparent paucity of evidence on the issues: a lack that perhaps explained why even experts can hold such different views. Several of us were still concerned about the use of a system of socio-economic categorisation that seems outmoded, not least in having been devised before British society achieved its present multi-ethnic make up.

Ethnicity was the theme of the first of two more presentations on the origin of health inequality. The second tackled the issue of gender. Several of us viewed one or both with a degree of scepticism.

Rena Papadopoulos of Middlesex University reviewed the various factors – culture, genetics, racism, migration etc – that may play a part in determining the health of minority groups. Following the presentation one member emphasised that anyone belonging to a minority group living here in the UK should enjoy the same rights and resources as any other citizen. In spite of the sympathy for this view, some members questioned what they had heard. For example, among ethnic minorities the inability to speak English is, we were told, a handicap when it comes to finding and using health and social services. This was not denied; but one of us suggested that the remedy - learning English - lay in the hands of the individuals apparently disadvantaged. “You’ve not persuaded me that people are necessarily unable to make good choices. They just choose not to.” Another member chided our speaker for having delivered a presentation not about the need for equality but for special treatment.

Karen Newbigging of the Care Services Improvement Partnership explored the role of gender as a determinant of health. She suggested that it would help our understanding of the issue if more data on health in relation to, for example, social class could include gender in its analysis. Once again there were dissenting views – and not only from the men among us. “Is this an argument about equality or just about difference?” one of us asked. Another suggested that she wanted to be treated not as belonging to a group – women – but simply as an individual person. A third member said he was persuaded that inequality exists, but not necessarily inequity. “Two things can be unequal without necessarily being unfair.” This prompted a discussion about the difference between the two words. We decided that equality is a condition in which everybody is treated equally, regardless of their needs. Equity, on the other hand, is a condition in which people are treated with regard to the needs rather than the same as everyone else.

Someone else observed that "People have got to accept responsibility for their own actions. If you want the best you've got to take responsibility for yourself and do something about it."

The closing discussion of our first day - in which we reflected on what we'd heard about the effects of social inequality in general, and on health inequality in particular - began to take on a note of desperation. "These are not NHS problems, these are not NICE problems," one member complained. "We're the wrong people to be talking about them." And another member added, "We're trying to solve the world's problems."

Fortunately this brief "wobble" resolved itself – in part through some helpful closing comments from Mike Kelly. He conceded that while only the NHS is obliged to take notice of what NICE recommends, the adoption of its public health role has greatly enlarged its potential audience. He reminded us that local authorities in Britain have traditionally played an active role in public health, and said he was confident that they would be likely to embrace recommendations from NICE. Other public and private bodies might prove less enthusiastic – but he remained hopeful that they too would pay heed to NICE suggestions.

Day two – final presentations

After we had completed our second tracking questionnaire (see Appendix 2) we listened to the remaining two presentations. In the first, Dr John Soady, assistant director of public health for the Sheffield West Primary Health Care Trust, joined us to describe the first three years of CIRC, the Citywide Initiative for Reducing Cardiovascular disease. He described how Sheffield had made a success of tackling cardiovascular disease within its most deprived communities[2]. In the second, Dr Ian Roberts of the London School of Hygiene and Tropical Medicine outlined the relationship between socio-economic class and road traffic accidents; he then argued that carbon rationing is essential to minimise global warming, and suggested that this was an issue on which NICE might take a view.

Both presentations were followed by vigorous discussion. The Sheffield project in particular raised issues that bore very directly on the alternatives which NICE had set us. We therefore divided into four groups to discuss the following question: "If NICE were to recommend that this kind of targeted initiative be used more widely, what would you see as the benefits and drawbacks?"

[2] Before CIRC began some 26,000 people out of a population of 540,000 in Sheffield were estimated to be suffering from cardiovascular disease. As judged by the index of multiple deprivation, the separation of Sheffield's most and least advantages inhabitants make it is the most polarised of English cities. With £1 million of Health Action Zone money spread over 2 years, and further £1 million from mainstream resources, the programme set itself a goal: "Too accelerate the decline in cardiovascular disease and reduce the inequalities between geographical areas and social and ethnic groups through targeting secondary prevention into the areas of greatest need."

The first aim was to identify at least 85% of the people with symptomatic heart disease in 51 Sheffield practices with a higher than average prevalence of the condition and with high-risk (South Asian) ethnic minorities. The second was to ensure that least 80% of the individuals so identified received a package of a help ranging from dietary advice to drugs within 2 years. In a further 44 practices with below average prevalence the corresponding target figure was 40%.

When targeted practices were compared with those that had received no special attention, there was evidence by the end of the scheme of a clear additional decline in mortality. This amounted to 21 per cent in the less deprived areas, and 38 per cent in the more deprived. In short, while a decline in cardiovascular disease continued throughout Sheffield, the CIRC intervention brought about the fastest rate of decline in the most deprived section of the population.

When we met again in plenary session, each of our groups put forward one important benefit and one drawback from those that had been discussed. On the positive side, the responses were:

- That targeting has brought particular benefit to particular individuals.
- That the existence of the scheme should make all GPs more aware of deprivation.
- That it's had measurable outcomes offered a clear justification for its wider use.
- That it was successfully levelling geographical differences.

The main reservations were:

- That it might ignore any genetic components of diseases under consideration.
- That it was a top-down programme, with something done to a community as opposed to empowering people to take responsibility for themselves.
- That it had imposed substantial short term costs.
- That it could cause resentment if some people get what others don't, and might lead to the equivalent of post-code prescribing.

There was an even more vigorous discussion of Dr Roberts's presentation. But while many of us were intrigued by his arguments, responses ranged from the sympathetic to the overtly hostile. In the end, most of us felt slightly over-whelmed by the scale of the project and wondered if a meeting such as ours was a suitable forum in which to be arguing for change as radical as he was proposing.

Who are we – and is it fair?

We began the afternoon with an exercise that seemed straightforward but, for most of us, became discomforting. We were asked to leave our seats and stand in groups beside signs on the wall numbered I to V according to our own assessment of the socio-economic group to which belonged. For some this proved difficult; a consequence, perhaps, of changes in our lives or circumstances, or of the existing categorisation having been devised in an age when lives were simpler to pigeonhole. One member, for example, felt she was in one group on some days of the week, but a different group on other days!

Some members really disliked the process of division into groups, or felt it was confrontational. However, we had already learned that these divisions do still have a practical value because they consistently predict the average health level of the people who fall into them. Our discomfort was reinforced when we were reminded that those of us clustered round the Group II sign could expect to live several years more than those of us in Group V. While it is one thing to know such facts, it is quite another to be divided up and facing each other.

Does fairness mean that we should be making more resources available to people in the lower groups? "It concentrated my mind morally to realise I was in Group II," one of us mused. "I wouldn't want to deprive anyone in Group V." But another said, "I think NICE should be in the businesses of everything for everybody." A Group V council member had a further argument: "It's good for all the rest of you if we're healthy too!"

Some members, though, felt that others' relatively disadvantaged position was on account of bad choices that they themselves had made:

- "Whatever group you're in you can live longer if you make good choices."
- "What's the point of getting into a higher socio-economic group if you're rewarded for being in a lower one?"

- "I don't think that genuine poverty, of the kind my grandparents knew, really exists any more."
- "The white middle class tend to be criticised simply for being assertive and using the system as it's supposed to be used."

By contrast, several members suggested it was right to focus extra resources on people whose problems were for reasons they couldn't influence, such as biologically inherited illness. "You can't move out of your genes, and you can't be educated out of your genes, and here there's a clear cut case for giving extra resources."

As we swapped experiences it became harder and harder to say what's fair. Is someone's good fortune due to luck or to hard work? Is it the product of initiative, or self-esteem, or in-built confidence? Is it fair just to hand extra resources to needy people, or should they have to earn them?

For some of us, a concern that was initially raised by Sheena Asthana remained. Would targeting resources mean that the poor and disadvantaged in prosperous areas, which in practice often means rural areas, would be doubly disadvantaged?

It was a relief to return to our previous (and class-unrelated) seating arrangement! But while few of us relished the exercise we'd just done, it did help to concentrate our minds on the potential impact of the question that NICE had set us. Painful as it may have been to stand in our groups, the experience was revealing and, as such, valued by at least some of us.

Key issues sessions

Our task in the next two sessions was to compile a list of some of the key issues that might be represented in the report. In each session we dealt with some half dozen topics suggested by individual members. Congregating around a set of flip charts marked with the various topics, we added our own thoughts.

Some of our suggestions overlapped, some contradicted each other. Our list (in no particular order, and as recorded on the flip charts along with added comments in italics - most sympathetic, but some not) included the following:

- The gap between advantaged and disadvantaged members in society is a natural phenomenon.
  We're all born different, we're meant to be different, and no amount of money/resources will change that. It's all down to the individual to change. Is the NHS meant to serve society or to structure it?
- We must target groups with appropriate messages that they can understand.
  Messages must have the right cultural tone.
- The gap between advantaged and disadvantaged is society's problem and too big for the NHS.
  What we need is social equality, not social engineering. If we're trying to make society more equal, our starting point shouldn't be the NHS. Inequality is feature of society. Politicians need to stop pretending that inequality can be solved by throwing money at the symptoms, and address the cause of the inequality – which is where the true unfairness lies. There needs to be a cross cabinet approach to tackling health inequalities.
- Any intervention must be efficient and accountable.
  Interventions need to be carefully identified. Even if something works in one area, it may not in another. Projects should be localised, and the results must be made public.

- We should help the disadvantaged now because having to do so at some future point will be less cost-effective.
  Future benefits to the wider population will include the prevention of a worse outcome, fewer visits to the doctor, less hospitalisation, and a reduced burden on the family.
- We should target groups with specific genetic susceptibilities.
  Offer help to those who can't by themselves do anything about a problem.
- Concentrating resources on the disadvantaged sucks money out of universal provision.
  Special teams, projects, action groups etc suck money away and create bureaucracy and waste. If a marginal group needs extra help, this is best done from the "bottom up", not "done to" i.e. by empowerment and capacity building. You may end up creating new kinds of deprivation; someone will always be at the bottom. And treating different racial groups differently might feed racism, not reduce it.
- Target resources to help people who need it most.
- The NHS is there to serve, not to restructure society.
  Limited NHS resources should be directed to health, with the principle of benefit to all.
- To serve society, the NHS needs to be a driver of health change.
  Sometimes you have to treat people differently to give them the same opportunity. Investing in disadvantaged groups brings benefit to society as a whole.
- The NHS should be pro-active, not reactive.
  Primary care trusts should do more to educate the local population on better healthcare.
- Advice should be available to all – but, within that, specific groups should be targeted.
  Prevention is better than cure. It may not be the NHS's responsibility at the moment to cure society but if nothing is done it will be the NHS that pays in the long run.

With this buzz of sometimes contradictory opinion in our heads, we needed time to reflect. This would soon be available because we were nearing the end of our second day. Only two further tasks remained.

The first was to consider the wording of the NICE question as it had originally been posed[3]. Nine of us felt that the bald reference in Option 2 to "narrowing the gap" implied that this might involve not just an increase in resources to the less advantaged, but an actual removal of resources from the more advantaged. We were assured that this was not the intention, and asked that the question be modified to make this clear. The agreed version is the one that appears at the head of this report.

This was not a trivial matter. A show of hands revealed that, for at least three of us, the wording of the question would affect our choice of Option.

Having sorted this out, we made our preliminary and provisional choice between the two Options. At this stage nine people were in favour of Option 1, but 16 preferred Option 2.

[3] The NICE question as it had originally been posed: "Is it appropriate for NICE to concentrate resources on trying to narrow the gap between the least and most disadvantaged members of our society, even if this has only a modest impact on the health of the population as a whole?"

Those of us who favoured Option 1 offered a variety of reasons:

- There's no point in pouring resources into groups that make bad choices.
- Targeting social group V or ethnic groups may mean fewer resources for broader public health measures with a greater dividend.
- Disadvantage is a social and political problem, not an NHS or health one. Improving the health of the disadvantaged is better done through employment, economic regenerations etc.
- It's better to encourage people to improve than imposing it on them.
- Decisions should be made on the basis of need, not on narrowing gaps.
- Targeting is too blunt an instrument.

Among our thoughts on Option 2:

- It counters the discrimination experienced by disadvantaged groups.
- If we don't pursue this strategy the NHS will go bust!
- Early intervention is more effective.
- Possible medical treatments could be tried out and piloted and then if proven to be cost effective could be launched into the main stream.

A number of Option 2 supporters were keen to add caveats: as long as it's not to the detriment of the whole population; as long as the gap is narrowed upwards, not downwards; as long as needs are properly identified, and schemes are properly monitored; as long as no group is positively excluded from access to resources; as long as accountability is monitored; and as long as schemes aren't allowed to become media-led and too hyped-up.

Although none of us actually said as much, these cautions and warnings suggest that members who backed Option 2 were conscious that it represents the more difficult, the potentially more contentious, and may even be the riskier of the two strategies.

Final thoughts – and final vote

Overnight, one of our members had looked up a 2002 Department of Health publication titled *Tackling Health Inequalities*. She quoted a passage: "Babies born to poorer families are more likely to be born prematurely, are of greater risk of infant mortality and have a greater likelihood of poverty, impaired development and chronic disease in later life." Should we or should we not, as a society, be doing something about this? Our near unanimous view was that we should. But as we had been finding out, unanimity about the need to tackle a problem is one thing; unanimity about how to do so is another.

In the closing hour of the meeting we listed some more thoughts and views that we wished to see recorded in our report.

Some, though not all of us, had reservations about targeting on the grounds that giving resources to one group inevitably means denying them to other. We felt that discrimination, along with excessive "nannying", is likely to create resentment, or even reduce social cohesion. Inflexible targeting will also have a tendency to create a "post-code lottery" state of affairs. Others felt that the NHS is being asked to do too much. But there was also the contrary view: "There will be times it's worthwhile and cost-effective in the long term to spend money in going out and looking for illness."

"Life is meant to be a struggle," one member insisted. And, in equally philosophical mood, another pointed out that, "Some people make a conscious choice to have a

short and merry life, while others opt for a longer and more austere one." Not deprivation or disadvantage, in other words, but choice! One of us, reflecting on personal responsibility, said: "You shouldn't expect the doctor to phone you up every morning to ask if you're sick!" People should be expected to take some responsibility for themselves, he added. His observation prompted murmurs of approval.

The final vote revealed that, overnight or during the morning, the split in opinion had moved slightly closer to parity. Option 1 finally received 10 votes, and Option 2 attracted 15. One of us found it impossible to come down on one side or the other.

During our final discussion, one broad strategic suggestion earned the approval of many of us - and perhaps most of us. It concerned the manner in which NICE should exercise the principle expressed in our choice, and in the underlying emphasis of any plan or proposal it may put forward. One member summarised it like this: "We should concentrate on the health needs of people, not on their ethnicity, or their class, or their geographical location," In other words, under most circumstances the process of allocating resources should be driven first and foremost by the identification of a health condition worth tackling; only then should we consider who suffers from it, and whether resources need to be targeted disproportionately to particular sections of the community. If those individuals happen to belong to a particular ethnic or socio-economic group – so be it. Target them. By contrast, to launch a process with the primary and expressed aim of helping out this or that ethnic or economic group will, we suspect, invite complaints of unfair discrimination, and generate avoidable controversy.

Should we be surprised by the divide in our own opinion? Probably not. If society itself was undivided in its view of inequality, or if the process and consequences of achieving equality were socially and financially cost-free, surely action would already have been taken. In spite of our shared feeling (as expressed at the beginning of this section) about the unacceptability of the extremes of health inequality, we simply could not reach unanimity on which of the two strategies we were offered for tackling it is the better.

Appendix 1 The question

It is recognised that, in Britain, there are very significant differences in people's health that relate to their socio-economic status, ethnicity or other influences. These are often considered to be due to so called "wider determinants of health".

Wider determinants of health

Socio-economic factors

Socio-economic differences in health have been studied, in the UK, for 150 years. Since 1911, the Registrar General has defined peoples' socio-economic groups by their current (or former) occupation (see Table 1). Although this classification system has been elaborated in recent years, much historical data about health differences in Britain is based on this system.

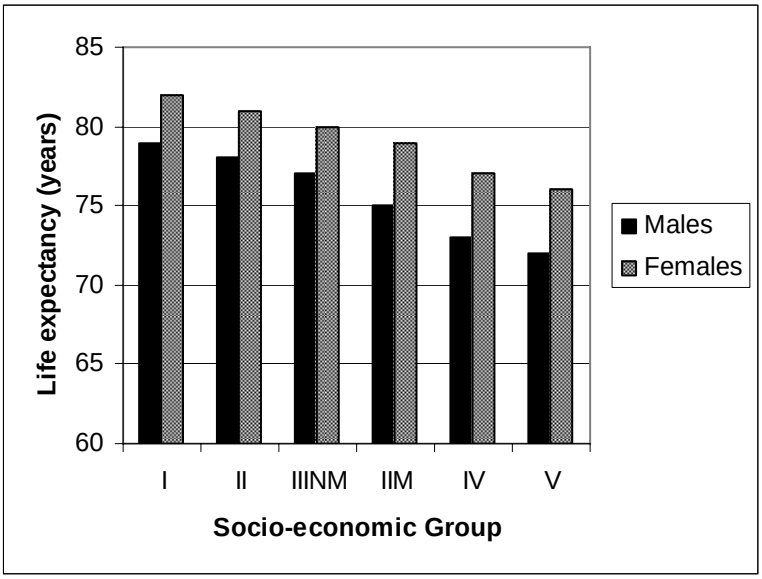
Table 1: Registrar General's socio-economic groups.

Socio-economic group (% population)	Description	Examples
I (10.6)	Professional	Doctors, lawyers, accountants
II (22.2)	Intermediate	Managers, teachers, journalists
IIIN (10.5)	Skilled non-manual	Clerks, cashiers, retail staff
IIIM (7.4)	Skilled manual	Plumbers, electricians, bus drivers
IV (9.5)	Partially skilled manual	Security guards, care assistants
V (12.9)	Unskilled	Labourers, cleaners, messengers

As we move across these groups, from I to V, people have less disposable income, poorer housing, and fewer educational opportunities. There are also marked disparities in health. Those in socio-economic group I have a life-expectancy that is seven years greater that those in group V (Figure 1).

There are three particular points to note in Figure 1. First, these are "average" life expectancies. Second, the life expectancies of women, in all socio-economic groupings, are greater than those of men in the same group. And, thirdly, there is a decreasing life expectancy from one socio-economic group to the next. This is often described as "a gradient".

Figure 1: Life expectancy amongst different socio-economic groups

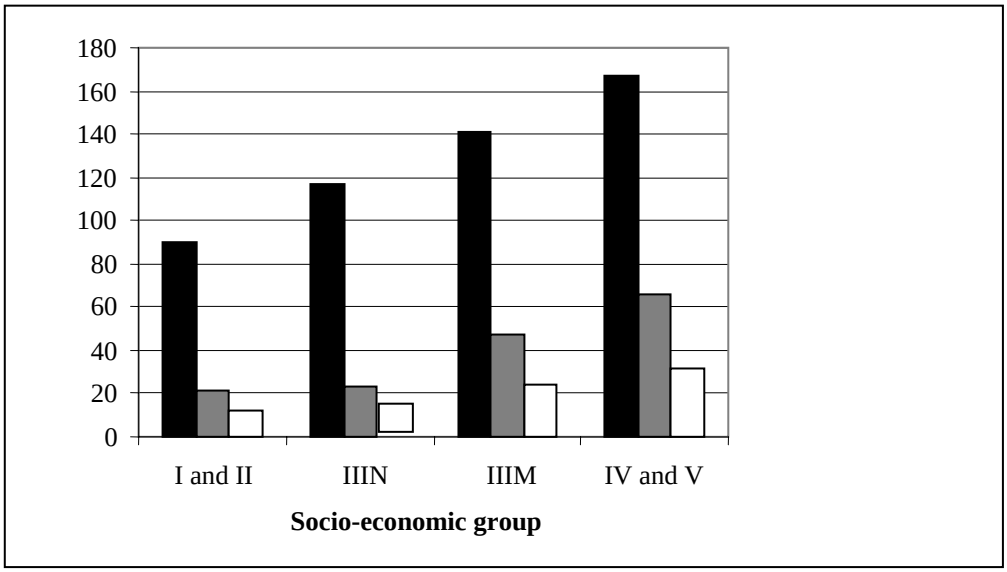


Gradients showing disparities in health between socio-economic groups exist for many common conditions (Table 2) and are shown, graphically, for three of them (heart disease, lung cancer and stroke) in Figure 2.

Table 2: Common conditions showing significant socio-economic gradients in disease prevalence.

Disease area	Condition
Cardiovascular disease:	Coronary artery disease
	High blood pressure
	Stoke
Metabolic and endocrine:	Diabetes (maturity onset)
	Obesity
Lung disease:	Asthma
	Chronic bronchitis
	Lung cancer
	Pneumonia
Mental illness:	Schizophrenia
	Depression
	Anxiety
	Suicide
Others:	Infant mortality (all causes)
	Childhood accidents
	Bladder cancer
	Gastric and duodenal ulcers

Figure 2: Mortality gradients (deaths per 100,000) for heart disease (solid bars), lung cancer (grey bars) and stroke (white bars) amongst socio-economic groups



A few conditions, however, show a “reverse gradient” with people in group I having a higher burden of illness than those in other groups. Examples include breast and prostate cancers, leukaemia, malignancies of the lymph glands, and melanomas of the skin.

The Registrar General’s socio-economic grouping captures only one element (occupation) of inequalities between people. Other methods have therefore developed such as the “Townsend Index of Deprivation” and, more recently, the “Index of Multiple Deprivation 2000”. This latter index combines a number of individual indicators which are converted into a single “deprivation score”. These indicators include

- income,
- employment,
- health and disability,
- education,
- skills and training,
- housing, and
- geographical access to services.

Despite the more sophisticated approach of the Index of Multiple Deprivation 2000, the gradients remain very similar to those seen using the socio-economic groups.

Gradients, relating to socio-economic factors, are not confined to Britain but are seen in all other European countries as well as in North America. In Europe, France has the “steepest gradient” (ie the greatest disparities between socio-economic groups) and Sweden the least.

The causes of these socio-economic inequalities in health are only partly understood but they include diet, environment, exercise habits, and housing conditions and the impact of these things over the life span. Smoking is responsible for some of these gradients because of the marked differences in tobacco consumption between socio-economic groups I through V. Differences in smoking accounts for much of the gradients for lung cancer, chronic bronchitis and heart disease. Yet there are also a significant gradient, between socio-economic groups, even amongst smokers: other factors, too, appear to be involved. There is evidence that the higher socio-economic groups make more and better use of preventive services.

Ethnicity

In general terms the health of migrant groups to the UK tends to be worse than that of the indigenous population. For some groups their experience of education, unemployment and other social and economic factors are worse than the indigenous population. Direct and indirect racial discrimination not only perpetuates some of these social causes of ill health but also prevents access to the provision of appropriate health care. In addition the interaction between genetic predisposition and environmental factors seems to substantially increase the rate of diseases such as diabetes, heart disease and stroke in some ethnic minority communities – for instance up to three to four times the rate than in the indigenous population. There are also some specific conditions that affect particular communities exclusively due to genetic causes. For example Sickle Cell disease in African Caribbean communities, Thalassaemia in Greek Cypriot communities, and Tay Sachs disease in some Jewish communities.

Health and other inequalities

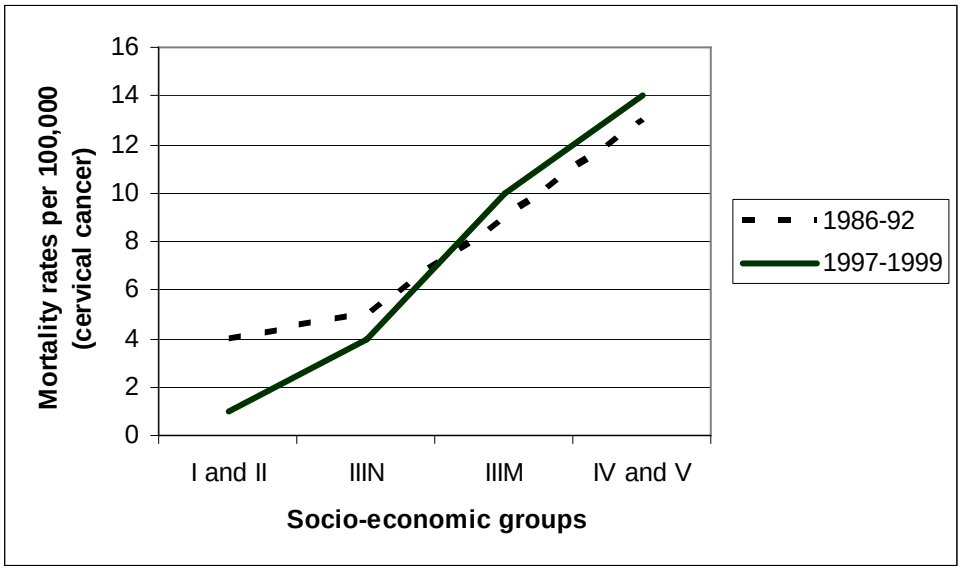
Homelessness and unemployment are both associated with ill health. This, again, is partly associated with peoples' socio-economic groupings but there are also other factors. Even within socio-economic groups, for example, unemployed people have worse health than those in employment.

EFFECTS OF POLICIES TO REDUCE INEQUALITIES

Over the past century or more a wide range of measures have been introduced to improve the health of people in Britain. And these have been very effective. As a result British people are now, collectively, more healthy than at any time in history. Yet there is a paradox; in the most recent period of time the health inequality gradient has got more pronounced and the problem of health inequalities remains stubbornly resistant to change. The health of the least and less well off has either improved more slowly or, in some cases, is getting worse. This is demonstrated in the figure below. Between the years 1986 to 1999 mortality rates in the age range 35-64 years have fallen in all socio-economic groups but that the gap between the most and least well off has widened (proportionately).

Figure 3

Mortality rates for cervical cancer for the years 1986-92 and 1997-1999



THE QUESTION(S)

1. Is it appropriate for NICE to issue guidance that concentrates resources on improving the health of the whole population (which may mean improvement for all groups) even if there is a risk of widening the gap between the socio-economic groups?

Or

2. Is it appropriate for NICE to concentrate resources on trying to narrow the gap between the least and most disadvantaged members of our society even if this has only a modest impact on the health of the population as a whole?

And

3. For each of these strategies, are there factors that should merit special consideration?

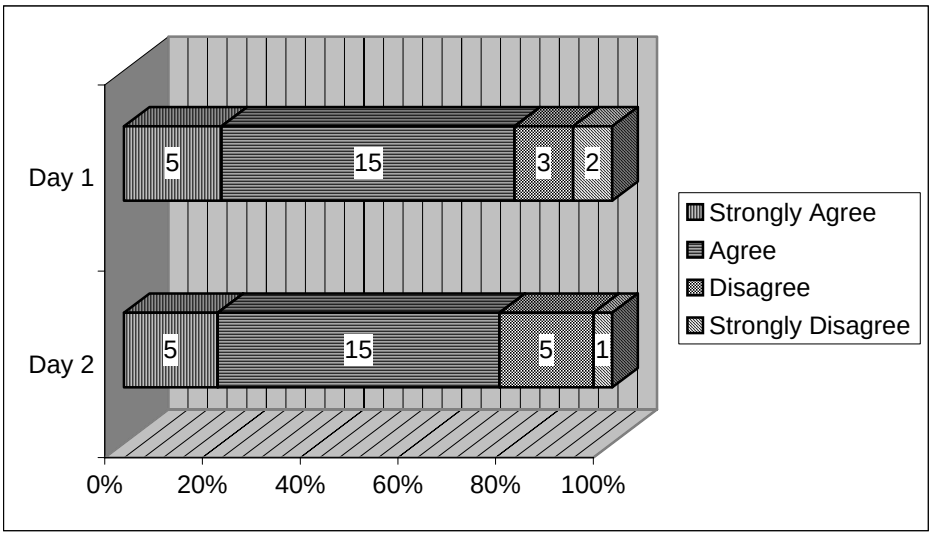
Citizens Council Committee
May 2006

Appendix 2 The tracking questionnaires

On the morning of the first and second days we answered the same questionnaire. Each comprised six questions with the options of choosing “strongly agree” (SA), “agree” (A), “disagree” (D), or “strongly disagree” (SD). Differences in the overall totals reflect that fact that one us did not complete one of the questionnaires, and some of us did not respond to every question.

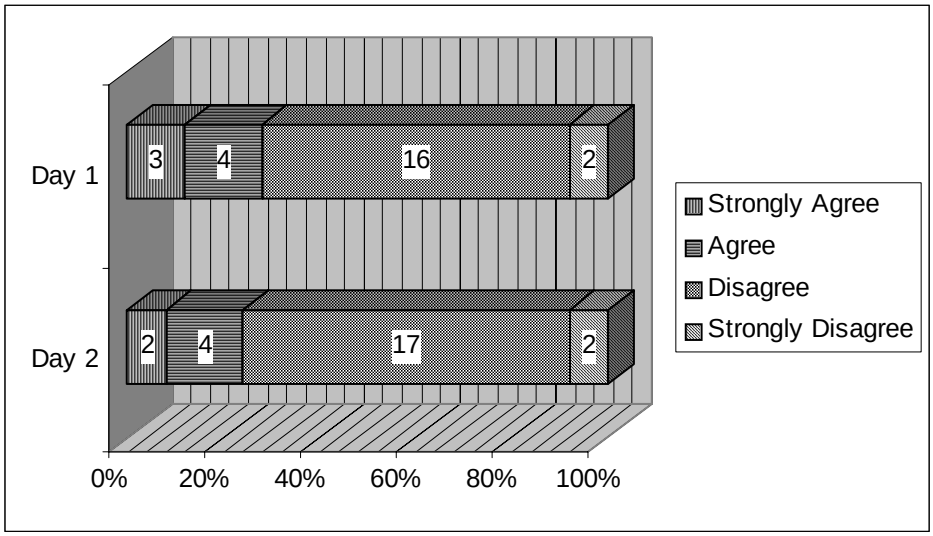
1) Nice should issue guidance that concentrates resources equally amongst the population regardless of their socio-economic background.

	SA	A	D	SD
Day 1	5	15	3	2
Day 2	5	15	5	1



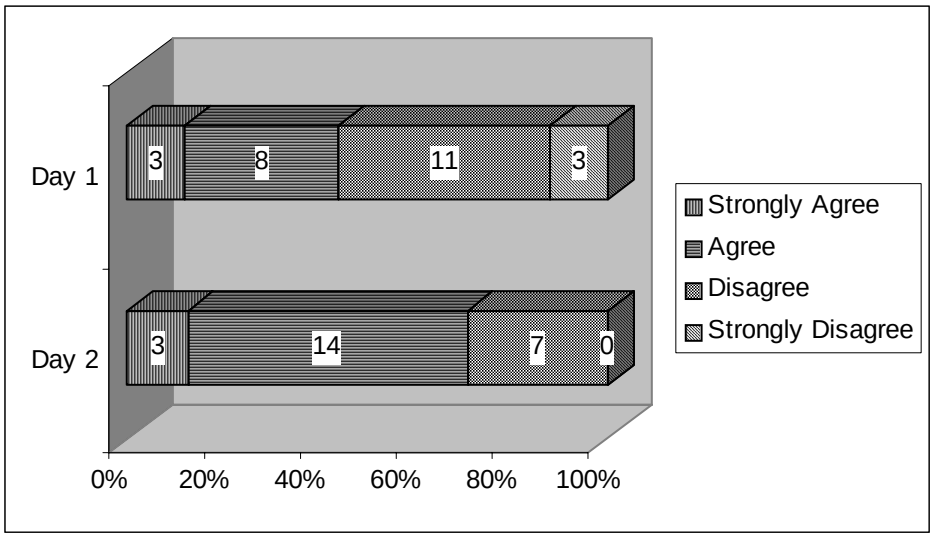
2) NICE should issue guidance that concentrates resources equally amongst the population regardless of their healthcare needs.

	SA	A	D	SD
Day 1	3	4	16	2
Day 2	2	4	17	2



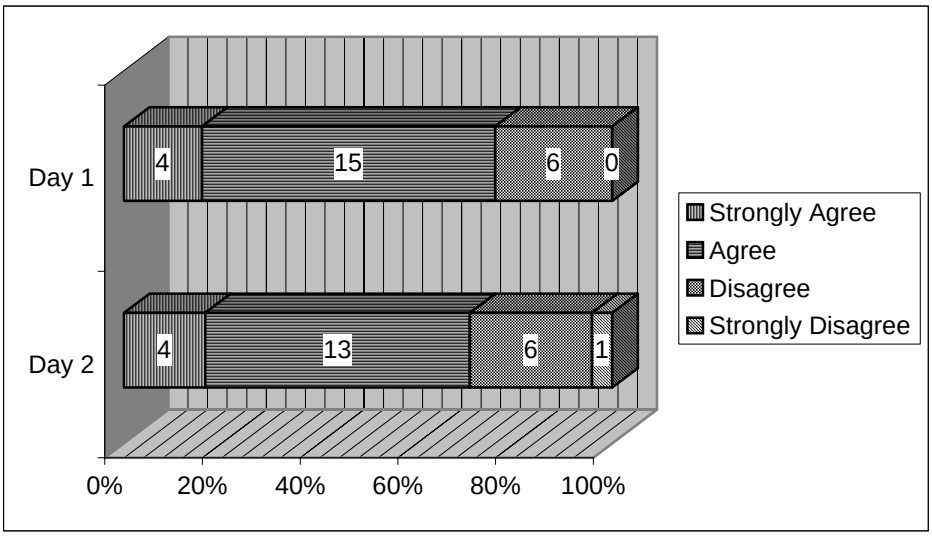
3) NICE should issue guidance that concentrates resources equally amongst the population even if those with the highest healthcare needs are least likely to use them.

	SA	A	D	SD
Day 1	3	8	11	3
Day 2	3	14	7	0



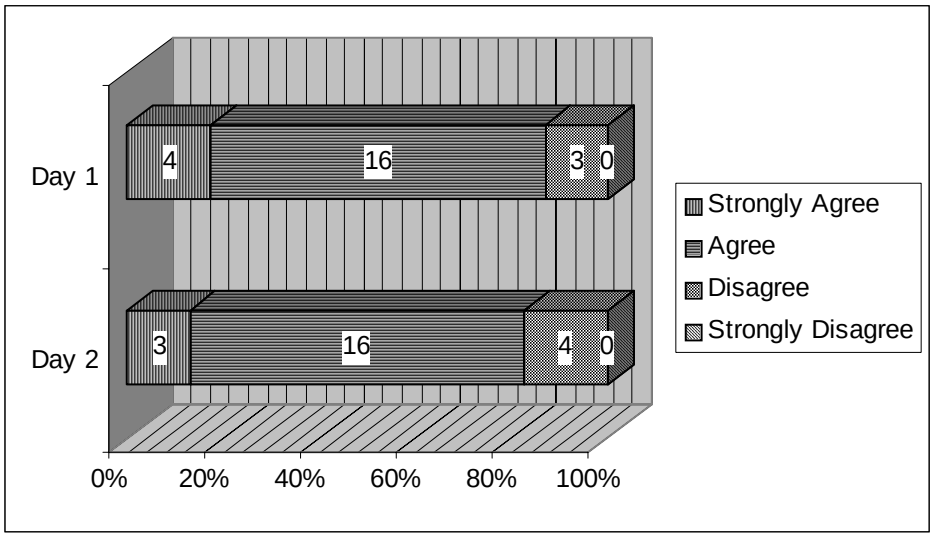
4) NICE should issue guidance that concentrates resources on those whose healthcare needs are greatest.

	SA	A	D	SD
Day 1	4	15	6	0
Day 2	4	13	6	1



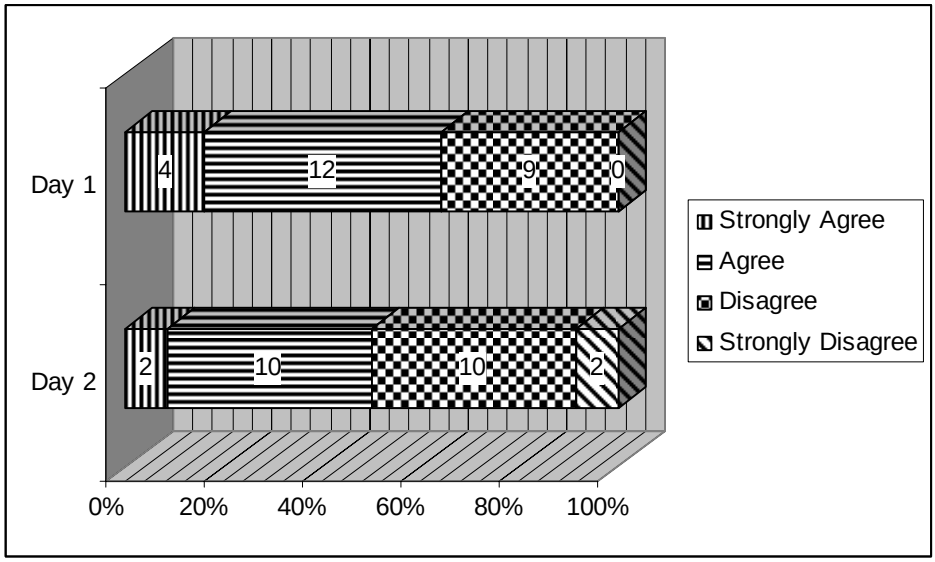
5) NICE should issue guidance that concentrates resources on where it will have the greatest impact on the whole population.

	SA	A	D	SD
Day 1	4	16	3	0
Day 2	3	16	4	0



6) It is the responsibility of the NHS to attempt to narrow the gap between the least and most disadvantaged in our society in terms of public health.

	SA	A	D	SD
Day 1	4	12	9	0
Day 2	2	10	10	2



To summarise the message of those figures, a majority of us felt that resources should be concentrated on those whose healthcare needs are greatest (Q2 & Q4) and where they will have the greatest impact on the population (Q5), irrespective of peoples' socio-economic background (Q1). This view remained broadly unchanged. A weak initial balance of opinion that it was the responsibility of the NHS to narrow the gap between the most and least favoured (Q6) disappeared between the first and second surveys.

The only noticeable shift in our opinion was in Q3. A weak feeling that resources should not be distributed equally amongst the population if those with the highest needs were least likely to use them was replaced by a stronger feeling that they should be so distributed. Although rather different in focus from the two main Options that NICE had given us, the fit between our final conclusion on Q3 and our preference for Option 2 seems, at best, ambiguous.

Appendix 3 The programme

DAY 1		
Time	**Title**	**Who**
9.00am – 9.15am OPEN	Welcome from Vision 21	Ela, Brendan, Helen & Jess
9.15am – 10.00am OPEN	Welcome from NICE Introduction to the question and public health	Professor Sir Mike Rawlins Professor Peter Littlejohns
10.00am – 11.00am OPEN	'Why the fuss?'	Professor Mike Kelly
11.00am – 11.20am OPEN	BREAK	
11.20am – 12.00pm OPEN	Consequences	Ela Pathak-Sen
12.00pm – 1.00pm	**LUNCH**	
1.00pm – 2.30pm OPEN	Question Time Panel	Professor Richard Wilkinson – University of Nottingham Professor Sheena Asthana – University of Plymouth Dr Richard Cookson – UEA David Stout - Chief Executive, Newham PCT Professor Nick Bosanquet – Imperial College London
2.30pm – 3.00pm OPEN	BREAK	
3.00pm – 4.30pm OPEN	Some determinants of health inequalities: Ethnicity & Mental Health	Professor Rena Papadopoulos – Middlesex University Karen Newbigging - Care Services Improvement Partnership
4.30pm – 5.00pm	Reflection	

DAY 2		
Time	**Title**	**Who**
9.00am – 9.30am	Recap	
9.30am – 1.00pm incorporating half hour break OPEN	Case Studies Child RTAs Coronary Heart Disease	 Dr Ian Roberts – London School of Hygiene and Tropical Medicine John Soady – Assistant Director of Public Health & Sheffield CHD Implementation Manager, Sheffield West PCT
1.00pm – 2.00pm	LUNCH	
2.00pm – 5.00pm	Initial Conclusions	
DAY 3		
Time	**Title**	**Who**
9.30am – 12.00pm	Drawing conclusions and deciding what goes into the report	
12.00pm – 12.30pm	Close and thanks	Professor Peter Littlejohns
12.30pm	LUNCH	

Appendix 4 The speakers

Marthe R. Gold MD, MPH

Marthe was in attendance throughout the meeting as an interested observer. Marthe provided a view on how systems worked in the US as well as providing the Council with her own experiences at various points during the meeting.

Marthe Gold joined the faculty of the City University of New York Medical School in 1997, where she is Logan Professor and Chair of the Department of Community Health and Social Medicine. She attended medical school at Tufts University and received her public health training at Columbia University. She completed her clinical training in family medicine at the University of Rochester and subsequently served on the faculty of the Department of Community and Family Medicine at that institution. From 1990-1996 she was Senior Policy Adviser in the Office of the Assistant Secretary for Health where she worked on economic and financing issues for clinical preventive services and public health programs. She was a member of the Clinton Administration's Task Force for Health Care Reform, where she worked on benefit design and protections for under served and vulnerable populations.

Dr. Gold directed the work of the Panel on Cost-Effectiveness in Health and Medicine, a non-federal expert panel whose final report, issued by the U.S. Department of Health and Human Services in 1996, remains an influential guide to cost-effectiveness methodology for academic and policy uses. Her research interests include: socioeconomic predictors of disparities in health and health care, measurement of health outcomes, and the use of cost-effectiveness analysis in resource allocation. Her recent work focuses on the public deliberation and decision making with respect to setting priorities for health care resources. Her clinical practice has been in rural and urban under served settings.

Prof Mike Kelly
Public Health Excellence Centre Director
Mike graduated in social science from the University of York, holds a master's degree in sociology from the University of Leicester, and undertook his PhD in the Department of Psychiatry at the University of Dundee. Before becoming director of research and information at the HDA in December 2000, he was professor of social sciences and head of the school of social sciences at the University of Greenwich. Before that he was senior lecturer in health promotion at the University of Glasgow. Mike is a medical sociologist with special research interests in coronary heart disease prevention, chronic illness, disability, exercise and health and community involvement in health promotion.

Panel Session

Prof Richard Wilkinson
After several years of manual work, and a first degree at the London School of Economics, Richard trained in epidemiology and worked briefly in the National Health Service before taking up a career of research on health inequalities and the social determinants of health. He is now Professor of Social Epidemiology at the University of Nottingham Medical School and visiting professor at University College London.

Working in this field for 30 years, Richard has played a formative role in research and public awareness of health inequalities and the social determinants of health. Since

persuading the Secretary of State to set up the working party which in 1980 produced the Black Report on Health Inequalities, he has worked particularly on the health effects of income and income inequality. As well as an interest in what society tells us about health, he is also interested in what health tells us about society. His latest book is The Impact of Inequality: how to make sick societies healthier (New Press, NY, 2005).

Prof Sheena Asthana
Sheena Asthana obtained her first degree (in Geography) from Oxford University and her PhD (in Community Medicine) from the London School of Hygiene and Tropical Medicine. She began her research career working on the health needs of the urban poor and people vulnerable to HIV/AIDS in India. Due to the arrival of the first of her many children, she has since specialised in health care equity, health inequalities and evidence-based public health with respect to the UK. Her publications include Asthana, S. and Halliday, J. (2006) What Works in Tackling Health Inequalities? Pathways, Policies and Practice through the Lifecourse (Bristol: Policy Press). Sheena Asthana is currently Professor of Health Policy at the University of Plymouth and a Board Member of the Commission for Rural Communities.

Dr Richard Cookson BA MPhil DPhil
Reader in Health Economics, University of East Anglia
Richard Cookson is Reader in Health Economics at the University of East Anglia and Visiting MRC Research Fellow at the University of York. He received an MPhil in Economics from the University of Oxford and a DPhil in Economics from the University of York. He helped set up the cross-disciplinary, cross-sectoral UK Health Equity Network, sponsored by the Nuffield Trust, Kings Fund and ESRC and has been a member of the NICE Appraisal Committee since 2002. His main research interests are in health equity and health policy.

David Stout
David Stout has been the Chief Executive of Newham Primary Care Trust in East London since it was established in April 2001. Prior to joining Newham PCT, David was the Deputy Chief Executive and Director of Mental Health & Learning Disabilities services in Camden & Islington Community Health Services NHS Trust. He originally joined the NHS as a management trainee in 1984.

Newham is the 11th most deprived local authority in England & Wales, with high levels of unemployment. Newham is the most ethnically diverse area in the country with 61% of the population from black & minority ethnic backgrounds. Standardised mortality rates in Newham are 18.5% higher than the national average and life expectancy is two years lower than the national average.

Nick Bosanquet
Current Positions
Professor of Health Policy and Honorary Senior Fellow Imperial College.
Non-executive Director Richmond and Twickenham PCT. (Since 2002)
Special Advisor on public expenditure to the Commons Health Committee. (Since 2000).
Advisor to Sussex Health Care.
Director REFORM.
Director TBS GB.

Experience

Labour relations Advisor to the King Edward's Hospital Fund (1977-84) and Fellow at the King's Fund College. 1973-86.
Member of ACAS panel of arbitrators. 1983-90.
Advisor to CARE UK. 1995-2003.
Senior Research Fellow centre for health Economics University of York. 1984-88.
I was a Councillor in the London Borough of Camden from 1974-82 and served s chairman of its Social Services Committee.

Recent projects
I have worked on the development of new health services on the theme of "doing more with less".
--In late 1980s carried out project with United Leeds Trust (then LGI) on re-engineering and redevelopment.
--Carried out evaluation of new methods of treating leg ulcers.
--Helped to found Inner City network of mental health Trusts for improving services.
--Planned Dukeries health Alliance. Mansfield –winner of BMA/Glaxo/Wellcome prize for integrated care 1998.
--Forecasts on future care needs for diseases of aging including Report on stroke care for the Stroke Association and review of palliative re published 1999 by the OUP.
--Currently working with Prof Karol Sikora in developing forecasts for cancer services in cancer services. With KS recently published; "The Economics of Cancer Care" Cambridge University Press. 2006.
--Forecasts of NHS funding in recent REFORM Report. "The NHS in 2010: Reform or Bust"

Determinants Session

Prof Rena Papadopoulos
I am the Chair of the Research team for Nursing, Midwifery and Allied Health Professions at the School of Health, and Social Sciences, and the Head of the Research Centre for Transcultural Studies in Health. I have been working within the NHS and the University sector for the last 30 years. During this period I have led a number of projects aimed at changing nursing practice, developing new curricula, developing new assessment tools, establishing quality systems, and integrating nursing education within the higher education sector. I have conducted various research projects using a range of methodologies, and have provided consultancy to individuals and institutions. I have also been responsible for my school's research capacity programme which aimed at developing research skills for academic staff and research students. I am currently leading the Masters in Applied Health Research, the Intensive European Programme in Transcultural Nursing, the Masters in European Nursing, as well as supervising research students. My main research interests are culture/ethnicity/diversity and health, inequalities in health, disability and health, consumer involvement, regeneration and health, and the contribution of the voluntary sector to health and social welfare. I led the Research Assessment Exercise for the 'Nursing' Unit of Assessment, both in 1996 and 2000, and have been instrumental in establishing the Ethics Committee of the School of Health, Biological and Environmental Sciences, and the School's Journal of Health, Social and Environmental Issues. I have a vast experience related to the voluntary sector. In 1994 I co-founded the 'Greek and Greek Cypriot Community of Enfield', a very successful voluntary organisation. I have also been -amongst others- an elected executive member of the Enfield Racial Equality Council, and Southgate Citizen's Advice Bureau. My contribution in the voluntary sector has involved my participation

in a number of committees and close liaisons with policy makers and funders at local and national level.

Karen Newbigging
National Programme Lead for Gender Equality and Women's Mental Health, National Institute for Mental Health, Care Services Improvement Partnership

Karen has over twenty years experience of mental health and NHS service provision, commissioning, consultancy and research. She originally trained and practiced as a Clinical Psychologist in the NHS for 16 years. During this time she developed specific provision for women and training in relation to women and mental health. Karen subsequently worked for four years as the lead commissioner for mental health services for a Health Authority. Since 1999 she has been involved in supporting the implementation of the National Service Framework for Mental Health and has led a broad range of consultancy and research projects at a local, regional and national level including projects which have focused specifically on improving services for women. Karen took up post as the national programme lead at the beginning of 2006 and currently works for NIMHE on a part-time basis as she is also working at the Centre for Ethnicity and Health, University of Central Lancashire, on the development of an international programme on mental health, equality and human rights.

Case Studies

Dr Ian Roberts
Ian Roberts trained as a paediatrician in the UK and then in epidemiology at the University of Auckland, New Zealand and at McGill University, Canada. His research interests include the prevention, treatment, and rehabilitation of injury, with the aim of providing rigorous research evidence on which to base intervention strategies. He is co-ordinating editor of the Cochrane Injuries Group, an international network of individuals who prepare and maintain systematic reviews of the effectiveness of interventions in the prevention, treatment and rehabilitation of injury. He is currently Professor of Epidemiology and Public Heath at the London School of Hygiene & Tropical Medicine.

John Soady
Assistant Director of Public Health at Sheffield West Primary Care Trust
I currently lead on a number of public health policy areas citywide in Sheffield including coronary heart disease, heart failure and smoking. I work across four Sheffield Primary Care Trusts, which presents a challenge in itself in working with health inequalities. However we are in the process of amalgamating these four organizations into one. In relation to the specific topic of this meeting, along with the then Director of Public Health, I designed and managed the implementation of a large interventional programme aimed at tackling the very significant inequalities in heart disease that had become apparent from our analysis in anticipation of the publication of the National Service Framework for Coronary Heart Disease in 2000. This became known as the Sheffield CIRC programme. Its apparent successful outcome has subsequently attracted a lot of attention, including from the Prime Minister's Delivery Unit, The Cabinet Office Equality Review Team and the Department of Health Inequalities Unit. The programme was cited as a case study in the 'Choosing Health' White Paper.

Appendix 5 The Council

John Baldwin - an electrician who lives in Widnes, Cheshire

Jonathan Barwick – is a lecturer and trainer in hospitality and travel at a Further & Higher Education college in Norfolk.

David Batchelor – an engineer from Leicester.

Auriol Britton – a singer who lives in Bristol.

Brian Brown - an electrical engineer, from Chester-le-Street, County Durham.

Jennifer Brown - a local government accounting technician and a part-time fitness instructor who lives in Derby, Derbyshire

Rod Crowshaw - a store assistant who lives in Castle Bromwich, West Midlands.

Trevor Davison - a supervisor scaffolder, who lives in Lincoln, Lincolnshire.

Freda England – works for the Citizens Advice Bureau and is from Lymington in Hampshire.

Ron Findley – a database administrator from London.

Geraldine Fost - a retired careers guidance manager, who lives in Hungerford, Berkshire.

Lorna Girling - lives in Norfolk, and is a part time literature student and a housewife and mother of two.

Marie Goorun - a dressmaker and part-time French tutor who lives in Gillingham, Dorset.

Terry Hamer - lives in Southampton. He works on the cruise ships at the terminal.

Meryl Hobbs – a retired teacher and farmers' wife from Herefordshire.

Susan Jackson – is a cabin crew member from Surrey.

Robert Jones - works as a warehouse operative and is a football referee in his spare time. He lives in Cwmbran, Wales.

Catherine Kaer-Jones – a student support leader working in a Bradford school.

Jack Kelley – is from Doncaster and worked in the construction industry but is now in security.

Claire Marshall – is a freelance writer from London.

Tina McDonnell – a trainer with a High Street bank from London.

Sharon Morgan - a milliner who lives in Birmingham, West Midlands.

Linda Moss - currently unemployed, trained as a TEFL teacher and now lives in Todmorden, West Yorkshire.

Bob Osborne - a retired former pilot who lives in Horsham, West Sussex.

Paul Pendlebury - an assembly worker, who lives in Preston, Lancashire.

Patricia Roberts – an accounts assistant from Flintshire.

Heena Sabir - worked for a while in human resources, and has recently moved to Huddersfield, where she is looking for suitable work.

Mohammed Shakil – is from Rotherham and training to be an accountant.

Paddy Storrie - a secondary school Deputy Headteacher, lives in Harpenden, Herts.