

# NICE CITIZENS COUNCIL REPORT ON AGE

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## NICE CITIZENS COUNCIL REPORT ON AGE

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**PREFACE**

- 1.1 We were discussing difficult moral and social value judgements. We suspect that in line with the rest of the general public, we have a range of very strongly held views on these subjects. We felt it was more important to articulate and explain these views than to attempt to find an artificial consensus.
- 1.2 Frequently we found ourselves observing that the question we had been asked to consider did not lend itself to easy distinctions. There were many shades of grey but few black or white answers.
- 1.3 It is important to stress in our report that when we talk about “age”, we are not using this as shorthand for “old age”. We considered age at all stages of life, from newborn babies to people in old age, and every age in between. Although it is easier to think of age-related issues for people at the very start and the very end of life, it is important to note that our discussions were wider than that.
- 1.4 Although there is no upper age limit for being a Citizens Council member and we have people of all adult ages amongst us, the youngest of us is 18 years old. We felt it was important to include the views of children and young people too, and so at our November meeting, we considered a report from the National Childrens Bureau on consultation that had been done with 5-18 year olds on this topic. Where appropriate, we have made reference throughout the report to how our views co-incided or differed from those of children and young people.
- 1.5 Please note that although there are 30 members of the Citizens Council, one member was not able to attend the meeting in May and a different member was not able to attend the meeting in November. Therefore, when the numbers of people holding particular views are mentioned, they will add up to 29 rather than 30 people.
- 1.6 All of us learned a lot over the intensive six days that we spent discussing these issues – from the expert witnesses and from each other. The Council meetings helped us develop and articulate our thoughts and opinions.
- 1.7 As such, we hope that we are able to offer NICE some valuable information about the views of the general public on these issues – and the motivations and values that underlie those opinions – to help them when they make their decisions about how treatments and therapies should be used in the NHS.

**INTRODUCTION – HOW WE ANSWERED THE QUESTION WE WERE SET**

- 2.1 At our meeting in May we were asked: “Are there circumstances in which the age of a person should be taken into account when NICE is making a decision about how treatments should be used in the NHS?” There were also some supplementary questions, asking us to expand on various aspects of our answer.
- 2.2 At the end of the three days discussion at our meeting in May – half way through our deliberations - about half of us did think that there are circumstances in which age should be a factor when NICE is making decisions about how treatments are used in the NHS.
- 2.3 A significant minority of us did not think there were any circumstances in which age should ever be a factor in these decisions.
- 2.4 A further significant minority of us did not want to give a yes or no answer because we were concerned that the impact of describing any circumstances in which a person’s age should be a factor would be used as a justification for withholding treatment from sections of the population.
- 2.5 In November, we had a chance to further discuss these issues. Over the summer, we'd asked NICE to clarify their question relating to cost effectiveness.
- 2.6 The new question that was put to us by NICE in November was this: “Should we be more generous in our definition of what constitutes value for money for some age groups rather than others. And if so, why?”
- 2.7 We had the chance to discuss this question, and what it meant for NICE, with the Chairman and the Chief Executive, Professor Sir Michael Rawlins and Andrew Dillon, on Thursday 20<sup>th</sup> November at the start of the third Council meeting. We were then able to continue this discussion with Professor Rawlins on the morning of Saturday 22<sup>nd</sup> November, before we came to our conclusions.
- 2.8 We understand that when a treatment is described as not being cost effective, it’s because we don’t get *enough* benefit for what it’s costing us. We agree that NHS resources need to be placed where they make the maximum difference. It is possible for NICE to just set a mathematical threshold when considering the cost effectiveness of treatment, and judge that any treatments above that amount are automatically not cost effective, and therefore not a justifiable use of NHS resources. However, NICE wanted to know if they should be more flexible than that, particularly when they are looking at treatments that are extremely expensive per quality adjusted life year (QALY) gained.
- 2.9 Should they sometimes be more generous when they are deciding where to set the bar? And if so, should age ever be one of the reasons for being flexible?
- 2.10 By the end of the November meeting, every one of us thought that there are some circumstances in which the age of a person should be taken into account when NICE is making a decision about how treatments should be used in the NHS.

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- 2.11 But when all other things are equal, we do not think NICE should adopt a policy of being more flexible in recommending treatments, based on age alone. One of us explained what many of us thought: “The age of a patient can and should be used to inform the clinician of the most appropriate treatment so that each person can be treated in the most beneficial way. Being more or less generous to a patient simply on the basis of their age is as unacceptable as is the allocation of treatment simply on the basis of their social role.”
- 2.12 We do think that when age is linked to other factors such as risk, clinical effectiveness, social roles or life experience, there are circumstances when we think NICE could be more flexible in deciding whether to recommend that particular treatments are value for money.
- 2.13 The question, therefore, is what might those circumstances be?
- 2.14 In order to answer this question fully, we looked at four types of circumstances. Should NICE be more generous in deciding what is value for money in these circumstances:
- a)...where some age groups are at a greater risk than others?
  - b)...if the treatment offers greater clinical effectiveness for some age groups?
  - c)...because people tend to have different social roles at different ages?
  - d)...based on how much chance people have had to experience life due to their age?
- 2.15 For each one of us, the circumstances in which we thought it was acceptable to be flexible on the grounds of age differed. This report, therefore, sets out as clearly as we can, the various positions we took.
- 2.16 The first two types of circumstances – where age is an indicator of risk or of capacity to benefit – can perhaps already be judged on the technical or clinical evidence that’s available to NICE, but in this report we offer our 'public' perspective on this.
- 2.17 The second two issues - where age could be seen as an indicator of current social role or of remaining life expectancy - really do involve making social value judgements about what people can expect from life. Of course, it's much harder to answer these kinds of things. Some of us frequently felt uncomfortable when discussing these issues - and yet of course that's exactly why we were asked to come together. Clinicians are generally no better trained in making these value judgements than are members of the public, and so the Citizens Council can probably be of most use to NICE in articulating our reasoning when considering these aspects of the question.
- 2.18 We’ve tried to indicate where a judgement might be a majority view, so that NICE can see the weight given to certain views by the Citizens Council. However, we also thought it was important to give space to explain the reasons behind the judgements of those who were in a minority.

**In summary –**

**When NICE is deciding what constitutes value for money to the NHS ...**

**... and when age is an indicator of likely risk, most of us (22 people) think that age differentiation when considering cost effectiveness is legitimate, indeed vital in some instances.**

**Most of us (25 people) think that NICE should be more generous to some age groups rather than others if certain age groups are more likely to benefit from a treatment.**

**Most of us (22 people) don't think that NICE should be more generous to some age groups rather than others on the basis of the social roles that people have at different ages.**

**Most of us (21 people) don't think that NICE should be more generous in their definition of what constitutes value for money for some age groups rather than others based on how much chance people have had to experience life due to their age.**

**Should we be more generous in our definition of what constitutes value for money for some age groups rather than others where some age groups are at a greater risk than others?**

When we considered age as an indicator of likely risk, most of us - 22 of us - felt that age differentiation when considering cost effectiveness was legitimate, indeed vital in some instances. Flu jabs were one example. When treatments are very expensive, it may not be justifiable or possible to pay for them for everyone. If we treat everyone "the same", this may end up with us not resourcing very expensive treatments at all on the grounds that if we can't all have them, then no-one should have them.

To most of us, this just didn't seem right. After all, not everyone is equally affected by a particular illness or condition. Because of their age, someone may be much more vulnerable or at risk. If, because we can't afford for everyone to have it, we then deny them treatment, we're actually putting them more at risk and treating them less favourably than everyone else. Sometimes, treating everyone the same isn't treating everyone fairly.

Three of us were unsure about this, because we weren't sure how often age is an accurate indicator of risk. We wanted to ensure that some vulnerable people wouldn't lose out because of generalisations made about age groups.

Four of us felt NICE should not be more generous to some age groups when assessing what's 'cost effective' even if they were at a greater risk because of their age. We were concerned that something fundamental about the NHS being there when you needed it might be undermined by discussions that linked concepts of 'value for money' with 'age'.

**Some age groups – if they are at greater risk – should be treated more generously**

3.1 For some of us it was simple:

3.2 "There are some drugs and procedures which we have been told benefit certain age groups rather than others because these groups are at greater risk. As these benefits go hand in hand I think I can have no moral dilemma with this issue."

3.3 "Medicine should be given to those that need it. If one age group is at a greater risk of getting something or risks adverse side effects to a drug then of course funds will be put (or not put) in that age group."

3.4 "If someone's age may put them at risk of worse side effects of a medical condition, then if we cannot afford to treat the whole population it would nevertheless be cost effective to treat them."

3.5 "There may be some ages or age groups who may be at greater risk at certain times therefore this is a time when age must be taken into account."

3.6 "Yes! For example flu jab for over 65's, just move the bloody goal post as and when necessary."

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- 3.7 We noted that in their consultations, the children and young people tended to agree that although it was often very difficult to do, judgements about cost effectiveness and risk could be justified. As one of them said in their report: “You can’t afford to give everyone the choice – it comes down to who’s gonna need it.”
- 3.8 Some of us who thought age differentiation on the grounds of greater age-related risk was justified explained it as follows:
- 3.9 “I do feel we should differentiate on the grounds of age and risk. However it is important to recognise that this does not mean that a particular age group is discriminated against. There will be circumstances where costs of treatment would be the same for any/all groups so ‘value for money’ of that treatment would, on the face of it, appear to be equal.
- 3.10 “However, if one particular group would potentially experience adverse side effects, and another group would not, (one group has a risk factor) then that ‘value for money’ would diminish. Looking at it from another angle, it could be that a treatment is available (for example, the flu jab) which would prevent everyone from getting a particular illness.
- 3.11 “If there were infinite amounts of money available, everyone would get this treatment. The reality of course is that with limited funds available, choices should be made. Using the flu jab example, elderly people may die if they get the flu, (and potentially very young children). Those in between would generally feel ill for a few days and then make a full recovery. It therefore makes sense to only offer this to those groups ‘at risk’, potentially saving life.”
- 3.12 And another said:
- 3.13 “I feel that when a vulnerable age group are facing illness and they are high risk, it is cost effective to treat them as quickly as possible even if it looks as though you are favouring them above other groups. Failure to do so could - and sometimes does - mean extra cost in trying to correct or put right what early intervention would have prevented. This approach leaves other resources available for the wider population. Prevention is better than cure and a quick cure is better than a long illness.”
- 3.14 One Citizens Councillor explained: “If it’s a question of a risk then those who have a higher risk of, in the most extreme case of death, need to have priority. Their need is greatest. I believe this is already in practise though. Young children are given MMR jab at a certain age because it is the age at which they are most at risk. If you treat those age groups that have a higher risk of a disease you are going to get a better return in the long run.”

### **But there may be a need for flexibility**

- 4.1 Some of us wanted to be certain that general guidelines wouldn’t prevent individual clinical decisions being taken about people who ‘broke the rules’ for their particular age group: “Where a certain age group is identified as being at risk from a particular disease or complaint, it is accepted that certain things occur at certain times in our lives. However we do need to be flexible in looking at a particular



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group and accept that in some cases an individual is just as deserving of equal generosity even if their age does not fall into the group we have targeted.”

- 4.2 “Doctors should take a flexible approach to when people become old-aged. It can’t be as non-negotiable as saying one person is 65 therefore he gets the vaccine, or another person will be 65 tomorrow therefore he doesn’t get it. Age along with fitness is one of a number of factors to take into account.”
- 4.3 “It is important that we act to bring the greatest good to the majority of the public. However if it was our relative/family my view may be different and that the whole argument of ‘value for money’ goes out of the window, as I would expect my relative/family to be treated, irrespective of age and value for money.”
- 4.4 However, not all of us agreed with that: “We need to be generous about reducing risks in other age groups rather than being selfish and wanting priority for ourselves and our immediate family. We are not the best people to judge what is considered to be high risk and we should give authority to experienced medics to make the best decision for the patient in front of them.”

### **Is age really the defining characteristic?**

- 5.1 Some of us argued that although age when it interacts with clinical conditions may well lead to different judgements being made about the cost effectiveness of a treatment for different age groups, it isn’t ‘age’ per se that makes the difference:
- 5.2 “Age is not relevant but clinical need is. The greater the risk = a greater clinical need, and some treatments are more effective for some age groups.”
- 5.3 “All those at greatest risk whatever their age should be given equal consideration.”
- 5.4 “If an age group is considered to be of a greater risk they will appear to the doctor as having a greater clinical need. This will require allocating more resources.”
- 5.5 “The nature of the risk could in fact be considered to be a clinical need and it is this clinical need that should be considered. The fact that the need coincides with or pertains to a particular age group should be irrelevant.”
- 5.6 “It is not that age has anything to do with it really, because it’s the ‘risk factor’ and not the ‘age’. It just happens that in some examples the ‘risk factor’ is age. Look at diabetics - they can be any age what so ever, but they have a high risk of flu being fatal and therefore are also given preferential treatment. So it’s the ‘risk’ factor that matters and if age happens to be that factor, then yes, use it.

### **But on the other hand – shouldn’t we treat everyone the same?**

- 6.1 Although in a minority, a few of us felt that age and the risks that tend to go with certain ages should not be a factor when determining cost effectiveness:
- 6.2 “Assuming this is analagous to varying the threshold for QALY’s across different bands I want a fair system ie fair to all. The lower level analysis will ascertain the value for money each treatment offers to different age bands. Such analysis will have as one of its criteria the risk to the individual patient. The COX II inhibitor is an example where the lower level analysis ascertained the vulnerability of the over

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65's to ulcers etc and therefore the cost savings providing them with COX II. Likewise with flu. However, the baseline value applied to each age group would be common to determine breakpoints in cost effectiveness.”

6.3 Another explained:

6.4 “Where some age groups are at greater risk than others, this can justify targeting that group with individual treatments for specific conditions.

6.5 “When deciding whether a particular treatment is ‘cost effective’ the definition of cost effectiveness remains the same. I do not advocate a strict definition (i.e. over x pounds = no, under x pounds = yes) but within a range.

6.6 I cannot justify varying a ‘definition of cost effectiveness’ on the grounds that we are considering any particular age group. The reason is that my perception of fairness is that the definition of ‘value for money’ should be more or less the same for all age groups because each age group has a ‘case’.”

6.7 And for one of us, it was described this way:

6.8 “If ‘value for money’ is a ‘driver’ in selecting age groups as priority users of NHS resources then the basic ideal of equal opportunities within the NHS net disappears. There should be a level for all recipients of health-care and it must follow that those at greatest risk (within any age group) will require and receive help.”

**Should we be more generous in our definition of what constitutes value for money for some age groups rather than others if the treatment offers greater clinical effectiveness for some age groups?**

We considered circumstances where a treatment might offer greater clinical effectiveness for some age groups than for others.

Almost all of us (25 out of 29 people) felt that this was a straightforward decision about making best use of NHS money. It didn't feel hard to say that priorities should be based on what will bring the greatest benefit overall – in fact this health maximisation principle is what the NHS is based on. If that greatest benefit happens to belong to some age groups rather than others in some circumstances then this isn't discrimination.

Moreover, like the children and young people in their report, many of us placed great importance on seeing prevention as vital. If some treatments would set people up to be healthier in later life – even if they're so expensive they would normally be regarded as not cost effective – then we may regard them as value for money. We noted that this point was also made a number of times by the children and young people too.

However, we did raise some important cautions. Where age does tend to coincide with an ability to benefit to a greater or lesser extent, we'd like to see a proportionate response, and clinical judgments used rather than strict cut-offs. On a whole-population basis, age can be an important indicator of capacity to benefit. But we'd like it recognised that other lifestyle factors may have an impact, and individuals of the same age may have very different levels of health and fitness, which may have a greater impact than chronological age on their ability to benefit. Again, this was another area of agreement that we had with the children and young people when they were consulted on this aspect of the question.

And secondly, we wanted to point out that the research that's done isn't always adequate, and that can discriminate against some age groups. What we 'know' to be effective is often skewed by what has been researched. If there isn't evidence available about the effect of treatments on some age groups, then great care must be taken when making judgements about effectiveness issues.

Once again, four of us were concerned with the concept of linking "age" with "value for money". For us, the age of a patient may have an affect on the clinical effectiveness of the treatment, but should not be used to decide of that treatment was value for money.

- 7.1 We acknowledged that we might not be able to please everyone: "As we go through life our attitudes towards different age groups are likely to change, particularly in respect of our priorities, so we need to be prepared to accept that

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medical decisions for certain groups of people might not match our own current values.”

### **Using age as an indicator of how best to target resources**

- 8.1 Some of us said there were moral as well as pragmatic reasons for always striving to make most effective use of the resources available: “As we are all tax payers, value for money must have a part in decisions made as this is common sense and morally there is then more in ‘the pot’ for other groups and ailments. Therefore to use treatments which offer greater clinical effectiveness for some groups, rather than others cannot be viewed, in my opinion, as other than a sensible and realistic measure.”
- 8.2 “It is public money and we should look at what is offered to ensure greatest clinical effectiveness – but it is important to ensure that ‘other groups’ are not forgotten and get a look in.”
- 8.3 “I realise that the funds are not a bottomless pit, and therefore it’s important to look at the clinical effectiveness.”
- 8.4 “Administering more expensive drugs could be money well spent in older groups (plus exceptions for other at risk groups) because the patients would avoid the side effects that are less likely to be a problem for younger and middle-aged adults. Similarly targeting provision to age groups who can most benefit from it will be a better use of resources than giving it to everyone who needs it.”
- 8.5 “Some treatments are more effective for some age groups than others and this is a practical, clinical issue so my answer is therefore YES.”
- 8.6 “If we are aiming for achieving the best value from each pound spent, then it follows that we should tend to spend the pounds where it will achieve the greatest effect.”
- 8.7 “Treatment should be offered to those who will benefit the most in order to be ‘value for money’.”
- 8.8 “If a treatment is not effective it is not value for money at any cost.”

### **Sometimes it may be justified to be more generous to younger people**

- 9.1 Some, though not all of us, would make a distinction between children and adults.
- 9.2 “Clinical effectiveness is very important when age enters into the equation. The clinical effectiveness in a younger age group, I believe, should carry more weight because they have the greatest amount of life years to come. They must be allowed to have a good quality of life as opposed to an elderly patient with not many years left – this is using the ‘fair innings’ argument really.”
- 9.3 “Some age groups are more needy of a particular treatment that might be more expensive at one age than another, for example hip replacements. If you need one while young a metal joint is required to last longer. If it’s done when a person is older a plastic one should suffice. This should be considered as positive discrimination.”

- 9.4 Sometimes there may be a good reason for being more generous to children. One of us felt: “Nothing is worse, except maybe obesity or disfigurement, than a child being teased in the school playground because they are lacking in stature.”

**Investing in prevention should be seen as value for money**

- 10.1 “In some cases, a treatment given while young might help people for the rest of their lives, whereas there would be less to be gained from giving it to those who are older, and it might save money in the long run if you give it while young.”
- 10.2 “A treatment that offers greater clinical effectiveness for some age groups rather than others is value for money. For example, flu-jabs appear to prevent crowded surgeries and (in theory) should save hospital beds for illnesses that cannot be prevented.”
- 10.3 Again, the children and young people raised this point several times in their discussions. We saw in their report that some of them felt that we should give preference to treatments that would set people up to be healthier in later life, because there would be more chance that they would not need to use the same level of financial resources for health later on: a cost effective use of funds now to save money in the future.

**Other lifestyle factors may need to be taken into account**

- 11.1 We were keen, though, to try to use a more sophisticated understanding of age than just a chronological fact, and we recognised that age and other factors may interact with each other.
- 11.2 “If a younger adult needs a hip replacement, they could be given a metal joint, in the hope that it would be longer lasting and not need to be replaced. This is not a hard and fast rule because an older patient with as active lifestyle might benefit from this treatment than from the standard version.”
- 11.3 This was a point that was also made by the children and young people: the vast majority of them felt that age should not be the only consideration in making decisions and that lifestyle and potential lifestyle need to be taken into account. In their report, they said: “Some young people thought that if people were inactive before receiving a hip replacement they might become active if they were given the opportunity to have the metal hip: therefore the potential for a better quality of life needs to be discussed. It was generally thought that decisions would be made on a case-by-case basis and that a one size all rule is not fair and that no segment of the population is more important than another.”

**But we’d also like to question the quality and availability of some of the research**

- 12.1 “I interpret ‘greater clinical effectiveness’ as ‘better outcome’ for some groups. If we are to spend money on treating a particular illness, if one particular group has a much higher success rate or less chance of adverse side effects, then this is better ‘value for money’. However, that is not to say the other groups should be ignored – more research, and ways to alleviate any adverse side effects should be investigated. I guess I am saying – never say never.”

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- 12.2 “The expected outcome of the treatment will be the important factor even though the cost may be excessive. But there is lack of research attached to some treatments, and this can be a problem.”
- 12.3 “If a treatment, whether drugs or an operation, is obviously more effective on one group than any other surely it must be used in the most effective way. However, that is not to say that they can queue jump any other group to obtain preferential treatment. It is also important that every effort is still made to find a more effective way at treating the other groups.”

### **We want a proportional response – use judgement rather than strict age cut-offs**

- 13.1 “Yes, but it does depend on how much greater the difference in effectiveness is. If it is only a matter of one age group getting one day longer and another getting two, then no added ‘value’ or money should be given to one over the other. However, if in one age group it means you have a few days off work and curl up in bed, and in another it means you potentially die, of course age matters.”
- 13.2 “There is no point, and is not cost effective (value for money) to give a drug to someone who will probably not benefit – according to medical trials. In the case of the human growth hormone more trials need to be done before I could be happy about them being available to adults. We don’t really know what the effects are. If a drug or treatment is more clinically effective for one age group than another then of course it makes sense to give it to them and use individual judgement on singular cases outside these areas. Cut off points for age groups should never be 100% absolute.”
- 13.3 “The interaction of clinical effectiveness and age should only be considered together - but not age on its own. Age should be taken into account with clinical effectiveness but an individual should not be discriminated against due to age alone. Age should be used to inform but not decide.”

### **Again, just as for age and risk factors combined, a number of us argued that age was almost coincidental:**

- 14.1 “Again it is the clinical effectiveness that should be the deciding factor - should that coincide with a certain age group, then so be it. However if a treatment is found to be 100% beneficial to a particular age group it should not follow that someone from outside that group should not receive treatment even if their benefit is only 50%.”
- 14.2 “For this question age is not relevant. What is relevant is the clinical effectiveness of the treatment. Some treatments are more effective for some age groups than others and this is a practical, clinical issue and perhaps the inclusion of age is a coincidental factor.”

### **And a few of us weren’t happy with any variation in cost effectiveness based on age:**

- 15.1 “If a treatment is more beneficial on the whole to a particular age band, this should not sway the underlying baseline/benchmark measure. Why is someone at 66 more justified than someone at 64? Patient case analysis will ascertain whether the frailty or vulnerability of a person outside the age band warrants the treatment.”

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15.2 “Quality of life, pain-free, independence has to be a consideration, so age is not the only factor.”

**Should we be more generous in our definition of what constitutes value for money for some age groups rather than others because people tend to have different social roles at different ages?**

We then thought about this dilemma: should we bring in the contribution that people make to society as a factor when we're trying to decide what's good value for money? If we're working out what is cost effective to society as a whole, should we weigh up the fact that someone in work helps support themselves, perhaps supports their family, and contributes taxes to help support others? Should we count the pleasure that children bring as being good value to society in itself? What about those who don't work and don't pay taxes but contribute in other ways to life? Should we be more generous to older people because of the many years they've already given to society and to those who know them?

Unsurprisingly, at this point, the discussions became more heated. This was when we began to really make value judgements – in fact, it's when we discussed the extent to which value judgements ought to play any part in making decisions about clinical and cost effectiveness at all.

Remember, that we were not being asked about withholding treatment from anyone. We were being asked to consider what NICE should do if it's faced with a treatment that might not normally be regarded as cost effective enough for the NHS to pay for. Should we ask them to make an exception and recommend it for certain age groups anyway, because of the role that those age groups tend to have in society?

When the children and young people discussed this issue, some of them felt that those people who contribute to society in financial terms should expect to receive more expensive treatments – but most of them said that a person's ability to pay or their financial circumstances should have no impact.

Overall, the majority of us on the Citizens Council (22 of us) felt very strongly that no judgement should be made about being more generous to certain age groups because of the social roles those age groups tend to fulfil. A couple of us felt that it would be impractical – it's almost impossible to generalise about what people do or don't contribute at any given age – but most of us rejected these judgements on principle. We describe our reactions to this question below.

Four of us however, disagreed, and three were uncertain. Those of us who thought differently from the others said that although these are very uncomfortable and perhaps unpopular positions to take, they are issues that should be faced. In a society where we are expected to give as well as take, should we not be more generous to those who contribute most in various ways?

**It isn't possible to generalise about someone's social role at any given age**

16.1 "You cannot generalize about social roles – not at all. Everyone has some value at some point in their life. I would be very uncomfortable with someone or some group making value judgments about age groups. Within one particular age



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groups will be all sorts of differences, I think this would be a morally wrong approach.”

- 16.2 “In this instance the answer is no. The NHS was set up to treat all people equally, fairly and free at the point of delivery. Social roles cannot become a part of the equation. Who can possibly justify that one person is more important than another? The doctor or physician doesn’t have the time and should not be interested, he has a Hippocratic oath to follow. The thought of setting up a database to place everyone into categories sounds like something out of 1984! Horrendous and extremely expensive. Who would pay – the taxpayer of course. Unless taxes were increased, that would mean less money for the NHS.”
- 16.3 “People having different social roles at different ages is a generalization, which has no place in the NHS. It should not be a consideration.”
- 16.4 “Each individual’s role in the community can’t be assessed by strangers.”
- 16.5 “At macro-economic level this is exceptionally difficult to document in a guideline. It is very dangerous to try and make ‘glib’ assumptions about the social roles people may have at different points in life. From an holistic viewpoint, case analysis of each individual ought to recognize the knock-on effect some action or lack of action may have on the rest of society. Suppose one has two men who each need to have a certain treatment. Both have a wife and two kids of identical age. One is highly disabled and finds life a struggle. The other is a highly influential person in society. Who deserves it? Who will get it?”
- 16.6 “How can anyone say that just because you are aged 12, 40, or 96, you must be socially draining, helpful etc? Even if you did say that, how are you going to work out which age is what? This kind of blanket comment will mean things are as ridiculous as getting car insurance. For example I rang to get quotes for my fiancé, one week before he was 21. In their eyes, he was still ‘young and immature’ and was probably going to wrap the car around a tree. Out of those companies that would give a quote, the cheapest was well over a grand. However, only one week later, he has had a personality change overnight! Suddenly now he is 21, he’s mature, must be working, putting something in and lo and behold his insurance is £600. This idea of overnight personality changes based on your age is stupid. You cannot say ‘you are this age ... so you must be like this ...’.”

### **It wouldn’t be right give preference to any age group or social group, even if we could find a way to generalise**

- 17.1 “No group should be disadvantaged because they may have a different social role at a different age. All age groups contribute to society in many, many different ways and the NHS is for everyone regardless of age and social standing. As a caring and compassionate society we should care for those in need and contribute to the system whilst we are able.”
- 17.2 “Absolutely not – on moral grounds or any other grounds anybody can think of. Who are we to judge someone’s importance or social values? Pain is pain and injury is injury regardless of your education/wealth/behaviour/employment record etc. If we only took out what we put in we might as well all go private where only

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the most wealthy people would get treatment and the fundamentals of the NHS could be scrapped.”

- 17.3 “There is a temptation to quantify any individual’s value to society and use that as a basis to allocate various resources. If this is applied to health care, it would present the health care professional with a daunting assessment problem that they are unqualified to make. The patient must therefore be treated on the basis of clinical need alone.”
- 17.4 “No. People all have some value as human beings however antisocial or horrible they are. Who are we to decide who is a valuable contribution and who is not? If you count taxpayers as being good value for money – what about infants and disabled people? Infants will probably grow to adulthood and then start making contributions to society but are we to discount a disabled person as ‘not worthy’ because they may not ever contribute in this way? Being a dependent happens to most people at some time in their lives!”
- 17.5 “I believe that social role should not influence treatment as who has the right to decide if and who is a valuable member of society? All members are valuable to someone – everyone is someone’s son or daughter and thus, important to them.”
- 17.6 “If a person is unemployed for example, it may not be their fault. They may gain employment in the future that positively contributes, or play some other role in the community of which we are not aware. Even if they do not, we must be compassionate and non-discriminatory or society would become once again hard and uncaring. We cannot move backwards – we must improve society not detract from it.”
- 17.7 “Everyone should be offered the same treatment regardless of social standing.”
- 17.8 “All people should have the same treatment whatever their social class. Whoever is the most needy will be treated first. Everybody is socially equal to the NHS.”
- 17.9 “I felt that this question was a moral one. We are not here to judge people or individuals on their social status or way of life. Who decides who has given little or nothing to society? An unemployed individual might argue that their grand-father had fought and died in the war for a free society - free NHS for all.”
- 17.10 “No. All people in society have a valuable role to play, from 31 year-old carers to 90 year-old grandparents. Social position should not be a guide. Even though some people do not pay taxes or contribute to society in accepted ways, it is the ongoing benefit to society i.e. by buying clothes, or food they provide jobs to others, as do newborn babies or children. That makes them valuable and contribute as a whole.”
- 17.11 “No! It would be very difficult to make judgements on whose role in society is of more value than someone else’s role. (Caretaker, Mother, Dustman, Grandparents etc) Who has the right to make that judgement?”
- 17.12 “You can’t say that a member of a particular age group has the same social roles as other members of that group. Each person is individual. Different age groups

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contribute to society in different ways as do different members of society in general.”

17.13 “No. Health care should be for all according to the principles of the founding fathers of the health service. We should not pass judgement on how people spend their lives. However if someone’s condition, which need not be serious, is having such a disabling effect that they cannot do their job or care for others or generally carry out their day-to-day activities, then there becomes a greater medical need for them to have treatment. When we say that certain treatments are more appropriate at one age than another, we should do so only on health grounds and not for our own subjective social reasons.”

17.14 “Every individual’s life is important. Who are we to place restrictions or to judge how important someone’s social standing is? I feel it would be dangerous to make such discriminatory remarks. Who would measure this importance/social standing? If someone needs treatment then it should be given to them on the basis of their clinical need not social contributions.”

17.15 Some people thought it was complicated:

17.16 “I am undecided on this one. Morally I think it would be wrong to judge people on their level of ‘input’ into community – and who is to judge who is better than others? No one should be able to tell me that the guy next door is more important and should be treated first simply because he earns more than me. However, I think it is a human characteristic to judge people. If two people arrive at A&E with nose bleeds and one of them is drunk and abusive, they are seen in a much different light than the person who has simply fallen over. More often than not the drunk person will have to wait longer. On another basis, children in society do not pay into the system – their social status is ‘child’ and therefore you cannot generalize roles within society. Overall I think no, we shouldn’t be more or less generous on these grounds - but is it not human to look at social roles and unthinkingly judge people?”

### **Is there ever a case for being more generous to certain professions?**

18.1 Although most of us felt that there wasn’t a case for this, a couple disagreed. Perhaps society as a whole needs to prioritise those who it most relies on to function?

18.2 “Given that the cure is available and the condition fits the cure the money should be forthcoming. A better quality of life is important to each and everyone and, with a better quality of life, it is to be hoped that the individual will be less of a ‘drain’ on the NHS in future. Not only that, but depending on the age of the patient, he or she should be able to re-enter the workforce earlier or if he or she is currently unemployed the chances of getting a job are improved. In either way this means that the patient can get back to a normal existence and pay tax, thus contributing to, rather than taking from society.”

18.3 “Social roles include carers: there are 6million, plus 175,000 children carers. Without them there would be even more cost to the NHS. The contribution they make to society is immense, and therefore perhaps they should be regarded as

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deserving more generosity if we're thinking about funding treatments that may disproportionately be of use to them.”

18.4 “I can however justify an individual getting treatment where their profession puts them at risk. For example, medical staff, armed forces, but again age doesn't play a part in that decision.”

18.5 But there would be bad news for the politicians if it were left to one Citizens Council member ...

18.6 “You have:

- A. A 30 year-old MP
- B. A 90 year-old (retired dustman).

18.7 Both need a life saving drug. Which one would you save? ‘B!’”

### **Society has the right to make judgements about paying most for what it values most**

19.1 It was a minority view, but some of us felt that – although unpopular and uncomfortable – in a world of limited resources there may be a case for making collective decisions about being more generous to those who contribute in a way that we approve of.

19.2 “Because demand on the NHS is great, a mechanism has to be in place in determining who gets it and who doesn't. There is no doubt that clinical need would supercede social roles (depending upon the urgency) but I do feel that in some way this needs to be looked at. For example, a family – dad needs an operation – life and death situation – possibly disabled if operation not provided – he is the breadwinner – otherwise they might be a burden on the state.

19.3 “There may also be an impact upon the benefits system and social services. Therefore I feel as a member of the Citizens Council I have a responsibility not just to the NHS, but to the wider picture in ensuring public money is protected. I realise that it would not be a popular way of declining or judging who gets what, but it is not a bottomless pit and we need to look at this.”

19.4 Some - but not all - of the children and young people agreed. In their discussions, some of them said that as elderly people are not giving money to the economy, prolonging their life is not cost effective because there is no benefit to society. Others felt that even if an elderly person's life should be prolonged the chances are that the quality of their life would be low. Therefore money would be better spent on giving treatment to a younger person who has a greater chance of a good quality of life.

19.5 However, as these quotes from their report show, their lively discussions brought out a number of different positions:

19.6 “Young people are going to pay taxes in the future – they should get good treatment,” said one girl from inner London, while another countered: “But if you're

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older what about the money you've already paid into the country? That should count too."

- 19.7 And one young person from Birmingham said: "Old people deserve the best treatment because of their age and what they have contributed to society."
- 19.8 One Citizens Council member said that it was important to balance what people put into society with what they take out:
- 19.9 "I personally think input and contribution to society is a major factor which should influence a decision like this to decide whether an individual should receive treatment. For example – National Insurance contributions, it's like a bank situation, you have to give to receive back. If someone went into a bank, pays thousands of pounds and keep making large contributions for a great length of time and at the end of the day he/she is refused payment, it would feel such a great loss and would mean the individual has not been treated fairly."
- 19.10 Another said: "It's not a politically correct or morally comfortable view but I would prefer the 'upstanding citizen' to get the treatment in favour of the 'criminal/layabout/addict' etc. Having said this though I think our NHS should be for all but I understand there are constraints on the budget. Has NICE thought of recommending a direct tax increase for NHS alone? Would the Government consider a referendum on the subject? Because while I accept that it's a politically fashionable argument not to "throw money at the problem" I feel that health service budget is too limited."
- 19.11 "At the end of the day what you put into society you should receive in return."
- 19.12 "Yes. There is no bottomless purse of money to be used for the health service. New and extremely expensive treatments are being discovered continually. At the moment the dilemma is left in the hands of the doctors and health authorities, which is very unsatisfactory. They already have difficult decisions on how to make the budget stretch to meet the clinical needs of the patients in their care. I personally think the time has come for "Joe Public" to be made aware that this cannot go on forever and some important and difficult decisions have to be made. I do not support the opinion 'I've paid all my life therefore it's payback time.' I think personally, there comes a time when we have to think of what benefits society as a whole and that could mean looking at the people's social roles. I therefore think this question needs closer consideration. "

**Should we be more generous in our definition of what constitutes value for money for some age groups rather than others based on how much chance people have had to experience life due to their age?**

The thing about age is that most of us expect to experience each stage of life. In this respect, making a distinction based on age is a bit different to making a distinction on other grounds, such as gender, ethnicity, or sexual orientation – if all goes ok, we'll probably all have a chance at being young, then middle-aged, then old.

So, what about the idea that we should all expect to live a 'normal' lifespan? Do we have a right to this expectation? Should the NHS be expected to help us live a long and healthy life if at all possible? Should we expect the NHS to pay more to prolong our lives if we are young than if we are close to the end of a normal life expectancy?

This issue is basically the "fair innings" argument: although it is always sad when someone dies, does it feel more unfair when a child or a young person dies than when a very old person dies?

Just over two thirds of the Citizens Council members – 21 of us - didn't accept that it was, and we explain why below. Six members thought that it was, and therefore NICE should sometimes go beyond what is normally seen to be cost effective if it meant that someone would be given the chance to live their normal lifespan.

Two of us were unsure – we explain our dilemma below. Because even if it does feel more unfair if a child dies, we shouldn't necessarily vary resources to compensate.

How did this fit with what the children and young people thought? They didn't comment much in their discussions about this, although a small number of them felt that younger people should be given priority due to their age: "Young people have all their life to live and older people have already done it," said one boy from Derbyshire. However, while it was often easier for them to concentrate on their own personal experiences, it was interesting to find that the majority of them expressed strong concern for elderly people too.

**It's a very tricky decision to take**

20.1 A couple of us agonised, unable to make a final decision:

20.2 "The elderly have had experiences of life so one might say in fairness the young are more deserving. But, the elderly have contributed, so why should they not deserve priority?"

20.3 "This is a tricky moral dilemma. A young scholar would get the preference in many people's minds over a house-bound pensioner in an old people's home. Equally a pensioner giving a great deal to society would get preference in many people's

minds over a young vagrant hooked on drugs. My dilemma is that assessing value can take into account so many other things than age.”

- 20.4 Balancing these competing claims exercised us all, though most of us didn't accept that young people should be treated more generously.

**Every life is precious, however long or short it lasts**

- 21.1 “How much chance people have had to experience life due to their age, ‘the fair innings principle’ is an idea to which I am attracted. On a personal level I would favour my child rather than my mother. I do not know whether I would favour some one else’s child rather than my mother. I have no right to ask anyone else to favour my child rather than their mother. I come back to my perception of fairness.”
- 21.2 “If we did give preference on the grounds of the number of years lived, we would give young people everything and old people nothing. Once again treatment should be according to medical need. However when giving treatment we cannot ignore how effective it will be, outcome and capacity to benefit, but we must be careful not to use these factors as excuses for age-discrimination.”
- 21.3 “It is human to favour the young of course, and it is not fair when a child dies. But who is to say there is more grief than when someone loses a parent who they have experienced so much with? Life is not fair.”
- 21.4 “All life is precious regardless of an individual’s age or quality of life. It doesn’t matter if they are an hour old, ten years, teenager, middle-aged, etc...each should be regarded equally. No group should be advantaged or disadvantaged.”
- 21.5 “Within a family group, it is normal for one group to be prepared to sacrifice some benefits in favour of another. But looking at the overall community, we cannot make those sacrifices on behalf of large section of the population. Better to treat each age group simply on the basis of clinical need.”
- 21.6 “It is very sad when a child is seriously or critically ill but it is also sad when an adult is suffering too. I appreciate the loss to society if a person is cut off at a tender age – and to the family involved this is a terrible grief, but I am very reluctant to put a higher value on one age group as it immediately implies and creates a lesser value to another. All age groups are important as each person is a unique individual who cannot be replaced.
- 21.7 “Losing a child is very painful – losing a parent (for the child) is very painful too.”
- 21.8 “I felt this was an uncomfortable question to answer because my judgment was clouded on an emotional level. It is human nature to favour children over other ages based on the fact they have not had enough life experience, and we expect children to be able to grow up. However I don’t feel that a child’s life is more important than an adult’s life - or for that matter that we should be more generous to any age group on the basis of their age.”

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- 21.9 “To target any particular age group - in this case the young - to receive ‘special dispensation’ based solely on their period of life can only disadvantage other age groups.”

### **You can’t know how long someone might have lived**

- 22.1 “None of us knows how long we have left to live; there is an assumption that an old person will not live as long as a young person and therefore gain less from treatment. Age is just one of many factors in an overall picture.”
- 22.2 “Again no. Illness at any age is dreadful and seeing tiny graves in graveyards is heartbreaking, but often it has been a blessed relief. This question almost asks the doctor to play God, and decide how long people should live. A year in anyone’s life is precious to that individual.”
- 22.3 “Life does not come with any guarantees other than one day you will be dead. Clinical need is clinical need and everybody should be given the same chance of survival no matter what their current age is. The clinicians can use their own professional judgment to decide if the treatment is viable or the patient can decide if they want to continue, but a governing body or advisory panel should not play god.”
- 22.4 “I don’t think there should be guidance on this – it should be the kind of decision made separately for each individual.”
- 22.5 “Life experience shouldn’t be one of the grounds used to make decisions about value for money. It should be decided on things such as the needs of the patients, the risk to their lives, and the probability of a successful outcome. If all that is equal between groups and there are choices to be made, then it should be those who have been waiting longest who get the resources – not one age group given preference over another.”

### **Different people find fulfilment at different stages of life**

- 23.1 “Everyone is equal regardless of age. Thinking about the example of Nelson Mandela justified this for me! To say yes would be to support the discrimination of some users just because of how old they are.”
- 23.2 “It doesn’t matter what stage a person is in their life, that life is important, and EQUAL to any other age or age-group. Whatever age you are, there is still life to experience, just because you’re experienced, shouldn’t make your life less valuable.”
- 23.3 “Age cannot determine how much or little of a life you have had. Think of the example of someone who has been in a coma for 30 years! They haven’t had a ‘good innings’. And just because someone has ‘had a good innings’ doesn’t mean they don’t still have lots to give. Look at Nelson Mandela – he was very old, having spent much of his life in prison, when he became President of South Africa. The length of time someone has been on this planet doesn’t determine how important or valuable they are.”
- 23.4 “I would answer no to this question, although I would ask NICE to be more generous to different age groups if they faced a different risk or possessed a



different capacity to benefit. We tend to give more weight to children and vulnerable people. I think this is a human instinct. But people should be treated according to their individual needs, not on whether they've had a fair innings in life or not. Every life is important, whether it's a young baby, a teen, a middle aged or old aged person. We all should be given a chance to have a crack at this precious life whatever our age."

**If you don't expect to live much longer, perhaps each extra year of life means proportionately more?**

- 24.1 One of us suggested we should approach the question the other way round: not asking how long someone has lived already – but how much longer they might be expected to live in the future without treatment.
- 24.2 "An extra year of life to a person with only a short expected life span is more important to that person than 10 years of extra life to someone with 50 years of expected life span. Perhaps we should aim for a greater percentage increase in years gained, regardless of the age of the patient? Concentrate not on the age group affected, but on what we think is the remaining life expectancy, and make that as long and as high a quality as possible."

**But on the other hand, we should give everyone the chance to experience a full life – and that means sometimes being more generous to children and young people**

- 25.1 There were six of us who felt that there is a case for doing more than 'normal' to try to extend the life of those who haven't yet had the chance to experience much of it. And there were some others, who despite being uncertain, expressed some sympathy with these views.
- 25.2 One Council member said: "Again the fair innings argument comes into play. The crazy thing is most people who are elderly faced with this dilemma would advocate favouring the young. Value for money for me is giving everyone the chance at a full and long life so obviously I would weight it to the youth to enable him to have what the older person has already had."
- 25.3 "I seem to be favouring the children, as I think it is unfair if a young person dies, or is in a lot of pain. I think that the public at large will always protect them."
- 25.4 "It is unfair when anyone dies young – or younger than they should – be it an infant, a child, young adult or older adult – if they die before their time. Most people should be able to have a decent quality of life as an automatic right whatever the cost."
- 25.5 One member thought: "It is unnatural to allow a young person to die! And therefore I feel everything should be done to ensure survival, against other groups of people, who have experienced life."
- 25.6 "All people are equal and should have the same opportunities to experience life."

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- 25.7 “This is a big question with no Yes or No answer. I think if someone from an older generation was asked the question in most cases I think (if they had the heart!) they would let someone of the younger generation be given more resources for treatment.”
- 25.8 During our meeting, we allocated ‘money’ to people of different age groups. One of the Council members commented: “I noticed that we continuously voted the baby in the incubator as the one who should be given a chance to life as opposed to the others. Personally I think if the health service were given the opportunity to spend more of the budget on the young and the family, the benefits in the long term due to better health and therefore better cost effectiveness would be good for everyone.”
- 25.9 “My gut feeling on this is yes. Children are the future and must have their chance at life. The older age groups have been young themselves and had a life. A quote from one speaker that meant a lot to me is ‘everyone is young, not everyone gets old’.”
- 25.10 “I would say yes, because the opportunity to spend NHS resources on a sick child is preferable to some other group such as the elderly, on the basis that the child has the right to a life-span that an older patient has already enjoyed. Children are the generations that will take on the responsibility for an older generation.”

Appendices written by Vision 21

## **APPENDIX 1: How does the Citizens Council operate?**

The National Institute for Clinical Excellence's Citizens Council was formally established in November 2002 following a comprehensive recruitment process to attract members of the public to fill the 30 places. Over 35,000 enquiries were made for the Citizens' Council, of which 4,327 people eventually applied. The final 30 members of the Council – stratified to reflect the wider public – were confirmed at an induction meeting in London on Friday 1<sup>st</sup> and Saturday 2<sup>nd</sup> November 2002.

The first full Citizens Council meeting took place on the 21<sup>st</sup>, 22<sup>nd</sup> and 23<sup>rd</sup> November 2002 in Salford and the report on the Citizens Council members' conclusions and recommendations on the topic set for them at this first meeting ('What should NICE take into account when making decisions about clinical need?') is available on NICE's website [www.nice.org.uk](http://www.nice.org.uk).

The second and third Citizens Council meetings were held as part of a two-stage discussion on the issue of "age".

The second Citizens Council meeting was held at City Hall in Cardiff on the 8<sup>th</sup>, 9<sup>th</sup> and 10<sup>th</sup> May 2003.

The third Citizens Council meetings was held at the Hilton hotel in Sheffield on the 20<sup>th</sup>, 21<sup>st</sup>, 22<sup>nd</sup> November 2003.

The process followed during the six days of the Citizens Council meetings in 2003 can be summarised as follows:

- Briefing on the topic by Professor Sir Michael Rawlins, chairman of NICE.
- Discussion on the witnesses to be called and questions to ask them.
- Working through case studies.
- Calling of expert witnesses in public.
- Access to a camcorder and a tape recorder to record their own views informally during breaks and lunchtimes.
- Deliberative sessions to discuss and identify key issues to come from the evidence presented.
- Informal discussions amongst Council members during the course of the event.
- Workshops to finalise the Citizens Council's conclusions and recommendations.

The Council meetings are facilitated and managed by Vision 21, media relations activity is co-ordinated by Nexus Structured Communications, and the process is continuously evaluated by staff from the School of Health and Social Welfare at the Open University, and the College of Health.

As a result of feedback about the first meeting from the Citizens Council members themselves, from the independent evaluation team, and from Vision 21, NICE's Board agreed that some changes should be made to how the Citizens Council operated at its May and November 2003 meetings. The most significant of these are:

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- Citizens Council members were given the topic well in advance;
- Council members had some involvement in setting the wording of the questions;
- Council members were involved in deciding which witnesses were called;
- The minimum term of office of Council members has been extended from one year (two meetings) to at least three meetings, in recognition of the steep learning curve involved in taking part in this initiative.

**APPENDIX 2: Who are the Citizens Council members?**

The members of the Citizens Council are:

- John Baldwin, an electrician who lives in Widnes, Cheshire.
- Auriol Britton, training to be a singer, from Bristol.
- Brian Brown, an electrical engineer, from Chester-le-Street, County Durham.
- Jennifer Brown, a clerical officer who lives in Derby, Derbyshire.
- Sylvia Brown, a retired local government officer who lives in London.
- Scott Chapman, a printer who lives in Corby, Northamptonshire.
- Tracey Christmas, an accountant who lives in Hull, East Yorkshire.
- Rod Crowshaw, a store assistant who lives in Castle Bromwich, West Midlands.
- Trevor Davison, a supervisor scaffolder, who lives in Lincoln, Lincolnshire.
- Marie Goorun, a dressmaker and part-time French tutor who lives in Gillingham, Dorset.
- Mark Handley, a project manager who lives in Kingston-upon-Thames, Surrey.
- Susan Jones, a retail clerk who lives in Cardiff, Glamorgan.
- Rashad Khan, an administrator who lives in Keighley, West Yorkshire.
- Deborah Lee, a part-time advertisement make-up artist and housewife who lives in Bournemouth, Dorset.
- Raymond Longstaffe, a former builder who lives in Brecon, Powys.
- John MacGlashan, Retired security officer, Liverpool, Merseyside.
- Melanie McClure, a mother of one who lives in Hebburn, Tyne and Wear.
- Susan McNeill, a secretary who lives in Market Harborough, Leicestershire.
- Anthony Messenger, an insurance broker who lives in Windsor, Berkshire.
- Sharon Morgan, a milliner who lives in Birmingham, West Midlands.
- Sunita Nanda, a local government officer, who lives in Middlesex.
- Bob Osborne, a retired former pilot who lives in Horsham, West Sussex.
- Paul Pendlebury, an assembly worker, who lives in Preston, Lancashire.
- Audrey Pestell, a retired head teacher, who lives in Woodhall Spa, Lincolnshire.
- Marie Raynor, a housewife, who lives in Sale, Greater Manchester.
- Ian Simons, a taxi driver, who lives in London.
- Colin Stewart, a self-employed IT systems advisor who lives in London.
- Fiona Taylor, a wine marketing assistant, who lives in Sidbury, Devon.
- Peter Thomas, a teacher, who lives in Rhondda, Cynon Taff.
- Judith Ward, a wood turner, who lives near Stoke on Trent, Staffordshire.

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### Statistics on the make up of the Citizens Council

Population (England & Wales)	Criteria	Panel No's required to match population statistics	Actual Panel Members meeting the criteria
10%	under 25 years	3	4
20%	over 60 years	6	6
12%	disability	3	3
5% (10%)	ethnic minority	3	4
13%	home, student, unemployed	4	5
19%	partly skilled/unskilled	6	4
25%	skilled manual	7	8
26%	skilled non-manual	8	7
14%	managerial & technical	4	4
3%	professional	1	3
49%	male	15	15
51%	female	15	15
95%	live in England	28	27
5%	live in Wales	2	3

Population (England )	Region	Panel No's required to match population statistics	Actual Panel Members meeting the criteria
7.9%	East Midlands	2	2
10.2%	East	3	3
4.8%	North East	1	2
13.0%	North West	4	4
15.2%	South East	5	4
9.3%	South West	3	4
10.0%	West Midlands	3	3
9.5%	Yorks & Humber	3	2
15.0%	London	4	3

Population statistics from the ONS (Office for National Statistics).

### **APPENDIX 3: How did the Citizens Council inform its discussions?**

As outlined above, Citizens Council members spent three days in May 2003 and three days in November 2003 learning and discussing the topic, by working through case studies pertaining to age and health; calling and questioning expert witnesses in public; going through a process of deliberative sessions to discuss and identify key issues to come from the evidence; informal discussions amongst fellow Council members during the course of the event; and a number of workshops to finalise the Citizens Council's conclusions and recommendations.

At each of the three-day Council meetings, the final day was spent working in small groups and as a full Council, to pull these discussions together and agree the content of their report to NICE.

#### **The witnesses**

Over the two meetings the Citizens Council received brief presentations from 14 expert witnesses from a variety of backgrounds, and were able to discuss the subject with them.

The witnesses who appeared in the main Council sessions in May 2003 were:

#### **Professor David Barnett**

David is Chair of NICE's Appraisal Committee. He is professor of Clinical Pharmacology and head of the Department of Medicine at the University of Leicester Medical School, and an Honorary Consultant Physician at the Leicester Royal Infirmary with a special interest in cardiovascular disease.

#### **Professor Bruce Campbell**

Bruce is Chair of NICE's Interventional Procedures Advisory Committee. He is a consultant in vascular and general surgery at the Royal Devon and Exeter Hospital, where he was Chairman of Clinical Audit for many years.

#### **Harry Cayton**

Harry is Chief Executive of the Alzheimer's Society. He is also Director of Patient Experience and Public Involvement, Department of Health.

#### **Dr Mark Drayton**

Mark is a Consultant Neonatologist at the Dept of Child Health, University Hospital of Wales.

#### **Professor Sir John Grimley Evans**

John Grimley Evans is Professor of Clinical Geratology, Nuffield Department of Clinical Medicine, University of Oxford.

#### **Dr Chris Heneghan**

Chris is a member of the Council of the Royal College of Anaesthetists and a specialist in Intensive Care at the Nevill Hall Hospital, Abergavenny.

**Dr Tim Kendall**

Tim is Co-Director of the NICE National Collaborating Centre for Mental Health; Deputy Director of the Royal College of Psychiatrists Research Unit; and Medical Director and Consultant Psychiatrist at Sheffield Care Trust.

**Karen Newbigging**

Karen is Director of the Centre for Mental Health Services Development England, which is part of Kings College London. She originally trained and practiced as a Clinical Psychologist in the NHS for 16 years working with people with mental health problems in a range of settings.

**Professor Alan Williams**

Alan Williams is Professor of Economics, Centre for Health Economics, University of York.

In addition to the main sessions, the Citizens Council was helped by five further experts, who advised them during the case study work on the Friday morning. These experts were:

**Stan Davison**

Stan is an active member of the Barnet Pensioners Forum, and co-chair of the Older People's Reference Group for the Department of Health.

**Glenys Evans**

Glenys has a son with cerebral palsy, and is a founder member of the Bobath Children's Therapy Centre in Cardiff.

**Dr David Greville**

David is a GP in Ystrad Mynach, Hengoed.

**Ann Higgins**

Ann is a lay member of the Rhondda Cynon Taf Local Health Board, as well as being a chief officer for Age Concern.

**Judith Paget**

Judith is Chief Executive of Caerphilly Local Health Board.

At the November meeting, the Citizens Council heard from a smaller number of external expert witnesses. At this stage, their main requirement was not for more information, but for more time to discuss their views on the value judgements they were being asked to make; for people who would help them think through the implications and consequences of their views and set them in the context in which NICE operates.

The witnesses who contributed to discussions at the Council sessions in November 2003 were:

**Professor David Barnett**

David is Chair of NICE's Appraisal Committee. He is professor of Clinical Pharmacology and head of the Department of Medicine at the University of Leicester Medical School,



and an Honorary Consultant Physician at the Leicester Royal Infirmary with a special interest in cardiovascular disease.

**Shuna Beckett**

Shuna is from Young NCB at the National Childrens Bureau, and worked on the consultation with children and young people.

**Professor Paul Dolan**

Paul is Professor of Economics at the University of Sheffield, and has been involved in many studies that have elicited public preferences relating to QALYs and fairness issues.

**Carole Longson**

Carole is the Appraisal Programme Director at NICE.

**Rachel Monaghan**

Rachel is Young NCB Co-Ordinator at the National Childrens Bureau, and co-ordinated the consultation with children and young people.

**Professor Ray Tallis**

Ray is from Manchester University, and is also professor of geriatric medicine at Hope Hospital, Salford.

Citizens Council members wish to express their gratitude to all those witnesses who gave up time in their busy lives to attend the meeting and help debate the questions NICE set the Council. Without exception, they provided the Citizens Council with food for thought and with stimulating discussions.

#### **APPENDIX 4: The views of Stakeholders and general public**

NICE and the Citizens Council members were interested to hear the views of the wider public and interested organisations about the questions that the Citizens Council was asked to consider.

The interim discussion document produced by the Citizens Council members after their meeting in May 2003 was published on NICE [www.nice.org.uk](http://www.nice.org.uk) and Vision 21's [www.visiontwentyone.co.uk](http://www.visiontwentyone.co.uk) websites, and people and organisations were invited to respond. In addition, some 57 organisations were written to and asked to submit comments.

Those who responded were:

##### **Organisations**

- Action for Pensioners
- Age Concern
- Association of the British Pharmaceutical Industry
- Civil Service Pensioners Alliance
- Help the Aged
- MENCAP
- NSPCC
- Rainbow Trust Children's Charity
- Royal College of Paediatrics and Child Health

##### **Individuals**

- Catherine Andrews – Senior staff nurse, Notts
- Stan Davison
- Bridget Harris
- Mary Keating – Senior community nurse, Gloucester
- Christine Monck
- Brian Payne – Consultant physician, Department for the Elderly, Norfolk and Norwich University Hospital
- Gill Pearson
- Colin Reisner – Consultant in Healthcare of the Elderly, Queens Hospital, Burton on Trent
- Eve Scott – Theatre manager, Rotherham General Hospital
- Dr Manan Vasenwala – Consultant cardiologist, India
- Wendy Watson-Teague – Nurse practitioner, Wolverhampton
- Kim Woodend – Staff nurse/visitor to the elderly

Their responses were sent to Citizens Council members prior to the November meeting. Copies are available on request from Vision 21.

**APPENDIX 5: The views of children and young people**

Over the summer and autumn 2003, the National Childrens Bureau was commissioned to research the views of children and young people on the issues covered by the Citizens Council. The views of these children and young people were presented to Citizens Council members at their meeting in November, and considered along with other evidence.

The report of the views of Children and young people is presented on the following pages in full.