



NICE Citizens Council Report

Rule of Rescue

January 2006

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Contents

1. Foreword	4	
2. NICE's question	5	
3. Executive Summary	6	
4. Introduction	7	
5. The Rule of Rescue	8	
6. Answering the question	9	
7. Conclusion	16	
Appendix 1	NICE's briefing to the Citizens Council	17
Appendix 2	The way we worked	20
Appendix 3	The tracking survey	21
Appendix 4	Rationing and role-play exercises	26
Appendix 5	Presentations and speakers	30
Appendix 6	The Citizens Council	34
Appendix 7	The Agenda	36

1. 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 whether NICE and its advisory bodies should take account of the so-called "Rule of Rescue". The question was "whether there is a preference to save the life of someone in imminent danger of dying instead of improving the quality of life of someone else whose life is not in immediate danger or saving future lives through disease prevention programmes." The Council was also asked whether, if there is such a preference, there are limits and, if there are limits, what they are.

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

2. NICE's question

Is there a preference to save the life of people in imminent danger of dying instead of:

1. improving the life of other people whose lives are not in immediate danger? or
2. saving the lives of many people in the future through disease prevention programmes (such as treating high blood pressure or lowering blood cholesterol levels)?

If the Council considers that NICE should ignore the Rule of Rescue – why?

If the Council considers that the Rule of Rescue should be applied – when?
And what limits are there?

3. Executive Summary

We felt that the term Rule of Rescue was open to different interpretations – ranging from immediate life-saving to improving the quality of life of the terminally ill - and was therefore unhelpful in answering NICE’s questions. We therefore replaced the term Rule of Rescue with ‘exceptional case’.

When we were asked whether NICE should reject the Rule of Rescue a minority of us (6 out of 27) were opposed to any exceptional case treatment, arguing that the NHS does not have a duty to save life at any cost. It has a duty to groups as well as individuals.

A majority (21 out of 27) said that it should not be rejected completely and it should be applied in certain exceptional cases.

Recognising that the NHS does not have infinite resources, this majority group were able to specify when NICE should apply the Rule of Rescue and define what these limits should be.

Factors NICE need to consider when developing their criteria for applying the Rule or Rescue:

- Is the intervention required to avoid immediate loss of life?
- Is there a good chance of an increased life expectancy?
- Will it result in a significant improvement in quality of life? Are the treatment’s side effects very severe and do they outweigh the good the treatment would do?
- What will be the consequences should the treatment not be received?
- What are the alternative treatments and how do they compare?
- Are future medical gains probable because of the research engendered by the treatment?
- Are the costs prohibitive to the NHS? To what extent does it increase the burden of costs on the NHS and society at large?
- To what extent is cost effectiveness demonstrable?
- Are there good grounds for believing it would set a precedent for other patient groups lobbying for less cost effective treatments?
- Will it avert danger to public health e.g. threat of an epidemic?
- Will people feel society’s worth is diminished if it appears to be acting inhumanely by ignoring the Rule of Rescue?

4. Introduction

The Citizens Council consists of a diverse group of individuals drawn from all walks of life. Although the Council is made up of 30 members, only 27 were able to attend the meeting. Our purpose is not necessarily to achieve a consensus but to explore and explain the different perspectives that arise over an issue. The views of the Council are rarely unanimous and may change over time. This is a reflection of the cut and thrust of any vigorous debate and the fact that when challenged open-minded people may change their views!

Readers should take this report as a whole. Not all statements will stand alone and must be read in the context of the discussions that we had, which are contained within this account.

For ease of reading we have used terms such as 'most', 'several' and 'a few' when discussing the balance of opinion rather than always providing the exact numbers. Sometimes this is necessarily unquantifiable because it refers to the mood of a discussion.

5. The Rule of Rescue

From the start members were unsure on what the term Rule of Rescue meant and as a result expressed widely diverging views on how it should be applied.

This was perhaps not surprising given that some of the experts we heard from confessed they had not heard of the term – although they suspected they had been applying it in practice for many years! But it also appeared that different people define it in very different ways and that there is a much wider debate taking place which we could not hope to resolve in three days.

Gradually over the course of the first day, a series of definitions emerged representing a continuum from immediate life-saving at one end to improving the quality of life of the terminally ill at the other. In broad outline the range of definitions were:

- It was the first response to an emergency where someone's life was in immediate danger. Most who subscribed to this definition felt that once you moved beyond immediate danger you were no longer talking about the Rule of Rescue but duty of care – that is, a clinician's professional obligation to do the best for the patient in their care.
- Others felt the Rule of Rescue should cover all those in imminent, not merely immediate danger, including terminally ill patients. It could therefore apply to a new drug that would help extend a cancer patient's life, for example.
- Some widened the definition to people whose life expectancy could not be increased but whose quality of life could be improved. Motor neurone disease patients, for example, might be given 2-4 months freedom from a tracheotomy as a result of a new but expensive drug. This was, as one person put it, a case of rescuing quality of life rather than life itself.

However, these definitions did not necessarily help us understand when it should be applied to NICE's decisions¹. So, for ease of our discussions over the coming days, we agreed to replace the term with the less ambiguous phrase 'exceptional case'. In most subsequent answers the term Rule of Rescue should therefore be read as shorthand for 'exceptional case'.

¹ In general, NICE considers that treatments costing less than around £5,000 to £20,000 per increased quality-adjusted life year (QALY), or life year gained, are usually cost effective. NICE expects its advisory bodies to explain explicitly, however, their reasons for recommending – as cost effective – those treatments costing in excess of £20,000 to £30,000 per QALY or life year gained. Applying the Rule of Rescue means that the Institute's advisory bodies could be prepared to accept higher costs per QALY or higher costs per life year gained.

6. Answering the question

Is there a preference for saving the lives of people in imminent danger of dying over improving the lives of those not in immediate danger or saving lives of many people in the future through disease prevention programmes?

We found this an agonisingly difficult question to answer. In fact a number of us did not want to have to prioritise one option over another but felt that we should be able to choose all of the options.

When we answered this question at the end of day two, 12 of us said that saving lives in immediate danger was our top priority. Six of us favoured improving health in the long and short-term. Nine of us felt unable to choose either option.

However, by the final day, all of us had fallen into one of two groups – 21 of us were in favour of defining or applying ‘exceptional circumstances’, whilst 6 of us were not.

For those who said saving life was their top priority, their reason was simple. Death is final – if you did not save the life in the first place, there would be no chance of improving quality or applying health education.

‘I believe that saving a life is the most important first part of any medical care,’ said one. ‘Then the assessment can be made about quality of life, long-term benefit and improving the lives of others.’

‘If your life is in danger you should have priority,’ said another. ‘We should save life at whatever cost depending upon the quality of life and success of treatment.’ Most agreed: the quality of that life was also critical.

And another noted that ‘the science of preventing disease, prolonging life and promoting health starts with saving life’.

Another felt we should also treat non-urgent conditions and prevent future illness but reluctantly accepted that ‘if the money is not available to do both, then we have to prioritise the more seriously ill people who would die without treatment’.

The importance of putting compassion above pure economics emerged in several answers. One gave the example of the costly and ultimately unsuccessful rescue attempt of a whale stranded in the Thames earlier this year. ‘We would be diminished as a society if we hadn’t made that attempt.’

A minority believed firmly that life-saving should have no special priority over disease prevention programmes. ‘If the outcome is only to extend a life by a short span of time with no possibility of recovery, the money should be used in cases where chance of recovery is high,’ commented one of us.

And another felt 'saving many lives in the future' was not only more important but more cost effective, bearing in mind the potentially huge costs of aftercare if the Rule of Rescue was applied.

One of us was concerned that any preference given to one type of health intervention over another could be seen as inequitable. All cases should be decided on the basis of cost effectiveness. 'Everything above the defined range becomes a political decision.'

'I strongly believe that improving the lives of people who are not in immediate danger is also important and that it should be balanced with longer term disease prevention. Prevention must be cheaper than cure – you have to speculate to accumulate long-term benefits.'

However, a significant minority felt unable to choose between the two options. Several felt that cases should be evaluated on an individual basis, taking into account clinical need and cost effectiveness.

'My preference is to find a balance between treatment to a patient in imminent danger of dying and aiding the [future] health of people,' said one of us. And another stated that although saving lives should be a priority, this should not be at the expense of improving life or disease prevention. 'If these are ignored, then in the future the consequences would be far too high.'

Others felt that the line between saving life and improving quality was an elastic one, and often it was impossible to separate the two. As an asthmatic, said one member, her inhaler not only improved quality of life, it also saved her life.

If the council considers NICE should ignore the Rule of Rescue, why?

Although the majority of us favoured prioritising life-saving treatment over any other option, a minority of us felt that the Rule of Rescue should be ignored.

'The NHS does not have a duty to save life at any cost,' commented one of the minority. 'It has a duty to groups as well as individuals, and the boundaries between the different roles of curing, treating and preventing and educating will have to be determined by some formula such as QALYs.'

We felt that the Rule of Rescue would open the floodgates, with all patient groups demanding treatment and new drugs as their right. It might also increase the pressure from the pharmaceutical industry, the media, the public and patients, one member warned. 'The financial implications are horrendous.'

Another wanted to know what the limits were once you allowed exceptional case treatment. 'How many other factors do you allow to be used to justify a greater value?' Preference was another word for discrimination in his view.

Agreeing, another member felt the Rule of Rescue could not be waved around as a blank cheque to justify any new medication or medical action. There had to be some cut-off point, she said.

And where patients' lives were in immediate danger, some wondered whether treatment would not be guaranteed anyway through the clinician's duty of care.

Several of us felt the Rule of Rescue should be rejected on the basis of fairness and subjectivity. 'Why does the system have to favour one group or individual over another?' someone asked.

Although we accepted that it was far from perfect, there was support from both groups for the QALY system as at least being an open, objective and equitable way of determining which treatments gained approval.

However, some of us were concerned about how the QALY is applied in practice and that it may discriminate unfairly against less able bodied people. But this is something that needs further examination.

Some also saw the term Rule of Rescue as over-prescriptive. 'If you say rule you are saying always.'

One member suggested that perhaps the strongest argument against the Rule of Rescue was there is a danger that when it is applied locally we could revert back to the 'postcode prescribing' which NICE was set up to avoid.

If the council considers that the Rule of Rescue should be applied – when and what limits are there?

Most of us (21) felt the Rule of Rescue – or exceptional case treatment – should be applied in certain situations, although everyone was keen to emphasise this should be within limits, as the NHS does not have infinite resources.

Most of us believed either that the existing criteria needed to be spelt out more clearly, or that they should be expanded.

Everyone in taking this position agreed there was a need for greater openness. 'NICE seem to use criteria other than QALYs but they're not explicit enough and that's the nub of the problem,' commented one member. 'Whatever NICE decides I do insist on transparency.'

NICE's decision to allow the expensive riluzole for motor neurone disease had convinced another of the need for this. 'I was really amazed to find they had exceeded the limit by such a margin.' Another council member wondered whether NICE was leaving itself open to criticism and challenge because the lack of clear criteria could mean that NICE was seen to act unfairly.

It was also important that patient groups who were fighting to get a particular drug approved or appealing a NICE decision knew the basis on which those decisions were made. 'If anyone's going to effectively appeal anything they must know the criteria on which the judgement was made.'

The importance of having criteria was that they introduced some consistency into the system, said one member of the majority group. 'Doing things differently doesn't matter to me so long as you've got criteria to justify it. People are always being judged differently. The key thing is having some basis for that judgement.'

One of us felt the additional criteria could strengthen NICE's position in the face of external pressures. This would help to make the whole process more transparent and therefore more robust, he said.

Others felt exceptional cases were justified in some instances but that the existing criteria that NICE used in reaching those decisions were perfectly acceptable. They were against making them public and explicit, fearing they would immediately be misinterpreted by the media, causing unnecessary anxiety for patient groups.

Some also wondered if the purpose of this exercise was more to do with marketing than genuinely seeking extra information. 'Is the aim of additional criteria to assist NICE in reaching decisions? Or a tool to explain to others how they reach their decision?' they asked.

The minority group's spokesperson felt the issue was clear-cut. 'I see this whole debate as one where you either accept the principle that there's a cut-off point that NICE should apply or you don't.'

'If you don't it's just giving carte blanche to everyone. If you do, you have to say this is it and we stick with it. Do we accept the principle that there's a cut-off point that NICE should apply or not?'

For those of us who opposed the Rule of Rescue the whole point was that it effectively abandoned all limits. 'This is financial suicide,' said one. NICE is in the best position to consider all the guidance, not just the financial constraints, said another, although he acknowledged that some of the limits imposed by QALYs seemed unfair.

Factors NICE need to consider when developing their criteria for applying the Rule of Rescue

Those of us in the majority group drew up a list of factors that should be considered when applying 'exceptional case treatment'. The overriding principle underpinning these factors must be that any decision is not just assessed on the impact to a particular patient group but to the NHS and society at large.

- Is the intervention required to avoid immediate loss of life?
- Is there a good chance of an increased life expectancy?
- Will it result in a significant improvement in quality of life? Are the treatment's side effects very severe and do they outweigh the good the treatment would do?
- What will be the consequences should the treatment not be received?
- What are the alternative treatments and how do they compare?
- Are future medical gains probable because of the research engendered by the treatment?

- Are the costs prohibitive to the NHS? To what extent does it increase the burden of costs on the NHS and society at large?
- To what extent is cost effectiveness demonstrable?
- Are there good grounds for believing it would set a precedent for other patient groups lobbying for less cost effective treatments?
- Will it avert danger to public health e.g. threat of an epidemic?
- Will people feel society's worth is diminished if it appears to be acting inhumanely by ignoring the Rule of Rescue?

A factor that should be considered by NICE when forming its decision on these exceptional technologies for people in immediate or imminent danger of dying, is the urgency of the required intervention. Some of us thought that the more urgent the need, perhaps the more justified the expense of the intervention.

Several stressed that the quality of life and life expectancy following the intervention were just as important as saving life in the first place. 'There's no point saving life if it is only prolonging the inevitable,' said one.

'Life should be saved where the patient can enjoy a reasonable quality of life after an intervention,' commented another. 'Patients should not be kept alive where suffering would be prolonged – for example, life saving treatment after a critical incident that we know can result in profound brain damage.'

Another spoke from personal experience. Receiving dialysis had saved his life but the quality of his life during that period was appalling. It was only when he had a kidney transplant that he was able to lead a fulfilling life again. 'Saving life on its own is irrelevant,' he said. 'You have got to go a lot deeper.'

Many of us believed there also had to be limits on saving life for its own sake. In some circumstances a 'life saved may not be a life'. Due to technological advances we now have the ability to keep people alive no matter what their quality of life, where in the past, they would have passed away.

And another put it this way: 'it is not always best to save life even if you can. NICE may need to be robust to refuse approval to treatments where the costs are not warranted by outcomes in real terms.'

Some wanted patients themselves to be closely involved in these decisions. 'The patient and family should have a say in whether some one would want to extend their lives by just a few weeks,' commented one. There is only so much intervention a person can withstand, someone else noted. Patient groups' views should also be given due weight when considering quality of life issues.

After considering the case studies that NICE presented to us, we felt that a wider consideration and discussion on how quality of life is weighted on the QALY scale is needed. A separate issue that we also wanted to understand was how NICE considers the proportionate increase in life expectancy against the absolute increase.

We felt that if there were limited treatment options for an 'exceptional case', the new treatment should receive more serious consideration than it may otherwise receive. The fewer alternatives that are available the more important the new technology may be as a means of 'buying hope'. NICE's committees should also take into account whether or not less costly treatments are available.

Future research possibilities could also justify making exceptions. If approving the technology aids further research into that disease, present costs might be partially offset against potential future benefits.

We were concerned when saving life could produce a very large continuing cost in care and maintenance and a low quality of life. 'As research continues these areas of difficulty will increase,' warned some of us.

Many felt the NHS' ability to save the maximum number of lives it could was limited first and foremost by the resources available to the service itself. There would be limits in terms of funding, facilities, equipment, staff and the ability to supply the drugs. But one person felt the only limit was the political will to provide more money.

We accept that cost effectiveness is a very important factor in making decisions about treatments and the majority of us considered the QALY system proposed by economists as the fairest 'until we can rethink it'. 'Nobody suggests NICE should use any different starting point but there are other things people want to factor in,' said the group's spokesperson. Cost effectiveness is not the most important and overriding factor.

'Exceptional case' interventions might also be justified to prevent the spread of highly infectious diseases. Where public health is at risk, NICE's current QALY thresholds should be reconsidered.

Allowing 'exceptional case treatment' was the mark of a civilised and humane society, many felt. 'It is human nature to help people in an emergency,' said one member. The Rule of Rescue sometimes should be applied for the common good of the population. Helping those in imminent danger we felt, had a much wider impact than simply on the individuals directly benefiting. 'For example, the global feeling of solidarity we felt following the Asian tsunami. Even though we can't quantify the benefit, we felt better about ourselves as a society. This goes to the heart of our values,' stated another member.

Even those of us who accepted the value of health promotion also said 'Knowing you will get the help you need if in a crisis is a fundamental part of my confidence as a citizen. In contrast, the abstract and covert effect of health promotion, even if it were to add three years to my life span, would be something which would go unnoticed and relatively unvalued.'

'I know I will die one day. I do not see as the role of the state to offer me a long a comfortable life. I see it as their role to bale me out if I'm in deep trouble.'

‘Those who would favour life improvement/ disease prevention are looking to be fair by levelling up life opportunity. But my way would be to try to help people through the unfairness of random accidents or terminal prognosis.’

‘This also creates a sense of well being, knowing that if you are in an emergency situation that your needs will be catered for.’ This ‘social capital’ accrues from showing willingness to help some minority groups.

Similarly, there were special cases where society demanded that money be spent to save a life regardless of the chances of success or the disproportionate costs involved. ‘For instance,’ said one of us, ‘if a child is trapped down a mine, and the case is highlighted in the press, we will spend a fortune getting them out even if we know the child is probably dead.’

Another member warned that pursuing this approach ‘could cause problems, because who is to judge which case is more deserving, there is no bottomless pit of money, at some point we have to say no.’

Whilst the majority group did think that exceptional case treatment should be applied in certain situations, this did not mean we rejected the arguments of the group who opposed this position. We were aware that should the rule of rescue be applied this could set a precedent for future decisions that NICE makes. However, having explicit criteria would allow NICE to demonstrate robust decision-making that would stand up to scrutiny and challenge.

7. Conclusion

In the final analysis most of us agreed that individuals in desperate and exceptional circumstances should sometimes receive greater help and prioritisation than was justified by a purely utilitarian approach.

A number of reasons were put forward for this but one of the strongest that came though time and time again was that this was the mark of a humane society – it was ‘our badge of humanity’ – and in this sense it had a wider, significance in terms of ‘social capital’ than it might seem at first glance.

Quality of life was key to deciding whether to save or prolong life. Indeed some had shifted to believing that improving the quality of the remaining months of someone with a terminal illness was as important as saving life in the first place.

None of us felt comfortable with the tough choices we were being asked to make between competing examples of deservedness. And most of us tried at the beginning of the meeting to circumvent the law of ‘opportunity costs’, which states that in a world of finite resources, helping one person means that someone else cannot be helped.

Ultimately most Council members agreed that the NHS had a duty to save life – but not at any cost and this must depend to some extent on the quality of the life being saved. Where we differed was on whether the Rule of Rescue – or exceptional case treatment – was an appropriate way of achieving this.

Those of us who opposed its use did so on the basis of cost and equity. As one said: ‘you have got to help [patients in immediate danger of dying] but not at the cost of the overall well-being of the population as a whole.’

But for the majority, there would inevitably be exceptional cases where these arguments were over-riden by other considerations. In fact society as a whole would be diminished if we did not intervene in these situations. ‘It cannot always be about cost but about how we care for those in most need with all our resources,’ commented one member. Another put it even more simply: ‘We must be able to afford our principles.’

Those of us who rejected the Rule of Rescue altogether, did so believing that all funding decisions had to be made on the basis of the greatest good for the greatest number. This was the only approach that was transparent and equitable, they felt.

There would always be a long queue of deserving exceptional cases, they pointed out. Once you accepted one of these, you would open the floodgates to everyone seeking exemption and where would that end? ‘This is certain financial suicide.’

Regardless of which side of the argument we were on, most believed the approach we favoured would ensure consistency and fairness. ‘We as a cross section of the public, don’t expect to like all the decisions made by NICE; but what we do expect is to know the basis on which these decisions are made.’

Appendix 1

NICE's briefing to the Citizens Council

All healthcare systems have limited resources (including money, personnel, and facilities) and all healthcare systems have greater demands placed on them than there are resources available. All healthcare systems are therefore forced to make choices and set priorities.

The Rule of Rescue

There is an inherent human desire to save, wherever possible, endangered life. A society spends time, energy, and money to rescue individuals from peril even when the costs are extremely high. Examples of unstinting acts of communal generosity (and, sometimes, courage) include rescuing trapped pot-holers, sailors lost at sea, and even whales caught under the polar ice².

To what extent does – or should – this principle be extended to healthcare? Should a healthcare system (such as the NHS) spend disproportionate resources (including money) to save, or at least prolong, the lives of patients in imminent danger of dying? And particularly if this is at the expense of denying non-lifesaving treatment for many others or at the cost of taking measures that would prevent future ill-health (and premature death) such as treating high blood pressure or raised cholesterol levels?

The Rule of Rescue has been expressed (defined), by various writers, in different ways:

“A perceived duty to save endangered life wherever possible”

“The sense of immediate duty that people feel towards those who present themselves to a health service with a serious condition”

“An ethical imperative to save individual lives even when money might be spent more efficiently to prevent deaths in the larger community”

“The powerful human proclivity to rescue a single identified endangered life, regardless of cost, at the expense of many nameless faces who will therefore be denied care”

“We will always prefer to save the life of someone in danger of dying than improve the quality of life of someone else whose life is not in imminent danger, or even to saving future lives through disease prevention programmes”

Applying the Rule of Rescue is not necessarily expensive, for example treating childhood meningitis, with penicillin saves lives at the cost of a few pence; and defibrillating someone after a heart attack is almost equally inexpensive (provided a defibrillator is at hand). There are many

² In 1988, millions of US\$ were spent by an international effort to rescue 3 whales trapped under the polar ice-cap. At the same time Japanese whalers were spending millions of dollars locating and harvesting whales.

circumstances, though, where adopting the Rule of Rescue is expensive; and carries with it what is known as an “opportunity cost”. That is to say, the resources used in applying the Rule of Rescue could – in all likelihood – be more “efficiently” spent in treating other people: and in circumstances where, in the longer term, more lives would be saved by using the resources in other healthcare programmes.

The problem for NICE

In general, NICE considers that treatments costing less than around £20,000 per increased quality-adjusted life year (QALY), or life year gained, are cost effective. NICE expects its advisory bodies to explain explicitly, however, their reasons for recommending – as cost effective – those treatments costing in excess of £20,000 to £30,000 per QALY or life year gained.

Applying the Rule of Rescue means that the Institute’s advisory bodies could be prepared to accept higher costs per QALY or higher costs per life year gained. Examples of what might appear to be the application of the Rule of Rescue, from previous NICE appraisals, are shown below (with the equivalent cost per life year gained given)

Temozolomide: In people with brain tumours that have relapsed following previous therapies, it increases survival by an average of 6 weeks and at a cost of £35,000 per life year gained.

Riluzole: In people with motor neurone disease it delays the need for a tracheotomy (the insertion of a tube into the windpipe just below the larynx) by an average of 2 to 4 months at a cost (depending on various assumptions) of between £34,000 and £43,500 per QALY.

Imatinib: In people with very advanced leukaemia, it extends life by 6.5 months at a cost of £48,000 per QALY.

Should NICE accept the Rule of Rescue and accept higher costs per QALY or life years gained? Or is this unfair on others, with longer-term needs, who also depend on the NHS for their care?

Arguments for and against

There is considerable debate about whether, or when, the Rule of Rescue should be adopted by healthcare systems.

Points in favour include:

1. People cannot stand idly by when an identified person’s life is visibly threatened. And although this response is most compelling for life-saving interventions it also applies when an identified person is in need of urgent treatment that is not necessarily life saving (e.g. a broken arm).
2. The Rule of Rescue encourages our sense of fairness in providing for the needs of others.

3. Strict application of cost effectiveness analysis (particularly in life threatening situations) gives rise to conclusions that most reasonable people regard as inappropriate and morally offensive.
4. There is a perceived sense of social value in acts driven by compassion and/or moral duty. It has a “symbolic value” and describes an important motivation that has hitherto been ignored by orthodox economics.
5. Intense media pressure results in continued societal pressure, and shame, even if the intervention for a life-threatening situation is unlikely to be effective.

Arguments against include:

1. Society cannot afford to provide every possible beneficial service. If the Rule of Rescue is applied – where does it begin and where does it end?
2. The Rule of Rescue conflicts with the logic of cost effectiveness analysis which asserts that the lower the cost per QALY, the greater the value for money for the health care system as a whole and thus the higher the priority.
3. The Rule of Rescue disregards opportunity costs (“act first, ask questions later”).
4. The Rule of Rescue discriminates on morally dubious grounds.
5. Applying the Rule of Rescue may mean, overall, that more lives are likely to be lost. Is this action appropriate for a public body– such as a Primary Care Trust – to take? Even in the face of public demand?

Appendix 2

The way we worked

The Citizens Council met over two and a half days between January 26 and 28 at Goodenough College in central London.

We heard from a number of experts, ranging from health economists and commissioners to clinicians, about how the Rule of Rescue was applied in the NHS and its potential economic impact.

We also took part in a simulated rationing exercise as well as a role play where we were asked to put ourselves in the shoes of NICE's appraisal committee and decide whether to approve two new drugs (see Appendix 4). Much of the rest of the time was devoted to discussion in plenary and breakout sessions.

In addition we filled in a tracking survey to measure how our views were changing and at the end of the second day we answered a further questionnaire, producing our individual responses to the four questions NICE had set us.

We completed the first tracking survey following the introduction to the question by the Chair of NICE but prior to any external speakers, on the morning of the first day, and then for a second time at the end of the first day. By this stage, we had heard from a panel of experts and completed the 'rationing exercise' (Appendix 4) with the assistance of further experts. The questionnaire was then completed a third time during lunch on the second day following the input of the last of the external experts and finally, the fourth questionnaire was one of the last exercises on the final day after agreeing the contents of the final report and following group and plenary discussions on the previous afternoon and that morning (for full details see Appendix 3).

On the final day we discussed these responses in greater detail. The majority of us then produced a list of criteria to help establish which treatments merited special treatment.

For biographical details of speakers see Appendix 5.

Appendix 3

The tracking survey

Tracking surveys completed at the following times:

Survey 1 – Day 1 morning

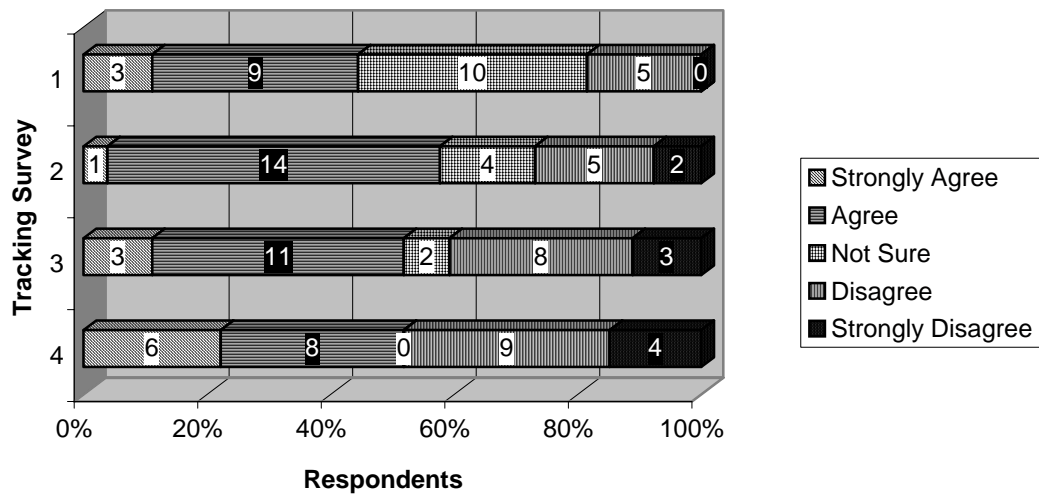
Survey 2 – Day 1 evening

Survey 3 – Day 2 midday

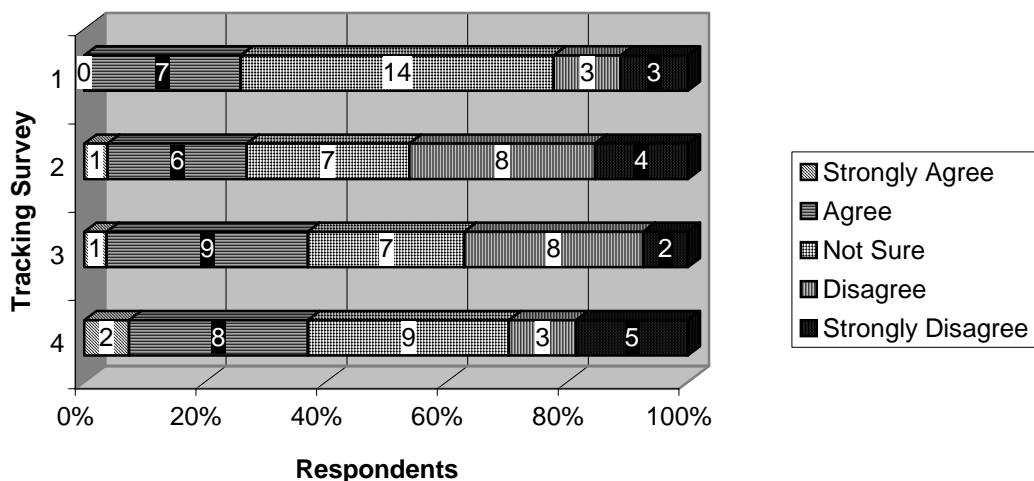
Survey 4 – Day 3 midday

For further details see Appendix 2

It is more important to put resources into saving the life of someone who is in immediate danger of dying, rather than use them to improve the life of others who lives are not in immediate danger.



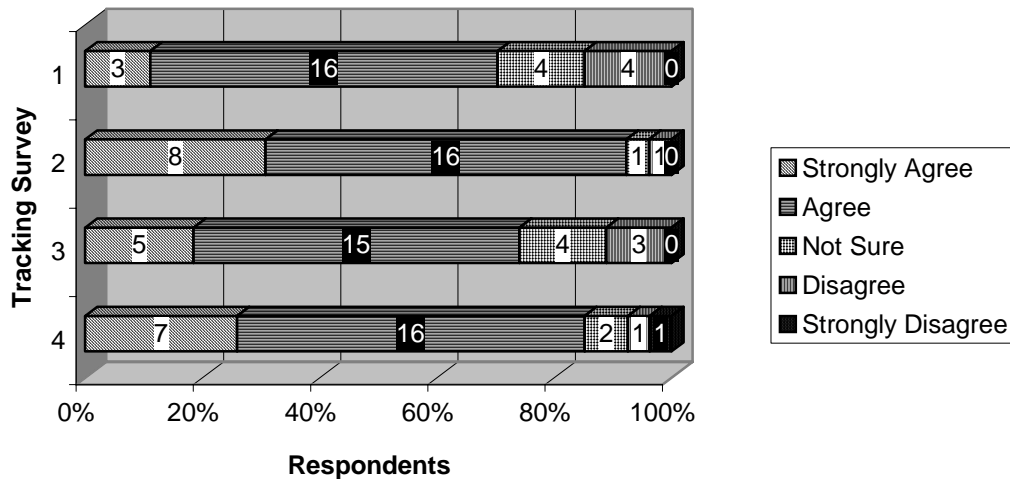
The NHS should spend money to save and / or prolong the lives of patients who are in immediate danger of dying, even if this means denying non-life saving treatment for many others.



These two charts above show that there is not much change in those who agreed with this statement but those that were unsure at the beginning, decided that they did not agree that it's more important to save life than improve the lives of those not in immediate danger. No one was unsure about

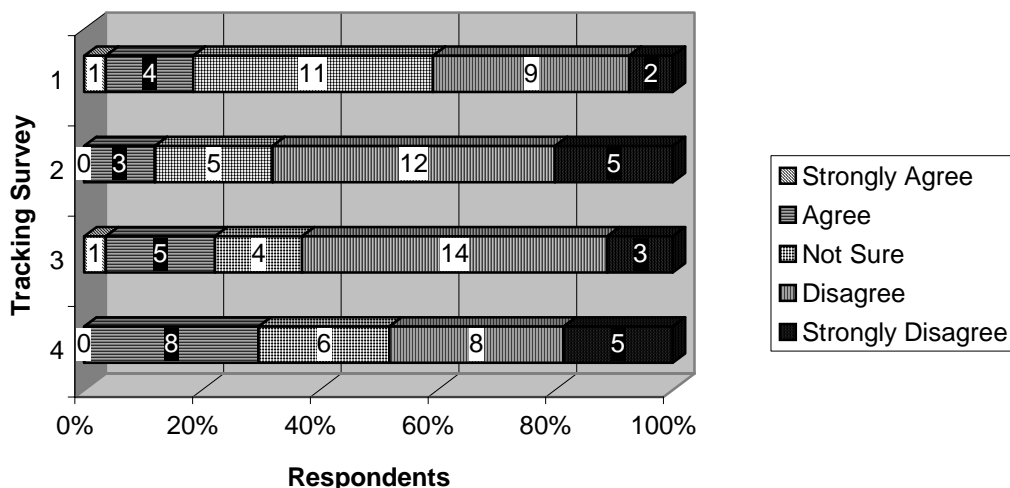
this question by the end of the three days and the split was fifty-fifty as to whether it was more important to save lives in immediate danger or improve the lives of those not in immediate danger.

When a doctor has to make a decision about using resources to treat a seriously ill patient in front of them, they must also consider how they will use their resources to treat all the other patients in the waiting room.



The answers to this question suggest that most of the Council believed, right from the start, that clinicians should make decisions about their resources based upon populations/groups and not just in individual cases in isolation. This feeling strengthened throughout the three days of the meeting, but peaked following the panel discussion, members of which included clinicians.

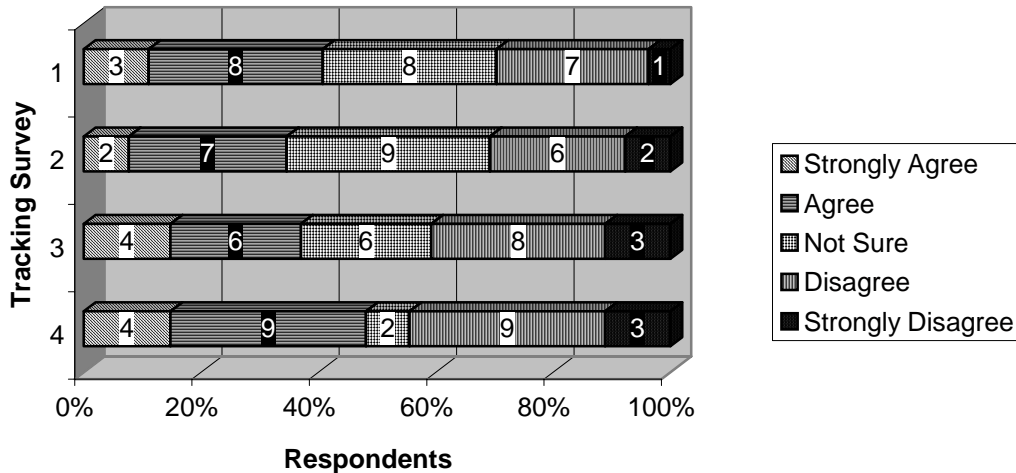
The NHS should spend whatever money it takes, to save, or at least prolong the lives of patients who are in immediate danger of dying.



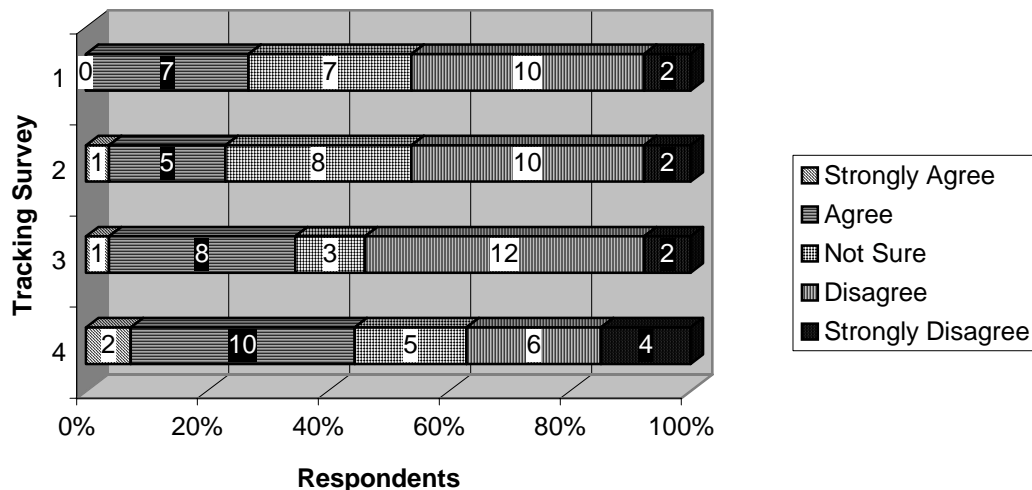
The Council were very split as to whether the NHS should not spend whatever it takes to save or prolong a person’s life that is in immediate danger. In tracking questionnaire 1 and 2, following the presentations from the speakers – clinicians as well as health economists - there was an increase in the feeling that the NHS should pay whatever it takes. Once the Council spent more time discussing the issues with each other in small groups and in plenary session, the number of those that thought the NHS should pay whatever it takes

increased slightly overall, but by the time the question was asked for the final time, so had the number of those that thought the NHS shouldn't.

It is more important to put resources into saving the life of someone who is in immediate danger of dying, rather than use them to save the lives of many people in the future through disease prevention programmes, (e.g. preventing high blood pressure).

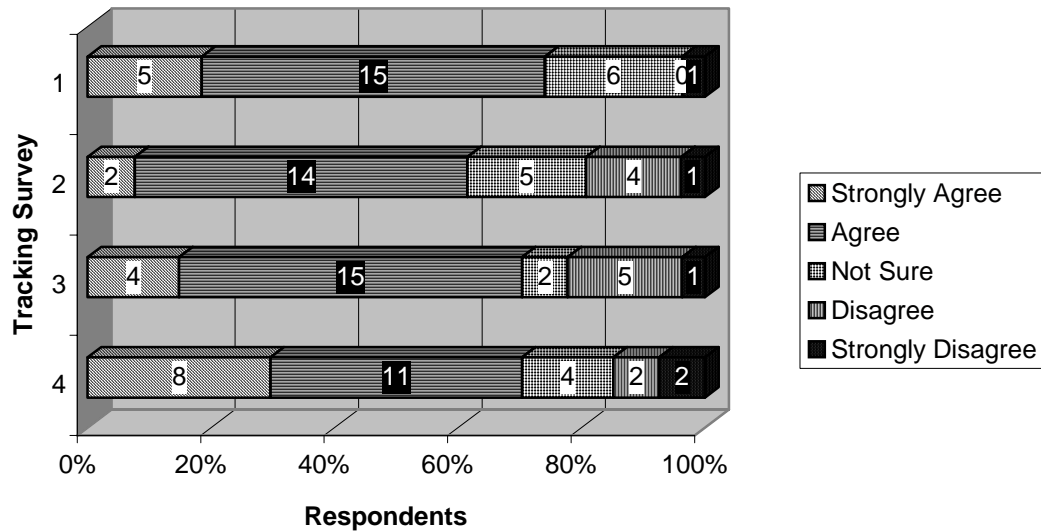


The NHS should spend money to save and / or prolong the lives of patients who are in immediate danger of dying, even if this means not funding measures that would prevent future ill-health and / or premature death.

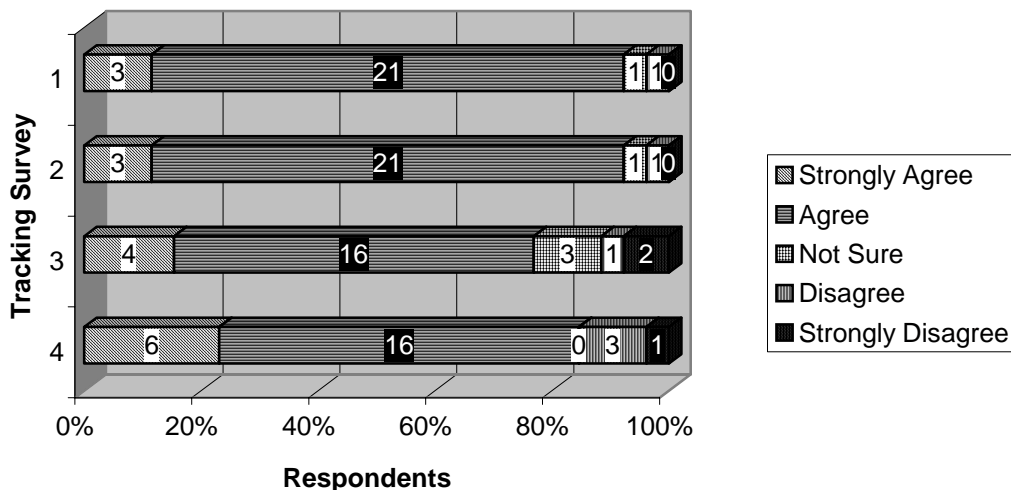


When answering the two questions above, the split was again very even by the end of the meeting as to whether it is better to put resources into saving lives in the short term rather than into long term preventative measures. Those who were unsure at the beginning divided fairly evenly into both camps. There were still a couple of Council members unsure by the end of the meeting. These results suggest that the Council feel that there is more merit in putting resources into situations that are more immediate than those long term measures whose effects are not seen as apparently.

Society has a moral obligation to give priority to saving the lives of individuals that it is aware of.

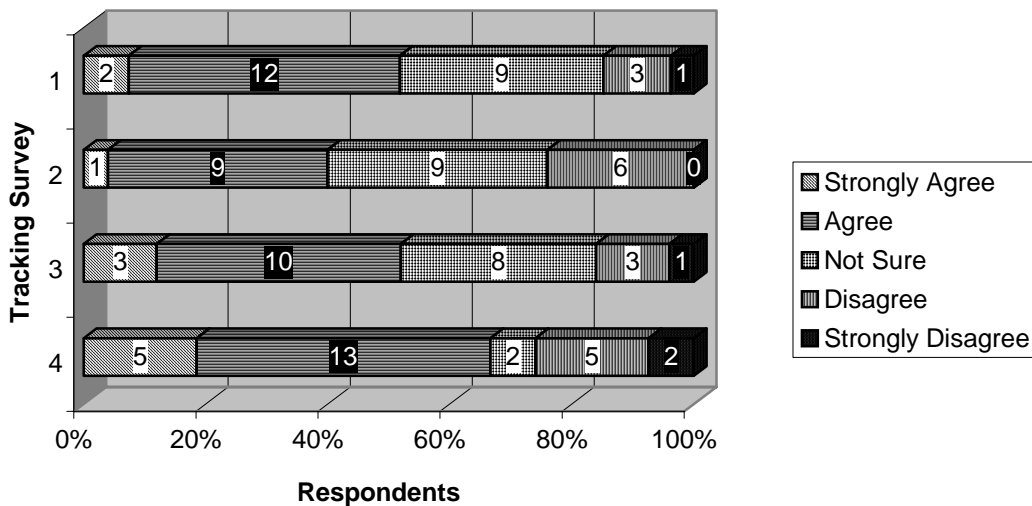


Society has a moral obligation to give priority to investing in the future health of the population.



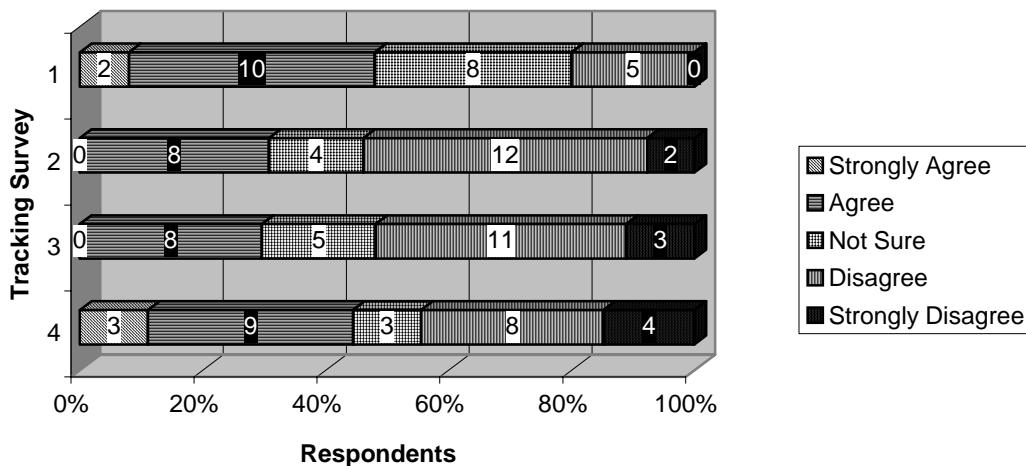
The results from these two questions suggest that the Council feel strongly that they have a moral obligation to save the lives of those they know to be in imminent danger of dying and this conviction stayed with the majority of people throughout the debate and discussions of the three days. However, there was an even stronger feeling that society is obliged to give priority to investing in the future health of the population. These two results do not necessarily sit perfectly together, but do illustrate the difficulty that the Council had in deciding whether a strictly utilitarian decision was always the morally correct one. The results here do correspond with the variation within the Council's conclusions. Most people believed that there must be room within the NHS for exceptional cases but that there needed to be strict criteria for judging these otherwise we would jeopardise the future health of the population.

Society gains positively from saving the lives of identified individuals.



There were a minority of Council members who felt that there was no gain to society from saving the lives of identifiable individuals. They held these beliefs throughout the Council meeting and were joined by a few others by the end of the meeting. Most of the Council members that weren't sure at the beginning, decided that there was an overall gain to society as a whole by the end of the meeting.

Rejecting the 'rule of rescue' means that patients with life threatening illness may receive lower priority when being treated.



This question shows that the Council were concerned about the application of the Rule of Rescue – would it be used on the front line, in individual cases or would it be just something that would influence strategic decision making? Following the discussions with speakers on the first day of the meeting, the number of people unsure about their answer to this question diminished but their views did shift to agreeing during the meeting that rejecting the Rule of Rescue may mean patients with a life threatening illness may receive lower priority when being treated, before ending up evenly split on the last day.

Appendix 4

Rationing and role play exercises

We carried out two simulation exercises, which helped to focus on some of the dilemmas health commissioners and other decision-making bodies face in prioritising treatment. Much of this fed through into the final responses to NICE's questions on the Rule of Rescue.

- *Rationing exercise*

In the rationing exercise we were divided into four groups, each of which was asked to carry out the same task of deciding which of four deserving cases should receive £4,000 in funding. We were not allowed to share the money out!

The four patients were:

Patient S. An 18-year-old car crash victim who required plastic surgery for severe facial scarring and psychological problems.

Patient M. A 65-year-old woman in need of a hip replacement that would allow her to live independently

Patient J. An HIV positive woman, 44 years old, who could receive drug treatment with a 75% chance of success

Patient D. A nine-year-old boy with cancer with a 50-50 chance of survival who could receive a new drug partially tested on a limited number of cancers.

There were heated arguments within each group over who would benefit most from the money. Issues of age, 'deservedness' and the emotive impact of some diseases were all discussed, as were the relative merits of such criteria as length of life, quality of life, effectiveness of treatment and immediate threat to life.

Those who were drawn to the need to save life above everything else tended to support patients J or D. Others tended to focus more on quality of life issues, noting that the life-saving interventions were not necessarily reliable. On the other hand, money could transform patient S's life and could make a very significant difference to that of patient M.

One of us said she had been helped in coming to her decision by focusing on what would have happened to the individuals in five years' time, with or without the treatment.

She also found it been useful to write down the pros and cons for each case. This had helped to test, and in some instances revise, her original gut instincts. 'You think you've got it all wrapped up but when you write them down and all the information is there, it does put a different perspective on it.'

Interestingly, a different patient was eventually prioritised by each of the groups. Even when asked to vote individually, the votes were fairly evenly divided with patients M and J receiving 8 each, patient S 6 and patient D 5.

One slight surprise was that patient D – for obvious reasons the most emotive though arguably the least likely to benefit – received fewest votes, largely it seems as a result of the process of debating the issues within the different groups. ‘This morning I would have chosen patient D,’ confessed one member. ‘But now my viewpoint has completely shifted.’ Another talked about battling between ‘my conscience’ (which favoured patient D) and the logic of the group’s discussion, which pointed toward patient S.

- *Role play exercises*

On the second morning we were divided into two groups, designed to simulate the process the NICE appraisal committee goes through in considering applications for approval for new treatments. One group was asked to decide on the merits of a new drug to treat acute sepsis, the other for a drug for motor neurone disease.

A. New drug for motor neurone disease

The drug Riluzole has the effect of delaying the need for a tracheotomy (the insertion of a tube into the windpipe just below the larynx) among MND patients by an average of 2 to 4 months at a cost of between £34,000 and £43,500 per QALY.

But, the group was told, the advantages for patients, who on average have only three years to live following diagnosis, are enormous. This drug gives them an extra few months’ independent living at a time when every extra day is precious. Moreover, some say they would rather be dead than have to be reliant on a tracheotomy.

Another consideration for the group was that the QALY assessment of patients’ quality of life before having a tracheotomy might be unduly low. Clearly if this was the case then the relative gain from being tracheotomy-free might be greater.

In reality the NICE committee evidently took many of these arguments into account in deciding to make an exceptional case of Riluzole and approve it for use in the NHS. The Citizens’ Council, however, was almost evenly divided on the issue.

For those in favour the strongest argument was that this would make a very significant difference to the quality of life of a group of patients who had little to hope for. Riluzole was not going to save life or even necessarily prolong it, but it would immensely enhance what was left.

‘At first I thought no, this is a pretty pointless treatment,’ said one of us. ‘But now I’ve totally changed my view and I would say yes absolutely.’

‘This is a horrible disease which is going to kill you. There’s nothing else that can be done for you, so for you that extra two months or so would be quite

significant and for the family, knowing that the NHS was doing everything possible in the face of that horror is philosophically important.’

Others felt the drug offered some hope given there were no other treatments available. It was also pointed out that the costs would be relatively low since the numbers affected were small. And, noted another member, the costs of the drug would be offset to some extent by savings in the nursing care involved in looking after someone with a tracheotomy.

However, those who were opposed felt this was money that could be spent in more evidently productive ways if diverted elsewhere. As one member noted, the consequence of spending this money on people needing hip replacements would be hundreds of people pain free and independent. In the case of the MND patients, they would be dead with or without the new drug.

We all wanted to help anyone in desperate circumstances, said another. But you had to be dispassionate. ‘We have got to have a way of comparing one disease with another and sadly QALYs is the best that we’ve got and we’ve got to stick with that measure. We haven’t got millions to throw at every condition.’

He also asked those who supported this as an exceptional case where would they draw the line. If they approved a drug with a cost per QALY of £35,000, would they set their limit at £50,000 or at £100,000? And if not, where would the limit be?

But at least two of those who backed the drug were unprepared to accept any upper limit. It was clear that the higher the cost, the stronger the case that would have to be made. But you could not stop it being considered in the first place simply because it would be very expensive.

B. New drug for sepsis

Members in this group were asked to decide whether to approve the use of Xigris, a new drug that can treat people with severe sepsis whose lives are in immediate danger.

They heard that the drug can cut mortality rates in patients affected by 6.5% as well as saving significantly on intensive care costs. It also promises a return to near normal quality of life for those who are successfully treated – although there are some safety concerns.

In fact NICE’s appraisal committee had little difficulty in deciding to approve the drug, on certain conditions, given that the cost per QALY worked out at around £11,000, well below NICE’s threshold.

However, when Citizens Council members were asked if they would still give approval if the cost per QALY was £30,000 – i.e. above the threshold – a big majority (10-3) voted in favour. Some indicated they would be prepared to approve it even if the costs went higher still because it met the central principle of the Rule of Rescue – that it saved life.

Asked what we would choose to disinvest in order to fund Xigris, we came up with several suggestions including IVF (because having babies is not essential for good health), endless resuscitation at either end of life – or even (a bit of a sleight of hand, this!) raising prescription charges.

However, most (11) agreed with the proposition that although life-saving should always be prioritised, the quality of life resulting from a particular treatment was also vital.

As one person said, receiving dialysis had saved his life but the quality of his life during those six months was appalling. It was only when he had a kidney transplant that he was able to lead a fulfilling life again. ‘Saving life on its own is irrelevant,’ he said. ‘You have got to go a lot deeper.’

Appendix 5

Presentations and speakers

The main presentations that the Citizens Council heard were:

Five differing perspectives on the Rule of Rescue

Dr Simon Lewis, Clinical Director and Dr David Bevan, Vice Chairman,
Magpas Emergency Medical Team
Sharon Swain, Brain and Spine Foundation
Dr Richard Smith, Senior Lecturer, School of Medicine, Health Policy and
Practice, University of East Anglia
Prof Alan Craft, President, Royal College of Paediatrics and Child Health
Dr Daphne Austin, Consultant in Public Health, West Midlands Specialised
Services Agency

Case Study – The Rationing Exercise

Dr Richard Smith, Senior Lecturer, School of Medicine, Health Policy and
Practice, University of East Anglia
Rob Williams, Chief Executive, BLISS, the premature baby charity

Role-play. NICE Technology Appraisal

Prof Parveen Kumar
Meindert Boysen, NICE
Louise Longworth, NICE

Biographies

Dr Daphne Austin BSc MBChB FFPHM

Dr Austin grew up in Nottingham and emigrated to New Zealand aged 18. She completed a science degree at Victoria University in Wellington followed by a medical degree at Otago University, Dunedin.

Her 5 years of clinical experience was largely hospital based, working as a junior doctor in a variety of specialties and hospital settings in both New Zealand and England.

Public health was Dr Austin's first chosen specialty and she entered the West Midlands Public Health Training Scheme in 1990. Since that time she has worked in the West Midlands region. She spent 7 years as a consultant in Worcestershire and now works as a consultant in public health with the West Midlands Specialised Services Agency. The Agency is an NHS organisation funded by the 30 primary care trusts of the West Midlands and is the most recent incarnation of a regional specialised services commissioning body, which has existed in the West Midlands since the late 1980s.

Dr Austin's work has primarily been focused on hospital care, and service configuration issues and specialised services in particular. She has regional expertise in the managed introduction of new technologies, priority setting and the management of complex cases.

She is currently working with a group of public health specialists and ethicists to more fully explore the how the rule of rescue fits into health care policy. This builds on the work which the West Midlands undertook, supported by Mark Sheehan, in 2003 on the Rule of Rescue.

Professor Sir Alan Craft

Professor Sir Alan Craft is the James Spence Professor of Child Health at the University of Newcastle upon Tyne. This is a large Department which provides teaching for 390 medical students each year and has a major research portfolio.

He trained as a paediatrician and a paediatric oncologist and spent 25 years setting up and directing an oncology service for the north of England. The management of bone tumours in young people has been a special clinical and research interest and he has been a leader of major studies both in the UK and across Europe. He was a founder member of the United Kingdom Children's Cancer Study Group (UKCCSG) and was its Secretary and Chairman. At an international level he has been involved with the International Paediatric Oncology Society as both Secretary General and President.

At a national level in the UK he has been Vice President and now President of the Royal College of Paediatrics and Child Health and also chairs the Academy of Medical Royal Colleges.

He has over 300 publications and has been a holder of major research grants.

In his spare time he does crosswords and runs half-marathons, but not simultaneously. His ambition is to run 100 half-marathons by the age of 60 and complete The Times and Daily Telegraph crosswords on the same day.

He received a knighthood from the Queen in 2004 for services to medicine.

David Bevan

David Bevan is a GP in Cambridgeshire and has been providing Immediate Medical Care as a member of Magpas since 1984. He is a current member of the Magpas Emergency Medical Team providing critical care across Cambridgeshire and Peterborough. He is also Vice Chair of the charity and Chair of the operational management group supporting Magpas operations.

In the recent past David has been executive Chair and Clinical Governance lead for a PCT and was clinical lead for choice policy Norfolk, Suffolk and Cambridgeshire StHA. He has a career-long interest in the provision of pre-hospital trauma systems.

Simon Lewis

Dr Simon Lewis is a Specialist Registrar in Emergency Medicine in Cambridge and Clinical Director of the Magpas Emergency Medical Team. He has long been interested in all aspects of Prehospital Care clinical provision and delivery, from Community First Responders to specialist critical care provision, to frameworks within which this can be optimally delivered.

Sharon Swain BA (Hons) PhD, Helpline and Project Officer, Brain and Spine Foundation

After graduating in psychology, Sharon Swain went on to research the cognitive functions of the prefrontal cortex at the Institute of Psychiatry, Kings College, London. Subsequently, Sharon has worked with adults with mental health problems, co-ordinating clinical trials into the effectiveness of computerised cognitive behaviour therapy for the treatment of anxiety and depression. As a result of this work, Sharon became interested in the management of chronic illness.

This interest has been developed at the Brain and Spine Foundation, both working on the Brain and Spine Helpline and as a project officer. Sharon is responsible for co-ordinating the Brain and Spine Foundations' response to the National Institute for Clinical Excellence (NICE) technology appraisals, guidelines on interventional procedures and clinical and service guidance. Sharon has explored the impact of GP and patient information on the management of neurological conditions. She also contributed to the development of the children's and young adults information and support services.

Richard Smith

Richard Smith is a Reader in Health Economics at the University of East Anglia's School of Medicine, Health Policy and Practice. Richard completed his undergraduate and postgraduate education in Economics and Health Economics at the University of York in 1991. Since then he has held positions in Sydney, Cambridge, Bristol and Melbourne, before joining UEA in June 1999. He is also an Honorary Professor in Health Economics at the University of Hong Kong.

Richard has published widely in both economic and medical journals, as well as various books, chapters and reports. His research interests and experience range extensively across many facets of health economics, including the economics of antimicrobial resistance, genomics and chronic illness, health care reform, including most recently aspects of Globalisation and trade in health services, and, of most relevance to the topic of 'rule of rescue', healthcare decision making, priority setting and health outcome assessment for economic evaluation, in money and non-money terms. In these latter respects, Richard is involved with the Universities of Newcastle and Aberdeen in a current DoH/NICE funded project looking at the 'societal value of a QALY'.

Richard has extensive worldwide collaborations, including colleagues at the WHO, UN and WTO, and Universities in Europe, North America, Australia and Asia. He has acted as a consultant to a number of national and international governments and organisations on topics concerning antimicrobial resistance, globalisation and health and health outcome assessment. He is also a member of the WHO External Scientific Resource Group on Globalization, Trade and Health, the WHO Human Genetics Programme, the Centre for Medical Genetics and Policy, University of Cambridge, the Global Biopolitics Research Group at UEA and is Director of the WHO Collaborating Centre on Globalization, Trade and the Macroeconomics of Health.

Rob Williams

Rob Williams joined BLISS as Chief Executive in August 2003. Prior to that he spent ten years working in international development including spells as Country Director for Concern Worldwide in Cambodia and Burundi and two years leading rapid response teams to conflict zones in Africa and Asia. As Concern's Operations Director in New York from 1999 to 2002 he was responsible for child survival programmes in several countries, achieving large reductions in maternal and infant mortality in poor urban and rural communities.

Rob graduated in law in 1986 and qualified as a Chartered Accountant with Ernst and Young before joining the voluntary sector.

Louise Longworth

Louise is a Health Technology Analyst in the Technology Appraisal Programme within NICE.

Meindert Boysen

Meindert is a Health Technology Analyst in the Technology Appraisal Programme within NICE.

Professor Parveen Kumar

CBE BSc MD(Lond) FRCP

Chairman MSc in Gastroenterology

Institute of Cell and Molecular Science, Queen Mary, University of London

Professor Kumar is not only a very experienced gastroenterologist, but also one of Britain's leading medical educators. She is Professor of Medical Education at Barts and The London and is highly appreciated as a teacher by students in the Medical School. She is the author of one of the world's most successful textbooks in medicine, with ML Clark, Clinical Medicine (fifth edition, WB Saunders, Edinburgh). Professor Kumar established the educational programme for the Royal College in which she introduced the Continuing Professional Development scheme and the Internet learning programme. She established the MSc course in 1992.

In addition Prof Kumar was a founding non executive Director of NICE, is the ex Vice President of the Royal College of Physicians, the ex Chair of the Medicines Commission, a non executive director of an acute hospital trust. Prof Kumar is a trustee of Cancer Bacup and the President elect of the BMA.

Appendix 6

Citizen Council Members

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.

Appendix 7

The Agenda

THURSDAY 26 JANUARY	
9.00-9.30am OPEN	<p>Introductions and warm up</p> <ul style="list-style-type: none"> • Facilitate introductions • Agree group working ground rules
9.30-10.30am OPEN	<p>Understanding the question & Council business</p> <p>Prof Sir Mike Rawlins Prof Peter Littlejohns</p> <ul style="list-style-type: none"> • Presentation: NICE to set the context • What NICE want by the end of the meeting • How NICE anticipate using the answers, including when and in which situations • NICE based examples: Council members understand in what context the rule of rescue applies • Discussion about what happened with the Public Health Report.
10.30-10.50am BREAK	
10.50-12.30pm OPEN	<p>Five differing perspectives on the Rule of Rescue</p> <p>Dr Simon Lewis, Clinical Director & Dr David Bevan, Vice Chairman, Magpas Emergency Medical Team</p> <p>Sharon Swain, Brain and Spine Foundation</p> <p>Dr Richard Smith, Senior Lecturer, School of Medicine, Health Policy and Practice, University of East Anglia</p> <p>Prof Alan Craft, President, Royal College of Paediatrics and Child Health</p> <p>Dr Daphne Austin, Consultant in Public Health, West Midlands Specialised Services Agency</p>
12.30-1.30pm LUNCH	
1.30-4.00pm (with break included) CLOSED	<p>Case Study – The Rationing Exercise</p> <p>Dr Richard Smith, Senior Lecturer, School of Medicine, Health Policy and Practice, University of East Anglia</p> <p>Rob Williams, Chief Executive, BLISS, the premature baby charity</p>
4.00-5.00pm CLOSED	<p>Plenary Discussions</p> <p>What are your thoughts so far?</p>
7.30pm	Dinner Holiday Inn Bloomsbury

FRIDAY 27 JANUARY	
9.00-9.30am CLOSED	Recap from previous day.
9.30-1.30pm (with break included) CLOSED	Role-play. NICE Technology Appraisal Prof Parveen Kumar Meindert Boysen, NICE Louise Longworth, NICE
1.30-2.30pm LUNCH	
2.30-5.00pm CLOSED	Open Space Individual reflection time
7.30pm	Dinner Holiday Inn Bloomsbury

SATURDAY 28 JANUARY	
9.30 – 1.00pm CLOSED	Agree the content of the report Clarify next steps, housekeeping and how the report will be produced
1.00 – 1.30pm CLOSED	Close Prof Peter Littlejohns
1.30 – 2.00pm LUNCH	