What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?

Citizens Council
Meeting report: 8-9 May 2014
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Message from the Chair of NICE

It is my great pleasure to introduce the report from the 2014 NICE Citizens Council meeting.

The Citizens Council is a group of thirty members of the British public, who reflect the diversity of our society. Every year, the Council provides us with advice on challenging social and moral issues that come up during the development of NICE’s quality standards and guidance. For example, previous Citizens Council meetings have explored questions such as whether age should be a factor in access to treatment or whether self-inflicted illness should be given reduced priority. Woven through each of these is a common question about how we reach appropriate balances between the competing demands of ensuring we get as much as we can from limited public funds (efficiency) whilst also ensuring there is fair distribution (equity).

This year, we asked the Citizens Council to explore the efficiency versus equity debate further so we could get insights into the public’s view of how resources should be distributed. We wanted to know their overall thoughts on the issue and identify the range of societal values that underpin judgements about what appropriate balances of equity and efficiency look like.

NICE’s remit has grown over the years, from our initial focus on health care to the addition of public health and more recently social care, so we were especially keen to find out whether the Citizens Council felt the same societal values were important across all three areas of our work or where there might be differences. We were also interested to know the Council’s views on any ‘special circumstances’ when we should place a particular emphasis on achieving either equity or efficiency.

In May 2014, Council members spent two days listening to expert speakers and deliberating these issues. This report provides an account of their discussion and the conclusions they reached. As in previous years, it has been written independently on behalf of the Citizens Council, expressing the opinions of its members, with the purpose of offering NICE a window of insight into the breadth and depth of views held by the UK population.

This report will now be presented to the NICE Board so that my colleagues and I can together consider the Citizens Council’s conclusions and discuss how the findings might help shape the work of NICE going forward.

On behalf of NICE, I would like to thank the Citizens Council members both for their time and for the energy with which they interrogated the topic we gave them. The Citizens Council is an invaluable part of NICE’s fabric and this report will be very helpful in developing our understanding about how best to make judgements of social value when producing our guidance.

Professor David Haslam CBE - Chair, NICE
Foreword

The Citizens Council has done a fantastic job of examining the question and debating the ways in which societal values impact on decisions that are ultimately about balancing equity and efficiency. We set a tough challenge in asking the Council to respond to a question that is largely deliberated in academic circles, but they embraced the topic with their usual enthusiasm and have produced a comprehensive set of conclusions.

Interestingly, some of the values identified by the Council are not values in a technical sense, but are broad constructs — for example, ‘education’ and ‘family values’ — that symbolise other broader values that are of importance when considering how to distribute national resources. Further work is required to unpick these and establish how they interact with those values that are more specific to health and social care, with the aim of identifying how these values can be incorporated into NICE’s activities. For example, the value of ‘education’ might be reflected in the importance of explaining the reasons for decisions and supporting implementation. There is also similarity between some of the Council’s values — for example, ‘freedom/liberty’ and ‘independence’ — and so we must consider whether and how they are distinctly different or whether they are really the same value just described using different words.

The big question now is: ‘so what next?’ In choosing the topic for this year’s Citizens Council meeting, we wanted to ask a question that would support our current work to update a key NICE document titled ‘Social Value Judgements: principles for the development of NICE guidance’. This document describes the principles, drawn from societal values, which NICE advisory bodies should apply when developing their recommendations and making decisions about the effectiveness and cost effectiveness of interventions.

This report from the 2014 meeting of the Citizens Council therefore provides a very timely input into the update process. However, the particular strength in its conclusions is that they are described in Council members’ own words, rather than the ‘official’ terminology of academics and others with expertise in societal values. This will be invaluable for ensuring that NICE’s future discussions of societal values can be described in ways that feel relevant to the real world. It will also enable us to ensure that any development of our processes and methodology has those values at the core.

Going forward, the updated Social Value Judgements document will need to take into account NICE’s growing remit and a significant consideration in this is whether or not a single set of principles can appropriately guide our work across all three main areas of our work: public health, social care and health care. The Council’s views on the similarities and differences between these three areas
in terms of societal values will support this reflection, as will their discussions about the ‘special circumstances’ they felt required a greater emphasis on either equity or efficiency. It is interesting to see that in considering what might constitute special circumstances, members touched on topics of previous Citizens Council meetings such as whether age or self-induced illness should be a factor in decisions about eligibility for services.

I would like to thank the Citizens Council members who dedicated their time and contributed their views to the two day meeting and this report. They have provided NICE with important and useful insight which will without doubt help shape the updated Social Value Judgements document as we prepare a draft for public consultation later this year.

Professor Sarah Garner - Associate Director, Research and Development, NICE
About the Citizens Council

What is the Citizens Council?
The Citizens Council is a panel of thirty members of the public that largely reflect the demographic characteristics of the UK. Council members serve for up to three years.

What is the role of the Citizens Council?
The Citizens Council provides the National Institute for Health and Care Excellence (NICE) with a public perspective on overarching moral and ethical issues that NICE and its advisory bodies have to take account of when producing guidance. As members of the Council, our recommendations and conclusions are incorporated into a document called Social Value Judgements and, where appropriate, into NICE's methodology.

The Citizens Council does not produce NICE's guidance (such as for health, local government or social care services), nor does it input directly into any individual pieces of guidance that NICE produces. There are other mechanisms NICE uses for incorporating the views of patients and the public into these aspects of NICE's work.

How does the council operate?
We meet for two days at a time and our discussions are arranged and run by independent expert facilitators. The meetings are open to public observers. During the meetings, Council members listen to different views from experts on a topic and undertake exercises which allow us to examine the issues in detail and discuss our own views. Our views and conclusions are captured by an independent writer and the report is circulated for our comment and amendment before it is finalised. After a meeting, the report is made available for public comment. A summary of these comments along with the report are then presented to NICE's Board for discussion.

How are topics chosen?
Potential topics usually arise during the guidance development process from points considered by NICE's advisory bodies as they explore issues that require value judgements to be made. They can also arise when there are changes to the setting that NICE operates in, such as government policy.

Please note:
The views expressed in the report, including all quotations, are those of the Citizens Council members; they do not represent the views of NICE.
Executive summary

In May 2014, the Citizens Council met for two days to discuss the question of

What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?

During the two day meeting, we looked in depth at this question. We spent a lot of time unpicking the question and discussing what equity, efficiency and societal values mean to us, both as individuals and as a society. We started by defining our understanding of what constitutes a ‘good society’ and the societal values which underpin it. We considered ‘societal values’ as a term and whether it was the right terminology at all — could we relate to it? We voted on whether we preferred the terms ‘social values’, ‘societal values’ or ‘public values’. None of us chose ‘public values’ and, although some of us felt that ‘social values’ was easier to understand as it was jargon-free, we agreed the best term was ‘societal values’ as it states “how we function as a society and what message our behaviour sends out to society”.

With the help of experts in the fields of public health, social care and health care, we then looked in depth at a series of case studies to examine how different societal values of our ‘good society’ should be involved in making real life decisions about the provision of care. We then looked at the differences and similarities between public health, social care and health care and also discussed any ‘special circumstances’ where we considered there is a need for greater emphasis on either equity or efficiency. We also discussed whether some key values, such as ‘dignity’ and ‘humanity’ should always be taken into account no matter which area or what the circumstances are.

None of the case studies we looked at had clear right or wrong answers and we found that the discussions we had often involved competing arguments. For example, there were differing opinions in how important the ‘right to die’ should be or if ‘the right to life’ incorporated everything we were trying to say regarding the right to die. As Council members, we understand that we represent the wider views of UK society and that there are a range of opinions because of the diversity of our population; there are no straightforward answers to the question we met to discuss.

However, the important elements of the meeting were in the discussions we had and the journey we went on to understand and answer the meeting question. Many Council members shared personal stories which resonated with other members and the speakers. While all of us are very knowledgeable about our own situations and often the situations of those closest to us, having this arena to share our views and learn from others is a key part of being Council members. This meeting gave us the freedom to phrase things in our own way.
At the end of the meeting we created a list of key societal values that we thought should be considered across public health, social care and health care. We felt that these values should underpin all three areas of public health, social care and health care, not just when looking at trade-offs between equity and efficiency but as guiding principles for all of NICE’s work. However, we felt that, depending on the situation, some of these are more pertinent than others. ‘Safeguarding the vulnerable’ was seen as a vital societal value as many people can’t speak for themselves. There were also other societal values that weren’t in our top fifteen, but that we felt deserved being taken into consideration in particular areas of care and these are shown below in purple.

Although we found it difficult to define how they should influence the trade-offs between equity and efficiency when making decisions, we hope we have provided insights to form the basis for further exploration by NICE.

**Key societal values to be considered across public health, social care and health care:**

- Accountability
- Collective responsibility
- Dignity
- Education
- Fairness
- Honesty
- Humanity
- Individual rights
- Justice
- Maximising total benefit/benefit for most/utilitarianism
- Quality of life
- Respect
- Right to health and welfare for all
- Safeguarding the vulnerable
- Value/quality of service
Prioritised values from our social care discussions:

- Dignity
- Right to health and welfare for all
- Value/quality of service
- Maximising total benefit/benefit for most/utilitarianism
- Safeguarding the vulnerable
- Consequentialism
- Freedom/liberty
- Being non-judgemental

Prioritised values from our public health discussions:

- Accountability
- Collective responsibility
- Education
- Individual rights
- Maximising total benefit/benefit for most/utilitarianism
- Safeguarding the vulnerable
- Consequentialism
- Freedom/liberty
- Respect for the majority/democracy

Prioritised values from our health care discussions:

- Humanity
- Justice
- Respect
- Compromise

- Realism
- Empathy
- Being non-judgemental
Two themes emerged during the two day meeting as we developed our discussions of factors affecting decisions about trade-offs between equity and efficiency. The theme of ‘good communication’ came up throughout our discussions, in the context of how societal values are felt and experienced when the reasoning behind decisions is not effectively communicated. A lack of good communication could lead to patients or service users feeling that the decision did not match up with their expected values and not feel ‘fair’. The tension between ‘individual rights’ and wider society was also a recurrent theme and we often found it difficult to find a balance between the two, for example how the individual right to drink alcohol can create problems for society and what should constitute “the greater good” in that situation.

We also discussed some ‘special circumstances’ where we considered there is a need for greater emphasis on either equity or efficiency. We did not all agree on these circumstances but feel it is important to include all of them here so that all of our views are represented.

**Special circumstances where greater emphasis on efficiency is needed:**

- Non-essential cosmetic surgery

**Special circumstances where greater emphasis on equity is needed:**

- Public health intervention in times of epidemic or natural disaster
- Social care services for children
- Social care services for people with autism

**Circumstances where the tensions between equity and efficiency were difficult to unpick:**

- Considerations of age in health care
- Treatment for non-UK residents
- Treatment for ‘self-inflicted’ alcohol and drug abuse
Introduction

What NICE does

NICE provides national guidance and advice to improve health and social care. Formed in 1999 as the National Institute for Clinical Excellence, it aimed to reduce variation in the availability and quality of NHS treatments and care. In 2005, the newly named National Institute for Health and Clinical Excellence also took on a remit to develop public health guidance and advice and, since 2013 and the start of the Health and Social Care Act (2012), the organisation has a remit for producing social care guidance. The Institute was therefore renamed the National Institute for Health and Care Excellence.

The question we were asked

NICE asked the Council to look at the question of:

What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?

At the start of the meeting, we learned that NICE often faces decisions where it has to find the ‘acceptable’ balance between equity and efficiency. What that acceptable balance is can be different depending on the circumstances. Understanding the values of our society, in other words ‘societal values’, will help NICE make judgements about what the most acceptable balance is. Although we often came up with more questions than answers, our views on the question will provide NICE with insight into what values are important to the public and inform its guiding principles for producing public health, social care and health care guidance.

How we worked on this question

We worked through the question in a structured way through the two days. Our meeting objectives were:

- to identify and explore the societal values that should underpin NICE’s work and why they are important;
- to reflect on and discuss equity and efficiency trade-offs in public health, social care and health care, with a view to exploring the similarities and differences in these three areas;
- to record any specific instances that justify a much greater emphasis being placed on achieving either equity or efficiency.
We listened to and worked with five expert speakers who helped us to think through different aspects of the question. First, Sarah Garner helped us to cement our understanding of the terms equity and efficiency, and Catherine Max helped us to identify the key societal values that underpin our vision of a good society. We were then presented with information about three broad areas of NICE’s work: public health with Mike Kelly; social care with Mercy Jeyasingham; and health care with Paddy Storrie. Working in groups, we examined a number of case studies that represented real-life situations where decisions about equity and efficiency had to be made. The case studies included newspaper articles, recent data/facts and figures, acted scenarios and character interviews. We concluded the meeting with a final session of group work to draw comparisons between the different areas of public health, social care and health care and to identify any ‘special circumstances’ in which we felt more emphasis should be placed on achieving either efficiency or equity.

"[Over the next two days] I'm looking forward to listening to the views of interesting speakers and being able to voice our opinions."
Understanding the question

David Haslam CBE, Chair, NICE, welcomed us to the meeting. He spoke about how much NICE is in the news on a daily basis and, with millions of GP consultations every year, it is no wonder that its guidelines come up in the media regularly. David explained that stories in the media that raise questions about ‘doing the right thing’ highlight how absolutely essential it is that NICE takes note of ethical issues at every level of its work. David emphasised how important the work of the Citizens Council is to this process and told us that the NICE Board received last year’s meeting report and welcomed our recommendations. He explained the importance of transparency to NICE and how the organisation routinely involves patients and the public. With David Haslam’s opening presentation, we felt not only welcomed but also that what we were about to undertake over the two day meeting would really count in terms of how NICE works — in other words, our voice matters.

"The input that 'Joe Public' does make into the meetings does matter, they do take notice of it so I feel it is worthwhile."

Sarah Garner, Associate Director of Research and Development at NICE, wanted to make sure we all understood why we were there and what NICE does. We had all read through the briefing paper and generally understood what the areas of public health, social care and health care meant and how NICE works. Sarah pointed out that NICE makes a lot of decisions for the public and that our opinions are necessary to put into context all the evidence, research and studies that NICE looks at. She explained that there were no right or wrong answers to the question; she was interested in our range of experience, views and insights.

Sarah told us that, at previous Citizens Council meetings, the members had been given definitions of specific societal values and asked to explore how they related to a particular issue of concern for NICE. Often these arose from occasions when NICE was faced with making decisions that required striking a balance between equity and efficiency. However, for this 2014 meeting, NICE wanted to ask us to consider equity and efficiency balances as a general concept, so that we could define the underpinning societal values in our own terms. To demonstrate an example of where a trade-off between efficiency and equity would be inherent in making decisions, she gave us the example of how much it costs to support a premature baby; society would not even question the very high cost versus the implicit humanity of helping that baby to live. By understanding what we think about
societal values and the balancing act between equity and efficiency in decision making, NICE can make sure its guidance reflects our common values. She also noted that, as NICE now covers public health, social care and health care, it is interested in our views about whether the same set of societal values can be used for all three areas or whether some values have more relevance to a particular area. The Council could help NICE figure this out by starting with ‘an open book’ — deciding for ourselves what societal values mean to each of us.

**Equity and efficiency**

Although we had been briefed on the question before the meeting, just thinking about what the words ‘equity’ and ‘efficiency’ actually mean to us produced a lot of questions for this first session. We split into small groups and noted down all the key words and phrases that meant ‘equity’ and ‘efficiency’ to us.
What does **equity** mean to you?

- "ethical justice"
- "equally divided"
- "money is distributed fairly on a budget"
- "evenly distributed"
- "fair"
- "value for money"
- "providing the best service with little wastage"
- "equality irrespective of cost or resources available"
- "fair"
- "equal amounts of resources"
- "need over cost"
- "spreading investment across widest spectrum"
- "fairness and consideration of all needs equally"
- "equality in resources"
- "fairness and consideration of all needs equally"
- "equality in resources"
- "error

Sarah Garner then went on to talk through her understanding of the **key terms** of efficiency and equity.

**Efficiency**

Getting the most from the resources you have so every pound spent goes further and gets more ‘bang for your buck’.

**Equity**

Distributing wealth and resources fairly to everyone but this may mean that less is achieved overall.
Sarah pointed out that a focus on efficiency could mean some people experience greater disadvantage than others, for example, a direct train from Glasgow to London would be fast and transport people quickly but people from other towns would not be able to get on the train. However, equity can also disadvantage some people. With the train example, we could see that a train that stops in every town means that everyone can get on but it would be slow because of the frequent stops and may disadvantage some people by making them late or mean that the train is not used. She also introduced the issue of how difficult it was to define what is ‘fair’ and how to determine ‘need’.

Sarah reflected that, as a Council, we had already identified common words that meant equity and efficiency: for equity, we all talked about justice, fairness and equality; for efficiency, we all talked about stopping wastage and getting the most out of the money available. Those common words provided the cornerstone for our understanding of the overarching question of which societal values should be discussed when looking at issues of equity and efficiency.

In small groups, we looked at a simple family scenario, unrelated to NICE’s work, in which the eldest of three daughters wants to go on a school trip to help with her Geography A Level coursework. With not enough money for trips for all three girls, and other financial demands within the household, the parents have to decide on the right course of action. We looked at what would be an efficient decision, an equitable decision, and how we would balance efficiency and equity in order to make that decision in real life. Although this looked like a simple scenario, our groups realised that there would be a lot to take into account when making our decision, for example, ways of reducing the cost, the importance of the trip to the daughter’s coursework, achieving the learning in other less expensive ways, finding a way to increase the funds available and deciding on the ‘fairness’ of the trip; in other words, if the other two daughters also wanted the same trip in the future, would the funds be available? Although we did not reach an overall decision, this scenario enabled us to be explicit about what is taken into account in the background when any decision is made, how this particular decision can be shown to be an example of equity and efficiency trade-offs and how each of us varied in how we approached it. In such circumstances, it is never as simple as just making one quick decision.

We then went on to look at a health related scenario set in the fictional country of Fictopia. A new treatment could restore lost eyesight but the treatment is very expensive and is not permanent. Fictopia is a small country with a limited annual health budget but, unlike the UK, patients can directly
purchase treatment if it is not available from the Fictopian health service. Our groups were split to look at different decisions: two groups looked at equity with no regard to efficiency; two groups looked at efficiency with no regard to equity; and the final group had to look at achieving a balance between equity and efficiency.

This scenario tested our mathematical skills as well as our own ideas about what was fair and what was efficient. We all talked about how to judge who should have the treatment and discussed the possibility of means-testing the affected population so that those who could afford it could pay for the treatment themselves. This proposal was controversial. Also, we considered the possibility of putting a cap on how many treatments a patient could receive within a certain amount of time as the treatment was not permanent. The group which was looking to achieve balance felt that it was not right to treat the eyesight of those with only partial sight impairment as they could be treated in other ways, for example, with corrective glasses. We felt we could not find a perfect balance, just a solution that would help the most severely affected.

What we value and why: the ‘good society’

The first two group exercises helped us understand the terms equity and efficiency but we still needed to think about what societal values mean. Catherine Max led us through a series of exercises to help us achieve this. Catherine is an independent consultant who works across health and social care, in policy and service improvements. She is also a former Associate of Ethox, a multidisciplinary bioethics research centre in Oxford. Catherine wanted us to think about values in the broadest sense, explaining that there were no wrong answers and that our ideas might change over the course of the workshop, let alone the course of our lives. She gave us a few definitions of values as a starting point:

**Values**

- A value is a belief that something is good and worthwhile.
- Values may be defined as measures of goodness and desirability.
- Societal values are collective beliefs that operate as guiding principles.
- Values are concepts or beliefs that transcend particular situations.

Using these definitions as a starting point, Catherine asked us to develop our creativity and think about values further by getting us all drawing. In our small groups, we drew what we thought of as ‘a good society’ — what it would look like, what it would consist of and the start of what we felt that society would hold as values.
From our ‘good society’ drawings, Catherine asked us to think about the values that underpin that society. In fact, many of the characteristics of the ‘good society’ we had drawn were themselves values. Using a combination of blank cards and pre-written suggestions, we worked through what we saw as values for our ‘good society’ — this provoked a lot of debate. In our groups, we talked about the idea of utopia and how we’d like to see all the values ‘in a perfect world’. We also discussed how ‘collective responsibility’ has changed over time — that ‘fifty years ago, you could walk out your door and leave it open’ but that people no longer looked out for each other’s welfare and how, ‘if everyone’s being responsible, you wouldn’t need a professional authority’ overseeing everyone, such as the police and government. We all came up with a large amount of values so we prioritised our personal top three. Catherine stressed this did not mean that the other values were not important as well. We then reflected back in pairs on one of our prioritised values and whether they were values for just us personally or for everyone as a whole society.

What we value and why: from individual to societal values

In order for us to differentiate individual values (those that we have ourselves and drive our personal conduct) from societal values (those that underpin how a society operates and are shared by members of that society), each group separated their value cards to reflect what is important to us as individuals and which values are shared. It became clear that there can be a lot of overlap between these two categories, and we debated such issues as: ‘merit/just deserts’ and whose place it might be to judge who is deserving of reward or particular treatment; whether ‘freedom’ and ‘autonomy’ are values of a good society as well as valued by individuals. We also discussed how ‘safeguarding the vulnerable’ related to other values, for example ‘compassion’.

We then put together our societal value cards to create a full list and discussed some of our choices, including any we had not expected to see. We talked through any new values that Council members had added using the blank cards, for example, ‘community leadership’, explaining this meant making sure communities stayed together by building resilience and empowering them as a means of creating ‘bottom-up leadership’. Group members also clarified a further two examples: ‘promoting education’, meaning ensuring that everyone has a good standard of education and ensuring
that education is encouraged in home life, and ‘the right to death’ meaning ‘being allowed to die if you want to’. Both of these values were debated as to who they affected and why, as well as where responsibility should sit (with the individual, society or the state/public services). We then reviewed the master list as a whole and, again, prioritised the values we felt were most important to each of us. Catherine encouraged us to talk through some of our most prioritised values. At this stage, the prioritised values were ‘community spirit’, ‘dignity’, ‘diversity’, ‘family/family values’, ‘honesty’, ‘integrity’, ‘justice’, ‘non-discrimination’, ‘education/promote education’, ‘quality of life’ and ‘trust’. Throughout the rest of the meeting, the master list that included these prioritised values then formed the foundation of our explorations of trade-offs of equity and efficiency in real life.

“To me, family is everything and, once you have kids, you realise all the trouble you caused your parents.”
Exploring real life trade-offs and societal values

Having created our master list of societal values and unpicked the original question so that we all fully understood it, we needed to look at how the question related to different areas of care. We heard from expert speakers and discussed case studies that helped us to understand the real life decisions and consequences when looking at equity and efficiency, as well as which societal values are needed when making decisions about provisions of care.

Public health

Mike Kelly is the Director of the Centre for Public Health at NICE and he gave us a quick guide to public health. He talked about the cholera outbreak of 1854 which affected everyone in London. At the time, there were some people who were opposed to government attempts to finding a solution because they considered they were being "bullied into health". Mike explained how Joseph Bazalgette created a series of public sewers that saved the population of London and established water systems as a concern of public health. By the end of the 19th Century, doctors were starting to understand the risks of infection and epidemics. Mike went on to highlight the availability of fatty foods, cheap alcohol and tobacco as the modern equivalents of cholera, in other words, that public health today is concerned not just with disease but also how we live our lives. The statistics he presented were very stark:

- Tobacco use costs the NHS an estimated £2.7 billion every year.
- Treatment for health problems related to being overweight or obese costs an estimated £4.2 billion every year.
- Physical inactivity costs the NHS an estimated £1.06 billion every year.
- Treating chronic or acute effects of alcohol misuse is estimated to cost up to £1.7 billion per year.

He explained that, with the public health objectives of disease prevention, health protection and health promotion, there have been some successes, such as improved infant health and overall increased life expectancy. But, there are inequalities that have remained consistent over the years and this is called the 'health gradient'. The gradient shows that, even as life expectancy has risen overall, the state of health of people from a lower socio-economic status (such as people from areas of high deprivation and who are in manual labour industries) has always remained lower than those of a higher socio-economic status (such as people in professional industries). An example of this is
the number of people dying from smoking related diseases each year, the highest proportion of which being those from a lower socio-economic status.

Mike asked us to think about this health gradient: should we be thinking about allocating resources in a way that shifts the gradient so that people from a lower socio-economic status could live as long as people from a higher socio-economic status? Or should provision be made to improve the life expectancy for everyone, regardless of status? In new groups, we explored the trade-offs between equity and efficiency and the societal values involved in public health. We discussed the societal value of ‘utilitarianism’ and how someone’s utility is always someone else’s disutility, for example minimum alcohol pricing to improve health would affect the drinks industry, pubs and supermarkets in a negative way and could then affect the people employed by those industries.

**Utilitarianism**

The idea that the best course of action is the one that achieves the greatest total amount of benefit (also known as utility) for the greatest possible number of people.

Mike then asked us to think about equity and efficiency in relation to smoking and alcohol. We looked at graphs that showed smoking and alcohol sales in the UK and the USA over the last century, as well as bar charts that showed cigarette smoking by socio-economic status in both countries. We discussed how trends in alcohol and smoking in the UK and USA have changed over the past fifty years, the cost effectiveness of smoking cessation interventions, and whether the interventions that have been used so far are equitable or not.

We talked about ‘binge drinking’ (in other words, drinking to excess in short periods of time) and the effects it has on wider society as well as how government policies affect individuals and the wider society. We also discussed how smoking and alcohol go together for many people and how the wider issue of job satisfaction can affect smoking rates, for example, people who are not happy in their jobs may relish the opportunity for smoking breaks. We talked about e-cigarettes and how some people have used them to stop smoking but we also noted that their long term effects were still unknown. We asked about how much revenue the government receives through taxes on tobacco and discussed the impact that reducing smoking rates might have on this. Mike also pointed out that the major tobacco companies now own most of the e-cigarette companies and we are seeing a return to the type of glamourised marketing reflective of tobacco marketing several decades ago. He concluded that public health is often about competing values and the ‘moral maze’ of whose values trumps whose, for example, does ‘freedom of choice’ mean a rise in binge drinking and therefore more Accident and Emergency (A&E) admissions and endangering others through violence?
After exploring public health with Mike, we worked in small groups to discuss the societal values that needed to be considered when making decisions about this area of care. We recognised the biggest tension arose from where individual rights affected the wider society. It is difficult to achieve a balance of ‘respect for individual rights’ with ‘the greater good’. This led to us discussing the importance of people understanding that their actions may have consequences for society as a whole, which we found out was termed ‘consequentialism’. This was discussed with regard to smoking and how it can affect the health of those around the smoker, such as children when a parent is a smoker.

**Consequentialism**

The idea that behaviour or decisions are considered ‘right’ or ‘wrong’ depending on the results they bring. The more good that results from a behaviour or decision, the more ‘right’ it is considered to be.

We also talked about the consequences of binge drinking and how violence brought on by drinking can affect all of society, from partners and families to bystanders on the street to how busy the emergency services become at weekends. However, we also noted that some activities, such as drinking in pubs and having smoke breaks at work, could create ‘social inclusion’ and good ‘quality of life’ for people. We felt that people should have the right to choose how they live their lives, with ‘liberty/freedom’ needing to be considered but with a proviso that people’s individual freedom and choices should not cause harm for others. Regarding public health, we could see how much individual choices could affect society as a whole so that ‘liberty/freedom’ would always need to be carefully weighed up against ‘respect for the majority’ so that the wider society does not suffer as a whole.

**Social care**

Day two began with Mercy Jeyasingham talking to us about social care. Mercy is a health and social care consultant who works in patient
advocacy and with charities. She has worked with social services, setting up care standards across the UK and, as a carer for her deaf and blind mother, Mercy is also herself a user of social care. Mercy asked us what we thought social care was and we gave quite varied answers including protecting the vulnerable, care in the community, looking after children in care, and supporting people with non-medical care (such as shopping or taking someone out to get their hair cut). Mercy agreed that the definition of social care is very broad as it covers many types of service, but she gave a definition of social care as:

*The provision of social work, personal care, protection or social support services to children or adults in need or at risk, or adults with needs arising from illness, disability, old age or poverty.*

Users of social care include older people; children, young people and families; people who have mental health problems; and people who have physical or learning disabilities. Social care services also provide support to the families and carers of social care service users.

Mercy told us that social care can be funded by Local Authorities, the government, charities and people paying for their own care. Social care services are provided by Local Authorities, charities and the voluntary/not for profit sector as well as private companies. Private companies may provide services independently, such as care homes, or they may be contracted out by Local Authorities. Service users can also pay for private company services or use a combination of state provided funding and private finances. Social care is an area that quite a few Council members have personal experience of and we shared our stories. Mercy highlighted how values might underpin social care activities, for example, getting older people out of their homes for a regular bingo club or fish and chips night meant they were no longer isolated, so ‘social inclusion’ was a factor, and the activity helped cut down on depression and dementia, incorporating ‘dignity’ and feelings of ‘freedom/liberty’ and ‘independence’.

Mercy explained that although services such as housing, welfare benefits and criminal justice do not form part of social care, there can be a lot of overlap between these areas. For example, a person with learning disabilities may need social care support, such as a care worker, to access housing and benefit services, and there are examples of social care projects helping to lower the rates of women going back into prison by supporting them when they are first released.

In small groups, we looked at three different real life social care situations described in newspaper and online news articles. Mercy asked us to consider:

- What are the equity issues?
- What are the efficiency issues?
- What are the societal values being traded off in each situation?
Budget cuts and adult social care eligibility criteria

The first article looked at a Local Authority that was revising its eligibility criteria for adult social care in light of budget cuts and financial pressures. The article reported that, under the new arrangements, anyone assessed as having a ‘high-moderate’ need would no longer be eligible for social care funding. It explained that those with greater than high-moderate needs, in other words those assessed as having critical or substantial needs, would still receive funding. The article included quotes from an advocacy support worker and service users, expressing concern that changing the criteria would lead to a crisis situation for those currently assessed as high-moderate. It also suggested the potential for service users to be left without carers thus reducing their independence and quality of life. The Local Authority was quoted as saying that, with a limited budget, it had to work within its means and this meant difficult choices had to be made. A public consultation had reportedly found 70% of people supported the decision to target the limited funds available at those with the highest level of need.

Generally, although we understood the financial difficulties, we felt that the situation was not equitable, if only a few people would benefit from assistance, and potentially not efficient if the savings in the short term would only lead to more costs in the long term. Some members also questioned who was assessing the service users and how they would perform the assessments. We also felt that, while savings could be made, there could be long term problems as the skilled workforce (such as carers and support workers) could be lost as well as creating additional pressure on the remaining workforce. We discussed people not getting the help that they might deserve and how less support could lead to loss of independence and a reduced quality of life, for example, if a service user does not have the support of a care worker, they might not be able to go to the shops by themselves. We felt that it was important to consider how fair the assessments were so that ‘services for all’ was not losing out to financial constraints. We all agreed that the service users with a high-moderate need were still entitled to their ‘right to health and welfare’ and that, although they were not being seen as having critical or substantial needs, nevertheless their ‘quality of life’ and ‘independence’ were still important. The way the changes were communicated was also relevant as we felt that, for the individuals losing the support, the reported Local Authority’s stance of having a limited budget, could be viewed as a lack of ‘compassion’ for the service users, with short-term efficiency gains only leading to longer term inequality.

Service users’ personal budgets

We then looked at two articles about adult service users and their personal budgets. Personal budgets were explained in both articles as money that is allocated to service users who have been assessed by their Local Authority as needing support to help live independently. The first article reported a female service user who had used her personal budget to buy a football season ticket and a source in the article implied that Local Authority funds were being wrongly used. A Local Authority spokesperson noted that personal budget allowances were carefully assessed and that the personal budgets allowed service users to become more independent and tailor their own package of care.
The second article looked at how personal budgets were the answer to providing services that people need and quoted a report that found only 15% of service users, when given their personal budget, chose to make a complete change to their care and support. The article noted that service users being able to choose without restrictions meant that leisure activities could be introduced as a means of social care support to improve quality of life, and campaigners suggest that having choice had actually created a reduction in spend by Local Authorities.

We felt that there was a clear tension between equity and efficiency in both articles as individual choice and freedom needed to be balanced against how much money the Local Authorities had available and how it was allocated. In terms of equity, we noted that personal budgets could create a huge mental health boost for service users as they could gain confidence by spending the money on their individual interests. This freedom to choose helped service users feel like they were equal to other members of society and not being dictated to, as one Council member noted “who are they [the Local Authority] to choose what the social activity is”. In efficiency terms, members talked about how personal budgets could be a better use of money as it’s “what they want to do, rather than just sitting in a day centre” but also that the system could be open to abuse and that it needed to be controlled properly by the Local Authority.

We felt that having the right to choose their services was reflected in the societal values of ‘independence’ and ‘individual choice’. We also discussed how being able to choose services created a sense of ‘dignity’ for service users and, in turn, allowed them to increase their own ‘quality of life and quality of service’. We noted that ‘gone are the days of isolation and institution’ for service users in that personal budgets have brought opportunity for personalised support, rather than everyone being allocated places at day centres with no choice. We also felt that Local Authorities could show
their ability to be ‘non-judgemental’ by not setting conditions on what the budgets could be used for. It was felt that allowing service users individual choice about how they were supported would still create savings for the Local Authority in the long term as it prevented problems that might arise from isolation or institutionalism, such as depression.

“...compassion, dignity and supporting people to have an independent life. Just because you have a disability doesn't mean you shouldn't have that right to have an independent life and can contribute in some way to society.”

Provision of respite services

The last article we looked at was about the proposed closure of a respite centre for children with severe disabilities. Family members were quoted as saying the service was very much needed and was a long established and welcome service for them. The Local Authority noted that the service was only used by eight children and the closure would free-up funds to provide better home-based care for the children and their families. We talked about how few children reportedly used the respite centre so it did not seem to be providing ‘value for money’ but also that the Local Authority could be seen to be showing a lack of ‘compassion’ and, through the closure proposal, creating a loss of ‘individual rights’ for service users. As with the other articles, we could see how ‘communication’, and the paper’s reporting of how the Local Authority communicated with the families, had compounded their feelings of injustice.

Some of us felt that ‘trust’ was at stake as it was reported that the families did not feel reassured that an effective alternative would be put in place and that ‘quality of service’ might also be at stake. We also discussed how the disruption in ‘routine’ could affect the families and that some families were reported to be unhappy as they felt the alternative provision would not suit their needs. However, with so few children reported to be using the centre, we felt that issues of efficiency overrode the equity issues, with the centre not being cost effective and that more at-home care could be provided to more families with the money saved by closing the respite centre.

When we fed back to Mercy on our discussions, we examined further what some of the values we had identified actually meant. Mercy explained that ‘employment’ isn’t a value as such — the value would be ‘maximising an individual’s economic stability’ and the method of doing that might be through employment. Also, ‘integrity’ is a value that we all define differently. For Mercy, she felt integrity was about honesty and the group felt that the value of integrity being discussed was in reference to the integrity of the funder (the Local Authority in this case) rather than the integrity of the service user.
We also discussed how ‘safeguarding the vulnerable’ is not just about protecting people, it is about listening to what people want. For example, Mercy talked about how, when setting care standards for older people in care homes, it was a requirement that each person had an individual room as privacy was considered to be important. However, when they asked the older people what they actually wanted, many said they wanted to share rooms as that brought a sense of ‘safety’ and ‘community’ to their lives.

“Safeguarding the vulnerable is important to society to protect people who are vulnerable; if you can't do that, you're living in a society that's not compassionate.”

We felt that all of the articles highlighted certain key societal values for social care including ‘being non-judgemental’, ‘services for all regardless of economics’, ‘safeguarding the vulnerable’ and ‘independence’. Mercy commented that unpicking these further may reveal underlying values, for example, you want people to have self-esteem and you do this by having ‘trust’, ‘privacy’ and ‘independence’. We also recognised how ‘communication’ affected these situations and how many of these societal values can be supported by having better communication between providers and service users.
Health care

The final area of care we looked at was health care. Paddy Storrie is the Deputy Headmaster at St. George’s School in Harpenden. As well as being a previous Citizens Council member, he has sat on appraisals committees at NICE. Paddy explained to us what health care encompasses and, with a quiz, his presentation and acted scenarios; we talked in depth about the societal values involved in this area of care.

Paddy gave us a quiz so we could start thinking about what health care actually means. In pairs, we worked through the questions and then got the correct answers through Paddy’s presentation, subsequently learning a lot about what health care is and how much it costs each year.

Paddy told us that health care includes services such as:

- acute care
- primary care
- hospital care
- dentistry
- midwifery
- rehabilitation
- psychiatric and mental health care

What health care does not include are services provided by charities and private health care. As only estimated 8% of the UK population has private health care insurance, Paddy noted that, in terms of social solidarity, we’re mostly in it together as the vast majority of us rely on the NHS for our health care needs. Paddy also pointed out that, out of all government annual spending, the Department of Health takes a large amount, with the NHS’s budget set at just over £100 billion in 2009/10.

Paddy told us that, although the NHS budget for 2012-13 was ten times the original 1948 NHS budget, many things have changed: technology has improved so more people can be treated more effectively; we’re therefore living longer so the population has grown and people are consuming more health care as a result. Health care spending per person is now around £2,000 per year, which, as Paddy noted, is actually very good value for the services and expertise we receive. Paddy also talked about the commissioning of health care services, who does the commissioning and how that has changed a lot in recent years.
Paddy concluded that:

- More health care than ever before is being delivered.
- Health outcomes are improving.
- There is a limited budget and we cannot afford all we would like.
- You don't get health care at all unless someone "commissions" it.
- Through its guidance, NICE helps gate-keep what are and are not worthwhile and cost effective treatments as well as ensuring treatments are delivered in the best way.

So that we could fully discuss the societal values that might be considered when looking at equity and efficiency in health care, we were introduced to two actors who helped us to explore examples of 'real' people's situations. For the first example, the actors played a couple discussing changes to the heart clinic that one of them attended. The local clinic was one of many that had been relocated to a larger central hospital. The woman who attended the clinic was worried about having a longer journey to the hospital and the possibility of seeing a different consultant at each visit. The man explained that a central 'centre of excellence' meant that the clinic would have more up to date equipment and appointments would be available throughout the week.

After the actors had performed, we discussed the equity and efficiency issues involved in the scenario and came up with a range of societal values. These included 'access to facilities' and 'compromise' — the woman's lack of willingness to compromise was compounded by the lack of 'access to information' and 'communication' so she couldn't see the benefits of the change to her personally. We felt the woman's 'trust' in the service offered was compromised because the reasons for the change were not being given, with one member noting that "if you've got the knowledge, you can accept things a bit easier rather than feel like you're being thrown into the abyss". This issue with effective communication also affected her feelings of 'consistency' as she would lose the rapport with the doctor she had always seen by having to go somewhere else and starting that patient and doctor relationship from the beginning. However, the group commented that it was also unfair for her to rely on one doctor and that the change could mean more 'equality' and would 'maximise the total benefit' as the reliance on one doctor would disappear and would therefore make the service more sustainable.

We then moved on to two character interviews. We split into two large groups and got to question two characters, called Frank and Sally, about their situations. Through our questioning, we needed to find out:

- Their condition/needs and how they and others were affected by them.
- How they hoped the NHS might meet their needs.
- Obstacles to them getting a good health outcome.
- Issues in their situation/background which might affect our view of the 'fairness' of the situation.
‘Frank’
Through questioning Frank, we found out his life story, how he had come to get lung cancer as a result of exposure to asbestos in the workplace and had less than a year left to live. He had had surgery to improve his symptoms but now faced chemotherapy in the hope of prolonging his life by ten months. Frank had heard about a new treatment which might increase his life expectancy by a further six months but his doctor had said no as it was not a recommended treatment due to its lack of cost effectiveness and many side effects. Frank felt that it was unfair he was denied a drug that could have given him six more months of life especially as he was a carer for his mother and wanted to see his daughter get married in those six months. The members asked him if he had tried to get compensation from his previous employers. He said he had thought about it but that the first twelve months after his diagnosis were hard for him so he was only now looking at compensation in order to secure some financial security for his daughter and his mother once he had gone.

We discussed the equity and efficiency issues as well as the societal values that came up in Frank’s case: for example, Frank being told the drug treatment he felt he should have was not seen as ‘cost effective’ versus the view that he had worked his whole life and “paid in to the system” so he should have “a fair innings”. We felt that ‘quality of life’ was a key societal value in that Frank should be given the chance to sort out his family affairs and put a support network in place for his mother before his death. We also discussed ‘empathy’ and ‘respect’ and the importance of explaining reasons for decisions. Without an explanation of the bigger picture, for example the reasons why cost effectiveness needs to be considered and that every pound spent on treatment for one patient means a pound not being spent elsewhere, Frank felt a sense of ‘injustice’ and that the doctors were lacking in ‘humanity’. In the scenario, Frank suggested that if there had been better ‘communication’ from his doctor, beyond a clear “no” on the grounds of cost effectiveness, he may have been more accepting of that decision. Without any explanation, he said he was left to question the morality of not being allowed the treatment and could only see the inequality of the situation he found himself in.

‘Sally’
By questioning Sally, we found out she was a 39 year old mother of a teenage son and was married for the second time. Her request for IVF treatment had been rejected by her local Clinical Commissioning Group (CCG), which is responsible for making decisions about funding IVF in her area. She felt that they were refusing to give her the treatment because she already had a child at home and because she had to have been trying to conceive for three years and she had only been trying for two. She was frustrated because, if she kept trying for another year, she would be 40 years old and then not be eligible for IVF because of her age.
The group asked if she would consider moving so that she would be covered by a different CCG but she felt she shouldn’t have to move. We also asked her if she would adopt and she said she had not looked into it at all. Some efficiency and equity issues came up through questions we asked her, such as whether the taxpayer should pay for IVF and whether marital status was a factor. We fed back that the biggest societal value from Sally’s point of view seemed to be ‘fairness’ and her view that the situation was unfair to her. However, the groups felt that there was a need there for ‘compromise’ and ‘realism’ that Sally was not prepared to think about. ‘Equality’ and ‘services for all regardless of economics’ were also brought up as societal values in that we questioned why one person might be offered treatment when another might be refused it. There were some differences of opinion about the issue of ‘equality’ and whether Sally had a right to treatment or whether more factors about her situation needed to be taken into account, such as her age. The question of good ‘communication’ was also discussed in that Sally was not prepared to listen to the reasoning behind the decision, that the availability of funding for IVF treatment has to be balanced against funding needed for other types of health care, which may offer more benefits to more people. Paddy noted that, as a society, you have to be realistic but at the same time, there is the need for compassion and trying not to judge.

“She didn’t seem to want to help herself.”

We concluded our session on health care by reflecting on all three scenarios and discussing the societal values involved. ‘Communication’ was discussed, in that poor communication from the doctors and health care providers led to confusion and feelings of injustice in all three scenarios. We felt that good communication from the health care providers would mean that the recipients felt they were being treated fairly and with ‘respect’. Good communication would then reflect a sense of ‘empathy’ and ‘compassion’ from the providers to the recipients and recipients may feel more willing to compromise if they feel they are being listened to. However, we also concluded there was a need for realistic expectations from recipients, for example, ‘compromise’ is needed between a doctor and their patient so that a realistic goal can be achieved. A member summarised this as a requirement for the recipient “to accept legitimate barriers”.

Examining our discussions

Identifying ‘special circumstances’

With all the information we'd gathered over the two day meeting, we could really see how important the public and patient perspective is to NICE and how our list of societal values could be used by NICE to underpin all of its work. With this in mind, we thought about any 'special circumstances': instances that might justify a greater emphasis on either efficiency or equity. In our small groups, we talked about the issue of age and IVF treatment and whether a higher success rate for a younger woman would mean efficiency would "win" over equity with regards to age. We also talked about the dilemma of equality for all versus the view that you should only get out what you put in, for example, with Frank who had rarely been ill before and had "paid his dues" his whole life. Other dilemmas identified from other examples we discussed included:

- If two people needed kidney transplants and one was 17 years old and the other was 70 years old, would you give the transplant to the 17 year old because of their future potential to contribute more to society or should you give the transplant to the 70 year old because they’ve already contributed to society their whole life?
- Should how you got a condition change the availability of treatment, for example, lung cancer through smoking versus lung cancer from working with asbestos?
- Should you continue to treat a liver transplant patient if their transplant fails through alcohol misuse?

We fed back to Sarah Garner some special circumstances where there should be a greater emphasis on equity. In terms of social care, children's services and autism were highlighted as circumstances where there should be greater emphasis on equity as it was felt that early intervention would always be better than letting something reach a crisis point. Age was discussed as a factor that should not be a reason for greater emphasis on efficiency within social care. Within public health, everyone agreed that times of epidemic or natural disaster should be circumstances where there is a greater emphasis on equity. We discussed whether efficiency and
therefore cost should be emphasised for treatment for non-UK residents and for "self-inflicted" illness resulting from alcohol and drug abuse and acknowledged that these were complex issues that would warrant further discussion. Similarly, we considered whether health care, unlike social care, ought to place a greater emphasis on efficiency in considerations of age, for example by prioritising younger people who have longer to "give back" to society, and found this was not a straightforward issue to unpick because of the contributions that older people have made to that society. In terms of equity, members felt that access to treatment should not be dependent on the economics of a person.

We then spent some time ‘sense checking’ our initial master list of forty-eight values that we developed from our ‘good society’ drawings on day one — did we all have a mutual understanding of what each value meant? Although we could define the values according to what they meant to us personally, there were some terms that could potentially be open to different interpretations. Sarah asked us to discuss in more detail two of these terms — ‘family values’ and ‘justice’ — so that we could all be very clear about what we meant. We felt that family values meant ‘respect’, ‘parental guidance’, ‘unconditional love and support’, ‘considering cultural differences’ and ‘promoting family cohesion’. To us, ‘justice’ meant ‘equal consequences for all’, ‘learning from mistakes’, ‘putting what has gone wrong right’ and that, without it, "organisations could be open to abuse".

**Exploring similarities and differences**

Sarah asked us all to reflect on the similarities and differences between public health, social care and health care in terms of societal values and if any of the forty-eight values we had come up with were pertinent to any one area of care. This was the hardest question for us as our general consensus was that you could potentially apply all of the societal values to all three areas. However, our groups did consider that some values were more important for one area than others. It was felt that ‘control over own lives’ and ‘independence’ were most important in social care — this reflected discussions during Mercy’s session regarding service users having the right to choose how they were supported and how that right led to ‘independence’. We also felt that ‘collective responsibility’ was most important in public health reflecting discussions during our time with Mike Kelly regarding how individual choices, such as binge drinking, affected the wider society and how we are all responsible together to help improve that society. ‘Humanity’ and ‘being humane’ were key to the area of health care as shown by how members responded to the acted scenarios and the view that, without proper communication by health care professionals, their decisions about someone’s treatment choices can be seen as lacking in humanity.
Sarah also took us right back to the beginning of our discussions and whether ‘societal values’ was the right terminology at all — could we relate to it? We voted on whether we preferred the terms ‘social values’, ‘societal values’ or ‘public values’. None of us chose ‘public values’ and, although some of us felt that ‘social values’ was easier to understand as it was jargon-free, we agreed the best term was ‘societal values’ as it states “how we function as a society and what message our behaviour sends out to society”.

The most important societal values that should underpin NICE’s work

Our final exercise looked at what we thought were the key societal values from the initial list of forty-eight that we had generated. First, we worked in small groups with each group identifying its own five top values. When we compared what each group had prioritised, we found there was a lot of similarity so we were able to conclude with a list of fifteen societal values that we all felt needed to be considered most when making decisions about trade-offs between equity and efficiency (one of which, ‘honesty’, had not made it to the list of forty-eight values but had been discussed throughout the meeting). Our list of fifteen consisted of ‘accountability’, which we felt was essential for all providers of care, underpinning an excellent standard of delivery and promoting trust and confidence, ‘collective responsibility’, which emphasises the need for everyone to be responsible within a society, and ‘dignity’, which is integral to who we are and life in general, as well as helping us to maintain our own self-identity. ‘Education’ itself is not a societal value but we felt it was important to include it as ‘education’ is “the key to solving problems” and “sows the seeds for future generations”.

‘Fairness’ to us meant that everyone is treated equally and in a fair way and alongside that is ‘justice’ as it underpins everything in society
and affects the way we behave. By showing ‘respect’ for each other, we also show our ‘humanity’ and respect creates understanding and trust in others. Alongside respect though, there has to be ‘honesty’ so “you can believe what you’re being told and can trust any information you’re being given”. We felt that ‘individual rights’ was important, including the right to have “a happy, decent life” through ‘quality of life’ as well as the ‘right to health and welfare for all’ with no bias and “judgement-free”. ‘Maximising total benefit/benefit for most/utilitarianism’ was viewed as important so that we could get the most out of the resources available alongside value/quality of service’ as it was felt that “better service equals better results for everyone”. Finally, ‘safeguarding the vulnerable’ was seen as a vital societal value as “many people can’t speak for themselves”.

We felt that, overall, the top fifteen societal values can underpin all three areas of public health, social care and health care, not just when looking at trade-offs between equity and efficiency but as guiding principles for all of NICE’s work. Through the work we all undertook during the two day meeting, we ended on a very positive note: that the values we selected could not only be applied to the work of NICE but to all of us with the aim of creating “a good society”.

“I think that we all have an individual responsibility for society and a collective responsibility to society and our actions and how those choices we might possibly make might have an impact on society at large.”
Summary of conclusions

We explored, in depth, the societal values that we think should underpin NICE’s work, we discussed the equity and efficiency trade-offs in public health, social care and health care, and we recorded some special circumstances that would justify a greater emphasis being placed on either equity or efficiency. We found that balancing equity and efficiency is an extremely difficult exercise and that there will never be a perfect balance, hence our discussions around any special circumstances as well as some circumstances that were too difficult for us to fully unpick and therefore need further examination. We also found that, by defining the underpinning societal values in our own terms, some of the words and phrases we came up with are not ‘values’ as such but reflect underlying values. For example, ‘education’ is not a value but was chosen as it reflects underlying values, such as ‘promotion of education for all’ and “sowing the seeds for the future” by educating everyone to become good members of society. Again, unpicking the societal values we hold dear inevitably leads to a need for more examination of those terms.

‘Good communication’, as a theme, occurred throughout our discussions in that this is crucial for explaining the reasoning behind decisions about trade-offs between equity and efficiency. A lack of good communication could lead to perceptions that values such as justice, equality and trust are not being upheld. The tension between ‘individual rights’ and wider society was also a recurrent theme and we often found it difficult to find a balance between the two, for example, in the area of public health, individual rights can be accepted as long as no harm is caused. As soon as harm is caused, for example, with binge drinking affecting public order, “the greater good’ needs to be considered.

The top fifteen societal values we chose are all relevant to public health, social care and health care. However, we felt that, depending on the situation, some of these might be more pertinent to one particular area than another, such as prioritising ‘safeguarding the vulnerable’ to social care situations. There were also other societal values within our master list of forty-eight values that were not in our top fifteen, but that we felt deserved being taken into consideration in particular areas of care and these are shown in purple in the lists on the following pages.

“When we first had the question of equity and efficiency, I must admit, I didn’t really know where we were gonna start and I think it’s been quite a good journey to get to answer those questions.”
Key societal values to be considered across public health, social care and health care:

- Accountability
- Collective responsibility
- Dignity
- Education
- Fairness
- Honesty
- Humanity
- Individual rights
- Justice
- Maximising total benefit/benefit for most/utilitarianism
- Quality of life
- Respect
- Right to health and welfare for all
- Safeguarding the vulnerable
- Value/quality of service

Prioritised values from our public health discussions:

- Accountability
- Collective responsibility
- Education
- Individual rights
- Maximising total benefit/benefit for most/utilitarianism
- Safeguarding the vulnerable
- Consequentialism
- Freedom/liberty
- Respect for the majority/democracy
We also discussed some ‘special circumstances’ where we considered there is a need for greater emphasis on either equity or efficiency. We did not all agree on these circumstances but feel it is important to include all of them here so that all of our views are represented. We also discussed some circumstances which we felt were difficult to unpick and therefore need further examination.

**Prioritised values from our social care discussions:**

- Dignity
- Right to health and welfare for all
- Value/quality of service
- Maximising total benefit/benefit for most/utilitarianism
- Safeguarding the vulnerable
- Services for all regardless of economics
- Independence
- Individual choice
- Representation/voice
- Being non-judgemental

**Prioritised values from our health care discussions:**

- Humanity
- Justice
- Respect
- Compromise
- Realism
- Empathy
- Being non-judgemental

**Special circumstances where greater emphasis on efficiency is needed:**

- Non-essential cosmetic surgery
Over the two day meeting, our discussions have enabled us to understand the complexities involved in the work of NICE and also appreciate that, although we are all very different individually, it's the common aspects of what we all want for society that bring us together. Although we identified the top fifteen values we thought were important to NICE, we found it difficult to articulate why those fifteen societal values are important when making decisions about trade-offs between equity and efficiency. Nevertheless, we hope that our conclusions bring a greater understanding and depth to the “ethical issues” that David Haslam explained underpin all of NICE’s work.

“"We have got a varied opinion of things and obviously, we all have different ideas but, in the end, they're all brought together and that's the one thing that's stuck in my mind; although we're chalk and cheese, we've ended up being one solid group."
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Note: two members were unable to attend

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**Paddy Storrie**
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Facilitators
Pete Spriggs and Mandy Sims
Clearer Thinking www.clearerthinking.co.uk

Report writer
Susan B. Bentley
www.susanbbentley.com

Actors
Aston Kelly and Sharon Heywood
www.medicalroleplayers.co.uk

Thanks also go to the NICE staff who organised the meeting:
Sarah Garner – Associate Director, Research and Development (R&D)
Gill Fairclough – Project Manager, R&D
Jan Robinson – Programme Manager, R&D
Moni Choudhury – Analyst, R&D
Ian Wall – Coordinator, R&D
Tonya Gillis – Media Relations Manager, Communications Team
# Appendix 1
Briefing paper

## Citizens Council Meeting 2014
Briefing Paper

### The purpose of this briefing paper

This briefing paper is for the Citizens Council members who will be attending the Citizens Council Meeting 2014. It provides a summary of the meeting practicalities: an introduction to the meeting question and objectives; an outline of the agenda; and a short introduction to the topic that the meeting will consider.

Please take a few minutes before the meeting to read this paper. You are not asked or expected to do any further reading around the topic.

We very much look forward to meeting you in May.

### Meeting practicalities

<table>
<thead>
<tr>
<th><strong>Dates:</strong></th>
<th>Thursday 8 May – Friday 9 May 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Times:</strong></td>
<td>Thursday 8 May: 09:30 arrival (for a 10:00 start) – 17:30</td>
</tr>
<tr>
<td></td>
<td>Friday 9 May 2014: 09:30 – 17:00</td>
</tr>
<tr>
<td><strong>Venue:</strong></td>
<td>The meeting will be held in The Whitworth Suite at the Palace Hotel.</td>
</tr>
<tr>
<td><strong>Meals &amp; refreshments:</strong></td>
<td>All meals and refreshments will be provided, including a packed meal for your journey home. Any special dietary requirements will be noted in advance on your behalf.</td>
</tr>
<tr>
<td><strong>Overnight accommodation:</strong></td>
<td>If you require overnight accommodation, you will be staying at the Palace Hotel, Oxford Street, Manchester, M60 7HA <a href="http://www.palacehotelmanchester.co.uk">www.palacehotelmanchester.co.uk</a></td>
</tr>
</tbody>
</table>

### Question for the meeting

At each Citizens Council meeting, the Council is asked for its views on a topic which is of interest to NICE and its work. The meeting topic is put to the Council as a specific question that enables members to discuss a range of issues around the topic during the meeting.

The 2014 Citizens Council meeting aims to answer the following question:

**What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?**
An Introduction to the topic of the meeting

In developing guidance, advisory bodies and committees at NICE are faced with striking a balance between efficiency and equity.

In economics, efficiency means getting the most you can from the limited resources at your disposal. Equity involves distributing the wealth of a society fairly among all of its members.

Providing services based purely on maximum efficiency means that the pounds spent go furthest in terms of overall population health and wellbeing. However, this might lead to some parts of the population being put at a greater disadvantage than others. Alternatively, providing services based purely on equity, or ‘fairness’, means that not as much can be delivered within a given, fixed budget.

NICE’s remit has been extended to include not only health care and public health, but social care also. So, the close examination of the differences and similarities across these three areas will be of great benefit.

The speakers at the meeting in May will clarify the terms ‘public health’, ‘health care’ and ‘social care’, and will explain what they cover, but the brief explanation below may be useful in the meantime:

What is ‘public health’?
It can be described as the measures taken to promote and protect health and well-being, preventing ill-health and helping people live longer and healthier lives. Public health professionals monitor and address the health of entire communities and promote healthy practices and behaviours to ensure that populations stay healthy.

What is ‘health care’?
It can be described as the diagnosis, treatment, management and prevention of disease, illness, injury and other physical and mental health conditions.

What is ‘social care’?
It refers to services provided or arranged for children and adults who need extra support in their daily lives. This includes: vulnerable children, children and adults with learning or physical disabilities or mental health problems, people who misuse drugs and alcohol, and older people. It includes the provision of: foster care, care homes [including children’s homes], day centres, equipment and adaptations, meals and personal care at home, personal assistants and services to help carers.
Objectives for the meeting

To help answer the question on page 1 the meeting has the following objectives. By the end of the meeting we will have:

1. Identified and explored the societal values that should underpin NICE’s work and why they are important;

2. Reflected on and discussed equity and efficiency trade-offs in public health, social care and health care, with a view to exploring the similarities and differences in these three areas;

3. Recorded any specific instances that justify a much greater emphasis being placed on achieving either equity or efficiency.

Meeting outline

The meeting will be run by two independent facilitators, Pete Spriggs and Mandy Sims from Clearer Thinking www.clearerthinking.co.uk

An outline agenda is shown below. The final, more detailed, agenda will be provided on arrival at the meeting.

Day 1 – Thursday 8 May 2014

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>09:30</td>
<td>Arrival</td>
</tr>
<tr>
<td>10:00</td>
<td>Welcome</td>
</tr>
<tr>
<td></td>
<td>Introducing the question</td>
</tr>
<tr>
<td></td>
<td>Efficiency vs Equity exercise</td>
</tr>
<tr>
<td></td>
<td>Societal values explained &amp; demystified</td>
</tr>
<tr>
<td></td>
<td>A quick guide to public health</td>
</tr>
<tr>
<td>17:30</td>
<td>Public health – exploring the trade-offs &amp; societal values</td>
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<tr>
<td></td>
<td>Close</td>
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</table>

Day 2 – Friday 9 May 2014

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>09:30</td>
<td>Looking back on Day 1 &amp; forward to Day 2</td>
</tr>
<tr>
<td></td>
<td>A quick guide to social care</td>
</tr>
<tr>
<td></td>
<td>Social care – exploring the trade-offs &amp; societal values</td>
</tr>
<tr>
<td></td>
<td>A quick guide to health care</td>
</tr>
<tr>
<td></td>
<td>Health care – exploring the trade-offs &amp; societal values</td>
</tr>
<tr>
<td></td>
<td>Reflecting on our discussions</td>
</tr>
<tr>
<td>17:00</td>
<td>Depart</td>
</tr>
</tbody>
</table>
Appendix 1 cont.

Briefing paper

Any questions?

For enquiries about the content of the meeting please contact Pete Spriggs M: 07749 821 438 E: pete.spriggs@clearerthinking.co.uk

For enquires about travel, accommodation and any dietary or support requirements please contact: Ian Wall T: 020 7045 2185 E: ian.wall@nice.org.uk

For general enquiries about the Citizens Council and NICE please contact: Gill Fairclough T: 0161 870 3096 E: gill.fairclough@nice.org.uk
Appendix 2
Agenda day one

National Institute for Health & Care Excellence
Citizens Council Meeting 2014
Thursday 8 May – Friday 9 May 2014
The Whitworth Suite, Palace Hotel, Oxford Street, Manchester M60 7HA

Question for the Meeting
What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?

Agenda

Day 1 – Thursday 8 May 2014

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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</thead>
<tbody>
<tr>
<td>09:30</td>
<td>Arrival</td>
</tr>
<tr>
<td>10:00</td>
<td>Welcome from NICE’s Chair</td>
</tr>
<tr>
<td></td>
<td>Introducing the question</td>
</tr>
<tr>
<td></td>
<td>Some definitions to get us started – recap &amp; refresh</td>
</tr>
<tr>
<td>11:15</td>
<td>Break</td>
</tr>
<tr>
<td></td>
<td>Efficiency vs Equity exercise</td>
</tr>
<tr>
<td></td>
<td>What we value &amp; why – part 1 The good society</td>
</tr>
<tr>
<td>13:00</td>
<td>Lunch</td>
</tr>
<tr>
<td>14:00</td>
<td>What we value &amp; why – part 2 From individual to societal values</td>
</tr>
<tr>
<td></td>
<td>A quick guide to public health</td>
</tr>
<tr>
<td>15:30</td>
<td>Break</td>
</tr>
<tr>
<td></td>
<td>Public health – exploring the trade offs &amp; the societal values</td>
</tr>
<tr>
<td></td>
<td>Wrapping up day 1, looking to day 2</td>
</tr>
<tr>
<td>17:30</td>
<td>Close</td>
</tr>
</tbody>
</table>
### Appendix 3

**Agenda day two**

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**National Institute for Health & Care Excellence**

**Citizens Council Meeting 2014**

Thursday 8 May – Friday 9 May 2014
The Whitworth Suite, Palace Hotel, Oxford Street, Manchester M60 7HA

### Question for the Meeting

What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?

### Agenda

**Day 2 – Friday 9 May 2014**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
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<tbody>
<tr>
<td>09:30</td>
<td>Looking back on Day 1 &amp; forward to Day 2</td>
</tr>
<tr>
<td>09:45</td>
<td>A quick guide to social care</td>
</tr>
<tr>
<td>10:45</td>
<td>Social care – exploring the trade offs &amp; the societal values</td>
</tr>
<tr>
<td>11:15</td>
<td>Break</td>
</tr>
<tr>
<td>11:30</td>
<td>A quick guide to health care</td>
</tr>
<tr>
<td>12:15</td>
<td>Lunch</td>
</tr>
<tr>
<td>13:15</td>
<td>Health care – exploring the trade offs &amp; the societal values</td>
</tr>
<tr>
<td>14:00</td>
<td>Break</td>
</tr>
<tr>
<td>14:15</td>
<td>Reflecting on our discussions</td>
</tr>
<tr>
<td>14:30</td>
<td>Nearly done!</td>
</tr>
<tr>
<td>17:00</td>
<td>Depart</td>
</tr>
</tbody>
</table>
Appendix 4
Introducing the question – Sarah Garner

1. National Institute for Health and Care Excellence

2. First, a recap...
   - The Citizens Council is invaluable to NICE’s work.
   - 2013 report on social care is already making an impact.

3. This year’s question
   What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?

4. Why we are asking it
   - NICE often faces decisions where it has to find the acceptable balance between equity and efficiency.
   - Achieving both completely is not usually possible: more of one means less of the other.

5. Why we are asking it
   - ‘acceptable’ balance may be different to ‘acceptable’ balance in others.
   - Understanding societal values will help NICE understand what is meant by ‘acceptable’.

6. Understanding the terms
   - This morning, we’ll explore what we mean by the terms: equity, efficiency, societal values.
   - This afternoon and tomorrow, we’ll consider how these relate to real life from three different perspectives.

7. Three perspectives for NICE
   We’ll explore these using case study examples.
   Note: case studies may involve issues that are outside of NICE’s remit.

8. Three perspectives for NICE
   We want to know: In what ways are the societal values relevant to these three perspectives similar or different?
Appendix 5

Some definitions to get us started – Sarah Garner

1. NICE National Institute for Health and Care Excellence

Some definitions to get us started, & Equity vs efficiency exercise
Sarah Garner, Associate Director
Research and Development, Centre for Health Technology Evaluation

A double session
Some definitions to get us started
• exercise to explore what we mean by the words ‘equity’ and ‘efficiency’

Equity vs efficiency exercise
• looking at the way equity and efficiency are balanced in real life

2. NICE

3. NICE

Group exercise
What do we mean by the words ‘equity’ and ‘efficiency’?

4. NICE

Group exercise – instructions
• Please work as two groups of three on your table - Group 1 & Group 2
• Group 1 discusses ‘equity’
• Group 2 discusses ‘efficiency’
• Each group notes their initial thoughts as they think about trying to define the term.
• Share your thoughts with the other group; let them add their ideas and suggestions.

5. NICE

Group exercise - feedback
• Each group highlights (with a pen) key words or phrases they have written down.
• A volunteer from each group feeds back verbally the words or phrases highlighted.

6. NICE

Feedback
Efficiency
getting the most from resources you have
• every pound spent goes further and achieves more
  but
• some people experience greater disadvantage than others

7. NICE

Feedback
Efficiency
• e.g. a direct train from Glasgow to London
  • fast and transports people quickly, but
  • people from other towns can’t get on

8. NICE

Feedback
Equity
• distributing wealth and resources fairly to all
  but
• what is fair?
  • everyone gets the same?
  • most goes to those with most need?
  • something else?
• may mean less is achieved overall
Some definitions to get us started – Sarah Garner

**Feedback**

- **Equity**
  - e.g. a train that stops in every town.
  - everyone can get on, but it’s slow and some people arrive too late.

**A familiar example…**

Meet Dave and Denise.

A familiar example…

The eldest daughter wants money for a school trip that will help her complete her A-level geography coursework.

A familiar example…

But Dave and Denise can’t afford school trips for all three daughters. And some cut-backs in other things will have to be made.

A familiar example…

What would be equitable? What would be efficient? How would you decide what to do?
Appendix 5 cont.
Some definitions to get us started – Sarah Garner

17 Equity vs Efficiency
- Decisions often involve making a compromise between equity and efficiency

18 Group exercise
Exploring a health care example of equity v efficiency

19 Group exercise - instructions
- Groups 1 & 2 Task: to work out a solution based on equity with little regard to efficiency
- Groups 3 & 4 Task: to work out a solution based on efficiency with little regard to equity
- Group 5 Task: to find a balance between equity and efficiency

20 Feedback & questions
Appendix 6
Equity vs efficiency exercise

Exploring a health care example of equity v efficiency

A work of fiction

Fictopia is a very small country with a population of 10,000. In Fictopia, an amazing new treatment has been discovered which offers to fully restore vision.

Research has found it has a 100% success rate. It works every time, no matter how bad your eyesight is to start with – whether you just need reading glasses or whether you have no sight at all – by the end of the treatment you will have perfect 20-20 vision. It also doesn’t matter how long you’ve had poor / no eyesight, or even what caused it – the same treatment will work on everyone first time.

The results are not permanent because the treatment will not prevent vision loss in the future – it is more like a ‘reset’ button than an ‘off’ switch. Eyesight may decline again after the treatment, although it would be medically safe to receive the treatment more than once if it were needed.

In Fictopia, approximately 40 in every 100 people (4000 Fictopians) have some form of sight difficulty. Approximately 2 in every 100 (200 Fictopians) have a severe sight problem with no vision or almost no vision.

The treatment costs £500k to treat one person. Fictopia has an annual health budget of £2bn (= £2000 million).

Unlike in the UK, in Fictopia people are allowed to directly purchase drugs and medical interventions if they are not available on the healthcare system.
Appendix 7
What we value and why – Catherine Max

1. What we value & why – part 1
   The good society

   Catherine Max
   Catherine Max Consulting
   The Future Health Partnership

2. What are the characteristics of a good society?
   - Get creative!
     - We have 20 minutes ... and lots of kit.

3. What values underpin a good society?
   What values underpin a good society?
   1. Discuss on your tables.
   2. Write your suggestions on the blank cards.
   3. Use any of the cards provided.

   Work fast ... We have 15 minutes for this.

4. Over lunch
   1. Admire each other’s pictures of ‘the good society’. Think about:
      - What is the same?
      - What’s different?
   2. What are your ‘top’ values?
      - Put a green sticker on the 3 values you think are most important.

5. What we value & why – part 2
   From individual to societal values

6. Individual versus societal values
   1. On your tables, discuss the values and divide them into two groups:
      - (i) individual or (ii) societal.
   2. Place the societal values on the master space in your chosen category.
      - You can play ‘snap’.
      - You can contradict each other.

   We have 15 minutes for this.

7. Societal values, health, care and wellbeing
   1. Whole group reflection and discussion.
   2. Adjusting the master set:
      - Making the connections between values, health and social care.
      - What are my top 3 priorities now?

   We have 25 minutes for this.
Appendix 8
‘A good society’ drawings
Appendix 8 cont.

‘A good society’ drawings
Appendix 8 cont.
‘A good society’ drawings
Appendix 8 cont.
‘A good society’ drawings
Appendix 8 cont.
‘A good society’ drawings
Appendix 9
Initial master list of values

List of Societal Values Generated on Day 1

- Access to facilities
- Access to information
- Accountability
- Activities for young people
- Being non-judgemental
- Charity
- Collective responsibility
- Communication
- Community leadership
- Community spirit
- Compassion
- Compromise
- Consequentialism (right action is the one with the best consequences)
- Consistency
- Cultural cohesion
- Dignity
- Disability access
- Diversity
- Efficiency
- Empathy
- Employment
- Environment (access to clean air, green space, water etc.)
- Equal opportunities
- Equity
- Fairness
- Family / family values
- Freedom / liberty
- Good schools / equal and inclusive
- Honesty
- Humanity (being humane)
- Impartiality
- Inclusiveness
- Individual rights
- Integrity
- Justice
- Maximising total benefit / benefit for most (utilitarianism)
- Non discrimination
- Non maleficence (avoiding needless harm)
- Openness / transparency
- Privacy
- Professional authority
- Progress
- Promote education
- Prudence (prudent use of resources)
- Quality of life
- Realism
- Reason
- Reducing inequalities e.g. health
- Reducing waste
- Regard for future generations
- Representation / voice
- Resilience
- Respect
- Respect for majority / democracy
- Right to death
- Right to health and welfare
- Right to life
- Routine
- Safeguarding the vulnerable
- Safety
- Services for all regardless of economics
- Solidarity / common good
- Sustainability
- Trust
- Wellbeing
Appendix 10
A quick guide to public health – Mike Kelly

1. NICE National Institute for Health and Care Excellence

2. The scope of public health

3. NICE

4. But even in the face of a deadly epidemic there were doubters and opponents.

5. “The nation, which is but the aggregate of us all is ... little disposed to endure a medical tyrant... Mr Chadwick and Dr Southwood Smith have been deposed, and we prefer to take our chance of cholera and the rest than be bullied into health...”
   *The Times 1st August 1854, p8.*

6. “An ounce of prevention is worth a pound of cure”
   *Benjamin Franklin, 1726*

7. NICE

8. NICE
Appendix 10 cont.
A quick guide to public health – Mike Kelly
Appendix 10 cont.
A quick guide to public health – Mike Kelly

18
- The current level of tobacco use is estimated to cost the NHS around £2.7 billion every year.
- Treating people with health problems related to being overweight or obese is estimated to cost the NHS £4.2 billion annually.
- Physical inactivity is estimated to cost the NHS £1.05 billion per year.
- The costs of treating the chronic and acute effects of alcohol misuse up to £1.7 billion per year.

19
- Disease prevention.
- Health protection.
- Health promotion.

20
- Cholera - clean water and sewage.
- Vaccine preventable diseases.
- Infant health.
- Smoking.
- Overall increased life expectancy.

21
- But........

22
- Health Inequalities

23
- Age standardised death rates per 100,000 population for coronary diseases under 75 by area of deprivation.

24
- Age standardised death rates per 100,000 population for cancer under 75 by area of deprivation.
Appendix 10 cont.
A quick guide to public health – Mike Kelly

25
The health gradient

26
The health gradient

27
The health gradient

28
Shifting the health gradient

Conclusions
• Social justice.
• Distributive justice.
• Someone’s utility is always someone else’s disutility.
• Equality versus efficiency.
Smoking, alcohol, equity and efficiency.

Please examine the graphs depicting smoking and alcohol sales in the United Kingdom and the USA over the last century.

First what do the graphs tell us about trends over time in smoking and in alcohol use?

What have been the consequences of the changes in rates of tobacco sales?

What are the consequences of the rates of change in alcohol sales in the two countries?

What do the rates of change suggest about public health policies in the two countries? The first paper describing the deadly effects of cigarette smoke was published in 1952 in the UK.

Now examine the bar charts on cigarette smoking by socio economic status in the two countries.

What do the bar charts demonstrate?

Would we judge anti-smoking interventions to have been effective?

Discussion point – the cost effectiveness of smoking cessation interventions.

Have anti-smoking interventions been equitable?

Is this a classic trade-off between equity and efficiency?

What might be done to make them more equitable?
Appendix 12
Public health case study diagrams

Sales of Tobacco and Alcohol - USA

Source: Alcohol Data - UK Beer and Pub Association (Personal Correspondence, 2014)
Source: Tobacco Data –(Forey et al., 2012)

Sales of Tobacco and Alcohol - UK

Source: Alcohol Data - (Nephew et al., 2003)
Source: Tobacco Data – Prof. Cristine Delneo, Rutgers-School of Public Health, (Personal correspondence)
Appendix 12 cont.
Public health case study diagrams

Percentage of US adults who were current cigarette smokers in 2012

![Bar chart showing percentage of US adults by education level and deprivation status in 2012.]

Source: www.cdc.gov/tobacco

Prevalence of Cigarette Smoking by Socio-economic Classification - UK, 2012

![Bar chart showing prevalence of cigarette smoking by employment grade and deprivation status in the UK in 2012.]

Source: ASH Factsheet, 2013
Appendix 13
A quick guide to social care – Mercy Jeyasingham

1

Introduction
- What is social care?
- Who uses it?
- Who funds it?
- Who provides services?
- What services are provided?
- What is not social care?

2

Social Care

The provision of social work, personal care, protection or social support services to children or adults in need or at risk, or adults with needs arising from illness, disability, old age or poverty.

3

Who uses it?

4

Social Care

5

Adults

Adults – this includes support for older people, people with mental health problems, learning or physical disabilities, those with alcohol and substance misuse problems, the homeless, prevention of abuse or neglect, domestic abuse and associated support for families and carers.

6

Children, young people and families

Children, young people and families – this includes preventative family support and child protection services, child placement, fostering, adoption, working with young offenders, children and young people who have learning or physical disabilities, or homeless, as well as support for families and carers.

7

Funding
- Local authority
- Government
- Charities
- Individuals paying for their own care

8

Service Providers
- Local authority
- Charities/voluntary sector/Not for Profit
- Private organisations
Appendix 13
A quick guide to social care – Mercy Jeyasingham

Some Examples of Services
- Residential homes
- Day Care
- Counselling, support, advocacy
- Adoption and Fostering
- Home care
- Personal care (helps with dressing)
- Activities

Social care is different from
- Health
- Housing
- Education
- Criminal Justice
- Welfare benefits
Appendix 14 cont.

A quick guide to health care – Paddy Storrie

People are living longer
People are consuming more health care
Health care inflation tends to exceed the general rise in prices
New health goods sometimes provide small additional benefit for substantially increased cost

“Commissioning....”

“planning, agreeing, and monitoring services”
“empower and support clinical leaders at every level of the NHS through clinical commissioning groups (CCGs), networks and senators, in the NHS itself and in providers, helping them to make genuinely informed decisions, spend the taxpayers money wisely and provide high quality services.”

Commissioning health care – just like running a school!

How is it organised? – possibly the dullest slide in the History of powerpoint.....

NHS Commissioning Board Authority → The NHS Commissioning Board → NHS England (Identity & Controls)

→ National Health Service (England) which...

→ Commissioners (12k bn on primary care services e.g. GPs)

→ Funds and supports the 212 Clinical Commissioning Groups (which post 2012 replaced “Primary Care Trusts” and “Strategic Health Authorities”) who organise other health provision at a local level. CCGs are led by clinicians, largely GPs, and commission elective care, acute care, community health services, mental health services.

→ Funds some specialist services direct

The role of NICE

Guidance on most appropriate use in the NHS of current treatments or procedures, and appraisal of new treatments for possible NHS use

In summary:

Health outcomes are improving. More healthcare than ever before is being delivered.

We are skint and cannot afford all we would like

You don’t get health care at all unless someone “Commissioned” it

NICE helps gatekeep what are, and are not, worthwhile and cost effective treatments, and ensures treatments are delivered in the best way
**Appendix 14 cont.**

A quick guide to health care – Paddy Storrie

---

**Health-Care Exploring the trade-offs and societal values**

---

**Warm-Up**

- Listen to the dialogue between a heart patient and their partner
  - Their condition / needs and how they and others are affected by them
  - What their priorities are in terms of health care
  - Clues as to whether a good health outcome is intrinsic to them or external to them
  - Anything in their circumstances / background which might affect your view of the "fairness" of their situation

- In your group discuss for 10 minutes and list on poster paper the societal values which might be considered when deciding how far to trade equity with efficiency

- Equity = distributing wealth and resources fairly to all

- Efficiency = getting the most from the resources you have.

---

**You will interview 2 further people with health care needs:**

- Frank, with a terminal diagnosis of lung cancer
- Sally, in need of IVF to start a second family

---

**Frank in the real world**

- Permetrexed not licensed for his set of circumstances
- Costs £8000 for a course of treatment
- One year survival chances 50% as opposed to 38% on standard treatment
- Even for "best fit patients" would cost £37,000 per QALY.

- For Frank, would cost more than £60,000 per QALY

---

**After dividing into groups you will:**

- Interview each person for 10 minutes. Through your questioning try to establish
  - Their condition / needs and how they and others are affected by them
  - How they hope the NHS might meet their needs
  - Obstacles to them getting a good health outcome – intrinsic to them or external to them
  - Issues in their situation / background which might affect your view of the "fairness" of their situation

- In your group discuss for 10 minutes and list on poster paper the societal values which might be considered when deciding how far to trade equity with efficiency

- Equity = distributing wealth and resources fairly to all

- Efficiency = getting the most from the resources you have.
# What is Healthcare?

<table>
<thead>
<tr>
<th>Your answer</th>
<th>The right answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What % of adults in the UK have private health insurance?</td>
<td></td>
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<td>2. On average, how many prescription items does each person in England get in a year?</td>
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<td>3. In which out of England, Scotland, N. Ireland, and Wales do people get the most prescriptions each year?</td>
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<tr>
<td>4. On which of these does the NHS spend most each year: cancer, mental disorders, or heart/lung disorders</td>
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<tr>
<td>5. The UK population is 60 million. How many million Accident and Emergency attendances are there a year in the UK?</td>
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<tr>
<td>6. What is a CCG?</td>
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<tr>
<td>7. What is the difference between the NHS Commissioning Board, NHS Commissioning, NHS England, and the National Health Service (England)</td>
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<tr>
<td>8. How far do you really care about the above answer?</td>
<td></td>
</tr>
<tr>
<td>9. Within 100,000, how many people do you think work for the NHS?</td>
<td></td>
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<tr>
<td>10. “A recent NICE guideline covered a procedure to transplant faeces from a donor to a sick recipient in order to resolve illness caused by C. Diff infection”. True or false?</td>
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Citizens Council 2014
Health care – exploring the trade offs & the societal values
Scenario 1 - Sketch

A and B are played by the role-play actors.

Paddy:  Meet A, at home with his/her spouse.

[A enters carrying an opened letter]

A:  Well, I told you it was coming... ours was the last one standing, and now it's finally happened.

B:  What's that love?

A:  They've moved it, haven't they? They've moved my clinic to Leicester General. It happened in New Town, then in Old Town, and now it's happened here.

B:  Let's have a look [takes the letter and reads it].

A:  No more appointments at the Health Centre down the road. I'll now have to get the 95 and the 124.

B:  It might not be too bad.

A:  It'll take me ages – all afternoon – and you know we need an early tea on Tuesday to get done in time for bowls.

B:  Ah, well, you won't have to go on a Tuesday if you don't want to. It says here that they do appointments all week at the hospital – mornings as well. You can get it out of the way first thing in the morning if you want to.

A:  I'd have to leave at the crack of dawn to get there for an early appointment. And it's an enormous place. I'll never find where they hold the clinic.

B:  It might take a bit of hunting first time you go, but after that, you'll be sorted. And look, it says that it's a Cardiac Centre of Excellence. That means you will get the best treatment.

A:  You couldn't get better than that nice Dr Neuberg.

B:  She'll still be at the clinic, I'm sure. She is the consultant after all... there may be other ones too, of course.
Appendix 16 cont.
Health care scenario sketch

A: You might be sure there will be. It'll probably be a different face every fortnight.

B: Well, I wouldn't be surprised if it ends up not having to be every fortnight. You said yourself that the equipment down the road is as old as the hills. They will have the newest equipment at Leicester and you will get all the latest tests. Dr Neuberg used to say that she couldn't do the most modern tests from the Health Centre, didn't she? I bet it will end up being better all round, in spite of the bus journey.

A: Bus journeys [emphasising the plural], you mean. Well, we shall see... I just don't understand why they've done it — I bet there are loads of old folk like me who used the local clinics and will struggle to get to Leicester General.

Freeze.
Appendix 17

Health care scenario 2 – Frank’s brief

Citizens Council 2014
Health care – exploring the trade offs & the societal values
Scenario 2 – Improvisation brief for male actor – “Frank”

Frank is a 55 year old, who followed 5 years in the Royal Navy as a school leaver with 30 years working in a shipyard. A life-long taxpayer who rarely needed to visit his GP. Frank, was made redundant voluntarily 2 years ago, at which time he was experiencing some ill health. Subsequently he was referred to the Christie Hospital in Manchester, where a consultant chest physician diagnosed a rare form of lung cancer associated with exposure to ASBESTOS. Frank blames his illness on working with asbestos lagging in the navy and then in the shipyard. He is angry that it turned out in the 1980s that the company he worked for had known for decades about health risks with asbestos.

Frank’s initial symptoms were loss of weight and breathlessness. Frank underwent CT scans, then more invasive biopsies to confirm the diagnosis. Frank had been told in January that he had a life expectancy of only around a year, regardless of treatment. He has had surgery to improve his symptoms, and now faces chemotherapy in the hope of prolonging his life by around 10 months.

Frank has learnt of a new treatment which one study suggested might increase his life expectancy by a further 6 months. Side effects of the treatment can include nausea, vomiting and diarrhoea, but because the drug also lowers the blood count, these can be potentially life threatening. Nonetheless, Frank is keen to try the new drug if he can.

The new drug is very expensive and NICE has assessed that it is not very cost effective for the results that the drug can achieve. NICE has therefore not recommended the drug as an appropriate use of NHS money.

If NICE recommends a drug for use in the NHS, the NHS must offer it. However, if NICE does not recommend a drug, local NHS trusts are still able to offer if they wish – this decision is made locally. Frank’s doctor has confirmed that his local NHS Trust will not fund a course of the new drug.

Frank’s only child, a daughter, is due to be married, and the wedding has been brought forward to August. Frank fears he will not be well enough to enjoy this. Frank is a widower, and acts as sole carer for his 80 year old mother, who is no longer capable of independent living and has moved into a ground floor room at his home. Frank worries about how her needs will be met when he dies.

Frank is not well today. He feels fatigued, with chest-wall pain and a cough. He is short of breath on any exertion. He has been told that some patients like him can get a collapsed lung, and this frightens him, as his surgery has already left him with reduced lung capacity.
Appendix 18
Health care scenario 3 – Sally’s brief

Citizens Council 2014
Health care – exploring the trade offs & the societal values
Scenario 3 – Improvisation brief for female actor – “Sally”

Sally is a 39 year old mother of one. Her child, Keith, is 17 and is about to leave home for University. He will be the first generation of the family to have this opportunity. Sally’s first husband, Keith’s father, was abusive, and they divorced many years ago. Sally did not go out to work through Keith’s childhood, focusing on bringing up her son, and the two of them were supported with state benefits.

Sally had been exploring returning to employment as Keith got older, but two years ago met and married Slobodan, or “Dan”, a 25 year old neighbour and asylum seeker from Kosovo. Sally now wants to start a second family with Dan, but has proved unable to conceive. Tests have shown that it is her infertility which is the obstacle, as is the case with around 1 in 7 women in the UK. Around 50,000 couples a year go through IVF and around 2% of babies born in the UK are conceived this way. Sally was advised by her GP to make lifestyle changes which might increase her fertility, reducing alcohol intake, improving diet, and cutting soft drug use. She says she has found these changes hard to implement due to her low income and the social environment of the disadvantaged estate where she and Dan live.

Sally has been told that the local NHS will not fund even one course of IVF treatment for her. This is because at the moment she has a child living at home with her, and she has only had fertility problems for 2 years – even in September when Keith goes to University, and she reaches the three year mark, Sally will be 40 and too old to qualify. Sally’s GP has stated that this age cut-off is because older women have radically less chance of conceiving on IVF (and the success rate overall is only 25%). He also explained that of successful outcomes, a quarter end up being multiple births (twins or triplets etc.), and Dan is nervous about their ability to house and support more than one child should this happen.

Sally is angry that she has been turned down for treatment. She has done some research, and has found that if she lived in an area covered by a different CCG, she might be allowed one, two, or even three NHS funded cycles of IVF. Of course, if she was in work and wealthy, she would be able to fund IVF privately, but this is not an option for her. Sally feels that having supported Keith through to a successful University application, she has proved that she is a good mother who contributes to society in ways beyond employment.

The cost of a course of IVF to the NHS would be £8,000. At age 39, the chance of conceiving is 19% from one course of treatment.