NICE National Institute for Health and Care Excellence

The NICE Citizens Council and the role of social value judgements

Professor David Haslam, Chair, NICE 31 March 2016

Contents

- History of the Citizen Council at NICE
- Role of Citizen Council and of NICE Board

 Role of Social Value Judgments in NICE guidance and SVJ document



Science is not enoughreflecting social values





The Citizens Council

- In 2002 NICE established the Citizens Council to ensure the perspective of the public is reflected in the methodology and processes that NICE uses to develop its guidance
- The Citizens Council is a panel of 30 members of the public that largely reflect the demographic characteristics of the UK
- They provide NICE with a public perspective on overarching moral and ethical issues that NICE has to take account of when producing guidance.



What is the role of the Citizens Council?

- The Citizens Council provides NICE with a public perspective on issues that NICE has to take account of when producing guidance. The Council's 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 doing this.

How does the Council operate?

- Members meet once a year for 2 days at a time. The meetings are open to public observers.
- Council members listen to different views from experts on a topic and undertake exercises which allow them to examine the issues in detail and thoroughly discuss their own views.
- The members' views and conclusions are captured for a report
- 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 the topics chosen?

 Potential topics usually arise as a result of the activities of NICE's advisory bodies during the guidance development process as they explore issues that require value judgements to be made

Citizens Council meeting Report 2014

•The most recent Citizens

Council report came out in 2014 and was shared with the NICE board.

•The council were asked to consider the **societal values** that need to be considered when accessing **equity and efficiency**

•The Council's findings are being used to update its Social Value Judgements document, which outlines the principles for the development of NICE guidance 66 What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency? ??



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"This report from the ...Citizens Council...provides a very timely update. 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... those values at the core"

Professor Sarah Garner, Associate Director, Research and Development, NICE



The NICE Board

The NICE Board is made up of:

- Directors
- Executive Directors
- Non-Executive Directors
- The role of the Board is to provide good governance for the organisation.
- One of the ways in which the Board does this is by their assessment and evaluation of the Citizens Council report and deciding how to use the findings



Social Value Judgements- principles for the development of NICE guidance

- The Social Value Judgement document describes the principles that NICE should follow in designing the processes it uses to develop its guidance (recommendations), and in developing individual pieces of guidance. It is mainly about the judgements that NICE and its advisory bodies should apply when making decisions about the effectiveness and cost effectiveness of interventions, especially where such decisions affect the allocation of NHS resources.
- The document was developed by the board of NICE. It builds on the first edition of 'Social value judgements', which was prepared in 2005.
- All NICE guidance, and the procedures NICE uses to develop its guidance, should be in line with the Institute's legal obligations and the social value principles set out in this document..



8 guiding principles for Social Value Judgements:

Principle 1

•NICE should not recommend an intervention (that is, a treatment, procedure, action or programme) if there is no evidence, or not enough evidence, on which to make a clear decision. But NICE's advisory bodies may recommend the use of the intervention within a research programme if this will provide more information about its effectiveness, safety or cost.

•Those developing clinical guidelines, technology appraisals or public health guidance must take into account the relative costs and benefits of interventions (their 'cost effectiveness') when deciding whether or not to recommend them.



•Decisions about whether to recommend interventions should not be based on evidence of their relative costs and benefits alone. NICE must consider other factors when developing its guidance, including the need to distribute health resources in the fairest way within society as a whole.



•NICE usually expresses the cost effectiveness of an intervention as the 'cost (in £) per quality-adjusted life year (QALY) gained.' This is based on an assessment of how much the intervention costs and how much health benefit it produces compared to an alternative. NICE should explain its reasons when it decides that an intervention with an ICER below £20,000 per QALY gained is not cost effective; and when an intervention with an ICER of more than £20,000 to £30,000 per QALY gained is cost effective.

•Although NICE accepts that individual NHS users will expect to receive treatments to which their condition will respond, this should not impose a requirement on NICE's advisory bodies to recommend interventions that are not effective, or are not cost effective enough to provide the best value to users of the NHS as a whole.



•NICE should consider and respond to comments it receives about its draft guidance, and make changes where appropriate. But NICE and its advisory bodies must use their own judgement to ensure that what it recommends is cost effective and takes account of the need to distribute health resources in the fairest way within society as a whole.

•NICE can recommend that use of an intervention is restricted to a particular group of people within the population (for example, people under or over a certain age, or women only), but only in certain circumstances. There must be clear evidence about the increased effectiveness of the intervention in this subgroup, or other reasons relating to fairness for society as a whole, or a legal requirement to act in this way.



•When choosing guidance topics, developing guidance and supporting those who put its guidance into practice, the Institute should actively consider reducing health inequalities including those associated with sex, age, race, disability and socioeconomic status.

