

Press Release

NICE Citizens Council publishes report on role of age in healthcare decision-making

The Citizens Council of the National Institute for Clinical Excellence (NICE) today publishes a report that reflects the Council's views about whether there are circumstances in which the age of a person should be taken into account when NICE is making a decision about how treatments should be used in the NHS. The Council considered age at all stages of life, from newborn babies to people in old age, and every age in between.

The Citizens Council is made up of members of the public drawn from all walks of life that reflect the make-up of the population in England and Wales. Their ages range from 18 to 76. In addition to hearing from expert witnesses on the topic of 'age', the National Children's Bureau was commissioned to research the views of children and young people on the issues covered by the Citizens Council and the Council considered their views alongside other evidence.

At its most recent meeting in November 2003 the Council considered the question: "Should we be more generous in our definition of what constitutes value for money for some age groups rather than others and if so why?"

Summary Findings of the Council:

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

- And when age is an indicator of likely risk, most of the Council (22) thought that age differentiation when considering cost effectiveness is legitimate, indeed vital in some instances.

- Most of the Council (25) thought that NICE should be more generous to some age groups rather than others if certain age groups are more likely to benefit from a treatment.
- Most the Council (22) did not think that NICE should be more generous to some age groups rather than others on the basis of the social roles that people have at different ages.
- Most of the Council (21) did not think that NICE should be more generous in their definition of what constitutes value for money for some age groups rather than others based on how much chance people have had to experience life due to their age.

The report also explains the reasons behind the judgments of those who were in the majority but also those in the minority.

Responding to the report, **Professor Sir Michael Rawlins, Chairman of NICE**, said: "I very much welcome this report from the Citizens Council. The Council are a hugely dedicated group of people, committed to debating the questions that we ask of them. After two meetings of deliberation and discussion, this report reflects the clear thinking of the Council. Their thoughts and views allow us to bring the public's voice into the work and decisions of NICE."

"It is extremely interesting that this question has generated a range of thoughts and views on how the issue of 'age' should be incorporated into our guidance. We will need to take time to consider how best we can take the views expressed into consideration. I would like to thank all the members of the Council for the time and commitment they have put in to producing this report."

One Citizens Council member said: "I am really enjoying my time on the Council. As a group, we are now past the learning curve and our discussion and debate has got better and better. As we considered the question of age, it became clear that age is a factor when deciding on treatment and care."

Another member said: "When the Citizen Council was established in 2002 it was a new idea. All thirty members and a team of facilitators, had a lot of learning to do.

Now that we have attended three meetings, each lasting three days, we have a better understanding of how to investigate a topic because of the information that we received from expert witnesses and the experience we gained from our discussions.”

“At the beginning of the Cardiff meeting half the members said there were no circumstances where age should be taken into consideration when NICE is preparing guidelines. After 6 days of discussions all those people changed their mind and said there are some circumstances where age can be taken into consideration.”

Another member stated: “This was a complex question, and after a period of deliberation it was very difficult to reach a consensus. The meetings allowed us to talk through our differences and explain our thoughts on the issue.”

The report was presented to the NICE Board at its public meeting on Wednesday 21 January 2004 in Preston. NICE will issue a formal response setting out the Board’s reaction to the recommendations contained in the report at the next NICE Board meeting on **Wednesday 17 March**. The report is published on the NICE website.

Ends

Notes for editors

1. The Citizens Council and its work

- The Citizens Council is an innovation to reflect public opinion in the guidance that NICE publishes about the clinical and cost effectiveness of treatments and care for the NHS.
- A full list of councillors’ names, together with a statistical breakdown of the council’s membership and a group photograph can be found on the NICE website at <http://www.nice.org.uk/cat.asp?c=38969>.
- The NICE Citizens Council met in May and November 2003 to discuss the issue of ‘age’. During the two, three-day meetings, expert witnesses gave evidence and Council members were able to ask them questions. Expert witnesses included:
 - Harry Cayton, Director of Patient Experience and Public Involvement, Department of Health
 - Professor Alan Williams, Professor of Economics, Centre for Health Economics, University of York
 - Karen Newbigging, Director of the Centre for Mental Health Services Development, England
 - Professor David Barnett, Chair, NICE Appraisal Committee

- Carole Longson, NICE Appraisal Programme Director.
 - The Council is facilitated by an independent company, Vision 21. Most decisions were reached by consensus, with votes being taken where necessary.
 - The Open University has been appointed to independently evaluate the work of the Citizens Council for the first two years following its inauguration. Their research will provide information for NICE on how to maximise value from the Citizens Council.
- 2. NICE Response:**
- The report will be presented to the NICE Board on Wednesday 21 January. NICE will issue a formal response setting out the Board's reaction to the recommendations contained in the report at the next NICE Board meeting on **Wednesday 17 March**.
 - The response will be published on the NICE website alongside the Council's report, and will make clear how the recommendations made will inform the Institute's work and that of the independent groups and committees who advise it.
 - The report is published on the NICE website at www.nice.org.uk