


# NICE citizens council

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## The Citizen's Council

- Attracted by citizen's jury approach, but:
  - We wanted a larger group (30 people)
  - And a more stable membership – but with planned turnover
  - Independent facilitation
  - *External evaluation*
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## Citizens Council topics

- Clinical need
  - Age
  - Patient confidentiality
  - Funding of treatments for very rare diseases
  - Mandatory public health measures
  - Rule of rescue
  - Health inequalities
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## Age and Rare Conditions

- Are there circumstances in which the age of a person should be taken into account when NICE is making a decision about ho treatments should be used in the NHS?
  - Should the NHS be prepared to pay premium prices for drugs to treat very rare conditions?
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## Age - conclusions

- Health should not be valued more highly in some groups than others
  - Individuals' social roles, at different ages, should not influence considerations of cost effectiveness
  - Where age is an indicator of either benefit or risk, age discrimination (positive or negative) is appropriate
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## Rare conditions - conclusions

- Yes, but ....
  - The condition should be severe or life-threatening
  - The treatment should produce real and demonstrable improvements in health
  - Some limit – unquantified – should be placed on the amount that the NHS should be asked to pay
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## Applying the Citizens Council's output

- The key 'receptor points' inside NICE are its independent advisory bodies
  - Principle vehicle is our *guide to social value judgements*
  - Informed by the Citizens Council advice
  - Principles, covering:
    - Process
    - Economic evaluation
    - People
    - Conditions
  - Subject to period review and updating
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## Concluding observations

- Establishing the ‘value’ of an intervention requires a ‘values’ based approach – since it’s clear that the former is influenced by the latter
  - The challenge is establishing what values to take into account, in a diverse, multi-ethnic society
  - The Citizens Council is part of a broader effort by NICE to engage with the public
  - *Ultimately requires a wider debate – involving those who account, ultimately, for the health system*
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