

# Patient involvement in NICE technology appraisals

**Marcia Kelson, Associate Director,  
Patient and Public Involvement Programme  
National Institute for Health and Clinical Excellence (NICE)**

# Outline of presentation

3. Opportunities for patient and carer involvement in NICE technology appraisals
5. What patients say about involvement

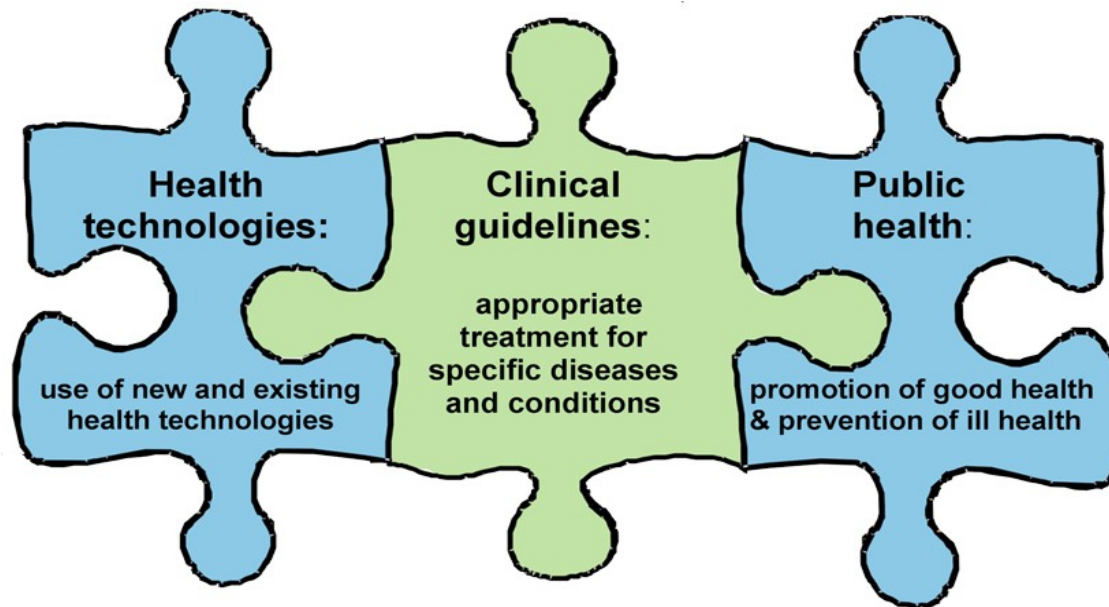
# The Role of NICE

To provide national guidance on the promotion of good health and the prevention and treatment of ill health.

Most NICE guidance draws on evidence of both clinical and cost effectiveness

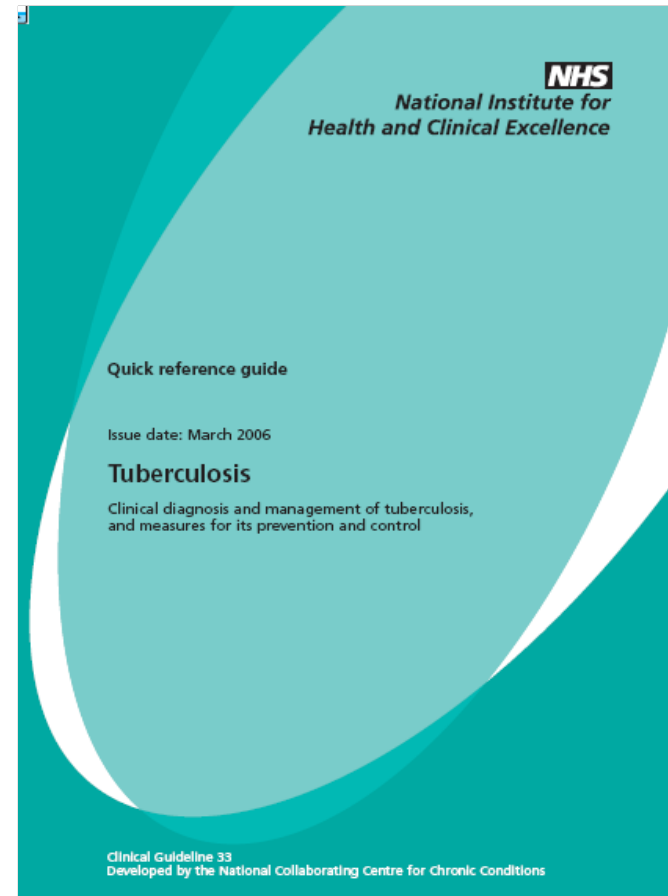
## NICE activities...

**NICE produces three main types of guidance**



# Essential features of NICE guidance

- Robust
- Transparent
- Inclusive
- Independent

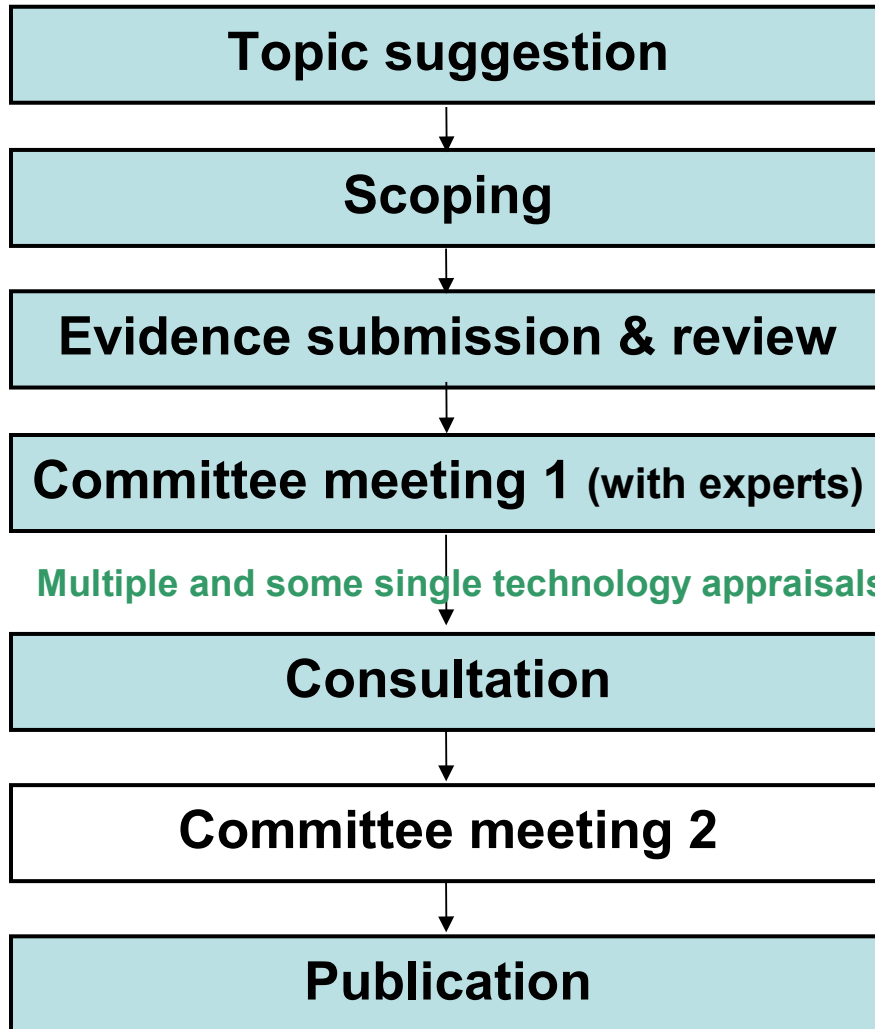


## **NICE patient/public involvement policy**

The views of patients and the public matter to NICE. We want to involve them, as well as doctors, nurses, other healthcare professionals and managers in our work.

By working with patients, patient organisations and the public, NICE aims to produce guidance that addresses patient/ public issues, reflects their views and meets their healthcare needs.

# When can patients get involved in NICE technology appraisals?



Patient and carer participation throughout process

Single Technology appraisals only

# Patient involvement in NICE appraisals: who gets involved?

- **Three lay people** on each appraisal committee
- **National, condition/client relevant patient groups** can:
  - comment on draft documents
  - provide written submissions of evidence
  - nominate patient experts
  - [appeal]
- **Individual patients/carers** can attend as patient experts
- **Anyone** can suggest topics/comment on draft recommendations
- **Citizens Council** advises on overarching societal values

# What information do patients provide to NICE?

- The personal impact of the condition
- Outcomes patients want from the technology
- The impact of a technology on outcome, symptoms, physical & social functioning, quality of life
- Ease of use, side effects and costs of the technology
- Subgroups who benefit more/less from the technology
- Information that complements/challenges professional or researcher views

NICE states that patient evidence is most useful when it balances positive and negative views

# What do patients say about the NICE appraisals process?

# Sources of information on patient views

- The Press
- Formal commentaries from patient organisations
- Informal feedback from patient organisations and involved patients
- NICE survey of patient experts

# Patient views in the press

**DYING - FOR THE SAKE OF £70 PER DAY**

LUNG cancer victim Tony Harper has only weeks to live.

**Victims of the IVF postcode lottery**



**Give us the sight-saver**

**New drug that can prevent blindness 'is being denied'**

By Ben Quinn

THOUSANDS risk losing their sight because they are being denied a 'breakthrough' drug on the NHS, it is claimed.



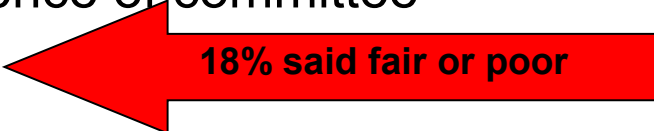


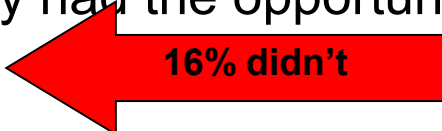
# Views about the NICE appraisals process: patient organisation views \*

General acceptance of NICE role **but** concerns about:

- Lack of research evidence on patient views/preferences
- Outcome/quality of life measures often determined by professionals/researchers
- The weighting NICE places on patient evidence
- Technical language/modelling are difficult to engage with/challenge
- NICE 'blight'
- Variable access to NICE recommended technologies

\* Source: patient group submissions, Health Select Committee 2007

# Views about the NICE appraisals process: survey of patient experts

- 82% patient experts said overall experience of committee meetings was excellent or good 
- 96% understood all the questions that were asked
- 38% fully understood the slide presentation 
- 42% fully understood the committee discussions 
- 82% felt they had the opportunity to raise all the issues they wanted to 

# Patient quotes (1)

- “NICE plays a critical role in ensuring that NHS treatment is equitable, cost effective and of a uniformly high standard.” 😊
- “NICE listened carefully to patient representations [...] and changed their technology appraisals as a consequence” 😊
- “NICE has provided a valuable conduit to address issues surrounding South Asian health, a conduit that before the inception of NICE never existed.” 😊

## Patient quotes (2)

- “The views of patients may not always be given as much weighting as the more traditional sources of evidence.” 😞
- “Evidence from people with experience of the drugs is used as pointers to consider further published research rather than as evidence in its own right: *Methods for incorporating patient evidence into the appraisal process should be developed*” 😞
- “Decisions place greater weight on evidence for survival benefits of treatment, than on improvements to quality of life” 😞

## Patient quotes (3)

- “Committee meetings can be intimidating for patient experts [...] dominated by technical discussion” 😞
- “Health economists seem to find it particularly difficult to present their work in a form that is intelligible to the non-specialist. It is therefore very difficult for a lay participant to challenge the economic evidence.” 😞
- “Clinical trial design should be re-evaluated to ensure that appropriate evidence is presented to NICE.” 😞

# Challenges for patient involvement

## in HTA

- Patient involvement is resource and time intensive
- Eliciting information relevant to HTA (what and how?)
- Complexity and technical nature of HTA
- Maximising transparency in how patient views influence decision making
- Managing expectations
- You cannot please all of the people all of the time!

*Thank you for listening*

