

Patient, carer and public involvement in NICE technology appraisals

**Marcia Kelson, Associate Director,
Patient and Public Involvement
Programme**

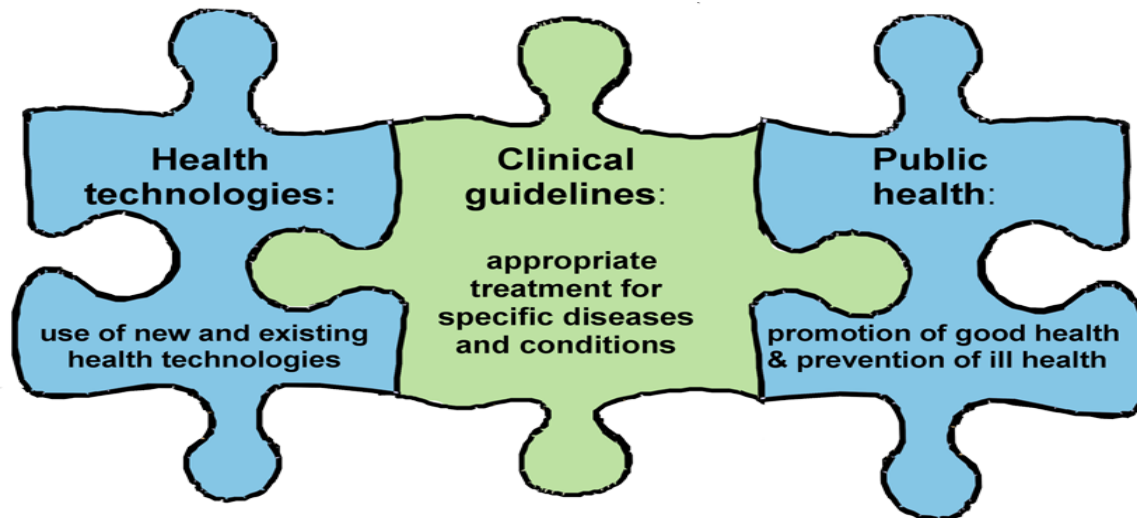
**National Institute for Health and Clinical
Excellence (NICE)**

Outline of presentation

1. The role of NICE and opportunities for patient, carer and public involvement in NICE technology appraisals
2. What patients and the public say about the NICE appraisals process

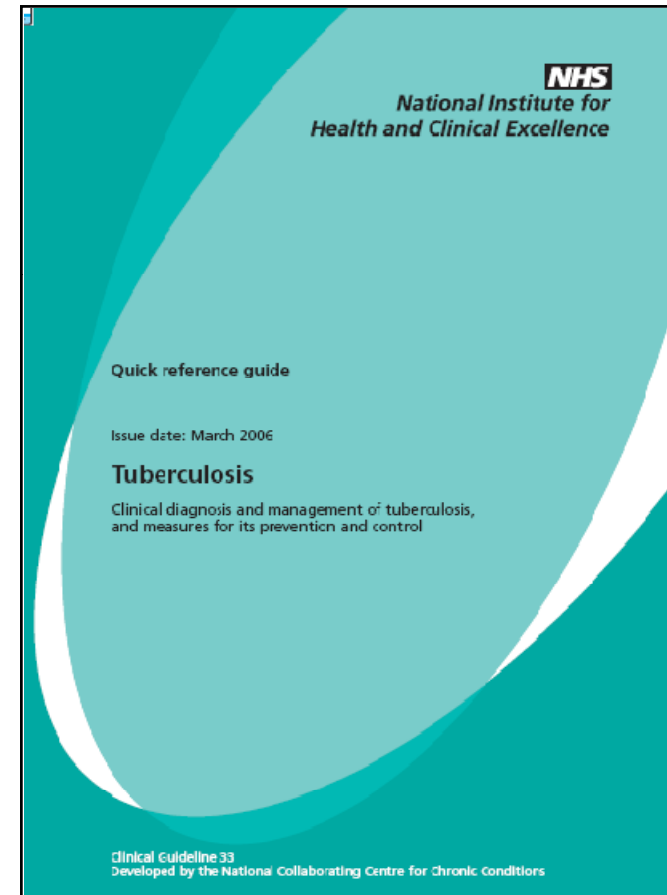
What is NICE?

- The organisation responsible for providing national guidance on promoting good health and preventing and treating ill health
- NICE guidance draws on evidence of both clinical and cost effectiveness
- NICE produces three main types of guidance



Essential features of NICE guidance

- Robust
- Transparent
- Independent
- Inclusive

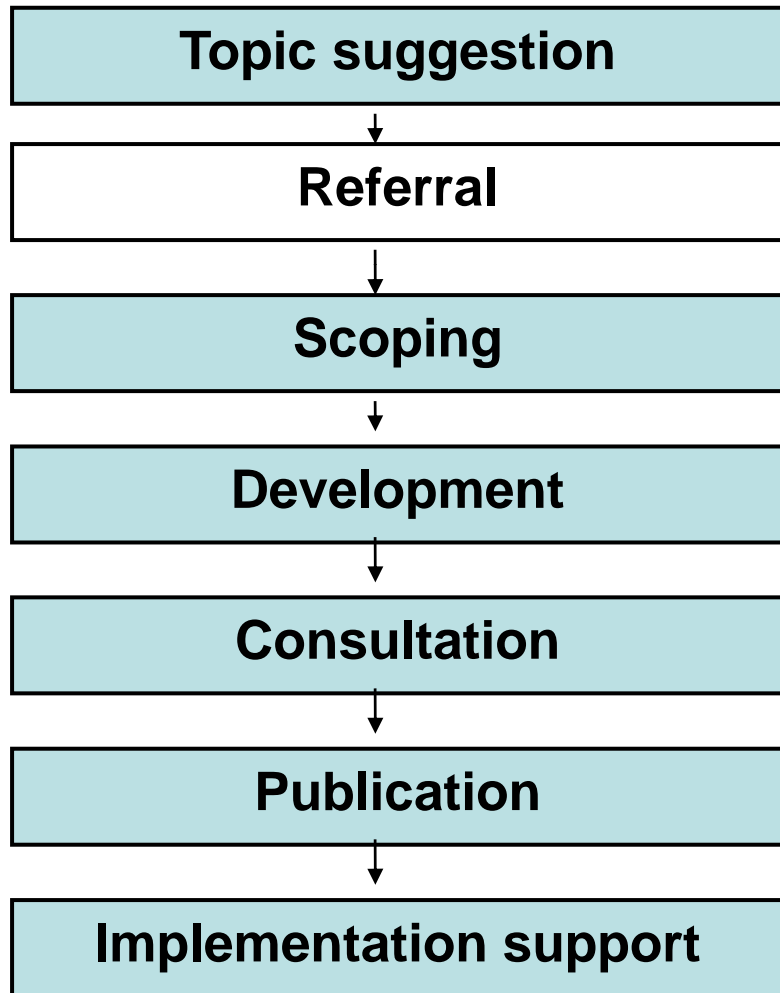


NICE patient/public involvement policy

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.

NICE technology appraisals: WHEN can people get involved?



Patient/ public participation throughout development and implementation

NICE technology appraisals: WHO can get involved?

- **Three lay people** on each appraisal committee
- **National, condition/client relevant patient groups** can:
 - Contribute to development of the appraisal scope
 - comment on draft documents
 - provide written submissions of evidence
 - nominate patient experts
 - Support uptake of positive guidance
- **Individual patients/carers** can attend as patient experts
- **Anyone** can suggest topics/comment on draft recommendations
- **Citizens Council** advises on overarching societal values

NICE technology appraisals: WHAT can patients tell us?

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

Patient evidence is most useful when it balances positive and negative views

The Citizens Council: Public views on social value judgements

- 30 members of the public
- Use deliberative methods to consider societal and ethical issues
E.g. should
 - NICE take age into account?
 - NICE consider self inflicted nature of some conditions?
 - The NHS pay more for treatments for people with rare conditions?
- Council's views underpin **social value judgements** used by NICE advisory bodies



Social Value Judgment principles developed from Citizen Council reports

- **Age:** patients should not be denied, or have restricted access to, NHS treatment simply because of their age.
- **Self inflicted illness** NICE ... should avoid denying care to patients with conditions that are, or may be, self-inflicted (in part or in whole).
- **Rare conditions:** NICE considers that it should evaluate drugs to treat rare conditions, known as 'orphan drugs', in the same way as any other treatment

What do patients, carers and the public say about the NICE appraisals process?

Patient/public 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.







NICE appraisals process: patient organisation views *

General acceptance of NICE **but** some concerns:

- Lack of research evidence on patient experiences
- Quality of life measures often determined by professionals
- The weighting NICE places on patient evidence
- Technical language and modelling are difficult to engage with or challenge
- Variable access to NICE recommended technologies

Source: patient group submissions to the parliamentary Health Select Committee

NICE appraisals process: patient expert views

- 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 guidance 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 and the public may not always be given as much weighting as the more traditional sources of evidence.” 😞
- “Decisions place greater weight on the evidence for survival benefits of treatment, than on improvements to quality of life” 😞
- “Meetings can be intimidating [...] dominated by technical discussion. It is therefore very difficult for a lay participant to challenge the economic evidence.” 😞

Challenges for patient and public involvement in HTA

- Patient involvement is resource and time intensive
- Eliciting information relevant to HTA (what and how to balance?)
- Complexity and technical nature of HTA
- Maximising transparency in how patient views influence decision making
- Securing involvement when decisions are not always acceptable to patients and the public

Contact details

Marcia Kelson

Associate Director

Patient & Public Involvement Programme

**National Institute for Health and Clinical
Excellence (NICE)**

Tel: +44 (0) 20 7045 2051

Email: marcia.kelson@nice.org.uk

Website: www.nice.org.uk