

Assessment and measurement of patient needs and experiences

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Overview of presentation

- Description of National Institute for Health and Clinical Excellence (NICE)
- Patient and public Involvement
- Nature of evidence
- Role of patients in evidence

NICE....what is it ?

The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. It was established in 1999 as a Special Authority and in 2005 it was expanded to include the functions of Health Development Agency



Core principles of all NICE guidance



- Comprehensive evidence base
- Professional input
- Patient and carer involvement
- Independent advisory committees
- Genuine consultation
- Open and transparent process
- Equalities considerations
- Regular review

NICE patient and public involvement policy

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

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

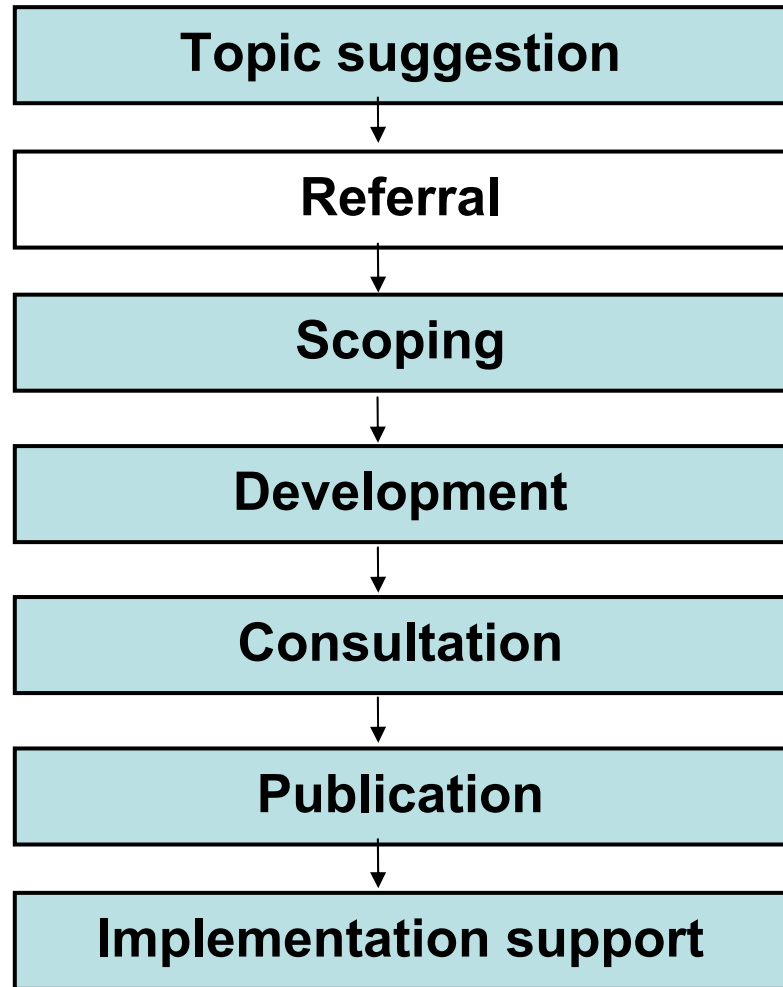
NICE patient and public involvement: Aims

- To develop fair, transparent, accountable and effective **procedures** for patient/public involvement
- To ensure that patient/public perspectives are **represented** in NICE processes and products

“Levels” of patient/ public involvement at NICE

- **Direct input:** membership of NICE advisory bodies (minimum 2, often 3, can be 6!)
- **Consultation** with patient and voluntary organisations
- **Patient/carer experts** (personal testimony)
- **Citizens Council** (societal values)
- **Patient/public versions** of NICE guidance

Stages for patient/public involvement in guidance development



Patient/ public participation throughout development and implementation

NICE Patient & Public Involvement Programme (PPIP)

- Advises NICE on methods for involving patients, carers and the public
- Identifies patient and community participants (organisations and individuals)
- Provides information, training and support to patients and lay people who engage with NICE (as individuals or organisations)

The Nature of Evidence

*“What is now proved
was once only
imagined”*



*Picture of Sir Isaac Newton by William Blake –
English Poet and Artist (1757-1827)*

***To support innovation NICE needs to be able to handle
“immature” evidence***

Evaluating the evidence



Judgements to be made

NICE adopts a new approach to evidence

“One law for the lion and the ox is oppression.”



Assess evidence in relationship to its “fitness for purpose” rather than according to pre-ordained hierarchies

NICE approach has 4 steps to assessing evidence

Step 1: Define the clinical or public health question

Step 2: Identify the evidence

Step 3: Synthesise and assess the body of evidence

Step 4: Issue the recommendations

William Blake – English Poet and Artist

*“God forbid that truth
should be confined to
mathematical
demonstration ”*

*NICE makes scientific
and social values
judgements*



Voice of the Public – the citizens council

The screenshot shows the NHS website's 'Reports' page for the Citizens Council. The navigation menu includes Home, Our guidance, Using guidance, Get involved, News & Events, and About NICE. The main content area is titled 'Reports' and explains that the Council submits reports to NICE. It lists several reports with their dates:

- Citizen's Council report: Rule of rescue** (16/06/2006)
- Citizens Council report: Mandatory public health measures** (05/10/2005)
- Open University Evaluation report** (23/03/2005)
- Citizens Council report: Ultra Orphan drugs** (14/02/2005)
- Citizens Council report: Confidential enquiries** (27/07/2004)
- National Children's Bureau report** (05/07/2004)
- National Children's Bureau report, Appendix 1** (05/07/2004)
- National Children's Bureau report, Appendix 2** (05/07/2004)

On the left, a sidebar lists 'Get involved' options, including 'Patient and public involvement' and 'Citizens Council'. On the right, there are search and order guidance boxes.



What information do patients and carers provide to NICE?

- The personal impact of their condition
- Outcomes patients want the technology to help with
- The impact of a technology on outcome, symptoms, physical & social functioning, quality of life
- Impact on family, friends and employers
- Ease of use, side effects and costs of the technology
- Patient preferences
- Subgroups who might benefit more/less from the technology
- Challenges to professional or researcher views
- Areas needing further research

Patient evidence is most useful when presented as a summary that balances positive and negative views

Testimony from patient experts: patient preferences

Case study – Targeted biological therapies

Some patients prefer self-injecting at home: greater flexibility, fewer costs incurred

Some patients however prefer intravenous infusions: fixed regular appointments, problems with 'sharps' collections

However most people prefer oral administration over both.



Testimony from patient experts: adding to the evidence base

Case study – Psoriasis

Clinical research told us the amount of psoriasis was what most affected the quality of life.

Patients told us that the location of the flare-up (e.g. face or joints) was more significant.



Consultation with patients groups: adding to the evidence base

Case study – Kidney dialysis

Committee assumed patients would prefer dialysis at home.

Some patients told us they disliked home machines as it meant their illness dominated their lives.



Patient feedback on draft guidance: challenging the evidence

Case study – Age-related Macular Degeneration (AMD)

Vision in one or two eyes:

Evidence suggested that loss of sight in one eye impacts little on quality of life.

Patient organisations, patients and carers clearly indicated that there were significant negative effects of loss of binocular vision on daily activities and quality of life.



Patient/public concerns with NICE

- Lack of research evidence on patient/carer views, experiences and preferences
- Quality of life measures often determined by professionals and don't reflect issues of most importance to patients
- The weighting NICE places on evidence from patient submissions and patient experts
- Process doesn't take account of wider societal costs
- Technical language and modelling are difficult to engage/challenge
- NICE 'blight'/ variability in access to NICE recommended technologies/ Political priorities dominate



MRC/NICE Methodological Research Prioritisation Exercise

- Area 1: Analysis and design of effectiveness studies and their synthesis**
- Area 2: Synthesis of evidence from patients, the public and stakeholders**
- Area 3: Economic analysis and uncertainty**
- Area 4: Measurement and valuation of benefits**
- Area 5: Decision-making at NICE**

More information

Patient and Public Involvement at NICE:

www.nice.org.uk/getinvolved/patientandpublicinvolvement

Patient guidance collection:

www.nice.org.uk/patientsandpublic/index.jsp

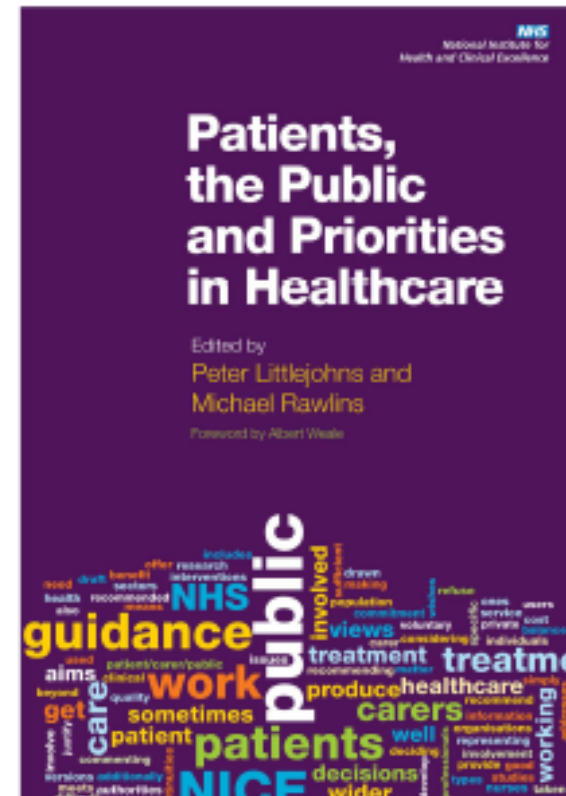
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