

Patient and Public Involvement in the work of NICE



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Involving people - a key NICE policy



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

Who do we involve?

- People with personal experience of the condition, illness or health problem
- Relatives and carers
- Members of organisations representing patient and public interests
- Advocates and other relevant staff from organisations representing patient and public interests
- Members of the general public



How do we involve patients and public?

- **Citizens Council**
 - members of public advise on society's values
- **NICE committees and other advisory groups**
 - individual patients, carers, users of social care services, and other members of the public with relevant experience
 - at least 2 'lay' members on each committee
 - plus patient / community testimony
- **Organisations representing patient and public interests**
 - consultation at key stages of NICE work

Public Involvement Programme



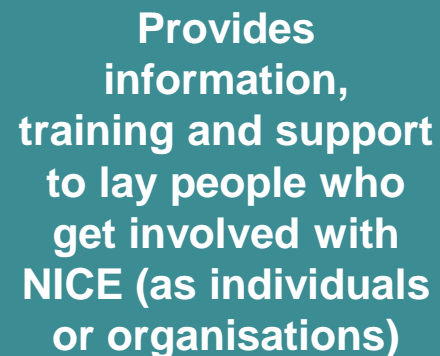
Supports involvement of patients and the public across all NICE work programmes



Advises NICE on methods of involvement



Identifies patient and public participants (organisations and individuals)



Provides information, training and support to lay people who get involved with NICE (as individuals or organisations)

The Citizens Council: advising on social values

- Considers societal and ethical issues relevant to NICE work. For example
 - Should NICE take age into account?
 - Should the NHS pay a premium for treatments for people with rare conditions?
- Council views underpin social value judgement document used by NICE committees and other advisory bodies



Social value 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...unless self-inflicted cause(s) of the condition influence the clinical or cost effectiveness of the use of an intervention
-

Equality Act 2010: governs NICE's approach to applying social value principles when considering legally protected groups.

Joining NICE committees

- All committees and groups that produce NICE recommendations include at least two lay members
- People apply through an open and transparent public recruitment process
- NICE provides lay members with information, training and support



What does NICE look for when recruiting lay members?

Example - patient membership of a clinical guideline group

- No *formal* qualifications are needed
- Experience of the illness or health problem
- Understanding the views of a wider network of patients
- Time to commit to meetings and reading papers
- Communication and team working skills
- Not representing an organisation, or just one point of view



What do patients and the public provide to NICE?

- The personal impact of an illness, disease or condition
- Experiences of care
- Preferences and values
- Outcomes people want from treatment and care
- Impact on family, friends and employers
- Ease of use of a treatment or service; side effects
- The needs of specific groups
- Challenges to professional or researcher views

Patient preferences

Example - 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



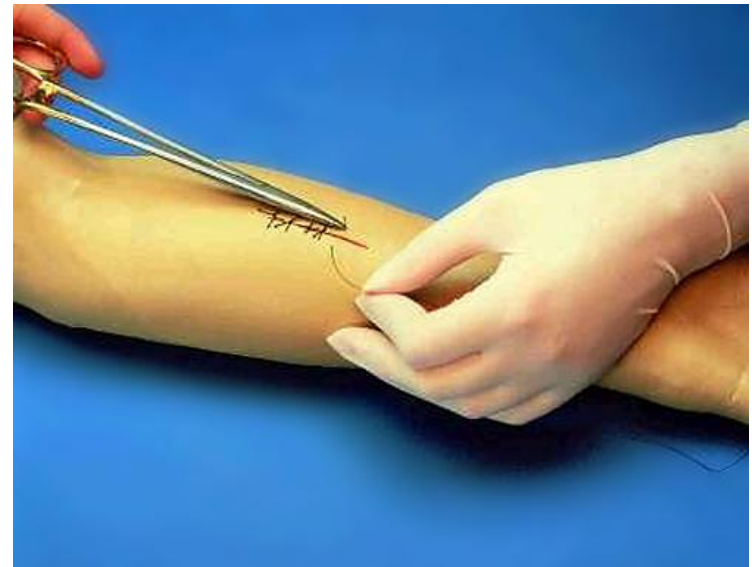
Patients' experience of care

Example – people who self-harm

People in mental distress who self-harm told us that they were not routinely offered anaesthesia or pain relief for sewing up wounds in the hospital emergency department

Nothing in the published research to indicate this

NICE made recommendations to address this



Alison's story...

- What was it like to be a lay member of the guideline development group?

The experience was brilliant, terrifying, rewarding and frustrating in equal measures!

I am very glad I took part and would urge anyone who has experience of their own illness, who has the time to devote to meetings and do the background reading, to step forward now, because they really can help NICE to make a difference.

More information

NHS
National Institute for Health and Clinical Excellence

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Patients and the public



Putting patients and the public at the heart of NICE's work

NICE is committed to involving patients, carers and the public in the development of its guidance and other products. By involving the very people for whom the guidance will be relevant, we put the needs and preferences of patients and the public at the heart of our work. This page gives more information about the opportunities for patient, carer and public involvement at NICE, and how you can get involved with our work.

Developing our guidance with you



Find out how you can suggest a topic and how you can help us develop guidance.

Suggest a topic
Help develop guidance
Our guidance in development

How we involve patients and the public



Our Patient and Public Involvement Programme welcomes your contribution.

Our patient and public involvement policy
Our equality scheme
Contact us

Lay members' perspectives



Our lay members share their thoughts on what it's like being part of a group that develops our guidance.

Alison's story
Linda's story
Susan's story

Putting our guidance into practice



Find out how to put NICE guidance into practice, and how you can help.

Benefits of putting our guidance into practice
Your care
Stakeholder organisations

Public Involvement Programme leaflet

<http://www.nice.org.uk/media/D92/88/PPIPLeflet.pdf>

Search for NICE guidance for patients and the public

<http://www.nice.org.uk/patientsandpublic/index.jsp>

<http://www.nice.org.uk/getinvolved/patientsandpublic/>