

Supporting patients and clinicians in getting the right outcomes

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# What is NICE?

- The independent UK organisation responsible for providing national evidence-based guidance, advice and standards on the most effective ways to prevent, diagnose and treat disease and ill health, promote good health and care, and to reduce inequalities and variation.
- Guidance supports NHS, local authorities, care homes, charities and others to make sure that the care they provide is of the best possible quality and offers the best value for money.
- Guidance supports patients and the public to make informed decisions about their treatment and care, and better manage their health
- We also offer support to those wanting to put our guidance into practice.

# Patient and public involvement at NICE – key principles

- Those most directly affected by our guidance should have the opportunity to contribute to its production – embedded in our methods and processes
- Individual involvement – membership of committees and groups
- Organisational involvement – consultation with key groups
- Outputs for the public – plain English versions

# Patient and public involvement at NICE

- Fundamental and integral part of business
- One of the key building blocks
- Centralised and dedicated team to support PPI
- Formal Board-level policy
- Support from the Senior Management Team
- Key liaisons within other teams

# 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



# What do they tell us?

- The personal impact of an illness, disease or condition
- Experiences of care
- Preferences and values
- Outcomes people want from treatment and care
- Impact of treatment or care on outcome, symptoms, physical & social functioning, quality of life
- 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
- Areas needing further research

# Patient preferences

## ***Example - kidney dialysis***

Committee assumed patients would prefer dialysis at home

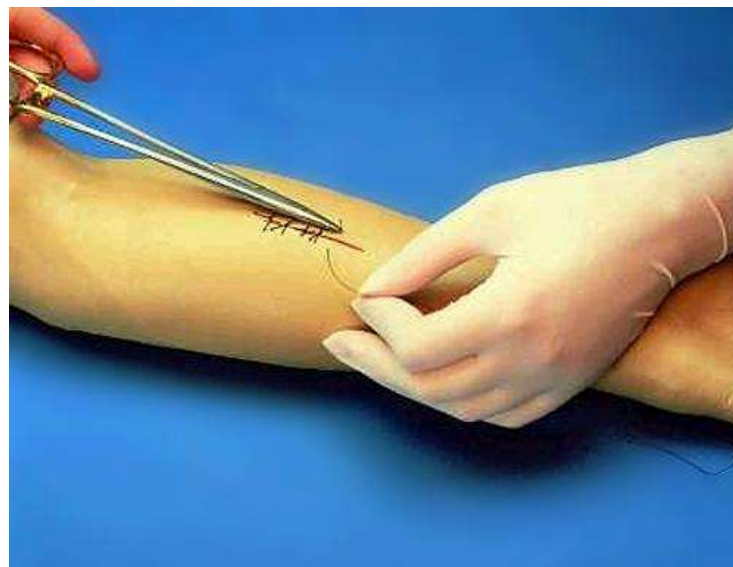
Some patients told us they disliked home machines as it meant their illness dominated their lives



# 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 was an issue
- NICE made recommendations to address this





# Information for the Public

- Summarises NICE recommendations in plain English
- Suggests questions that people might want to ask their doctor, nurse or therapist
- Contains information about patient organisations that can provide additional information and support
- Available on NICE website with printable version  
[www.nice.org.uk/patientsandpublic/index.jsp](http://www.nice.org.uk/patientsandpublic/index.jsp)



The screenshot displays the NICE website interface. At the top, the NHS logo and 'National Institute for Health and Clinical Excellence' are visible, along with navigation links for Home, News, and Get it. Below this is a search bar and a menu with options like 'Find guidance', 'NICE Pathways', 'Quality standards', 'Into practice', and 'QOF'. The main content area features a header for 'Information for the public' published in February 2012, with an icon of three people and the title 'Experiencing good NHS care: what you can expect'. There are buttons for 'View version for health professionals', 'Next', and 'Select chapters share'. A table of contents on the right lists sections such as 'About this information', 'Why NICE has written this', 'Treating you as an individual', 'Help with basic needs', 'Involving you in your care', and 'Your relationships with the NHS'. The bottom of the page shows a footer with the NICE logo and an Internet icon.

# How NICE guidance can inform self-care

- Clinical guideline No 69 – Respiratory Tract Infections (RTIs)

<http://guidance.nice.org.uk/CG69>

- Information for the public

<http://publications.nice.org.uk/use-of-antibiotics-for-respiratory-tract-infections-in-adults-and-children-ifp69>

# Key messages from the guideline

- Most RTIs will get better by themselves
- Most RTIs are caused by viruses and viruses don't respond to antibiotics
- Antibiotics can have unpleasant side effects
- Expected duration of most RTIs
  - Ear infection: 4 days
  - Sore throat: 1 week
  - Common cold: 1½ weeks
  - Sinusitis: 2½ weeks
  - Cough: 3 weeks

# Key messages from the guideline

- Option for ‘delayed prescriptions’
- Occasions when antibiotics should be prescribed immediately
  - children who are younger than 2 years with an ear infection (called acute otitis media) that affects both ears
  - children who have both acute otitis media and discharge from the ear
  - people with severe sore throat who have swollen lymph nodes, discharge on their tonsils and fever
  - people at risk of further complications e.g. those with serious long term conditions, immune system problems

# Additional information in the patient version

- Information about managing symptoms
- Questions to ask your doctor or nurse
- Sources of further information e.g. NHS Choices

# Empowerment for self-care

- Evidence-based information is an intervention
- All decision makers need access to high quality information – patients and clinicians
- NICE guidelines – enables patients to know what care they should (and shouldn't) get
- Manages expectations – patients and clinicians
- Allows for informed conversations and shared decision-making

# Thank you

The screenshot shows the NICE website header with the NHS logo and navigation links. The main content area features a large image of a man and a young girl, with the heading 'Putting patients and the public at the heart of NICE's work'. Below this is a paragraph of text. A grid of four smaller sections follows, each with a title, an image, and a brief description of the content.

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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	How we involve patients and the public	Lay members' perspectives	Putting our guidance into practice
 <p>Find out how you can suggest a topic and how you can help us develop guidance.</p> <p>Suggest a topic Help develop guidance Our guidance in development</p>	 <p>Our Patient and Public Involvement Programme welcomes your contribution.</p> <p>Our patient and public involvement policy Our equality scheme Contact us</p>	 <p>Our lay members share their thoughts on what it's like being part of a group that develops our guidance.</p> <p>Alison's story Linda's story Susan's story</p>	 <p>Find out how to put NICE guidance into practice, and how you can help.</p> <p>Benefits of putting our guidance into practice Your care Stakeholder organisations</p>

Contact us:  
[PIP@nice.org.uk](mailto:PIP@nice.org.uk)

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