

# How NICE involves patients & the public

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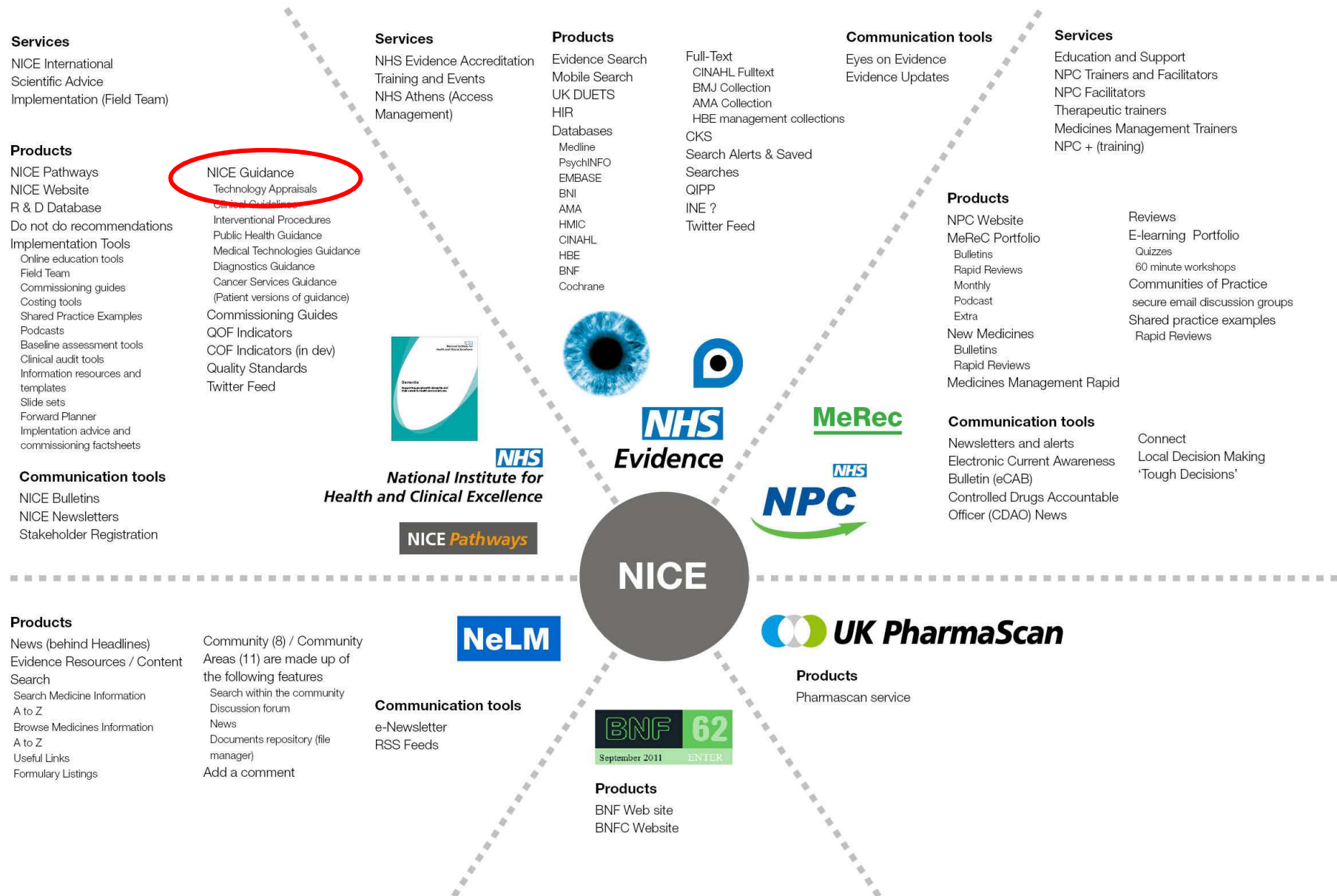
Patient and Public Involvement Programme (PPIP)

National Institute for Health and Clinical Excellence (NICE)

# What is NICE?

- “The independent UK organisation responsible for providing national guidance on promoting good health and preventing and treating ill health”
- Set up in 1999
- ~560 staff in 3 offices: London, Manchester and Liverpool
- 2011-12 budget: ~£68m

# Current NICE products & services



# Core principles of all NICE guidance

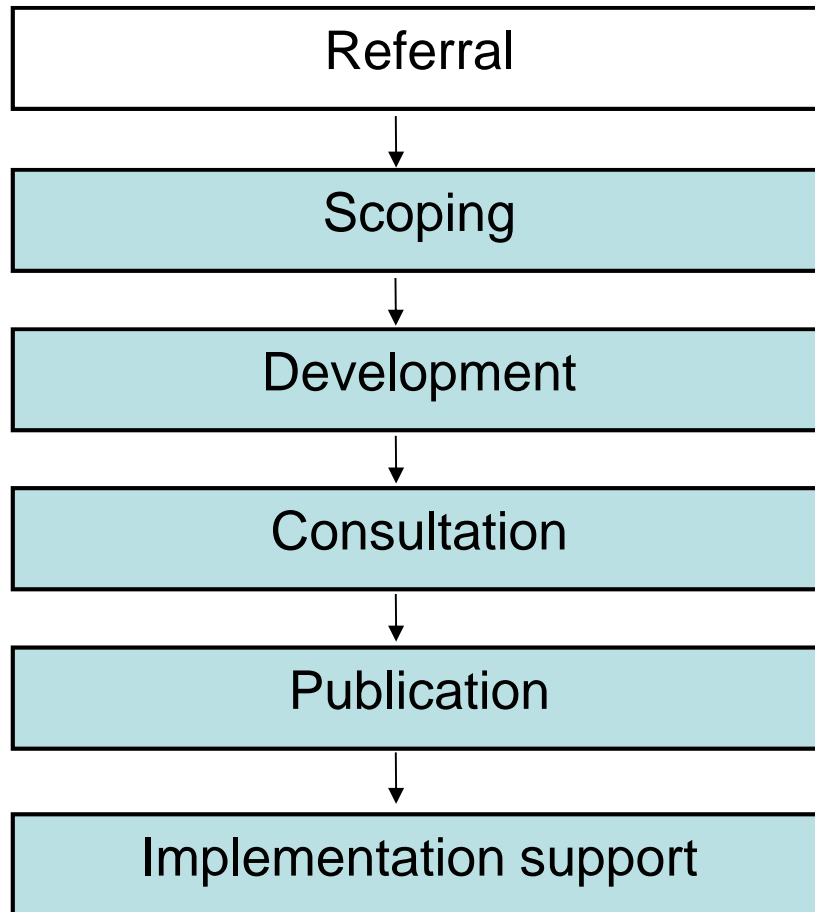


- Comprehensive evidence base
- Expert input
- Patient and carer involvement
- Independent advisory committees
- Genuine consultation
- Open and transparent process
- Equalities considerations
- Regular review

# Patient and Public Involvement: Introduction

- 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
- NICE Patient & Public Involvement Policy

# Stages for patient/public involvement in guidance development



Patient/ public participation throughout development and implementation

# “Levels” of patient/ public involvement at NICE

- **Consultation** with patient and voluntary organisations/charities
- **Patient/carer evidence and views** (submission)
- **Patient/carer experts** (personal testimony)
- **Lay members** (part of decision making – minimum 2, often 3, sometimes 6!)
- **Patient/public versions** of NICE guidance
- **Citizens Council** (societal values)

# What information do patients and carers provide to NICE Technology Appraisals?

- 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



# Making a difference - 1

## 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.



# Making a difference - 2

## 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.



# Making a difference - 3

## 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.



# Making a difference - 4

## 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.



# The Citizens Council: Advising on Social Value judgements

- 30 members of the public
- Use deliberative methods to consider societal and ethical issues for all NICE guidance. For example:
  - Should NICE take age into account?
  - Should the NHS pay a premium for treatments for people with rare conditions?
  - Should NICE take severity into account in the QALY calculation?
- Council's views underpin social value judgements used by NICE committees



# Patient & public involvement - support

- **Patient & Public Involvement Programme (PPIP)**
  - 12 members of staff
  - Advise NICE on methods for involving patients, carers and the public
  - Identify patient and public participants (organisations and individuals)
  - Provide information, training and support to patients and lay people who engage with NICE (as individuals or organisations)





## 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](#)

# More information

- Patient and public involvement at NICE - [www.nice.org.uk/getinvolved/patientsandpublic](http://www.nice.org.uk/getinvolved/patientsandpublic)
- PPI policy - [www.nice.org.uk/getinvolved/patientandpublicinvolvement/patientandpublicinvolvementpolicy](http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patientandpublicinvolvementpolicy)
- Guidance for patients & the public - [www.nice.org.uk/patientsandpublic/index.jsp](http://www.nice.org.uk/patientsandpublic/index.jsp)



# Contact details

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