NICE National Institute for Health and Care Excellence

Stakeholder Engagement in Health Technology Appraisals

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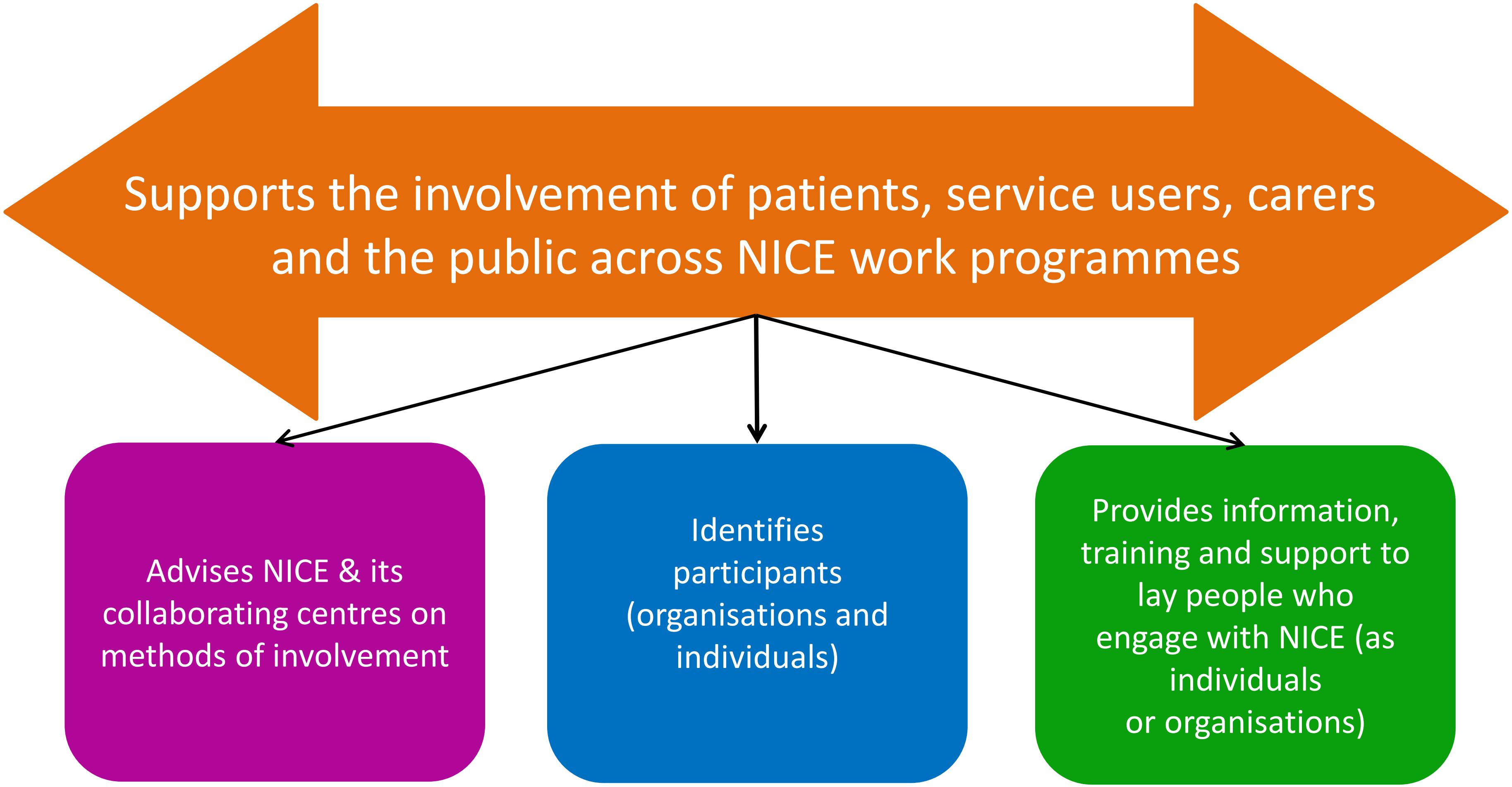
Public Involvement Programme (PIP)



Supports the involvement of patients, service users, carers and the public across NICE work programmes

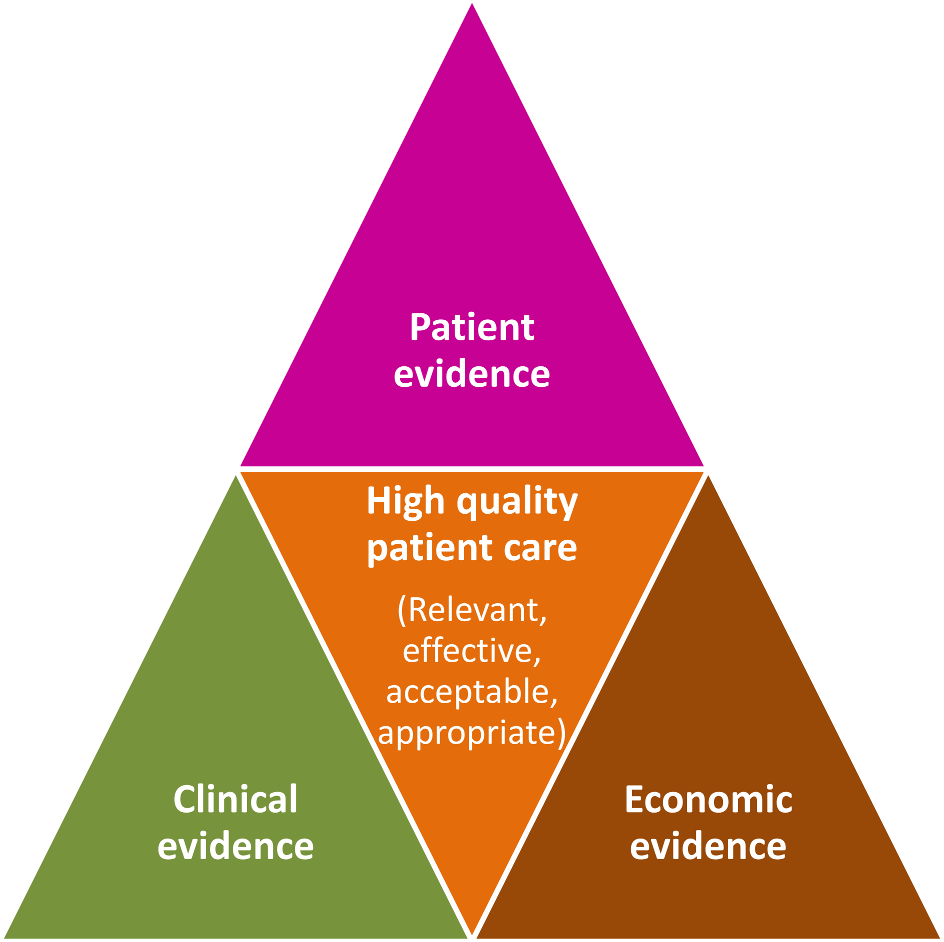
Advises NICE & its collaborating centres on methods of involvement

Identifies participants (organisations and individuals)

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

http://www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy

The nature of evidence



Patient evidence

High quality patient care

(Relevant, effective, acceptable, appropriate)

Clinical evidence

Economic evidence

Acknowledgement: Dr Sophie Staniszewska, RCN Research Institute, University of Warwick

Why should we involve patients?

1. New evidence and information
2. Challenges to evidence/conventional wisdom e.g. outcomes
3. Qualitative context to quantitative data
4. Challenges to professional assumptions
5. Value to the patients in being involved
6. Completing the ‘triangle’

Benefits for patients

- Empowers patients to be more involved in managing their condition

- Empowers patients to become more involved in choices about their care and treatment

- Patients have reported developing new skills and confidence which has helped them in their day-to-day life

- Ensures that health interventions and treatments are relevant to patients and meet their needs

Different types of NICE guidance

Health technologies:

- **Technology appraisals** (drugs etc)
- **Highly specialised technologies** (ultra-orphan drugs)
- Interventional procedures (surgery)
- Medical devices
- Diagnostic technologies

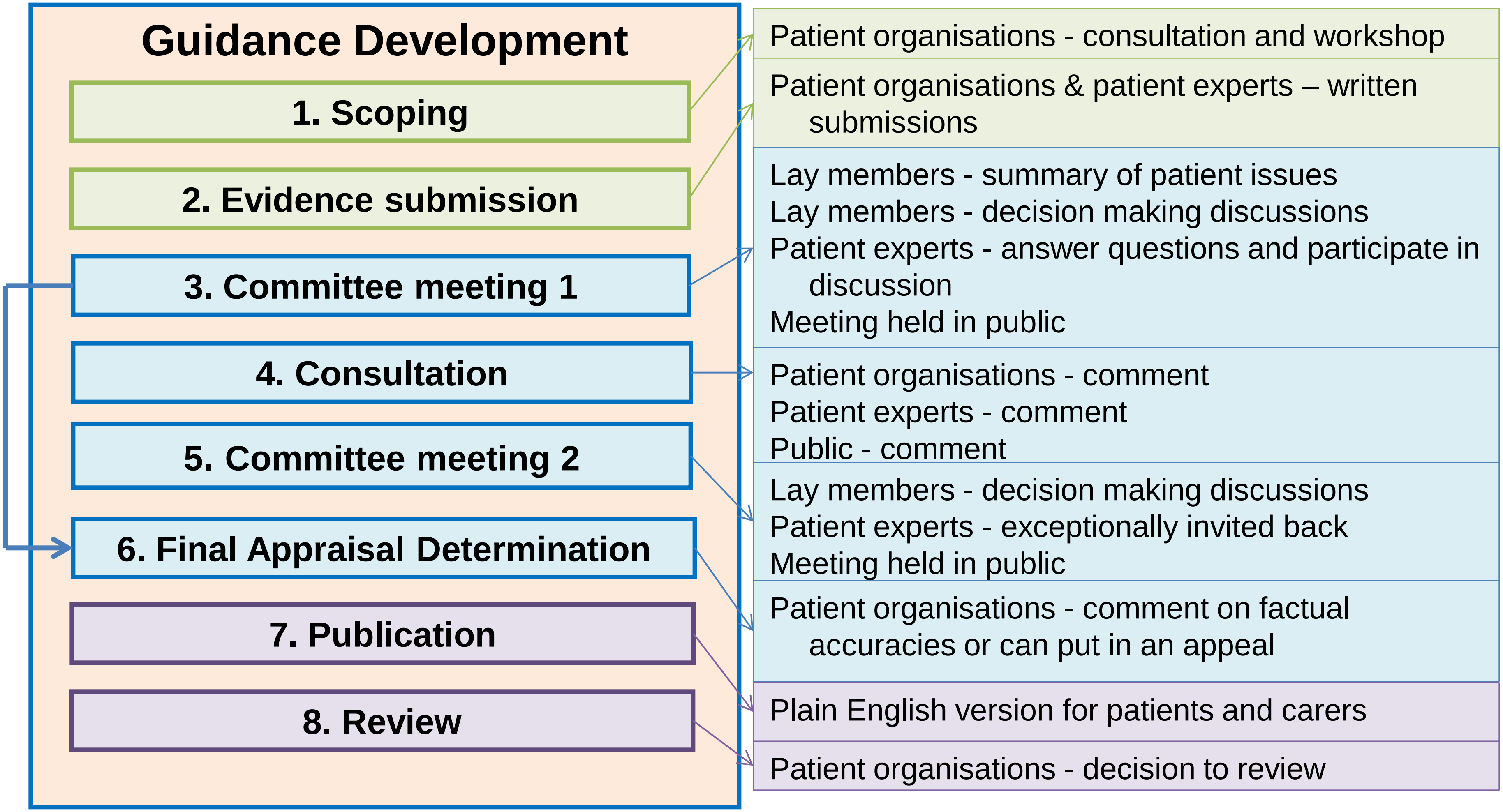
Guidelines and quality standards:

- Clinical guidelines (guidance and standards)
- Public health (guidance and standards)
- Social care (guidance and standards)

4 Key Stakeholders

- **Lay members:** 2 lay people on each appraisal committee
- **National charities:** national patient organisations can comment on draft recommendations and provide submissions
- **Patient experts:** individual patients/carers can attend meetings and provide personal statements
- **Public:** anyone can comment on draft recommendations

Opportunities for patient involvement



Guidance Development

1. Scoping
2. Evidence submission
3. Committee meeting 1
4. Consultation
5. Committee meeting 2
6. Final Appraisal Determination
7. Publication
8. Review

Patient organisations - consultation and workshop

Patient organisations & patient experts – written submissions

Lay members - summary of patient issues
Lay members - decision making discussions
Patient experts - answer questions and participate in discussion
Meeting held in public

Patient organisations - comment
Patient experts - comment
Public - comment

Lay members - decision making discussions
Patient experts - exceptionally invited back
Meeting held in public

Patient organisations - comment on factual accuracies or can put in an appeal

Plain English version for patients and carers

Patient organisations - decision to review

1. The role of the lay members

Appraisal committees

- each include 2 lay committee members
- lead lay member for each appraisal topic

Lay committee member’s role

- lay committee member’s role is the same as other members

PLUS

- to contribute a lay perspective
- to highlight patient and carer issues

2. The role of patient experts

Patient Experts attend as individuals and will have either:

- experience the broader patient population

and/or

- their own personal experience?

Patient experts usually also provide individual statements (or submissions) which may help with information for the lay lead slides – if provided on time.

3. National Organisations

National charities (patient groups)

- participate in scope development (written and oral)
- provide written submissions of evidence
- nominate patient experts
- comment on draft documents (consultation)
- [appeal]

Work with PIP to identify appropriate patient experts and understand their engagement/role with NICE

Patient evidence written submissions

- Standard template
  - Consistency across topics
  - Patient organisations know what the committee wants
  - Patient experts know what the committee wants
- Part of formal evidence-base for topic
- Can be supplemented, or endorsed, by experts' statements

Patient submissions: purpose

Need to get **relevant evidence** and views from **stakeholders** to help the committee understand the condition and issues

- Seek to identify evidence not otherwise available
- Evidence about real-life use (compared with trials)
- Patient and carer views and preferences

The submission template covers

Experience:

Having the condition, or caring for someone with it
Receiving care for the condition
Having treatments

Acceptability and outcomes:

Treatment outcomes important to patients or carers
Acceptability of different treatments
Preferences for different treatments
Expectations about the risks and benefits

Any other issues (including equality and innovation)

Other ways of involving patients

- Consultation – feedback and comment on draft recommendations, from both patient organisations and individual patients

- Appeal a decision

- Support the adoption of final recommendations in health systems

More information

Public involvement

http://www.nice.org.uk/about/nice-communities/public-involvement

PPI Policy

**www.nice.org.uk/getinvolved/
patientandpublicinvolvement/
patientandpublicinvolvementpolicy/patient_and_public_involvement_policy.jsp**

Factsheets/hints and tips

http://www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance

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