



# Optimising patient and patient group involvement in NICE technology appraisals

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Public Involvement Programme

# The background: why NICE was set up

1999

- Established

Aim

- To reduce variation in the availability and quality of treatments and care (the so called 'postcode lottery')

Value for money

- To resolve uncertainty about which medicines and treatments work best and which represent best value for money for the NHS



**NICE**

# Core principles of NICE's work

Based on the best evidence available

Expert input

Patient, service user and carer involvement

Independent advisory committees

Genuine consultation

Regular review

Open and transparent process

Social values and equity considerations



# What we do at NICE (some of it).



# What works? And how much does it cost?



NICE guidance takes into account both

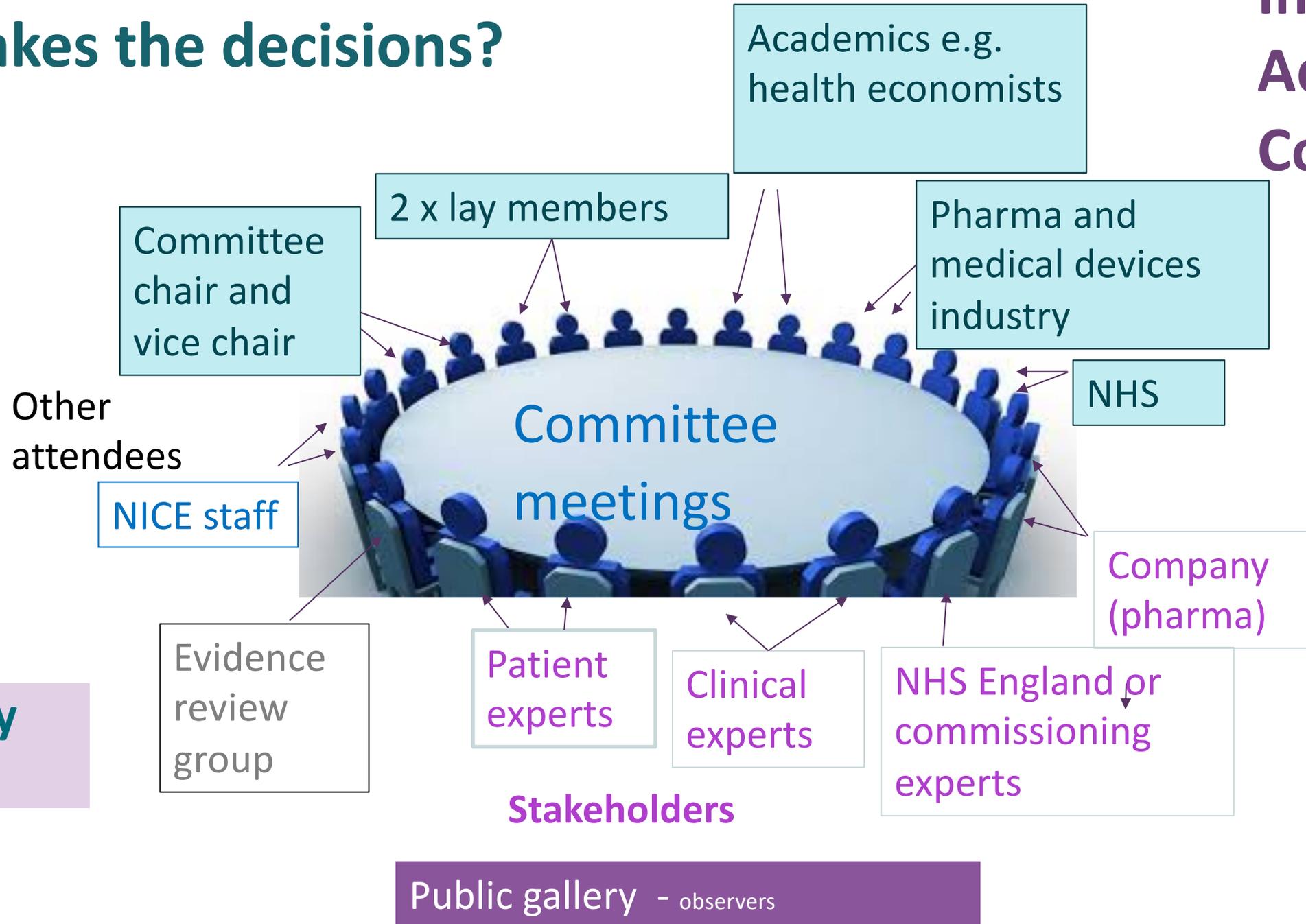
- **clinical** effectiveness
- and **cost** effectiveness



**NICE**

# Who makes the decisions?

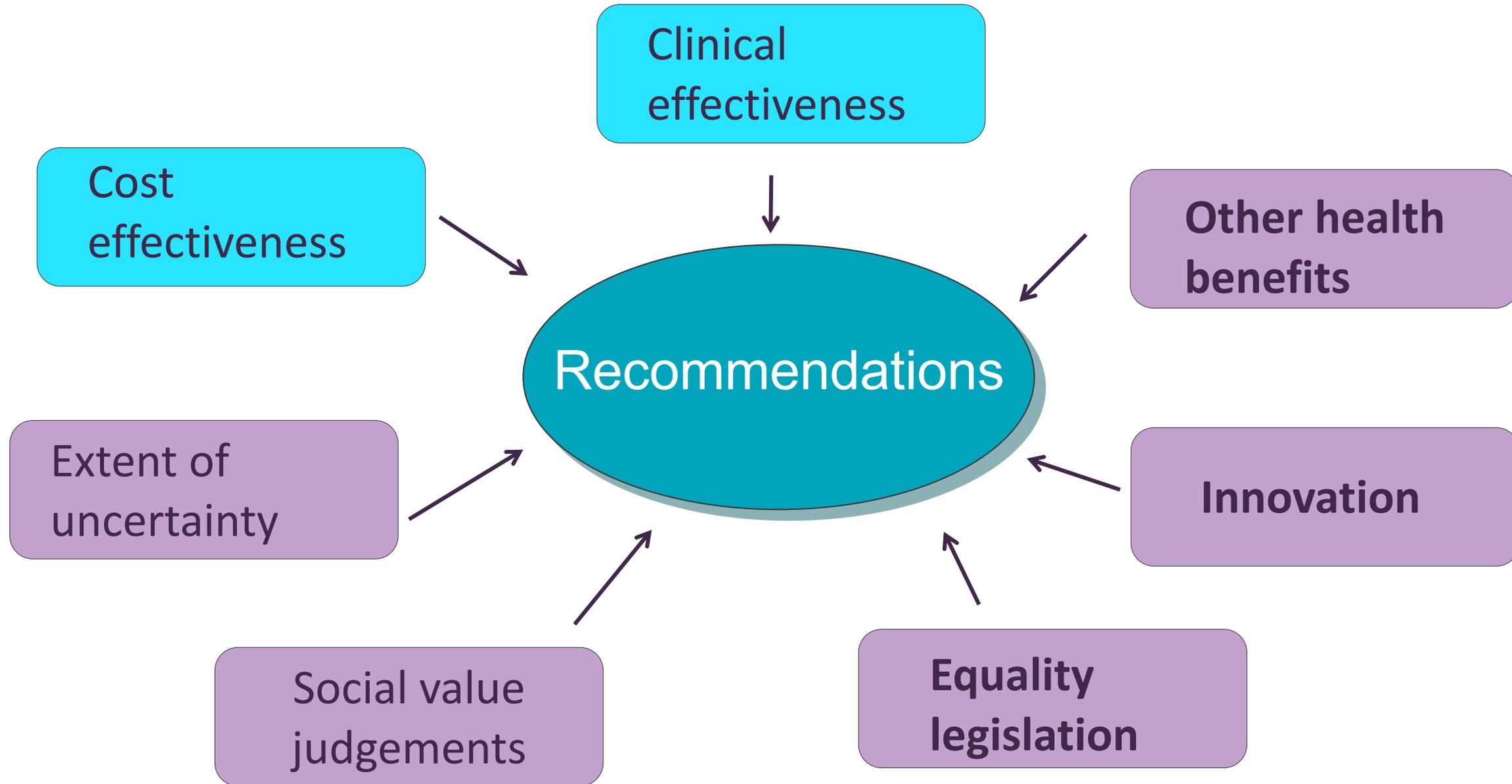
## Independent Advisory Committee



Technology Appraisals

NICE

# Committee decision making



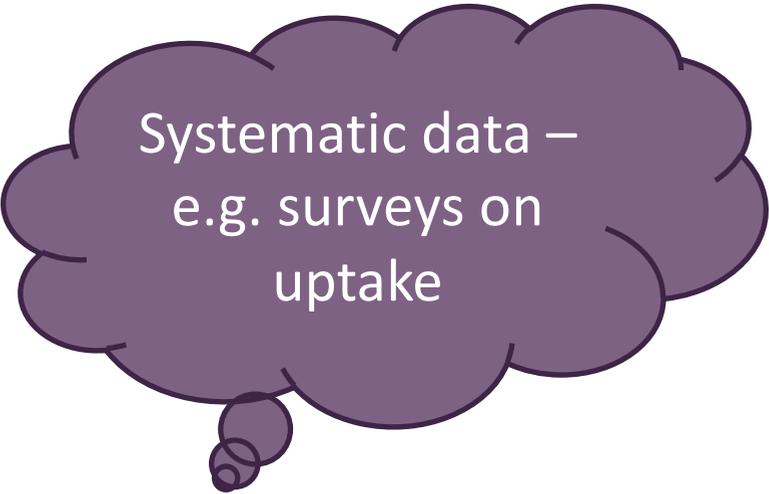
# How can patients help the committee?



Spectrum of disease



Ideas on start and stop criteria



Systematic data –  
e.g. surveys on uptake



Detail on the milder patients



Expectations of treatment



What treatment does not give

How can patients and the public get involved in medicines' appraisals?

(Technology appraisals)



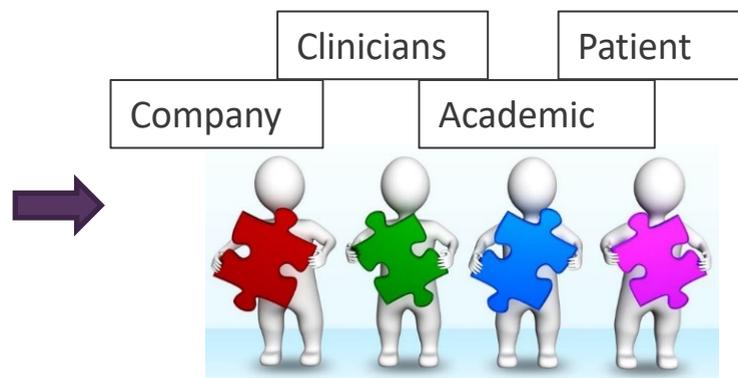
# Key Stakeholders



# What is the process?



Setting the question – includes patients, clinicians and the company



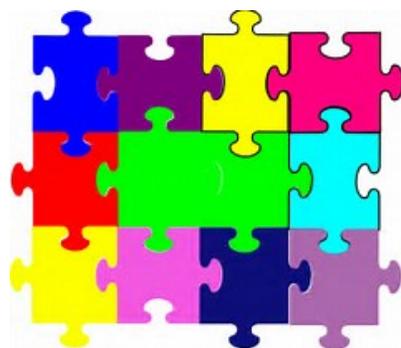
Evidence provided



Evidence sent to the committee



Committee works out how it fits together and identifies gaps.



Puzzle completed



Committee inserts extra pieces



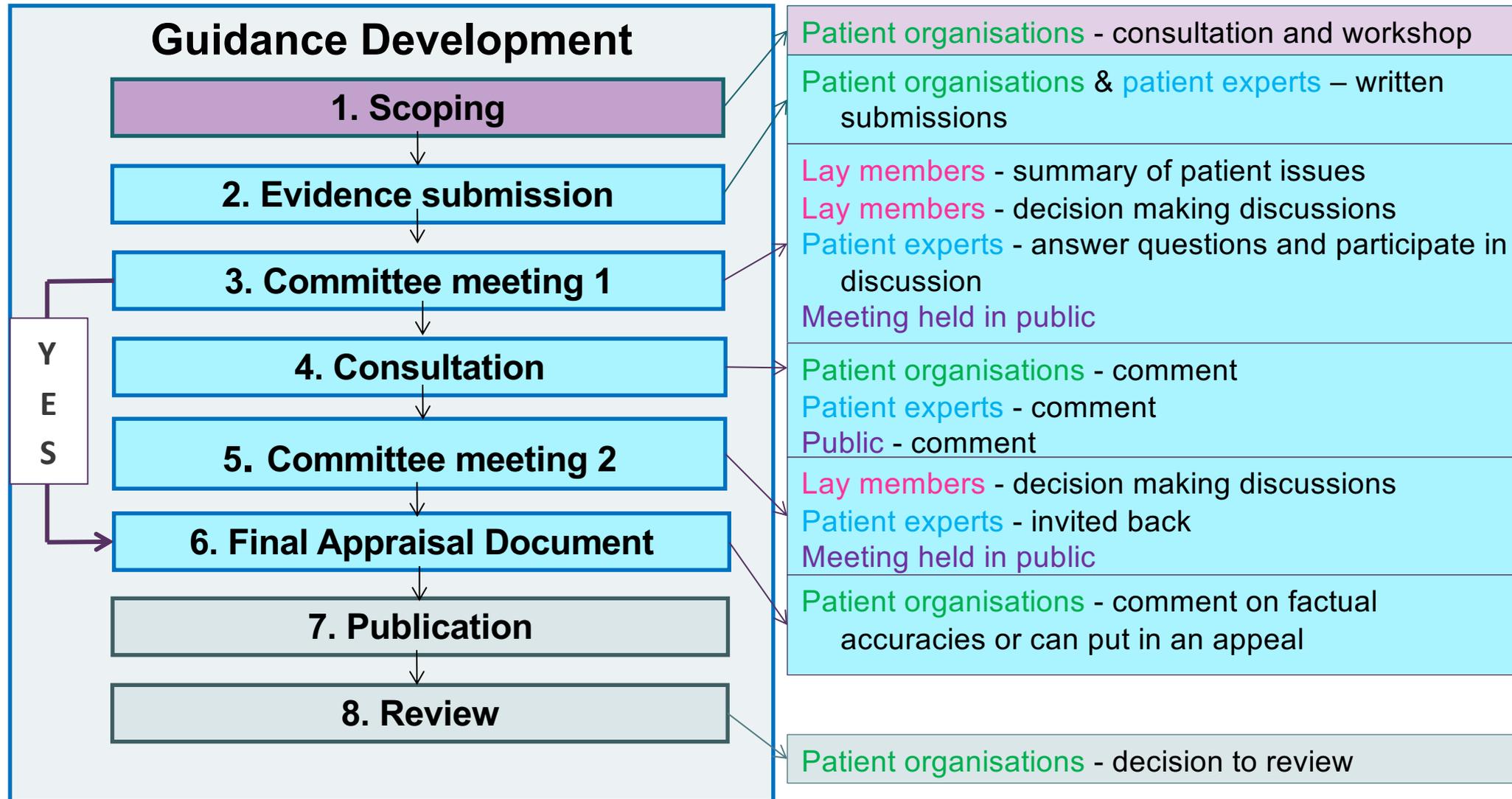
Patients (and others) provide information to fill gaps

# Opportunities for patient involvement in technology appraisals.

(Includes new step – technical engagement.)



# Opportunities for patient involvement in highly specialised technologies



# National organisations' contribution (patient groups)



Scoping

Evidence submission

Nominating experts

Consultation

Appeal

# What do we ask for from patient organisations for scoping?

(Setting the question.)



Treatment



Patient important outcomes



Comparators



Unmet need



Population & sub groups



Equality



The right stakeholders?



Innovation



# What to include in your submission



## Experience

- Those who have the condition
- Their carers and family
- Range of experiences
- Not only exceptional experiences

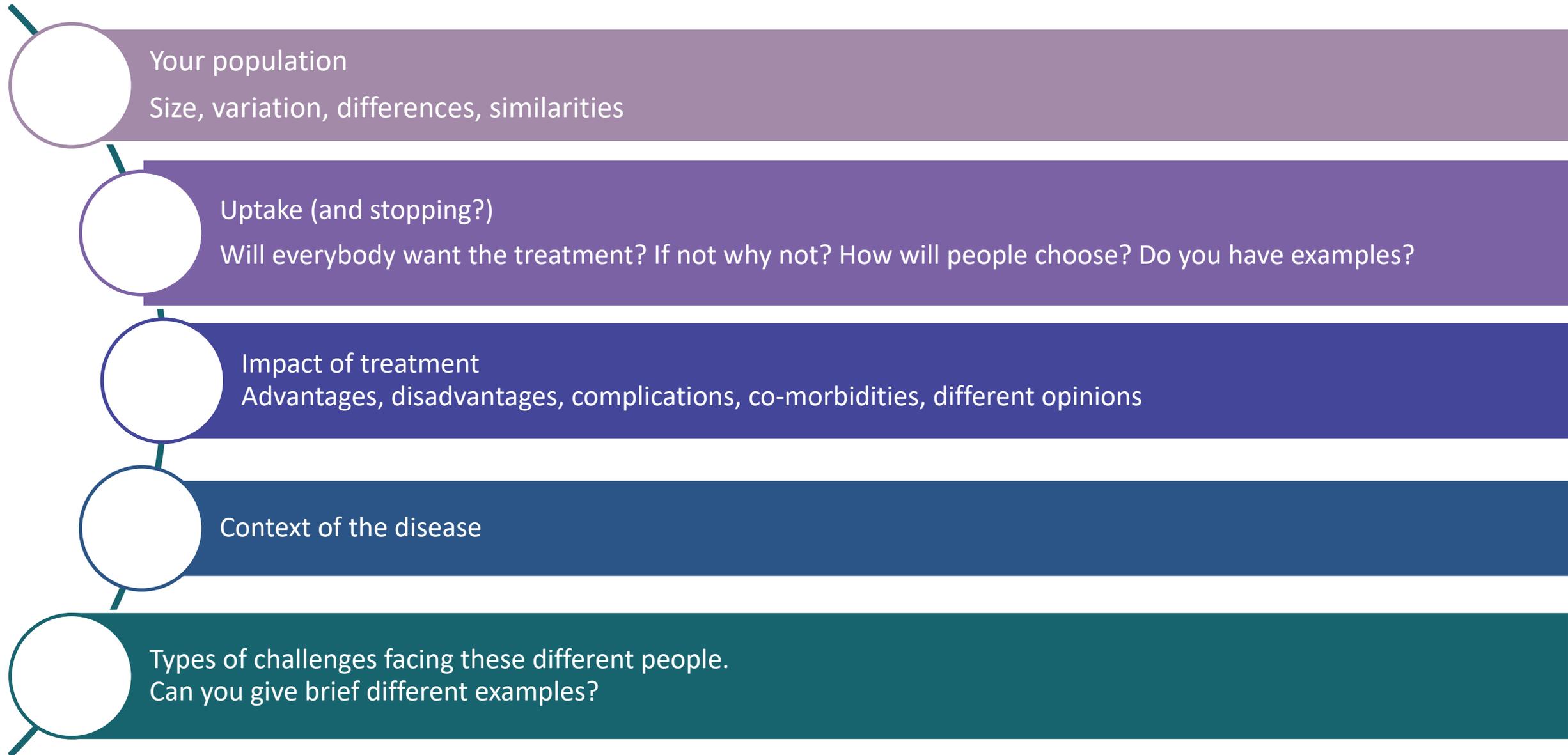
## Quality of Life

- Patients
- Carers and families

## Balance

- Advantages
- Disadvantages

# Things to consider for your submission



# What not to include in your submission



<b>Not necessary</b>	<b>Reason</b>
Clinical or scientific evidence	The company provides this.
Summarised or reworded information from other sources	We already get this. The patients' views, opinions and experiences are unique and we want to hear them from you.
The same message repeated under different headings	Please answer the specific question with the most relevant information so that the committee has the best evidence to make their decision.
Emotive language	This detracts from your key points
An unbalanced submission	Include experiences of a range of people. Include positives and negatives.

# How we can provide support for organisations



Written guides  
Templates  
Online information (written, videos)

Formal  
support



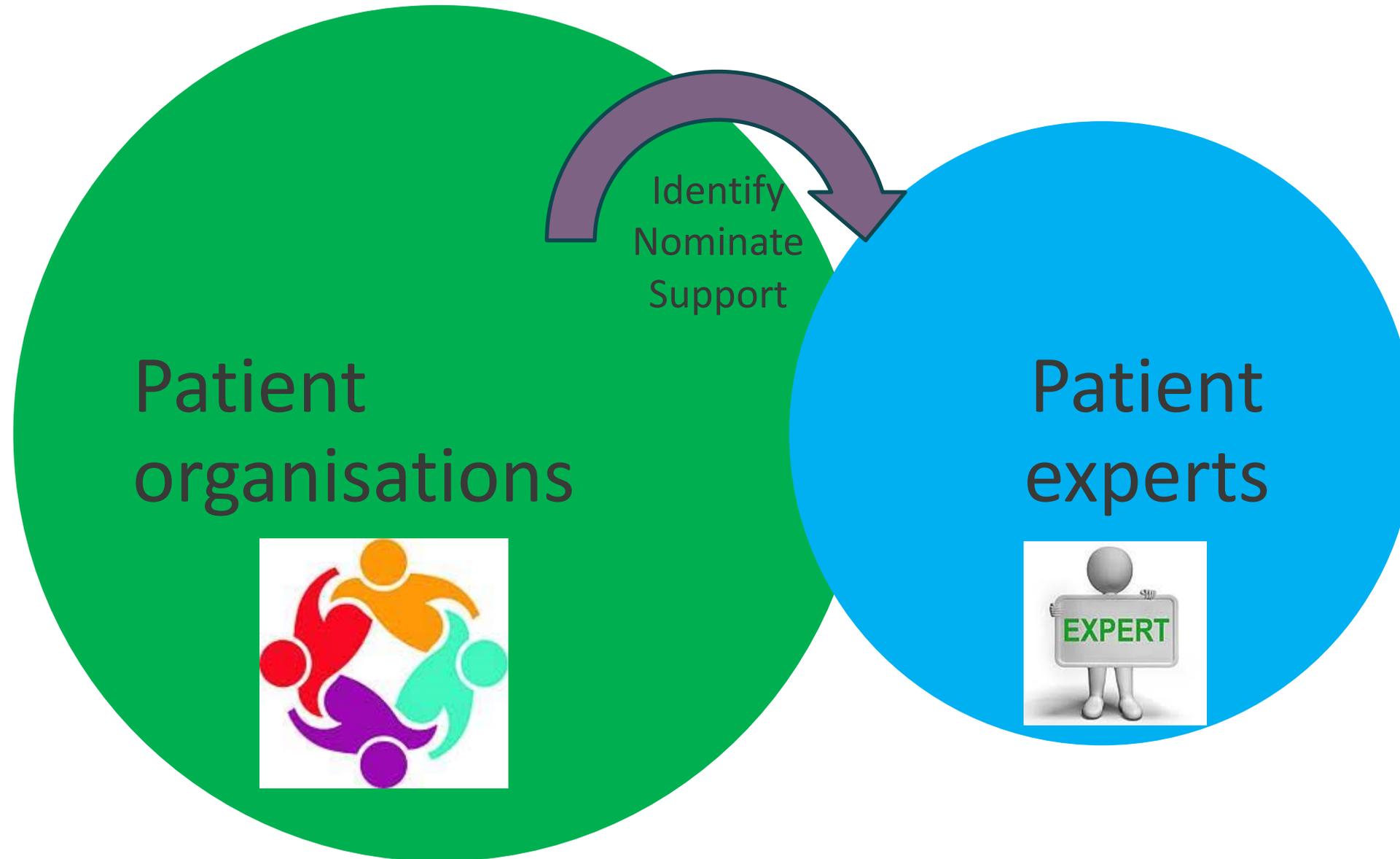
Training  
Presentations  
Meetings



Day to day informal support throughout  
Telephone, email.  
Meetings

Informal  
support

# Relationship between patient organisations and experts



# Patient experts



1. Written individual statements
2. Attend the committee meeting as **individuals**
3. Respond to consultation

**Patient experts attend the meeting as individuals  
NOT representatives of their nominating organisation**

# The value of experts



“...patient and clinical experts add an invaluable insight into medical conditions and how a product may be of benefit...it is considered crucial that experts are available to answer queries of individual committee members to aid understanding.”

TA consultation summary paper, phase 1, January 2018

<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/technology-appraisal-guidance/consultation-on-changes-ta-programme-phase-2>

# How we can provide support for patient experts



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Templates  
Online information (written, videos)

Formal support



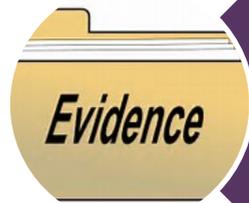
About the committee meeting:  
Call before  
Support at  
Follow up

Informal support



Day to day informal support throughout  
Telephone, email.

# What do we ask for from patients during consultation?



Do we have all the evidence?



Have we interpreted it correctly?



Will it make suitable guidance for the NHS?



Have we considered equality?



**Consultation**

# Appeal



- Any stakeholder (consultee) organisation who has been involved can appeal.
- The grounds for appeal are not whether you agree or disagree.
- The specific grounds are:

**Ground one:** In making the assessment that preceded the recommendation, NICE has:

a) failed to act fairly

or

b) exceeded its powers

**Ground two:** The recommendation is unreasonable in the light of the evidence submitted to NICE.

<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-technology-appraisal-guidance/technology-appraisal-and-highly-specialised-technologies-appeals>

**There is a  
template letter  
to use to  
appeal.**

Please let your  
PIP lead know if  
you are putting  
in an appeal  
and would like  
support with  
the process.



# How we can support patient organisations at Appeal



- Encourage appeals
- Help with the content of the appeal



- Offer process support
- Explain what an appeal hearing is like
- Attend in public gallery
- Explain decision (what happens next).

# More information

## Patient groups

- Overview
- Scoping
- Developing guidance
- Nominating patient experts
- Submission guide
- Submission template

## Patient experts

- Hints and tips for patient experts
- Statement template

## General audience

- TA methods and process guide  
<https://www.nice.org.uk/process/pmg9/chapter/foreword>
- Appeals guide  
<https://www.nice.org.uk/process/pmg18/chapter/foreword>

<https://www.nice.org.uk/about/nice-communities/public-involvement/develop-NICE-guidance>





## Public Involvement Programme

[www.nice.org.uk/about/nice-communities/public-involvement](http://www.nice.org.uk/about/nice-communities/public-involvement)



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