

The Patient Perspective

Value of Patient Involvement:

- HTA's should obviously have their roots placed firmly in research and science, however for them to have real value they should maintain a patient focus
- Patient involvement avoids the potential for the huge costs of a wrong decision
- Patients offer information and insights about the impact their condition and treatments have on their daily lives
- This information is not available anywhere else



The Patient Perspective

Criteria for involvement:

- It's vital patient representatives feel valued
- Patient representatives should be involved in all stages of HTA including planning phases, in order to help optimize their influence and ensuring their input is relevant and acceptable
- Barriers to inclusion must be removed i.e travel and accommodation expenses, child care provision, accessibility issues addressed etc
- There should be a variety of views represented. This can be achieved by having both individual patients represented as well as members of patient action groups



The Patient Perspective

Summary:

- Patient experts tend to fall within one distinct group. We all seem to be middle class, well educated professionals whom can take time from their work to engage in these activities.
- We should really seek to attract a more diverse cross section of the community to fully understand the impact of conditions and treatments on daily lives.



How might the patient voice be better incorporated into the NICE process?

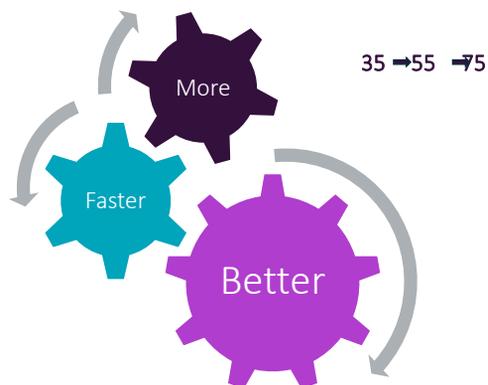
Heidi Livingstone

Public Involvement Adviser

heidi.livingstone@nice.org.uk

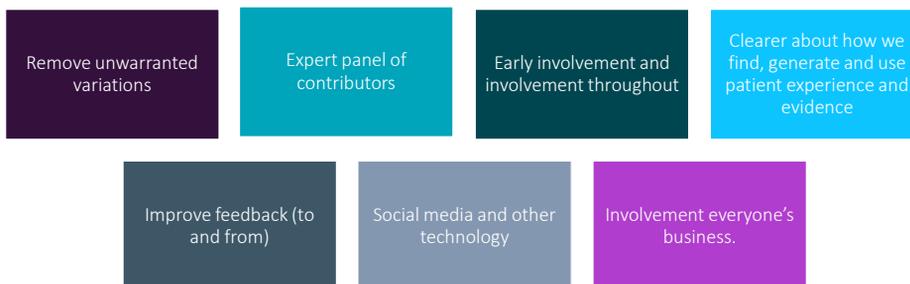
NICE National Institute for
Health and Care Excellence

The challenge

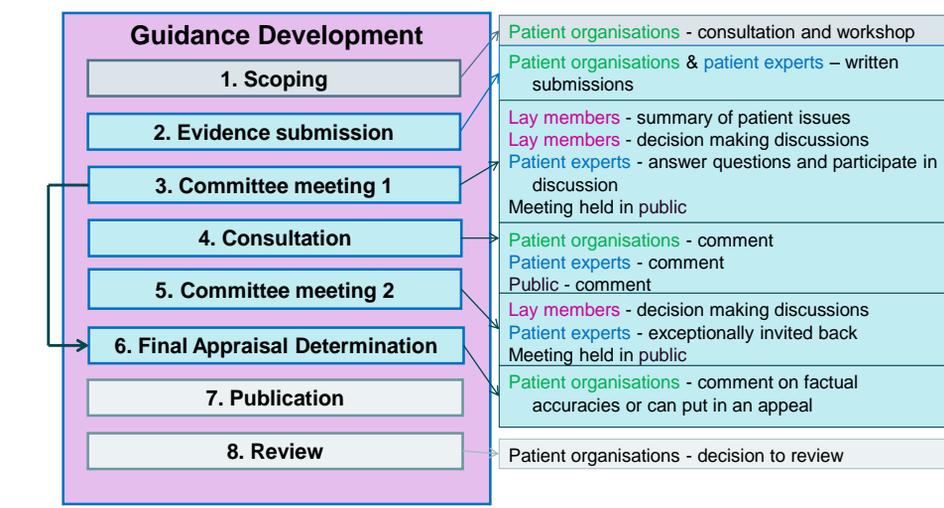


Challenge of **strengthening** patient voice and involvement, whilst producing **more** HTAs and developing them more **quickly**.

Public Involvement Review – wider than HTAs

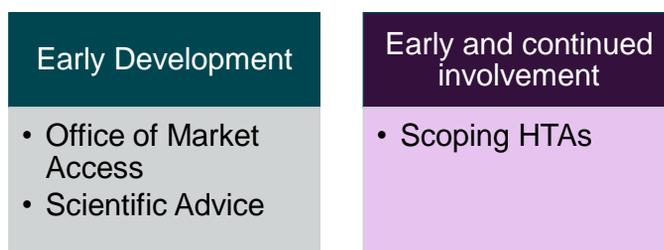


Current opportunities for patient involvement at NICE (Technology Appraisals)



NICE National Institute for Health and Care Excellence

Early and continued involvement



NICE National Institute for Health and Care Excellence

9

Help with submissions



- **Help with submission** and more **collaborative involvement** before the committee meeting.
 - Help from PIP
 - Collaboration with Lay lead and NICE technical team?
 - PACE-like involvement?
 - Other ideas?
- **Would patient groups feel more comfortable about being more frank, and critical if needed, if their written submissions weren't published?**

Experts

Current



Future – for discussion

- Remain the same?
- Whoever has written the organisation's submission attends?
- Individual with the condition on the treatment – retain?
- Written only with involvement before the meeting – NOT at the meeting?
- Other?

Feedback



Current

From experts to NICE



Future

From NICE on patient group submissions

From patient groups to NICE

Impact and training



- More insight on how best to use patient 'evidence' and involvement
- Collection of examples of impact.



Training for:

- NICE chairs
- Committees
- Staff

Currently train patient organisations

Declarations and conflict of interest



Individuals

- Updating our policy

Organisations

- Developing our policy

Other ideas?



Consultation

Consultation on proposed changes to the technology appraisals programme

Closes 16 November

<https://www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/technology-appraisals/increasing-transparency-consultation.pdf>

For specific references to patient organisations and experts (patient, clinical or commissioning see sections 21 and 29)



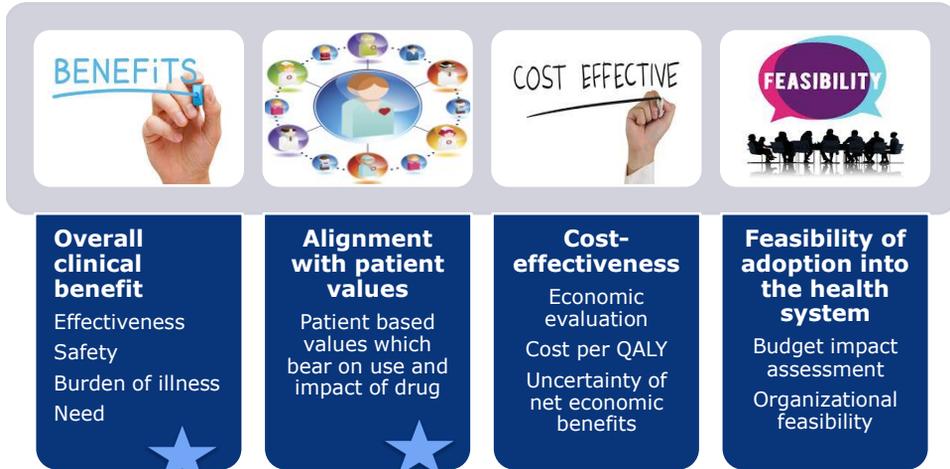
<https://www.nice.org.uk/about/nice-communities/public-involvement>

Can we learn from other models globally?



The Canadian pCODR pERC deliberative decision-making framework

 = patient input



Where could patient input be relevant?



Characteristics of condition

Severity/burden of disease
Unmet need
QALY shortfall



Process of care

Patient/carer experience
Patient preferences
Service delivery



Health gain

QALYs
LYG/QoL
Other clinical outcomes



NHS objectives

Integration
Quality
Pathway efficiency

Could the patient input be more structured, around the key areas of uncertainty for the Committee?

Does the recent NICE 'increasing TA capacity' consultation risk diminished patient input?

- The consultation states the following:

"As is currently the case, stakeholders will be asked to nominate clinical and patient experts, who will be asked to submit personal statements. If the statements from non-company stakeholders are sufficiently clear, and/or individual clarification resolves enough of the uncertainty, this earlier timing of their engagement may **reduce the need** for experts to attend the committee meeting"

Will the patient voice be properly heard if they don't attend the Committee meeting?

Concluding questions and remarks

- Is there anything in the Canadian pCODR model that could be applied to NICE?
- How can patient input be structured for the NICE Appraisal Committees to incorporate into decision making?
- If structured in a way that reduces the key areas of uncertainty identified by the Committee, patient input can be invaluable to decision making
- Can Patient Groups be accredited in a way that allows them to have a voice in the decision making and thus avoids conflict of interest concerns?
- Structured, deliberative decision making centred around the needs of the patient (the 'end user' of all 'products' reviewed by NICE) must be the way forward



Thank you

