Patient and Public Involvement

Involving the patient in HTA

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Patient involvement in HTA

Integrating patients’ needs, preferences and experiences

Patient evidence
Research into patient aspects

Patient input
Patients and patient groups participating in HTA process

What can we learn from each other about patient perspectives and adding value?

• HTA can be considered as a bridge between scientific evidence and decision making

• Patients’ perspectives can illuminate the HTA bridge by describing therapeutic context and added value, helping reduce uncertainty in decision making
  • Clarifying burden - illness, health service organisation, treatment
  • Highlighting areas of unmet need
  • Identifying important outcomes
    • benefits and disbenefits
  • Interpreting outcomes as patient benefit
Patient based evidence

- Research into patient aspects (needs, preferences and experiences)
- By researchers (sometimes collaboratively with patients)
- Robust scientific methodology
- Published
- Peer reviewed

Robust qualitative and quantitative research
When the aim of a study is to achieve a deeper understanding of a person’s subjective perception of – for example – quality of life, a person’s individual perceptions, experiences, impressions and actions, then qualitative research methods may be more relevant. Such methods offer an understanding of associations from the individual’s perspective.
Qualitative research methods

• Systematic collection, organisation, interpretation of textual material derived from talk or observation
• Interviews, focus groups, participant observation
• Carefully planned with ethical approval
• Themes derived according to pre-specified methods
• Explanation of diversity of views
• Discussion of researcher’s bias and study limitations
• Conclusions that are study specific
What do we get from patients and the public?

- Social values
- Personal experience of living with a condition
- Experience of treatment or care and its impact
- Outcomes that people want from care
- Risks, benefits and acceptability
- Personal preferences and values
- Information, communication and support needs
- Equality issues and needs of specific groups
- Recommendations for further research
Why does NICE involve patients and the public?

Core principles of all NICE guidance

• Comprehensive evidence base
• Expert input
• Patient and carer involvement
• Independent advisory committees
• Genuine consultation
• Regular review
• Open and transparent process
What are the benefits of including the lay (patient) perspective?

‘The expertise, insight and input of these lay members is essential to the development of all NICE guidance and advice, and helps us to make sure that our work reflects the needs and priorities of those who will be affected by them.’

NICE Charter
Why should we involve patients and carers?

The benefit to the HTA organisation

New evidence and information

Challenges to evidence and conventional wisdom e.g. outcomes

Qualitative context to quantitative data

Challenges to professional assumptions

Value to the patients in being involved
2 main stages for patient involvement

- Early engagement in evidence development plans:
  - Scientific advice

- Participation in HTAs:
  - Scoping (setting the question)
  - written submissions
  - patient experts
  - consultation

PIP: Public Involvement Programme at NICE
Why do we involve patients in NICE Scientific Advice?

• Patients are the people for whom the advice that NICE Scientific advice provides will ultimately be most relevant.

• Patients have the chance to influence how clinical trials are set up in order to provide the best evidence that the proposed outcomes can meet patient’s needs.

• We have involved patients in over 25 projects so far.

Companies get powerful feedback as to the relevance of their decisions early in a product’s development.
Key stakeholders for NICE’s HTAs

**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 (medicines)

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

Patient organisations - decision to review
Examples of patient involvement impact

1. TA342 Ulcerative colitis – vedolizumab

2. TA 383 ankylosing spondylitis and non-radiographic axial spondyloarthritis - TNF- alpha inhibitors
1. What patients told the committee
(guidance - paragraph 4.1)

Impact of condition

Housebound, unable to work and often hospitalised.

Population

Often affects teenagers and young adults – their ability to study, socialise, find a partner and so quality of life

Comparator

Surgery unacceptable to younger adults – impact on fertility, irreversibility, risks and life-long impact

New treatment

New treatment gave complete remission, so ability to work and ‘gave their life back’
1 Committee conclusion

“Committee concluded that a drug treatment which brings disease into remission would have a major effect on quality of life, and that avoiding surgery was important to people with ulcerative colitis.”
2 How the patient organisation contributed

Submission

Survey open for 4 weeks.
608 responses

Consultation

Survey open for 8 days.
858 responses

To produce data around the two negative areas of the consultation
“Treatment with another tumour necrosis factor (TNF) -alpha inhibitor is recommended for people who cannot tolerate, or whose disease has not responded to, treatment with the first TNF-alpha inhibitor, or whose disease has stopped responding after an initial response.”
Patient Involvement in HTA
(Facey, Hansen, Single. Springer, June 2017)

- Academic book for
  - HTA professionals,
  - policy makers and
  - Researchers
  - Industry

- More than 80 authors from a variety of disciplines
If you’re not involving patients, you're not doing HTA!...

Dr. Brian O’Rourke, President and Chief Executive Officer, CADTH
Do you have any questions?