

OS30: Patient input: a definition for optimising use

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Patient involvement in HTA

Integrating patients' needs, preferences & perspectives

- ▶ **Research** into patient aspects
- ▶ Patients and patient groups **participating** in HTA processes

Patient-based evidence

research into patient aspects

by researchers

sometimes collaboratively with patients

robust scientific methodology

published

peer reviewed

Patient involvement in HTA

Research

Participation of patients
& patient groups

Patient-based evidence

Patient input

researchers

patients & patient groups

published literature (or
primary research)

experienced-based experts

robust scientific
methodology

interactive

Common types of patient input

Written

- Topic proposals
- Comments on draft documents
 - Consultation reports
 - Submissions

Face-to-face

- Scientific advice (early dialogue)
- Multi-stakeholder committees
 - Hearings

HTAi Patient Group Submission Templates - Summary of Key Elements

Impact of the condition

Challenging symptoms

Limits to usual daily living

Emotional & psychological issues

Impacts on family life & caregivers

Financial implications

Particular issues for groups of patients

Experiences with currently available health interventions

Health interventions currently used

Extent to which they control/reduce most difficult aspects of condition

Most important benefits of currently available interventions

Burden of taking currently available health interventions on daily life

Distressing/difficult to tolerate side effects

Financial implications

Implications for caregivers

Areas not addressed

Particular issues for groups of patients

Summary of Key Elements cont.d

Experiences with health intervention being assessed (views from patients who have received technology)

Main reasons for use compared with other interventions

Extent to which it controls/reduces most difficult aspects of the condition

Limitations

Side effects difficult to tolerate & those willing to tolerate

Burden of taking on daily life

Financial implications

Impact on caregivers

Aspects patients would like to change

Expectations of health intervention being assessed (views from patients who have not received technology)

Importance of studied outcomes to patients

Minimum level of improvement of most important symptoms patients would like

What patients would most like to see from the intervention being assessed

Main reasons why it may not be used

Perceived advantages & disadvantages

Financial implications

Impact on caregivers.

Groups of patients that might benefit most from health intervention

Potential contribution to HTA

- ▶ A lens through which to assess or appraise the evidence
- ▶ Contributes to the value construct of a decision (Lopes)
- ▶ Inform design of clinical research & economic models
- ▶ Provide insights gained in the 'real world' to facilitate interpretation of results, e.g. contextualising in local healthcare setting
- ▶ Focus deliberations towards the implications for patients
- ▶ Fill gaps & highlight important outcomes not in published literature
- ▶ Provide insights when uncertainties about clinical benefits (Menon)

Optimising its use

increasing benefit reducing burden

- ▶ Need for recognition of the qualities & potential of patient input (ie equally important to patient-based evidence not a substitute)
- ▶ Achieving better participation (not evaluating as evidence)
 - ▶ Credibility: ability to contribute knowledge that is considered valid & relevant & will result in mutual learning & generating new solutions
 - ▶ Legitimacy: ability to speak on behalf of people affected by health services

Optimising patient input

- ▶ Support for preparing input
 - ▶ Provide training (including how to gather & report information, what is HTA, what to expect at a hearing, etc)
 - ▶ Identify influence (& when it won't change outcome)
 - ▶ Share information (between HTA bodies & patient groups)
 - ▶ Give feedback on input to explain how & what was used
- ▶ Supporting shared learning and problem solving
 - ▶ Ensure two-way communication
 - ▶ Foster the relationship (interacting before, during & after HTA)
 - ▶ Be responsive
- ▶ Building the evidence-base
 - ▶ Identify issues for patient aspects research

Patient input belongs in a mosaic of participation

Patient involvement in HTA

Patient-based evidence

Robust qualitative & quantitative research

Patient input

Dialogue for shared learning & problem solving