# How can patients improve HTA decision-making?

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# Patients' and carers' experiences

- Living with an illness
  - 'No one knows better what it is like to live with an illness day in, day out, than those who are doing this – the patients and their family and friends who care for them.'

    Understanding HTA. Health Equality Europe. 2008
    (Available in several languages). http://www.htai.org/index.php?id=744

- Unique knowledge ("perspectives")
  - Experiences (good and bad) of the health care system in terms of diagnosis, support for healthy living and treatment
  - Preferences, needs

# Issues with patients' contributions to HTA?

- Patients' views are subjective
- Are they representative?
- Are they the mouth-piece of industry?

# Patient influenced HTAs

What does the treatment effect mean in real life?

What are the long-term effects of treatment?

Who will benefit most from this medicine?

Value Judgements

Value Judgements

Recommendations

Recommendations

# Theorized Goals of Public and Patient Engagement in Health Technology Assessment

Public Engagement for HTA at HQO—Final Report from the OHTAC Public Engagement Subcommittee. April 2015

| | |
|---|---|
| **Democratic** | Achieving more informed, transparent, accountable, and legitimate decisions about health technologies |
| **Scientific** | Promoting a more robust and comprehensive approach to HTA that incorporates social values and ethics, as well as patients' problems, lived experiences, outcomes, and preferences |
| **Instrumental** | Making better-quality decisions across all stages of the HTA process |
| **Developmental** | Increasing public understanding of health technologies and HTA, and strengthening the public's and patients' capacity to contribute to health technology policy issues |

# Patients' perspectives in HTA: a route to robust evidence and fair deliberation

(Int. J. Tech Assess Health Care, 2010, 334-340)

- Patients' views and preferences contributing to HTA:
  - Through participation in the HTA process
  - In the form of robust evidence from qualitative or quantitative research

# Patient and Patient Group Participation in HTA processes

At every stage:

- Study design to produce evidence (individuals)
- Topic proposals (groups)
- Scoping
- Submission of information
- Presentation of patient experience to expert committee
- Consultation on recommendations
- Patient friendly summaries
- Dissemination/communication
- Designing & reviewing patient engagement processes
- Use HTA to inform charity investments
- Contributing to governmental review of HTA

# Challenges to patient participation (in HTA)

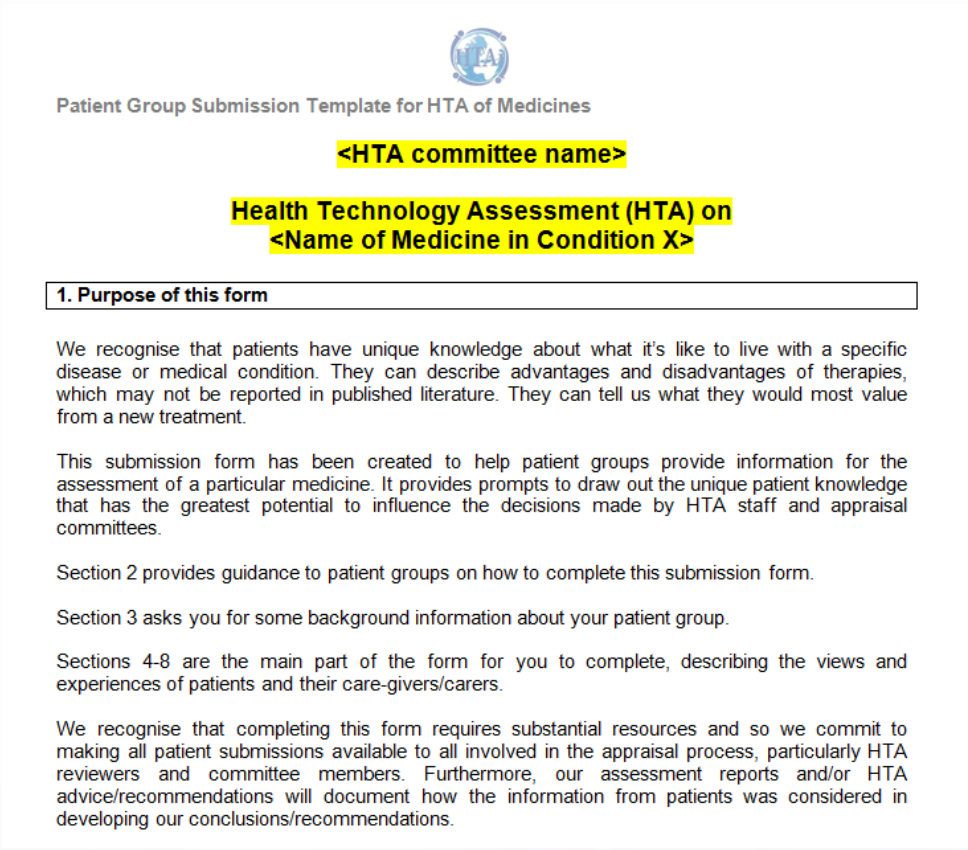
- Lack of awareness of processes
- Interaction of researchers and patients
- Mechanism of participation
- Identifying a “patient position”
- Nature and extent of patient representation
- Technical demands
- Training and education
- Use of patient input
- Balancing information from researchers, literature and patients
- Time demands and remuneration
- Resources
- Few evaluations of patient involvement

# Interest-Sub Group on Patient/Citizen Involvement in HTA

- Monthly bulletins
- 2010 paper on evidence and involvement
- Website of resources for patients ww.htai.org/index.php?id=545
  - HEE Guide to HTA in 5 languages
  - Glossary for HTA and clinical research
  - Links to training materials (webinar, eMEET, etc)
  - HTA Agency approaches to patient/public involvement
  - Templates and guides for patient group submissions
  - Refocussing social domain of EUnetHTA Core Model
  - Book on Patient Involvement in HTA
  - Values & Quality Standards

# Patient Group Submissions

- What it is like to live with the illness
- Experience with current therapies
- Expectations or experience of new therapy
- 3 most important items



Patient Group Submission Template for HTA of Medicines

**<HTA committee name>**

**Health Technology Assessment (HTA) on <Name of Medicine in Condition X>**

**1. Purpose of this form**

We recognise that patients have unique knowledge about what it's like to live with a specific disease or medical condition. They can describe advantages and disadvantages of therapies, which may not be reported in published literature. They can tell us what they would most value from a new treatment.

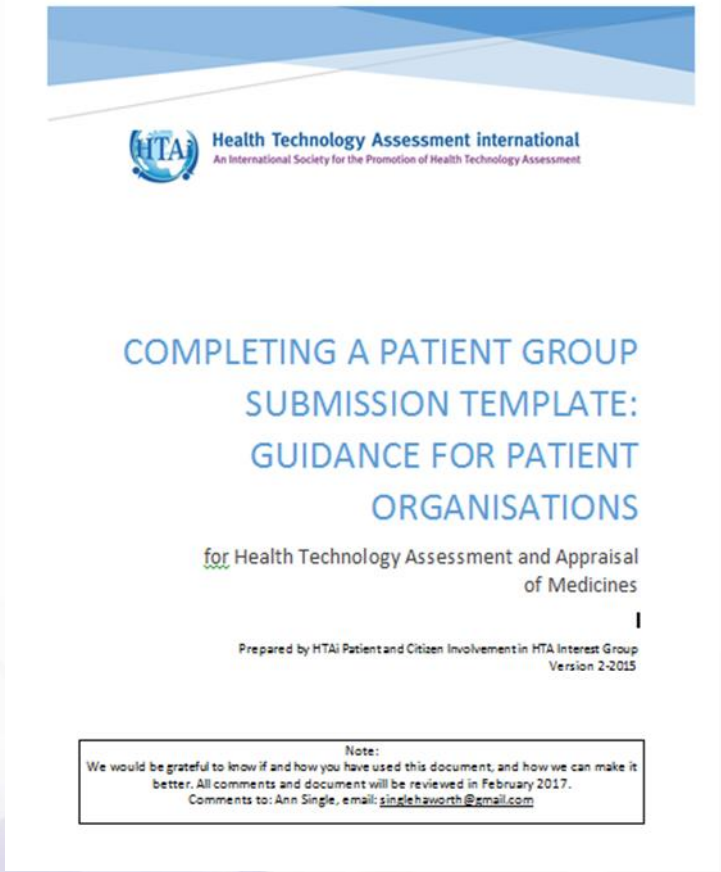
This submission form has been created to help patient groups provide information for the assessment of a particular medicine. It provides prompts to draw out the unique patient knowledge that has the greatest potential to influence the decisions made by HTA staff and appraisal committees.

Section 2 provides guidance to patient groups on how to complete this submission form.

Section 3 asks you for some background information about your patient group.

Sections 4-8 are the main part of the form for you to complete, describing the views and experiences of patients and their care-givers/carers.

We recognise that completing this form requires substantial resources and so we commit to making all patient submissions available to all involved in the appraisal process, particularly HTA reviewers and committee members. Furthermore, our assessment reports and/or HTA advice/recommendations will document how the information from patients was considered in developing our conclusions/recommendations.



Health Technology Assessment international

An International Society for the Promotion of Health Technology Assessment

COMPLETING A PATIENT GROUP SUBMISSION TEMPLATE: GUIDANCE FOR PATIENT ORGANISATIONS

for Health Technology Assessment and Appraisal of Medicines

Prepared by HTAi Patient and Citizen Involvement in HTA Interest Group
Version 2-2015

Note:
We would be grateful to know if and how you have used this document, and how we can make it better. All comments and document will be reviewed in February 2017.
Comments to: Ann Single, email: singlehaworth@gmail.com

Ethical issues for patient groups to consider when collecting and reporting information for HTA submissions
- in preparation

# Guiding principles

Public Engagement for HTA at HQO—Final Report from the OHTAC Public Engagement Subcommittee. April 2015

| | |
|---|---|
| **Purposeful** | Engagement activities will be aligned with clearly stated goals and rationales. |
| **Fair and equitable** | Engagement activities will be designed in a manner that ensures the inclusion of a broad range of perspectives determined by those most affected or potentially affected by the relevant condition or technology being reviewed. |
| **Transparent** | Processes and decisions will be clearly described and communicated to ensure a broad understanding among interested constituencies (e.g., patients, interested members of the public, stakeholder groups) that facilitates their engagement. |
| **Proportional** | The degree of public and patient engagement is proportional to the nature and purpose of the technology, size and demographics of the targeted patient population, and disease incidence and prevalence. |
| **Pragmatic** | Methods of engagement will, to the extent possible, take into account the level of rigour, time, resources, and effort required. |
| **Evidence-informed** | Engagement approaches and methods will be informed by the best available evidence. |

# Values for Patient Involvement in HTA

## Relevance

Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.

## Fairness

Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.

## Equity

Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.

## Legitimacy

Patient involvement facilitates those affected by the HTA recommendations/decision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process.

## Capacity building

Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

# Quality Standards for Patient Involvement in HTA

## General HTA process

1. HTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients.
2. HTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA.
3. HTA participants (including researchers, staff, HTA reviewers and committee members) receive training about appropriate involvement of patients and consideration of patients' perspectives throughout the HTA process.
4. Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA.
5. Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them.

## For individual HTAs

6. Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.
7. Clear timelines are established for each HTA with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained.
8. For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA.
9. In each HTA, patients' perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported.
10. Feedback is given to patient organizations who have contributed to an HTA, to share what contributions were most helpful and provide suggestions to assist their future involvement.

For more information, please see the resources available on the HTAi Interest Sub-Group for Patient/Citizen Involvement in HTA at www.htai.org/index.php?id=545

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# HTA and decision making

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

- Patients' perspectives can illuminate the HTA bridge by
  - Clarifying burden - illness, health service organisation and treatment
  - Identifying important outcomes – benefits and disbenefits
  - Highlighting areas of unmet need
  - Describing real added value

# Thank you!

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