



Health Technology Assessment International

An International Society for the
Promotion of Health Technology Assessment

HTA – What role for patients?

EPF Regional Meeting
Lund Sweden, Nov 24th 2015

Sophie Werkö, HTAi Interest Sub-Group for
Patient/Citizen Involvement in HTA



Health Technology Assessment

(www.eunethta.net)

HTA is a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to use of a **health technology*** in a systematic, transparent, unbiased, robust manner

It aims to inform policy at national, regional or hospital level about “added value”.

*any health intervention: screening , vaccines, diagnostics, medicines, devices, education, rehabilitation....



What can patients tell us that's relevant to HTA and health care policy and decision-making?



Patients' and care-givers' 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.’
- The technology
 - Their needs and preferences, and benefits and unwanted effects

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



How can patients' and care-givers' perspectives be combined with evidence from controlled clinical trials or complicated economic models of cost and benefit?



How do their views stand up against managers or doctors?



Gathering patients' experiences

- Systematic, transparent, robust
- Evidence: facts not emotion
- Patient stories
- Social networking
- Review of helpline questions
- Survey/questionnaires
- Qualitative research (interviews, focus groups...)



HTAi Patient Group Submission Template

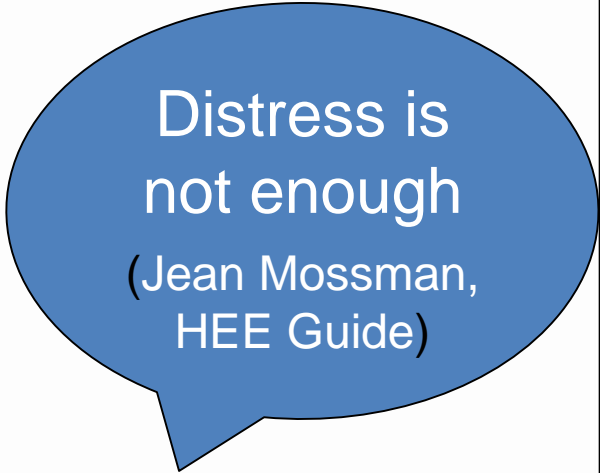
Impact of condition

On patients

- Most challenging aspects at different stages
- Activities that are difficult
- Emotional and psychological issues
- Support needed for daily living
- Groups of patients most affected
- What patients would most like to get from a new treatment

On care-givers

- Challenges
- Pressures



Distress is
not enough
(Jean Mossman,
HEE Guide)

HTAi Patient Group Submission Template

Experiences with currently available health interventions

- Main health interventions used
- Extent to which they control symptoms
- Most important benefits
- Burden of current interventions
- Side effects
- Financial issues
- Issues for carers
- Unmet needs

- Which groups have particular needs?

HTAi Patient Group Submission Template

Expectations of new health interventions

- Anticipated advantages and disadvantages
 - Did the clinical studies include the right outcomes?
 - Minimum level of improvement of most important symptoms that patients would like to see
 - Impact on healthcare services
 - Impact on care-givers
-
- Which groups might particularly benefit?

HTAi Patient Group Submission Template

Key messages

In up to 5 statements list the most important points of your submission

- Biggest challenges of living with the condition are...
- Current health interventions are inadequate because...
- The intervention being assessed will be beneficial because...



Health Equality
Europe

Understanding Health Technology Assessment (HTA)



This guide describes how patients and the public can get involved in decisions about what healthcare should be available. It can also be used to help raise awareness of patient needs.

Available in English, Spanish, Italian, Polish, Mandarin, **Greek**
www.htai.org/index.php?id=545

HTAi consumer and patient glossary

A beginner's guide to words used in health technology assessment



Compiled by Ann Single and Biotext Pty Ltd
with contributions from Eleanor Ahern,
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Version: 1
October 2009

[www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/Glossary/
HTAiPatientAndConsumerGlossaryOctober2009_01.pdf](http://www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/Glossary/HTAiPatientAndConsumerGlossaryOctober2009_01.pdf)

When collaboration make a difference

Examples of results of patient involvement at SBU

Sophie Werkö

The Swedish Agency for Health Technology Assessment and
Assessment of Social Services

www.sbu.se



SBU – FOUNDED IN 1987

- **SBU has no legislative power to implement change.**
- **SBU makes no decisions concerning approval or reimbursement of drugs.**
- **SBU has no supervision function.**
- **SBU can only rely on our ability to convince decision makers and the professionals to change practice if they believe we are right and trustworthy.**

SBU's conference on collaboration with healthcare users



The Government's Comissions to SBU in psychiatry

- Diagnosis and monitoring of mood disorders
- Diagnosis and treatment of ADHD and autism spectrum disorders
- Implementation of psychiatric guidelines and evidencebased knowledge in primary care
- Medicinal treatment of psychosis/schizophrenia
- Organisational aspects on care of psychosis/schizophrenia, ADHD and autism spectrum disorders
- Patient participation in decision-making in cases of psychosis/schizophrenia, ADHD and autism spectrum disorders

Reference group

The Reference group consisted of two representatives from the following organisations of patients and/or their families:

- Swedish Autism and Asperger Association
- Swedish Depressive and ManicDepressive Association
- Swedish National Association for Mental Health (NSPH)
- Swedish National Association Attention
- Swedish Association for Social and Mental Health (RSMH)
- Swedish Association for Schizophrenia and Allied Disorders
- Swedish Association for Obsessive Compulsive Disorder-
Ananke

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(fram t o m 2011-04-28)

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Patientsakkunnig

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Patientsakkunnig

Conclusions from "Patient Participation in decision-making: autism spectrum disorders"

- ❑ Delaktigheten för personer med autismspektrumtillstånd och deras anhöriga behöver förbättras. Deras egna uppfattningar och åsikter om vård och skola bör efterfrågas i större utsträckning. Idag kan personer med autismspektrumtillstånd och deras anhöriga uppleva stigmatisering, social isolering, otillräckliga kunskaper hos vård- och skolpersonal, resursbrist och maktlöshet. Tidig diagnostik kan motverka stigmatisering.
- ❑ Det är viktigt att bristande delaktighet inte hindrar vårdens och skolans strävan att nå god kommunikation och kontakt. Det är också viktigt att rikta särskild uppmärksamhet till syskon, som annars kan få svårigheter med sociala relationer och ibland även utsättas för skrämmande och våldsamt beteende. Den vetenskapliga kunskapen kring betydelsen av delaktighet vid autismspektrumtillstånd kan förbättras avsevärt.



Conclusions

Patient participation in decision-making : autism spectrum disorders

- Delaktigheten för personer med autismspektrumtillstånd och deras anhöriga behöver förbättras. ~~och de behöver mötas med ett större intresse från omgivningen när det gäller deras egna uppfattningar och åsikter om vård och skola~~ Deras egna uppfattningar och åsikter om vård och skola bör efterfrågas i större utsträckning. Idag kan personer med autismspektrumtillstånd och deras anhöriga uppleva stigmatisering, social isolering, otillräckliga kunskaper hos vård- och skolpersonal, resursbrist och maktlöshet. ~~Stigmatiseringsproblem kan motverkas av en tidig diagnos.~~ Tidig diagnostik kan motverka stigmatisering.

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Advice from the patients/users – write two reports!

”Diagnosis and treatment of ADHD and autism spectrum disorders”

Became:

- ADHD – diagnostics and treatment, organization of the health care and patient involvement 2013 (528 pages)
- Autism spectrum disorders – diagnostics and treatment, organization of the health care and patient involvement 2013 (208 pages)

Prioritisation of scientific uncertainties

- Treatment of ADHD

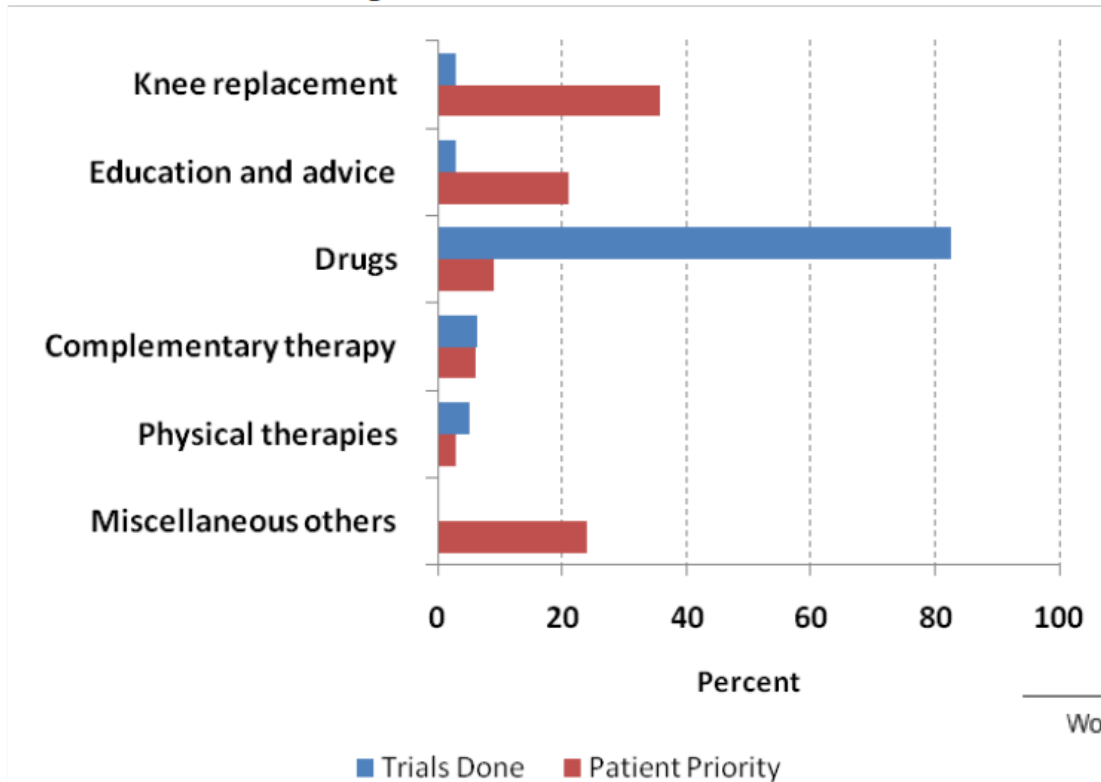
SBU:s report on ADHD from 2013 identified many scientific uncertainties

- **Purpose:**
 - Emphasize the perspective of patient, their families and school and care personnel's perspective on what is important to do research on regarding ADHD





Why involve consumers?



Working in partnership with



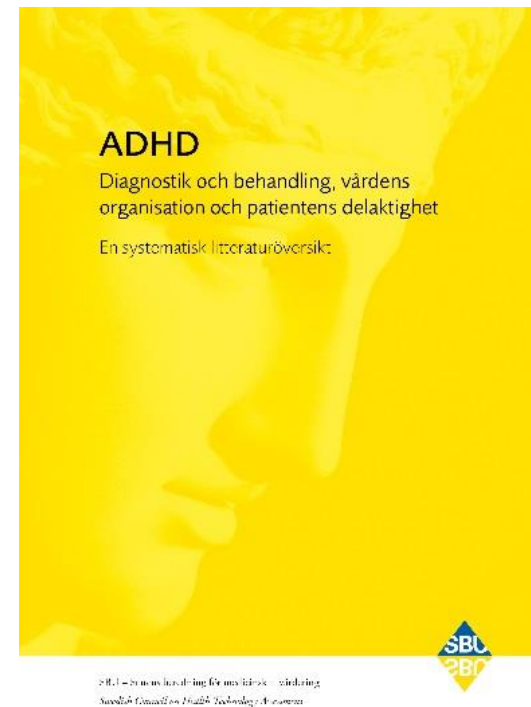
National Institute for
Health Research

Tallon, D. *et al.* (2000) 'Relation between agendas of the research community and the research consumer', *The Lancet*, Vol. 355. pp. 2037-40



Framework

- The scientific uncertainties to be prioritised concern ADHD and treatment methods and are from the SBU-report
- Focus on needs of patients/users and concerned personnel
- The group:
 - 7 patients/users
 - 7 health or school professionals; psychologists, psychiatrists, physicians, correctional treatment staff, school welfare officer and special pedagogue



Workshop Aug 25, 2014



Some results (individual rankings)

- The group with professionals chose 3 scientific uncertainties that no one in the patient group chose
- In reverse, the patient/user group chose 1 scientific uncertainty that no one in the professional group chose (family therapy).
- Rank 1-5 were all among the ten highest ranked both within the patient group and within the group of professionals.

PRIO – The Swedish government's investment within the area of mental ill-health

Overall aim: to improve the lives of persons with mental ill-health.

Prioritised groups are children, adolescents and young adults as well as persons with extensive or complex psychiatric problems.

Through PRIO, the government ultimately aims to prevent **mental ill-health** and to **improve the health services and care** for persons with this condition.

The project runs until 2016.

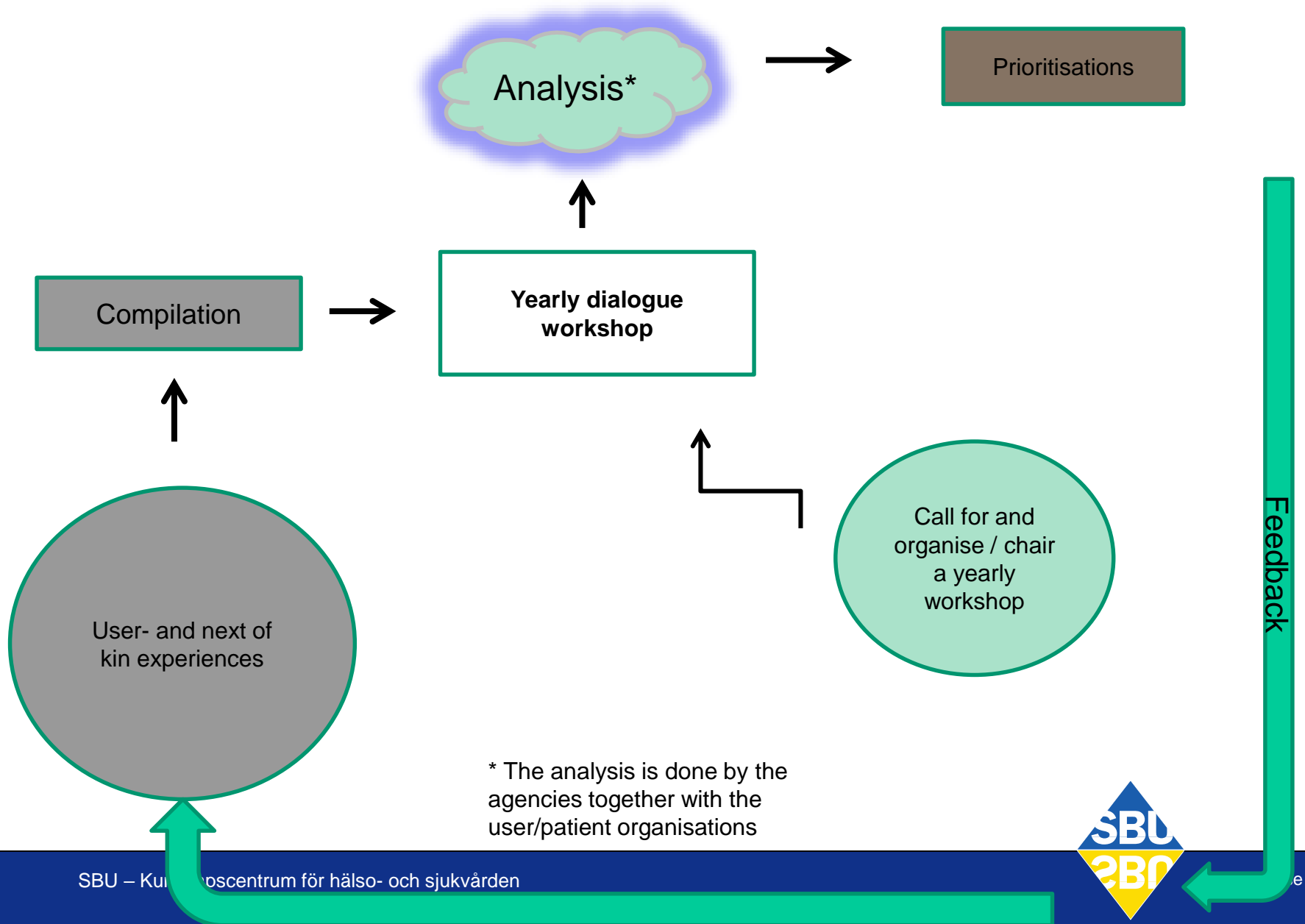
Network to strengthen the collaboration with patient/user organisations and agencies

- *National Partnership for Mental Health, NPMH (alt NSPH) is made up of a network of organizations for patients, users and next of kin within the psychiatric field.*
- *Public Health Agency of Sweden*
- *Medical Products Agency*
- *National Board of Health and Welfare*
- *SBU*



Responsibility of the users / patients

Responsibility of the agencies



* The analysis is done by the agencies together with the user/patient organisations

Thank you for the attention!



SBU – Kunskapscentrum för hälso- och sjukvården

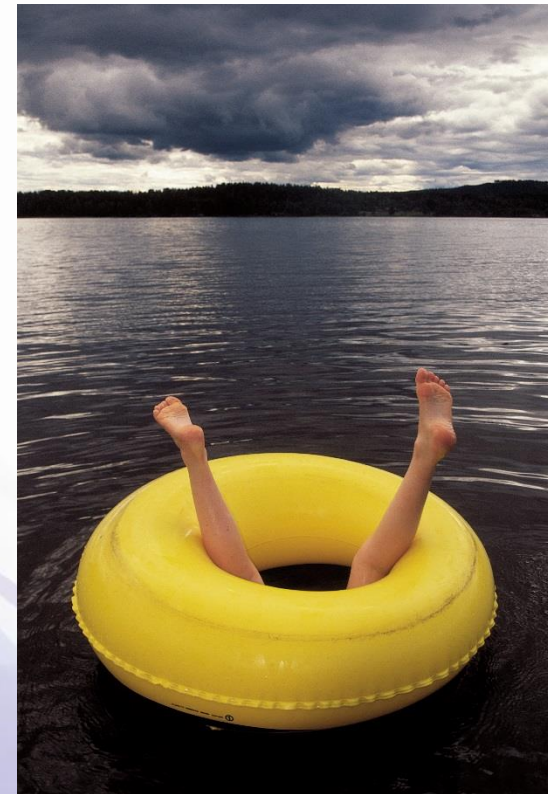
SBU – Swedish Council on Health Technology Assessment | www.sbu.se

www.sbu.se

Over to you!



Sophie Werkö –
sophie.werko@sbu.se





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An International Society for the Promotion of Health Technology Assessment

COMPLETING A PATIENT SUBMISSION TEMPLATE: GUIDANCE FOR PATIENT ORGANISATIONS

For Health Technology Assessment and Appraisal
of Medicines

DRAFT ONLY – FOR M&I WG

Prepared by HTAi Patient and Citizen Involvement in HTA Interest Sub-Group, 2014



EUnetHTA HTA Core Model

1. Health problem
2. Technical description of technology
3. Safety
4. Clinical Effectiveness
5. Cost effectiveness and budget impact
6. Ethical analysis
7. Organisational aspects
8. Social aspects
9. Legal aspects



Interest-Sub Group on Patient/Citizen Involvement in HTA

- Quarterly ebulletin and email list
- Contributions to annual HTAi conference
- Website of resources

www.htai.org/index.php?id=545

- Information on HTA Agency approaches to patient/public involvement
- Values & Standards for patient involvement in HTA
- HEE Guide to HTA in 5 languages
- Glossary for HTA and clinical research
- Templates and guides for patient group submissions
- Links to training materials (webinar, eMEET, etc)
- Free Access to themed edition of HTA journal



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

General HTA process

- 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.
- HTA organizations designate appropriate **resources** to ensure and support effective patient involvement in HTA.
- 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
- Patients and patient organizations are given the opportunity to participate in **training** to empower them so that they can best contribute to HTA
- 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.



Quality Standards

For individual HTAs

- **Proactive communication** strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.
- **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.
- For each HTA, HTA organizations identify a **staff member** whose role is to support patients to contribute effectively to HTA.
- In each HTA, patients' perspectives and experiences are **documented** and the **influence** of patient contributions on conclusions and decisions is reported.
- **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.