

Patient involvement in HTA

How to communicate?



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EBHC - HTA & Efficient Management of Basic Benefit Package

Patient Involvement in HTA – How to Communicate

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, benefits and unwanted effects



Understanding HTA. Health Equality Europe. 2008

<http://www.htai.org/index.php?id=744>

HTA and decision making

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



- Patients' views can help to ensure rational decision-making, lighting up the HTA bridge

How can patients get involved in HTA?

- A patient's view is an individual's subjective experience
 - Is it representative?
 - Is it biased by industry influence?
- How can patients' and carers'/care-givers' views be combined with evidence from controlled clinical trials or complicated economic models of cost and benefit?



How can patients' perspectives in HTA be a route to robust evidence and fair deliberation?

- Patients and carers can contribute to HTA:
 1. By providing EVIDENCE about their experiences and preferences
 2. Through PARTICIPATION in the HTA process



Scottish Medicines Consortium (SMC)

Submission of Evidence Template (04/12)

Section 1: Details of submitting organisation (including conflicts of interest)

Section 2: Experience of patients, carers and families on

- **Impact** of the health problem on patients, carers, families (symptoms, problems in every day activities, tasks where patients require assistance)

- Impact on personal /family relationships, ability to work, social life.

- Unmet needs



SMC Submission of Evidence Template

Section 3 - Views of patients, carers and families on the difference the new medicine will make.

- Canvas those who have participated in clinical trials, or
- Share pharmaceutical company “Summary Information for Patients” with members and get their views through focus group, surveys, talking to members
 - **Side effects**, form of administration, better compliance
 - Less reliance on health care professionals or carers
 - **Fewer visits to hospital**
 - Shorter recovery times and able to return work



SMC Submission of Evidence Template

Section 3 - Views of patients/carers/families on difference the new medicine will make

- Unmet needs or gaps in treatment choices/support
 - Does the new medicine fill any of those gaps?
 - How does it fill those gaps?
 - Will it make a real difference?
- How strongly do you support this medication?
- Summary of key messages to SMC



Section 4 - Additional Information

- Anonymised patient stories/vignettes or quotes from members

Patient evidence

- Ideally, concise and balanced overview that reflects the range of patients perspectives
- Variations in clinical practice
- Personal perspectives about benefits and difficulties with the technology
- Views on rules for starting and stopping treatment
- Evidence and facts, not emotion

Gathering patients' experiences

- Partnership in research
- Review of helpline questions
- Social networking
- Survey/questionnaires
- Patient stories (videos)
- Qualitative research (interviews, focus groups...)
- Building an evidence base



Gathering patients' experiences



Patient/Citizen Involvement Sub-Group (PCISG)
Research Project

Pilot the template

Building an evidence

2. PARTICIPATION in the HTA process

At every stage:

- Study design to produce evidence
- HTA topic selection
- Scoping
- Submission of evidence
- Presentation of patient experience to expert committee
- Sitting on an HTA decision-making 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

Nasza rola w procesie Oceny Technologii Medycznych

Nowy przewodnik dla stowarzysze chorych

Przewodnik dla Stowarzyszeń osób chorych i wszystkich chcących uczestniczyć w procesie podejmowania decyzji o dostępności opieki medycznej.

Niniejszy poradnik ma również wartość edukacyjną, podnosząc poziom świadomości społecznej o potrzebach pacjentów.

ISBN: 978-83-924739-8-5

Warszawa 2010

http://www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/EffectiveInvolvement/HEEGuidetoHTAforPatientsPolish.pdf



G-I-N PUBLIC Toolkit:
Patient and Public Involvement in Guidelines

[www.g-i-n.net/document-store/working-groups-documents/
g-i-n-public/toolkit/toolkit-combined.pdf](http://www.g-i-n.net/document-store/working-groups-documents/g-i-n-public/toolkit/toolkit-combined.pdf)



PCISG **draft** principles for patient engagement in HTA

- Legitimacy
- Mutual respect
- Commitment
- Patients provide unique knowledge
- Patients' perspectives are useful and used
- Transparent process
- Inclusive process, regularly reviewed
- Open, realistic, appropriate process
- Resourced properly



PCISG **draft** principles for patient engagement in HTA



Work in progress
Join the consultation rounds

• Open, realistic, app

- Resourced properly

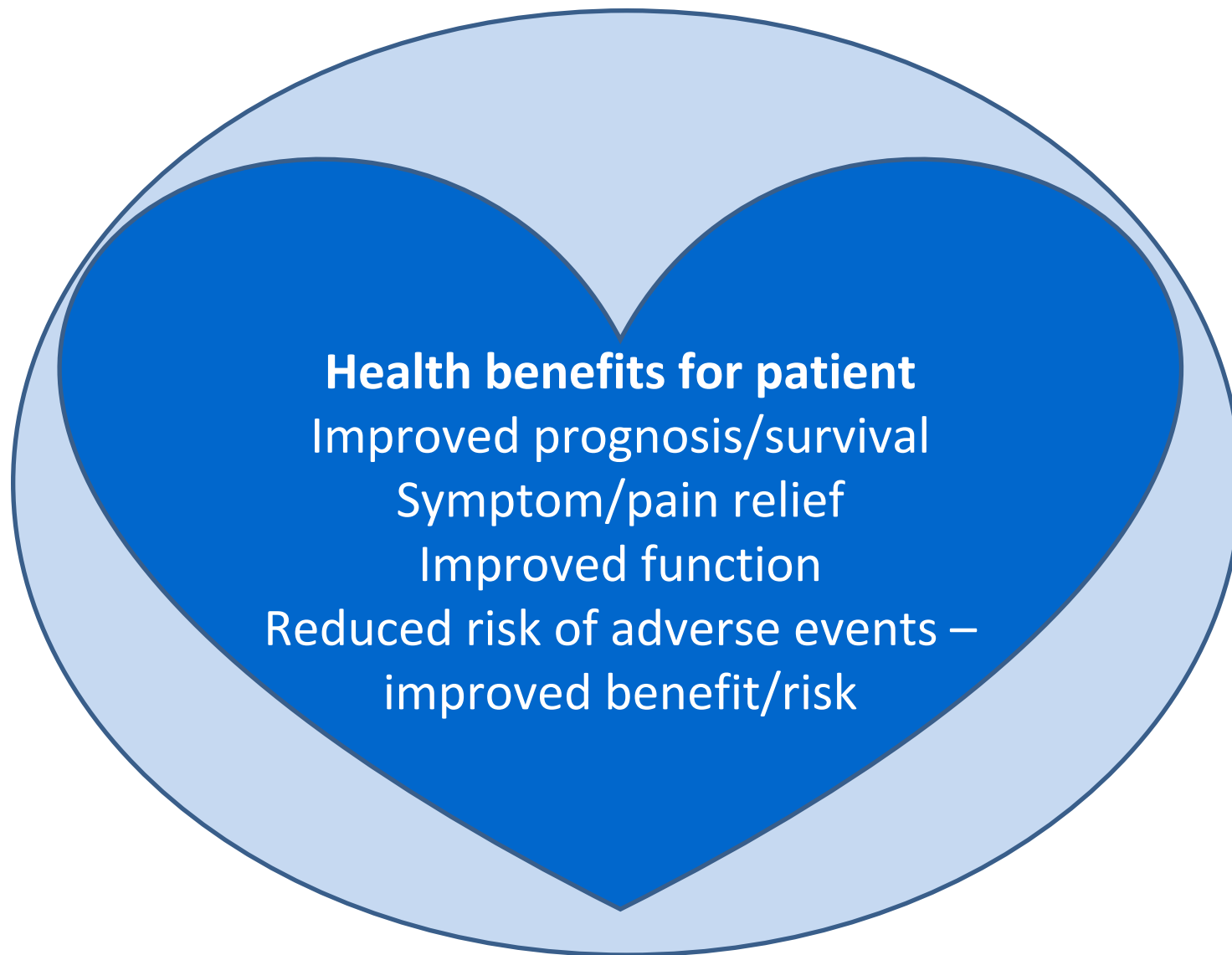
Panel discussion

Patient involvement in HTA

Next steps for Central and Eastern Europe?

HTA, value-based decision making and innovation

Henshall and Schuller, IJTAHC, 2013

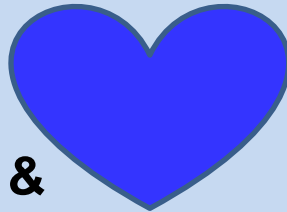


Wider Elements of Value?

Non-health benefits for patients -

Reduced health costs, convenience, return to work, reduced uncertainty, availability of alternatives

Carers – reduced burden of care, improved health



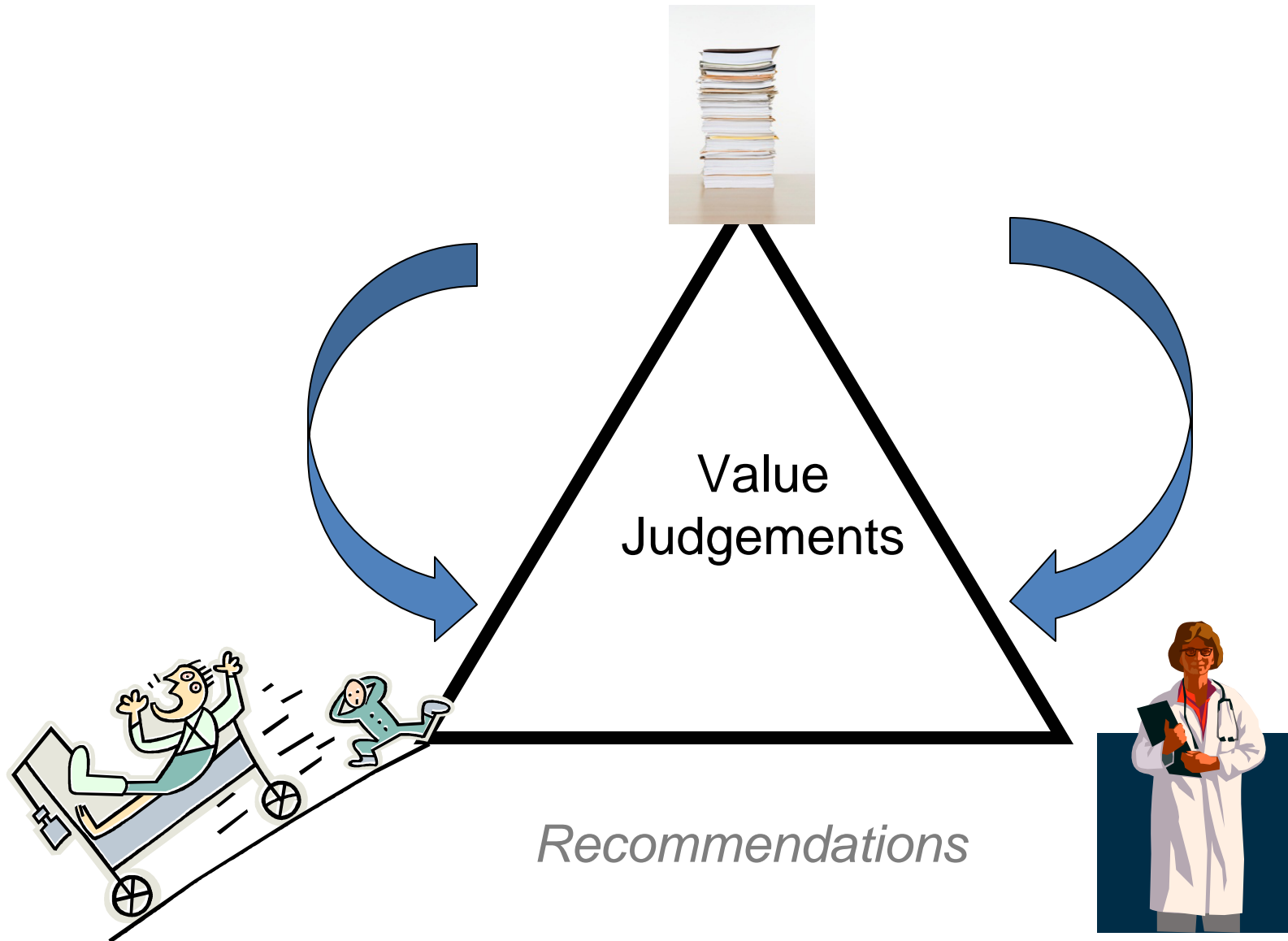
Benefits for health & social care systems

Improved efficiency, quality and organization of care;
Net gain (loss) in public health

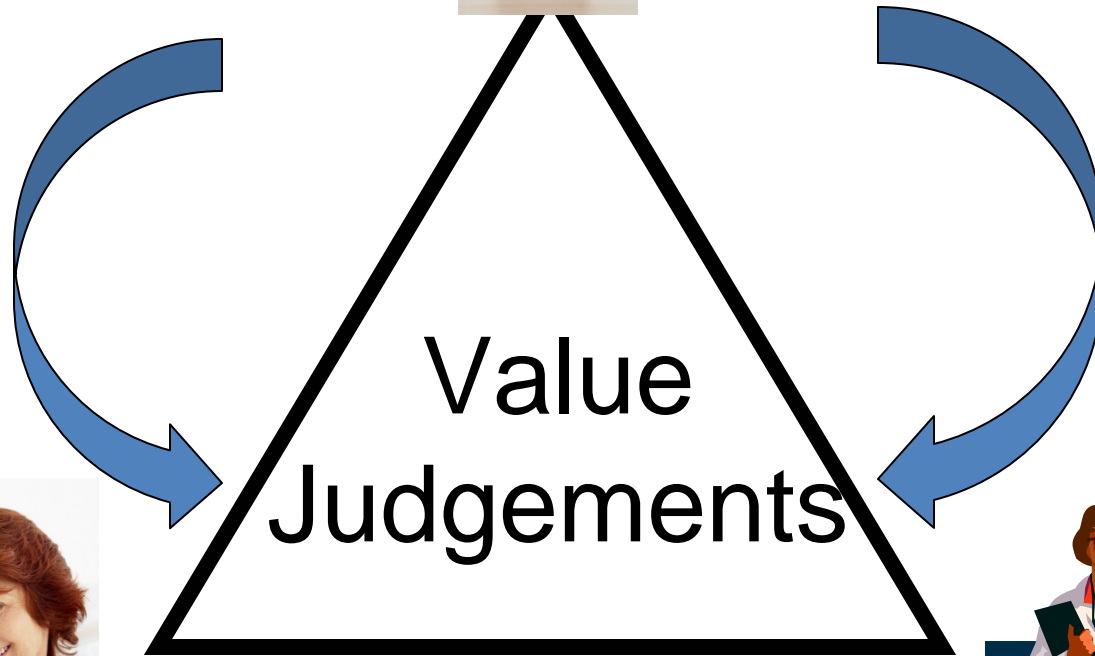
Benefits for society

Support for disadvantaged
Improved productivity
Promise of health benefits vs risk of unrealised expectations
Economic benefits of innovative technology sector

Good patient communication in HTA



Good patient communication in HTA



Recommendations