



Programme

- Introduction – The patient and HTA
- Qualitative interviews and participant observations (Helle Ploug Hansen)
- Why are patients important to our work in Asia (Karen for Fiona McMaster)
- Inclusive HTAs – patient involvement practices in HTA (Ann Single)
- **Value of patient involvement in HTA**
- **HTAi Interest Group**
- Close



Barriers to 'consumer' involvement (AHFMR, 2005)

- Time
- Cost
- Enthusiasm of staff and patients
- Concern about bias
- Lack of staff training about public involvement
- Tokenism!
- Lack of patient support to manage meeting papers
- Providing information to patient that is too technical
- Inability to balance different perspectives
- Lack of social science expertise



How are patients involved in HTA?

INAHTA survey (Hailey, 2006)

- 37 agencies (90%), 21 agencies involved 'consumers'
- 24 involve consumers in formulation of HTA topic
- 14 ask for opinions about the disease or technology
- 12 use consumers to review protocols/draft HTA reports as part of an advisory panel
- 12 involve consumers in development of easy to read summaries
- 12 involve consumers in dissemination



INAHTA survey (Hailey, 2006)

- 8 HTA agencies reviewed where and how consumers were involved
- 4 evaluated influence of input on HTA quality and relevance
- 4 provided training
- 2 involved consumers in assessment of evidence



DACEHTA survey, 2007

- Random sample of 50 HTA reports on HTA database
- 43 (86%) included assessment of patient issues
- Variety of issues, but often addressed simplistically
- A few reports had a comprehensive assessment with
 - systematic reviews
 - primary research
 - mostly questionnaires or interviews
 - few direct observations, expert group involvement
 - preference instruments, focus groups
- These reports provided knowledge about whether or not to implement technology and in planning implementation



Organisation of services for diabetic retinopathy screening

- Patient organisation member involved in advisory group
 - 97% uptake of annual screening in Western Isles, but won't attend screening if given eye drop – so evaluate need for eye drops
- Active participation at all stages:
 - defining key research questions
 - organisation of focus groups (identification of patients)
 - interpretation of findings
 - consultation workshops to discuss emerging findings
 - preparation of easy-to-read information about HTA
 - disseminate HTA information through local networks



Easy to read guide

Health Technology Board for Scotland



Understanding HTBS Advice

Diabetic retinopathy screening in Scotland

(C) Karen Facey 2009

April 2002



HTBS Organisation of services for diabetic retinopathy screening

Evidence

- 'Expert patient': empowerment for self management of chronic disease
- Coordinated services, timely results
- Targeted methods of invitation (letters, videos, posters, television, web, etc)
- **In appropriate formats!**
- No more than 2 written reminders, but use diabetes nurse specialist for follow-up



Panel Session - Tuesday afternoon

Impact of including patient aspects in HTA

Patient aspects in Danish HTAs: from caesarean section → chronic renal failure	Helga Sigmund
Patient views on wireless capsule endoscopy in Italy: illuminating safety and acceptability	Marco Ratti
Smoking cessation programmes in pregnancy: what are women's concerns?	Sandy Oliver



Patient participation in HTA?

- HTA Topic selection (topic proposals, priorities)
- Scope HTA questions
- Comment on issues of clinical effectiveness
 - Is the benefit really meaningful – what's the impact on daily living?
- Provide input to elements of economic model
 - Pathway of care and disease (+organisational issues)
 - Utility of slowing disease progression
 - Impact of side effects
 - Costs of illness/disease progression



...Patient participation in HTA?

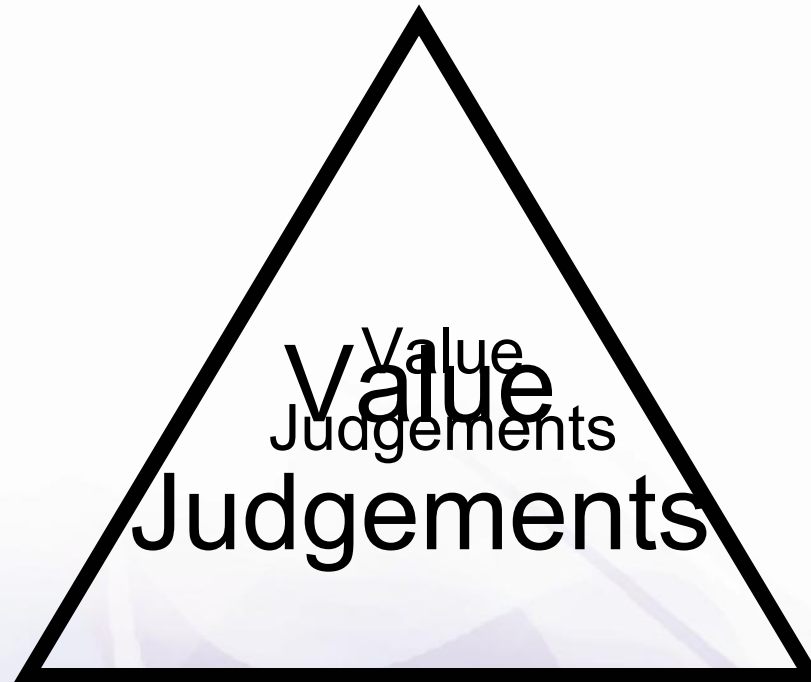
- Comment on social impact, ethical & psychological issues
 - Organisational issues (e.g. factors that affect uptake/compliance)
 - Need for informed consent before screening
 - Stigma of treatment, stress caused by uncertainty
- Commission research to input to HTAs
- Help assess evidence
- Comment on reports and patient information
- Communication of HTA results
- Helping Agencies to involve patients better!



HTA - the deliberative

process

Scientific publications
and submissions



Patient
aspects

Health
professionals'
experience

Guidance



HTAi Interest Group

Patient/citizen involvement in HTA

Expectations of participants

- Get to know other people working in the field, either in the HTA community or in other scientific/policy fields.
- Share expertise about processes, methodology and tools
- Develop a common discourse (terminology and understanding) about public participation, the role of the citizen, customer/user focus, etc.
- Discuss what can be realistically achieved in an HTA report in terms of eliciting patient/carers preferences and views
- Discuss how citizens views can be incorporated into the HTA process
- International collaboration!!



HTAi Interest Group

Patient/citizen involvement in HTA

- Main activities
 - Survey of members
 - Development of HTA glossary for patients
 - Manuscript for IJTAHC
 - Information sharing
- Resources on website
 - HEE guide on HTA
 - Patient decision aids
 - References
 - Interactions with rest of HTAi



HTAi Interest Group

Patient/citizen involvement in HTA

- Business meeting – Tuesday lunchtime
- What can we do to help you promote the most effective engagement of patients in HTA?
- Sign attendance form to receive outputs and slides from this meeting

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