

International approaches to engaging patients in technology decisions



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Involvement in HTA

International approaches to engaging patients in technology decisions

- Patients
- Health Technology Assessment (HTA)
- Patients' perspectives
- Robust evidence
- Effective patient participation
- The future

Who?

- ‘patient’
 - service user and other beneficiaries of a health technology (including health promotion)
 - carer/care-giver (who looks after a patient)
- ‘*citizen*’
 - *member of the public who does not have experience of the illness or technology, but is a user of the health service and wants fair access to good quality services*

Patients (Courtesy of Ann Single)

expectations

interests

experience

ethnicity



values

age

beliefs

location

roles

hopes & dreams

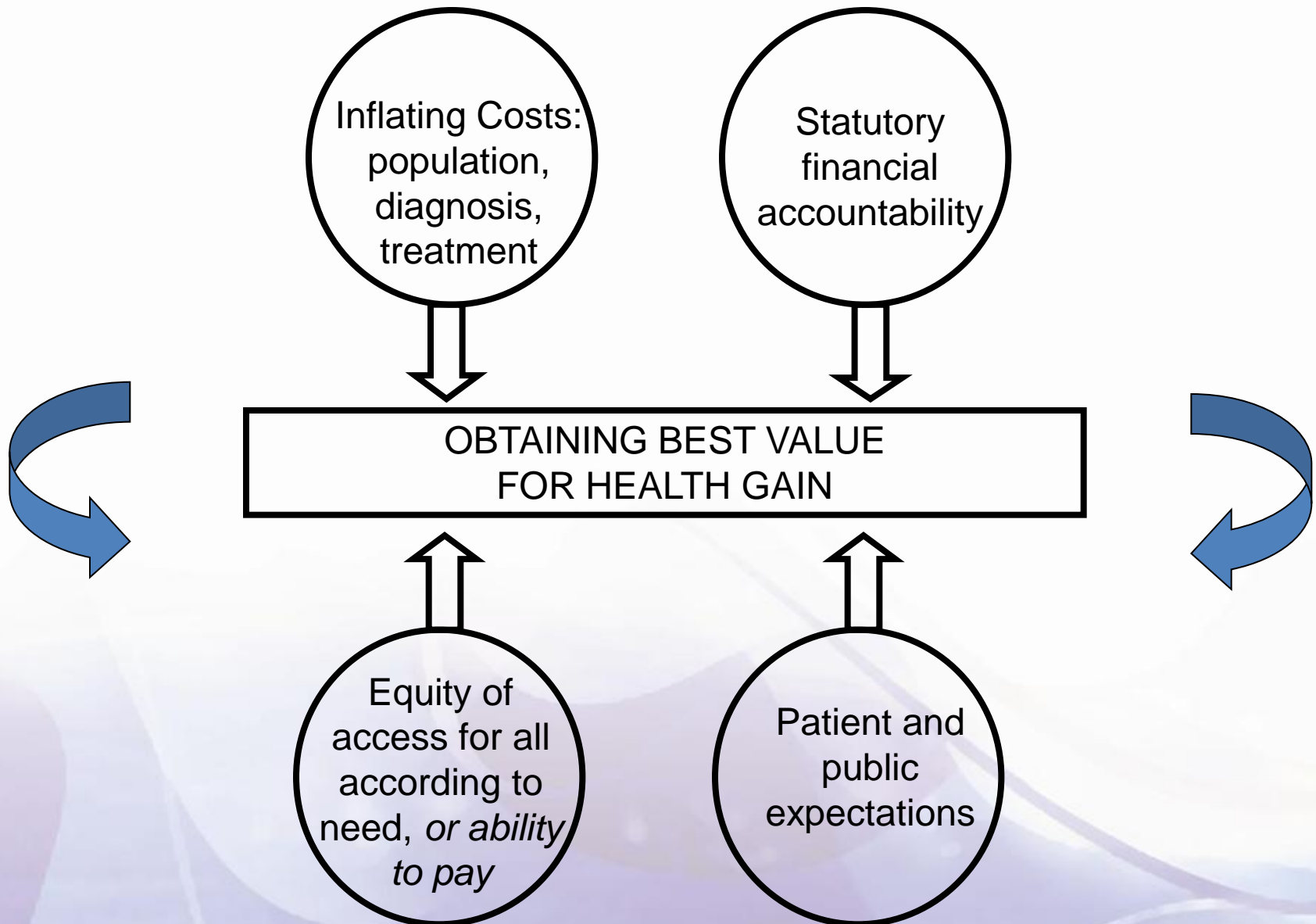
education

medical history

Communities (geography, ethnicity, peers, circumstances...)



The healthcare paradigm



Health Technology Assessment

HTA is the research-based,
practice-oriented assessment
of relevant available evidence and knowledge
on the direct and intended effects
of health care technologies,
as well as the
indirect and unintended consequences
(www.htai.org)

Health Technology Assessment

- Clinical effectiveness (relative effectiveness)
- Costs and cost effectiveness
- Patient aspects
- Organisational issues

Focus varies depending on
HTA Agency remit, topic and technology

All seek to 'inform' policy decisions,
by focussing on national/regional context



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.

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HEE Understanding HTA

Patients and carers can provide experiential evidence to an HTA about:

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.’

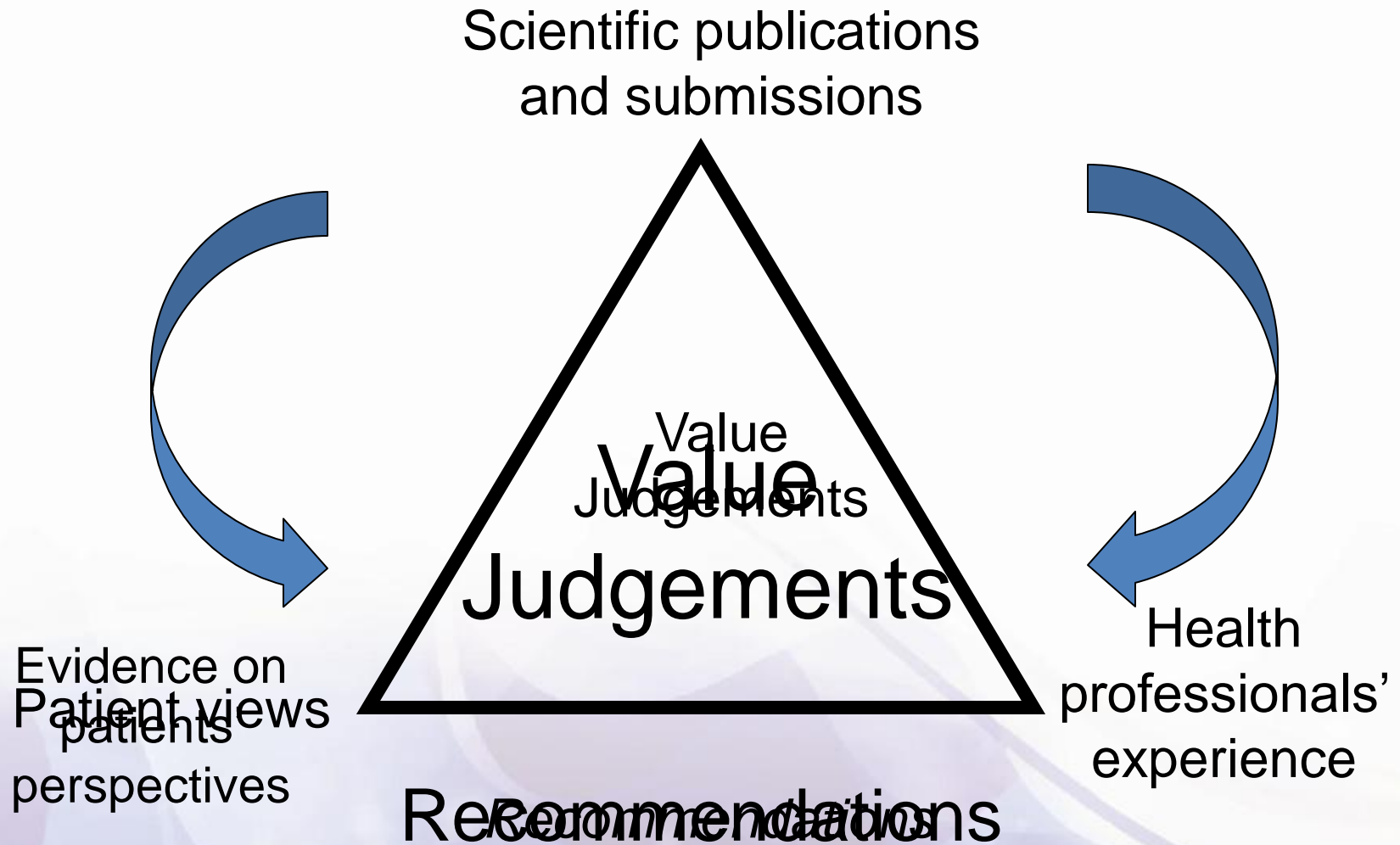
The technology

Their needs and preferences, and benefits & unwanted effects

HEE Patient Evidence – Describing burden of illness

- Nature of illness
 - Short or long-term
 - Symptoms: limited or many, difficult to live with, fatal
- Limitations illness imposes on
 - Daily life, Ability to work, Social life, Mental wellbeing, Enjoyment of family and friends
- Activities that people with the illness find difficult
- Whether the illness prevents fulfilment of chosen role in life
- The most difficult aspect of the illness
- How pain from illness or treatment interferes with daily activities and whether pain relief is needed

HTA: Evidence based decision-making





Health Technology Assessment International

An International Society for the
Promotion of Health Technology Assessment

‘Patients’ perspectives in HTA: a route to robust evidence and fair deliberation’

Javier Gracia,
Spain

Helle Ploug Hansen,
Denmark

Alessandra Lo Scalzo,
Spain

Jean Mossman,
Scotland



Antoine Boivin,
Canada

Ann Single,
Australia

Patients' perspectives in HTA

- Patients' views and preferences contributing to HTA:
 - In the form of robust evidence
 - Through *participation* in the process

Evidence about patients' perspectives

- Through generation of robust evidence about patients' views on the intended and unintended consequences of using a health technology
 - Well planned and structured
 - Systematic
 - Presented clearly showing sources, methods, assumptions and findings

Qualitative research

(Malterud, 2001)

- Perspectives on the disease or health technology – but not anecdotal!
- Systematic collection, organisation and interpretation of textual material derived from talk or observation
- Findings are descriptions, notions or theories applicable in a specified setting

Synthesis

(based on DACEHTA HTA handbook)

- Synthesis of qualitative research studies (meta-ethnography) to combine often diverse conceptions into a coherent whole to:
 - Acquire better understanding of patient aspects
 - Make generalisations based on repeated themes
 - Go beyond the conceptual or theoretical development found in each study (so more than the simple aggregation of findings in a meta-analysis)
- Often exploratory and iterative

Systematic reviews: Databases

- PubMed
- Embase
- PsycINFO
- Sociological Abstracts
- Social Sciences Citation index
- Campbell Collaboration
- DUETS
- Web search – for patient organisations

Systematic reviews: Journals

- The patient
- Health expectations
- Value in health
- Medical anthropology
- Social science and medicine
- Culture, medicine and psychiatry
- Anthropology and medicine
- Sociology of health and illness
- Int J Technol Assess Health Care

Systematic reviews: Quality assessment 'translation in different countries'

- Rationale for study (is it up to date?)
- Context (population/setting comparable?)
- Rationale for methods (appropriate)
- Transparency of data generation, analysis, interpretation (including limitations)
- Connection between research questions & conclusions
- Clear report of knowledge generated given the methods (taking account of biases)
- Assessment criteria – Popay et al (1998)

Primary research

Qualitative research

- Questionnaires/surveys
- Individual interviews
- Focus groups discussions and interviews
- Delphi
- Futures workshops
- etc

Scottish Medicines Consortium (SMC) Submission of Evidence Template

- Overview of organisation (and number of patients)
- Declarations of interest
- Experience with medicines currently available
 - Perceived advantages and disadvantages
 - Preferences, Needs: met and unmet
- Information to help Consortium understand how the health problem affects patients/carers (describe source)
- Potential impact
 - How would it match up to user needs and preferences
 - Advantages/disadvantages over current medicines
 - Impact on lives of patients & carers (describe source)

HEE Patient Evidence – The technology

- Patient and carer expectations
- Benefits/unwanted effects compared with existing treatments and how these are balanced
- How easily technology fits into daily life
- Whether it helps fulfilment of chosen role in life
- Outcome from a treatment that would be most valued
- Impact on daily life and mental wellbeing
- Financial impact of technology (cost of travel, loss of earnings, cost of paying carer)
- What would happen to patients if access was limited
- How patients and carers value the technology

Patient perspectives about screening for diabetic retinopathy (NHS QIS HTA1)

- Literature search including important grey literature: websites, patient leaflets, government strategies, national surveys, registries etc
 - Empowering people with diabetes (long-term conditions, expert patient)
 - Role of health professionals (multiple examinations, specialist nurses, pharmacists, optometrists)
 - Patient information should be accessible to different patient groups and readable
 - Methods to improve attendance (don't send multiple reminders, diabetes specialist nurse is encourager)

Patient perspectives about screening for diabetic retinopathy (NHS QIS HTA1)

- Focus groups – patients want:
 - Education about screening process (take account of information overload of newly diagnosed patient and use variety of approaches)
 - Coordinated services for people with diabetes
 - Choice of timing (remember work commitments)
 - Welcoming attitudes and comfortable surroundings
 - Don't like eye drops!
 - Timely results (with photograph) and clear explanation of implications
 - Support to deal with visual impairment

Fair deliberation

- Through effective 'involvement' processes to enable participation in the HTA process
- *(to help translate evidence from different countries)*

International Association for Public Participation Spectrum of public participation (www.iap2.org)

	Inform	Consult	Involve	Collaborate	Empower
Goal	Balanced & objective information to assist understanding	Gain public feedback on analysis, alternatives, decisions	Work directly with public throughout process so concerns understood & considered	Partner with public in each aspect, identify alternatives & preferred solution	Place final decision-making in hands of public
Promise	Informed	Informed, listen to you, provide feedback on influence	Concerns directly reflected, feedback	Look to public for advice & solutions & include to maximum	Implement what you decided
Example	fact sheets web sites	focus groups public meetings	workshops deliberative polling	citizens' advisory committees consensus building	ballot delegated decision citizens' jury

Patient Research Partners

(Hewlett et al, 2006)

Challenges experienced by patients

- Contribution hindered by difficulties with access and communication
- Relationship (doctor supremacy, fear of preferential care)
- Tokenism (political correctness)
- Anxieties of new role –
unclear about role and ability to contribute,
perceived value of contribution, not appearing
foolish, lack of familiarity with technical terms

Patient Research Partners

(Hewlett et al, 2006)

Solutions: **FIRST**

- **F**acilitate: inclusion/contribution
- **I**dentify: projects/potential partners
- **R**espect: roles/contribution
- **S**upport: confidentiality/communication-working
- **T**rain: research processes

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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www.htai.org

Patient perspectives about screening for diabetic retinopathy (NHS QIS HTA1)

- Diabetes UK fully involved in assessment
- Scoping: 97% uptake of annual screening in Western Isles, but won't if given eye drops
- Fully involved in assessment of evidence
- Consultation workshops
- Dissemination of reports through local reports
- Development of 'Understanding' for patients to explain HTA process and format

Engaging patient organisations in HTA (1)?

- Inform HTA Agency of your role and possible input (and what you expect from them)
- HTA topic selection (proposals and prioritisation)
- Help scope HTA questions
- Clinical effectiveness – clarify outcomes of importance to patients and meaning of effect
- Provide input to elements of economic model (particularly Quality of Life, clinical pathway, positive and negatives effects, preferences etc)

Engaging patient organisations in HTA (2)?

- Get involved in research to determine patients' perspectives on social impact, ethical and psychological issues
- Commission/undertake 'research' to input to HTAs
- Help assess evidence
- Assist with consultation on reports
- Help develop patient information
- Communicate HTA results
- Help HTA Agencies to involve patients better!

The future?

- Improved methods for combining qualitative research studies
- A toolkit for agencies to support patient participation at each step of the HTA process
- Section on patients' perspectives in every HTA
- Greater transparency in decision making to show how all forms of evidence have been judged and how they have influenced the decision
- More financial support for robust research into patients' issues.....