Results of the survey on Ethical Issues among INAHTA organizations

Survey on handling of ethical issues among INAHTA members

Health Technology Assessments, however strongly based on solid scientific evidence, have normative elements. Scientific data need interpretation and value judgments inevitably are introduced, sometimes explicitly, more often in an implicit manner, for example in a cost-utility analysis. But normative aspects already are present when we prioritize our work program: what do we find important and what can wait?

Policy decisions, however evidence-based they seem to be, are never value-free, because of societal implications they have.

HTA and ethics cannot, therefore, be separated. We have developed consensus about what constitutes a good technology assessment. We have not yet developed an equally clear notion of how we should deal with the ethical issues. Should they be separated from the HTA as such, or should an ethical analysis be an integral part of the assessment? Or should it perhaps be seen as a political responsibility, an element in the decision-making process? Who are best qualified to make the analysis and what role should they play? What should be the goal of an ethical analysis: explaining and analyzing the moral dilemma’s and leaving the conclusions to others (clinicians? consumers? politicians?) or would it be all right to express one’s views?

How do INAHTA-members deal with this matter?

These are some questions we would like to discuss. In preparation for our next Annual Meeting we want to ask you to answer the following questions. Please feel free to add any comment that you would want to make.
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No of organizations 92% (36/39)

1) Do the terms of reference or your agency
   47% (17) Explicitly mention including ethical issues in your assessments?
   44% (16) Imply such activities?
   3% (1) Rule them out?
   8% (3) N/A

2) Has your agency a system for handling ethical issues as part of HTAs?
   25% (9) Yes
   19% (7) No
   56% (20) Ad hoc

3) Does your agency include ethical issues in health technology assessments?
   14% (5) Always
   56% (20) Sometimes
   11% (4) Often
   17% (6) Never
   3% (1) N/A

4) What forms of ethical considerations?
   78% (28) Integral part of the assessment, made by:
   31% (11/36) Clinicians
   36% (13/36) Methodology experts
   19% (7/36) Professional ethicists
   44% (16/36) Multidisciplinary expert group, including ethicists

   25% (9) Separate assessments
   11% (4/36) Under the auspices of the agency
   6% (2/36) Not under the auspices of the agency
   0% (0/36) Peer review of HTA reports by professional ethicists
   11% (4/36) Peer review of HTA reports by a group assembled for the occasion
   0% (0/36) Peer review of HTA reports by others

   14% (5) N/A

5) Are consumers involved?
   53% (19) No
   47% (17) Yes, in patients views/perspective (6), Consumer associations (1),
   represented in committees/boards/panels (8), throughout the project (1), separate
   publications (1), advisory groups (2), in clinical guidelines (2), discussion
   groups/conferences (2)
6) Has your agency been engaged in ethical questions besides the HTA-reports?
   
   39% (14) No
   
   61% (22) Yes:
   
   - 33% (12/36) In seminars/workshops
   - 31% (11/36) Public debate
   - 11% (4/36) Formal education
   - 3% (1/36) Fellowships
   - 22% (8/36) Other, namely consulting activities (2), ongoing projects (2), guidelines (1), courses (1), committees (2)

7) Name one or two recent assessments by your agency that show how you deal with ethical issues.
   
   72% (26/36) gave examples of recent assessments see next page

8) Does your agency have written instructions on how to deal with ethical aspects of an assessment?
   
   17% (6) Yes (only 2 examples in English)*
   
   83% (30) No (8% (3) are preparing or planning to prepare written instructions)

* CCOHTA: Written instructions on ethical aspects of an assessment are included in the CCOHTA- Guidelines for Authors which is available on the website [www.ccohta.ca].

ICTAH

MTU-FSIOS: flowchart draft English

SBU: Only in Swedish

SMM: Only in Norwegian

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Examples of recent assessments that show how your agency deals with ethical issues

**ASERNIP-S:**
1. Systematic review on radiofrequency ablation of liver tumours – RCT not recommended as unethical to randomize patients to a new treatment such as RFA or other new treatments, without accompanying treatment of surgical resection.
2. Systematic review of intra-operative radiotherapy (IORT) for breast cancer – caution on how RCT set up as unethical to offer IORT only as a treatment and not the standard proven treatment of postoperative radiotherapy.

**AETMIS**
The use of electroconvulsive therapy in Quebec (2003)
Fragile X syndrome: The role of molecular diagnosis in an integrated service approach (2002)

**AETS**
HTA report about “Transexual surgery” with a panel of clinical experts

**AETSA**
Users support in health-related decision-making: available tools and synthesis of the evidence.
Health care of gender identity disorders in Andalusia

**AHFMR**
Personal Directives
Left Ventricular Assist Device

**ANAES**
Access to patient file
Delivering information to patients
Patient Information about prostate cancer screening

**CAHTA**
Living donor liver transplant
Evaluation of prenatal diagnosis for Down Syndrome

**CCOHTA**

**CEDIT**
Cochlear implants

**CMS**
Positron Emission Tomography for Alzheimer’s disease
Implantation of left ventricular assist devices for heart failure destination therapy

**CVZ**
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Cochlear implants: Health Technology Assessment and Interactive Evaluation. Funded by our investigative medicine program

DACEHTA
2. Beta-interferon-behandling ved dissemineret sklerose. Medicinsk Teknologivurdering 1999;1(2)

DAHTA
1. Droste S; Brand A: Biochemisches Screening für fetale Chromosomenanomalien und Neuralrohrdefekte - eine Verfahrensbewertung
2. Droste S, Gerhardus A, Kollek R: Ethical and social science rapid HTA

FinOHHTA
Neonatal screening of inborn errors of metabolism (ongoing project)
Internet health information -quality, ethics and trust (ongoing project)

GR
2. Cochlear implantation in children. (publication # 2001/11. In Dutch, with an Executive Summary in English)

ICTAHC
GLIVEC
MABTHERA

ITA
Genetic diagnosis (1996) & predictive genetic diagnosis (2002), all assessments on “inappropriate Use” (overuse, waste of ressoirces) = ICU-Planning, expensive Pharmaceuticals etc.

MTU-FSIOS
Publifocus on IVF
Ethical debate on LLT

NHSC
Riluzole for the treatment of motor neuron disease. The drug is not very cost-effective in comparison with other treatments used within our health service but there are issues around equity (there are no other specific treatments available). We included a special section called the patient perspective to address this element.
In a report that is still ongoing and in the confidential stage we discussed as a team how to deal with data that has been deliberately withheld by a pharmaceutical company. We decided to be explicit about the exclusions and include a hypothetical analysis of its possible results.
Our team currently has a policy of not accepting commissions from for-profit organisations, such as pharmaceutical companies, despite the fact that such work is considerably better resourced than the work we do, in order to avoid potential conflicts of interest. This has been much debated with the counter argument of the gain from being able to cross subsidise our public work being put forward.
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**NHSQIS**  
Working on ultrasound scanning in pregnancy  
Completed screening for diabetic retinopathy

**NICE**  
Ethical conditions or social value judgements are implied in all our evidence.

**OSTEBA**  
The “Genetic Therapy” report included ethical considerations in the assessment process, with participation of a multidisciplinary team, including an ethicist and a lawyer.

**SBU**  
Obesity – problems and interventions 2002, Chapter 9 Ethical issues  
Advanced Home Care 1999, Chapter 5 Difficult questions in home care  
Prevention of Caries 2002, Chapter 9 Ethical issues  
Alert – all reports on new medical methods contain a subheading named “ethical aspects” which is sometimes rather extensive for a short report of this kind.

**SMM**  
Treatment of Ovarian Cancer  
Children born from intracytoplasmic sperm injection  
Bracyteraphy and Prostate Cancer

**TA-SWISS**  
Human Stem Cell/ Xenotransplantatin, PubliForum on Transplantation Medicine, Publifocus on Embryonal Stem Cell

**VATAP**  
Most of our reports address the ethics of each issue implicitly, but none to date have had an ethical perspective that required addressing it more explicitly.