

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)

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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].

ICTAHC

MTU-FSIOS: flowchart draft English

SBU: Only in Swedish

SMM: Only in Norwegian

TA-SWISS: Morals and Shaping Technology (http://www.ta-swiss.ch/www-remain/reports_archive/publications/2003/030131_TA_Ethik_e.pdf)

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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 “Transsexual 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

1. Noorani HZ, Connolly SJ, Talajic M, O'Brien BJ, Hoffmaster B, Dickens BM. Implantable cardioverter defibrillator (ICD) therapy for sudden cardiac death. *Canadian Journal of Cardiology* 2000, 16:1293-1324.

2. Noorani HZ, McGahan L. Predictive genetic testing for breast and prostate cancer. Ottawa: Canadian Coordinating Office for Health Technology Assessment (CCOHTA); 1999.

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

1. Præimplantationsdiagnostik – en medicinsk teknologivurdering. Medicinsk Teknologivurdering - puljeprojekter 2002;2(1)
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

FinOHTA

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

GR

1. Contraception for people with mental retardation (publication # 2003/14. In Dutch, with an Executive Summary in English).
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 resources) = 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
Brachytherapy and Prostate Cancer

TA-SWISS

Human Stem Cell/ Xenotransplantation, 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.