PubliForum on Transplantation Medicine

« Getting the Dialogue with the Man and Woman on the Street going »

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The Swiss Center for Technology Assessment

TA-SWISS...

- is affiliated to the Swiss Science and Technology Council

- has a mandate to support (political) decision making related to new technologies
TA-SWISS…

• can evaluate technologies using ”classical” TA studies involving scientific analysis and expert discussions

• can evaluate technologies by participative methods (PubliForum) involving the general public
The PubliForum on Transplantation Medicine
The current legal situation in Switzerland (2002)

• Constitutional basis for regulating transplantation medicine accepted by the Swiss people in a referendum in 1999:

"The Confederation establishes directives in connection with the transplantation of organs, tissues and cells. In so doing, it safeguards human dignity, personality and health."
Current political situation around transplantation medicine

• A federal law on transplantation medicine has been submitted to Parliament (late 2001)

• This law must now be discussed within Parliament

• Once adopted, the law can be submitted to popular referendum (50’000 signatures)
PubliForum: Goals

To involve citizens in the assessment of the impact of a new technology at an early stage

- Contribute to an informed public debate

- Provide recommendations for decision-makers in politics, industry and research (on the general public’s preferences, their understanding of the problem, their hopes and fears etc.)
PubliForum: Definition

The PubliForum is a meeting involving about 30 lay citizens selected from the general public where they can:

- Obtain information on a particular topic
- Take part in an active dialogue with experts and ask them questions
- Have their recommendations included in a report
The PubliForum on Transplantation Medicine

- Participative process (Citizens discuss transplantation medicine with experts)
- November 24th.-27th. 2000
- organised by:
  - TA-SWISS
  - Federal Office of Health
  - Swiss National Science Foundation
Invited Experts

- Physicians
- Nurses
- Psychologists
- Patients
- Relatives of organ donors
- Representatives of Swisstransplant

- Representatives of the « Etablissement français des greffes »
- Lawyer
- Philosopher
- Religion scientist
- Ethnologist
- Researcher (Biologist)
Citizens Panel’s Questions

- Definition of death, time of death
- Persons concerned
- Organ donation: consent / conflicts
- Organ allocation
- Research (Alternatives)
- Xenotransplantation
Citizens Panel´s Recommendations

- Information and Transparency
- Psychological Care
- Allocation of Organs
- Organ donations
- Research
Citizens Panel’s Recommendations

Information and Transparency

• The Swiss Confederation should pursue a more active information policy for the general public on the consequences of organ donation
Citizens Panel’s Recommendations

Psychological Care

- Psychological support should be given by hospital departments to the donors and their relatives

- Psychological support and coaching of nursing personnel is necessary
Citizens Panel’s Recommendations

Allocation of organs

- Standardisation of criteria for setting persons on the waiting lists of transplantation centres

- Medical criteria should be given priority when allocating organs
Citizens Panel’s Recommendations

Organ donations

• The Citizen Panel recommends the Extended Consent Model
Citizens Panel’s Recommendations

Research

- Finding alternatives to reduce the shortage of organs (Preventive action, donation by living donors, artificial organs, tissue engineering) is considered to be very important

- No moratorium on xenotransplantation
Impact of the PubliForum

• Integration of the PubliForum´s recommendations in the Federal Council´s submission to parliament on the Federal Law on Transplantation (September 2001)

• Application by the St. Gall cantonal hospital for the setting-up of a department for the psychological care of those involved in a transplant (donor, recipient)
Impact of the PubliForum

• Citizen Panel will be invited to present and discuss the results of the PubliForum to the Commission on Social Security and Health (CSSH) of the National Assembly and the Assembly of States (the parliamentary commission responsible for the Transplantation Law)
Conclusions

• The general public judges transplantation medicine to be basically positive

• However, Transplantation Medicine raises many questions in the general public

• These questions must be taken seriously in order to preserve the general public’s basically positive attitude