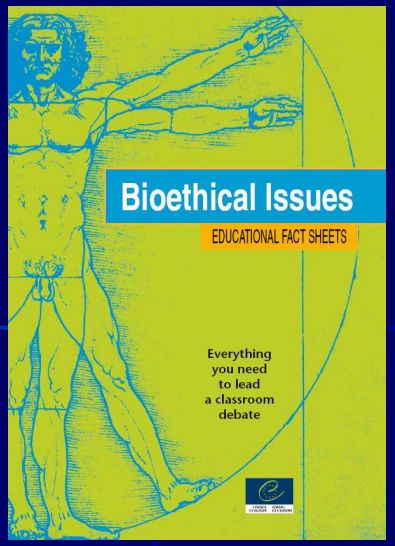

Personal reflection and public debate on organ donation:

a teaching aid from the Council of Europe

Tina Garani-Papadatos
Steering Committee on Bioethics
Council of Europe
http://www.coe.int/bioethics

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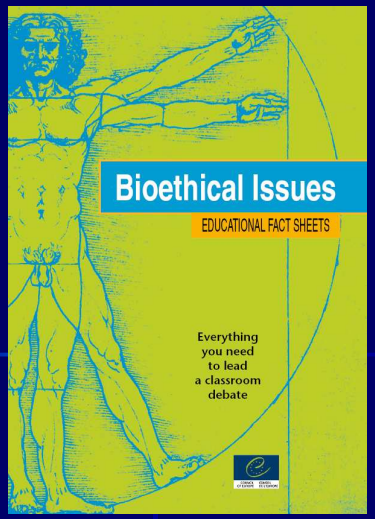

Convention on Human rights and Biomedicine

Article 28 - Public debate

- «Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion in the light…of relevant medical, social, economic, ethical and legal implications…»

Ethics education of health professionals, professors, and the general public

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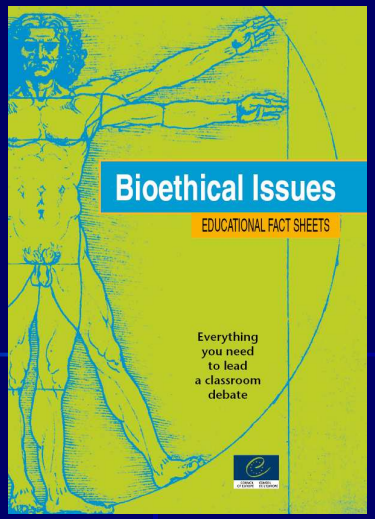
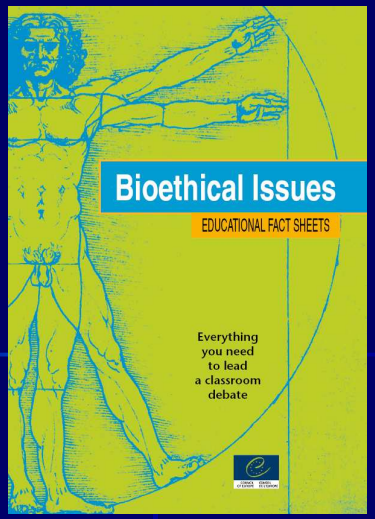


Purpose of Public Debate

- To raise awareness among all members of the society on the importance of this debate and their legitimate participation

Young people = members of the society - future of this society



Initiative of the Council of Europe

- Development of a teaching aid intended for professors/teachers wishing to address and discuss bioethical issues with young people

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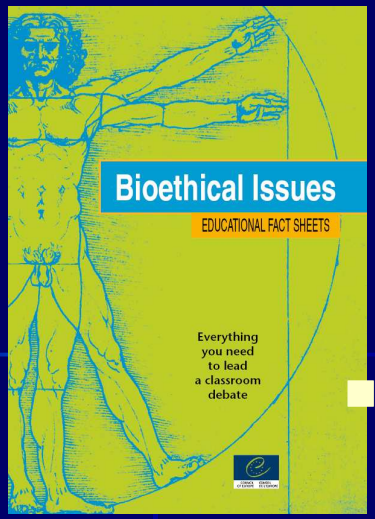

Objectives

- To make young people aware of bioethical issues
- To foster independent thinking
- To promote a participatory approach to debates on societal issues
- To open up to the European dimension of the debate (international)
- To clarify key scientific and medical concepts

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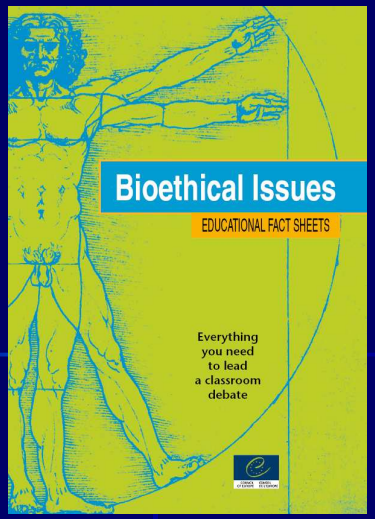

Design of the project

The concept of this teaching aid was developed in collaboration with MSc students at the Louis Pasteur University (Strasbourg, France)

Determining elements:

- Education programmes (biology, philosophy, civic education…) and limited time – Flexible use
- Social and cultural differences between countries
- Possibility of use in other contexts, in particular professional education

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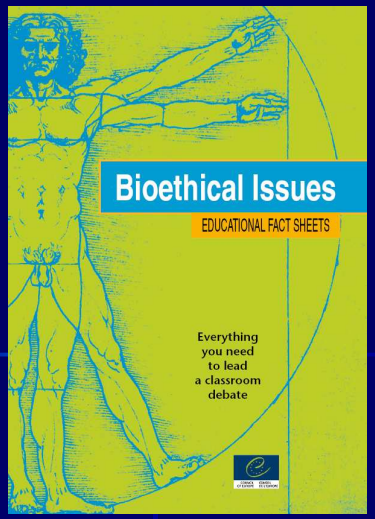

Project of teaching aid

- A set of educational fact sheets intended for professors/teachers and students

- Not intended to exhaust the subject, but to provide essential information to tackle the subject and initiate an open debate on bioethical issues

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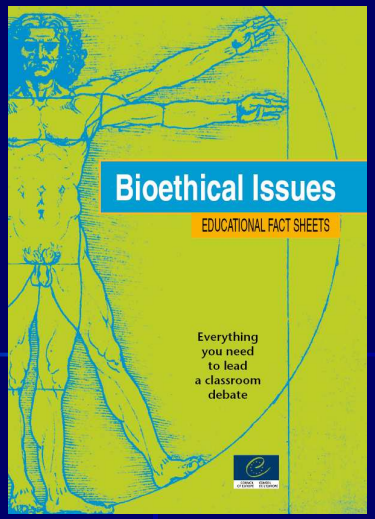

A Set of educational fact sheets

- 2 educational fact sheets to the attention of teachers/professors
- 5 educational fact sheets to the attention of professors /teachers and students

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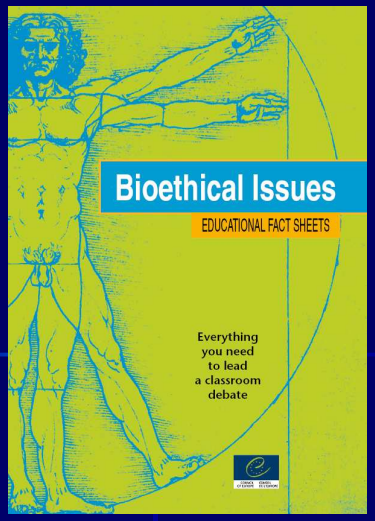
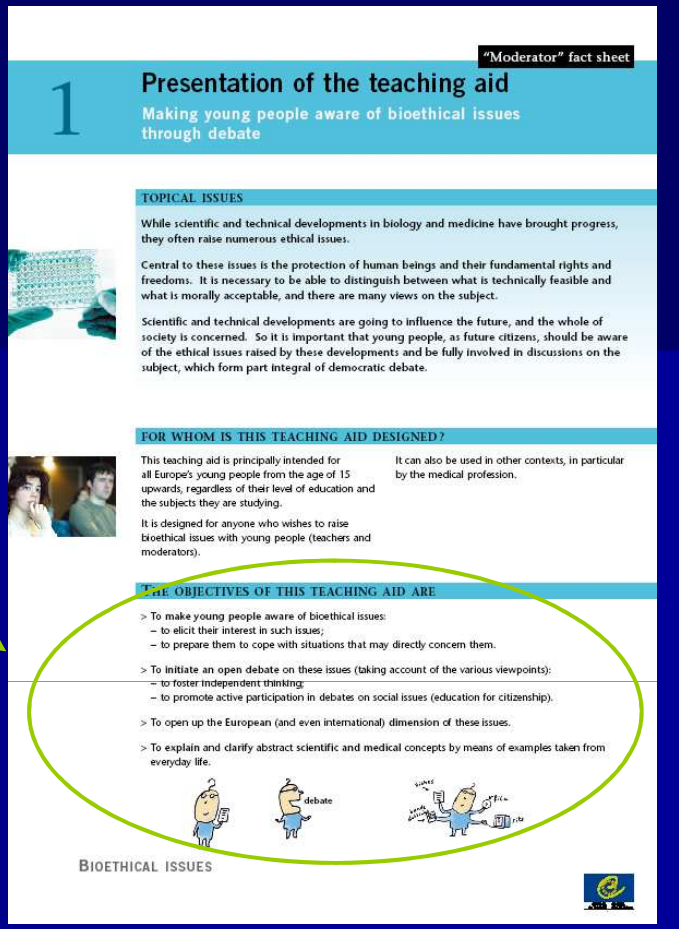


2 educational fact sheets to the attention of professors/teachers

Presentation: tool objectives and general description


"Moderator" fact sheet

1 Presentation of the teaching aid

Making young people aware of bioethical issues through debate

TOPICAL ISSUES

While scientific and technical developments in biology and medicine have brought progress, they often raise numerous ethical issues.

Central to these issues is the protection of human beings and their fundamental rights and freedoms. It is necessary to be able to distinguish between what is technically feasible and what is morally acceptable, and there are many views on the subject.

Scientific and technical developments are going to influence the future, and the whole of society is concerned. So it is important that young people, as future citizens, should be aware of the ethical issues raised by these developments and be fully involved in discussions on the subject, which form part integral of democratic debate.

FOR WHOM IS THIS TEACHING AID DESIGNED?

This teaching aid is principally intended for all Europe's young people from the age of 15 upwards, regardless of their level of education and the subjects they are studying.

It is designed for anyone who wishes to raise bioethical issues with young people (teachers and moderators).

It can also be used in other contexts, in particular by the medical profession.

THE OBJECTIVES OF THIS TEACHING AID ARE

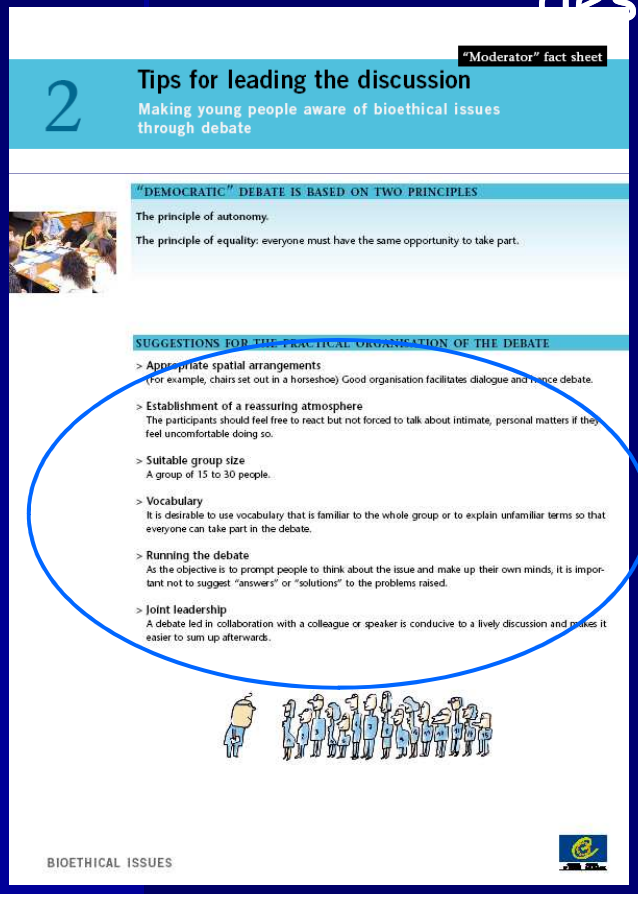
> To make young people aware of bioethical issues:
– to elicit their interest in such issues;
– to prepare them to cope with situations that may directly concern them.

> To initiate an open debate on these issues (taking account of the various viewpoints):
– to foster independent thinking;
– to promote active participation in debates on social issues (education for citizenship).

> To open up the European (and even international) dimension of these issues.

> To explain and clarify abstract scientific and medical concepts by means of examples taken from everyday life.

BIOETHICAL ISSUES


"Moderator" fact sheet

2 Tips for leading the discussion

Making young people aware of bioethical issues through debate

"DEMOCRATIC" DEBATE IS BASED ON TWO PRINCIPLES

The principle of autonomy.

The principle of equality: everyone must have the same opportunity to take part.

SUGGESTIONS FOR THE PRACTICAL ORGANISATION OF THE DEBATE

> Appropriate spatial arrangements
(For example, chairs set out in a horseshoe) Good organisation facilitates dialogue and hence debate.

> Establishment of a reassuring atmosphere
The participants should feel free to react but not forced to talk about intimate, personal matters if they feel uncomfortable doing so.

> Suitable group size
A group of 15 to 30 people.

> Vocabulary
It is desirable to use vocabulary that is familiar to the whole group or to explain unfamiliar terms so that everyone can take part in the debate.

> Running the debate
As the objective is to prompt people to think about the issue and make up their own minds, it is important not to suggest "answers" or "solutions" to the problems raised.

> Joint leadership
A debate led in collaboration with a colleague or speaker is conducive to a lively discussion and makes it easier to sum up afterwards.

BIOETHICAL ISSUES

Recommendation for the organisation of the debate & complementary activities

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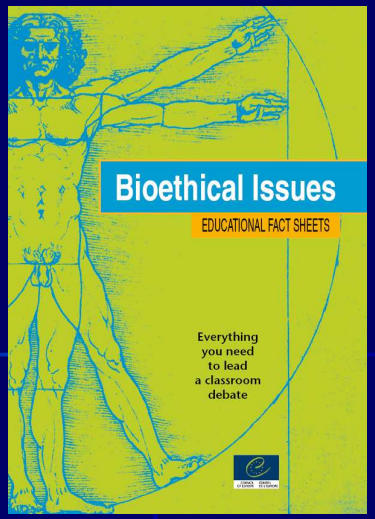

Educational Fact Sheets for professors and students

5 educational fact sheets centred on the subject

⟶ *Example: organ donation*

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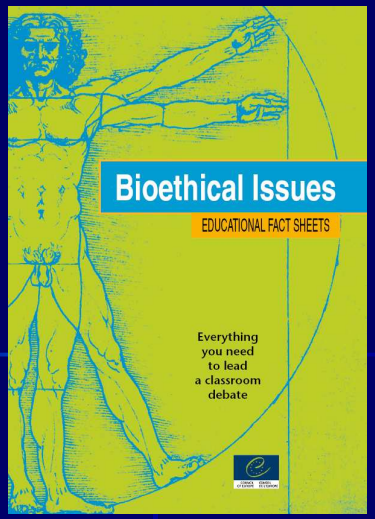
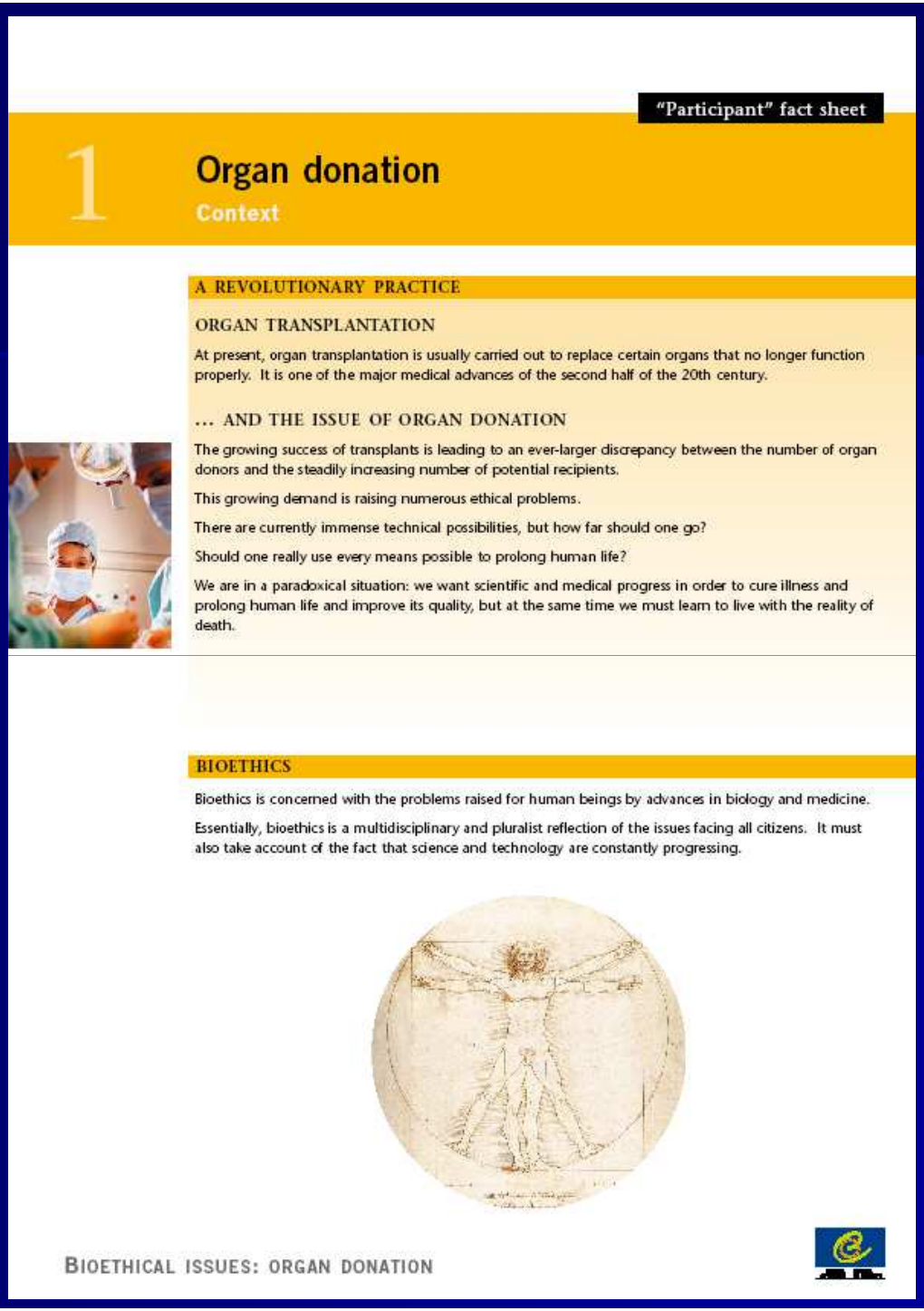


1st Introductory fact sheet

- Sets the issue in context
- describes the medical technique
- provides some key figures



"Participant" fact sheet

1 Organ donation

Context

A REVOLUTIONARY PRACTICE

ORGAN TRANSPLANTATION

At present, organ transplantation is usually carried out to replace certain organs that no longer function properly. It is one of the major medical advances of the second half of the 20th century.

... AND THE ISSUE OF ORGAN DONATION

The growing success of transplants is leading to an ever-larger discrepancy between the number of organ donors and the steadily increasing number of potential recipients.

This growing demand is raising numerous ethical problems.

There are currently immense technical possibilities, but how far should one go?

Should one really use every means possible to prolong human life?

We are in a paradoxical situation: we want scientific and medical progress in order to cure illness and prolong human life and improve its quality, but at the same time we must learn to live with the reality of death.

BIOETHICS

Bioethics is concerned with the problems raised for human beings by advances in biology and medicine.

Essentially, bioethics is a multidisciplinary and pluralist reflection of the issues facing all citizens. It must also take account of the fact that science and technology are constantly progressing.

BIOETHICAL ISSUES: ORGAN DONATION

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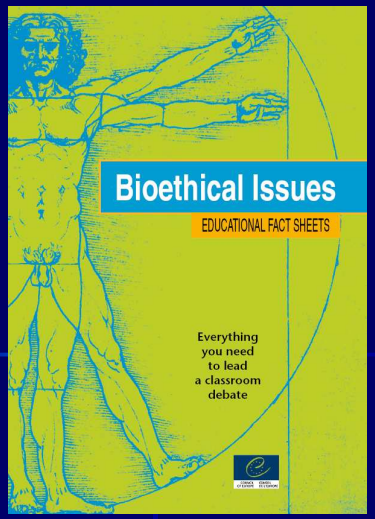


2nd Scientific fact sheet

The information is presented in simple terms that everyone can understand.

"Participant" fact sheet

2 Organ donation

Scientific data

A transplantation* is usually carried out in order to replace or "take over" a vital organ* which is failing in its functions.

Transplantation* entails removing an organ or tissue from one person and grafting it to another person.

Organs: heart, lungs, liver, kidneys, pancreas

Tissues: cornea, skin, bones, heart valves, blood vessels

ORGANS AND TISSUES THAT MAY BE TRANSPLANTED

Living donors

Living people may donate bone marrow, a kidney or skin.

Deceased donors

Only organs and tissues that are still viable may be transplanted. Essential organs such as the heart and the lungs remain viable for a short period after death. If the person in question is considered brain-dead* (rare situation), however, certain bodily functions (for example, heart and lungs) may be artificially maintained and, after authorisation, organs and tissues may be removed.

THREE TYPES OF TRANSPLANT

Autografts

The donor and the recipient are the same person (as in the case of a skin graft).

Allografts

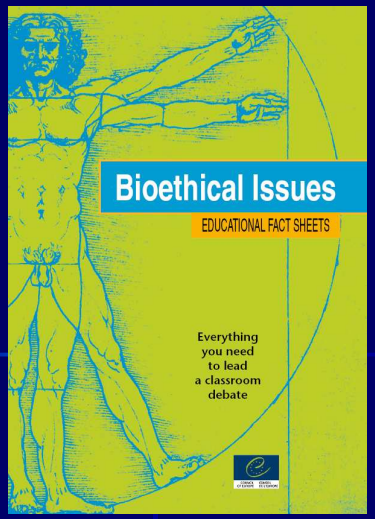
The donor and recipient are separate but belong to the same species.

Heterografts/xenografts

The donor and recipient are from different species.
A xenograft* entails, for instance, transplanting animal organs or tissues into a human being. It is mainly relevant to experimental research.
The term "heterograft" is also used when the transplanted organs are artificial.

COMPATIBILITY AND THE IMMUNE SYSTEM

Everyone is familiar with the A B O system blood groups, which determine whether a donor and a recipient are compatible and hence whether a blood transfusion will be successful. In the case of transplants, compatibility between the donor and the recipient is based on the HLA* (Human Leucocyte Antigen) system, also known as the MHC (Major Histocompatibility Complex) system, which can be considered to provide a tissue identity card. The molecules present on the surface of every cell in an individual, which are coded by this system, allow the immune system to differentiate between "self" and "non-self". In the case of a transplant (allograft or heterograft), the recipient's immune system will identify these molecules on the surface of the cells of the transplanted organ. If it identifies them as alien, a defence process designed to eliminate the transplanted organ is set in motion: this is known rejection*.

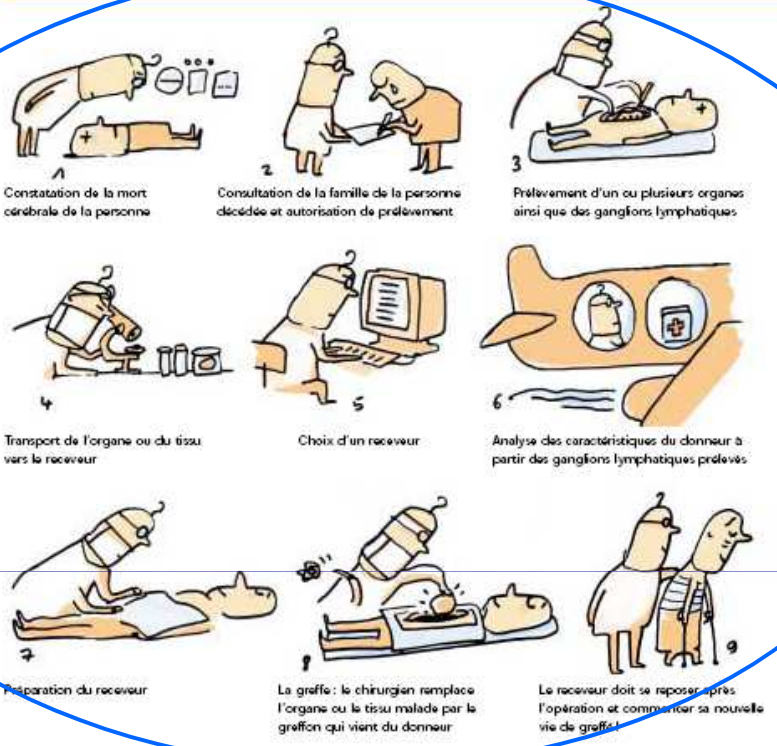


Scientific fact sheet (2)

Procedures involved (schematic presentation)

2 Transplantation

LES DIFFÉRENTES ÉTAPES DE LA TRANSPLANTATION



1 Constatation de la mort cérébrale de la personne

2 Consultation de la famille de la personne décédée et autorisation de prélèvement

3 Prélèvement d'un ou plusieurs organes ainsi que des ganglions lymphatiques

4 Transport de l'organe ou du tissu vers le receveur

5 Choix d'un receveur

6 Analyse des caractéristiques du donneur à partir des ganglions lymphatiques prélevés

7 Préparation du receveur

8 La greffe : le chirurgien remplace l'organe ou le tissu malade par le greffon qui vient du donneur

9 Le receveur doit se reposer après l'opération et commencer sa nouvelle vie de greffé

DE QUOI DÉPEND LA RÉUSSITE D'UNE GREFFE ?

Pourquoi une greffe réussit-elle ?

Pour qu'une greffe* réussisse, il faut choisir un tissu ou un organe dont les caractéristiques tissulaires sont les plus proches de celles du receveur.

Le rejet* de greffe est d,autant plus intense qu'il s'agit d'une greffe entre deux espèces différentes et que donneur et receveur sont éloignés du point de vue «génétique». Le rejet est la principale complication de la greffe d'organes. D'autres risques demeurent, comme la transmission de maladies.

Comment éviter le rejet de greffe ?

Il faut surtout que le donneur et le receveur soient, sur le plan immunologique, le plus compatibles* possible, ce qui est le cas entre membres de la famille proche (parents, enfants).

Le receveur doit également suivre un traitement approprié à l'aide de puissants immunosuppresseurs* pour que le phénomène naturel de rejet de greffe soit évité. Ainsi l'organisme diminue ses réponses aux intrusions de corps étrangers.

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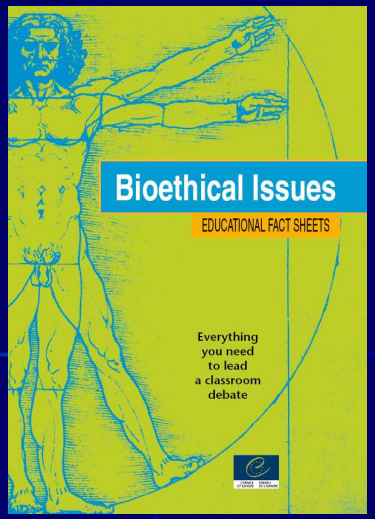


Fact sheet presenting fundamental ethical principles

- Provisions of the **Convention on Human Rights and biomedicine** and its additional Protocol
- Some ethical, legal and social aspects are underlined (*e.g. organ trafficking*)

"Participant" fact sheet

3 Organ donation

Key points

Legal references

Convention on Human Rights and Biomedicine (known as the Oviedo Convention), Council of Europe, April 1997

Additional Protocol to the Oviedo Convention concerning Transplantation of Organs and Tissues of Human Origin, Council of Europe, January 2002

FUNDAMENTAL PRINCIPLES

- The dignity and identity of all human beings must be protected.
- Everyone must be assured of respect for his or her integrity, other rights and fundamental freedoms with regard to the application of biology and medicine.
- The transplantation of organs and tissues helps to save human lives or considerably improve their quality.
- The shortage of organs and tissues necessitates appropriate measures to encourage people to donate.
- The ethical, psychological and socio-cultural problems inherent in the transplantation of organs and tissues must be taken into consideration.
- Improper use of transplantation could threaten people's lives and well-being and undermine human dignity.
- Transplantation shall take place under conditions that protect the rights and freedoms of organ donors, potential donors and recipients and ensure that human body parts are not sold.

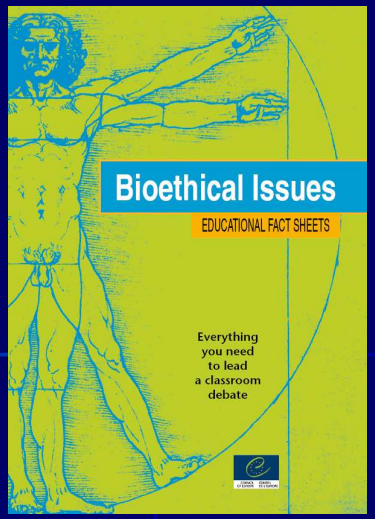
CONSENT

Organs* are removed primarily from deceased people. It is possible to envisage removing organs that are not vital and tissues such as skin from a living person.

- In any event, "an intervention in the health field may only be carried out after the person concerned has given free and informed consent* to it" (Article 5 of the Oviedo Convention).
- The potential donor must therefore be informed of the nature of the removal, the risks incurred and the consequences of the operation. The risks to the donor's physical and mental health must be assessed and limited.
- It is necessary to obtain the donor's consent (if he or she has registered during his or her lifetime on a list or register of donors) or the family's agreement.
- In some countries, consent may be presumed: the person is considered to be consenting unless he or she registered a refusal during his or her lifetime.
- Special arrangements have been made for people considered not able to consent, such as minors and certain people with mental disabilities (Article 6 of the Oviedo Convention).

CONDITIONS PERTAINING TO THE REMOVAL

- An organ or tissue may not be removed from a deceased person unless the death has been duly ascertained in accordance with the law. Criteria for establishing death may vary from country to country.
- The doctors ascertaining the death must not be those directly involved in removing the organ or tissues or the subsequent stages of the transplant*.



"Participant" fact sheet

4

Organ donation

Concrete situations

CASE No. 1

17-year-old Timothy is in hospital undergoing dialysis. He expresses his discontent with having to be there again. His doctor comes and sees him and explains once again why he needs dialysis, what purpose the kidney serves, what dialysis does, and so on.

When his parents arrive, the doctor informs them that their son needs a kidney transplant, but explains that Timothy and they are not immunologically compatible*. Timothy is put on the list of people awaiting a transplant and will need to wait until a compatible* kidney becomes available.

Timothy's friends have got together in the school yard because they want to help him. His best friend, Frank, offers to donate one of his kidneys. Another of his friends takes the view that one cannot donate one of one's organs just like that. He is afraid of falling ill at a later date and needing both his kidneys.

Timothy's friends go to hospital to visit him. They ask him whether it is possible for a friend to donate one of his kidneys and want to know what formalities need to be completed. Timothy tells them there could be a compatibility problem. A discussion ensues with Timothy's father. Who could donate an organ? Is it possible to obtain an organ elsewhere or to remove an organ from an animal?

QUESTIONS

Timothy's position

- What are the advantages of a transplant for Timothy?
- Does he have reason to be afraid of a transplant?
- What about the possibility of transplanting an organ from a deceased person?
- Is it better to wait for an organ from a deceased person or to remove one from a relative or friend?
- If Timothy receives a transplant thanks to a donation, is it better that he should not know who the donor is?

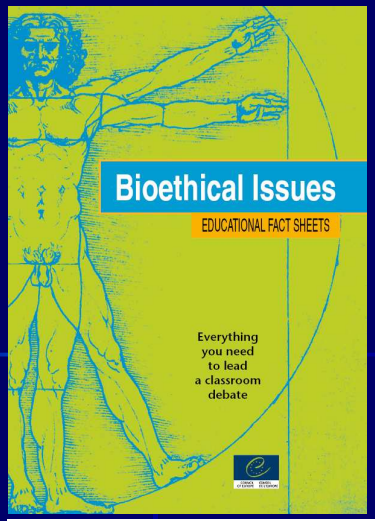
The position of his family and friends

- What should be done if the medical team cannot find an available kidney?
- What should be done if no member of Timothy's immediate family is immunologically compatible* with him?
- What about his friends' offer to donate a kidney? Should this be allowed?
- What about people who go and buy organs in foreign countries?
- How far can one go to save Timothy's life?

Fact sheet presenting concrete situations

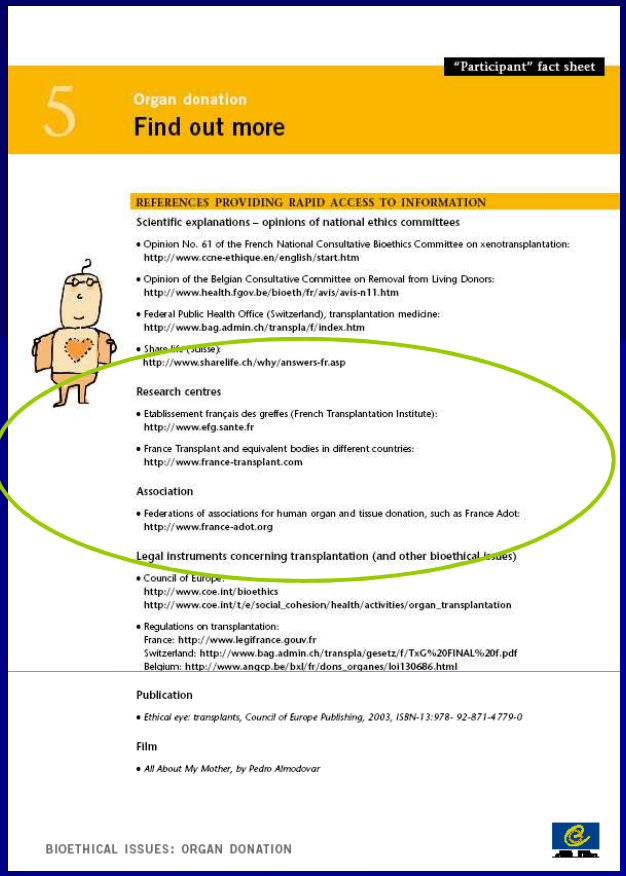
Case study: basis for the debate,

Questions to facilitate initiation of the debate



Find out more

website, publications references on the subject



"Participant" fact sheet

5 Organ donation

Find out more

REFERENCES PROVIDING RAPID ACCESS TO INFORMATION

Scientific explanations – opinions of national ethics committees

- Opinion No. 61 of the French National Consultative Bioethics Committee on xenotransplantation: http://www.ccne-ethique.en/english/start.htm
- Opinion of the Belgian Consultative Committee on Removal from Living Donors: http://www.health.fgov.be/bioeth/fr/avis/avis-n11.htm
- Federal Public Health Office (Switzerland), transplantation medicine: http://www.bag.admin.ch/transpla/f/index.htm
- Sharelife (Suisse): http://www.sharelife.ch/why/answers-fr.asp

Research centres

- Etablissement français des greffes (French Transplantation Institute): http://www.efg.sante.fr
- France Transplant and equivalent bodies in different countries: http://www.france-transplant.com

Association

- Federations of associations for human organ and tissue donation, such as France Adot: http://www.france-adot.org

Legal instruments concerning transplantation (and other bioethical issues)

- Council of Europe: http://www.coe.int/bioethics http://www.coe.int/t/e/social_cohesion/health/activities/organ_transplantation
- Regulations on transplantation: France: http://www.legifrance.gouv.fr Switzerland: http://www.bag.admin.ch/transpla/gesetz/f/TxG%20FINAL%20f.pdf Belgium: http://www.angcp.be/bxl/fr/dons_organes/loi130686.html

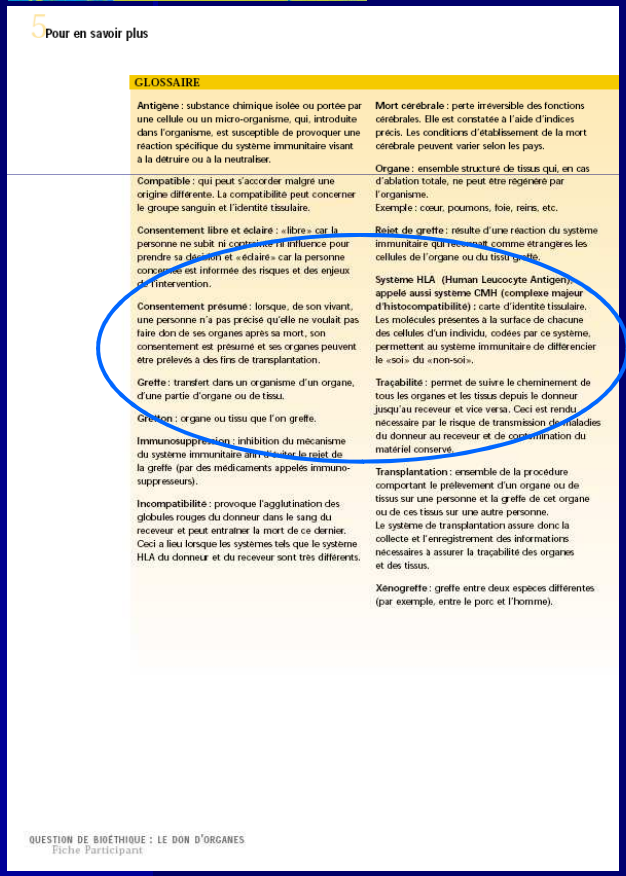
Publication

- *Ethical eye: transplants, Council of Europe Publishing, 2003, ISBN-13:978- 92-871-4779-0*

Film

- *All About My Mother, by Pedro Almodovar*

BIOETHICAL ISSUES: ORGAN DONATION



5 Pour en savoir plus

GLOSSAIRE

Antigène : substance chimique isolée ou portée par une cellule ou un micro-organisme, qui, introduite dans l'organisme, est susceptible de provoquer une réaction spécifique du système immunitaire visant à la détruire ou à la neutraliser.

Compatible : qui peut s'accorder malgré une origine différente. La compatibilité peut concerner le groupe sanguin et l'identité tissulaire.

Consentement libre et éclairé : «libre» car la personne ne subit ni contrainte ni influence pour prendre sa décision et «éclairé» car la personne concernée est informée des risques et des enjeux de l'intervention.

Consentement présumé : lorsque, de son vivant, une personne n'a pas précisé qu'elle ne voulait pas faire don de ses organes après sa mort, son consentement est présumé et ses organes peuvent être prélevés à des fins de transplantation.

Greffe : transfert dans un organisme d'un organe, d'une partie d'organe ou de tissu.

Greffon : organe ou tissu que l'on greffe.

Immunosuppression : inhibition du mécanisme du système immunitaire afin d'éviter le rejet de la greffe (par des médicaments appelés immuno-suppresseurs).

Incompatibilité : provoque l'agglutination des globules rouges du donneur dans le sang du receveur et peut entraîner la mort de ce dernier. Ceci a lieu lorsque les systèmes tels que le système HLA du donneur et du receveur sont très différents.

Mort cérébrale : perte irréversible des fonctions cérébrales. Elle est constatée à l'aide d'indices précis. Les conditions d'établissement de la mort cérébrale peuvent varier selon les pays.

Organe : ensemble structuré de tissus qui, en cas d'ablation totale, ne peut être régénéré par l'organisme.
Exemple : cœur, poumons, foie, reins, etc.

Rejet de greffe : résulte d'une réaction du système immunitaire qui reconnaît comme étrangères les cellules de l'organe ou du tissu greffé.

Système HLA (Human Leucocyte Antigen), appelé aussi système CMH (complexe majeur d'histocompatibilité) : carte d'identité tissulaire. Les molécules présentes à la surface de chacune des cellules d'un individu, codées par ce système, permettent au système immunitaire de différencier le «soi» du «non-soi».

Traçabilité : permet de suivre le cheminement de tous les organes et les tissus depuis le donneur jusqu'au receveur et vice versa. Ceci est rendu nécessaire par le risque de transmission de maladies du donneur au receveur et de contamination du matériel conservé.

Transplantation : ensemble de la procédure comportant le prélèvement d'un organe ou de tissus sur une personne et la greffe de cet organe ou de ces tissus sur une autre personne.
Le système de transplantation assure donc la collecte et l'enregistrement des informations nécessaires à assurer la traçabilité des organes et des tissus.

Xénogreffe : greffe entre deux espèces différentes (par exemple, entre le porc et l'homme).

QUESTION DE BIOÉTHIQUE : LE DON D'ORGANES
Fiche Participant

Complementary definitions [Glossary]

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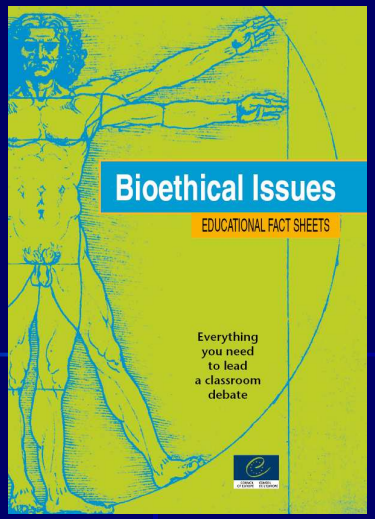

Fact sheets available in 2008:

Organ donation, M.A.R., Genetics
Cloning, Biomedical research

- Objective: to find partnership for translation and distribution in the members States of the Council of Europe

- Project: to adapt the sheets for **university and health professionals** educational programmes

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