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Review of Organ and Tissue Donation Procedures Select Committee  
(Queensland, July 2008)

The comments on this paper are a summary of experience made by the chairman of the scientific committee of ETCO personally. The point of view is working as a procurement coordinator in Germany and having contact to other European countries.

#### Basic considerations:

Introduction of any system of presumed consent without changes in the healthcare system will not increase organ or tissue donation rates in a country with a previously implemented opt-in system.

Changes in the healthcare system must include:

- An active system of donor detection for organ and tissue donation like implemented in Spain and copied successful in many other countries. There are physicians and nurses - coordinators - dedicated to the work of detecting a potential organ donor before brain death at a hospital and introducing organ donation and tissue donation as another goal of therapy in the care at end of life - mostly in intensive care medicine departments plus adjacent emergency departments are involved. Above this a coordinating reference centre - like ONT in Spain or AIRT and CNT in Italy - must exist on State as well as National level in sharing, and communicating the local experience plus taking care of efficient procedures.
- The population of a State of Queensland must be informed about the changes with the argument that everybody has the right to donate an organ or tissue after death if he or she does so. This will require continuous education for more than ten years until severe benefits will be measured. For the convenience of the population a presumed consent system will be implemented, asking the people to register their wills in the Australian Donation Registry (Consent and Objection). If no Objection is found in the Registry, Queensland resident state that they would like to donate after death. Still it is wise to have the practice of good communication with the next of kin about the personal wills of a deceased person - as done in Spain any way.
- The presumed consent legislation will give a relief to the person making the donation request. She or he will feel more comfortable asking while knowing that the legal framework would just be to have a look in the registry. Respecting any wishes of the deceased will give a different feeling than just insisting on the law.
- Again: Regular information and incentives to register as donor in the National registry combined with the Information of the Queensland Donation policy will be the best to inform the population. Medical staff needs a continuous education (CME). For the populations the informers must make sure not to raise misconceptions and fears about organ donation.

No further comments are necessary, because this has been outlined by Prof. Matesanz, President of ONT from Spain.

## Comments to the Questions of the Document:

Ref. page 6: You may also transplant the intestine as organ and vessels as a tissue.

Ref. page 16:

*What requirements for consent to organ and tissue donation should apply?*

See basic consideration.

*Should the role of the next of kin or family be different if a person has given written consent to organ and tissue donation?*

Yes, since at the time point of death even persons in favour of organ donation may refuse consent due to the bad news of death and its disturbances (personal experience in work and privately). In the case of written consent the question should be: "do any changes in her or his opinion of donation as documented exist or not?" By this you may avoid mixing up the request for organ donation with the trouble caused by death of a loved person.

*What is the best way to use a donor register in connection with consent when donation is being considered?*

After death certification the hospital must consult the registry in every case immediately and document the wishes of the deceased. After this step the next of kin have to be approached as mentioned above. Consultation of the registry has to be done in every case and the hospital will be penalized if not having done so.

*Do you support introduction of an opt-out or presumed consent system?*

More Yes than No

*What reasons do you have for supporting or not supporting an opt-out or presumed consent system?*

Yes: Forcing the people to make a decision towards organ donation (Even for the price of a rate of higher objections in a Registry)

No: Historically seen my grand-parents and parents made a very bad experience before World War II with some opinions driven by the government - where part of the family had to leave the country because of minority religious beliefs as well as they were punished for this. Therefore I do not like to be forced in opting out for any personal decisions by the official authorities. If the opting out system would be confidential enough this "no"-argument has to be declined.

*What role should a deceased person's family or next of kin have in consent to organ and tissue donation?*

They should have the privilege of controlling confidentially of the system and getting informed about the procedure.

Ref. Page 19:

*If a presumed consent system was to be introduced, what mechanisms should be introduced for people to opt out?*

Either Registration in the Australian Donor Registry (first choice) or a donor card indicating the objection against donation (second choice) or any written document indicating the same (third choice) should be allowed as opt-out. Tolerating any express of the personal

wishes orally only would be the most democratic way of having an opt-out system, but this gives people to have a good excuse for not thinking about organ donation.

*How could simple and reliable access to an opt-out mechanism be ensured?*

See above, the question is on how to have a secure access to the Australian Donor Registry. This must be simple but safe (e.g. like https: and the banking via internet - are there any projects concerning healthcare data?)

*Should children and people with impaired decision making capacity be part of a presumed consent system?*

*Should particular categories of people be automatically excluded and not presumed consent to donate?*

*When should children be able to opt-out of presumed consent?*

Every person on the world has the right to donate his or her organs after death or not. Including the "yes to donate" should be open to any disabled person and any child. For formal reasons in children parents should sign the objection until the age of some years. This needs to be defined. For example in Germany any person may refuse organ donation, if he or she is older than 14 (freedom of religious beliefs) and may consent to donation, if he or she is older than 16 (end of mandatory visiting of schools). Otherwise - if no statement exists - parents decide until the age of 18 (adulthood, freedom to vote, own business etc.). For mentally disabled persons an individual decision-making process is the rule. You must find some kind of comparable and generally acceptable rules - which I do not know as giving a comment from a foreign country.

Presumed consent rules should not be applied to children, unless a personal statement is available. The definition of a cut-off-age should be orientated on ages commonly used for decisions in the life of growing people. For mentally disabled person some kind of opt-in should be preferred to be used in order to avoid ethical debates. Again, you need a cut off definition for mentally disabled.

*What support would be required for clinical staff if a presumed consent system was introduced?*

Basic skills of communication with grieving people besides continuous medical education about organ and tissue donation are mandatory independently of any consent system.

Ref. Page 20:

*What safeguards and limitations should apply to a presumed consent system?*

Clear documentation of death certification and mandatory request to next of kin that the presumed consent information (registry, donor card etc.) will be contacted now will be safe. If any formal error occurs the hospital will not receive its reimbursement for organ donation plus the care of the dead person before his or her death.

*Are there specific religious or cultural issues that should be addressed in consent to donation of organs and tissues?*

Yes, always in every case!!!!

For practical reasons and an experience of 18 years: Each case of a donor is an individual case and there is nothing that could be standardized

Ref. Page 21:

*If an opt-out or presumed consent system is introduced should it apply only to transplantation to another person or also to other purposes such as research?*

It should only apply to transplantation of an organ or tissue to another person. Otherwise you will generate a conflict of interest and a misunderstanding of the needs for organ and tissue donation. So strictly no.

*In an opt-out or presumed consent system should it be possible to opt-out of donating for one purpose but continue with presumed consent for another purpose?*

Yes. For example: permission for kidney, liver and heart retrieval but not for cornea must be possible. Included should be the option to have an opt-in system for consent for research. Autopsy should be asked separately (if not required by the coroner any way).

Ref. page 22:

*If an opt-out or presumed consent system is not introduced, is the current system appropriate?*

No, all changes besides the opt-out system as it itself have to be implemented also.

*Are there changes you consider should be made to the decision making or consent system?*

Recommendations were already mentioned above.

Ref. page 27:

*What action should be taken to improve organ and tissue donation in Queensland?*

*Are there particular hospital based strategies that should be considered in Queensland to improve donation rates?*

Recommendations were already mentioned above. Beyond this a mandatory request by the hospital plus a medical record review working up the mortality facts should be implemented.

*Should any incentives be offered to potential donors for organ and tissue donation?*

Yes and No

*What are your main reasons for supporting or opposing incentives? If you support incentives what type of incentives do you consider may be appropriate?*

The benefit for society as a whole by transplantation is great (e.g. lesser costs for medical care and rehabilitation and other social expenses in end-stage-kidney-failure when comparing kidney transplantation with dialysis). This benefit has to be returned to the donors. During life time this happens by lower amount of health insurance (e.g. due to cheaper therapy of end-stage-kidney-failure by kidney transplantation), but why should we not consider a donation to funeral costs - making most people bankrupt - to the relatives of a donor plus some imaginary honour like a diploma or a bulletin issued by the President of the State of Queensland as a thank you not? These incentives are acceptable, more incentives would state that commercialisation is not fare a few including the fear of organ trafficking.

*What action should be taken to promote better public awareness of organ and tissue donation?*

The mass media should reach every day every person with one single convincing spot for a few seconds.