

Commission de l'éthique  
de la science et de la technologie



# Ethical Issues Surrounding The Donation and Transplantation of Organs

C o n s u l t a t i o n   P a p e r

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## **INTRODUCTION**

The Commission de l'éthique de la science et de la technologie (Québec) was created in September 2001 in order to critically assess the development and the applications of science and technology, and to co-ordinate a reflection on the related ethical issues for society. This mission is revealed in the preparation of opinion papers that seek to give guidance to those whose decisions must be ethical (in governments or institutions).

In one of its next opinion statements submitted to the government, the Commission will focus on the ethical questions surrounding the donation and transplantation of organs in Quebec, notably in the context of a shortage of organs in relation to the actual need. The choice of this subject is justified by the fact that science and technology are involved to an increasing degree in transplant medicine. The success rate and the complexity of transplants, the development of drugs that reduce the risks of rejection and increase hope for survival, the creation of artificial organs or maintenance measures for patients awaiting transplants, and current work on the cloning of cells and xenografts, are ample testimony to this fact. Ethically speaking, in the context of a shortage of organs, society is called upon to make crucial decisions that concern all citizens, whether they be donors or potential recipients. Among other urgent questions is that of the acceptability of certain strategies.

As part of the preparation of its statement, the Commission wants to consult in a specific way the various stakeholders involved in the donation and transplantation of organs, but it also wishes to seek the opinion of the wider public. The Commission's consultation is in two parts that will be carried out simultaneously: consultation in the form of workshops that bring together the diverse players engaged, in one way or another, in the process of donation and transplantation of organs; and consultation involving a call for written opinions – which could be in the form of reports, letters, or e-mails addressed to the Commission. To facilitate this, the consultation paper and a form facilitating the sending of opinions by fax or by e-mail are available on the Commission's web-site, at the following address: <http://www.ethique.gouv.qc.ca>

This consultation paper first of all briefly notes the situation with respect to organ donation and transplantation in Quebec. It then focuses on the following themes and their associated ethical questions: donation, the different categories of donors, the differing types of consent, recipients and the allocation of organs, the efforts to educate about organ donation, other ways to counteract the shortage (artificial organs, the sale of organs, enlarging the pool of donors\*), and the impact of transplant medicine on the health care system. Each of these issues raises questions that appeal to fundamental values, such as autonomy, justice, beneficence, and altruism, to name but a few. In relation to the information offered and the questions raised, it is important to note that it should not be presumed that the Commission favours any one opinion, other than its recognition of the legitimacy and importance of organ donation and the goals of transplantation.

The Commission will take due notice of the results of this consultation in preparing its opinion statement. The reactions and the comments obtained will enhance its reflection and enable it to take into account the opinions of both experts and citizens in its recommendations to the government on the subject. The Commission's opinion statement will be submitted and made public in December 2004.

## **ORGAN DONATION AND TRANSPLANTATION: THE QUÉBEC CONTEXT**

In Québec, the health insurance card is the principle tangible means of expressing one's consent to organ donation. When acquiring or renewing this card, citizens receive a leaflet informing them about organ donation. In order to give consent to the donation of one's organs in the event of one's death, one must just sign the sticker provided.

The organs appropriate for donation, and which will be considered in the Commission's opinion statement, are the vital organs described as complete or solid: heart, kidney, lung, liver, pancreas, intestine,<sup>1</sup> whether transplanted whole, or in part. In fact, segments of some of these organs can also be transplanted, as is the case with lobes of the lung or the liver, as well as sections of an intestine. Consequently, a single donor can, in donating organs, save the lives or enhance the quality of life of several recipients.

A non-profit organization, Québec-Transplant, was created in 1992. It received, from the Ministry of Health and Social Services (MSSS), the mandate to "co-ordinate and facilitate all activities related to the identification, procurement and allocation of human organs in order to contribute to the continuous improvement of the quality of services offered to the people in need of the graft of an organ)."<sup>2</sup>

The progress achieved in organ transplantation has led to a growth in the number of potential recipients, but there actually exists a shortage of organs for transplantation. This shortage of organs is a relatively well-known and well-documented phenomenon, experienced by most technologically advanced societies. In 2003, in Québec, 860 patients were waiting for one or several organs, whereas five years earlier, this number stood at 627<sup>3</sup>. The waiting period for persons varies considerably according to the organ required<sup>4</sup>. Some die before receiving a new organ: in 2003, 46 potential recipients died.

In attempting to make up for this shortage and to increase the number of donors, a pilot project, initiated by Québec-Transplant, provides some hospital centres with resource-nurses to solicit donations before death, or at the time of the patient's death. In its 2001-2002 annual report, Québec-Transplant described the responsibilities of these nurses in this way:

"Their mandate is the co-ordination of all the activities surrounding the donation of organs and tissues in the hospital centre. Their involvement with those concerned at every stage of the donation process, from the identification of the potential donor up to

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<sup>1</sup> Presently, in Québec, intestines are not transplanted, however an initiative to include them is underway.

<sup>2</sup> Translated from QUÉBEC-TRANSPLANT, *Rapport annuel 2000-2001*.

<sup>3</sup> These statistics are drawn from Québec-Transplant's web site [<http://www.quebec-transplant.qc.ca/public.html>] (February 25, 2004). More detailed statistics are available in the appendix.

<sup>4</sup> See Table IV in the appendix.

transfer or harvesting, facilitates the different phases of the donation of organs and tissues. Their principal role, after identification, is to approach and support the family throughout the process, and to ensure follow-up).”<sup>5</sup>

Other strategies are also possible and must be evaluated, particularly from an ethical point of view. They are considered in the following pages.

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<sup>5</sup> Translated from QUÉBEC-TRANSPLANT, *Rapport annuel 2001-2002*.

## **ORGAN DONATION AND ITS DISTINCTIVE FEATURES**

The donation of an organ differs from an exchange regulated by the State or the market. In fact, the donor is not expecting any compensation. Moreover, the recipient must not feel any obligation to give such compensation. In the context of organ donation, it is a matter of a gift of the self, of a part of one's body to another person, leading to an "eternal debt," but one which can be acknowledged by the recipient in several ways.<sup>6</sup>

### **ANONYMITY**

For now, the anonymity of both the donor and the recipient are preserved, in that neither knows the identity of the other. But some express the wish to contact the recipient, the donor, or the donor's family, as the case may be. It is possible to do so anonymously, by means of a letter passed on by a third party (Québec-Transplant, the surgeon, etc.).

### **GRATUITY**

The *Civil Code* of Québec formally forbids all remuneration in relation to organ donation: "The alienation by a person of a part or products of his body shall be gratuitous."<sup>7</sup> The donation of organs must thus be free of any undue coercion that the promise of compensation might exert.

#### **Some Ethical Questions**

- What are the reasons or the values that might encourage a person to donate organs? What are the reasons or the values that could discourage him or her from doing so?
- Why should a donation be anonymous? What would justify the donation's not being anonymous?
- Is there a place for varying rather than uniform practices here? Why?
- How could the donation of organs be recognized, encouraged and promoted other than financially? What forms of financial compensation could be considered? How could their possible repercussions be avoided?(for example, refusal of life-support for the patient by the relatives wanting to benefit from the compensation offered for donation)?

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<sup>6</sup> Jacques T. GODBOUT, *Le don, la dette et l'identité. Homo donator vs homo æconomicus*, Montréal, Boréal, p. 132-133.

<sup>7</sup> *Civil Code of Québec*, 1991, c. 64, a. 25.



## **CATEGORIES OF DONORS**

Technically speaking, the principal criteria employed by physicians in the selection of donors are “the general physical condition, the medical and social history, as well as the general state of the donor at the time of death.”<sup>8</sup> There is no age limit for donating organs.

### **CADAVERIC DONATION BASED ON THE CRITERION OF BRAIN DEATH (OR NEUROLOGICAL DEATH)**

This group of donors meets the criteria for a diagnosis of brain death; their cardiac and respiratory functions are being artificially maintained in order to preserve their organs in a good state. In Canada, the Canadian Neurocritical Care Group presented, in 1999, their *Guidelines for the Diagnosis of Brain Death* or neurological death<sup>9</sup>:

- Brain death is possible, given the patient’s illness. Furthermore, potentially reversible causes of death have been excluded
- The patient is in a deep coma\*,<sup>10</sup> and shows no response within cranial nerve distribution to stimulation to any part of the body. No movements arising from the brain should be present.
- Brain stem\* reflexes are absent.
- The patient is apneic\* when taken off the respirator for an appropriate time.
- The conditions listed above persist when the patient is reassessed after a suitable interval.
- There should be no confounding factors for the application of clinical criteria (hypothermia, intoxication, other signs simulating death).

In 2003, the rates of cadaveric donors per million inhabitants were 19,2 for Québec and 13.3 for Canada, average rates for Western countries. On the international scale, a notable exception is Spain, which recorded, in 2002, a rate of 33.7 cadaveric donors per million inhabitants. In Québec, this type of donor represents around 1.5% of all the deaths occurring in hospital.<sup>11</sup> In 2003, there were 386 referrals\*, but only 142 donors were finally accepted.

Legally, harvesting “cannot be carried out before the death of the donor has been attested by two physicians who do not participate either in the removal or in the transplantation.”<sup>12</sup>

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<sup>8</sup> Translated from QUÉBEC-TRANSPLANT, *Rapport annuel 2001-2002*, 2002, p. 9.

<sup>9</sup> Note should be taken of the fact that the question of the criteria for the determination of death is constantly debated, although a consensus around brain death seems to be emerging.

<sup>10</sup> The terms followed by an asterisk are defined in a glossary at the end of the document.

<sup>11</sup> This information comes from a meeting with Québec-Transplant that took place on May 14, 2003. These donors meet the criteria for brain death.

<sup>12</sup> *Civil Code of Québec*, 1991, c. 64, a. 45.

**Some Ethical Questions**

- Are you comfortable with the notion of “neurological death”? Is this approach to determining death offensive to any of your values?
- The medical team that certifies that the patient is deceased must be independent of the one that removes the organs. Does this suffice to avoid all conflicts of interest? In practice, is this always possible?
- How do you react to the fact that some patients who could not be saved are stabilized in the hope that they will later respond to the criteria for brain death? Must they be given futile care in order to know this?
- Given the cost of hospital care and the financial difficulties that the health care system is experiencing, to what point must we (or may we) go in providing maximum care to a person whose death is imminent?
- Are you concerned that there could be too great a zeal to remove organs to the benefit of a recipient, but to the detriment of a donor?
- What are the values that must prevail in such situations?

**DONATION BETWEEN LIVING PERSONS**

The kidney, the liver (a lobe), the lung (a lobe) and the pancreas (the islets) are the only vital organs that can be donated by living persons. In 2003, in Québec, of a total of 281 renal grafts, 52 were from a living donor, which corresponds to a rate of 18,5 %.<sup>13</sup> In relation to this, Québec appears to be behind the United States for example, a country whose rate has been over 50 % since 2001.<sup>14</sup> Moreover, the rate of living donors per million population, Québec's rate (6.1) is below the Canadian average.<sup>15</sup> This practice of donation between living donors is seen as a strategy that could offset, at least in part, the shortage of organs.

Usually, a gift between living persons is considered a directed gift: the giver “directs” his or her gift to a person to whom he or she is linked, whether genetically (family) or emotionally (spouse, friends, etc.). It also happens, although more rarely, that a person indicates a desire to donate a kidney, a lobe of the liver or a lobe of a lung without designating a recipient: the case of the

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<sup>13</sup> QUÉBEC-TRANSPLANT, *Rapport annuel 2002-2003*.

<sup>14</sup> A statistic from the website of the ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK [<http://www.optn.org/latestData/rptData.asp>].

<sup>15</sup> QUÉBEC-TRANSPLANT, *Rapport annuel 2002-2003*.

“good Samaritan.” This practice has existed for a long time for the gift of blood or sperm, and it is more and more frequent for bone marrow.

On the other hand, the *Civil Code* regulates the practice of donation between living persons. In fact, a “person of full age who is capable of giving his consent may alienate a part of his body *inter vivos*, provided the risk incurred is not disproportionate to the benefit that may reasonably be anticipated.”<sup>16</sup> As well, the donor must consent in writing. In the case of a minor, or an adult considered incapable of giving consent to the donation, it is possible to donate “a part of his body only if that part is capable of regeneration and provided that no serious risk to his health results [...]”<sup>17</sup> which automatically excludes the donation of organs by these persons.

One risk underlying this practice is the removal of an organ, or a section of an organ, from a healthy individual, the quality of whose life could eventually (although not necessarily) be affected in either the short or the long term. Some feel such a practice is unjustifiable, since it is unquestionably a mutilation that *a priori* brings no benefit to the donor and contradicts the principle of non-maleficence. For others, this practice is acceptable as long as the risk posed by the surgical intervention is also an acceptable one.

#### *Some Ethical Questions*

- How can the validity, the authenticity and the freedom of a living person’s consent to the donation of a kidney, or even a lobe of the liver or the lung, be assured when the recipient is a relative or if there exists an emotional tie between them?
- What attitude should the physician adopt when a potential donor, related to the recipient, refuses to donate? Should the truth be told to the patient waiting for a graft? Must the potential donor be assured of confidentiality? What values should prevail in such a situation?
- What is the degree of risk that would make it acceptable for a living person to donate an organ? On what basis should such a decision be taken and with what kind of assistance? Is this a personal or a family decision? What possible consequences should be considered? What values are involved?

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<sup>16</sup> *Civil Code of Québec*, 1991, c. 64, a. 19.

<sup>17</sup> *Civil Code of Québec*, 1991, c. 64, a. 19.



## **THE QUESTION OF CONSENT**

There are several types of consent to the donation of organs: explicit consent, presumed consent, mandated choice and voluntary registry. Each type has specific characteristics and associated risks.

### **EXPLICIT CONSENT**

In Québec, it is possible to give consent to organ donation by signing a sticker that one attaches to the back of the health insurance card. This type of consent is explicit, in that it requires persons to clearly indicate their preference. They do so after becoming informed on the topic via a leaflet in the mail reminding them to renew their health insurance card and their driver's licence.

Legally, an adult or a minor 14 years and older can consent to the removal of his or her organs following death. A minor younger than 14 years may also give consent, with the agreement of the person having parental authority or the guardian.<sup>18</sup> The *Civil Code* also specifies that the wishes "be expressed verbally before two witnesses, or in writing, [...] may be revoked in the same manner," and that they "shall be followed, except for a compelling reason."<sup>19</sup> However, according to a study carried out by the Committee promoting organ and tissue donation at the University Hospital Centre in Quebec (CHUQ), 70% of doctors believe that it is the oral or written consent of the donor's family that must be received before the transplantation process can begin.<sup>20</sup>

Moreover, "a part of the body of a deceased person may be removed in the absence of knowledge or presumed knowledge of the wishes of the deceased, with the consent of the person who could give consent to care or could have given it."<sup>21</sup> This consent "is not required when two physicians attest in writing to the impossibility of obtaining it in due time, the urgency of the operation and the serious hope of saving a human life or of improving its quality to an appreciable degree."<sup>22</sup>

### **PRESUMED CONSENT**

Presumed consent implies that those who do not wish to donate their organs must express their refusal, rather than their consent. In the absence of such a refusal, consent to the donation of organs is presumed, which authorizes the harvesting of organs at the time of their death. There are many ways of registering refusal, but the most widespread is the use of a registry in which

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<sup>18</sup> *Civil Code of Québec*, 1991, c. 64, a. 43.

<sup>19</sup> *Civil Code of Québec*, 1991, c. 64, a. 43.

<sup>20</sup> IMPACT RECHERCHE, *Étude sur la connaissance et les perceptions des médecins concernant le don d'organes et de tissus*, prepared for the Committee promoting organ and tissue donation at CHUQ, June 19, 2003, 75 p.

<sup>21</sup> *Civil Code of Québec*, 1991, c. 64, a. 44.

<sup>22</sup> *Civil Code of Québec*, 1991, c. 64, a. 44.

individuals are asked to record their unwillingness to donate their organs when they die. Expert opinion is divided as to whether presumed consent has an impact on the rates of organ donors per million population. While some studies tend to show that the number of donors has increased in those countries that have adopted presumed consent, others suggest that different factors can explain this increase, such as a significant number of programs for the transplantation of organs, or even the launching of campaigns to educate the public and the health professionals who participate in this growth.

## **MANDATED CHOICE AND THE VOLUNTARY REGISTRY**

Other strategies are considered for changing the type of consent in order to increase the number of organ donors. Among these, we note the establishment of a system of mandated choice, whereby each person considered legally capable is obliged to declare whether or not he or she wishes to donate. In such a system one may, however, change one's mind. In certain cases, the decision could be declared legally binding, thus preventing any intervention from one's family.

On the whole, a vast majority of people appears to be in favour of organ donation, Canadians as well as many others. However, this support in principle does not always result in consent.<sup>23</sup> The system of mandated choice, since it is supported by the establishment of a register listing the donors, can prove to be very flexible: it allows the donors to state very precisely which organs or which tissues they wish to donate, or even whether they prefer to delegate the responsibility for the decision to a family member. These are some of the reasons supporting the establishment of a system of mandated choice; in other words, one would be obliged to make known one's wishes regarding organ donation. However, such a strategy can appear to be intrusive: people do not really have the right to be indecisive, unless the declaration includes "I do not know" as one of the choices.

In fact, there are several ways to seek the wishes of the public. For example, a relevant question could be asked in the annual income tax form. No response to the question would result in the form being refused as incomplete. There is a major drawback to this however: it would not reach the whole population, as does the health insurance card. The creation of a voluntary registry and a national database allowing citizens to record their consent or refusal<sup>24</sup> can also be included in the strategies considered.

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<sup>23</sup> According to a survey conducted in April 2002 by the firm Léger et Léger for the report of the Canadian Kidney Foundation, 77% of those in Québec are in favour of donating their organs, but 46% have not yet taken the necessary steps to make their wishes known.

<sup>24</sup> A database such as this has been created in the Netherlands and in Australia. Physicians can access it to obtain patient information. Has there been consent to organ donation? Has the decision been delegated to the family? Which organs does he or she wish to donate?

**Some Ethical Questions**

- Which of the types of consent presented appears to you to be the most acceptable? Why? Which would you consider to be the most questionable? Why? Is there a type of consent that would be totally unacceptable to you? Why?
- What values must prevail in relation to individual consent: autonomy, solidarity, freedom, or others? Are these values different from those on which the creation of a national mechanism for consent must be based? What then would be such values?
- Should it be taken for granted that those who have not declared their preference are implicitly in agreement with their organs being removed after death?
- Does solidarity amongst humans imply an obligation to donate one's organs? Why?
- Should the request to the family for their consent to organ donation be made before or after the declaration of death? Why?



## **THE RECIPIENTS**

### **WHO CAN BE A RECIPIENT?**

There is no uniform policy related to the criteria for selection of candidates for a transplant. A study in Québec indicates that medical criteria count the most in evaluating candidates for a transplant.<sup>25</sup> Nevertheless, certain psychosocial criteria are also considered to be important: the candidate's motivation, the presence of family or social support, abusive use of drugs,<sup>26</sup> the presence of a mental illness. Age does not appear to be an important determining factor.

### **THE ALLOCATION OF ORGANS**

In the current context of a shortage of organs, their allocation inevitably becomes a major issue. At the heart of this issue is the question of the criteria for allocating the organs available. The principal established criteria are the blood group, tissue compatibility\*, the weight and the size of the organ, medical urgency, and time on the waiting list. These criteria are largely medical, similar to those applied in the selection of candidates for a transplant.

With the focus on the shortage of organs and the lengthening time on waiting lists, some countries are considering scenarios such as including moral criteria for referring a candidate for a graft and for prioritizing those on the waiting list. Criteria such as alcohol, tobacco or drug dependency or, in some countries, the fact of being a prisoner condemned to death, could be prejudicial factors in this regard.

The lifestyle of potential recipients and their degree of responsibility in the future are not predictable. However, an organ recipient benefits from a rare and precious resource. The success of the graft in the medium and the long term will depend in part on medical factors, but equally on the person's lifestyle and degree of responsibility (risky behaviour, adherence to drug protocols, etc.)

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<sup>25</sup> Jocelyne SAINT-ARNAUD, Yvette GRENIER and Sonia GAUTIER, "Enquête sur le processus de sélection des candidats à la greffe au Québec," *L'allocation des ressources rares en soins de santé : l'exemple de la transplantation d'organes*, under the direction of Jocelyne SAINT-ARNAUD, Montréal, Édition Acfas, 1996, p. 78-79.

<sup>26</sup> This criterion can also be considered to be a medical criterion, since the use of drugs can have a devastating effect on organ transplants.

**Some Ethical Questions**

- Should there be greater uniformity in the criteria for referring recipients to the waiting list? Why, or on the basis of which values?
- Should criteria other than medical be applied in prioritizing patients waiting for an organ graft (age, lifestyle, presence of risky behaviours, social status, etc.)? On the basis of which values? Can such discrimination be justified?
- Should access to transplantation be restricted to those who have already recorded their willingness to donate their own organs? Which values are at stake here? Do these values take precedence over other values? What are they? Does proceeding in this way appear to you to be acceptable?
- Would it be justifiable to impose constraints on the recipient in order to maximize the chances for a successful graft in the medium and the long term? Could this be seen as the undermining of one's autonomy? Could other values prevail over autonomy? If so, which ones?

## **INFORMING THE PUBLIC AND HEALTH CARE PROFESSIONALS**

In Canada, for the last three years, the last week in May has been designated as National Awareness Week for Organ Donation. During this week, the public is invited to wear a green ribbon to indicate support for organ donation. Launched by Health Canada, this multifaceted campaign seeks to:

- inform and motivate the undecided
- urge citizens to speak with their families about organ donation
- dispel false myths and erroneous opinions
- promote Health Canada's website dealing with organ and tissue donation.

For its part, Québec-Transplant has used other devices to reach its objective of informing health professionals and the public: its website ([www.quebec-transplant.qc.ca](http://www.quebec-transplant.qc.ca)), the creation of leaflets, posters, and videos. This organization is also engaged in a number of projects: amongst others the National Week for Educating about Organ Donation, various colloquia, establishing the "resource-nurse"\* program, and the intra-system campaign.<sup>27</sup> It must also be pointed out that Québec has a telephone information line about organ donation.<sup>28</sup>

As have others, Québec has looked to Spain to find solutions to the shortage of organs. In fact, in that country, the rates of organ donors per million population have reached 32.5 and 33.7 in 2001 and 2002 respectively.<sup>29</sup> These results are considerably higher than those reached in Québec (18.4 and 17.1) and in Canada (13.5 and 13.0) in the same period.<sup>30</sup>

Several factors contribute to the success of the Spanish model. Among them, informing the public and health professionals has proven to be a key factor. It is the Organizacion Nacional de Transplantes (ONT) that directs the educational strategies. The organization believes that maximizing the donation of organs must go beyond educating the general public, to include the health professionals. In order to avoid missing any potential donors, health professionals are offered training in the best methods of identifying donors and obtaining the family's consent. Some of the professionals working in the area of organ transplantation also have the role of coordinating organ donations. The coordinators (present in each hospital) are responsible for reviewing the death register in the hospital in order to ensure that potential donors have not been overlooked. As well, they participate, at the regional or national level, in the framing of policy

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<sup>27</sup> The intra-system campaign is addressed to the directors and professionals in the health system in Québec, and seeks to both gather support for them and to educate them regarding the importance of organ donation.

<sup>28</sup> This line is INFO-DON (1-877-INFODON).

<sup>29</sup> ORGANIZACION NACIONAL DE TRANSPLANTES, Espagne  
[[http://www.msc.es/Diseno/informacionProfesional/profesional\\_transplantes\\_e.htm](http://www.msc.es/Diseno/informacionProfesional/profesional_transplantes_e.htm)] (22-01- 2004).

<sup>30</sup> CANADIAN ORGAN REPLACEMENT REGISTER (CORR), *Statistics for 2002 (January 1 to December 31, 2002 in Canada and in the provinces)*

[[http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=services\\_corr\\_e](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_corr_e)] (12-09-2003).

addressing the donation of organs. The teams associated with organ donation are employed and paid for this function, which takes priority in their work at the hospital.

Spanish acceptance of the harvesting of organs from donors declared dead on the basis of the criterion of death through cardiorespiratory arrest has also been due to a number of differing means of communicating with the media and the public. This practice is not widespread, and it is controversial (it is not practised in Canada, but is, notably, in some American states, in the Netherlands and in Japan). Moreover, the Spanish Organ Donor Service, a public relations service, makes an effort to highlight the good news and to minimize the bad news about organ donation – not only for the public and the health professionals, but also for the media. This service thus makes available a hotline that makes accessible the most recent news about organ donation. Finally, periodic conferences attempt to create a more positive attitude and to increase media awareness in this area.

***Some Ethical Questions***

- How can the public and health care professionals be informed (or educated) about organ donation? Should cultural and religious differences be taken into account?
- To what point may we go in soliciting organ donation? Are there “marketing” techniques that would violate certain values? Could you name the techniques? Which values are thus at stake?

## **OTHER WAYS TO ALLEVIATE THE SHORTAGE OF ORGANS**

### **CADAVERIC DONATION BASED ON THE CRITERION OF DEATH BY CARDIO-RESPIRATORY ARREST (CDCA)**

The donors declared dead on the basis of the criterion for death by cardiorespiratory arrest are patients whose hearts stop beating before organs are harvested. The beating-heart can stop following withdrawal of a treatment, but it can also occur spontaneously. If, in a specified period of time it does not spontaneously restart, the patient is pronounced dead on the basis of the cardiorespiratory criterion and the transplantation team can proceed to harvest organs within a very short time (to preserve the quality of the organs and the chance of a successful graft). In Canada, this type of donor is not considered.

#### ***Some Ethical Questions***

- Is increasing the number of available organs an acceptable reason for modifying the criteria for the determination of death? What values would underlie such a decision? Is it a case of the end (saving more lives or obtaining more organs) justifying the means (changing the established criteria for determining death, which is useful only in the context of organ donation)?
- Furthermore, given that some potential cadaveric donors are at the same time dying persons, how can it be guaranteed that they will be perceived and treated as such and not primarily as donors?<sup>31</sup>
- What would be the basic reasons for establishing a new category of donor (such as those pronounced dead on the basis of the criterion of cardiorespiratory arrest) and on which values should they be based?

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<sup>31</sup> This topic highlights an ethical dilemma: it can happen that the medication given by the palliative care\* team to potential CDCA cadaveric donors affects the quality of their organs that might be grafted.

## THE USE OF ARTIFICIAL ORGANS

The use of artificial organs raises, amongst others, the symbolic issue of the perception of the self. At the present time, hemodialysis, used as a substitute for the kidney while patients wait for a graft, as well as systems that compensate for pancreatic or heart dysfunction, are available. As with the ventricular pump used to assist the heart, these technologies are perceived more as “bridges” to obtaining an organ, rather than viable alternatives to transplantation. Moreover, the quality of life of a patient with an artificial organ is appreciably diminished due to the reduction of his or her degree of autonomy.

Besides, in a situation of limited resources, the high cost of this kind of technology (and the fact, for example, that a mechanical heart cannot be reused by another patient awaiting a transplant) calls into question the entire system of the allocation of resources.

### Some Ethical Questions

- What can be done to ensure that technologies like the mechanical heart benefit the greatest possible number of patients, while at the same time taking into account a situation of limited resources?
- If other artificial organs become available, what would be your reaction to their implantation in the human body? Would the “human being” be thereby transformed? Would some of our values be affected? If so, which ones?

## TRADE IN ORGANS

The debate surrounding the trade in organs is not new. The archipelago of Tonga, off the coast of Australia, as well as Italy, and the United States were forerunners in the area of legislation in relation to the donation and transplantation of organs, proclaiming laws forbidding the sale of organs even before the 1970's, when transplantation medicine was just beginning. Since then, a certain international consensus has formed and become stronger, forbidding any form of payment for organs. In its guiding principles on organ transplantation, the World Health Organization (WHO) recommends that the human body and all its parts never be made the object of commercial transactions.<sup>32</sup>

Some countries allow financial compensation to the living donor for costs of travel, a loss of salary, or other expenses linked to donation (living expenses, for example). However the laws of

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<sup>32</sup> WORLD HEALTH ORGANIZATION, *Guiding Principles on Human Organ Transplantation*, Geneva, 1991.

several countries (among them Canada, France, Belgium, the United States and Great Britain) are clear that such compensation must never be regarded as remuneration. In Québec, any compensation (whether in the form of reimbursement for traveling costs or loss of salary) is forbidden by the *Civil Code*.<sup>33</sup>

If some believe that creating financial incentives for organ donation would encourage many more to consent to donation, others believe that such a practice would have unfortunate consequences: loss of the meaning of gift, strong coercion on the more deprived, commodification of the human body\*, etc. Thus strategies seeking a compromise between the creation of a free market and its prohibition have been proposed in order to, in some way, compensate donors (or their families, if necessary): a tax credit, reimbursement of funeral expenses and costs linked to the hospitalization, payment of a fixed sum to the estate, or even to a charity of the donor's choice, etc.

An alternate solution sometimes proposed involves legally ascribing an economic value to organs. Thus, non-profit organizations would pay the full price of an organ to third parties situated between the donor and the recipient (surgeons, hospitals, etc.), who eventually would bill the State or insurance companies. This price would reflect what the donor would have been paid for the organ. This system would have the advantage of preventing certain intermediaries from making a profit from the sale of organs, and would encourage the rational and economic use of the organs donated.

Moreover, the traffic in human organs and what is called what can be described as "transplant tourism" raise many concerns in the international community. The Council of Europe "disapproves of recent trends in some Western European countries towards less restrictive laws, which would allow greater scope for unrelated living donation."<sup>34</sup> Moreover, periodic studies mention the trafficking in organs in countries such as India, Pakistan, Iraq, the Philippines, Moldavia and Brazil. According to the report of the Council of Europe, "international criminal organisations have identified this lucrative "gap" and put pressure on people in extreme poverty, particularly in countries of Eastern Europe, to resort to selling their organs."

**Some Ethical Questions**

- Is it acceptable to place a monetary value on the organs of the human body? By virtue of what criteria would it be justifiable to do so?
- How can we ensure that putting into place financial incentives designed to motivate people to donate their organs does not exert undue pressure on the most deprived?

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<sup>33</sup> *Civil Code of Québec*, 1991, c. 64, a. 25.

<sup>34</sup> COUNCIL OF EUROPE, *Trafficking in Organs in Europe*, June 3, 2003.

- Would the establishment of a system of non-financial compensation to donors and their families appear acceptable to you? Is the hope of increasing the number of donors a sufficient reason?

## **THE ECONOMIC IMPACT OF TRANSPLANT MEDICINE ON THE HEALTH CARE SYSTEM**

Transplant medicine is costly, especially when one takes into consideration the limited number of beneficiaries. For example, in the United States, the state of Oregon made a decision related to this concern; it abandoned the financing of transplantation programs, which came to the assistance of 34 people, in order to help 1,500 people who until then had not been covered by hospital insurance.

On the one hand, it should be pointed out that a graft is a more economical and a more effective treatment than the costly treatments given to patients waiting for a kidney transplant.<sup>35</sup> On the other hand, there are high costs associated with the anti-rejection medication that beneficiaries of grafts must take. The use of operating rooms, as well as the need for medical teams to carry out the graft also generate important costs, and result in a lessened availability of professional (physicians, nursing staff) and material resources for other uses in the hospital. On another level, creating better procedures for locating donors, campaigns to inform and educate, and other methods demand financial resources that could otherwise be used to improve the functioning of the health care system.

In a situation where resources are limited and where the decision-makers attempt to justify the costs engendered by health care, a number of ethical questions arise which put in question even the future of transplant medicine.

### **Some Ethical Questions**

- How can transplant medicine be justified in a situation of limited resources? Is it justifiable? If it is, on the basis of which values?

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<sup>35</sup> In Canada, according to LAUPACIS and others (1996), the total cost of renal transplantation after five years is \$244,670, whereas the total cost for hemodialysis for the same period is \$400,680.



## **CONCLUSION**

The various players engaged in activities associated with the donation and transplantation of organs, but also all of society, must reflect upon the values that underlie the available choices and those which must prevail if enlightened and responsible decisions are to be taken.

In relation to ethics, this is the goal intended by the consultation initiated by the Commission de l'éthique de la science et de la technologie and by the preparation of a consultation paper on the topic. Throughout this text, a number of questions have been raised to help the Commission discover what values inform the opinions expressed by both the experts and the public about the different aspects of organ donation and transplantation. All of these questions are repeated below.

The Commission would like to thank in advance all those who will be involved in this consultation, and who will contribute, through their reactions, comments and opinions of all kinds, to the enrichment of its reflection. It hopes that each of the participants in the consultation will find an echo of his or her concerns in the opinion statement that will be published on the subject, and in the recommendations that will be made to the political decision-makers.

### **A REVIEW OF THE QUESTIONS**

#### ***Organ Donation and Its Distinctive Features***

- What are the reasons or the values that might encourage a person to donate organs? What are the reasons or the values that could discourage one from doing so?
- Why must a donation be anonymous? What would justify the donation's not being anonymous?
- Is there a place for turning to varying rather than uniform practices here? Why?
- How could the donation of organs be recognized, encouraged and promoted other than financially? What forms of financial compensation could be considered? How could the possible repercussions of such a proposal be avoided (for example, refusal of life-support for the patient by the relatives wanting to benefit from compensation offered for donation)?

**Cadaveric Donation Based on the Criterion of Brain Death (or Neurological Death)**

- Are you comfortable with the notion of “neurological death”? Is this approach to determining death offensive to any of your values?
- The medical team that certifies that the patient is deceased must be independent of the one that removes the organs. Does this suffice to avoid all conflicts of interest? In practice, is this always possible?
- How do you react to the fact that some patients who could not be saved are stabilized in the hope that they will later respond to the criteria for brain death? Must futile care be provided in order to discover this?
- Given the cost of hospital care and the financial difficulties that the health care system is experiencing, to what point must we (or may we) go in providing maximum care to a person whose death is imminent?
- Are you concerned that there could be too great a zeal to remove organs to the benefit of a recipient, but to the detriment of a donor?
- What are the values that must prevail in such situations?

**Donation between Living Persons**

- How can the validity, the authenticity and the freedom of a living person’s consent to the donation of a kidney, or even a lobe of the liver or the lung, be assured when the recipient is a relative, or if there exists an emotional tie between them?
- What attitude should the physician adopt when a potential donor, related to the recipient, refuses to donate? Should the truth be told to the patient waiting for a graft? Must the potential donor be assured of confidentiality? What values should prevail in such a situation?
- What is the degree of risk that would make it acceptable for a living person to donate an organ? On what basis should such a decision be taken and with what kind of help? Is this a personal or a family decision? What would be the possible consequences to consider? What values are involved?

**The Question of Consent**

- Which of the types of consent presented appear to you to be the most acceptable? Why? Which would you consider to be the most questionable? Why? Is there a type of consent that would be totally unacceptable to you? Why?
- What values must prevail in relation to individual consent: autonomy, solidarity, freedom, or others? Are these different values from those on which the creation of a national mechanism for consent must be based?
- Should it be taken for granted that those who have not declared their preferences are implicitly in agreement with their organs being removed after their death?
- Does solidarity amongst humans imply an obligation to donate one's organs? Why?
- Should the request to the family for their consent to organ donation be made before or after the declaration of death? Why?

**The Recipients**

- Should there be greater uniformity in the criteria for referring recipients to the waiting list? Why, or on the basis of which values?
- Should criteria other than medical be applied in the prioritizing of patients on a waiting list for organ grafts (age, lifestyle, presence of risky behaviours, social status, etc.)? On the basis of which values? Can such discrimination be justified?
- Should access to transplantation be restricted to those who have already recorded their willingness to donate their own organs? Which values are at stake here? Do these values take precedence over other values? What are they? Does proceeding in this way appear to you to be acceptable?
- Would it be justifiable to impose obligations on the recipient in order to maximize the chances for a successful graft in the medium and the long term? Is this a question of the undermining of one's autonomy? Could other values prevail over autonomy? If so, which ones?

**Informing the Public and the HealthCare Professionals**

- How can the public and health care professionals be sensitized to organ donation? Should cultural and religious differences be taken into account?
- To what point may we go in soliciting organ donation? Are there “marketing” techniques that would violate certain values? Could you name the techniques? Which values are thus at stake?

**Cadaveric Organ Donation Based on the Criterion of Death by Cardiorespiratory Arrest**

- Is increasing the number of available organs an acceptable reason for modifying the criteria for the determination of death? Which values would underlie such a decision? Is it a question of the end (saving more lives or obtaining more organs) justifying the means (changing the established criteria for determining death, and useful only in the context of organ donation)?
- Furthermore, given that some potential cadaveric donors are at the same time dying persons, how can it be guaranteed that they will be perceived and treated as such, and not primarily as donors?<sup>36</sup>

**The Use of Artificial Organs**

- What can be done to ensure that technologies like the mechanical heart benefit the greatest possible number of patients, while at the same time taking into account the context of limited resources?
- If other artificial organs become available, what would be your reaction to their implantation in the human body? Would the “human being” be thereby transformed? Would some of our values be affected? If so, which ones?

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<sup>36</sup> This topic highlights an ethical dilemma: it can happen that the medication given by the palliative care team\* to potential CMAC donors affects the quality of their organs that might be grafted

**Trade in Organs**

- How can we ensure that establishing financial incentives designed to motivate people to donate their organs does not exert undue pressure on the most deprived?
- Is it acceptable to place a monetary value on the organs of the human body? By virtue of which criteria would it be justifiable to do so?
- Would the establishment of a system of non-financial compensation to donors and their families appear to you to be acceptable? Is the hope of increasing the number of donors a sufficient reason?

**The Economic Impact of Transplant Medicine on the Health Care System**

- How can transplant medicine be justified in a situation of limited resources? Is it justifiable? If so, on the basis of which values?



## **GLOSSARY**<sup>37</sup>

<b>Apneic:</b>	Not breathing spontaneously.
<b>Brain stem:</b>	Part of the central nervous system containing in particular the centres responsible for the physiological wake-sleep cycle and spontaneous respiration.
<b>Coma</b>	A state of profound unconsciousness caused by disease, injury, or poison.
<b>Commodification of the human body:</b>	All of the practices which, while part of research or the application of biomedical techno-science, seek equally, and even predominantly, to engender financial profits.
<b>Conflict of interests:</b>	A situation produced when persons or organizations, in the exercise of their functions, must choose between self-interests and the interests of clients or any other entities to whom they are accountable.
<b>Deep coma:</b>	A coma in which survival is possible only by artificial means.
<b>Immunology:</b>	The branch of biology studying normal and pathological immunities.
<b>Palliative care:</b>	Care that no longer seek to continue treating the illness and its cause, but seek rather the reduction of symptoms and the maintenance of the patient's physical and mental comfort.
<b>Pool of donors:</b>	All of the potential donors as determined by means of selection criteria.

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<sup>37</sup> The definitions are drawn from the Merriam-Webster's *College Dictionary*, or translated from the following works: *Le petit Robert*, *Le Grand dictionnaire terminologique*, *la Nouvelle Encyclopédie de Bioéthique* and the *Rapport annuel 2001-2002* de QUÉBEC-TRANSPLANT.

<b>Referral:</b>	Each call received at Québec-Transplant to report a donor of organs or tissues.
<b>Resource-nurses:</b>	Nurses who act as coordinators of all of the activities surrounding organ donation in Québec hospitals.
<b>Tissue compatibility:</b>	The matching or degree of matching of the tissues of the donor and the recipient of a graft, playing a role in the survival of the graft.

## **APPENDIX – THE STATISTICS FOR QUÉBEC**<sup>38</sup>

**Table I - Number of referrals and donors**

<b>Year</b>	<b>Total number of referrals</b>	<b>Referrals rejected</b>	<b>Referrals accepted</b>	<b>Donors not accepted</b>	<b>Donors accepted</b>	<b>Living Donors of kidneys</b>
<b>1995</b>	257	124	133	16	117	26
<b>1996</b>	258	121	137	24	113	14
<b>1997</b>	266	152	114	18	96	16
<b>1998</b>	273	129	144	24	120	30
<b>1999</b>	342	193	149	18	131	31
<b>2000</b>	316	158	158	23	135	31
<b>2001</b>	287	128	159	23	136	46
<b>2002</b>	293	139	155	27	127	45
<b>2003</b>	395	216	169	27	142	52

**Table II - Number of patients waiting for organs**

<b>Year</b>	<b>Kidney</b>	<b>Kidney/ Pancreas</b>	<b>Pancreas</b>	<b>Liver</b>	<b>Heart</b>	<b>Heart/ Lung</b>	<b>Lung</b>	<b>Total</b>
<b>1995</b>	450	8	2	30	27	1	27	514
<b>1996</b>	471	16	5	32	24	1	28	577
<b>1997</b>	498	26	8	42	31	3	29	637
<b>1998</b>	486	37	6	38	29	4	27	627
<b>1999</b>	593	38	15	53	28	3	34	764
<b>2000</b>	637	47	29	46	17	4	35	815
<b>2001</b>	716	57	30	67	31	7	28	936
<b>2002</b>	689	38	28	90	36	4	39	925*
<b>2003</b>	638	32	18	91**	27	6	48	860

\* 1 recipient waiting for an intestine.

\*\* 4 recipients waiting for a liver-kidney graft.

<sup>38</sup> According to data from Québec-Transplant

**Table III – Number of transplantations**

Year	Kidney	Kidney/ Pancreas	Pancreas	Liver	Heart	Heart/ Lung	Lung	Kidney (live)	Total
1995	199	2	1	87	51	2	14	26	382
1996	184	1	2	95	37	0	10	14	341
1997	167	1	3	86	44	2	22	16	341
1998	170	3	8	90	36	2	17	30	356
1999	201	7	13	112	39	2	22	31	427
2000	217	3	17	111	44	2	29	31	454
2001	214	6	11	100	39	1	25	46	442
2002	191	8	23	99	43	4	19	45	432
2003	229	3	17	113	47	2	25	52	488

**Table IV – Waiting time (in days) for the recipients who have received the graft**

Year	Kidney	Kidney/ Pancreas	Pancreas	Liver	Heart	Heart/ Lung	Lung
1995	502	152	318	82	113	148	443
1996	538	36	122	80	84	0	182
1997	474	78	412	90	109	739	426
1998	696	150	331	87	169	166	284
1999	742	734	103	80	223	298	301
2000	653	1708	640	126	141	104	327
2001	622	434	358	114	137	372	258
2002	709	654	506	125	119	367	478
2003	760	641	231	151	177	894	350

**Table V - Number of deaths while awaiting an organ**

Year	Kidney	Kidney/ Pancreas	Pancreas	Liver	Heart	Heart/ Lung	Lung
1995	ND	ND	ND	9	14	2	1
1996	ND	ND	ND	14	11	0	7
1997	ND	ND	ND	10	11	0	8
1998	ND	ND	ND	9	7	1	2
1999	ND	ND	ND	9	12	0	2
2000	23	2	0	13	3	1	8
2001	25	1	1	9	8	0	7
2002	24	0	0	18	12	1	7
2003	12	3	0	12	12	2	5

**Table VI - Comparison of the rates of cadaveric donors:  
Québec, the provinces and Canada for the year 2003**

	Québec	Maritimes	Ontario	Manitoba	Saskatchewan	Alberta	British Columbia	Canada
Population (million)	7 410	2 375	11 874	1 150	1 015	3 064	4 095	31 081
Number of donors	142	36	143	11	19	31	39	421
Rates of cadaveric donation per million population	19.2	15.2	11.8	9.5	18.9	9.9	9.4	13.3

**Table VII - Comparison of rates of cadaveric donors per million population (worldwide)**

	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>	<b>2002</b>
<b>Québec</b>	12.9	16.2	17.8	18.3	18.4	17,1
<b>Canada</b>	15.1	14.4	13.8	15.4	13.5	13,1
<b>United States</b>	20.4	21.2	21.3	23.5	21.4	21,5
<b>Spain</b>	29	31.5	33.6	33.9	33.7	33,7
<b>France</b>	15	16.9	16.2	16.2	17.8	20,0
<b>Italy</b>	11.6	12.3	13.7	15.3	17.1	18,1
<b>Great Britain and Ireland</b>	14.5	13.5	13	13.5	15.5	13,0