

Principles of a Canadian Organ and Tissue Donation and Transplantation System

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In order to direct the development of an integrated Canadian organ and tissue donation and transplantation (OTDT) system, a shared understanding of common values or principles is important to lay the foundation or framework for the system.

Many of these principles and values have previously been articulated. The Canada Health Act outlines the principles under which the health care system operates: universality, accessibility, portability, comprehensiveness and public administration. Canadians confirmed their belief in these values in the Romanow report¹ in 2002, making it clear they continue to strongly support the values of equity, fairness and solidarity. First Ministers reaffirmed their commitment to these principles, at the 2003 First Ministers' Accord on Health Care Renewal and again in 2004 at the First Minister's Meeting on the Future of Health Care:

- universality, accessibility, portability, comprehensiveness, and public administration;
- access to medically necessary health services based on need, not ability to pay;
- reforms focused on the needs of patients to ensure that all Canadians have access to the health care services they need, when they need them;
- collaboration between all governments, working together in common purpose to meet the evolving health care needs of Canadians;
- advancement through the sharing of best practices;
- continued accountability and provision of information to make progress transparent to citizens; and
- jurisdictional flexibility.

Given that the OTDT system must fit within the context of Canadian health care, these principles will be at the core of the design and management of the system. However, there are unique elements associated with OTDT that deserve additional consideration. The OTDT Committees have proposed the following additional principles with which to guide the design of the OTDT system.

- **Collaboration and Integration**

Donation and transplantation of organs and specific tissues are highly specialized health care services where the demand for transplantable organs and tissues far exceeds the supply. In Canada, these services are decentralized. Yet, in order to maximize the number of donations and improve outcomes of transplants,

¹ "Building on Values, The Future of Health Care in Canada", November 2002

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collaboration must underline all activities. Integration is needed not only between and within provinces and but also between all OTDT service providers.

- **Fairness**

As stated in the Romanow report, Canadians view their health care system as a national program, delivered locally but structured on intergovernmental collaboration and a mutual understanding of values. Canadians expect similar access to services of common quality, regardless of location. A national system for OTDT implies the integration of existing and developing components of the system.

- **Self-Sufficiency in Organs**

The Canadian organ donation system should pursue self sufficiency, by professionalizing donation services and increasing the supply of organs. In doing this, we meet the expectations of our population, as well as meeting our ethical and legal obligations to mitigate transplant tourism and organ trafficking.

- **Security of Tissue Supply**

It is possible to ensure that the all legitimate tissue needs of Canadian patients are met. The Canadian tissue system should ensure the adequate, safe and secure supply of tissues, from a combination of Canadian and imported tissue.

- **Population based system**

Organs and tissues are a public resource. The OTDT system should meet the needs of the population it serves, which includes not only patients and donors, but also the broader Canadian public. Interventions and outcomes should be evaluated, decisions should be evidence-based and consideration should be given to obtain the maximum benefit for the maximum number of patients. By looking at the needs of the population as a whole, we position our system to meet current needs as well as future needs.

- **Safety**

Because organ and tissue transplants come from living and deceased donors, there are inherent safety risks in their use. There can also be safety risks for living donors. However, because of the life-saving nature of transplantation, decisions to proceed are made even when risks are identified. Given this, traceability from donor to recipient is critical and should be complete for both organs and tissues. As well,

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safety decisions should be made based on evidence and assessment of risks, taking into consideration impact on organ and tissue supply and cost-benefit.

- **Accountability**

OTDT needs to be driven by clear authorities with clear objectives, where each participant understands their role and responsibilities and is held accountable for their results. As shareholders of the public health care system, Canadians have a right to be informed on the performance of the system and participants are obliged to explain their results to the Canadian public and to other partners in the system.

- **Cost-Effectiveness**

As part of a publicly funded system, OTDT should optimize resources and outcomes to be as efficient and effective as possible.

- **Privacy**

Privacy of individuals, both donors and patients, should be respected and protected, as required by law. However, privacy should not be used as a barrier to hinder development of inter-provincial systems which are beneficial to all Canadians.

- **Ethical Practices in Organ and Tissue Donation and Transplantation**

There are many ethical issues associated OTDT, e.g. consent to donation, compensation for organs and tissues, allocation of organs. Canadians have a moral and legal obligation to ensure that activities associated with organ and tissue donation and transplantation are carried out in an ethical manner, and are consistent with basic human rights and values, in order to prevent exploitation of vulnerable people both within and outside of Canada.

Additional Organ Allocation Principles

Canada is unable to meet the demand for organs, therefore difficult decisions must be made about which patient among the many waiting will receive a transplant. The following principles are proposed to help guide the development of organ allocation policies.

- **Evidence-Based Criteria**

Organs should be allocated based on medically, scientifically and socially sound evidence. Allocation criteria should be organ specific, and should be regularly reviewed, validated and modified to ensure algorithms reflect current information.

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- **Transparency**

All allocation policies and processes should be developed by organ specific experts with input from the public and professionals, and should be clear and readily available to all.
- **Accountability**

Recognizing that organs are under the collective stewardship of those involved in ODT, processes, actions and outcomes should be monitored and audited to ensure compliance with allocation and utilization policies, as well as to enable policy improvement.
- **Fairness**

Canadian patients should be treated consistently, without consideration to wealth, status or location. Similar groups of patients should have similar access, and efforts should be made to improve access for currently disadvantaged patient groups.
- **Utility**

Organs should be allocated to minimize death or disability on the transplant waiting list and maximize post-transplant outcomes, in terms of quality of life and additional years of life for transplant recipients.
- **Medical Need**

Organs should be allocated according to medical need, objectively measured, to minimize death on wait lists.

Because the principles of fairness, utility and medical need may sometimes conflict, criteria needs to be developed to balance these factors in a way that reflects the values of our society.