



Canadian Blood Services

it's in you to give

Organ Donation and Transplantation International Benchmarking Study – Phase 1

Version 1
2009-09-25

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1.0 Introduction

This benchmarking study provides comparisons of Organ Donation and Transplantation (ODT) data among selected international jurisdictions, along with Canadian data. It is intended to lead to the identification of best practices and provide information towards developing a national strategic plan for ODT activities. The study is being conducted in two phases. Phase 1 involves the collection of key ODT data measures and their definitions. Phase 2 will focus on selected measures and perform in-depth analysis on those measures.

The information from Phase 1 is provided in this document. It contains key ODT data measures and their definitions, showing graphs and charts of comparative data. It includes observations about data collected, including clarification of data content. It also identifies factors potentially affecting each measure. As a reference, the appendix to this document shows the organization of ODT systems for each country in the study.

Phase 2 of this study will follow. A subset of ODT measures will be chosen, based on their significance and potential in improving Canadian ODT performance. These will then be analyzed in detail to identify success factors and best practices that can be applied to the Canadian system.

2.0 Methodology

Several countries were chosen for the study. Spain, Belgium and United States were chosen as they have high donation rates and are leaders in this area. While Australia and United Kingdom are not high performers, both jurisdictions have announced major efforts and funding to improve their donation rates. Germany's performance is on par with Canada's in many measures and provides an interesting comparison.

Where applicable and available, Canadian provincial data was also included on graphs and tables. Transplantation rates and wait list rates per million population by province were not included. Because of the number of patients who are on wait lists and receive transplants outside their province of residence, these calculations would be skewed, resulting in invalid comparison between provinces.

Data came from many different sources, all publicly available through issued reports from unrestricted websites. (As data was collected entirely from public sources, names were not blinded in this study.) 2007 and 2008 data were obtained where available, although for some measures 2006 data was the latest data available. The main data sources are:

- Canadian Organ Replacement Register (CORR) – for Canadian and Provincial ODT data.

- Trillium Gift of Life Network 2008 Annual Report – for Ontario donor potential data
- Manitoba Measurement Strategy – 2009Q1 – for Manitoba donor potential data
- Comité des intensivistes de Québec-Transplant – 2009-05-12 – for Québec donor potential data
- International Registry of Organ Donation and Transplantation (IRODaT), via www.tpm.org – for donor and transplant data for Spain, UK, US and Australia
- Eurotransplant (www.eurotransplant.nl) – for all ODT data for Belgium and Germany
- Australian and New Zealand Organ Donation Registry (ANZOD), via www.anzdata.org.au – for Australian transplant survival data, and validation of Australian ODT data.
- ODT websites– for wait list details for all countries, and for validation of ODT data and inclusion of any missing data not covered by sources above. For any data differences, domestic ODT data was always assumed to be most correct and superseded the other data sources. Sites accessed include:
 - www.ont.es
 - www.dso.de
 - www.transplant.be
 - www.uktransplant.org.uk
 - www.ustransplant.org

Note that this study will continue to evolve as more data is collected and analyzed.

3.0 General Observations

For donation and transplantation rates, there are three countries performing well above the rest. Spain has the highest donation and transplant rates. Belgium has adopted the Spanish model, with great success. The United States has a high deceased donation rate coupled with a high living donation rate. The U.K. and Australia have the lowest performances, though both countries have begun to implement significant changes and funding to improve their rates. Their performance will be tracked to see the effect of these changes. Canada and Germany are comparable for most measures; however, Canada's living donor rates are much higher, comparable to the top performing countries. Canada also has organ utilization rates and patient post-transplant survival rates on par with other countries.

The lack of available data for some measures did not allow a full benchmarking study to be performed, especially for donor potential, referral, consent and conversion rates. In some cases, definitions for measures were significantly different, making comparisons more difficult (Figure 7, 11, 12, 13). This is expected to improve in the future, through on-going national and international work to standardized data and measure definitions. Efforts continue to collect more data, but gaps in timely and complete data on ODT performance is an issue faced by several countries, including Canada.

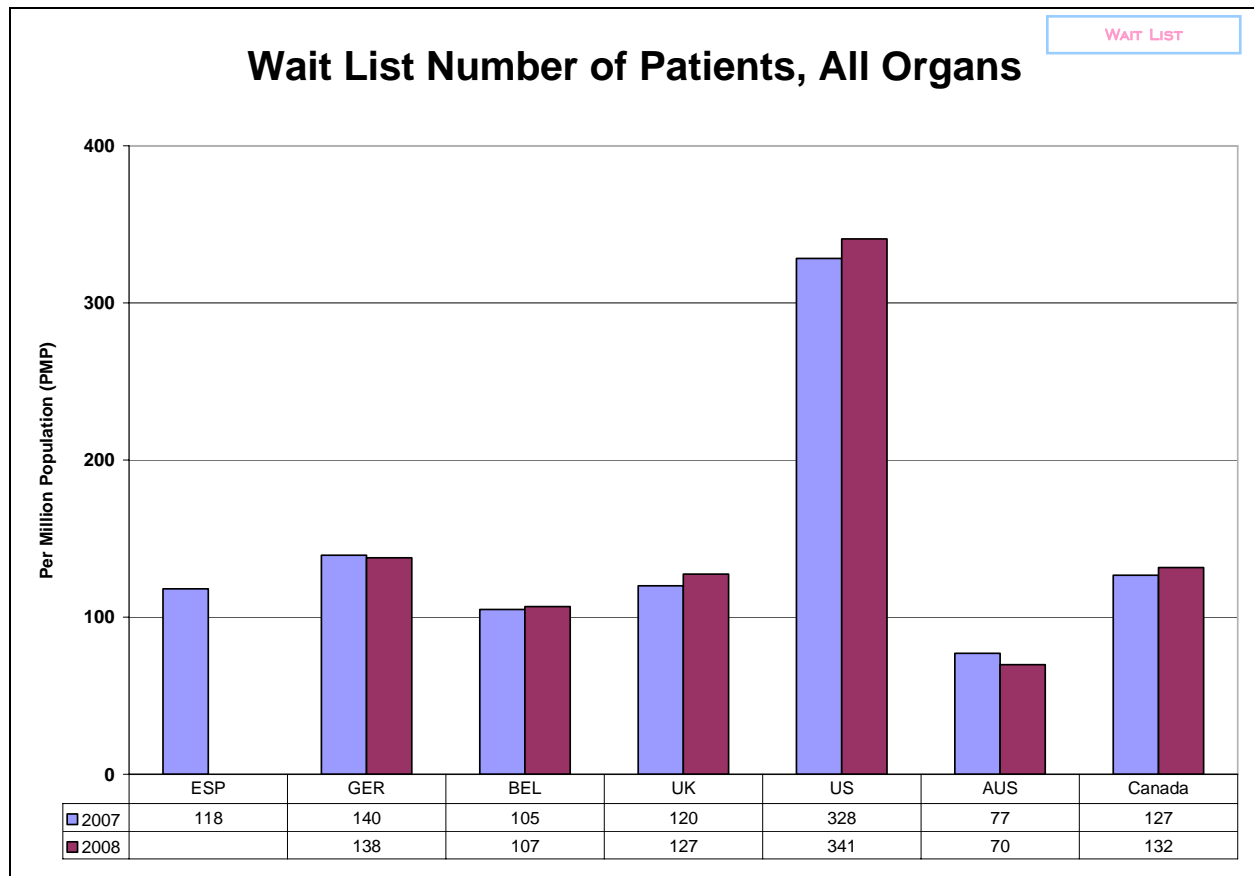
4.0 Wait List

Definition

4.1 Wait List (# of patients) - All organs, per million population (PMP)

Number of patients on a wait list for an organ transplant, as a ratio of total population.

Figure 1. Wait List Number of Patients, All Organs



Observations:

- Number of patient includes both active and on-hold patients.
- In the U.S., patients are put on waiting lists immediately after being diagnosed as potential transplant recipients. This is a requirement prior to being treated, and also allows patients to accumulate points towards determining priority for receiving an available organ.
- In the other study countries, many patients who are potential transplant recipients are not wait listed until their assessment for transplantation is complete.

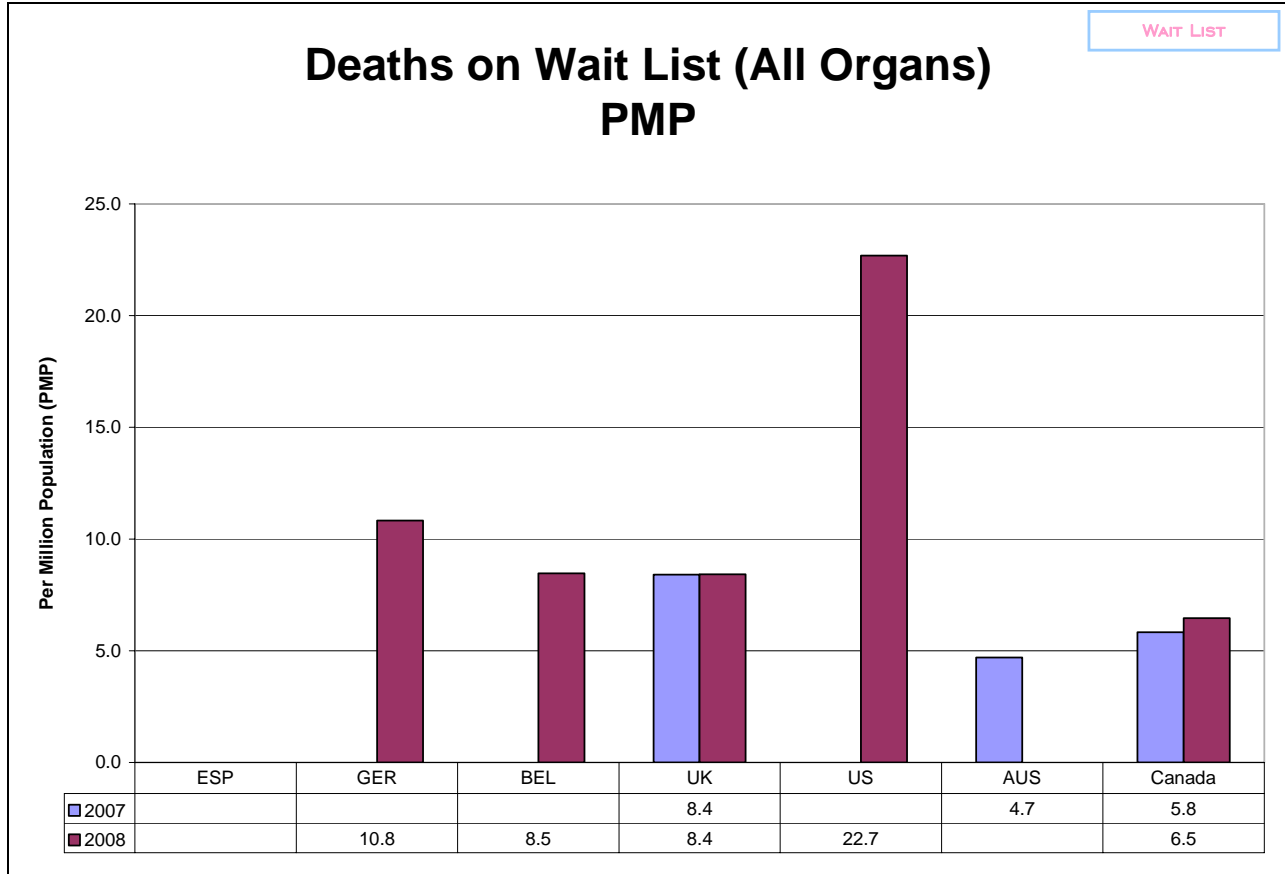
Factors potentially affecting this measure:

- Wait list criteria and practices (including pre-emptive listing)
- Health and demographics of the jurisdiction
- Some jurisdictions may list to obtain funding, others with no funding incentive may be less likely to list patients

Definition

<p>4.2 Deaths on Wait List (# of patients) - All organs, per million population (PMP)</p>	<p>Number of patient deaths while on an organ wait list, as a ratio of total population.</p>
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Figure 2 Deaths on Wait List – All Organs



Observations:

- The U.S. has a significantly higher number of deaths on wait lists.
- Data for Spain was unavailable.

Factors potentially affecting this measure:

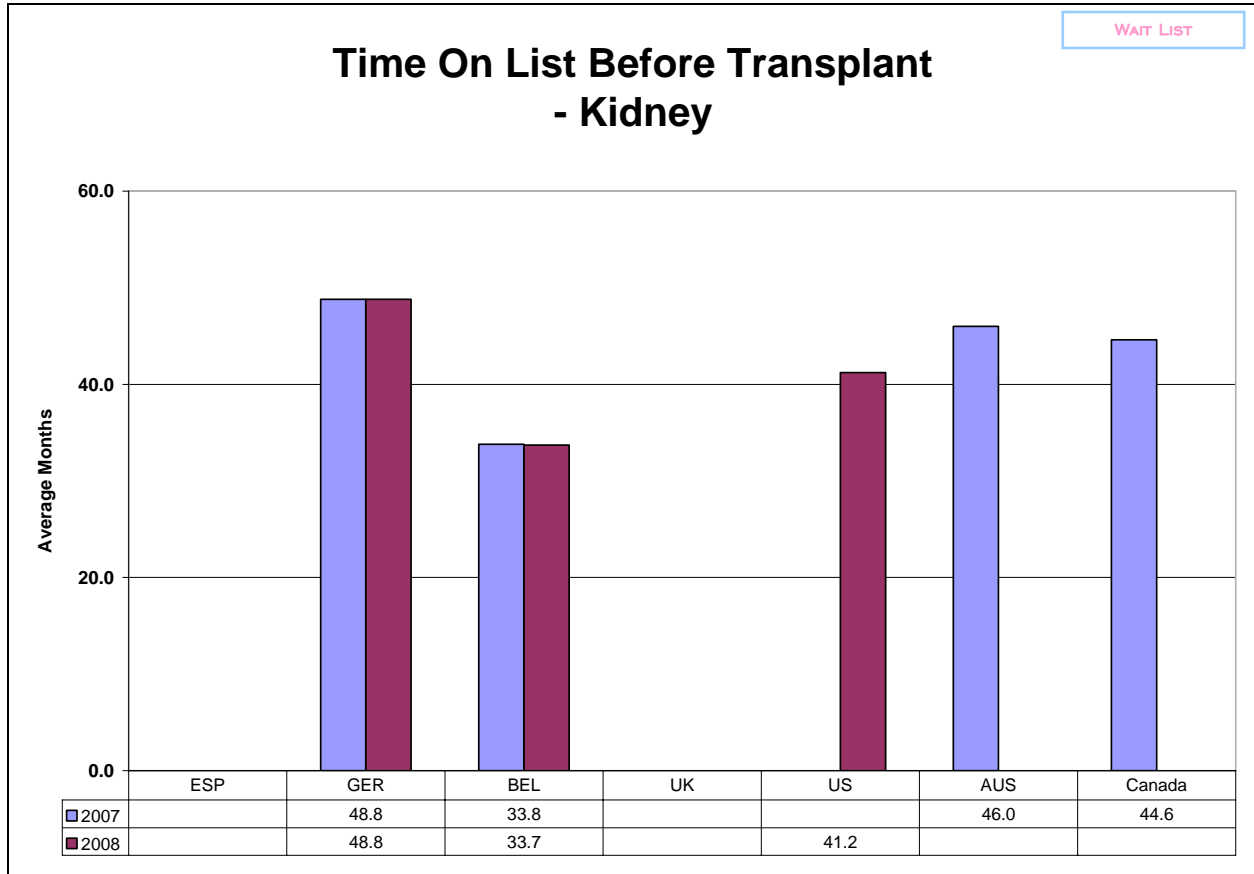
- Relative size of the wait list
- De-listing wait list patients before they die
- Very sick patients may not be listed if they can't be transplanted

Definition

4.3 Time on list - Kidney (average # of months)

Average number of months that a patient on a wait list has waited before they received their kidney transplant.

Figure 3. Time on List Before Transplant – Kidney



Observations:

- Data is shown by year, for all patients transplanted in that year.
- Data for Spain and the UK were unavailable.
- In spite of having a much larger waiting list, the U.S. still has a comparable rate to other study countries.

Factors potentially affecting this measure:

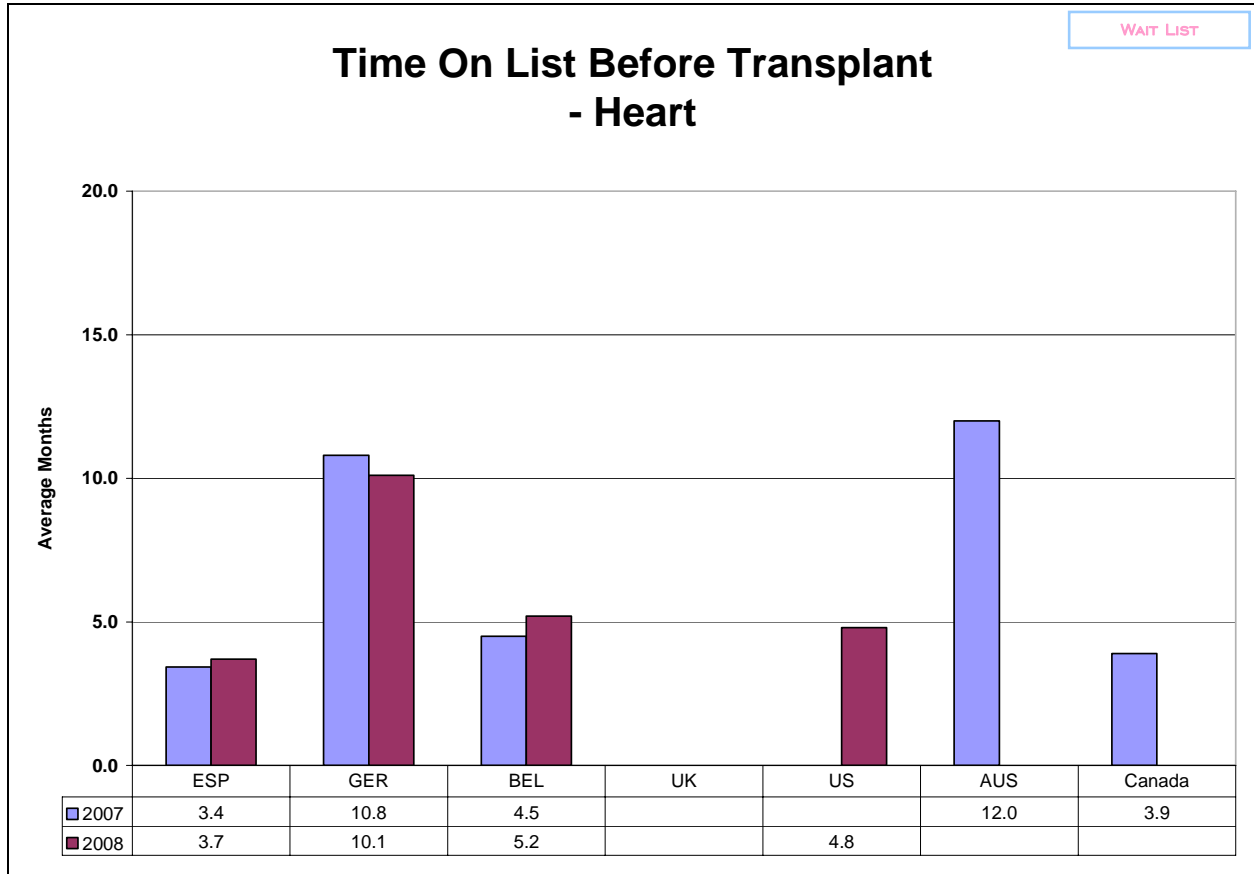
- Size of the wait list
- Level of donation and transplantation in the country
- Health status of patients on the wait list
- Number of highly sensitized patients on the wait list

Definition

4.4 Time on list – Heart (average # of months)

Average number of months that a patient on a wait list has waited before they received their heart transplant.

Figure 4. Time On List Before Transplant –Heart



Observations:

- Data for the UK was unavailable.
- Australia and Germany had longer average heart wait list times.

Factors potentially affecting this measure:

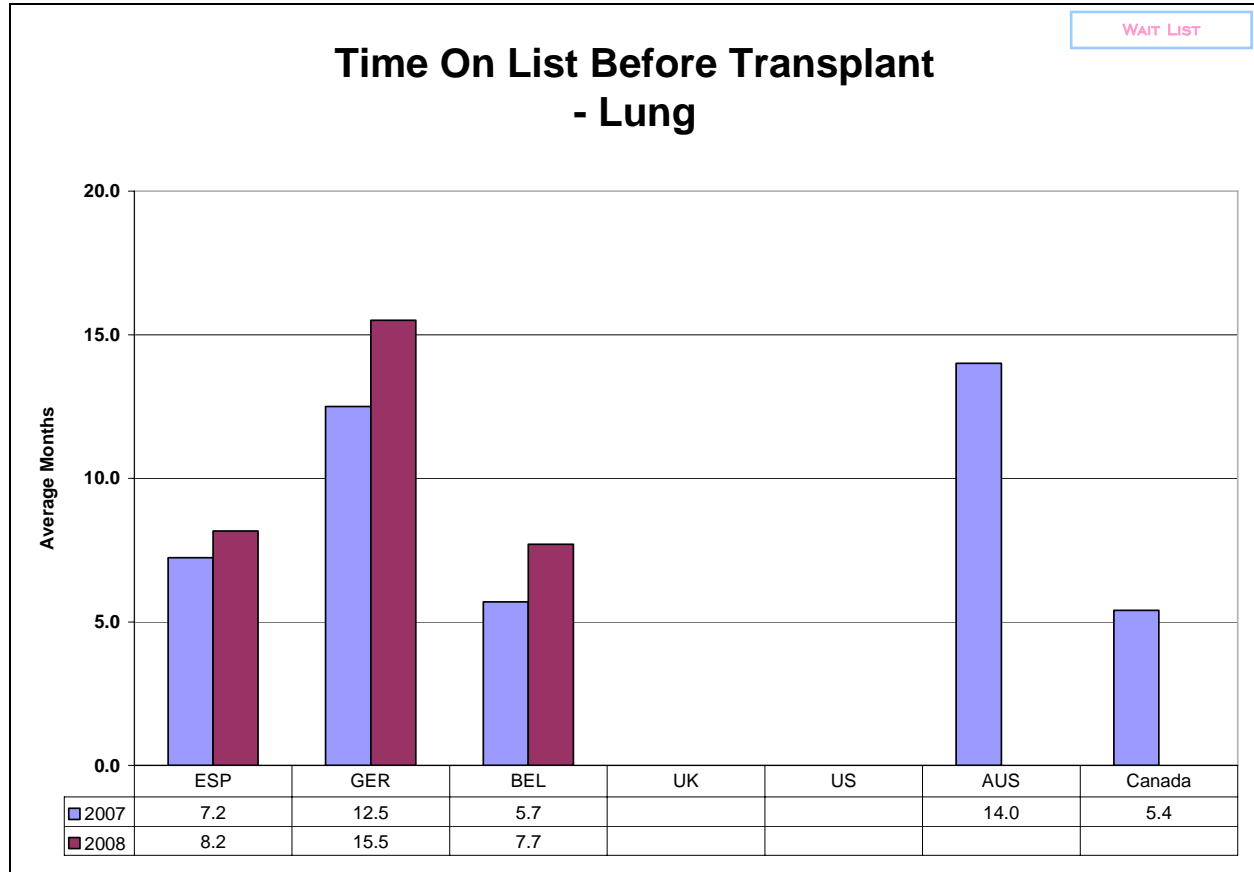
- Size of the wait list
- Level of donation and transplantation in the country
- Health status of patients on the wait list
- The availability of bridges to heart transplantation (e.g., LVAD heart machine)

Definition

4.5 Time on list – Lung (average # of months)

Average number of months that a patient on a wait list has been waiting before they received their lung transplant.

Figure 5. Time On List Before Transplant –Lung



Observations:

- Data is shown by year, for all patients transplanted in that year.
- Data for the UK and US were unavailable.
- Australia and Germany had longer average heart wait list times.

Factors potentially affecting this measure:

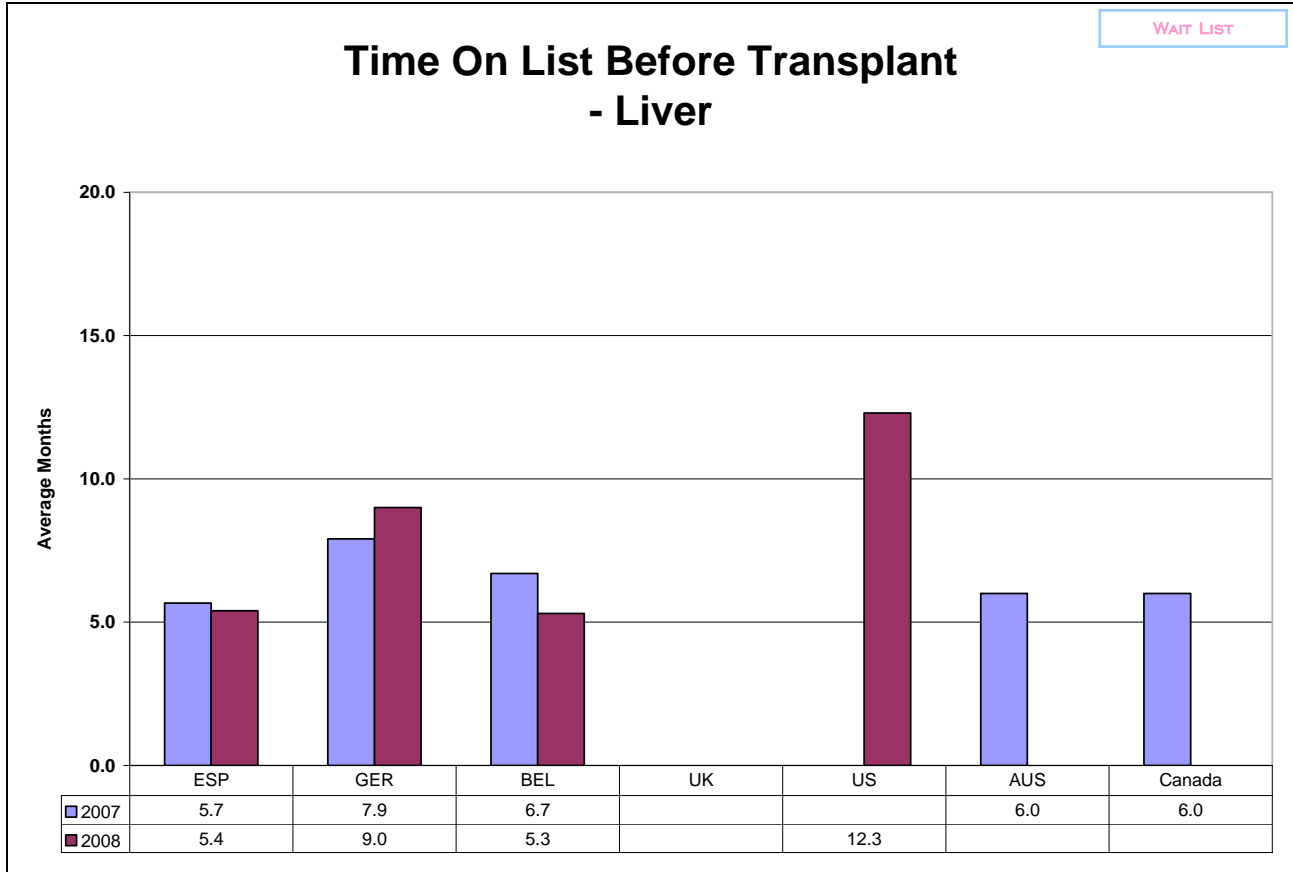
- Size of the wait list
- Level of donation and transplantation in the country
- Health status of patients on the wait list

Definition

4.6 Time on list – Liver (average # of months)

Average number of months that a patient on a wait list has been waiting before they received their liver transplant.

Figure 6. Time On List Before Transplant – Liver



Observations:

- Data is shown by year, for all patients transplanted in that year.
- Data for the UK is unavailable.
- U.S. has the longest wait times for liver transplant.

Factors potentially affecting this measure:

- Size of the wait list
- Level of donation and transplantation in the country
- Health status of patients on the wait list

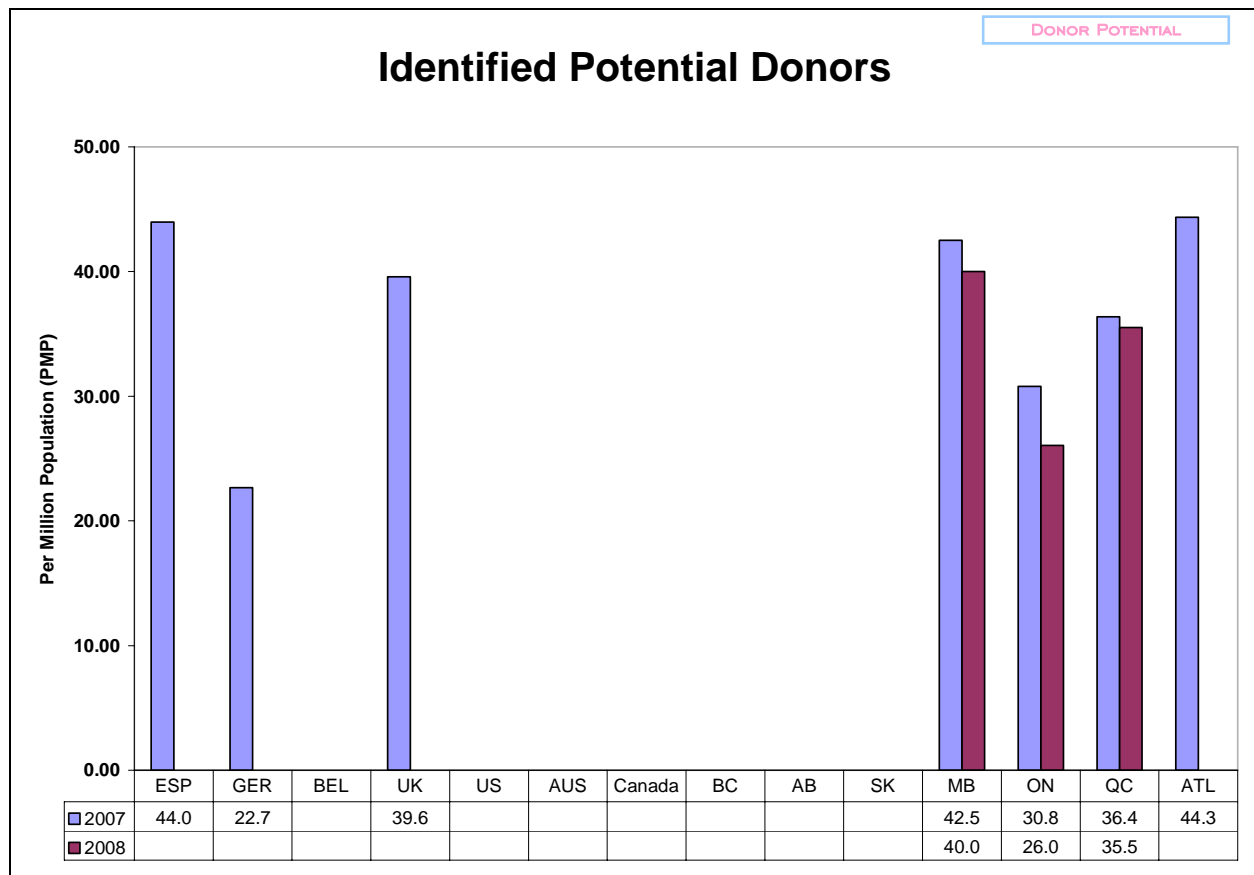
5.0 Donor Potential

Definition

5.1 Identified potential donors, per million population (PMP)

The number of people as a ratio of total population with severe brain injuries, no prognosis for survival, for whom life support will be withdrawn, and with no contraindications to donation.

Figure 7. Identified Potential Donors



Observations:

- Efforts continue to obtain data for more countries and for Provinces.
- In Canada and the UK, includes realized DCD cases.

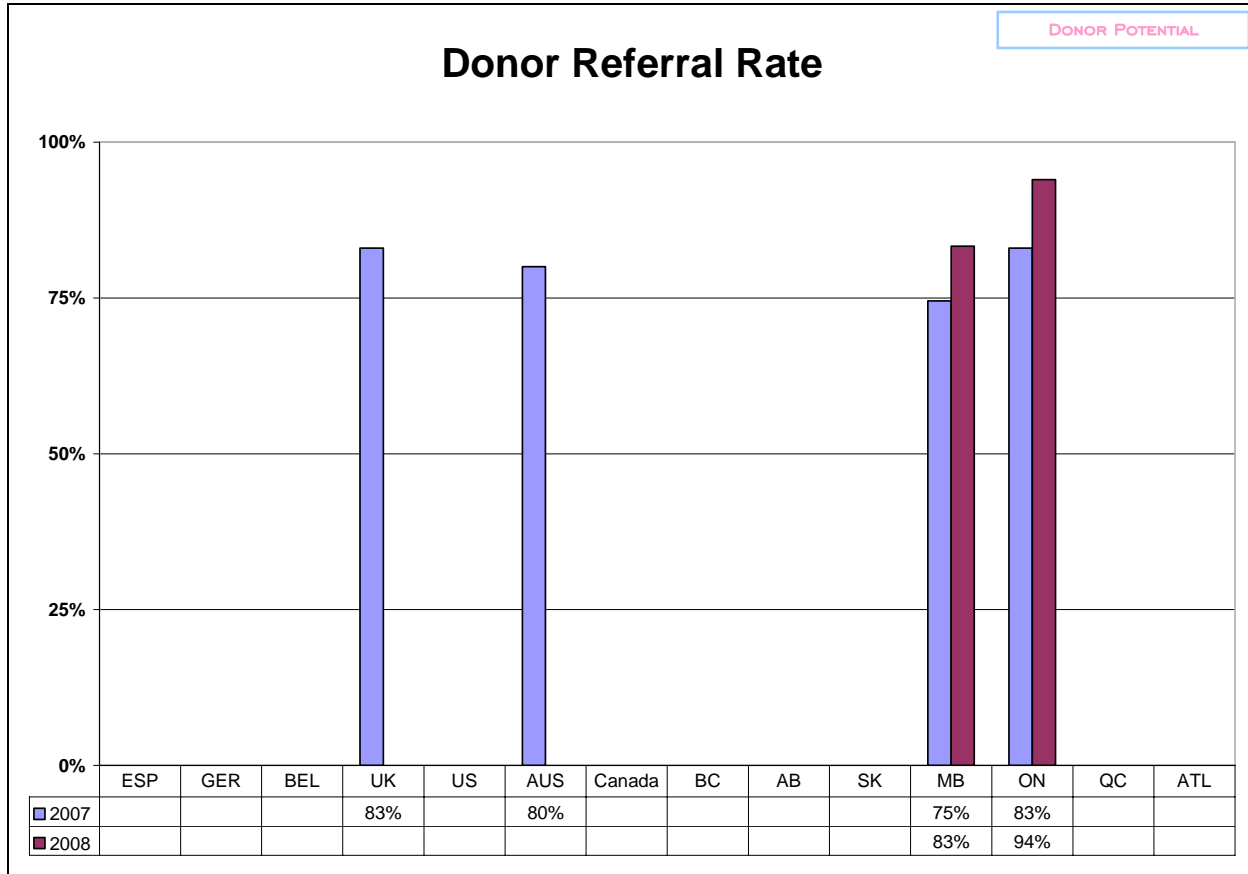
Factors potentially affecting this measure:

- Health professional awareness of donation as a standard of end of life care
- Trained and dedicated resources in hospitals to assess deaths for donation potential
- Financial incentives for hospitals to assess deaths
- Varied definitions for potential donor exist

Definition

5.2 Donor referral rate	Percentage of potential deceased donors referred to an organ procurement organization (OPO) to realize the donation opportunity.
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Figure 8. Donor Referral Rate



Observations:

- Some countries claim a 100% referral rate, but hard data is lacking for most countries and provinces.
- Efforts continue to obtain data for more countries and for Provinces.

Factors potentially affecting this measure:

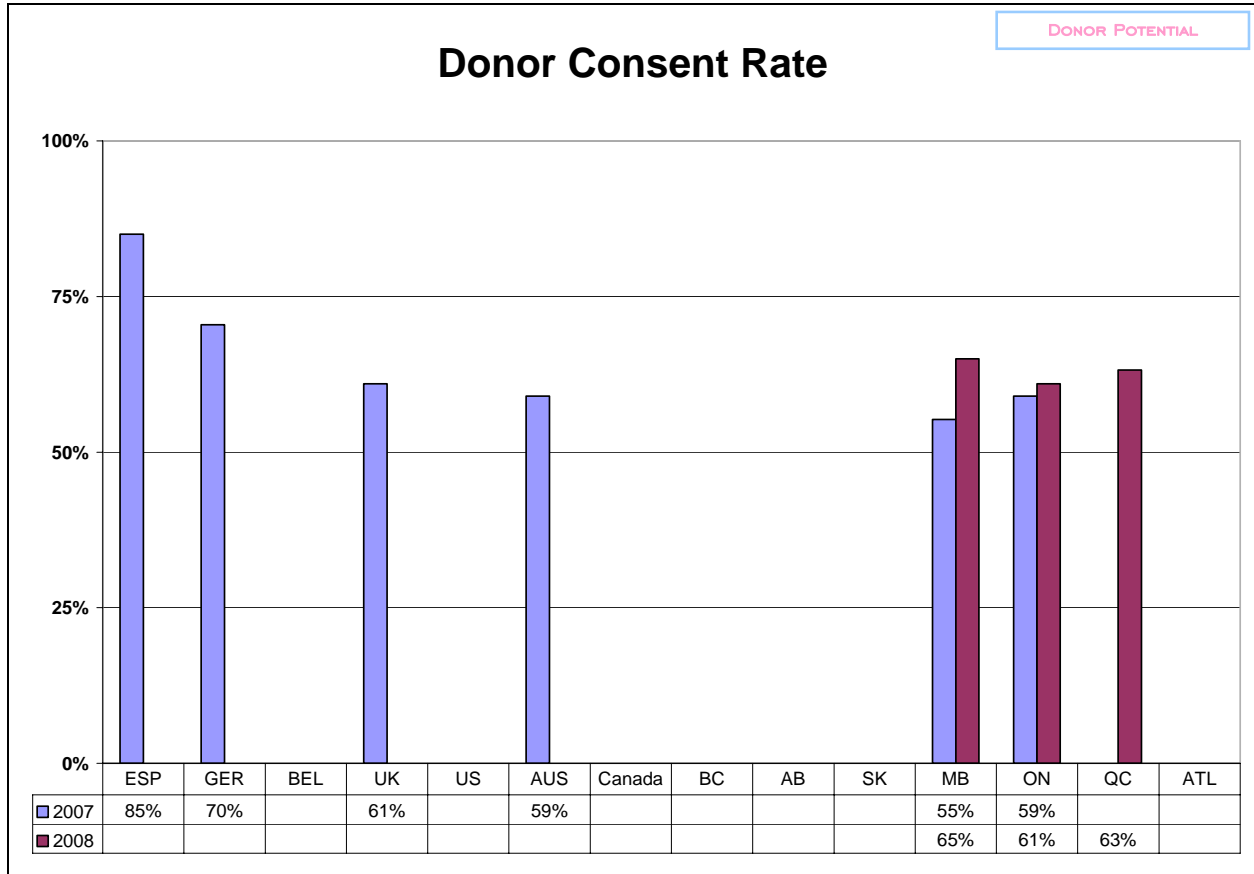
- Identification of potential donors
- Hospital process to support referral activities
- Accessibility of OPO resources to make referrals
- Legislated requirement to refer

Definition

5.3 Donor consent rate

Percentage of referred cases (or approached cases in Ontario) where consent is obtained for deceased organ donation.

Figure 9. Donor Consent Rate



Observations:

- Efforts continue to obtain data for more countries and for Provinces.

Factors potentially affecting this measure:

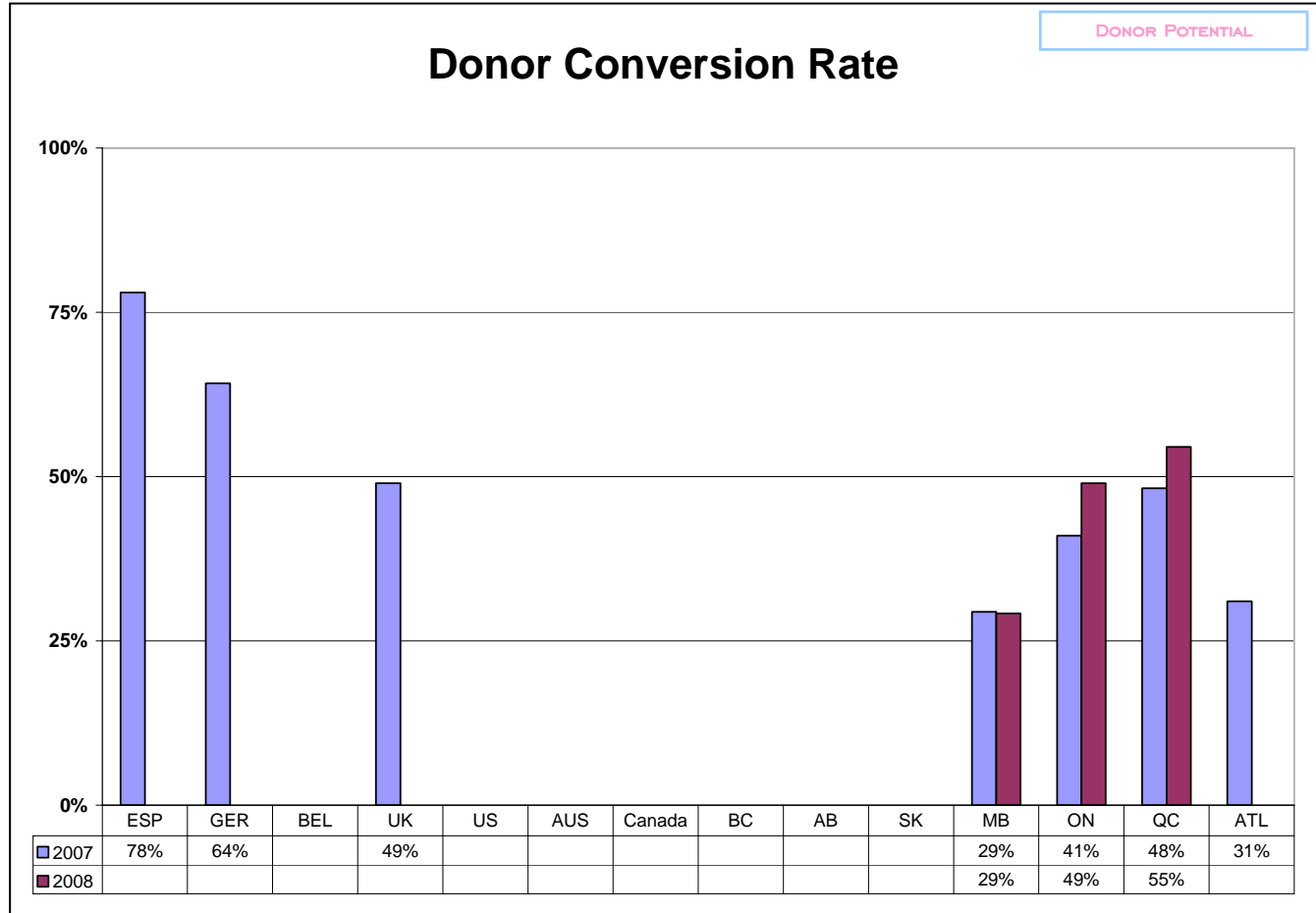
- Presumed consent
- Access to trained and dedicated donation requesters
- Public awareness of donation
- Availability of donor intent information

Definition

5.4 Donor conversion rate

The percentage of potential organ donors converted into actual organ donors.

Figure 10. Donor Conversion Rate



Observations:

- Efforts continue to obtain data for more countries and for Provinces.

Factors potentially affecting this measure:

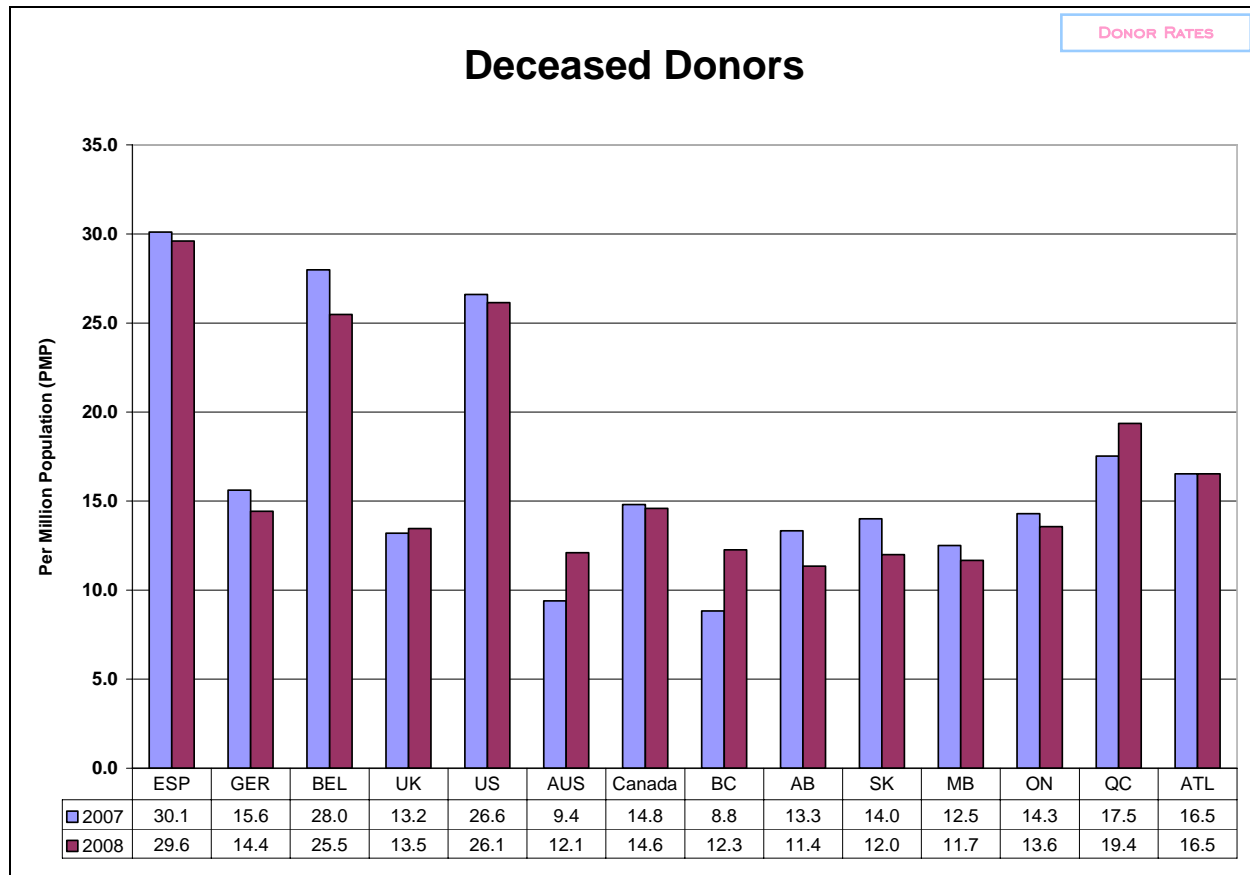
- Total of the identification, referral and consent steps
- ICU and OR capacity to manage donors and retrieve organs
- Retrieval team and transport availability
- Donor assessment results in exclusion

6.0 Donor Rates

Definition

6.1 Deceased donors PMP	Total number of deceased donors, as a ratio of total population.
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Figure 11. Deceased Donors



Observations:

- For Canada and Spain, the data represents donors from whom at least one organ was transplanted. Other countries' data represents donors from whom at least one organ is recovered for transplant. Because Spanish and Canadian data used the "organ transplanted" definition, their donor rates are understated by about 10% in comparison to the other countries.
- Note that there is considerable debate internationally about the appropriateness of Donors PMP as a comparative measure of donation, as it does not factor in actual donor potential in a country.

Factors potentially affecting this measure:

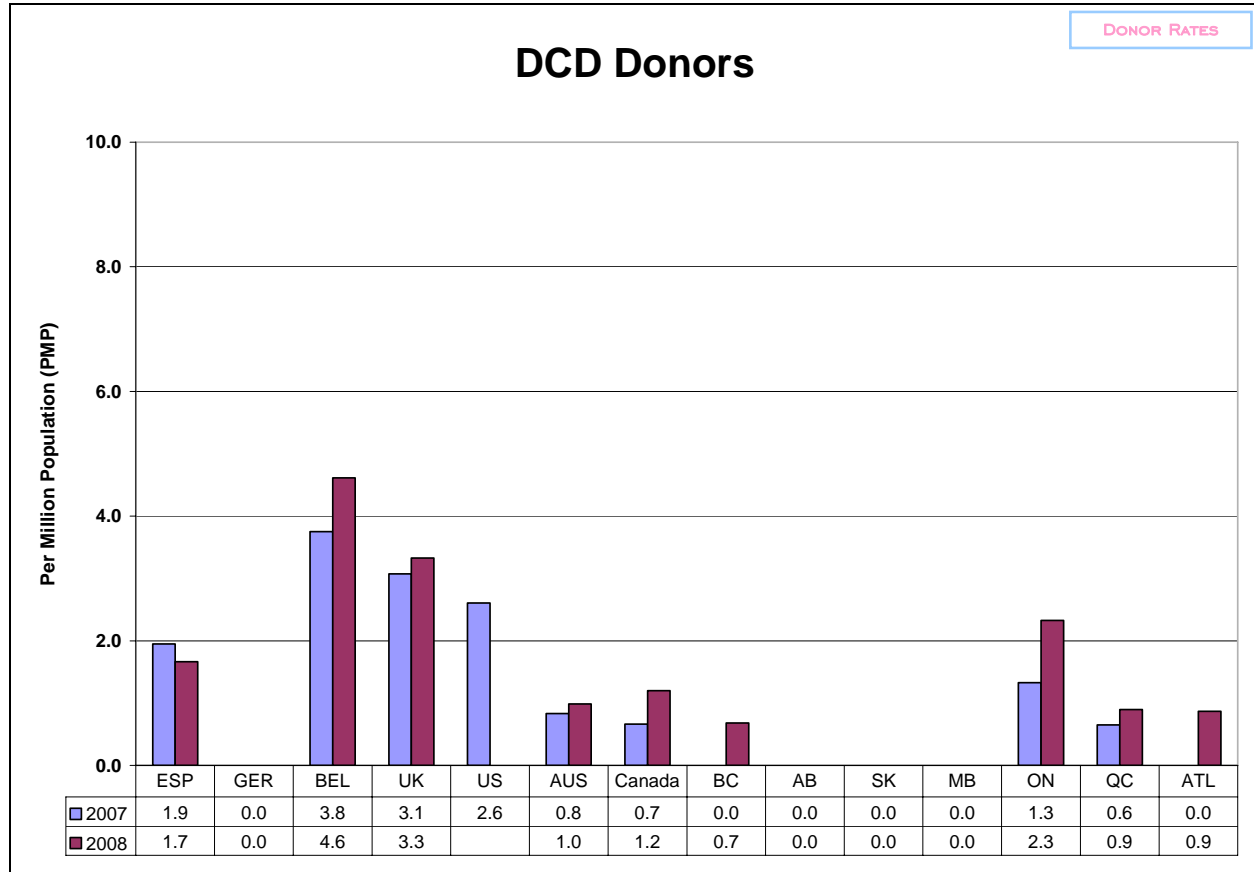
- Public awareness of donation
- Access to trained donation professionals
- Ability to convert potential donors to actual donors

Definition

6.2 DCD donors PMP

Total number of Donation after cardiocirculatory death (DCD) donors, as a ratio of total population.

Figure 12. DCD Donors



Observations:

- DCD donation began in Canada in 2006, and is not currently practiced in all provinces.
- In Canada, a donor is counted only if at least one organ is recovered and transplanted.

Factors potentially affecting this measure:

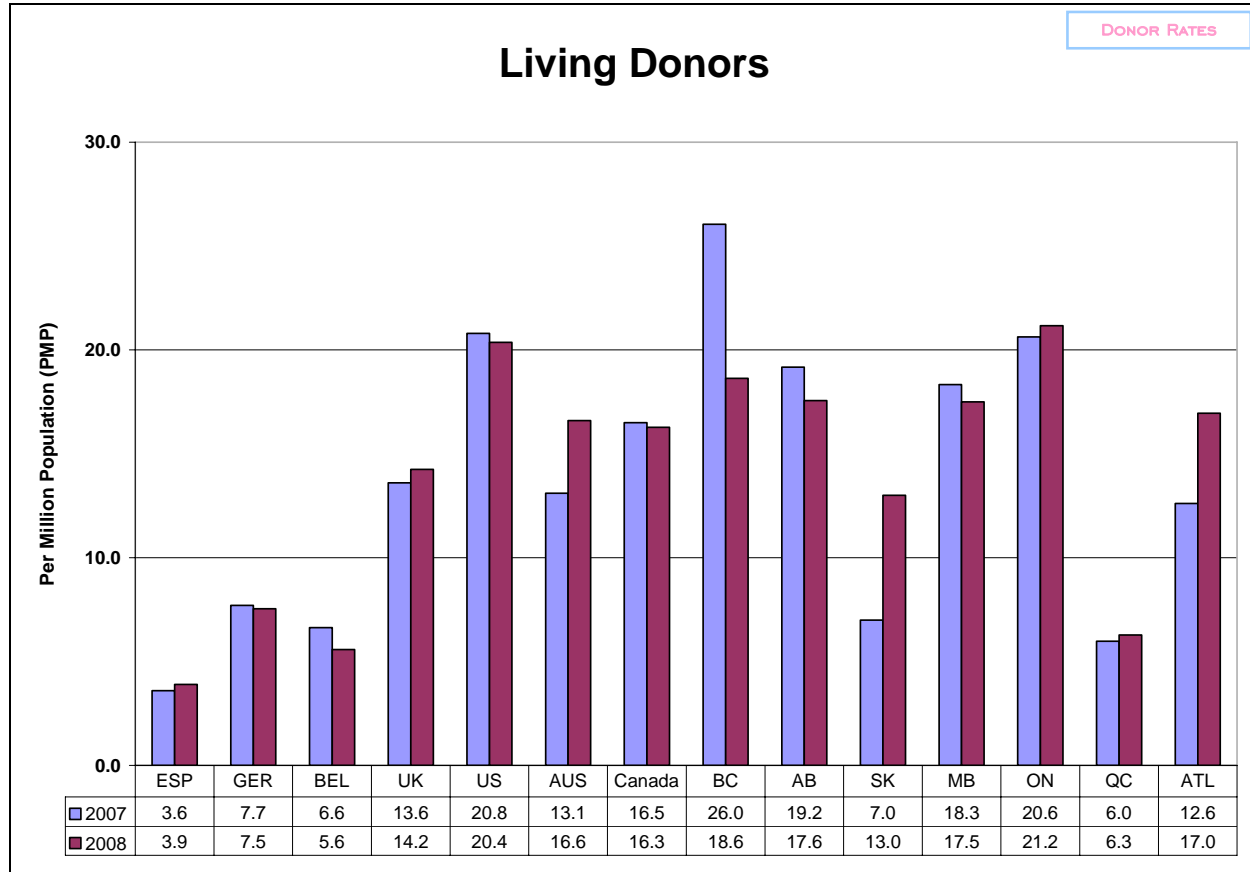
- Policy within the country/province to accept DCD donors
- The types of DCD donation in place: controlled DCD (in the hospital, discussed with family, a planned withdrawal of life-sustaining therapy) and/or uncontrolled DCD (immediately upon unexpected cardiac death)
- Educated and aware hospital staff to identify potential DCD donors
- Public awareness
- Processes in place to manage and retrieve from this type of donor

Definition

6.3 Living donors PMP

Living donors from whom an organ was removed for transplantation, measured as a ratio per million population.

Figure 13. Living Donors



Observations:

- In Canada, the organ must also be transplanted to count the donor. Because Canada uses this definition, their donor rates are understated by about 10% in comparison to the other countries.
- Some Canadian provinces rival the rates of the best performers.

Factors potentially affecting this measure:

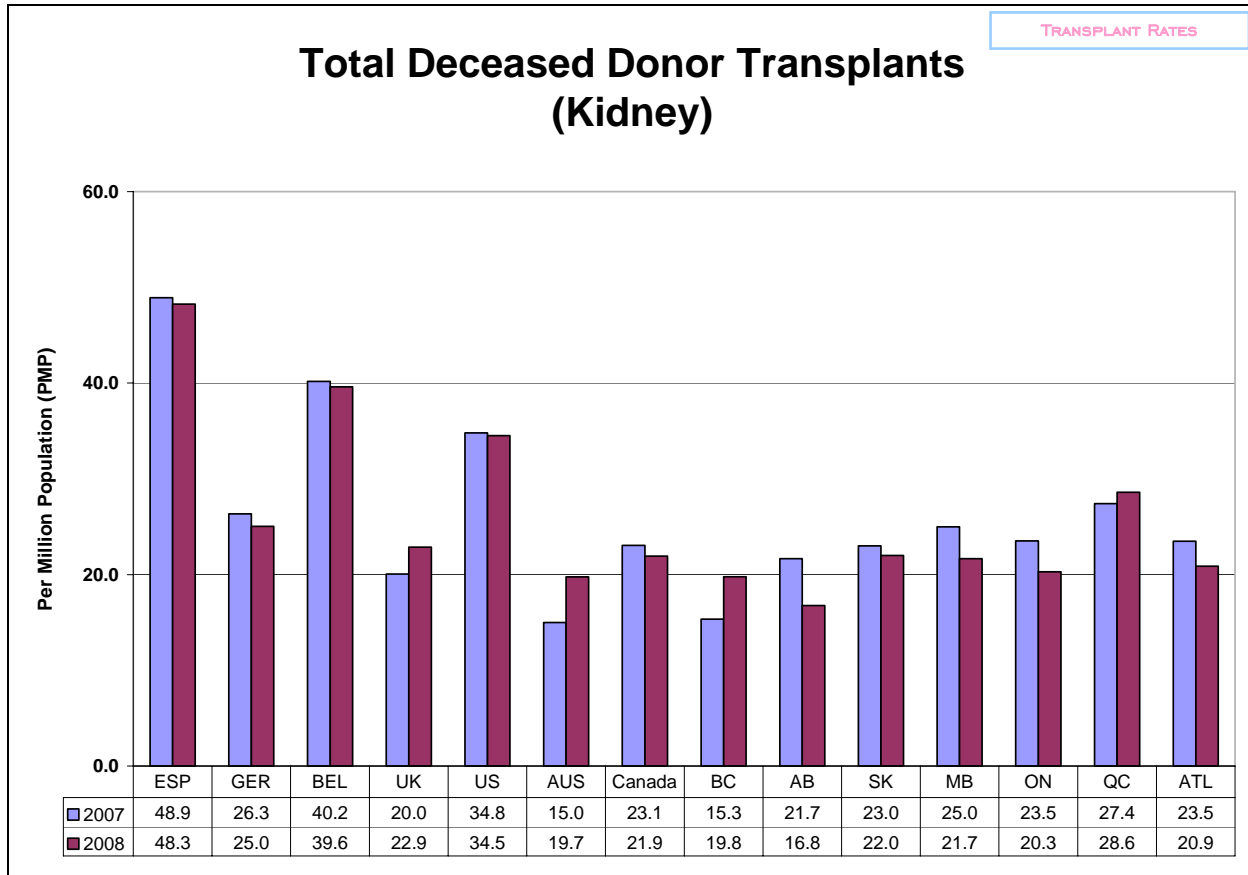
- Awareness and acceptance of living donation
- Registries to enhance living donor opportunities
- Capacity for donor assessment, transplant and follow-up activities
- Degree of emphasis on living versus deceased donation

7.0 Transplant Rates

Definition

<p>7.1 Kidney total deceased donor transplants PMP</p>	<p>Total number of patients transplanted with a kidney from a deceased donor, as a ratio of total population.</p>
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Figure 14. Total Deceased Donor Transplants – Kidney



Observations:

- Includes double kidney transplants, but excludes combination transplants with kidney and other organs.

Factors potentially affecting this measure:

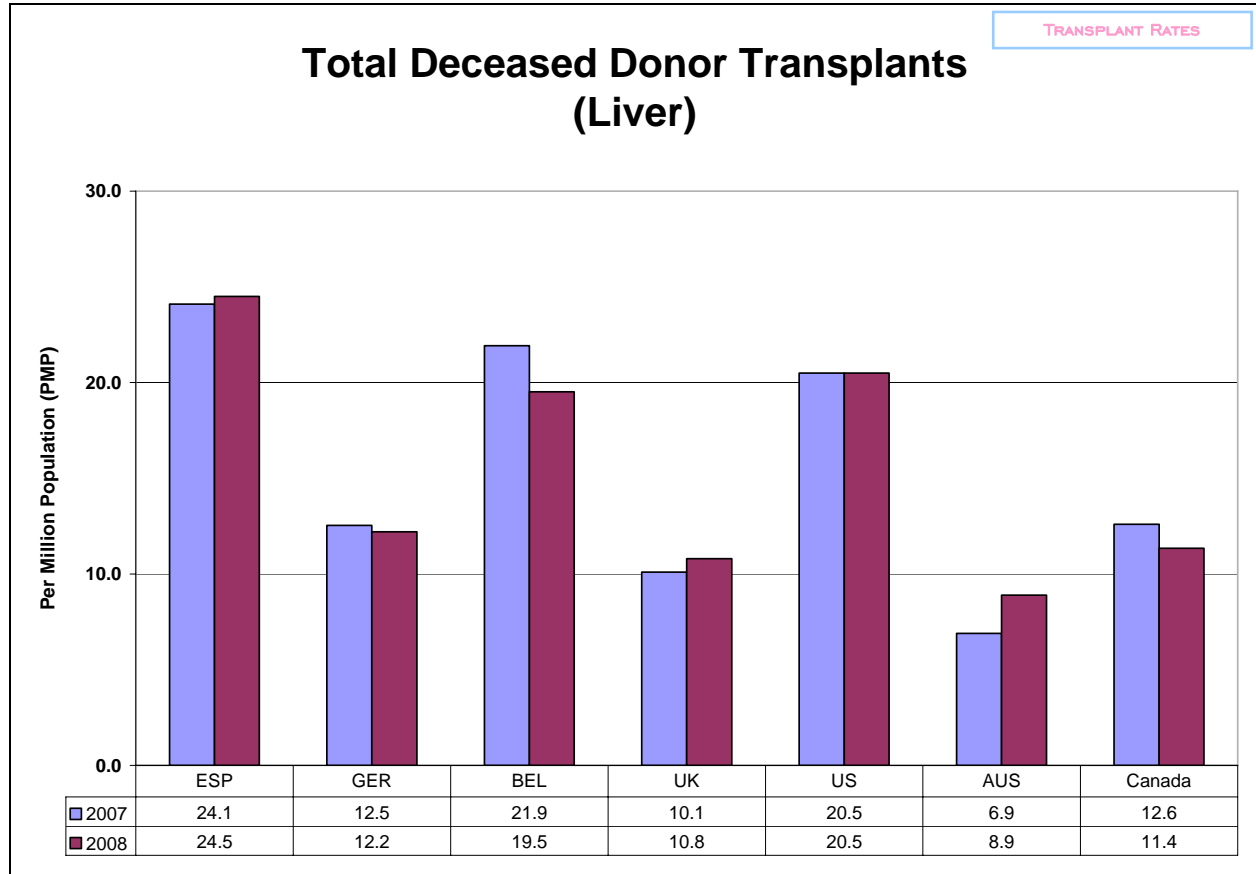
- Donation rates
- Utilization practices

Definition

7.2 Liver deceased donor transplants PMP

Total number of patients transplanted with a liver from a deceased donor, as a ratio of total population.

Figure 15. Total Deceased Donor Transplants – Liver



Observations:

- Includes split liver transplants, but excludes combination transplants with liver and other organs.

Factors potentially affecting this measure:

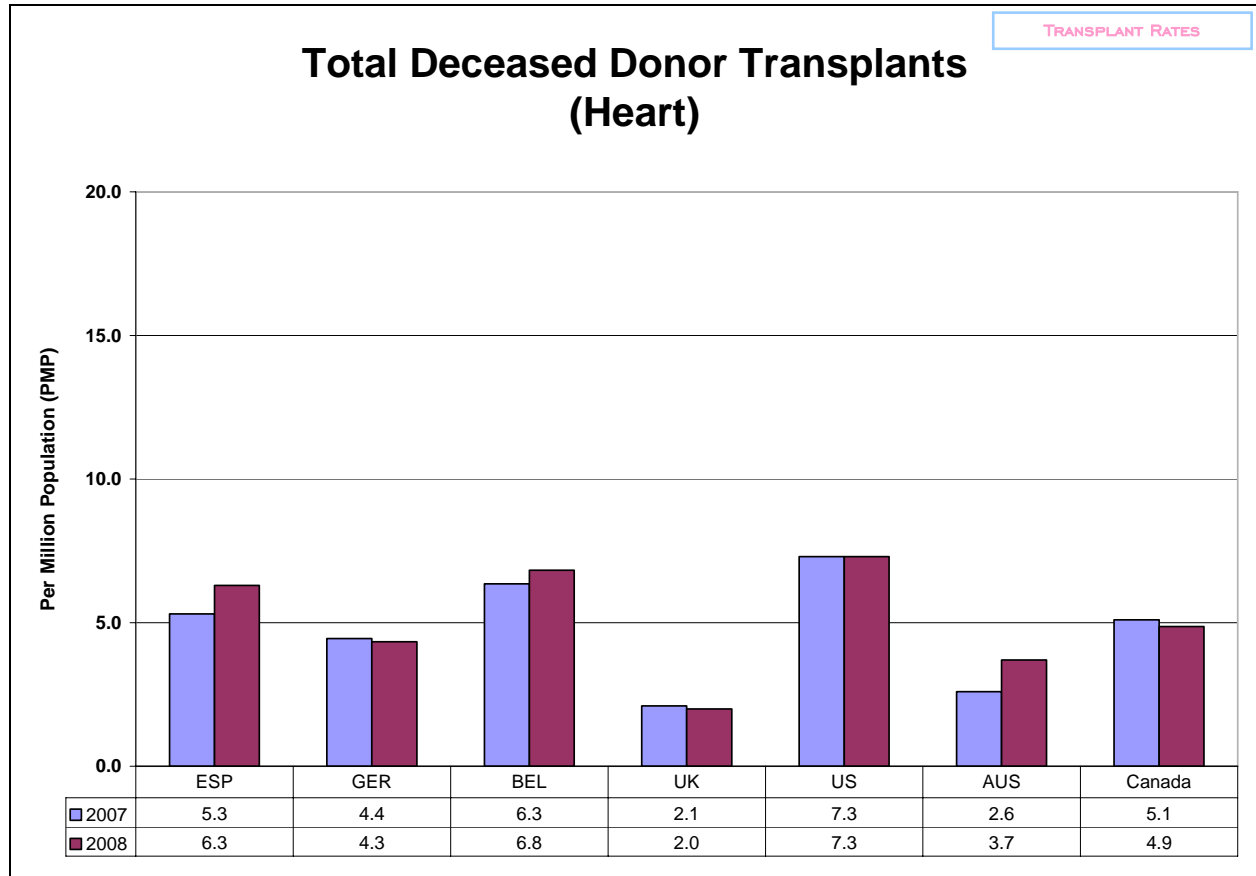
- Donation rates
- Referral and wait list practices
- Lack of available bridges to transplantation
- Utilization practices

Definition

7.3 Heart deceased donor transplants PMP

Total number of patients transplanted with a heart from a deceased donor, as a ratio of total population.

Figure 16. Total Deceased Donor Transplants – Heart



Observations:

- Excludes combination transplants with heart and other organs.

Factors potentially affecting this measure:

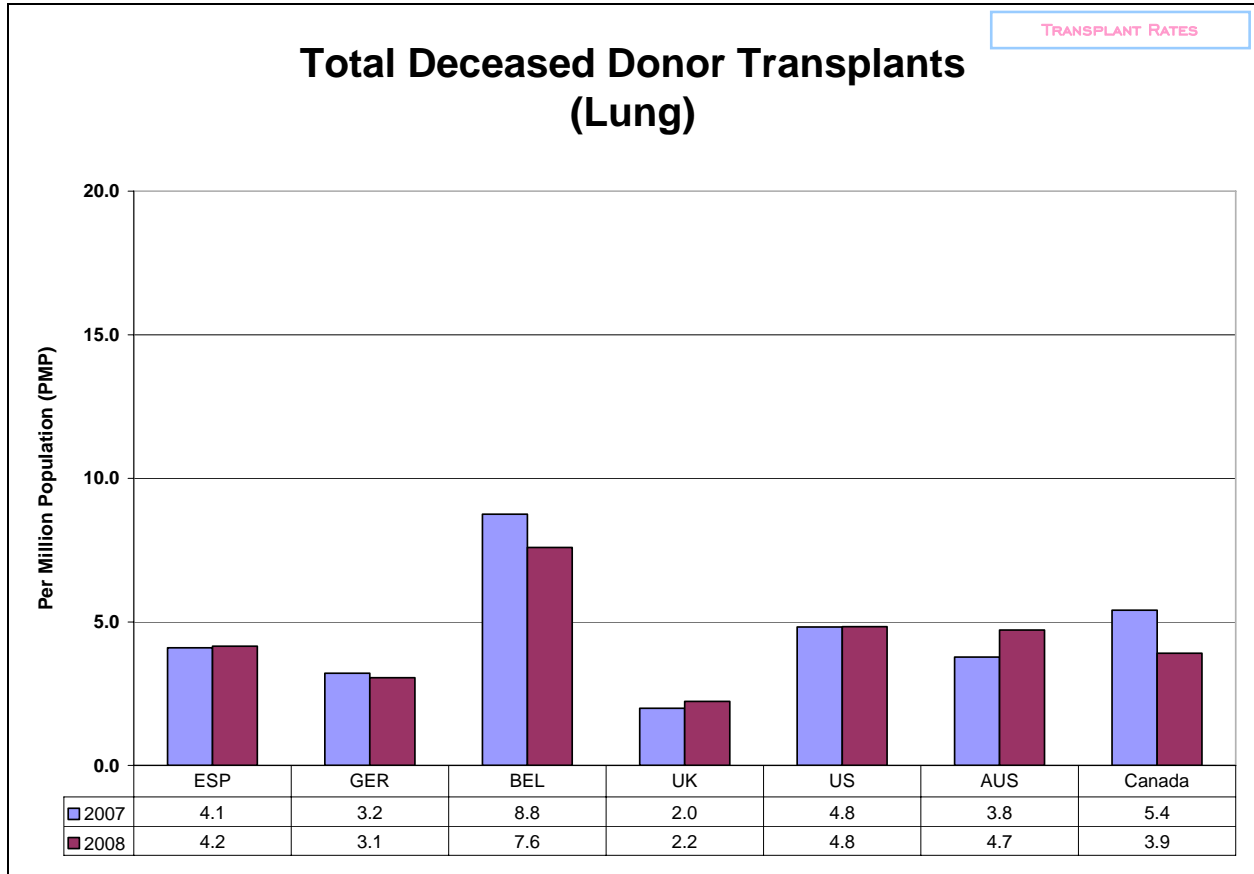
- Donation rates and geography
- Referral and wait list practices
- Availability of resources for bridging technologies
- Utilization practices
- Use of donor management best practices

Definition

7.4 Lung total deceased donor transplants PMP

Total number of patients transplanted with a lung from a deceased donor, as a ratio of total population.

Figure 17. Total Deceased Donor Transplants – Lung



Observations:

- Includes double lung transplants, but excludes combination transplants with lung and other organs.

Factors potentially affecting this measure:

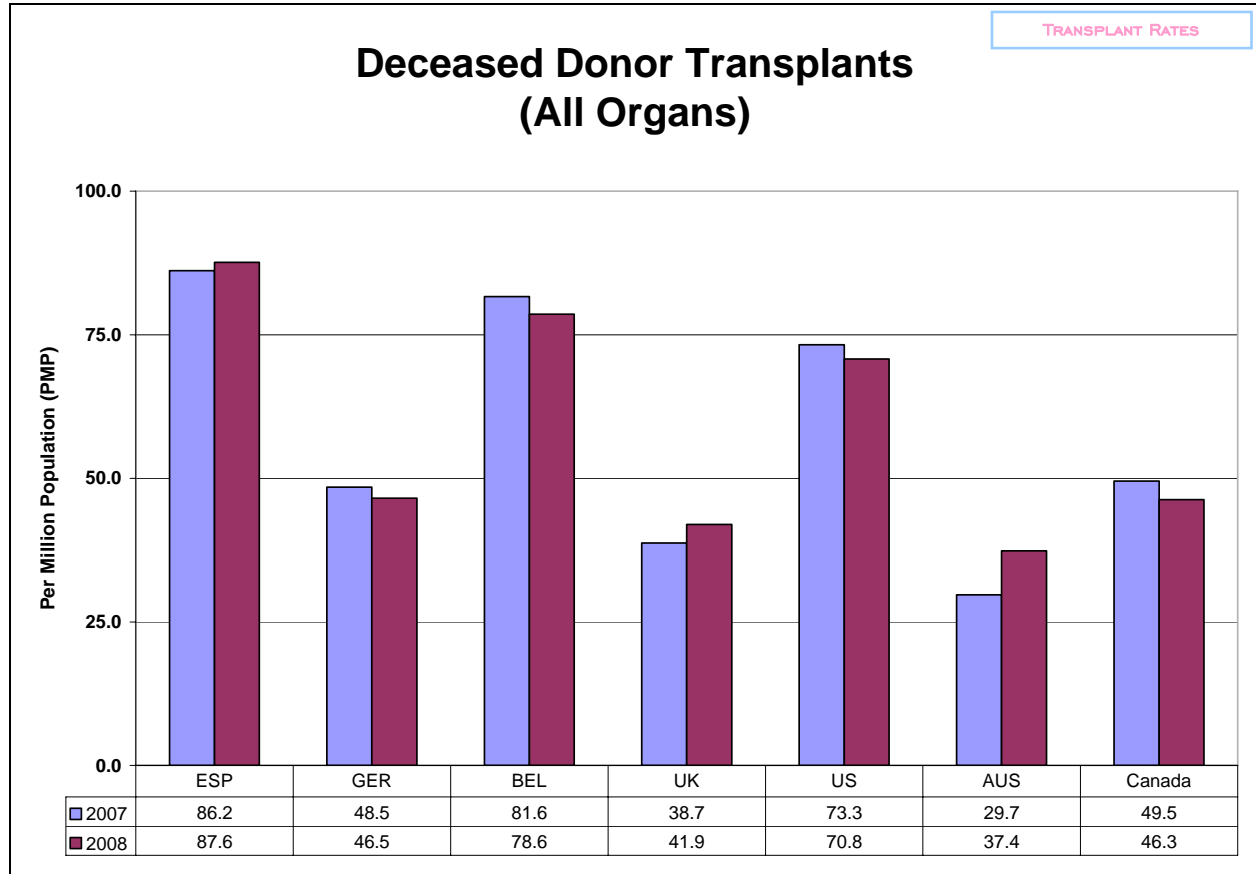
- Donation rates and geography
- Referral and wait list practices
- Utilization practices
- Use of donor management best practices

Definition

7.5 All organs deceased donor transplants PMP

Total number of patients transplanted with an organ from a deceased donor, as a ratio of total population.

Figure 18. Deceased Donor Transplants – All Organs



Observations:

- Includes all organ and combination organ transplants.
- Spain, Belgium and US have the highest rates.

Factors potentially affecting this measure:

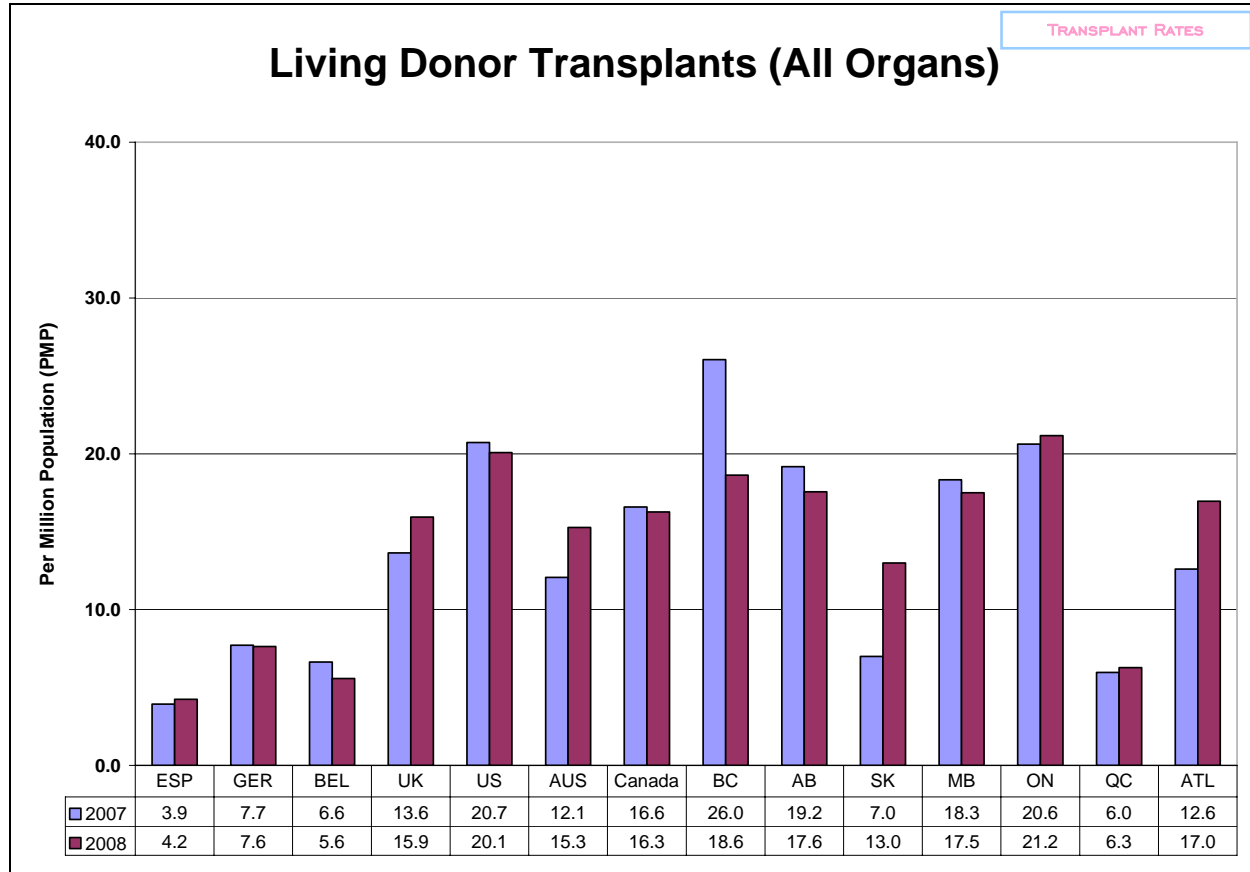
- Donation rates
- Referral and wait list practices
- Utilization practices
- Donor management best practices

Definition

7.6 All organs living donor transplants PMP

Number of patients transplanted from a living organ donor (for kidney, liver or lung), as a ratio of total population.

Figure 19. Living Donor Transplants - All Organs



Observations:

- Some Canadian provinces rival the rates of the best performers.
- Spain and Belgium have the lowest rates.

Factors potentially affecting this measure:

- Living donation rates
- Registries to enhance living donor opportunities
- Capacity for transplant and follow-up activities

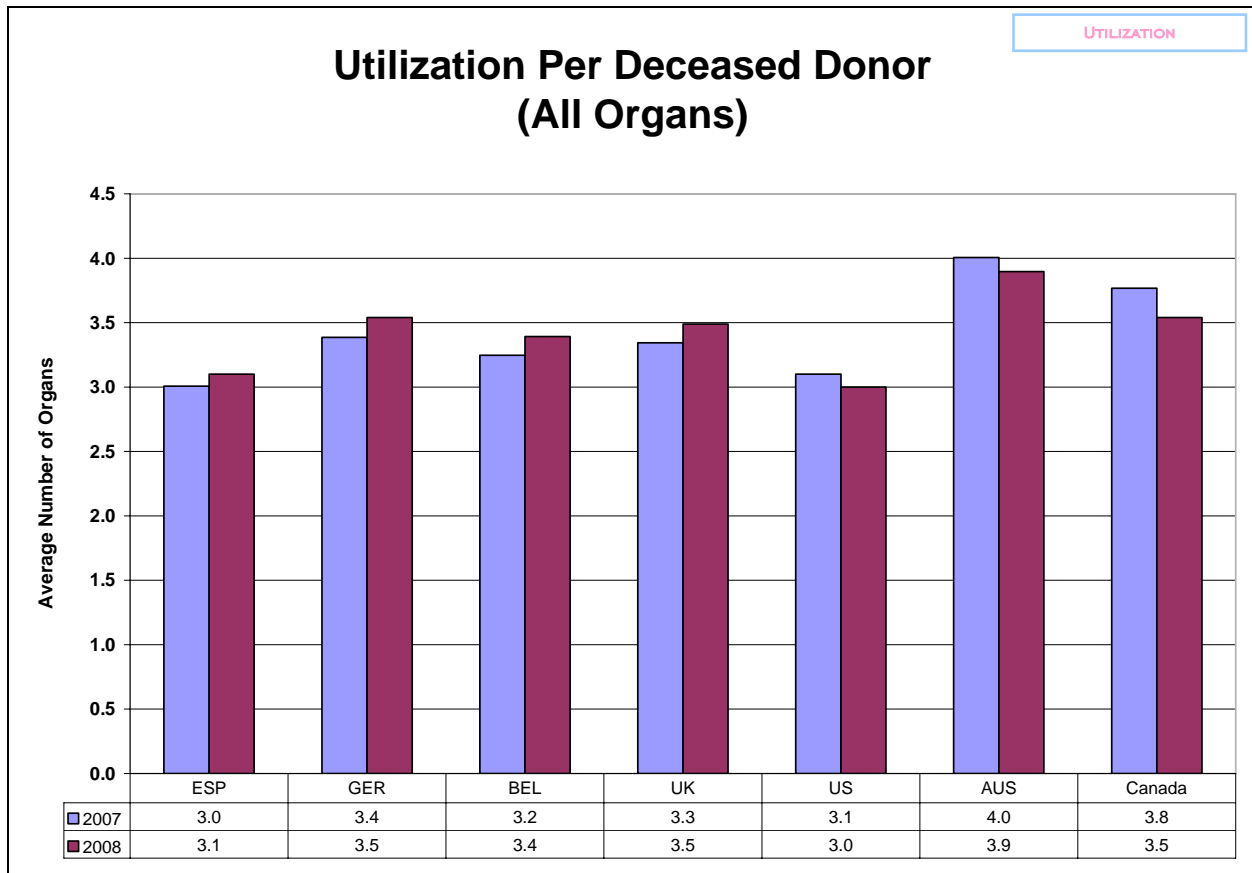
8.0 Utilization

Definition

8.1 All organs utilization per deceased donor

The average number of organs transplanted, per deceased donor

Figure 20. Utilization Per Deceased Donor – All Organs



Observations:

- Canada has as high or slightly higher organ utilization rate than most other countries.

Factors potentially affecting this measure:

- Medical management of donors
- Utilization practices
- Use of DCD and Extended Criteria Donors (ECD)

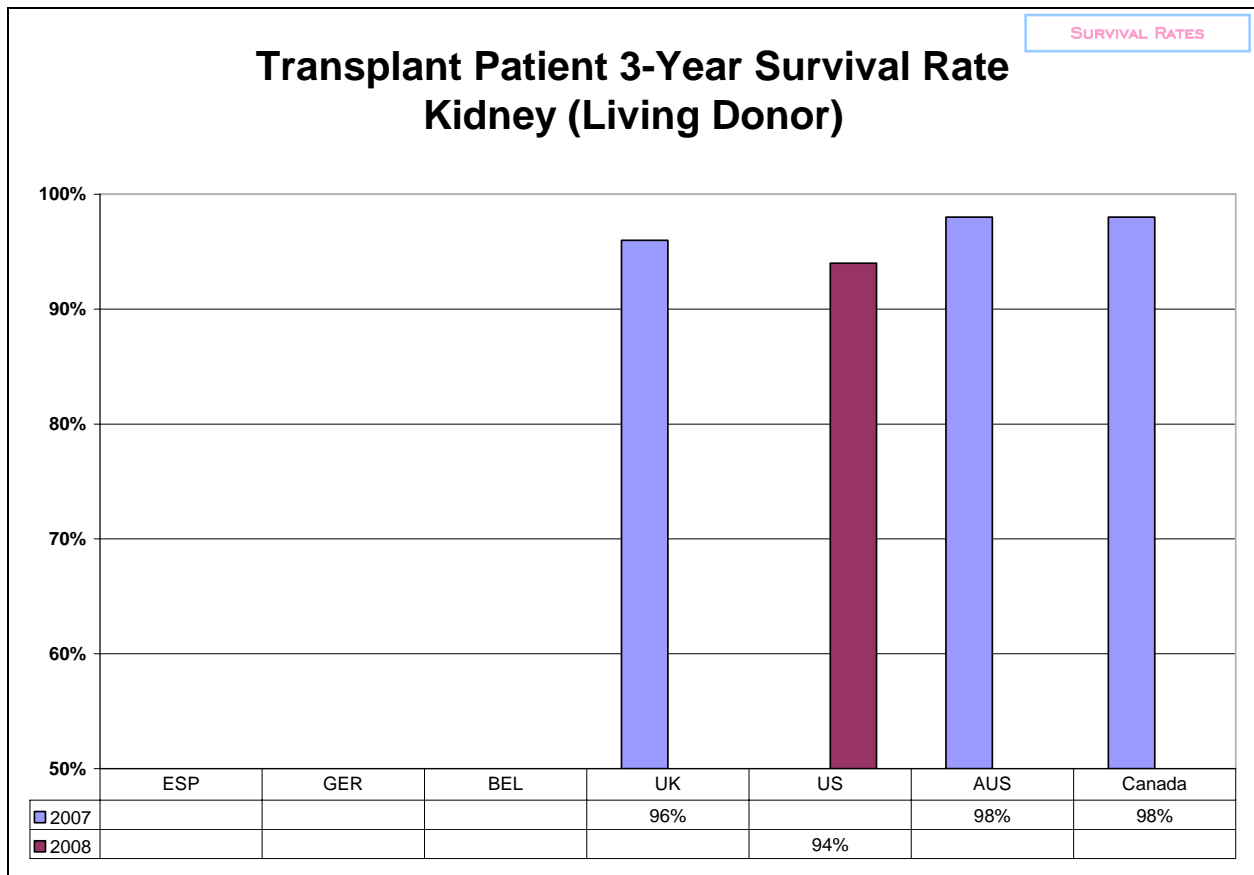
9.0 Survival Rates

Definition

9.1 Patient 3 year survival Kidney (living donor)

Patient survival rate (as a percentage of total transplanted patients), 3 years after receiving a kidney transplant from a living donor.

Figure 21. Transplant Patient 3-Year Survival Rate - Kidney (Living Donor)



Observations:

- Survival rates are very high in all study countries with available data.
- Data from Spain, Germany, and Belgium unavailable.

Factors potentially affecting this measure:

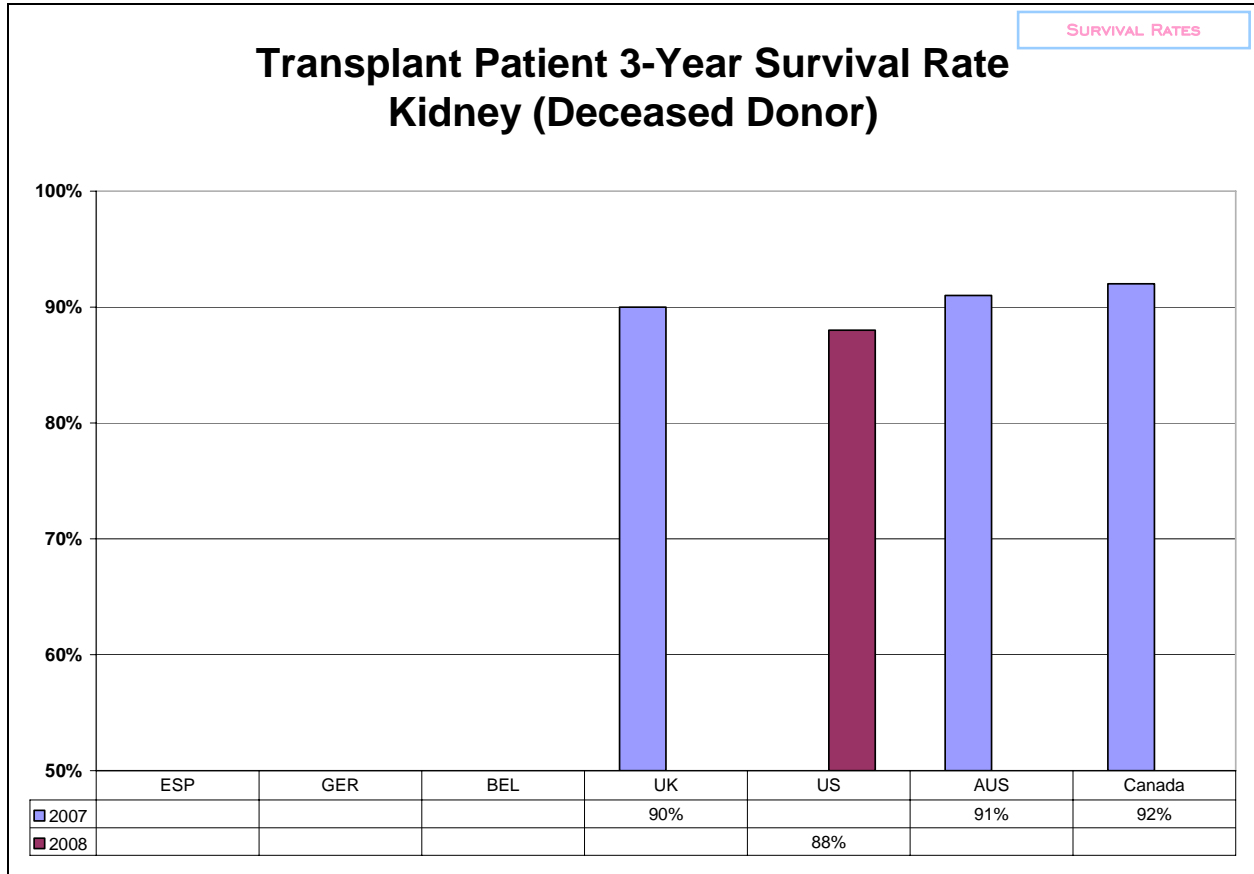
- The initial health of the patient
- The condition of the donated organ
- The quality of the match between organ and recipient
- Recipient compliance
- Follow-up care

Definition

9.2 Patient 3 year survival Kidney (deceased donor)

Patient survival rate (as a percentage of total transplanted patients), 3 years after receiving a kidney transplant from a deceased donor.

Figure 22. Transplant Patient 3-Year Survival Rate – Kidney (Deceased Donor)



Observations:

- Survival rates are very high in all study countries with available data, though lower than survival rates with living donors.
- Data from Spain, Germany, and Belgium unavailable.

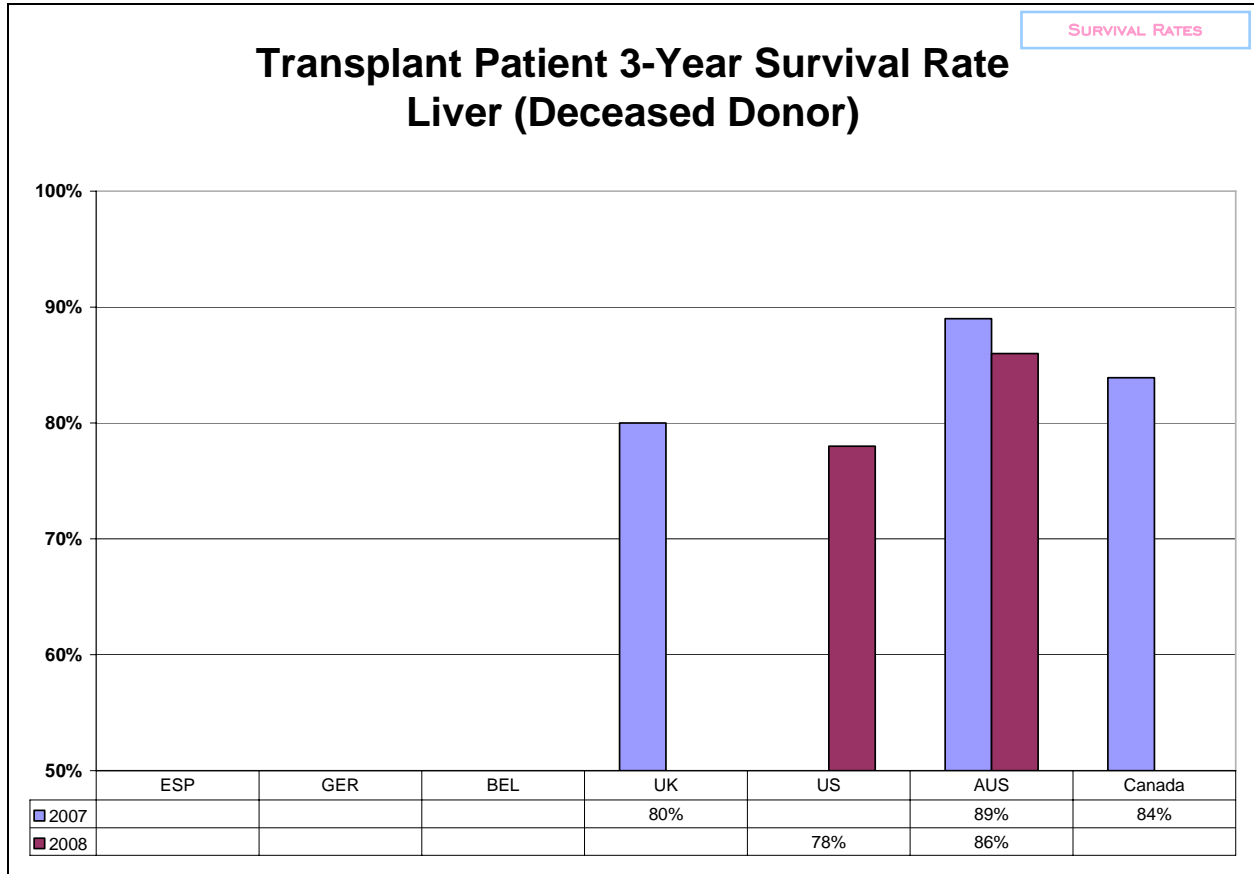
Factors potentially affecting this measure:

- The initial health of the patient
- The condition of the donated organ
- The quality of the match between organ and recipient
- Recipient compliance
- Follow-up care

Definition

<p>9.3 Patient 3 year survival Liver (deceased donor)</p>	<p>Patient survival rate (as a percentage of total transplanted patients), 3 years after receiving a liver transplant from a deceased donor.</p>
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Figure 23. Transplant Patient 3-Year Survival Rate – Liver (Deceased Donor)



Observations:

- Survival rates vary by country.
- Data from Spain, Germany, and Belgium unavailable.

Factors potentially affecting this measure:

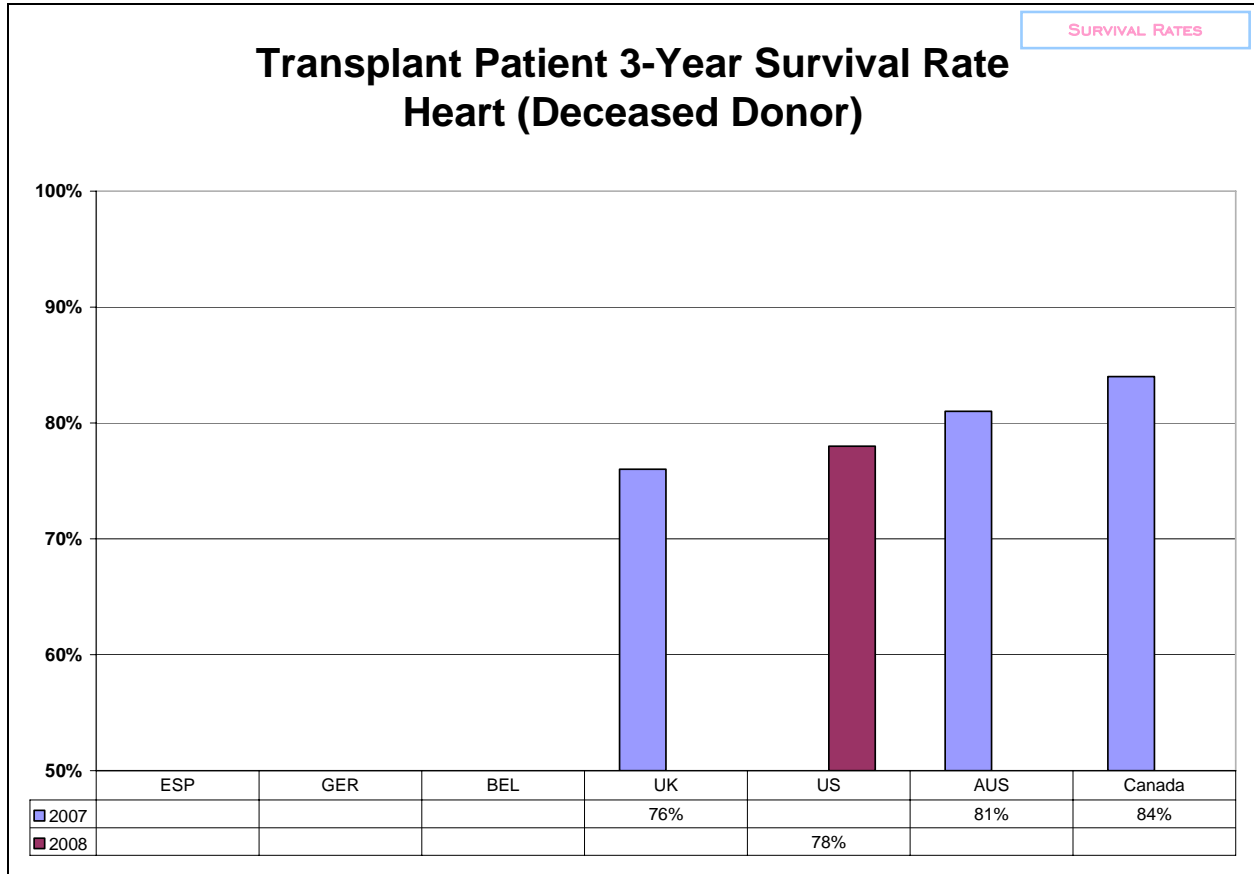
- The initial health of the patient
- The condition of the donated organ
- The quality of the match between organ and recipient
- Recipient compliance
- Follow-up care

Definition

9.4 Patient 3 year survival Heart (deceased donor)

Patient survival rate (as a percentage of total transplanted patients), 3 years after receiving a heart transplant from a deceased donor.

Figure 24. Transplant Patient 3-Year Survival Rate – Heart (Deceased Donor)



Observations:

- Survival rates vary by country, with Canada having the highest rate.
- Data from Spain, Germany, and Belgium unavailable.

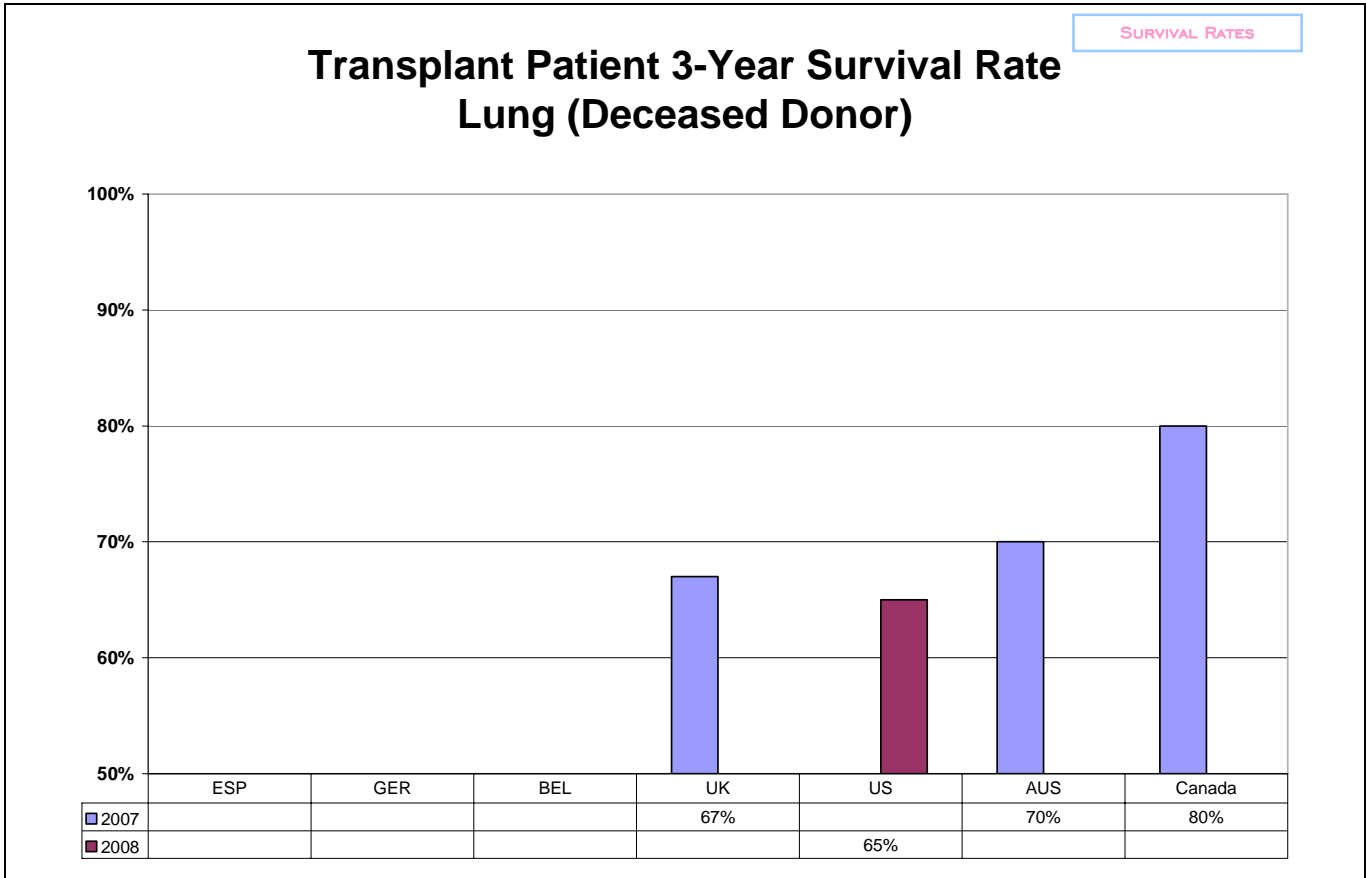
Factors potentially affecting this measure:

- The initial health of the patient
- The condition of the donated organ
- The quality of the match between organ and recipient
- Recipient compliance
- Follow-up care

Definition

<p>9.5 Patient 3 year survival Lung (deceased donor)</p>	<p>Patient survival rate (as a percentage of total transplanted patients), 3 years after receiving a lung transplant from a deceased donor.</p>
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Figure 25. Transplant Patient 3-Year Survival Rate – Lung (Deceased Donor)



Observations:

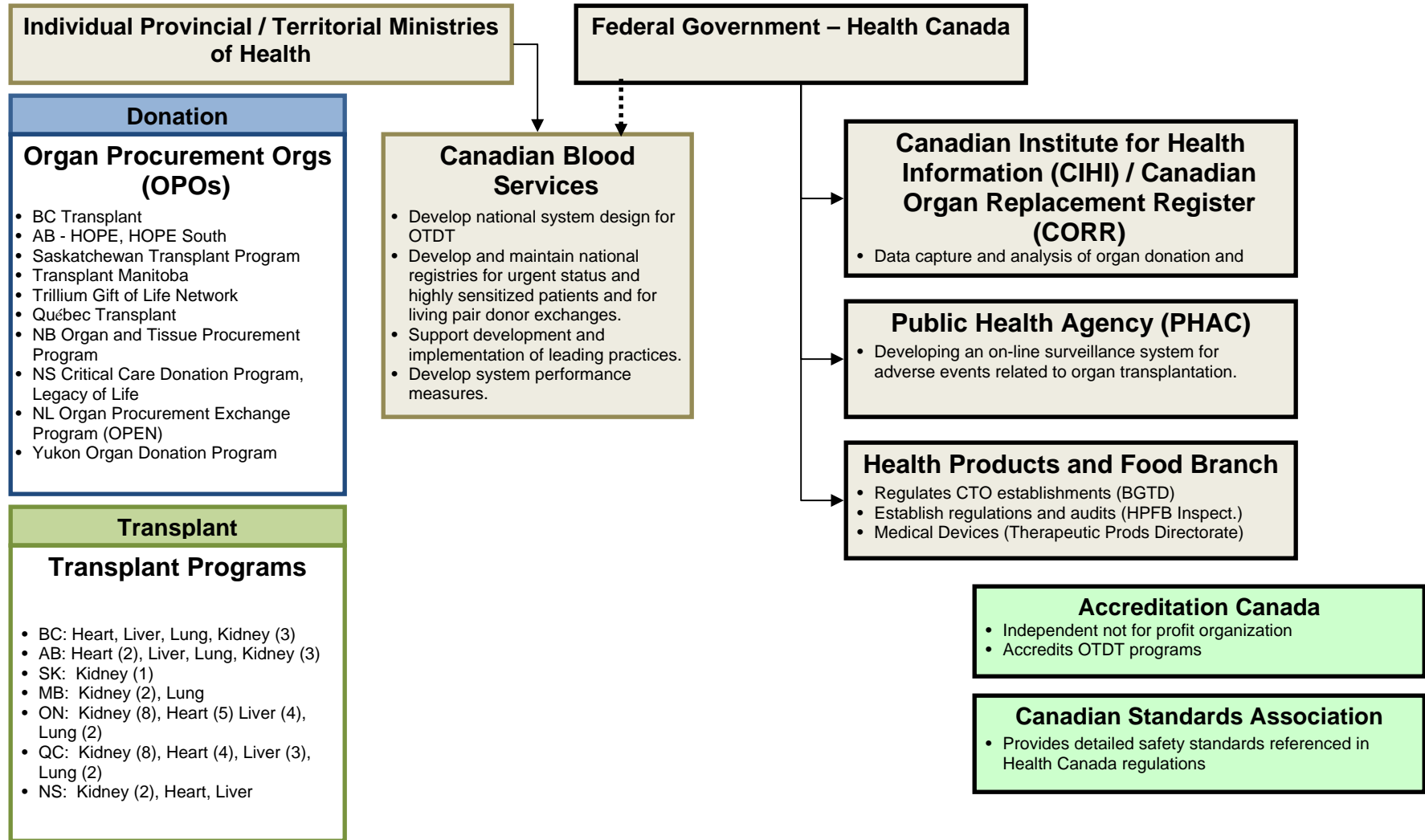
- Survival rates vary by country, with Canada having the highest rate.
- Data from Spain, Germany, and Belgium unavailable.

Factors potentially affecting this measure:

- The initial health of the patient
- The condition of the donated organ
- The quality of the match between organ and recipient
- Recipient compliance
- Follow-up care

Appendix 1:
Organization of OTD Systems in Study Countries

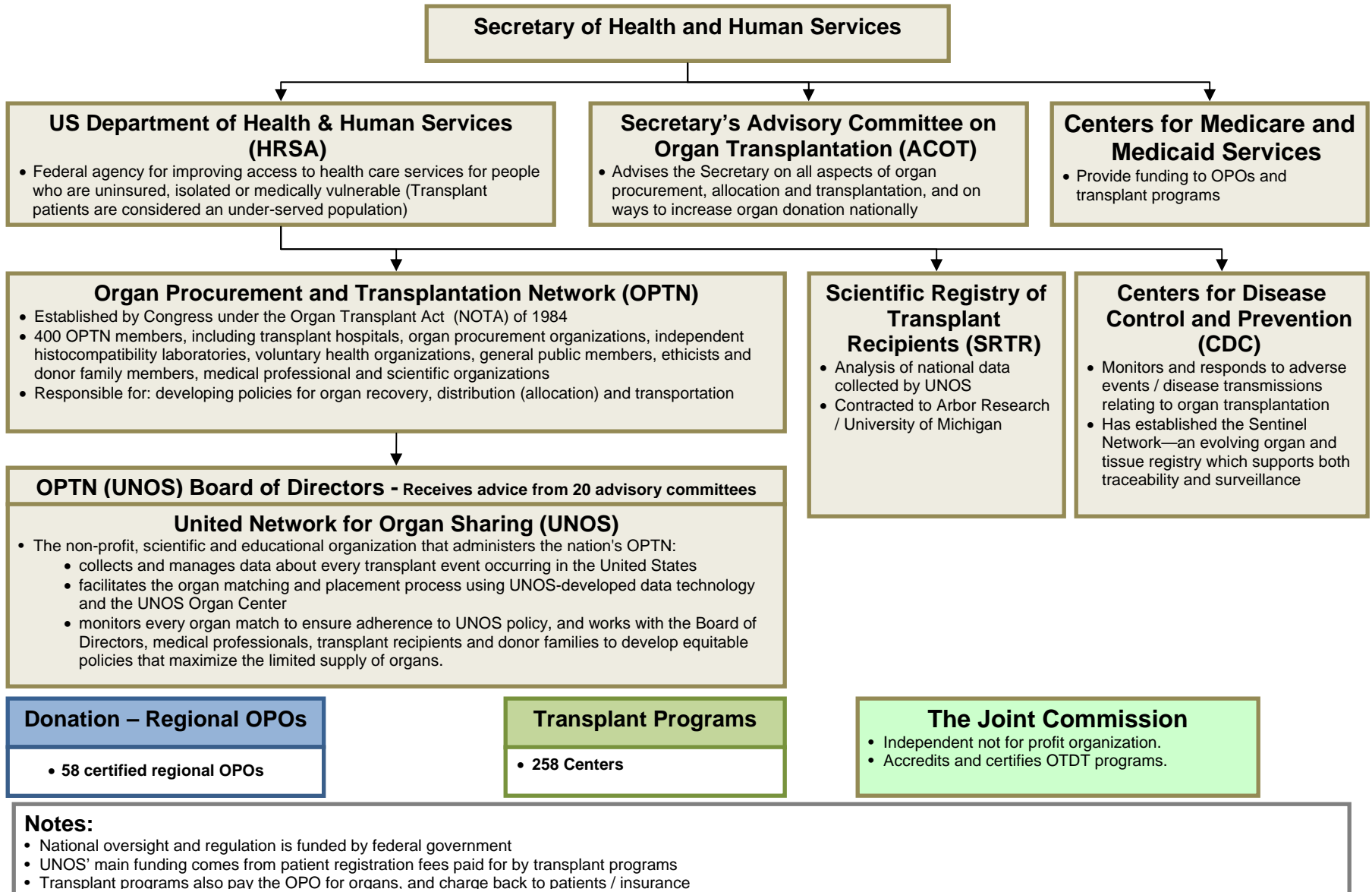
Canada



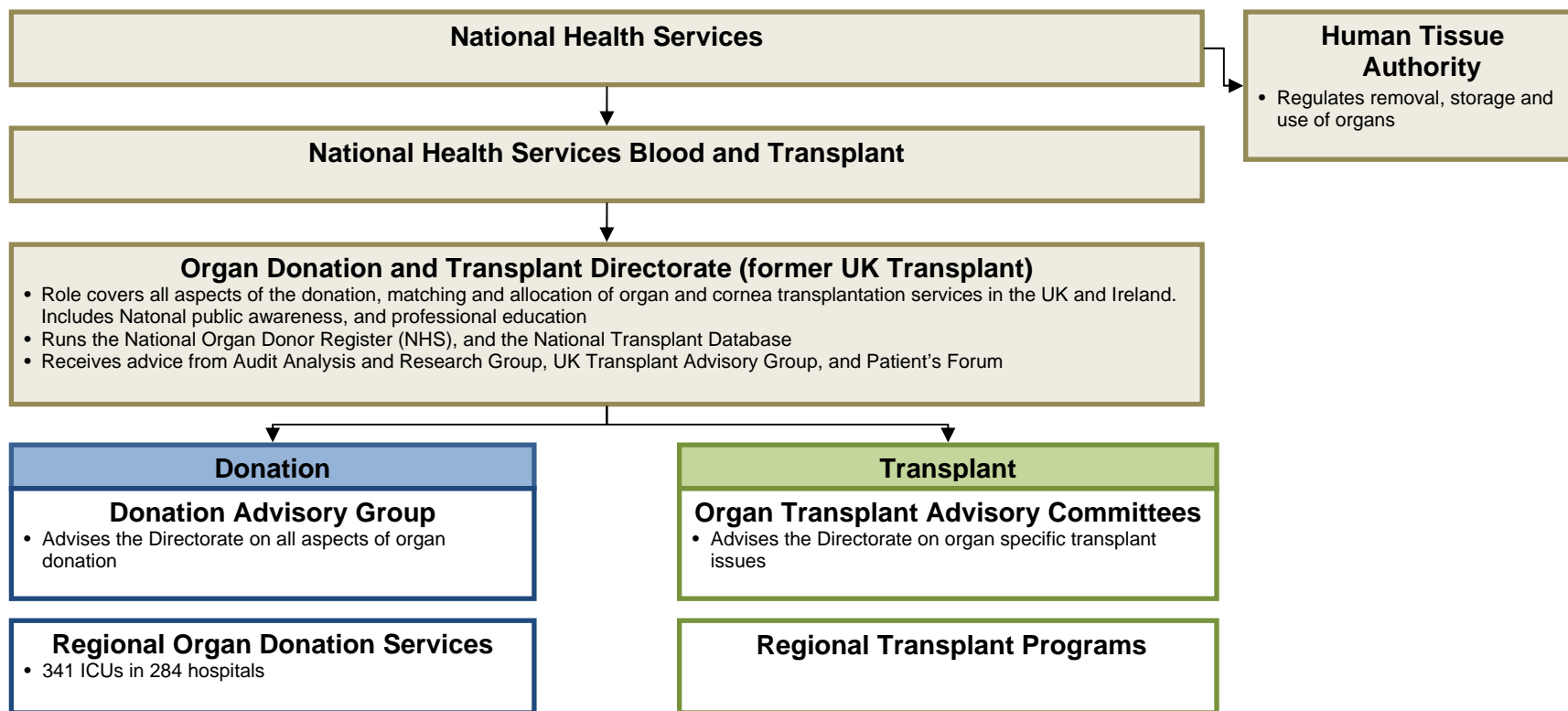
Notes:

- OPOs and transplant programs are funded through individual Provinces and Territories, either directly or through hospital budgets
- Some national direction exists, mainly in the setting of safety standards, through Health Canada and the Canadian Standards Association
- There is limited national coordination in organ allocation - provinces maintain their own patient wait lists and intent/consent to donate registries. There is some sharing through the urgent patient status listing, as well as the Canadian Blood Services Living Donor Paired Exchange Registry.
- The Federal government provides funding for OTDT through a Health Canada contribution agreement.

United States



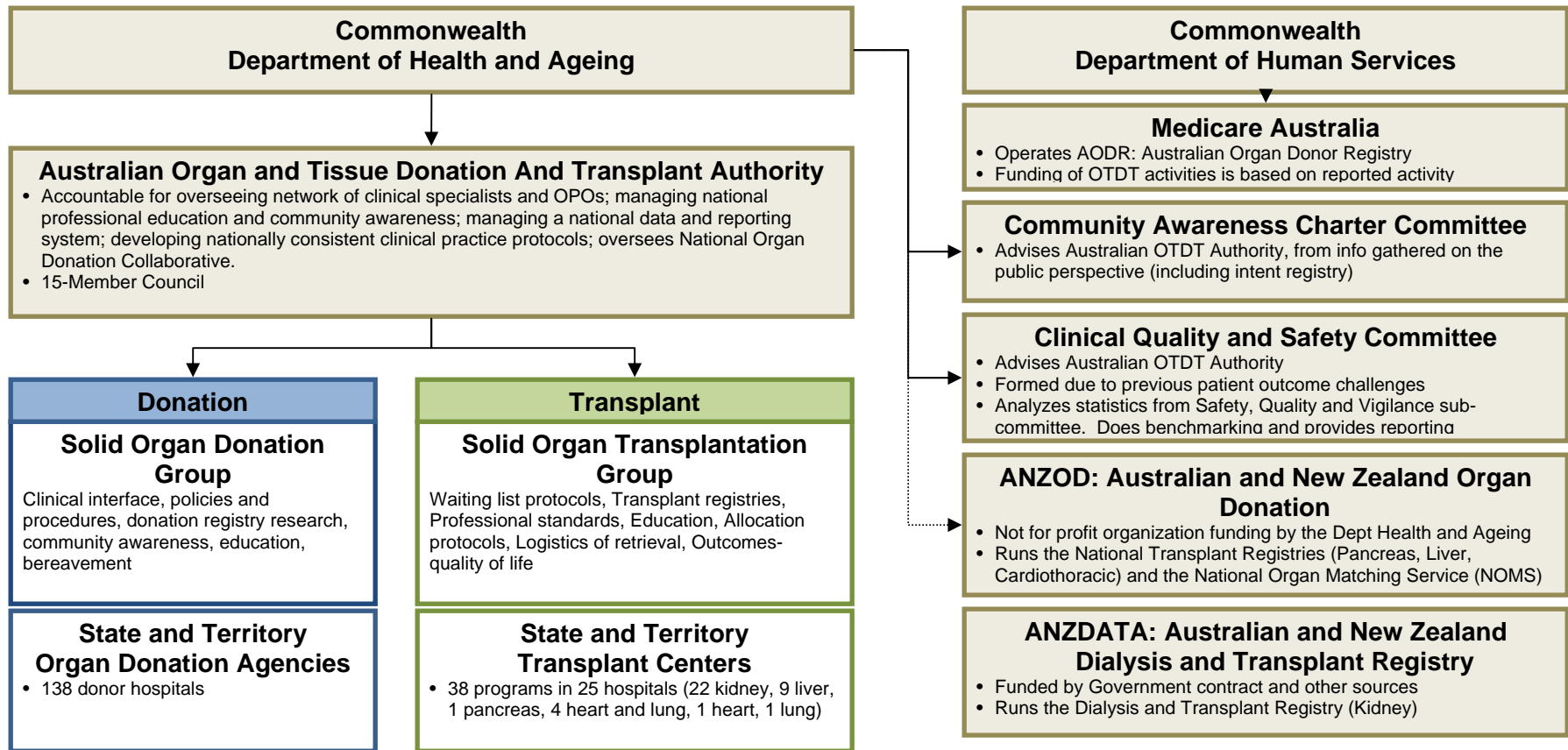
United Kingdom (In Transition)



Notes:

- Regional programs are currently both privately and publicly funded.
- In 2006, the Organ Donation Taskforce was established at the request of the Government to provide recommendations to improve organ donation and transplant rates. The Taskforce reported in January of 2008.
- The Government announced it would back the recommendations of the Organ Donation Taskforce, which targeted a 50 per cent increase in organ donation in the UK within five years - resulting in an additional 1,200 transplants per year.
- The report proposed a shift from existing arrangements, recommending the recruitment of ~100 extra donor transplant coordinators to work with hospitals and guide and support bereaved families through the donation process. These extra front line staff and existing coordinators would be employed centrally by NHS Blood and Transplant rather than individual Trusts. In addition, a new strengthened network of dedicated organ retrieval teams would also be established and be available 24 hours a day, working closely with the critical care teams in hospital to retrieve safe high quality organs for transplant across the UK.
- The Government confirmed £11 million of funding in 2009 with more money to follow.

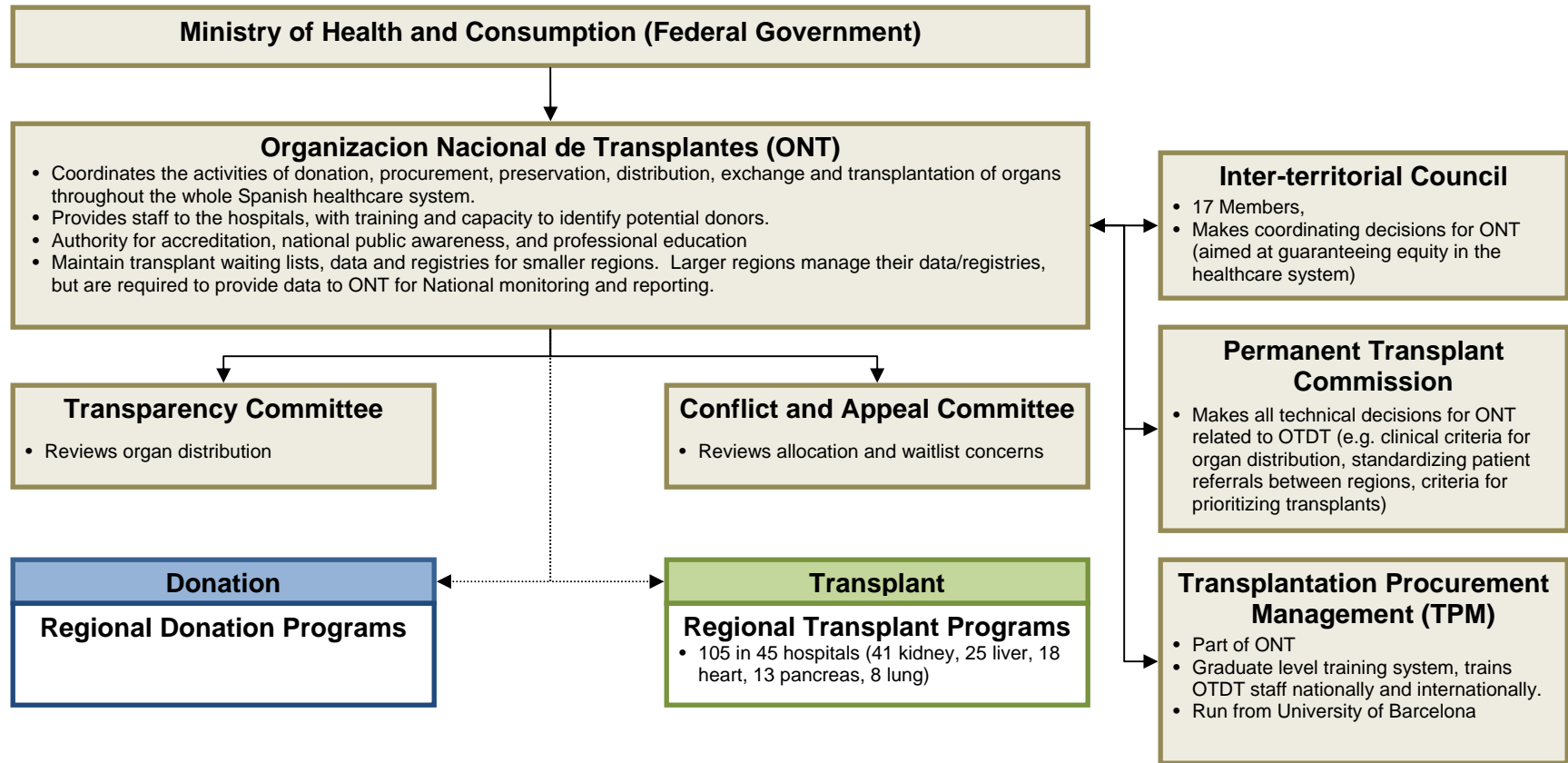
Australia (In Transition)



Notes:

- A reform package was announced in July 2008, with \$151.1 million (Australian) to establish a nationally consistent, coordinated system for organ and tissue donation including:
- \$67 million over 4 years to fund dedicated organ donation specialist doctors and other staff in public and private hospitals
- \$17 million over 4 years for hospitals for additional staffing, bed and infrastructure costs associated with organ donation
- \$13.4 million over 4 years to continue national public awareness and education
- \$1.9 million over 4 years for support for families of deceased donors
- Other significant measures including enhanced professional education programs, consistent clinical protocols, clinical trigger checklist for appropriately identifying potential donors, and data collection
- \$46 million to establish a coordinated, consistent national approach, of which \$24.4 million over 4 years will fund the Authority's operations and infrastructure
- The National Authority was created January 2009, established through a government act

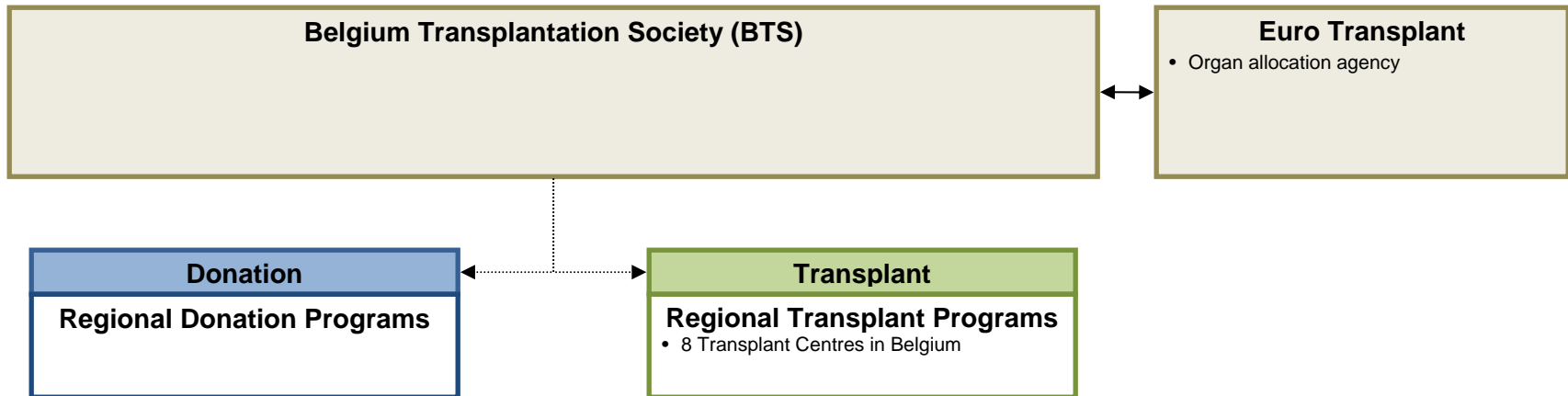
Spain



Notes:

- After the creation of the Organizacion Nacional de Transplantes in 1989, Spain went from 14 donors per million population (dpmp) to 35.1 donors pmp in 2005, changing its ranking from an intermediate-low position in Europe, to having the highest deceased donor rate world wide.
- Key success factors include ability to implement best practices consistently throughout its system, and having an infrastructure and model that actively support organ donation: presumed consent, hospital champions, dedicated, trained and funded staff, system capacity and authority.
- Donation and transplant programs are regionally managed and funded, but ONT funds and coordinates a national network of clinicians and hospital staff dedicated to organ and tissue donation.

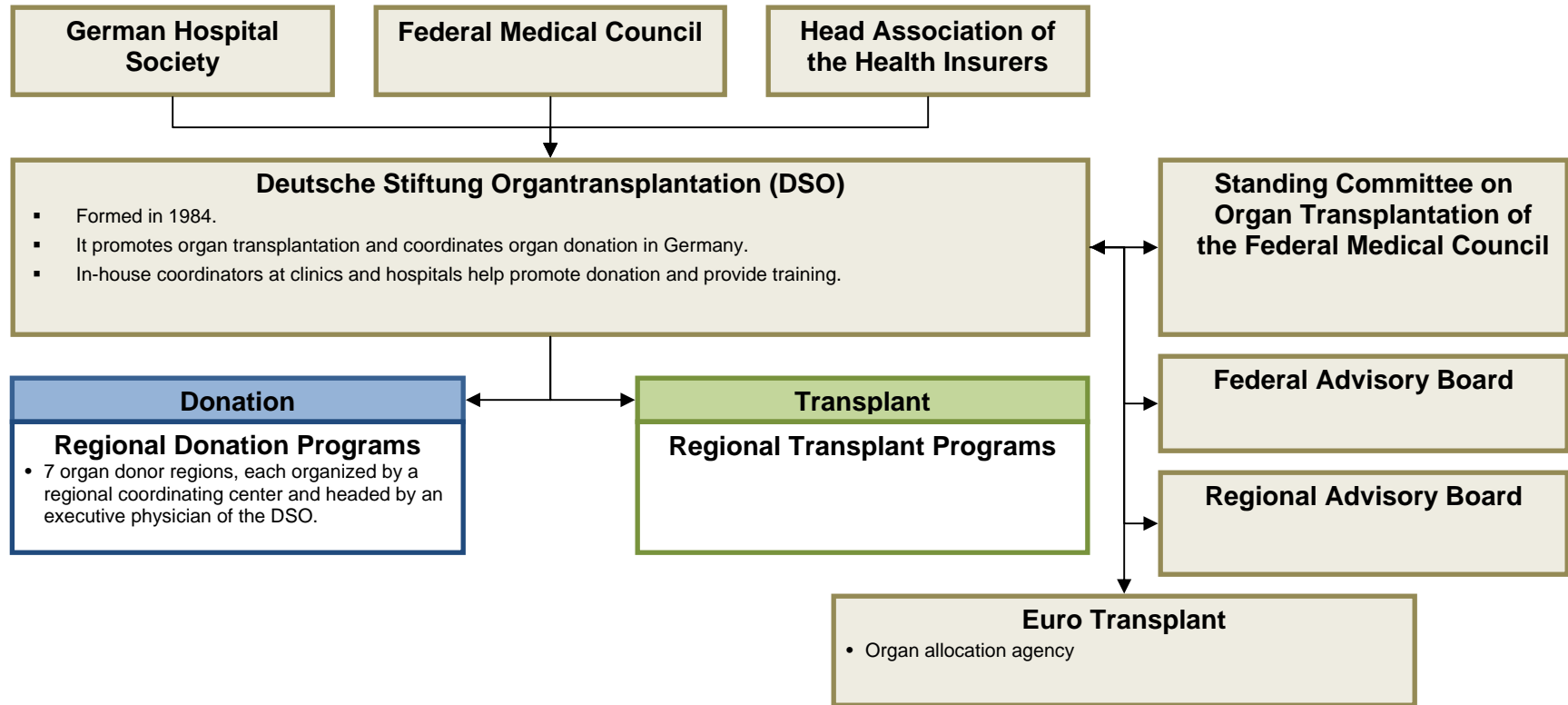
Belgium (Draft)



Notes:

- Information collection on Belgium is in progress

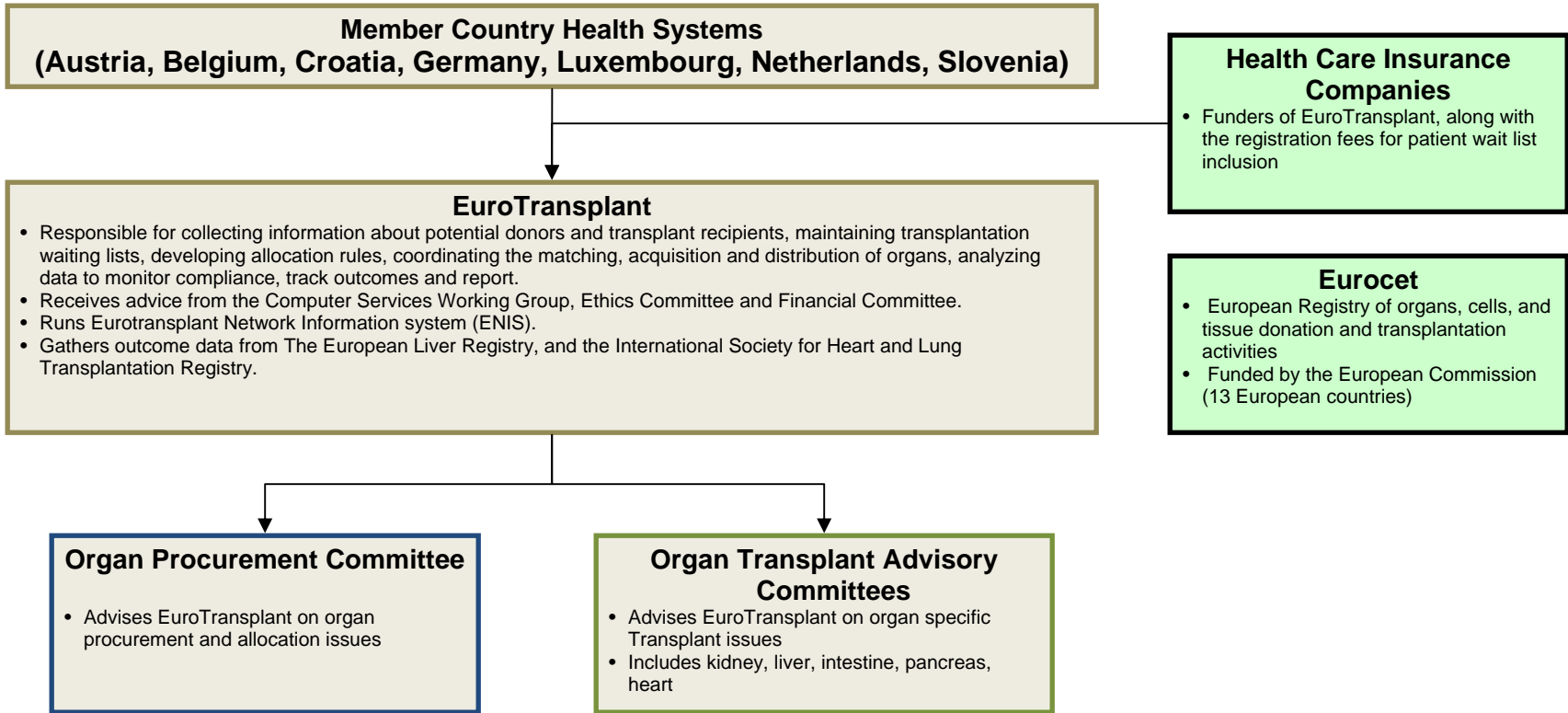
Germany (Draft)



Notes:

- Information collection on Germany in progress

EuroTransplant (Allocation Only)



Notes:

- EuroTransplant is an organ allocation and sharing group across participating countries in Europe
- EuroTransplant is enabled through a Framework of Collaboration and detailed Articles of Association
- They do not fund or manage the member countries organ donation and transplant programs