Deceased Donation - Why Data?

Damon C. Scales MD PhD
Deceased Donation – Why Data?

“Without data you’re just another person with an opinion.”
– W. Edwards Deming
Deceased Donation – Why Data?

- Describe and explain variation
- Understand trends
- Performance measurement and comparisons
- Evaluate policy decisions
- Address supply-demand mismatch
Deceased Donation – Why Data?

Canadian organ donation
Supply vs. demand 2005 - 2014

- Donors
- Persons transplanted
- Persons on waitlist

Canadian Blood Services
it's in you to give

sources & limitations - refer to data notes page
243,643 Deaths
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>243,643 Deaths</td>
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<tr>
<td>117,156 Hospital Deaths</td>
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Donation in Perspective – Canada 2012

- 243,643 Deaths
- 117,156 Hospital Deaths
- 3,711 Potential Donors
Donation in Perspective – Canada 2012

- 243,643 Deaths
- 117,156 Hospital Deaths
- 3,711 Potential Donors
- 542 Actual Donors
Organ donation rate (ODR)
Measuring Organ Donation Potential

Organ donation rate (ODR)

Conversion rate  Donors

Potential donors
# Measuring Organ Donation Potential

## Organ donation rate (ODR)

<table>
<thead>
<tr>
<th>Conversion rate</th>
<th>Donors</th>
<th>Standard definitions</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Potential donors</td>
<td></td>
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*Slide courtesy of Karen Hornby*
Measuring Organ Donation Potential

Organ donation rate (ODR)

Conversion rate

Donors

Potential donors

Not available at the International level

Slide courtesy of Karen Hornby
Measuring Organ Donation Potential

Organ donation rate (ODR)

DPMP

Donors

Million population

Readily available for international comparisons

Slide courtesy of Karen Hornby
Measuring Organ Donation Potential

Organ donation rate (ODR)

Donors
Million population

Higher DPMP

Readily available
for international comparisons

Slide courtesy of Karen Hornby
Donors
Million population

Organ donation rate (ODR)

Higher DPMP
Better program?

Readily available for international comparisons

DPMP

Slide courtesy of Karen Hornby
Measuring Organ Donation Potential

Organ donation rate (ODR)

DPMP

Higher DPMP

Larger pool of potential donors?

Donors

Million population

Readily available for international comparisons

Slide courtesy of Karen Hornby
Measuring Organ Donation Potential

Organ donation rate (ODR)

Donors
Million population
Factors affecting donation potential
Readily available for international comparisons

DPMP
Higher DPMP
Larger pool of potential donors?

Slide courtesy of Karen Hornby
Organ donation rate (ODR)

- DPMP
- Higher DPMP
- Larger pool of potential donors?

Factors affecting donation potential:

- **Demographics**
  - age, ethnicity, religion

- **Mortality patterns**
  - CVA, TBI etc.

- **Infrastructure**
  - ICUs, transplant & OD programs

- **Public policy**
  - speed limits, helmet laws etc.

Slide courtesy of Karen Hornby
Organ donation rates across countries for different denominators, 2002

Slide courtesy of Karen Hornby
Organ donation rates across countries for different denominators, 2002
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Organ donation rates across countries for different denominators, 2002

- Donor per million population
- Donor per thousand deaths
- Donors per thousand deaths < 65 yrs

Countries

Slide courtesy of Karen Hornby
Organ donation rates across countries for different denominators, 2002

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Organ donation rates across countries for different denominators, 2002

- Donor per million population
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- Donors per thousand eligible deaths
- Donors per thousand eligible deaths < 65 yrs

Countries

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Organ donation rates across countries for different denominators, 2002

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Donor per million population

Donor per thousand deaths

Donors per thousand deaths < 65 yrs

Donors per thousand eligible deaths

Donors per thousand eligible deaths < 65 yrs

Donors per thousand CVA & TBI deaths

Donors per thousand CVA & TBI deaths < 65 yrs

Countries

Countries

Countries

Countries

Countries

Countries

Slide courtesy of Karen Hornby
Organ donation rates across countries for different denominators, 2002

Slide courtesy of Karen Hornby
Organ donation rates relative to Spain (100%) based on different denominators, 2002

Denominators:

- **Australia**
- **Austria**
- **Canada**
- **Finland**
- **France**
- **Germany**
- **Netherlands**
- **United Kingdom**
- **United States**

### Denominators:

- **Million population**
- **1,000 deaths**
- **1,000 eligible deaths**
- **1,000 eligible deaths < 65 yrs**
- **1,000 CVA & TBI deaths**
- **1,000 CVA & TBI deaths < 65 yrs**

*Slide courtesy of Karen Hornby*
Canadian Challenges – Deceased Donation Data

- Multiple, incomplete data sources - CORR, OPO, CTR, Tx programs
- Different data definitions and datasets
- Different triggers (potential donors)
- Lack of data prior to consent
- Lack of timely reporting
- Difficulty comparing regions/provinces
- Lack of performance data in relation to implementation of leading practices
Australia:
National summary of potential donors and actual donors, transplant recipients
National Audit of Potential Donors

All audited patient deaths in UK Intensive Care Units (ICUs) and emergency departments, excluding wards and patients over 80 years of age
**Breakdown of audited deaths in ICU's, 1 April 2014 – 31 March 2015**

**Source:** Transplant activity in the UK, 2014-2015, NHS Blood and Transplant

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**Figure 13.1 Donation after brain death**

<table>
<thead>
<tr>
<th>Audited Deaths</th>
<th>36,145</th>
</tr>
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<tbody>
<tr>
<td>Was the patient ever on mechanical ventilation?</td>
<td>No 16,925, Yes 19,220</td>
</tr>
<tr>
<td>Were all criteria for neurological testing met?</td>
<td>No 17,487, Yes 1,733</td>
</tr>
<tr>
<td>Were neurological tests to confirm death performed?</td>
<td>No 289, Yes 1,444</td>
</tr>
<tr>
<td>Was death confirmed using neurological criteria?</td>
<td>No 22, Yes 1,422</td>
</tr>
<tr>
<td>Were there any absolute medical contraindications to solid organ donation?</td>
<td>No 1,372, Yes 50</td>
</tr>
<tr>
<td>Were the family formally approached for consent/authorisation for solid organ donation?</td>
<td>No 89, Yes 1,283</td>
</tr>
<tr>
<td>Was consent/authorisation for solid organ donation given by the family?</td>
<td>No 425, Yes 858</td>
</tr>
<tr>
<td>Did solid organ donation occur?</td>
<td>No 79, Yes 779</td>
</tr>
<tr>
<td>What type of donation happened?</td>
<td>DBD 766, DCD 13</td>
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**Figure 13.2 Donation after circulatory death**

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<td>No 17,798, Yes 1,422</td>
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<tr>
<td>Was imminent death anticipated?</td>
<td>No 11,073, Yes 6,725</td>
</tr>
<tr>
<td>Was treatment withdrawn?</td>
<td>No 289, Yes 1,444</td>
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1 Patients for whom tests were not performed due to; cardiac arrest despite resuscitation occurred, brainstem reflexes returned, or neonates - less than 2 months post term are excluded from the calculation of the neurological death testing rate.
Figure 13.1 Donation after brain death

Audited Deaths
36,145

Was the patient ever on mechanical ventilation?
No
16,925
Yes
19,220

Were all criteria for neurological testing met?
No
17,487
Yes
1,733

Were neurological tests to confirm death performed?¹
No
289
Yes
1,444

Was death confirmed using neurological criteria?
No
22
Yes
1,422

Did solid organ donation occur?

Figure 13.2 Donation after circulatory death

Audited Deaths
36,145

Was the patient ever on mechanical ventilation?
No
16,925
Yes
19,220

Was death confirmed using neurological criteria?
No
17,798
Yes
1,422

Was imminent death anticipated?
No
11,073
Yes
6,725

Was treatment withdrawn?
No
697
Yes
6,028

Did solid organ donation occur?

¹ Patients for whom tests were not performed due to; cardiac arrest despite resuscitation occurred, brainstem reflexes returned, or neonates - less than 2 months post term are excluded from the calculation of the neurological death testing rate.
UK Potential deceased organ donor population, 1 April 2014 – 31 March 2015

- Transplants: 3,322
- Organs transplanted: 3,736

Consent/authorisation rates by Organ Donation Services Team, 1 April 2014 – 31 March 2015


DBD

Consent/authorisation rates
40 - <45%
45 - <50%
50 - <55%
55 - <60%
60 - <65%
65 - <70%
70 - <75%
>=75%

DCD

Consent/authorisation rates
40 - <45%
45 - <50%
50 - <55%
55 - <60%
60 - <65%
65 - <70%
70 - <75%
>=75%
Figure 13.3: Stages at which potential organ donors lost the opportunity to become actual donors, 1 April 2014 – 31 March 2015

- Potential donors
- Neurological death tests performed (DBD only)
- Neurological death confirmed (DBD only)
- Contraindications
- Family approach
- Consent/authorisation
- Donation

DBD, 779 donated (45% of potential donors)
DCD, 494 donated (8% of potential donors, 12% of those not contraindicated)

1 Potential DBD donor - A patient who meets all four criteria for neurological death testing excluding those for which cardiac arrest occurred despite resuscitation, brain stem reflexes returned, and neonates less than 2 months post term
Potential DCD donor - A patient who had treatment withdrawn and death was anticipated within four hours

Deceased Organ Donor Potential in Canada

Report

December 2014
All inpatient death cases* 117,156 patients

Younger than age 70

36,824 patients

Inclusion criteria (brain deaths and cardiocirculatory deaths)

7,774 patients

With mechanical ventilation

4,790 possible donors

Conversion rate

14% \(\frac{520}{3,711}\)

Updated exclusion criteria

3,711 potential donors

520 actual donors

520 potential donors per million

107

Strict exclusion criteria

17% \(\frac{520}{3,088}\)

3,088 potential donors

520 actual donors

89
DCD as percentage of total deceased donors
2008 - 2012
DECEASED DONATION DATA WORKING GROUP

- Organized by CBS
- Tasked with making recommendations for a Minimum Data Set using standard definitions
- Coordinates activities with other transplant data working groups
Canadian Data Capabilities

Statistics

Yearly Statistics
Statistics 2012 (*French version only)
Statistics 2011 (*French version only)

Most frequently requested data
Number of people waiting for an organ transplant and number of recipients of Quebec by region, in 2012 (*French version only)
Number of people waiting by region, by organ type or combination, in 2012 (*French version only)
Number of references for organ donation and treatment of the reference by region, in 2012 (*French version only)
Les donneurs potentiels d’organes dans les hôpitaux - Étude du Collège des médecins du Québec (*French version only)

Living donation
Living donors per million (LDM), Quebec, Canada, in 2011 and in 2012 (*French version only)

Trillium Gift of Life Network

Canadian Blood Services
it's in you to give
POPULATION - 34,754,312
DEATHS – 243,643
HOSPITAL DEATHS – 117,156
VENTILATED DEATHS - 4,790*
BRAIN-INJURED VENTILATED DEATHS
POTENTIAL DONORS (PD) – 3,711
REFERRED PD – 3,000
ELIGIBLE DONORS (ED) - 728
APPROACHED ED
CONSENTED DONORS
ACTUAL DONORS
542

National, aggregate, data
CBS – D3WG Working copy

Individual data
data based on local standards
data based on national standards
DRAFT DATA FOR 2012
Identifying Potential Donors in Canada

**ON**: Ventilated and any of the following: Grave prognosis or GCS = 3 OR Injured brain or non-recoverable injury/illness OR Family-initiated discussion of donation or withdrawal of life-sustaining therapy (WLST) OR Therapy-limited, de-escalation of treatment, or WLST discussion planned

**QC**: Severe neuro insult + mechanical ventilation

**AB (EDM)** - ventilated with severe/devastating illness or injury, neuro consult ruling out recovery. Indicators include, but are not limited to: GCS 3 OR GCS 3 or + absent brain stem reflexes OR Plans for WLST OR Family initiated donation discussion

**BC** - GCS < 5, Injury to brain, Ventilated, EOL care

**SASK** - GCS ≤5 OR Injured brain OR Ventilated (no respiratory effort) OR EOL discussion of WLST

**MAN** - GCS ≤5 + Severe neuro insult/injury + Ventilator dependent + Grave prognosis/EOL discussion

**NS** - GCS < 5, Irreversible Brain Injury, Ventilated, End of life discussion

**AB (CAL)**: Patient who is brain dead
Deceased Donation – Why Data?

- Currently available Canadian data lack information to estimate potential donors
- Standardized definitions and clinical triggers are needed to facilitate meaningful comparisons
- More data needed to inform strategies to address donation-transplant gap
damon.scales@sunnybrook.ca
## Variation in Donor Definitions

<table>
<thead>
<tr>
<th>Country</th>
<th>Definition – “Donor”</th>
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<tbody>
<tr>
<td>Australia</td>
<td>retrieval operation commenced for purpose of transplantation</td>
</tr>
<tr>
<td>Austria</td>
<td>reported to ODO but no transplant realized + actual donors</td>
</tr>
<tr>
<td>Canada</td>
<td>donation criteria met, no transplant realized + actual donors</td>
</tr>
<tr>
<td>Finland</td>
<td>transferred to operating room, at least 1 solid organ retrieved</td>
</tr>
<tr>
<td>France</td>
<td>subjects from whom organs were taken (preleve)</td>
</tr>
<tr>
<td>Germany</td>
<td>reported to ODO but no transplant realized + actual donors</td>
</tr>
<tr>
<td>Netherlands</td>
<td>reported to ODO but no transplant realized + actual donors</td>
</tr>
<tr>
<td>Spain</td>
<td>transferred to operating room, at least 1 solid organ retrieved</td>
</tr>
<tr>
<td>U.K.</td>
<td>At least one solid organ retrieved with the intention to transplant</td>
</tr>
<tr>
<td>U.S.A.</td>
<td>At least one organ recovered for the purpose of transplantation</td>
</tr>
</tbody>
</table>