

National Registries and Transplant Outcomes: An Update from the Canadian Organ Replacement Register (CORR)

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Vice President, CORR Board of Directors
BC Kidney Days 2012
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Outline

- Introduction
- Purpose
- History
- Organization
- Data (scope, elements, sources, quality)
- Trends in kidney transplantation, 2001 to 2010
- Access to Kidney Transplantation Feasibility Study
- Future directions

Introduction

- Canadian Organ Replacement Register (CORR) is the national information system for end-stage renal disease and solid organ transplantation
- Day-to-day operations currently based at the Canadian Institute for Health Information (CIHI)
- Mission: To provide a national database on vital organ replacement therapy in Canada, with the goal of enhancing treatment, research, and patient care
- CORR Board of Directors is responsible for providing strategic advice to CIHI re: the register

Purpose

- Collect, process and analyze summary data on end-stage organ failure and organ transplants
- Provide a pan-Canadian view on end-stage organ failure statistics for comparative analyses
- Increase the availability of comparative material to facilitate development of treatment algorithms
- Provide statistics on long-term trends that can be used for program and system planning
- Provide a feedback mechanism to facilities, a quality assurance function for treatment, and a national standard for comparison

History

- 1972 – CORR began as a renal failure registry under the leadership of Dr. Arthur Shimizu
- 1973 – Registry transferred to Statistics Canada in collaboration with Kidney Foundation of Canada (KFOC)
- 1974 – First report produced
- Mid-1970's – Detailed reports of dialysis and kidney transplantation activity continued
- 1980 – Registry revived after few years of inactivity under new partnership between KFOC, Health and Welfare Canada, and Statistics Canada
- 1981 – Data collection re-initiated on all chronic renal failure patients on RRT (data previously collected were lost)

History (cont'd)

- 1985 – Advisory Committee on Institutional and Medical Services (ACIMS) recommended including data on extra-renal organ transplants in registry
- 1987 – Hospital Medical Records Institute (HMRI) awarded contract to operate new expanded registry
- 1988 – CORR started collecting data on extra-renal organ transplants
- 1990 – CORR incorporated
- 1994 – Merger of HMRI and sections of Health Canada and Statistics Canada to form the Canadian Institute for Health Information (CIHI)
- 1995 – CORR became fully integrated within CIHI

Organization

- CIHI houses and operates the CORR
 - President & CEO: John Wright
 - Director, Clinical Registries: Greg Webster
 - Manager, Clinical Registries: Claire Marie Fortin
 - Program Lead: Bob Williams
 - Analysts: Frank Ivis and Yingbo Na
- CORR Board functions in an advisory role to CIHI providing strategic advice on scientific and health policy matters as well as representing the interests of the renal and organ transplantation communities

CORR Board of Directors

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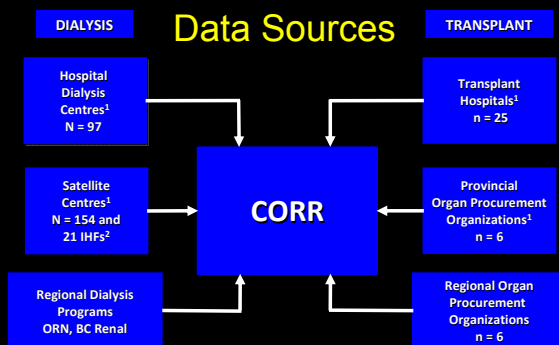
Scope

- CORR is patient-oriented
 - Followed until death or lost to follow-up
- Captures information on:
 - Treated patients
 - Specific treatments
 - Organ donors
 - Aggregate transplant waiting list statistics from OPOs
 - Transplant and dialysis facilities
- Access to Kidney Transplantation Project
 - Referral and wait-listing activity at patient-level

Data Elements

- Nearly 600 data elements in CORR database
 - Patient demographics (DOB, sex, race/ethnicity, postal code)
 - Diagnosis and co-morbidities
 - Treatment specific information (HD, PD, solid organ transplants)
 - Treatment changes (hospital transfers, modality changes, dialysis withdrawal)
 - Outcomes (organ failures, death)
 - Donor information (demographics, organs donated and transplanted)

Data Sources



¹ Provinces reporting include: Atlantic, QC, ON, MB, SK, AB, and BC
² IHF=Independent Health Facility

Data Quality

- CORR is a voluntary registry (i.e., data submission is not provincially or nationally mandated)
- In 2008, coverage of transplants in CORR is 98.5% vs. coverage of transplants in Discharge Abstracts Database
- In 2009, 99.7% of aggregate data on kidney transplant counts from OPOs reflected patient-level data in CORR
- From 2000 to 2009, CORR failed to capture only 77 of 9,344 deceased and living donors
- From 2000 to 2009, item non-response $\geq 10\%$ occurred in race, causes of graft failure or death, and various comorbid conditions (low to moderate SN, high SP)

A Validation Study of the Canadian Organ Replacement Register

Louise M. Moist,^{a*} Heather A. Richards,[†] Dana Miskulin,[‡] Charmaine E. Lok,[§] Karen Yeates,[¶] Amit X. Garg,^{‡*} Liliyanna Trpeski,[§] Ann Chapman,[¶] Joseph Amuah,^{**} and Brenda R. Hemmelgarn^{††}

- Medical records from 1,125 incident dialysis patients registered in CORR from 2005 to 2006
- Agreement > 97% for HCN, DOB, sex and 71% (47% to 89%) for primary renal disease
- Comorbid conditions generally under-reported with SN ranging from 0.47 (95% CI, 0.38 to 0.55) for PVD to 0.89 (95% CI, 0.80 to 0.92) for HTN
- Specificity for comorbid conditions > 93% except for HTN
- Adjusted hazard ratios for death similar whether calculated with data from CORR or medical record

Moist et al. *Clin J Am Soc Nephrol* 2011;6:813-8.

Trends in Kidney Transplantation 2001 to 2010

Outline

- Donor activity
- Waiting list statistics
- Transplant activity
- Transplant outcomes

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15

Donor Activity

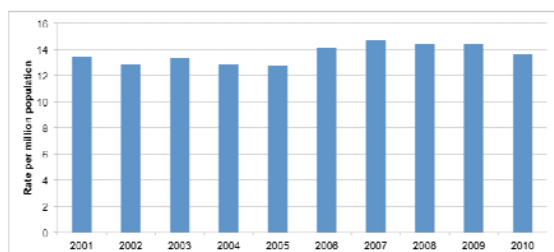
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Deceased Donor Rate (PMP) by Year



Source: Canadian Organ Replacement Register, 2012, CIHI

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17

Deceased Donor Rate (PMP) by Region

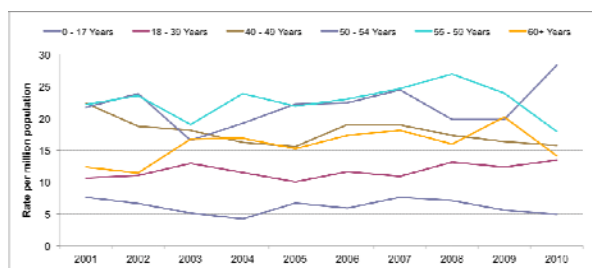
	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Deceased Donor	13.4	12.9	13.3	12.9	12.7	14.1	14.7	14.4	14.4	13.6
Province										
B.C.	9.1	7.3	9.4	7.4	5.9	8.4	8.8	12.3	7.2	10.8
Alta.	17	17.3	11.4	16.2	14.1	14.8	13.7	11.4	10.6	8.9
Sask.	15	12	17.1	9	15.1	10.1	14	12.8	12.6	12.5
Man.	7.8	9.5	10.3	6	5.1	11	12.6	11.6	11.5	15.4
Ont.	10.8	11.3	11.6	12.3	11.8	13.6	15.5	13.6	16.7	15.1
Que.	18.3	16.8	19	18	17.8	18.2	18.2	19.5	17.6	15.1
N.B.	22.7	14.7	16	13.3	21.3	13.3	17.4	10.7	14.7	10.6
N.S./P.E.I.	9.7	11.8	11.8	9.6	13.9	20.3	15	17.1	16	20.1
N.L.	28.7	27	19.3	9.7	13.6	23.5	9.9	15.8	13.8	9.8

Source: Canadian Organ Replacement Register, 2012, CIHI

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18

Deceased Donor Rate (PMP) By Age Group

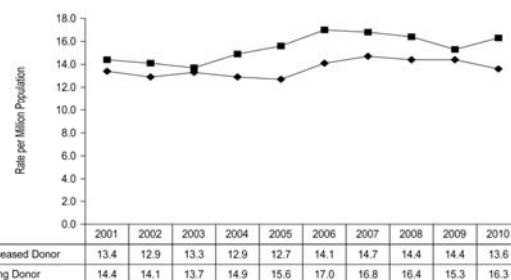


Source: Canadian Organ Replacement Register, 2012, CIHI

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19

Donor Rate (PMP) by Donor Source (Deceased vs. Living)



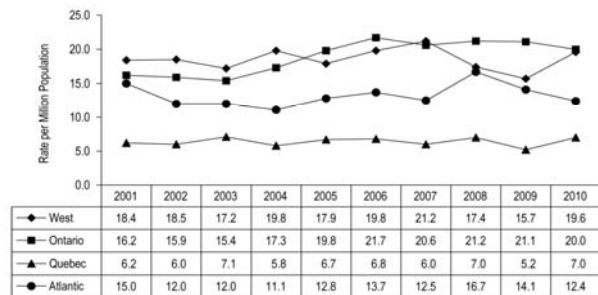
Source: Canadian Organ Replacement Register, 2012, CIHI

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20

Living Donor Rate (PMP) by Region

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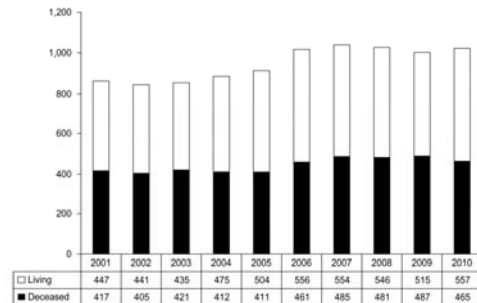
Source: Canadian Organ Replacement Register, 2012, CIHI

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21

Number of Canadian Organ Donors by Donor Source

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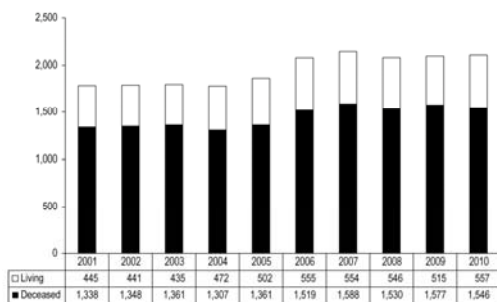
Source: Canadian Organ Replacement Register, 2012, CIHI

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22

Number of Solid Organ Transplants by Donor Source

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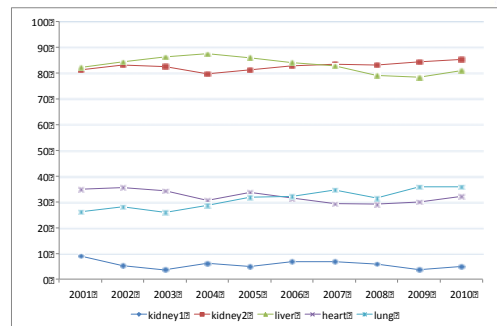
Source: Canadian Organ Replacement Register, 2012, CIHI

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23

Deceased Donor Organ Utilization

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Source: Canadian Organ Replacement Register, 2012, CIHI

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24

Donation After Cardiac Death by Province, 2006 to 2011

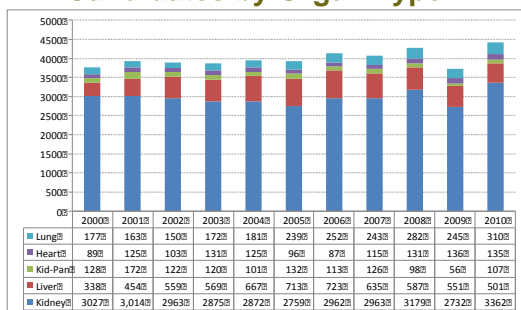
Province	2006	2007	2008	2009	2010	2011
British Columbia	0	0	2	0	1	7
Alberta	0	0	1	1	1	3
Ontario	4	17	30	37	35	42
Quebec	0	4	7	5	7	13
Nova Scotia	0	1	2	0	2	2
Total	4	22	42	43	46	67

Waiting List Statistics

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Number of Wait-Listed Transplant Candidates by Organ Type



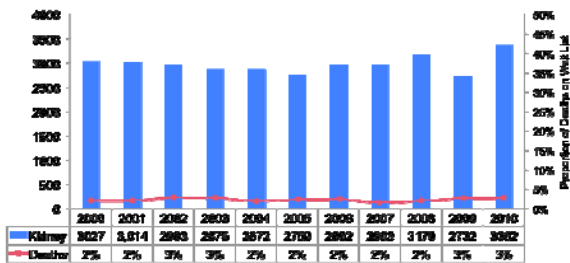
Source: Canadian Organ Replacement Register, 2012, CIHI

Duration of Dialysis Prior to First Kidney Transplant by Province, 2008 to 2010

	B.C.	Alta.	Sask.	Man.	Ont.	Que.	N.S.	Canada
Duration on Dialysis (Median Days), Deceased Donor	2,017	1,034	832	1,910	1,580	844	754	1,280
Duration on Dialysis (Median Days), Deceased Donor, No Pre-Emptive	2,017	1,054	843	1,915	1,602	992	833	1,340
Duration on Dialysis (Median Days), Living Donor	166	319	383	363	404	102	217	308
Duration on Dialysis (Median Days), Living Donor, No Pre-Emptive	647	473	384	393	660	400	465	532.5

Source: Canadian Organ Replacement Register, 2012, CIHI

Number of Wait-Listed Kidney Transplant Candidates and Death Rates on the Waiting List



Source: Canadian Organ Replacement Register, 2012, CIHI

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29

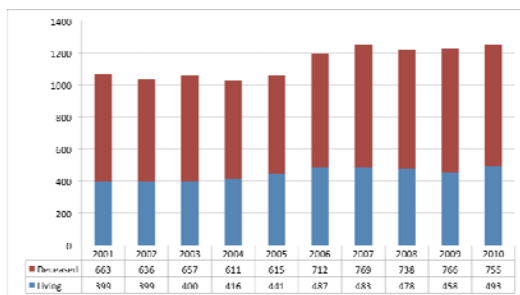
Kidney Transplant Activity

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Number of Kidney Transplants by Donor Type

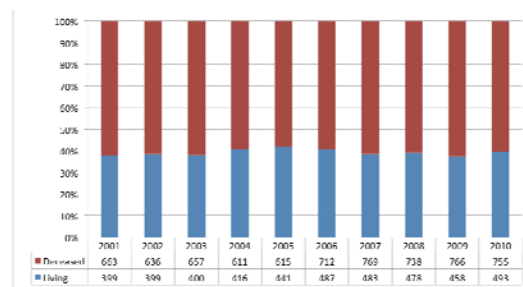


Source: Canadian Organ Replacement Register, 2012, CIHI

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31

Proportion of Kidney Transplants by Donor Type

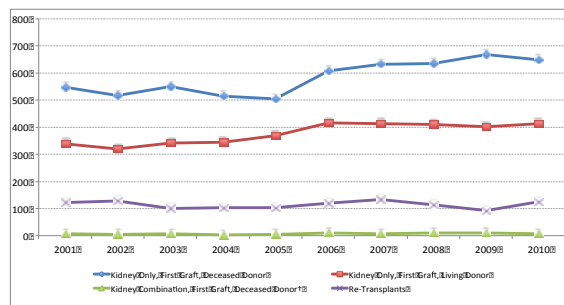


Source: Canadian Organ Replacement Register, 2012, CIHI

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32

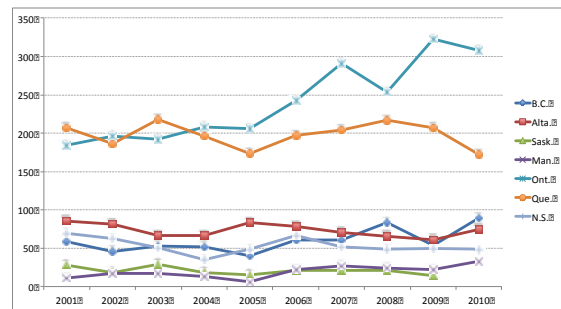
Kidney Transplants by Year and Donor Type, 2001 to 2010



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33

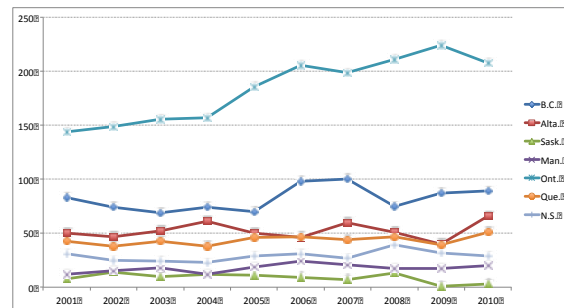
Deceased Donor Kidney Transplants by Year and Province, 2001 to 2010



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34

Living Donor Kidney Transplants by Year and Province, 2001 to 2010



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35

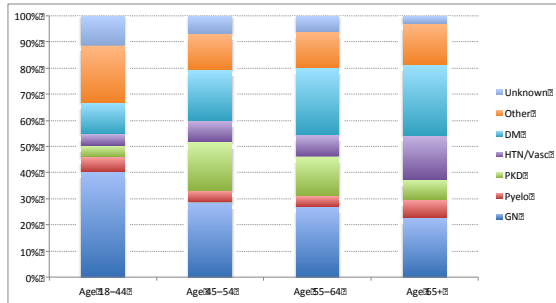
Number of Kidney Transplants by Diagnosis, 2001 to 2010



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36

Kidney Transplant Recipients by Age Group and ESRD Diagnosis, 2010

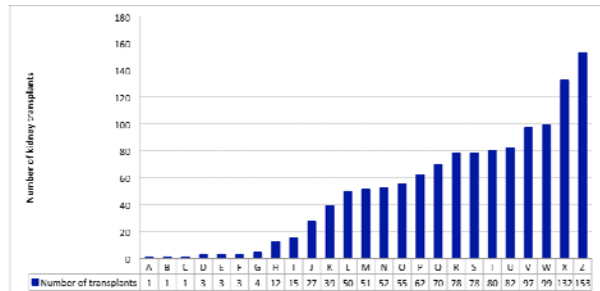


Source: Canadian Organ Replacement Register, 2012, CIHI

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37

Number of Kidney Transplants by Centre, 2010

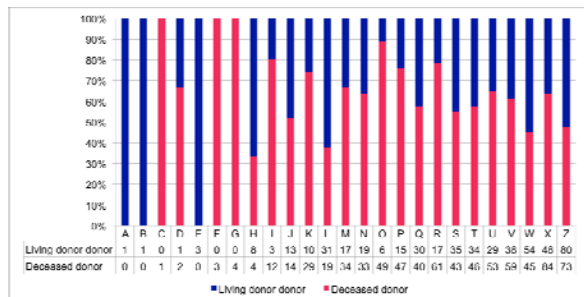


Source: Canadian Organ Replacement Register, 2012, CIHI

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38

Proportion of Kidney Transplants from Deceased vs. Living Donors, 2010



Source: Canadian Organ Replacement Register, 2012, CIHI

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39

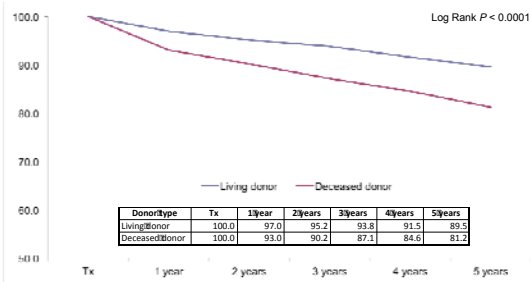
Kidney Transplant Outcomes

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Total Graft Survival, First Kidney, by Donor Type, 2001 to 2010

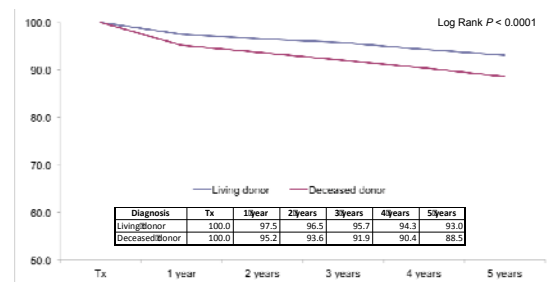


Source: Canadian Organ Replacement Register, 2012, CIHI

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41

Death-Censored Graft Survival, First Kidney, by Donor Type, 2001 to 2010

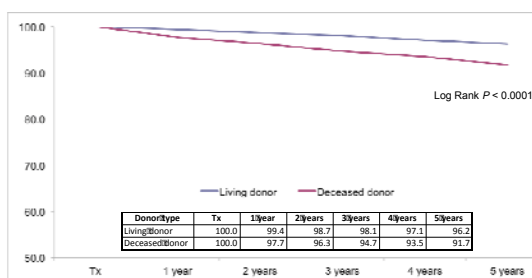


Source: Canadian Organ Replacement Register, 2012, CIHI

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42

Patient Survival, First Kidney, by Donor Type, 2001 to 2010

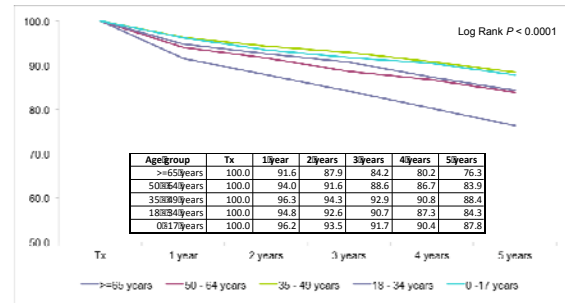


Source: Canadian Organ Replacement Register, 2012, CIHI

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43

Total Graft Survival, First Kidney, by Age Group, 2001 to 2010



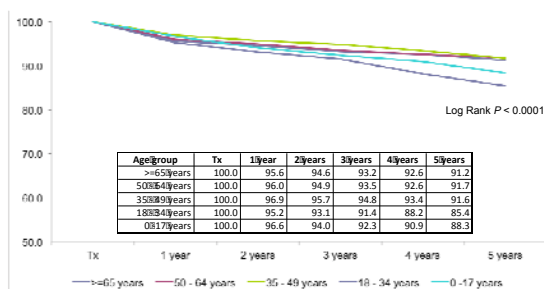
Source: Canadian Organ Replacement Register, 2012, CIHI

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44

Death-Censored Graft Survival, First Kidney, by Age Group, 2001 to 2010

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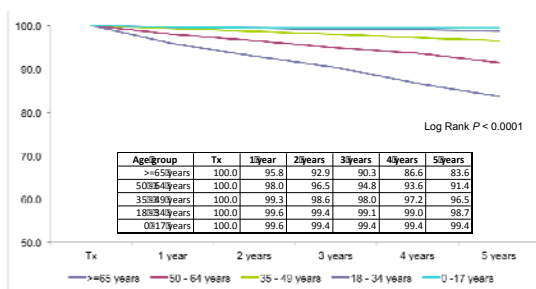
Source: Canadian Organ Replacement Register, 2012, CIHI

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45

Patient Survival, First Kidney, by Age Group, 2001 to 2010

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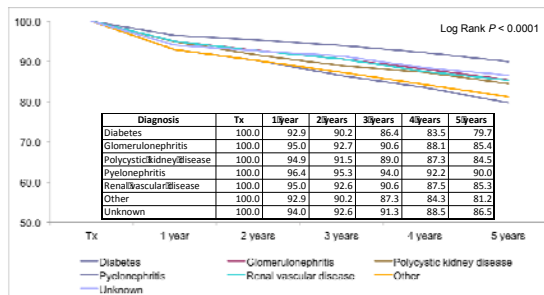
Source: Canadian Organ Replacement Register, 2012, CIHI

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46

Total Graft Survival, First Kidney, by ESRD Dx, 2001 to 2010

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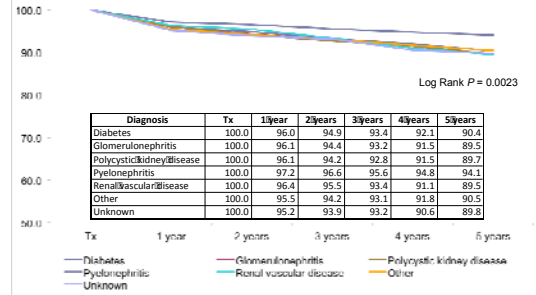
Source: Canadian Organ Replacement Register, 2012, CIHI

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47

Death-Censored Graft Survival, First Kidney, by ESRD Dx, 2001 to 2010

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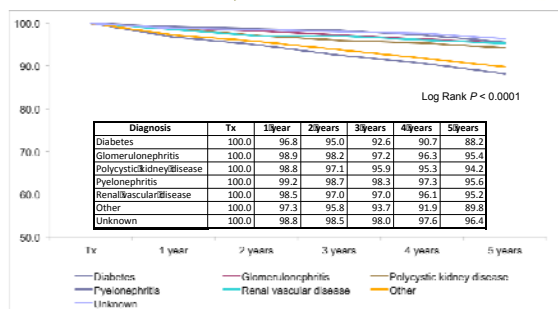
Source: Canadian Organ Replacement Register, 2012, CIHI

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48

Patient Survival, First Kidney, by ESRD Dx, 2001 to 2010

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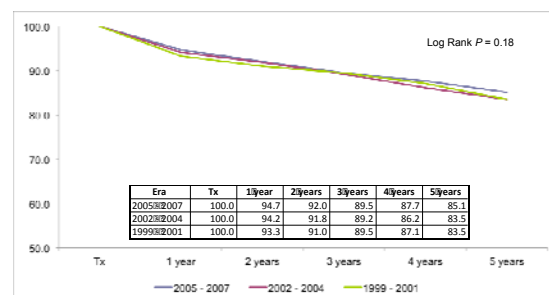
Source: Canadian Organ Replacement Register, 2012, CIHI

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49

Total Graft Survival, First Kidney, by Transplant Era, 2001 to 2010

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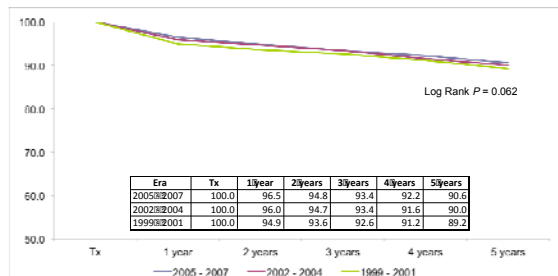
Source: Canadian Organ Replacement Register, 2012, CIHI

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50

Death-Censored Graft Survival, First Kidney, by Transplant Era, 2001 to 2010

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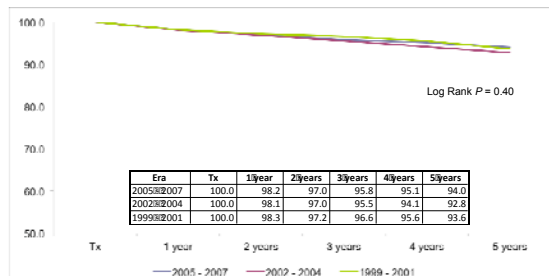
Source: Canadian Organ Replacement Register, 2012, CIHI

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51

Patient Survival, First Kidney, by Transplant Era, 2001 to 2010

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Source: Canadian Organ Replacement Register, 2012, CIHI

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52

Summary and Conclusions

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- Gains in deceased donation activity in some regions while stagnant in others
- DCD continues to be a promising means to expand the deceased donor pool
- Ongoing mismatch between supply and demand for all solid organ transplants
- Relative stability in number of solid organ donors and transplants over the last several years
- Favourable outcomes for recipients of solid organ transplants

Source: Canadian Organ Replacement Register, 2012, CIHI

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53

CORR Access to Kidney Transplantation Feasibility Study: An Update

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CORR Access to Kidney Transplantation Feasibility Project

55

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- Five-year feasibility project that collects referral and wait-list activity on a cohort of ESRD patients referred to Canadian transplant centres
- Sponsored by CORR Board in partnership with CIHI
- Data collected directly from transplant centres with follow-up on those activated onto the deceased donor waiting list
- For analysis, data to be linked to CORR to capture wait-list and post-transplant outcomes
- At end of project, discussions on maintaining this data collection stream on a permanent basis.

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56

Project Steering Committee

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| • Dr. John Gill | St. Paul's Hospital |
| • Dr. Joseph Kim, | Toronto General Hospital |
| • Steve Brulé | Canadian Blood Services |
| • Dr. Trish Campbell | University of Alberta |
| • Dr. Marcelo Cantarovich | Royal Victoria Hospital |
| • Dr. Bryce Kiberd | QE II HSC |
| • Dr. Greg Knoll | Ottawa Hospital |
| • CIHI: | |
| – Greg Webster, Director, Clinical Registries | |
| – Claire Marie Fortin, Manager, Clinical Registries | |
| – Bob Williams, Program Lead, CORR | |

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Methodology

- Sixteen actively participating transplant centres
- Patients enrolling over 3 year period (started with all new referrals as of 1 Jun 2010)
- Follow-up on cohort until end of data collection period on 31 Mar 2015
- Data submission via paper or electronic files to CIHI
- CORR Board sponsoring a Microsoft Access application used for data entry and creation of data files to send to CIHI

Type of Information Collected

- Time of referral:
 - Patient demographics, referral date, dialysis status, date dialysis initiated
- Final disposition:
 - Date seen by physician, date of final disposition
 - Wait list type and reasons why/why not activated
 - Serology (for those wait-listed)
- Wait List Activity
 - Date of removal (if 6+ months off list)
 - Reasons for removal
 - Date of reactivation

Referral-Disposition-Activation Summary by Quarter of Referral

Wait-listing Stage	2010 Q2	2010 Q3	2010 Q4	2011 Q1	2011 Q2	2011 Q3	2011 Q4	2012 Q1	2012 Q2	2012 Q3	Total
Referral	204	560	504	587	559	495	363	268	230	11	3,781
Disposition	101	231	207	196	160	120	63	29	10	0	1,117
Disposition rate (%)	49.5	41.3	41.1	33.4	28.6	24.2	17.4	10.8	4.3	0.0	29.5
Activated to DD wait-list	57	137	132	116	96	67	36	15	6	0	662
Not activated to DD wait-list	45	94	77	80	64	53	27	14	4	0	458

Source: Canadian Organ Replacement Register, 2012, CIHI

Patient Characteristics at Referral	Summary Measure
Total sample size	3,781
Age (mean, years)	52.0
Age ≥ 65 years (%)	18.3
Sex (%)	
Female	36.6
Male	63.4
Race (%)	
Caucasian	39.9
Other	23.2
Unknown	36.9
Valid HCN (%)	99.5
Valid postal code (%)	98.8
On dialysis (%)	61.1
Not on dialysis, SCr (mean, µmol/L)	388.1
Not on dialysis, SCr missing (%)	7.5

Source: Canadian Organ Replacement Register, 2012, CIHI

Characteristics of Patients with Known Final Disposition	Summary Measure
Total sample size	1,172
Average time from referral to being seen by nephrologist (days)	117.1
Average time from referral to disposition (days)	237.6
Death before disposition (N)	53
On dialysis (%)	76.1
Not on dialysis, SCr (mean, $\mu\text{mol/L}$)	0.0
Not on dialysis, SCr missing	471.4

Source: Canadian Organ Replacement Register, 2012, CIHI

Summary and Conclusions

- Cohort of over 3,700 patients referred for kidney transplantation in under 2 years
- Proportion with reported final disposition below 50% and lower in more recent quarters
- Approximately 39% of patients are not on dialysis at the time of referral
- PRA data missing in 24% to 34% of patients at the time of wait-listing

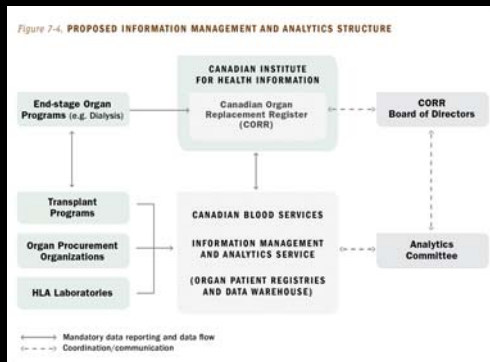
Source: Canadian Organ Replacement Register, 2012, CIHI

Next Steps

- Reconciliation of total referrals at each transplant centre with those reported to CORR/CIHI
- Update and complete reports on final disposition for all referred patients
- Explore ways to improve timeliness and completeness of PRA data at time of wait-listing
- Ramp up data collection on holds and reactivations for patients on the wait-list
- Link to CORR for mortality and transplant events

Future Directions

CORR/CIHI and CBS Partnership



Canadian Blood Services, *Call to Action*, 2012

Future Directions

- Data collection and follow-up of patients in the Access to Kidney Transplantation Feasibility Study
- Comprehensive transplant data element review
- eCORR electronic data entry
- Re-evaluate and revise data request process to improve access to CORR data for investigators
- Operationalize partnership with Canadian Blood Services around acquisition and management of transplant data

Questions