



Working toward a complete picture of kidney transplant patients – Access to Kidney Transplant Feasibility Study

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Canadian Organ Replacement Register (CORR)



- CORR is a pan-Canadian information system for organ failure and organ replacement therapy
- Collects data from hospital dialysis programs and independent health facilities offering dialysis services; regional transplant programs; and organ procurement organizations
- Longitudinal database: patients are tracked from their first treatment for end-stage organ failure to their death
- CORR currently follows close to 42,000 patients with end-stage kidney disease (“kidney failure”)
 - 58% of patients are on dialysis
 - 42% are living with a functioning kidney transplant



CORR Access to Kidney Transplantation Feasibility Study

Rationale

- Kidney transplantation is the treatment of choice for end-stage kidney disease (ESKD)
- ESKD patients must be referred to a transplant centre to determine candidacy for kidney transplant, become activated on the waiting list, or to explore options for living kidney donation
- Patient-level data on the rate of wait-listing and outcomes while waiting for transplant are not currently available
- Data from the point of referral to each milestone along the pre-transplant assessment process is important to evaluate / improve quality of care
- No known transplant registry in the world currently collects data starting from the point of patient referral

Methodology

- Five-year feasibility project to collect data on referral and wait-list activities on a cohort of patients with ESKD
- Sixteen of the 18 adult kidney transplant centres in Canada are participating in the study
- Data are collected directly from kidney transplant centres via paper forms or electronic submission to CIHI
- CIHI developed database using Microsoft® Access® and distributed to participating transplant centres to facilitate data collection

Methodology

- Patients were enrolled over a 3-year period, started with new referrals as of June 1, 2010
- Recruitment period ended on May 31, 2013
- Two additional years of follow-up to May 31, 2015
- Patients are followed from referral, time when final disposition made, waiting period, through to transplantation

Type of Information Collected

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



Summary of the Data

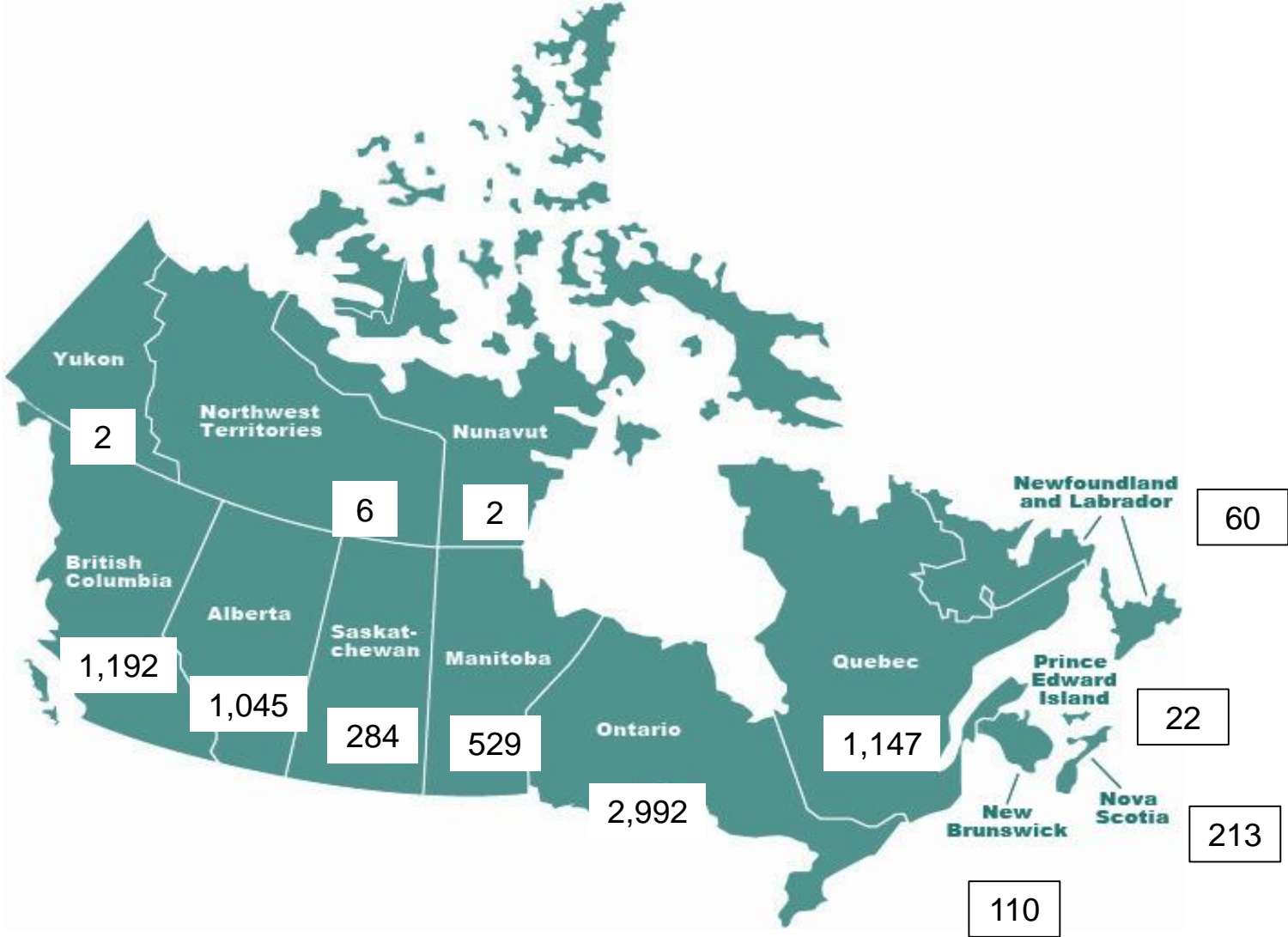


Numbers of Referrals, Dispositions, and Activations by Year of Referral



Cohort Data Flow	2010 Total	2011 Total	2012 Total	2013 Total	2014 Total	All Years Total
Referrals	1,383	2,438	2,473	1,214	96	7,604
Dispositions	1,044	1,726	1,474	571	6	4,821
Disposition rate	75.5	70.8	59.6	47	6.2	63.4
Activated to DD wait-list	569	951	749	287	0	2,556
Not activated to DD wait-list	480	777	726	292	6	2,281

Numbers of Referrals by Patient's Province of Residence



Source: Access to Kidney Transplantation Feasibility Study, 2015, CIHI

Patient Characteristics at Referral	Summary Measure
Total sample size	7,604
Age (mean, years)	52.3
Age ≥ 65 years (%)	19.2
Sex (%)	
Female	37.2
Male	62.8
Race (%)	
Caucasian	52.3
Other	28.7
Unknown	19.0
Valid HCN (%)	99.7
Valid postal code (%)	98.5
On dialysis (%)	61.3
Not on dialysis, SCr (mean, $\mu\text{mol/L}$)	383.3
Not on dialysis, SCr missing (%)	7.8

Characteristics of Patients with Known Final Disposition	Summary Measure
Total sample size	5,242
Mean (median) time from referral to being seen by nephrologist (days)	135.6 (103)
Mean (median) time from referral to disposition (days)	347.2 (284)
Death before disposition (N)	306
On dialysis (%)	74.8
Not on dialysis, SCr missing	5
Not on dialysis, SCr (mean, $\mu\text{mol/L}$)	398.1

Variations in time from Referral to Being Seen by Transplant Nephrologist, and to Final Disposition, select provinces



	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario
Median Time from Referral to being seen by Transplant Nephrologist (days)	192.4	147.8	193	70	155.4
Median time from Referral to Disposition (days)	189	322	468	384	295

Type of Listing among Patients Activated on Deceased Donor Waiting List



Wait-listing Type	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Standard deceased donor	2,447	75.9	2,447	75.9
Expanded criteria donor	634	19.7	3,081	95.6
Kidney-pancreas	105	3.3	3,186	98.9
National highly sensitized patient registry	29	0.9	3,215	99.8
Hepatitis C donor	6	0.2	3,221	100

Reasons for Patients Not Being Activated on the Waiting List



Wait-listing Type	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Patient has living donor	693	31.3	693	31.3
Patient declined	287	12.9	980	44.2
High-risk CVD	146	6.6	1,126	50.8
Patient left to another program	109	4.9	1,235	55.7
History of poor adherence	106	4.8	1,341	60.5
Recent/metastatic malignancy	93	4.2	1,434	64.7
Poor life expectancy	64	2.9	1,498	67.6
Patient left country	26	1.2	1,524	68.8
Active/untreated infection	17	0.8	1,541	69.6
Unstable/untreated mental illness	12	0.5	1,553	70.1
Current drug abuse	8	0.4	1,561	70.5
Other reason	653	29.5	2,214	100.0

Summary

- Cohort of over 7,600 patients referred for kidney transplantation since inception of study
- Median time from referral to seeing transplant nephrologist or to disposition varies considerably across the country
- Approximately 40% of patients were not on dialysis at the time of referral
- Approximately 42% of patients have been activated to the deceased donor wait list
- One-third of patients not activated to the waiting list have a potential living donor

Success

- This is the first known project to fill an important information gap regarding referrals onto waitlists for kidney transplants, and provides a more complete picture of patient-level access to kidney transplantation
- The cohort of patient records was collected using a low cost solution that allowed for high level of participation from transplantation centres, and quick implementation
- Linkability to CORR allows for less redundant data capture
- Demonstrated feasibility to capture this data

Potential Uses of Data

- Data can be linked to the CORR using patient identifiers to
 1. ascertain patients newly started on dialysis over the study period
 2. complete picture on patients' dialysis status, transplant outcomes, and mortality
 3. examine regional variation in referral rates among incident dialysis patients
 4. support health system managers in understanding current practice and identify ways to optimize the workup of potential kidney recipients
- Patients in the study can also be followed across the health care continuum via linkages to other databases – for instance, hospital utilization among patients while waiting for a disposition / activation to wait list



Thank You

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