
Inventory of National Rural Health Research Related Databases

Database name: **Canadian Organ Replacement Register**

Thematic Coverage: This survey records, analyzes and reports on the level of activity and outcomes of vital organ transplantation and renal dialysis activities in Canada

Maintained by: CIHI

Availability: Data disclosure is determined by CIHI's Privacy and Confidentiality Policy (see www.cihi.ca). If privacy and confidentiality criteria are met, data can be released at the sub-provincial level. Costs are dependent upon the level data required, plus programming and processing fees.

Start Date: 1981 – dialysis and kidney transplantation
1990 – extra renal transplantation and organ donation

Release Date: Approximately 14 months after data collection period (year ending December 31)

Frequency of collection: Annual

Data Collection: Data come from participating dialysis centres, transplant centres and organ procurement organizations in Canada.

Sample size: This is a registry database that, with some exceptions, contains all the end-stage renal disease patients and organ transplant patients who initiated treatment from Jan. 1, 1981 across Canada. Patients are followed from their start of treatment to death,

Geographic coverage: All provinces and territories

Lowest geographic level collected: Postal code. It is collected at the time of the patient's initial treatment for end-stage organ failure. A record of their most recent postal code is not available. Postal code collection was not made mandatory until 2001.

Lowest geographic level of release: Forward Sortation Area for regional health councils/planning boards.

Existing rural variable: No

Rural definitions that can be constructed from this database include (building block)[†]:

- ✓ Census "rural areas" (Enumeration Area)
- ✓ Rural and Small Town definition (Census Subdivision)
- ✓ Metropolitan area and census agglomeration Influenced Zones (Census Subdivision)
- ✓ OECD "rural communities" definition (Census Consolidated Subdivision)
- ✓ OECD "predominantly rural regions" definition (Census Division)
- ✓ Ehrensaft's "Beale codes" (Census Division)

[†] Results for these areas of geography could conceivably be derived from postal codes if respondent confidentiality is ensured.

Data Elements:

Patient-specific treatment and outcome data on end-stage organ failure patients receiving dialysis or transplantation in Canada, including:

- patient demographics
- risk factors
- follow-up, including graft failures
- number, type and outcome of vital organ transplants
- number of living and cadaveric organ donors
- number of patients on the transplant waiting list

Notes:

Some data collected prior to 1997 are very incomplete (e.g., postal codes, risk factors). Although participation in CORR is voluntary, all dialysis and transplant programs participate. Completeness of data varies from centre to centre.

Reports generated by CIHI are typically at the national and province level; health region reports are possible, but may be affected by the incomplete postal code information.

For more information, contact corr@cihi.ca