Cancer Registry Data Quality How Fit Are We?

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Canada

Lawrencetown Beach – Nova Scotia – Fall 2010

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Presentation Overview

- **Introducing Canada**

- **Canadian Registries**

- **Registry Quality**

  – Defining Quality

  – Quality Approaches in Canada

Canadian Facts

Location of Provincial/Territorial and National Cancer Registries in Canada

- 13 Provinces/Territories
- Population - 31.2 Million
  - Range of 30,000 (Yukon)
  - to 12.1 million (Ontario)
- Significant geographic variation & large rural component
- Indigenous Aboriginal, Métis & Inuit populations
  - Manitoba / Saskatchewan ~ 15% Aboriginal
- Immigrant foci
  - 18% total population
  - Lower mainland BC / Toronto - GTA~ 50%
- Aging population
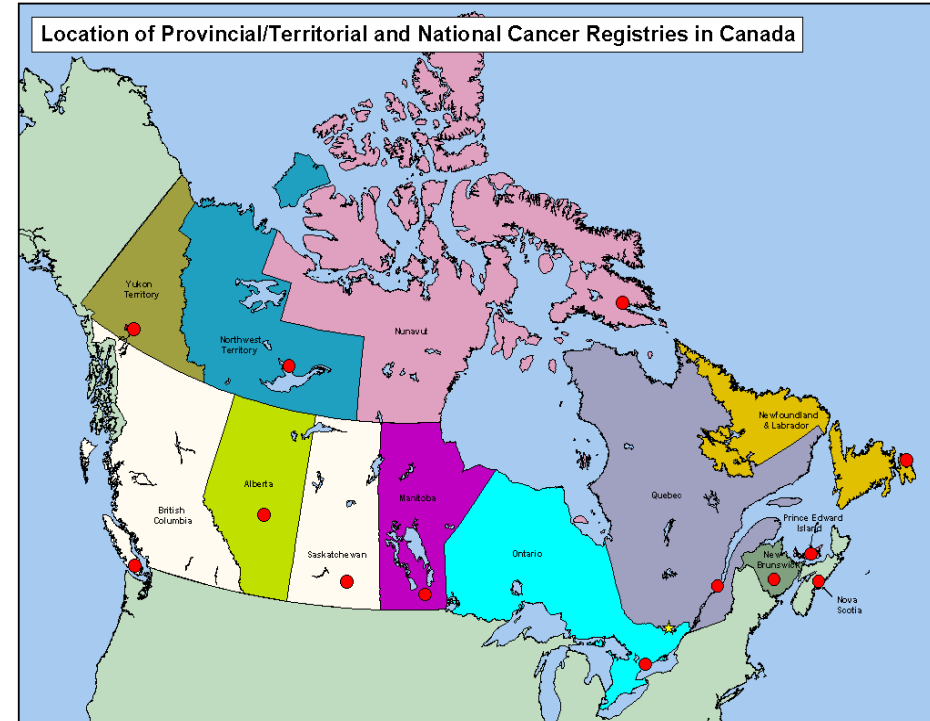
Canadian Health Care System

Federal/Provincial split on health care responsibilities

- Majority of health services delivered by provinces/territories (P/Ts)
- Significant federal funding to P/Ts (transfer payments)
  - Provinces supplment with provincial taxation
- Canada Health Act identifies key principles for service delivery
  - Universality; Access; Portability; Comprehensiveness; Public Funding

P/Ts – Departments of Health

- Variation on health service delivery structures/coverage
  - Majority of acute care delivered in publicly funded facilities
    - Not all illness costs covered in public system (e.g. cancer chemotherapy)
  - Increasing private components (but still relatively limited)
  - Supplemental private insurance
  - Physicians – still primary gatekeeper
    - Community based care increasing

Cancer Care System

- Provincial Cancer Control Agencies/Programs
  - Most cancer registries reside here
- Long history of coordinated cancer service delivery
- High degree of centralized care
  - Cancer Center based care delivery model for oncologist care (most centers have ambulatory focus)
  - Affiliated with tertiary/specialty hospital
  - Few hospital based registries
- Initial access to cancer services often via family physician
  - Organized screening growing (breast; colon; cervix)
- Core treatment modalities
  - Investigation/Surgery at community, regional,tertiary facilities
  - Radiation Treatment almost exclusive to cancer centers ~ 40
  - Chemotherapy at cancer center/outreach program/home

Canadian Cancer Registry System

- **Essentially Two Tier System**
  - Provincial/Territorial Registries arrived first – then national
  - Emphasis on central registries
  - Use trained cancer registrars
- **Use of data linkages to enhance registry operations**
  - Take advantage of:
    - *unique identifiers (health card numbers)*
    - *Other health care/administrative databases*
  - Linkages support:
    - Case finding/ascertainment
    - Outcome measures (death data)
    - Expanded view of the cancer continuum
      - e.g. Link screening & cancer registry for evaluation purposes
- **Expanding use of electronic data collection direct from emerging electronic health records**
  - Current focus on Pathology and Surgery data

Provincial/Territorial Registries

- Originated at varying times across country

  - 1935 – British Columbia & Saskatchewan

- All fully Population Based

- Auspices of provincial Dept of Health or Cancer Agency

  - In last 10 years - all Territories have collaborated with a provincial registry to carry out operations

- Legal/Regulatory Authority varies

  - No federal requirement to report; P/Ts vary

  - Health Information Privacy Legislation having a growing impact on operations from case finding to research

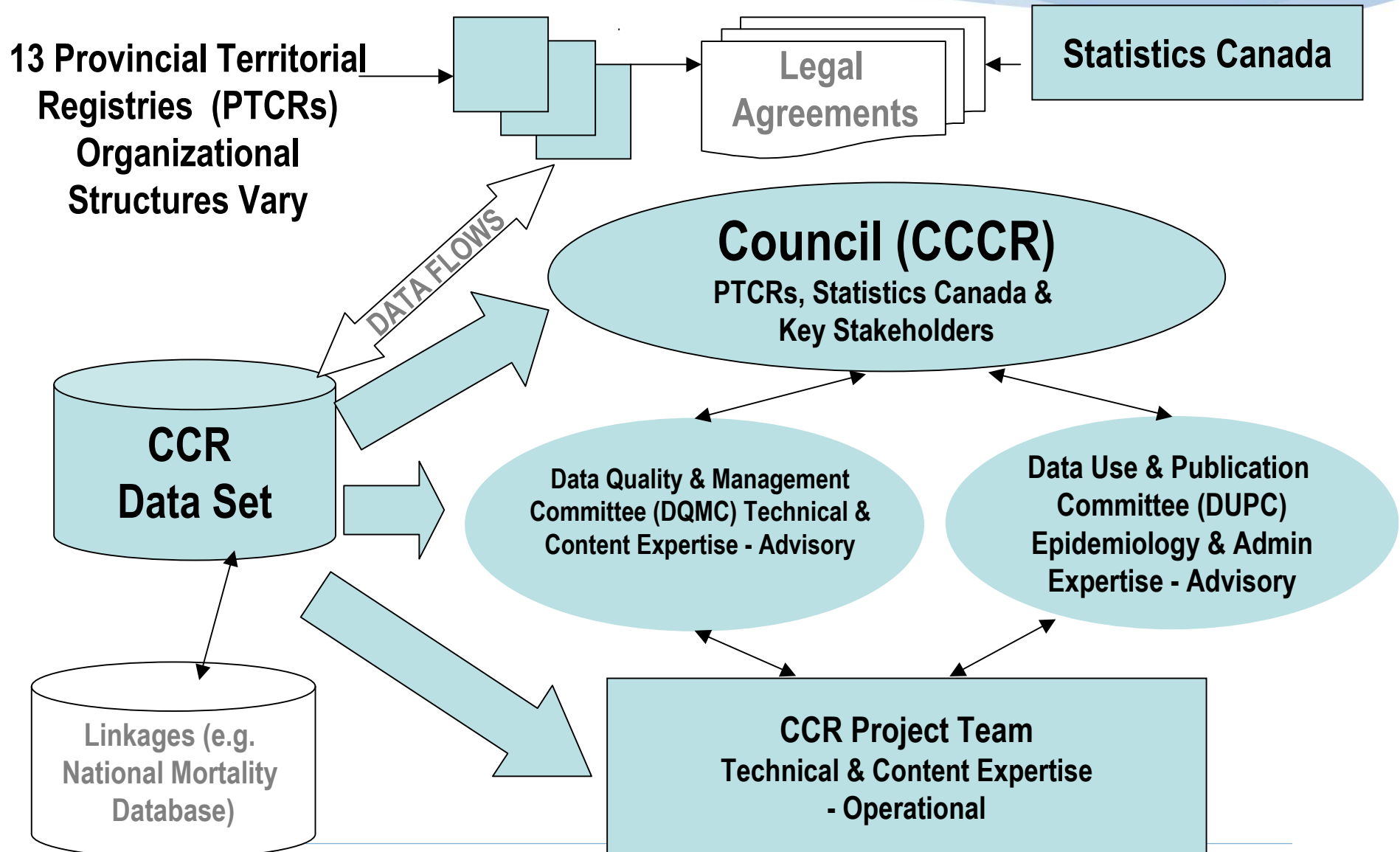   - e.g. Privacy Impact Assessments; New Approval Processes

Provincial/Territorial Registries

- Data Collection – some variation
  - Demographic (key exception – ethnicity)
  - Disease (ICD-O-3)
    - Benign Brain – 7/13; Non-Melanoma Skin 6/13; In-situ majority
  - Stage data collection – standards set in 2004
  - Outcome – mortality data
  - Treatment limited/no common standards

- Registry Information Systems
  - Until last 5 years most developed in house/now vendor based
    - Ontario has completely automated case finding system
  - Electronic pathology (Epath) becoming standard

Provincial/Territorial Registries

- Case Ascertainment – use of multiple sources
  - Fundamental element of quality data collection
    - Anatomic Pathology
    - Other Laboratory Services (e.g. cytology)
    - Cancer Centers/Outreach clinics
    - Hospital Reporting
      - CIHI – Discharge Abstract Data / or specialized cancer abstract
    - Physician claims (billing)
    - Reciprocal Reporting
    - Provincial Vital Statistics
    - Special Screening of target areas

  - Most registries still use some paper based data sources

Canadian Cancer Registry Overview

13 Provincial Territorial Registries (PTCRs) Organizational Structures Vary

Legal Agreements

Statistics Canada

DATA FLOWS

CCR Data Set

Council (CCCR)
PTCRs, Statistics Canada & Key Stakeholders

Data Quality & Management Committee (DQMC) Technical & Content Expertise - Advisory

Data Use & Publication Committee (DUPC) Epidemiology & Admin Expertise - Advisory

Linkages (e.g. National Mortality Database)

CCR Project Team
Technical & Content Expertise
- Operational

National Registry

- National registry under auspices of Statistics Canada
  - **Generation I**: 1969 – 1991 ***National Cancer Incidence Reporting System (still available for use)***
    - Event oriented system
  - **Generation 2**: 1992 – 2003 ***Canadian Cancer Registry - CCR***
    - Person oriented system (person & tumour records)
    - CCR ID for communication
    - Internal linkage – duplicates
    - National death linkage
    - Focus on standards (e.g. ICD-0; last update 2001 to version 3)
  - **Generation 3**: In development 2005 - Present
    - 2004-2010 – Focus on Stage Data & new standards for diagnosis data collection
    - Now exploring treatment data collection
  - Post 2009 submission ~ 2.7 million tumour records

CCR – Core Patient Record

- Reporting Province
- Patient ID number
- *CCR ID Number*
- Surnames
- Given Names
- Sex
- Date of birth
- Heath Insurance #

- Place of birth
- Date of death
- Place of death
- Death registration number
- Underlying cause of death
- Date of transmission

CCR – Core Tumour Record

- Reporting Province
- Patient ID number
- *CCR ID Number*
- Tumour Reference number
- Residence at diagnosis
- Postal code at diagnosis
- Heath Insurance #

- Method of diagnosis
- Date(s) of diagnosis
- Cancer site
- Morphology
- Date of Transmission
- Stage (all variables)

Key Cancer Surveillance Stakeholders

- Provincial/Territorial Departments of Health
  - P/T Cancer Registries
- Statistics Canada
- Public Health Agency of Canada
- Health Information Agencies
  - Canadian Institute of Health Information
  - Canada Health Infoway
- Canadian Cancer Society
- Canadian Institute for Health Research
- Cancer Professionals (e.g. clinicians)
- Canadian Partnership Against Cancer
- North American Association of Central Cancer Registries

Defining Data Quality

- "Fitness for Use"
  - Relates to the purpose(s) for which you collect the data and your user community
    - User satisfaction
    - Products/Publications
  - Other defined characteristics
    - e.g. Accuracy; Timeliness; Accessibility; Completeness
  - Quality is dynamic
    - Needs change; systems change
  - Quality has a cost/resource implication

Assessing Key Data Quality Characteristics

- Accuracy – does the data reflect what was meant to be collected
    - Computerized edit checks
        - Built into the data system
            - Field ranges (allowable values)
            - Inter field checks (prostate diagnosis not allowed for female)
            - Inter record checks (when multiple data sources used)
            - Inter database checks (e.g. cause of death data compared to disease registration)
        - Applied from standardized edit sets (emerging in Canada)
    - Visual editing
    - Recoding Audits – coding rules applied correctly
    - Reabstraction Audits – go back to source

Assessing Key Data Quality Characteristics

- ## Case Completeness
  - If purpose is to collect all cases – need to ensure none have been missed and that duplicates have not been enrolled
    - Case finding audits
    - Monitoring death certificate only cases
    - Compared expected/actual reporting
    - Evaluate duplicates (e.g. internal linkages)

Assessing Key Data Quality Characteristics

- ## Data Completeness

  - Also use computer edit checks
    - Build data fields to ensure completeness can be assessed – minimize opportunity for empty fields

  - Use process controls to monitor frequency of missing/unusual codes
    - Monitor rates of unknowns or ill-defined codes

Assessing Key Data Quality Characteristics

- Timeliness (becoming a real pressure point in terms of 'Fitness for Use'
  - Monitor lag time from reporting sources
    - Provide feedback/coaching
  - Monitor time to closure of data periods
  - Consider releasing some data components earlier than others

Data Quality in Canadian Registries

- Structure/Process
  - Council to establish / monitor standards
    - Strategic relationships with stakeholders
    - Networking
    - Sharing best practices
  - Standards/Standards/Standards
    - Coding for Disease; Stage; Multiple Primaries
    - Address assignment
    - Alignment to North American Association of Central Cancer Registries (NAACCR) standards
  - Written CCR System Guide (all 420 pages)
    - Data Dictionary
    - Inclusion/Exclusion criteria
    - Record layouts
    - etc……
  - Edit tools (e.g. collaborative stage CCR edit file)

Data Quality in Canadian Registries

- **Structure/Process**
  - Standardized coder training
  - Now focus on analytic training
  - Data Quality Committee of Council
    - Reviews questions/issues
      - Interpretation forum
    - Special subgroups as needed
  - Standardized call for data (annual)
    - Use of CCR ID – returned to provinces
    - Edit Cycles during submission period
    - New/Update/delete options
    - Internal Linkage/case resolution process
  - National death clearance

Data Quality in Canadian Registries

- Monitoring
  - Year over year analysis during call for data
  - Data quality report cards
    - Sent to Ministry of Health (recent)
  - NAACCR certification
    - Similar to CCR report card but through North American lens
  - New focus on audits
  - Statistics Canada Departmental review

Canadian Registry Quality Assessment

	Indicator Name and Description	Metric	Optimal Value	A	B	C	D	E
Accuracy	**1. Completeness of Case Ascertainment**	% ratio	**≥ 90** **2.60:1**	83.0 2.18:1	103.9 2.53:1	106.0 2.56:1	113.0 2.66:1	94.8 2.25:1
	2. Records Rejected by Edit System	%	**< 1**	0.8	0.5	0.2	0.4	1.3
	3. Microscopically Confirmed Cases	%	**≥ 93**	96.7	90.8	89.6	93.6	78.0
	4. Death Certificate Only*	%	**≤ 3**	N/A	0.5	1	0.2	N/A
	5. Unknown Primary Site of Cancer	%	**< 2.3**	2	2.2	2.5	1.5	2.2
	6. Missing Information							
	Postal code	%	**< 1**	0.0	0.0	0.0	0.0	0.0
	Month of diagnosis	%	**< 1**	0.0	0.0	0.2	0.0	0.0
	Month of birth	%	**< 1**	0.0	0.0	0.0	0.0	0.0
	Death registration number	%	**< 10**	N/A	18.8	1.0	0.4	N/A
Comparability	**7. Reporting of Staging Data using the Collaborative Staging System**	**Yes/No**	**Yes**	Yes	Yes	Yes	Yes	No
	8. Reporting of Cancer Records using ICD-O-3	**Yes/No**	**Yes**	Yes	Yes	Yes	Yes	Yes
	9. Reporting of Multiple Primaries (CCR rules†)	**Yes/No**	**Yes**	Yes	Yes	Yes	Yes	No
Timeliness	**10. Data Submission Delay** After data submission deadline of March 12, 2010.	**Days**	**≤ 30**	0	0	7	11	48
Usability	**11. Cancer Incidence Fully Reported†**	**Yes/No**	**Yes**	Yes	Yes	Yes	Yes	No

Notes

*For Indicator 4: Death Certificate Only - N/A indicates that a provincial or territorial cancer registry does not do a provincial or territorial death clearance; DNR indicates that a provincial or territorial cancer registry performs a provincial or territorial death clearance but does not report the data to the CCR.

** The 2008 Quebec cancer incidence data have not been submitted to the CCR. The Data Quality Indicator results for Quebec are based on 2007 data.

† 2006 CCR rules.

CCR: Canadian Cancer Registry; N/A: Not applicable; ICD-O-3: International Classification of Diseases for Oncology, Third Edition.

CCR Report Card Indicator

Data Quality Dimension	Accuracy
Indicator 2	Records Rejected by Edit System
Description	This indicator illustrates the percentage of records rejected by the CCR editing system.
Calculation	A/B × 100%, where: A = The number of records rejected due to data element level edit errors, by province/territory B = The total number of records submitted, by province/territory Note: The Canadian Cancer Registry database contains only valid and coherent patient and tumour records. Thus, invalid or incoherent records that fail the CCR edits, or that are outside the scope, are rejected by the data editing process.
Use	Each provincial and territorial cancer registry supplies information to the CCR for each new patient and each new tumour in a standard, pre-edited format. Validity edits verify that fields contain valid entries and correlation edits verify that relationships between patient and tumour records make sense. Those failing edits are rejected and returned to the provincial and territorial cancer registries for verification or correction.
Impact/Interpretation	The number of records rejected by CCR Edit System is usually a good indicator of the quality of the registry operations, a problem arising from the interpretation of a new rule or edit, or, in some situations, simply a transmission problem. The optimal value for this indicator is less than 1% of the number of new records submitted to the CCR returned to the cancer registry. The data quality flag was assigned as follows: a green flag was given for less than 1%; a yellow flag was given for 1-2%; and a red flag for greater than 2%.
Limitations	One or more element level edit errors may exist in any rejected record. This indicator looks at the proportion of records rejected, and not the number of individual edit errors contained within them. As such, for the purpose of this report, a record with one data element level edit error is treated the same as a record with multiple data element level edit errors. A low edit error rate does not necessarily imply that all data are accurate. A cancer code may be valid and pass the edit checks, but it may still be an incorrect code.

Data Quality in Canadian Registries

- Data Use is new focus
  - Annual Canadian Cancer Statistics Publication
    - Incidence actual and projected
    - Prevalence
    - Survival
    - Mortality
  - Detailed annual cancer survival
  - Limited Use Data File (and other linkages)
    - A work in progress
  - Annual release to PHAC – special studies
  - Collaboration with Canadian Partnership
    - Cancer Risk Management Platform
    - Analytic Networks
    - System Performance

Thank You - Obrigado !

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