Cancer Care Ontario

The Ontario Cancer Registry and its Data Quality

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Ontario
Cancer Care Ontario

Objectives

- Become familiar with cancer registration in Ontario, including issues related to data quality and geography
- Gain proficiency in the use of SEER*Stat
- Generate specific indicators for cancer incidence as defined by APHEO to meet the Ontario Public Health Standards

Outline

- Definitions
  - Terminology
  - Measuring the cancer burden
- The Ontario Cancer Registry
  - Sources of information
  - Record linkage and ‘Case Resolution’
- Data Quality
  - Four dimensions of cancer data quality
  - How does the OCR stack up?

What is cancer?

- A term used for diseases in which abnormal cells divide without control and are able to invade other tissues
- There are more than 100 types of cancer
- Cancer cells can spread to other parts of the body through the blood and lymph systems (“metastasis”)
- Tumour/neoplasm: “An abnormal mass of tissue that results when cells divide more than they should or do not die when they should”

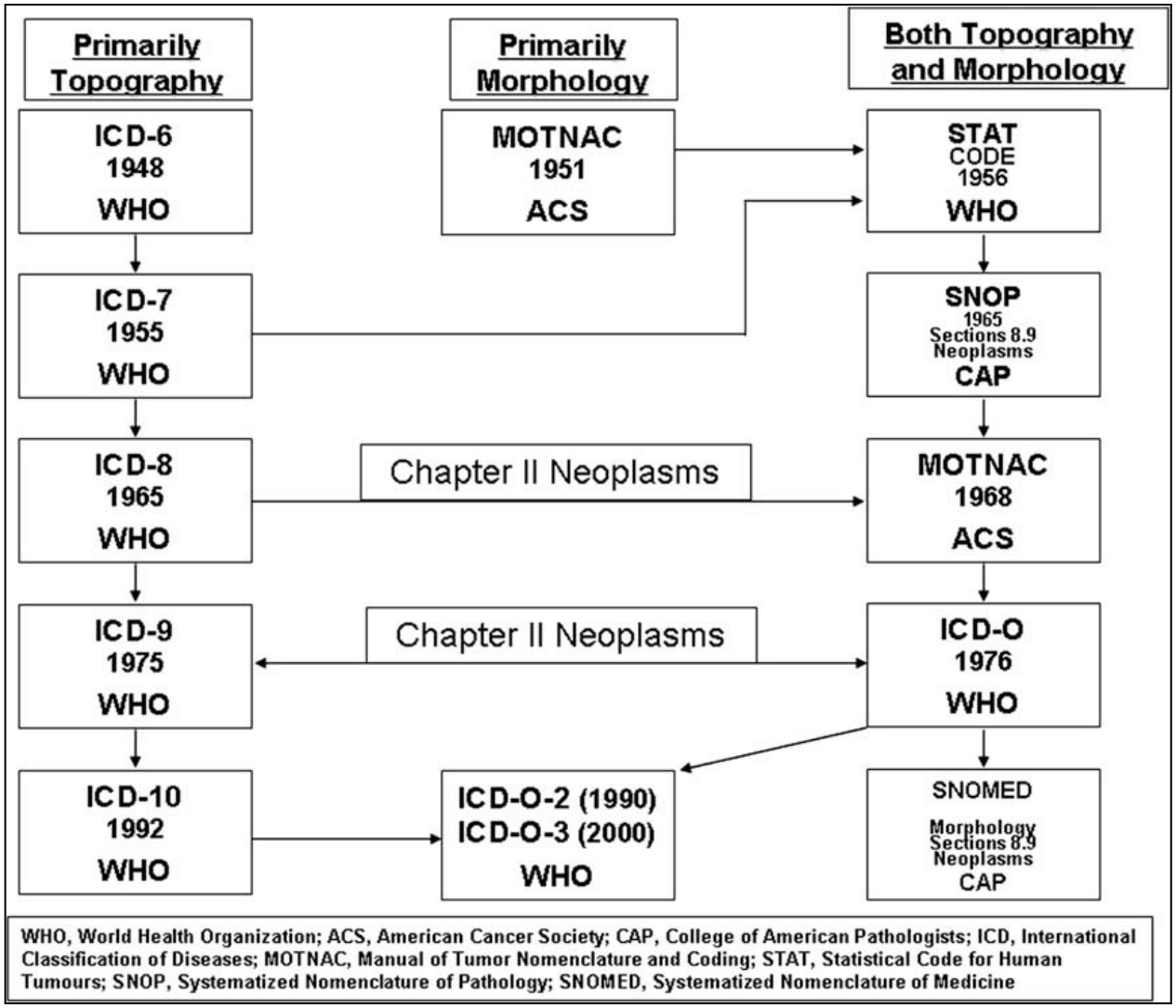
Classifying cancer

- Topography: *a code indicating the site of origin of a neoplasm*
- Morphology: *a code describing the type of cell what has become neoplastic and its biologic activity*
  - 4 digits cell type (histology)
  - 1 digit behaviour

5th digit behaviour code for neoplasms

- /0 Benign
- /1 Uncertain whether benign or malignant (borderline)
- /2 Carcinoma in situ
- /3 Malignant, primary site
- /6 Malignant, metastatic or secondary site
- /9 Malignant, uncertain whether primary or metastatic site

Cancer coding systems over time



Measures of cancer burden

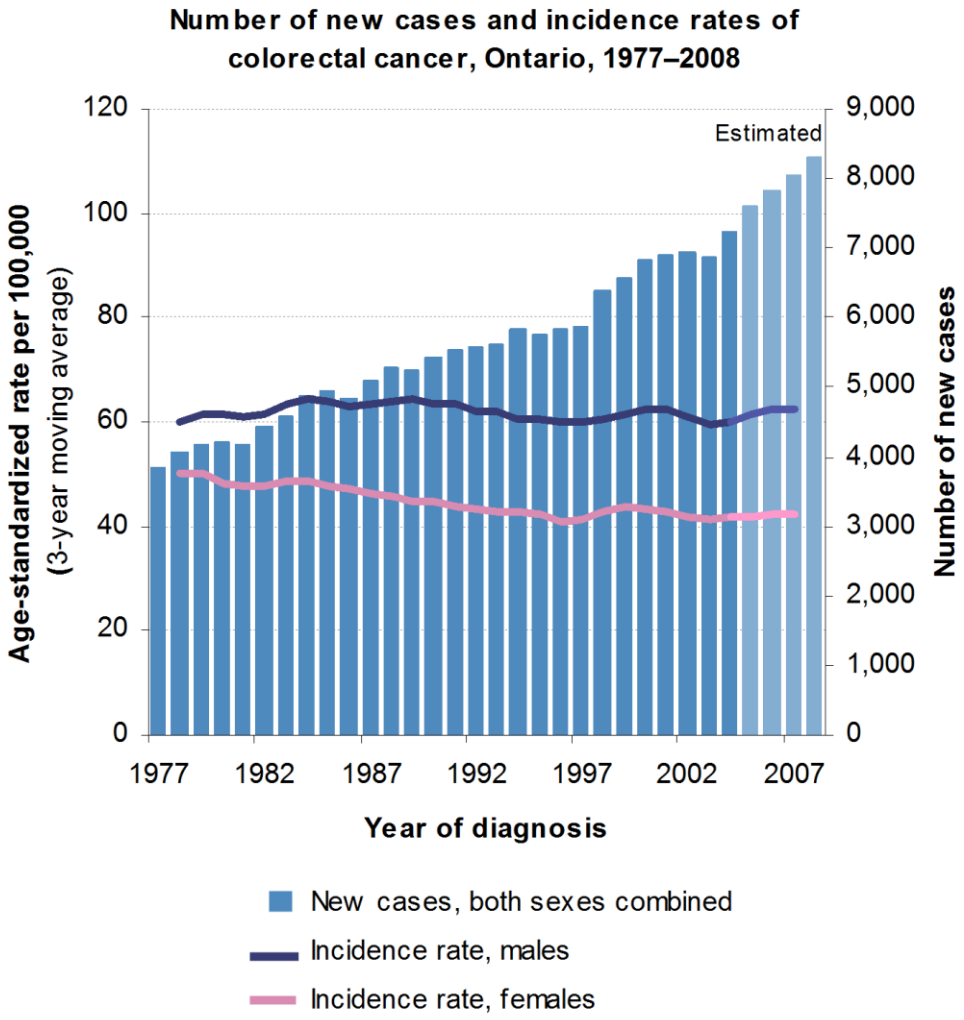
- Incidence
- Mortality
- Survival
- Prevalence

Incidence

- **Definition:** the number of *new* cases of a disease (e.g. cancer) diagnosed in a given population within a *specified period of time*
- Typically expressed as a rate:

$$\frac{\text{\# new cases in a specified time period}}{\text{\# persons at risk of disease during the same time period}} \times 100{,}000$$

Example – Ontario colorectal cancer incidence



Source: Cancer Care Ontario (Informatics, 2007)

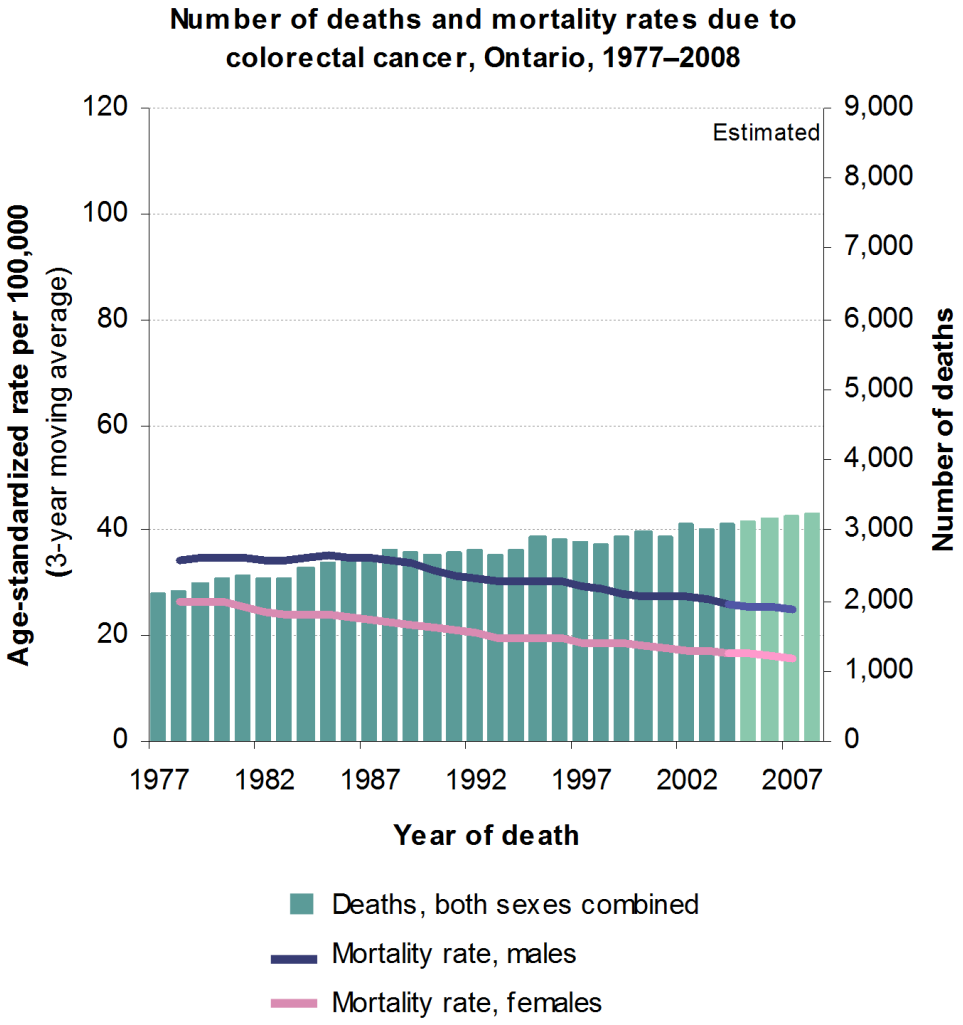
Mortality

- **Definition:** the number of *deaths* due to a disease (e.g. cancer) in a given population within a *specified period of time*
- Typically expressed as a rate:

$$\frac{\text{\# deaths in a specified time period}}{\text{\# persons at risk of dying during the specified time period}} \times 100{,}000$$

  - *Note:* the denominator includes the entire population at risk of dying from the disease, including those that are currently disease-free.

Example – Ontario colorectal cancer mortality



Source: Cancer Care Ontario (Informatics, 2007)

The Ontario Cancer Registry

- Ontario currently has a population of 13.2 million
  - 38.7% of the Canadian population
- The OCR is population-based
  - Incidence from 1964; mortality from 1950
  - Unique cancer registration methods
    - Passive registration
    - Reliant on administrative records created by others
    - Computerized record linkage and automated medical logic
  - 63,660 malignant incident cases diagnosed in 2007

Passive registration

- The reporting of cancer is *not* legally mandated in Ontario
- There is no staff who visit hospital or non-hospital facilities to find/abstract cases
- The Ontario Cancer Act protects those who provide information on cancer cases to CCO, although it does not mention a cancer registry explicitly

Data Source 1: Hospitals

- Provided by:
  - 1981- March 1986: Ontario Ministry of Health
  - April 1986+: Canadian Institute for Health Information (CIHI)
- Coding:
  - 1981-March 2002: ICD-9 / ICD-O-1
  - April 2002+: ICD-10-CA / ICD-O-2
  - morphologies only provided for ~5% of records

Data Source 1: Hospitals

- Coverage:
  - Discharge Abstract Database (DAD): all years
  - Same Day Surgeries (SDS): April 1993-March 2001
  - National Ambulatory Care Reporting System (NACRS): April 2001 to present

Data Source 2: Regional Cancer Centres

- Number of RCCs (including Princess Margaret Hospital)
  - 1981: 8 RCCs
  - c1985 – Sudbury RCC opened
  - 2003-2009: 6 more RCCs opened
- Topography coding:
  - RCCs: 1981-2001, ICD-9; 2002+, ICD-10
  - PMH: 1981-1998, ICD-9; 1999+, ICD-O-3

Data Source 2: Regional Cancer Centres

Coding System	RCCs	PMH
ICD-O-1	1981-1987	1981-1987
ICD-O-T	1988-1992	1988-1998
ICD-O-2	1993-2001	
ICD-O-3	2002 +	1999 +

Data Source 3: Pathology

- Phases:
  - 1981-1987: Implementation & expansion
  - 1988-2002: Continued growth
  - 2003: electronic pathology system introduced
- Coding:
  - 1981-1992: ICD-9 / ICD-O-1
  - 1993-2001: ICD-O-2
  - 2002+: ICD-O-3

Data Source 4: Death Certificates

- Extreme delays in the receipt of coded death certificates from the Registrar General of Ontario hamper timeliness of registration
  - 2006 deaths received May 2009
  - 2007 deaths received March 2010
  - 2008 deaths received January 2011
- Coding:
  - 1981-1999: ICD-9
  - 2000+: ICD-10-CA

Probabilistic Record Linkage

- "the bringing together of information from two records that are believed to relate to the same individual" (Newcombe, 1988)
- You can calculate the likelihood of a correct linkage by comparing the individual identifiers (names, sex, dates, health numbers) and the outcome of these comparisons (exact agreement, partial agreement, disagreement)

“Case Resolution”

- A COBOL program with thousands of lines
- Automated medical logic written in 1981-2
- Tables and logic based in ICD-9 / ICD-O-1
- Some quirks based on beliefs of MD/epidemiologist involved in design (“Breast wins”)
- Conservative multiple primary rules used due to data quality concerns

Ontario's Multiple Primary Rules

- Timing and laterality do not count (= IACR)
- A new tumour must differ from previous primaries on **both** topography (ICD-9 3 digits) **and** morphology ("Breg table", pg xxxvii, ICD-O-2) to be identified as a multiple primary
- IACR rules: different topography **or** morphology

Geography

- Residents of NW Ontario frequently to go Winnipeg for treatment
  - File received annually from CancerCare Manitoba with Ontario residents registered in Manitoba
- Residents of Gatineau, QC frequently go to Ottawa for treatment
- New York, Michigan, Minnesota??

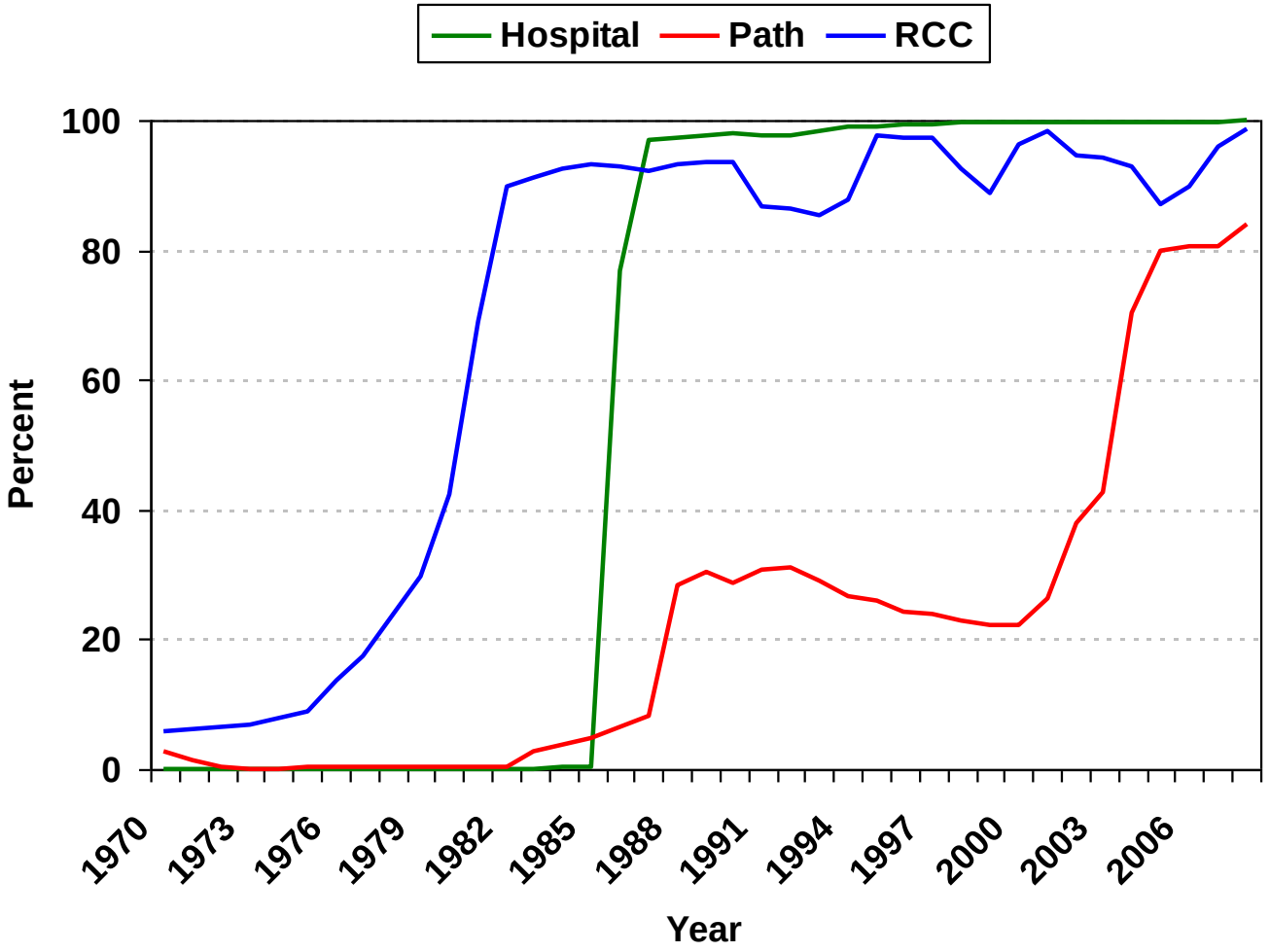
Which OCR data sources use what codes?

Source	SGC	MOH	Postal Code	RG SGC
Hospital	No	Yes	Yes	No
Path Labs	No	No	Maybe	No
RCCs	No	Yes&No	Yes?	No
Deaths	No	No	No	Yes

Residence at diagnosis

- PCCF+ is used to assign the postal code on every source record to an SGC code (CD+CSD)
  - Postal codes which cross boundaries are randomly assigned to an SGC using population weights & a SAS program
- The SGC code on the record closest to the date of diagnosis is taken as the residence at diagnosis
  - Usually the same day, but can be earlier or later
- CDs & CSDs map nicely to PHUs in southern Ontario; it's more complicated in northern Ontario, but I've tried to do the best assignment possible…
  - Brant & Haldimand/Norfolk – Six Nations & New Credit IR

Completeness of postal codes by source



Missing residence

- Varies by site and time

Cancer Site	1986-1988	2005-2007
Melanoma	10.72%	0.77%
Oral Cavity	3.10%	0.53%
Thyroid	1.82%	1.58%
All Cases	1.37%	0.37%

- Historically, has been more of a problem for sites with a high percentage of pathology only cases
- Tends to be a characteristic of the hospital/clinic/lab

Postal code or MOH code?

- 355,787 hospital records, 2001
- PCCF+ run on the postal code
  - 1.9% no match
  - 20.1% assigned using population weights
  - 76.7% no problem
- MOH to SGC conversion table
  - 0000 patient w no fixed address

Postal code or MOH code, cont'd

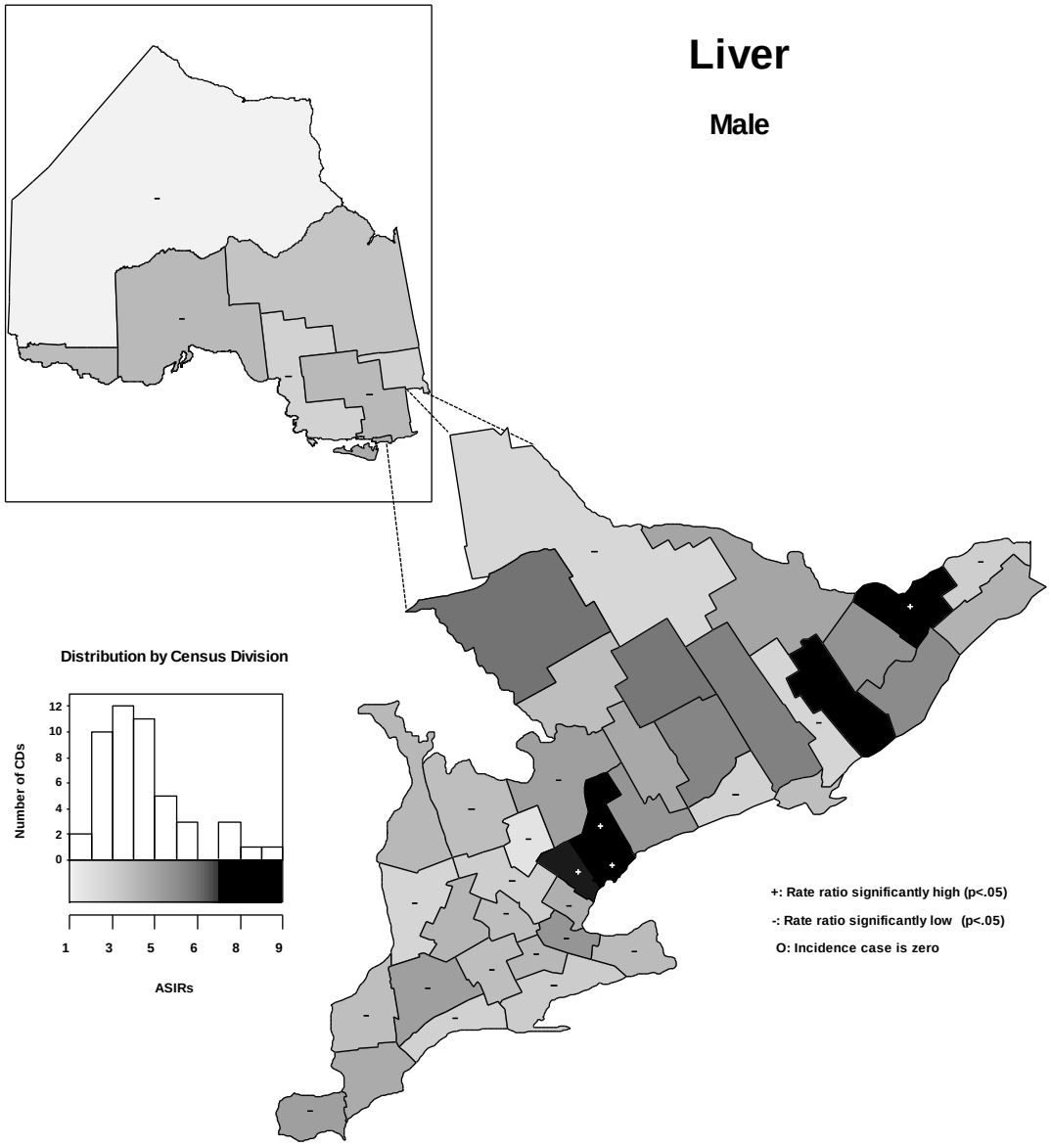
- SGCs compared for 272,981 records with no problems
  - 97.9% postal code & MOH agree
  - 1.4% CD agrees, but CSD disagrees
  - 0.7% nothing agrees
- Common disagreements?
  - MOH says Toronto, postal code says no: 28%
  - Postal code says Toronto, MOH says no: 6.5%
  - Wrong MOH code for 2 places with the same name

Differential misclassification bias in residence assignment

- In 1991, Marrett & Weir looked at the accuracy of the residence data for Frontenac County cases for 1988
  - 14% of cases had an incorrect residence
  - 7% involved Kingston, with people living outside Kingston were being incorrectly attributed residence in Kingston
- As a result, Kingston rates were too high and the rest of Frontenac County rates too low

Liver

Male



Age Adjusted Incidence Rate
Ontario, 1996-2005

Data Quality in cancer registries

- The uses of cancer registries are changing
  - Used to be mainly surveillance and epidemiology
  - Now expected to be used to monitor screening programs, evaluate treatment and prevention programs, project future incidence, etc.
- The ability of a cancer registry to effectively perform the above functions depends on the registry's *data quality*

Data Quality in cancer registries

- Both internal and external factors affect data quality

Internal factors	External factors
• Registry operations	• Purpose of data collection
• Registry resources	• Resources of external data sources
• Access to additional data sources	• Reporting diligence

Dimensions of data quality in cancer registries

- Four dimensions of data quality (Parkin & Bray (2009)):
  1. Comparability
  2. Completeness
  3. Accuracy (validity)
  4. Timeliness

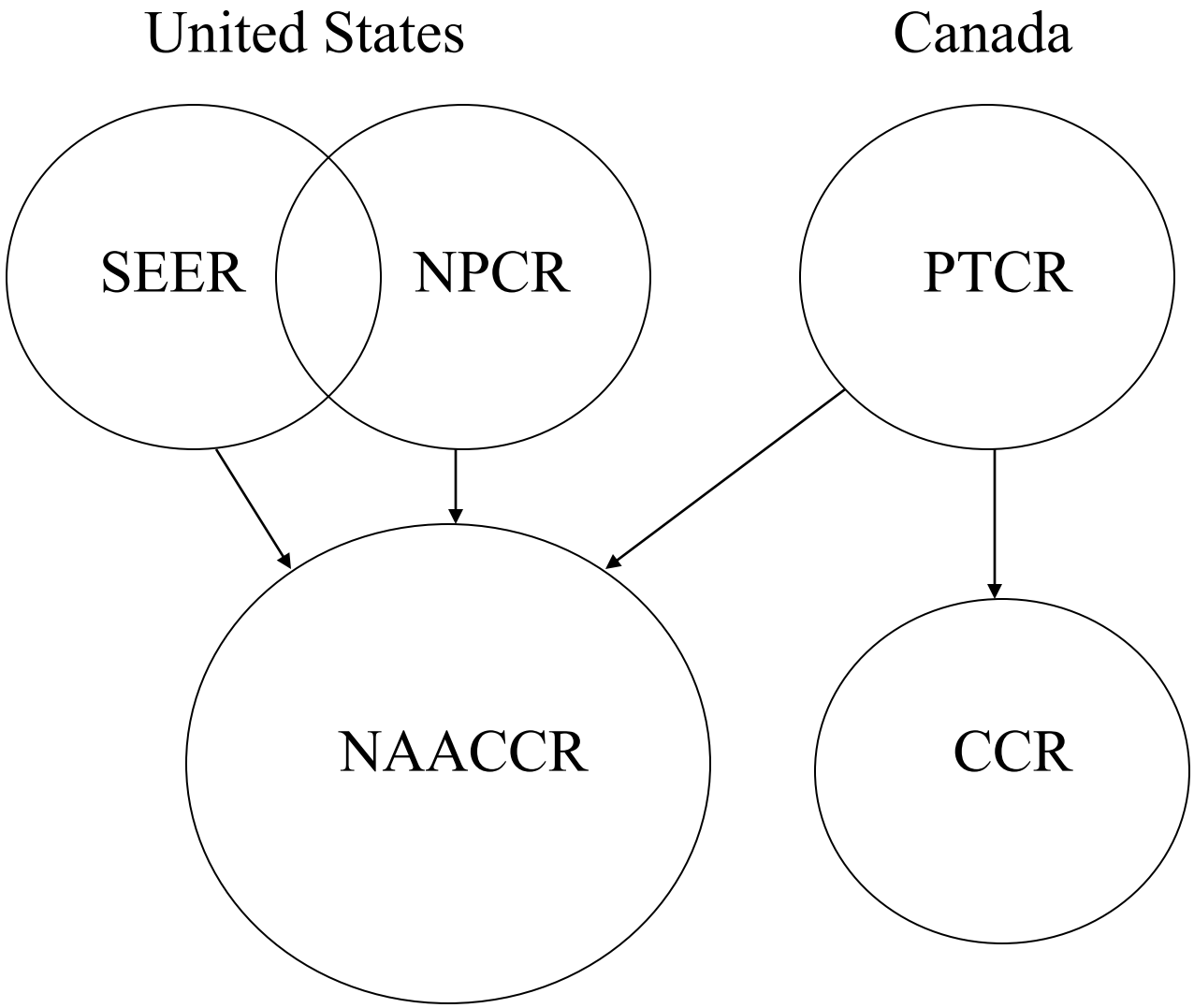
Comparability

- Definition: *the extent to which registry practices (e.g. criteria for registration, coding practices, etc.) adhere to standard guidelines and can be compared over time and across registries.*

- Important when analyzing and interpreting variations in cancer burden across space and time

- Methods to ensure comparability:
  - Documentation of registry practices
  - Standards for registration and coding (e.g. NAACCR, CCR guidelines)

North American cancer registries



Comparability

- Classification and coding systems
  - Example: the coding of behaviour for borderline malignant ovarian cancers
- Definition of incident cases
  - Behaviour codes captured
    - In situ (/2) bladder; benign brain cancers
- Definition of a primary cancer
  - SEER, IACR, CCR rules for counting multiple primaries

Completeness

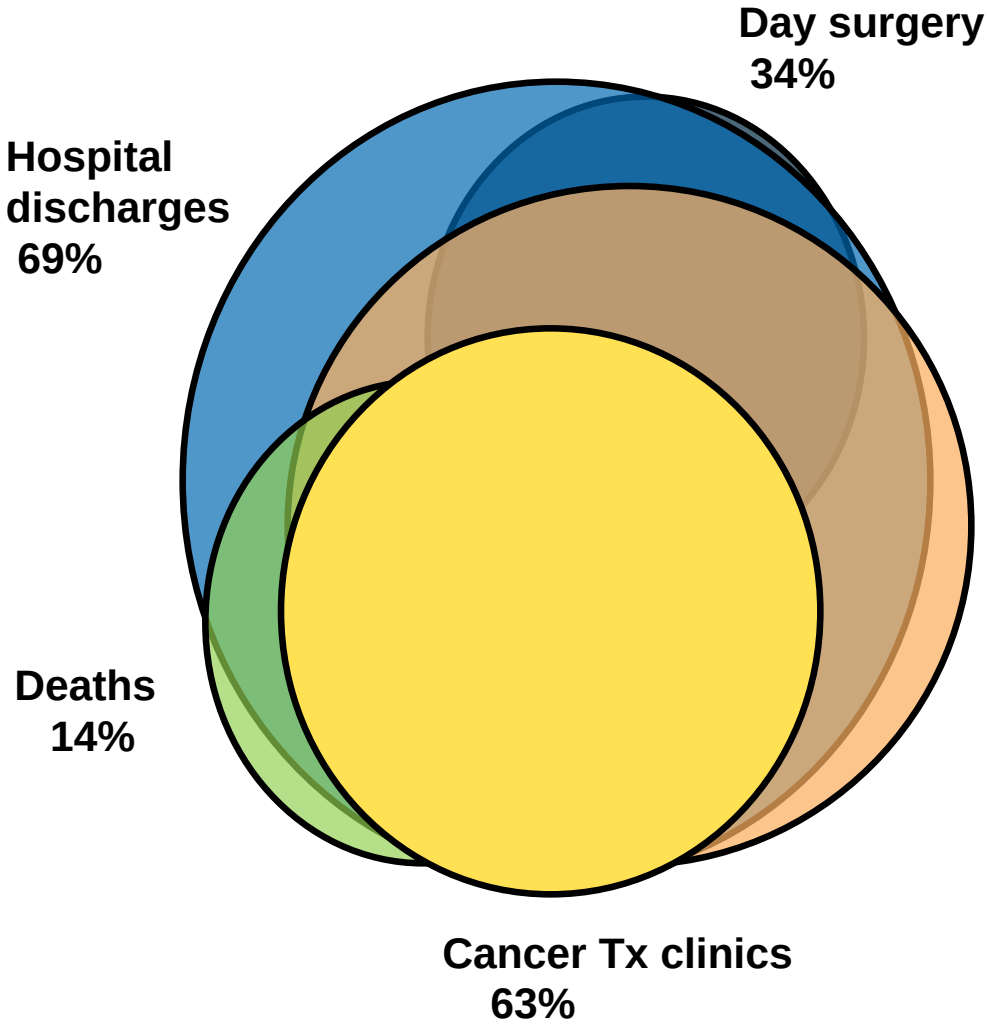
- Definition: *The extent to which all incident cancers in the population are included in the registry (i.e. case ascertainment).*
- Indicates how closely incidence rates and survival proportions reflect their true value
- Methods to ensure completeness:
  - Multiple data sources to register cases
  - Legislation for reporting incident cases
  - Record linkage with other databases (e.g. other registries, national/provincial death clearance)

Completeness

- *Semi-quantitative* methods for assessing completeness:
  - Historic data methods
    - E.g. compare counts/rates to historic values or to other jurisdictions
  - Incidence:mortality (mortality:incidence) ratios
  - Number of sources per case
  - % single sources (e.g. death certificate only, hospital only, etc.)
- *Quantitative* methods for assessing completeness:
  - Independent case ascertainment
    - Case-finding audits (i.e. rescreening of a sample of sources)

Completeness

- Reporting sources for incident cases in the OCR, 2007



% Single Source	
Hosp only	5%
Path only	7%
DC only	2%
Clinics only	3%
(Day surgery only	+2%)

Accuracy (validity)

- Definition: *the proportion of registered cases with a given characteristic that truly have that attribute.*

- Methods to ensure accuracy:
  - Multiple sources to register cases
  - Training of registry personnel
  - Electronic ‘edits’
  - Record linkage to other databases (e.g. provincial health insurance plans)
  - Trace-back and follow-back procedures

Quantitative methods for assessing accuracy

- Reabstraction studies and recoding audits
  - Assess agreement with source records or among coders
- Histologic verification:
  - % microscopically verified (e.g. histology, cytology, autopsy)
- Death certificate only (DCO) cases
- Missing information
- Internal consistencies

Timeliness

- Definition: *the speed with which a registry can collect, process, and report complete and accurate cancer data*
- Depends on two time intervals:
  - Time until receipt: *time from diagnosis to receipt of report*
  - Process time: *time from receipt to data availability*
- Ensures up-to-date data is available to health researchers, providers, and planners
- A trade-off exists between the timeliness of the data and the completeness and accuracy

Data quality standards for cancer registries

- Several standards for acceptable data quality (e.g. NAACCR criteria, SEER, CCR guidelines, etc.)
- Data quality should always be considered in context of use
  - *Example:* Standards for assessing common indicators for accuracy

	Indicator Name	CCR Optimal Value	NAACCR Gold Standard
Accuracy	Microscopically Confirmed Cases	≥ 93%	--
	Death Certificate Only†	≤ 3%	≤ 3%

Data quality implications for the OCR

- Comparability
  - Multiple primary rules
  - Population data
- Completeness
  - AB/MB/ON Case Ascertainment Study
- Accuracy/Validity
  - Ontario re-abstraction study
- Timeliness
  - Not so good…

References

- Bray F and Parkin DM. Evaluation of data quality in the cancer registry: Principles and methods part I: Comparability, validity and timeliness. Eur J Cancer 2009;45:747-755.
- Parkin DM and Bray F. Evaluation of data quality in the cancer registry: Principles and methods part II: Completeness. Eur J Cancer 2009;45:756-764.