

# The Ontario Cancer Registry and its Data Quality

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# 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”

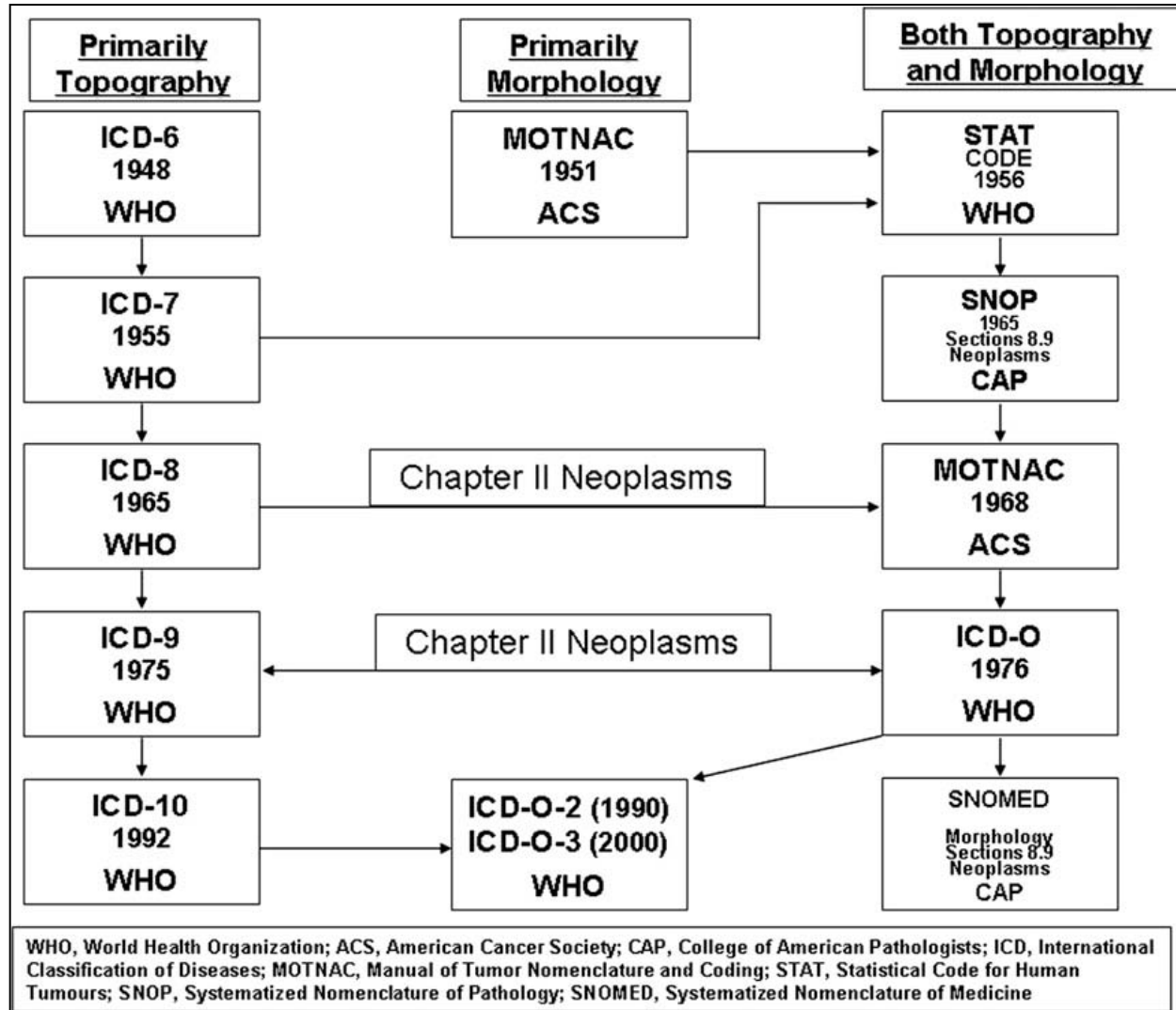
# Classifying cancer

- 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

## 5<sup>th</sup> 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

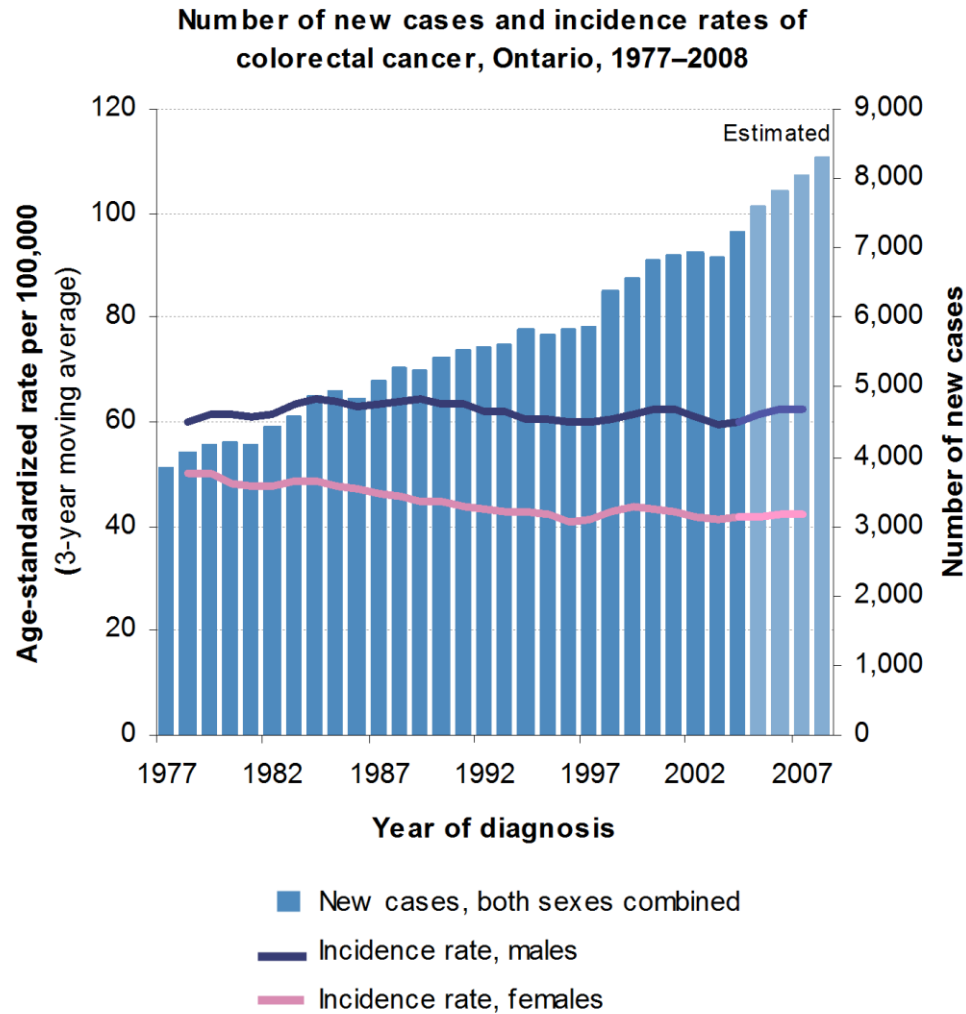


# Incidence

- **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)

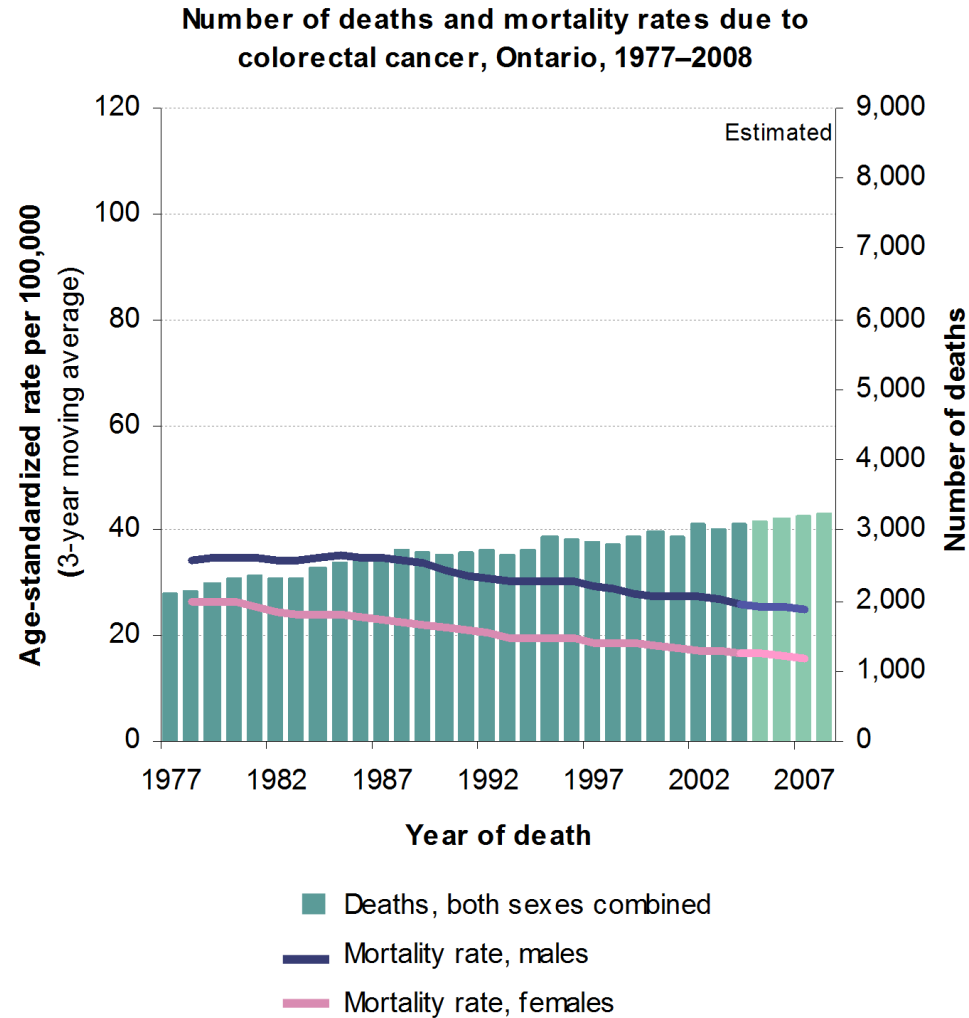
# Mortality

- **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

<b>Coding System</b>	<b>RCCs</b>	<b>PMH</b>
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??



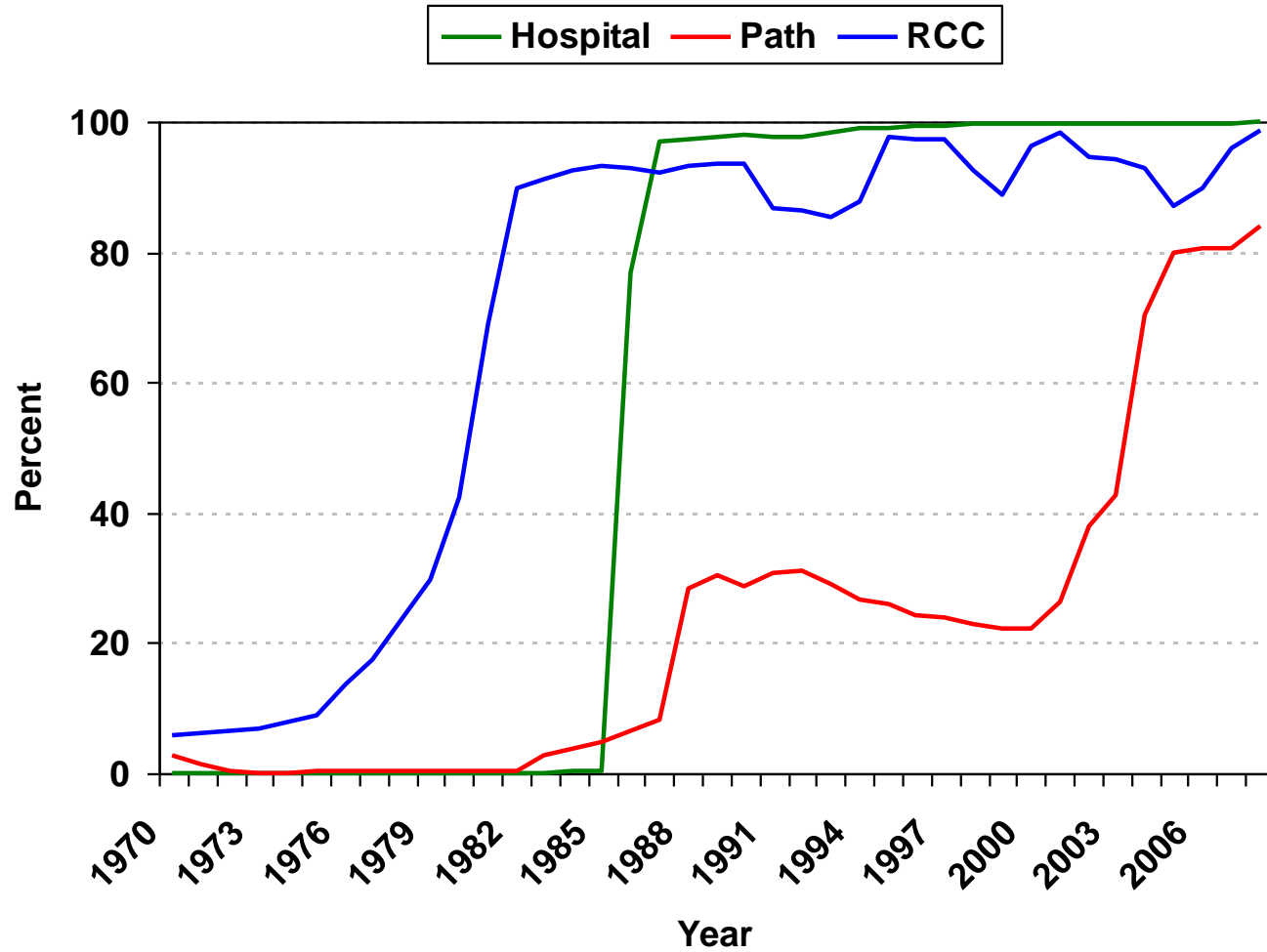
# Which OCR data sources use what codes?

<b>Source</b>	<b>SGC</b>	<b>MOH</b>	<b>Postal Code</b>	<b>RG SGC</b>
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

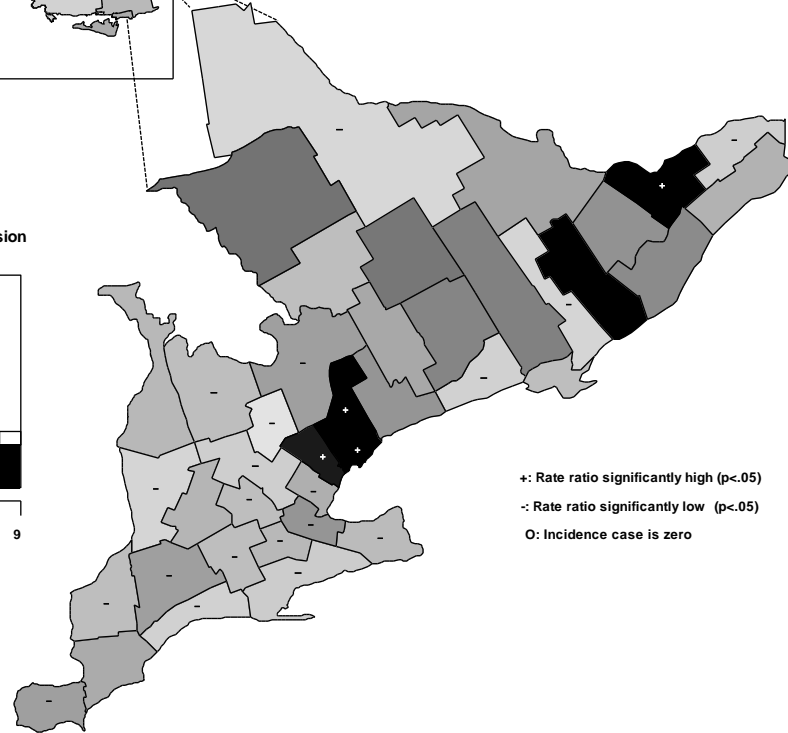
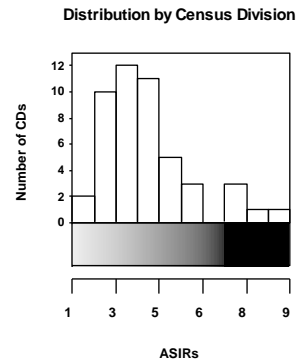
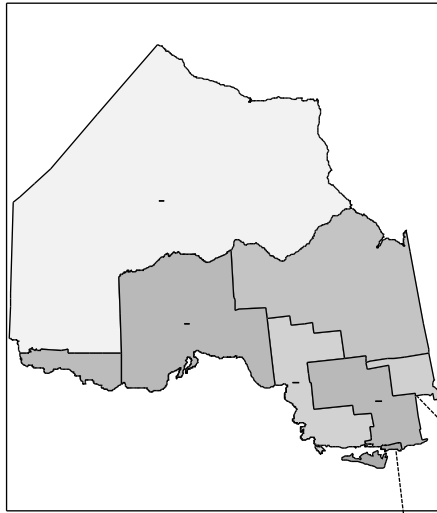
- SGCs compared for 272,981 records with no problems
  - 97.9% postal code & MOH agree
  - 1.4% CD agrees, but CSD disagrees
  - 0.7% nothing agrees
- Common disagreements?
  - MOH says Toronto, postal code says no: 28%
  - Postal code says Toronto, MOH says no: 6.5%
  - Wrong MOH code for 2 places with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



- + : Rate ratio significantly high ( $p < .05$ )
- : Rate ratio significantly low ( $p < .05$ )
- O : Incidence case is zero

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
<ul style="list-style-type: none"><li>• Registry operations</li></ul>	<ul style="list-style-type: none"><li>• Purpose of data collection</li></ul>
<ul style="list-style-type: none"><li>• Registry resources</li></ul>	<ul style="list-style-type: none"><li>• Resources of external data sources</li></ul>
<ul style="list-style-type: none"><li>• Access to additional data sources</li></ul>	<ul style="list-style-type: none"><li>• Reporting diligence</li></ul>

# Dimensions of data quality in cancer registries

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

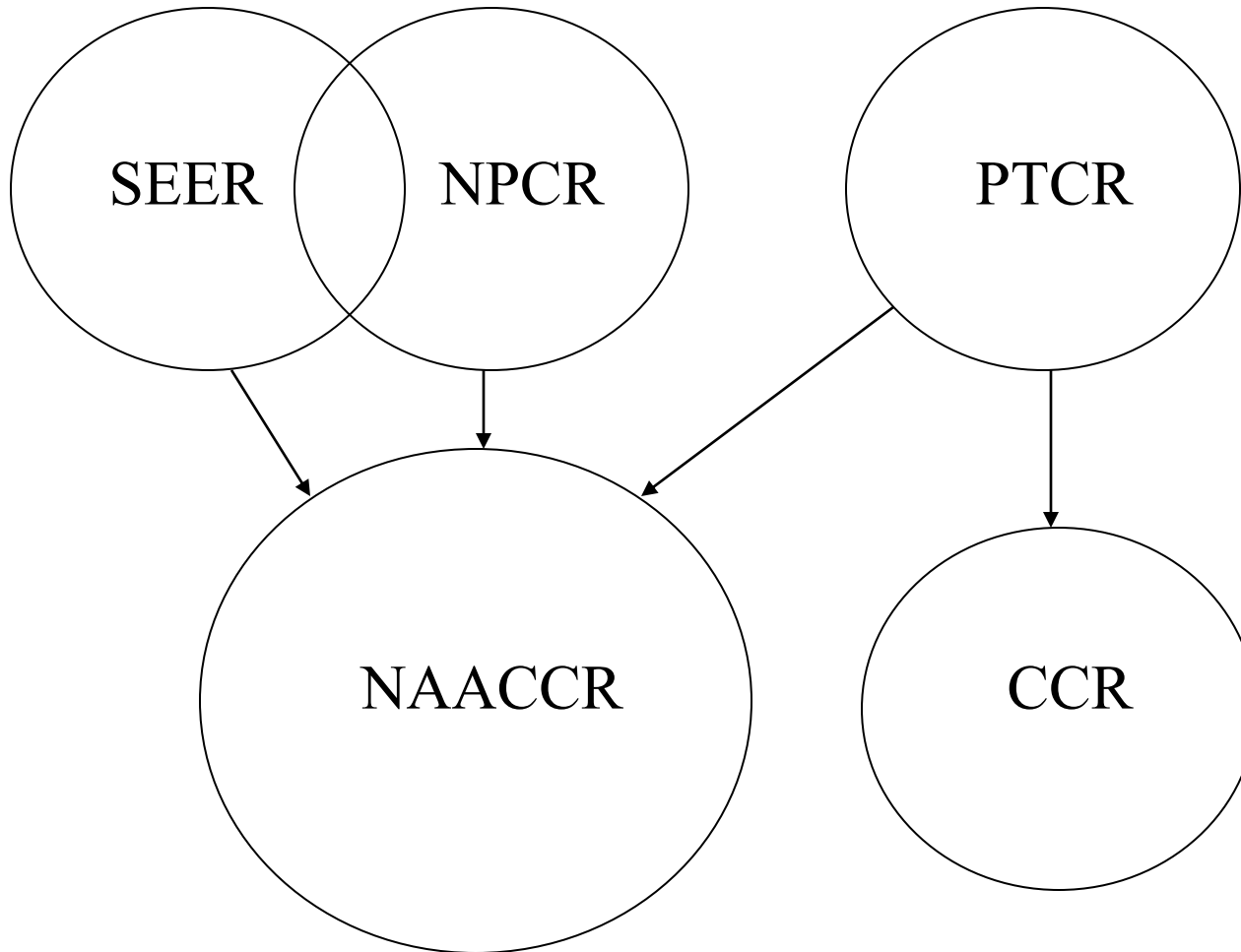
# Comparability

- **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

United States

Canada



# 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)

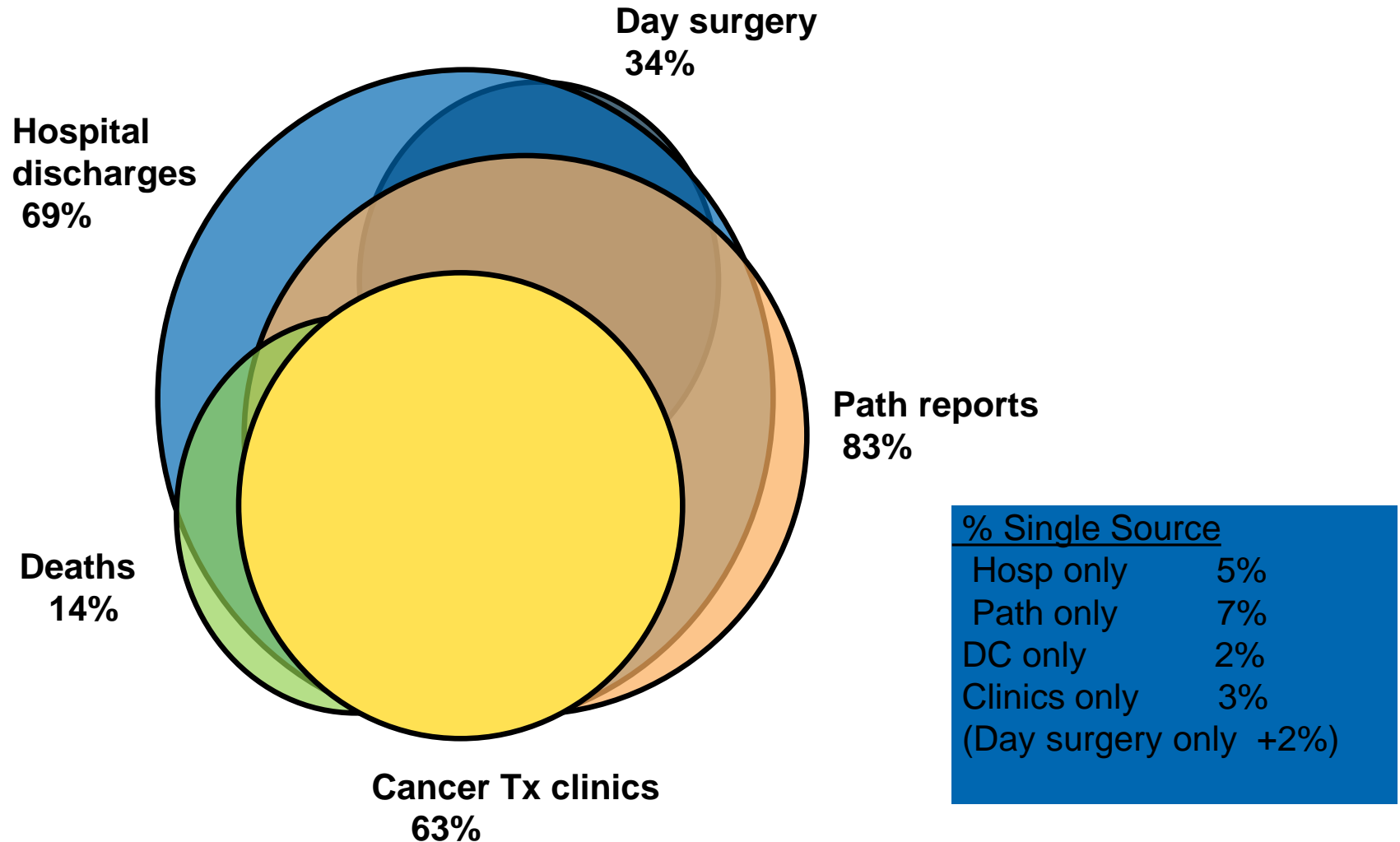
# Completeness

- *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



# 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 <sup>†</sup>	≤ 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.