



Understanding Cancer Registry- Based Treatment Data

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What are Cancer Registries?

- Cancer registries are the primary source of high-quality epidemiologic data

Cancer Registry: an information system designed for the collection, storage, management, and analysis of data on persons with cancer, usually covering a hospital or group of hospitals

A primary source for

- Unbiased population-based case control studies
- End points for cohort studies and clinical trials
- Beginning point for survival analysis

Purpose:

- To establish and maintain a cancer incidence reporting system
- To be an informational resource for the investigation of cancer and its causes
- To provide information to assist public health officials and agencies in the planning and evaluation of cancer prevention and cancer control programs



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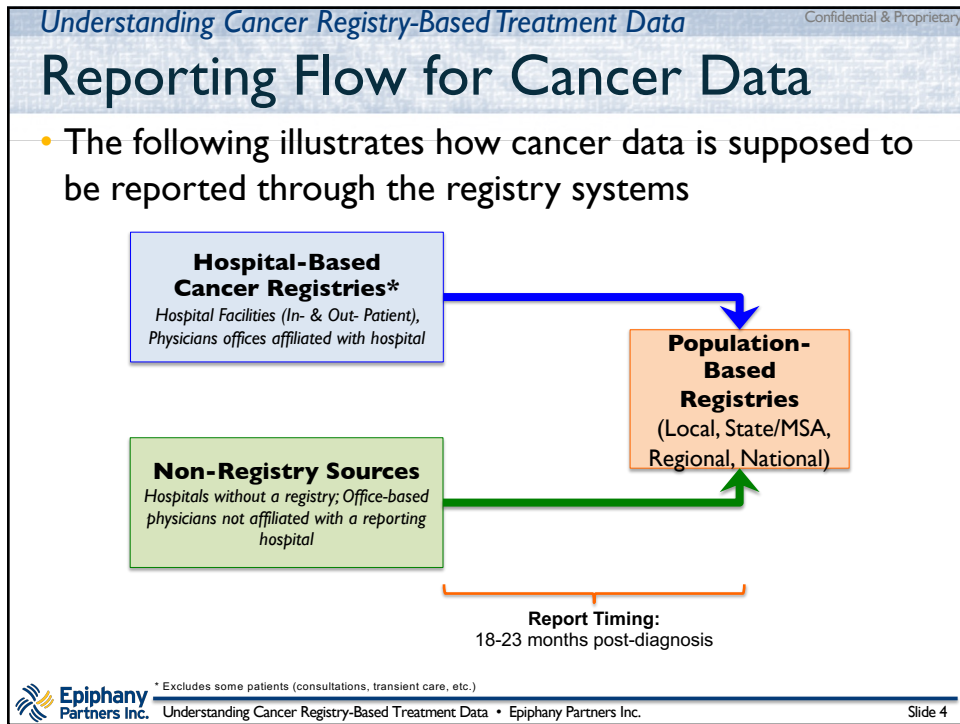
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Examples of Types of Registries

Type	Hospital-Based Registry	Population-Based Registry
Example	California Pacific Medical Center Registry <i>San Francisco, CA</i>	Greater Bay Area Cancer Registry, CA <i>San Francisco-Oakland, San Jose-Monterey</i>
Source	Single Hospital and Collective Registries	Administrative, Research, or Cancer Control Oriented
Purposes	<ul style="list-style-type: none"> Improvement of patient care Professional education Administrative information Clinical research 	<ul style="list-style-type: none"> Cancer prevention Early detection Determination of cancer rates and trends Patterns of care and outcomes Research Evaluation of control efforts
Details	<ul style="list-style-type: none"> Maintain data on all cancer patients diagnosed and/or treated at a particular facility Provide medical audit-type evaluation of outcomes within the institution Supporting institutional registries with common standards and pooled data 	<ul style="list-style-type: none"> Record all new cases in a defined population (e.g. geographic area) with an emphasis on epidemiology and public health Inform cancer agencies and organizations of cancer statistics in specific populations Inform cancer research programs for an unbiased group of cases to be selected for studies


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First-Course Treatment Data

- Only the initial or “first course” of treatment is required to be collected by registries, mainly for in-patient treatment
 - The following are the “required” type of “First Course” modality data
 - Surgery
 - Radiation therapy
 - Chemotherapy
 - Hormone therapy
 - Immunotherapy
 - Targeted therapies
 - Hospital-based data may reflect modalities used in early-stage patients (surgery, radiotherapy), but may not accurately reflect later stages where systemic therapies are more common in advanced/recurrent patients or hematological malignancies


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In-Patient vs. Out-Patient Data

- Data collected by a hospital-based registry fall into the categories shown in the table:

Diagnosis Location	Treatment Location	Hospital Registry Status
Diagnosed at this hospital	All or part of the first course of therapy given at this hospital (In-Patient)	ANALYTIC CASE
Diagnosed elsewhere	All or part of the first course of therapy given at this hospital (In-Patient)	ANALYTIC CASE
Diagnosed at this hospital	All of the first course of therapy given elsewhere (Out-Patient)	ANALYTIC CASE
Diagnosed elsewhere	All of the first course of therapy given elsewhere (Out-Patient)	NOT CAPTURED
- Patients diagnosed and treated outside the hospital are not collected in the reported registry treatment data
- This could be a major limitation given that the majority of late-stage patients are usually treated in the community setting


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In-Patient vs. Out-Patient Data

- Most community oncologists and other cancer-treating physicians (urology, dermatology, etc.) send their data to a population-based registry, **NOT** a hospital-based registry
 - Therefore, the majority (~95%) of data from a hospital-based registry are for “in-patient” records
 - Available registry data estimates in-patient treatment at 95%, compared to COA and ACCC estimates that out-patient treatment is 80%+

Diagnosis Site	Treatment Site	Number of Cases	% In-Patient Treatment	% Out-Patient Treatment
In-Patient	In-Patient	637,471	61.84%	—
Out-Patient	In-Patient	329,096	31.92%	—
In-Patient	Out-Patient	64,322	—	6.24%
In-Patient	In-Patient	—	—	—
ALL SITES PATIENTS		1,030,889	93.76%	6.24%

Source: NCDB, 2015 Data, Accessed March 2018; Community Oncology Association, 2014.

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Limited Out-Patient Treatment Data

- Given that limited out-patient treatment data is collected, hospital-based registry data may not accurately assess the out-patient treatment trends
 - From 25% to 50% of out-patient records list “No Therapy” as their first-course treatment which is significantly higher than the in-patient “No Therapy” estimates

Cancer Site	% Out-Patient Data	% of Out-Patient No Therapy	% of In-Patient No Therapy
AVERAGE	6.24%	32.98%	7.03%
Bladder	1.02%	47.93%	2.53%
Kidney & Renal Pelvis	4.82%	42.61%	7.59%
Pancreas	16.24%	40.50%	31.76%
Non-Small Cell Lung	12.11%	32.44%	16.57%
Breast	4.69%	27.13%	1.87%

Source: NCDB, 2015 Data, Accessed March 2018.

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Treatment Data Limitations

Sample Size	<ul style="list-style-type: none"> • Large registry-based datasets include National Cancer Data Base (no longer publicly available) and SEER-Medicare (access fee required) • Variable sample sizes and accessibility issues • Age-based limitation on SEER-Medicare data (only patients over 65 years)
Not Longitudinal at Patient Level	<ul style="list-style-type: none"> • Data is longitudinal within a population, but not at the patient level
First Course Treatment Data	<ul style="list-style-type: none"> • Only first course of treatment are collected with high degree of quality control • Supplemental data (2nd- or 3rd-course) have limited availability and quality issues • Less common modalities (e.g. transplantation, consolidation, and maintenance therapy) are not captured
Focus on Hospital-based Patients	<ul style="list-style-type: none"> • Hospital-based registries capture mostly in-patient data, since community oncologists and other physicians often send patient data directly to population/regional/state registries
Lack of Out-patient Data	<ul style="list-style-type: none"> • Patients diagnosed and primarily treated outside the hospital are not included in the treatment data • Most late-stage patients are not treated in the hospital setting


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