Epiphany Partners Inc.

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:**
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> - 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
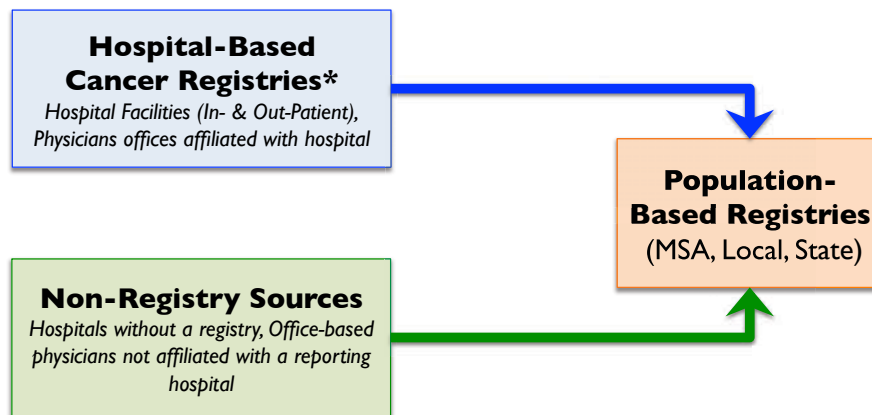
Types of Registries

Type	Hospital-based	Population-based
Example	California Pacific Medical Center Registry *San Francisco, CA*	Greater Bay Area Cancer Registry, CA *San Francisco-Oakland, San Jose-Monterey*
Source	Single Hospital and Collective Registries	Administrative, Research, or Cancer Control Oriented
Purposes	• Improvement of patient care • Professional education • Administrative information • Clinical research	• Cancer prevention • Early detection • Determination of cancer rates and trends • Patterns of care and outcomes • Research • Evaluation of control efforts
Details	• 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	• 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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Reporting Cancer Data Flow

• Population-based registries contain data from hospital-based registries and supplementary sources

Hospital-Based Cancer Registries*
Hospital Facilities (In- & Out-Patient), Physicians offices affiliated with hospital

Population-Based Registries
(MSA, Local, State)

Non-Registry Sources
Hospitals without a registry, Office-based physicians not affiliated with a reporting hospital

* Excludes some patients (consultations, transient care, etc.)

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
  - 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 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)	EXCLUDED (NON-ANALYTIC CASE)

- Patients diagnosed and treated outside the hospital are excluded from the registry treatment data
- This is a major limitation given that the majority of late-stage patients are usually treated in the community setting

Registry Data Flow

- Most community oncologists and other physicians (urology, dermatology, etc.) with cancer patients send their data directly to a population-based registry
  - Therefore, the majority (95%+) of data from a hospital 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	No. of Cases	% In-Patient Treatment	% Out-Patient Treatment
In-Patient	In-Patient	133,786	66.0%	—
Out-Patient	In-Patient	60,754	30.0%	—
In-Patient	Out-Patient	8,122	—	4.0%
OVERALL		**202,662**	**96.0%**	**4.0%**

Source: NCDB, 2008 Data, Case 0 (Out-Patient), Accessed April 13, 2011; Community Oncology Association, 2012.

Cancer Registry Limitations

Sample Size
- Largest registry-based treatment dataset is the National Cancer Data Base (43.1% coverage), but other registry-based treatment datasets (e.g., IMPAC's National Oncology Data Alliance) represents less than 10% coverage
- Low samples exist in some hematologic malignancies
- Sample sizes are variable from year to year

Not Longitudinal at Patient Level
- Data is longitudinal within a population but not at the patient level

First Course Treatment Data
- Only first course of treatment are collected with high degree of quality control and coding
- Supplemental data (2nd- or 3rd-course Tx) are usually "incentivized"
- Less common modalities (e.g. transplantation, consolidation, and maintenance therapy) are not well captured

Focus on Hospital-based Patients
- Hospital-based registries capture mostly in-patient data, since community oncologists and other physicians send data directly to population registries

Lack of Outpatient Data
- Patients diagnosed and treated outside the hospital are not included in the treatment data
- Most late-stage patients are not treated in the hospital setting, resulting in less rigorous late-stage treatment trends

Isn't it Time You Had an Epiphany?

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