Cancer Registry Data: A Powerful Tool for Every Cancer Program

By: Dawn DeBolt

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Cancer data collection is common practice, as mandated by law, but do oncologists, administrators and other healthcare providers fully understand what the data can tell them? And do they know that access to the data is right at their fingertips?

In a previous article, "Understanding Cancer Registry Data Collection and Data Mining,"[a] we discussed the who, what, when, where, why and how of cancer registry data collection. We highlighted the key components of data collection and the value of the collected data. We also pointed out how, unfortunately, the data are underused. Clinicians and administrators should understand the various types of data available from their cancer registry and how these data can tell a story about cancer care and outcomes at their institution.

Cancer registry data provide limitless data analysis and review opportunities. The data can be used to assess cancer care and clinical outcomes at any healthcare institution nationwide. The cancer registry department is always eager to share the data they have meticulously collected. The data can answer questions such as:

- How many patients were diagnosed and/or treated at your institution by:

  - cancer site?

  - cancer site, stage of disease, grade of disease, histologic type of disease, or any combination of these?

  - zip code or county?

- How many patients were diagnosed with cancer at your institution but received their treatment elsewhere (out-migration), or were diagnosed elsewhere but treated at your institution (in-migration)?

- How much time passed between a patient's abnormal mammogram and ultrasound-guided needle core biopsy?

- What was the span of time between date of first contact for a cancer diagnosis, date of first positive biopsy, date of first surgical procedure, date of first radiation, chemotherapy,

hormonal therapy or immunotherapy treatment?

- How many total cancer cases were diagnosed at your institution in a specific year, by primary site, by sex, by age group, by stage, etc.?

- What was the number of lung cancer patients by smoking history and stage?

These are a few examples of possible data requests. A cancer registry dataset provides numerous ways to query and use your cancer data to better understand your program.

How often is cancer registry data used at your institution? Did you know data requests can be made through the cancer registry department and data can be queried for any period of time from the cancer registry reference date (i.e., start date) to the present? The reference date must be established for the cancer registry database in Commission on Cancer (CoC) Accredited Cancer Programs.[b]

Taking a closer look at the cancer registry data at your institution can paint a clearer picture of your institution's success stories and areas for improvement.

The cancer registry department will assist you with the data request process. Staff will help define and refine the data request to produce meaningful reports and data displays. Cancer registrars are data experts and can offer advice on other key metrics that may be of interest to the cancer committee or oncology clinicians. Data requests can be provided on an as-needed basis and updated information can be shared at specific time intervals of interest (i.e., monthly, quarterly, annually).

Oncology leadership may be interested in what types of cancer are most commonly diagnosed and/or treated at the institution and whether patients are receiving all of their care at the institution or choosing to go elsewhere for some or all of their treatment. Evaluating out-migration to determine why patients are seeking their treatment elsewhere is a key point of interest for strategic planning and cancer registry data can provide these answers. Out-migration statistics help hospital administrators and caregivers understand why patients may be looking to other

healthcare institutions for administration of their treatment.

Hospital administrators want to ensure their patient population has access to state-of-the-art treatment modalities and other services; however, unless out-migration is being reviewed, it may not be evident patients are seeking care elsewhere. Patients may seek treatment elsewhere for many reasons such as: access to clinical trials for patients whose diagnosis or cancer status prohibits them from receiving a standardized treatment modality; the institution does not provide access to transportation services for patients who are unable to get to and from their appointments on their own; or the facility across town may have recently opened a state-of-the-art cancer center and the patients want to ensure they are treated with the latest and greatest technology.

Review of Out-Migration or In-Migration

This information helps facility administrators understand how many patients are being diagnosed and treated solely at the reporting institution compared to how many patients are being diagnosed at the reporting institution but receiving part or all of their care elsewhere (out-migration), and how many patients are being diagnosed elsewhere but receiving part or all of their care at the reporting institution (in-migration) (Figure 1a).

Tumor registrars can query the cancer registry data to identify the names and locations of the facilities that patients are seeking care from outside of the reporting institution. Doing so can help determine if the reporting institution is lacking certain resources patients are looking for. The same holds true for in-migration. If you notice an influx of in-migration, tumor registrars can help identify the facilities that patients are coming from for a deeper look at why patients are choosing ABC Cancer Care Facility over other area healthcare providers.

To further dissect out-migration data, tumor registrars can query various data points to capture a clearer picture of what may be causing the out-migration. The example in Figure 1b is specific to breast cancer treatment, but this in-

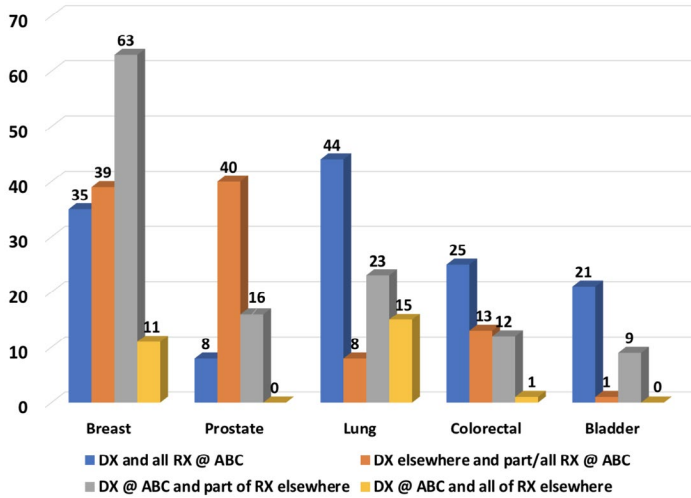reach and education or expansion of satellite healthcare centers to underutilized areas (Figures 2a and 2b).

Figure 1a: 2016 In- & Out-Migration Statistics, Top 5 Cancer Sites for ABC Cancer Care Facility
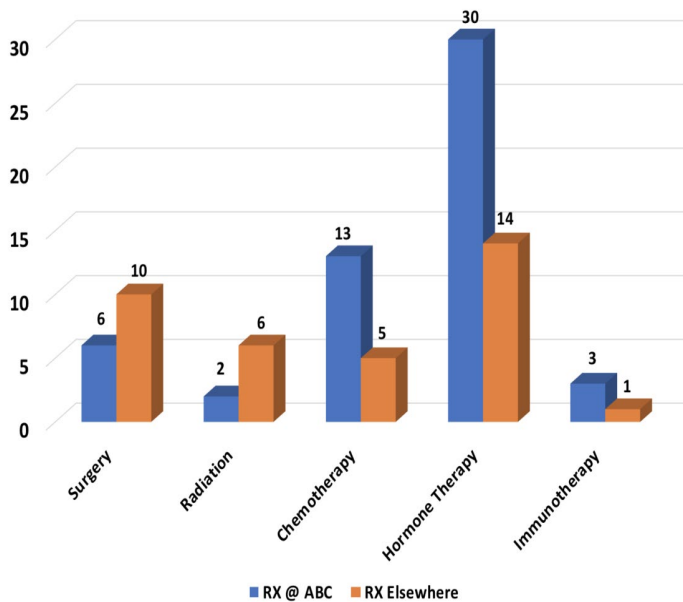

Figure 2a: 2016 Zip Code Distribution for ABC Cancer Care Facility (n=1,553)

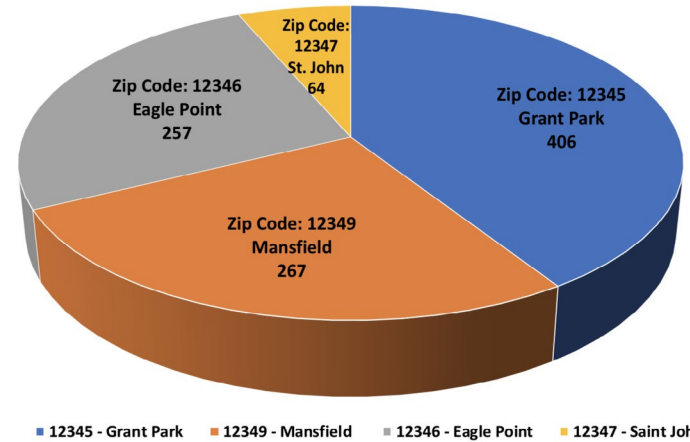Figure 1b: 2016 In- & Out-Migration Statistics, Breast Treatment, ABC Cancer Care Facility

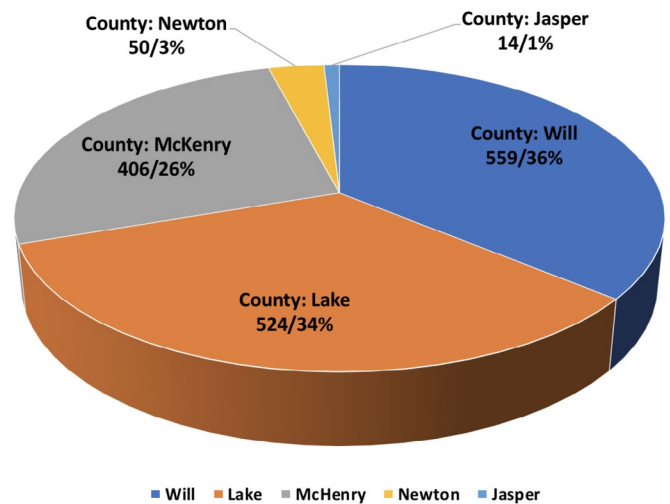Figure 2b: 2016 Country Code Distribution for ABC Cancer Care Facility (n=1,553)

formation can be provided for any cancer site of interest.

Patients by Zip Code or County Code

This information can be queried for all cancer sites combined, for one specific cancer site, for top five cancer sites, etc. Reviewing zip code and/or county distribution can help identify geographic areas not seeking care at the reporting facility. This information could help build a case for new marketing campaigns, community out-

Oncology care providers find it important to evaluate patterns of care and whether the National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology are being followed as the standard of care for their cancer patients.[c] Additionally, oncology leadership needs to understand the most common cancer sites being diagnosed and treated at their institution and the stage of disease at diagnosis. This information can help identify areas where further community awareness and education is

Site	Total	Sex		Class of Case		Status		Stage Distribution (Analytic Cases Only)							
		M	F	Analytic	Non-Analytic	Alive	Expired	Stg 0	Stg 1	Stg 2	Stg 3	Stg 4	88	Unk	Blank
Prostate	30	30	0	25	5	25	5	0	10	10	5	5	0	0	0
Bladder	15	8	7	12	3	13	2	0	5	5	2	3	0	0	0
Colorectal	20	12	8	17	3	20	0	1	4	4	5	0	0	4	2
Lung/Bronchus	11	7	4	10	1	11	0	0	4	1	1	1	1	2	0
Breast	106	0	106	95	11	105	1	12	53	19	2	1	0	1	7

Figure 3: 2016 Primary Site Table for ABC Cancer Care Facility (Summary by site, sex, class of case, status and stage – Top Five Sites)

needed (e.g., how to spot skin cancer), or whether additional access to preventative screening programs is warranted (e.g., an increase in late-stage melanomas diagnosed at the reporting institution).

Cancer Cases by Primary Site, Sex, Class, Status and Stage

Figure 3 shows a primary site table for the reporting institution summarizing the top five primary sites diagnosed in 2016 with a breakdown by sex, class of case, status and stage. This table can include all primary sites diagnosed, not only the top five.

Tim Laugh, service line director, Cancer Services at Tidelands Health in South Carolina, supports using cancer registry data to understand progress within his institution's cancer program and to identify areas for improvement or further review by his cancer program constituents. "The data really help with strategic planning and targeting those areas for growth or deficiencies—for example, is a thoracic surgeon needed due to out-migration? or why do we have more stage III or IV cases compared to state or national averages?" he said. "The pie and bar charts that can be created with the data paint a clear picture for senior leadership, especially when compared to the national data registry."

Your cancer registry department also has access to national datasets for benchmarking purposes through its software vendors, central cancer registries at the state level, the Commission on Cancer's National Cancer Database (NCDB)[d] and the American Cancer Society Cancer Facts and Figures,[e] to name a few.

The use of national benchmarks allows for comparison of key metrics from one institution to others across the country, and sometimes, depending on the dataset, the ability to compare your facility to facilities of similar size and type (e.g., community cancer programs, comprehensive cancer programs, network cancer programs, etc.).

Review of survival statistics helps facilities measure treatment success and long-term patient outcomes. Tumor registrars complete lifetime follow-up on all analytic patients within the cancer registry database. Follow-up helps capture periods of disease-free survival, evidence of cancer recurrence, diagnosis of subsequent primaries and, if a patient died, whether their cause of death was cancer-related or the result of a separate healthcare condition.

Examples of comparing institution level data with national benchmark data are presented in Figures 4a, 4b and 4c. These three examples illustrate the endless possibilities and types of data
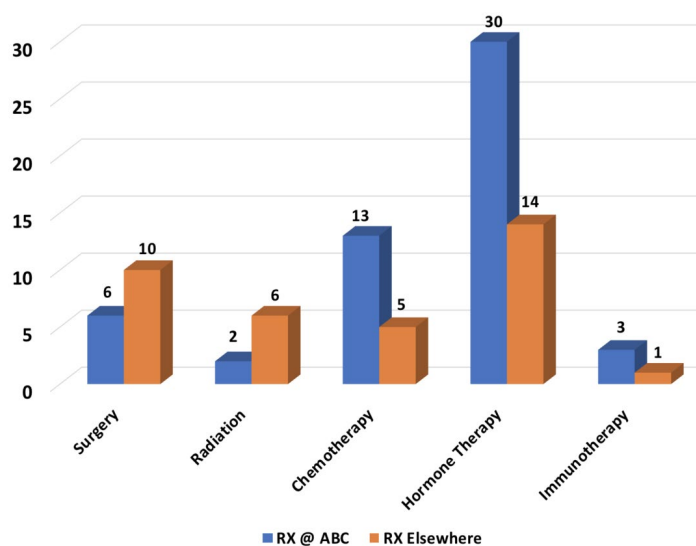

Figure 4a: Breast Cancer by Age Group (2006–2016) at ABC Cancer Care Facility vs. Comprehensive Cancer Centers in the U.S. (national) (Data from 586 hospitals)
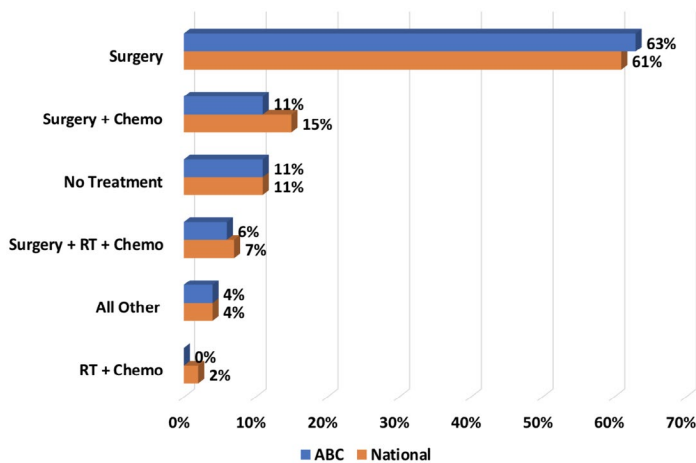
within the cancer registry.

Figure 4b: 2016 Colorectal Cancer by First Course Treatment at ABC Cancer Care Facility vs. Comprehensive Cancer Centers in the U.S. (national)
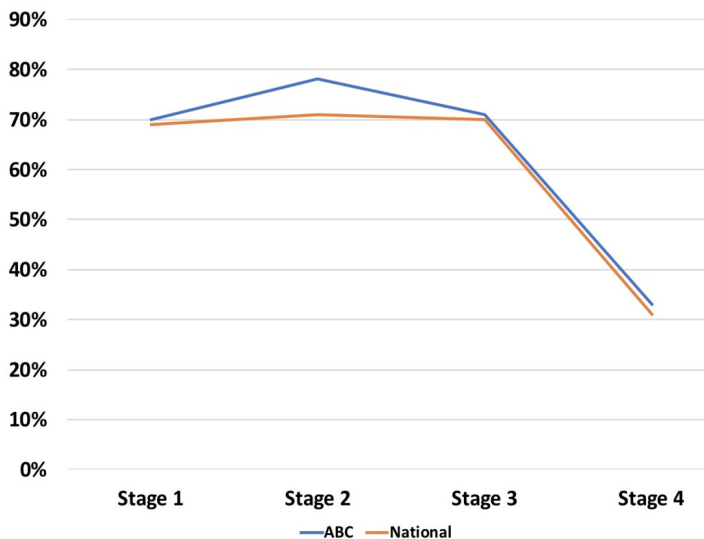

Figure 4c: 2012–2016 Prostate Cancer 5-Year Survival Rates at ABC Cancer Care Facility vs. Comprehensive Cancer Centers in the U.S. (national)

Put Your Data to Work

Cancer registry data are readily accessible to clinicians and administrators nationwide. Get to know your cancer registry team. Cancer registry departments are happy to receive requests for data reports. Take the time to educate your cancer care team members so they recognize the value and power of the data being collected. Either you or members of your team may also want to spend some time with cancer registry department staff to learn about the types of queries and how they can help you achieve specific goals. Using data analytics to identify institution-wide improvements, to evaluate the effectiveness of care being provided and to analyze the success of patient outcomes are integral to the delivery of patient-centered care.

Endnotes

[a] "Understanding Data Collection and Data Mining" was published in Radiation Oncology News for Administrators, Vol 27, No 4, 2017. Radiation Oncology News for Administrators is published by the Society for Radiation Oncology Administrators.

[b] Read more about the Cancer Registry Reference Date.

[c] Read more about the NCCN Clinical Practice Guidelines for Oncology.

[d] The National Cancer Database is a nationwide oncology outcomes database that currently collects information on approximately 70% of all new invasive cancer diagnoses in the U.S. each year. It serves as a powerful clinical surveillance and quality improvement mechanism for cancer programs participating in the American College of Surgeons (ACoS) Commission on Cancer (CoC) approvals program.

[e] The American Cancer Society Cancer Facts and Figures is an annual report providing the estimated number of new cancer cases and deaths, current cancer incidence, mortality and survival statistics and information on cancer symptoms, risk factors, early detection and treatment.

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