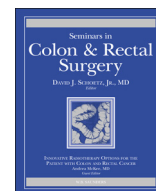




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The American College of Surgeons National Cancer Database: A successful initiative in improving colorectal cancer outcomes



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The National Cancer Data Base (NCDB) was created by the American College of Surgeons and the American Cancer Society, in an effort to improve cancer care, by collecting data about patients treated for oncologic disease on a national level. In capturing more than 70% of patients treated for malignancy in the United States, it has allowed researchers to understand the natural history of colorectal cancer (CRC) and analyze the progression and efficacy of therapeutic strategies aimed at CRC. Due to its focus on oncologic disease alone, the NCDB has also allowed subset analysis of specific tumors and patient populations as well as the validation and refinement of staging strategies. While data from the NCDB have contributed significantly to the study of colorectal cancer, the database remains underutilized with regard to its potential for furthering the understanding of colorectal cancers and improving the care of patients with these tumors.

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Background

The National Cancer Data Base (NCDB) was founded in 1989 as a joint effort by the American College of Surgeons and the American Cancer Society to track and study oncologic disease, treatment patterns, and patient outcomes. At its inception, all hospitals nationwide were able to participate and submit data; however, in 1996, only those hospitals that were Commission on Cancer (COC) approved were invited to report their patient-level data to the database. As a member of the COC, hospitals are now obligated to submit outcomes data to the registry, and in return these facilities receive comparison data from other participating institutions to assist with quality improvement strategies and help create benchmarks in care. While only one-third of all US hospitals contribute patient data to the NCDB, over 70% of all patients treated for malignant disease—including over one million new cases are added to the database annually—making the NCDB one of the largest clinical databases in the world.^{1,2}

Data collection for the NCDB

There are a number of different types of data collected by the NCDB including patient-specific, tumor-specific, and hospital-specific data fields. In preparation for submission, chart reviews are performed by specially trained Certified Tumor Registrars who

are knowledgeable about the nuances of various malignancies. These registrars are also able to contact individual care providers to ensure completeness of staging data and treatment plans. To ensure the integrity of the dataset, the NCDB has numerous quality control measures in place, protecting each participating institution from having their data shared publicly.¹

The data collected for each case includes patient demographics, comorbidities, cancer staging, tumor histology, treatment course and outcomes—including 5-year overall survival (Table 1). Along with standard demographic data, facility type and geographic region, the dataset also includes tumor-specific variables, making it more specialized than many administrative, or even clinical, databases. Tumor-specific variables include histology, grade, clinical and pathologic staging, regional lymph node examination, site-specific clinical markers such as CEA, and the timing of therapeutic interventions from the date of diagnosis. Data sets from more recent years also include operative approach and conversion data for minimally invasive techniques. Further, each individual is assigned a unique patient identifier that allows their care to be tracked at multiple facilities.¹

Select data from the 14 most common solid tumors in the NCDB are publicly available in published Public Benchmark Reports. One can enter the tumor site, facility type and location, and three other variables (i.e., patient demographics, tumor stage and/or histology, and treatment strategies) into an online search engine to evaluate how various tumors are managed in their region. While this does allow patients to better understand treatment trends, a shortcoming is lack of survival data.

However, researchers intending to study outcomes and more specific clinical questions can obtain more complete datasets

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Table 1
Review of variables included in National Cancer Database.

Data type	Variable	Description
Hospital	Facility key	Unique identifier
	Facility type	Community, Comprehensive, Academic, Integrated Network Cancer Centers
	Location	Regional Location in US—9 subdivisions
	Multiple source	Case data collected from multiple institutions
Patient	Case Key	Unique identifier
	Demographics	Age, gender, race, Hispanic origin
	Socioeconomic status ^a	Education, income, community (urban, suburban, and rural)
	Insurance status	Private, medicare, medicaid, government, not insured
	Travel distance ^a	Distance from patient zip code to treatment facility
	Comorbidity Score	Charlson Comorbidity Index, scores 0–2
Tumor	Primary site	ICD-O-3 topography code
	Year of diagnosis	
	Class of case	Breakdown of diagnosis and treatment facilities
	Identification	Method of diagnostic confirmation, days from diagnosis to confirmation
	Biologic characteristics	Histology, behavior, grade, and size
	Lymph node status	Number of nodes examined and with disease
	Stage	AJCC clinical and pathologic staging, NCDB analytic stage group, Collaborative Stage Data Collections System variables
Treatment	Status	Patient treatment vs. surveillance, sequence of therapy
	Surgery ^b	Surgical procedure/site, approach, regional lymph node evaluation, margin status
	Radiation therapy ^b	Location, volume, modality, boost therapy, and number of treatments
	Systemic therapy ^b	Chemotherapy, hormone therapy, immunotherapy, hematologic transplant, and endocrine procedures
	Other treatment ^b	Treatment outside of surgery, radiation and systemic therapy, includes experimental therapy, embolization etc.
Outcomes	Palliative care	Includes radiation, systemic therapy, and surgical procedures targeted at controlling symptoms
	Length of stay	Surgical inpatient stay
	Readmission	Readmission within 30 days of surgical discharge
	Mortality	30-Day and 90-day
	Last contact	Months between diagnosis, last date of contact and vital status at that time

Adapted from NCDB Data Dictionary Participant User File 2013. For a more complete review of variables in NCDB please see <http://ncdbpuf.facs.org/>

^a Based on patient zip code data.

^b All treatment variables include treatment-specific days from diagnosis to intervention and indication for no therapy.

through an application process that is held biannually for organ-specific data files. The application includes the objectives of the research project, a designated principal investigator (PI), and an overview of the research plan that ensures the proposed investigation is clinically relevant and feasible within the limits of the dataset. Applicants also agree to maintain the dataset as HIPAA compliant—de-identified at the hospital level—and also to assist with refining the data dictionary, to mentor new users and to not link the database.¹

Strengths and weakness of the NCDB

In capturing over 70% of new cancer cases in the US, including almost all cases treated at NCCN and NCI designated cancer centers and over half of VA Hospitals, the NCDB is a very powerful research tool. In addition to the focus on cancer specific variables as described above, the size of the dataset allows the study of rare tumors that practitioners may only treat a few times over their career, and are nearly impossible to study with clinical trials due to difficult accrual.^{3,4} The vast patient population also allows for very specific subset analysis based on patient characteristics, tumor behavior and stage, and treatment strategies. Further, the NCDB tracks patients' long-term outcomes and provides 5-year survival data. The data have also been validated as having comparable data to the NCI sponsored Surveillance, Epidemiology and End Results Program (SEER) database.⁵

While the information provided in the NCDB is very useful for furthering the study of oncologic disease, there are a number of shortcomings of the dataset. Similar to most national databases, clinical outcomes are limited to 30 days. Secondly, while 5-year overall survival is monitored, disease-specific survival is not recognized, making natural-history survival inferences difficult to

make. Thirdly, there are no cost data to allow for comparison of economic disparities in care, nor determine the financial burden of care felt by these patients. Fourth, as it is required to be a COC accredited hospitals to participate in the NCDB, smaller, rural hospitals that deliver cancer care are also missed. Thus, generalizing care from the more specialized COC approved hospitals may not reflect cancer-directed therapy received at less specialized institutions, and may also under-estimate disparities in care. Additionally, due to the commitment to maintain facility anonymity, the dataset cannot be linked with other databases to augment cost or outcomes data not collected by the NCDB. Finally, previous studies have suggested that up to 25% of patients may be lost to follow-up,⁶ and minorities may be underrepresented in the dataset.⁵

Use of the NCDB in the study of colorectal cancer

For the study of colorectal cancer specifically, the NCDB divides the dataset into colon, rectum/rectosigmoid junction, and anus/anal canal/anorectum specific participant user files (PUFs). Initial research in colon, rectal, and anal cancers was descriptive and sought to evaluate trends in neoadjuvant and adjuvant care, including annual evaluations of treatment patterns.^{7–12} As the size—as well as access to—the database increased, so have the impact and number of publications.

Colon cancer

The first analyses of the data collected in the NCDB were descriptive and sought to assess practice patterns and outcomes in order to foster more standardized care and set the stage for future areas of investigation. Annual reviews of patient care, with

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