



# National Cancer Database: The Past, Present, and Future of the Cancer Registry and Its Efforts to Improve the Quality of Cancer Care

Ryan M. McCabe, PhD

The National Cancer Database (NCDB) continues to evolve to improve the care of the cancer patient. Over the last 30 years, the NCDB has compiled nearly 40 million patient records submitted by over 1500 hospitals across the country. Addressing new challenges, the NCDB is transitioning to ensure data flow is more timely and data collection more efficient. The Rapid Cancer Reporting System will be a significant step toward bringing data abstraction into real time and providing a quality data platform to support the information needs of high-quality clinical practice.

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## The Past

The National Cancer Database (NCDB) was established in 1989 by the American College of Surgeons' Commission on Cancer and the American Cancer Society. In those early days, hospital registrars would source paper charts to abstract tumor cases into hospital registries. During the annual Call for Data, years of completed cases were submitted to the NCDB via mailing floppy disks. Staff loaded these discs one at a time onto a computer to compile the data, compute reports, and conduct analyses. Over time as newer technologies began to be implemented throughout health-care, the way data were abstracted and submitted also changed. Instead of abstracting from stacks of paper records into registry software, registrars used electronic health record (EHR) screens as input. Sending a file of case records to the NCDB's Call for Data became similar to attaching a file to an email.

The first step many of these technologies achieved was to replace paper charts, floppy disks, and postage stamps with graphical user interfaces, databases, and transmission lines. This phase of technological adoption could be referred to as, "paving over the cow path." This double-edged idiom acknowledges the piecemeal progress being made while also

pointing out a potential gap between prior ways of doing things and a paradigm shift made possible by combinations of emerging technologies creating new tipping points – perhaps the cow path can be redirected as it is being paved.

## The Present

The NCDB has grown over the past 30 years into a sizeable collection of registry-based data. At the start of 2019, over 39 million analytic patient cases have been submitted to the NCDB, resulting in 32.6 million unique patients comprising the NCDB's accumulation of data, some of whom were diagnosed before 1989. Registrars continue to follow up on some patients' vital statuses from diagnoses decades ago. The Call for Data continues – in its paved cow path form – and across nearly 1500 hospitals collects 1.46 million newly diagnosed patient cases as well as more than 8 million updated cases each year. This collection covers 75 different diseases and over 72% of newly diagnosed patients in the United States.<sup>1</sup>

The enduring vision of the NCDB is to improve the care of the cancer patient. The current uses of NCDB data could be organized into two categories: quality improvement and quality research. Both uses are leveraged at the hospital level for teams of care providers. One of the biggest strides in quality improvement by the NCDB over this time has been the use of quality measures. In 2006 the NCDB developed five National Quality Forum-endorsed quality measures across two cancer sites – breast and colon – and implemented those quality measures in our web and database

American College of Surgeons, Chicago, IL

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Address reprint requests to Ryan M. McCabe, PhD, American College of Surgeons, 633 N. Saint Clair St., Chicago, IL 60611-3211.

E-mail: [rmccabe@facs.org](mailto:rmccabe@facs.org)

platform. In the NCDB environment, quality measures are neither sampled nor directly abstracted for compliance. All patients in the database are considered for eligibility for each quality measure, and compliance is computed by a rule-based algorithm using dozens of variables from a given patient record. Over the last several years, the NCDB has grown to provide 23 quality measures in our technology platform covering 10 disease sites. These quality measure performance rates are available in the Cancer Program Practice Profile Report (CP<sup>3</sup>R), which is updated with new data for all hospitals participating in the NCDB on an annual basis.

In 2011 the Rapid Quality Reporting System (RQRS) was developed and made available to hospitals in the NCDB. The RQRS was focused on getting more timely data from hospital registries to provide performance rates for six quality measures, which were also linked to real-time patient alerts. These time-based alerts provided another layer of assurance preventing errors in patient care. During the prototype beta phase, approximately one-third of participating hospitals reported preventing at least one patient error via utilization of RQRS,<sup>2</sup> for example, radiation therapy not administered within one year of diagnosis for breast cancer patients under age 70 receiving breast-conserving surgery. Initially participation was voluntary – participating hospitals moved toward more timely data abstraction and routinely submitting data to a separate system from the Call for Data. Today RQRS is a required component of participation in the NCDB.

Throughout this same time course, the focus on quality research also expanded. Originally NCDB statisticians worked directly with teams of disease-specific clinicians to generate research manuscripts. The success of this approach was quickly realized along with the limitations. In 2010 the Participant User File (PUF) program was begun by creating de-identified, patient level data files for each disease site, which are made available to investigators affiliated with hospitals participating in the NCDB. Currently the NCDB receives nearly 1000 applications for PUF files each year and has generated over 1000 peer-reviewed publications since the PUF program inception. Because the NCDB captures 72% of all incident cancer patients across the United States, it is a powerful resource for examining patterns of care and assessment of guideline adherence, which is an important aspect of high-quality cancer care.

## The Future

The Rapid Cancer Reporting System (RCRS) is in the process of being developed and tested. The RCRS represents a paradigm shift in what the NCDB provides its participant hospitals, clinicians, and patients. In addition to providing a new and more efficient technology implementation and upgrade, the RCRS is the first installment of a quality improvement data platform for the nation's cancer hospitals. This platform will combine and replace the best of the RQRS and NCDB Call for Data submission standards into a new way of thinking about cancer hospital registry data. Hospital registrars

will move away from abstracting cases after treatment has been completed and will abstract patient data along a continuum of the natural course of disease, submitting these data to the RCRS along the way. Registrars and clinicians will more easily and effectively be able to monitor patient alerts, quality measure performance, and quality measure national and regional comparisons on an integrated platform.

As hospitals adapt registry practices to this real-time model, they will also be able to consume quality data and reports in new ways. Patient count by stage will be immediately available, and quality measure data will be available in real clinical time as treatment data are added. As a patient record matures along this lifecycle and all treatment modality data and short-term outcomes are recorded, that patient case would then be included in the NCDB's long-term repository used to populate research files like the PUF. Registrars will appreciate the efficiency of submitting all data to a single technology stream and having a more interactive interface to work cases and provide more informative details to clinicians. Hopefully soon after, manual data submission and redundant data abstraction will become automated further.

If an achievement of the NCDB in the past has been the scale of accumulated data over time, the future emphasis will be timeliness and agility. The NCDB will be able to provide more information to hospitals and clinicians in a variety of more useful formats; in browsers, on phones and tablets, in C-suite dashboard reports, and in public-facing web sites. This will become even more relevant as national efforts toward interoperability combine with artificial intelligence techniques to make hospital registrars more efficient and productive than they already are today. The NCDB will be able to quickly utilize these advances as they become feasible.

As the NCDB and our hospitals realize the time efficiencies created by this new quality data platform, we will be able to more precisely determine what data items to collect and which ones to discontinue to meet our goal of real-time quality monitoring and quality improvement. There are many ways the NCDB data collection model should be updated to reflect current clinical practices. To create that bandwidth, we are aspiring to discontinue collection of 20% of the data items currently required. By scaling back time costs at the hospital level, we will be able to appropriately respond to relevant updates to our clinical scope.

Several critical needs for the NCDB to address continue to be identified by our clinical leadership and constituency across the nation, including patient-reported outcomes, details of systemic therapy, and long-term outcomes including recurrence and cause of death. As the American Joint Committee on Cancer evolves how cancer stage is defined and how often staging definitions are updated and made available, we will be able to update our data collection practices, including prognostic factors, in a real-time manner to support clinical advancement.

Multiple new reporting paradigms may appear closer to the horizon from this new RCRS platform. A significant enhancement for improving hospital quality of care would be to

display internal quality data at the provider level. Additionally, a Comparative Effectiveness Research platform could more efficiently be used to extend randomized clinical trial research into communities across the country in real time by tracking relative risks across diverse patient demographics and communities as new science disseminates into clinical best practices. The NCDB cancer registry data could also be used as a backbone to link with other types of data (such as healthcare costs, genomics, and other clinical tests) — therefore widening the types of research questions that can be answered.

The RCRS will provide the NCDB with a quality improvement data platform allowing us to adapt more rapidly to evolving clinical and technological needs. As approaches toward cancer treatment become more precise for the individual patient while also becoming more comprehensive in approach, breakthroughs may come from any direction — surgical and radiation techniques, immunotherapy, genomics, microbiome,

virology, etc. The NCDB will also be able to utilize advances in technologies powering the platform — from artificial intelligence approaches like natural language processing and machine learning, to interoperability and a growing “internet of things” and personal devices — and continue to evolve as a cancer registry and platform for improving the quality of cancer care across the United States.

## References

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