

COMMENTARY

# Leveraging State Cancer Registries to Measure and Improve the Quality of Cancer Care: A Potential Strategy for California and Beyond

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## Abstract

Despite recent increased attention to healthcare performance and the burden of disease from cancer, measures of quality of cancer care are not readily available. In 2013, the California HealthCare Foundation convened an expert workgroup to explore the potential for leveraging data in the California Cancer Registry (CCR), one of the world's largest population-based cancer registries, for measuring and improving the quality of cancer care. The workgroup assessed current registry operations, the value to be gained by linking CCR data with health insurance claims or encounter data and clinical data contained in health system electronic health records, and potential barriers to these linkages. The workgroup concluded that: 1) The CCR mandate should be expanded to include use of its data for quality of cancer care measurement and public reporting; and 2) a system should be developed to support linkage of registry data with both claims data and provider electronic health record data.

Despite the enormous cancer burden sustained by Americans (1–3), measures of cancer care performance and quality are not readily available to patients, healthcare providers, payers, policymakers, or the general public. The underdevelopment of cancer care performance and quality measures (4) leaves patients to navigate uncertain waters in choosing cancer care providers and impedes provider efforts to improve the quality of cancer care. As Americans age, cancer exacts an increasing toll on population health, while at the same time the range of treatment options and complexity of care grows

and is generating the need to focus on meaningful patient outcomes (1,5). Rising costs are also a concern, and assessing the value of cancer care requires measures of the quality of this care. For these reasons, the Institute of Medicine, among others, has called for development of “a national quality reporting program for cancer care as part of a learning health care system” (1,6).

Against this backdrop, the California HealthCare Foundation convened a multidisciplinary group of experts in cancer care, research, and outcomes measurement to examine

opportunities for leveraging the CCR (7) for measuring and improving the quality of cancer care. This expert group (the “Workgroup”) focused on how public reporting of cancer quality metrics by providers might facilitate improved decision making by patients, providers, payers, policymakers, and the general public.

This commentary describes the current status of cancer registration, plus opportunities for linking other data (eg, administrative claims and electronic health record [EHR] data) to those in the cancer registry to generate quality of care measures. We further describe some likely barriers to implementing such a system and make recommendations for developing a public, quality of cancer care reporting system. The approach described herein for California may also be a model for other states and possibly for a “national quality reporting program for cancer care” (1). Also, because the data systems to be used already exist, we believe such an integrated system in California can be achieved in years, not decades.

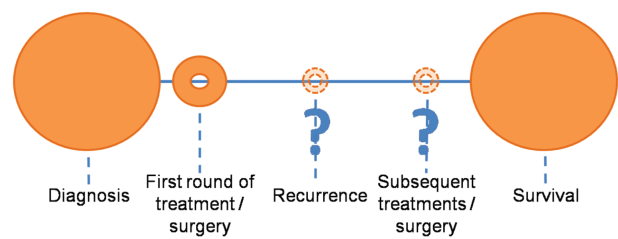
## Cancer Registries: An Overview

Cancer care presents a unique opportunity to inform health care decision-making because of the existing national system of state-based cancer registries and recent advances in health information technology. Much data already exist that would be useful for improving cancer care, but which are not currently configured to assist with decision-making because they are not made available by provider group or health care institution (6).

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) and the National Program of Cancer Registries of the Centers for Disease Control and Prevention (CDC) support national population-based registries and together report annual cancer incidence rates for the nation (8). The NCI, the CDC, and the North American Association of Central Cancer Registries (NAACCR) have also established and monitor standards of data quality for these registries. The CCR, on which this paper focuses, is part of this national system, but on its own is one of the largest population-based cancer registries in the world.

In addition to the state-based and national cancer registries, a separate National Cancer Data Base (NCDB) is maintained by the American College of Surgeons, and partially supported by the American Cancer Society. Compared with the federal registries, the NCDB includes more detailed data on the stage of cancer at diagnosis and on the first course of treatment (9,10). However, the NCDB is not population based and includes data on only 70% of new cancer cases identified at cancer programs that are part of the NCDB’s Commission on Cancer (CoC) accredited network (11). Development of ways to collect, manage, and analyze ever-increasing amounts of data, such as that sponsored by the American Society of Clinical Oncology, are still in development but are not likely to be as highly curated as the state cancer registries, though they are much more likely to contain detailed and longer-term treatment and toxicity information (12).

Cancer registries contain the information needed to monitor cancer from a broad public health perspective; these data include cancer diagnosis (incidence) and mortality (from vital records). Statistics from cancer registries are of high quality and capture a high percentage of all cases in the United States; for example, SEER registries require reporting of 98% of all cases. The registries’ data are used for public health surveillance by



**Figure 1.** Cancer registries: A wealth of information is captured on diagnosis and survival, and some information on the first round of treatment, but nothing related to recurrence or subsequent surgery or other treatments. Adapted from the California HealthCare Foundation.

monitoring trends in cancer incidence and mortality by age, gender, race and ethnicity, and type and stage. Researchers routinely make use of registry data for describing patterns in cancer occurrence and for generating hypotheses for clinical and epidemiologic studies to inform cancer prevention and treatment improvements.

## Limitations of Cancer Registries for Reporting Quality of Care

Despite their proven value, population-based cancer registry data are of limited utility as a tool for reporting and understanding the quality of cancer care. They lack details about the first course of treatment that are vital to assessing quality, and there is no information on recurrence and subsequent treatment (Figure 1). In addition, although most registry data are collected within a few months of diagnosis, complete incidence year datasets are generally not available until 18 months or more after cancer diagnosis and have limited value in assessing the quality of cancer care closer to current time. The more recent the data, the better it informs real-time provider and patient decision-making.

Importantly, however, some information that cancer registries lack can be found in other data sources. Health insurance claims data and clinical data contained in health system EHRs can provide complementary data (eg, information on treatment regimen, side effects, and adverse reactions, relapse and utilization and costs of care) that can be used to provide a more complete picture of the quality of cancer care and health system performance.

## Linkages of Cancer Registries with Claims Data

A number of linkages between cancer registry data and health insurance claims or encounter (hereafter claims) data have already been achieved. Perhaps the most successful and productive of these has been the linkage of SEER with Medicare administrative data. Established in 1991 by the NCI and the Centers for Medicare and Medicaid Services (CMS), this linkage has allowed cancer researchers to understand claims patterns for cancer patients age 65 years and older using data on Medicare-covered medical services that are not reported or reported incompletely through SEER (13). Examples of projects in which linkages were made of state cancer registries to other data sources are summarized in Table 1. These efforts demonstrate that it is both technically and administratively feasible to link claims data to cancer registries and that such registry-claims linked datasets can provide valuable information about cost and quality.

## Linkage of Cancer Registries With Electronic Health Records

There have been substantial research efforts to link cancer registry data to medical records through manual medical record review (14,15). In addition, research has been initiated on linking cancer registries and clinical data contained in health system EHRs (16,17), which are now employed in approximately 77% of oncology practices nationally (18). However, they are not yet used for standardized reporting because of the limited interoperability of the many different proprietary EHRs currently in use.

The use of EHRs represents a different set of challenges from claims data, and research in this area is still nascent. However, a number of examples exist of EHR linkages to cancer registries. Investigators at Intermountain Healthcare used inpatient hospital discharge data and vital records in their enterprise data warehouse and found that 99% of these cancer records could be successfully linked to a record in the Utah Cancer Registry (19). The Oncoshare project developed methods of linking EHR data from Stanford University Health System and the community-based Palo Alto Medical Foundation health system with the CCR database to evaluate outcomes for breast cancer patients (and did so without sharing patient identifiers between health institutions) (20,21). Investigators at the University of California, Davis are exploring the components of a “next-generation” cancer registry that would utilize an EHR/cancer registry linkage for quickly identifying new cancer cases (“rapid case ascertainment”) in its Project Interoperability to Support Practice Improvement, Disease Registries, and Care Coordination (INSPIRE) (22). Project INSPIRE investigators advocate for structured electronic

checklists for consistent sourcing of key cancer data for clinical care, as well as for automated transmission to a cancer registry (23). The College of American Pathologists demonstrated the feasibility of a structured electronic cancer checklist that has been implemented in the anatomic pathology module of a commercial laboratory information system. This project produced surgical pathology reports that could be transmitted to a registry to support quality measurement in cancer care (24). Finally, Artificial Intelligence in Medicine, Inc. has been working with registries to incorporate additional data electronically as exemplified by their templates for NAACCR's E-path guidelines for electronic case-finding and pathology data gathering (25).

## Improvements to Quality of Cancer Care Measures

Neither patients, providers, payers, policy makers, nor the general public can benefit from quality of cancer care data from registries and linked databases until provider-specific measures on both process (eg, performance of recommended procedures) and outcomes (eg, quality of life) are defined and made available. Quality of cancer care measurement has been a topic of research and practice since the 1990s, when the NCI first sponsored “patterns of care” studies. With formation of the National Quality Forum (NQF) in 1999, measurement development and adjudication by multiple stakeholders became formalized with a public-private collaboration of providers, payers, regulators, researchers, and patient and public representatives (26,27). The National Committee for Quality Assurance, the American College of Surgeons' Commission on Cancer, the National

**Table 1.** Examples of linkage projects with state cancer registries\*

Type of linkage	Study	Data sources used	Major findings
Registry - Claims	Schrag et al., 2009 (41)	CA Medicaid claims data CA Cancer Registry	Medicaid claims provided important information on the indigent population of adults younger than 65 years
Registry - Claims	Brooks et al., 2013 (42)	National SEER-Medicare linked data	SEER-Medicare linked data identified wide regional variations in spending for advanced cancer care
Registry - Survey	Kent et al., 2014 (43)	National SEER-Medicare Health Outcomes Survey (MHOS)	SEER-MHOS linked data found poor outcomes related to quality of life for survivors of multiple myeloma and pancreatic cancer
Registry - Claims	Sinclair et al., 2012 (44)	New York Statewide Planning and Research Cooperative System NY cancer registry NY Medicare claims NY Medicaid claims NY hospital discharge data	Demonstrated feasibility of quality of cancer care assessment for Medicare and Medicaid patients Evaluation of three treatment quality measures for colorectal cancer found majority of patients received recommended care, but room for improvement exists
Registry - Claims	Camacho et al., 2009 (45)	NC cancer registry NC Medicare claims NC Medicaid claims	Found differences in cost burden for patients with metastatic breast cancer taking oral vs intravenous first-line chemotherapy
Registry - Claims -EHR	Lipscomb et al., 2011 (46)	GA cancer registry GA Medicaid GA Medicare GA state health benefit plan claims data Kaiser Permanente claims data GA hospital discharge data	Demonstrated feasibility of linking several state-wide data sources, including both public and private payers claims data

\* EHR = electronic health record; SEER = Surveillance, Epidemiology, and End Results.

Comprehensive Cancer Network, the American Society of Clinical Oncology, and others have developed specific measures and submitted them to the NQF for review and endorsement. Parallel to that effort, however, these organizations have also developed their own sets of measures, resulting in a lack of standardization in quality of cancer care measures and a concomitant inability to compare cancer care provider performance.

Most existing cancer care quality measures track the processes of care (eg, frequency of mammography screening), which correlate with desirable outcomes (eg, improved survival or quality of life) (28). With the exception of patient experience of care measures (eg, satisfaction with care); however, very few cancer care quality measures assess actual long-term outcomes. Although improving outcomes is the ultimate goal, many important cancer outcomes do not occur until years after care is delivered, by which time an individual may have moved, changed health plans, or died from another cause, making it difficult to attribute an outcome to a specific healthcare provider or provider group.

In the cancer care quality reporting system envisioned by the Workgroup, cancer care providers would not be required to do anything new and measures would be calculated automatically from existing data. Examples of such measures include level of pain and other symptom management, evidence of multidisciplinary consultation, attention to comorbid conditions, and metrics related to the experience of providers based on the volume of case patients treated. Most of the 63 quality of cancer care measures presently endorsed by the NQF (29) could potentially be reported by this cancer care quality reporting system, and a large majority of them could likely be extracted from a new data infrastructure that would link the CCR, health insurance claims data, and health system EHRs.

In summary, there already exists in California and in many other states a highly functional cancer case registration system for new cancer cases, cancer deaths, tumor stage and extent of disease at presentation, and survival. Research studies have shown that linkage with various claims databases can realistically be performed and that such linkage can produce a more complete picture of the nature and quality of cancer care delivered by provider groups. However, such data are not currently broadly available nor are data contained in health system EHRs, which have the potential to add further value.

The alternative to creating such a new system linking existing databases is to massively augment the existing data collection efforts of the CCR. This alternative seems less desirable, or feasible, because it would require or result in extensive additional training of personnel with new skills, duplicating existing efforts, increased costs, add additional data collection burdens. For these reasons, the Workgroup explored what might be required to provide performance metrics that would improve evaluation of and decision-making about the quality of cancer care.

## The Workgroup's Vision for the Future

The current registry system captures detailed data on initial occurrence of cancer and on mortality, but limited information on initial treatments and no information on recurrence and subsequent treatments. Moreover, registry data are usually available for complete incidence years only after 18 months following diagnosis. The Workgroup envisions instead a system that provides reliable registry data on cancer patients within six to nine months of diagnosis plus routine linkage to health insurance claims data for cancer patients across all health systems. Eventual linkage to cancer care providers' EHR data would capture additional clinical detail regarding treatment, recurrence,

and follow-up. The data on quality of cancer care generated by this reporting system could be used to inform consumers and providers about care decisions, as well as to benefit health care systems and quality improvement organizations.

The envisioned reporting system would be a bi-directional learning system, with data flowing rapidly from claims databases to the CCR and the CCR offering timely information back to providers regarding health services received by their patients from other providers and hospitals as well as their outcomes. By providing additional data on cancer patients, including treatments received at other health systems and vital status, the CCR would increase the value of the registry not only to providers but also to local and state public health officials. These linkages would also lead to the development of quality of cancer care performance measures, which in turn would become available to patients, providers, payers, policymakers, and the general public to help identify providers and treatment options based on performance, without compromising patient privacy. Overall, the cancer registry and its existing well-developed infrastructure would serve as the backbone on which quality of cancer care data would be linked, collected, and made available to the public.

## Steps to Achieving the Workgroup's Vision

Multiple steps need to be taken, with technical issues to be addressed within each, in order to establish linkages between and among the CCR database, health insurance claims data, and health system EHRs (see Table 2 regarding the different types of information currently captured by these three key database sources).

### Standardization of Data

Claims data are to some extent already standardized with regard to coding systems (eg, ICD-9, CPT codes), and some linkages have already been established (eg, SEER-Medicare). Accomplishing linkages with health system EHRs, however, will require harmonization of record formats across existing EHR systems or interoperability between the EHRs and cancer registries. For that purpose, tools that apply standardized methods for reporting structured data elements to cancer registries are needed. These are steps to be taken to ensure that rapid, accurate, and comparable data are being obtained from the multiple EHR systems currently in use.

**Table 2.** Data elements found in each data source

Data elements	Cancer registries	Claims data	Electronic health records
Patient identifiers	X	X	X
Patient address	X	-	X
Patient demographics	X	X	X
Clinical history and comorbidities	-	X	X
Tumor characteristics	X	-	X
Treatment data	X*	X	X
Patient reported data	-	-	X*
Post-acute care treatment	-	X	X
Patient vital status	X	-	X
Provider identifiers	X	X	X

\* Incomplete data. - = not available in data source.



The adoption of such standardization requires that the same data capture formats on pathology and treatment be used across cancer care providers (30). Alternatively, given the time that may be needed to achieve EHR interoperability, a short-term approach might be for providers to report data for selected quality metrics in a common format using EHR information similar to what is done in the CoC's Rapid Quality Reporting System (RQRS) (31).

Other challenges also must be overcome before EHRs can be used for the routine application of quality of cancer care reporting. For example, EHRs continue to have highly variable and inconsistent narrative-text styles of clinical documentation that parallel the paper record documentation they are replacing. This makes it difficult to identify key cancer data elements and transfer and incorporate them automatically to a remote cancer registry. Also, EHRs do not yet contain patient-reported information on symptoms or health-related quality of life that can be automatically linked to other data sources. Further, the multiplicity of noninteroperable EHRs precludes organizing them into one reporting system.

### Data Quality

The data generated for this new system would need to be of sufficiently high quality to minimize duplicate reporting and mismatches when patients visit more than one provider. The data may not have to meet the standards established for complete cancer case reporting (ie, current CCR practice) to be useful for making judgments on the quality of cancer care but they must at least capture multiple episodes of care across different health care settings and providers, and there is a need to establish organizational systems to facilitate data acquisition and linkage over time. If public reporting is to occur, the names, identifiers, and locations of practitioners and institutions also must be accurately linked to all information. Finally, for CCR data to be most valuable to patients, providers, payers, policy makers, and the general public, the data need to be available in something close to real time and need not be tied to complete annual incidence releases.

### Methodologic

Several studies (Table 1) have shown that linkages can be accomplished using methods and technologies currently available. But developing such linkages on a large scale will require additional steps. For example, a system must be developed to assign attribution (ie, which provider or practice is most directly responsible for a patient's condition). Given that multiple oncologic specialties and sometimes multiple institutions deliver cancer care, this is a major challenge. Likewise, a process must be established to make appropriate case-mix adjustments (ie, dealing with the variability in complexity of patients' conditions at the population level). Persons with cancer often have comorbid conditions such as diabetes and heart disease that can influence the course of illness, treatment decision-making, and response to treatment.

Even with the CCR linked to both health insurance claims and health system EHRs, there are likely to be some critical data missing. This issue will need to be further examined, but multiple imputation methods may allow for the substitution of values for the missing data (eg, estrogen receptor status [32], comorbidities [33]) based on other characteristics of the patient and the provider system being assessed. The related question of missing data that are not collected in the first place (eg, symptoms

or assessments of quality of life) presents other challenges and would have to be addressed by other means. For example, both claims and EHR data could be used to assess comorbidities with the Charlson index (34) or other measures.

The rapidity of reporting would be crucial to the effectiveness of an improved linked system, and a workable balance would need to be found between providing timely, useable data to aid decision-making on provider choice and patient care, on the one hand, and the practical aspects of the work involved to produce the data, on the other. Something much less than the current lag in registry reporting would be needed for quality reporting purposes if that reporting is to most effectively assist patient and provider decision-making. Aspects of the claims system allow for rapid reporting because medical bills must be paid in a timely fashion, so it would seem feasible that a similarly rapid quality of care reporting system infrastructure could be developed.

### Stakeholder Concerns

There are many stakeholders in the development of quality of cancer care performance measures. After cancer patients, other key stakeholders include cancer care providers and healthcare systems, the self-insured employer health plans, insurance companies, government programs that pay for cancer care, and policymakers.

For patients, their confidentiality is already protected in the CCR and would also be protected in the system the Workgroup envisions—the system would not report individually identifiable patient information. But to serve patient decision-making, a fundamental goal of the proposed system, quality measures would be reported for identified providers (eg, oncology practices, cancer centers/hospitals).

Patients also are stakeholders in terms of the ultimate use of the data. There is an emerging direction in health care that asks consumers to take more responsibility for their own care. Within this movement, quality ratings are one of many factors that patients can take into account in making decisions. Programs in Wisconsin and West Virginia (35,36) demonstrate how consumer-focused quality of care reporting systems can catalyze rapid improvement. Although many patients will not consider quality ratings when making decisions about their providers, even simply making performance information publicly available can stimulate quality improvement (37).

Reporting data on specific providers, however, will be a substantial challenge because of the sensitivities involved, particularly those of a financial and reputational nature. Experience has shown that health care providers are generally leery of performance reporting systems. However, providers' concerns about quality reporting could be mitigated by inclusion of provider stakeholders in the development of the reporting system and by a phased implementation. For example, the system could delay the initial round of public reporting so that provider groups could review the results, provide input about the measures and measurement process, check the accuracy of reported results, and address questions about their performance. Participation in the reporting system could also be done in stages, with providers initially participating on a voluntary basis, giving them the opportunity to inform the system about what they perceive as needed improvements.

New incentives in CMS's EHR "meaningful use" program may motivate provider groups to report on quality measures despite their misgivings. The Medicare and Medicaid EHR Incentive

Programs provide financial incentives to providers for the “meaningful use” of certified EHR technology to improve patient care (38). Reporting of cancer care outcomes might be incorporated into these programs’ Stage 3 requirements, which are still in development (38).

Responsibility for reporting quality measures is another stakeholder issue. Should the CCR, another state government agency, or some other entity be responsible for reporting these data? The Workgroup considered a number of possible scenarios in this regard but believes this issue needs further consideration with key stakeholders involved.

## Legal Issues

The enabling statutes of the CCR require reporting of cancer cases by each provider who diagnoses or treats the condition. The data generated are used for public health surveillance purposes and can be made available for research after appropriate proposals have been approved by the CCR (39,40). All data stored in the CCR, including provider data, are confidential (39). These provisions effectively prevent the public reporting of provider-specific data.

In addition, California Department of Public Health policy further limits data access to the CCR to those researchers who provide a study protocol of their research project, documentation of peer review for scientific merit, and documentation that the research study has been reviewed and approved by the investigator’s institutional review board or the California Committee for Protection of Human Subjects. These added requirements present a legal barrier to expanded use of CCR data for health care quality improvement purposes. Accordingly, the Workgroup has concluded that statutory, regulatory, and administrative policy changes would be needed to address these legal issues.

## Conclusion

After considering a number of opportunities for and barriers to improving the quality of cancer care by leveraging the strengths of the CCR database and through public reporting of cancer care quality measures, the Workgroup recommends:

1. The legislative mandate for the CCR should be expanded to include use of registry data for quality of cancer care measurement and public reporting. To accomplish this:
  - Relevant oncologic care providers would need to be defined and identified so that required reporting of cancer quality measures is appropriately specific.
  - A set of quality of cancer care performance measures and other standardized data should be identified as suitable for use in public reporting.
  - A publically transparent process should be developed to identify a neutral, trusted third party to efficiently aggregate data from the sources the Workgroup has identified, and from other sources that may emerge, to serve as a broker for public reporting.
2. The CCR, other relevant state agencies, and health care payers in the state should work toward developing a system for routinely linking CCR data with health insurance claims data.
3. A strategy should be developed for linking clinical data contained in health system EHRs and the CCR; cancer care providers should be deeply involved in this effort.

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