Review

Using informatics to improve cancer surveillance

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ABSTRACT

Objectives: This review summarizes past and current informatics activities at the Centers for Disease Control and Prevention National Program of Cancer Registries to inform readers about efforts to improve, standardize, and automate reporting to public health cancer registries.

Target audience: The target audience includes cancer registry experts, informaticians, public health professionals, database specialists, computer scientists, programmers, and system developers who are interested in methods to improve public health surveillance through informatics approaches.

Scope: This review provides background on central cancer registries and describes the efforts to standardize and automate reporting to these registries. Specific topics include standardized data exchange activities for physician and pathology reporting, software tools for cancer reporting, development of a natural language processing tool for processing unstructured clinical text, and future directions of cancer surveillance informatics.

Key words: cancer surveillance, interoperability, electronic health records, laboratory information systems, natural language processing, public health

INTRODUCTION

Cancer surveillance informatics is the systematic application of information, computer science, and technology to cancer surveillance practices, research, and learning.¹ The activities are implemented to gain insights, which help identify better ways to employ emerging technology, incorporate automated processes, and improve electronic data exchange for cancer prevention and control. As the need for information and the volume and complexity of cancer data continues to increase across the healthcare community, the concept of capturing timely data once and using it to meet multiple needs becomes more critical. Cancer surveillance data are used to monitor cancer trends over time, guide planning and evaluations of cancer control programs, help set priorities for health resource allocation, and advance clinical, epidemiologic, and health services research.² Thus, ensuring the collection of quality cancer data at the time of

patient care from clinicians, laboratories, and other healthcare systems is of utmost importance, as this can improve the timeliness and completeness of public health reporting.^{3–8}

National Program of Cancer Registries

Established by Congress through the Cancer Registries Amendment Act in 1992, and administered by the Centers for Disease Control and Prevention (CDC), the National Program of Cancer Registries (NPCR) collects data on cancer occurrence (type, extent, and location of the cancer), the type of initial treatment, and outcomes.⁹ This article details the activities implemented by the NPCR to improve cancer surveillance and outcomes.

Before NPCR was established, 10 states had no central cancer registry (CCR), and most states with registries lacked the resources and legislative support needed to gather complete data. Today, through NPCR,

Figure 1. Potential data sources for cancer surveillance. Pathology laboratories—freestanding and hospital—send data to both hospital registries and central cancer registries.

the CDC supports CCRs in 46 states, the District of Columbia, Puerto Rico, the Virgin Islands, and the U.S. Pacific Island jurisdictions.²

Together with the National Cancer Institute's SEER (Surveillance, Epidemiology, and End Results) Program, NPCR provides a census of new cancer cases for the entire U.S. population.¹⁰ This national coverage enables researchers, clinicians, decision makers, public health professionals, and the public to monitor the burden of cancer (incidence, mortality, and survival); evaluate the successes of program interventions designed for cancer prevention and early detection; and identify additional needs for cancer prevention and control efforts at national, state, and local levels. The CCRs use these data in various ways, including addressing the cancer burden in their states more effectively through identification high-risk groups, identifying the need for increased screening in underserved areas, and investigating possible cancer causes.⁹

STANDARDIZED ELECTRONIC DATA EXCHANGE ACTIVITIES

The North American Association of Central Cancer Registries (NAACCR), an umbrella organization for CCRs, plays a lead role in developing standards for reporting.¹¹ Most information is reported to CCRs from hospitals, where highly trained cancer registrars transfer information from patients' medical records to the hospital cancer registry's software using NAACCR standards. These data are sent to the CCR and subsequently to the CDC (Figure 1). However, for hospitals without a cancer registry and nonhospital healthcare reporting sources (eg, pathology laboratories and physician offices), the standards are less likely to be implemented. In these settings, CCRs often work independently to develop methods to receive critical data, resulting in a variety of data collection, transmission, and reporting systems (or tools).¹² This lack of coordination contributes to incomplete reporting of cancers from nonhospital sources. Moreover, the growing emphasis on increased data timeliness and completeness highlights the need for standardization and automation in collecting critical cancer data from these additional data sources.

To advance automation of cancer registration, NPCR collaborated with the national cancer surveillance community to develop best practices for cancer surveillance. The goal of the initiative was to develop a set of models, requirements, and products to take advantage of emerging health information technology (eg, electronic health record [EHR], federal eHealth initiatives, cloud-based services), as well as national and international standards (eg, the Health Level 7 [HL7] Standard). These were applied to 2 key areas: pathology and physician reporting.

Pathology reporting

The information collected and included in pathology laboratory reports represent a critical data source for CCRs, as over 90% of cancer cases are diagnosed using methods that generate a pathology report.¹⁷ Prior to reporting standards, laboratories submitted cancer pathology data in different formats (eg, spreadsheets, PDF files, paper) based on the specific requirements of each CCR. This meant that the laboratories were burdened with reporting data in different ways to each CCR, a process that is resource-intensive, time-consuming, and vulnerable to errors in transcription. However, studies have shown that standardized electronic reporting of laboratory data improves the timeliness, accuracy, and case completeness for public health surveillance.^{18–20}

National standard for laboratory pathology reporting

In 1999, the NAACCR collaborated with CCRs and a national laboratory to develop a national standard for reporting cancer pathology data to CCRs. This built on previous work by the CDC for standardized electronic laboratory reporting of infectious diseases to state public health agencies.²¹ The reporting standard was first documented in the NAACCR Standards for Cancer Registries in March 2002 and then became a separate NAACCR standards guideline document in 2005 (NAACCR Pathology Laboratory Electronic Reporting Volume V).²²

The CDC also collaborated with Integrating the Healthcare Enterprise anatomical pathology domain to harmonize the NAACCR

Figure 2. Implementation of Integrating the Healthcare Enterprise (IHE) transaction and content profiles to support interoperable data exchange. ¹Structured data capture ¹³; ²Anatomic Pathology Reporting to Public Health ¹⁴; ³Cross-enterprise Document Reliable Interchange ¹⁵; ⁴Retrieve Form for Data-Capture ¹⁶.

Volume V pathology standard with international standards. The result is an Anatomic Pathology Reporting to Public Health profile, which is internationally recognized for reporting text-based pathology reports using the HL7 v.2 messaging standard (Figure 2).

Electronic pathology reporting

As the need for interoperability grew, it became apparent that the cancer registry community needed to move forward with more standardized and automated reporting. Thus, the NPCR-AERRO (Advancing E-cancer Reporting and Registry Operations) (formerly known as Modeling Electronic Reporting Project) was launched. The project sought to develop and test a model for automated, electronic capture and reporting of cancer registry data to CCRs from data sources including EHRs, laboratory systems, and treatment centers. Text-based pathology reports from laboratories were chosen as the first data source tested for implementation. To accomplish the task, the Electronic Pathology implementation project (ePath) started in 2005 to implement electronic reporting of anatomic pathology reports and cancer biomarkers using NAACCR Volume V and the business rules defined in the NAACCR Electronic Pathology Reporting Guidelines.²³ ePath began as a pilot project with the CDC's Division of Cancer Prevention and Control (DCPC), Laboratory Corporation of America Holdings, the CDC's National Center for Public Health Informatics, NAACCR, and 18 CCRs.²⁴

Electronic pathology software and implementation processes. Registry Plus, a suite of publicly available software programs compliant with national standards, was developed by the CDC DCPC for CCRs to collect and process cancer registry data.²⁵ The electronic mapping, reporting, and coding software (eMaRC Plus)²⁶ is one of the tools in the suite to help CCRs receive and process HL7 version 2.3.1 and 2.5.1 ePath reports received from laboratories.

The process of working with laboratories includes an orientation to the requirements for implementing electronic pathology reports to CCRs. Guidance is provided on the development of the HL7 report and setup of secure data transmission using the Public Health Information Network Messaging System (PHINMS).²⁷ The CDC staff work with laboratories to test and finalize the HL7 data structure and ensure that the filtering method used to identify cancer

cases for reporting works properly. CCRs then use the ePath module of eMaRC Plus to receive and process the files received from the laboratories for inclusion in their main database. The ePath module imports narrative and structured (coded) HL7 files in 3 ways: manual upload, directly from a folder, or through the PHINMS queue. It ensures the files contain the required data items; parses, and stores data from HL7 messages; auto-codes unstructured textual data to standard coded data for 5 key elements (primary site, histology, behavior, laterality, and grade); and maps HL7 data elements to the appropriate NAACCR data elements. As of 2020, the CDC has implemented electronic reporting successfully from more than 28 national and regional laboratory networks (which include approximately 683 stand-alone laboratories, apart from hospital and individual pathology laboratories) to more than 45 CCRs (Figure 3). Additionally, states work directly with local laboratories to implement ePath reporting. To further improve ePath reporting, California has passed legislation for 100% ePath reporting.²⁸ An evaluation is currently in progress using Lean Six Sigma to identify best practices for ePath reporting to improve timeliness and completeness. To reduce the burden on laboratories to maintain individual reportability lists for every CCR, the CDC collaborated with CCRs to develop (1) a standard "core" reportability list of International Classification of Diseases–Tenth Revision–Clinical Modification diagnosis codes that laboratories use to filter reportable cases for all CCRs and (2) an "expanded" list for a small number of CCRs needing additional cases.

In October 2018, the CDC began a pilot project with the Association of Public Health Laboratories (APHL) and Quest Diagnostics ("Quest") to test implementation of ePath cancer reporting using the APHL Informatics Messaging Services (AIMS) Platform. The AIMS platform, built on Amazon Web Services cloud services, allows Quest to submit all CCR cancer data to one portal for distribution to the appropriate CCR. This eliminates the need for the laboratory and public health agency to maintain individual connectivity points with every data exchange partner. Three states will soon go live for the first time with ePath reporting from Quest. Most Quest laboratories were previously reporting to CCRs by paper; electronic reporting should reduce resources and improve timeliness and completeness. Barriers to faster implementation include lack of sufficient financial resources, capacity, and prioritization in

Figure 3. States receiving data from laboratories through electronic pathology reporting. PHINMS: Public Health Information Network Messaging System.

APHL and laboratories for onboarding to AIMS. The CDC's Data Modernization Initiative is focused on improving interoperability with external data exchange partners and plans to address these barriers by funding the expansion of the AIMS Platform and tool development to onboard and support more laboratories and CCRs using a cloud-based system.

Electronic biomarker reporting

Over the past decade, the CDC has worked with College of American Pathologists (CAP) to develop site-specific cancer protocols and electronic cancer checklists (eCCs) for standardized reporting of coded cancer pathology and biomarker data. These templates standardize most of the cancer data from pathology and genetic testing laboratories reported to CCRs. The eCCs were piloted in collaboration with PathGroup Laboratories to all CCRs using the NAACCR Volume V standard, and by November 2016, accurate and near real-time electronic cancer data transfer to CCRs began.²⁹ Over 6000 pathologists are currently licensed to use CAP eCCs in the United States; integration of the eCCs by pathologists and laboratories has been slow because there have been no incentives for pathology laboratories to change their current workflows and information systems. Enabling standardized, coded cancer data collection allows clinicians to readily identify key pieces of information from pathology reports to make care and treatment decisions for their patients. Implementation, use, and reporting of standardized, structured data for cancer pathology and biomarker tests performed by all laboratory information system (LIS) vendors, pathologists, and laboratories can help public health agencies provide timely, accurate, and high-quality cancer surveillance data in the United States.

Physician reporting

Advances in medicine and changes in the healthcare delivery system allow patients to obtain their care outside acute care hospital settings, as private oncology clinics now deliver 80% of all cancer care.³⁰ However, data collected from these sources (eg, physician offices/clinics and radiation therapy centers) are not as consistent or complete compared with hospitals, making comprehensive cancer data more difficult to collect and leading to underreporting of cases.

Studies have shown that some cancer sites such as prostate and bladder, often diagnosed and treated outside of a hospital setting, as well as myelodysplastic syndrome and myeloid leukemia, are some of the most underreported cancers.^{31–33} EHR data have been shown to be useful for public health surveillance and epidemiology.^{5,34} Physician offices, together with pathology laboratories, have the potential to provide CCRs with more complete treatment and biomarker data, resulting in a more comprehensive cancer coverage.^{35,36}

Manual physician reporting, medical record abstraction by staff with limited training, and high staff turnover rates lead to reduced quality and completeness of reporting. The need to access the data contained in physician offices with limited resources has driven the efforts to develop an automated electronic process for accessing and using the physicians' EHRs to identify and report cancer cases to CCRs.

National standard for electronic physician reporting

In 2009, NPCR-AERRO established the Clinic/Physician Office project to develop standards for automated electronic reporting to CCRs from physician EHRs. The goal was to move the cancer registry community forward in using consistent standards for electronic clinic/physician office reporting. The project resulted in the first published version of the physician cancer reporting standard, Physician Reporting to a Public Health Repository—Cancer Registry, in 2010 through Integrating the Healthcare Enterprise.³⁷

Modifications to Physician Reporting to a Public Health Repository—Cancer Registry resulted in publication of the Implementation Guide for Ambulatory Healthcare Provider Reporting to Central Cancer Registries, August 2012 ("2012 Cancer IG"),³⁸ which defined a single standard for the format, content, and rules for electronic transmission of cancer reports to CCRs. In April 2015, the CDC completed development of a new version, the HL7 CDA Release 2 Implementation Guide: Reporting to Public Health Cancer Registries from Ambulatory Healthcare Providers, Release 1, DSTU Release 1.1—U.S. Realm ("April 2015 Cancer IG")³⁹ and published it through the formal HL7 balloting process. Existing national cancer surveillance community standards made the development and implementation of these electronic standards easier, so all

stakeholders benefit from having a single national standard rather than individual state-specific requirements.

Meaningful use

The American Recovery and Reinvestment Act enacted in February 2009 included many measures to modernize the nation's health information technology (IT) infrastructure. One of these was the Health Information Technology for Economic and Clinical Health Act, which supports the concept of EHR Meaningful Use (MU), an effort led by the Centers for Medicare and Medicaid Services and the Office of the National Coordinator for Health Information Technology (ONC). The Health Information Technology for Economic and Clinical Health Act proposed the meaningful use of interoperable electronic health records throughout the U.S. healthcare delivery system as a critical national goal.⁴⁰

The DCPC was instrumental in establishing cancer reporting from Eligible Professionals (EPs) to registries as a public health objective for MU Stage 2. The Stage 2 Final Rule, released in September 2012, included an optional objective for EPs to demonstrate the "[c]apability to identify and report cancer cases to a state cancer registry except where prohibited, and in accordance with applicable law and practice."⁴¹ The ONC 2014 Edition Health IT Certification Criteria Final Rule,⁴² released in September 2012, defined the standards and specifications to be used by EHR vendors, and identified the 2012 Cancer IG³⁸ as the required standard to be used for MU electronic cancer reporting. The ONC 2015 Edition Health IT Certification Criteria Final Rule⁴³ identified the April 2015 Cancer IG as the required standard for MU electronic cancer reporting for Stage 3.

As a result of the inclusion of cancer reporting in MU, at least 36 CCRs currently receive electronic reports in the HL7 Clinical Document Architecture (CDA) format from physicians, EPs, and healthcare systems. These physician reports are used to rapidly identify cases and provide treatment information not reported from other sources. Electronic reporting has improved the timeliness of the data and completeness of case ascertainment (unpublished data, Florence Tangka, et al, January 2020). In 2019, North Carolina analyzed the data received from dermatologists through MU reporting and identified improvements to case completeness as indicated by 836 skin cancer cases for the year 2017 that would otherwise not have been reported (unpublished data, Nigar Salahuddin, December 2019). They did find that more manual processes were needed to process these data, an issue the CDC is addressing through other efforts to improve the content of these reports. Other evidence in support of use of EHRs for public health includes a literature review of more than 200 articles that found more facilitators than barriers for their use to support public health surveillance and disease prevention.⁴⁴ The CDC works closely with CCRs to provide technical assistance with validation reports, as well as coordinate meetings with EHR vendors to address issues identified during validation. These collaborative efforts have successfully addressed issues and provided guidance to improve future processes. An evaluation is in progress to identify successes and barriers to implementation and measure the timeliness and completeness of electronic reporting from physician EHRs.

Physician reporting software

The functionality of eMaRC Plus was expanded to process reports from physician office EHRs in the HL7 CDA format. This physician reporting module imports CDA files manually or directly from a folder or PHINMS queue, parses and displays the data elements,

and maps and translates the HL7 data elements to NAACCR data elements.

CDA Validation Plus is another Registry PlusTM tool for physician reporting. Developed to assist CCRs and EHR vendors with testing and validation of the CDA cancer reports for MU cancer reporting, it augments the validation process and improves interoperability for cancer reporting. Since its release in 2013, added features include checks for required elements and valid vocabulary values, generation of user-friendly reports that can be printed and saved to an extensive number of file formats, stand-alone desktop application, single and batch file processing, and batch automation through a command line interface.

FUTURE

New proposed Centers for Medicare and Medicaid Services and ONC policies, as well as adoption of newer standards such as Fast Healthcare Interoperability Resources (FHIR), have the potential to lead to much greater improvements in interoperability. ONC proposed rule "21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program" includes requirements to (1) expand the standard core data that certified health IT systems must collect; (2) prevent health IT vendors and providers from engaging in information blocking, which hinders system interoperability; and (3) set standards for application programming interfaces, including the required use of FHIR, to enable easier health information access and exchange.⁴⁵

The diversity of EHR and LIS vendors requires that the cancer registry community continue to work more closely with vendors, providers, and national standard-setting organizations to achieve timely, complete, and high-quality cancer data. These foundational principles can be enhanced in the era of EHRs using innovative approaches and greater automation, which may even allow data elements to be collected at a lower cost.

As the DCPC moves forward, interoperability remains challenging for CCRs to overcome and meet the CDC's public health mission. Specific issues include varying EHR system workflows, as well as use of different vocabularies, coding systems, and data collection methods in each system. The CDC is in the process of a phased approach to modernize its surveillance system by implementing innovative data collection methods to overcome these known challenges. A formal evaluation of this project is planned to assess performance indicators such as measuring improvements in case finding, timeliness, and treatment completeness. Some of the planned and in progress solutions include expanding the work with national and local laboratories (eg, Quest), use of FHIR, and cloud-based solutions.

Natural language processing

To address issues with differences in vocabulary, the CDC and Food and Drug Administration received funding for 2 years in 2016 through the Assistant Secretary for Planning and Evaluation to develop a natural language processing (NLP) Workbench called the Clinical Language Engineering Workbench. The Clinical Language Engineering Workbench, designed to be housed on a shared Web service platform, is architecturally designed to provide access to NLP and machine learning tools needed to develop and share language models that map unstructured clinical text to standardized coded data. Operating it as a public Web service can allow any registered user to utilize the shared language models or develop a new one to process their own unstructured data. To demonstrate usage,

the Food and Drug Administration employed its surveillance for blood products and vaccines, while the CDC used pathology reports for cancer surveillance. The current method being utilized by the Registry Plus software for NLP is dictionary-based; internal analysis indicated precision and recall near 85%. To increase the completeness, timeliness, and accuracy of data, the goal is to migrate from the current NLP methods to a statistical NLP method leveraging supervised machine learning. Migration to statistical NLP should reduce the resources needed for human intervention in reading and analyzing unstructured data to identify critical data needed for research and surveillance purposes.

Structured data capture

To enable standardization of clinical data, a structured data capture (SDC) profile was developed. The profile enabled a LIS, EHR, or other application to retrieve a data capture form and submit data from the completed form, thus promoting uniformity and completeness of data. CAP developed SDC-compliant forms to be used by pathologists to capture and report pathology and biomarker data based on its cancer protocols and eCCs. An ongoing collaboration with CDC targets developing standardized reporting of cancer biomarker test data for registries.

Fast Healthcare Interoperability Resources

HL7 FHIR is a modular framework that allows for quick and easy implementations to solve interoperability issues across systems that require the exchange and use of patient health data.⁴⁶ There are several cancer registry use cases for HL7 FHIR, including the use of SDC to capture key patient cancer data and clinical decision support services to define reportability requirements. CCRs rely on physicians and their EHRs to document and report patient cancer details to the CCR. After physicians document the encounter information, the EHR system determines cancer reportability based on a coded trigger list. The development of a centralized clinical decision support service can be maintained by the standard-setting organizations and EHRs could utilize this with few local modifications. If the case is determined to be reportable, the EHR system transmits the cancer case report to the appropriate CCRs. “Electronic case reporting (eCR) Now” has been successful for COVID-19 (coronavirus disease 2019) reporting to public health agencies. Using services as described, with FHIR for case identification and case report transmission, as of April 2020, more than 142 000 cases of COVID-19 were identified and sent from 7 eCR implementations. As expected, this effort confirmed that electronic reporting was faster and more complete than manual methods.⁴⁷ In 2018, the CDC participated in the HL7 FHIR Connectathon by testing a proof-of-concept FHIR profile for reporting cancer data elements. Building on this effort, we are identifying the content and process requirements for using FHIR for cancer reporting to CCRs by building on the framework developed by eCR. The ONC proposed requirement for health IT vendors to develop FHIR application programming interfaces further supports our ability to implement FHIR-based cancer reporting from EHRs to CCRs.

Cloud-based computing platform

The CDC has prioritized modernizing the cancer surveillance system by focusing on real-time data. Support for successes of real-time data acquisition includes findings from the CDC’s Pediatric and Young Adult Early Case Capture program that focuses on increasing the speed of reporting pediatric and young adult cancer cases by

leveraging electronic reporting; the data obtained have resulted in research studies that demonstrate the potential to use faster data collection to guide public health intervention strategies.^{48–50} A 5-year plan for implementation of the cloud-based computing platform (CBCP) focuses on establishing connectivity between data submitters, laboratories and healthcare providers, and the CBCP and developing services that leverage informatics techniques like supervised statistical NLP; patient matching, linkage, and de-duplication; Web portals for users to visualize and interact with data; and extraction, translation, and loading. This platform could help to coalesce cancer surveillance data more accurately, efficiently, and in near real time, and reduce the need for local technical support at the CCRs, as applications and resources hosted on the CBCP will be kept current centrally eliminating the need for local IT to test and schedule local application updates.

CONCLUSION

The CDC has been at the forefront of moving cancer surveillance into the electronic age by providing software and tools to overcome the barriers and challenges with interoperability. Our challenge remains making data more available in real time. Thus, going forward, we plan to shift focus to more, real-time data at the patient level. These real-time data will provide rapid reporting of all cancer cases, accelerate the use of effective interventions, enable effective resource allocation, identify potential patients for clinical trials, and define research priorities.

The many cancer informatics efforts described previously are moving us closer to providing real or near real-time data and illustrate how CCRs are working to meet their core functions for more timely, accurate, and complete data. The CDC is employing all lessons learned over last 25 years of NPCR to move us into the future with more efficient and modernized collection and exchange processes.

AUTHOR CONTRIBUTIONS

All authors contributed substantially to the conception and design of this work and helped to draft and revise the manuscript. All authors approved the final version to be published and are accountable for all aspects of this work.

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CONFLICT OF INTEREST

The authors have no potential conflicts of interest to declare with respect to the research, authorship, and/or publication of this article.

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