

**NAACCR  
Real-Time Reporting Task Force**

**Report to the Board**

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**North American Association of  
Central Cancer Registries, Inc.**

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## **1 Executive Summary**

The NAACCR Real-Time Reporting Task Force is pleased to submit this report on real-time reporting to the NAACCR Board of Directors. The task force was formed as a result of a high-priority recommendation from NAACCR Board and Committee Chairs following a retreat held in Freeport, Maine, in 2002. At that time, the retreat participants identified the need of NAACCR member registries to move toward electronic, real-time reporting from all of their sources. A task force was formed in 2003 and included IT and central cancer surveillance experts from NAACCR-sponsoring organizations, cancer registries, and vendors. Sponsoring organizations in Canada such as the Canadian Association of Provincial Cancer Agencies, Health Canada (now the Public Health Agency of Canada), and Statistics Canada as well as several Canadian cancer registries were invited to participate but no one accepted and designated a volunteer to work on the task force.

This report summarizes the recent efforts by former Department of Health and Human Services (DHHS) Secretary Tommy Thompson and the National Health Information Technology Coordinator, David Brailer, to encourage the development and adoption of interoperable electronic health record systems (EHRS), which would allow physicians and other medical practitioners to access health and medical information on their patients. An important aspect of these systems is the development of real-time reporting of health care information in an interoperable format that would need to be shared among hundreds of medical systems that collect and store data on patients. This report also summarizes the role that the Health Insurance Portability and Accountability Act (HIPAA) and standards setting organizations have in developing the health informatics systems that would be needed to meet the DHHS goal of an interoperable EHRS within 10 years.

This report also presents some examples of current efforts to implement real-time reporting systems in the cancer surveillance community and highlights the importance of real-time reporting for the timely and complete collection of cancer data. The task force also makes recommendations to NAACCR to embrace these national efforts and to work with national organizations that are developing health data standards for the health informatics community involved with interoperable EHRS, in part, to ensure that the needs of the cancer surveillance community are met.

## **2 Introduction**

The promise of real-time data collection for cancer registries is based on the availability of networked source data from the various departments of originating facilities (e.g., hospitals, anatomical pathology laboratories, physicians, vital records, etc.) in some standardized and electronically digitized formats. Real-time reporting presents the opportunity to improve current cancer surveillance methods through automated reporting of reportable tumors to central cancer registries and to improve both the completeness and timeliness of cancer registration efforts. For example, many pathology laboratory information systems are already configured to automatically search for reportable cancers and to send final diagnostic reports in real-time to both the hospital and the central cancer registry. In addition, some systems that utilize artificial intelligence technology are demonstrating that information in free-text form can be collected and any associated cancer terms coded and transmitted with a high degree of sensitivity and specificity. Also, there are other systems that allow the hospital-based cancer registry to be

integrated with the central cancer registry to share both database and software applications with high levels of security.

In 2004, DHHS Secretary Tommy Thompson appointed David Brailer as the National Health Information Technology Coordinator. In this newly created position, Dr. Brailer's tasks are to encourage the private sector to adopt interoperable electronic health records (EHR) and to develop local or regional health information networks that would allow physicians to access all medical and health information related to their patients. These local or regional networks would then be able to communicate across other local or regional networks that would comprise a national system of health information. Estimates of the projected savings that may be expected by the successful development of an interoperable EHR system range from \$140 to \$300 billion a year.

In July 2004, DHHS released a document entitled "Framework for Strategic Action: The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care." This report outlined an approach toward nationwide implementation of interoperable EHR. The four major goals are to:

- (1) Inform clinical practice by accelerating the use of EHRs;
- (2) Interconnect clinicians so that they can exchange health information using advanced and secure electronic communication;
- (3) Personalize care with consumer-based health records and better information for consumers; and
- (4) Improve public health through advanced bio-surveillance methods and streamlined collection of data for quality measurement and research.<sup>1</sup>

In November 2004, DHHS released a Request for Information (RFI) to develop and adopt, within 10 years, an interoperable EHRS. The 10-year goal, which presents an enormous challenge to health informatics providers, would result in the ability to exchange complete health information about patients within a wide variety of health settings in real-time. Further, these health data would have to be transmitted under stringent security to protect the patient's privacy.

A note about the difference between EHRs and EMRs (electronic medical records) is in order because the terms are sometimes used interchangeably. For the purpose of this report, the EHR refers to the totality of electronic or digitally stored information about a patient throughout the health care system. The EMR is a subset of this information and refers to the medical information contained within a health care facility, such as a hospital, clinic, or physician's office. The EMR is a less complicated entity than the EHR and easier to implement for real-time reporting than the more complex EHR.

This report, by the NAACCR Real-Time Reporting Task Force, summarizes past, current, and anticipated real-time reporting efforts and recommends to NAACCR the steps that will be required by the organization to keep abreast of efforts to develop interoperable EHRS.

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<sup>1</sup> Statement of David Brailer, MD, PhD, National Coordinator for Health Information Technology, U.S. Department of Health and Human Services, testimony before the Subcommittee on Health of the House Committee on Ways and Means, July 27, 2005 (<http://waysandmeans.house.gov/hearings.asp?formmode=view&id=2944>)

### **3 Definition of Real-Time Reporting**

For the purposes of this report, real-time reporting for cancer registries describes any automated computer system with the capability of transmitting structured or semi-structured electronic medical data (including text) about cancer patients to cancer registries within minutes or days of the completion, or a portion thereof, of cancer-related information. Data in these systems might originate from a variety of medical settings, including but not limited to medical records departments, pathology laboratories, radiology clinics, physicians offices, or a network of multiple databases. Data would also be transmitted over the Internet using widely accepted Internet security standards.

### **4 The Real-Time Reporting Task Force**

As previously mentioned, the idea to create a Real-Time Reporting Task Force arose at a NAACCR retreat held in Freeport, Maine. The retreat participants, which included the NAACCR Board of Directors, NAACCR Committee Chairs, and NAACCR staff, recognized that the future success of cancer registries will rely to a great extent on the ability of registry systems to accurately and rapidly obtain information about cancer cases, and that real-time case reporting from all of their sources would soon become a necessity. NAACCR also recognized that real-time reporting of cancer information to regional and local registries would help to identify all newly diagnosed cases of cancer by health care facilities and increase the registries' ability to efficiently and accurately capture information related to the diagnosis, treatment, and survival of cancer patients.

### **5 Background**

Standards-setting organizations in the cancer community use their data for different purposes. Historically, some data elements had different meanings depending on the organization's use of the data. The earliest standards setters were the American College of Surgeons (ACoS), Commission on Cancer (CoC), and the National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) program. At that time, hospital-based cancer registries followed CoC codes and coding rules, while central cancer registries followed the SEER codes and coding rules. These two organizations were not always in agreement. During the 1980s, the CoC and SEER began working together to make codes and definitions in their manuals consistent. During the same period, the California Cancer Registry was developing a statewide system that allowed facilities to report electronically to their state regional registries. To facilitate implementation of standards within its program, the California Cancer Registry requested that CoC and SEER establish a formal committee to pursue data standardization and requested membership on this committee. In 1987, the function of that original committee was transferred to NAACCR's Uniform Data Standards Committee (UDSC).

UDSC membership includes representation from standards-setting organizations, software vendors, and central registries. The UDSC provides a formal mechanism for reviewing and recommending proposed changes in data codes and/or the addition of new items to ensure that data remain comparable among central registries. Data item definitions and format standards for cancer registration are published, through a contract with the National Program of Cancer Registries (NPCR) at the Centers for Disease Control and Prevention (CDC), in the *Standards*

*for Cancer Registries, Volume II: Data Standards and Data Dictionary.* Objectives of the standardization effort include providing a comprehensive reference to ensure uniform data collection; reducing the need for redundant coding and data recording between agencies; facilitating the collection of comparable data among groups; providing a resource document to help registries that are establishing or revising their databases; and encouraging the adoption of these standards by all parties.

Currently, the NAACCR data exchange record layout is in an ASCII, fixed-length, flat-file format that is designed to facilitate electronic transmission of cancer registry data among registries for multiple purposes. The layout is used to: provide standardized data from reporting sources to central registries; share tumor reports on residents of other states/provinces from one central registry to another; or report data from diverse facilities or states/provinces contributing to a combined study. The layout is intended to provide a common language for cancer registry systems. It was not NAACCR's intent to require that systems would necessarily use the NAACCR data item names and layouts internally. However, it has proved to be convenient for some systems to do so. The standard has been widely accepted both for data exchange and local use.

## **6 Historical Perspective—Cancer Registry Operations**

Historically, the administrative and clinical information flow within health care facilities has not been uniformly digitized, standardized, and networked for possible access to the cancer registry. Without access to an integrated hospital information system and without a built-in interface to that system, tumor registries in hospital settings often had to set up their own cancer registry systems. In addition, tumor registrars spent most of their time manually collecting, coding, and keying the required data. It is reported that in certain situations cancer registrars use printouts of findings from one hospital computer system to re-enter that data into the cancer registry database.

Hospitals incorporate a variety of information systems, and each medical department is more likely to have its own information systems with different data structures; a major roadblock to systems integration. Information systems for hospital admissions and billing, anatomical pathology, clinical laboratory, radiology, and especially the physician's private office are just a few of the many sources of medical information systems that need to be integrated with each other to enable the real-time reporting to capture the information required for an EHR.

An abundance of changes and influences need to occur to set the stage for possible real-time data collection. The current objective to create a standard EHR will help to solve one of the major problems facing medical information systems today, which is the choice of standards by the medical informatics community to develop the interfaces that will enable different information systems to communicate with each other.

One of the early successes in this regard is the work of Dr. Clement McDonald of the Regenstrief Institute for Health Care at the Indiana University School of Medicine. In 1997 at the Indiana University Medical Center, an integrated medical record system was in place that tracked the records of 1.4 million patients. The system handles full-text narrative documents, millions of orders annually, and holds more than 100 million coded patient observations and test results. Although it did not eliminate the paper patient chart because physicians were still handwriting notes, it provided staff with ready access to patient information through a computer terminal.

Today, the Internet provides even greater access to physicians needing to access medical information on their patients. From this and other medical information systems in other hospital settings, the integrated EHR is leading to better physician practice and care processes.

## 7 Role of the Health Insurance Portability and Accountability Act (HIPAA)

Important research developments in national data standards and data streaming between medical facilities are being gradually implemented. Further development of, and central cancer registry access to, such data streams should be encouraged. Given the impact of the HIPAA Public Law 104-191 on such data streams, it is important to the cancer registry community to examine and understand HIPAA. HIPAA amends the Internal Revenue Service Code of 1986. Also known as the Kennedy-Kassebaum Act, Title II includes the section on Administrative Simplification, which requires efficiency in health care delivery by standardizing electronic data interchange, and protection of confidentiality and security of health data through setting and enforcing standards.

Title II of HIPAA calls for the following:

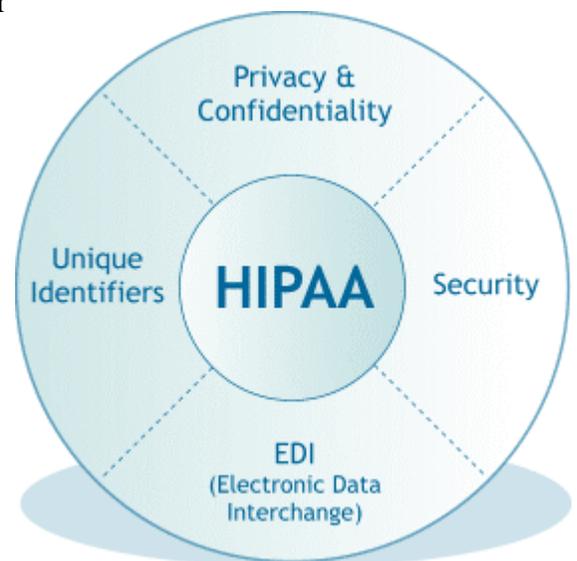
- Standard health, financial, and administrative data for electronic interchange.
- Unique identifiers for employers, health plans and health care providers.
- Security standards that specify protocols for the transmission of electronic health information.
- Privacy standards that protect the confidentiality of “individually identifiable health information.”

HIPAA regulations directly affect:

- Health care providers;
- Health care payers;
- Health care claims clearinghouses; and
- Health plans, both public and private.

Covered entities that are named in the HIPAA legislation are health plans, health care clearinghouses, and health care providers who transmit any health information in electronic form in connection with a transaction referred to in Section 1173(a) of the Act. For public health agencies, HIPAA states, “Nothing in this part shall be construed to invalidate or limit the authority, power, or procedures established under any law providing for the reporting of disease or injury, child abuse, birth, or death, public health surveillance, or public health investigation or intervention.” The regulation implementing the HIPAA privacy provisions allows public health exemptions for disclosure without patient consent of individually identifiable health information for the purposes quoted above.

Under HIPAA, state cancer registries qualify as a public health authority operating as an agency authorized by law to “collect or receive such information for the purposes of preventing or controlling disease to conduct public health surveillance, public health investigations, and public health interventions.” (45 CFR 164.512) As such, public health reporting to state agencies or the designated state cancer surveillance authority from pathology laboratories is exempt from



HIPAA privacy rules. For example, health care facilities, pathology laboratories, and other health care providers, as covered entities, may report this public health information to state cancer registries using the Health Level 7 (HL7) standard as described here and HIPAA provisions will not alter these reports.

### 7.1 National Provider Identifier (NPI)

This rule proposes a standard for a national health care provider identifier and requirements concerning its use. The use of this identifier would improve the Medicare and Medicaid programs, other Federal health programs and private health programs, and the effectiveness and efficiency of the health care industry in general by simplifying the administration of the system and enabling the efficient electronic transmission of NPI information. NPIs would be issued by one or more organizations and can be any of the following:

- Registries
- Private and Professional Organizations
- Federal Health Plans and Medicaid
- State Health Organizations.

The deadline for health care providers to receive NPI codes is spring of 2007. Providers can apply for their NPI code now.

### 7.2 Transaction and Code Set Rules

The Administrative Simplification section of HIPAA establishes national standards for electronic health care transactions, which require the use of specific electronic formats developed by the American National Standards Institute (ANSI). Health providers and plans use a variety of electronic formats, which often results in cumbersome or erroneous processing and transfer of information. The adoption of Transaction and Code Set standards, therefore, will improve the efficiency and effectiveness of the national health care system by moving systems toward the use of Electronic Data Interchange (EDI) and uniform sets of standards.

At present, the X12 and HL7 standards are used for designated electronic HIPAA-compliant transactions:

- **X12:** Developed to facilitate the exchange of e-commerce data, X12 specifies only the *format* and *data contents* of e-business transactions. It has a broad application, but is not sufficient for HIPAA. For data interchange in general, the principal standard today is X12.
- **HL7:** Provides specifications pertinent to health care information, the most widely used of which is a messaging standard that enables different applications to exchange key sets of clinical and administrative data. The HL7 standard addresses the *definition* of data to be exchanged, the *timing* of the exchange, and *error notification*.

The term “Electronic Health Transactions” includes health claims, health plan eligibility, enrollment and discontinuation of enrollment, payments for care and health plan premiums, claim status, first injury reports, coordination of benefits, and related transactions. Exact transaction types to be included in the final Transaction and Code Set Rule are yet to be determined.

The scope of the transaction standard will include:

- Electronic transmission using all media, even when the transmission is physically moved from one location to another using magnetic tape, disk, or CD media; and
- Transmissions over the Internet, extranet, leased lines, dial-up lines, and private networks.

### **7.3 Standards and Standards Maintenance Organizations**

HIPAA requires that health organizations also must adopt Standard Code Sets to be used in *all* health transactions. For example, coding systems that describe diseases, injuries, and other health problems—as well as their causes, symptoms, and any actions taken related to them—must become uniform. All parties to any transaction will be required to use and accept the same coding terminology.

The final HIPAA Transaction and Code Set Rule will include, but not be limited to, the following standards:

- International Classification of Diseases (ICD9/ICD10);
- National Drug Codes (NDC) ;
- Health Care Financing Administration Common Procedure Coding System (HCPCS);
- Logical Observation Identifier Names and Codes (LOINC<sup>®</sup>); and
- Current Procedural Terminology, Fourth Edition (CPT-4).

On August 17, 2000, the Secretary of State identified a number of Designated Standard Maintenance Organizations (DSMOs). As their name suggests, these organizations are charged with maintaining standards for the health care transactions adopted by the Secretary. Also, they are responsible for receiving and processing requests for the adoption of new standards or for the modification of existing standards. Should the DSMOs develop XML-based standards that are subsequently adopted by industry, DHHS would consider adopting them as the HIPAA standards as well.

DSMOs include:

- National Uniform Billing Committee;
- National Uniform Claim Committee;
- The Dental Content Committee of the ADA;
- The National Council of Prescription Drug Programs;
- The X12 standards developing organizations; and
- The HL7 standards developing organizations.

For additional information, please visit the DHHS Transaction and Code Sets page.

### **7.4 Security Standards**

The HIPAA Security Standard defines standards as well as requirements for the Electronic Signature Standard. The Security Standard applies to individual health information that is maintained or transmitted by a broad range of health care organizations, amounting to a much broader reach than the specific transactions defined explicitly in the law. The Electronic

Signature Standard applies only to the transactions adopted under HIPAA, although none of the transactions adopted under HIPAA requires an electronic signature at this time. The categories of security that will be impacted are:

- Administrative procedures;
- Physical safeguards;
- Technical security services;
- Technical security mechanisms; and
- Electronic signatures.

## **8 The National Health Information Infrastructure (NHII)**

The NHII is a Federal initiative with a mission to improve the effectiveness, efficiency, and overall quality of health and health care in the United States through facilitating a comprehensive knowledge-based network of interoperable health and public health systems. The NHII will utilize a set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health. This system will allow ease and quickness of communication to prevent errors in treatment, improve decision making, lower administrative costs, and allow for rapid responses to emergencies.

From a process perspective, the NHII can be viewed as a series of local health information infrastructures with the ability to communicate in real-time. Among the challenges are connectivity of systems, the need for standardization of terms, and capture of information in machine-readable form.

The NHII Web Site identifies a number of standards-setting organizations and efforts. Organizations include ANSI; the American Medical Association (AMA); American College of Radiology (ACR); National Electrical Manufacturers Association (NEMA); HL 7 Organization; Health Information Standards Board (HISB), a subgroup of ANSI; Institute of Electrical and Electronics Engineers (IEEE); National Council for Prescription Drug Programs (NCPDP); and the Institute of Medicine (IOM). Specific messaging and terminology standards mentioned include HL7, X12N, DICOM, LOINC, SNOMED, and UMLS. A summary of standards and standards-setting organizations for health care can be viewed at <http://aspe.hhs.gov/sp/nhii/standards.html>.

## Technology and Standards for Health Care Informatics

Messaging Standards	Used for:
HL7	Clinical data
X12N	Financial data, HIPAA-mandated transactions
DICOM	Images
NCPDP	Prescription from providers to pharmacies
IEEE	Bedside instruments, medical information bus
Terminology Standards	
LOINC <sup>®</sup>	Codes laboratory observations and common clinical measurements
Drugs	NLM/FDA/VA collaboration on RxNorm, NDF-RT
Billing	CPT, ICD-9CM
Clinical	UMLS, SNOMED, and others

Table adopted from Stan Huff, MD, HIMSS, 2003.

Three stages are seen for implementation of the NHII over the next decade. The first, emphasizing Federal leadership and development of a clear policy and plan for the NHII, increased Federal emphasis on acceleration of standards development and commitment of required resources, is viewed as a 2-year process. This will be followed by a second stage, reaching completion in 5 years, and emphasizing establishment of multiple necessary collaborations that the NHII requires involving Federal, state, local community, and private stakeholders. The last stage, which involves implementation, will be accomplished in 10 years.

On April 27, 2004, President Bush called for most Americans to be covered by interoperable EHRs within 10 years, and established the position of the National Coordinator for Health Information Technology within DHHS. The National Coordinator was charged with designing and implementing a strategic plan that utilizes information technology in the public and private sectors to achieve four goals: (1) use health IT to inform clinical practice with the use of EHRs; (2) interconnect clinicians to enable the exchange of health information; (3) personalize care with consumer-based health records; and (4) improve population health by improving surveillance methods and streamlining the collection of data for quality measurement and research. Central to this effort is the issue of interoperability in terms of data storage, processing and access, identification management, Web services architecture and security. Standards for data elements and transmission algorithms also must be established and maintained.

On November 15, 2004, to gain broad input regarding the best mechanisms to achieve nationwide interoperability, the Office of the National Coordinator for Health Information Technology (ONCHIT) released an RFI. The RFI encouraged the public to comment on the form that a nationwide health information network (NHIN) could take; how it would relate to regional health networks; how it could be financed, governed, and operated; and the role the Federal government should play. The results of this effort are available online at <http://www.hhs.gov/healthit/rfisummaryreport.pdf>.

## **9 Federal Health Architecture**

The Office of the National Coordinator (ONC) in DHHS also oversees the Federal Health Architecture (FHA). Basically, the FHA is both a methodology for developing health information interoperability standards and an initiative to help support health IT for public health. The FHA has two goals: (1) improve coordination and collaboration on national health IT solutions, and (2) improve the efficiency, standardization, reliability, and availability of comprehensive health informatics solutions. Almost all Federal departments or agencies involved in the health care industry participate in the FHA. Thus far, the FHA has produced governance and program plans; defined architecture development methodology and developed standard templates to capture information; assimilated the Consolidated Health Informatics (CHI) initiative (see next section); formed work groups to review architecture efforts of participating agencies; identified interoperability focus areas; and distributed a survey to Federal agencies that deal with EHRs and HL7 models. More information on the FHA may be found at: <http://www.hhs.gov/fedhealtharch/>.

## **10 Consolidated Health Informatics (CHI)**

CHI is a Federal initiative with the goal of adopting existing clinical vocabulary and messaging standards to enable interoperability in the Federal health care enterprise. Within the Federal Government, there are a multitude of agencies involved directly and indirectly with health-related missions. These agencies need a way to share their health information and therefore need to adopt the same clinical vocabularies and the same ways of transmitting that information. This sharing of information within and between agencies promotes interoperability.

This initiative will establish a portfolio of existing clinical vocabularies and messaging standards enabling Federal agencies to build interoperable Federal health data systems. This commonality will enable all Federal agencies to “speak the same language” and share that information without the high cost of translation or data re-entry. Federal agencies then could pursue projects meeting their individual business needs aimed at initiatives such as sharing EMRs and electronic patient identification. CHI standards will work in conjunction with the HIPAA transaction records and code sets as well as HIPAA security and privacy provisions.

About 20 departments/agencies, including DHHS, Veterans Affairs (VA), Department of Defense (DOD), Social Security Administration (SSA), General Services Administration (GSA), and National Institute of Standards and Technology (NIST), are active in the CHI governance process. Through the CHI governance process, all Federal agencies will incorporate the adopted standards into their individual agency health data enterprise architecture to build all new systems or modify existing ones. There is a Consolidated Health Informatics Work Group that leads the effort and is one of the five established FHA Work Groups. CHI conducts outreach to the private sector through the National Committee on Vital and Health Statistics. Records and schedules are available at <http://www.ncvhs.hhs.gov/>.

## **11 College of American Pathologists (CAP) SNOMED CT Encoded Cancer Protocols and Checklists**

In April 1999, CAP, under the leadership of the CAP Cancer Committee, published “Reporting on Cancer Specimens Protocols and Case Summaries.” As of 2005, CAP has developed and published 43 site-specific cancer protocols and checklists encoded in SNOMED (SNOMED CT

encoded CAP checklists). The purpose of the checklists is to “aid the surgical pathologist with completeness, accuracy, and uniformity in the reporting of malignant tumor specimens from adult patients and with quality assurance issues related to such specimens.” The checklists may be used as a framework for full narrative reporting, alternative reporting formats, or clinical research protocols. The ACoS CoC has recognized the value of the CAP cancer checklists in caring for cancer patients. Starting January 1, 2004, the CoC mandated that pathologists at CoC-approved cancer programs include a subset of the checklist concepts in their surgical pathology reports.

Below is an example of a section from the 2004 version of the colon-rectum checklist.

<p>Colon and Rectum</p> <p>Protocol applies to all invasive carcinomas of the colon and rectum. Carcinoid tumors, lymphomas, sarcomas, and tumors of the vermiform appendix are excluded.</p> <p style="text-align: right;"><i>Protocol revision date: January 2004 Based on AJCC/UICC TNM, 6th edition</i></p> <p>COLON AND RECTUM: Polypectomy</p> <p>Patient name: Surgical pathology number:</p> <p><b><i>Note: Check 1 response unless otherwise indicated.</i></b></p> <p>MACROSCOPIC</p> <p>Tumor Site</p> <p><input type="checkbox"/> Cecum</p> <p><input type="checkbox"/> Right (ascending) colon</p> <p><input type="checkbox"/> Hepatic flexure</p> <p><input type="checkbox"/> Transverse colon</p> <p><input type="checkbox"/> Splenic flexure</p> <p><input type="checkbox"/> Left (descending) colon</p> <p><input type="checkbox"/> Sigmoid colon</p> <p><input type="checkbox"/> Rectum</p> <p><input type="checkbox"/> Not specified</p> <p>Polyp Size</p> <p>Greatest dimension: ___ cm</p> <p>*Additional dimensions: ___ x ___ cm</p> <p><input type="checkbox"/> Cannot be determined (see Comment)</p>
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Subsequent to the creation of the protocols and checklists, SNOMED International enhanced the CAP checklists by encoding them on an item-by-item basis with SNOMED CT. This smoothed the way for electronic transmission of the data and promoted the effective delivery of the information necessary to provide quality patient care. The SNOMED CT encoded Cancer Checklists are an electronic enrichment of the CAP Cancer Checklists.

Below is an example of a section from the 2004 version of the SNOMED CT encoded colon-rectum checklist.

**COLON AND RECTUM: Resection [P1-573F9, 107944001] Large intestine excision (procedure)**

**MACROSCOPIC [F-048D6, 395526000] Macroscopic specimen observable (observable entity)**

SPECIMEN TYPE [R-00254, 371439000] Specimen type (observable entity)

Right hemicolectomy [G-8371, 122648004] Specimen from colon obtained by right hemicolectomy (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Transverse colectomy [G-8372, 122649007] Specimen from colon obtained by transverse colectomy (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Left hemicolectomy [G-8373, 122650007] Specimen from colon obtained by left hemicolectomy (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Sigmoidectomy [G-8374, 122651006] Specimen from colon obtained by sigmoidectomy (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Rectal/rectosigmoid colon (low anterior resection) [G-8375, 122652004] Specimen from colon obtained by rectal/rectosigmoid (low anterior) resection (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Total abdominal colectomy [G-8369, 122647009] Specimen from large intestine obtained by total abdominal colectomy (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Abdominoperineal resection [G-8368, 122646000] Specimen from large intestine obtained by abdominoperineal resection (specimen)

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Other (specify):  not coded

\*Length:  cm [R-00408, 384606002] Length of specimen (observable entity)

Not specified [G-8365, 122643008] Tissue specimen from large intestine (specimen)

These checklists and protocols are available for individual use by pathologists at the following Web site: [http://www.cap.org/apps/docs/cancer\\_protocols/protocols\\_index.html](http://www.cap.org/apps/docs/cancer_protocols/protocols_index.html). The protocols contain the checklists, as well as background documentation, explanatory notes, and references. The use of the checklists for commercial purposes requires a license.

The implementation of the SNOMED CT encoded CAP checklists in anatomical pathology laboratories and the transmission of that data to cancer registries can potentially enhance the quality of data and facilitate the processing of such data in the cancer registry. Given this recognition, CDC-NPCR has developed two pilot projects to implement the SNOMED CT encoded CAP checklists in participating pathology laboratories and to transmit that data to cancer registries, using national message or format standards. These pilot projects are referred to as the Reporting Pathology Protocols (RPP) projects.

The first RPP project, which started in 2001, focused on colon and rectum cancers and was implemented in two states: California and Ohio. The report of this project is nearing completion. In this project, the participating pathology laboratories used an electronic version of the checklist and the information was formatted into a project standard HL7 message, using LOINC<sup>®</sup> codes as the question and SNOMED CT codes as the answers.

The second RPP project, which started in 2004, focused on cancers of the breast, prostate, and melanoma and is being implemented in three states: California, Maine, and Pennsylvania. This second project hopes to further test this approach to reporting cancer surveillance data and to address, if possible, limitations identified in the first RPP project. For example, some of the issues identified in the first RPP project include: multiplicity of checklists available, fees for the use of the SNOMED CT encoded checklists, unavailability of checklists for some reportable cancers, processing of reports with multiple cancer primaries, and lack of some data items needed for staging cancer.

## **12 Logical Observations, Identifiers, Names, and Codes (LOINC<sup>®</sup>)**

LOINC<sup>®</sup> is a standard coding system or a set of universal names with associated codes for identifying laboratory and clinical observations. The purpose of LOINC<sup>®</sup> is to provide a universal identifier for laboratory and clinical observations, so that information about observations may be pooled in EMRs to facilitate the exchange of comparable clinical and laboratory results and support clinical care, outcomes management, and research. Typically, LOINC<sup>®</sup> is used within the HL7 message to designate the associated test, procedure, or observation.

The LOINC<sup>®</sup> database now includes names, codes, and synonyms for 36,000 concepts. It is particularly rich in content from laboratory, radiology, cardiology, general clinical measurements, survey instruments, ventilator management, ophthalmology, and obstetrical measurements. Significant milestones for LOINC<sup>®</sup> in 2003–2004 include:

- March 2003: DHHS Secretary Tommy Thompson announces adoption of Laboratory LOINC<sup>®</sup> as the standard for ordering and reporting laboratory tests and for identifying clinical reports.
- November 2003: The National Committee on Vital and Health Statistics recommended LOINC<sup>®</sup> as the terminology for representing the laboratory observations as part of Patient Medical Record Information (PMRI) terminologies.
- July 2004: The National Committee for Quality Assurance (NCQA) announced that the Health Plan Employer Data and Information Set (HEDIS<sup>®</sup>) would support the use of LOINC<sup>®</sup> codes for some measures.

The DOD has adopted LOINC<sup>®</sup> as a standard for radiology as well as laboratory ordering and reporting. Many large health care institutions, health care insurance organizations, and referral laboratories have adopted LOINC<sup>®</sup> and use it in clinical messages. LOINC<sup>®</sup> also has garnered international attention. The German national standards organization (DIN) adopted LOINC<sup>®</sup> as a national standard, and it has been adopted in New Zealand, Canada, Australia, and China as well. The Swiss have translated the most common 3,800 terms into German, French, Spanish, and Italian.

LOINC<sup>®</sup> was first organized in 1994 by Dr. Clement J. McDonald and is supported by the Regenstrief Institute, the National Library of Medicine, and the CDC. The collection and assignment of names and codes for laboratory observations was begun in 1994, and those for the clinical observations were begun in 1996. As such, LOINC<sup>®</sup> consists of two main committees: Laboratory LOINC<sup>®</sup>, chaired by Dr. McDonald, and Clinical LOINC<sup>®</sup>, chaired by Dr. Stanley M. Huff. Both committees meet at least three times a year with open public meetings. There are a number of subject areas in the Clinical LOINC<sup>®</sup> domain, including those for Pathology Findings and Tumor Registry. Many of the NAACCR data items already have associated LOINC<sup>®</sup> codes.

The LOINC<sup>®</sup> database is available to download from the Regenstrief Web Site (<http://www.loinc.org/>). In addition to the LOINC<sup>®</sup> database, the Regenstrief Web Site contains an associated mapping tool or browser, the Regenstrief LOINC Mapping Assistant or RELMA. This tool allows users to search for observations in the LOINC<sup>®</sup> files. Both the LOINC<sup>®</sup> files and RELMA are available free of charge.

### 13 C-Change

C-Change is comprised of the Nation's key cancer leaders from government, business, and nonprofit sectors. These cancer leaders share the vision of a future where cancer is prevented, detected early, and cured or is managed successfully as a chronic illness. The mission of C-Change is to leverage the combined expertise and resources of its members to eliminate cancer as a (major) public health problem at the earliest possible time. In 2004, C-Change sponsored a Cancer Surveillance and Information Summit that brought together 86 experts from the broad field of cancer surveillance. The purpose of this summit was to seek ways to reduce the burden from cancer through the full application of information. The Summit sought to review the current state of the science, identify near and long-term contributions to the surveillance enterprise, identify barriers to progress, and determine the research and development needed to move the field forward to develop strategies and plans, as well as recommend key initiatives, timeframes, and groups who could propel the field forward.

Seven recommendations were developed at the 2004 Cancer Surveillance and Information Summit: (1) *Data Standards*: The recent agreement by major registries and coding systems on common stage specifications is a model for future action in data standardization. To move this recommendation forward, all groups setting data standards such as NAACCR, HL7, SNOMED, and others must be convened to create an inventory and work toward common terms and specifications. (2) *Expanded Scope for Cancer Surveillance*: An expanded vision for cancer surveillance goes beyond cancer registration to include risk factor data, pre-neoplastic events, quality indicators, and patient-centered outcomes. The vision needs to be embraced by all entities within the surveillance enterprise. (3) *Leadership*: The activity of collecting and disseminating cancer surveillance information requires leadership and financial support. Central leadership is needed to guide activities by individual agencies and organizations. The Presidential appointment of a National Health Information Technology Coordinator in May 2004, Dr. David Brailer, provides such a leader and an appropriate overall administrative entity to oversee the development of cancer surveillance in the future. (4) *Incentives*: These are needed for participation in expanded surveillance activities and may include accreditation, reimbursements, and provider certification for participation. (5) *Health Disparities*: These need to be addressed across the spectrum of cancer surveillance by adopting measures of socioeconomic status as well as age, gender, race, and ethnicity into national dataset and medical record systems. (6) *Surveillance Tools*: Surveillance data must be more readily available for clinical and public

health practice. Government, academic, industrial, and health care systems must be engaged to develop and implement tools for comprehensive cancer planning. (7) *Legislative Mandate*: This may be needed to authorize the collection of patient-centered data and other data elements under an expanded scope of surveillance.

The next step is to engage critical players in implementing the top priority, that of achieving standards across the cancer surveillance enterprise, including coding, data collection, procedures, and information dissemination. The C-Change Access to Quality Cancer Care Team has taken on this task and is proceeding with a major planning effort in the next 12 months for a meeting to address the critical issues involved in setting standards for cancer surveillance and information. This meeting will focus on the CAP cancer protocols and checklists, their dissemination, implementation, and lessons that can be transferred to other standardization efforts.

## **14 Current Examples of Real-Time Reporting**

### **14.1 Cancer Bio Informatics Grid (caBIG)**

caBIG was initiated by the NCI to test the feasibility of developing and deploying a biomedical informatics infrastructure that could facilitate integration of efforts of multiple cancer center institutions. Members of the cancer research community will be provided with access to shared and enhanced data, applications, standards, and technologies. These, in turn, may lead to improvements in outcomes for patients and communities. Applications developed under caBIG also will be made available to broader audiences. The NCI-designated comprehensive cancer centers are the primary participants in the caBIG pilot, which is anticipated to run for 3 years.

CaBIG technical principles include open source, open access, open development, and federation. The pilot participants initiate all caBIG specific activities. Technical specifications for compliance with caBIG will be formulated in conjunction with Cancer Center participants. At a high level, caBIG is organized into a number of workspaces. There are three domain workspaces: Clinical Trial Management Systems, Integrative Cancer Research (including the Population Scientists Special Interest Group), and Tissue Banks and Pathology Tools. Two crosscutting workspaces, the Architecture Workspace and the Vocabularies and Common Data Elements (CDEs) Workspace, also have been designated. The domain workspaces develop products or solutions that address specific needs of the participants and that can be used to test the grid as a method of dissemination of applications. The crosscutting domains address areas of common concern across workspaces such as consistency and congruence of caBIG activities. Three strategic-level working groups, caBIG Strategic Planning, Data Sharing, and Intellectual Capital and Training, support the caBIG initiative as a whole.

### **14.2 CDC Public Health Information Network (PHIN)**

The purpose of real-time reporting in public health is to use information science and technology to detect, monitor, and assess outbreaks of disease, either naturally occurring or from bioterrorism. Public health covers a wide range of diseases and conditions, including infectious disease such as SARS, food-borne diseases such as *Salmonella*, and chronic diseases such as cancer. The objectives of public health are to: conduct surveillance to detect disease outbreaks, assess the health status of a population, and assist in health planning; investigate causes and disease transmission patterns; and develop effective interventions to prevent disease and promote

health. Real-time reporting, as defined in this document, is an essential communication tool for the different partners and actors in the surveillance system.

Given this public health need for disease surveillance, the CDC has developed a system to improve public health communications by using and promoting health data and technology standards. This system is referred to as PHIN. Through defined data and vocabulary standards and strong collaborative relationships, the PHIN enables consistent exchange of health and disease tracking data between public health partners. Rather than develop unique standards for public health, CDC-PHIN uses industry standards for messaging, vocabulary, modeling, and security. Much of these standards revolve around the work conducted by the HL7 organization. The HL7 message typically uses the LOINC<sup>®</sup> and SNOMED CT vocabulary codes, as does the CDC National Electronic Disease Surveillance System (NEDSS). PHIN includes a number of component systems including the NEDSS.

The NEDSS project “is a public health initiative to provide a standards-based, integrated approach to disease surveillance and to connect public health surveillance to the burgeoning clinical information systems infrastructure” (<http://www.cdc.gov/nedss/>). A primary goal of NEDSS is the ongoing, automatic capture and analysis of data that are already available electronically. The vision of NEDSS is to have integrated surveillance systems that can transfer appropriate public health, laboratory, and clinical data efficiently and securely over the Internet. Although the methods of disease surveillance systems may differ, there are many common elements in the way that data are collected, managed, transmitted, analyzed, and disseminated. Through the creation of standards, NEDSS facilitates the handling of data across each of these steps. In brief, the NEDSS system provides the framework or architecture for electronic disease reporting from laboratory and clinical information systems to public health organizations.

In addition, the NEDSS model envisions the electronic transmission of all laboratory and clinical data to a single source or portal within the state health departments where the data are directed to the appropriate unit within the health department. This concept streamlines the disease reporting process of participating laboratory and clinical facilities.

Historically, in the cancer registry community, data have been copied onto diskettes in hospitals and mailed to the central cancer registry. Although this procedure may have been appropriate in the mid-1990s, technology today allows for data to be transmitted securely over the Internet from hospital and other reporters to central cancer registries. The CDC, through the Public Health Information Network Messaging System (PHINMS), promotes this transfer of secure data over the Internet. “PHINMS uses the Electronic Business Extensible Markup Language, ebXML, infrastructure to securely transmit public health information over the Internet.” This system is a “generic, standards-based, interoperable and extensible message transport system. It is platform-independent and loosely coupled with systems that produce outgoing messages or consume incoming messages.” (*Source: Public Health Information Network Messaging System: An Overview of PHINMS*)

The NEDSS software in the respective states consists of either the NEDSS Base System, software developed by the CDC, or a compatible system. States can develop compatible systems using the NEDSS specifications or deploy the NEDSS Base System. The NEDSS specifications can be regarded as a set of standards (i.e., set of prescribed specifications). The initial focus of the NEDSS project has been on communicable disease surveillance. The first version of the

NEDSS Base System included 93 notifiable diseases as well as modules for vaccine preventable diseases, hepatitis, bacterial meningitis, and pneumonia.

State health departments are in the process of implementing PHIN/NEDSS standards for disease reporting. As such, PHIN/NEDSS is a useful model and tool for cancer registration, particularly in the areas of anatomical pathology laboratory reports, including cytology and hematology reports and offering tools for secure electronic transmission over the Internet. NPCR, as a program administered by the CDC and implemented in state health departments (or the health department's designated operator), is bound to move towards conformance with PHIN/NEDSS standards, especially in the area of transmitting data from pathology laboratories and clinical facilities to NPCR registries.

#### **14.3 SEER Data Management System (SEER\*DMS)—The Use of Modeling in the Design/Development of a Cancer Surveillance Data Management System**

Historically, each central cancer registry in the SEER Program has handled data management system (DMS) functions independently. However, due to aging of software applications and hardware infrastructures, the need of some registries to enhance data management functions, the costs of upgrading multiple systems, and the desire for greater standardization and interoperability, it was decided that the NCI would develop a data management system (SEER\*DMS) appropriate for all SEER cancer registries. Benefits resulting from the development of the SEER\*DMS include: incorporation of electronic data transmission (e.g., e-path), improved data quality and consistency, improved timeliness and efficiency of data submission and reporting, increased flexibility in data item definition and collection, ability to quickly enhance and modify the DMS for all SEER registries, cost containment by the elimination of redundancy, and increased sharing of knowledge and experience between the various registries. Currently, SEER central cancer registries receive data in a variety of formats. SEER\*DMS will provide greater efficiency in interfacing with electronically transmitted data, bringing registries closer to real-time reporting.

The initial phase of the SEER\*DMS project included requirements analyses to completely define the roles and operations (business rules and actors) of the SEER registries. A modeling approach, similar to Unified Modeling Language (UML) models, was used to document requirements and processes. A Joint Development Approach (JDA) was utilized for gathering the requirements. This involved participation by Subject Matter Experts (SMEs) from multiple registries in focus groups, site visits, video- and tele-conferences, and iterative review of the models. The ultimate purpose of these models was to develop blueprints for designing and developing the components of the SEER\*DMS system. It is anticipated that these models will contribute to a national consensus cancer registry model.

Various categories of models, including process, object, location, and socio-political, are available on the Web site at <http://www.seer.cancer.gov/seerdms/>. Business use cases are available by request (refer to the contact information on the Web site).

#### **14.4 NPCR—Modeling Electronic Reporting Project (NPCR-MERP)**

NPCR was authorized by the Cancer Registries Amendment Act, Public Law 102-515, and is administered by CDC's Division of Cancer Prevention and Control. The purpose of the awarded funds was/is to support states in their efforts to enhance state cancer registries or plan and

implement cancer registries where they did not exist. NPCR currently supports population-based cancer registries in 45 states, the District of Columbia, and three U.S. territories. Since the inception of NPCR, central cancer registries and affiliated hospitals are required to report and use a standard nationally defined set of specific data items and codes. This set of national data item definitions and associated format standards have been and are defined by NAACCR, an association of state cancer registries and national cancer registry organizations, including among others the CDC NPCR, NCI SEER program, Statistics Canada, and ACoS CoC accreditation hospital cancer program.

In the summer of 2003, Secretary Thompson announced an initiative of DHHS to promote the use of EHRs in hospitals and other health care facilities. This initiative is proceeding as the HL7 organization works to establish standards for the EHR. Hospitals and other health care facilities in the population areas of NPCR registries are required (by state law as mandated in PL 102-515) to report cancer information to the respective central cancer registry.

The reporting of cancer data normally begins with the date of diagnosis and ends when treatment has been completed. Typically, hospital cancer registries review the data in the hospital medical record, record the pertinent text information, code the reportable data items, assess the quality of the data item codes, and submit the report to the central cancer registry. By enabling real-time electronic transactions with hospital information systems, data can be submitted to the hospital and central cancer registries in a more timely manner and consequently provide more timely information to those engaged in comprehensive cancer control. The deliverables from this project can serve as a model to develop systems to transmit data in the EHR and hospital database system to the hospital cancer registry and, where appropriate, to the central cancer registries in real-time or near real-time.

The NPCR-MERP is a collaborative effort to position the cancer surveillance community to take advantage of the EHR for cancer surveillance. This will be accomplished by developing UML and non-UML models to represent the flow of data into all levels of the cancer surveillance system, including flow processes from the hospital's EHR (which includes multiple database systems) and other cancer registry data sources (such as private pathology laboratories) to both the hospital and central cancer registry and from the central cancer registry to the CDC. This will include, but not be limited to, pathology reports, admissions/discharges/transfers, clinical trials, operative reports, history and physicals, discharge summaries, and disease indexes. The focus on pathology reports will include both the traditional text-based reports and the College of American Pathologists (CAP) Cancer Protocols and Checklists. In addition, this project will focus on the NPCR required and recommended data items as noted in the *NAACCR Standards for Cancer Registries, Volume II* and will comply with CDC's PHIN/NEDSS data messaging standards. The project also will use the standards and methods of integrated EHRs established by the ONCHIT.

The purpose of the NPCR-MERP is to advance the cancer surveillance community in automated capture of electronically available data from the EHR and other data sources and to enhance the completeness, timeliness, and quality of cancer surveillance data.

The project objectives are to:

- Create robust, scalable, and transportable models for electronic case ascertainment.
- Create PHIN-compliant data exchange messages (HL7) using standards vocabularies (LOINC<sup>®</sup>, SNOMED CT, ICD-9CR, CPT, etc.) between hospital and central cancer registries.
- Develop a national plan and model that will provide an infrastructure to marshal resources for cancer surveillance around an agreed upon set of national priorities and that will allow cancer registries to advance toward receiving the majority of cancer data electronically.
- Assess the feasibility and utility of the model through an implementation pilot.

Current partners include the Virginia Commonwealth University Hospital System (VCUHS), the Virginia Cancer Registry (VCR), the NCI/SEER, the CDC-NPCR, Northrop Grumman IT, and Scientific Technologies Corporation.

Phase I Activities: Activities listed below have been completed or are currently underway. The project is leading towards the launch of Phase II activities, which include the following:

- Work with VCUHS and VCR to develop models of the current and proposed VCUHS models and the general proposed hospital model.
- Test the implementation of the model in VCUHS.
- Finalize models for distribution and comment from the broader cancer community.
- Develop a NPCR-MERP Web Site to provide the cancer surveillance community with project information. Visit the Web Site at [www.cdc.gov/cancer/npcr/merp](http://www.cdc.gov/cancer/npcr/merp).
- Distribute the models for comment via the NPCR-MERP Web Site and NPCR-MERP listserv.

Phase II Activities:

- Refine and enhance the current and proposed VCUHS/VCR models and the general proposed hospital model.
- Host multiple sessions with small groups of subject matter experts to gather input on the accuracy and completeness of the model.
- Assess the transportability of the model in other health care systems.
- Form a national work group of subject matter experts from the broader cancer surveillance community to:
  - Provide input on the models;
  - Synchronize vocabularies;
  - Collaborate on the development of a national plan;
  - Leverage resources to meet national priorities; and
  - Extend the model to reflect the national best practice.

#### **14.5 Electronic Pathology Laboratory Reporting**

The benefits of electronic pathology laboratory or e-path reporting in real-time are found in improved case-finding, timeliness of reporting, and in studies requiring rapid case ascertainment. Most major private pathology laboratories, in general, are HL7 compliant so that messages containing the data elements required by cancer registries can be created for efficient retrieval and delivery.

For many years, the NAACCR Pathology Laboratory Subcommittee has been working to help facilitate real-time reporting of cancer cases from pathology laboratories to central cancer registries. The Pennsylvania State Cancer Registry (PSCR) initiated the first successful application of e-path reporting. PSCR used HL7 messaging to develop an effective pathology laboratory reporting system that could be used to generate electronic pathology laboratory reports for the registry. Since then, many other registries in the United States and Canada have created e-path reporting systems based on HL7 messaging.

To help other registries develop the tools to implement e-path reporting, the NAACCR Pathology Laboratory Subcommittee, in 2000, produced and distributed the Pathology Laboratory Electronic Reporting: Items, Formatting, Recommendations document that later became included as Chapter Six of the *NAACCR Standards for Cancer Registries, Volume II*. This document was the first attempt by NAACCR to define standards and guidelines for electronic reporting of pathology laboratory reports to central cancer registries. In 2004, NAACCR identified the need to update the original e-path reporting document and the Pathology Laboratory Subcommittee created the E-Path Transmission Work Group, chaired by Eric Durbin of the Kentucky Cancer Registry. The latest draft of the *Implementation Guide for Transmission of Laboratory Based Reports Using Version 2.3.1 of the Health Level 7 (HL7) Standard Protocol* is available for review and comment on NAACCR's Web Site.

Currently, several states (e.g., California, Florida, Iowa, Minnesota, and New Jersey) are implementing e-path reporting. In Canada, e-path reporting is ongoing in Ontario province at Cancer Care Ontario. Vendors, following the NAACCR e-path reporting recommendations, have played an important role in supplying the software systems and technical support to implement e-path reporting. For example, SEER registries are using a vendor, Artificial Intelligence in Medicine (AIM), to implement e-path reporting under a contractual agreement between SEER and AIM. Under this agreement, state cancer registries enlist the cooperation of pathology laboratories that agree to install and implement the AIM software with their laboratory information systems. Other states, such as Florida, Minnesota, and Pennsylvania, have developed their own reporting systems following NAACCR guidelines and standards.

For example, the Minnesota Cancer Surveillance System (MCSS), within the Minnesota Department of Health, is making use of its long-standing partnership with the pathology laboratories to implement e-path economically. Pathology laboratories modify existing HL7 messages within their facility to meet the NAACCR standard or build a message specifically for MCSS. The NAACCR ASCII pipe-delimited file structure, an alternative to an HL7 message, also is an option for submission. The MCSS uses a local company, VisionShare, to provide secure connectivity between the laboratories and MCSS. VisionShare is used by a significant number of Minnesota facilities for transferring confidential data and also is used by the Minnesota Department of Health NEDSS. Many facilities are looking towards the coordination of both infectious and cancer reporting into one messaging system.

As a part of its e-path system, the MCSS developed java-based mapping software as a stand-alone method of parsing an NAACCR HL7 message into a NAACCR ASCII file. This software allows both types of messages to be processed automatically by the MCSS. The mapper software has been made available to other states and has been submitted to the E-Path Transmission Work Group of the NAACCR IT Committee, requesting that this committee take charge of the software for members' use. Of particular note, MCSS is using e-path reporting to perform a rapid

ascertainment for a study of acute myelogenous leukemia. Reports are available to the MCSS within 48 hours after the pathology report is determined final by the pathologist.

#### **14.6 A Web-Based Cancer Registry System Example: Health Registry Network**

Web-based cancer registry systems offer an approach that supports faster (real-time) reporting of cancer incidence reports from the medical facilities to central cancer registries. An example of a Web-based cancer registry system is the Health Registry Network (HRN). HRN is a freely supported health registry data management system that uses an open-source Web software platform. The HRN can be used for various types of health data collection operations, including cancer registration. Currently, the Mississippi, North Carolina, North Dakota, and South Dakota central cancer registries use HRN to receive reportable cancer cases from many of their hospital and non-hospital based registries. The following narrative provides examples of how a Web-based data management system may provide real-time reporting for a cancer registry operation.

**Description of a Patient-Centric Registry System:** The patient-centric database allows the cancer registry to store and reconcile multiple cancer-reports (from multiple facilities). The shared database allows users to read, write, update, and delete data from the database. The system allows a central registrar to access cancer records from all hospitals while the hospital registrar can access only their facility's records/abstracts. Web browser access provides real-time data entry of a partial or complete cancer abstract.

**Use Case:** The hospital registry abstracts a new cancer-report into the shared database. The central registry receives the report as soon as the hospital registrar completes data entry. Followup information added by the hospital registrar is instantly accessible by the central registrar.

**Description of a Document Management System:** The document library allows the cancer registry to store source documents, photos, and videos for cancer reporting purposes in a searchable library. Group folders can be created so that those documents from one hospital can be stored separately from another hospital's documents. The document library provides a secure way of transmitting copies of relevant medical records (i.e., admission face sheet, surgical notes, discharge summary, etc.) from the hospital or clinician's office to the central registry.

**Use Case:** A hospital registrar uploads a copy of a patient's admission face sheet to the document library. The central registrar receives an e-mail notification about the new document; the central registrar logs onto the document library, views the admission face sheet, and then updates the patient's cancer report accordingly in the database.

**Description of a Discussion Manager System:** The discussion manager provides a threaded discussion forum for hospital registrars, reporting facilities, and the central cancer registry to resolve technical cancer reporting issues.

**Use Case:** A dermatologist's office wants to verify if a possible skin cancer diagnosis is reportable to the central cancer registry. The dermatologist starts a discussion thread asking if a squamous cell carcinoma of the skin is reportable to the central cancer registry. The central registrar is sent an e-mail notification of a new discussion thread posting; the central registrar logs onto the discussion manager and replies to the dermatologist's question. The dermatologist receives an e-mail notification that the central registrar has replied to his/her question, and the

dermatologist logs onto the discussion manager to read the registrar's reply.

**Description of Public and Private Calendars:** The calendar allows a cancer registry to track meetings and events for registry staff or the public.

**Use Case:** A central registry has five staff assigned to abstract cases for several hospitals and physician offices. The registry manager can enter the assignments on the calendar. Staff receives an e-mail message indicating that they have a new event/assignment on the calendar. Staff may access the calendar from any Internet-connected computer.

The above tools offer registries the ability to foster collaboration of data collection, data exploration, and data dissemination. A Web-based registry system also may provide a foundation for creating communities of cancer registries by:

- Connecting hospital and central cancer registries with real-time data access and sharing abilities.  
Connecting clinician offices to the central cancer registry by offering real-time transmission (direct data-entry) of partial cancer reports.  
Providing secure Web tools for sharing documents and electronic communications

## **15 Barriers to Real-Time Reporting and Its Promise**

The DHHS goal of creating interoperable EHRS in 10 years is an ambitious undertaking, and there are many barriers to its successful creation. First, this project has been estimated to cost up to \$280 billion over 10 years. Will the government be willing to invest those dollars with the hope that the system will save us hundreds of billions of dollars a year in administrative costs?

Second, although real-time reporting and real-time surveillance exist in a number of forms today to help treat and administer patient needs, the task of making hundreds of systems work together seems insurmountable within this timeframe.

Third, for cancer registries to move toward providing timely and complete information to researchers and the public, it is clear that real-time reporting needs to be embraced by the cancer registry community. HIPAA standards provide the legislative clout to gather and transmit information in standardized codes and in a standardized format (HL7 and X12 among others). For many of us, this will mandate that hardware and software systems will need costly upgrades to comply with DHHS and HIPAA standards, among others. For example, cancer registry software will need to be redesigned to accept information in standardized formats such as HL7 and X12. This could result in more frequent hospital (and other health care provider) data submissions from not only the hospital cancer registry but also from other units within the submitting organization. This will have a major impact on the consolidation aspects of cancer registry systems. The systems also will need to consider whether electronic real-time data is in text or in discrete data item-specific format. A major challenge exists to convert text data into the appropriate code and determine what portion of the consolidation activities should involve human intervention and decision. The cancer registry software redesign also will need to examine each piece of data to ascertain those that can be mapped directly to NAACCR cancer abstract data items and those that may be indirectly mapped. For example, conceivably specific chemotherapy and hormonal therapy agent could be gleaned from real-time reporting systems and converted to the NAACCR chemotherapy and hormonal therapy data item codes. In addition

to developing the appropriate algorithms to convert such data, the cancer registry software will need to ascertain if the actual agent-specific information should be retained. This could contribute to an increase in additional data items definitions or a modification to the definitions within the NAACCR data dictionary domain.

Fourth, despite the establishment of standards and legislative mandates, will the diverse interests that control medical information systems be able to cooperate among themselves to effect the needed technological and administrative changes? A related obstacle is the associated software development cost for national standards that evolve over time. For example, if a vendor has developed a data transmission format consistent with HL7 Version 2.3.1 and a new HL7 version 3.0 standards is required, there will be significant software development costs for that vendor which will, in turn, be passed onto the vendor's customer (i.e., the hospital).

Last, will we at the national EHR-level and the cancer surveillance level be able to develop sufficiently secure systems to prevent hackers from breaking into these systems once they are developed? Many national organizations are developing data transmission security standards. Will these security standards be consistent and will they make a difference? Do we have sufficiently trained IT staff and CTR staff? If not, how and where will they be found and developed?

Although the barriers are formidable, the promise is that cancer registries will benefit from real-time reporting. Successful implementations of real-time reporting systems promise more complete case-finding and improvements in timeliness of reporting. Registries that conduct rapid case ascertainment studies also will benefit from real-time reporting. In addition, we should see less time spent by registry staff on manual case-finding and coding tasks and more time made available to address other registry tasks such as quality assurance, followup, and special studies.

We have tried to present examples of real-time reporting efforts applicable to cancer registries in this report and hope that these systems will contribute to the goal of the interoperable EHRS in the next few years. We hope that NAACCR keeps abreast of these developments and embraces the new technologies that will soon become our standards for health informatics systems.

## 16      **Recommendations for NAACCR**

In January 2006, the recommendations to the NAACCR Board are under development and will be released as a companion document to this report when they are completed.