Medical Informatic Basics for the Cancer Registry

DEVELOPED BY:

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National Cancer Registrars Association

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"Medical Informatics is the intersection of science, computer science and health care. It deals with the resources, devices and methods required to optimize the acquisition, storage, retrieval and use of information in health and biomedicine. Health informatic tools include not only computers but also clinical guidelines, formal medical terminologies and information and communication systems." —Unknown Author

A Cancer Registry utilizes all of the above and is the most sophisticated and defined database within a hospital and/or state.

Utilizing and implementing computerized and automated information from a Cancer Registry can help find the ultimate treatment combinations that can improve the outcome of cancer patients for years to come.

Electronic applications and interfaces will allow the registrar more time for retrieving and analyzing data for clinicians and researchers and will decrease the time needed for casefinding and entering data.

Certified Tumor Registrars (CTRs) are and will always be in high demand to verify and code the information for end results analysis and reporting.

The objective of this presentation is to provide:
- an introduction to terms and concepts of eReporting,
- an update of where the technology currently stands,
- a knowledge of organizations involved in these endeavors, and
- the place this concept holds in the broader areas of electronic health records (EHR) and eMedicine.

Electronic reporting, or eReporting, includes the following characteristics:
- automated, unattended transmission of data
- in electronic format
- between two or more parties
- within or between organizations.

Examples of eReporting enhancements to a registry include:
- automated casefinding,
- downloaded abstracting through templated documentation,
- electronic signature on TNM staging,
- interfacing visit dates to update follow-up information, and
- videoconferencing of Cancer Conferences.

Currently, the cancer registry collects data from many different sources

of information and in different ways.

For example, while some casefinding may be in an electronic format, such as the disease index, other activities require manual review of information and manual input of data into a registry software system. Some of these data may be from electronic systems, such as an electronic medical record or an electronic pathology laboratory system, but manual input is required because the systems are not compatible, or there is no interface, or both.

Information from other reports, such as an operative report or discharge summary, may be in text format and may not be able to be downloaded unless put forth into a templated format.

There are many other examples of activities that could be performed more efficiently with the increasing amount of technology that is available. In the future, the cancer registrar's role will evolve from collecting and inputting data to assimilating and interpreting the data that have been brought together into one system through eReporting.

However, there are many challenges to reaching the point where eReporting brings data together into one system. Since many sources of information that a cancer registrar currently uses to abstract cases are in text format, a method for encoding these data will need to be developed and implemented. Standardization for this process is essential and will take time to develop. Interfaces must be developed to allow one computer system to share data with another. All of these activities will be costly and will take time to develop and implement.

Included in President George W. Bush's Executive Order on April 27, 2004 on Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator is "a vision of developing a nationwide interoperable health information technology infrastructure that: (a) ensures that appropriate information to guide medical decisions is available at the time and place of care; (b) improves health care quality, reduces medical errors, and advances the delivery of appropriate, evidence-based medical care; … (e) improves the coordination of care and information among hospitals, laboratories, physician offices, and other ambulatory care providers through an effective infrastructure for the secure and authorized exchange of health care information."

Efforts to incorporate available technologies (and developing technologies) into the cancer registration field are consistent with this vision. Several groups and organizations are working toward developing standards and technologies which will benefit not only cancer registry activities, cancer research, and cancer surveillance, but also the health profession as a whole. Electronic reporting in the cancer registry will be a part of a larger health care informatics system.

Efforts that have been underway for several years are helping to facilitate these activities. **HL7, or Health Level Seven**, is a Standards Developing Organization (SDO) accredited by the American National Standards Institute (ANSI). It operates in the healthcare arena, specifically addressing clinical and administrative data. HL7 was originally developed by hospital information officers as a tool or

mechanism to enable the multitude of hospital software products to communicate with one another. It is a not-for-profit volunteer organization whose members are providers, vendors, payers, consultants, government groups, among others. These members make up an international community of healthcare subject matter experts and information scientists.

HL7 has developed a messaging standard for the exchange of clinical and administrative data through its focus on interface requirements. One of the standard structures for HL7 messages includes the use of **LOINC codes** to indicate the question or data item and the use of **SNOMED CT codes** to indicate the answer or data item value. HL7 represents the format, and LOINC/SNOMED CT represent the vocabulary.

LOINC is the Logical Observation Identifiers Names and Codes. The purpose of the LOINC database is to facilitate the exchange and pooling of clinical laboratory order and numeric results for blood hemoglobin, serum potassium, as well as numeric values for vital signs, clinical care, outcomes management, and research. Currently, there are laboratories and other diagnostic services using HL7 to send results electronically from their reporting system to their care systems. However, laboratories and other diagnostic care services often identify tests in these messages using their own internal and idiosyncratic code values. Thus, the care system cannot fully "understand" and properly file the results they receive unless they either adopt the producer's laboratory codes (which is impossible if they receive results from multiple sources), or invest in the work to map each producer's code system to their internal code system. LOINC codes can help solve this problem by serving as universal identifiers of clinical laboratory test orders. LOINC has two main categories, the laboratory portion of the database and the clinical portion of the database. The laboratory portion of the LOINC database contains the clinical laboratory categories including chemistry, hematology, serology, microbiology, and toxicity; as well as categories for drugs and the cell counts you would find reported on a complete blood count or a cerebrospinal

fluid cell count. The clinical portion of the LOINC database includes entries for vital signs, hemodynamics, intake/output, EKG, obstetric ultrasound, cardiac echo, urologic imaging, gastroendoscopic procedures, pulmonary ventilator management, selected survey instruments, and other clinical observations such as the NAACCR data items.

SNOMED International is a division of the College of American Pathologists (CAP) and is committed to advancing excellence in patient care. This is accomplished through the delivery of a dynamic and sustainable, scientifically-validated terminology that enables clinicians, researchers, and patients to share health care knowledge worldwide and across clinical specialties and sites of care. The vision of SNOMED International is to be the leader in clinical terminology for encoding the electronic medical record with SNOMED CT (the Systematized Nomenclature of Medicine Clinical Terms). SNOMED CT is a comprehensive

and precise clinical reference terminology that health care providers, health care information technology suppliers, and institutional researchers can use to compare data analysis.

With capabilities such as these, several projects are exploring ways to electronically capture, integrate, and provide more complete cancer research and cancer surveillance data in an efficient manner. The **Cancer Biomedical Informatics Grid (caBIG)** was created in 2003 by the National Cancer Institute (NCI) as a cancer-based biomedical informatics network to address the needs of NCI based clinical trials and research. It is an open-source, open-access, voluntary information network that will enable cancer researchers to share tools, standards, data, applications, and technologies according to agreed upon common standards and needs. caBIG will create an informatics infrastructure that will link teams of cancer and biomedical researchers as part of a collaborative network, or grid. When

completed, caBIG will help redefine how research is conducted, care is provided, and patients and participants interact with the biomedical research enterprise.

MERP (Modeling Electronic Reporting Project) is a project of the NPCR (National Program of Cancer Registries) which is administered by the CDC (Centers for Disease Control and Prevention). It is an effort to position the cancer surveillance community to take advantage of the electronic health record by developing a freely accessible national model for the transmission of data from the hospital's electronic health record (comprised of multiple database systems) and other data sources (such as reference pathology laboratories) to hospital cancer registries and central cancer registries. The purpose of such a model is to promote electronic reporting for cancer surveillance that takes advantage of the emerging technology surrounding the electronic health record. This effort should improve completeness, timeliness, and quality of cancer registry data.

NEDSS (National Electronic Disease Surveillance System) is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state, and local levels. A primary goal of NEDSS is the ongoing, automatic capture and analysis of electronically available data. NEDSS was originally developed to collect communicable disease data but has been expanded to include other disease reporting.

Ultimately, these efforts and the work to integrate these initiatives into registry operations will provide the means to improve the process by which cancer data are collected, maintained, reported, and analyzed, thus helping to meet the goal of C-Change which is to eliminate cancer as a major public health problem at the earliest possible time.

Glossary and References

ACoS—American College of Surgeons: The ACoS is a scientific and educational association of surgeons founded to improve the quality of care for the surgical patient by setting high standards for surgical education and practice. www.facs.org

caBIG—cancer Biomedical Informatics Grid: caBIG is a voluntary network or grid connecting individuals and institutions to enable the sharing of data and tools, creating a World Wide Web of cancer research. The goal is to speed the delivery of innovative approaches for the prevention and treatment of cancer. caBIG is being developed under the leadership of the NCI's Center for Bioinformatics. www.cabig.nci.nih.gov

CAP—College of American Pathologists: CAP is the principal organization of board-certified pathologist. CAP produces cancer protocols as a resource to pathologists in effectively delivering the information necessary to provide quality patient care. SNOMED International is a division of the CAP. www.cap.org

C-Change: C-Change is comprised of the nation's key cancer leaders from government, business, and nonprofit sectors to leverage the combined expertise and resources of its members to eliminate cancer as a major public health problem at the earliest possible time. Former President George Bush and former First Lady Barbara Bush are Co-chairs of C-Change. www.cchangetogether.org

CDC—Centers for Disease Control and Prevention: CDC is one of the 13 major operating components of the Department of Health and Human Services (HHS), which is the principal agency in the US government for protecting the health and safety of all Americans. CDC supports many state cancer registries, as well as cancer prevention and control programs, campaigns, and initiatives. www.cdc.gov

CoC—Commission on Cancer: CoC, a program of the ACoS, is a consortium of professional organizations dedicated to reducing the morbidity and mortality of cancer through education, standard-setting, and the monitoring of quality care. www.facs.org/cancer

EHR—Electronic Health Record: An EHR refers to an individual patient's health record that has been compiled into a digital format and may be made up of electronic medical records (EMRs) from many locations and/or sources. Electronic health record systems co-ordinate the storage and retrieval of individual records with the aid of computers.

EMR—Electronic Medical Record: An EMR is a medical record in digital format. The term EHR is often used to describe the broader concept while EMR is used to describe a discrete localized record.

eReporting: The automated, unattended transmission of data in electronic format between two or more parties or within/between organizations.

HL7—Health Level Seven: HL7 develops specifications, the most widely used being a messaging standard that enables disparate healthcare applications to exchange key sets of clinical and administrative data. www.hl7.org

LOINC—Logical Observation Identifiers Names and Codes: LOINC codes are universal identifiers for laboratory and other clinical observations. The LOINC data base facilitates the exchange and pooling of results, such as blood hemoglobin, serum potassium, or vital signs, for clinical, outcomes management, and research. The LOINC data base and its supporting documentation are maintained by the Regenstrief Institute. www.regenstrief.org/loinc

MERP—Modeling Electronic Reporting Project: MERP, a project of the NPCR, is an effort to position the cancer surveillance community to take advantage of the electronic health record by developing models for the transmission of data from the hospital's electronic health record (comprised of multiple database systems) and other data sources (such as reference pathology laboratories) to hospital cancer registries and state central cancer registries eventually allowing cancer registries to obtain the majority of cancer data electronically, which would potentially produce more complete, timely, and accurate cancer surveillance data. The NPCR-MERP addresses the President's health initiative to have an electronic health record implemented within ten years. www.cdc.gov/cancer/npcr/MERP

NAACCR—North American Association of Central Cancer Registries: NAACCR is a professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America. www.naaccr.org

NCI—National Cancer Institute: The NCI is a component of the National Institutes of Health (NIH), one of eight agencies that compose the Public Health Service (PHS) in the Department of Health and Human Services (DHHS). The NCI is the Federal Government's principal agency for cancer research and training. The National Cancer Act of 1971 broadened the scope and responsibilities of the NCI and created the National Cancer Program. www.cancer.gov

NCRA—National Cancer Registrars Association: NCRA is a non-profit, professional organization whose mission is to serve as the pre-

mier education, credentialing and advocacy resource to cancer data professionals, thus improving lives through quality cancer data management. www.ncra-usa.org

NCRA Education Foundation: The NCRA Education Foundation is a non profit 501(c)(3) organization with the mission of supporting the advancement of the Cancer Registry profession through education and research. www.ncraeducationfoundation.org

NEDSS—National Electronic Disease Surveillance System: NEDSS is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels. A primary goal of NEDSS is the ongoing, automatic capture and analysis of data that are already available electronically. It is a major component of the PHIN (Public Health Information Network). www.cdc.gov/nedss

NPCR—National Program of Cancer Registries: NPCR, a program of the CDC, supports registries in 45 states, the District of Columbia, and three territories, representing 96% of the US population. Data collected by cancer registries enable public health professionals to better understand and address the cancer burden. www.cdc.gov/cancer/npcr

PHIN—Public Health Information Network: PHIN is CDC's vision for advancing fully capable and interoperable information systems in the many organizations that participate in public health. PHIN addresses the Health and Human Services' goal of improving public health information systems. www.cdc.gov/phin

SEER—Surveillance, Epidemiology, and End Results: The SEER program of the NCI is an authoritative source of information on cancer incidence and survival data from population-based cancer registries covering approximately 26% of the US population. www.seer.cancer.gov

SNOMED CT—Systematized Nomenclature of Medicine Clinical Terms: SNOMED CT is a dynamic, scientifically validated clinical health care terminology and infrastructure that makes health care knowledge more usable and accessible. The SNOMED CT core terminology provides a common language that enables a consistent way of capturing, sharing and aggregating health data across specialties and sites of care. www.snomed.org

XML—Extensible Markup Language: A markup language is a mechanism to identify structures (both content such as words, pictures, etc. and what role that content plays such as a section heading or footnote or content in a database table) in a document. www.xml.com