Real-Time Reporting Task Force
Report to the Board

June 2006

Ken Gerlach, MPH, CTR
Toshi Abe, MSW, CTR
Overview

- NAACCR Vision
- Primary Issues
- Process
- Review of Report to the Board
  - Definition of Real-Time Reporting
  - Background – Environment
  - Barriers
  - Recommendations
NAACCR #1 Overarching Goal

Real Time Reporting Group will:

- Map current transmission standards to modern methods in full synchronicity with national standards
- Focus on informatics
- Look for ways to connect NAACCR to national efforts to develop the electronic medical record (EMR) and electronic health record (EHR)
Definition: Informatics

- **Medical informatics** is the application of computer technology to all fields of medicine - medical care, medical teaching, and medical research.

- **Public health informatics** is the systematic application of information and computer science and technology to public health practice, research and learning.
NAACCR - Primary Issues

- Registries use 1980s technology
- Data transmission issues: e.g., security and real time reporting
- Opportunities - if we were able to exchange data in various formats, HL7, SNOMED, ICD-9, CPT, and J-codes
Primary Issues (2)

- Need to ID and assess existing data standards - leverage data, data elements, processes, and partners
- Need to integrate NAACCR into overall national efforts through organizations such as NCCCS, C-Change, and NHID (National Health Informatics Development)
Primary Issues (3)

- NAACCR should be able to speak from a position of highest authority/expertise with a unified voice in regard to cancer surveillance and research efforts in the US and Canada on issues such as making public health policy decisions, electronic medical records, and data transmission standards.
NAACCR Charge to Task Force

- Develop a Report on Real Time Reporting for the Board
Process

- Task Force Formed – March 2004
- Challenge: Outside Typical Cancer Surveillance Realm
  - Learning Curve
- Outline with Writing Tasks
- Editing, Editing, Editing
- Work in Progress
What’s in the Report?

- Definition
- Background
- Historical Perspective
- Role of HIPAA
- National Health Initiatives
- Current Examples
- Barriers
- Recommendations
Real-Time Reporting: Task Force Definition

- Computer system capable of transmitting structured or semi-structured electronic medical data - minutes or days
- Sources: medical records departments, pathology laboratories, radiology clinics, physicians, etc.
- Data should be transmitted over the Internet with widely accepted security procedures
National Health Information Technology Coordinator

- Secretary Thompson - Appointment
- Goal: Interoperable EHR in 10 Years
  - Allow Physicians to access all medical/health information
- Local, Regional, and National Health Information Networks (NHIN)
  - Regional Health Information Organizations (RHIOs)
Inform clinical practice by accelerating the use of EHRs

Interconnect clinicians so that they can exchange health information - secure

Personalize care with consumer-based health records and better information for consumers;

Improve public health through advanced bio-surveillance methods and streamlined collection of data for quality measurement and research
National Healthcare Initiatives

- HIPAA (Health Insurance Portability and Accountability Act)
  - Transmission Standards: HL7/X12
  - Transactions/Code Sets
  - NPI (National Provider Identifiers)
  - Security Standards
- NHII (National Health Information Infrastructure)
National Healthcare Initiatives

- Logical Observations, Identifiers, Names and Codes (LOINC)
- College of American Pathologists (CAP) SNOMED CT Encoded Cancer Checklists
- C-Change – Key cancer leaders from government, business, and non-profits – to eliminate cancer
National Healthcare Initiatives

- FHA – Federal Health Architecture
- CHI – Consolidated Health Informatics
- NCI caBIG – Cancer Bioinformatics Grid
- CDC PHIN – Public Health Information Network
- SEER*DMS – SEER Database Management System
- NPCR-MERP – Modeling Electronic Reporting Project
Cancer Registry Examples

- Electronic Pathology Reporting
- Health Registry Network
Barriers

1. Investment Cost: $140 - $300 Billion
   • Cost to comply with New Standards
2. Security
3. Cancer Registry Software Impact
   • More Frequent Submissions
Recommendations #1

- Participate in the national efforts to effect the creation of EHRs and interoperability standards
- The NAACCR UDS and IT Committees have been aware of national efforts and have participated in bringing NAACCR data items to the attention of HL7 and others to adopt standards for medical reporting
Recommendations #1 (cont)

- The formation of a new Interoperability Workgroup to develop plans to implement new data items such as the National Provider Identifier (NPI) code is an example of how NAACCR may insure that data items are compatible with national standards relevant to cancer registration.

- Responsible committees: IT and UDS
Recommendations #2

• Encourage the adoption of national standards for EHRs
• Several groups are actively working to promote national standards in the public health
  • National Health Information Infrastructure
  • Public Health Information Network
  • C-Change
• Responsible committees: IT and UDS
Recommendations #3

- Develop, maintain, and promote implementation guides and procedures for real-time reporting
- Important: implementation guides/procedures for transmission and receipt of EHRs be consistent with national standards
  - E-Path Standards - Volume V: HL7 and Pipe-Delimited Implementation Guide
  - Cancer Abstract Transmission Workgroup - new
Recommendations #3 (cont)

- Cancer Abstract Transmission Workgroup
  - Charge: explore the feasibility of transmission format and vocabulary for cancer abstract data (Volume II)
  - Application of computer edits and conformance-testing tools
- Responsible committees: IT and UDS
Recommendations #4

- Cancer registry software developers should
  - Modify software, in consultation with subject matter experts, to accept data directly from electronic healthcare sources
  - Design systems to process that data within their respective software
Recommendations #4 (cont)

- Cancer registry software developers
  - Have an important role
  - Should be involved in national efforts to form EHR Standards
- Responsible committees: IT and UDS
Recommendations #5

- Educate and Train - members about the transmission and receipt of medical data in real-time
- As registries embrace new technologies to further the development of real-time systems that transmit and receive medical data
  - NAACCR must be prepared to educate and help train its member registries through workshops, conferences, and in committees and workgroups
  - Responsible committees: Education, IT, and UDS
Recommendations #6

- Monitor and explore opportunities to improve our ability to link cancer surveillance data with regional (Regional Health Information Organizations (RHIOs)) and national EHRs networks
  - Opportunities for national linkages could be conducted in a similar way to the linkage of the SEER database with Medicare/Medicaid
Opportunities to better link cancer surveillance data and special studies data with cancer center clinical trials data should be explored

- These records may be maintained separately from medical records

- Although EHR should overcome this problem we should monitor to ensure that it does

- Responsible committees: IT and UDS
Recommendations #7

- Monitor evolving changes in national standards for vital statistics records
- As birth and death certificates evolve toward full electronic formats
  - NAACCR should monitor those changes and adjust cancer registry systems
- Responsible committees: IT, UDS and Registry Operations
Work in Progress

- Send input to NAACCR
  - Informatics – Evolving
  - New Ideas, Tools, Models
- Volunteers Needed
- Web Address: www.naaccr.org
  - Statistics & Reports/Epidemiologic Reports
  - Registration Standards/Standards
Task Force Members

- Toshi Abe
- Timothy J. Carney
- Eric Durbin
- Ken Gerlach
- Barry Gordon
- Lori Havener
- Kenneth Hill
- Mary Kennedy

- Jim Martin
- Herman Menck
- Steven Peace
- Jeri Lynn Phillips
- Marsha Reichman
- Lynn Ries
- Randi Rycroft
- Bette Smith
- And Many Others
Thank you