NPCR-MERP: A NATIONAL MODEL
Phase II

NAACCR 2006 Annual Meeting
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Presentation Overview

• Intelligence Gathering Strategy
• Building the Business Case for Innovation
• Provide update on NPCR-MERP activity
  – Describe the rationale for NPCR-MERP
  – Review Methods and Approach
  – Share preliminary findings
  – Outline next steps
When Best Practices may Result in Organizational Failure

"The new era of dynamic and discontinuous change requires continual reassessment of organizational routines to ensure that organizational decision-making processes, as well as underlying assumptions, keep pace with the dynamically changing business environment. This issue poses increasing challenge as ‘best practices’ of the gone yesterday -- turn into ‘worst practices’ and core competences turn into core rigidities."

Cancer Surveillance Intelligence
Gathering Domains

• Organizational Intelligence
  – What people do, where they do it, how it’s done, when, and why?
  – Efficiency & Effectiveness Issues (Cost & Quality)

• Scientific/Public Health Intelligence
  – Health Outcomes
  – Completeness

• Technical Intelligence
  – Data Progression Strategies
  – Timeliness
Informatics

The systematic application of information science and information technology to public health practice, research, and learning.

Ensure IT supports organizational structure

Provide access to meaningful information

Promote effective use of IT

Facilitate effective analysis
Informatics Strategy for Cancer Surveillance

• Identify gaps, defects, or vulnerabilities in the Cancer Data Progression

1. Data – Assessment of data architecture; transfer methods; retrieval, storage, and dissemination strategies; integrity; and utilization & translation patterns
2. Information – Assessment of tools/practices for analysis; relevance; policy & procedures
3. Knowledge – Assessment of knowledge products; knowledge recipients; relevance
4. Decisions – Assessment of reliability (policy makers, program managers, researchers, clinicians, general public)
5. Outcomes – Assessment of impact on cancer burden
Cancer Informatics Infrastructure

Public Health Informatics

Clinical/Medical Informatics

Consumer Health Informatics

Translational Bio-Informatics
Expression of Findings

Textual Reports

Requirements Findings

NPCC/MEP Central Cancer Registry Strategic Assessment and Modeling Session (QAMG)
Atlanta, GA March 9 - 10 2006

CDC/DCPC/NPCR
National Program of Cancer Registries – Modeling Electronic Reporting Project (NPCC/MEP)

Revision date: 10-13-05

Graphical Summaries

Hospital-based Cancer Registry Overview: flow for a typical case of cancer

Notes
Process
Timeline

Casefinding

Pathology
Report

Find new
Case

Disease
Registry

<table>
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<tr>
<th>Notes</th>
<th>Process</th>
<th>Timeline</th>
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<tr>
<td>Revision date: 10-13-05</td>
<td>Flowchart depicting the process of casefinding, pathologic report, disease registry, and timeline events such as date of diagnosis, reportability, and potential case of cancer.</td>
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- Casefinding
- Pathology Report
- Disease Registry
- Potential Case of Cancer
- Reportability (based on "class of case" should be determined)
- Report cases to Central Cancer Registry
- Provide cancer information
Current View of Cancer Surveillance – NPCR-MERP *Simplified* Overview
Central Cancer Registries
Central Cancer Registries

National Cancer Programs
CDC, NCI, CoC
National Cancer Programs
CDC, NCI, CoC

Lack of IT Standards

Variety of Reporting Methods

Varying Architectures

Lack of Consistent Policy & Procedures
Central Cancer Registry
Central Cancer Registry

Other Data Source

Other Data Source

Other Data Source

Other Data Source

Other Data Source

Other Data Source

Other Data Source
Data Sources
Internal                   External
Slow Infusion of National IT Standards

Varying EHR Architectures
…We just don’t know enough???

EHR Adoption Slow & Costly

HI PPA Issues not easily resolved

Cancer Case

CTR

Hospital Cancer Registry

Data Sources
Internal
External

Information Sharing
NCDI
Clinical Trial
General Cancer Information

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Summary of Issues

• Individuated Reporting
• Lack of IT & Procedural Standards
• Long processing times of surveillance data (2 years)
• Questions arising on ROI of Cancer Surveillance
  – Are we really any smarter?
• Changing patterns of data usage
  – Historical – Simple counts of incidence
  – Future – Increased demands
  • Interconnectedness of Surveillance, Research, Intervention, and Program Management realms (Knowledge Synthesis…R.A. Hiatt, Cancer Informatics 2002)
  • Growing consumer health responsibility
  • Increasing demand for responsiveness to new/developing policy
• National IT Infrastructure Development & Integration
• Global health comparisons
The Cancer Surveillance *Orbits*!
What might be!

National Health Information Network

- Interoperable & Complimentary Architectures
- Standardized Messaging & Transmission
- Streamlined Reporting at all levels
- Enhanced CTR Driven Analytical Capability
Goals for Architecture & Standards

• National Objectives*
  – Communication within episodes of care
  – Aggregation of data across patient populations
  – Integration of knowledge for decision support
  – Continuity of care over patient’s lifetime

• HHS Announced award to 4 contractors to build NHIN prototype (Accenture, IBM, CSC, and Northrop Grumman) – 11/2005

• 9 States selected for federal health IT RHIO (Regional Health Information Organization) study (CA, CO, IN, FL, MA, ME, UT, RI, TN) – 5/2005

• Bridges to Excellence & eHealth Initiative form partnership to improve quality, safety, and efficiency through health information exchange – 4/2006

*Background Paper: ARCHITECTURE AND STANDARDS TRACK
NHII 2004 Meeting
NPCR-MERP Approach

• Proactive Approach to defining what goes under the umbrella
  – Assessment of Needs & Capabilities
  – Identify opportunities to streamline reporting practices
  – Work in partnership with other national cancer programs to convene a national audience toward defining an ideal cancer surveillance model
NPCR-MERP Activity

- Phase I – Feasibility/Pilot Project
- Phase II – Engage National Audience
- Next Steps – Contribute to National Effort
NPCR-MERP Phase I

- Examine & diagram cancer reporting practices in a single hospital & central cancer registry
  - Virginia Commonwealth University Health System (VCUHS)
  - Virginia Central Cancer Registry

- Outcomes
  - Increased understanding of hospital reporting practices
  - Observe the process as they moved from manual to electronic reporting…Lessons Learned!
  - Created some diagrams and reports to inform the national dialogue (Strawman Model)
NPCR-MERP Phase I

• Activity - Started in August 2004
  – Two site visits - Strategic Assessment & Modeling Sessions (SAMS)
    • September 2004
    • February 2005
  – Periodic conference calls to review and update diagrams and documents
  – Team consisted of members from CDC, NCI, VCUHS, VCR, Northrop Grumman, and other contractors
  – Phase I Activity
    • CDC – Final output was the strawman model
    • VCUHS/VCR – Continue software implementation project and contribute to Phase II activity
NPCR-MERP Phase II

- Activity – Started in February 2006
  - Convened the first national Strategic Assessment & Modeling Session (SAMS), Richmond, VA
    - Hospital-based (CTR’s, vendors, Administrators, pathologists, and others)
    - Other invited participants and observers (SEER, NAACCR, CoC, others)
    - Formal facilitated sessions
  - Objectives
    - Define hospital cancer registry core functions (focus electronic reporting)
    - Identify best & worse case scenarios
    - Identify barriers to electronic reporting
    - Identify opportunities for immediate impact
    - Review Diagrams
NPCR-MERP Hospital SAMS Participants

25 participants & 14 observers total
NPCR-MERP Phase II

• March 2006 convened central cancer registry focused SAMS, Atlanta, GA
  – Open invitation to NPCR Program Directors
  – Objectives
    • Define central cancer registry core functions (focus electronic reporting)
    • Identify best & worse case scenarios
    • Identify barriers to electronic reporting
    • Identify opportunities for immediate impact
    • Review diagrams
  – Planning detailed CCR SAMS August/September 2006
NPCR-MERP CCR SAMS Participants

19 participants & 13 observers total
Categorization of Findings
Hospital SAMS

• Core Functions (Case Finding, Abstracting, Editing, and Follow-up)
  – Access to Data
  – Coding problems
  – Problematic areas of reporting
  – CTR issues
  – Resistance to change (personnel or organizational)
  – Financial
  – Software/IT Issues
  – Standardization
Categorization of Findings
Hospital SAMS

• Response Resolution Groupings
  – Process Issues
  – Organizational & Data Structure Issues
  – Business Rules Issues
  – What is Possible Issues
Categorization of Findings
CCR SAMS

- Core Functions list expanded
  - Casefinding
  - Rapid Case Ascertainment
  - Abstracting
  - Source Record and Cancer Level Editing
  - Patient Linkage
  - Tumor Linkage
  - Consolidation
  - Follow-up
  - Death Clearance
  - Data Enhancement
  - Research Linkage
  - Audits/Quality Control
  - Calls for Data
  - Data Use
  - Training
Categorization of Findings
CCR SAMS

• Participant Categories
  – Issues for IT Operations
  – Changes to Central Cancer Registry
  – Early Opportunities
Converting Ideas into Action

Diagramming Excellence
Needs & Capabilities Assessment Tool Samples
NPCR-MERP Needs Assessment Purpose

• Purpose
  – To provide an up-to-date view of cancer registration
  – To minimize assumptions
  – To build a business case
  – To identify & prioritize gaps and capabilities in the reporting process that NPCR-MERP can address or enhance
NPCR-MERP Needs Assessment Characteristics

• Comprehensive
• Modular (component for each workgroup)
• Simple and easy to deliver and respond
• Done in partnership with other National Cancer Programs
  – Ensure high level of representation
  – Eliminate duplication of effort
  – Provide a resource for similar efforts
• Establish baseline measures for continual monitoring of progress toward *Ideal Infrastructure*
Overview of NPCR-MERP Structure

- Hospital Operations Workgroup
- Central Cancer Registry Workgroup
- RHIO interface Workgroup
- E-Path Pilot Project Workgroup
- Messaging Vocabulary & Standards Workgroup
- Data Utilization & Translation Workgroup

NPCR-MERP
Summary of Guidelines, Recommendations, and Best Practices

- Hospital Operations Report of Findings
- Data Utilization & Translation Report of Findings
- RHIO interface Report of Findings
- Messaging Vocabulary & Standards Report of Findings
- Central Cancer Registry Report of Findings
- NPCR-MERP Consolidated Report of Findings
- E-Path Pilot Project Report of Findings

Summary of Guidelines, Recommendations, and Best Practices
NPCR-MERP Future Activity

• Continue SAMS and other informal information gathering exercises

• Develop and deliver NPCR-MERP Needs and Capability Assessment for each of the six workgroup categories

• Work with NCI to form a National “Oversight” Committee for development of a National Consensus Model

• Present NPCR-MERP findings at a formal gathering of cancer surveillance experts Spring 2007
Successful Technologies should Resonate with Human Behavior…

"The technologies that will be most successful will resonate with human behavior instead of working against it. In fact, to solve the problems of delivering and assimilating new technology into the workplace, we must look to the way humans act and react.... In the last 20 years, US industry has invested more than $1 trillion in technology, but has realized little improvement in the efficiency of its knowledge workers - and virtually none in their effectiveness. If we could solve the problems of the assimilation of new technology, the potential would be enormous."

John Seely Brown, in "The Human Factor", Information Strategy, Dec 96-Jan 97