National Program of Cancer Registries

Electronic Health Reporting and Cancer Surveillance in the U.S.

NAACCR 2006 Annual Meeting
June 13, 2006

Sandy Thames, CDC

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Presentation Overview

- President’s Health Initiative
- Electronic Health Records (EHR)
- National Initiatives
- Examples of e-Reporting Projects in Cancer Surveillance
- Final thoughts…

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"By computerizing health records, we can avoid dangerous medical mistakes, reduce costs, and improve care."

--President George W. Bush, State of the Union Address, January 20, 2004

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President's Health Initiative

- 10 years – Most Americans will have access to their EHR at any time and place, no matter where it originates
- Voluntary patient participation
- EHR to share information privately and securely among health care providers - when authorized by the patient

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President's Health IT Plan

- Adopt Health Information Standards
- Increase funding for demonstration Projects on Health Care IT
- Use Federal Government to foster adoption of Health IT
- Create a new Office of the National Coordinator for Health IT

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Public Health Challenges with EHR

- Understand public health organization:
  - Domain/programs fragmentations
  - Organizational hierarchy
- Understand commonalities among PH domains/programs and PH settings in terms of data sources, users, public health goals and functions
- Define the role of the EHR in integrating primary care and PH practices
- Define the processes for involving the various PH stakeholders in the national effort for the standardization of health care data via the EHR
- Develop PH vocabulary

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The 2003 IOM Letter Report, *Key Capabilities of an EHR System*, defined the EHR System as including:

- Longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or health care provided to an individual
- Immediate electronic access to person- and population-level information by authorized users
- Provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care
- Support of efficient processes for health care delivery (reduce duplication of effort and redundancies)

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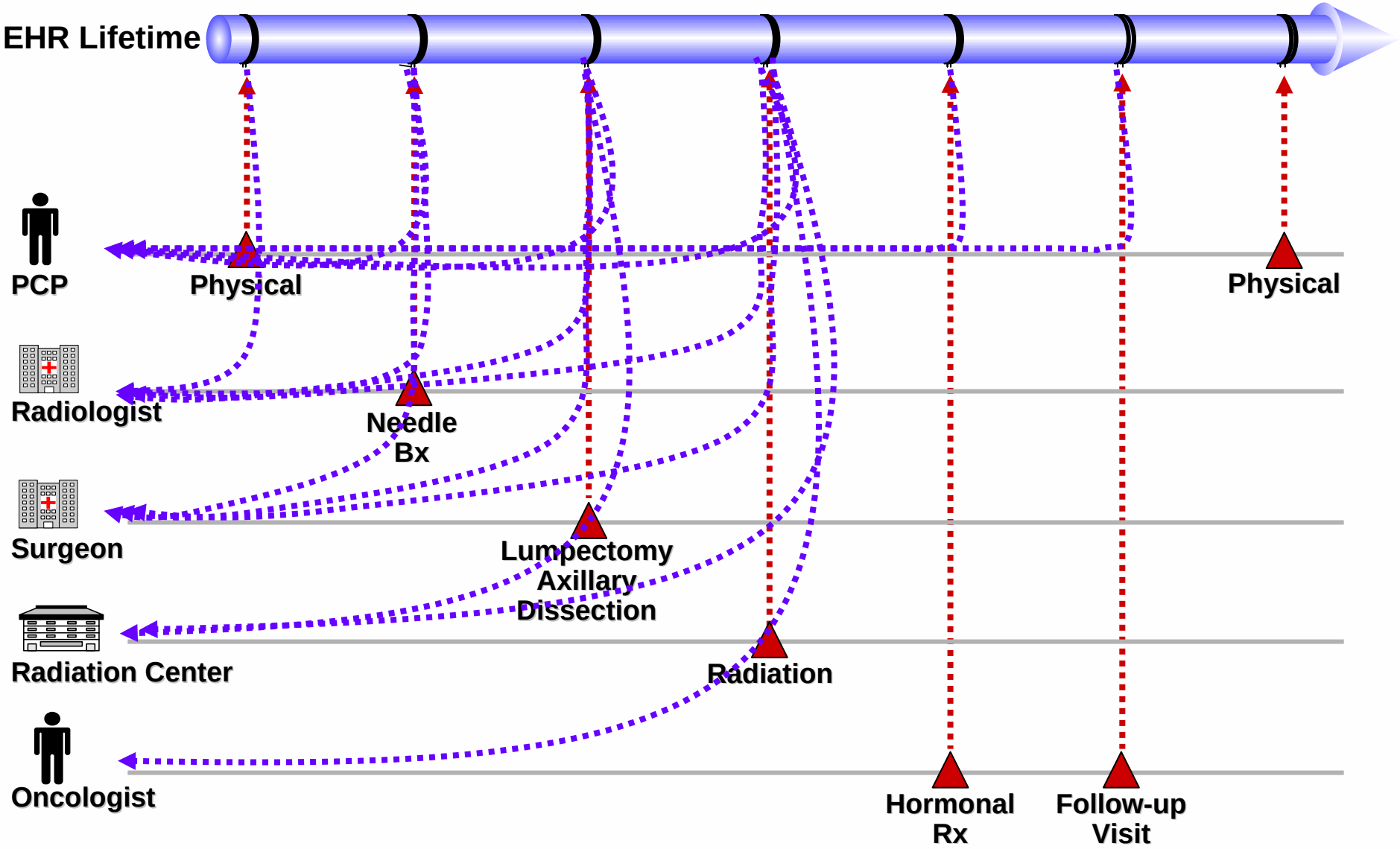
Introduction to the EHR



PCP: Primary Care Physician

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Child Health • Global Partnerships • Minority Outreach • Monitoring Health • Community Partnerships
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Health Education • Epidemiology • Workplace Health • Immunization • Workplace Safety • Training • C
LTH • Prevention Research • Private Sector Partnerships • Public Health Workforce • Women's Health

The Electronic Health Record?

- Talking about EHR for 20+ Years
- All or most hospitals have some type of electronic systems
  - Billing
  - Disease Index
  - Physician Dictation
- Today – Hybrid EHR
- Today - New emphasis on EHR

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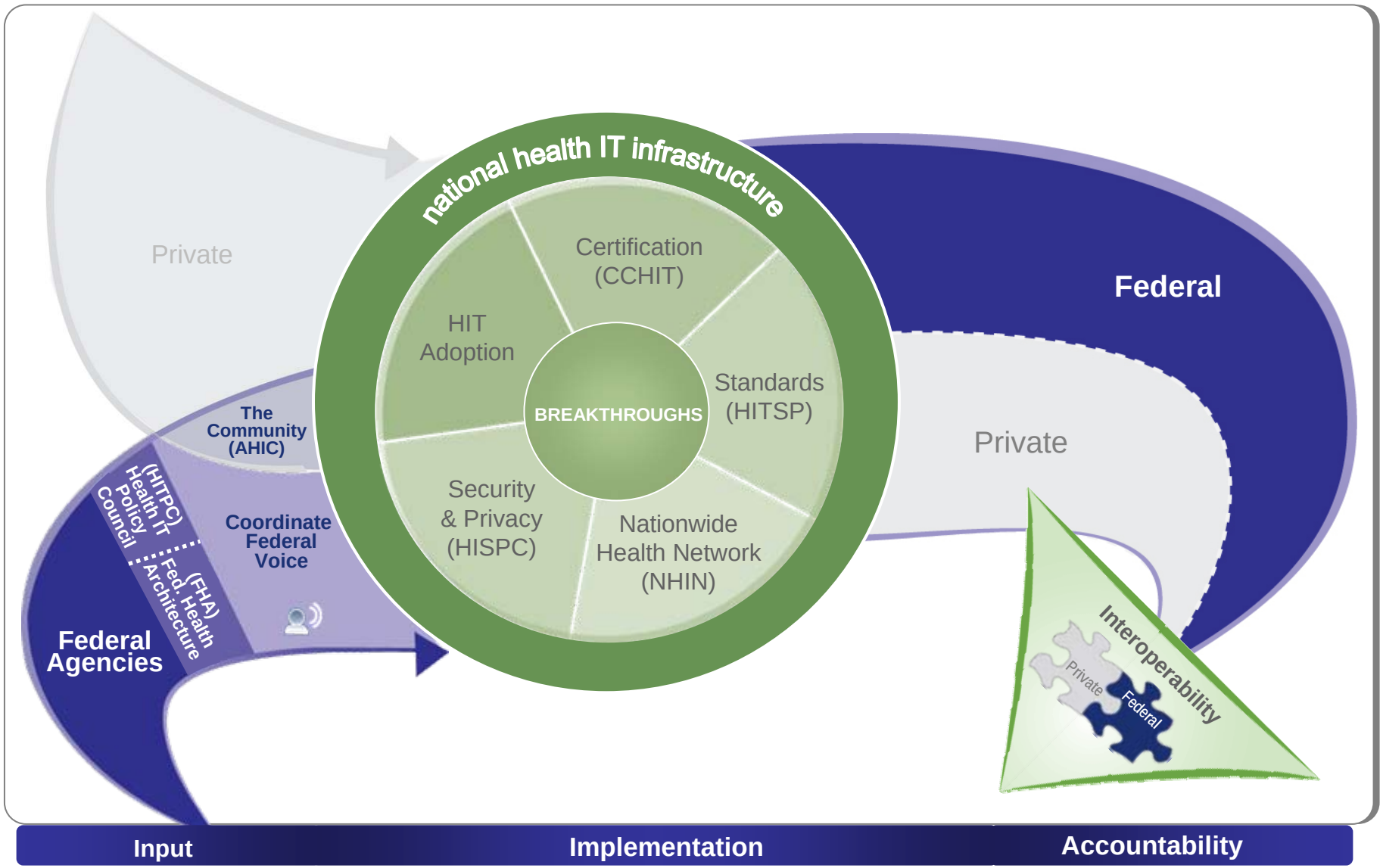
EHR Standards to HL7

- Charge to HL7 – Accelerate Development of EHR Standards
- Who and what is HL7?
  - Standards setting organization - ANSI
  - A tool for clinical data transfer
- EHR-S Functional Model and Standard
  - Summary of Functions
  - Describes Behavior of a System from Functional Perspective
  - http://www.hl7.org/ehr/downloads/index.asp

National Initiatives

Federal Participation in President's Health IT Plan



Nationwide Health Information Network

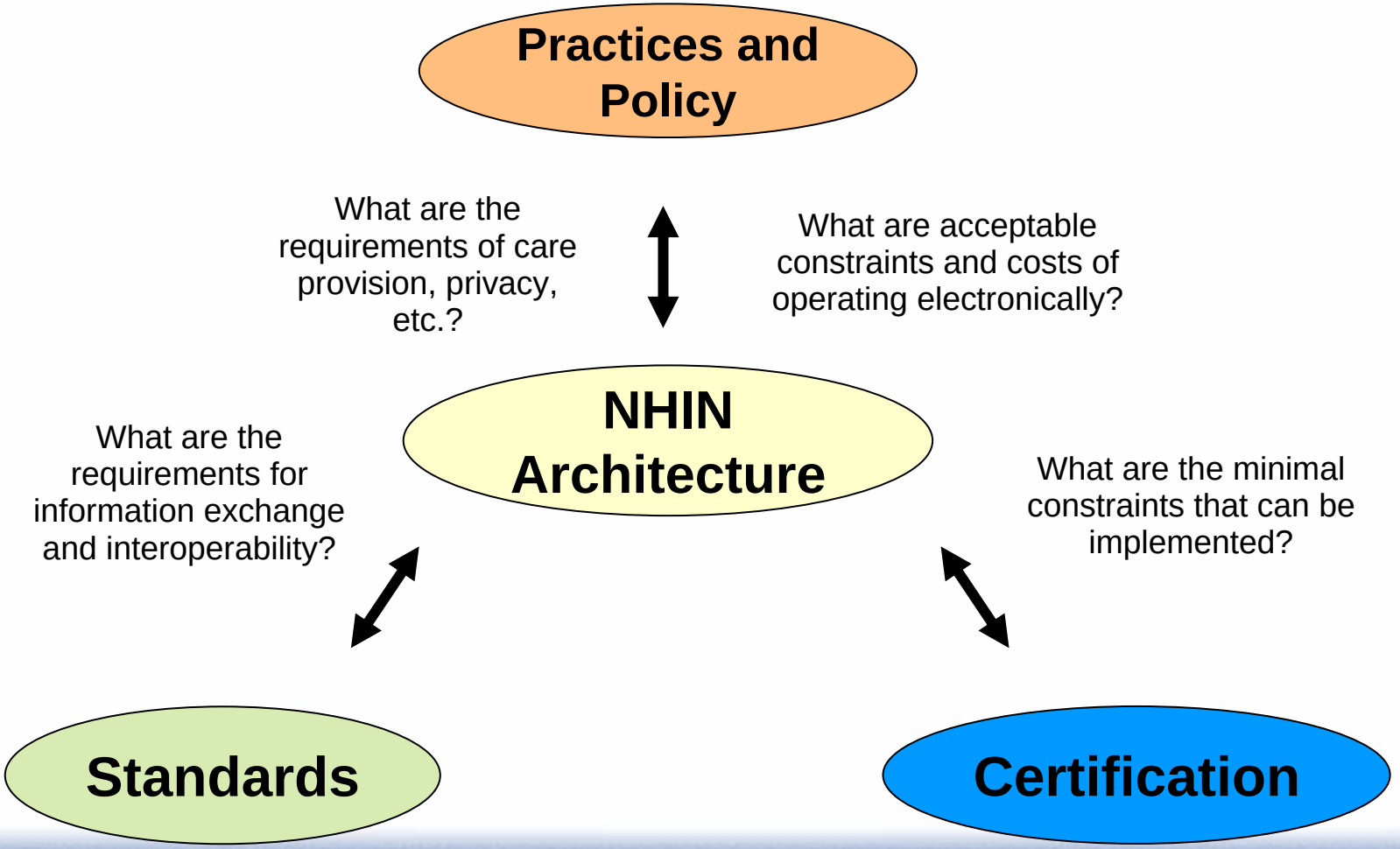
Nationwide Health Information Network…

“ …widely available services that facilitate the accurate, appropriate, timely, and secure exchange health information.”

Nationwide Health Information Network will…

- Specify information exchanges and interoperability architectures necessary to realize the President’s vision for health care IT
- Interconnect health records
- Transport electronic health information to inform clinicians and follow the consumer

“NHIN” is a Part of the Solution



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NHIN Iterative Development

	Progress
Phase I (2006)	• Form Consortia • Develop Use Cases • Develop High Level Standards • **Develop Harmonization Requests** • **Develop Business Models** • **Develop Prototypes**
Future (2007-)	• **Develop a shared architecture with best elements** • **Produce operational implementations** • **Establish environment for sustainability**

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NHIN Participants

- Broad Participation
  - Public, Private, Federal
  - Providers, Payers, Researchers, Regulators, Population Health Monitors
  - Domain and Technical Experts
- Collaboration
  - Functional Requirements
  - Interoperability Specification
  - Privacy and Security Approaches
  - Revenue and Cost Model

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NHIN Functional Requirements Purpose

- Identify minimal set of functions needed to interconnect systems and provide interoperable exchange of health information
- Focus attention on capabilities needed to support use cases emanating from the American Health Information Community (AHIC)
- Provide specifications for steps of NHIN process
- Inform CCHIT's certification criteria
- Inform HITSP's process

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Regional Health Information Organizations (RHIOs) or Health Information Exchange (HIE)

- A group of organizations with a business stake in improving the quality, safety and efficiency of healthcare delivery
- Purpose of a RHIO is to electronically exchange health information in a secure format so that the receiver can use the information
- Local/state level development of interoperable health records must happen first to build a national network
- Building blocks of the NHIN initiative
- Currently over 100 RHIOs exist
- Robert Wood Johnson Foundation studying interoperability of RHIOs

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HIMSS RHIO Federation

- Goal is to foster the RHIO/HIE industry through education, outreach and advocacy activities at the local, state and federal level
- Three focus areas:
  - Business Rules
  - Harmonization
  - Chain of Trust

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Agency for Healthcare Research and Quality (AHRQ) Health IT Grants

- HHS Awarded $139 million for Health IT in 2004
- In Oct 2005, over $22.3 million awarded to 16 grantees to implement Health IT systems – selected from 2004 grant recipients for planning Health IT systems
- 11 of 16 grants awarded to small/rural communities
- Focus on sharing health information between providers, labs, pharmacies, and patients and help ensure safer patient transitions between health care settings
- Promoting adoption of health IT by local communities/health care providers and working with states to develop RHIOs

Consolidated Health Informatics (CHI)

- Office of Management and Budget's (OMB) eGov Initiative and is part of the FHA in the ONC
- Collaborative effort to adopt health IT standards for implementation in federal gov't systems (particularly vocab and messaging standards)
- Participation of 20 department/agencies in governance process
- Adopted 20 uniform standards for electronic exchange of clinical information to be used in the federal gov't – Published in Federal Register Dec 2005
- Currently in Phase II – implementation, maintenance, and identify/adopt new standards

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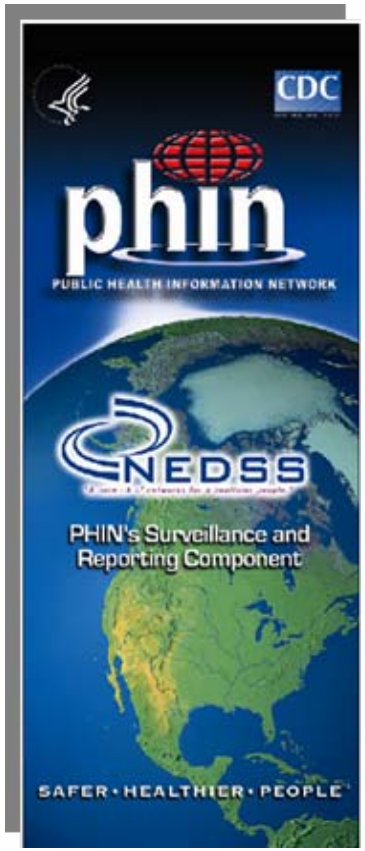
Public Health Information Network (PHIN)



Will enable consistent exchange of response, health, and disease tracking data between public health partners through:

- defined data and vocabulary standards
- architectural standards
- strong collaborative relationships

Public Health Information Network

Early Event Detection
BioSense

Outbreak Management
Outbreak Management System, lab result reporting

Surveillance
NEDSS

Secure Communications
Epi-X

Analysis & Interpretation
BioIntelligence analytic technology

Information Dissemination & KM
CDC Website
Health alerting

PH Response
Countermeasure administration; isolation, vaccine, prophylaxis

phin
PUBLIC HEALTH INFORMATION NETWORK

Federal Health Architecture, NHIN & Consolidated Health Informatics

Infectious Disease Protection • Immunization • Injury Prevention • Pri
Child Hea ships • Minority Outreach • Monitoring Health • Community Partnerships
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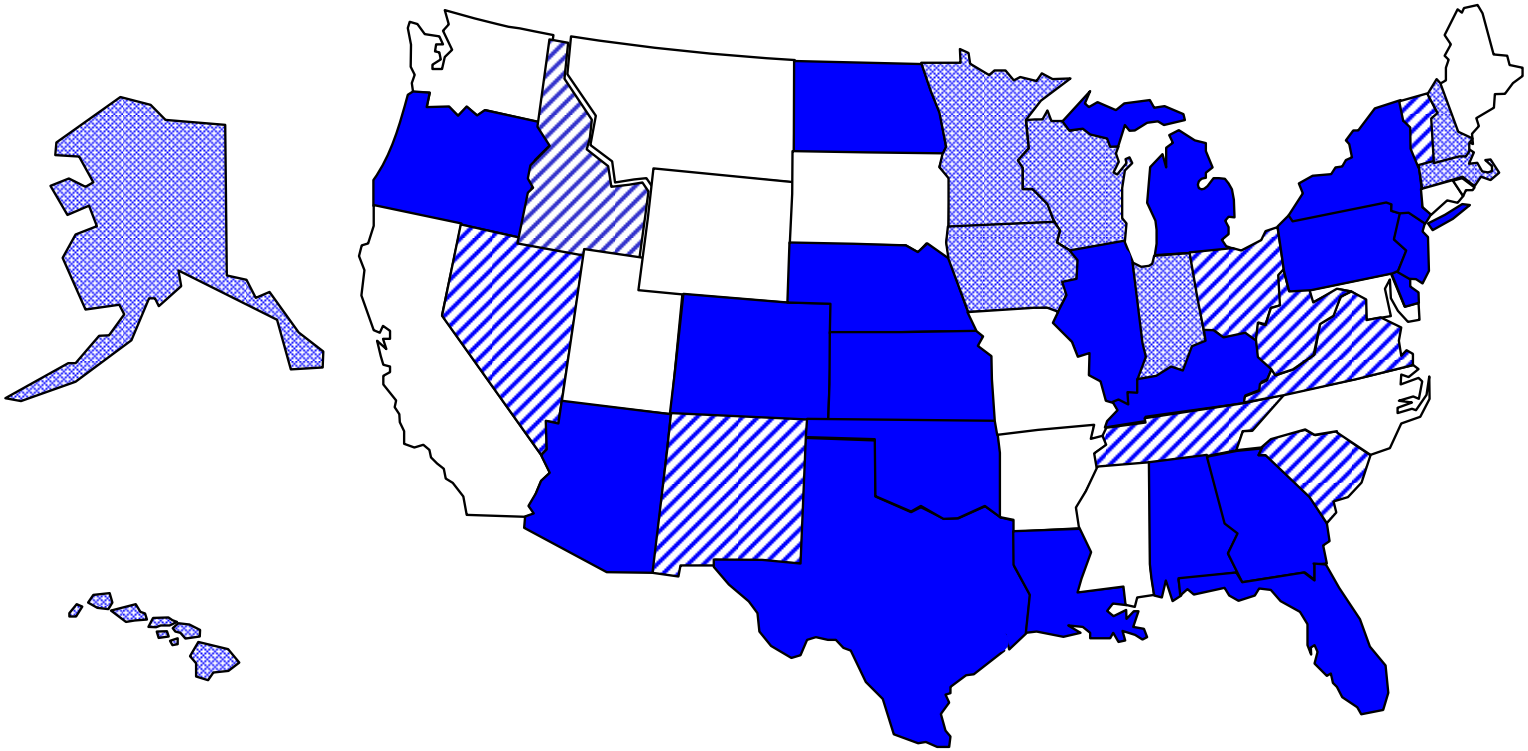
National Electronic Disease Surveillance System (NEDSS)

- **NEDSS is the surveillance component of PHIN**
- **NEDSS includes the PHIN data and architecture standards necessary for interoperable state and local surveillance systems**
- **The NEDSS Base System (NBS) and NEDSS Program Area Module (PAM) Platform (NPP) are a specific instance of a NEDSS compatible system**

State NEDSS Surveillance Functions, 2006

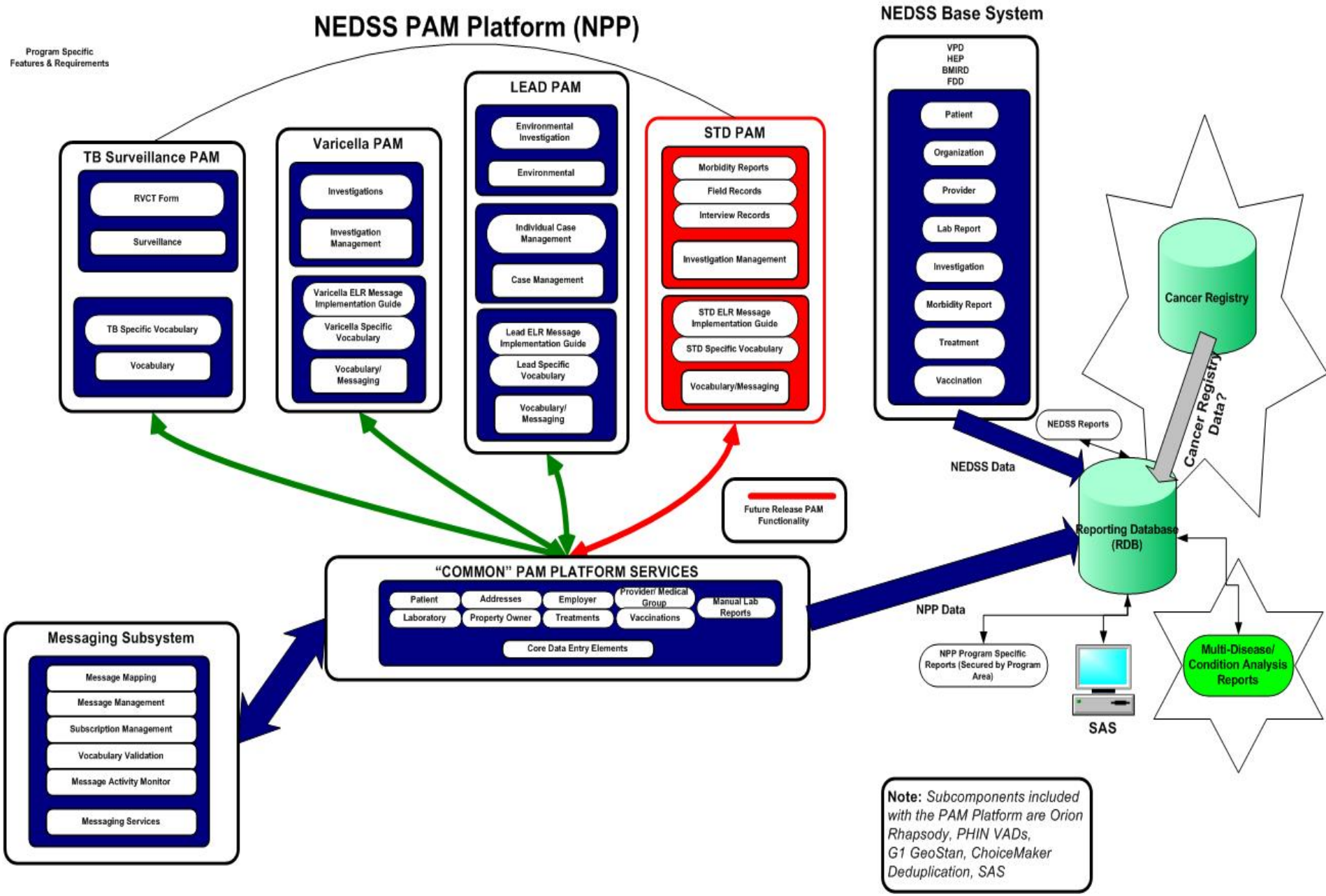


Surveillance using web-based data entry -9

Electronic Laboratory Reporting - 8

Both - 19

Planning/implementing internet based systems - 14


NEDSS PAM Platform (NPP)
Program Specific Features & Requirements
TB Surveillance PAM
RVCT Form
Surveillance
TB Specific Vocabulary
Vocabulary
Varicella PAM
Investigations
Investigation Management
Varicella ELR Message Implementation Guide
Varicella Specific Vocabulary
Vocabulary/ Messaging
LEAD PAM
Environmental Investigation
Environmental
Individual Case Management
Case Management
Lead ELR Message Implementation Guide
Lead Specific Vocabulary
Vocabulary/ Messaging
STD PAM
Morbidity Reports
Field Records
Interview Records
Investigation Management
STD ELR Message Implementation Guide
STD Specific Vocabulary
Vocabulary/Messaging
NEDSS Base System
VPD
HEP
BMIRD
FDD
Patient
Organization
Provider
Lab Report
Investigation
Morbidity Report
Treatment
Vaccination
Cancer Registry
Cancer Registry Data?
NEDSS Reports
NEDSS Data
Future Release PAM Functionality
Reporting Database (RDB)
"COMMON" PAM PLATFORM SERVICES
Patient
Addresses
Employer
Provider/ Medical Group
Manual Lab Reports
Laboratory
Property Owner
Treatments
Vaccinations
Core Data Entry Elements
NPP Data
Messaging Subsystem
Message Mapping
Message Management
Subscription Management
Vocabulary Validation
Message Activity Monitor
Messaging Services
NPP Program Specific Reports (Secured by Program Area)
SAS
Multi-Disease/ Condition Analysis Reports
Note: Subcomponents included with the PAM Platform are Orion Rhapsody, PHIN VADs, G1 GeoStan, ChoiceMaker Deduplication, SAS

How does PHIN/NEDSS improve local and state capacity?

- **Web entry**: case information available to local & state health departments immediately on entry (no paper, no mail)
- Electronic connectivity with local providers
  - Communication, alerting
  - Case reporting via web
- Standardized data sent electronically to CDC
- Same application for over 140 diseases, replacing disease specific “stovepipe” applications

How does NEDSS deliver value to local & state health?

- **Electronic laboratory results** reporting (ELR) from clinical diagnostic laboratories
  - For pre-defined results of public health importance, electronic message to health department **automatically sent**
  - Message includes structured data including test, result, provider ID, patient age, sex
  - Multi-jurisdiction labs, public health labs, some local labs

ELR and Public Health
Nebraska Interim Report – 2/04

Parallel evaluation of ELR vs. usual paper-based LabCorp notifiable disease reports, January - June, 2003

Reporting Completeness:

- 280% increase in cases reported (1044 ELR vs 373 paper)

Reporting Timeliness:

- mean interval to receive results 3 days vs. 24 days (ELR vs.paper)

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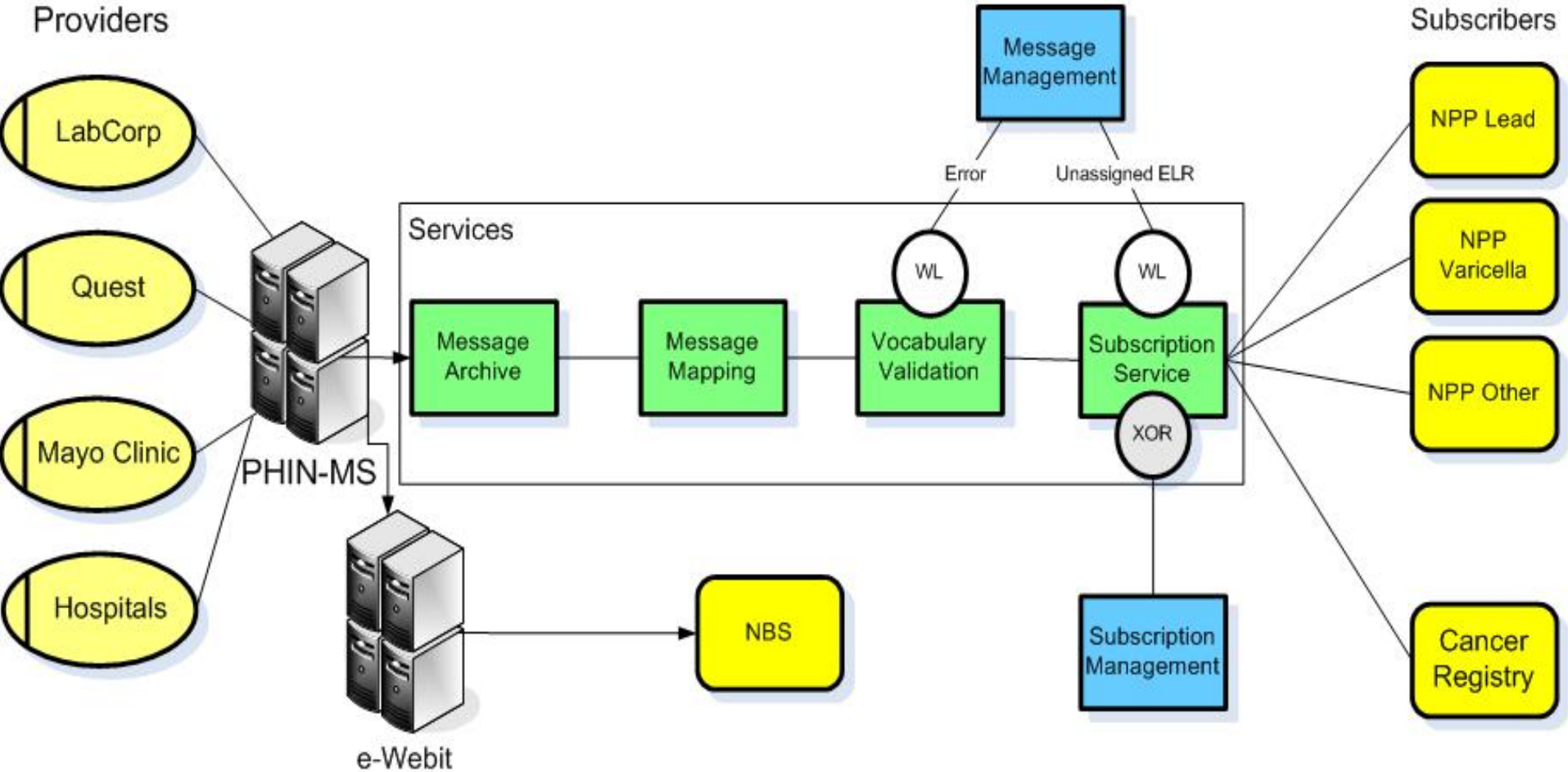
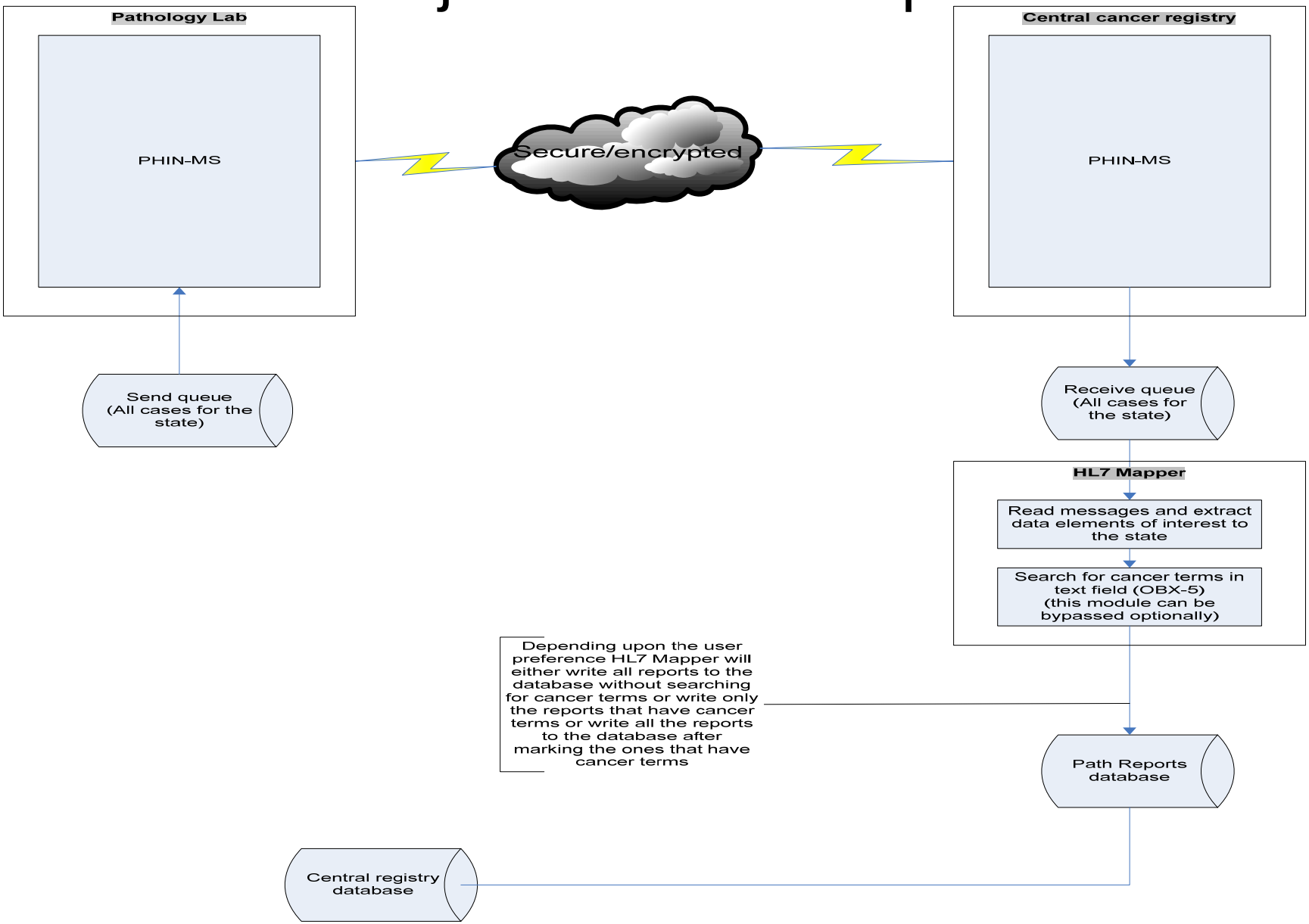
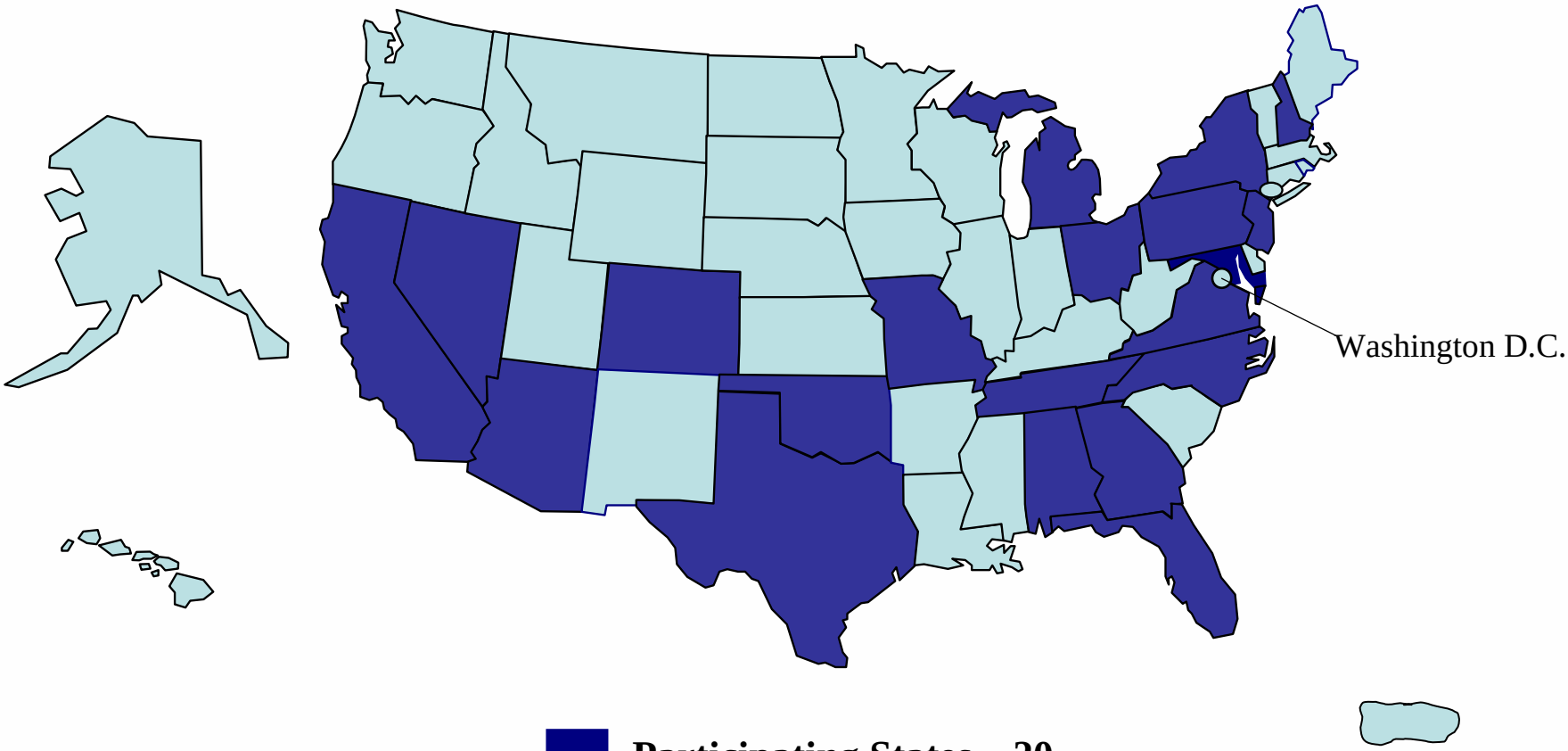


Messaging Subsystem: A Conceptual View

Data flow of messages in ePath Reporting Pilot Project with LabCorp



Participating State Cancer Registries in ePath Pilot Project with LabCorp



Participating States – 20
AL, AZ, CA, CO, FL, GA, MD, MI, MO, NV, NH, NJ, NY, NC, OH, OK, PA, TN, TX, VA

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ePath Reporting Pilot Project Objectives

- Test and document the implementation of ePath reporting from a national laboratory to central cancer registries
- Adopt and/or develop software needed to successfully implement ePath reporting
- Provide guidance to central cancer registries and path labs on implementation requirements for ePath reporting – tools and lessons learned will be distributed to all

Examples of E-Reporting Projects in Cancer Surveillance

- NAACCR Workgroups:
  - NAACCR Vol V - Pathology Laboratory Electronic Reporting, Version 2.0
  - Work underway on E-Path Process Guide
  - Explore/test use of HL7 CDA format for submission of NAACCR Vol II data (Cancer Abstract)
  - UML Modeling of Death Clearance and NAACCR Hispanic Algorithm
- NCI/SEER:
  - E-Path Project with AIM
  - SEER Data Management System (SEER*DMS)

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Examples of E-Reporting Projects in Cancer Surveillance (con't)

- CDC/NPCR
  - Reporting Pathology Protocols - CAP Cancer Checklists
  - VA Project
  - NPCR-Modeling Electronic Reporting Project
  - ePath Pilot Project with LabCorp
- State Projects
  - Web Plus Urology Project
  - E-Path Implementation
- Others
  - Radiological Society of North America: RadLex – Lexicon for uniform capture/index/retrieval of Radiology Information Resources

Reporting Pathology Protocols (RPP)

- Demonstration projects funded by CDC NPCR
- Implement SNOMED CT Encoded CAP Cancer Checklists
- In 2001
  - California and Ohio
  - Cancers of the colon and rectum
- In 2004
  - California, Maine, and Pennsylvania
  - Cancers of the breast, prostate, and melanoma of the skin

VA Project

- Drs. V. J. Varma and Theresa W. Gillespie at the Atlanta VAMC proposed to implement
  - A two year project
  - Template-based reporting
  - Using SNOMED CT Encoded CAP Checklists
  - Top 5 cancers
    - Lung, breast, prostate, colon and rectum, pancreas
  - Store values in a database in the pathology lab

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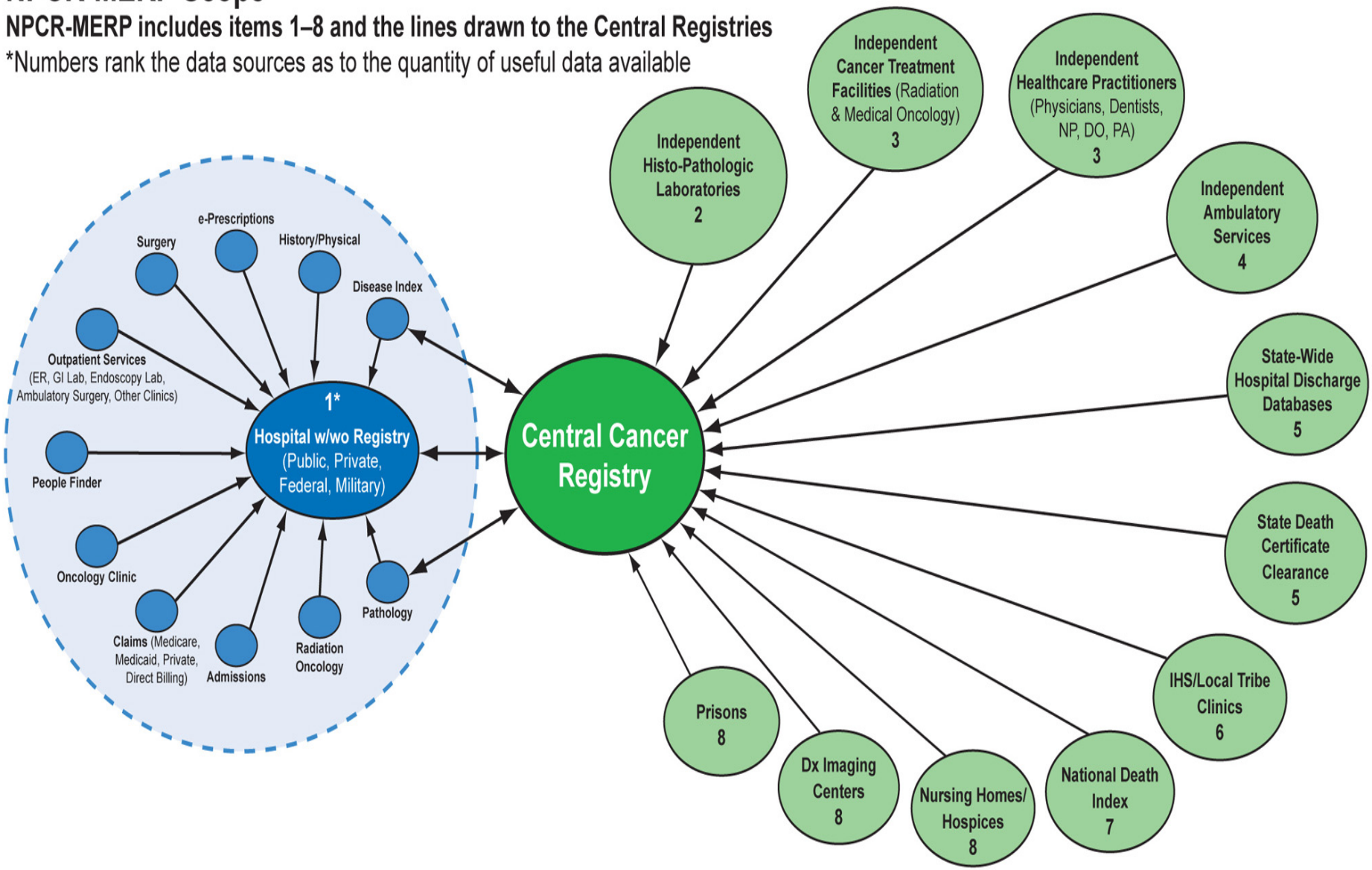
NPCR-MERP

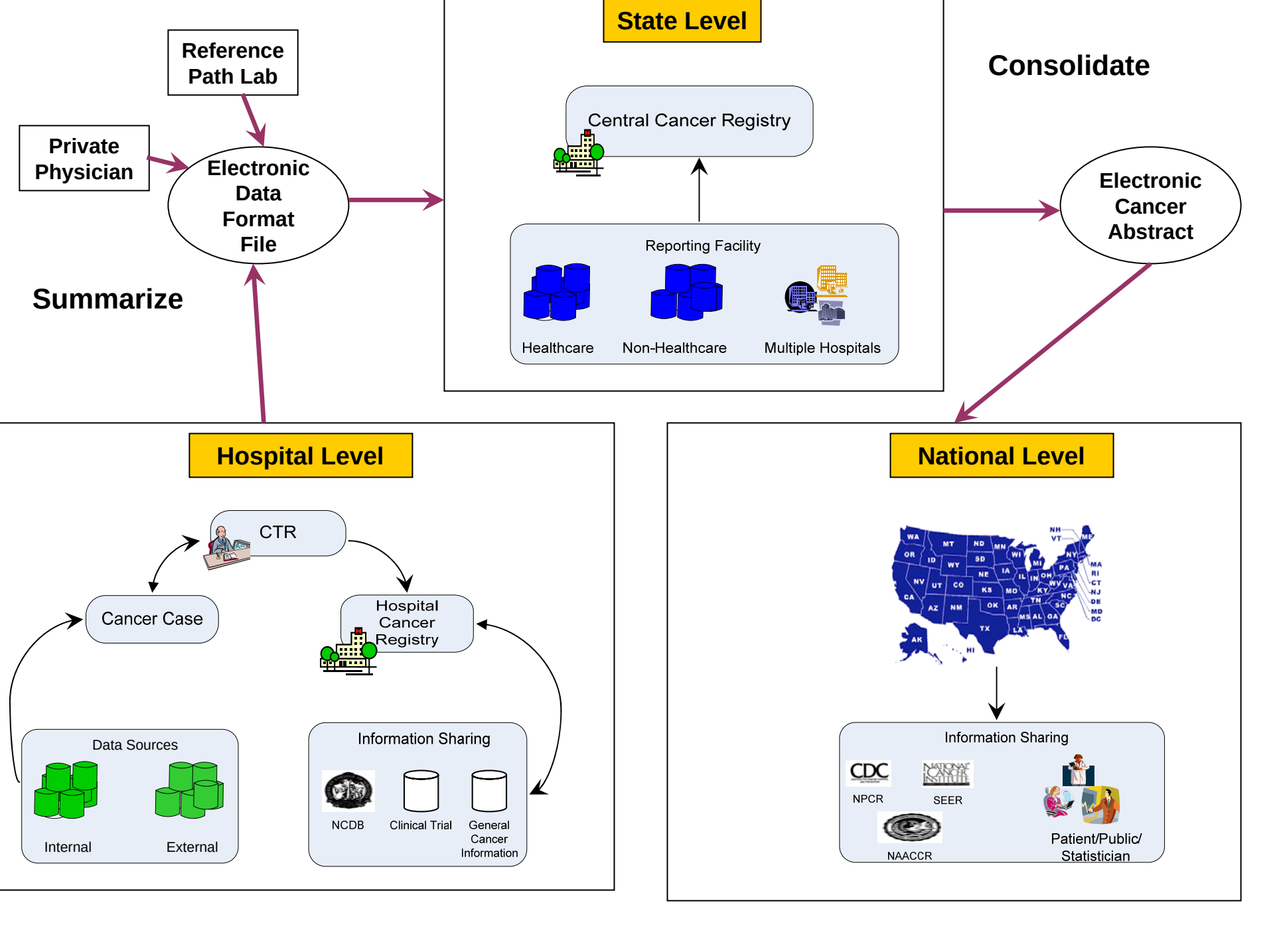
- Collaborative project to develop an electronic reporting model (recommendations, guidelines, and diagrams) for cancer surveillance to:
  - Promote the utilization of the EHR
  - Standardize electronic data exchange from:
    - data sources to the Central Cancer Registries (CCR)
    - CCR to the National Cancer Surveillance Programs (i.e. NPCR, SEER, CoC, NAACCR)
- Complete a formal Needs and Capabilities Assessment to provide an up-to-date view of cancer registration

NPCR-MERP Scope

NPCR-MERP includes items 1–8 and the lines drawn to the Central Registries

*Numbers rank the data sources as to the quantity of useful data available




Reference Path Lab
Private Physician
Electronic Data Format File
Summarize
State Level
Central Cancer Registry
Reporting Facility
Healthcare
Non-Healthcare
Multiple Hospitals
Consolidate
Electronic Cancer Abstract
Hospital Level
CTR
Cancer Case
Hospital Cancer Registry
Data Sources
Internal
External
Information Sharing
NCDB
Clinical Trial
General Cancer Information
National Level
Information Sharing
NPCR
SEER
NAACCR
Patient/Public/ Statistician

Final Thoughts…

- Cancer Surveillance is doing a lot of great work in the area of electronic reporting
- Need to work together more within and outside of our cancer community
- Better utilization of resources
- CDC-NPCR and NCI-SEER will work together to form a National “Oversight” Committee

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