



**National Program of Cancer Registries**



# **Integration of Cancer Registry Software with a Public Health Network (PHIN) Based, NEDSS Compatible Public Health Surveillance System**

**NAACCR 2006 Annual Meeting**

**June 13, 2006**

**Regina, Saskatchewan**

**Sandy Thames, CDC**

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LTH • PREVENTION RESEARCH • PRIVATE SECTOR PARTNERSHIPS • PUBLIC HEALTH WORKFORCE • WOMEN'S HEALTH

# Acknowledgments

Scott Danos, CDC

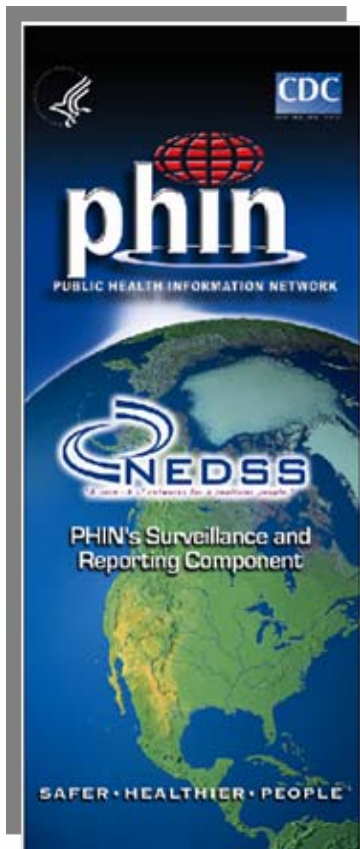
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# Public Health Information Network (PHIN)



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



Federal Health  
Architecture, NHIN  
& Consolidated  
Health Informatics

# 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**

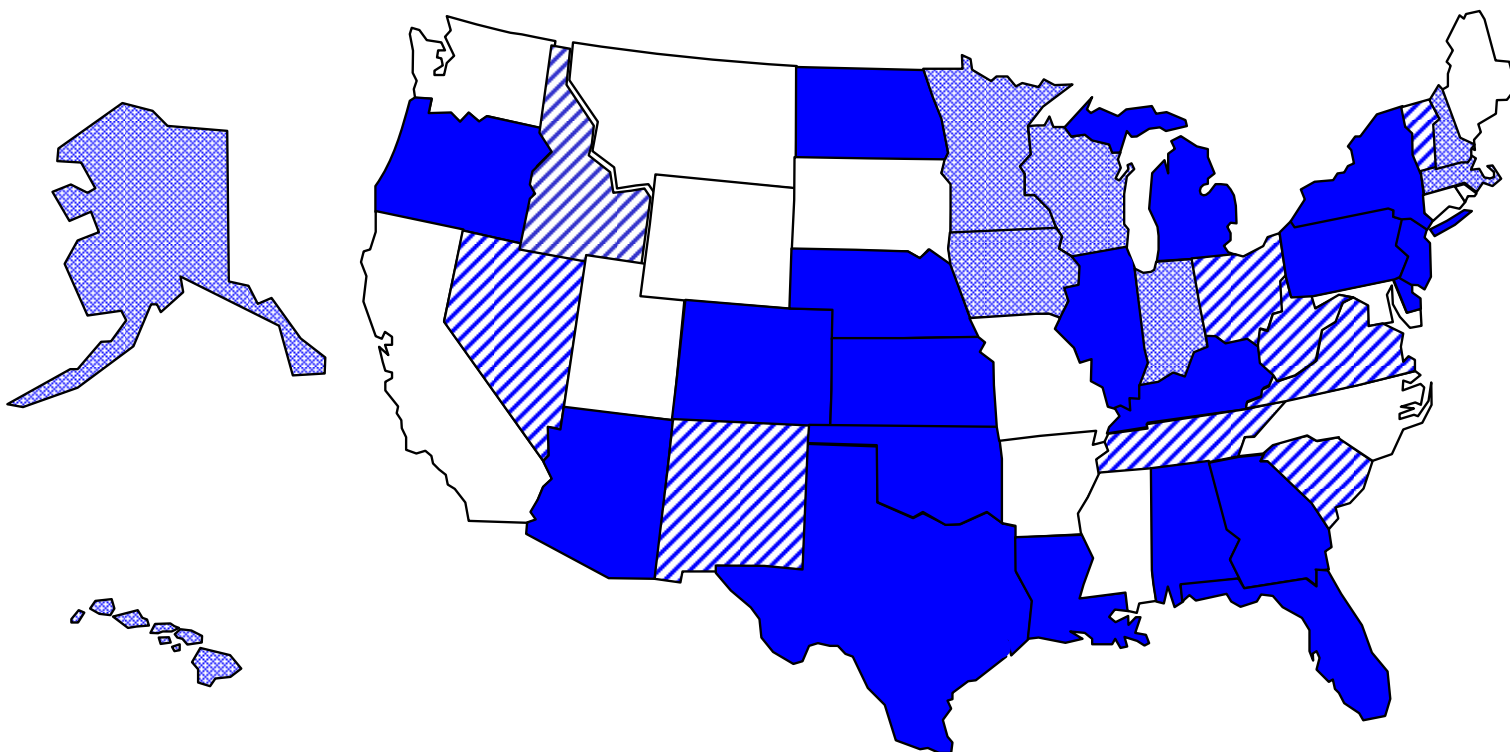
# Why NEDSS?

- Multiple disease/condition-specific systems
- States, CSTE request
- Data incomplete, often not timely
- Current systems not using best technology
- Web-based, data integration
- Current system deficiencies

# Benefits of NEDSS

- Integration with other program areas and data sources
- Web-based: improves coordination of surveillance and case management
- ELR module
- Higher quality data, improved communication, improved timeliness of reporting, reduced data entry
- Easier data reporting to CDC

# ***State NEDSS Surveillance Functions, 2006***



**Surveillance using web-based data entry -9**



**Electronic Laboratory Reporting - 8**

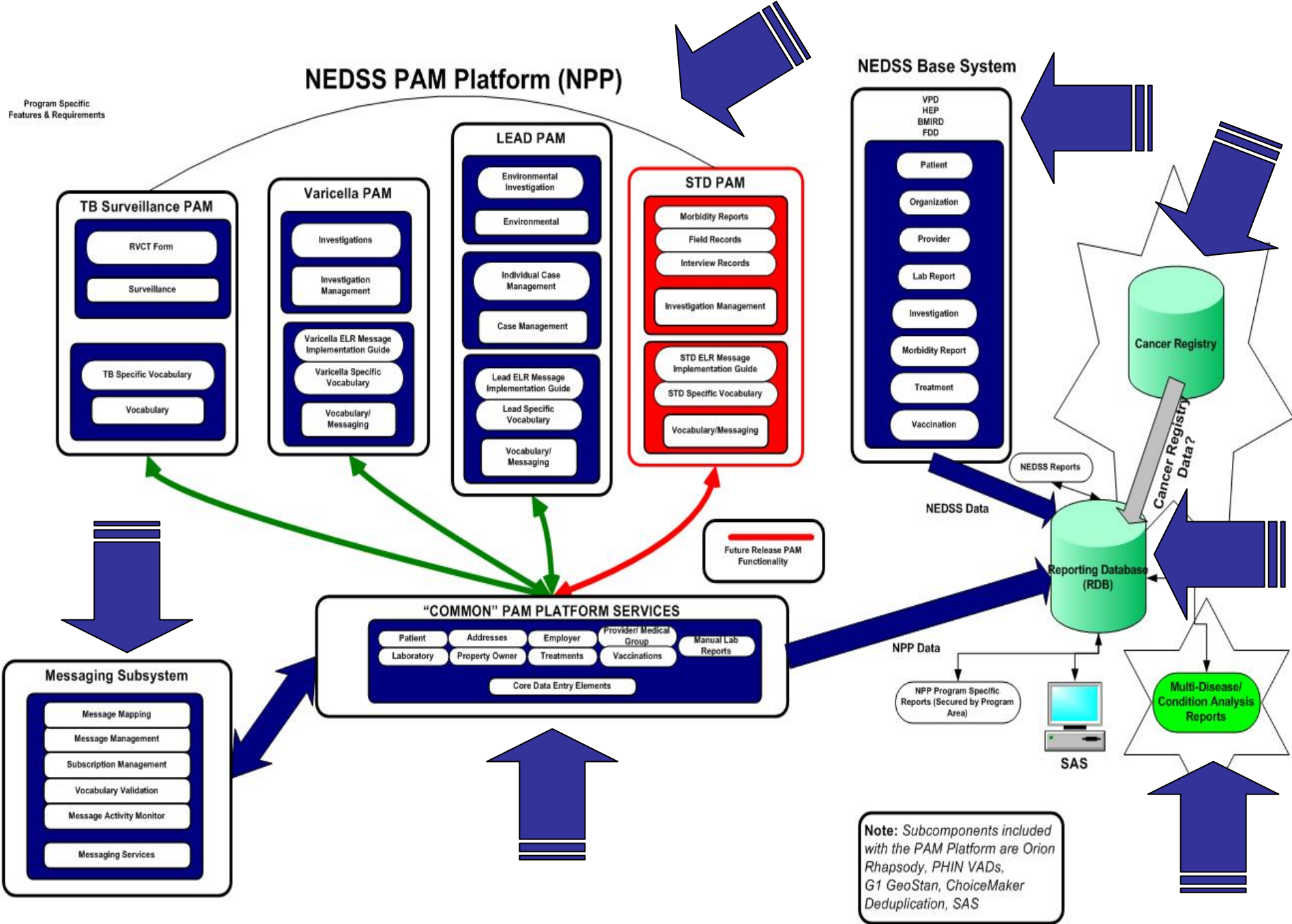


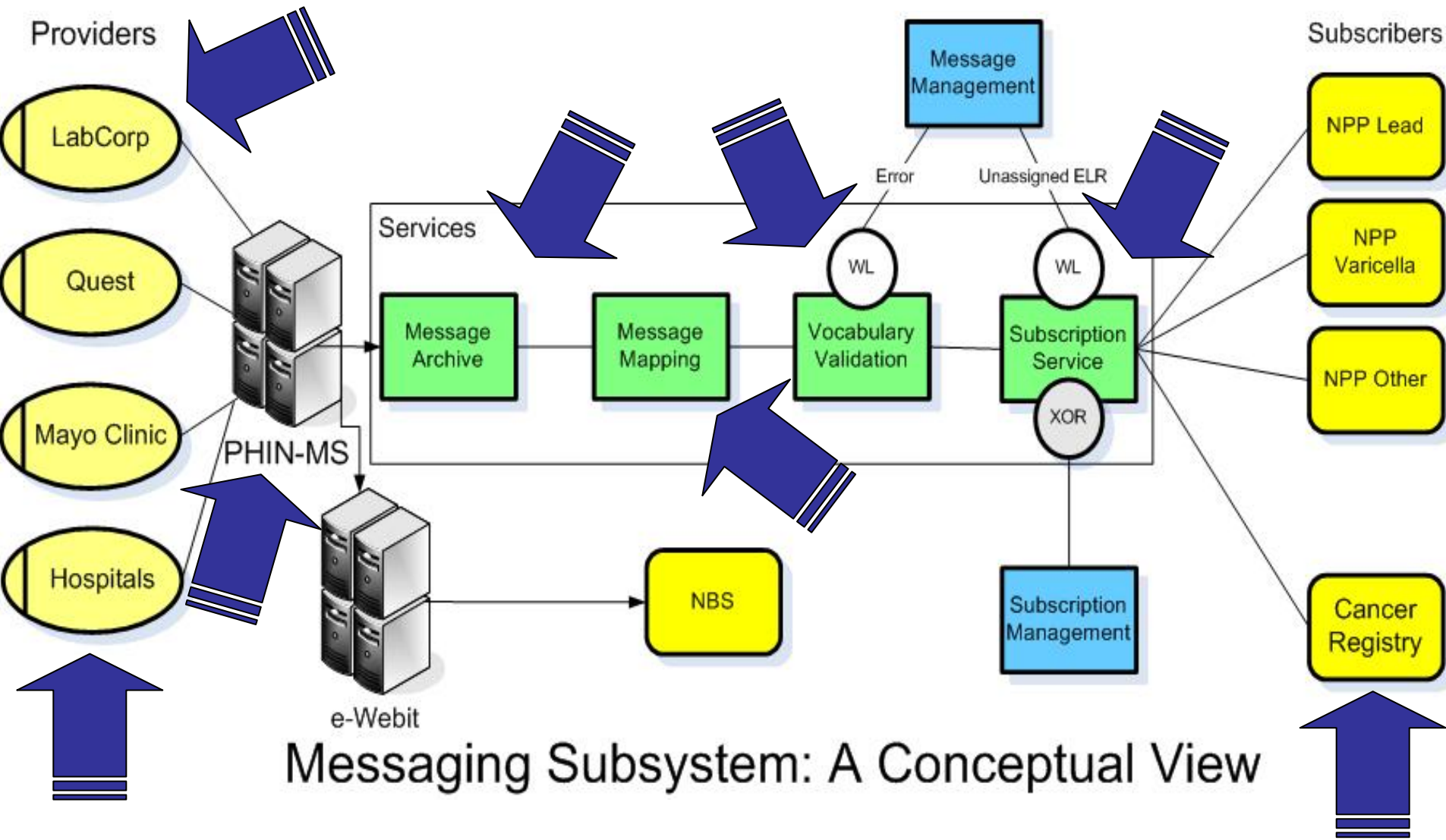
**Both - 19**



**Planning/implementing internet based systems - 14**







Messaging Subsystem: A Conceptual View

# NPP Messaging Subsystem (Orion Rhapsody and Symphonia)

- Not dependent on NPP or NBS
- Messages not limited to lab messages
- System will receive any format – not just HL7
- Native format is transformed to specified format
- Vocabularies are validated and any local codes are transformed to standard codes
- Messages are scanned and sent to subscribers with matching criteria
- System will generate/send emails or data to multiple subscribers
- State Cost: \$2,100 maintenance costs due upon deployment

# Current Status of NEDSS

- NBS has been deployed in 15 states and contains surveillance data for
  - Vaccine Preventable Diseases (VPD)
  - Hepatitis
  - Bacterial Meningitis and Invasive Respiratory Diseases (BMIRD)
  - Foodborne Illnesses
- NPP Messaging Subsystem (only) has been deployed in TX for beta testing
- NPP has been deployed in OH for beta testing (production by Spring 2006) and contains surveillance and patient management data for
  - Lead
  - Varicella
  - Tuberculosis

# 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)

# Opportunities for Cancer Registry Utilization of PHIN/NEDSS Tools

- Data standards to facilitate data collection
  - use PHIN Vocabulary Application Distribution System (VADS) to incorporate vocabularies for cancer registry surveillance
- Transport messages (data) securely from LabCorp, hospitals, etc. to the state central registries
  - PHIN/NEDSS Messaging System
- Assess how state data warehouse could benefit cancer registry (i.e. cross-disease analyses, risk factors, denominators, etc.)

# Benefits to Cancer Registry

- Better use of resources
- Standardized and interoperable with other health programs
  - Less burden on clinical providers for data exchange
- Improved timeliness
  - Eg Identifying patients for clinical trials
- Linkage with other data sources (census data, hepatitis, risk factors, environmental, etc.)



# Needs Assessment and Requirements Gathering Session

- Held session in March 2006 with approximately 20 NPCR state central cancer registries.

Discussions included:

- Advantages/disadvantages of integrating cancer data into the NEDSS state RDB – where access to data is still controlled by cancer registry
- Development of a NEDSS Program Area Module (PAM) for Cancer Registry
- Use of the NEDSS PAM Platform Messaging Subsystem to route incoming messages (LabCorp, Hospitals, etc) to the state central registries

# Conclusions from Needs Assessment Session

- Integrating data into the NEDSS State Reporting Database:
  - Did not see the current value of the data currently in NEDSS (notifiable diseases, Lead, Varicella, TB, etc.)
  - Concerned about security of data – Cancer privacy issues comparable to that of HIV/AIDS
- Development of a NEDSS PAM for Cancer Registry:
  - Cancer Registry surveillance is very complex
  - Current systems are already web-based (such as Registry Plus software)
  - Better utilization of resources to modify current Cancer Registry systems to be interoperable with NEDSS
- Use of the NPP Messaging Subsystem to route incoming messages (LabCorp, Hospitals) to the state central registries:
  - Would be very useful for Cancer Registries
  - Would streamline data exchange and better utilize state resources

# Proposed Plan for Integrating Cancer Registry with PHIN/NEDSS

- Re-assess the benefits of integrating cancer data into the NEDSS state RDB at a later date
- Will not develop a NEDSS PAM for Cancer Registry, instead will make Cancer Registry systems and data interoperable with NEDSS
  - Map cancer surveillance vocabularies to PHIN Vocabulary Application Distribution System (VADS)
  - Formal evaluation and certification of the Registry Plus suite of tools and make any modifications as needed
- Test the use of the NPP Messaging Subsystem to route incoming messages (LabCorp, Hospitals) to the state central registries with TX and OH using the data from the ePath Pilot Project with LabCorp