An Informatics Approach to Establishing a Sustainable Public Health Community

by

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ABSTRACT

This work involved the analysis of a public health system, and the design, development and deployment of enterprise informatics architecture, and sustainable community methods to address problems with the current public health system. Specifically, assessment of the Nationally Notifiable Disease Surveillance System (NNDSS) was instrumental in forming the design of the current implementation at the Southern Nevada Health District (SNHD). The result of the system deployment at SNHD was considered as a basis for projecting the practical application and benefits of an enterprise architecture. This approach has resulted in a sustainable platform to enhance the practice of public health by improving the quality and timeliness of data, effectiveness of an investigation, and reporting across the continuum.

DEDICATION

I dedicate my dissertation to my loving wife Sarah, and sons Jackson and William. A special feeling of gratitude to Debbie and Phil Jackson for their encouragement, and unwavering support.

I also dedicate this dissertation to my mother; thank you for your patience, understanding, love, and belief in chasing my dreams.

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CHAPTER 1

INTRODUCTION

“We need strong public health institutions to respond to any challenge. We need to deal with critical infrastructure. The reality is that very little money has flowed to communities to help our first responders; to help our hospitals; to help the public health infrastructure.”
— Senator Robert Menendez

This work involved the analysis of a public health system, and the design, development and deployment of enterprise informatics architecture, and sustainable community methods to address problems with the current public health system. Specifically, assessment of the Nationally Notifiable Disease Surveillance System (NNDSS) was instrumental in forming the design of the current implementation at the Southern Nevada Health District (SNHD). The result of the system deployment at SNHD was considered as a basis for projecting the practical application and benefits of an enterprise architecture. This approach has resulted in a sustainable platform to enhance the practice of public health by improving the quality and timeliness of data, effectiveness of an investigation, and reporting across the continuum.

Overview of the problem and approach

The Nationally Notifiable Disease Surveillance System operates through its local, State, and Federal public health partners for the day to day activities upon which our public health surveillance system is founded. (CDC 1998) (Importance of nationally notifiable disease surveillance system) Historically, the public health continuum has relied upon on manual procedures to support the surveillance activities in which data is collected, aggregated, analyzed, and communicated. (Importance of public health data interchange) The evolution of these activities led to a divide in the organizational fabric of the local and State public health agencies, and the Federal program offices, as each was responsible for the collection, analysis, and dissemination of their respective data.

The development of the Centers for Disease Control and Prevention (CDC) Surveillance Coordination Group in 1985 laid the foundation for public health agency practice today, focusing on improved surveillance activities and communication. Initiatives set forth by the group focused upon shifting the burden from manual processes, to electronic systems with the promise of a revolutionary change across the continuum. (Sacks 1985) Unfortunately, the migration from antiquated paper-based practices occurred with seemingly little or no regard in the assessment of the underlying processes or use of standards and best-practices, furthering isolating programs. This lack of standardization and best practices has harmfully impacted the public health continuum, resulting in disparate, inconsistent, error-prone instruments for collection, transport, delivery, consumption, and analysis of data. (Koo and Wetterhall 1996)

Local and state agencies who have come to depend on the CDC as the de-facto authority for the development, implementation, and support of critical infrastructure, are left with frustration as CDC developed solutions have not met the promised intent, outlived their utility, or been removed from service with little or no warning. As a result, these agencies have become reactionary in an attempt to reduce interruption of services to the community of which they serve. This fractionation has been a systemic issue within public health practice, as it has not been a priority on local, state, and federal agendas, forcing each to rely on thin internal resources, having little program oversight, project management, or core competencies in the areas of informatics, software development, project management, etc. in the assessment of need, integration, and overall vision of the public health and the supporting programs mission. (Smith, Kriseman and Kirkwood 2011)

Importance of nationally notifiable disease surveillance system: The National Notifiable Disease Surveillance System was initially introduced in 1878 as a component of the U.S. Marine Hospital Service to collect data on a limited set of emerging diseases. (CDC 2011) This program was instituted to improve the public's health by implementing at the local, state, territorial, and federal agencies the necessary methodologies, and tools in which to support collection and dissemination of public health data. The information gathered, analyzed, and synthesized across the public health continuum are critical in the understanding of disease etiology, emerging threats, bioterrorism activities and the like, resulting in the effective application of evidence based decision making and action.

Importance of public health data interchange: The exchange of public health data paints the local, State, and national picture of disease. This complex interchange requires public health data to cross many boundaries, involving disparate partners, and to be collected and aggregated to formulate information and applied knowledge. This information and knowledge is inextricable from a functioning and sustainable Nationally Notifiable Disease Surveillance System (NNDSS).

Limitations of the nationally notifiable disease surveillance system: Lack of oversight, organizational support, processes, and technologies have resulted in a patchwork of legacy systems plaguing the NNDSS. (Smith, Kriseman and Kirkwood 2011) The ongoing change of direction and priority at each level in public health has often resulted in incomplete implementations. The ill defined and constantly changing national direction has led to varying degrees of adherence to standards, while change in technologies have resulted in systems with limited scalability and portability across the continuum. With the lack of an enterprise wide focus, the cycle of repetitive failure continues.

Approach to address the shortcomings of the current system, which can be widely adopted and self-sustaining: This work reported in this dissertation develops a community-driven sustainable public health infrastructure for the NNDSS. This platform consists of the necessary governance structure, protocols, and processes to create an integrated network of collaboration amongst public health.

Limitations of current public health data interchange: Majority of public health data interchange relies upon antiquated technologies such as phone, fax, and email which do not adhere to standards. Such methods often incorporate free form text to capture data, and lack the ability to efficiently integrate into a larger system. Furthermore, such antiquated technology has a high potential for error as the information passes through the many public health channels.

Approach to address the shortcomings of the current public health data interchange: In order to address the aforementioned limitations, part of this work develops a universal public health information infrastructure. This infrastructure automates the step-wise processing of data from disparate providers through normalization, standardization, rules, and knowledge application; ensuring that the consumer receives a standardized, validated data stream.

Finally, it will be demonstrated that the informatics-based solutions presented herein lead to the creation of an extensible and sustainable public health platform. The analysis of this system demonstrates its ability to be extrapolated across the NNDSS, its membership, and partner communities. Chapter 2 provides a background of NNDSS and the public health continuum, supplying context of the assessments conducted in Chapters 4, 5 & 6. These chapters present a comprehensive assessment of NNDSS, and the public health continuum, a model for sustainability in public health, and the architecture and design of a novel, sustainable public health platform. Chapter 7 demonstrates a practical implementation of the system at a local health department, which is evaluated in Chapter 8. A discussion of the methods utilized, results and interpretation, remaining challenges, and future directions are offered in Chapter 9. This dissertation is a paradigm shift in the way in which integration and enterprise architecture have been applied throughout the public health continuum resulting in an extensible, sustainable public health infrastructure, summarized in Chapter 10.

CHAPTER 2

BACKGROUND

Public Health

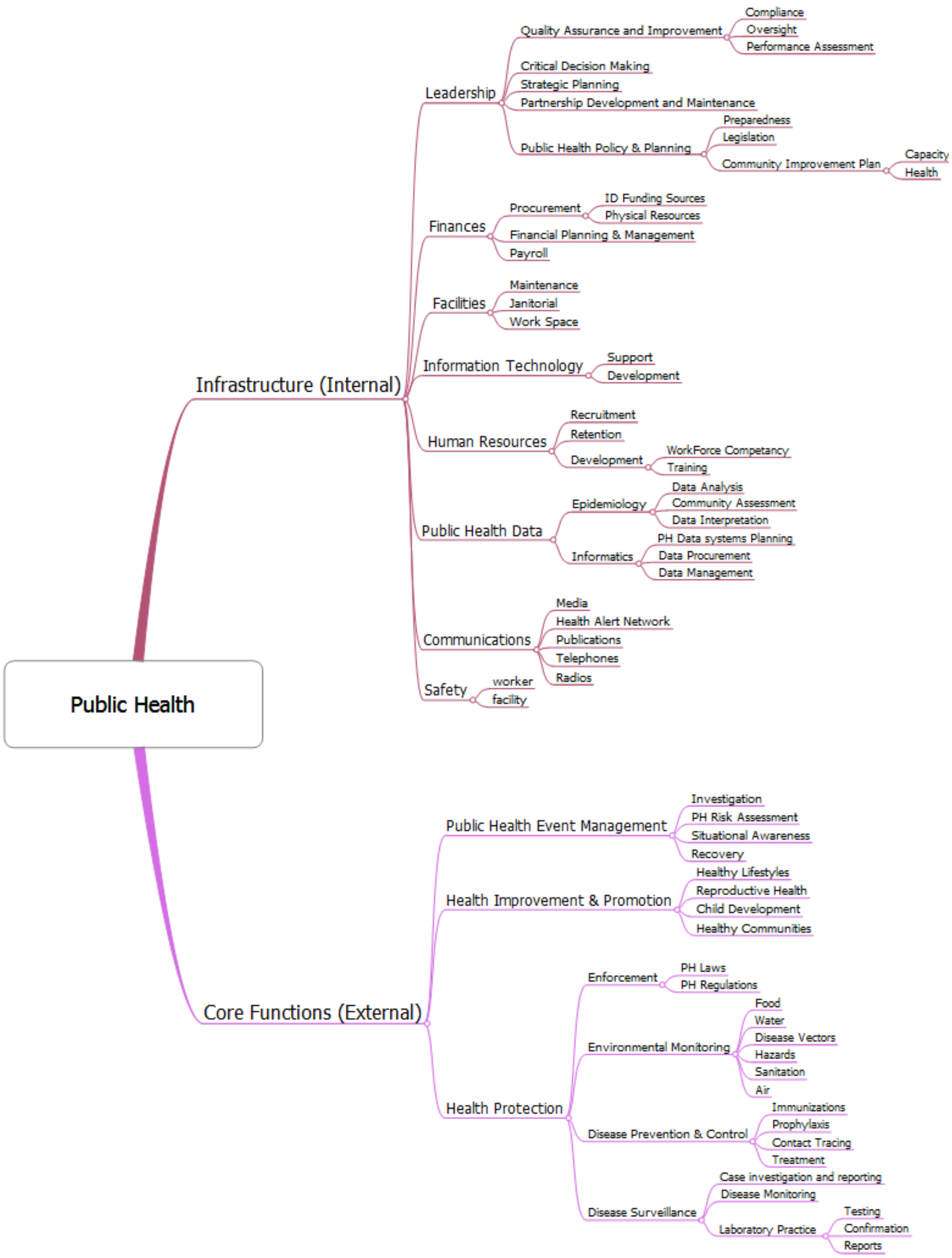


Figure 1. Public Health Infrastructure and Core Functions.

The tenth amendment, which states that “powers not delegate to the United States by the constitution nor prohibited by it to the States are reserved to the States respectively or to the people” was ratified in 1791, but not until 1850 was there an outline of the administration of public health, as a matter of state and local importance. While public health organizations and regulations existed in the pre-colonial period, it was not until 1889 the first state, Massachusetts, founded the first state health department. This organic growth was a natural result of the need at the state and local level in the prevention and control of disease within its population. While this works well for local control of disease, it works as a prohibition to the development of a strong federal health presence with regulatory authority over state or local public health issues. Consequently, there has been no centralized development of public health, limiting the federal government agencies activities.

While the public health community can agree on many of the core functions of public health domain (Figure 1), it is often difficult to place a defined boundary around it. Public health is inherently a population focused domain, and as a result, the population being served defines the boundaries of the domain. Thus, public health metamorphoses to fit an array of conditions specific to the environment in which it is practiced. Many functions of public health, such as disease surveillance, childhood immunization, and restaurant inspections can be found in every health department. Beyond those core functions, each community defines the needs of that community and the parameters necessary to create an environment where people can be healthy.

As a result in many communities, the lines between public health and medicine have been blurred. Direct patient care services, such as clinical and community hospitals, are often placed within the prevue of public health. This is similar to academia, where research often straddles the line of public health practice and medicine, public health often incorporates many aspects of direct patient care. From a purist standpoint, public health is about preventing disease at a community level, where medicine is about the treatment of disease at an individual level.

Public health grew out of medicine, and never completely emerged as an independent domain; today we see the same trend in public health informatics as it is an outgrowth of medical informatics, having not matured as its own domain. In order to define the domain of public health informatics, we face the challenge of defining needs as diverse as the population it serves.

Evolution of the Public Health Enterprise

An enterprise by definition systematically implements *terminology*, *entities*, *internal/external relationships*, and most importantly the fundamental *processes* which promote its evolution. Ideally, this is a unified vision. The NNDSS Enterprise, through it many transformations, has led to challenges in the identification, coordination and execution of a single focus.

The initial point of contention is inherent due to the federalized model of public health in the United States, as expressed in the U.S. Constitution's Fourteenth Amendment: "it is generally conceded that states could exercise power to protect public health, safety, and morals." (Mount 2001) This history of decentralized public health activities makes it difficult to coordinate and execute underlying processes with partners over which federal agencies have no direct control. While the federal agencies can promote the development of enterprise solutions, it is important to note that the enterprise itself extends beyond the walls of those guiding agencies, to many key stakeholders that reside in local, State, and Federal public health agencies.

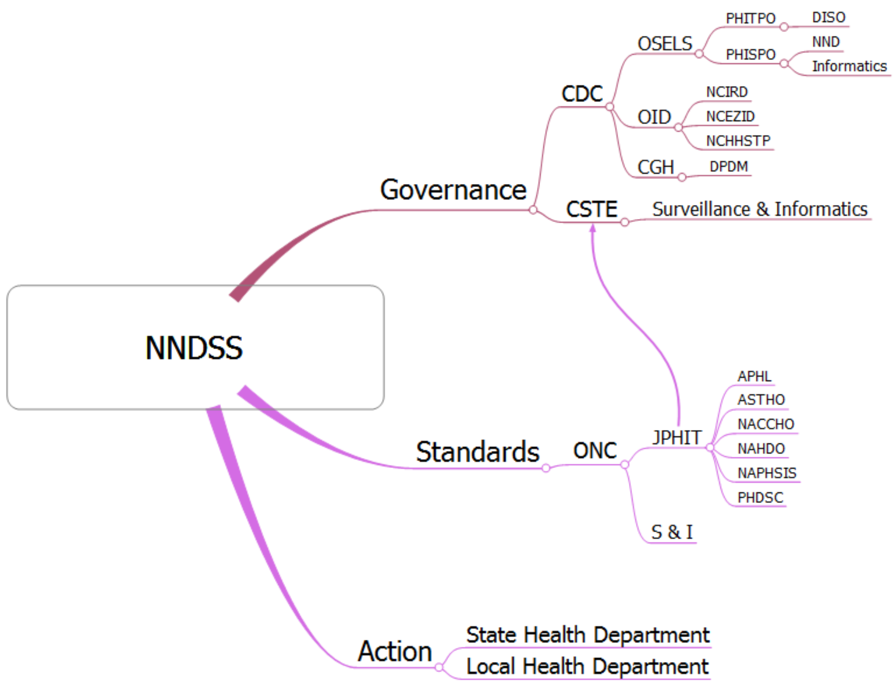


Figure 2. The NNDSS Enterprise is comprised of a multitude of epidemiological, technical, and supporting agencies.

The conceptual framework of the NNDSS, as illustrated in Figure 2, suffers not only from its broad functional scope that serves many stakeholders, but also from lack of clarity in its primary goals, objectives, and priorities. State and local health departments see this reporting system's main function as the means to receive actionable information to allow them to intervene and manage disease, and secondarily to report to Federal partners. Federal agencies see NNDSS primarily as a mechanism of receiving accurate and timely information on notifiable cases for national surveillance tracking, special studies, and, where indicated, reporting to the World Health Organization under the International Health Regulations (IHR). (CDC 1998) The Federal stakeholders who depend on the NNDSS for receiving data are the faction having the most influence in terms of budget and organized access to leadership, while dependency on local, and state data collection means that no solution really succeeds without support from these jurisdictions.

Targeted financial support relating to the transmission of data from State agencies to the Federal programs is often provided by the requesting program. Each program provides direction based upon its individual need independent of the broader public health continuum, outside of the boundaries of the NNDSS enterprise. It does not however, generally provide support for the resources and time taken to implement these protocols at the local agencies which are responsible for carrying out the directives. (CDC n.d.) As a result, the cost of data collection is not born by the Federal agency and its programs, but by the agencies that operationalize the request which is generally not considered in the overall cost of operations. It is the responsibility in the creation of a sustainable framework that NNDSS provide leadership and technical guidance, while managing expectations with its internal and external partners, understanding the impact on downstream business functions, resources, cost and risks.

Characterization of public health surveillance data

Over the past century the amount of public health data utilized throughout the aforementioned activities has dramatically increased.

(Sweeney 2001) Physical population size has led to an increase in data stemming from the need to have a unique medical record maintained for each individual over time (Figure 3A); each record contains a comprehensive assay of clinical information including additional diagnostic tests (Figure 3B) and respective codes (Figure 3C). This data has become increasingly complex as the number of diagnostic testing methods available increases, and the number of codes associated with tests, and conditions have become more granular. (Beaglehole and Bonita 2004)

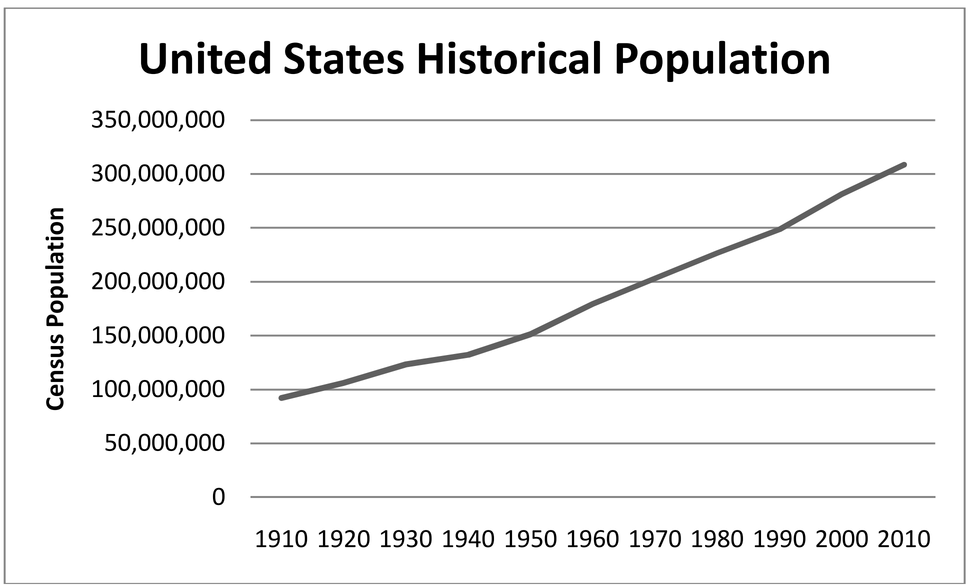


Figure 3A. 100 year Population trend of the United States

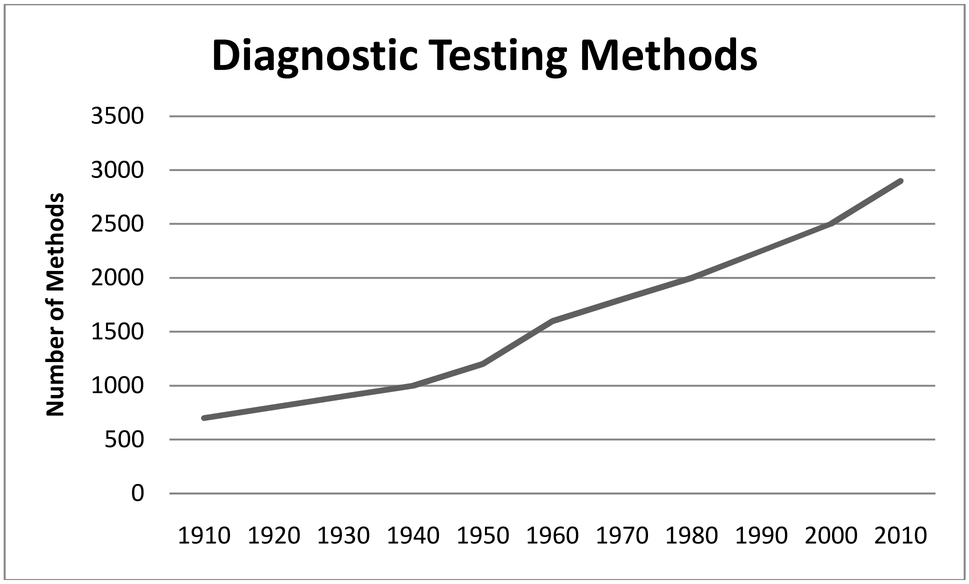


Figure 3B. 100 year trend of available Diagnostic Tests Methods

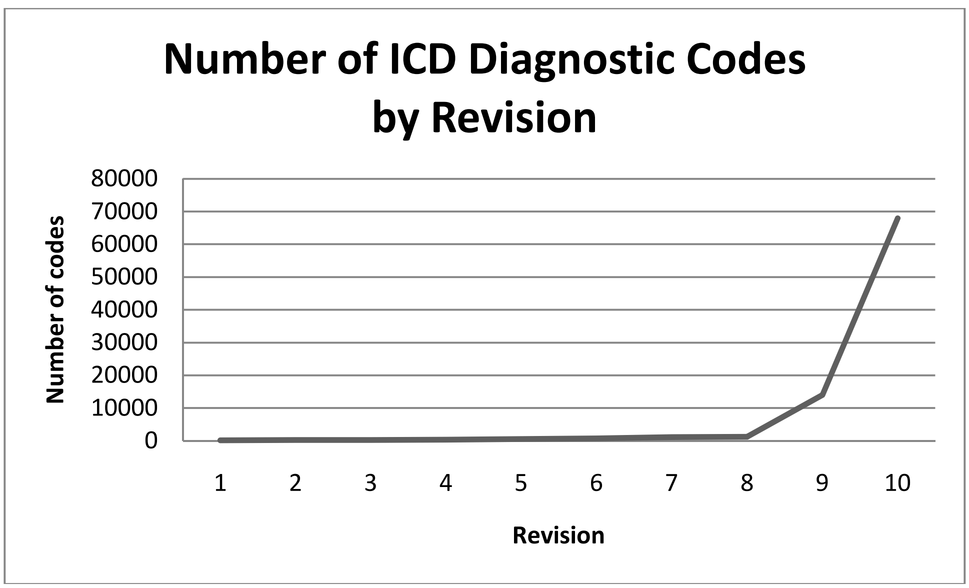


Figure 3C. Number of ICD codes by Revision

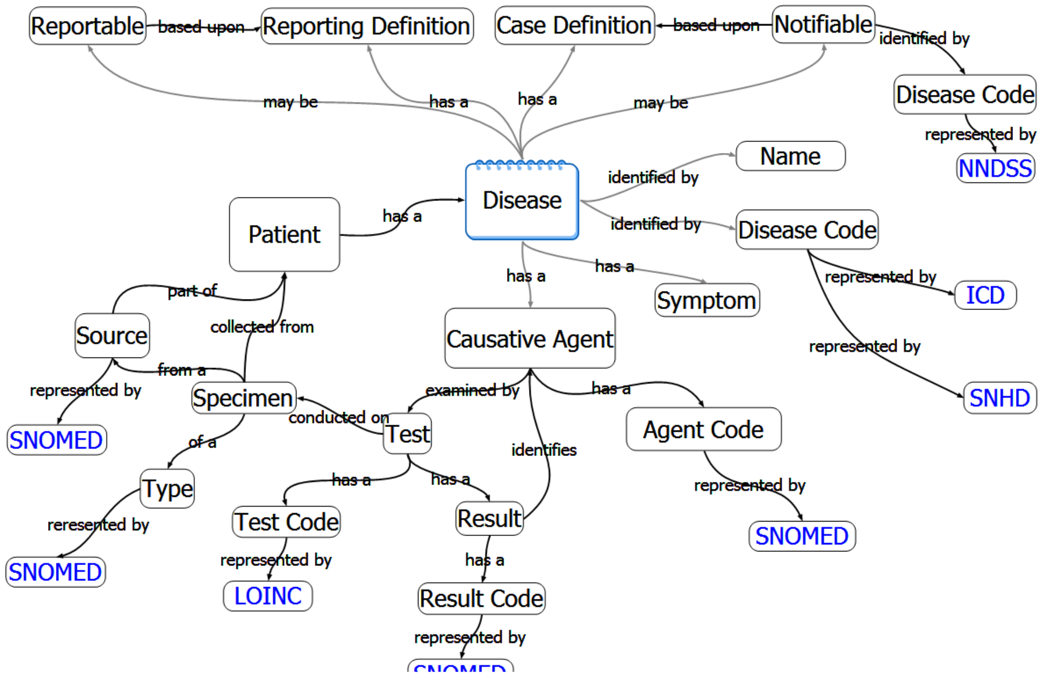


Figure 4. Public Health Data Characterization. Public Health data is complex when examined; the number of diseases, specimens, tests, organisms, and representative code sets, and revisions.

Public health surveillance is made up of a diverse set of data from a multitude of partners in a coordinated effort to paint a picture of disease within a community. While these data originate from a variety of sources, they may all be characterized by similar attributes as they represent fundamental core elements such as Data Types, Relationships, and Complex Data Types. (Brackett 1994) (Buneman, Khanna and Tan 2001)

Fundamentally, the initial dimensionality is defined by an Ordering data element, Quantitative, Ordinal, or Nominal which expresses the range of plausible actions to be taken on the element. This element is typically accompanied by both a Coordinate – Spatial, temporal, and

Amount – number which provide information about its origin, direction, and magnitude.

The additional dimension of data is represented by Relationships, the connections maintained, and constraints imposed (Figure 4). Coverage dictates the mapping of data between sets of data, while Cardinality and Uniqueness defines the way in which the relationship is constrained. Collectively, these types and relationships make up Complex Data Types, and when applied with Semantic constraints construct an ontology which conceptualizes the inter-related nature of the data, Fig. 4

Public Health Data Partners

Table 1. Description of Data Partner

Partner	Description
Laboratory	
NCL	National Commercial Laboratory
LCL	Local Commercial Laboratory
SPHL	State Public Health Laboratory
HL	Hospital Laboratory
PH Agencies	
SHD	State Health Department
LHD	Local Health Department
CDC	Centers for Disease Control and Prevention

Table 2. Delivery method, and what syntax, nomenclature

Partner	Delivery	Attributes
Laboratory		
NCL	Fax, Phone, ELR*	HL7, Text
LCL	Fax, Phone, ELR*	HL7, Text
SPHL	Fax, Phone	
HL	Fax, Phone, ELR	HL7, Text
PH Agencies		
SDH	Fax, Phone	
LHD	Fax, Phone, ELR	Excel, NETSS, HL7, Text
CDC	ELR	NETSS, NBS,Text,HL7

* Only LabCorp delivers standardized nomenclature

Table 3. Issues / Impediments

Partner	Issues / Impediments
Laboratory	Nonstandard reporting, disparate legacy systems are not integrated, lack of incentives
NCL	*More apt to adopt standards
LCL	*No core competency to develop standardized protocols
SPHL	*Limited core competency, limited understanding of the overall requirements, and enterprise implementation
HL	Competing priorities, Initial EHR failures leave little resources for ELR as many partners are migrating
PH Agencies	Legacy systems, lack of resources and funding have plagued PH. < 3% of total government spending for medical initiatives (Martin)
SHD LHD	Limited resources and priorities, change in leadership and direction
CDC	Dysfunctional internal programs and processes are unable to create a unified vision and the necessary approach

The voluminous nature of the data being exchanged through the numerous public health data partners (Table 1) directly affects the workflow of public health practitioners, and the mechanisms employed to capture and analyze data (Table 2). Currently, manual methods of data collection dominate field level investigation, while many ad-hoc systems have been developed as a result of reactionary need, and pressure from local, state, and federal agencies (Table 3). Similar ad-hoc systems have been introduced across agencies as short-term fixes, not intended to be utilized long-term, but have survived in perpetuity further exacerbating the magnitude of the problem.

Public Health Surveillance Systems

Currently, NNDSS is made up of a multiplicity of supporting programs and systems representing a high degree of overlap in the support of surveillance activities as illustrated in Figure 5. (Smith, Kriseman and Kirkwood 2011) None of the systems are generalizable or capable of incorporating more than the specific type of surveillance activities for which it was built. These systems remain disparate in nature, grown out of reactionary necessity within the respective program, with no regard to adherence to enterprise architecture.

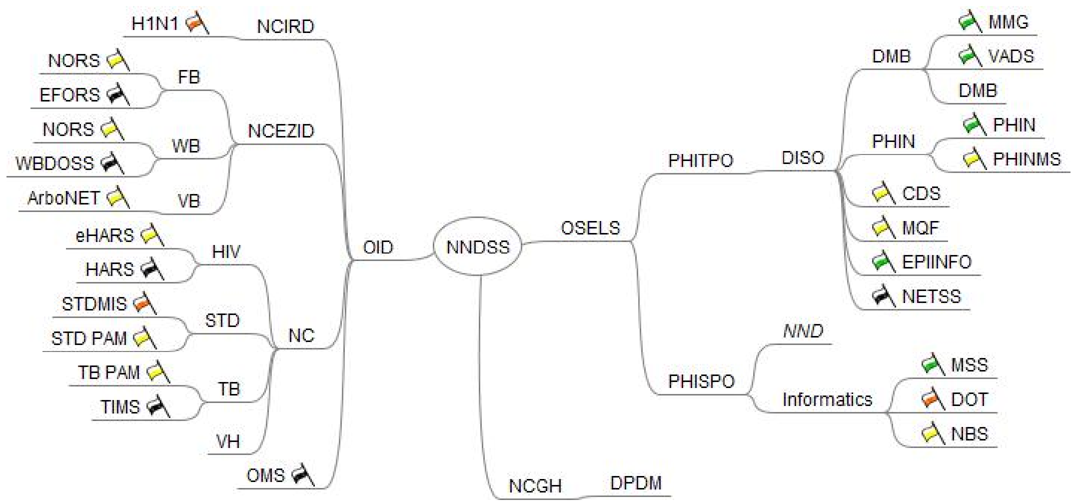


Figure 5: NNDSS supporting programs, and systems, illustrating the various states – Green = functional, Black = Decommissioned, Orange = Phased, and Yellow = Questionable.

Related Work

This section reviews a number of approaches which have been used in an attempt to meet local, State, and Federal aforementioned requirements, discussed in the previous section.

Data Exchange: The current state of data exchange between public health data partners relies on the ability to comply with the requirements as mandated by the Center for Medicare and Medicaid Services (CMS), data exchange between partner agencies must meet criteria defined as mandated by CMS (page 2034 of the federal register document, Row 6, Submission of Lab Results to Public Health Agencies), and in accordance with CDC guidance, June 2006, and CSTE Position Statement 06-EC-02. Chelsom (Chelsom 2010) introduces Open Health Informatics, and discusses the creation of open interfaces to create a plug-and-play infrastructure to meet the previously discussed CMS mandate. This mechanism for data integration allows for a flexible architecture leveraging open source components, and open source development efforts. This "best of breed" approach has the added benefit of distribution of the underlying foundation to local, state and national health authorities.

Nguyen illustrates the existence of multiple protocols and delivery mechanisms for compliant messaging (Nguyen, Thorpe et al. 2007) . Indeed there is no statutory requirement for the use of standard vocabularies and messaging syntax and protocols. Thus, data partners can meet their legal requirements through any mechanism of their choosing, resulting in a variety of message types and delivery channels. Compounding the problem is the use of various messaging vocabulary and syntax within the agency. Because various public health systems are siloed in nature, and have no requirement to communicate with any of the disparate systems within or outside of the respective agency, each has developed internal nonstandard vocabularies to meet their needs.

While the approaches discussed are novel, and idealistic, many attempts at negotiations with data partners who embrace the utility of integration have only occasionally resulted in the rapid deployment of solutions. The majorities of negotiations were protracted and frequently did not result in the implementation of desired systems. As Lorenzi (Lorenzi 2003) illustrates conflicting missions, trust/control, ownership and financing all are significant barriers in the development and acquisition of data partners.

Disease Surveillance and Investigation: The current state of surveillance and investigation was evaluated by a statewide epidemiology working group which reported out in a consensus Disease Investigation and Electronic Surveillance System (DIESS) whitepaper which also listed desired system attributes. (Department of Health and Human Services 20009) DIESS was an attempt to develop a solution to replace the CDC developed National Electronic Disease Surveillance System (NEDSS) Base System (NBS). (Center for Digital Government 2004) While this document was largely end user-focused, it did recognize the core importance of electronic disease surveillance, investigation, and reporting. The desired framework and characteristics of an electronic solution were described in detail, and focused upon the specific need of the stakeholders. This initiative lost traction, and was discarded just months after the change in administration. The lack of direction and core competency forced the state to continue utilizing the inefficient and burdensome NEDSS Base System.

Other states such as Florida were reactive to the limited functionality of NBS, and with the CDC distribution of funds to develop NEDSS compatible systems resulting in the well provisioned Merlin system which serves 67 counties across the state. Merlin has been in production since 2002, and offers a comprehensive, real-time investigation system with a robust logic tier, and reporting capabilities. (Florida Department of Health 2010)

CHAPTER 3

METHODS

Introduction

The key stakeholders and operational components of the NNDSS will be evaluated herein, as well as systems development, design, and implementation approaches. The nature of the problem and research question lend themselves to an empirical investigation, uncovering new paradigms in collection, normalization, standardization, consumption, transformation, and dissemination of data, which may result in further quantitative studies, and development efforts.

Numerous documents were reviewed, including history and background material on the NNDSS, documentation of vocabulary, architecture, data warehousing, messaging and validation, a draft 2009 strategic plan for NEDSS, and results of a recent data provisioning survey. (Jajosky, et al. 2011) Information gained from this background literature review provided the foundation from which to build survey, interview and observation guidelines.

Two primary methods were utilized to conduct the assessment surveys 1) Questionnaires and Interviews, and 2) Direct Observations at local, state, and federal agencies. In the process of conducting direct observations a number of critical components were routinely observed specific to the process under investigation.

Problem Assessment

Questionnaires

Survey questionnaires were developed based upon the need to collect comprehensive data relating to the organization and processes utilized throughout NNDSS. The survey was designed and conducted by the CDC utilizing paper forms. (Jajosky and Ward 2011) The survey participants were randomly selected from the NNDSS community, resulting in a 64% response rate (n=53/83).

The respondents have a wide range of roles from within the NNDSS, including Epidemiologists, Data Analysts, Data Managers, and the like who have worked in the field from <1 year to > 20 years.

Interviews

In person interviews were conducted at CDC with 81 staff, and 14 contractors; at SNHD with 8 program staff; at KDHE 8 program staff, and 2 contractors; at UDOH 4 program staff, 1 contractor.

Interviews included one to several staff at a time and started with a brief overview of the purpose of the interview. A set of pre-formulated questions was administered, each followed by an open ended discussion. Interviewed staffs were encouraged to explain their role in the NNDSS, its strengths and weaknesses, problems they had identified, their ideas for resolving the problems, and any recommendations. Participants were encouraged to share their thoughts openly and were assured that their comments would not be attributed to them individually.

Observations

Observations were conducted on-site at local, State, and Federal public health agencies. A number of critical processes were identified for observation utilizing natural, controlled and participatory methods. The staff was observed in the natural environment to assess workflow, and systems usability where care was taken to not interrupt the natural workflow so as to obtain as unbiased results as possible and minimize the Hawthorne effect. (Adair 1984) The staff was also asked to demonstrate specific functions, and was observed carrying out those tasks to completion. Finally, the staff and observer performed tasks together so that the observer participated in the activity to gain domain knowledge and perspective.

Design, Development, and Implementation

Planning

The business need was determined based upon a comprehensive review of the program offices, and a feasibility study conducted utilizing the problem assessment methods. A loose charter and statement of work were created to present the intent to the SNHD Executive Team, Board of Health, and ultimately to the funding agency, the Department of Homeland Security (DHS). Included in the SOW was a rough estimate of the overall schedule and cost of the project. The project was funded by DHS based upon its novel, Open Source approach to the public health continuum; and subsequent presentations have been requested and fulfilled to the DHS committee and the Governor of Nevada. Further planning and alignment of these technologies to Federal initiatives across the continuum have been discussed with executive leadership at the CDC, and remains ongoing.

Requirements and Design

As illustrated in chapters 4, 5 & 6, requirements were gathered and gaps in the current deployments identified by interview and observation, and a Systems Specification developed. From the Systems Specification a Design Specification emerged, in which all of the functional requirements were assessed, prioritized, and aligned to the objectives of the system. From this the functional design was established, and a prototype developed to determine feasibility of the architecture, design and supporting infrastructure.

Budget

The final budget was developed based upon the system requirements and design, by phase of the implementation, functional deliverables to be met, tasks to be performed, and funding cycles. The budget, as discussed in Chapter 5, was reflective of the task breakdown and completion criteria, and rolled up into the project schedule. It was then further decomposed to meet the deliverables of the DHS grant, and to ensure it would remain on target throughout the project lifecycle.

Scheduling

A comprehensive project schedule was developed based upon the project budget, providing a detailed description of the progression of tasks, budget for those tasks, and timeline in which the tasks were to be completed to ensure the project remained on track and within budget. The tight integration of the two documents has been critical in uncovering and mitigating potential dependencies and risks.

Risk Management

A risk management matrix was developed, outlined the potential risks throughout the project, was reviewed and updated continually to ensure that the proper mitigation strategies were in place, and being exercised.

Software Development

The software development lifecycle (SDLC) is an iterative approach to software engineering, and accepted throughout the information technology (IT) community. (Highsmith and Cockburn 2002) Following the principles of this methodology, 1) the initial creation of an analysis model was developed based upon information gathered from the problem domain, and developing of use-cases reflective of the public health continuum, Chapter 4; 2) the translation of the analysis processes, workflow, and data definitions into the overarching architectural design was developed through careful consideration of the NNDSS community, involving local, State, and Federal partners; 3) interfaces were developed based upon the integration of common touch points, with adherence to design patterns gleaned from interdisciplinary sciences as illustrated in Chapter 7; 4) the end user community was engaged in applying the use-cases defined, in the development of storyboards and pilot User Interfaces. This ensured user compliance, and comprehensive understating of the system *they* designed, prior to it being built; 5) The process and interface definitions, and usability criteria were broken down into their respective components, and stripped of dependencies to ensure a loosely coupled architecture was developed; 6) the development cycle was based upon an iterative approach, and metrics evaluated throughout each iteration to ensure compliance, reliability, performance, etc.

The application of this methodology resulted in the successful deployment, and ongoing interest in the software, community, and design principles illustrated below.

CHAPTER 4

RESULTS: DESIGN AND PROCESS ASSESSMENT

Introduction

The research herein was conducted under the auspices of the Public Health Surveillance Program Office (PHSPO) at CDC, and The Division of Community Health at Southern Nevada Health District (SNHD). A systematic assessment of the NNDSS began in December of 2009 at SNHD, and at CDC from August 2011. The scope of this assessment was focused primarily on data handling processes of data collection at local and State agencies, and CDC and messaging from States to CDC.

The overall goal of the NNDSS assessment is to better understand the processes and supporting procedural systems through a collaborative effort with key representative stakeholders from public health at the local, State, and federal levels, and to enhance notifiable disease surveillance, investigation, response, mitigation, and prevention activities. The specific goals of this assessment include:

- Evaluating the NNDSS business goals and processes,
- Identifying critical problematic areas of the NNDSS enterprise,
- Recommending solutions and next steps, including recommendations for later phases of the assessment of NNDSS.

Organizational

A common theme across local, State, and Federal agencies was revealed through a series of interviews with staff and management. The fundamental core components of an enterprise organization were limited or missing including a unified 1) *strategic vision*, 2) *commitment*, 3) *oversight*, 4) *support*, 5) *project management*, and 6) *education / skill set*. These components are addressed respectively by the implementation of a sustainable community of practice which includes the ongoing assessment and development of goals, oversight, relationships, areas of influence, and planning in Chapter 5.

Strategic Vision

Aggregated results from the questionnaires, interviews and observations discussed above all strongly suggest the lack of a unified strategic vision of the NNDSS. However competing political interests combined with the lack of open channels of communication between strategic partners perpetuates multiple competing goals for NNDSS.

Commitment

Stemming from the lack of a strategic vision the NNDSS and its organizations are faced with the difficult task of attempting to plan for an uncertain future. As a result, given the limited resources available, NNDSS related organizations have remained reluctant to commit these precious few resources for fear of strategic change which may render their decision obsolete. Furthermore, participants stressed the dysfunctional and disparate nature of the NNDSS which is a further barrier to making future commitments.

Oversight

The large number of stakeholders in NNDSS, the interrelatedness of health information systems, and the ongoing difficulties in improving the functionality of NNDSS for local, State, and CDC users, all highlight the need for oversight of the NNDSS enterprise. Such a complicated system is doomed to repeated functional deficiencies while wasting efforts and resources without a robust mechanism for developing a clear strategic vision for the NNDSS, for making decisions, ensuring stakeholder input and acceptance while providing ongoing oversight and accountability.

The need for better oversight has already been recognized in relation to the PHIN. Currently, a draft CDC Public Health Information Network (PHIN) Governance Sub-Committee Charter is under consideration (personal communication, Seth Foldy). The Charter proposes a committee structure composed entirely of CDC members ("All voting and non-voting members will be internal to CDC") with responsibility for guiding "the PHIN strategic planning process and implementation" and promoting "the interoperability of public health systems across CDC and the public health enterprise". Although it states that external subject matter experts will inform voting by participating in a PHIN Technical Committee, the PHIN Technical Committee is proposed to consist of a chair and internal CDC members with external subject matter experts “work(ing) closely with the Committee". This proposal appears to keep external stakeholder input from distant from the decision making process, with no direct input to the PHIN Governance Sub-Committee.

Another draft CDC document, the National Electronic Disease Surveillance System (NEDSS) Strategic Plan, 2010-2015, dated September 14, 2009, addresses the need for better oversight by recommending that NEDSS have an integrated policy framework for surveillance, which ensures NEDSS policies are compatible with state and local surveillance, and informatics.

Support

As is common among local, State, and Federal public health agencies there are frequent changes in leadership, which account for the numerous changes in direction thereby affecting all aspects of the NNDSS. The history of frequent leadership and organizational changes creates significant challenges for maintaining and supporting a national system as extensive and complicated as NNDSS. Organizational changes and the lack of consistent direction from leadership contribute to the following general adverse outcomes:

- Frequent changes in project and task priorities within and across programs, leading to extended project life cycles and failed implementation of new systems or discontinuation of systems after considerable investment;

- Lack of clarity in decision making and who has authority to approve system designs and changes; program-level staff are setting task priorities without guidance from higher leadership who should have the broader strategic vision for NNDSS;
- Lack of clarity of responsibility for technical and policy decisions between programs which have technical staff capable of building and managing information systems themselves;
- Less than optimal coordination and communication among NNDSS partner agencies;
- Less than optimal coordination between surveillance program experts and technical systems experts within and between programs; and
- Less than optimal oversight of outside contractors working on NNDSS projects, with some contract work not always overseen by well-trained federal project managers.

Some specific examples of adverse outcomes have included:

- Poor management and changing priorities have resulted in performing an inordinate amount of special data handling to meet the “one-off” needs of disease reporting. Initial development of standard processes and controls could have avoided the current situation of complicated and error-prone data processing;

- Projects delayed, and implementations cancelled due to program staff taking initiative without having proper direction and approval from management;
- Mismanaged prioritizations;
- Multiple disparate systems with high degrees of overlap. Ideally, there should be one core service that can be invoked by various applications where needed;
- Lack of generalized vision
- Loss of knowledge and momentum due to poor contract transition, minimal cross training, and lack of knowledge transfer.

Although it is not consistently clear to program-level staff how priorities are determined by leadership or reconciled with the needs of stakeholders in the local, State, and CDC programs, the NNDSS system does function and meets many needs throughout the continuum.

Project Management

Many of the dysfunctional aspects of NNDSS data systems could be greatly improved by following better project management practices. Many local, State, and Federal programs use an Enterprise Performance Life Cycle model for project management, and current attempts to improve project oversight are evident, however lack of training, and professional development in project management result in poorly functioning systems. (U.S. Department of Health and Human Services n.d.)

The inadequate implementation of good project management practice appears to stem from several factors: conformance to the SDLC, insufficient support of project management by staff, and lack of project management follow-through. Lack of follow-through may result from confusion over how the requirements development process should integrate with overall project development. There have been instances where the technical staff had requirements that were not fully described in the initial requirements gathering process with the program staff, and instances in which misunderstandings of the requirements were not realized until after the process was complete. The end result is dissatisfaction with the features of the solution such that some program staff may never used it.

One management area of special concern is the oversight of NNDSS contract staff. Generally, NNDSS does not seem to have enough technical expertise to effectively oversee technical contractors. A particular problem can occur when contracts lapse and no transition planning has been conducted to minimize loss of knowledge and skills.

Education / Skill Set

Many of the subject interviewed illustrated that they had been assigned roles, or promoted to positions that are outside of their respective area of expertise. Promotion and job selection in government organizations is not entirely merit based, and may often be biased in favor of current employees or military personnel. Entitlement based upon time and service is common irrespective of the candidate's qualification for the job. Specifically, while many individuals may have comprehensive specialized skill sets, they lack the business and managerial skills necessary to effectively run an organization. A terminal degree is not necessarily a qualification to run an organization.

Processes

A common theme across local and State agencies was uncovered during the assessment of the NNDSS processes (Figure 6). The fundamental lifecycle of surveillance activities, and stepwise processes in the management of data from partners at the local and State through to Federal programs including data 1) *collection*, 2) *syntax*, 3) *vocabulary*, 4) *transport*, 5) *pre/post processing*, 6) *consumption*, 7) abstraction and storage, and 8) analysis. These components are addressed respectively by the implementation of standardized data collection mechanisms; messaging protocols including data normalization, standardization, transport, rules authoring and execution, consumer adapters; and data warehousing, analysis, visualization and reporting in Chapters 6 and 7.

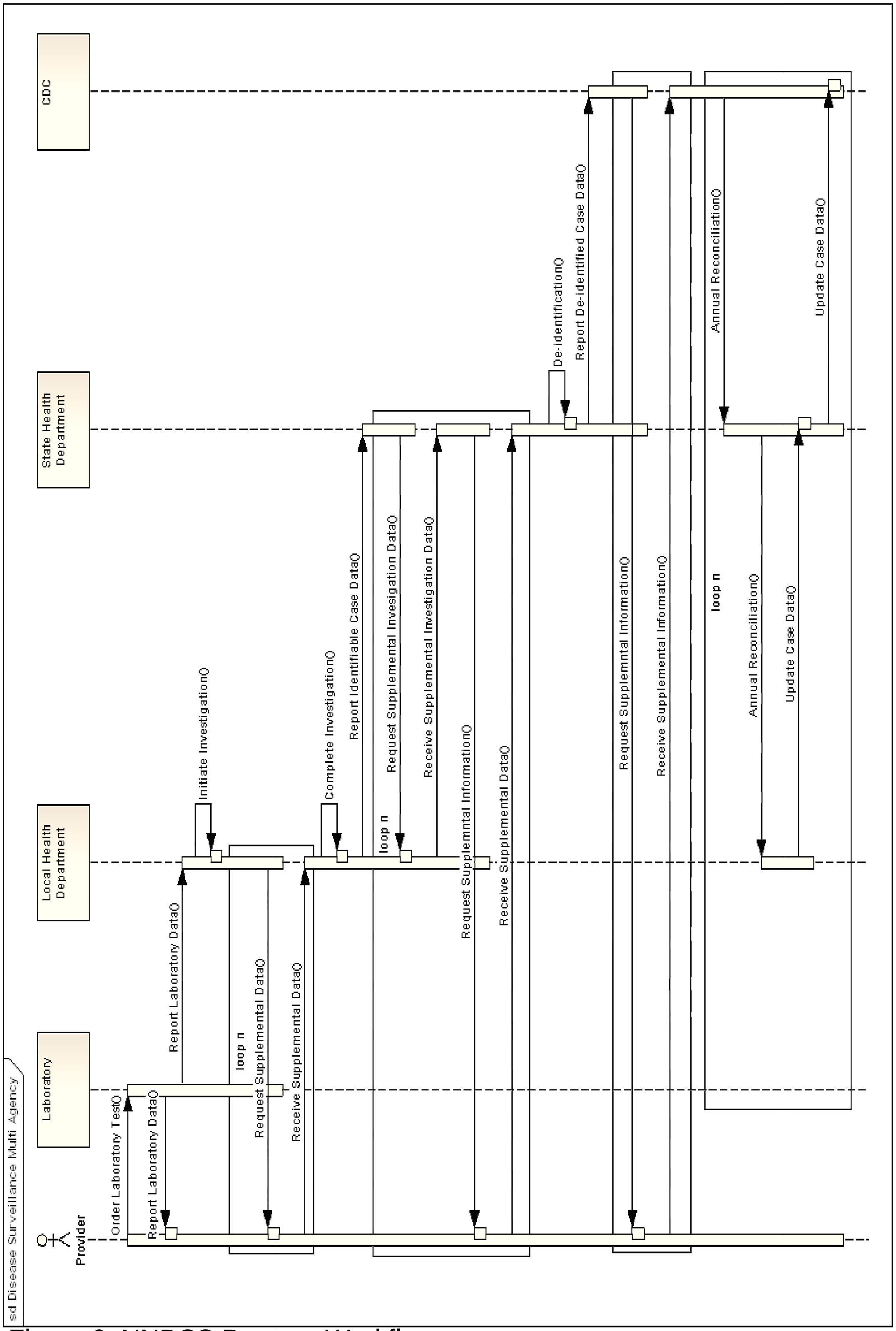


Figure 6. NNDSS Process Workflow

Data Management

Syntax

Another critical component in the successful exchange of public health data between partners is syntax. Data interchange protocols are often limited to the underlying structure and/or function of the sending system which dictate the syntax utilized. One such example is the CDC developed National Electronic Telecommunications System for Surveillance (NETSS). NETSS grew out of a reporting need, and thus the elements defined in the exchange of data were limited to those captured for reporting purposes by internal CDC programs and at the time were well defined and constrained.

The NETSS syntax however, was limited and over time surveillance syntax needs have evolved. The NETSS system was constrained, and incapable of expanding upon its initial design. This introduced a significant challenge as new data elements were needed for risk factor analysis. The majority of local and State agencies reported utilizing the NEDSS NETSS standard for reporting of notifiable conditions to CDC. (Battelle 1991)

The introduction of the Extensible Markup Language (XML) provides a dynamic container for a multitude of message types, remaining scalable to align with the ever changing landscape of data needs. During the initial development of XML containers however, limited standards existed and fewer were ultimately effective. For example, the NEDSS

Base System (NBS) utilizes a proprietary XML based upon the Health Level 7 (HL7) Reference Implementation Model (RIM), which was an academic pursuit and not practical, as evidenced by failed attempts to implement its bloated architecture. (Health Level Seven n.d.) While this syntax was initially implemented for transport of data from the current NBS system to the CDC, it was soon superseded by the development of a standardized public health messaging syntax utilizing HL7. Further complicating the use of syntax, the current NBS system has been expanded to utilize the HL7 messaging framework in a limited capacity, so that it may produce data in either the legacy XML or the HL7 2.3.1 format.

Literature review illustrates the growth of HL7 out of the need for standards and interoperability in an electronic environment across the medical domain, and thus has been defined by the need of clinical practice. (Greenes, et al. 2001) While much of the information captured in the messaging syntax spans the health care continuum, there is a distinct difference between the intent of the clinical message and those utilized by public health partners. To better describe public health messaging syntax utilizing HL7, public health is working closely with the standards organizations in the creation of public health specific syntax and standardized Message Mapping Guides (MMG) to define message structure and intended use. However, this process has introduced new time-consuming impediments into the enterprise lifecycle. (CDC 2011)

While federal agencies are pushing the local and States for the latest version of HL7 2.5x, and CDA, their respective data partner's remain largely in version 2.3.x. (Health Level Seven 2011) The lack incentive coupled with the exorbitant cost, with limited funding prevent local and state agencies from adopting newer versions.

Local agencies interviewed expressed their inability to process the variety of message syntaxes delivered from their data partners. CSTE passed a position statement in 2006 (CSTE 06-EC-02) that established HL7 2.5 as the national standard for the receipt of electronic reporting by January 1, 2008. (CSTE 2006) At the same time, CDC had also issued guidance that called for the use of HL7 2.5 in the electronic reporting of nationally notifiable diseases to the CDC from state health authorities, and encouraged widespread use of HL7 2.5 for the purpose of reporting to public health. While this guidance encouraged the use of HL7 2.5 throughout public health, it did not, and cannot require commercial laboratories or other entities reporting to public health to use this message syntax. This frustration was strongly expressed in a number of interviewees; as reporting continues to occur though a variety of standard and proprietary formats as of 2012.

Vocabulary

A comprehensive review of the literature provided combined with interviews of key local, State, and Federal partners suggests that the burden of standardization has remained with the public health authority, as no single standard has been agreed upon across disciplines. While the Council of State and Territorial Epidemiologists (CSTE) and CDC guidance has named HL7 2.5 as the recommended syntax to be used in the reporting of information to public health, no such guidance has been developed for the nomenclature used within the constructs. Recent federal activity generated by the ONC, in an attempt to move the nation's laboratories toward using both a standard syntax and nomenclature, do not provide public health with the necessary, comprehensive data set needed to conduct population surveillance, investigation, and intervention. (DHHS 2010)

A challenge in mandating a standard nomenclature is that constitutionally, public health is a state, and not federal responsibility. As a result, there is no one "public health authority" that can make enforceable decisions for all state and local health departments. The adoption of national standards for nomenclature and syntax would require each public health entity that has a legal authority for mandating disease reporting, generally states and territories, to individually adopt identical standards. Any one of those entities has the ability to "opt out" of any such agreements. In practice, the number of individuals working in public health who have the expertise to choose a nomenclature is limited, and as there are no financial incentives for choosing any given nomenclature, the selection of national standards could be reasonably achieved with a small team of individuals, making decisions for the entire public health community. The actual process of making the chosen standard enforceable within each state through statutory changes would be a much greater challenge.

Many local and State agencies conform to the Public Health Information Network (CDC 2011) standards for transport and nomenclature. PHIN was developed to support the harmonization of public health processes, nomenclatures, and constructs utilized in the NNDSS framework and other emerging national public health functions [such as emergency communication and alerting, and connectivity with clinical electronic health records that use the Office of the National Coordinator for Health Information Technology (ONC) Meaningful Use standards]. (DHHS 2010) The success of the NNDSS architecture appears to depend on the ability to practically implement standard PHIN messaging, vocabulary, and syntax to facilitate inter/intra-public health agency communications. Local and State agencies conveyed that while PHIN is largely a success in delivering standards, implementation is difficult resulting in failure to comply.

A considerable proportion of those interviewed stated that the vocabulary services provided by PHIN resulted in 1) considerable wasted effort due to the *overdevelopment* of vocabulary, and 2) incomplete means in which to interrogate the vocabulary within the respective agencies. The practice of public health utilizes only a small subset of the large vocabulary needs of health practice generally. For example, in an effort to align with the latest federal initiatives focusing on interoperability, CDC has developed and supported standardized vocabulary (e.g., LOINC, SNOMED) through its PHINVADS. PHINVADS contains 533 value sets, and over 1,850,000 concepts, of which only a small subset are needed for public health. The overhead for simply maintaining such a comprehensive terminology is excessive and impractical.

Local and State agencies agree that PHINVADS was not designed to be an end-to-end solution and lacks the ability to constrain terminologies or apply ontological definitions to proprietary terminologies. Thus, other services must be deployed for these functions if desired, leaving PHINVADS largely unusable at the local and State due to the inability to integrate the proprietary and standardized vocabulary utilized throughout the continuum. (CDC 2011)

Transport

Standard practices for data transport have been largely adopted across local, State, and Federal agencies. The frustration conveyed during several interviews highlighted the lack of uniform guidelines, and their existence in the governing of data transport. Currently, many public health providers transmit and accept messages via telephone, fax, email, and electronic methods. In an attempt to standardize public health transport, the CDC has developed and advocated for a proprietary mechanism to support this process. The Public Health Information Network Messaging System (PHINMS) is the primary method of transport of NNDSS compliant data to the CDC. (CDC 2011)

PHINMS was introduced as a component of the PHIN framework in 2001 for the standardized, encapsulated transport of messages to the CDC. Technical personnel interviewed responded negatively to the proprietary nature of PHINMS, coupling two standard protocols which introduced an unnecessary level of complexity for data partners, some of whom may have implemented protocols using best standards and practices, such as Secure Socket Layer (SSL) over File Transfer Protocol (FTP) or Hyper Text Transfer Protocol (HTTP). Personnel tasked with implementing NBS however were supportive of PHINMS, as it is provided through a seamless integration within NBS.

Finally, since its inception in 2001, the infrastructure of PHINMS has remained largely intact, utilizing centralized identity management at CDC and often involves mounting EB-XML messaging servers by senders. This is the root of large concern within the community, as it has limited shelf life due to an inherent inability to scale to accommodate electronic reporting by large numbers of healthcare providers to public health. Thus, active search for a replacement is underway that can incorporate appropriate levels of authorization and authentication, encryption, and simplicity of transmission and digestion. The scalability of future solutions is necessary precursor for the creation of a sustainable architecture.

Transformation

Local and State agencies have developed, purchased, or utilized CDC systems internally for daily operations. (Jajosky and Ward 2011) Unfortunately, these systems do not utilize a uniform standard and thus the delivery of data between disparate partners forces transformation of data prior to consumption into one of the many supporting public health systems. This introduces significant complexity and potential constraints as the variety of data sources, and the inconsistent ability to capture and expose data differs from system to system. NNDSS data originates at the local level, where the brunt of transformation occurs. Jurisdictions consist of the local partner base including hospital systems, laboratories, clinician, etc. Transformation of data from each partner institution is largely absent from the workflow, resulting in inconsistent delivery and consumption of data. The potential for error introduced by the lack of transform flows upstream, compounding the problem for state and federal partners.

State agencies are unable to find utility of this proprietary data, and are limited in their ability to conduct meaningful analysis. Furthermore, data delivered from the State to CDC bypassing PHINMS must conform to the legacy NETSS format, or another program specific proprietary format. These transforms lose much valuable data. For example, for those states reporting in NBS or HL7, CDC internal processes truncate risk factor data which is not present in the legacy NETSS format. The end result is that the requesting programs lose the ability to effectively analyze the data.

Pre Processing

Interviewees were questioned about the level of processing, both pre and post applied throughout the data exchange lifecycle. Preprocessing allows for transformations, filters, and knowledge to be applied prior to consumption into the respective endpoint. Typically preprocessing routines should exists for each respective data stream and are common when dealing with a diverse set of data. Preprocessing does not typically exist at the local and State public health agencies, and the data is simply “passed-through” to its consumer.

Interviews with the CDC contract development staff who had developed preprocessing routines for the three standard NNDSS message types, NETSS, XML, and HL7, were conducted. Each developer had unique responsibility in the development of the underlying logic. The NETSS preprocessing routines have been in production for nearly a decade, and occurs in two step-wise stages, 1) the data is delivered from the state agency, and rudimentary validation is conducted via a manual SAS program, and 2) once validated, the message is output and available for consumption and dissemination. The XML and HL7 preprocessing has been developed over the last six years, and the processing has evolved with each version of the CDS. The CDS employs a proprietary workflow via Informatica for execution of underlying SQL Server packages which move the data through each process step from transformation through to consumption of the message into the CDS.

Within the repository, each message type is stored in its native syntax and nomenclature, and underlying metadata is applied to define the message type, elements expected, and the methods used to extract, transform and load (ETL) the data into the respective data marts for downstream use by program personnel. While fundamentally this is an ideal architecture in which to achieve portability, there appears to be fundamental issues which have carried over from previous versions into the latest architecture, including:

- Processes that perform much of the underlying work reside in a SQL Server repository but are executed by Informatica, a proprietary system for the processing of data. Informatica was initially introduced by the contractor because it was a familiar package with which to control data and its workflow through stepwise procedures. But its proprietary nature introduces unnecessary complexity into the environment.

- The metadata tier utilized by these processes is hard coded in a pseudo Entity Attribute Value (EAV) model, which limits the ability to scale beyond what is currently “known”. (Nadkarni 1998) EAV is utilized to reduce sparsity; the pseudo EAV format utilized by the CDS introduces sparsity, thus increasing the storage space needed to house the data. Furthermore, the structure limits the ability to introduce new elements beyond the current values, which may result in further needed development and another major revision.
- The “widgets” [1] in the CDS appear not to be portable or scalable beyond the CDS. The underlying XML structure representing the independent data streams to which these programs refer, is data type-specific and not unified, resulting in structural issues, some of which appear to be carried over from the initial design of the CDS through to version 3.x. While many of these issues are not critical to deploying version 3.x in a production environment, they may inhibit future growth, because the knowledge necessary to enhance the CDS and supporting systems resides with the contractor.
- To date, no detailed documentation has been developed to articulate each process, the procedures construction, and the procedural relationships to the metadata and workflow through the ETL to CDS. Documentation is critical to building core competency

[1] Widgets are data type-specific programs utilized in the manipulation of data.

within NNDSS, and knowledge has not always been transferred to the necessary staff to support these systems.

Consumption

Local and State agencies who utilize electronic mechanisms to consume surveillance related data do so via an integration engine, direct consumption, or PHINMS. Much of the public health data stream currently being consumed involves ELR transmissions. However, the need has been identified by the community for bi-directional messaging and supplemental data processing Integration Engines such as Mirth or Rhapsody are flexible, scalable and remain system agnostic. (Mirth 2010) (Orion Health 2011) PHINMS as a mechanism for direct consumption is however limited to systems which interact within the scope of it limited protocols.

It is generally known throughout the public health community that there is no direct mechanism or standard protocol to transmit and consume data from a local health agency to the respective State agency. An attempt to facilitate this interaction has been in progress since 2007 with the introduction of the Public Health Case Report (PHCR). (HiTSP n.d.) The PHCR is an XML container for public health case delivery from one institution to another for case reporting, and out of jurisdiction transmissions. The standard was introduced due to limitations of NBS, without concern of third-party systems. As a result PHCR has not been successful to date.

There is however a standard mechanism, as described earlier, to deliver data from the State to the CDC. These standard mechanisms may be classified into NNDSS and Non-NNDSS messages. NNDSS accepts three standard message types, NETSS, XML, and HL7. Transformed NBS and HL7 messages are consumed into the CDS, while simultaneously the Data Operations Team (DOT) processes NETSS data which are consumed into the CDS and SAS data files. (CDC 2011)

Data in several stand-alone program systems, bypass the NNDSS processing and the CDS, and continue directly to the CDC disease-specific program. These data are consumed and stored utilizing a variety of methods distinct to each program. The method of communication typically dictates the storage mechanism: Excel spreadsheets are stored in a file system; SAS datasets may be stored in a data repository. The data streams that bypass the CDS and go directly to disease-specific programs raise a number of questions: 1) are there compelling reasons to change these “work-around” systems so that they are incorporated into the mainstream NNDSS data flow; 2) would data quality and system flexibility be jeopardized by integrating them; 3) how would integration impact the state and local health departments; and 4) if desired, how would integration be funded and 5) how would the transition period be successfully managed?

Post Processing

Post processing typically occurs once the data has been consumed and must undergo further action, and resides with, or applies directly to the consumer. Given the plethora of unique systems and reporting requirements required at the local, and State levels it is difficult to generalize the mechanisms needed to facilitate post processing.

The internal CDC post processing routines are maintained by the contract developer who outlined its operation. Post processing occurs on two of the three data streams, the comprehensive XML and HL7 data once consumed, are extracted from the CDS and overly simplified into the NETSS format and proprietary nomenclature. This oversimplification loses much of the data that the OID program staff requires to perform daily operations.

These pre and post processing routines have been the source of much program frustration, as the processing black box is not well documented or understood, and knowledge of has been lost over the course of administrative reorganizations, and contract turnover.

Distribution

Data distribution is agency and data type dependent. Inbound, LHDs may receive data from a variety of partners and formats, via a variety of different mechanisms. Data partners include: educational facilities, EMS, police, fire, doctors, hospitals, laboratories, mental hospitals, home health, and more. While many of these data streams do not directly affect routine surveillance activities, many of them provide supplemental data during investigations of outbreaks, treatment, and related service based activities to compile the overall picture of disease. Outbound, LHDs provide data to the community at large based upon the services provided, and community need. Reports are created to convey disease etiology to the clinical community, while aggregate data and research is targeted to educate the public. These reports are directed towards the audiences they serve, and in generally acceptable formats for wide distribution. Surveillance data is one small portion of data distributed from a LHD, and such data is typically sent directly to the State agency.

Typically, LHD Disease Investigation (DIIS) staff and program epidemiologists interviewed did not have the expertise in data structures to compile these disparate resources into a centralized location in order to conduct meaningful analysis.

Inbound, State agencies may receive data as a LHD, and conduct investigations requiring communication from the same providers. Typically, SHD receive case and summarized data from the local jurisdictions to paint the overall picture of disease in the State, and for policy and program development. This data is aggregated internally and provides the underlying structure for output generate by the SHD. Outbound data is delivered in the form of either reports to educate policy makers, and program officials on direction and status, or directly to Federal agencies such as the CDC and NNDSS for summarized reporting. Limited State resources, when interviewed, appeared to lack the technical expertise to compile, consume, and distribute data beyond the tools provided by the aggregate Surveillance and reporting system.

NNDSS data are distributed to OID programs via a number of outputs. Data that are aggregated in the CDS are delivered to programs through abstractions and data marts, which expose only the program specific data needed. Program staff responsible for extraction and interrogation of the data from the data mart conveyed that limited training and the delivery of data did not meet their need. While this is the most scalable mechanism of delivery, it is not fully developed.

Many OID program epidemiologists conveyed that they were not responsible for the necessary pre and post processing needed to cleanse and format the data, nor did they have the expertise to create complex queries to extract data from the data mart. Some have resorted to using SAS datasets generated from the legacy NETSS dataset, forgoing the CDS altogether. SAS is a familiar application to epidemiologists, and SAS databases are an acceptable output for CDC programs. NETSS data are also utilized in generating the MMWR tables, supporting NNDSS LINK and CDC Wonder. (CDC 2009)

Data Collection

The process of passive surveillance begins with reports of disease from the astute clinician or laboratory reporting to the local health department (LHD), followed by investigation, intervention and mitigation activities when applicable. The results of the investigation, once confirmed are communicated to the state. In addition to sometimes assisting the LHD in the investigation, the state is responsible for aggregate, jurisdiction-wide summation of data, and notification of cases to the CDC. These activities are conducted utilizing non-standard methods and systems, many of which have been born out of CDC program offices.

Upon initial review of the systems utilized for data collection, further themes were observed: 1) systems were developed around individual practice with disregard to broader workflow; 2) the systems developed in silos, often in a reactionary mode; 3) little consideration was given to enterprise-wide integration of methods, processes, and services, and 4) once a system was placed into active duty, it tends to live on in perpetuity. Each of these themes contributes in part to the dysfunction of the NNDSS.

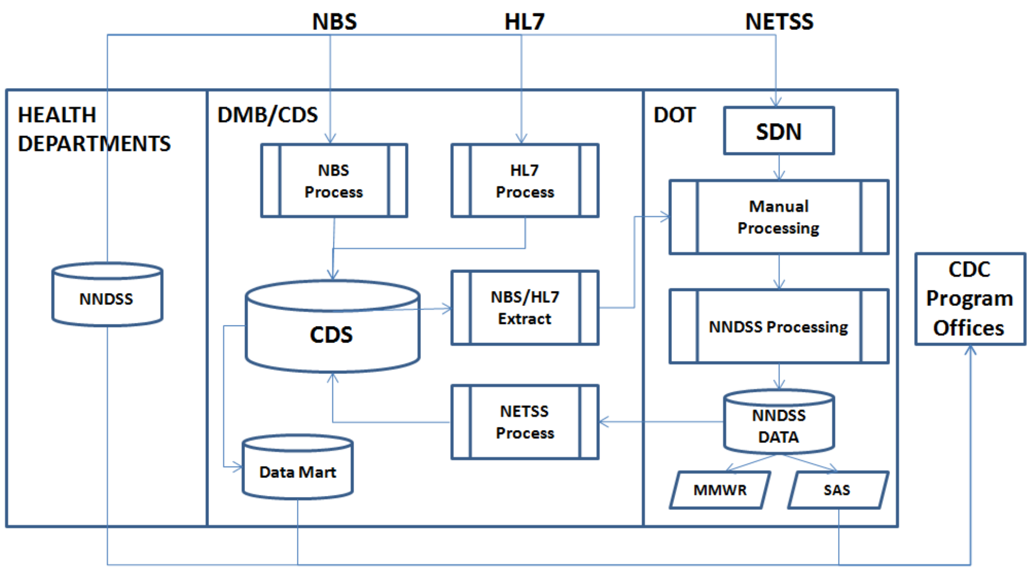


Figure 7. NNDSS “As Is” workflow; CDC data type processing.

Initial assessment of workflow processes formed a better understanding by all involved parties who were largely unsure of the process, and its components in its entirety (Figure 7). The process of disease surveillance and investigation begins with the local public health data partners relaying information about a potential emerging threat of disease in the community to the respective LHD. The data from each respective need undergo processes to prepare the data to conduct an investigation. Data collection is performed during the investigation within a NEDSS compliant system for processing and delivery to the respective State agency. The State agency then de-identifies the data, and sends it on to the CDC. For historical reasons, case report data are collected, stored, and sent to CDC by local and State health departments in one of three formats: NETSS, HL7, and an NBS-derived XML format.

Once received by CDC, each type of data feed undergoes a different data processing as illustrated above. The processing ends with data maintained in a uniform, common data store (CDS), with several methods for CDC programs to access their data, including program-specific data marts and SAS files. Many of the internal data processes wrestle with multiple standards and with the harmonization of data streams, with a result that the infectious disease program staff often have difficulty verifying the validity of data processed.

The numerous NNDSS data streams and data transformations create problems as far downstream as the local health departments, with an inability to trace the root cause. Transformation of NBS and HL7 messages into the NETSS format results in further corruption of data. As a result, programs may utilize alternative mechanism for gathering data, or may not have access to information on reported cases, and must directly contact partner states to obtain it.

Another problem is that the number of cases of a disease may differ depending on which originating data stream, and resulting data output is used. For example, the number of cases reported in the weekly MMWR not infrequently fails to match the number of cases in the SAS reports from state agencies generated for the same disease. When data problems occur, it is often difficult to track down the cause, due to the number of data partners, respective data streams, and processing steps involved.

A major functional shortcoming of NNDSS is its lack of flexibility in adapting to changes in data needs over time. Similarly, NNDSS is unable to provide information that is critical for multi-state outbreak detection. These system shortcomings limit local, State, and CDC's ability to respond to national public health threats and jeopardize health.

Regarding additional desired functionality, NNDSS lacks fundamental surveillance functionality such as an outbreak management system (OMS). However, whether the NNDSS should include OMS functionality, or simply define guidelines within NEDSS is a debatable question and may deserve further consideration. Last year CDC decommissioned an OMS developed by a separate office at CDC due to the development of the system not being clearly defined as either an OMS of an Outbreak Investigation System (OIS); much like NBS. These internally developed systems have a proven track record of not meeting their intent, and this further illustrate how important it is to critically assess and prioritize functional needs of systems' users since resources limit what can be developed and maintained.

Many of the above problems noted demonstrate the inherit complexity of NNDSS case reporting, with errors occurring at the local and state health department level, as well as at the CDC. The NNDSS is complex and based on interdependencies of all NNDSS users at the local, state and federal levels. With the complexities involved, it is important that all desired data and both functional (program-related) and non-functional (technical) requirements be clearly stated, critically assessed, and deemed sufficiently important to justify building them into NNDSS.

An important ramification of the problems across NNDSS is the general loss of confidence among program staff in the ability of CDC development and guidelines. This lack of confidence has prompted the development of more work-a-rounds, stand-alone systems and ultimately more confusion. The NNDSS data processing system is broken and time and patience are running out.

The National Electronic Disease Surveillance System (NEDSS) architecture and Public Health Information Network (PHIN) were introduced in 1998 to further enhance interoperability in the reporting of data to the CDC. NEDSS is an architecture utilized within the NNDSS, not a solution, allowing the states to create, purchase, or adopt systems which meet the guidelines for the reporting of data to CDC, while remaining flexible to allow the states to make their own choice of how to implement said systems. (CDC 2009)

The CDC supported states by offering grant funding for proprietary development, purchase of supporting systems, or installing a newly developed CDC NEDSS Base System (NBS) that became available in

2001. Both the NEDSS framework and the NBS system, as with the NETSS system, focused on the *reporting* of surveillance information, and not the functionality necessary to support the collection, investigation, case management, intervention and mitigation activities which are the foundation of public health practice. As a result, many states chose to continue the use of homegrown systems, or apply for grant funding to accommodate critical internal procedures and build them into home grown or purchased solutions, thereby decreasing the number of states opting to use the NBS solution.

The NNDSS community has confirmed the dormant NBS adoption rate, and attributed it to the inherent issues of a *reporting* based system not meeting the requirements of *investigation* activities. Internally, CDC programs have been unable to realize the NBS investment due to limitations of both NBS and its supporting systems, leaving the programs unable to extract a *complete* dataset for use in analysis.

NEDSS Gap Analysis

The following gap analysis of the NEDSS Base System documented in Table 4, was conducted by the Southern Nevada Health District in January 2010, and measured against an aggregate list of requirements defined by the SNHD and the DEISS document.

Requirement Prioritization

Requirements herein are prioritized as to their level of criticality within the business unit utilizing an alpha scale. The following table illustrates the levels of priority:

Table 4. NNDSS Gap Analysis

Priority	Description	Assessment method
E	Essential	Essential requirements are vital to the mission of the business unit, necessary for day-to-day operation, and impact both internal and external to the organization.
O	Operational	Operational requirements impact daily operations, and may/may not impact the mission of the organization.
I	Improvement	Improvement requirements have been identified by the stakeholders as improvements in existing processes to meet new goals and objectives; these are value added and promote cost savings in the unit / across the organization.
D	Desired	Desired requirements are often referred to as "nice-to-have". These requirements may reflect usability, design, and functions that do not impact day-to-day operations, but make the system pleasing to the end user.

Gap Identification

Gaps will be identified and coded as to their degree of "Fit" to the user requirement. The following table illustrates the levels of gaps which will be identified herein:

Priority	Description	Assessment method
M	Met	The solution meets the intent
A	Acceptable	The solution meets >80% of the requirement, and will work with minor

		modification to business process, and no cost impact.
P	Partial	The solution meets <80% of the requirement, and may work with modification to the business process and/or the solution, cost associated.
G	Gap	The solution does not meet the intent. Enhancement/Customization needed.

Case Initiation

Receipt

Requirement Number	Priority	System	Gap	Description
Receipt-1	E			Messaging – The system must have the ability to receive laboratory messages in a standard format; with the ability to adjust to changes in those formats as needed. HL7 messages must be compliant to versions 2.5+.
		NEDSS	G	The current system is constrained to HL7 2.3.1; the CDC has confirmed plans to create an interface making the message format agnostic; however, no proposed timeframe was mentioned.
Receipt-2	E			Data entry – The system must facilitate the manual entry of data via a web-based interface; as this solution may be used on-site, in the field, and satellite locations throughout the state.
		NEDSS	M	
Receipt-3	E			Clinical Interface – The system must be flexible in an attempt to directly interface with third-party clinical systems. While these systems may/may not follow standard messaging protocols, tight integration with middleware agents for transformation may be

				utilized to ensure standard messages are provided.
		NEDSS	G	NBS supports limited HL7 messaging, and offers no APIs.
Receipt-4	I			Case Transfer – The system must allow for a protocol definition for case acceptance/transfer from other public health jurisdictions. Escalation and notification rules to be imbedded in the protocol.
		NEDSS	G	The current NBS solution does not support decentralized implementation.

Pre-Processing

Requirement Number	Priority	System	Gap	Description
PreProc-1	E			De-Duplication – The system must implement a high degree of de-duplication of messages to ensure the integrity of data within the system.
		NEDSS	U	
PreProc-2	E			Prior Case Verification – The system must facilitate both a manual and automated method to validate a previously reported case. The audit system will track prior case verifications.
		NEDSS	M	
PreProc-3	E			Case Creation – When identified as a "new" case, the system must provide a mechanism to manually or automatically create the case record. The audit system will capture the method in which each case is created.
		NEDSS	M	
PreProc-4	E			Case Routing – The system will promote case routing to respective program areas.
		NEDSS	M	

PreProc-5	O			Notification – The system must provide a mechanism to manually and automatically deliver user configurable notifications based upon program area, disease, and workflow activity.
		NEDSS	G	No calendar of events was listed in the documentation, or presented in the webinar. [1]
PreProc-6	E			The ability to add diseases
		NEDSS	G	Unable to add disease definitions at the local level.

Investigation

Administration

Requirement Number	Priority	System	Gap	Description
Admin-1	E			Case Assignment – Upon the receipt of a case, the system must provide the ability to assign it to an investigator, capturing the date of assignment which is in turn added to their queue. (including appropriately handling standby duty)
		NEDSS	M	
Admin-2	O			Signoff Cycle – The system must provide the ability to define the signoff cycle based upon disease or program area.
		NEDSS	P	The system currently allows for user permission "Mark as Reviewed", however it is unclear as to the ability to further define the signoff. In the NEDSS demonstration server, it allows a case which has been submitted to the state or CDC to be edited; only providing a user warning. While this may be a configuration issue for demonstration

				purposes, it raised a red flag for production usage.
Admin-3	O			Case Accept/Reject - The ability to accept/reject case based upon signoff definition
		NEDSS	P	The system currently does not differentiate the between accept/reject, and simply relies on the “Mark as reviewed” to escalate the process.
Admin-4	I			Automated review of case for completeness
		NEDSS	G	The system does not support integration with Business Intelligence.
Admin-5	O			Management of investigators case load
		NEDSS	G	The system does not support management of investigators case load.[1]
Admin-6	I			Ability to define the automatic notification of case assignment, submission and review. (including standby duty)
		NEDSS	M	
Admin-7	E			The ability to enter data in real-time
		NEDSS	G	The NEDSS based system is not designed for investigation, but for reporting. As a result, many pieces of information that are crucial to the investigation, but not the final report of the disease cannot be recorded.

Demographics

Requirement Number	Priority	System	Gap	Description
Demo-1	E			Ability to track multiple instances of like locators (geographic, telephonic, or electronic locator).
		NEDSS	M	
Demo-2	E			Ability to track multiple instances of like identifiers assigned by external systems (driver's license, patient id, health card id, etc.)
		NEDSS	M	
Demo-3	E			The system must facilitate the recording of standard demographic information (race, ethnicity, etc.) as well as be extensible in nature to allow for multiple of these instances to be captured within the same area.
		NEDSS	M	
Demo-4	E			The Ability to define legal responsibility (parent, representative, legal guardian), and attach the appropriate documentation to the functional area.
		NEDSS	G	While NEDSS can capture multiple address, telephone, etc, it does not have the ability to designate parent, legal guardian, etc.
Demo-5	E			Real-time assessment of criteria to determine like-kind demographic linkages (boyfriend/girlfriend residing at the same address, home phone, etc.)
		NEDSS	G	

Laboratory

Requirement Number	Priority	System	Gap	Description
Lab-1	E			The system must provide the capability to track multiple laboratory reports for an individual case; designating the source of the report whether it be manual or ELR.
		NEDSS	M	
Lab-2	I			The system must provide the necessary interface to automate the generation of test requests, providing a mechanism to manage the message type and destination.
		NEDSS	G	

Clinical

Requirement Number	Priority	System	Gap	Description
Clinical-1	E			The system must provide the functionality to track multiple results for a sign or symptom, and track longitudinal data elements.
		NEDSS	G	The relevant symptoms are those only defined by CDC in their case reporting protocol, and not those necessary to complete a case investigation. There is no defined mechanism to capture longitudinal data.

Treatment / Prophylaxis

Requirement Number	Priority	System	Gap	Description
Treatment-1	E			Ability to record mood code; a mood code is analogous to a verb, indicating whether an act (event) has happened, is requesting something to happen, or goal. Act may be an observation, an encounter, or administration of treatment.
		NEDSS	G	The system only captures partial treatment information (critical missing items include: day prescribed, dosage, prescribing physician, etc.)

Epidemiological

Exposure

Requirement Number	Priority	System	Gap	Description
Exposure-1	E			As risk factors and the associated epidemiological questions are predefined (disease specific questionnaires), a mechanism must be in place to automate the insertion of these questions into the case record based upon disease.
		NEDSS	M	All questions are place in-line, in a single area.
Exposure-2	E			As the need arises, the system must facilitate the customization of the risk factor questionnaires, on the fly, for a disease; given the appropriate permissions.
		NEDSS	G	Although a forms builder was discussed, it is currently not fully implemented.

Source Exposure

Requirement Number	Priority	System	Gap	Description
SourceExp-1	I			The ability to track source of exposure
		NEDSS	G	Does not exist.
SourceExp-2	I			The ability to track participants, and link them internally within the system.
		NEDSS	G	
SourceExp-3	I			The ability to compare and notify of exposures / risk factors (e.g. location – restaurant, tattoo shop)
		NEDSS	G	

Contacts

Requirement Number	Priority	System	Gap	Description
Contacts-1	E			Ability to link to other uniquely defined persons in the database.
		NEDSS	M	
Contacts-2	I			Ability to generate a new case from a contact record.
		NEDSS	G	
Contacts-3	E			Recording of type, date, etc.
		NEDSS	G	Limited data provided no area to capture contact type.
Contacts-4	D			Ability to visually represent contact linkage
		NEDSS	G	

Encounters

Requirement Number	Priority	System	Gap	Description
Encounters-1	E			Ability to record multiple encounters for each case including the mood code.
		NEDSS	G	Does not exist.
Encounters-2	I			Ability to tie encounters to internal calendar \ Outlook, Project, SharePoint
		NEDSS	G	No encounters.
Encounters-3	E			Ability to record encounter types (phone, isolation, home visits, etc.)
		NEDSS	G	No encounters.

Actions

Requirement Number	Priority	System	Gap	Description
Actions-1	E			Ability to record case related workflow activities (phone call, send a letter, notification, etc…)
		NEDSS	G	Does not exist.

Travel / Events

Requirement Number	Priority	System	Gap	Description
Travel-1	I			Ability to record multiple travel/event instances for each case.
		NEDSS	G	Does not exist.
Travel-2	I			Ability to link travel event to contacts
		NEDSS	G	Does not exist.

Case Summary

Requirement Number	Priority	System	Gap	Description
Summary-1	E			Ability to track the disease and condition both as reported and determined after investigation.
		NEDSS	G	Unable to change the disease once the investigation has started.
Summary-2	E			Ability to track the status of the investigation; to specific workflow activities.
		NEDSS	G	Able to track the status open/closed.
Summary-3	E			Ability to track case classification; provide DSS / logic for assessment of case definition
		NEDSS	M	
Summary-4	E			Ability to capture unique identifiers assigned during the reporting process by third-party public health organizations.
		NEDSS	G	Does not exist.
Summary-5	E			Ability to track CDC reporting related data elements (disease determination, case classification, where acquired, link to outbreak, reporting related dates, event date, etc.)
		NEDSS	M	
Summary-6	E			Ability to link a case to a public health incident.
		NEDSS	M	

Data Exchange

Electronic Lab Reporting

Requirement Number	Priority	System	Gap	Description
ELR-1	E			Consume lab report data – (HL7, flat file)
		NEDSS	G	CSC demonstrated the capability to interface with national labs utilizing HL7 2.3.1 messaging; however the system does not support APIs to integrate further providers.
ELR-2	I			Automate Consumption / Routing of HL7 Message
		NEDSS	G	
ELR-3	E			The ability to utilize Standardized Terminology – (LOINC, SNOMED)
		NEDSS	M	
ELR-4	E			Track reporting provider.
		NEDSS	M	

Health Agency Reporting

Requirement Number	Priority	System	Gap	Description
HAReport-1	E			The ability to synchronize data with the SHD NEDSS Base System
		NEDSS	G	The NEDSS based system has no standard mechanism for data exchange.
HAReport-2	E			The ability to accept HL7 compliant messages or Bulk data transfer.
		NEDSS	A	While the system itself is not setup to perform this action, the ability to bulk load data to synchronize the repository is feasible.
HAReport-3	E			The ability to verify receipt (asynchronous) of transactions.
		NEDSS	A	Utilizing the Orion Rhapsody middleware, the systems are able to perform as requested.
HAReport-4	E			The ability to export / integrate data sources for analysis.
		NEDSS	G	No direct access to the NEDSS based system or underlying repository.

Geocoding

Requirement Number	Priority	System	Gap	Description
Geo-1	D			The ability to standardize and validate an address
		NEDSS	G	
Geo-2	D			The ability to determine latitude / longitude For a given location
		NEDSS	M	

Analysis, Visualization, and Reporting

Requirement Number	Priority	System	Gap	Description
AVR-1	E			Ability to query live / warehoused data
		NEDSS	G	The system requires you use the warehouse only whilst running queries.
AVR-2	E			Available canned reports (workflow, surveillance)
		NEDSS	M	
AVR-3	E			Ability to create Ad-Hoc reports
		NEDSS	A	The system utilizes and embedded SAS engine, which provides limited reporting.
AVR-4	E			Ability to create / modify reports
		NEDSS	M	
AVR-5	E			Ability to export data in standardized formats
		NEDSS	M	
AVR-6	I			Integration of user customizable dashboard; permission based
		NEDSS	A	Dashboard is not user customizable
AVR-7	D			Social networking diagrams / features
		NEDSS	G	
AVR-8	D			Integration of third-party GIS
		NEDSS	M	Utilizes GeoStan, no ability to integrate other third-party solutions.
AVR-9	I			Integration of third-party graphs and charting objects
		NEDSS	G	Utilizes the SAS packages, not extensible.
AVR-10	E			The ability to provide a standardized report to the Health Authorities per regulations.
		NEDSS	M	

Public Health Incident Investigation and Management

Requirement Number	Priority	System	Gap	Description
IIM-1	I			The ability to investigate and manage public health incidents
		NEDSS	G	
IIM-2	D			Ability to define an incidents criterion.
		NEDSS	G	

Decision Support

Requirement Number	Priority	System	Gap	Description
DSS-1	I			The ability to integrate decision support – Integration of case definition, treatment protocols.
		NEDSS	G	
DSS-2	D			Integrated field-level rule configuration (ULN/LLN, etc.)
		NEDSS	G	

Ad-Hoc Query

Requirement Number	Priority	System	Gap	Description
Query-1	E			Powerful and flexible search capability; implementation of “sounds-like” algorithm.
		NEDSS	P	While the data is available, the system does not provide a configurable search option out of the box
Query-2	E			Ad-Hoc query capability
		NEDSS	G	None exists.

System Design

Architecture

Requirement Number	Priority	System	Gap	Description
Arch-1	E			Web-based
		NEDSS	M	The system relies heavily on Javscript and Java; the underlying architecture appears suboptimal based upon standards and best practices available currently. Some functions, such as the tabbed links on the investigation page, are not functional with Firefox, but are functional with IE.
Arch-2	E			System architecture Design focused on case investigation
		NEDSS	G	The NEDSS Base System is an **example** of a NEDSS compatible system that can be used by a state health department for the **surveillance** and **analysis** of **notifiable diseases**. The NEDSS Base System provides a platform upon which modules can be built to meet state and program area data needs as well as providing a secure, accurate and efficient way for **collecting** and **processing data**.[1]
Arch-3	E			Patient-centric
		NEDSS	M	
Arch-4	E			System Independent (OS / RDBMS)
		NEDSS	M	
Arch-5	E			The ability to extend the systems capabilities
		NEDSS	G	The system is a CDC driven product developed and curated by CSC. Third-party organizations are unable to

				extend the application directly and must request modifications through the NUG; with **no guarantee the modification will be implemented**.
Arch-6	E			The ability to operate in a decentralized environment
		NEDSS	G	This functionality has not been demonstrated.
Arch-7	E			NEDSS / PHIN Compliant
		NEDSS	M	

Functional

Requirement Number	Priority	System	Gap	Description
Func-1	I			Standardized mechanisms for field-level interaction(Popup calendars for date fields)
		NEDSS	G	Many non-standard UI components are utilized.
Func-2	E			Ability to attach notes on indicated functional areas
		NEDSS	G	The system is reporting centric and does not facilitate the capture of investigative summary information in note form.
Func-3	I			Ability to attach electronic files to functional areas
		NEDSS	G	
Func-4	E			Intuitive navigation
		NEDSS	A	The system navigation is consistent, however poorly implemented.
Func-5	E			Consistent and Well-designed Interface
		NEDSS	G	While the interface itself is consistent, the UI is cumbersome and does not follow any of the HCI guidelines for UI development.
Func-6	D			User-friendly input validation / error handling

		NEDSS	G	User validation was gracefully handled, however error handling posed an issue as general errors, and unexpected errors were presented to the user with little or no explanation.
Func-7	I			Ability to generate / send form letters
		NEDSS	G	
Func-8	I			Increase Efficiency via HCI
		NEDSS	G	The system is not effective in the environment, and the situation becomes exacerbated when the volume increases as demonstrated by H1N1 outbreak.
Func-9	D			Ability to integrate a disease specific document library
		NEDSS	G	

Security

Requirement Number	Priority	System	Gap	Description
Security-1	D			The ability to resolve against Active Directory – Single Sign on, or RDBMS security
		NEDSS	M	
Security-2	E			Role-based security
		NEDSS	M	Uses non-standard terminology such as “permission sets” rather than “roles”
Security-3	E			Program area security
		NEDSS	M	
Security-4	E			RDBMS Encryption
		NEDSS	M	
Security-5	E			HIPAA Compliant
		NEDSS	M	
Security-6	E			The ability to audit ALL indicated aspects of the system
		NEDSS	G	
Security-7	E			Configurable Login and Timeout restriction
		NEDSS	G	
Security-8	E			SSL Encryption capabilities
		NEDSS	M	
Security-9	E			Ability to resolve necessary network security enforcement at state and local levels
		NEDSS	G	

System Administration

Requirement Number	Priority	System	Gap	Description
SysAdmin-1	E			The ability to manage questionnaires
		NEDSS	G	The CSC development team stated this would be available in future releases.
SysAdmin-2	E			The ability to manage reports / form letters
		NEDSS	G	
SysAdmin-3	I			The ability to manage workflow
		NEDSS	P	
SysAdmin-4	I			The ability to manage notifications
		NEDSS	M	
SysAdmin-5	E			The ability to manage lookup tables
		NEDSS	P	The ability to manage lookup tables is by direct input into the RDBMS only.
SysAdmin-6	E			The ability to manage field level constraints
		NEDSS	G	While the system does allow for custom field definition, the standard field definitions are not exposed for configuration.
SysAdmin-7	O			The ability to manage business logic based triggers
		NEDSS	G	Management of the system may become unwieldy, as implementation of business logic in the centralized system may differ between jurisdictions.
SysAdmin-8	E			Communication
		NEDSS	G	Notification of scheduled system maintenance, issue resolution.
SysAdmin-9	E			Ownership
		NEDSS	G	Single point of contact for issue resolution may result in poor response time.

SysAdmin-10	E			Quality Assurance
		NEDSS	G	No QA is done by State, and therefore no problems within the NBS system are discovered by the SHD. Question as to how the SHD is utilizing NEDSS internally, and to what degree.

System Performance

Requirement Number	Priority	System	Gap	Description
Perf-1	E			Stability
		NEDSS	G	The inability for NBS to be implemented in a decentralized environment raises concern, as the dependency on the SHD backbone, and the recommended CDC architecture raises configuration questions.
Perf-2	E			Latency
		NEDSS	G	As the state SHD multiple sources, introduction of latency is a concern. It is not feasible to do real-time data entry while interviewing; it is slower than the manual process of gathering the information on paper-based forms and entering the data into NBS upon completion.
Perf-3	E			Complexity
		NEDSS	G	System Architecture, Connectivity, Security, and Availability add to the level of complexity of a centralized solution for the state.

Table 5 illustrates the cumulative summary of the solutions ability to meet the requirements herein:

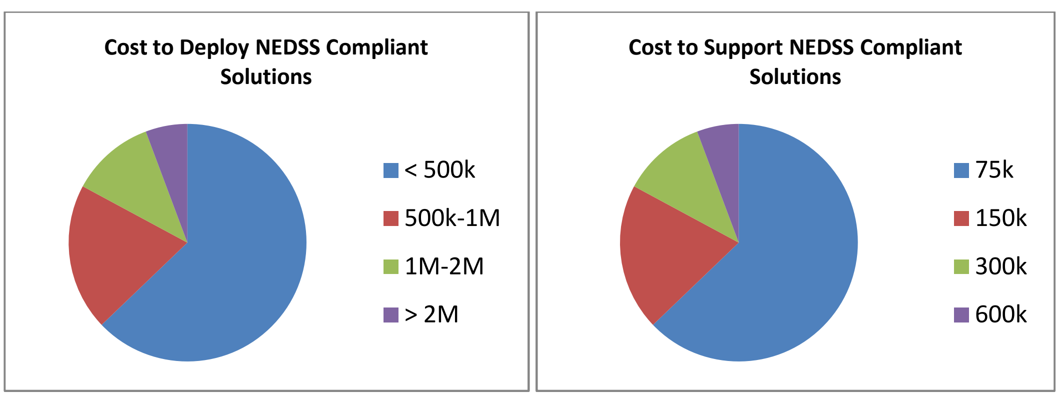
Table 5. Cumulative Summary of requirements met.

	Essential	Operational	Improvement	Desired	Total
Met	30	0	3	3	36
Acceptable	3	0	1	0	4
Partial	2	2	2	0	6
Gap	36	3	18	3	60

The common attributes utilized in the gap analysis herein were further cross matched against the current deployment of disease surveillance systems across the public health agencies in the United States. This CSTE study was conducted in 2008 (Jajosky, et al. 2011), and assessed NEDSS Base System (NBS) implementations with an emphasis on best practices and interoperability. From this study three State agencies Alabama, Florida, and Pennsylvania were selected for use in a comparative analysis. Additionally, due to the nature of the CSTE study, which reviewed a sample of the state health authority implementations, it was deemed appropriate to interview the NEDSS program manager from the state of Iowa to complete the representative sample.

The CSTE reported the results of the assessment in which 56% of the states utilize software systems provided by the CDC, public health departments, or private vendors; 16 of which utilize the CDC NEDSS Base System. The remaining states have home-grown solutions which better suit their public health needs. Of the total number of implementations, 70% are unable to communicate a HL7 compliant message for reporting to the CDC.

There was a wide range of development time and associated costs in the deployment Figure 8A and support Figure 8B, of both CDCs NEDSS Base System and state developed NEDSS compliant solutions. At the low end estimates, the NEDSS Base System solution provides a low cost alternative as the software and its maintenance are provided free of charge by the CDC; at the high end, vendors are selected and proprietary solutions developed which typically incur an upfront and recurring cost for licensing and support. The common incurred costs reflected across all implementations relate to hardware purchases and upkeep, staffing, training, and maintenance. Although these costs are common, the actual dollar amount varies base upon the complexity of the system and the amount of required maintenance.

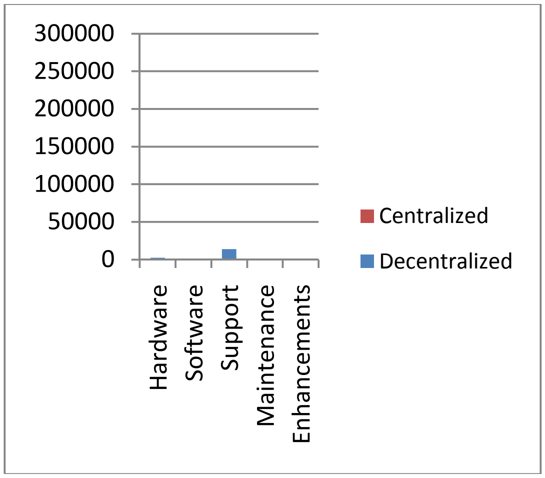


Figures 8A & B. NEDSS Deployment and Support Costs

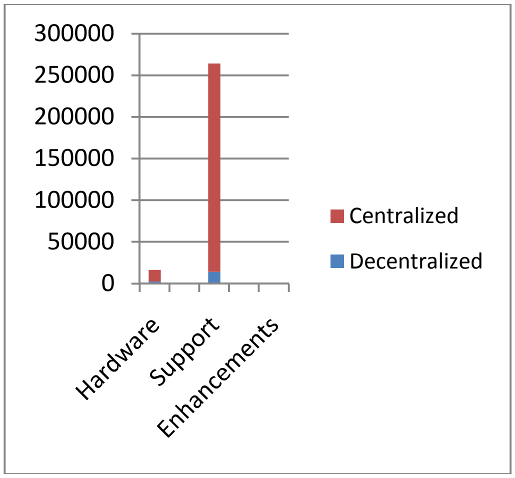
Cost / Resource Sharing

Upon review of the state wide implementations of centralized solutions , it was determined that these may adversely impact the state budget by effecting direct costs including procurement of hardware, software, maintenance contracts, enhancements, and resources; also affected are indirect costs including reliability, operational efficiency which directly affect the organizations morale and productivity (Figures 9A & B). Many of the participants in this assessment process were in support of a multi-jurisdictional implementation, a proposed cost-sharing model which may increase the states ROI and reducing the TCO by eliminating recurring and upfront costs. The cost sharing model consists of each jurisdiction taking ownership of their respective implementation, and costs incurred. As illustrated below, deconstruction of the current centralized architecture may decrease direct/indirect costs to the state.

Jurisdiction



State



Figures 9A & B. Cost of Ownership by Jurisdiction and State for both Centralized and Decentralized solutions

Field Investigation and Testing Analysis

Upon assessment of the field investigation and testing performed across several LHDs as presented in Figure 10, it was identified that the link between field work, screening, disease investigation, and current data management practices and tools should be enhanced to create a seamless and secure flow of data across multiple systems.

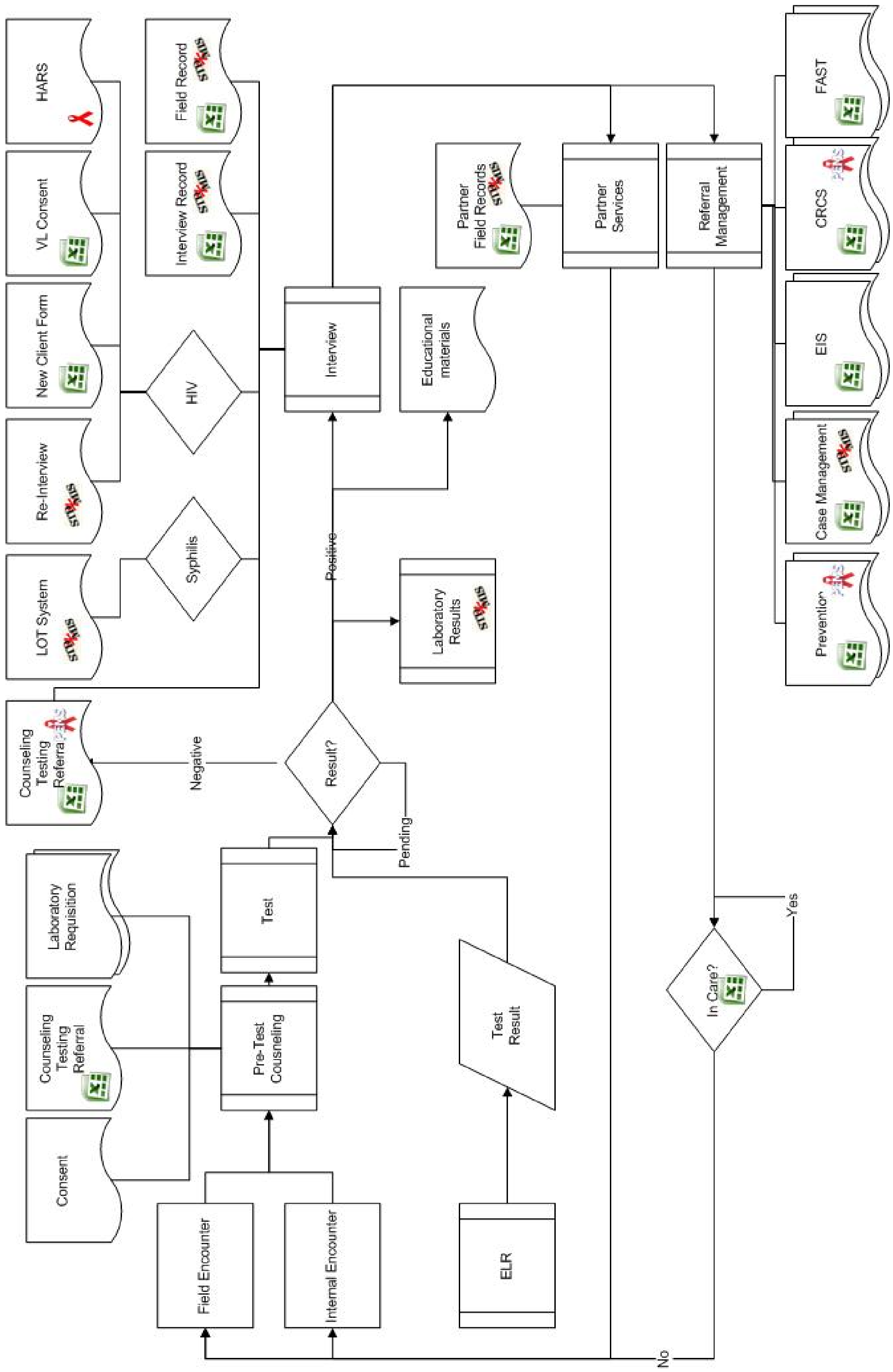


Figure 10. "As-Is" Field Investigation Workflow. The high level business process assessment defined the overarching complexity and redundancy within the current workflow within the HIV/STD program offices

A group interview consisting of three programs who rely upon field level investigation and testing was conducted to tease out the common workflow. When a provider (internal or external) identifies a need for testing and conducts the test, the provider will collect demographic information and perform the testing. If the result is negative, the demographic information collected will be added into the appropriate system(s), PEMS/Excel, to be managed, analyzed and reported out to the respective audience. If the result is positive, a confidential morbidity report (CMR) is completed and sent to Surveillance with the demographic information included. Currently the programs house testing information separated by site in Excel spreadsheets that are manually populated as the testing forms are received. The spreadsheets are used to collect information on testing for HIV, Syphilis, Gonorrhea and Chlamydia, TB and all other required variables: gender, race, zip code, risk, etc. The data management system currently used for HIV testing data is PEMS, although no specific system has been developed to capture TB information.

Once Surveillance receives the CMR and identifies a need for investigation, the case is assigned to an investigator, DIIS, in the form of a Field Record. Surveillance may need to open a Surveillance Log and contact the provider if the provider did not include all of the necessary information to initiate an investigation. The Field Record form contains information needed to begin an investigation: Index patient name and other identifying information, locating information, condition that is being investigated and other information that may have been collected at the time of testing. The paper Field Record is used to document the investigative activities by the DIIS up to the assignment of the appropriate disposition. Various systems are utilized throughout an investigation to identify co-morbidities, prior infections, case linkages, additional locating information, and any other pertinent information that may be needed to conduct a thorough investigation. Some of the systems currently utilized to search for this information are: STDMIS, HIVMIS, eHARS, Lexis Nexis, social networking sites, etc. These systems are currently only available internally, which decreases the DIIS's time in the field.

Upon the Index Patient has been interviewed, DIIS are required to fill out additional forms specific to the condition: Interview Record and ReInterview Record (all conditions), other LOT system paperwork-Syphilis (Cluster Interview Record, VCA, MAPS, narrative), HARS report-HIV, New Client Referral Form-HIV, Consents for additional testing-all conditions. If the client has co-morbidity, separate forms must be filled out for each condition and are given to separate staff for manual entry into different systems; all of the forms have essentially the same information written in the format required by that data management system. The DIIS will refer the Index Patient for other services as appropriate. Those referrals require more paperwork to be filled out with the same redundant information.

Once the agency/program receives the referral, they also have to collect specific variables and enter into separate systems for management and reporting. DIIS or surveillance staff also must follow up on the various referrals to fulfill new reporting requirements as to the status of referrals. At the time of interview, DIIS will conduct partner services. Once partners are identified, partner field records are initiated. The partner field records are filled out by the DIIS and given to data entry staff to manually enter into the appropriate systems. Again, if there are co-morbidities (HIV and Syphilis), the information must be entered into the respective systems. The activities of the partner investigations are documented on the partner field record up to the point where a disposition is assigned. Once the partner is located and tested, the above process is repeated.

Local and State agencies interviewed stated that the convoluted solution including the CDC PEMS solution which they relied upon to facilitate the aforementioned activities did not meet the intent, and was in the process of being replaced; and at the same time significant changes to the reporting requirements were to be enforced as of January 1, 2012. Further, the replacement system WebEval appeared to be yet another siloed solution introduced by the CDC which had not meet user expectations, nor does it integrate with NEDSS compliant solutions.

(Luther Consulting, LLC n.d.) The deployment of WebEval was fraught with issues which were discussed in detail, and resulted in much confusion and the ultimate delay of the initial deployment; leaving the LHD and SHDs to resolve to manual methods for collection and analysis of testing data whilst the problems are being resolved. The manual data management tools consisted of over 60 CDC forms, and more than 30 spreadsheets containing varying amounts of data elements.

Alternative mechanisms were discussed, and further review conducted. This review process of the forms and data tools took place between July 2011 and December 2011 and yielded the Master Element List below in Table 6. This list became essential in determining the variables required for collection and ensuring the necessary output capabilities exist. It became readily apparent that WebEval was an incomplete solution, unable to fulfill many critical requirements of the programs data collection needs. For example, WebEval facilitated testing collection, but no ability to conduct contact tracing, or ad-hock conversion to a morbidity record whilst in the field. This is critical for programs such as HIV and TB where there may be limited opportunities to conduct detailed interviews with cases.

Master Element List

+ indicates system will need to keep history and/or alias

Table 6. Field Investigation Master Element List

Variable	Operational Involvement	Considerations/Comments
Client Demographics		
Name+	ALL	First, Middle, Last, AKA, alias
Client ID	ALL	System Generated, unique ID
DOB+	ALL	Alias DOB
Race	ALL	
Ethnicity	ALL	
“New Race”	ALL	At the request of SHF, reporting agencies request format to be a combination of the race and ethnicity. Ex. White Non-Hispanic. Background variable?
Sex (assigned at birth)	ALL	M, F
Gender (current)	ALL	M, F, Trans—MTF or FTM or unspecified
Physical Address+	ALL	# and street name, residence type-IR code
City	ALL	
State	ALL	
Postal Code	ALL	
Phone+	ALL	Home, cell, work (differentiate- option for preferred contact)
Pregnant	Surveillance, Investigation, Referral	Y or n
EDC	Surveillance, Investigation, Referral	If yes to pregnant
Email/Internet Alias+	Investigation	
Parent/Guardian/ Emergency Contact	Surveillance, Investigation, Referral	
Primary Language	Surveillance, Investigation, Referral	

Birth Country	Surveillance, Investigation, Referral	
Date- Arrival in US	Surveillance, Investigation, Referral	If birth country answer is other than US
Occupation/ Employer/ School+	Surveillance, Investigation, Referral	
Marital Status	Surveillance, Investigation, Referral	
SSN+	ALL	
Signs/Symptoms	Surveillance, Investigation, Referral	Code on IR
Onset Date	Surveillance, Investigation, Referral	
Type of Insurance	Referral	
Income	Referral	
Highest level of education	Referral	
Smoker	Referral	Y or n
Alcohol	Referral	Y or n
Testing/Laboratory		
Specimen Collection Date	Specimen Collection, ELR, Surveillance	
Specimen Collection Time	Specimen Collection, ELR, Surveillance	
Program Announcement	Specimen Collection	EW code-PS12-1201 Category A
Unique Agency ID	Specimen Collection	EW code- 20502
Intervention ID	Specimen Collection	EW code- 175629
Site ID	Specimen	EW code

	Collection	
Site Type	Specimen Collection	EW code
Site Zip Code	Specimen Collection	EW code
Investigator	Specimen Collection, Surveillance, Referral	System Assigned (propose one worker ID per staff- currently have three)
Risk Factors (last 12 months)	Specimen Collection, Surveillance, Investigation, Referral	PEMS codes, see CTR and IR
Other Session Activities	Specimen Collection	PEMS codes, HISTORICAL DATA
Local Use Fields	Specimen Collection	At the request of SHF
Self report previous HIV test	Specimen Collection, Surveillance, Referral	Y or n
Self report result of previous HIV test	Specimen Collection, Surveillance, Referral	If yes to previous HIV test per client report, code from IR
Result provided to client	Specimen Collection, Surveillance, Investigation	
If not, why	Specimen Collection	If results not provided
Place- where was client diagnosed with HIV	Surveillance, Investigation Referral	If rapid preliminary positive and previously diagnosed (for CMR), City/State/Country
Date- client was diagnosed with HIV	Surveillance, Investigation Referral	If rapid preliminary positive and previously diagnosed (for CMR)
Form ID	FOR HISTORICAL DATA- ID# associated with HIV tests	When migrating data- a data element that is currently attached to each HIV test encounter

Laboratory Name	Specimen Collection, ELR, Surveillance	SNHD (rapid), SNPHL, Quest, Long Beach, Primex
Facility	Specimen Collection, ELR, Surveillance	Ordering, treating
Provider	Specimen Collection, ELR, Surveillance	Ordering, treating
Specimen Source	Specimen Collection, ELR, Surveillance	Blood, urine, etc—Code on IR
Test Type	Specimen Collection, ELR, Surveillance	Lab tests, cxr, ppd
Test Result	Specimen Collection, ELR, Surveillance	
Test Accession #	Specimen Collection, ELR, Surveillance	
Pay Source	Referral	Source of payment for EIS labs
Treatment		
Treatment Type	Surveillance, Investigation, Referral	Medications, Vaccinations, in care with MD (OB for preg)
Treatment Name/Dosage/ Frequency	Surveillance, Investigation, Referral	
Treatment Date	Surveillance, Investigation, Referral	
Investigation/ Interviewing		
Diagnosis	Surveillance, Investigation, Referral	200/300/700/710/720/730/740/745/900/950

Diagnosis Status	Surveillance, Investigation, Referral	Probable, preliminary, confirmed
Diagnosis Date	Surveillance, Investigation	Date of first positive confirmed lab for diagnosis
Create Date	Surveillance, Investigation	Date the record was created
Field Record Number	Surveillance, Investigation	STDMIS generated
Due Date	Investigation	NOT SURE IF THIS IS REQUIRED—auto generated based on create date
Ix only FR	Investigation	y or n
Internet Site/System	Investigation	Site that can be used to contact client or Site client uses to find partners, FR
OOJ#/Area	Investigation	Code
Referral Type (FR)	Investigation	Code- Partner, s/a, positive lab, OOJ/ICCR
OP ID	Investigation	FR# or WEBIZ# of original patient (identifier to link clients- contact tracing)
Physical Description- height, size, hair color, complexion	Investigation- obtained during original interview	Obtained during interview of original client; used to identify distinguishing characteristics of contacts to investigate
Other ID marks- tattoos, piercings	Investigation- obtained during original interview	Obtained during interview of original client; used to identify distinguishing characteristics of contacts to investigate
Exposure Information	Investigation	First date, frequency, last date
Date of disposition	Investigation	Rules defined on FR
New Case #	Investigation	STDMIS generated
Initiating Agency	Investigation	20502 or OOJ code
Investigating Agency	Investigation	20502 or OOJ code
Internet Outcome	Investigation	Code
Post Test Counseled	Investigation	Y or n
Investigation Notes	Investigation	DTAR- date, time, action, result

Interview Type	Investigation	code
Date- interview	Investigation	
Notifiability	Investigation	Code
Plan	Investigation	Code
Actual Method	Investigation	Code
Date- last 900 test	Investigation	Code
Referral to HIV testing (1)	Investigation	Code
Date- referral to test	Investigation	Code
Client living with	Investigation	
Time at address	Investigation	Weeks, months, years
Time in state	Investigation	Weeks, months, years
Time in country	Investigation	Weeks, months, years
Currently institutionalized	Investigation	Y or n
Name/Type Institution	Investigation	Name/Code
Pregnant at Ix	Investigation	Y or n
In Care	Investigation	If y to pregnant at Ix
Preg last 12 m	Investigation	Y or n
Preg Outcome	Investigation	If y to pregnant last 12 m
Method of Case detection	Investigation	Code
Interview Period	Investigation	
Place of Ix/Site ID	Investigation	Code/PEMS ID
Date Case Closed	Investigation	
#partners/contacts last 12 months	Investigation	M, F, T
#partners/contacts within interview period	Investigation	M, F, T
Places met partners	Investigation	Code
Places had sex	Investigation	code
HIV tested at this event	Investigation	**event that led to assignment of investigation, y or n
Date of previous HIV test	Investigation	
Provider	Investigation	Code

Confirmed		
Anatomic Site (symptoms)	Investigation	Code
Clinician Observed (symptoms)	Investigation	
Client Described (symptoms)	Investigation	
Duration (symptoms)	Investigation	days
Date of Death	Investigation	
State/Territory of Death	Investigation	
Referral		
Reported Risk Reduction	Referral	CRCS- Sub form
Session #	Referral	CRCS- Sub Form
Inmate ID	Referral	Detention- Sub Form
Entry Date	Referral	Detention- Sub Form
Housing Unit	Referral	Detention- Sub Form
Encounter	Referral	Encounter- Sub Form; Service, activity, incentive (type and quantity given)
Date of encounter	Referral	Encounter- Sub Form
HARS#	Referral	Perinatal- Sub Form
Agency/Program/ Test (referred to)	Investigation, Referral	Referral Tracking- Sub Form; Code (PS Form), y or n CTR form 2, EIS appointments
Referral Date	Referral	Referral Tracking- Sub Form
Did client attend first appointment for medical care within 90 days	Investigation, Referral	Referral Tracking- Sub Form ; If y to referral to medical care, Code (PS Form), y or n CTR form 2
Why?	Investigation, Referral	Referral Tracking- Sub Form; If no to client attending first appointment, CTR Form 2
Agency/Program (referred by)	Investigation, Referral	Referral Tracking- Sub Form
Ryan White eligible	Referral	Referral Tracking- Sub Form; If yes, registration forms for FAST- MHS?
CAREWARE client	Referral	Referral Tracking- Sub Form
Incentive	Referral	

Inventory		
LOT#	Inventory	
Perpetual Quantity	Inventory	
Program/Area	Inventory	The area that the incentives were checked out to
Events/ Educations/ Non-Client Based		
Date of Event	Reports	
Intervention ID	Reports	PEMS
Site ID	Reports	If testing occurred at outreach
Venue	Reports	Location
Emphasis/Event Type	Reports	
Total Attendance	Reports	
Total Court Ordered	Reports	HIV 101
Media Reach	Reports	
Target Pop/Data Focus	Reports	
# Provider packets disseminated	Reports	
Office Contact	Reports	
Standard Notes Library		
Other Locating Information	Investigation	
Investigation Notes	ALL	Field Visits, Telephone Calls, Record Searches, etc

Abstraction and Storage

In 2009 the number of reported cases of notifiable diseases across the United States was approximately 304,057 cases from the combined States and their respective jurisdictions. (CDC 2011) A staggering amount considering the average state health department employs 0.72 per 100,000 populations of skilled DIIS, epidemiologists, and supporting technical staff. (Public Health Funding Facts 2010)   CDC received over 1.5 million case reports of Gonorrhea and Chlamydia alone, which dramatizes the staggering amount of data that CDC receives yearly for the approximately 60 notifiable conditions and their supporting data elements.

Throughout many discussions with program personnel, the need has been identified to create a comprehensive data warehouse to effectively manage and utilize the data being reported throughout the continuum. Local and state agencies typically rely upon their Surveillance system to aggregate and generate reports. While the Surveillance system is an Online Transactional Processing System (OLTP) and not intended for Online Analytical Processing (OLAP), locals and states alike do not have the technical expertise to develop a comprehensive data warehouse.

The CDC initially developed the Common Data Store (CDS) internally in 2005, to resolve the aforementioned need for a scalable comprehensive data warehouse, which aggregates all notifiable data elements into a common storage schema for analytic use. While the anticipated utility of the CDS was exceptionally high in theory, in practice it has yet to be realized since nearly none of the programs utilize the repository for the analysis of their respective data. Initial inconsistencies in the delivery of data introduced doubt among CDC users, who have sidestepped the CDS for antiquated data reporting mechanisms which are perceived as more reliable. There is significant concern that the preprocessing, data manipulations, and validations utilized by the CDS staff are the cause of data corruption. This is difficult to trace due to the massive volume of data and poorly documented legacy processing programs. CDS suffers from a lack of knowledge of its architecture, development, and execution among core NNDSS personnel.

There is however, a critical issue in the fundamental design of the CDS, which appears to have existed since its first release. The underlying structure of the repository is limited, due to the fixed structure and variable types utilized. The introduction of a *pseudo* Enterprise Attribute Value (EAV) model, intended to reduce sparsity and accommodate evolutionary methods, resulted in suboptimal implementation of a metadata-driven architecture, raising questions regarding the scalability of the new CDS architecture. Additional issues involving the metadata tier and procedural processes have been uncovered during more extensive examination of the CDS version 3.x. (CDC 2011)

The program staff related that the CDS remains under-utilized, bloated, and overly complicated due to the lack of adherence to design patterns, standards, and best practices in data warehouse design. The problems have been further compounded by continual shifts in budgetary and leadership priorities, vision, and need.

Analysis

Throughout the interviews with program staff, SAS was brought forth as a widely accepted and utilized, enterprise analytics solution. (SAS n.d.) As a significant piece of the public health continuum, SAS integrates seamlessly across the enterprise in the compilation and analysis of data at the local, State, and Federal levels. Through observations at each level however, SAS was often misused and mischaracterized due to lack of expertise in data management, attempts have been made to use SAS as a data processing solution, and incorporate it into the data stream.

SAS invests heavily to ensure optimal numerical analysis and correctness of complex statistical methods and estimation routines. Despite the benefits of these modern methods in SAS, the process flow of calculating many simpler statistics is a bottleneck and impediment to a streamlined workflow. In the best case scenario, the time taken for SAS to retrieve the data from a source, perform the given result and then return provides increased processing time and complexity when the same analyses could be performed more efficiently utilizing other mechanisms. However, in practice, public health agencies do not take advantage of the enterprise connectivity within SAS, resulting in a burdensome workflow in where flat files must be exported, loaded into SAS, analyses performed, results exported and results loaded back into the data pipeline.

A number of critical organizational and process related problems have been identified and discussed. Effective measures need to be taken in order to address each of these as part of a larger ongoing attempt to create a sustainable public health infrastructure. Chapter 5 presents an approach to organizational refinement, and sustainability; Chapter 6 builds upon the sustainable model and presents an implementation framework for the NNDSS. The thorough review of NNDSS and extensive planning has resulted in the creation of a unified vision and sustainable implementation presented in Chapter 7.

CHAPTER 5

RESULTS: SUSTAINABILITY FRAMEWORK

Introduction

The NNDSS is failing to meet the needs of many users of the system, is endangering public health by failing to support important surveillance activities such as the detection of outbreaks and the tracking of selected diseases, and is costly to maintain. The lack of functionality and confidence in NNDSS spurs wasteful workaround systems which actually increase complexity and reduce functionality of public health disease surveillance.

The current deficiencies have not resulted from the lack of well-intentioned past attempts at correction nor the lack of dedicated staff, but the successful improvement of the NNDSS depends above all, on active involvement and support of all users and stakeholders of the system in the creation of a sustainable community of practice.

Looking into the future and beyond the scope of the current NNDSS which focuses on individual services, a sustainable infrastructure to support the NNDSS will be evolved through an iterative process resulting in a well-connected community base, inherent of an ever-growing set of services spanning the public health continuum. Such a system will be capable of addressing both short-term problems but be adaptable to accommodate long-term growth and change. The creation of a core set of services which comply with the principles of economic, social, and ecological sustainability, coupled with a long-term perspective and relationships will promote useful and meaningful innovations to shift the public health culture and its behavior.

Design

A number of core principles (Table 7) were determined to play a fundamental role in the design and development of a sustainable community of public health.

Table 7. Design Principles

Principle	Definition
Impact	Little effort to change the environment
Efficiencies	Process which do not waste resources, time, etc
Quality and durability	Effective solutions that are scalable, and meet demands
Reusability	Reusable components that span the continuum and beyond
Involvement	How involved are the members?
Leadership	Who are the leaders? are they leading?
Satisfaction	How satisfied is the current community?
Affordability	How is affordability defined?
Equitability	What is perceived as equitable?
Education	Where to focus membership development?
Security	How secure does the community feel?

The common attributes, goals, oversight, roles, relationships, and areas of influence defined below coalesce into an interdependent lattice capable of sustaining the community of practice.

Attributes

The public health community can be thought of as a macrocosm made up of local, State, Federal, and respective community partners who maintain a level of fluidity by the very nature of its practice and structure. The connectivity illustrated in Figure 11 may be well-defined or ad-hoc based upon the situational level of interaction.

Goals

The ultimate goal of surveillance at any level is to provide the data needed to make informed public health decisions. The public health decisions that need to be made at each level differ, and therefore the goals of those levels are to support the local decision making process and the population in which it serves. The national goals are often related to policy and national priorities, while the local and states typically focus on the legally mandated public health actions to serve individual community needs. Your goals may vary.

Oversight

There is no consistent mechanism or forum for making long-term strategic decisions, for involving all stakeholders, and for evaluating and reporting progress on milestones. This situation leaves the NNDSS adrift, with frequent changes of priorities, confusion over objectives, poor accountability with little public assessment of return on investment, functionality that fails to meet stakeholder expectation, and costly work-around systems.

The CDC has taken a de-facto role of oversight of the NNDSS enterprise. However, as the goals vary by level, one governing structure is not sufficient to represent all stakeholders across the continuum. While public health practice maintains governance though the CSTE, the governance structure is a community of common interest and not one of direct authority. In order for the governance structure to be effective, each stakeholder is treated as an equal, and states are not lumped together as a single entity. Local jurisdictions are often not represented in this governance structure; however, as the legal authority for public health surveillance often rests at the local level, local stakeholder may need to be afforded the same rights as the state stakeholders.

Roles

The community is made up of a diverse range of specializations, which may overlap at any time including: disease subject matter experts, surveillance staff, information specialists, technical staff, and leadership, at all government levels (local, State, and Federal) as shown in Figure 11.

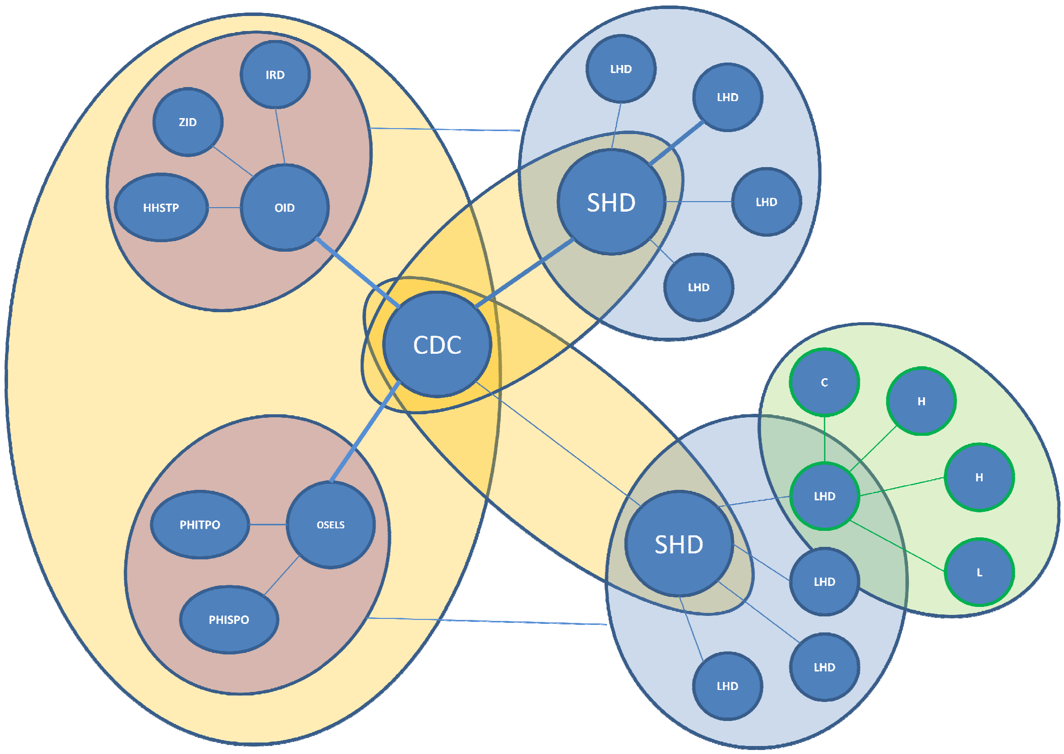


Figure 11. NNDSS Relationship Network. Network reflects the relationships, and areas of influence, what organization is at the core, who should be at the core providing leadership, where are the linkages to interdisciplinary domains. Additional linkages exist to governing entities, and influencing agencies such as CSTE, PHII, PHI, however they have been omitted to maintain the simplicity of the visualization.

Relationships

Mandated relationships set forth by state laws that place the LHD under the control of SHD, or mandate their interaction. (Mount 2001) For example, the county level health departments may be given a large degree of autonomy yet maintain certain reporting requirement to the SHD; Perceived relationships, The CDC is often placed by local and State agencies by virtue of their scientific expertise at the top of a hierarchical structure. This scientific expertise is often perceived as a mandate for activities when no such legal mandate actually exists. ; Implied relationships, CDC often presents requests on the local and State agencies to conduct activities using national goals as a platform to pressure compliance. For example, during the 2009 H1N1 outbreak, CDC requested that local authorities implement case reporting of hospitalizations and deaths. (Labus 2011) While states were given the option as to how they wished to participate in the program, it was never presented as an option not to participate even though CDC had no legal authority to compel participation; and actual relationships, through the funding of public health activities at local and State levels, there are contractual obligations which create a legally binding relationship between the CDC and the grantee.

Areas of Influence

The greatest area of influence is proportionate to the funding of public health activities within a community, by CDC. (Public Health Funding Facts 2010) This influence can result in changes in legal mandates within the jurisdiction or state that would allow it to successfully compete for funding. The goals of public health at a community level are directly driven by the needs of the community. This is readily apparent from the fact that different diseases are reportable across different communities.

Tax based funding also drives priorities at all levels of the system, and priorities can therefore be influenced by the political climate. For example, the political changes post 911 resulted in a huge influx of funding opportunities related to Bio-Terrorism (BT) events, even thought there may have been larger health threats.

Planning

In order to improve on the current state of public health, it is necessary to tease out the emerging patterns throughout the community. This will provide a platform capable of sustaining present and future growth. This will be accomplished utilizing the best practices of community planning. Inspiration for organic growth will be obtained through strategic alignment, shared goals, engagement and empowerment of the public health membership. A transparent governance of this community will arise through maintaining well defined roles and a loose level of control. This platform will provide the flexibility to react to an ever changing public health landscape of political, social, and biological changes.

Oversight

The Federal Advisory Committee Act (FACA) exists to ensure consistent federal advisory operations. As a result, FACA has the necessary organization mechanisms and tools to establish a designated body of which to oversee the NNDSS. This body should have strong representation from surveillance experts across the public health continuum. As defined herein, in the creation of an oversight body, it is imperative that it first develops of a clear statement of goals, objectives, and priorities of the NNDSS. To ensure NNDSS maintains a consistent vision and forward progress, regular review of priorities, and assessment of progress through measurable outcomes is necessary.

Some of the questions to be addressed by the NNDSS Oversight Committee include:

- What are the long-term goals, objectives, and priorities of the NNDSS?
- How should NNDSS progress be measured?
- What is the future vision?
- How can NNDSS be more technologically unified and aligned for success?
- What are best practices that should be promoted and supported within NNDSS?
- Which of the new standards that are available should be incorporated into NNDSS and how and when?
- What is the return on investment for projects within NNDSS?

Support

A more supportive environment needs to be created within NNDSS to foster mutual collaboration across domains in order to facilitate knowledge exchange amongst the membership. This would facilitate open and frequent communications amongst the community. As a result, each member is afforded the opportunity to better understand all facets of the community and play a more active role in the development and vision of the community. For example, members may actively participate in the overall NNDSS strategic vision by communicating through open channels with members of the NNDSS Oversight Committee.

It is imperative that these processes and procedures adhere to best project planning practices, placing membership's needs foremost, while at the same time holding them accountable for justifying their individual requests. Compromises must be considered throughout the processes as change in scope and direction may affect the initial intent.

To promote optimal organizational and leadership support for NNDSS, local, State, and Federal program offices should review and clarify lines of responsibility for decision making, for project oversight and accountability, and for communications both up and down NNDSS. Better delineation of responsibilities and authority are needed to improve internal NNDSS operations. NNDSS leadership must be supported and encouraged, where necessary, to develop the following skills:

- Ability to clearly delineate NNDSS tasks and responsibilities;
- Knowledge and understanding of programmatic needs for and use of surveillance data; and

- Knowledge and understanding of informatics and information technology;

Project Management

The assessment uncovered significant shortcomings in the relationship to project leadership and education, with respect to the ability to identify the appropriate project management disciplines and methodologies. Project management is, simply stated, the management of a step-wise process, procedures, resources, and the resulting artifacts necessary to see a project through to its completion. This management discipline can be applied utilizing low/high-ceremony approaches: Low-ceremony approaches allow for greater flexibility and adoption of change; while High-ceremony approaches are more constrained, and have lower risk of failure. (Breunlin 2004)

NNDSS can no longer afford to rely on ad-hoc, low-ceremony approaches to project management, forgoing the rigors of the discipline for the ability to quickly adapt to change. Furthermore, the use of a low-ceremony approach excludes many of the stakeholders that are critical to the process, focusing on small internal processes and issues rather than the interoperability amongst members and disciplines. Through the assessment (Chapter 4) common attributes of NNDSS projects were identified, structural elements and evolutionary flows defined. Repeated themes such as schedule and cost slippage, lack of communication, and over reliance on contract managers were uncovered, and no direction had been given to resolve these critical issues. It is these attributes which therefore high-ceremony approaches to project management, which reduce risk, may be more appropriate.

The implementation of change in the approach to project management, which has been largely absent across NNDSS, must be championed and managed by its governing body, and adopted by its membership. Initially the public health community and its members must develop a good understanding of their current status (Chapter 4), and what is needed to improve their respective processes (Chapter 5). This understanding will solidify the use of a high-ceremony approach, and the benefits it can provide.

High-ceremony approaches may increase up-front costs and resources needed, however the benefit of a well thought, documented, and traceable process far outweigh the risks introduced by less rigorous methods.

Regardless of the disciplines used, or the type of project the fundamental aspects of project management can be broken down into four major components 1) Cost, 2) Schedule, 3) Change, and 4) Quality.

Cost and schedule are typically dependencies, and used together to manage the overall cost and schedule of the project, as one has a direct effect on the other.

Cost

The lack of involvement and necessary education of relevant skill sets leads to an inability to accurately assess project costs. Initially, the project manger and team must determine the project budget by projecting the cost of the finished project, including administrative, project tasks, procurement and the like. Next, definition of the completion criteria is essential in managing expectations. This step is directly related to the tasks defined in the previous; indicating what characteristics of a task defines the task as completed. With these critical components defined, they may migrate to and create the project schedule. Unfortunately the project budgetary processes are often inaccurate and overinflated due to lack of engagement, and the necessary background competencies to make accurate, and well-informed decisions.

Schedule

The project schedule marries resources against specific tasks, and layout the progression of the tasks within the projects timeline. This method of utilizing the budget to drive the schedule is not typical, however is very effective when managing large, complex projects. A unique attribute of this method provides the basis from which to layout the budget, against the tasks defined, within specified periods of time period. The project now has a detailed breakdown of tasks, cost, resources, timelines, and dependencies. This critical step in effectively managing enterprise implementations is absent from many of the NNDSS membership workflows.

Configuration Management

Changes must be managed appropriately, as they affect every aspect of the project budget and schedule, and without Change Management processes in place, a project may run adrift. (Breunlin 2004) NNDSS has experienced continual scope creep, schedule slippage, and cost overruns due to this very issue. The necessary change review architecture, processes and procedures must be defined, adopted, and implemented to reduce risk and overall impact on the project deliverables.

Implementation of change management occurs when the definition of the work product is completed; this establishes a baseline from which everything is measured. Iterative reviews are conducted to assess both progress and potential impact of changes. Decisions are made on what changes get incorporated based upon the impact to the baseline budget, schedule, and overall impact factor.

Quality

Arguably the most significant part of project management is quality control. Adoption of continual process improvement protocols is critical in ensuring limited impact on the cost and schedule of a project. For example, NNDSS projects such as the CDS have had questionable quality issues since inception. These quality issues are evident by the number of iterations of the software and limited utility. Rigorous approaches to quality assurance avoid costly rework and reprioritization.

Quality Assurance (QA) defines the constraints of a project, enforces policies, and must be seamlessly integrated into the project to ensure limited defects over the course of the project lifecycle. (Breunlin 2004) QA Methods are present in every aspect of the project, inspecting processes and procedures, artifacts and schedules for risk by implementing statistical analysis, observation, and review. The findings are reported, and process improvement protocols initiated.

Contract Management

Several of the key principles including leadership, involvement, and education emerged during the in-depth, comprehensive assessments as recurrent problematic themes. These principles suggested that contract management and oversight are essential, to successful development, and deployment of systems within NNDSS. As local, State, and Federal partners turn to contract agencies to shrink the overall agency footprint, it is critical in maintaining communication as poor contractor oversight has typically resulted in a product that does not meet the needs of its users, often at great cost. For example, NNDSS has continually mismanaged contractors, providing oversight by contract managers that have no core competency in or communication with the projects and staff in which they are managing.

Contract Management throughout the NNDSS community should enforce the Project Management processes and protocols defined above, with the only caveat being that resources are contracted, and not internal.

Assessment

This design and methodological planning yields a better understanding of the underlying framework necessary to sustain public health practice at the local, State and Federal levels. A number of considerations were presented from which to begin the process of operationalizing the NNDSS community. Many of these considerations when placed in context resulted in actionable items from which to grow and learn.

Work in implementing the above mentioned actionable items has already begun to take place. For example, the community is active, with some notable recent developments involving UDOH, KDHE, SNHD, CSI, and possible alignment of these developments with CDC in developing the national framework. Furthermore, CT and ARK are actively engaged in productive discussions regarding their adoption of the platform, and participation in the community's growth.

Early results are promising, people are connecting, and projects are following the necessary rigors to ensure success through collaboration. The platform will continue to develop though multiple iterations, evolving organically as new members join, others leave, ideas are exchanged, and the inherent growth of the community takes over.

A number of beneficial results from the collaboration have already begun to emerge. Collectively these benefits include 1) the ability to identify areas of weakness, 2) establish mitigation strategies, 3) develop novel approaches to common problems, and 4) foster broader communication. No longer are local and State agencies relegated to the sideline, the community empowers them as a strategic partner and decision maker as they now have a common platform of understanding, know what questions to ask, and have a supportive community backing from which to answer.

It has become evident through the initial application of the framework that some of the inherent risks typically involved throughout the processes have been reduced, while this may be a perceived reduction it also may be directly correlated to the loosely defined membership and well defined roles and responsibilities which are spread throughout the community. This loosely coupled structure has lead to limited dependencies on any one person, role, or group.

We concede the foundation beginning to emerge of a sustainable public health community in three, traditional sustainable indicators: *Economic*, *Environmental*, and *Social*.

Economic: Financial resilience is being demonstrated throughout the public health community as evident by the community's ability to do ever increasing amounts of work in light of ever decreasing resources with which to accomplish activities. Additionally, the community has demonstrated its ability to remain nimble in this time of economic crisis as public health has seen their funding cut drastically. This indicator demonstrates the potential long-term viability of the community to remain sustainable. This the result of the fact that the diverse makeup of the community membership is able to be leveraged both inter and intra agency, allowing all participant to scale without having to expand upon their internal resources.

Environmental: Leveraging the community, the individual partner agencies are able to sustain a level use of resources, and develop more efficient and effective work processes by implementing community wide assessment of activities which reduce waste states throughout the public health continuum.

Social: Well defined roles and responsibilities are equally matched to membership, growing the number of local, State, and Federal partners.
The immediate growth of the community is in part related to a desire of members to collaborate and leverage the diverse skill set possessed by members of the public health continuum. As a result, the membership are

better equipped to aid in the advancement and growth of economic, and environmental potential across the continuum.

It is important to note that none of the aforementioned indicators come at the expense of another community of practice. The inherent architecture of the sustainable public health community and its mission is to drive innovation across the interdisciplinary sciences, and look to them for novel solutions to community problems.

CHAPTER 6

RESULTS: SYSTEM ARCHITECTURE AND DESIGN

Introduction

With a comprehensive understanding of the need to update the NNDSS discussed in Chapter 4, and the definition of a sustainable architecture developed in Chapter 5, Chapter 6 now begins to provide the detailed description, and methods necessary to implement the public health infrastructure using an sustainable enterprise approach. A number of common public health enterprise features, and community exposure methods are discussed including *Vocabulary*, *Syntax*, *Knowledge*, *Services Oriented Messaging* and *Disease Surveillance and Investigation*, and *Data Warehousing*.

System Design and Data Processes

NNDSS is an enterprise, and as such should follow the appropriate organizational approach. The inherent benefits of the unified vision and goals brought forth by an enterprise ethos will promote a synergistic relationship throughout the community of practice. In order to facilitate a community driven platform, the following critical steps must be performed:

- Engage all stakeholders involved in NNDSS throughout the Enterprise Performance Life Cycle, promoting communication, and establishing ownership and confidence throughout the enterprise;

- Further develop the landscape by reviewing the people, processes, and technology that make up the NNDSS enterprise and creating a topology that reflects the current environment, its programs, projects, personnel, skill sets and degrees of overlap;
- Simplify the landscape by aligning initiatives with the goal of reducing bloated processes, redundancy, and high resource utilization and cost**;**
- Prioritizing initiatives such as, for example, placing emphasis on critical, fundamental functionality first, and Analysis, Visualization, and Reporting (AVR) tools later;
- Manage expectations and cost, and mitigate risk by utilizing formal project management methodologies;
- Utilize enterprise architecture methods, standards and best practices and leverage design patterns developed across interdisciplinary sciences to assess what work has been done, successes, and failures; and
- Assess the utility of data outputs from NNDSS.

Enterprise Informatics Architecture

Vocabulary

There is a lack of ability to unify and distribute terminologies across the public health continuum. To develop this much needed capability, it is necessary to either dramatically expand upon current technologies such as the PHINVADS terminology services, or create new novel solutions.

Adding mechanisms to PHINVADS in the support of support ontological representation of standardized code sets coupled with the ability of the public health community to author, review, and approve/reject terminologies, both proprietary and standard would help promote community wide utilization. This solution however comes with a price, as PHINVADS was not intended to provide these services, and the architecture is unable to easily accommodate these functions. The cost of re-engineering PHINVADS is likely to be substantial; perhaps more than the complete development of a novel community driven system. Additionally, given the limitations of the current PHINVADS system, its ability to maintain and accommodate growth into the 21st century is also questionable.

A second and more sustainable solution is to utilize an Open Source terminology server such as Apelon, a mature ontological based terminology framework, to provide the ability to create and utilize ontological representations of both standard and non-standard terms. Apelon has an extensive API, which can easily be wrapped and exposed within a web service tier to promote community use.

Ultimately either solution should be available in the Cloud, empowering the community to control the outcome, releasing the liability and control of a single person, or agency in the definition, approval, or application of terminologies.

Syntax

To reduce the burden felt by local, State, and Federal agencies in having to adhere to a specific standard syntax, and implement that standard on an ongoing basis, it is prudent to consider the development of a “self-documenting and self-validating” structure. Expanding upon the current H7 and CDC XML implementations by application of the Open Archives Initiative Object Reuse and Exchange (ORE) Resource Map utilizing Atom, will provide a comprehensive and scalable mechanism to deliver unified context and validation.

ORE Resource Maps utilize the Atom Syndication Format in the delivery of elements in a standard format while maintaining semantic constraints, and can easily be integrated with ORE and RDF vocabularies. In practice, the Atom entry document (Resource Map) promotes both a machine and human readable format which captures the metadata, and its corresponding aggregate data. These aggregate data may be compiled via a terminology server, which will promote the use of standard terminologies, allowing for real-time validation prior to delivery and/or consumption. For example, the Atom link illustrated below will point to the implementation of “race” in the NEDSS solution, and return a code set and structure which describes and validates the data according to the Resource Map. This dynamic use of metadata will allow programs to make changes or updates to the schema on the fly, and promote the seamless integration of the NNDSS systems with Cloud based terminology, and knowledge services.

Knowledge

Knowledge is diffuse, not immediately aggregated and stored; and rarely in an electronic format. Individual packets of knowledge are routinely shared in small circles within public health, but are not disseminated well beyond these small circles While locals, States, and Federal partners may focus on specific areas of interest, the fundamental application of knowledge, its management, and integration are a consistent core area of research which is necessary to bridge the knowledge gap between currently disparate partners in the public health community.

Interdisciplinary sciences have leveraged knowledge repositories for over a decade (JBoss 2008), empowering the user community to author, review, approve/reject, and execute logic across a multitude of systems including manufacturing, quality, banking, and more. The well known and embraced Open Source Business Rules Management System (BRMS) Drools has been in constant development since its inception in 2001. Drools is an inference engine, made up of five components: Expert, Flow, Fusion, Guvnor, and Planner providing integration, workflow, event processing, knowledge management, and heuristic based planning.

Drools is easily integrated utilizing a comprehensive set of APIs which allow interaction with all of its fundamental components.

To maximally leverage the power of a knowledge repository, Subject Matter Experts (SME) must converge in a single point to share knowledge in a standardized way. Opening up a Drools based implementation in the Cloud would promote a community synergy, reduce redundant attempts at knowledge representation and management, while providing a single source for knowledge integration and dissemination.

Service Oriented Messaging Bridge Plan

Consolidation of data streams from the health authorities to the CDC by removing the need to continue support of the legacy NETSS format will reduce cost, increase efficiencies, and release the current constraints on the processing of NNDSS data. Migration from the current system should involve a parallel, multi-phased approach of maintaining the current data feed while systematically introducing a comprehensive, multi-faceted solution based upon a sustainable and scalable Enterprise Service Bus (ESB) architecture.

As illustrated in Figure 12 below, the initial phase will include the development or repurposing of a comprehensive web services tier. This web service tier will focus on best practices in service architecture, potential use of contract-first deployment methods, and use of corresponding adapter layers (interfaces). The web services tier will simply expose methods for interaction between external data partners and the CDC, while providing and enforcing the application of standard protocols.

The initial phase will leverage current technologies such as the Public Health Information Exchange (UNIPHI) open-source initiative. The inherent message-agnostic nature of uniPHii will reduce the need for institutions to implement a *new* standard protocol for delivery to the CDC, while ensuring that data delivered to the CDC meet the programs' expectations prior to messages being consumed.

A byproduct of this initiative will be the phasing-out or re-architecture of PHINMS. The removal of the unnecessary overhead associated with PHINMS would result in a reduction of the NNDSS footprint and in reliance upon standard mechanisms rather than proprietary solutions. However, PHINMS could easily be re-architected as an adapter type, and extended to not only conduct transport over supported protocols but also to facilitate the standardization, validation, and enforcement of business logic on a variety of message types prior to data delivery to the CDC. This will empower programs to define the elements needed for processing and allow validations and business logic to be conducted during transport. This removes unnecessary constraints and reliance on program staff to introduce new elements for use and to perform validations on data with which they may not be familiar.

Moving the quality assurance mechanism up front in the process shifts the burden *from* CDC-based internal auditing of messages and investigation into data inconsistencies *to* up-front automated validation and business logic processing, error handling, and robust alerting mechanisms at the local, State, and territorial health departments. This change will have several benefits. The change opens and enforces the communication channels between State agencies and CDC program personnel, creating a transparent exchange of data. This will also improve and harmonize efforts to unify data validation definitions. Currently, States that perform notifications with HL7 messages must conform to PHIN standards. However, the process of message mapping and certification is cumbersome, and only rudimentary validations are currently performed internally in CDC, with limited ability beyond the validation of the structure of the message.

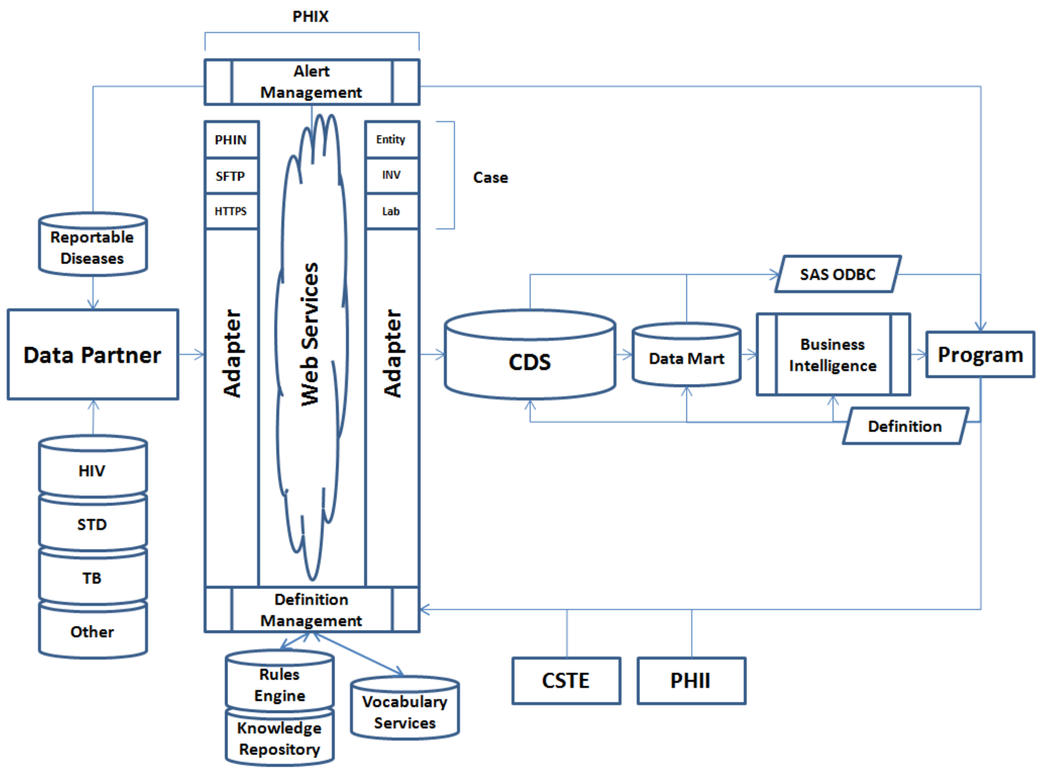


Figure 12. Service Oriented Bridge Plan. This bridge plan architecture could be used to allow for the decommissioning of the NETSS system and syntax. The introduction of an adapter concept, coupled with a robust web service tier, empowers the data partner to deliver data via a truly systems-agnostic data interchange engine, by supporting a variety of syntaxes, nomenclatures, and supporting ontology and knowledge through the definition management tier, mapping local syntax, nomenclature, and business rules directly to service calls or directives.

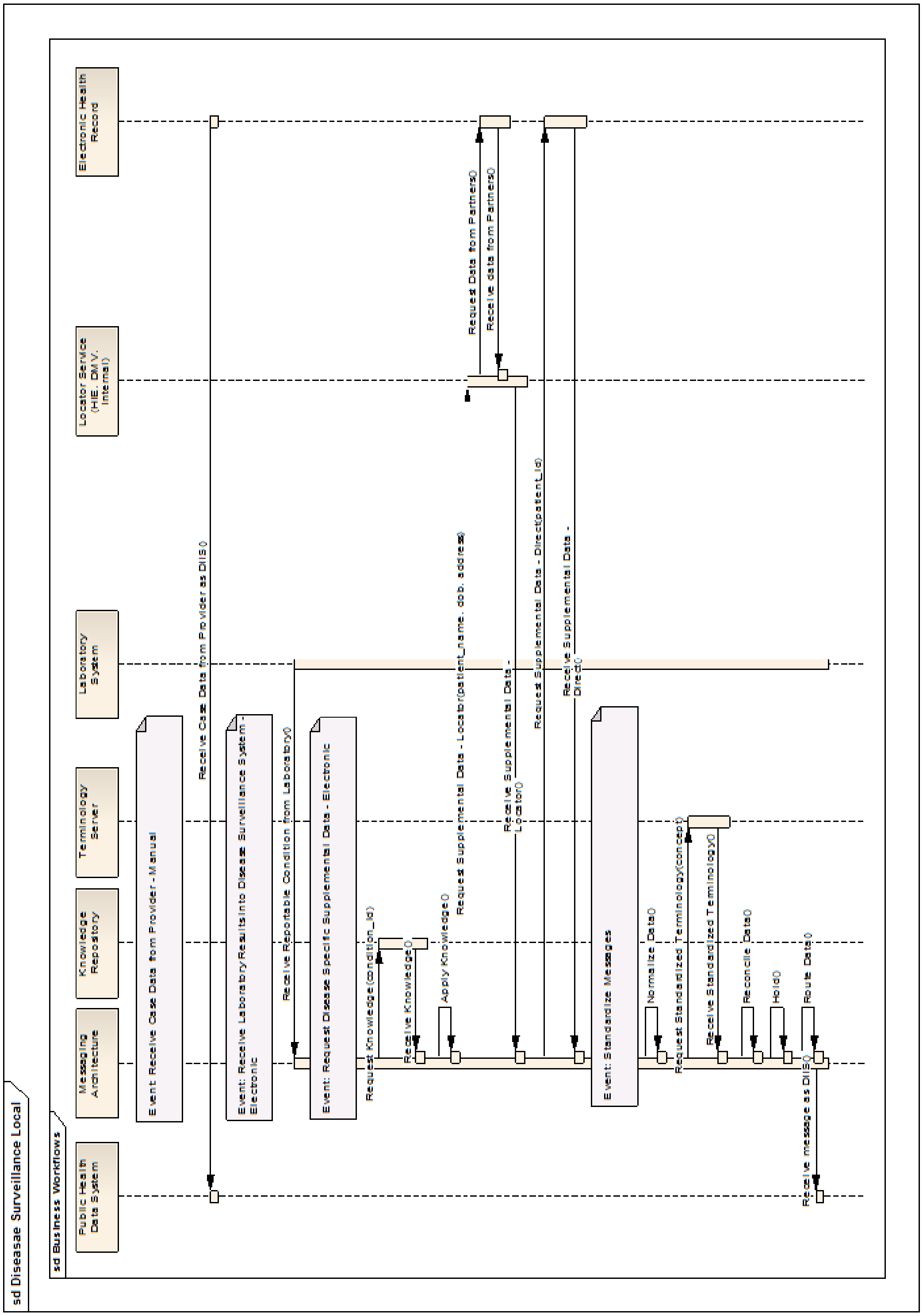


Figure 13. The NNDSS ideal processes and procedures involved in disease surveillance and investigation.

Integrated systems, standardization of practice, and portability will shift the burden from time intensive management processes to a seamless, secure, simultaneous flow of data within multiple systems in real time as presented in Figure 13. Enhanced data management within this system will allow a program to direct efforts towards populations with the greatest need. Reports will have the ability to be generated accurately and immediately upon data upload. Working within an integrated system will allow the end user to standardize data collection and documentation of investigative activities. Programs will cut costs by reducing staff time that is wasted by duplicating efforts, completing redundant forms, and greatly reducing the amount of paper wasted and eliminate the need for space to physically store records. Creating a standard of practice for testing and investigating all communicable diseases will increase efficiencies. The opportunity to intervene in disease is drastically increased if the investigator is able to convert from screening to investigation immediately and conduct searches for co-morbidities, prior infections, case linkages, and locating information within separate systems by querying one system that will search all databases currently being utilized. Furthermore, the communication and conversion engines used in the back-ground of the solution will create a robust and scalable framework from which to build. This will further cut down on investigation time.

Effective disease identification and investigation requires the need to conduct screenings and investigations in the field. More often than not, investigators must go out into the community to reach their target populations making portability imperative. The ability to conduct this work, while having all necessary tools on hand at all times, will allow for rapid response to communicable diseases. Conducting this work with the use of an open source application and portable technology will increase the identification, suppression, control and prevention of communicable disease in real time; which is a grand departure from the weak processes described in Chapter 3.

Service Oriented Disease Surveillance and Investigation

Offering a cloud based DSS that exposes services for laboratory consumption, interface directly with the data warehouse will shift the hardware and software needs to a SOA (Figure 14). This will provide a comprehensive set of software and services in a unified architecture to support disease surveillance partners and activities, while reducing the footprint and resources necessary. This will minimize many costs currently incurred across the public health continuum.

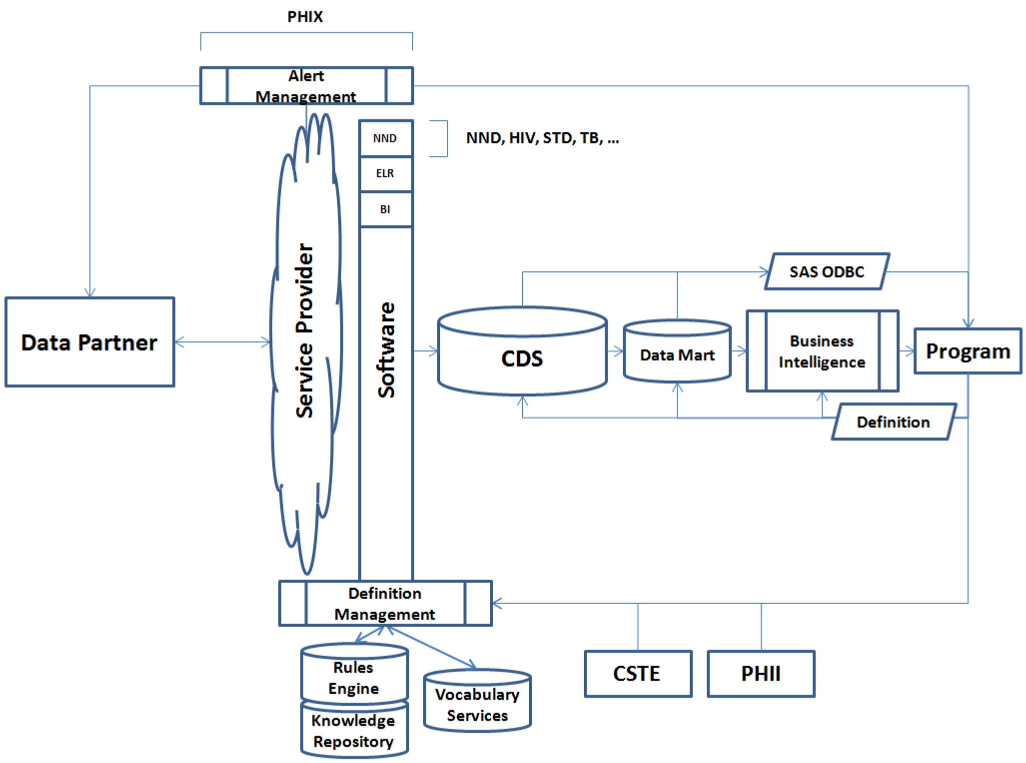


Figure 14. Service Oriented Disease Surveillance and Investigation.

Data Warehouse

Fundamentally, understanding the intent of the warehouse determines its design, dimensionality, architecture, and supporting analytical tools. Figure 15 illustrates a traditional process model performing Extraction, Transformation, and Load (ETL) procedures to obtain, validate, and transform data from the Online Transactional Processing (OLTP) systems for delivery into a staging area and the Common Data Store (CDS). It is important to note that disparate data systems can utilize the ETL, or bypass and subsequently utilize a direct access via database linkages (JDBC, ODBC, etc). The abstractions (data marts) are logical domain specific views into the data, which are exposed by the Ad-Hoc Query Builder, allowing for human readable query building, and the Business Intelligence (BI) engine, for detailed analysis and reporting. Many frameworks exist to accomplish these tasks in the open source realm and have been largely successful because they are built upon a large community of knowledge and support. To enhance the traditional data warehouse model, integration of semantic constraints utilizing the Resource Description Format (RDF) as shown in Figure 16, promotes machine locatable and sharable data resources which can uncover new utility of data which was otherwise not available.

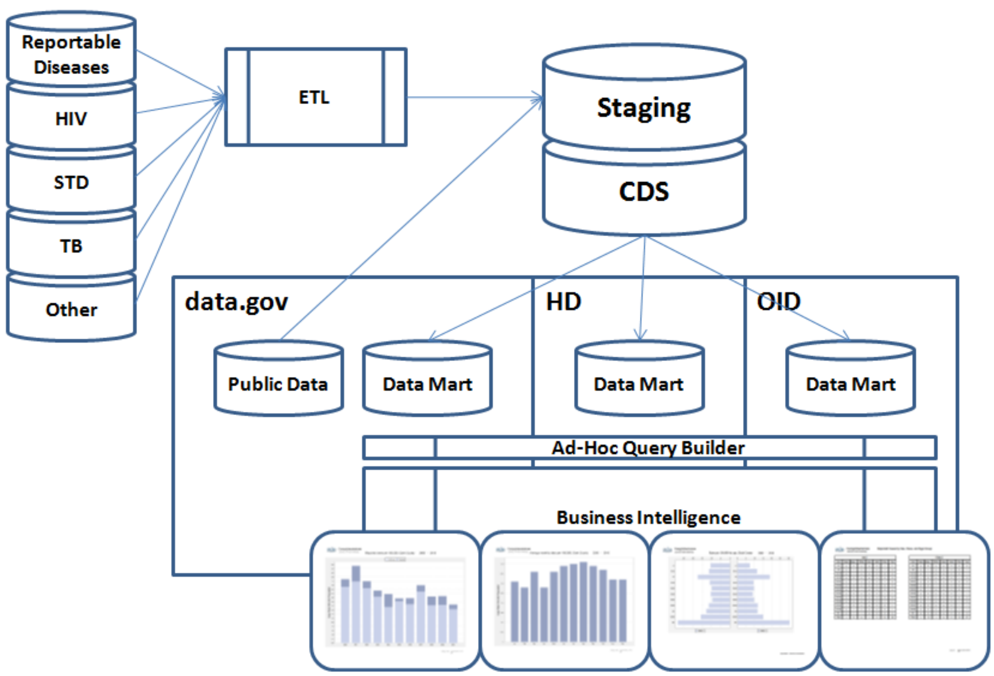


Figure 15. Enterprise Data Warehouse. This traditional approach to data warehousing would allow local, State, and Federal agencies to leverage a single architecture, creating a standardized environment in which to operate.

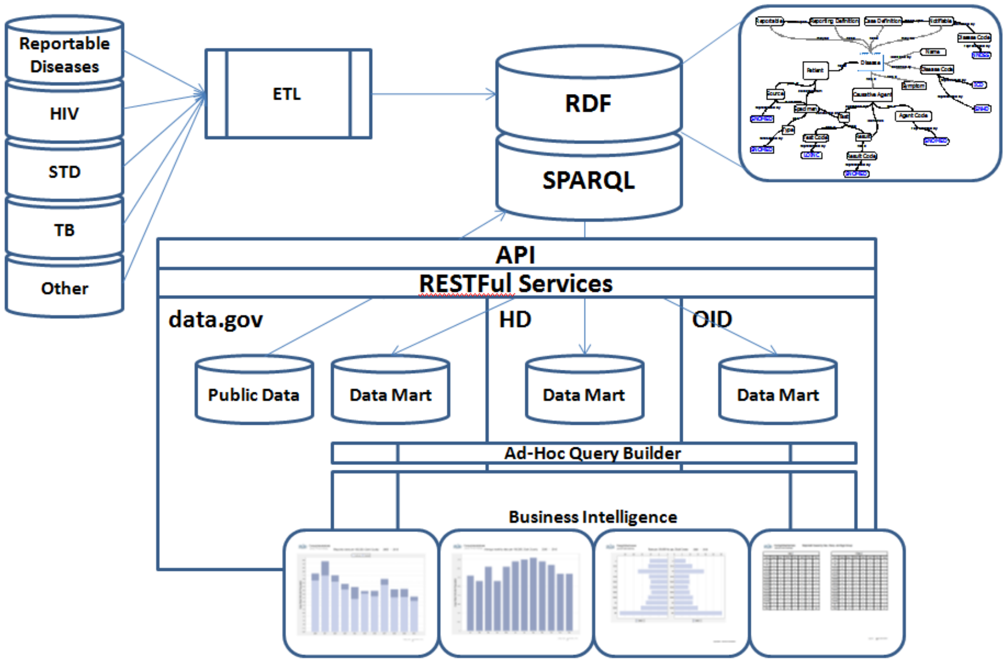


Figure 16. Service Oriented Semantically Constrained Enterprise Data Warehouse. The Resource Description Format (RDF) is applied in this Enterprise approach, maintaining semantic constraints, and a comprehensive service architecture to expose data and reporting to the respective agencies.

Assessment

The application of the sustainable architecture described in Chapter 5 provides the foundation on which to base the methodological design described in Chapter 6. The application of these methods at a local health department, illustrated in Chapter 7, demonstrate the practical implementation of a sustainable enterprise framework. A successful design can be assessed by a number of key metrics including the alignment with objectives, feasibility and sustainable nature of the design, adherence to best practices, and impact on quality.

Design

The design discussed herein is directly borne from the need to address the shortcomings that were uncovered throughout the assessment. Some of these items could not be addressed with simple fixes or updates, require planning, and bridging to ensure a seamless transition to new processes, architectures, and solutions. Comprehensive planning and bridged solutions help create a feasible design which minimizes the need to make compromises which may negatively impact the system and fail to align with necessary objectives.

The enterprise architecture (EA) enables the above mentioned strategic objectives by carefully aligning the sustainable oversight with the underlying functions to ensure the implementation spans the enterprise, and provides community wide enhancements. The sustainable architecture is directly borne from the notion of reusability in the development and use of processes, protocols, and technology.

The enterprise service oriented architecture (ESOA) provides a mechanism in which to realize the enterprise service, which by its very definition remains both flexible and scalable. The ESOA approach is a technology neutral, systems agnostic approach, which allows for the intermixing of best of breed services through open technologies.

Best Practices

The methods herein were built upon mature, proven processes, methods, and technologies with a track record of successes throughout interdisciplinary sciences. Leveraging knowledge of successful best practices and strategies, establish a concrete pattern from which to begin development. Specifically Enterprise SOA, Data Warehousing, and the Cloud based architecture are well documented, validated, and interregnal methods that were critical in this design.

The NNDSS Enterprise Architecture described herein carefully lays out a roadmap, and topology adhering to the sustainability design and implementation methodology. This approach has been applied in variety of organizational disciplines, built upon the need for a unified vision, supporting processes, and alignment of business goals. Illustrated through the assessment, and formulation of a high level business need (Chapter 3), the methods implemented (Chapter 4), and organization defined (Chapter 5), this chapter has realized a unified strategic vision; made up of the necessary components to ensure its viability, and constructed a design for the development in a practical setting.

The bridge plan designed in Chapter 6 was directly influenced by the considerations of the public health service offerings, the succession in which they will be made available, and where they are needed to be positioned within the overall architecture. ESOA was the optimal choice for legacy integration across a broad spectrum of technologies, as it is the most mature methodology, with the ability to grow the services as needed, organically. The inherent architecture promotes membership collaboration by enhancing the operational framework, in a structured fashion, maintaining neutrality between the services, providers and receivers when architected with EA in mind as will be illustrated further in Chapter 7.

At the intersection of the development of the enterprise and service oriented architecture is the notion of Cloud computing. The Cloud architecture is simply an "on demand" extension of the ESOA. Vocabulary and Knowledge services which reside in ESOA are good candidates for movement into a Cloud, as the Cloud would provide centralized mechanisms for convergence, and exposure to the public health community. For example, the above architecture allows for ESOA integration services such as Information as a Service, and Knowledge (Processes) as a Service to be exposed through Apelon and Drools in the Cloud. A further practical implementation of Cloud based systems have been illustrated in the recent development of the BioSense II project, developed by CDC. (Kass-Hout 2012) As with BioSense II, the re-architecture of the NNDSS platform is an ideal candidate for movement to the Cloud. Both solutions are newly developed based upon a well defined set of processes, applications, and integration touch points; and the normal evolution of the domain has pushed the need for ESOA based services out into the Cloud for the community to utilize.

Quality

The resulting incorporation of proven design and best practices in process development, supporting methods and technologies help ensure quality from inception. This research will demonstrate the ability to shift the burden of labor away from support infrastructure and antiquated architecture by providing the subject matter experts with the tools necessary to perform their duties, Chapter 7. This approach empowers programs to convey need, enforce directives, and maintain accountability, while removing unnecessary tasks across disparate programs; resulting in an integrated, cyclical process improvement strategy that will yield high levels of confidence, reduced error, increased communication, and an integrated workforce.

CHAPTER 7

RESULTS: IMPLEMENTATION

Introduction

The result of the aforementioned assessments and research has led to the implementation of the Southern Nevada Health District (SNHD) sustainable messaging solution uniPHii, and the disease investigation and surveillance system TriSano. uniPHii and Trisano began in December 2009 as a collaborative effort between the Office of Epidemiology (OOE) providing subject matter expertise; Informatics providing project management, architecture, and development; and support from Information Technology in operationalizing the infrastructure.

The initial planning stages of the SNHD implementation of the NNDSS enterprise structure defined herein occurred over a 3 month period, and included the gap analysis provided in Chapter 3, which defined the requirements for the newly developed systems. The development of the project charter and statement of work (SOW) included a proposed solution based upon the volatile funding streams of the agency to implement a completely sustainable, Open Source architecture. A feasibility study was conducted, reviewing the public health landscape which resulted in the identification of a newly developed Open Source disease Investigation and surveillance system, TriSano. Further process assessment uncovered the need for a messaging infrastructure to accurately facilitate rapid disease reporting, and support alignment with current national initiatives in the support of ELR, and the ONC S & I framework. (DHHS 2010)

The messaging architecture, uniPHii was architected and developed internally by the Department of Informatics, at SNHD. As described in Chapter 5, the sustainable community approach was implemented, and community partners and members were involved in the technical definition and flow needed to be truly systems agnostic. This novel approach loosely coupled together integration, terminology, and knowledge across a robust services based architecture which are available, and supported by the Open Source community at large.

uniPHii, and TriSano were developed, integrated, and deployed in parallel, over the following 4 months, and the resulting systems and the corresponding sustainable framework went into production in June of 2010. The development of this integrated, automated system has provided significant return on investment including:

- Decreased time to identify / investigate a case, which in turn may lead to reduction in morbidity
- Decreased time to the implementation of an intervention
- Increased provider and laboratory reporting rates
- Decreased staff time
- Increased quality of data

- Increased efficiency

Infrastructure

To support the internal SNHD initiatives, a multi phased plan was developed to implement a sustainable infrastructure to meet the needs of messaging, disease surveillance activities, and field investigation and testing. To determination the potential scale necessary to support the population, a preliminary investigation was performed to assess the number of messages expected, concurrent users of the system, allowing for growth and unexpected need resulting in the estimations in Table 8.

Table 8. Infrastructure per capita

Category	Years 1-2	Years 3-4
Population	2.2M[1]	2.3M[1]
Transient Population	~37.3M[3]	~36M[4]
Estimated ELR	~100,000	>400,000[2]
DIIS Staff	8	11

[1]Based upon Nevada State demographer's projections 2012
[2]Estimated ELR increase due to additional reporting of Hemoglobin A1C; NYCAR reported > 5k laboratory reports / day when HA1C was made reportable
[3]Estimated transient population based upon the Las Vegas Convention and Visitors Authority annual report.
[4]Estimated increase in growth based upon GLC analysis, 2010

Phase 1 – Integration environment provided a sandbox for end users to ensure that the system was performing as intended. The sandbox was a virtual environment which allowed for dynamic scaling to test capacity while completely integrated. The Phase 2 – Production infrastructure Figure 17, further leverages virtualization technologies through an updated technology stack. This technology allows for rapid deployment of severs should the need arise, with the ability to handle the inevitable load. Phase 3 – Production will reduce the footprint necessary by moving ALL of the components to the Cloud. This will provide dynamic provisioning as needed, while reducing “big iron”, its ongoing maintenance, and related costs. It will further facilitate adoption by partner agencies, as it will accommodate multiple end points under one umbrella solution; each having the ability to deploy to the single or a multiple instance framework based upon need.

To remain 100% sustainable, all components of the infrastructure are Open Source. The virtualization technology used is VMWare, which may be exported in the portable OVA format, allowing the framework to be placed in a multitude of environments. Each of the virtual machines supporting the environment are built upon the Ubuntu operating System, a well known, mature, and stable community project.

Connectivity

The production level architecture shown in Figure 17, demonstrates the highly scalable nature of the messaging infrastructure. External connectivity is provided by a separate 20M internet connection dedicated to this service, coupled with dedicated routers to monitor all ongoing traffic for source IP address and ports to ensure the integrity of the solution. External Traffic flows through a comprehensive hardware firewall with intrusion detection, which further monitors the messaging process. An internal high-speed switch connecting all servers related to this service keeps traffic isolated from the existing infrastructure.

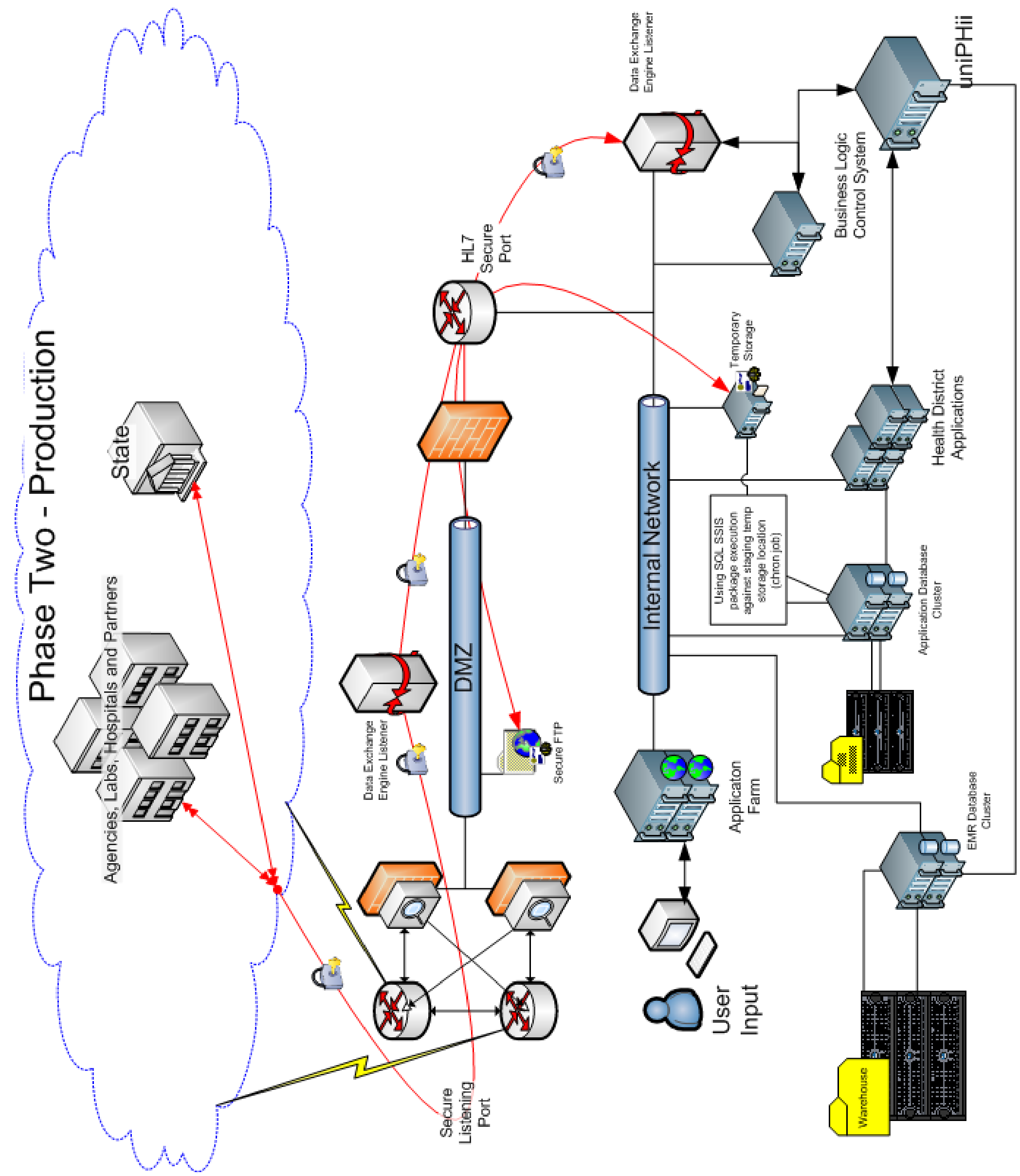


Figure 17. Phase Two – Production level architecture. This infrastructure is capable of scaling based upon the traffic initiated by the data partners and supplemental data requests. The movement from this architecture to the cloud will significantly reduce cost, and increase the level of portability, and possibly adoption of the systems for which it serves.

To eliminate need to establish dedicated connectivity with each provider, and the necessary ISAs to ensure compliance in the handshake between organizations, standard protocols are utilized including SSL over FTP, and SSL over HTTP. This connection is tightly controlled and limited to specific source IP addresses which are captured during the certification process. All inbound traffic will utilize an existing shared 9M internet connections. It passes traffic through a border router to an ASA firewall, finally routing to a server in the DMZ exposing SFTP and/or MIRTH.

The DMZ server passes inbound traffic on a secured network, specific encrypted port, to the internal endpoint consumers throughout the organization. Outbound, data to the SHD is transferred through to the County backbone. This backbone is a 10M connection that also carries all traffic to County servers used by various departments at LHD. LHD users connect directly to the internal web servers to access the application.

uniPHii: universal Public Health information infrastructure

Architecture

The underlying architecture of uniPHii (Figure 18), utilizes inter-connectable components to processes a variety of message types in a step-wise fashion, transitioning through four core modules, 1) *Integration*, 2) *Normalization*, 3) *Standardization*, and 4) *Knowledge Application*.

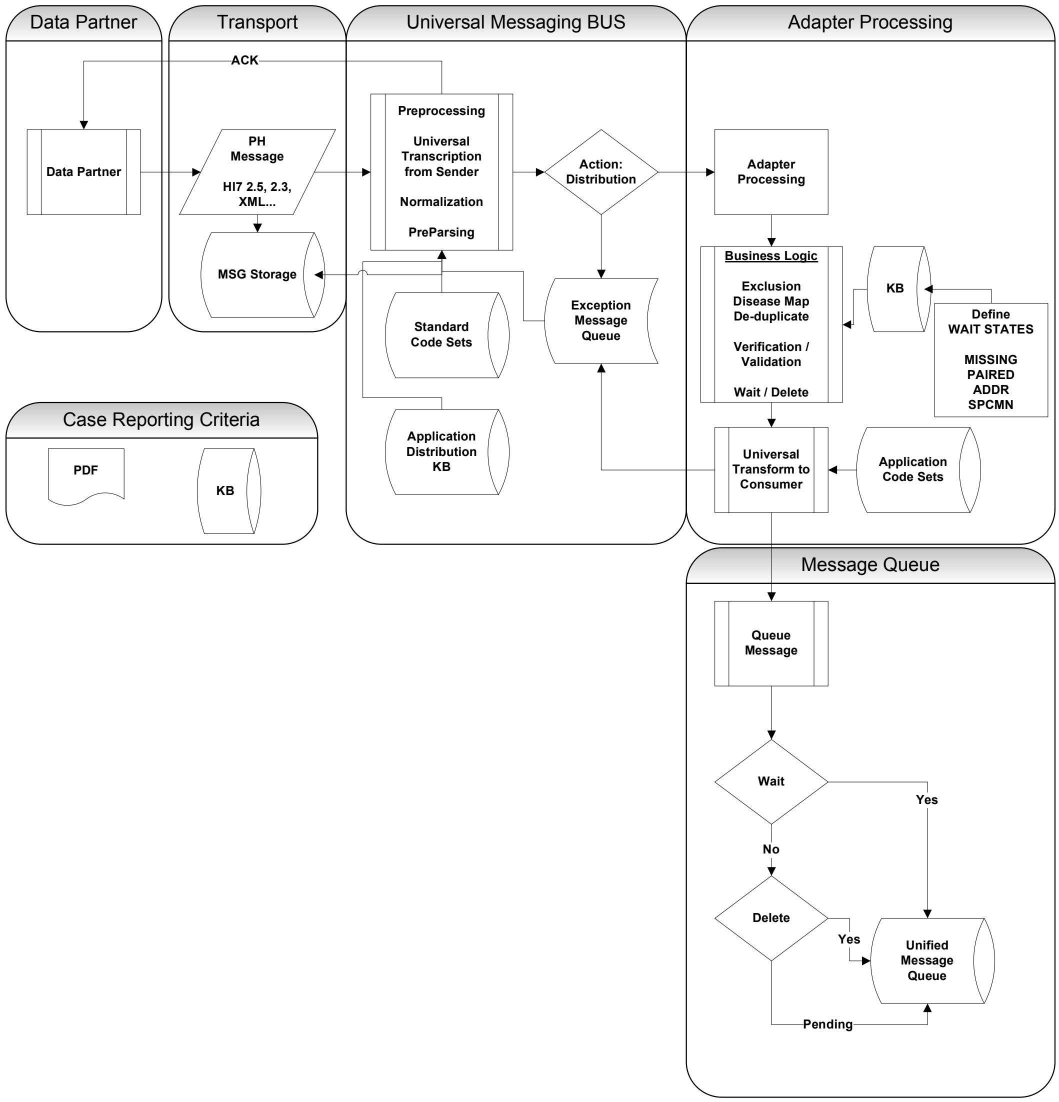


Figure 18. uniPHii architecture, and data flow

The first module *Integration* utilizes Mirth, an Open Source integration engine, to manage the movement of the message through a variety of steps which automate the receipt, transformation, delivery and consumption via standard, secure transmission protocols. Mirth has been widely adopted within the health care industry (Johns Hopkins, Allegiance Health System, Duke University Hospital System etc.), and is currently being utilized as a test platform in conjunction with the National Health Information Network (NHIN). (Mirth 2010)

The second module, *Normalization*, performs a transformation from the originating messaging syntax to an extensible syntax. This extensible syntax is representative of the business function in which it is utilized, so it is easily identifiable, minimizes the number of translations, and streamlines the application of processes utilized through the messaging lifecycle.

To ensure consistent use of vocabulary, the third module *Standardization* integrates Apelon, an Open Source terminology server, into the architecture, and standardized terminologies such as LOINC, SNOMED, and ICD may be applied to the message. (Apelon, Inc. 2010) Ontology development promotes user involvement and ownership by allowing the determination, definition, authoring, signoff and implementation to reside at the respective levels in which the terminologies exist.

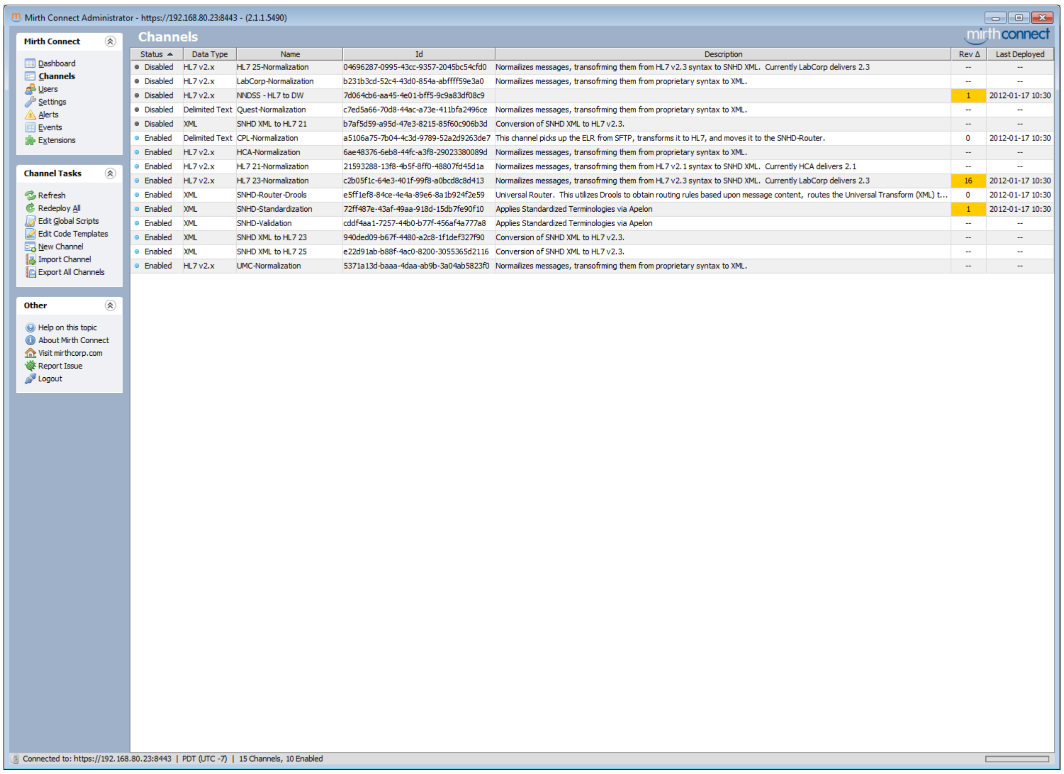
The fourth module provides *Knowledge Application*. The Drools Open Source application facilitates the authoring, approval, and execution of rules. (JBoss 2008) At each stage of the messaging lifecycle, applicable rule sets may be introduced, including rules for routing, validation, supplemental data requests, and filters.

Finally, a comprehensive web service tier exposes the core modules and underlying data. This service tier applies an Enterprise Service Bus (ESB) model, providing a level of abstraction that allows each core component of uniPHii to remain loosely coupled. This is a critical component which is fundamental in this plug and play environment.

Integration

Due to the variation of the systems from which public health data originates and is acquired, inbound messages first need to be integrated. Integration of disparate Public Health data requires the use of several technologies. At the core of uniPHii is the Mirth integration engine (Figure 19A), providing a robust feature set in the movement, transformation, and application of knowledge to a message. In the peripheral are secure protocols for use in delivery, including SSL over FTP, and SSL over HTTP. While other standard protocols are supported, the majority of data partners do not have the technical expertise to implement or support them. Upon receipt of messages from a data partner via a secure protocol, the integration engine begins its processing. Each partner may have a unique receiver, or share from a library of standard receivers based upon the syntax of the message. For example, those data partners who transmit messages in HL7 may use either the HL7 2.3, or 2.5 standard receivers. The receiver determines what is to be done with the message, and the subsequent steps, by application of rule sets based upon a messages type and syntax. Global knowledge may be applied to the message at this time, prior to *Standardization*, and routing.

Messages utilize adapters to facilitate the consumption of a message into an endpoint. Similar to a receiver, these adapters may be obtained from a standard library or custom built to meet a specific need. Adapters may apply specific knowledge, as opposed to the global knowledge applied further upstream.



Status ▲	Data Type	Name	Id	Description	Rev Δ	Last Deployed
Disabled	HL7 v2.x	HL7 25-Normalization	04696287-0995-43cc-9357-2045bc54cfd0	Normailizes messages, transofrming them from HL7 v2.3 syntax to SNHD XML. Currently LabCorp delivers 2.3	--	--
Disabled	HL7 v2.x	LabCorp-Normalization	b231b3cd-52c4-43d0-854a-abffff59e3a0	Normailizes messages, transofrming them from proprietary syntax to XML.	--	--
Disabled	HL7 v2.x	NNDSS - HL7 to DW	7d064cb6-aa45-4e01-bff5-9c9a83df08c9		1	2012-01-17 10:30
Disabled	Delimited Text	Quest-Normalization	c7ed5a66-70d8-44ac-a73e-411bfa2496ce	Normailizes messages, transofrming them from proprietary syntax to XML.	--	--
Disabled	XML	SNHD XML to HL7 21	b7af5d59-a95d-47e3-8215-85f60c906b3d	Conversion of SNHD XML to HL7 v2.3.	--	--
Enabled	Delimited Text	CPL-Normalization	a5106a75-7b04-4c3d-9789-52a2d9263de7	This channel picks up the ELR from SFTP, transforms it to HL7, and moves it to the SNHD-Router.	0	2012-01-17 10:30
Enabled	HL7 v2.x	HCA-Normalization	6ae48376-6eb8-44fc-a3f8-29023380089d	Normailizes messages, transofrming them from proprietary syntax to XML.	--	--
Enabled	HL7 v2.x	HL7 21-Normalization	21593288-13f8-4b5f-8ff0-48807fd45d1a	Normailizes messages, transofrming them from HL7 v2.1 syntax to SNHD XML. Currently HCA delivers 2.1	--	--
Enabled	HL7 v2.x	HL7 23-Normalization	c2b05f1c-64e3-401f-99f8-a0bcd8c8d413	Normailizes messages, transofrming them from HL7 v2.3 syntax to SNHD XML. Currently LabCorp delivers 2.3	16	2012-01-17 10:30
Enabled	XML	SNHD-Router-Drools	e5ff1ef8-84ce-4e4a-89e6-8a1b924f2e59	Universal Router. This utilizes Drools to obtain routing rules based upon message content, routes the Universal Transform (XML) t...	0	2012-01-17 10:30
Enabled	XML	SNHD-Standardization	72ff487e-43af-49aa-918d-15db7fe90f10	Applies Standardized Terminologies via Apelon	1	2012-01-17 10:30
Enabled	XML	SNHD-Validation	cddf4aa1-7257-44b0-b77f-456af4a777a8	Applies Standardized Terminologies via Apelon	--	--
Enabled	XML	SNHD XML to HL7 23	940ded09-b67f-4480-a2c8-1f1def327f90	Conversion of SNHD XML to HL7 v2.3.	--	--
Enabled	XML	SNHD XML to HL7 25	e22d91ab-b88f-4ac0-8200-3055365d2116	Conversion of SNHD XML to HL7 v2.3.	--	--
Enabled	HL7 v2.x	UMC-Normalization	5371a13d-baaa-4daa-ab9b-3a04ab5823f0	Normailizes messages, transofrming them from proprietary syntax to XML.	--	--

Figure 19A. Mirth Administration Console - Channel Definition

Normalization

To facilitate normalization, uniPHii utilizes the Open Application Group's (OAG) Business Object Document (BOD) architecture. This module is applied to all messages, regardless of origination or syntax (Figure 19B). OAG, beginning in 1995, is a non-for-profit organization focused on interoperability of information between entities, both intra- and inter-enterprise. The OAG Integration Specification (OAGIS) provides a point at which to begin an integration effort. Robust, real-world examples of common tasks are provided to assist the implementer or author in the adoption and/or creation of the messaging for a specific use case. A BOD is representative of specific tasks which need to be performed, and is characterized by the Verb + Noun which best describes the transaction. uniPHii utilizes a newly developed ELR specific BOD implementation, which has been created internally to facilitate general common procedures in the exchange of laboratory information including ListMessage, ProcessMessage, RequestMessage and SyncMessage. This architecture provides the necessary information to properly manipulate a message through its lifecycle. (Appendix C)

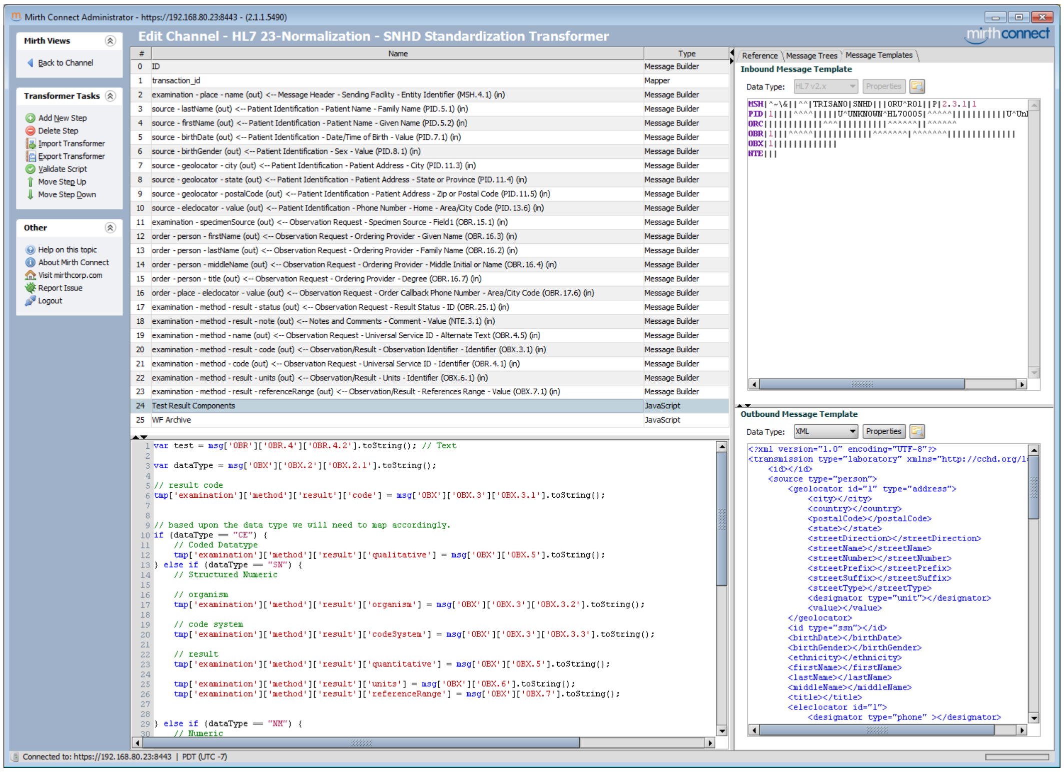


Figure 19B. Normalization of the HL7 2.3 structure to the Laboratory BOD.

Standardization

Standardized terminologies are utilized in the processing of messages, and standardization is applied at the global level for movement of the message, or at the adapter processing level where version specific terminologies may constrain the consuming system. The ideal situation would consist of data partners utilizing standard nomenclature such as LOINC, SNOMED, and ICD in the exchange of data; however this is most often not the case.

The initial step in the standardization process is currently performed outside of electronic processing. Instead, a manual process in used in creating an ontological representation of a vocabulary. The development of an ontology for both standard and non standard vocabularies allows for the mapping of a distinct set of entities to a standardized master set. uniPHii can then invoke a query based upon the messages vocabulary, and return a standard set of terms, and codes. The ontology creation is carried out, and maintained within Apelon, an Open Source terminology server. Apelon (Figure 19C) provides a flexible framework in which to develop the necessary vocabulary and constraints, and a robust set of APIs to support their integration throughout the data processing lifecycle. To maintain a truly portable solution, the native APIs exposed through Apelon have been wrapped and made available as web services.

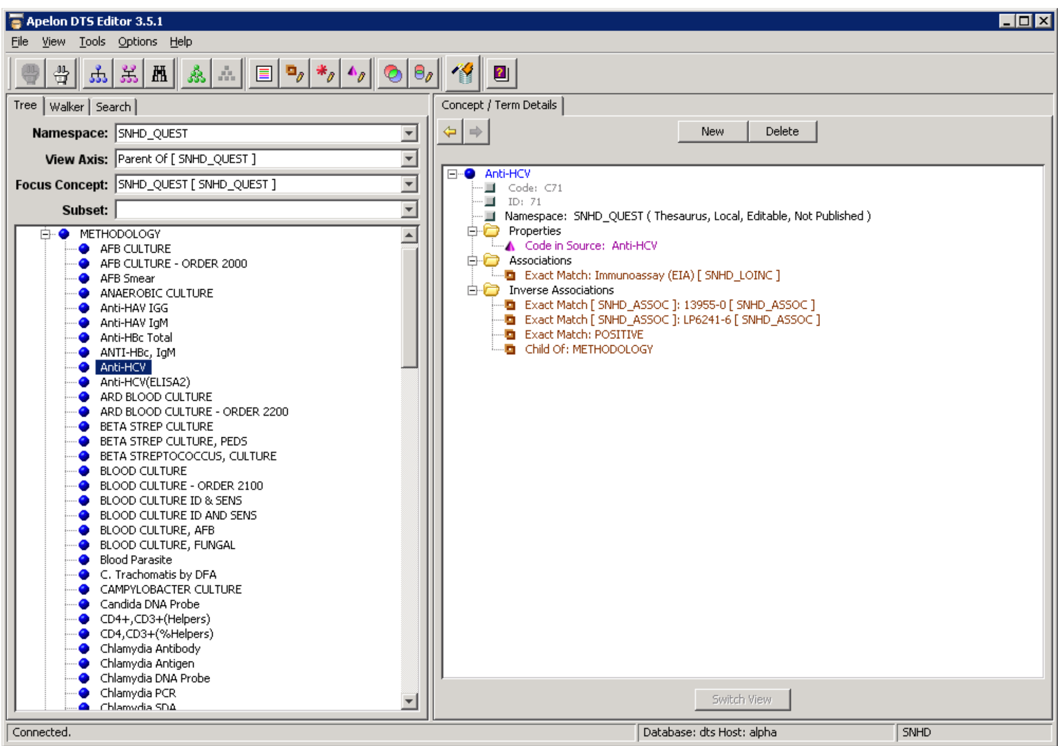


Figure 19C. Apelon ontological representation of laboratory methods, and the respective mapping to a standard nomenclature.

Knowledge Representation and Application

Reflective of the business processes for which it supports, the underlying uniPHii Knowledge Base is a dynamic, process focused framework that supports the gathering, authoring, approval and execution of knowledge. The foundation of this framework is the Open Source Drools suite (Figures 19 D, E & F), a well developed initiative with a vast community of developers and users alike. The initial development concentrated on defining the use cases and entities utilized in the construct of public health specific knowledge. This resulted in the creation of a domain specific, open source aligned, public health front end UI built using the Smart GWT SDK. This interface provides a robust mechanism to author, and approve rules for case definition, validations, routing, and the like. Once authored and approved, the rules are exposed natively by a set of APIs. The APIs have been wrapped as made available as web services to ensure portability and anticipating movement to the Cloud, as the rules may be executed from a variety of calling systems.

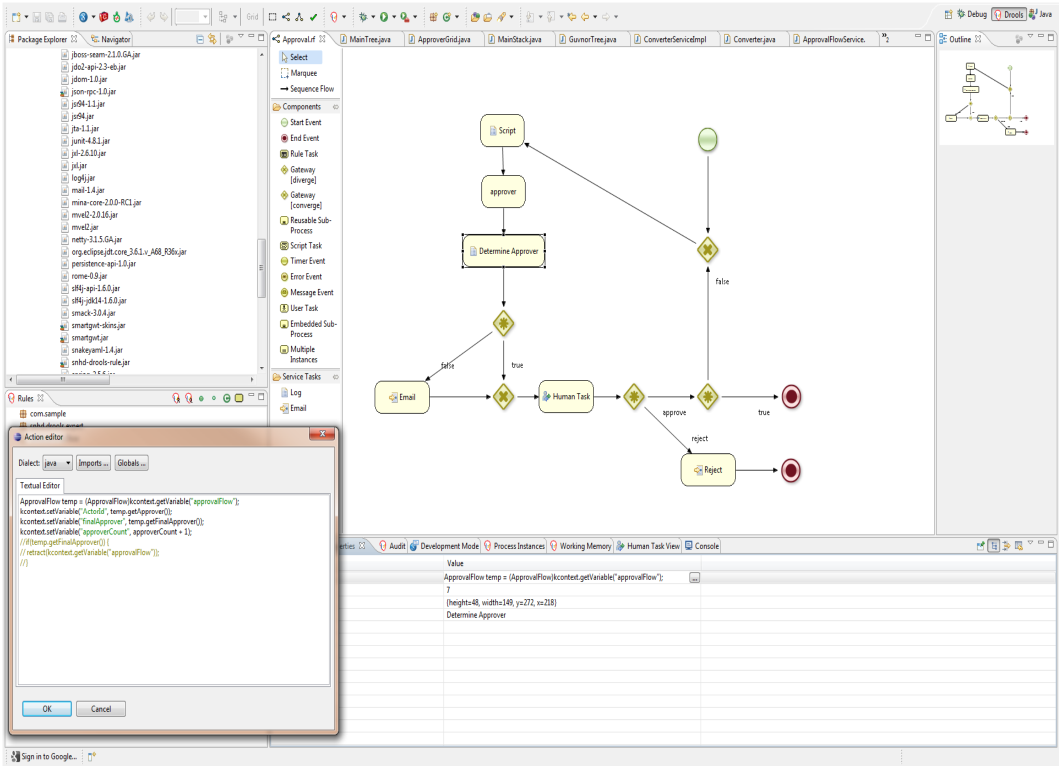
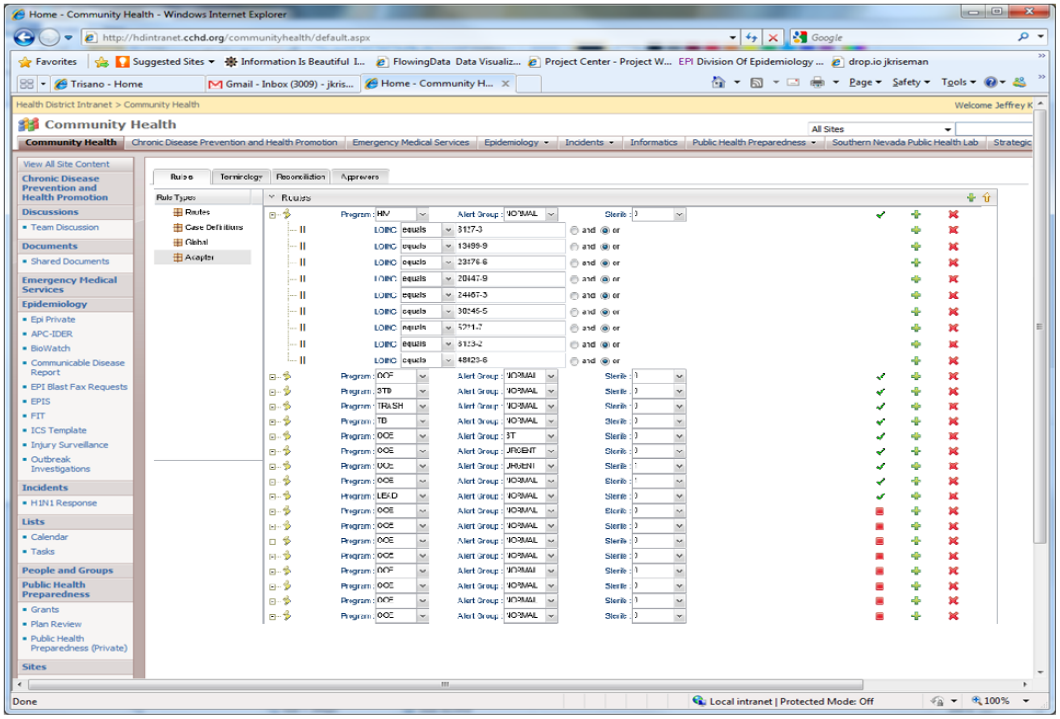
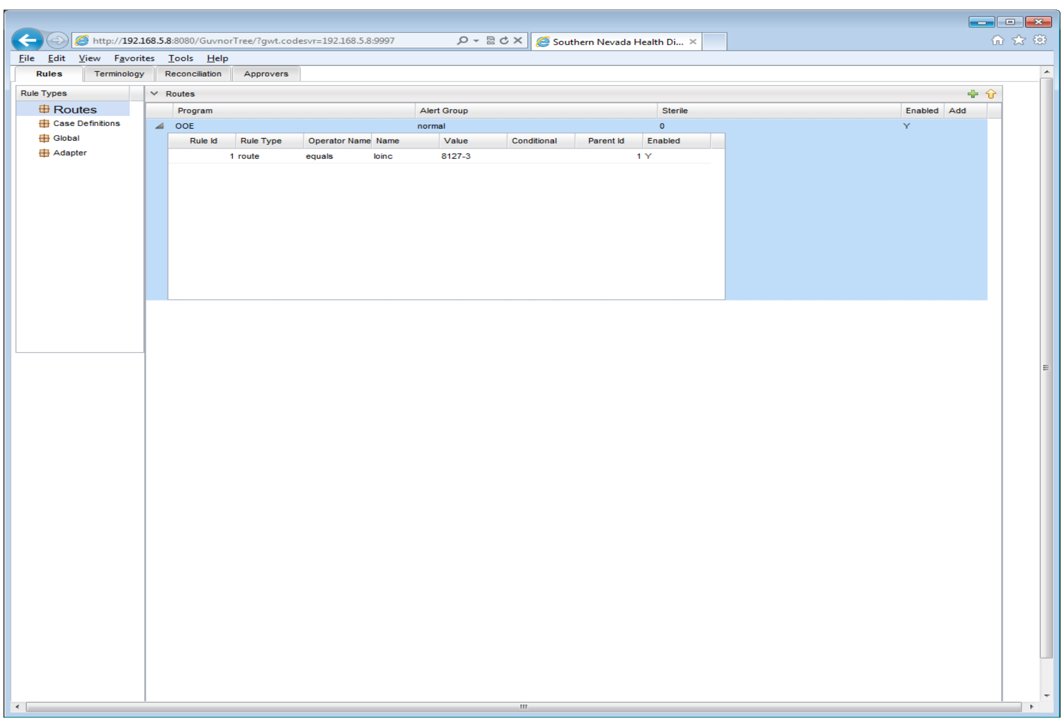


Figure 19D. Drools workflow definition for authoring, and approval.

The Drools knowledge base is invoked from the Mirth integration engine at both the global and adapter level of message processing. At the global level, filtering, global validations, and rules are applied regardless of the messages respective endpoint consumer. Once the global rules are applied, the normalized / standardized message is interpreted by the rules repository for routing. Each route may have its own set of logic which can be applied pre-consumption. An important feature of the architecture allows rule execution to request supplemental data from the data's originating source. This promotes integration with each of the data partners to facilitate a bi-directional relationship in electronic communications.





Figures 19E & F. Initial development of the uniPHii public health UI for administering rules, terminologies, reconciliation, and approval processes at the adapter (consumer). Latest development of a streamlined public health user interface based upon usability considerations, and HCI principles.

Audit / Error Handling / Reconciliation

Each raw message introduced into the uniPHii pipeline is initially stored in its raw format in an audit table. As the message moves through the step-wise processes, and transformations or standardizations applied, they are captured in detail. If any errors should occur during the process, the message is placed into a reconciliation queue which captures the error information including context, node, and type. As a part of the uniPHii Drools implementation, the UI includes a configuration area for alerting, and a reconciliation tool which empowers the end user in resolution of any discrepancies as presented in Figure 19G.

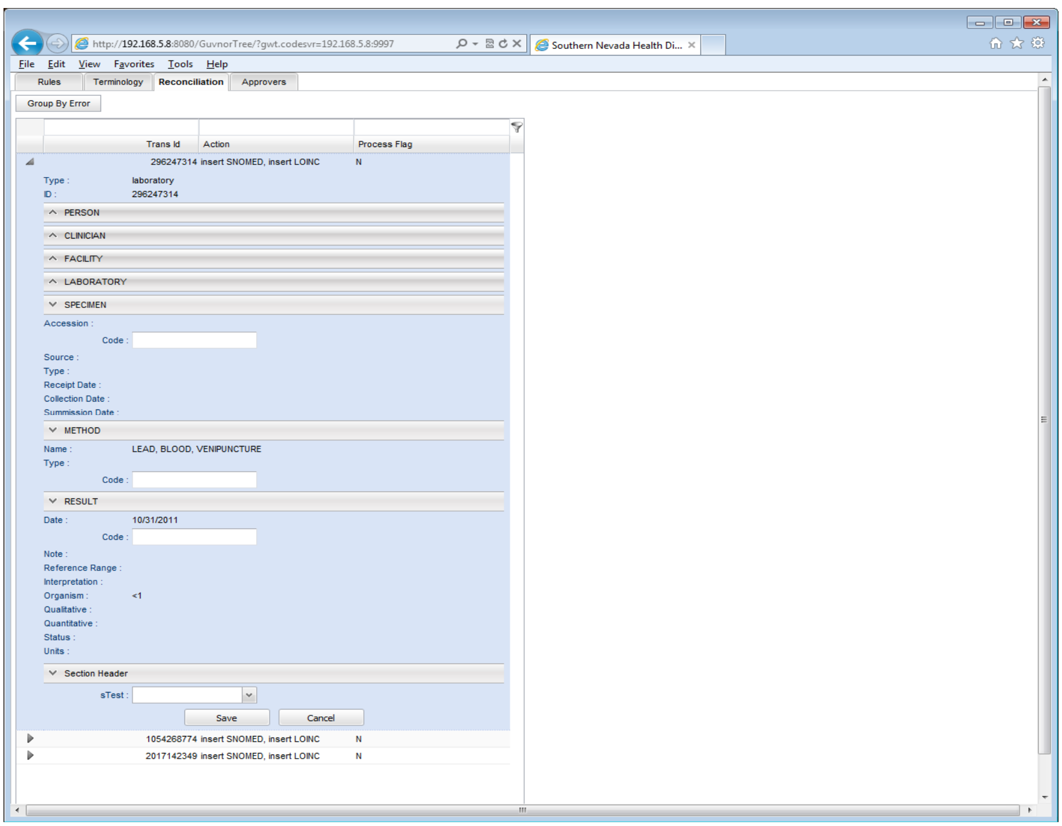


Figure 19G. Reconciliation of laboratory results.

Disease Surveillance and Investigation

Message Integration

A comprehensive set of web APIs were created through a collaborative effort which provides an exhaustive interface, as well as application of workflow from external sources which need to seamlessly interact with TriSano. The web API provides a dynamic XML structure, based upon underlying meta-data from within TriSano. All standardized libraries, validation criteria, etc are exposed within the document as Atom links, described above.

Electronic Laboratory Reporting (ELR) API exposes the functionality which allows HL7 2.x messages to be consumed by the application. ELR may be consumed independently and resolved in the *Staged Messages* queue (Figure 20A), or as part of a larger workflow in which the message is interrogated in uniPHii, knowledge applied through Drools, and a morbidity event created, the laboratory report consumed, and the morbidity approved for investigation by the jurisdiction and routed to the respective DIIS staff.

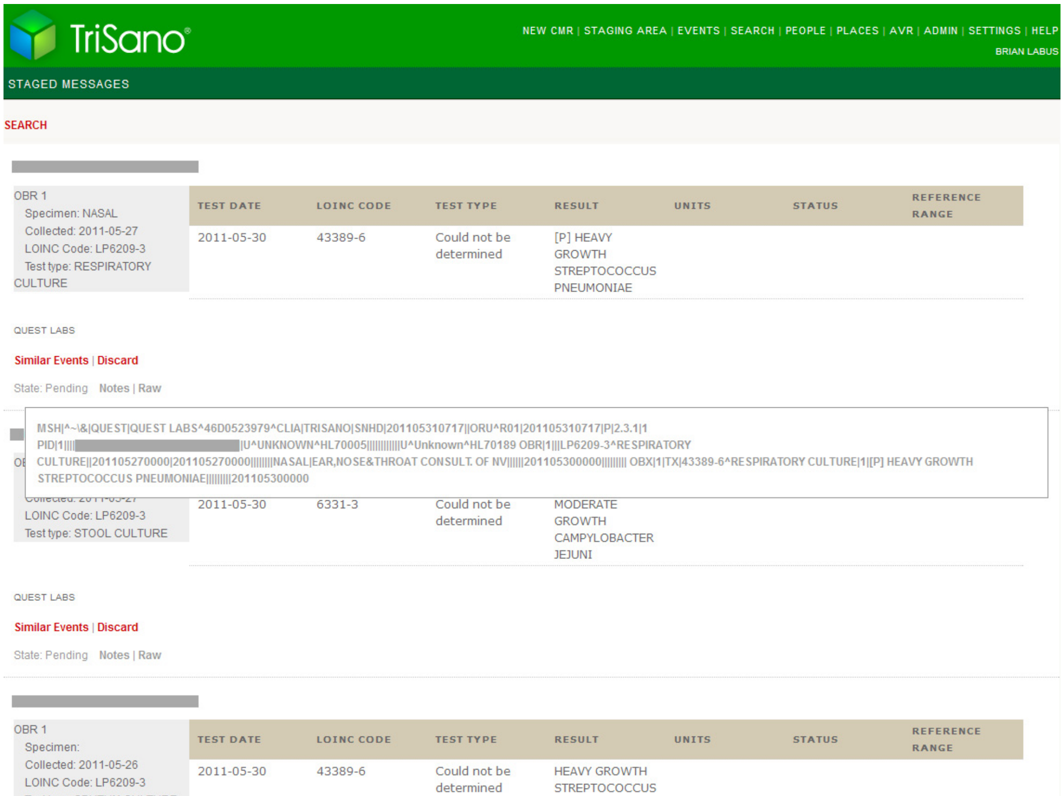


Figure 20 A. TriSano Staged Messaging

Through the same external mechanisms, TriSano provides a robust XML which can easily be transformed into standard outputs for transport of inter jurisdictional, State based or federal public health reporting. (Appendix D)

Investigation

Workflow

Investigation may begin with a simple phone call, fax, or ELR delivery of laboratory results. TriSano provides a configurable workflow which facilitates the movement of the confidential morbidity report (CMR) throughout its lifecycle. Initially, the CMR must be accepted by a state and/or a jurisdiction and routed to the respective agency for approval

(Figure 20B). Once approved, it allows for the assignment of an investigator who has an opportunity to accept/reject the report. Once the investigation has been completed, the system enforces the workflow through to completion at the local and/or state level.

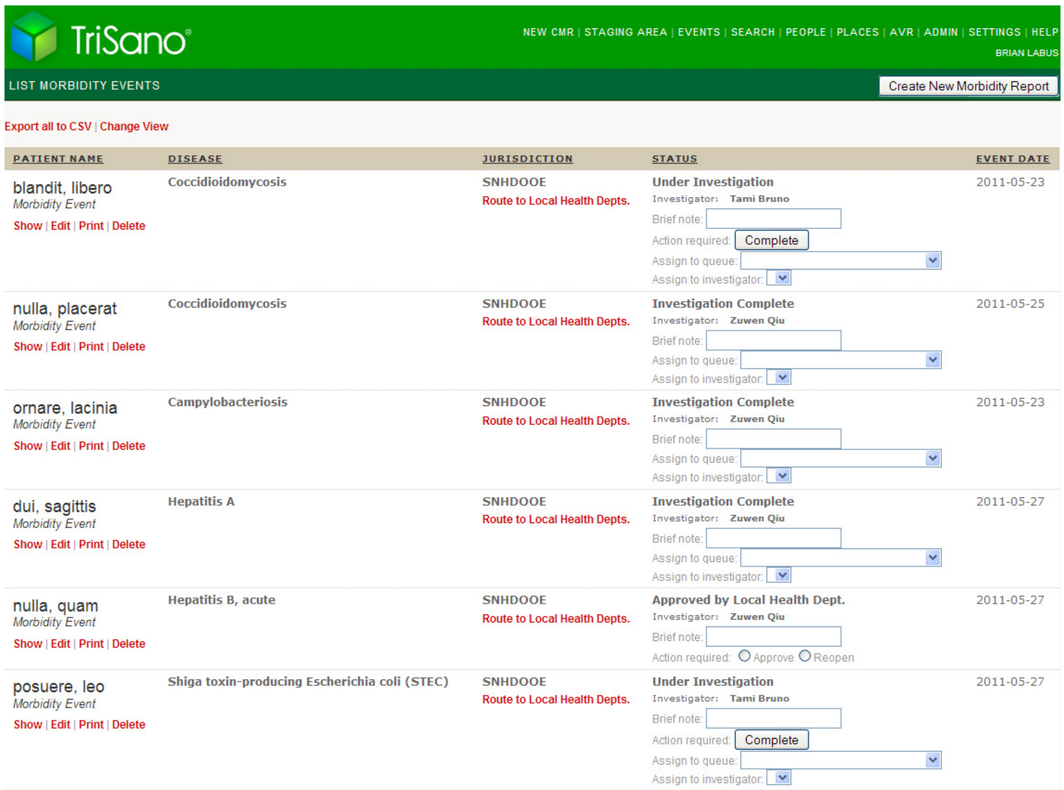
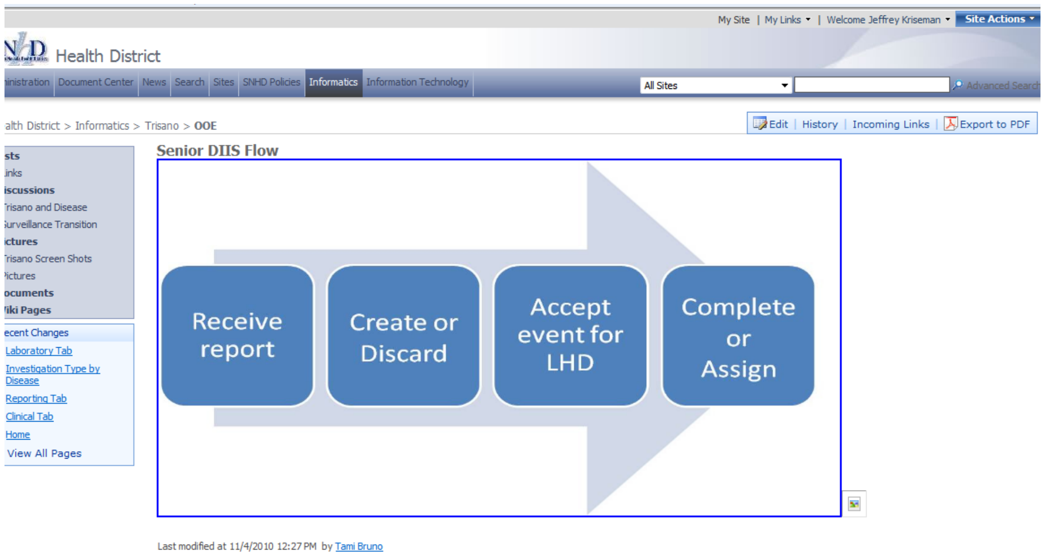
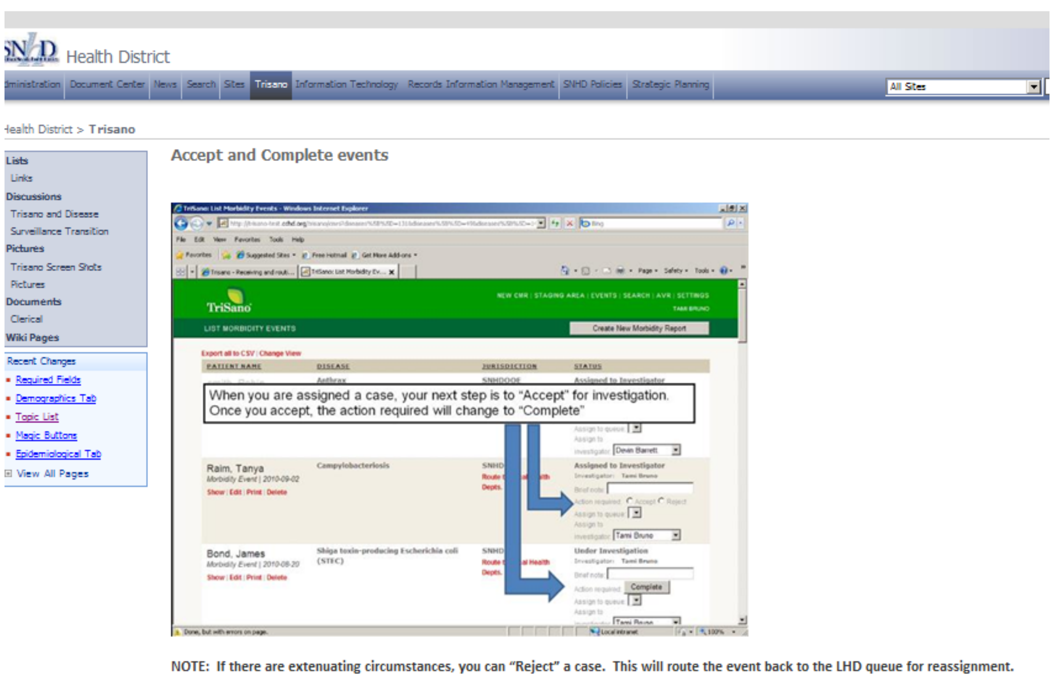


Figure 20 B. TriSano approval processes.

To ensure transparency, and cross training throughout the programs, a dynamic, program driven, workflow focused WIKI was created. Each role and respective workflow was defined, and linked to support and training pages to assist the end users in understanding the system, and transferring knowledge amongst peers at any point in time during an investigation (Figures 20 C & D).





Figures 20 C& D. TriSano Wiki.

User Interface Development

TriSano provides the core functionality to support disease investigations. It does not however define *what*, and *how* the data are collected. The User Interfaces (UI) illustrated below (Figures 20E – M) were developed internally through ha join effort between the informatics and program staff. Initial development of the UI focused on the CDC reporting criteria for specific disease types. Each CDC form, and their respective elements were entered into a spreadsheet, and unique and overlapping elements defined. The Master List contained a unique, non overlapping set of elements from which the forms were to be built. Each UI was constructed with the intent in nesting forms. For example, demographics, enteric and foodborne diseases, etc. were created as standalone forms which were then nested into the UI within the specified subsection as necessary. This resulted in a reduction of the number of forms necessary to facilitate investigation, and ease of implementation and maintenance. Disease specific risk factor data however was specified per disease based upon the reporting requirements of the CDC; and can be updated ad-hoc, and revisions maintained.

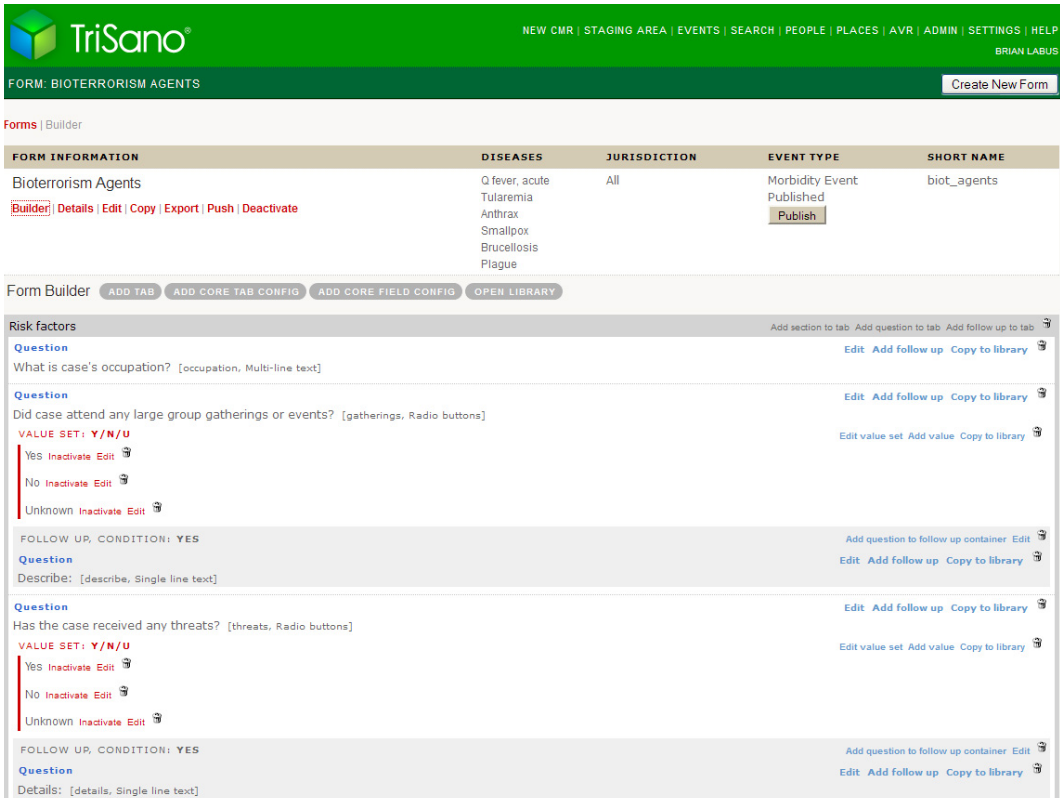


Figure 20 E. TriSano Form Builder. User defined layouts and objects provide a robust mechanism in which to define investigation and surveillance data collection.

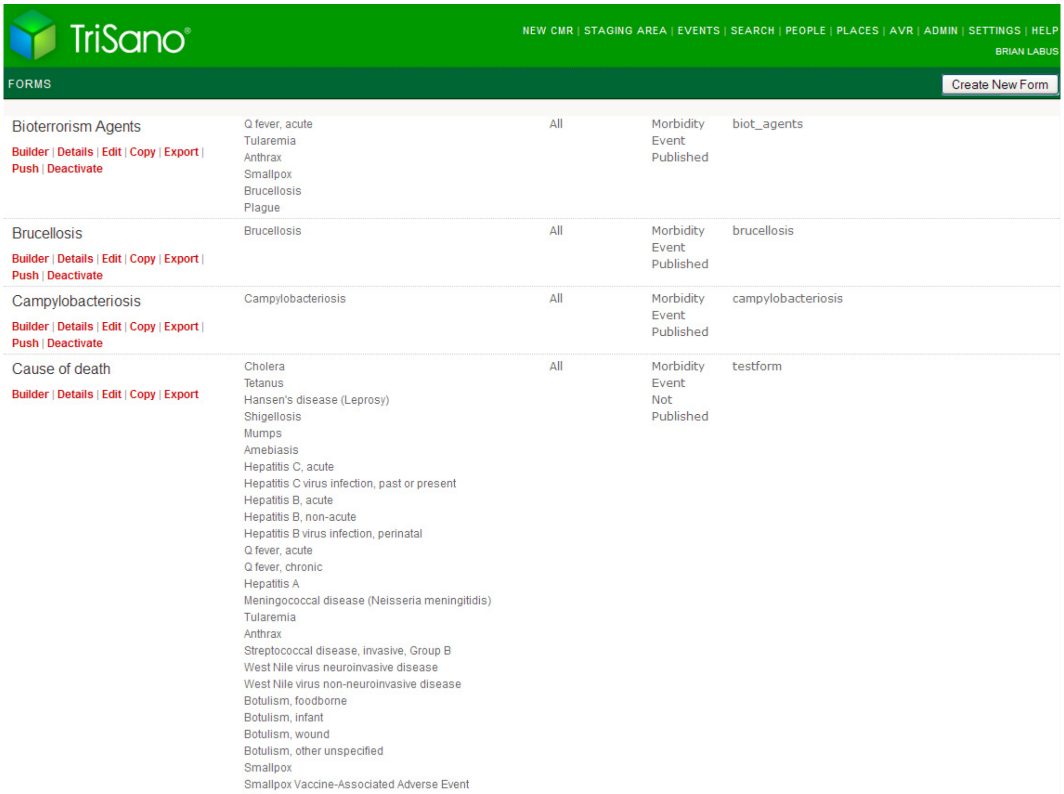
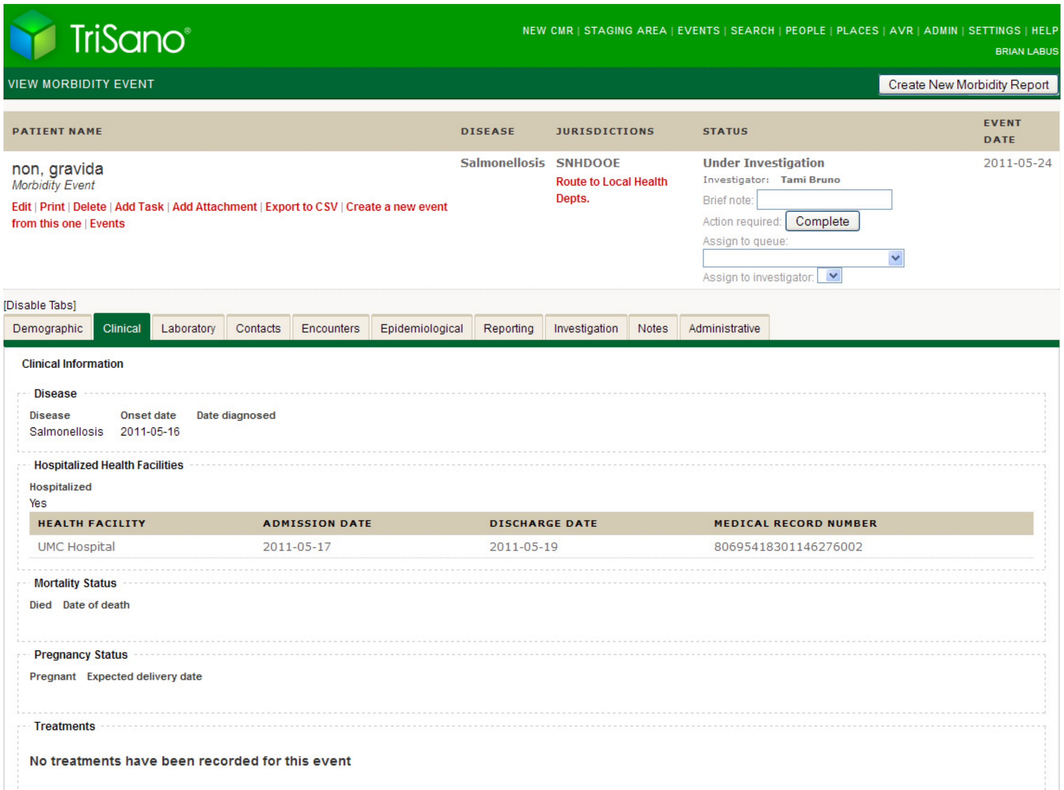
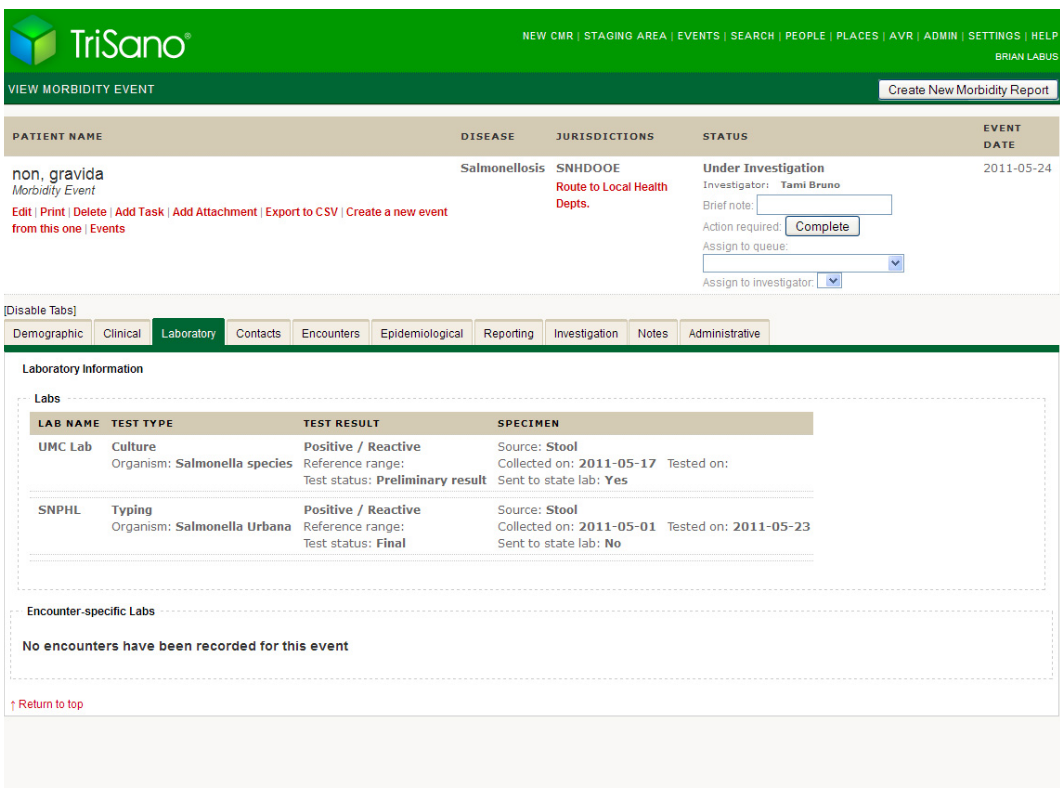


Figure 20 F. TriSano Form library. The form library may be shared within or across multiple public health agencies, further promoting the adoption of these sustainable tools.


TriSano
NEW CMR | STAGING AREA | EVENTS | SEARCH | PEOPLE | PLACES | AVR | ADMIN | SETTINGS | HELP
BRIAN LABUS
VIEW MORBIDITY EVENT
Create New Morbidity Report
PATIENT NAME
DISEASE
JURISDICTIONS
STATUS
EVENT DATE
non, gravida
Morbidity Event
Edit | Print | Delete | Add Task | Add Attachment | Export to CSV | Create a new event from this one | Events
Salmonellosis
SNHDOOE
Route to Local Health Depts.
Under Investigation
Investigator: Tami Bruno
Brief note:
Action required:
Complete
Assign to queue:
Assign to investigator:
2011-05-24
[Disable Tabs]
Demographic
Clinical
Laboratory
Contacts
Encounters
Epidemiological
Reporting
Investigation
Notes
Administrative
Clinical Information
Disease
Disease
Onset date
Date diagnosed
Salmonellosis
2011-05-16
Hospitalized Health Facilities
Hospitalized
Yes
HEALTH FACILITY
ADMISSION DATE
DISCHARGE DATE
MEDICAL RECORD NUMBER
UMC Hospital
2011-05-17
2011-05-19
80695418301146276002
Mortality Status
Died
Date of death
Pregnancy Status
Pregnant
Expected delivery date
Treatments
No treatments have been recorded for this event


TriSano
NEW CMR | STAGING AREA | EVENTS | SEARCH | PEOPLE | PLACES | AVR | ADMIN | SETTINGS | HELP
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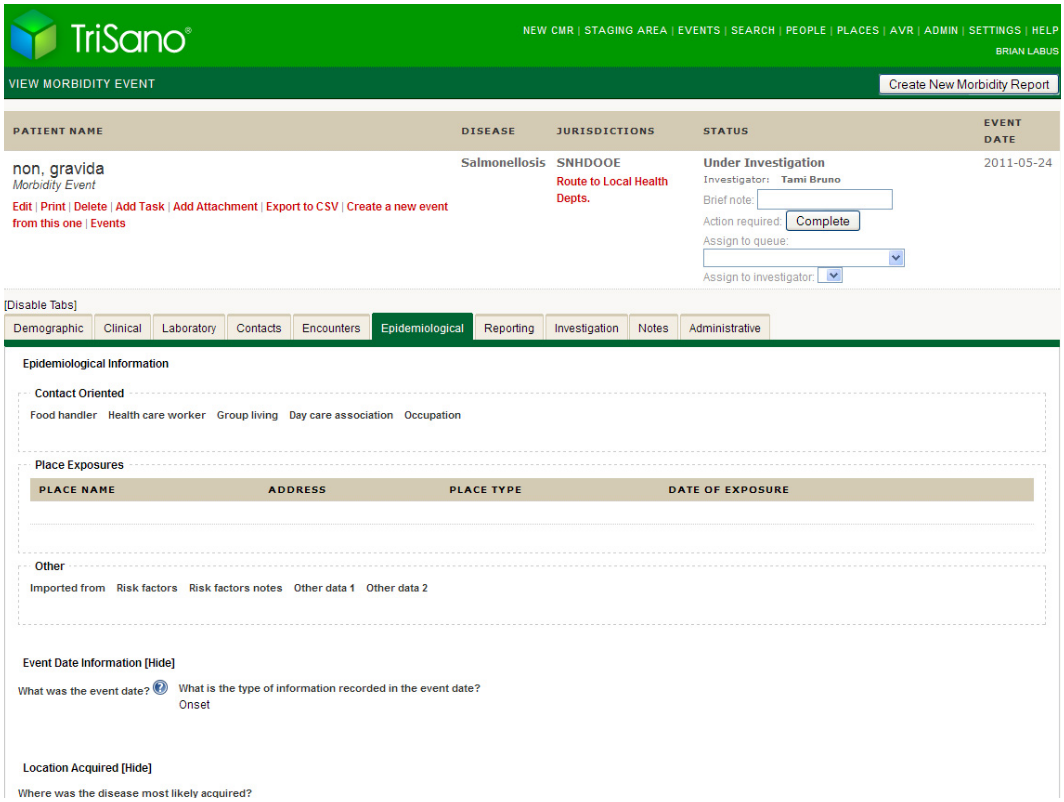
PATIENT NAME
DISEASE
JURISDICTIONS
STATUS
EVENT DATE
non, gravida
Morbidity Event
Edit | Print | Delete | Add Task | Add Attachment | Export to CSV | Create a new event from this one | Events
Salmonellosis
SNHDOOE
Route to Local Health Depts.
Under Investigation
Investigator: Tami Bruno
Brief note:
Action required:
Complete
Assign to queue:
Assign to investigator:
2011-05-24
[Disable Tabs]
Demographic
Clinical
Laboratory
Contacts
Encounters
Epidemiological
Reporting
Investigation
Notes
Administrative
Laboratory Information
Labs
LAB NAME
TEST TYPE
TEST RESULT
SPECIMEN
UMC Lab
Culture
Organism: Salmonella species
Positive / Reactive
Reference range:
Test status: Preliminary result
Source: Stool
Collected on: 2011-05-17 Tested on:
Sent to state lab: Yes
SNPHL
Typing
Organism: Salmonella Urbana
Positive / Reactive
Reference range:
Test status: Final
Source: Stool
Collected on: 2011-05-01 Tested on: 2011-05-23
Sent to state lab: No
Encounter-specific Labs
No encounters have been recorded for this event
↑ Return to top



Figures 20 G, H & I. TriSano Investigation Interface. The end result of user configuration is the investigation templates applied to the system, These template are defined by the end user, and rely upon underlying metadata, ,and standardized libraries of persons, places, and entities to drive standardized data collection.

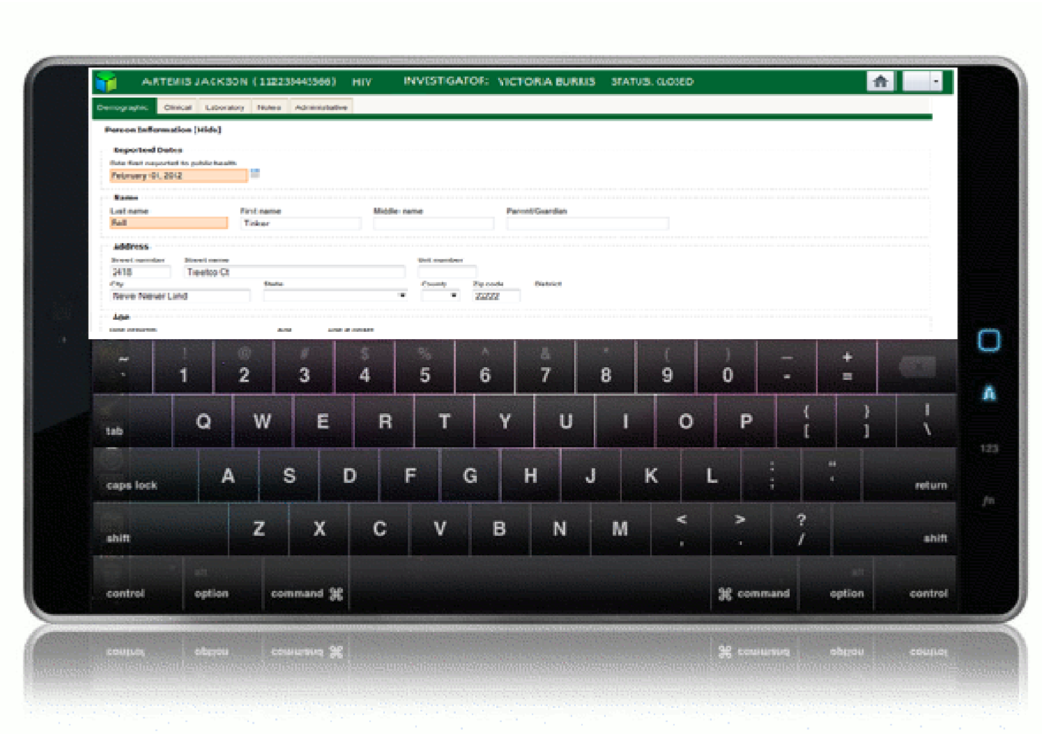
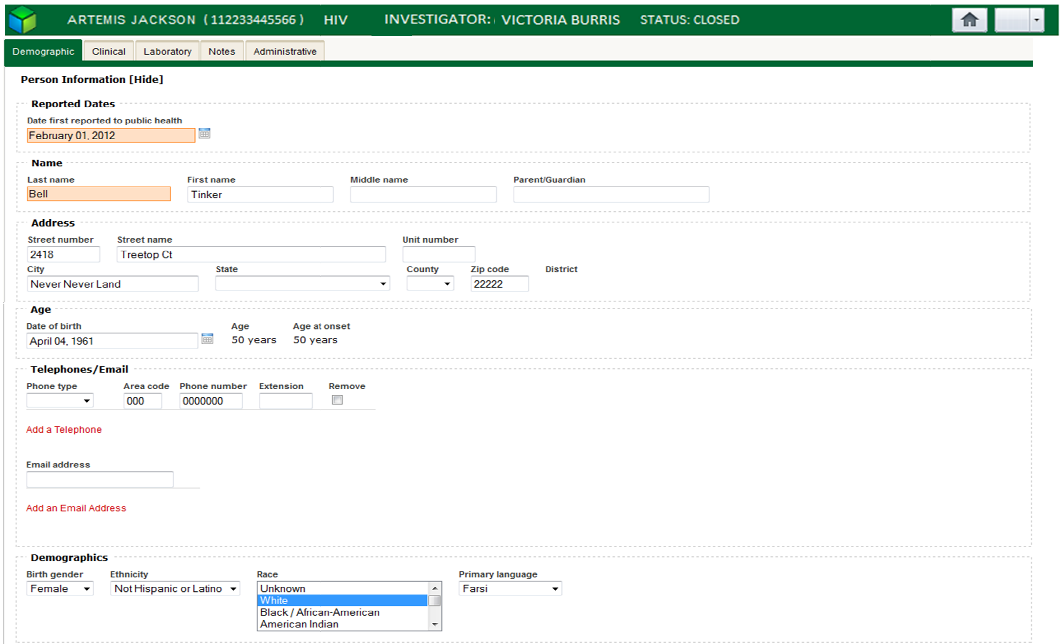
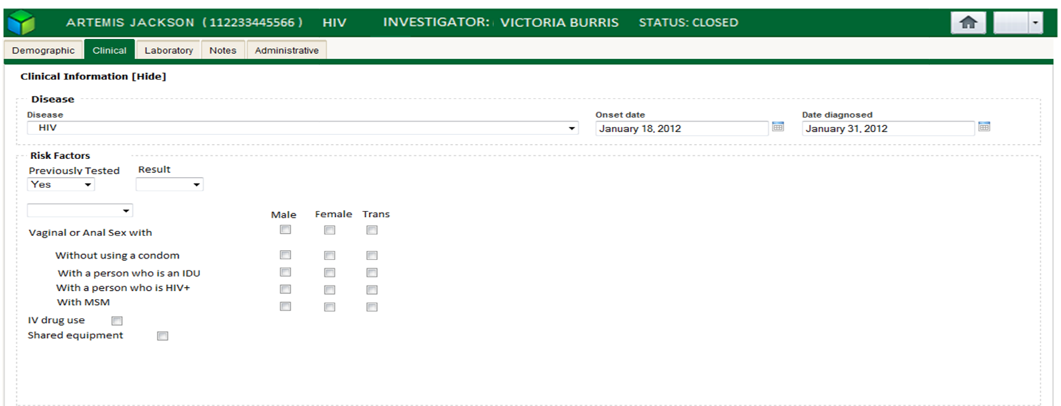
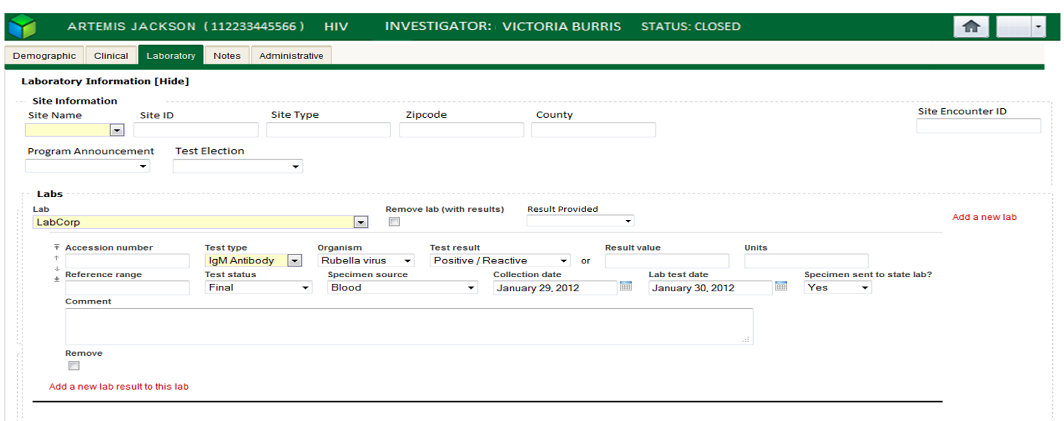


Figure 20 J. The most recent development, in-work, has been focused upon a mobile solution which may be deployed in an active or passive mode via a variety of mobile devices. This move the testing and investigation protocols to the front lines, where the DIIS staff may conduct rapid testing, have a positive result, and complete a morbidity and contact tracing in a single encounter.







Figures 20 K, L & M. The mobile application provides many of the same features as the server based solution.

Data Warehouse, Analysis, Visualization, and Reporting

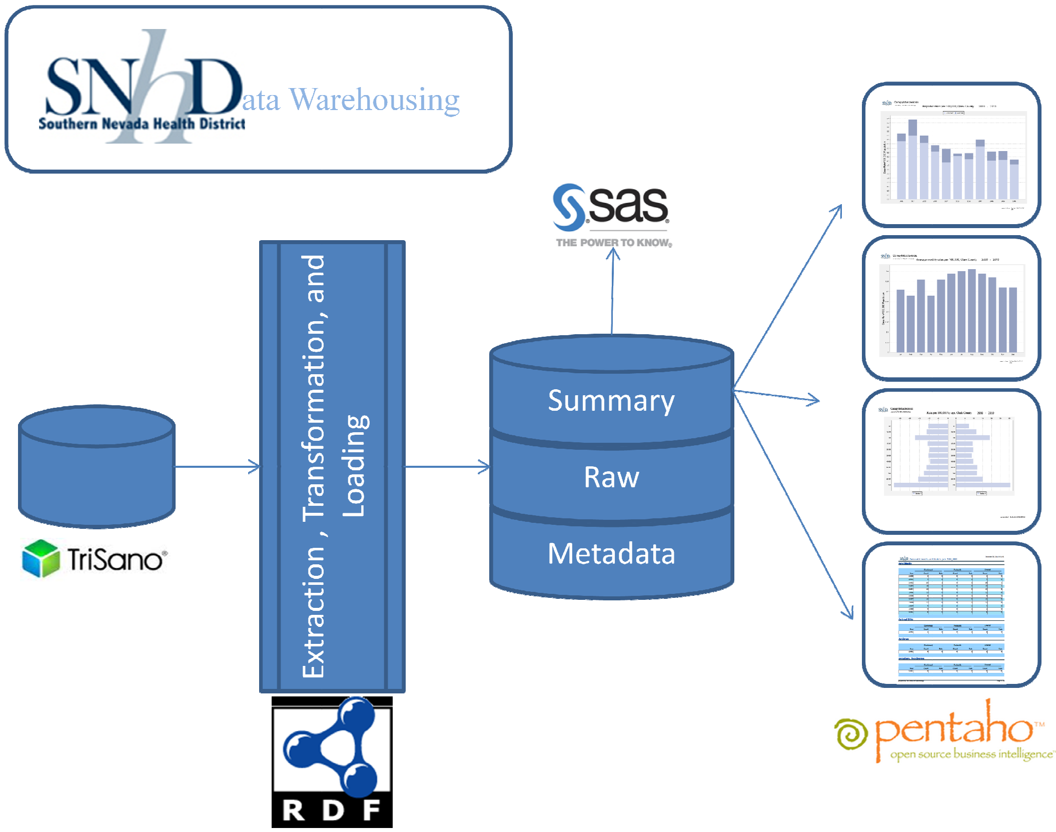


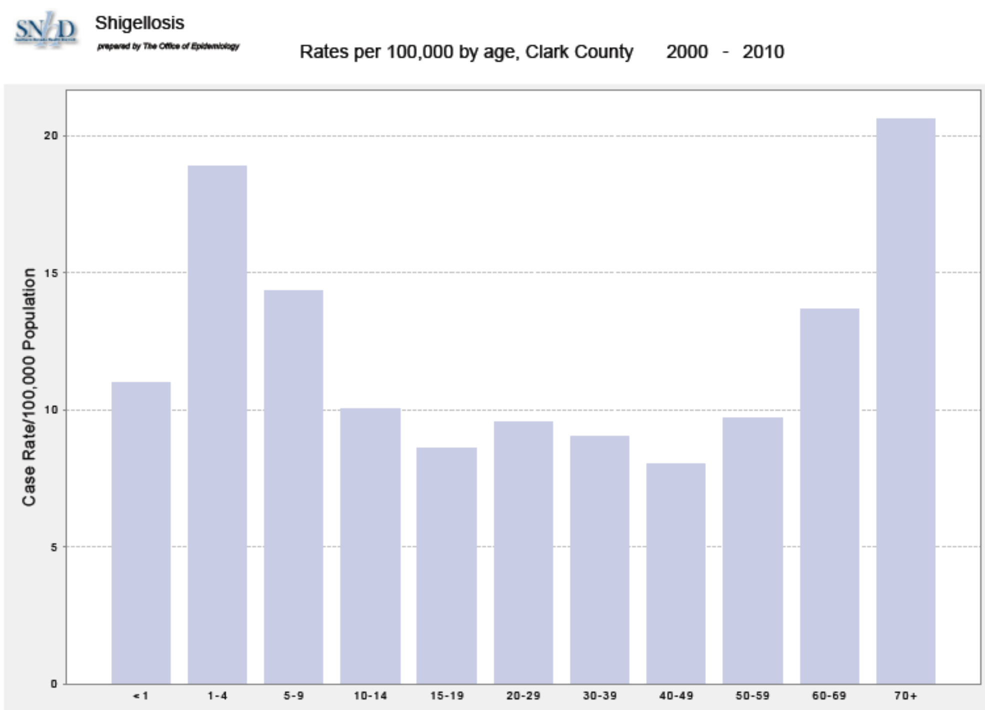
Figure 21. Data Warehousing

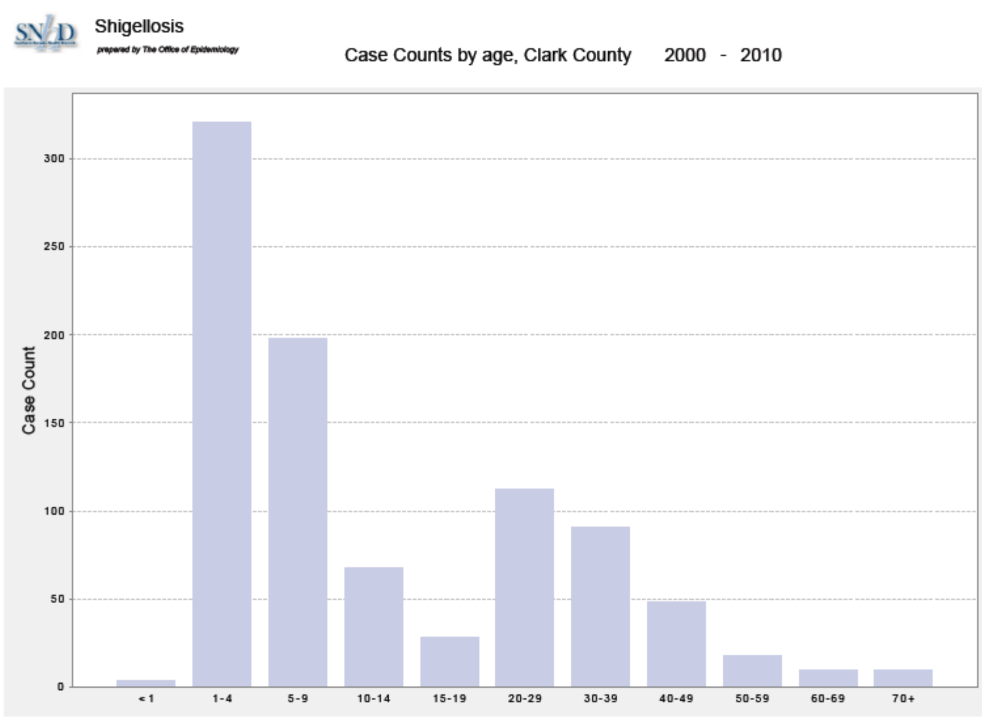
Extraction, Transformation, and Load

Figure 21 illustrates the Data Warehouse architecture. Data is initially *Extracted* from the TriSano Online Transactional Processing (OLTP) data repository, utilizing a meta-driven export function which in turn produces a XML document. The raw XML is not in a format suitable for analytical processing and must be *Transformed utilizing SPARQL* into a Resource Description Framework (RDF). The RDF representation of the data maintains the semantic constrains allowing the OTLP structure to be manipulated into a lower level form. The RDF structure is then *Loaded* into an Online Analytical Processing (OLAP) warehouse, and the respective abstractions, and cubes deployed for Analysis, Visualization, and Reporting (AVR) via the Pentaho Business Intelligence (BI) platform and/or SAS analytical processing.

AVR, SAS, and Reporting

Without the ability to examine the data, and make informed evidence based decisions upon it, the data itself is meaningless. While the compilation of epidemiological data was done as early as Jon Snow, the electronic mechanisms to support the evolving public health need have not been available to compile a robust picture, illustrating these fundamental concepts, co-morbidities, etc. until recently. In building the sustainable public health community, it was imperative to create a library of standardized, dynamic, flexible BI capabilities which are common utilized throughout public health. The following analytical reporting capabilities, Figures 22A – J, were drawn from numerous local, state, and research agencies, and have been developed and deployed at SNHD via an Open Source Business Intelligence framework, Pentaho.





Figures 22 A & B. Shigella older pop has a high rate of disease, small pop, the case count U shape is typical of many infectious disease related to immune system status…The age groups are more likely to seek medical care, so what is this showing, due to disease, or case seeking behavior.

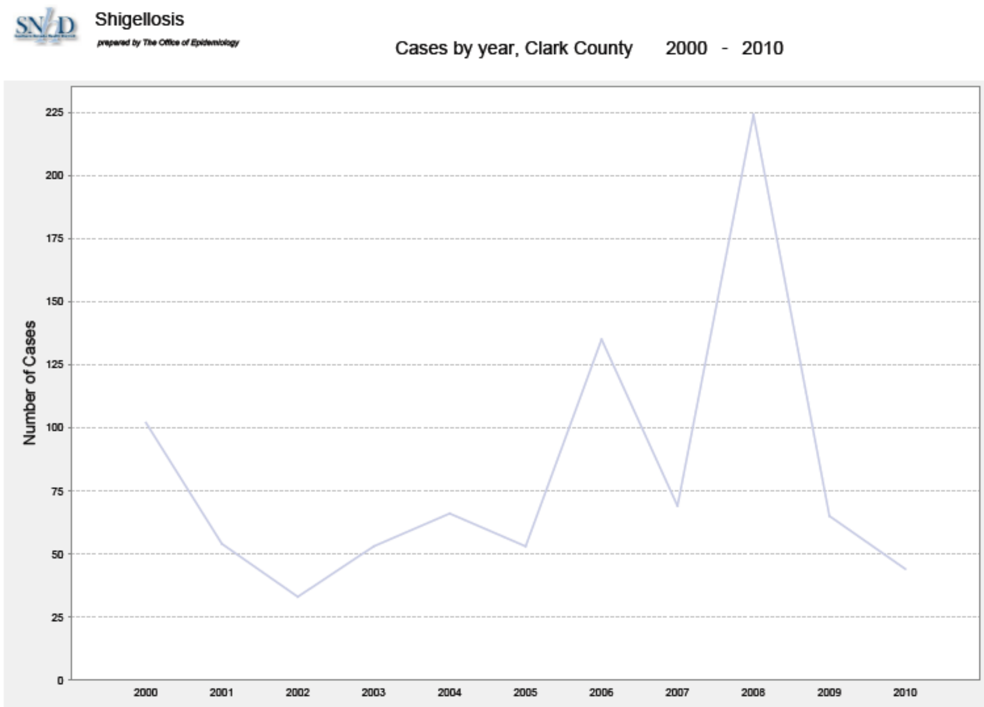


Figure 22 C. Shigella Outbreak, readily apparent from this graph. Difficult to figure out, unable to identify the common source, same strain around the community, but normal investigation, and affect on the Hispanic community (Next Figure)

Counts & Rates per 100,000 by age, Clark County 2000 - 2010

February 22, 2012 @ 03:20

Shigellosis

	White		Black		Asian		Hispanic		Unknown
Age Group	Count	Rate	Count	Rate	Count	Rate	Count	Rate	Count
0-4	25	1.7	0	0	0	0	140	9.53	29
5-9	14	1	0	0	3	0.21	76	5.45	15
10-14	6	0.44	0	0	0	0	19	1.4	4
15-19	1	0.07	0	0	0	0	15	1.1	2
20-24	7	0.48	0	0	1	0.06	16	1.11	6
25-29	6	0.4	0	0	0	0	20	1.33	13
30-34	13	0.85	0	0	0	0	7	0.46	5
35-39	6	0.4	0	0	0	0	12	0.8	9
40-44	6	0.41	0	0	1	0.06	10	0.68	6
45-49	1	0.07	0	0	0	0	4	0.29	6
50-54	3	0.24	0	0	0	0	1	0.08	1
55-59	2	0.18	0	0	0	0	0	0	0

Figure 22 D. Shigellosis Count & Rates by Age and Race, illustrating the high degree of incidence amongst the Hispanic community in children less than 9 years of age.

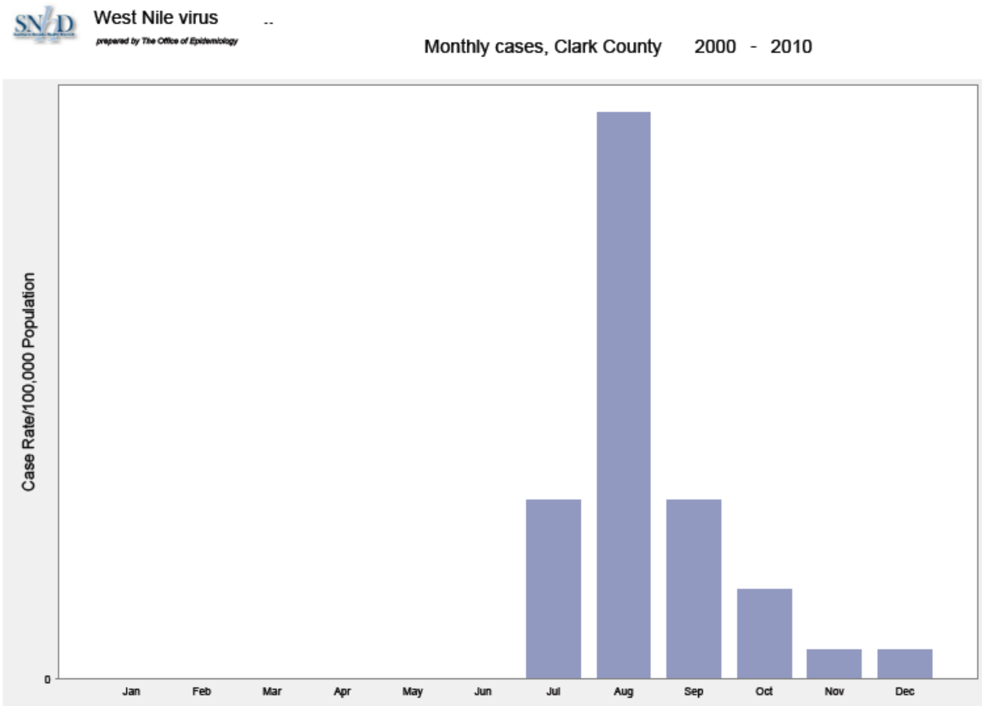


Figure 22 E. West Nile is an arboviral disease and this pattern is due to the fluctuating numbers of disease carrying mosquitoes

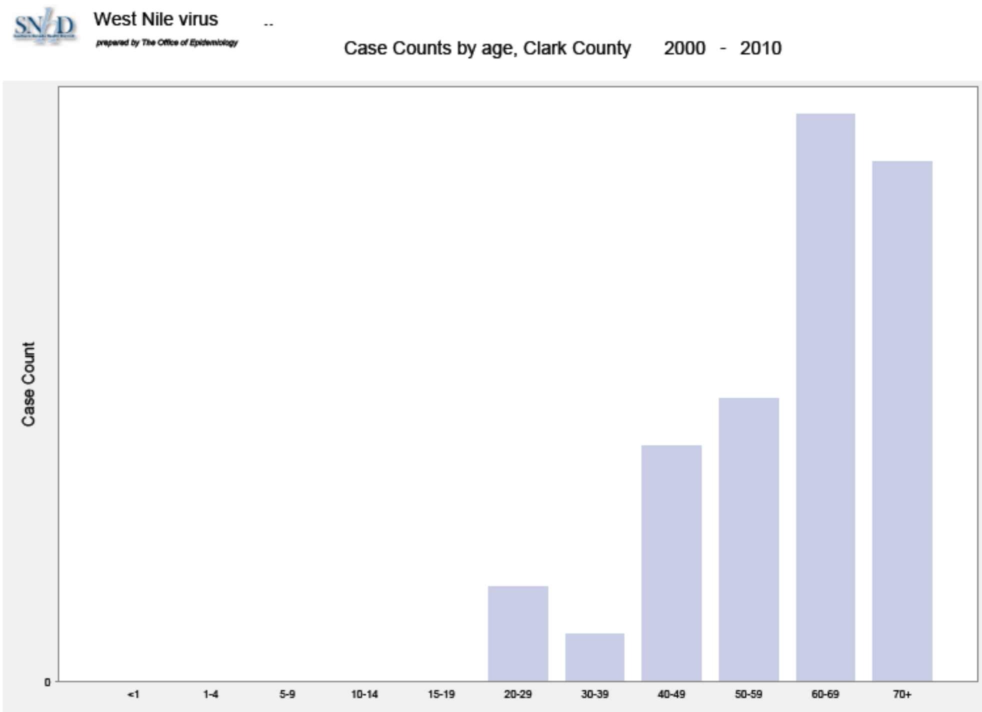


Figure 22 F. West Nile is largely an asymptomatic disease, as is been seen over the past decade. The risk of developing acute disease increase with age

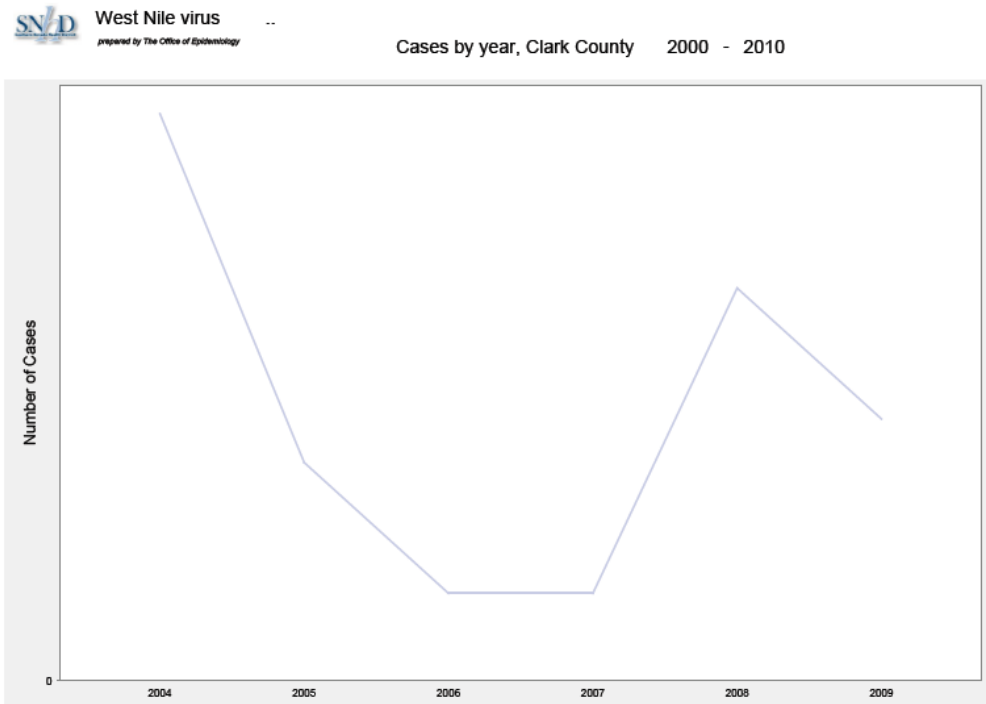


Figure 22 G. West Nile first was identified in Nevada in 2004, ecology of the disease has changed, and the disease has not been present in recent years; burned out susceptible hosts.

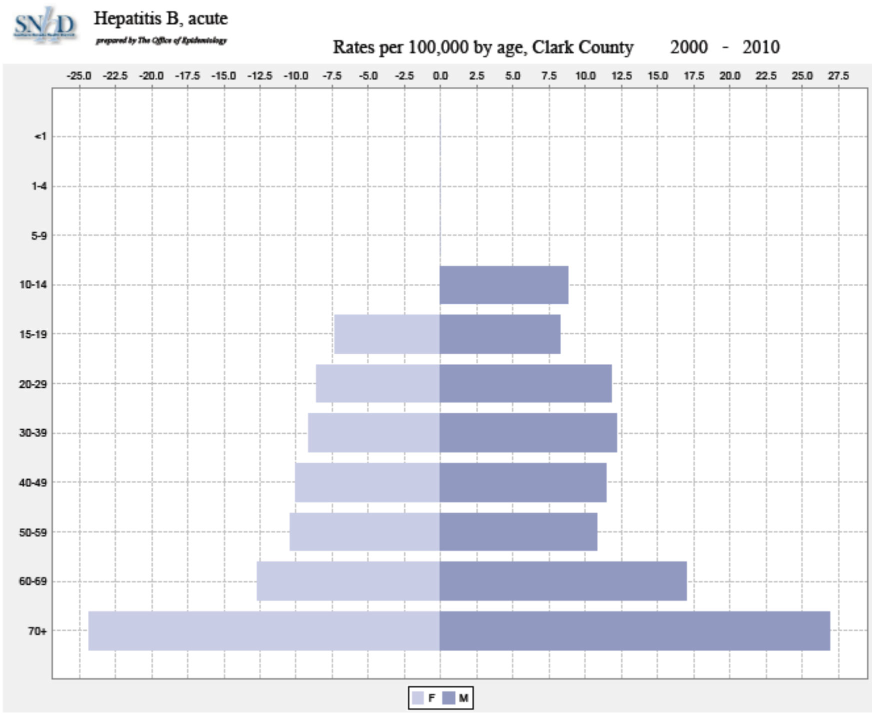


Figure 22 H. The greatest risk factors for Hepatitis B infection are sexual contact with an infected person, and inter-venous drug use; Two behaviors which are typically not seen in young children. The high rate in the older population is cause for concern, and something you would not expect based upon risk factors; however Hepatitis B can also be transmitted through improper use of medical equipment such as diabetic testing equipment in a long-term care facility.

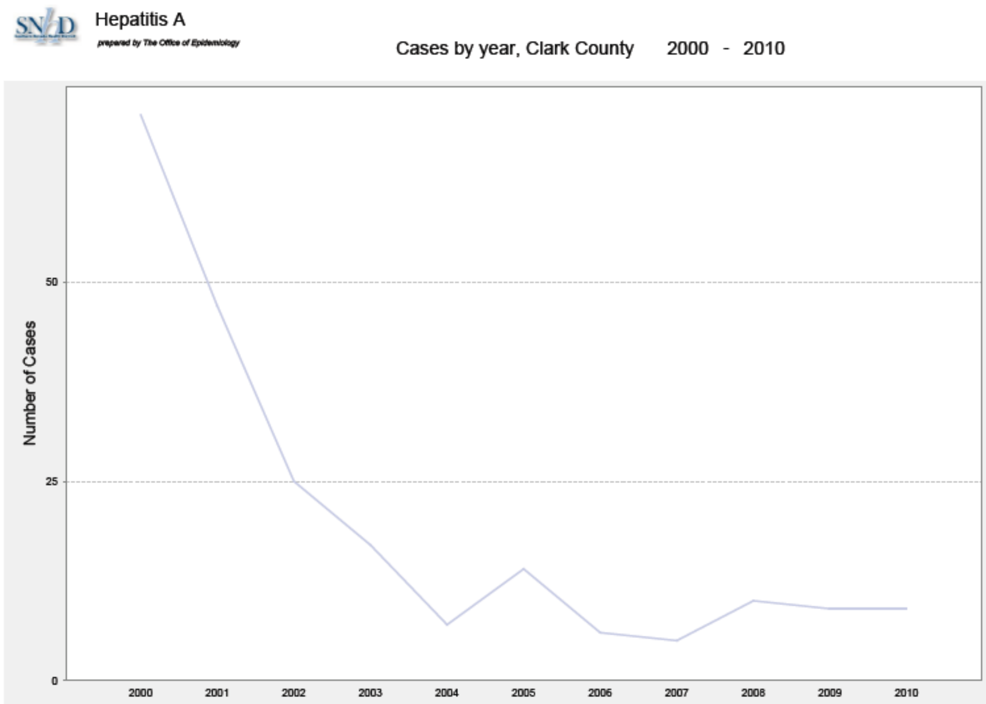


Figure 22 I. These trends have been seen both locally and nationwide, with rates of Hepatitis A reaching historical lows due to the availability and recommendation of the Hepatitis A vaccine.

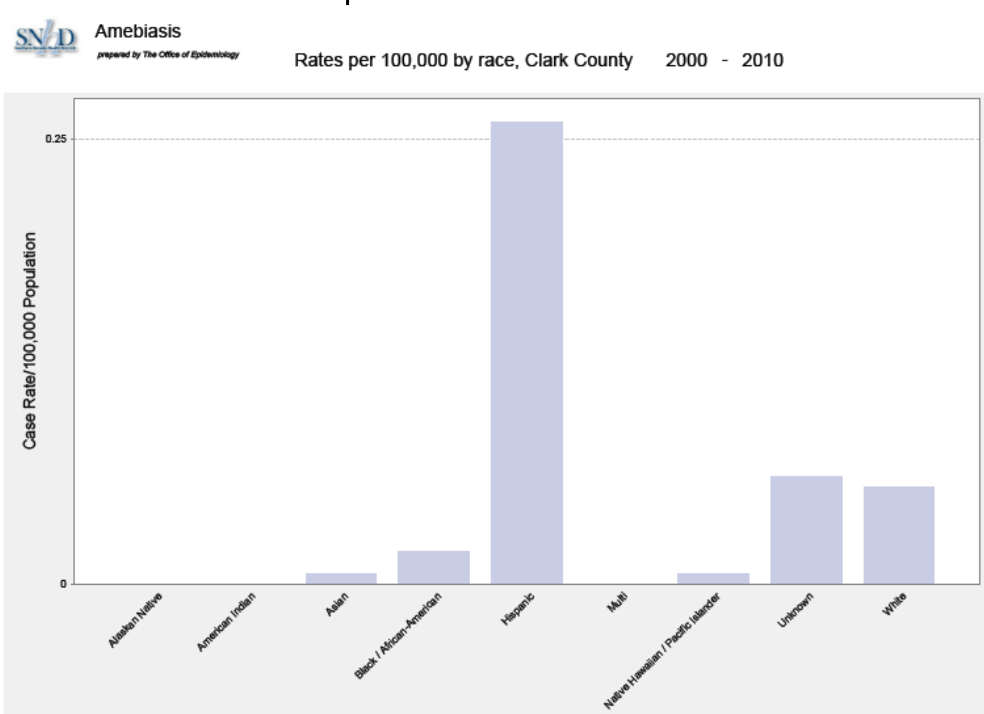


Figure 22 J. It is unknown as to why Amebiasis greater incidence in the Hispanic community.

CHAPTER 8

RESULTS: EVALUATION

Introduction

The alignment of needs discussed in Chapter 4 and sustainable architectural designs developed in Chapters 5 and 6 resulted in the implementation of enterprise informatics architecture in Chapter 7. This implementation facilitates the daily operations of the SNHD community, and the supporting infrastructure and solutions. This chapter focuses on the impact of these core components and systems: *Community*, *Messaging*, and *Disease Surveillance and Investigation* to gauge the potential for reusability beyond the walls of SNHD.

Community

The sustainability of the public health community has been largely dependent upon funding of a core set of services by State and Federal partners. The alignment of processes, protocols, and systems has proven to reduce the overall cost of ownership, as the costs are spread out amongst the community membership. The facilitation of the community partners, and orchestration of the SNHD implementation has demonstrated a significant increase in the level of communication necessary to coordinate these efforts.

A significant by-product of these communications is the immediate feedback loop developed as part of the community architecture, and its subsequent implementation at SNHD, resulted in built-in continual process improvement throughout the systems lifecycles. The ongoing self-evaluation of the processes, procedures, and supporting infrastructure has proved most useful in prompt risk identification, and mitigation. The inherent nature of this process and user involvement has boosted user confidence in the overall system, and further advocates continued participation.

Leveraging the community's trained informatics professionals in the development of the community architecture has demonstrated the effective intersection of domain expertise, and information technologies. The resulting developments have expedited the collection, aggregation, assessment, alignment and implementation of practical solutions which require minimal ongoing maintenance and resources; thus reducing the overall cost of core public health services, and enhancing the delivery of care to the community for which it serves.

Messaging

SNHD has received 15761 messages between the deployment of uniPHii and January 2012. While this number is low when compared to the initial projections (Table 8), this is mainly due to the notifiable conditions being reported currently via electronic delivery. As stated earlier, expectations of over 400,000 records per year is not unreasonable when HA1C is made reportable. The current electronic processing however makes up over 70% of the jurisdictions laboratory reporting through two laboratories Quest Diagnostics, and LabCorp. Community data partners have also been quick to respond to this initiative and the valleys 16 hospitals are currently on-boarding, having executed Memorandums of Understanding (MOU) (Appendix E), as there is limited impact and great potential benefits in the adoption of this approach. During the on-boarding process it became apparent that communications of the benefits, which far outweigh the risks, are conveyed to the partners in a standard manner utilizing language that is easily discernible across the organization.

Delivery and explanation of the processes and procedures, expectations, and impact are facilitated by a standardized ELR Messaging Guide (Appendix F), a technical reference guide, and an ICP Guide (Appendix G) which illustrates the potential impact on the data partner's internal processes. uniPHii ensures a standard implementation across all institutions by enforcing conformance to the certification process. This semi automated process allow the data partners to establish the intent, execute the necessary legally binding contract for data exchange, initiate test messages, and perform validations to assess the level of conformity. Once the partner achieves production level certification, uniPHii is made available in a production mode.

Analysis

To analyze the impact of uniPHii on both the data partner and the health district, an analysis was performed on a combined dataset consisting of the Quest and LabCorp laboratories from the deployment of the uniPHii architecture, and the remaining laboratories, hospital systems and commercial, which report utilizing manual methods during the same reporting period. Three diseases were chosen based upon the number of reported conditions, with the total number of observations of 1023. The analysis was performed utilizing a Poisson regression model, and results demonstrated in Figure 23 and Tables 9 A-C.

SAS Code:

```
ods html file="c:\temp\Lab Reporting Poisson with Univariate
Tests.html";
proc univariate data=comb_rep_pos;
var lab_reporting;
by elr;
Title "Univariate Statistics for Lab reporting Time By ELR 0=No
ELR 1 = ELR";
run;
quit;
proc glimmix  data = comb_rep_pos;
model lab_reporting =  elr  / link=log s dist=poisson ddfm=satterth ;
Title "Lab Reporting Poisson";
run;
quit;
ods html close;
```

The UNIVARIATE Procedure

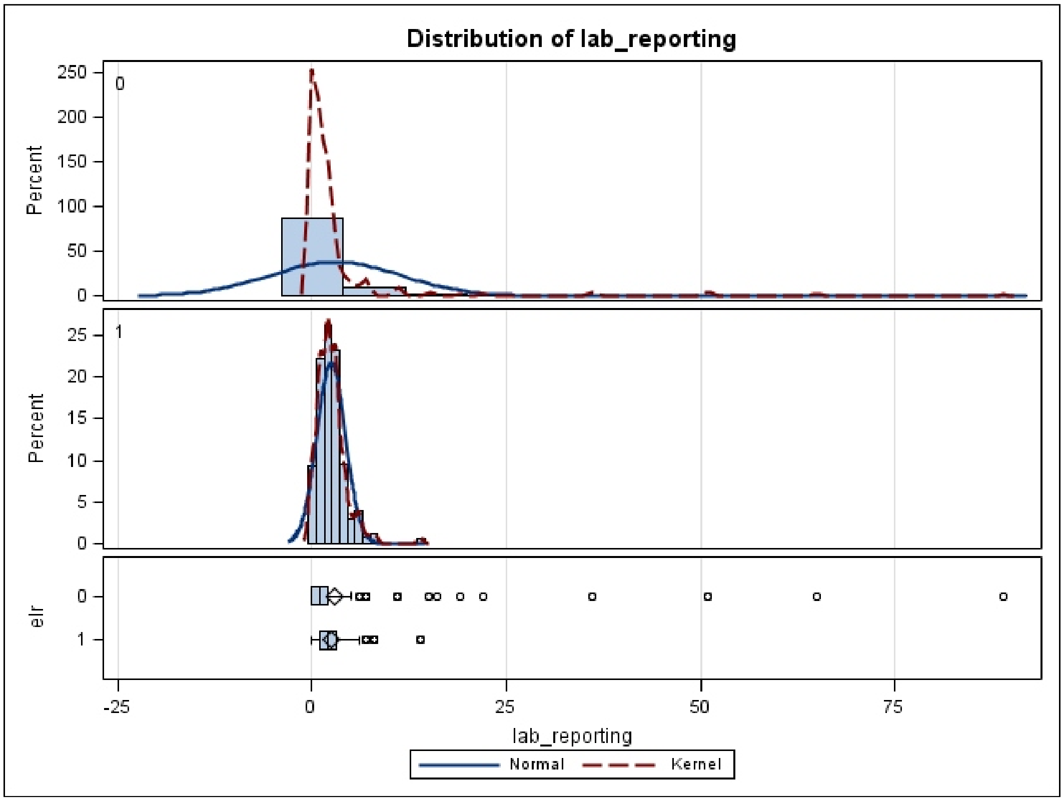


Figure 23. Lab Reporting Distribution Histogram, Box and Whisker Plot. The blue line is a normal probability curve composed of a normal distribution, the dotted redline makes no distributional assumptions and relies upon the data alone in its representation. Vast number of outliers in the non-elr group, and the mean is higher.

Lab Reporting Poisson

Table 9. A, B, and C. Poisson Analysis.

A. The Link Function, Log describes the model being utilized, a Poisson regression. This model was used as the analysis is counting the number of days it takes from the lab finding to the report to public health.

Model Information	
Data Set	WORK.COMB_REP_POS
Response Variable	lab reporting
Response Distribution	Poisson
Link Function	Log

Model Information	
Variance Function	Default
Variance Matrix	Diagonal
Estimation Technique	Maximum Likelihood
Degrees of Freedom Method	Residual

B. Negative, saying change in intercept from 0 to 1; time it takes for the group coded 1 is less than the group coded zero. Reaffirming ELR is faster.

Parameter Estimates					
Effect	**Estimate**	**Standard Error**	**DF**	**t Value**	**Pr > |t|**
Intercept	1.0594	0.03246	1021	32.63	<.0001
elr	-0.1670	0.04055	1021	-4.12	<.0001

C. This is statistically significant difference in processing time, ruling out the null hypothesis; This suggest that the .44 days difference observed between non and ELR labs is much less likely to occur than would be expected form chance alone. A .44 difference in days, equates to 10.5 hours which is more than one fill work day.

Type III Tests of Fixed Effects				
Effect	**Num DF**	**Den DF**	**F Value**	**Pr > F**
elr	1	1021	16.96	<.0001

Disease Surveillance and Investigation

Between 2010 and 2012, SNHD conducted investigations of 6,552 confirmed morbidity events with a staff consisting of 4 epidemiologists, 6 DIIS, and 4 administrative support staff serving a population of 2.2 million residents, and a transient population of ~36 million; or approximately 11.6% of the American population.

Utilizing methods described in Chapter 3, the requirements derived from the assessment in Chapter 4, and the sustainability and design principles discussed in Chapters 5 and 6 an evaluation of the TriSano implementation was conducted. The user community reported an overwhelming satisfaction of the TriSano system having exceeded the DIIS requirements, and enabling rapid and efficient disease surveillance activities. Activities conducted while utilizing this novel, flexible, standard mechanism for data collection resulted in a reduction of variability across investigations, and institutions. Alignment with the latest Federal initiatives, and the ONC S & I Framework was made possible by TriSano, and has proven beneficial in the timeliness and accuracy of daily operations.

The recent increase of outbreaks in the Las Vegas valley and subsequent investigations, have been a benefactor of the outbreak management, and inherent ad-hoc form builder capabilities of TriSano. This feature empowered the DIIS staff to initiate investigations faster and more effectively than ever before, providing them with the ability to define outbreak specific risk factor forms, and utilize the standard reporting mechanisms to investigate and monitor the emerging disease. More accurate real-time data facilitates enhanced disease mitigation strategies to prevent the further spread of disease.

The success of the aforementioned processed and supporting systems has peaked interest from the growing community membership, whom has identified the need for further independent evaluation by the community members including the CDC. The follow on evaluation may focus efforts on the replacement of the antiquated public health business model, its supporting processes and systems with a scalable, sustainable infrastructure.

CHAPTER 9

DISCUSSION

This work reported on an assessment of the NNDSS and the implementation of a sustainable public health infrastructure based upon an enterprise architecture. A number of methods including surveys, questionnaires, observations, planning, risk management, software design and development, and quantitative analysis of data were utilized. The results have uncovered significant problems in the NNDSS community, most egregiously including the lack of core competencies, communication, reusability, involvement, and leadership resulting in inefficient processes, poor quality of data, limited scalability and portability, and low user satisfaction.

Additionally, lessons learned from this assessment were instrumental in crafting the design for a sustainable community of practice, and the underlying infrastructure necessary to support its activities. Knowledge and integrated application of best practices and procedures from interdisciplinary sciences including computer science (CS), project management (PM), business administration (BA), and community practices (CP) formed the foundation from which to shift the public health paradigm.

These core principles were demonstrated through a practical, full-scale implementation of the sustainable community and its infrastructure at the Southern Nevada Health District (SNHD) between 2009 and 2012. The results of leveraging the best practices and protocols from multiple domains has been realized in the immediate increase in effective workflow processes which promotes the ability to react rapidly, process data, conduct efficient and effective surveillance and investigation activities, and apply the resulting data in continual process and program development.

The physical implementation at SNHD proved to be highly successful in a number of factors. For example messaging time has decreased, standardized investigation has increased the quality of data and its analysis, and overall user satisfaction. In fact, the successes of the implementation in Nevada have been so dramatic, that the States of Kansas, Connecticut and Indiana are considering adopting the system. This interest demonstrates the validity of the implementation and it ability to be extrapolated across the public health continuum.

This work has been limited by the adoption rate of laboratory providers, and hospital systems, as well as mandates imposed by local, State, and Federal public health agencies. The slow adoption rate of the laboratory and hospital systems has been attributed to prioritization, requisite skill sets and resources, and the inability to execute a Memorandum of Understanding due to political inefficiencies. Mandates at each level of public health may differ from locale to locale, introducing unknown variables into the equation. Utilization outside of the intended range and scope may produce adverse results.

Future Directions

Tuberculosis, STD, and HIV

Evaluation of the necessary workflow to sustain the Tuberculosis (Figure 24), STD, and HIV programs is underway. Utilizing the CDC data collection forms, and reporting criteria as a guideline, a thorough assessment of the interview, case management, and investigation processes is being documented, designed, and implemented in a test environment (Figure 25). It is easily understood why the complexities of these diseases have not yet been fully exercised within a single solution. However, the intermediate work has demonstrated promise with the potential of remediating current impediments as illustrated below.

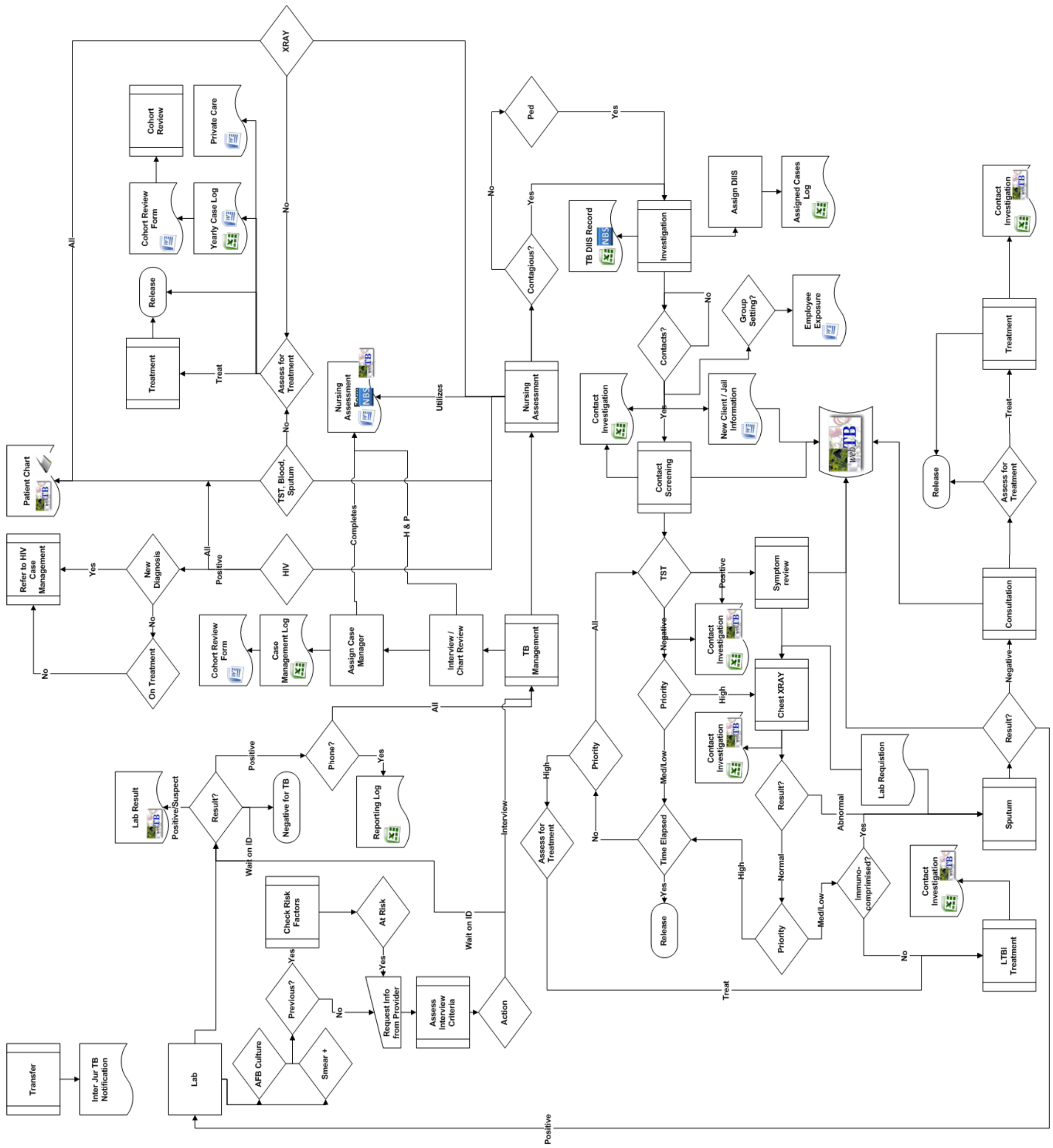


Figure 24. Tuberculosis Program Workflow. Including ancillary systems, and workaround procedures.

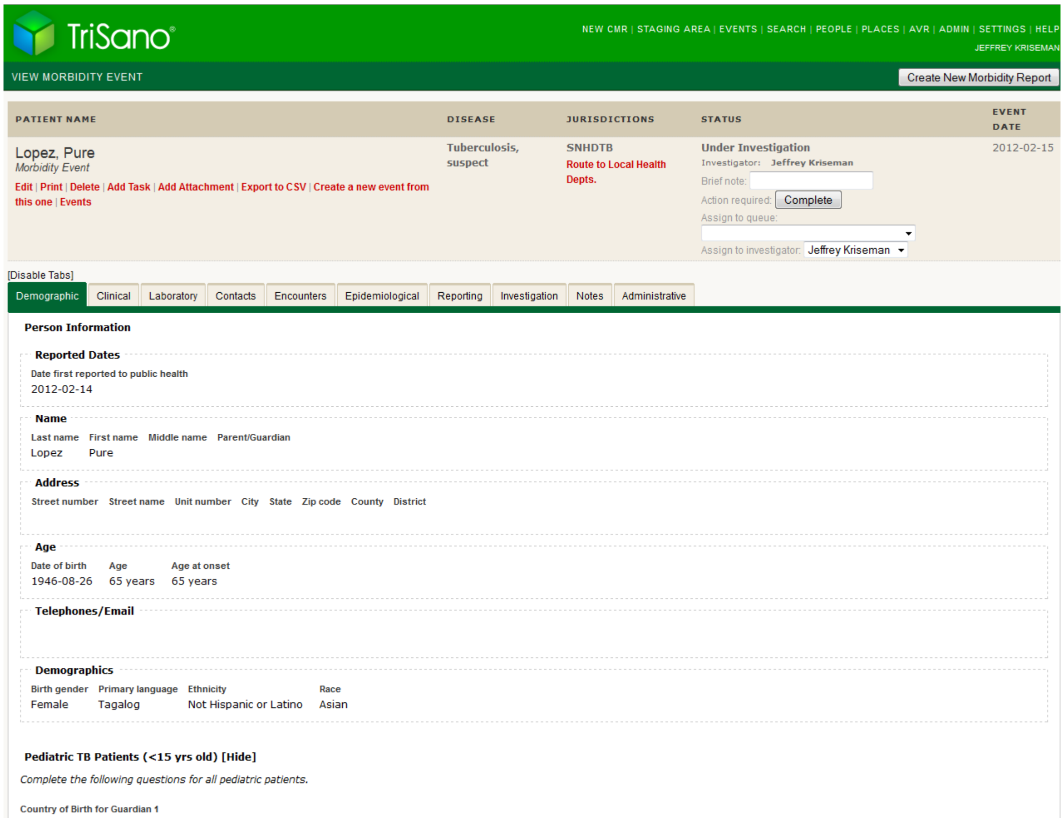


Figure 25. TriSano Tuberculosis integration test environment.

Co-Morbidity

The realization of a truly integrated environment will promote the ability to better understand many factors of disease, transmission, treatment, and uncover program critical co morbid conditions. SNHD is just seeing the benefits of this within OOE, STD, HIV and TB, providing new insights into otherwise disparate areas.

The Cloud

Much technical focused recently has been placed upon Cloud based technologies. These technology offer scalable technology stacks, the ability to pay as you go, based upon need in hopes to reduce the internal footprint of an organization, slicing away at large IT budgets. While there is justification for the hype, there are only a limited number of components of the underlying public health infrastructure that make sense in this environment. The government cloud is made available to local, state, and federal institutions to support their respective needs. This does not come without a price tag however, and many organizations are currently leveraging virtualization technologies and moving away from big iron, accomplishing much of the same benefits of the Cloud.

uniPHii was built during the ensuing budgetary crisis, out of necessity with both virtualization and the Cloud architecture in mind. uniPHii and all of its components can be easily deployed within the Open Source VMWare Server architecture, or into a Cloud based environment. Components of the architecture can be deployed independently, and current pieces of infrastructure leveraged in a hybrid model of both technologies. The ideal setting for uniPHii however, is one where authoring of ontologies and rules are done in the Cloud, and distributed across the public health continuum. Leveraging the sustainable community, current initiatives can be easily met across all agencies, as focus on a single vision, development effort, and deployment is shared by all. Currently efforts are underway to package the terminology server, and rule engine and deploy to the CDC Cloud for evaluation and test.

Initial efforts will be focused upon the messaging infrastructure deployed across SNHD, Utah Department of Health (UDOH), and Kansas Department of Health (KDHE), as they all share components of uniPHii within their departments. The next logical progression is to migrate the open source surveillance infrastructure into the Cloud. This will reduce the overall footprint, and maintenance needed as a single instantiation of the solution will provide for all three institutions. The further evaluation of these solutions will provide the necessary means to better understand how to grow the community infrastructure to serve the national population.

Finally, the not so distant future will provide the ability to do away with surveillance data collection as we know it, and fully integrate its activities leveraging the HIE allowing for real-time reporting or a comprehensive set of disease specific criteria which would be maintained by the rules engine in the sky. This ideal solution would provide more accurate and timely data, interface directly with data partners through the cloud, and reduce the footprint necessary to facilitate public health activities while growing a sustainable community.

CHAPTER 10

CONCLUSION

The success of this implementation of the sustainable public health community is demonstrated by its broad and rapidly growing membership. An online presence has been established through phConnect, an online resource for public health professionals for the governance, communication, and promotion of community activities. Both uniPHii and TriSano have been made available via Open Source, peaking interest and driving the adoption of best standards and practices.

The TriSano project has a growing community beginning with the statewide implementation at the Utah Department of Health (UDOH) in 2009 along with its 27 counties. As the initial site for deployment, UDOH was instrumental in developing the application and its robust core feature set. The Southern Nevada Health District implemented the core Open Source platform in 2010, and assisted the Collaborative Software Initiative (CSI) in the expansion of features. Recently the state of Kansas (KDHE) has adopted TriSano statewide, in all 105 counties. Kansas is using a cloud based deployment of TriSano, and is evaluating the uniPHii architecture as it fits well with their current deployment strategy. Finally, Arkansas and Connecticut are evaluating both solutions for full-scale implementation in their respective States and jurisdictions.

Federal recognition of the architecture presented herein by DHS, DHHS, NACCHO, CSTE, and CDC which has gained SNHD a collaborative spotlight alongside the CDC and CSTE at the 2012 CSTE meeting in Nebraska. This is a monumental paradigm shift in the way local, state, and federal agencies have done business, looking to leverage resources across the continuum in solving critical community issues, taking in to account sustainability in a time of crises.

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APPENDIX A

ASSESSMENT PARTICIPANTS

1. Southern Nevada Health District, Office of Epidemiology, Southern Nevada Public health Laboratory, Division of Community Health, Nursing, Office of Tuberculosis, and the Office of STD/HIV.
2. Utah Department of Health, Division of Disease Control and Prevention
3. Kansas Department of Health & Environment, Division of Public Health, Epidemiology and Public Health Informatics
4. Connecticut Department of Health, Public Health Initiative Branch
5. CDC Office of Science, Epidemiology, and Laboratory Services (OSELS), which includes the Public Health Surveillance Program Office and the Public Health Informatics Technology Program Office
6. CDC Office of Infectious Diseases (OID) and the Division of Parasitic Diseases and Malaria

APPENDIX B

PUBLICATIONS AND RECOGNITION

Publications and Recognition:

1. Jeffrey M Kriseman, Brian Labus, John Middaugh. Introduction of an Open Source Disease Surveillance Architecture. Council of State and Territorial Epidemiologists (CSTE) conference. 2010
2. Jeffrey M Kriseman. Expert Panelist. ELR Process Steps. Public Health Informatics (PHI) conference. 2011
3. Jeffrey M Kriseman. Expert Panelist. ELR and Meaningful Use. Public Health Informatics (PHI) conference. 2011
4. Perry Smith, Jeffrey M Kriseman, James Kirkwood. Evaluation of and Recommendations for the Nationally Notifiable Disease Surveillance System within the Federal Centers for Disease Control and Prevention. CDC. 2011
5. Kathleen Gallagher, Perry Smith, Jeffrey Kriseman. Critically Assessing the NNDSS Enterprise. Council of State and Territorial Epidemiologists (CSTE) conference. 2012
6. Jeffrey M Kriseman, Brian Labus. Chapter: Local/Regional Public Health*. Public Health Informatics and Information Systems.* 2012

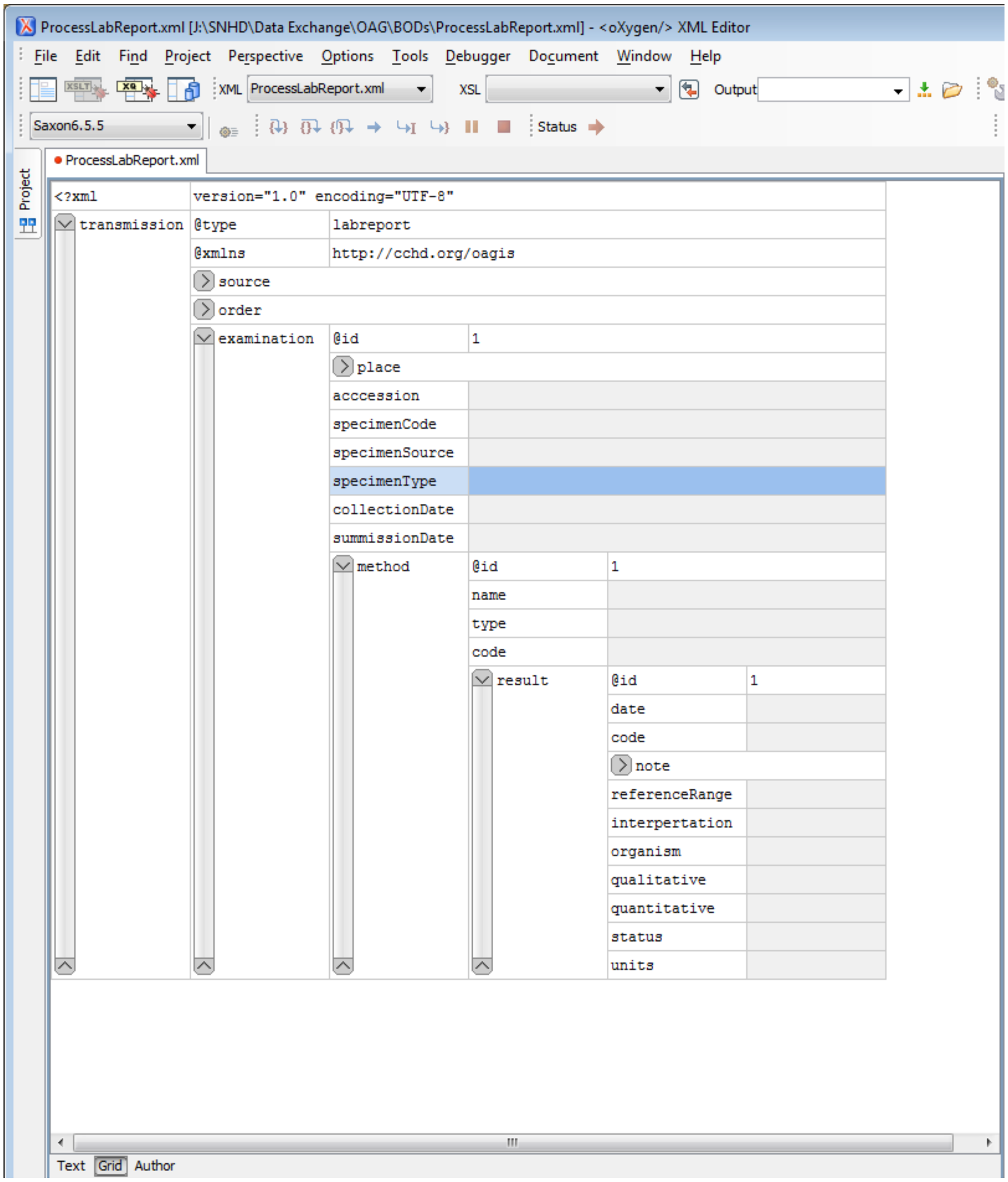
Software developed:

1. uniPhii, a universal Public Health information infrastructure for messaging.

2. The comprehensive development of a standardized ontological representation and semantic constraints to support laboratory reporting.
3. Enhancements to the Open Source TriSano system to support dynamic data interchange, and standardized reporting.
4. A universal XML framework for data transport throughout a public health agency; supporting laboratory results, demographics, patient, provider, facilities, etc.
5. A Public Health Data Warehouse and supporting Extraction, Transformation, and Load (ETL), and abstractions to support standardized query and reporting.
6. Standardized Analytics and Reporting functionality to support public health epidemiology and data dissemination.

APPENDIX C

BUSINESS OBJECT DOCUMENT


ProcessLabReport.xml [J:\SNHD\Data Exchange\OAG\BODs\ProcessLabReport.xml] - <oXygen/> XML Editor
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XSL
Output
Saxon6.5.5
Status
Project
ProcessLabReport.xml
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transmission
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@xmlns http://cchd.org/oagis
source
order
examination
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place
acccession
specimenCode
specimenSource
specimenType
collectionDate
summissionDate
method
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type
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units
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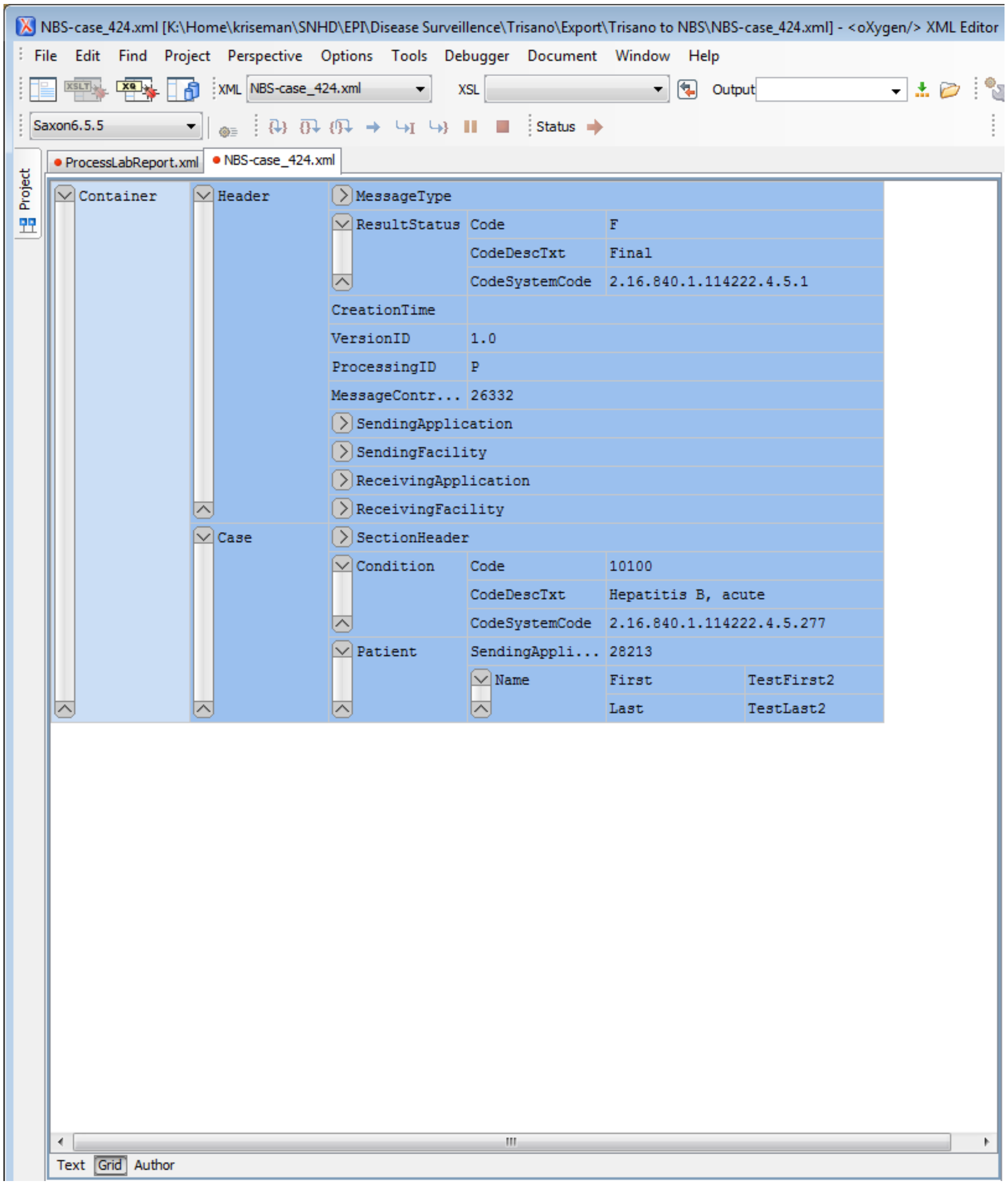
APPENDIX D

TRISANO XML


NBS-case_424.xml [K:\Home\kriseman\SNHD\EPI\Disease Surveillence\Trisano\Export\Trisano to NBS\NBS-case_424.xml] - <oXygen/> XML Editor
File Edit Find Project Perspective Options Tools Debugger Document Window Help
XML NBS-case_424.xml
XSL
Output
Saxon6.5.5
Status
Project
ProcessLabReport.xml
NBS-case_424.xml
Container
Header
MessageType
ResultStatus
Code
F
CodeDescTxt
Final
CodeSystemCode
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CreationTime
VersionID
1.0
ProcessingID
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MessageContr...
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SendingFacility
ReceivingApplication
ReceivingFacility
Case
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28213
Name
First
TestFirst2
Last
TestLast2
Text
Grid
Author

APPENDIX E

SNHD UMC MOU

MEMORANDUM OF UNDERSTANDING

Whereas University Medical Center of Southern Nevada ("UMC") and Southern Nevada Health District ("SNHD"), a political subdivision of the State of Nevada and the public health agency for Clark County as defined in Nevada Revised Statute NRS 439.350, desire to formalize their understanding regarding the exchange of health information.

UMC currently reports data as required in NRS 441A.150 via a manual process, and both parties desire to have the data submitted through an electronic process.

The parties wish to establish a relationship wherein UMC will provide, secure patient data feed from UMC to SNHD.

Therefore, UMC and SNHD agree to the terms and conditions set forth below:

1. UMC will provide data to SNHD to meet the requirements of NRS 441A.150.

2. The data to be sent will encompass patient laboratory results (diagnostic testing being performed and actual measure results), including patient demographic information (name, date of birth, address, social security number, medical record / account number, etc.).

3. The parties will utilize Health Level 7 (HL7) messaging standards to ensure data integrity and semantic constraints throughout the delivery process.

4. All such information received, stored or viewed by SNHD shall be kept confidential as required, per NRS 441A.220.

5. Health Insurance Portability and Accountability Act of 1996.

   a. For purposes of this Agreement, "Protected Health Information" shall mean any information, whether oral or recorded in any form or medium, that: (i) was created or received by either party; (ii) relates to the past, present, or future physical condition of an individual, the provision of health care to an individual, or the past, present or future payment for the provision of health care to an individual; and (iii) identifies such individual.

   b. All data shared by UMC under this agreement fall under the public health exemption in HIPAA (45 CFR 164.512(b)).

6. Nothing contained in this Memorandum of Understanding shall be deemed or construed to create a partnership or joint venture, to create relationships of an employer/employee or principal/agent, or to otherwise create any liability whatsoever upon one party with respect to the indebtedness, liability or obligation of the other party.

7. It is specifically agreed between the parties executing this Memorandum of Understanding that this Memorandum of Understanding is not intended to create in the public or any individual a status of third party beneficiary or to authorize anyone not a party to this Memorandum of Understanding to maintain a suit for personal injuries or property damage against any of the parties.

8. This Memorandum of Understanding should not be construed as an assumption of a specific duty to provide for the safety or any person or as an assumption of any other duty beyond that imposed by general law.

9. The term of this Memorandum of Understanding shall begin May 15, 2010 and shall be in effect until terminated by either party as provided for in this Memorandum of Understanding. Either party can opt out of this Memorandum of Understanding for any reason after providing the other party with thirty (30) days written notice.

University Medical Center of Southern Nevada	**Southern Nevada Health District**

APPENDIX F

SNHD ELR MESSAGING GUIDE

Implementation Guide for Transmission of Reportable Laboratory-based Public Health Information

Southern Nevada Health District

Version: 1.0 Published: September 2011

APPENDIX G

ICP WORKFLOW GUIDE

l

Infection Control Practitioners Workflow Guide for Reportable Laboratory-based Public Health Information

Southern Nevada Health District

Version: 1.0 Published: April 2012