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An assessment of information exchange practices, challenges and opportunities to support U.S. disease surveillance in three states

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Abstract

State and local public health agencies collect and use surveillance data to identify outbreaks, track cases, investigate causes, and implement measures to protect the public's health. We sought to better understand current practices at state and local public health agencies for collecting, managing, processing, reporting, and exchanging notifiable disease surveillance information. Over

an 18-month period (January 2014–June 2015), we evaluated the process of data exchange between surveillance systems, reporting burdens, and challenges within three states (California, Idaho, and Massachusetts) that were using three different reporting systems. All three states use a combination of paper-based and electronic information systems for managing and exchanging data on reportable conditions within the state. The flow of data from local jurisdictions to the state health departments varies considerably. When state and local information systems are not interoperable, manual duplicative data entry and other workarounds are often required. The results of the assessment show the complexity of disease reporting at the state and local levels and the multiple systems, processes, and resources engaged in preparing, processing, and transmitting data that limit interoperability and decrease efficiency. Despite ongoing challenges, considerable progress has been made in implementation of electronic systems and as a result, efficiency has improved substantially in the last decade.

Keywords

surveillance; notifiable diseases; data exchange; health information systems

Implications for policy and practice

Implications for Policy and Practice sections should conform to the following general guidelines:

1. The abstract of the article must include at least one sentence about specific implications for policy and practice. This is not simply a statement that the article includes implications for practice, but an illustration of at least one such implication.
2. Each article should include a clearly delineated section titled “Implications for Policy & Practice.” This includes a bold heading that introduces the section so it is easily found. If there are no direct implications for policy or practice because the article introduces a new research method or conceptual framework, it is still important for the authors to identify the relevance of the work to future policy or practice work. Manuscripts that address topics for which this relevance cannot be articulated may not be suitable for JPHMP.

This assessment identifies challenges and opportunities for improving data exchange practices to support disease reporting at state and local levels. Through this structured assessment, CDC has a better understanding of the complexities for surveillance of using commercial-off-the-shelf data systems (California and Massachusetts), and CDC-developed National Electronic Disease Surveillance System Base System (NBS). The use of both manual and electronic data exchange for reporting of conditions resulted in redundant data entry and data management. Since this assessment was completed substantial progress has been made in some jurisdictions to increase the proportion of case-related laboratory reports. More efficient data exchange and use of data will help facilitate interoperability between NNDSS systems.

Introduction

Surveillance of reportable conditions (mostly but not exclusively infectious diseases) is a cornerstone of public health practice. State and local public health agencies collect and use surveillance data to detect outbreaks, track cases, investigate causes, and implement measures to protect the public's health.¹ Many states have laws that mandate disease reporting from their hospitals, healthcare workers, and laboratories. The information that healthcare entities must report to public health for a case of a reportable disease or condition includes patient identifiers and data on signs and symptoms, vaccine history, travel history, medical history, and laboratory testing. States in turn submit some of these data to CDC as part of the National Notifiable Diseases Surveillance System (NNDSS). CDC receives de-identified data on approximately 100 infectious and noninfectious conditions from state, territorial and local health departments (57 jurisdictions) totaling about 5 million cases per year. CDC uses the data on nationally notifiable diseases (NND) to monitor disease trends, study etiology and risk factors, target resources, and evaluate prevention and control efforts.

Each state determines which diseases, conditions, and events are *reportable* in their jurisdictions. Determining which diseases, conditions, and events are voluntarily *notifiable* to CDC is a collaborative process between the Council of State and Territorial Epidemiologists (CSTE) and CDC disease-specific programs. This paper focuses primarily on local to state reporting of reportable diseases and the subset of those which are notifiable and reported to CDC.

CDC worked collaboratively with the Public Health Informatics Institute to use their i³ (informatics, innovation, implementation) Lab project³ to assess and document the data flow, business processes, surveillance systems, and other applications used within three states for NNDs. The objective of the qualitative analysis was to document: 1) the flow of reportable disease data (in three states) at local and state levels and the subsequent notification to CDC, and 2) the surveillance systems and tools used to gain insight into more practical, efficient and effective approaches for disease reporting. This assessment was well-aligned with CDC's Surveillance Strategy which provides a framework for CDC to consolidate surveillance systems, eliminate unnecessary redundancies, reduce reporting burden on state and local health agencies, and improve data availability, quality, and timeliness for all stakeholders.⁴ One component of the Surveillance Strategy is the NNDSS Modernization Initiative (NMI) to transition all NND reports to the HL7 v2.5 message format for submission to CDC.⁵ All states, including those participating in this assessment, are partnering with CDC and other public health organizations on NMI.

Methods

The Public Health Informatics Institute (PHII) worked with CDC through a cooperative agreement to recruit potential local and state public health agencies to serve as participant sites for a systems assessment of notifiable disease data exchange. Three locations California, Massachusetts, and Idaho were selected and agreed to participate. These three locations represent two types of integrated surveillance systems: commercial-off-the-shelf (COTS) systems (California and Massachusetts), and the CDC-developed National

Electronic Disease Surveillance System Base System (NBS)⁶ (Idaho). These systems are used by the states for their own surveillance of reportable diseases and data extracts from these systems are sent to CDC for NND reporting.

PHII assessed the three state systems with a focus on communicable diseases in a five-step process over an 18-month period from January 2014 through June 2015. First, PHII conducted a literature review to fully understand the current environment and common themes around information systems for reportable and notifiable disease surveillance within the three states.

Based upon this review of surveillance literature, PHII created a standard questionnaire regarding information flow, processes, tools, and other resources related to the exchange and standardization of reportable and notifiable disease data (Appendix 1). PHII then conducted a series of structured telephone interviews using the standard questionnaire with representatives from local and state health departments in the three states. These interviews gathered detail from public health practitioners on 1) how reportable and notifiable disease information flows from the provider level to CDC and 2) the multiple processes that support these information flows. PHII applied the Collaborative Requirements Development Methodology³ to document business processes and develop a model of current state practices. The model was used to analyze the interview responses from each local and state agency. The processes were validated via site visits to the participating local and state public health agencies. The assessments and analyses identified 1) process variations for the reportable and notifiable information flows within each state; and 2) inefficiencies and opportunities for process improvements. The findings and recommendations were presented to CDC in June 2015 and have been compiled in a report available from PHII.

Results

California and Massachusetts both have public health information systems for their largest and most populated areas that are separate from and are not interoperable with the information systems used in the rest of the state for reportable and notifiable diseases. The analysis also highlighted how the magnitude of a state's population correlates with the complexity of its reporting structure (e.g., the number of reporting entities and roles). Idaho's smaller population and implementation of one information system for reportable diseases across the entire state directly relates to a less complex flow of information. Regardless of the complexity of the reporting structure, each state's information systems has achieved some success in improving information exchange practices within their state. Examples of progress and positive impacts of automated information exchange and centralized surveillance applications include enhanced quality and timeliness of surveillance information; enhanced data sharing; and simultaneous access by local and state staff for collaboration on epidemiologic investigations and earlier detection of outbreaks. California, Massachusetts, and Idaho expressed some concern about CDC's transition to the HL7 v.2.5 format for the submission of NND reports and recommended CDC complete groups of messaging guides before requiring the new format for reporting. The state and local agencies identified in this report have been hesitant to convert to the new data standard since it would require their IT group to revisit and rework the same programming code multiple times,

driving up the cost of conversion. Additionally, data elements contained in the new messages should address all CDC program-specific needs, enabling the states to send all of the data in one message one time to CDC. This method would eliminate the need for states to send duplicate data feeds to different CDC disease specific systems or manually enter data which is still required for some systems.

California

PHII determined that there are different surveillance systems in use across the state. The California Reportable Disease Information Exchange (CalREDIE), a vendor-based system developed by ATLAS Public Health, has been fully implemented for reportable disease surveillance in 58 of the 61 local jurisdictions. Benefits of the wide implementation of the centralized surveillance system, CalREDIE, throughout most of the state are recognized by both local and state health department users and it has contributed to more timely, accurate, complete and efficient collection of communicable disease surveillance data for public health action. At the time of the PHII assessment in 2013, all jurisdictions throughout California used CalREDIE for reporting of TB and San Diego also used CalREDIE for reporting of sexually transmitted diseases. The remaining three jurisdictions (the counties of Los Angeles, San Diego and San Francisco) used a variety of local systems for surveillance of other reportable diseases and conditions. Unfortunately, these local systems and CalREDIE are not currently interoperable. The California Department of Public Health (CDPH) implemented CalREDIE in 2010 for communicable disease reporting and surveillance⁷. All reportable and notifiable conditions data for participating jurisdictions can be received and reported using CalREDIE, with the exception of HIV and AIDS data. Currently, HIV and AIDS data are managed using local health departments' internal databases and then subsets of the data are manually re-entered to report to the state and CDC using the Enhanced HIV/AIDS Reporting System (eHARS); however, California is in the process of fully automating HIV reporting in CalREDIE to improve this process.

Los Angeles, San Diego, and San Francisco Counties report 43 percent (as of 2013) of all reportable and notifiable cases in California. A file with basic morbidity data on reportable conditions for these three jurisdictions not using CalREDIE is transmitted weekly to CDPH. CDPH programs manually enter information for a subset of these reportable conditions into CalREDIE. Supplemental case report data may later be submitted on paper by these jurisdictions to state programs, which may also be manually entered by state staff into CalREDIE or other internal databases.

Figure 1 shows the complexity of California's reporting structure where each disease-specific program within local health departments uses an internal system (e.g., Microsoft Access or Excel) to record, manage, analyze, and report data to the state health department.

CalREDIE is designed to accept electronic laboratory reports (ELR) from both laboratories and providers throughout the state and has worked closely with the three jurisdictions not using CalREDIE to develop means for routing electronic lab report data to those jurisdictions. Currently, statewide approximately 80 percent of laboratory reports from 325 laboratories are received electronically by CDPH and routed to CalREDIE or the appropriate jurisdiction.

Variation in reporting (or updates) of cases may occur due to insufficient jurisdictional resources and heavy disease incidence. Due to a heavy workload, local jurisdictional staff may not be able to promptly enter all reports into CalREDIE or their internal system. Thus, data submitted weekly to CDPH may not be representative of the disease incidence for that time period. Additionally, when disease incidents are reported directly to the local health department through non-electronic methods, the state health department has no record of the reports being sent or received. Today, CDPH receives real-time data for 60% of the state's population, a substantial improvement over the status prior to the implementation of the shared CalREDIE surveillance platform.

Massachusetts

The state developed a web-based application, the Massachusetts Virtual Epidemiologic Network (MAVEN)⁸, which was first implemented in 2006. MAVEN is a locally configurable commercial-off-the-shelf (COTS), person-based disease surveillance and case management system that has role-based security and is configured and managed at the state level.

Through MAVEN, participating local health jurisdictions and Massachusetts Department of Public Health (MDPH) Bureau of Infectious Disease and Laboratory Sciences have access to critical clinical, laboratory and epidemiologic information to enhance surveillance, public health investigations, and case management activities. All reportable diseases and conditions have been fully integrated into MAVEN. The system interfaces with health information exchange efforts, including electronic laboratory and health record reporting, and provides automatic real-time notification to state and local officials of any event requiring their attention. MAVEN automatically parses and triages information to determine priority of the response needed and jurisdictional assignment. Approximately 97 percent of all laboratory reports received by MAVEN are electronic; however, laboratory reports are often incomplete, particularly for demographic and ordering provider information, and require time-consuming follow-up.

Responsibility for surveillance and case investigation is a shared responsibility between local jurisdictions and the MDPH. Massachusetts has 351 local public health jurisdictions, composed of local boards of health and health departments, with approximately 95% using the MAVEN system for their surveillance and case management activities. The state's capital and most populous city, Boston, uses the Boston Surveillance System (BoSS), a customized version of MAVEN. Although BoSS and MAVEN are both Consilience Software products, they are not interoperable. BPHC logs separately into MAVEN to access information on Boston residents reported to MDPH. BoSS sends follow-up case investigation data to MAVEN via an HL7 message. The 20 jurisdictions not using MAVEN typically have small populations and staff with limited access to computers or the Internet, or may not have adequately trained staff to use the system.

Although MAVEN is used for receiving and managing all reportable infectious disease events, certain disease data are not shared, by law, with local health jurisdictions, including sexually transmitted infection (STI) and HIV and AIDS data. The Boston Public Health Commission (BPHC) also requires by city regulation that all hospital laboratories and

providers in Boston send reports for all reportable diseases, including sexually transmitted infections, to BPHC. This requirement results in double reporting of laboratory and provider data to city and state.

Idaho

Idaho's 44 counties are organized into seven public health districts. Each district is an independent agency providing public health services. Idaho Department of Health and Welfare (IDHW) also has a board of health with representatives from each district which is not part of or a subsidiary of the state public health agency. All local jurisdictions in the state use the NBS (NEDSS Based System) for reportable disease surveillance (Figure 3). However, the limited functionality of NBS has led to local jurisdictions implementing parallel systems to generate reports from the same data collected in NBS. For example, a separate system is used to capture additional case information required by the state but not supported in NBS.

HIV and AIDS data are currently managed using local health departments' internal databases and are manually (e.g. paper and phone) reported to the state and CDC using eHARS. STI data, with the exception of chlamydia, are tracked locally and then reported manually to IDHW. IDHW uses a CDC-based system, STD*MIS, for managing STI data and reporting STIs to CDC.

IDHW and the local jurisdictions receive reportable disease information through a variety of methods (e.g., electronic, fax, and telephone). More than 95 percent (more than 23,000 annually) of all laboratory reports for reportable conditions are received electronically. All electronic reports are received at the state level by IDHW and processed by a Rhapsody Integration Engine before the data are sent to NBS. Fax and telephone reports are received by both IDHW and the local districts and are manually entered into NBS. Additionally, IDHW has an internally developed Outbreak Management System (OMS) to track disease outbreak information.

The two Idaho local jurisdictions assessed in this project use parallel systems for reporting on data that is captured in NBS. The staff at IDHW, Central District Health Department (CDHD) and Southwest District Health (SDH) stated that NBS is a "user-friendly" system in most cases and provides for easy data sharing and case report transfers. However, they also identified several challenges to utilizing the system. SDH uses an Excel worksheet to track all cases regardless of whether they are reportable to IDHW and CDC. CDHD uses Excel for similar purposes but also uses Access to track HIV and STI cases. Both districts use Excel because of the ease of use for developing customizable reports and searching for particular cases and patients. CDHD also uses Excel and Access to track its unique case number assignment. These functionalities do not exist within or are not user-friendly in NBS. The district and state staff identified additional usability challenges, summarized in Table 1.

Discussion

The assessment focused on three different states, two using vendor-developed systems, and one utilizing NBS. The results of the assessment showed that there is a moderate amount of

complexity that exists at the local and state level to collect, process, and transmit reportable disease data. To reduce some of the burden, both California and Massachusetts have taken steps to streamline the processes by transitioning to statewide reporting systems. While the conversion to these statewide systems is still not at 100 percent, significant progress has been made. Additional strides to reduce the reporting burden can be made by enhancing data exchange capacity and interoperability between systems (in California) and integrating surveillance systems within each state (Massachusetts and Idaho). States are using a variety of electronic and paper-based methods for disease surveillance which often requires redundant data entry. Additionally, data were found to be incomplete requiring significant staff time to follow-up on incomplete and missing information including electronic laboratory data. The flow of data illustrated in Figure 1 does not fully reflect the complexity of the relationships involved or the disparate data sources within public health. There are many reasons for the inefficient exchange of data within states and between states and CDC including categorically funded systems, disparate data collection processes, lack of interoperability and standards to support data exchange and use, shortage of technology savvy public health workers, data sharing policies, and others.⁸

Disease surveillance practices at the state and local level and processes for reporting on NNDs to CDC has implications for the interpretation of NNDSS data. CDC programs rely on NNDSS data to monitor disease trends, identify populations or geographic areas at high risk, formulate and assess prevention and control strategies, and formulate public health policies. Although some states are receiving an increased number of electronic laboratory reports, many of them were reported to be incomplete, requiring additional follow-up thus delaying time-sensitive reporting. Within jurisdictions counts and rates are particularly impacted in those low population states with suppression criteria/thresholds to maintain confidentiality for certain diseases. Additionally, redundant processes (e.g. data entry) introduces the potential for error.

Conclusion

Complete and timely information on individual cases of reportable diseases is critical for informing public health decision making and improving the health of populations. Systems must be designed and developed in a modular manner using widely available standards for technology that allow for greater integration and use across the public health enterprise (including healthcare). Data standardization and harmonization at the earliest point of collection will improve the integrity, reliability and interoperability of the data thus reducing the need for continuous transformation throughout the information supply chain. The CDC Surveillance Strategy addresses critical needs and gaps in surveillance systems and demands that CDC increase functionality and decrease unnecessary redundancies and reporting burdens on STLT agencies.⁴ CDC is working with state and local health departments to improve surveillance systems by taking advantage of advances in technology (e.g. systems, platforms, tools and standards) to create robust, integrated platforms that can be adapted for new surveillance needs⁴. This effort includes working with states to ease local and state reporting burden by transitioning to the widely used HL7 v2.5 format for notifiable disease reporting to CDC, creating message validation and processing services to ensure program data are complete, accurate and valid. There have been strides in the right direction, but

more work is necessary to lessen the reporting burden. CDC, state and local public health partners and developers of public health information systems should consider undertaking a study to define functional requirements for reporting and data analysis utilizing the business process documentation developed during the course of this project. Standardized reporting capabilities in these systems would increase efficiencies by decreasing the requirement for dual or external systems.

A coalition of partners in public health are working to leverage data from electronic health records (EHR) for reporting cases of notifiable conditions.¹⁰ Electronic case reporting (eCR) is defined as the generation and electronic transmission of case reports for reportable conditions from the electronic health record (EHR) to relevant public health authorities for review and action.¹¹ eCR likely represents the way public health surveillance will be conducted in the future and is an opportunity to work with partners in healthcare to promote data standards across the health enterprise.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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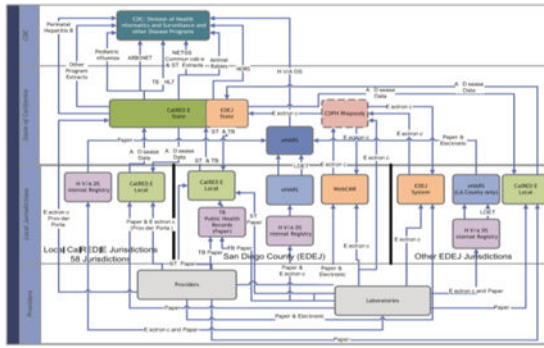
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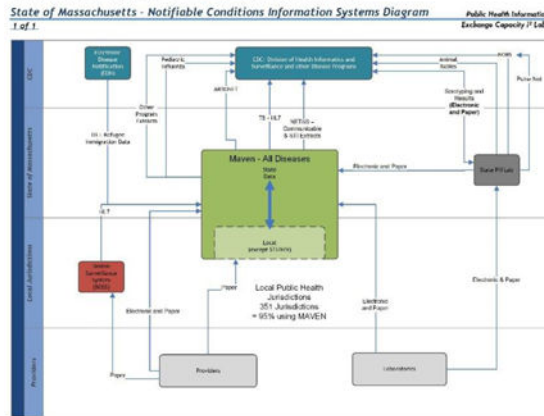
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Systems Diagram for California



Systems Diagram for Massachusetts



Systems Diagram for Idaho

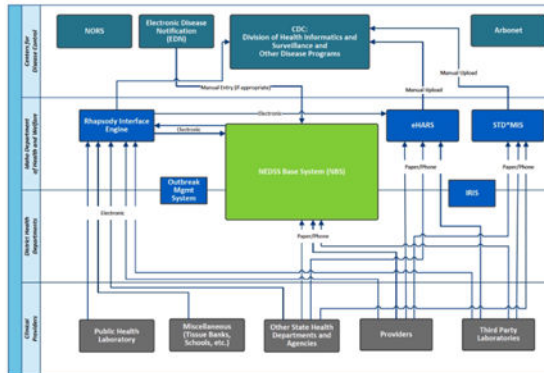


Figure 1: State Systems Diagrams

Project Name
Business Process Matrix Template

Business Process Name						
OBJECTIVES	BUSINESS RULES	TRIGGERS	TASK SET	INPUTS	OUTPUTS	MEASURABLE OUTCOMES
A concrete statement describing what the business process seeks to achieve. A well-worded objective will be SMART: Specific, Measurable, Attainable/ Achievable, Realistic, and Time bound.	A set of criteria that defines or constrains some aspect of the business process. Business rules are intended to assert business structure or to control or influence the behavior. Examples in healthcare and public health include laws, standards, and guidelines.	An event, action or state that indicates the first course of action in a business process. In some cases, a trigger is also an input.	The key set of activities that are carried out in a business process.	Information received by the business process from external sources. Inputs are not generated within the process.	Information transferred out from a process. The information may have been the resulting transformation of an input, or it may have been information created within the business process.	The resulting transaction of a business process that indicates the objectives have been met.

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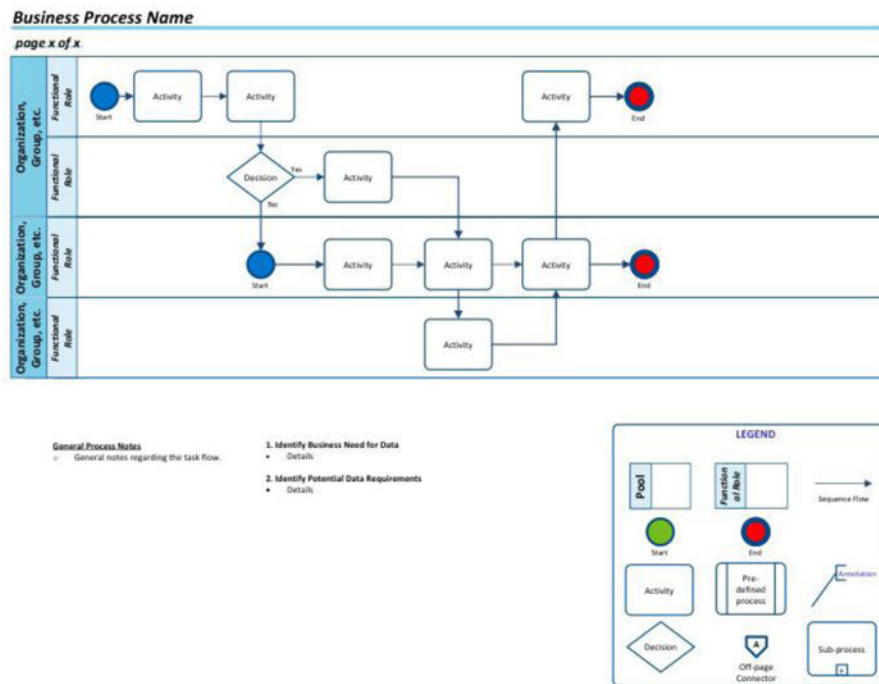


Figure 2:
Business Process Matrix Template

Public Health Information Exchange Capacity i3 Labs

Business Process Matrix

Idaho Department of Health and Welfare Level

Receive Data

OBJECTIVES	BUSINESS RULES	TRIGGERS	TASK SET	INPUTS	OUTPUTS	MEASURABLE OUTCOMES
<ul style="list-style-type: none"> To receive notifiable conditions electronic or paper reports from laboratories/ providers To manually enter phone and paper reports into NBS To identify and send other programs electronic lab reports to appropriate jurisdiction/program 	<ul style="list-style-type: none"> Federal and state laws, regulations and policies Information system restrictions HIPAA Meaningful Use specifications Notifiable conditions workflows 	<ul style="list-style-type: none"> A provider reports diagnosis of a patient with a notifiable condition Lab sends a finding suggestive of a notifiable condition 	<ol style="list-style-type: none"> Submit Laboratory Report Paper or Electronic? Extract Data Message Validated? Send Data to NBS Auto-Process Disease Data? Determine Jurisdiction for Report Queue Message for Review and Resolution Resubmit Missing Information Enter Data into NBS Review Report to Determine Jurisdiction Assign Report to Jurisdiction 	<ul style="list-style-type: none"> Notifiable condition definitions Patient demographics Notifiable condition occurrence confirmation Clinical information Laboratory information Provider/Submitter information 	<ul style="list-style-type: none"> Cases are automatically processed Case reports are provided to the appropriate jurisdiction for review Initial data quality review performed 	<ul style="list-style-type: none"> Number of incidents of each notifiable condition in a specified timeframe Number of incidents receiving manual review in a specified timeframe Number of lab reports (ELR) automatically processed for each notifiable condition in a specified timeframe Number of cases received electronically in a specified timeframe Number of cases received that have been manually entered in a specified time frame

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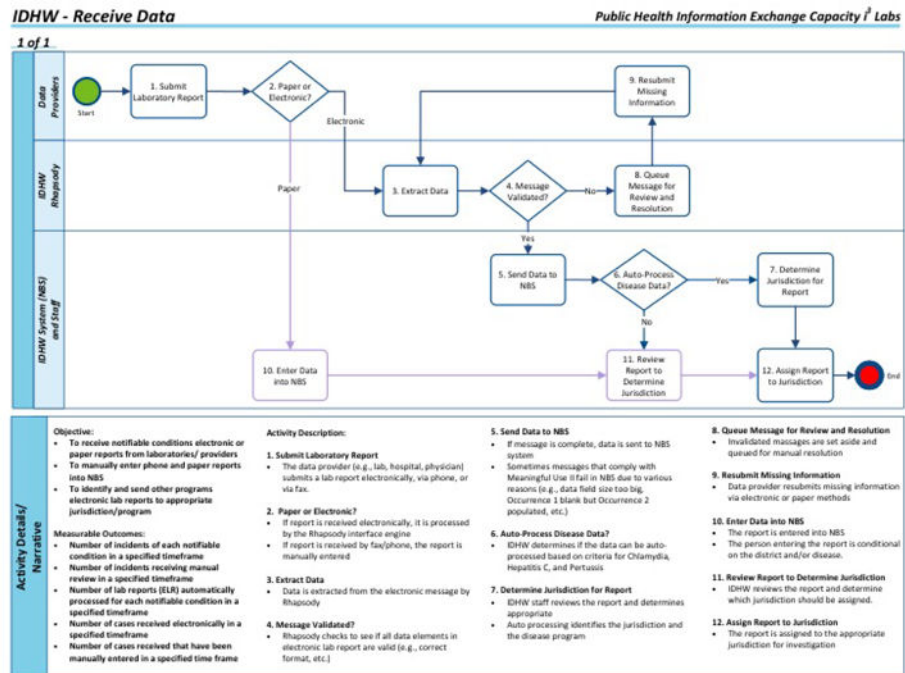


Figure 3: Business Process Matrix Sample

Table 1:

Suggestions for improvement to NBS

Improvement Area	Description
Condition/case Priority	Users are interested in an automatic priority ranking for conditions based on the Idaho defined protocol Based on the ranking assignment, an alert/email should be Generated by NBS for high priority conditions.
Regional Customization for Investigation Reports	Currently, all jurisdictions see all fields within an investigation Whether they are applicable or not. Users would like the investigations to be customizable by region/district.
Auto-populate Fields	Certain fields should be auto-populated based on the information received from the ELR message(e.g., county by ZIP).
Attach Additional Documentation	Users would like the ability to attach document to specific investigations.
Reportable vs Non-reportable Flag	Not all reports are reportable to the CDC These non-reportable conditions may not be tracked in NBS, therefore must be recorded by other means at the district level. Users Suggested a flag that would allow report/investigation to be notifiable but not reportable.
Improve Contact Tracing	The contact tracing functionality is not user friendly. Users requested an auto-population function for cases/contacts in the same household as well as the ability to auto-create cases/investigation from the contacts.
Home Screen	Users requested the ability to customize their home screen.
OMS Interface	Users requested an interface to IDHW's OMS (Outbreak Management System).
Browser Compatibility	Currently, NBS is incompatible with Google Chrome and the latest version Explorer.