INFORMATION SUPPLY CHAIN SYSTEM FOR MANAGING RARE INFECTIOUS

DISEASES

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by

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Chapter 1: INTRODUCTION

1. 1. Background

The goal for the current study is to accomplish a timely transfer of information to the public health system for increased responsiveness to rare infectious diseases. Earlier studies have identified the need for timeliness at the state and national level, but there have been no previous empirical studies on reporting of rare infectious diseases at the county level, which is the first level of response for containment of the diseases. The goal is to accomplish a more timely information supply chain system for managing rare infectious diseases, by analyzing archival data and using the data for a trace-driven simulation study. Towards achieving this goal, timeliness is the key construct, because as time passes it may be more difficult to contain the spread of these rare infectious diseases.

The diagnosis of rare infectious diseases is very difficult, so is their treatment. Then it becomes extremely important to contain the disease at the earliest possible time, in order to avoid the economic losses and also the spread of the diseases. Hence, timeliness is a key performance measure of public health rare infectious disease management systems. Jajosky and Groseclose (2004) reviewed studies involving timeliness and the reporting timeliness of National Notifiable Disease Surveillance System (NNDSS) data "to evaluate whether existing reporting system could support timely notification and state response to multi-state outbreaks" $(p,1)$. The research identified the reason for delay as different layers of reporting existing at the state and national level. Timeliness is extremely important at county and local health jurisdiction level, as they have been authorized with preventive and control measures. Hence timely reporting of rare infectious diseases becomes extremely important at the county level.

In a county public health level, timeliness can be achieved by minimizing lead time at various levels of reporting including hospitals, laboratories, and local health jurisdictions (LHJs). Timeliness can vary by disease type, reporting method, and stakeholders, in the county public health system level. Similar to inter-organizational product information supply chain (Schemm & Legner, 2008; Lawhorn, 2010), information about rare infectious diseases are being passed from one stakeholder to other in county public health system and hence the whole process from identification of disease to action taken at the local health jurisdiction (LHJ) level can be captured in the form of an information supply chain system for managing rare infectious diseases. This next section outlines key research goals in my dissertation.

1. 2. Research Objectives

This dissertation is aimed at establishing a basis for understanding the phenomenon of underlying interorganizational dependencies of information supply chain for managing rare infectious diseases at the county level. The research is used to explore these dependencies by systematically analyzing the acquisition and consumption of rare infectious disease information in hospitals, laboratories, and at various local health jurisdictions and hence explain the causes of delay at various levels of reporting. Building on the vision of the information supply chain by Marinos (2005) and Sun and Yen (2005), this research looks at issues associated with timeliness and integration of data in reporting of rare infectious diseases at the county level and finally comes up with a better information supply chain system for managing rare infectious diseases.

1. 3. Information Supply Chain

The information supply chain (ISC) has its base attributed to product supply chain management (SCM), which primarily focuses on the customer's demand by a network of companies, mainly including suppliers, manufacturers, and distributors (Marinos, 2005; Schemm & Legner 2008; Sun & Yen, 2005). As the supply chain (SC) has two primary objectives with regard to products: (a) to balance demand and supply and to improve efficiency and (b) to improve responsiveness (Corbeti, 1999; Fernie & Azuma, 2004), information supply chain (ISC) focuses on similar objectives with regard to information (Marinos, 2005; Sun & Yen, 2005). Hence, the concepts used in supply chain management system can be easily applied to information supply chain too. Here, instead of companies, a network of information sharing agents (ISA) or stakeholders gather, interpret, and satisfy the requirements with proper information (Sun $\&$ Yen, 2005).

Having mentioned the similarities between product and information, it is equally important to look at differences too. One material cannot fulfill demands from two, but information can fulfill demands of many stakeholders at the same time. Also, material handling like ordering, producing, packaging, and shipping is different from query, observing, and transforming, which are the steps in information processing and transfer. But the application of concepts, goals, methods and philosophy of product supply chain can improve information sharing results (Marinos , 2005; Schemm & Legner, 2008; Sun & Yen, 2005). The, Just-in-Time (JIT) philosophy, for example, "to avoid over supply" or to attain high volume productions with minimum inventories is similar to goal of information sharing in infectious diseases information

supply chain system—to avoid information overload.

1. 4. Significance of the Research

Rare infectious disease epidemics may last a few weeks or a few months and can overwhelm the everyday course of society. For this reason, planning to manage the numerous, complex, and connected impacts of an infectious disease disruption or disaster supports our case for a better ISC system for managing rare infectious diseases, which can assist in reducing the lag time between rare infectious disease reporting and response. This research addresses the issues associated with timeliness of information at various stages of information transfer and once the disease is confirmed, it proposes a better reporting system for managing rare infectious diseases.

In this study, we investigated the effects of different stakeholders (hospitals, laboratories, local health jurisdictions and county health department) and reporting method (fax, telephone or online) on timely reporting of rare infectious diseases in the county public health department level. The stakeholders are defined as various reporting entities from the point of entry of patients into the hospital to the action taken at the county level. *Reporting method* or *reporting mode* is the term used to indicate the method of reporting of information pertaining to rare infectious diseases: whether it is through fax, phone or online method. Laboratory type indicates the location of the laboratory whether it is within hospital, outsourced in-state for testing or outsourced out of state for testing. The results of our analyzes will indicate how these variables have significant impacts/insignificant impacts on information supply chain system for reporting of rare infectious diseases.

Chapter 2: DEFINITIONAL ISSUES AND THEORETICAL UNDERPINNINGS

2. 1. Definition of Rare Infectious Diseases

An infectious disease is said to be rare if fewer than 200,000 people in the United States have it. The definition of rare diseases by National Institute of Health (NIH; of which rare infectious diseases is a part) appeared to be confusing with regard to its time period and we wrote to Genetic and Rare Diseases (GARD) Information Center to clarify the definition for a rare infectious disease. In reply they wrote,

―The definition of a rare disease is based on disease prevalence, which is defined as the total number of cases of the disease in the population at a given time. This means that at any point in time, there must be fewer than 200,000 people affected with a condition in order for it to be considered a rare disease. The definition for a rare disease is not based on incidence, which is a measure of the risk of developing a disease within a specified period of time". (M. Greenwood, personal communication, April 12, 2012)

The selected reportable rare infectious diseases for this study are chosen from the list provided by Office of Rare Diseases Research by the NIH and Orphanet.

There are close to 7,000 rare diseases and about 25 million people in the United States have one (NIH, 2012). Rare diseases encompass genetic diseases, rare cancers, auto-immune disorders, congenital anomalies, toxin-induced diseases, infectious and other diseases like drug resistant communicable diseases. Thus, rare infectious diseases are a part of rare diseases. Among the rare diseases, infectious diseases are the one that need immediate attention (Brooks & Hoberg 2006). But still United States, Australia, and the Canadian provinces do not have national or provincial plans for managing these diseases (Elger, 2011). For the purpose of this article, we

will limit our discussion to rare infectious diseases in the United States only since the health-care management system in the United States, European countries, and other parts of the world vary widely (CSL Behring, 2011). To understand rare infectious disease in detail, it is important to look at their occurrence.

2. 2. Occurrence of Rare Infectious Diseases

Rare infectious diseases can be naturally occurring, accidentally occurring or deliberately occurring (American Medical Association; Carpenter and Wyman, 2008). Naturally occurring rare infectious diseases are endemic or emerging diseases by the presence of pathogen in a new host or an entirely new disease where the pathogen was unknown earlier or can be re-emerging diseases as in the case of presence of pathogen in hosts or geographies, previously responsive to preventive or therapeutic interventions (Carpenter and Wyman, 2008). Accidentally occurring rare infectious are generally a consequence of negligence and opportunistic pathogens like Methicillin-resistant Staphylococcus aureus or due to poor infection control. It can also occur as a consequence of ineffective or non-existent biosafety practices (WHO, 2002; WHO 2004). Last, but not least, rare infectious diseases can be deliberately occurring as in the case of bioterrorism, e.g., Anthrax (Carpenter and Wyman, 2008). To tackle any rare infectious diseases, diagnosis is the first and foremost step.

2. 3. Characteristics of Rare Infectious Diseases

However, the very fact that the disease is rare makes its diagnosis difficult (Kirchmayr et al., 2008). Most patients are not diagnosed properly or will get diagnosed only after several hospital visits or do have to see different doctors before they get diagnosed correctly (Al-Eissa et al., 1991).Yet another important characteristic of rare infectious diseases is that the symptoms are nonspecific and in most cases, the doctors will be treating the patient based on symptoms (Storla et al., 2008). Sometimes, the symptoms may be so unusual that this motivates the doctor to refer the patient to a specialist. Yet, other times, the motivation for reference is the non responsiveness to treatments. During my communication with a specialist, the doctor pointed out, "You may not have the textbook symptoms which persuaded the doctor to refer you to a specialist" (A. Maitra, personal communication, June 12, 2011). Apart from the above unique characteristics for rare diseases, to which rare infectious diseases belong, few other characteristics also exist like (a) availability of drugs and (b) geographic location.

Many of the rare infectious diseases are not completely curable with the available drugs in the United States (Dear et al., 2006). A disease which is considered to be common in one part of the world, can be rare in United States, or vice versa (e.g., tuberculosis is common in India but is considered to be rare infectious disease in the United States). Finally, the losses due to rare infectious diseases are too high (Sommerfield, 2004; Kaufmann et.al. 1997). Rare infectious diseases affect the availability of health workers and other resources in healthcare systems through change in patterns of population mobility and impact government health expenditure through changes in macroeconomic policy (Woodward et al., 2001).

2. 4. Economic importance of rare infectious diseases

The social and economic impact of delay in reporting of rare infectious diseases can be well understood from the CDC studies (Kaufmann et.al. 1997). Over \$ 200 million was spent to decontaminate anthrax-infected facilities in a small scale 2001 anthrax attack in United States. A CDC study also estimated that the economic impact of a bioterrorist attack could range from an estimated \$477 .7 million per 100,000 persons exposed (brucellosis scenario) to \$26 .2 billion per 100,000 persons exposed (anthrax scenario). A timeliness issue has been a concern for rare infectious disease management as the higher the exposure, the more severe will be the economic impact. Effective surveillance depends on systems that promptly collect, analyze and report the data to the decision makers (Bravata et al., 2004; Wagner et al., 2001). Our aim is to reduce lead time from disease confirmation at the laboratory level to the response at the county level, which leads to our research question, "What are the critical factors influencing delay at various levels of reporting in the information supply chain (ISC) system for managing rare infectious diseases at the county level?"

2. 5. Theoretical Underpinnings

2.5.1. Theory Development

Building on the overarching framework of coordination theory (March and Simon, 1958; Malone 1988; Malone and Crowston, 1994; Crowston, 1997), we argue that the interorganizational information supply chain system for managing rare infectious diseases is characterized by a set of dependencies between various stakeholders which needs to be explicitly managed. Crowston (1997) refers to coordination theory as "a still developing body of theories about how

coordination can occur in diverse kinds of systems" (p. 87). Dependencies may be inherent in the structure of the organization (e.g., local health jurisdictions interact with the hospital, that is required for the information to pass from the hospital to the local health jurisdiction) or dependencies may result from processes-task decomposition (i.e., a local health jurisdiction cannot act unless and until it get information from the hospital) or allocation to actors and resources (e.g., county health commissioners asking for information from local health jurisdictions face constraints on the details needed or the kind of changes they can make, without interfering with the functioning of each other). The dependencies can be task-task, taskresource, and resource-resource and each of these dependencies requires an appropriate coordination mechanism to manage it (Crowston, 1997; Li et al., 2002; Biazzo, 2000). These dependencies lead to increase in lead time for the information supply chain system and hence the need for coordination.

Malone and Crowston (1994) defined coordination as the process of managing dependencies between activities. The need for coordination in an information supply chain for managing rare infectious diseases in a county public health setup arises from the complex aggregation of diverse stakeholder systems including hospitals, laboratories and local health jurisdictions, all of which need to be operated in concert to produce desired outcomes. To understand the picture in detail, we can classify the organizations as comprising of actors, goals and resources. The actors in this case are various stakeholders including hospitals, laboratories and local health jurisdictions. The goal is reduction in lead time and the resources including communication medium and facilities involved in the collection and transformation of information.

The lead times at each stage gets added up until the information reaches the Ohio Disease Reporting System (ODRS) and subsequent preventive and control measures. "The Ohio Disease Reporting System (ODRS) was developed as a web-based system to make disease reporting more timely and efficient for disease reporters (e.g. hospitals, laboratories and physicians), and to improve communication about infectious diseases between disease reporters, local health jurisdictions, and ODH. Currently, ODH, local health jurisdictions and infection control preventionists have the ability to enter and update case and laboratory reports into ODRS" (Annual Summary of Reportable Diseases. 2009). Coordination problems are a consequence of dependencies in the organization that constrain the efficiency of task performance, which is taking preventive and control measures. In order to achieve the common desired outcomes, the multiple actors and interactions, resources and goals need to be coordinated and hence coordination theory suits the best for addressing our research. Instead of looking at one problem as a separate entity from the other, coordinating theory focuses on how a component of a system under study (e.g., lead time from laboratories to hospitals interacts with lead time from local health jurisdictions and finally to Ohio Health Department (ODH) or ODRS) (Aronson, 1998). Information supply chain for managing rare infectious diseases are systems in the sense that they comprise of elements that interact to produce a predetermined behavior or output (e.g., the action to be taken by public health department to control the spread of the diseases). If we go by traditional analysis, we focus on isolating individual parts. Instead we are using a systems thinking approach in the information supply chain system for managing rare infectious diseases, which expands the analytical spectrum to take into account the broader picture and examines

how the constituent parts including hospitals, laboratories, local health Jurisdictions and the ODRS interact with each other and result in coordination outcome (i.e., timeliness).

2.5.2. Propositions from Coordination theory

Through high levels of coordination, organizations gain process efficiencies in terms of timeliness, simply by reducing the lead time in exchanging and processing information. The various constructs, their description, its relevance for managing the information supply chain system for the rare infectious diseases and the case study design and data collection are given in the Table 1 below.

Constructs	Description	Importance of the information supply chain for managing rare infectious diseases	Case study design and data collection
Coordination problems	Based on type of dependencies (Malone et al., 1999; Shen and Shaw, 2004: Crowston and Osborn, 2003), (1) . Flow dependencies due to sequence of events e.g., county can act only after receipt of confirmatory lab report (2) . Sharing dependency due to shared resources e.g., when lab shares the information about the disease to the hospital, it uses the information for treatment and shares same report with county public health system for preventive and control measures.	Interorganizational dependencies in information supply chain system exist between different stakeholders e.g., from collection of disease information and confirmation activities (flow dependencies) and also multiple activities using the same information from collecting of specimen to confirmatory lab reports to LHJs (sharing dependencies) and finally treatment at the hospital side and control measures from county side.	Process analysis: examined the dependencies at several steps from the patient entering the hospital to the lab, from the lab to local health jurisdiction and from the local health jurisdiction to the ODRS/ ODH for the response, with respect to disease type and reporting method.
Coordination mechanisms	Generic mechanisms for coordination are coordination by plan and coordination by feedback (March & Simon, 1958; Frayret, 2004; Wittenbaum et.al, 1998). In this case Dynamic adjustment through IT supported learning from Ohio Disease Reporting system (ODRS) and adaptation (Gosain et al., 2004) is more applicable. The stakeholders have made progress in reporting through ODRS by learning and adaptation.	Electronic integration through Electronic Lab Reporting (ELR) into the ODRS facilitate transfer of information regarding rare infectious diseases along with nonelectronic methods of reporting like telephone, fax etc	Looked at the levels of usage of electronic (like ELR) and non electronic methods (fax, telephone etc.) by laboratories with respect to various type of rare infectious diseases and their influence in lead time in reporting till the information reaches the ODRS.

TABLE 1 Propositions from Coordination Theory

Table 1 (continued)

Chapter 3: EXISTING DECENTRALIZED INFORMATION SUPPLY CHAIN SYSTEM FOR MANAGING RARE INFECTIOUS DISEASES

The coordination between different stakeholders and the process of information transfer in the existing form is discussed below. Even though the Center for Disease Control and Prevention (CDC) provides the necessary assistance for states in regards to reporting of rare infectious diseases, each state has been given the autonomy to make their own list of rare infectious diseases to be reported to the state, except for some highly infectious diseases like Anthrax. This leads to the underreporting of many infectious diseases, which can be especially dangerous when they are rare infectious ones (Silk & Berkelman, 2005). With the inherent difficulty in identifying rare infectious diseases, any further delay in reporting after its confirmation can be extremely dangerous. Generally rare infectious disease reporting is done as per the guidelines of Infectious Disease Control Manual (IDCM).

3.1. Role of the Infectious Disease Control Manual (IDCM)

The Infectious Disease Control Manual (IDCM), which is a project of Ohio Department of Health State Epidemiology Office, contains sections two to seven dealing with reporting of suspected and diagnosed cases of infectious diseases, including the rare infectious ones (The Infectious Disease Control Manual, 2011). The IDCM also contains information for prevention and control of rare infectious diseases from a public health perspective. Based on the severity of the public health concern associated with rare infectious diseases, they are classified into Class A, Class B1, Class B2 and Class C diseases, the reporting time varies, though all are encouraged to report the incident at the earliest (Ohio's Communicable Disease Reporting Requirements, 2011). For Class A disease, immediate reporting is mandatory after a case, suspected case or a

positive lab result. For Class B1 diseases, reporting can be done by the end of the next business day after the existence of a case, suspected case or a positive lab result. For class B2 diseases, reporting can be done at the end of the work week after the existence of a case, suspected case or a positive lab result. For Class C diseases (including an outbreak, unusual incidence or epidemic), it should be reported by the end of the next business day. Though there are specific rules with regard to reporting of infectious diseases including rare infectious ones, previous researches have shown that there are timeliness issues at various levels of reporting. Previous researchers have identified different layers of reporting lead to timeliness issues in reporting of rare infectious diseases, which is in fact the starting point of our study which is shown in the Figure 1 below.

FIGURE 1

Delay in Reporting Due to Different Layers. *Note.* **Adapted from the Study by Jajosky**

R.A. and Groseclose S.L. (2004).

3.2. Decentralized Reporting System for Rare Infectious Diseases

Consider a patient entering in the hospital with suspected symptoms of a rare infectious disease. From the symptoms, doctor identifies a possible disease, which is uncertain and can be confirmed by laboratories through specimen analysis at some future point. The information becomes extremely important after the identification of the disease (i.e., confirmatory lab reports). The public health significance of the report is mainly with regard to control and prevention of the disease. The existing decentralized system with its reporting structure for reporting of rare infectious diseases is shown in the Figure 2 given below.

FIGURE 2

Decentralized Reporting System for Rare Infectious Diseases

b

There are four local health jurisdictions that functions autonomously with regard to reporting and taking control and preventive measures in the existing decentralized reporting system (in the county selected for research). In the existing decentralized system, each local health jurisdiction is responsible for reporting and taking action on rare infectious diseases reported in their respective areas. As information supply chain is very similar to any other supply chains (Sun & Yen, 2005), the next step was to look at the information supply chain for managing rare infectious diseases from a supply chain point of view. As in any supply chain, information supply chain for managing rare infectious diseases also measures the performance of the system by timeliness in passing information from one stakeholder to the other; hence the lead time in passing of information is the most significant factor affecting performance.

3.3. Component Reporting Lead Times

Timely reporting of rare infectious diseases is extremely important once a patient is identified with a rare infectious disease at the laboratory level (i.e., it becomes extremely important when lab confirms positive results for the analyzed specimen). Hence, we focused on the lead time taken in the laboratory and on subsequent steps till it reach LHJ for action. The decentralized reporting system with its reporting structure is shown in the Figure 3 given below.

FIGURE 3

Chapter 4: RESEARCH DESIGN AND DATA ANALYSIS

State and local health jurisdictions benefit from timeliness in reporting of rare infectious diseases, as they will be able to timely react (contain the spread of rare infectious diseases and take preventive measures) to any health event of rare infectious diseases. Ensuring timeliness for an information supply chain for rare infectious diseases is particularly challenging with the number of stakeholders involved in identification and confirmation followed by treatment, control and preventive measures. Ohio Department of Health (ODH) and local health jurisdictions depends on stakeholders not only to provide information in time but also in an accurate manner. One way of addressing this challenge is to analyze how stakeholders respond (with regard to timeliness) to different situations (with respect to type of disease, the laboratory locations, reporting method etc.). This allows measurement of lead times at various stages of reporting and how much each stakeholder or layer contributes to the overall delay. The ability to measure the lead times in reporting allow us to explore whether any change in the reporting process reflect the possible reduction in lead time in reporting of rare infectious diseases. The findings from the empirical analysis emphasize the need for a new reporting system for managing rare infectious diseases which requires stakeholders to change their reporting structure.

4.1. Details of the case study sample

In accordance with CDC classification of diseases, we classified the rare infectious diseases selected for the study into Type A, B1, B2 and C. Since there was no outbreak or food borne diseases in the county for the period of study (January 1, 2010 to March 31, 2012), there were no Type C rare infectious diseases included in this study. There were 28 Type A, 1187 Type B1 and 293 Type B2 rare infectious diseases found in a 2-year period from 1/1/2010 till 3/31/2012. The maximum number of rare infectious diseases included in the study belongs to the B1 type with a total of 1187 cases while the least number of rare infectious diseases occurred for the Type A diseases (i.e., 28). The frequency of the rare infectious diseases based on its location and the count of disease cases in each type is given in the Table 2 below.

TABLE 2

Frequency of Occurrence of Rare Infectious Disease Types in Different Local Health Jurisdictions

From the empirical analysis of the collected data, we have identified three major delays: (a) the delay at the laboratory level, (b) delay of reporting at the hospital to the local health jurisdictions, (c) delay in reporting from the local health jurisdictions to ODH/ODRS.

4. 2. Lead Time in Reporting Rare Infectious Diseases in Existing Decentralized Reporting System

4.2.1. Factors influencing Delay of Reporting (Lead time in Reporting) at the Laboratory Level

On empirical analysis, we have identified three main factors affecting the timeliness with regard to reporting of rare infectious diseases from laboratory which include disease type (Type A, B1 or B2, mode of reporting like electronic lab reporting (ELR) directly into the ODRS or through non-ELR methods like fax or telephone and the location of laboratories. For the purpose of parsimony, the laboratories (where disease confirmation takes place) are classified into three types: (a) located within hospital (within hospital), (b) outsourced within State for analysis of specimen (Outsourced In-State), (c) outsourced out of state for disease confirmation (Outsourced
out of state). The factors influencing the lead time at the laboratory level is shown in the Figure 4 given below.

FIGURE 4

Factors Influencing Lead time at Laboratories

When the lab adopts Electronic Lab Reporting (ELR) method for reporting of rare infectious diseases, it actually bypasses hospitals and LHJs and reports confirmatory results directly to the ODH (i.e., ODRS). The following section looks at lead times in various stages and the factors influencing the reporting in terms of type of stakeholders: (a) type of laboratories in terms of location whether it is within the hospital, outsourced for diagnosis within state or outside of the

state, (b) the types of diseases, (c) the mode of reporting of information in the supply chain (electronically (ELR) or non-electronically).

4.2.1.1. Lead Time in Reporting at the Laboratory Level by Disease Types

To get an overall idea on delay of reporting at the laboratory level with respect to rare infectious disease types, we plotted a bubble plot with lead time in reporting on Y axis and disease types on X axis. The bubble plot obtained is shown in the Figure 5 given below.

Bubble Plot of Lead Time (days) in Reporting from Lab by Disease Types

The bubble plot clearly shows that B1 and B2 type rare infectious diseases are having high lead times in reporting from laboratories. To understand the lead time in reporting from laboratories or labs, it is also important to look at the method of reporting too. The lab reports are send either electronically (i.e., Electronic Lab Reporting (ELR) or through nonelectronic methods like mail, phone, or fax). Of the total of 1508 rare infectious disease cases considered for the study, 759 cases were reported through electronic lab reporting and 749 cases were reported through nonelectronic method to hospitals and then the information was passed on to the LHJs and finally to ODH/ODRS for action. As a next step of empirical analysis, we looked at how lead time in reporting from lab is influenced by the reporting method.

4.2.1.2. Lead Time in Reporting at the Laboratory Level by Methods (mode) of Reporting

Earlier studies have already found that electronic reporting by lab has the least lead time in transferring the information from laboratories to the state public health system (Wurtz and Cameron, 2005; Faensen et al., 2006; Smith et al., 2002). In our research, we also looked at whether the reporting method has any influence in the lead time from laboratories. To get an overall idea on lead time of reporting at the laboratory level with respect to reporting methods, we plotted a bubble plot with lead time in reporting on Y axis and reporting method on X axis. The bubble plot obtained is shown in the Figure 6 given below.

Though the bubble plot gives only an overall picture about the difference in lead times in reporting from labs with respect to electronic and nonelectronic method of reporting, it can be well appreciated that there is significant difference in lead times in reporting between electronic and nonelectronic methods. The frequency of cases of rare infectious diseases reported electronically (ELR) and non-electronically is given in the Table 3 below

TABLE 3

Frequency Table on Reporting Methods of Rare Infectious Diseases

After conducting the empirical analysis to find the frequency of reporting both electronically and non-electronically based on disease types and laboratory types separately, the next section gives the combined influence of lead times with respect to various disease types and reporting types. We did an empirical analysis to find the number of rare infectious diseases in each type $(A, B1)$ and B2) reported through electronic and nonelectronic method (ELR and nonELR method). All of the Type A rare infectious diseases were reported through electronic lab reporting while out of the 1187 Type B1 cases of rare infectious, 697 cases of Type B1 diseases (58.72%) were reported through electronic lab reporting method and 490 cases (41.28%) were reported through nonelectronic lab reporting method. Of the reported 293 cases of rare infectious B2 type of diseases, only 34 were reported through electronic lab reporting (11.6%) and 259 cases were

through nonelectronic reporting method (88.4%). This can be diagrammatically represented in the Table 4 given below.

TABLE 4

Reporting method Percentage Count of Disease type A ELR 100.00% 28 **Grand Total** 100.00% 28 **B1 ELR** 58.72% 697 **non-ELR** 41.28% 490 **Grand Total** 100.00% 1187 **B2 ELR** 11.60% 34 **non-ELR** 88.40% 259 **Grand Total** 100.00% 293

Frequency Table on Reporting Methods Vs Disease Types

As a next step, we examined the combined influence of lab type (based on the location of the laboratories), reporting methods and disease types in lead time in reporting at the laboratory level. All Type A rare infectious diseases laboratory reports were reported through ELR but were not so in the case of Type B1 and Type B2 rare infectious diseases. The frequency table with rare

infectious diseases belonging to each type and the reporting method with respect to laboratory type is shown in the Table 5 given below.

TABLE 5

Frequency Table on Lab types (based on the location of the laboratories), Disease Types

and Reporting Methods

4. 2.1.3. Cause and Effect diagram for Lead Time/Delay in Reporting from Labs

The cause and effect for the delay in reporting from laboratories can be better represented in the form of the Cause and Effect (a.k.a. Fishbone) Diagram (Ishikawa, 1976), in the Figure 7 shown below. The factors or causes identified for the lead time in reporting from lab are disease types, reporting mode or reporting method and the lab locations.

FIGURE 7

Fish Bone Diagram for Lead Time in Reporting from Labs

4.2.1.4. Finding from Empirical Analysis of Lead time in Reporting at the Laboratory Level

From empirical analysis of the data collected for the two year period from January 1, 2010 to March 31, 2012, for calculating the average lead time in reporting from lab, we considered disease types, reporting methods and lab locations collectively, to find the overall influence of these factors on the lead time in reporting from labs. Table 6 given below gives details on

maximum lead time, minimum lead time, mean lead time, standard deviation and standard error along with the number of cases of rare infectious belonging to each group. Though previous studies have found the influence of electronic lab reporting in the lead time in reporting from lab, research have not considered other factors like disease types and lab locations in their studies. This makes our study more valuable and appropriate in a practical set up. As already established, we also observed that there is difference in lead time with respect to electronic method and nonelectronic method, in addition to this, our study has established that there is difference in lead time with respect to disease type and location of lab, in reporting from laboratories.

TABLE 6

Lab Types	Disease Types	Reporting methods	Number of cases	lead	Max Min lead time time	Mean	Std dev	Std error mean
within hospital	A	ELR	12	30	$\overline{2}$	6.75	8.08	2.33
within hospital	A	non-ELR	$\boldsymbol{0}$					
within hospital	B1	ELR	301	64	θ	17.71	21.45	1.23
within hospital	B1	non-ELR	301	86	θ	17.08	24.53	1.41
within hospital	B ₂	ELR	$\boldsymbol{0}$					
within hospital	B ₂	non-ELR	180	121	$\overline{0}$	5.26	14.4	1.078

Lead Time in Reporting from Lab with Respect to Lab Types, Disease Types and Reporting Methods for Rare Infectious Diseases

The table given above gives an idea about the delay in reporting of rare infectious diseases at the laboratory level. From the above analysis, ELR can easily be recognized as the preferred method of reporting of rare infectious diseases.

4. 3. Why Digitization is Not a Feasible Solution in the Present Scenario?

One may argue that digitization can solve the problem permanently. Yes, it is. But looking at the present scenario, many of the local hospitals are still not equipped to enter the details digitally into the ODRS. The ODRS access is available only to epidemiologists, few laboratories and LHJ officials. Those hospitals that initiate the process by entering electronically into the system are likely to get the information back electronically. Jernigan (2001) stated that "The laboratory landscape is changing. Large national and regional laboratories have developed advanced information technology (IT) capabilities and use standardized test codes, making ELR possible. However, many smaller laboratories do not have the technology necessary for ELR. Additionally, many states have reporting regulations that are not structured for electronic reporting, and health department staffs often have limited knowledge of electronic data interchange technology. In the past, public health agencies have focused more on epidemiology and statistics, and less on IT". Even in the year 2012, the situation has not changed considerably.

The presentation by Giljahn (2011) at the Infection Control Group (ICG) meeting on May 27, 2011, will give us a true picture regarding the electronic lab reporting and direct entry of details into Reporting System (ODRS) in the present scenario. "In 2007 approximately 20 hospitals entered directly into ODRS. By the end of March 2011, 71 hospitals were entering directly into ODRS". She also pointed out that "ELR fulfills a meaningful use requirement for hospitals. Line lists for ELR can also be created. A challenge for ELR into ODRS has been system compatibility." There is an ongoing project in ODH, through a grant from CDC, to work with three hospitals in the state on electronic medical record (EMR) transfer. According to Lynn Giljahn, "Hospital IPs discussed another challenge of using ODRS". She also mentioned that

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―some Local Health Jurisdictions do not want hospitals to enter some disease information there $(e.g., meningococcal, TB, HIV)$ as they would like to do that" (Infection Control Group (ICG) Minutes, 2011).

According to American Hospital Association of OHIO, there are 183 hospitals in Ohio (Ohio Hospital Facts, 2011). Of 183 hospitals, only 71 are currently using the ODRS system for reporting of rare infectious diseases. This turns out to be only 38.8% of the total hospitals. The plausible reasons can be inadequate staff and non-accessibility to the ODRS. Other reasons are IP address conflict and discouragement from LHJ with respect to certain diseases or system incompatibility (Infection Control Group (ICG) Minutes, 2011).

4.4. Non Electronic Cases of Lab Reporting

Of 749 cases of rare infectious diseases reported non-electronically from lab, 490 cases were of Type B1 (65.5%) and the rest 259 cases were of Type B2 (34.5%). Of the rare infectious diseases reported non-electronically, Tuberculosis cases topped the list with 412 cases (55%) followed by Giardiasis 143 (19%). Other rare infectious diseases reported non-electronically include 16 cases of Brucellosis (2.13%), four cases of Creutzfeldt-Jakob Disease (0.5%), one case of Dengue, two cases of Ehrlichiosis-Ehrlichia chaffeensis , 24 cases of Haemophilus influenzae (invasive disease) (3.2%), one case of Hepatitis E, one case of Herpes—congenital, 28 cases of Legionellosis (37.38%), one case of Malaria , 47 cases of Mycobacterial disease– other than tuberculosis , 20 cases of Pertussis (2.67%), two cases of Rocky Mountain spotted fever (RMSF), four cases of Shigellosis, 36 cases of Streptococcal–Group A–invasive (4.81%),

six cases of Varicella and one case of Yersiniosis. This is shown as pie chart in the Figure 8 given below.

FIGURE 8

Pie Chart Indicating Non-electronically Reported Rare Infectious Diseases

For non-ELR reporting of rare infectious diseases, the delay happens at two levels: (a) delay at the hospital level in passing confirmatory laboratory report to the LHJs and (b) delay at the LHJ level in entering the information to the ODRS.

4.5. Lead time of Reporting from Hospitals to LHJs

Once the lab result reaches the hospital, there is no more influence of the lab types (based on its location) in lead time in reporting from hospitals to LHJs. However, in order to rule out any possibility of influence of location of lab in the lead time at the hospital level, we did an analysis by lab type, hospital location and disease type first. Had there been any influence of lab location on the lead time at hospital level, the lab results send from the local hospitals (i.e., within hospital lab results) should have taken the lowest lead time and we found that it is not true. Hence, we decided to continue empirical analysis with respect to disease type and the location of hospitals (jurisdiction where hospital belongs to). To get an overall picture of the variations in lead times in reporting from hospitals to LHJs with respect to disease types and jurisdictions, we plotted bubble plots of lead time in reporting from hospitals to LHJs with respect to disease types and jurisdictions. The bubble plot showing the lead time at hospitals with respect to disease types is shown in Figure 9.

Bubble Plot of Lead Time in Reporting from Hospitals to LHJs by Disease Types

As there were no Type A cases of rare infectious diseases reported non-electronically, the plots shows only cases of Type B1 and Type B2 rare infectious diseases. We could easily appreciate that the lead time in reporting of Type B1 and Type B2 rare infectious diseases were not within the limits allotted by the ICDM and there were high variations in lead times in reporting of Type B1 and Type B2 rare infectious diseases over the last two years. The next bubble plot given in Figure 10 shows the variation in lead time with respect to jurisdiction.

Bubble Plot of Lead times (in days) in Reporting from Hospitals to LHJs by Jurisdictions

The above bubble plots gives an overall idea of delays (lead times) in reporting with respect to jurisdiction. There was a wide variation in lead times with respect to jurisdictions over the last two years. In order to understand the details, in-depth empirical analysis is required. Before conducting the empirical analysis, we thought that it is better to capture the causes of the lead time in the form of a cause and effect diagram.

4.5.1. Cause and Effect diagram for Lead Time/Delay in Reporting at the Hospital Level

The delay at the hospital level is calculated from the difference between the date of lab results made available to hospitals and the date in which it is reported to LHJs. Some values turned out to be negative, which is never possible in real life circumstances. It is because the hospitals already informed the suspected cases to LHJs, and hence, we have taken negative values to be zero as there was no delay in informing the LHJs about the disease. Since there was no Type A rare infectious diseases reported non-electronically, there was no delay in reporting for Type A rare infectious diseases from hospitals to LHJs. The delay from hospitals to LHJs was studied with respect to jurisdiction in which the hospital belongs to and with respect to the types of rare infectious diseases. The cause and effect can be expressed in the form of a fish bone diagram as shown in the Figure 11 below.

FIGURE 11

Fish Bone Diagram for Lead Time in Reporting from Hospitals to LHJs

4.5.2. Empirical Analysis of Lead times in Reporting at the Hospital Level when the Laboratory Reports are Send Non-electronically

4.5.2.1 Lead Time in reporting at the hospital level for Type B1 rare infectious diseases

Of overall 749 cases of Type B1 and Type B2 rare infectious diseases reported nonelectronically, we found that the mean lead time in reporting from hospitals to LHJs to be 3.42 days (*SD* = 9.29), which indicate a wide variation in lead times in reporting from hospitals to LHJs. The next step was to look at lead times in reporting of rare infectious diseases Type B1 and Type B2 separately.

There were 156 cases of Type B1 rare infectious diseases reported non-electronically from hospitals belonging to Jurisdiction 1 over the last 2 years from January 1, 2010*,* to March 31, 2012. The maximum value of lead time from hospitals to LHJs was found to be 46 days. The mean value of lead time in reporting from hospitals to LHJs was calculated to be 3.38 days (*SD* = 10.3), which indicated the wide variation in reporting times at the hospital level to the LHJs.

The empirical analysis indicated that 26 cases of Type B1 rare infectious diseases were reported non-electronically from hospitals under Jurisdiction 2 over the last 2 years. The maximum value of lead time from hospitals to LHJs was found to be 52 days. The empirical analysis demonstrated that the mean value of lead time in reporting from hospitals to LHJs to be 9.04 days $(SD = 18.8)$, which in-turn showed the wide variation in reporting times at the hospital level to LHJs.

The empirical analysis confirmed that 60 cases of Type B1 rare infectious diseases were reported non-electronically in Jurisdiction 3 over the last 2 years selected for the study. The maximum value of lead time from hospitals to LHJs was found to be 4 days. The mean value of lead time in reporting from hospital to the LHJ was found to be $0.15 \text{ day } (SD = 0.659)$.

For 248 cases of Type B1 rare infectious reported non-electronically in hospitals belonging to Jurisdiction 4 over the last 2 years, the maximum lead time from hospital to Jurisdiction 4 was found to be 35 days with a mean $(M) = 3.29$ days and $SD = 8.72$.

4.5.2.2. Lead time in reporting at the hospital level for Type B2 rare infectious diseases

The analysis of lead times from hospitals to LHJs for Type B2 rare infectious diseases reported non-electronically (non-ELR) in Jurisdiction 1 for the last 2 years, showed that the maximum lead time was 51 days and mean lead time was 6.29 days. The standard deviation for the lead times was found to be 14.1 showing the great variation in lead time from hospitals to LHJs. There were a total of 14 cases of Type B2 rare infectious diseases reported non-electronically in Jurisdiction 1 for the 2**-**year period considered for the study.

In Jurisdiction 2, there were 49 cases reported non-electronically for the 2-year period of study (January 1, 2010*,* to March 31, 2012), with mean lead time 2.18 days (*SD* = 2.4). The maximum lead time for Type B2 rare infectious disease in Jurisdiction 2 was 13 days. The mean lead time in reporting from hospitals to the LHJ for Type B2 rare infectious diseases (reported nonelectronically) in Jurisdiction 3 was found to be 1.84 days (*SD* = 1.89). During the 2-year period considered for the study, there were 19 cases of Type B2 rare infectious diseases reported nonelectronically from hospitals in Jurisdiction 3.

The mean lead time in reporting from hospitals to the LHJ for Type B2 rare infectious diseases (reported non-electronically) in Jurisdiction 4 was found to be 4.15 days (*SD* = 9.5). There were 177 cases of Type B2 rare infectious diseases reported non-electronically from hospitals in Jurisdiction 4 for the period of study. The lead time in reporting at the hospital level with respect to jurisdictions and disease types is shown the Table 7 given below:

TABLE 7

Jurisdiction	Disease	Number of	Max	Min	Mean	Standard deviation
	Type	Cases				
Jurisdiction-1	B1	156	46	θ	3.38	10.3
	B ₂	14	51	θ	6.29	14.1
Jurisdiction-2	B1	26	52	θ	9.04	18.8
	B2	49	13	θ	2.18	2.4
	B1	60	4	Ω	0.15	0.66
Jurisdiction-3	B ₂	19	7	θ	1.84	1.89
Jurisdiction-4	B1	248	35	θ	3.29	8.72
	B ₂	177	69	θ	4.15	9.5

Lead Time in Reporting from Hospitals to LHJs (in days)

From the empirical analysis of data, we could find that the third important lead time in the information supply chain system for managing rare infectious diseases takes place at the LHJ

level from LHJs to the ODRS/ODH (when the confirmatory lab report is reported nonelectronically).

4.6. Lead time of Reporting from LHJs to ODH

To get an overall picture of variation in lead times in reporting from LHJs to ODH with respect to disease types and jurisdictions, we performed a bubble plot of lead time in reporting from LHJs to the ODRS/ODH which is shown in the Figure 12 and Figure 13.

FIGURE 12

Bubble Plot of Lead Time (in days) in Reporting from LHJs to the ODRS by Disease Types

Bubble Plot of Lead Time (in days) in Reporting from LHJs to the ODRS by Jurisdictions

The bubble plots above give only an overall idea with the lead time in reporting of rare infectious at the LHJ level, and it is important to conduct an in-depth empirical analysis for details. As already stated, if the lab reports electronically through ELR into the ODRS, then there is no lead time in reporting to ODH for action. The action at LHJ level is initiated after the entry of the confirmatory report into the ODRS. The lead time in reporting from LHJ to the ODRS/ODH

with respect to diseases (when the laboratory reports the final results non-electronically) is shown as a fish bone diagram in the Figure 14 given below.

FIGURE 14

Fish Bone Diagram Showing Lead Time in Reporting from LHJs to the ODRS

For 749 cases of Type B1 and Type B2 rare infectious diseases reported non-electronically from labs to hospitals and then to LHJs, we found a mean lead time of 2.85 days from LHJs to the ODRS/ODH. The maximum lead time at LHJ level in reporting to the ODRS/ODH was found to be 40 days (*SD* = 4.25) for the non-electronically reported rare infectious diseases considered for the study. The next step was to analyze the lead times with respect to disease types and jurisdictions to understand the lead times in detail. Hence, in our empirical analysis, we used two different factors which can influence the lead times in reporting from LHJs to ODH. In addition to types of diseases, it seems likely the different LHJs takes different lead times in reporting from LHJ to ODH.

4 .6.1. Empirical Analysis of Lead times in Reporting at the LHJ Level for the Laboratory Reports Received Non-electronically

4.6.1. 1.Lead time in Reporting at the LHJ Level for Type B1 Rare Infectious Diseases

There were 156 cases of Type B1 rare infectious diseases reported non-electronically from LHJ-1 into the ODRS over the last 2 years from January 1, 2010, to March 31, 2012. The maximum value of lead time at Jurisdiction1 was found to be 2 days. The mean value of lead time in reporting from LHJ 1 to the ODRS/ODH was found to be 0.808 days $(SD = 0.938)$, which indicated the variation in reporting to the ODRS at LHJ-1.

The empirical analysis indicated that 26 cases of Type B1 rare infectious diseases were reported non-electronically by LHJ-2 over the last 2 years. The maximum value of lead time from LHJ- 2 to the ODRS/ODH was found to be 5 days. The empirical analysis demonstrated that the mean value of lead time in reporting from hospital to LHJ 2 to be 0.808 days (*SD* = 1.06), which in turn showed the variation in reporting time from LHJ to ODH at LHJ-2.

The empirical analysis confirmed that 60 cases of Type B1 rare infectious diseases were reported non-electronically in Jurisdiction 3 over the last 2 years. The maximum value of lead time from LHJ-3 to ODH was found to be 12 days. The mean value of lead time in reporting at LHJ 3 was found to be 10.8 days (*SD* = 3.63). For 248 cases of Type B1 rare infectious reported nonelectronically from Jurisdiction 4 hospitals over the last 2 years, the maximum lead time taken at the Local Health Jurisdiction 4 to enter into the ODRS was found to be 22 days ($M = 3.02$ days, $SD = 3.41$.

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4.6.1.2 Lead time in Reporting at the LHJ Level for Type B2 Rare Infectious Diseases

After the analysis of lead times at LHJ-1 for 14 cases of Type B2 rare infectious diseases reported non-electronically from hospital for the last 2 years, it was found that the maximum lead time was 4 days and mean lead time was 0.643 days. The standard deviation for the lead times was found to be 1.15 showing the variation in lead times in reporting from LHJ-1 to ODH. For Jurisdiction 2, there were 49 cases reported from LHJ to the ODRS ($M = 0.571$ days, SD = 1.19).The maximum lead time for Type B2 rare infectious disease reporting at the LHJ level in Jurisdiction 2 was 5 days.

The mean lead time in reporting at LHJ 3 for Type B2 rare infectious diseases (those reported non-electronically from lab) was found to be 0.368 days (*SD* = 0.831). During the 2-year period considered for the study, there were 19 cases of Type B2 rare infectious diseases reported into the ODRS at LHJ-3.

The mean lead time in reporting from LHJ to the ODRS/ODH at Jurisdiction 4 for Type B2 rare infectious diseases was found to be 3.1 days (*SD* = 5.09). There were 177 cases of Type B2 rare infectious diseases' whose lab results were reported non-electronically from hospitals belonging to the jurisdiction. The lead time in reporting at the LHJ level with respect to jurisdictions and disease types is shown the Table 8 given below:

TABLE 8

Lead Time in Reporting from LHJs to the ODRS/ODH (in days)

The lead times at the hospital level after the confirmatory lab report reaches the hospitals and the subsequent lead time at the LHJ level before it being entered into the ODRS are captured in the diagrammatic form in Figure 15 to Figure 22 below

Lead time for Type B1 Rare Infectious Diseases, LHJ-1

Lead time for Type B1 Rare Infectious Diseases, LHJ-2

Lead time for Type B1 Rare Infectious Diseases, LHJ-3

Lead time for Type B1 Rare Infectious Diseases, LHJ-4

Lead time for Type B2 Rare Infectious Diseases, LHJ-1

Lead time for Type B2 Rare Infectious Diseases, LHJ-2

Lead time for Type B2 Rare Infectious Diseases, LHJ-3

Lead time for Type B2 Rare Infectious Diseases, LHJ-4

Chapter 5: A SIMULATION MODELING APPROACH TO DECENTRALIZED VS. CENTRALIZED REPORTING OF RARE INFECTIOUS DISEASES

This chapter describes an effort that involved development of a simulation model for evaluating the various lead times in information transfer process, and factors influencing the lead times in the information supply chain for managing rare infectious diseases. It is then followed by an analysis to compare a new reporting system (*to-be*) i.e., centralized reporting system to the *as-is* existing reporting system, which is a decentralized or distributed reporting system, and to compare the information transfer lead times in order to determine value benefit, timeliness, in both of them.

The legendary CEO of IBM, Thomas Watson once stated, "All the value of this company is in its people. If you burnt down all our plants and we just kept our people and our information files, we would soon be as strong as ever" (Picolli, 2008). Information processing and transfer is an integral part of any organizational design (Tushman & Nadler, 1978) including public health departments managing rare infectious diseases, and the key performance indicator of transfer of information with regard to rare infectious diseases is its timeliness (Jajosky & Groseclose, 2004). The section provides an innovative perspective in the conceptualization of an information supply chain system simulation model, which has been designed and conducted to validate empirically the information supply chain for managing rare infectious diseases. Simulation tools have become popular for various environments including health care management (Bhattacharya et al., 2009) allowing potential decisions to be rapidly evaluated and compared. It has been especially used for issues associated with supply chain management and integration by

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operational management researchers in the last 2 decades (Angerhofer & Angelides, 2000; Chang & Makatsoris, 2001; Lee et al., 2002).

The objective of the simulation study was to determine the impact of stakeholders at various stages of the information supply chain, on the lead time of information before it reaches the state level public health system and subsequent response. The model was developed at a high level of abstraction keeping in line with the objective of the study and the data availability. The next section briefly reviews some of the relevant work in the area of supply chain simulation and the abstraction process. Section 3 describes the development of the simulation model, Section 4 deals with validation, Section 5 discussion of results and Section 6 deals with concluding remarks.

5.1. Previous Relevant Work

Stone and Veloso (1997) have used multi agent simulation systems to model supply chain network which involve interactions among various stakeholders with different (possibly conflicting) individual goals and proprietary information. Simulation based techniques were used for studying coordination of activities of e-commerce and Internet-based supply chain system for mass customization markets (Ghiassi & Spera, 2003; Turoski, 2002). Simulation-based architectures were proposed to facilitate the formation and organization of virtual enterprises for order management (Choy & Lee, 2002; Li & Fong, 2003). Simulation-based methods were also used to develop frameworks to evaluate and improve the performance of supply chain structures (Swaminathan et al. 1998; Valluri & Croson 2003; Zeng & Sycara, 1999). We also used simulation using Arena to conduct the research on inter-organizational dependencies and lead-

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time issues associated with information supply chain for managing rare infectious diseases.

Simulation is the process of modeling the system and it can help in imitating the system and its operation over time. Simulation imitates operations considering the influence of external and internal factors and help to forecast system's behavior in different circumstances (Teilans et al., 2008). Because of the modeling flexibility, simulation is often regarded as the proper means for supporting decision making on supply chain designs and "the ultimate success of supply chain simulation is determined by a combination of the analyst's skills, the chain members' involvement, and the modeling capabilities of the simulation tool" (Van Der Zee and Van Der Vorst , 2005).

5.2. Why Simulation Method is Selected and Why Arena is Used?

On empirical analysis using jump, we observed high standard deviations for all mean lead times calculated at various stages in the information supply chain for managing rare infectious diseases. Simulation was chosen as the method of study because of the very high variations (Jain et al., 2001; Fishman, 2001) in lead times during the transfer of information with respect to disease types, laboratory types and jurisdiction, considered for the research. Simulation has been extensively used by researchers for developing supply chain models (Stefanovic et al.,2001; Vieira, 2004 ; Vieira & Cesar, 2005). Arena has been used in this study because it supports the entire process of the simulation development cycle, including model building, data analysis, output analysis, and animation (Kelton et al., 2002). For data analysis, Arena includes ‗*Input Analyzer*' which is a better tool for fitting appropriate statistical distributions to input data.

We selected Arena simulation model for its modeling capabilities to provide a realistic simulation model, which is both transparent and complete. We strongly focused on all interdependencies and key attributes of different lead times in the information supply chain of rare infectious diseases and focused in developing a realistic simulation model for our study. For achieving the same, we looked at simulation model attributes essential for supporting successful design of information supply chain which can be generalizable and replicable. Then we compared the existing model to a new reporting system to contribute to improved decision making in terms of recognizing and understanding opportunities and thereby propose an improved information supply chain design.

5. 3. Simulation Model Development

The static information supply chain model for managing rare infectious diseases was transitioned into a dynamic simulation model with addition of fitted distributions to represent entity flow and the logic within the process steps. Features like delay and record blocks are added for statistics collection. These statistics are used to capture the performance measures of interest or key performance indicator— timeliness, i.e. the lead times at various stakeholder layers. Major aspects of the simulation model development are described below.

5.3.1. Assumptions

The major assumptions made in development of the simulation model include:

1. The activity times modeled are representative of the existing system in the county operating

with the current level of manpower. The constraints with respect to manpower are not explicitly modeled.

2. The distribution and information transfer activity times (lead times) modeled are representative of the system operating with the current hospitals, laboratories, local health jurisdictions and transfer capacities. Distribution and transfer constraints are not explicitly modeled.

3. Using detail data available, lead times are represented using the best-fit statistical distribution. 4. The attributes for lead times are accurately represented in the data collected for this study.

5.3.2. Context and Scope

The subject organization for this study is a county public health system that provides control and preventive services for a large population (380,000 approximately) distributed across all 4 local health jurisdictions. It maintains an information supply channel for collecting the information about the rare infectious diseases, which is considered for the study. The purpose of the analysis was to compare a new reporting system ("To-be") i.e. centralized reporting system to the "as-is" existing reporting system i.e. decentralized or distributed reporting system, and the transfer processes in order to determine value benefit, in terms of timeliness. The operational impacts were captured in terms of delay/ lead time in processing or transferring the information. The information supply chain system captures, processes and transfers information with respect to several rare and infectious diseases. The rare infectious diseases occurred in the county for the last 2 years was selected for building the model. The diseases selected included the rare infectious diseases occurred across all four local health jurisdictions considered for the period of study.

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The methodology for this research is based on use of simulation models to compare the 'As-Is' and the 'To-Be' reporting systems which is a part of information supply chain for managing rare infectious diseases. The major steps in this methodology are:

1. As-Is Process Model Development (decentralized reporting system)

2. As-Is Simulation Model Development (decentralized reporting system)

3. To-Be Process Model Development (Centralized reporting system)

4. To-Be Simulation Model Development (Centralized reporting system)

5.3. 3 Process Flow Representation

The static process flows as described in data analysis section are modeled using a discrete event simulation tool, ARENA, to create a dynamic representation of the real life process. Source blocks are created to model the arrival of entities (i.e. patients) into the hospital, to initiate the dynamic occurrences in the model. Similarly, decision blocks are coded with logic to implement the decisions or provided distributions to represent the percentage of entities that will flow through the respective output paths of the decision block. The flow of information through the information supply chain submodels (a) from hospital to various local health jurisdictions (b) from various local health jurisdictions to the ODH/ODRS) are linked by processes and decision logics to other parts of the model. The inputs and outputs of each activity represent the potential paths an entity can take through the system. Each activity is defined as a process in the simulation model with associated fitted statistical distributions for the activity times i.e. lead times or delay at various stages. The act of building the representation of the process flow,

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associated activity times and decision logic provides for the transition of the static process flow charts into a dynamic simulation model.

5.3.4. Statistics Collection

A number of customized features have been built in the simulation model for collection of the lead times at various stakeholder levels in the interest for validation. These include:

1. Lead time at the laboratory level

2. Lead time at the hospital level before it is transferred to different local health jurisdictions 3. Lead time at the local health jurisdiction level before it is entered into ODH/ ODRS The statistics collection was done using the Record features in ARENA. These key performance indicators (delays or lead times) were collected in the model for the whole county and with different breakdowns — by disease types, by laboratory types and by jurisdiction types. To ensure model accuracy and validation, fitted distribution using detailed data collected for last 2 years was used. Input analyzer function in Arena was used for finding the fitted distribution of various lead times included in the study (Altiok & Melamed, 2001).

5.3.5. *'As is'* Simulation Model Development

By analyzing the inter-dependencies between the different stakeholders and following empirical analysis of the data we could develop the 'as is' process model which is shown in the Figure 23 below.

FIGURE 23

'As is' **Process Model**

The simulation of patient arrivals and different lead times at various stakeholder layers in this study uses a robust approach that gives the capability to closely mimic 2 years of data available for the rare infectious diseases considered for the study. A key consideration in the modeling was the ability to create patient entry and subsequent lead times for the simulation with the same range of frequency and variation as viewed in the 2 years of historical data for each of the several types of rare infectious diseases (that comprised the representative sample for this study. The data used for the study was collected for the 2 year period from January 1, 2010 to March 31, 2012. An assign block was created with two attributes (a) arrival time and (b) percentage of each disease type. Arrival pattern and distribution is calculation in accordance with the real life data collected over the period of 2 years selected for the study. Using the decision block, the disease types were separated and then assigned the lab types based on the location of the laboratories and

finally assigned the reporting method used for reporting the laboratory results. The lead time distributions were assigned to calculate the lead time at the laboratory level and the delay block was used to represent the elapsing of entity processing time in laboratories. The fitted distributions for lead time at laboratories were calculated using input analyzer in Arena. The fitted distribution is shown in the Table 9 given below.

TABLE 9

Lab Types	Disease Types	Reporting Methods	Fitted distributions
Within hospital	A	ELR	$1.5 + 29 * BETA(0.165, 0.745)$
Within hospital	B1	ELR	$-0.5 + LOGN(22.3, 71.4)$
Within hospital	B1	non-ELR	$-0.5 + LOGN(24.1, 145)$
Within hospital	B ₂	non-ELR	$-0.001 + \text{WEIB}(2.21, 0.472)$
In-State Outsourced	A	ELR	$1.5 + 29 * BETA(0.165, 0.745)$
In-State Outsourced	B1	ELR	$0.5 + LOGN(20.5, 43.9)$
In-State Outsourced	B1	non-ELR	$-0.5 + LOGN(29.1, 98.1)$
In-State Outsourced	B ₂	ELR	TRIA(0.5, 4, 5.5)
In-State Outsourced	B2	non-ELR	$-0.5+75*BETA(0.58,1.28)$
Out-state Outsourced	A	ELR	$1.5 + 29 * BETA(0.348, 0.51)$
Out-state Outsourced	B ₁	ELR	$-0.5 + LOGN(17.5, 46.6)$
Out-state Outsourced	B1	non-ELR	$-0.001 + \text{WEIB}(13.9, 0.457)$
Out-state Outsourced	B ₂	ELR	$-0.5+ LOGN(10.3,17.1)$
Out-state Outsourced	B ₂	non-ELR	$-0.5 + EXPO(10.1)$

Fitted Distribution Using Arena Input Analyzer for Lead Times at Laboratories

Using the fitted distributions from the archival data for the past 2 years, we assigned the distributions to different disease and lab type (based on the location of the laboratories) combinations in the assign block. The delay is then recorded in a record block. The lead time with respect to different disease and lab types is shown in the Table 10 below.

TABLE 10

Lead Time in Reporting from Laboratories with Respect to Lab Types and Disease Types and Reporting Methods for Rare Infectious Diseases

The above table clearly shows the difference in lead times between ELR and non ELR method of reporting and also with respect to disease types and laboratory locations. The mean value is obtained by running 10 replications for 730 days similar to the 2 year period considered for the study. The half width values can be better explained as "the half width for 95% confidence intervals on the expectance of all performance measures" (Kelton et al., 2003, p. 40). Using the same logic, for example, lead time for Type A diseases confirmed within the hospital laboratories works out for 95% confidence interval (alpha=0.05) to be 7.59 days +/- 1.21. Because all Type A diseases are reported electronically by ELR , there was no lead time in reporting of Type A rare infectious diseases at the hospital level and at various local health jurisdictions.

The next stage where delay occurs was identified to be at the hospital level where there is lead time in reporting the results to the various local health jurisdictions. The arrival time and the

percentage of distribution of disease with respect to location were attributed at the assign block and using the decision block, the rare infectious diseases were separated with respect to disease types and jurisdiction types. The fitted distribution for lead times at hospital level was calculated using input analyzer from Arena and then assigned to the disease output from decision block. The delay block was used to represent the elapsing of entity processing time in hospitals. The delay was recorded using the record block.

Firstly, we fitted distribution to the lead times at the hospital level in different jurisdictions. The fitted distributions of hospitals at various jurisdictions are shown in the Table 11 below.

TADLE II							
	Fitted Distribution Using Arena Input Analyzer for Lead Times at Hospitals						
	Jurisdiction	Disease Types	Fitted distributions				
	$LHJ-1$	B1	$-0.5 + \text{WEIB}(2.01, 0.591)$				
		B ₂	$-0.5 + LOGN(5.28, 13.4)$				
	$LHJ-2$	B1	$-0.5 + LOGN(7.31, 25.2)$				
		B ₂	$-0.5 + LOGN(2.73, 2.73)$				
	$LHJ-3$	B1	$-0.5 +$ LOGN $(0.606, 0.263)$				
		B ₂	$-0.5 + \text{WEIB}(2.56, 1.33)$				
	$LHJ-4$	B1	$-0.5 + \text{WEIB}(2.27, 0.628)$				
		B ₂	$-0.5 + LOGN(3.91, 6.76)$				

TABLE 11

The simulation model was run for 10 replications for 730 days to record the average lead time with respect to jurisdiction and disease types at the hospitals. The lead time was recorded using the record block and the values obtained are shown in the Table 12 below.

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TABLE 12

Lead Time in Reporting from Hospitals with Respect to Disease Types and Jurisdictions

In the process model, we found that the last stage of lead time before the information on rare infectious diseases being entered into the ODRS occurs at the Local Health Jurisdictions (LHJs). The arrival time and the percentage of distribution of disease with respect to location was attributed at the assign block and using the decision block, the rare infectious diseases were separated with respect to disease types and jurisdictions similar to the one for calculating the lead time at the hospital level . The fitted distribution for lead times at local health jurisdiction level

was calculated using input analyzer from Arena and then assigned to the disease output from decision block. The delay block was used to represent the elapsing of entity processing time in local health jurisdictions. The lead time was recorded using the record block in Arena. For finding the fitted distributions, we used input analyzer function in Arena and we found the fitted distribution of the lead time at the local health jurisdictions which is shown in the Table 13 given below.

TABLE 13

Jurisdiction	Disease Type	Fitted distributions
$LHJ-1$	B1	$-0.5 + 3 * BETA(0.66, 0.86)$
	B ₂	$-0.5 + EXPO(1.14)$
$LHJ-2$	B1	$-0.5 + GAMM(0.58, 2.25)$
	B ₂	$-0.5 + 6 * BETA(0.487, 2.24)$
$LHJ-3$	B1	$-0.5 + 13 * BETA(0.4, 0.06)$
	B ₂	$-0.5 +$ LOGN $(0.815, 0.546)$
LHJ-4	B1	$-0.5 + 23 * \text{BETA}(0.751, 4.15)$
	B ₂	$-0.5 + 41 * BETA(0.369, 3.83)$

Fitted Distribution Using Arena Input Analyzer for Lead Times at LHJs

The simulation model was run for 10 replications for 730 days to record the average lead time with respect to jurisdiction and disease types at local health jurisdictions considered for the study. After running the simulation, the lead times is recorded at the record block which is given in the Table 14 below.

TABLE 14

Lead Time in Reporting in Local Health Jurisdictions (LHJs) with Respect to Disease

Types and Jurisdictions

The information on rare infectious diseases becomes extremely important once the disease is confirmed by the laboratory. When it is reported by electronic lab reporting, it is entered directly into the ODRS and hence there is no lead time at the hospital or at the various local health jurisdictions in electronic lab reporting. But we have observed that only half of the rare infectious disease confirmation occurs through electronic lab reporting. Of the 1508 cases

considered for lead time distribution calculations in developing the simulation model, 749 cases were reported non-electronically. The total lead time for non-electronically reported cases of rare infectious diseases after its confirmation to its entry into the ODRS can be calculated by adding the lead time at the hospital level and the lead time at various local health jurisdictions. The total lead time in reporting once the disease is confirmed in case of decentralized reporting system (as is) is given in the Table 15 given below.

TABLE 15

Lead Time in Reporting in the Case of Decentralized Reporting System

5.3.6. ‗*To be'* Simulation Model Development

The next step was to test a centralized system with monitoring in place. Instead of reporting to different jurisdictions we propose a centralized reporting system with county public health responsible for entering the confirmatory details about the rare infectious diseases. It not only provides monitoring but also avoids the confusion with regard to residence and hospital the patient gets treated for rare infectious diseases.

In the centralized reporting system, instead of reporting of confirmatory reports from hospitals to the local health jurisdictions, all hospitals and laboratories will be reporting to the county public health department. This will not only avoid the confusion associated with whom to report and where to report but also avoid the lead time in redirecting the confirmatory laboratory report from one local health jurisdiction to the other, when they receive confirmatory report of patients belonging to a different local health jurisdiction. The process flow of proposed centralized reporting system is shown in the Figure 23 below.

FIGURE 23

Proposed Centralized Reporting System for Rare Infectious Diseases

A lead time of up to 2 days (within the end of the next business day) was allotted to Type B1 disease and a lead time of up to 7 days was allotted to Type B2 disease as per the Ohio department of health infectious disease control manual (ICDM). We assigned triangular distribution to the Type B1 and Type B2 diseases, which are shown in the Table 16 given below.

TABLE 16

Distribution for Lead Times in the Proposed Centralized Reporting System

The arrival time and the percentage of distribution of disease types were assigned at the assign block and using the decision block, the rare infectious diseases were separated with respect to disease types. In this case, instead of the fitted distribution for lead times we assumed triangular distribution as per the infectious disease control manual (ICDM). The delay block was used to represent the elapsing of entity processing times. The lead time was recorded using the record block in Arena. After running the simulation model for 10 replications for 730 days we could obtain the lead times for Type B1 and Type B2 rare infectious diseases in county public health as shown in the Table 17 given below

TABLE 17

Jurisdiction		Disease Type Mean Lead time Half Width	
	B1	1.66	0.04
County public health department	B ₂	3.52	0.11

Lead Times after Disease Confirmation in the Proposed Centralized Reporting System

The mean lead time was found to be 1.66 days for Type B1 rare infectious diseases with a half width of 0.04 and mean lead time for Type B2 rare infectious diseases was found to be 3.52 days with a half width of 0.11. This means that lead time for Type B1 rare infectious diseases after confirmed in the laboratories at 95% confidence interval ($alpha=0.05$) was found to be 1.66 +/-0.04 days and for Type B2 rare infectious disease was found to be $3.52 +/- 0.11$. The proposed centralized reporting system (with no more redirection to county in which person resides) with its lead times is shown in the Figures 25 and 26 below. It is important to note that the control and preventive measures will continue to take place at local health jurisdictional (LHJ) level.

FIGURE 25

Lead time for Type B1 Rare Infectious Diseases in the Proposed System

FIGURE 26

Lead time for Type B2 Rare Infectious Diseases in the Proposed System

5.4. Validation

Simulation models are categorized into types based on the way that they are driven into 1.trace driven and 2. self driven. "A self-driven (distribution-driven or probabilistic) simulation model is the one which is driven by input values obtained via sampling from probability distributions using random numbers. A trace-driven (or retrospective) simulation model, on the other hand, is driven by input sequences derived from trace data obtained through measurement of the real system" (Balci, 1989, p.64). In trace driven, the trace data become the input data model which should be validated against the actual system input process (Balci $\&$ Sargent, 1983).

―The most powerful statistical validation is possible if both input and output of the real system are measured. In so-called trace-driven or correlated inspection simulation, analysts feed real input data into the simulation program, in historical order. After running the simulation program, these analysts compare some summary statistic (namely, the average X) for the time series of

simulated output with the same statistic (namely, Y) for the historical time series of real output" (Kleijnen et al., 2001, p.1533).The simulation model used in this research is a trace driven one and validated by comparing the means of the real life data with the simulated averages (Balci, 1990; Balci, 1995).

―Model validity is a necessary but insufficient condition for the credibility and acceptability of simulation results. Formulated problem accuracy greatly affects the acceptability and credibility of simulation results. It has been said that a problem correctly formulated is half solved (Watson, 1976)", (Balci, 1997 , p.354). Hence extreme care was given in formulating the research question and variables included for the study. "Albert Einstein once indicated that the correct formulation of a problem is even more crucial than the solution. The ultimate goal of a simulation study is to provide a solution that is sufficiently credible and accepted and implemented by the decision makers", (Balci, 1997, p.354). Our sufficiently large data sample and correct formulation of problem along with trace driven validation makes it sufficiently credible and acceptable for decision makers.

5.7. Discussion of the Simulation Results

The lead time in reporting at the hospital level and local health level was associated with Type B1 and Type B2 rare infectious diseases reported non electronically only as all the Type A rare infectious diseases were reported electronically (ELR) into the ODRS for the last two years. In the best case scenario, in a centralized reporting system, there will be no lead time from entering the confirmatory result from hospital to county public health department and subsequently into the ODRS and hence no lead time in reporting.

The best case scenario can be compared to the electronic lab reporting (ELR) and in both cases there will not be any lead time in reporting from laboratory to the ODRS once the rare infectious cases are confirmed. But this cannot be always be the case. There is a lead time of 2 days allowed for Type B1 rare infectious diseases and lead time of up to 7 days allowed for Type B2 rare infectious diseases. The hospitals are going to utilize this provision for reporting of Type B1 and Type B2 rare infectious diseases and hence we got 1.66 days and 3.52 days for Type B1 and Type B2 rare infectious diseases respectively. In the worst case scenario, we expect 2 days lead time in case of lead time in Type B1 rare infectious diseases and 7 days lead time in case of Type B2 rare infectious diseases.

5.10. Conclusions from the Simulation Model

This chapter was used to describe the development of a high-level simulation model for an information supply chain for managing rare infectious diseases. The abstraction process for determining the processes and how we found the fitted distributions for finding the various lead times was discussed. The processes to be modeled and the level of detail for each process were first captured in a process model. Subsequently, the simulation model was developed based on the flow of information captured in the process model. We found that centralized reporting system can reduce the lead time in entering the information into the ODRS and subsequent action as it avoids the confusion with regard to the jurisdiction the patient belongs to and the jurisdiction where the patient gets treated for the disease and also provides the opportunity for monitoring the reporting by the county.

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Chapter 6: DISCUSSION AND CONCLUSIONS

The lead time at the laboratory level is based on the location of laboratories, the reporting method and the disease type. We have observed that there are no Type A rare infectious diseases reported non-electronically over the last two years. Though we have confirmed that electronic laboratory reporting as the best method for transferring confirmatory lab results from laboratories to the ODH/ODRS, we realized that there are only 50.3 % of rare infectious diseases reported electronically over the last two years. The presentation by Lynn Giljahn at the Infection Control Group (ICG) meeting on May 27, 2011 confirmed that only 38.8% of hospitals are using the ODRS system for reporting rare infectious diseases. She identified several reasons including system incompatibility and discouragement from local health jurisdictions to enter some disease information directly into the ODRS (e.g. meningococcal, TB, HIV), for the lower percentage of electronic lab reporting (ELR). Our discussion with public health authorities also confirmed limited accessibility of stakeholders to the ODRS (restricted accessibility is mainly for protecting privacy and security; since only epidemiologists and authorized persons have access, it is very difficult to ensure direct entry of laboratory reports into the ODRS) as one of the main reasons for the lead time. We have identified two main lead times after confirmation of the disease viz. lead time at the hospital level before reaching the correct jurisdiction and the lead time at the local health jurisdiction level before it is being entered into the ODRS.

The lead time in reporting laboratory results from hospitals to LHJs can be due to several plausible reasons:

 Confirmatory laboratory reports sent to wrong jurisdictions by hospitals cause a lead time. For example, when a hospital sends a lab report to the jurisdiction where the health event occurred or where the hospital is located, and the if patient is residing at a different location, the reports should be redirected to the correct jurisdiction where the patient resides, to initiate control and preventive measures. Let me explain the same with an example. Consider a patient residing in Jurisdiction 3 and working in Jurisdiction 4. He/she goes to a hospital situated at Jurisdiction 1 and gets diagnosed with a rare infectious disease, there is always a chance that hospital at Jurisdiction 1 for contacting the public health authorities at Jurisdiction 1 for reporting the confirmatory lab findings. Sometimes they may even send the laboratory report to the wrong jurisdiction. When the hospital contacting the incorrect jurisdiction finds that the Jurisdiction 1 is not the place where the patient resides in, then they will have to contact the correct jurisdiction in which patient resides to report (which may take several days) to ensure response including control and preventive measures. This has been identified as one of the plausible causes of lead time in reporting laboratory result till it reaches correct local health jurisdictions.

 Another plausible reason for the lead time in reporting from the hospital is the lead time happening at the hospital level. Even though hospitals are required to send the report for notifiable rare infectious diseases within a specified time based on the type of diseases, this may not be always the case. There are lead times at the hospital level after receiving the confirmatory reports about rare infectious diseases from the laboratories.

The lead time at the LHJ to ODH can be due to several reasons:

 After discussing the lead time at the local health jurisdiction level with the epidemiologist (Personal communication, Drinkard, L., April 19, 2012), we found that the local health jurisdictions get reports of patients that do not belong to their jurisdiction. The LHJs are not responsible for the entry of such reports into the ODRS or taking any control and preventive measures. "If a disease report is inadvertently assigned to an incorrect health jurisdiction, the health department receiving the report can re-direct it to the correct one" (Annual Summary of Reportable Diseases. 2009). Generally if a local health jurisdiction receives a report belonging to another jurisdiction, they fax it or mail it to the responsible jurisdiction for entry into the ODRS. This may take several days, and hence this causes a lead time in reporting from LHJ to the ODRS/ ODH and responses.

The lead time at the local health jurisdiction can be explained with the help of an example. The jurisdiction in which patient goes for treatment, the jurisdiction in which he/she works and the jurisdiction in which he/she resides may not be the same. For example, consider a person living in Jurisdiction 3 and working in Jurisdiction 1 who gets sick and goes to a hospital in Jurisdiction 2. The confirmatory lab report received by mistake will not be entered by LHJ 2, instead they will hand it over to the LHJ 3 (where the patient resides). The LHJ 3 then enters the information into the ODRS. It is the responsibility of LHJ 2 to redirect the confirmatory lab report to LHJ 3, if they receive the laboratory report by mistake. There is indeed a lead time in passing the lab report from one LHJ to another when they do get lab reports not belonging to their jurisdiction. When the hospital passes the information non-electronically, mostly by fax, there will be

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a lead time in recognizing the correct jurisdiction and subsequent forwarding of the fax. This shows that there exists a lead time at LHJ level due to information passed from the hospital to wrong jurisdictions.

 Another plausible cause of lead time at the local health jurisdiction level can be the inherent lead time at LHJs in reporting to the ODRS/ODH for action. The laboratory report at LHJ is being delayed in the local health jurisdiction level because of inadequate staff or staff engaged in other priorities like preventive measures or control measures. Multitasking (both reporting to the ODRS and ensuring response) is required in decentralized reporting (and can be beneficial sometimes e.g. reduce labor cost), the loss of focus in reporting (from multitasking) can be another plausible cause for lead time at the local health jurisdiction level.

The accountability is comparatively low in the existing decentralized reporting system. All local health jurisdictions are given the authority to take actions for containing rare infectious diseases including control and preventive measures, and hence state or county public health are not monitoring the reporting into the ODRS at the local health jurisdiction level. It has already been proved beyond doubt that the accountability is low in the passive non-monitored reporting systems. The active and passive reporting system study in AIDS (Hsu et al., 2000) supported the low accountability existing in passive reporting systems.

Whatever the reason for the lead time in reporting after confirmation of disease into the ODRS, it can be extremely dangerous for rare infectious diseases, as timeliness in the information supply chain system for managing the rare infectious diseases is the most important thing for taking the control and preventive measures. There is no point in lead time at LHJ level before it is being entered into the ODRS (ODH) for responses.

Why a Centralized Reporting System is better than Decentralized Reporting or Distributed Reporting System for Managing Rare Infectious Diseases?

Previous study by researchers confirmed several reasons for the lead time or failure of health care providers and laboratories in reporting rare infectious diseases. The reasons cited include and are not limited to a lack of understanding of how or whom to report, lack of awareness of legal requirement to report, assumption that he/she is not responsible for reporting or someone else will report, insufficient reward or penalty for reporting (Rothenberg et al., 1980; Cleere et.al.1967; Jones et al., 1992; Weiss et al., 1988; Schramm et al., 1991; Konowitz et al., 1984). Our study also confirmed the lead time in transfer of information after disease confirmation due to reporting by hospitals and laboratories to wrong jurisdictions. The confusion associated with ‗whom' to report and ‗where' can be completely eliminated in a centralized reporting system. The main advantages of the proposed centralized reporting system are given below.

Accountability

In a decentralized reporting system existing in the county, neither county nor the state public health department is monitoring the events at the hospital level, as the Local Health Jurisdictions are authorized to collect the information and to take preventive and control measures. Empirical analysis has proved beyond doubt that there is lead time at the hospital level after receiving the confirmatory lab findings, and at the LHJ level before the information is entered into the ODRS (for subsequent action). Once the centralized reporting system is introduced, the stakeholders (hospitals) can be held accountable for the lead time at the hospital level. There will no longer be any lead time from sending the laboratory report to the wrong jurisdiction because once the centralized reporting is installed, all hospitals in the county have to send the confirmatory lab

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reports to the county public health in spite of any local health jurisdiction where the patient belongs to. Hence hospitals can be held accountable for the lead time in reporting at the hospital level. For example, when a non-electronic lab report comes from a national lab to a hospital in Jurisdiction 1/2/3/4, the hospital authorities are required to report the disease within the mandated time to the county public health department for entering the details into the ODRS.

Monitoring

Complete, centralized collection of all rare infectious disease information means that reports dealing with every step of the process can be easily generated. Regular monitoring using a centralized reporting system will help to resolve two key issues: late reporting and missing data. We can easily find the hospitals with longer lags; these longer lags can be shared with them and challenges to timely reporting can be identified and addressed, resulting in the improvement of timeliness in the information supply chain system for managing rare infectious diseases.

Monitoring is highly linked to accountability. The county public health can use the centralized reporting system for monitoring the reporting of rare infectious disease in the county. In a decentralized system, which exists now, there is very little monitoring taking place. The decentralized system can be advantageous only in unmanageably large cases e.g. at state level or national level. We have observed that local health jurisdictions entered hospital details for only 9 cases of 1508 reported cases of rare infectious diseases which we considered for the 2 year period of this study. It can be due to two plausible reasons: (a).The local health jurisdictions do not consider it mandatory to enter the details of the hospital into the ODRS, the state reporting system (b). The local health jurisdictions may have received the redirected reports from other

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jurisdictions and did not contain any information about the hospital, or the hospital information becomes redundant as the source of information being another jurisdiction. In a county of 380,000 people where only 1,508 cases of rare infectious diseases are reported in the last two years, it is highly applicable to install a centralized reporting system for managing rare infectious diseases. The Centralized Reporting System, once installed, will ensure monitoring at the county level, to ensure integration of data and to avoid the lead time in entering the information.

Completeness and Accuracy of Information

Centralized reporting can also improve the completeness of notifiable rare infectious diseases. It is interesting to note that there is high variation in the completeness of notifiable infectious diseases reporting in the United States (Doyle et al. 2002). The completeness varies from 9 to 99% with regard to the completeness of notifiable infectious diseases including rare infectious diseases. Another study on the completeness of the active AIDS reporting system (where monitoring is taking place) far exceeded the reporting completeness for the passive AIDS reporting system (Hsu et al., 2000). This highlights the importance of evaluating/monitoring completeness and timeliness and other surveillance system attributes concurrently, and hence makes the case of a new centralized reporting system.

Increased responsiveness

A centralized reporting system aligns the reporting structure to avoid the lead time in entering the information into the ODRS and hence ensures increased responsiveness to any event of rare infectious diseases. In our simulation based study, we found that there is significant reduction in lead times in an actively monitored centralized reporting system. For Type B1 rare infectious

diseases, the average lead time in the decentralized reporting system from hospitals to LHJs was found to be 2.78 days and from LHJs to the ODRS was found to be 3.19 days. Hence, the average lead time for the rare infectious diseases information to reach the ODRS after receiving the confirmatory laboratory report was found to be 5.97 days, while the average lead time in the proposed centralized reporting system would be 1.66 days. For Type B2 rare infectious diseases, the average lead time in the decentralized reporting system from hospitals to LHJs was found to be 2.94 days and from LHJs to the ODRS was found to be 2.44 days. Hence, the average lead time for the rare infectious diseases information to reach the ODRS after receiving the confirmatory laboratory report was found to be 5.38 days, while the average lead time in the proposed centralized reporting system would be 3.52 days.

Through a centralized reporting system, we can avoid sending the information to wrong jurisdictions both from hospitals and from LHJs. Moreover, the centralized reporting system allows LHJs to focus on control and preventive measures and relieve them from their responsibilities with regard to reporting the disease to the ODRS. With regard to control and preventive measures at local health jurisdiction level, it ensures that the ODRS will have regular updates on the preventive and control measures being taken with respect to any rare infectious disease reported in the county.

Faster Implementation of the Required Changes

In any centralized reporting mechanism, the changes can be implemented easily as it takes a top down approach. Hence, the county can implement the changes suggested by state and national public health system in a quicker manner.

A centralized reporting system monitoring rare infectious diseases at the county level outlines a standards-based approach to disease reporting, intending to connect hospitals and labs to the ODRS at the county level; this results in an improved public health surveillance infrastructure and increased performance at the response level i.e. LHJs. As a result, a centralized reporting system promises to implement changes suggested by national and state public health authorities in a faster manner.

Conclusion

Management of rare infectious diseases is a critical element in providing effective public health disease control and prevention services. In the United States, there is no central law governing the rare infectious diseases nor is there any centralized disease management system for managing rare infectious diseases. The rare infectious disease reporting is mainly regulated by state and local laws which make surveillance and management of rare infectious diseases difficult. Periodic evaluation of the rare infectious disease occurrence includes a case diagnosis component followed by a reporting component. Proper management of the rare infectious component requires continuous reporting which captures demographic, spatial and temporal trends in the country. Studies have confirmed the incompleteness and inaccuracy in reporting of rare infectious diseases in the United States. Several authors have explained reasons for the failure of health care providers and laboratories to report rare infectious diseases. The reasons cited include a lack of understanding how to report or whom to report to, lack of awareness of legal requirement to report, assumption that he/she is not responsible for reporting or someone else will report, insufficient reward or penalty for reporting. All these reasons point out the need

for monitoring the reporting, which is difficult in a passive decentralized system of reporting without proper monitoring.

This paper identifies lead times in reporting at the county level and suggests a better information supply chain system for managing rare infectious diseases. Our analyzes show a great deal of minute details that affect the lead time in reporting at the laboratory level, hospital level and in the local health jurisdictional level. This allows us to appreciate the need for centralized reporting system, that is, how a county's adoption of a centralized reporting system improves the timeliness in reporting of rare infectious diseases.

The use of empirical analysis at the county level sets this research apart from previous research on timeliness issues. Previous research could only identify delay in different layers of reporting and had to make strong assumptions without any empirical analysis for delays at laboratory, hospital and LHJ level separately. In addition to proposing a more timely information supply chain system for managing rare infectious diseases, this study analyzes whether there is any difference in lead time with regard to the type of rare infectious diseases, reporting method or jurisdictions involved in the information supply chain for managing rare infectious diseases.

One may argue that electronic laboratory reporting/digitization is the only solution to the problem. It is important to note that many of the laboratories and hospitals, performing specimen analysis for rare infectious diseases, do not have the required resources to perform electronic reporting. In the present scenario, centralized reporting system appears to be a more feasible solution than complete digitization of laboratories and hospitals.

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Limitations and Future Research

It is important to note that the rare infectious diseases included in this study need not be a representative sample of rare infectious diseases occurring in other counties in the U.S. Since the purpose of the study is not to look at the representative sample of rare infectious diseases occurring at the state or national level, but rather to look at the lead times at various stages in reporting at the county level in distributed or de-centralized reporting system and factors influencing the reporting, it is appropriate to generalize the county level lead times study to a state or national level.

The variations in timeliness of reporting rare infectious diseases across the county may result from: the volume of cases identified in the jurisdiction, periods of decreased reporting activity due to variable staffing levels at the local health jurisdiction level (for example, a few staff members leave the job or become sick etc.), case follow-up investigations by the local health jurisdiction staffs to verify the case report or to collect additional case information by the county authorities, computer system down-time for maintenance, upgrades, or development of applications. It was beyond the scope of this study to assess how these factors contribute to decentralized reporting timeliness. This study was purely based on actual data from the two year period of study.

We have introduced the concept of the information supply chain (ISC) for managing rare infectious diseases until it reaches the ODRS for response. We can extend our research for other relevant issues, such as how to address lead time in integration of data at the national level by looking at the lead time at the state level and national level public health systems.

Sharing information has to be both efficient and secure; the security part can be addressed in a future study, as the centralized reporting reduces the number of authorized personnel involved in

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reporting which can have a positive impact on trust and security. The sharing of information about rare infectious diseases requires a clear understanding about what to share, whom to share with, how to share and when to share. The ISC for managing rare infectious diseases explicitly captures these questions as information requirements, so that the rare infectious diseases' information transfer and reporting system provides the right information to be delivered to the right recipients in the right way and at the right time. Our research provides an interorganizational dependency based simulation model that ensures passage of information from an information pull perspective that assumes accuracy in the information provided. A study looking at the completeness of information being passed from one layer to another is also a very promising one. Finally, the tools and techniques used in this dissertation can be used to address several scenarios in information supply chain system for managing rare infectious diseases.

APPENDIX- DISTRIBUTION, HISTOGRAM AND DATA SUMMARY

Disease Type A, Laboratory Type: Within hospital, Reporting Method: ELR

Disease Type A, Laboratory Type: Instate Outsourced, Reporting Method: ELR

Disease Type A, Laboratory Type: Outstate Outsourced, Reporting Method: ELR

Disease Type B1, Laboratory Type: within hospital, Reporting Method: ELR

Disease Type B1, Laboratory Type: Instate Outsourced, Reporting Method: ELR

Disease Type B1, Laboratory Type: Outstate Outsourced, Reporting Method: ELR

Disease Type B1, Laboratory Type: Outstate Outsourced, Reporting Method: non ELR

Disease Type B2, Laboratory Type: within hospital, Reporting Method: non ELR

Disease Type B2, Laboratory Type: Instate Reporting Method: ELR

Disease Type B2, Laboratory Type: Instate, Reporting Method: non ELR

Disease Type B2, Laboratory Type: Outstate, Reporting Method: ELR

Disease Type B2, Laboratory Type: Outstate, Reporting Method: non ELR

Disease Type B1, Jurisdiction 2, Hospital to LHJ distribution details

Disease Type B1, Jurisdiction 4, Hospital to LHJ distribution details

Disease Type B2, Jurisdiction 2, Hospital to LHJ distribution details

Disease Type B2, Jurisdiction 4, Hospital to LHJ distribution details

Disease Type B1, Jurisdiction 2, LHJ to ODH distribution details

Disease Type B1, Jurisdiction 4, LHJ to ODH distribution details

Disease Type B2, Jurisdiction 1, LHJ to ODH distribution details

Disease Type B2, Jurisdiction 2, LHJ to ODH distribution details

Disease Type B2, Jurisdiction 3, LHJ to ODH distribution details

Disease Type B2, Jurisdiction 4, LHJ to ODH distribution details

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