An Evaluation of the Rates of Repeat Notifiable Disease Reporting and Patient Crossover Using a Health Information Exchange-based Automated Electronic Laboratory Reporting System

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Abstract

Patients move across healthcare organizations and utilize services with great frequency and variety. This fact impacts both health information technology policy and patient care. To understand the challenges faced when developing strategies for effective health information exchange, it is important to understand patterns of patient movement and utilization for many healthcare contexts, including managing public-health notifiable conditions. We studied over 10 years of public-health notifiable diseases using the nation's most comprehensive operational automatic electronic laboratory reporting system to characterize patient utilization patterns. Our cohort included 412,699 patients and 833,710 reportable cases. 11.3% of patients had multiple notifiable case reports, and 19.5% had notifiable disease data distributed across 2 or more institutions. This evidence adds to the growing body of evidence that patient data resides in many organizations and suggests that to fully realize the value of HIT in public health, cross-organizational data sharing must be meaningfully incentivized.

Introduction

Increasing evidence suggests that patients move across healthcare organizations and utilize services with greater frequency and variety than previously thought[1]. This important fact should inform the national health care dialogue on many fronts, including on matters related to health information technology (HIT) policy. One such well-known policy is the meaningful use criteria incentive program established by Medicare and Medicaid that aims to increase the adoption and use of health information technology (HIT) to improve health care quality and efficiency[2]. While meaningful use largely focuses on individual providers' and organizations' use of HIT, the incontrovertible fact that patient data resides in many organizations suggests that to fully realize the value of HIT, cross-organizational data sharing must be meaningfully incentivized.

To understand the underlying challenges faced when developing strategies for integrating cross-organizational health information exchange (HIE), it is important to understand the potentially differing rates and patterns of patient movement and utilization for many healthcare contexts. One such additional context is managing public health notifiable conditions across a population. A notifiable condition is one for which regular, frequent, timely information on individual cases is considered necessary to prevent and control diseases of public health significance.[3] Information on disease burden is captured in clinical care processes occurring across multiple departments and health care institutions, hence single instances of the electronic health record (EHR) system do not contain the complete picture for a given patient. Nonetheless, having comprehensive patient information across systems is essential for the efficient and effective work of public health and clinical care providers.

Previous studies have demonstrated that reporting of notifiable conditions is often incomplete but there are various strategies that can improve the notification process[4-11]. Estimates of reporting completeness across many notifiable

diseases varies from 6% to 90%. Undetected or underreported disease burden leads to suboptimal care of population based disease and hinder the ability to contain outbreaks in a timely manner. Practice based population health systems can facilitate communication among clinical providers and population health stakeholders to ascertain the population's true disease burden[10].

There has been an increase in the number of automated public health surveillance systems to comprehensively identify notifiable conditions, however strict use of electronic laboratory reporting (ELR) information is limited by lack of detailed patient information necessary for public health[12]. Moreover, these systems are limited in their ability to identify whether a given test result is a new case or an existing, known case of disease. An automated surveillance system leveraging data from an integrated health information exchange could overcome some of these limitations through enhanced patient and provider demographics, provision of medication history and temporal assessments of various laboratory results. We have previously demonstrated that a notifiable condition detector provides timely and complete reporting in a health information exchange[2,3].

Previous studies have examined the total rate of patient crossover in health systems[13] and observed different patterns of patient crossover among patients receiving emergency care[1] and neurosurgical patients[13]. Understanding the movement and distribution of patients with notifiable conditions across institutions would help illuminate the feasibility and potential value of using health information exchange to support public health as well as inform the design of such systems; yet, presently little is known about patient movement in this population. We hypothesized that crossover rates for patients with notifiable conditions would differ from the previously reported crossover rates of patients seeking emergency or surgical care. Thus, the purpose of this study is to investigate the distribution of patients with notifiable conditions and their crossover among institutions in an operational health information exchange.

Methods

Our medical informatics laboratory for this study was the Indiana Network for Patient Care (INPC)[14,15], a 16-year-old health information exchange operated in Indiana. The Regenstrief Institute made a pioneering commitment to standards, interoperability, and the interchange of clinical data for clinical, public health, and research purposes. Investigators at Regenstrief created the INPC in 1995 with the goal of providing clinical information at the point of care for the treatment of patients. The INPC now includes clinical data from over 80 hospitals, public health departments, local laboratories, imaging centers, large-group practices closely tied to hospital systems, with plans to continue expanding. The health information exchange data repository carries over 4 billion discrete clinical results, over 79 million text reports, for more than 25 million different patient registrations of over 12 million unique patients.

Investigators at Regenstrief also developed and implemented an automated Electronic Laboratory Reporting (ELR) and case-notification system called the Notifiable Condition Detector (NCD) that has been operating within the INPC for over 10 years [11,12,16,17]. The NCD uses a standards-based messaging and vocabulary infrastructure (including HL7 and LOINC), and receives more than 350,000 real-time HL7 clinical transactions daily, including laboratory studies, diagnoses, and transcription from more than 24 organizations, national labs and local ancillary service organizations. It translates local proprietary codes into LOINC codes, determines whether the results carried by the message indicate a notifiable condition using a variety of algorithms. It evaluates the presence or absence of an abnormal flags for lab results; if the abnormal flag is not set, the software compares the clinical result to indicator values from the CDC Reportable Condition Mapping Table or to specific organisms listed in the RCMT. This system is depicted in Figure 1.

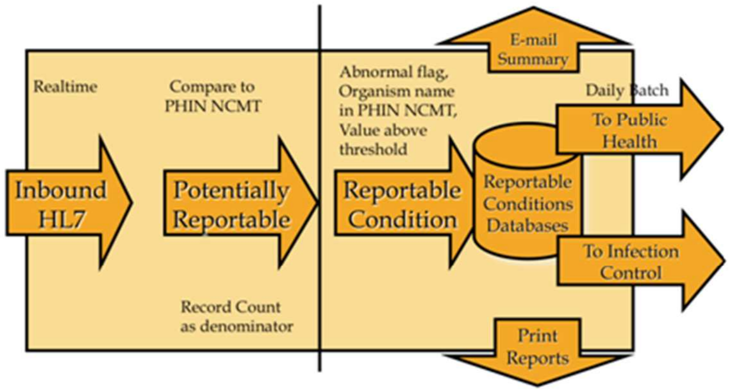

Figure 1: Data flow for the public health condition detector. Inbound HL7 messages are mapped to LOINC and if the test is potentially reportable, are passed to a second stage where its reportable status is adjudicated.

This study was conducted at the Regenstrief Institute after approval from Indiana University IRB to perform analysis. An overview of our approach is shown in Figure 2.

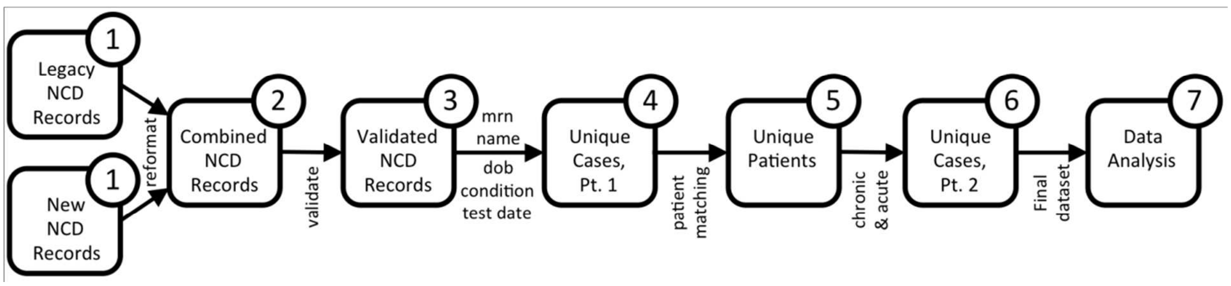

Figure 2: Process for preparing NCD case data. Because the data for this analysis is derived from real-world health care transactions, a substantial amount of data rationalization was necessary to prepare for analysis.

Format and integrate data from both NCD systems: The notifiable condition system[7] is implemented using two technologies, an earlier VAX based system, and a recently deployed open source implementation using Java and OpenMRS[18]. Data from the two systems was joined to form a single file for analysis.

Validate NCD Records: The Notifiable Condition Detection system has been operational for over a decade, and the data analyzed was retrieved between March 8, 1997 and December 15, 2011. The NCD is used both as a production system supporting public health case detection, and is also used as a public health informatics research laboratory[10-12,19]. As such, public health informatics investigators evaluate novel approaches to detecting conditions of potential interest to public health (e.g., tuberculosis) by applying various detection strategies (e.g., natural language processing tools) to nontraditional tests (e.g., chest x-ray text reports) in an effort to identify cases of interest to public health. For this analysis we sought to analyze only those conditions specifically reportable to public health via traditional clinical results (e.g., lab tests). To filter the NCD reportable results table for this analysis, we used the Indiana State Department of Health (ISDH) list of recommended notifiable conditions[20]. The real-world electronic transactions delivered to the health information exchange often require substantial cleansing. To improve the quality of the data for this analysis, we established consistent formats for dates, telephone numbers, Social Security numbers, and names. Further, placeholder values for these fields were identified and removed.

Establish unique cases: To identify unique cases we employed a two-step approach. First, we used five data elements to eliminate obvious duplicate reportable records; they included: (1) medical record number, (2) patient name (last and first), (3) full birth date, (4) notifiable condition (e.g., "Syphilis"), and (5) date of clinical result. Duplicate records containing identical values for these fields were merged, with the surviving record containing the most complete data.

Unique patients: We next identified unique patients among the set of reportable results. This task is identical to the process of finding duplicate patients in a patient registry: we linked the data set containing all reportable records to itself. To accomplish this we used an open source probabilistic linkage software package previously described.[21,22,23] To link patients we used various combinations of patient demographics, including global patient identifier, Social Security number, last and first name, gender, date of birth, and telephone number, as determined by the record linkage software. In this manner all reportable results belonging to the same patient were linked, forming a "patient group". We programmatically assigned a unique global patient identifier to each patient group. Each reportable result was assigned the appropriate global patient identifier.

Acuity: After identifying unique patients, we applied a second heuristic to finalize the set of unique cases. First, conditions were classified as 'acute' or 'chronic'. By definition, chronic conditions (e.g., Hepatitis B, HIV, etc.) generally persist over time and it's not uncommon in the course of routine care for patients to accumulate multiple repeat laboratory results for that same condition over extended periods of time. For the majority of results presented in this paper we included chronic conditions only once per patient when calculating the total number of unique cases. Sending public health the repeat case information for chronic cases once a case has been established requires using limited public health resources to filter the information, so to minimize these resources our public health partners prefer not to receive repeat case data for chronic conditions. The conditions classified as chronic included tuberculosis, hepatitis B and C, HIV/AIDS, MRSA, and sickle cell disease. To assess the number of reports received per condition, (in Table 2) we did not limit chronic disease to one instance per patient, but instead included any unique case present in the database. Acute conditions were defined as having limited duration, occurring no more frequently than once per patient per condition every 12 weeks.

Institutions: Reports received at the INPC are submitted from a variety of different health care institutions, which may operate in a single administrative capacity or as an enterprise with franchise. To identify unique institutions, we summarized a less granular level corresponding to the administrative units of all participating institutions that submit data to the INPC. This approach to identifying institutions allowed us to leverage existing institution data present in the notifiable disease repository. As a result, distinct institution codes used in our analysis may represent multiple hospitals, laboratories, etc., located at geographically distinct locations.

Data analyses: Lastly, we used the R statistical package to analyze the final dataset containing unique notifiable condition transactions and global patient identifiers, and to create visualizations of the data. To characterize the distribution of the reported notifiable conditions and the relationship between institutions, we calculated descriptive summary statistics about patients, their reportable cases, and the number of institutions they visited (crossover).

Results

Forty-three hospitals mapped to a total of six administrative institution codes contributed data to this analysis. The data contained 412,699 unique patients. Allowing for one acute reportable disease per patient every 3 months and one chronic disease per patient in total, this cohort totaled 473,840 unique cases, 126,942 (26.8%) as chronic conditions and 346,898 as (73.2%) acute conditions.

A summary of patient cross-over for individuals in the notifiable disease cohort is shown in Figure 3, which displays the counts for patients who visited one or more institutions. In summary, 19.5% (80,337/412,699) of patients visited (and therefore had data at) more than one institution. Because multiple hospitals are combined under single institution ID's, this figure represents a lower-bound estimate for the cross-over rate.

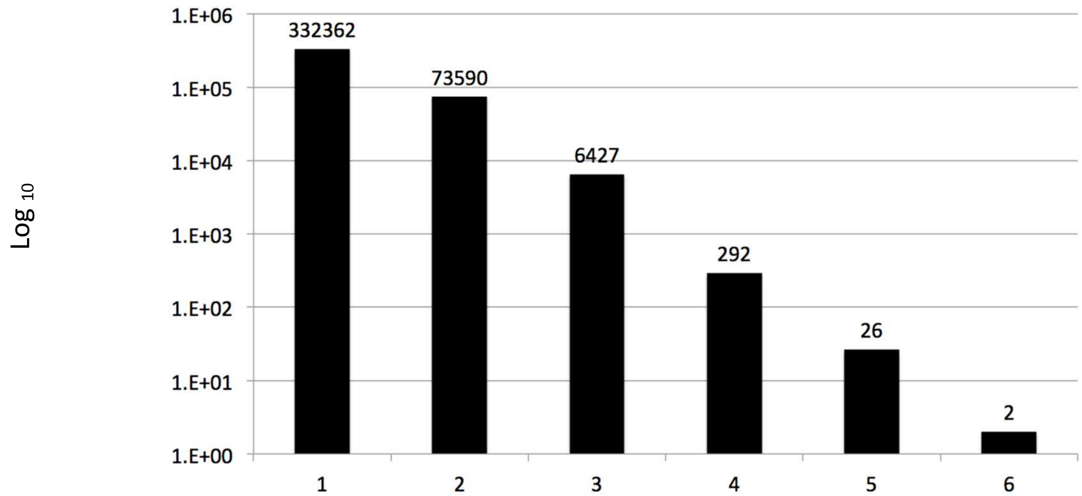

Figure 3: Distribution of patients by the total number of unique institutions visited per patient. These data illustrate that 20% of patients in this cohort have data in more than one institution

Figure 4 highlights the number of reportable cases observed for each patient. Approximately 11.3% (46,837/412,699) of the patients in this cohort have evidence of 2 or more reportable results. Multiple results may represent repeats for the same or different conditions.

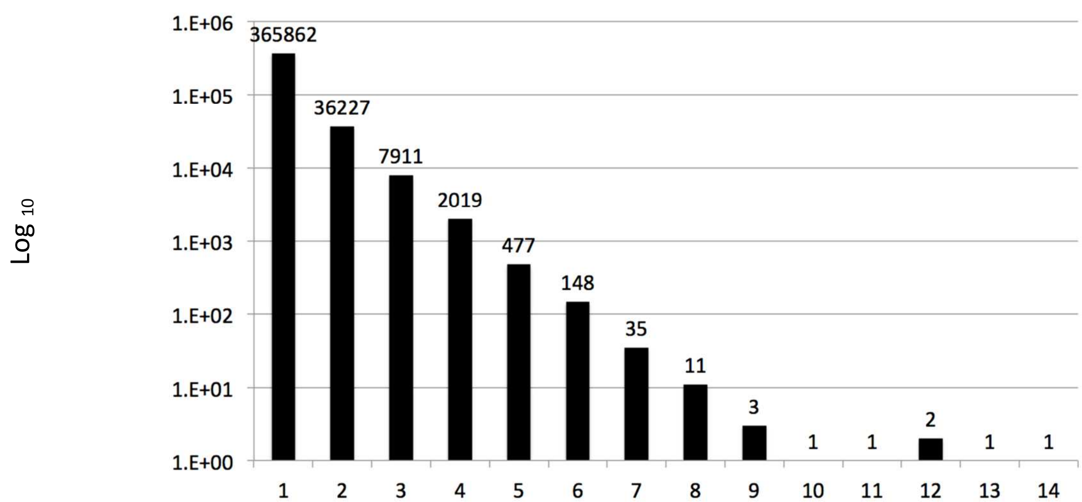

Figure 4: Distribution of patients by the total number of unique cases per patient. More than 10% of patients in this cohort have multiple notifiable conditions.

The distribution of the top notifiable conditions that caused multiple visits in the various institutions is as illustrated below in Table 1.

Condition	Avg Number of Institutions Visited per Patient
HUMAN IMMUNODEFICIENCY VIRUS	1.32
TRICHOMONIASIS	1.32
SYPHILIS	1.31
HEPATITIS A	1.29
SICKLE CELL DISEASE	1.27
GONORRHEA	1.25
GIARDIASIS	1.25
HISTOPLASMOSIS	1.25
CRYPTOSPORIDIOSIS	1.24

Table 1: Average number of institutions visited per patient by condition. This table shows the conditions associated with the most frequent patient crossover. Patients with HIV and Trichmoniasis are seen at multiple institutions with greater frequency than other conditions.

The distribution of the notifiable conditions that occurred with a high occurrence among various patients is as illustrated below in Table 2.

Condition	Avg Number of Case Reports per Patient
HUMAN IMMUNODEFICIENCY VIRUS	5.35
HEPATITIS A	4.37
SYPHILIS	4.13
SICKLE CELL DISEASE	3.71
GIARDIASIS	3.55
TUBERCULOSIS	3.47
HISTOPLASMOSIS	3.42
CRYPTOSPORIDIOSIS	3.06
HEPATITIS B	2.39

Table 2: Average number of case reports per patient by condition. On average, patients with HIV and hepatitis A have more repeat result for their condition than any other conditions.

Discussion

Patients utilize more than one health facility as they seek health care for many reasons, but uncoordinated care across multiple institutions and providers can contribute to errors in diagnosis or treatment; and additional cost from duplicate testing[24]. The reality of patient movement across institutions can be an important driver for implementing health information exchange systems. Furthermore, the Meaningful Use incentive program has increased interest in integrating information flows between clinical care settings and public health. Electronic health records (EHRs) have been used to communicate public health situational awareness to clinicians, but are not widely used to deliver alerts on positive notifiable conditions back to clinicians. Such alerts could not only highlight important results across multiple care settings, but also provide an opportunity for capturing additional data and clinical intervention. For example, it is important to know when a patient is diagnosed with a condition like MRSA[15]/VRE, so that when they have contact with a different health institution/ provider in future, proper interventions for disease control are implemented on time. Moreover, the primary care physician must be informed when patients have had multiple relapses and reinfection of conditions like sexually transmitted diseases, to implement counseling and follow-up interventions for such high risk patients.

Our research is consistent with previous studies assessing patient crossover characteristics, in that all health care is not local, and patients are mobile. The review of patient cross over in emergency room departments had a high percentage of patient data across institutions (40%) but for neurosurgery patients lower levels (5.45%) are reported.

Our findings of patient notifiable conditions data in multiple institutions (19.5%) further serve to document that characteristics of patient cross over are unique for each medicine specialty. One chief implication of all these studies is that health information exchange can be a useful tool for assessing such patient patterns, and integrating a patient's care history to facilitate better informed to care.

We hypothesize that patients with chronic notifiable conditions have data in multiple institutions which hampers continuous care and follow-up of such patients. This is represented in our results in Tables 1 and 2, where patients with HIV and Hepatitis had multiple institution visits. There is an increased demand by public health to improve the workflow process regarding multiple reports of chronic conditions. This information could be utilized to leverage HIEs to identify chronic cases, flag them so that they automatically go into a pile for "updates" rather than "new" case investigations to aid in public health work process improvement. This new information can be automatically merged into the existing case on file at the health department to provide complete public health data.

For purpose of ensuring population health and continuity of care, health care providers and public health needs to be aware of where patients are seen. There is need for a complete summary of patient data to provide timely and continuous care for patients with notifiable conditions. Without systems to effectively exchange data, then health care delivery for notifiable conditions will continue to be sub optimal.

Our analyses is limited by the fact that we analyzed only data from laboratory test results, while surveillance systems utilize syndrome surveillance, and imaging studies like chest X-rays. We studied crossover of patients at an instance, and further research on patient crossover as they transition from acute to chronic comorbidities would help inform patient crossover patterns. There is need for future research on effect of other comorbidities that are not directly classified as notifiable diseases on patient crossover across a health information exchange, as well as to explore frequency of comorbid reportable conditions in the database.

Conclusion

As new information architectures emerge, health data is collected and shared among various stakeholders. This study shows that patients move across various institutions with relative frequencies and occurrence. Patient data must be complete to meet the needs of clinical case management and public health surveillance. Therefore, public health must participate in the next generation system implementation to ensure that their needs are met.

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