

Chapter 54

Utilizing Combined Claims and Clinical Datasets for Research Among Potential Cases of Rare Diseases

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ABSTRACT

With data quality issues with administrative claims and medically derived datasets, a dataset derived from a combination of sources may be more effective for research. The purposes of this article is to link an EMR-based data warehouse with state administrative data to study individuals with rare diseases; to describe and compare their characteristics; and to explore research with the data. These methods included subjects with diagnosis codes for one of three rare diseases from the years 2009-2014; Spina Bifida, Muscular Dystrophy, and Fragile X Syndrome. The results from the combined data provides additional information that each dataset, by itself, would not contain. The simultaneous examination of data such as race/ethnicity, physician and other outpatient visit data, charges and payments, and overall utilization was possible in the combined dataset. It is also discussed that combining such datasets can be a useful tool for the study of populations with rare diseases.

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INTRODUCTION

The growth in the use of health information technology (HIT) has been substantial in the United States of America. The percentage of office-based physicians who utilized some form of an electronic health record (EHR) increased from 18% in 2001 to 83% in 2014 (Hsiao & Hing, 2014). Likewise, 96% of US hospitals had an electronic health record system as of 2015, although this percentage was lower for smaller or rural hospitals (68 & 70%, respectively) (Hsiao & Hing, 2014). HIT utilization has also grown across health care sectors, such as in emergency departments (Selck & Decker, 2016) and home health agencies (Mitchell, Bennett, & Probst, 2013). Much of this growth was spurred by the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act, which gave financial incentives to institutions that adopted electronic medical record (EMR) and other HIT technologies. The HITECH Act introduced meaningful use (MU), which established a set of criteria to ensure that the HIT adopted was clinically useful and eligible for the incentives (Blumenthal & Tavenner, 2010). Part of the MU criteria is to view, download, or transmit patient data electronically (health information exchange – HIE); as of 2015, 33% of providers and 14% of hospitals were able to do this (ONC, DHHS). In addition, up to 80% of hospitals were able to conduct some form of external electronic query of patient data (ONC, DHHS).

Health information also holds promise for health services researchers. By capturing patient, visit, and other data during encounters, researchers are able to get a fuller picture of health care utilization, outcomes, and the factors that affect them both. Data derived from clinically-based HIT systems is limited in its utility for researchers in several ways. First, data can be difficult to obtain unless the researcher has an established relationship with the HIT system owner (i.e., providers or organizations) and a method to retrieve the desired data. Additional difficulties can arise due to limitations or exclusions from the data to protect privacy (ensuring all data is adequately protected and/or de-identified), obtaining patient consent for the use of the data, or ensuring the completeness and appropriateness of the data extracted. Second, there are few HIT-based data sources that are representative of larger populations beyond service areas or insured populations. While larger hospital systems may have a larger service footprint, their data may still only capture their patient population and not be representative of an entire community, or may only capture one segment of care within the care continuum, such as inpatient care or ambulatory care. Third, HIT systems often have separate service lines, meaning that one department may not use the same HIT system or dataset as another department in that same health care system or network. While some institutions are working towards unified HIT systems and datasets (e.g., Veterans Administration, Kaiser Permanente), these are also limited to data from their own enrollees. Finally, data is often collected and catalogued in a manner that serves the clinical care needs of providers and delivery systems, and not the needs of researchers (Miriovsky, Shulman, & Abernethy, 2012; Rosenbloom et al., 2011).

For these reasons, the Healthcare Information and Management Systems Society includes in its definition of an electronic health record (EHR) the need to support ongoing performance measurement as well as support clinical research and evidence based research, facilitated by health information exchange (Handler et al., 2016). Larger databases that include clinical data derived from electronic health records have potential to provide sources of research data, while also providing an opportunity to shift the thinking of how research is conducted, towards a more rapid-based learning model (Abernethy et al., 2010; Etheredge, 2007). This model seeks to capitalize on the clinical content of the data, but the regular updating of such data allows for more time sensitive approaches to research.

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