Chapter 12
CoRDS Registry: An HIT Case Study Concerning Setup and Maintenance of a Disease Registry

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EXECUTIVE SUMMARY

The Coordination of Rare Diseases at Sanford (CoRDS) registry has been started to provide a central repository of data for participants suffering from a number of rare diseases and to provide those participants with a resource to learn more about their disease and, in a future enhancement, connect with others that are afflicted. The second purpose of the registry is to provide a resource for researchers to identify and recruit potential participants for their research studies. This case study will focus on the technical aspects of setting up a registry and providing access to participants and their medical team, who will enter data about their disease, and researchers, who will access de-identified data to include in their research. Security of the external website and access to Protected Health Information (PHI) are the main areas of concern with this registry.

ORGANIZATIONAL BACKGROUND

The CoRDS registry was started by David Pearce, PhD, who is employed by Sanford Research. Sanford Research is a partnership between Sanford Health and the University of South Dakota. Sanford Health is one of the largest rural healthcare systems in the United States with headquarters located in Sioux Falls, SD and
Fargo, ND. The 33 hospitals and 100+ clinics included in the health system spread across 6 states in the Midwest with a population of more than 2 million people in the covered region.

In February of 2007, Sanford Health was presented with a very generous gift of $400 million from philanthropist T. Denny Sanford with the goal of improving the human condition. An additional commitment was received from Mr. Sanford of $100 million in 2010 to focus on the way we treat breast cancer and search for new treatments and protocols. Many initiatives were started from these gifts including: a focus on pediatric care both in the Sanford Health region and around the world, an effort was started to make Sanford Research one of the top research facilities in the nation, the Sanford Project was started to bring in some of the top diabetes researchers to focus on finding a cure.

Sanford Health is using some of the most regarded software in the industry to handle all aspects of patient care, including EPIC (www.epic.com) for their Electronic Medical Record, Lawson (www.lawson.com) for Purchasing and Payroll and Velos eResearch (www.velos.com) for Clinical Trial Management Software. The Velos software will be utilized in the delivery and collection of the CoRDS registry data and information.

PROJECT BACKGROUND

In an article from Drolet and Johnson (2008), the authors reviewed a number of existing literature to formulate a more precise definition of a medical disease registry. They put forth the definition of “a medical data registry as a system functioning in patient management or research, in which a standardized and complete dataset including associated follow-up is prospectively and systematically collected for a group of patients with a common disease or therapeutic intervention” (pp. 1012-1013). They define 6 characteristics of a medical disease registry: merge-able data, standardized datasets, a set of rules for data collection, observations that are gathered over time, knowledge of outcomes through the use of follow-up, and characterizing the domain of the registry as chronic disease or acute/interventional therapy.

The CoRDS registry was initiated in June of 2010. As of October 2011, there were 98 registered patients covering 35 different rare diseases. The registry is being hosted at Sanford Research/USD in Sioux Falls, South Dakota and is supervised by Investigator David Pearce, PhD, Co-Investigator Chun-Hung Chan, PhD and coordinated by the CoRDS Administrator Liz Donohue. At this point in the registry’s existence contact between the registry and its participants is done primarily through telephone and postal mail. The administrator is also working with national and local organizations to promote awareness of the registry. The business needs for this
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