First, Ask Questions: How to Harness CDR Data for Better Patient Outcomes

written by Robert McNutt, M.D. | March 2, 2016

As more and better clinical data becomes available and demand grows for better outcomes, the Clinical Data Registry is positioned to fulfill the role of data manager—a vital mechanism for improving care.

The CDR is the engine driving a smoothly running system toward better outcomes. This involves much more than data collection. A high quality management function for CDR data requires making inferences from the data it collects.

But drawing inferences from present data sources presents significant challenges, no matter how big the data source. As a medical journal editor, I have reviewed many papers from countries with massive data sets on full populations, which, upon closer review, conclude with weak insights—or none at all. If this is the result, why collect all that data in the first place?

In my previous blog post, I outlined some of the reasons that inferences from present, large data sources fail to help physicians, administrators and patients. Data or information sources are only helpful if they tell us something we need to know, in such a way that we trust the insights. There are many unanswered questions about why certain results occur, and much more to understand about how patients and providers influence those outcomes. But we cannot expect a CDR to gather every piece of potentially meaningful data. We need to collect data in conjunction with a clearly focused plan related to clinical outcomes.

Less is More: Simple Data Points Give Clearer Answers

This sounds obvious but requires discussion. The data sources that help us most actually collect limited amounts of data. Consider the stock market. There are limited numbers of businesses that contribute data, and the outcome measure is a single, simple one: stock sales. What about weather data? We are given only a few points of outcome data: temperature, wind, predictions of precipitation and humidity.

These sources of data and outcomes are important to us because their meaning is intuitive and relevant, and we trust that the data are uniformly collected. Hence, we can have faith in the information and act accordingly. We do not ask of the weather data, on the other hand, how many trees fell in a storm; that is unimportant unless the wind might drop a tree on our house. These are useful and used sources of information because we understand the outcomes and can use the measures of those outcomes to decide how we might change our actions.

Stock and weather data are examples of how a CDR should function for physicians, administrators and patients. The CDR must, first, before asking questions of the data, collect outcome information that is meaningful in context, and collect it in a structured and uniformly trusted way.

For example, as a researcher, I am forced, thankfully, to limit the primary outcomes of a study and show how the information on the primary outcome will be collected. The primary outcomes must be relevant to clinical practice. The primary outcomes of these studies are life/death, physical/emotional functioning or, more commonly, outcomes relevant to the clinical situation (for example, A1C in diabetes care). These outcomes have meaning to us, and we can use the data on such outcomes to help our patients. Physicians will respond to such transparent data and act accordingly, but, again, only if it means something to them and they trust it.

Focus on Measure Data Numbs Physician Awareness—and Belief in—Results Data

Present day quality of care and utilization measures may be failing this CDR goal. There are hundreds, maybe thousands, of data points being measured with little ability to tie how some measures show the way to better outcomes. In fact, there is often confusion about what measurements are outcomes and which are explanatory for predicting outcomes. It is as if the proverbial cart is pulling the horse.

For example, is utilization of medical services an outcome measure or an explanatory measure? The present lack of clarity about what is outcome data and what is predictor data is undoubtedly a contributing factor to why so many physicians are resistant to interacting with data in the first place.

A high quality CDR must measure useful, limited outcome data as the core data requirement, and the mechanism for capturing the data must be transparent. We see this benefit at ICLOPS, where outcome measures are primary and standards for data collection and collating are in place: great first steps in the emerging use of a CDR.

Explanatory Data Is Essential to Careful, Meaningful Research

So, the road to transparent data must follow a rigorous map. As stated above, the outcomes measured must be limited, meaningful and trustfully collected. Next, research questions should direct the inclusion of explanatory sources of information, such as those outlined in *The CDR Advantage: Why Registry Research Minimizes Study Bias for Performance Improvement*. This fusion of a CDR and research is necessary to make useful inferences from large data sources. The failure of a thoughtful fusion of research and data collection, in our view, is why the large countrywide data sources I have read as an editor fail; the data was collected without reason or questions directing the collection methodology.

The CDR will become more useful to physicians and administrators when research questions are asked of the outcome data, and the information needed to answer those questions is added to the CDR in response. The future should focus less on "measures" and how providers perform with respect to those measures, but, rather, study how to improve performance. This allows for well thought-out secondary explanatory data that may more likely be related to improvements in outcomes.

By combining useful outcome measures, trusted data collection methods and the ability to collect useful data in response to clinical questions, a CDR can serve as a rich data source, an audit and management system, and a high quality, transparent and valued source for better patient care.

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