Addressing Sustainability and Informatics Challenges for Clinical Data Registries

Summary

In the spring 2014 edition of the Journal of Health Information Management (JHiM), Avalere’s Chris Boone published an article addressing modern-day challenges to clinical data registries (CDR).

Chris outlines the ways in which CDR act as the main vehicle for generating comparative effectiveness research (CER) evidence using electronic clinical data. He states that the industry uses both CDR and CER to aggregate data and generate reports on patient care, while explaining that much interest exists among healthcare stakeholders to leverage CDR data for research and policy analysis. According to Chris, these stakeholders face two very specific challenges: 1) unsustainable business models and 2) technical challenges associated with the collection, linkage and secure transmission of patient data from a variety of clinical data sources.

Chris’ qualitative, multi-cased, study analyzes the major barriers and lessons learned from establishing CDRs. In particular, he highlights the distinct business models of four U.S.-based CDR programs, addressing how each responds to these market-based challenges to CDR. Chris conducted 20 interviews with different stakeholders, such as program representatives, physicians, policy makers, technology experts and industry personnel.

View Chris’ complete JHiM article.

For more information on CDR or CER, contact Chris directly at CBoone@Avalere.com.