Pediatric Diabetes Registries: When Baby Steps Are Not Enough

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Abstract

Effective diabetes research relies on pattern recognition. Although information technology (IT) has been used to aid researchers in recognizing patterns, there are still barriers to effective data collection, analysis, and collaboration inherent in using outdated methods and technology designed to fulfill clinical, not research, purposes. This article discusses seven problems with current research and outlines a solution in which innovative IT can be harnessed to overcome each problem, resulting in better research outcomes.

New IT solutions on the market, such as meta-registries, are designed specifically to handle the complex data collection and analysis problems associated with diabetes research. A meta-registry with an ontology automatically harmonizes data from disparate sources, allowing researchers to devote their time to pattern recognition. With all essential data centralized and harmonized, researchers are also provided with a more complete view of each patient or research subject. When researchers can view and report across all data types at the same time, they are able to discover patterns and associations that are indistinguishable using traditional methodologies. This capability proves extremely beneficial, particularly for multifactorial disease research such as diabetes research.

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Abbreviations: (HIPAA) Health Insurance Portability and Accountability Act, (IT) information technology, (RDR) registry data repository

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