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SYMPOSIUM

Data Standards in Diabetes Patient Registries

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Abstract

Widespread adoption of electronic health records (EHRs) and expansion of patient registries present opportunities to improve patient care and population health and advance translational research. However, optimal integration of patient registries with EHR functions and aggregation of regional registries to support national or global analyses will require the use of standards. Currently, there are no standards for patient registries and no content standards for health care data collection or clinical research, including diabetes research. Data standards can facilitate new registry development by supporting reuse of well-defined data elements and data collection systems, and they can enable data aggregation for future research and discovery. This article introduces standardization topics relevant to diabetes patient registries, addresses issues related to the quality and use of registries and their integration with primary EHR data collection systems, and proposes strategies for implementation of data standards in diabetes research and management.

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Abbreviations: (AHRQ) Agency for Health Research and Quality, (CDE) common data element, (CDISC) Clinical Data Standards Interchange Consortium, (Diabe-DS) Diabetes Data Strategy, (EHR) electronic health record, (FDA) Food and Drug Administration, (HbA1c) hemoglobin A1c, (HIPAA) Health Insurance Portability and Accountability Act, (HITSP) Healthcare Information Technology Standards Panel, (HL7) Health Level 7, (LOINC) logical observation identifiers names and codes, (ONC) Office of the National Coordinator of Health Information Technology, (PHR) personal health record, (SNOMED CT) Systematized Nomenclature of Medicine—Clinical Terms

Keywords: chronic disease, controlled vocabularies, data standards, diabetes, disease management (systems), medical informatics, patient care management, registries

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