Challenges and Future Directions of the T1D Exchange Clinic Network and Registry

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Abstract

The T1D Exchange Clinic Network consists of 67 clinics throughout the United States. Among the more than 100,000 patients with type 1 diabetes mellitus (T1DM) who receive care at these centers, more than 26,000 have been enrolled in a registry. The registry includes participants over a wide age range, from age <1 to 93 years, and consists of both those newly diagnosed (more than 3000 diagnosed <1 year from the time of enrollment) and those with long-standing diabetes (more than 1000 with T1DM for at least 40 years). Data on diabetes history, insulin administration, diabetes management, monitoring, complications, medical conditions, medications, and laboratory results are collected at enrollment and annually through participant completion of Web-based questionnaires and data extraction from medical records. The clinic registry has provided a rich data set to address important clinical and public health issues, including important observations regarding the current state of treatment of T1DM in diabetes centers in the United States. Challenges encountered during the establishment of the clinic registry include establishment of criteria for a diagnosis of presumed autoimmune T1DM, standardization of data collected across clinics, data quality, and understanding of potential bias. Collecting the data and maximizing data quality has required considerable effort. Even with these efforts, certain data elements are difficult to capture in a meaningful way. A standard T1DM module used by all electronic health records could be developed based on the data collection instruments developed for the T1D Exchange clinic registry.

J Diabetes Sci Technol 2013;7(4):963–969

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Abbreviations: (BMI) body mass index, (CGM) continuous glucose monitor, (DKA) diabetic ketoacidosis, (EHR) electronic health record, (HbA1c) hemoglobin A1c, (SH) severe hypoglycemia, (SMBG) self-monitoring of blood glucose, (T1DM) type 1 diabetes mellitus

Keywords: clinic registry, database, diabetic ketoacidosis, electronic health record, severe hypoglycemia, type 1 diabetes mellitus

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