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Identifying all persons in Wales with type 1 diabetes mellitus using routinely collected linked data

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Introduction

Type 1 diabetes mellitus (T1DM) is an autoimmune condition characterised by hyperglycaemia, caused by the destruction of insulin producing β -cells in the pancreas. Previous epidemiological population level studies of T1DM and its complications have typically used recorded T1DM diagnoses to determine diabetes status and define cohorts.

Objectives and Approach

The objective was to identify all persons with T1DM in Wales from Primary (~70% population coverage) and Secondary Care (100% coverage) data held in the Secure Anonymised Information Linkage (SAIL) databank. People with a coded T1DM diagnosis (using Read codes in Primary Care data and International Classification of Disease (ICD10) codes in Secondary Care data), plus either insulin prescribed shortly after diagnosis or a hospital admission for diabetic ketoacidosis were identified as having T1DM. A sub-group of this SAIL e-cohort were validated using a register of persons diagnosed with T1DM in Wales under 15 years old (Brecon cohort).

Results

18,285 people had a T1DM diagnosis and 10,539 had more T1DM than type 2 diabetes mellitus (T2DM) diagnoses. 6,375 persons were identified with T1DM in Primary Care data using our criteria, with a median diagnosis age of 19.2 years (interquartile range 11.0, 35.5). 47.5% were diagnosed under 18 years of age. 39.6% of people with a T1DM diagnosis did not have T1DM using our criteria. False positive and negative rates of 4.8% and 4.5% respectively were achieved by comparing persons in the SAIL e-cohort against the Brecon cohort. Clinician estimated false positive and negative rates were 1.4% and 3.9% respectively. The prevalence of T1DM in Wales in 2016 was 0.37% or 11,049 people.

Conclusion/Implications

Our criteria for identifying people with T1DM was more reliable than using diagnosis codes alone, allowing for a more accurate, efficient and reproducible means of identifying individuals with T1DM for researchers utilising the SAIL databank, and other national health repositories.

