

Validating Self-reported Chronic Conditions in Alberta's Tomorrow Project Cohort: Data Linkage to Administrative Healthcare Data

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Introduction

Alberta's Tomorrow Project (ATP) is a province-wide cohort study of cancer and chronic diseases in Canada. Approximately 55,000 Albertans aged 35-69 years with no history of cancer, other than non-melanoma skin cancer, had joined the ATP. Nearly all (>96%) ATP participants consented to data linkage to administrative healthcare databases.

Objectives and Approach

To validate chronic conditions self-reported by the ATP participants, individual-level data of a total of 52,851 ATP participants were linked to Alberta Health (AH) administrative datasets using Personal Health Number. Cases of chronic conditions, including diabetes, cardiovascular diseases and gastrointestinal disorders, were identified by algorithms for disease diagnosis using International Classification of Diseases (ICD) codes in administrative healthcare data. Cases were identified as "prevalent" if the index date of diagnosis was before or within 6 months of ATP enrollment date. Self-reported chronic conditions were validated by the cases identified as "prevalent" using the linked AH datasets.

Results

Among the ATP cohort, 804 participants self-reported ever being diagnosed with myocardial infarction (MI), 451 with stroke, 2,907 with diabetes, 566 with ulcerative colitis, 362 with Crohn's disease and 112 with liver cirrhosis before or at the time of ATP enrollment. Using the linked AH administrative data, 339 participants were identified as prevalent cases with MI, 200 with stroke, 2,702 with diabetes, 208 with ulcerative colitis, 283 with Crohn's disease and 55 with liver cirrhosis. The sensitivity and specificity of self-reporting having chronic conditions by the ATP participants were 71.1% and 97.0% for MI, 44.4% and 99.3% for stroke, 78.1% and 98.4% for diabetes, 73.6% and 99.2% for ulcerative colitis, 65.7% and 99.7% for Crohn's disease and 50.9% and 99.8%

for liver cirrhosis.

Conclusion/Implications

By linking with administrative healthcare data, we were able to validate the accuracy of self-reporting chronic conditions in ATP participants. The sensitivity of self-reporting was acceptable for MI, diabetes, ulcerative colitis and Crohn's disease, but low for stroke and liver cirrhosis. The specificity was high for all chronic conditions.

