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Uncharted territory in linking population-based laboratory data for the epidemiology of celiac disease in Canada

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Introduction

We previously investigated the frequency of screening for celiac disease (CD) based on tissue transglutaminase antibody testing (tTG-IgA) and developed the first incident cohort of celiac autoimmunity in Canada.

Methods

Administrative data sources used in this study were population-based and covered the entire province of Alberta (~4.3M residents during study period). Various approaches to querying data were employed within a diverse team of health information managers, data analysts, clinical scientists, and gastroenterologists. This process involved a broad search for CD screening tests, thorough data inspection/cleaning, and numerous discussions to determine potential explanations for the findings.

Results

Approximately ~950,000 records for tTG-IgA were first identified. Records were then excluded due to missing/invalid patient identifiers or test results (0.8%), non-Alberta residency (0.4%), and duplicate records (1.1%). A final dataset included ~920,000 tTG-IgA tests on ~680,000 unique patients, which was also validated through a separate query performed by an analyst external to the study team. A conservative approach to excluding as many potential prevalent cases of CD was applied given a robust algorithm for CD has not yet been established in Canada. The final rate of celiac autoimmunity (34 per 100,000) offered further face validity based on prior estimates of diagnosed CD in Alberta and other countries reporting on celiac autoimmunity.

Conclusions

When developing a novel case definition or investigating unfamiliar outcomes using routinely collected data, collaboration across several disciplines is highly recommended. Certain stages of the project may require additional scrutiny and discussion to ensure findings are valid and reliable.

