Author’s response to reviews

Title: Validation of Administrative Health Data for the Pediatric Population: A Scoping Review

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Response to reviewers:

Reviewer 1

Major compulsory revisions

Discussion
The contents of Tables 3 and 4 appear for the first time in the Discussion – there is nothing in the methods that describes this additional piece to the scoping review – it would be better to describe the methods of how these studies were selected and for what purpose in the Methods and describe in Results – I appreciate this was not part of the main intent of the scoping but it impedes the flow of the Discussion as currently placed. It would also be helpful to better understand the purpose of the comparison and what conclusions can be drawn. For example, type 2 diabetes (the main form of diabetes in adults) is a much more common disease than type 1 diabetes (the most common in children) and so comparing and drawing conclusions from the relative number of validation studies in adult vs children with diabetes may not be that meaningful.

Response: Tables 3 and 4 were removed from the discussion, as per this comment and comment 3 from reviewer 2. The reference to types 1 and 2 diabetes in these paragraphs were thus also removed.

Minor essential revisions
Methods
The restriction of studies to English only should be mentioned not only in Limitations but also the Methods section.

Response: This restriction is listed as an inclusion criterion in the “Selection and Data Extraction” sub-section of the Methods section.

Discussion
In the Discussion reference 16 is incorrectly described as a pediatric study in an outpatient setting. This validation study was done on an inpatient population, chart reviews served as the gold standard and then an algorithm was developed which did use outpatient claims but that is not the same as the setting. In the same paragraph the authors then state that “no pediatric studies of diabetes mellitus validated … algorithms in the outpatient setting” which is correct but also refutes the other claim about reference 16 which is a study validating a pediatric DM algorithm.

Response: The paragraph describing this information has been removed, as per the response to the first comment by this reviewer and comment 3 to reviewer 2.

In the paragraph before Conclusions the statement “many paediatric conditions are treated in outpatient settings” should be sharpened. Really all chronic diseases of childhood will need some form of outpatient care and the biases of using inpatient samples is important to highlight. The authors could connect this to the difficulties inherent in doing validation studies in outpatient settings (small numbers of patients per office, difficulties in accessing charts etc) but highlight that access to EMRs for research purposes may facilitate studies of outpatient populations and should be a research priority for the field.

Response: That paragraph has been re-written to incorporate the thoughtful suggestions from the reviewer. It now reads as follows:

For conditions with several published validation studies in the pediatric population, such as diabetes, disease specific systematic reviews evaluating the quality of studies should be examined, but only once more studies have been published; at present, there are two few validation studies in pediatric publications to warrant systematic reviews. Many pediatric conditions are treated primarily in an outpatient setting, and almost all chronic diseases in this population require at least some outpatient care, yet validation studies in this setting are lacking. Patients with milder disease or better access to outpatient-based services may never need hospitalization, and validation studies primarily based on inpatient data likely do not capture the true spectrum of chronic disease severity. Validation studies in the outpatient setting can be challenging to conduct due to small patient numbers in individual centres, lack of standardized charting, and difficulties accessing medical records. As electronic medical records become more widely available, this could potentially facilitate validation studies in the outpatient setting.
Discretionary Revision

Finally, it might be worth flagging that for some important conditions, such as autism, research which uses routinely available cross-sectoral data (such as that from school systems on children with special needs or from other government sectors that serve children with mental and developmental disorders as is the case in most Canadian provinces) will no doubt enrich the ability to identify and better study services and outcomes for children.

Response: Although we agree with this comment, given that the focus of this study was validation studies, we did not add this to the manuscript.

Reviewer 2

Discretionary Revisions

1. Two authors applied the study inclusion criteria to a random selection of studies in which agreement was calculated for two types of comparisons: whether authors both decided to include or exclude the study; and for data abstracted from the studies. For the latter it was not clear how the agreement was calculated for data abstracted. Were only a number of characteristics evaluated or was it the sum of characteristics abstracted etc.? Please provide some information on how 'data abstraction' agreement was calculated and what was compared.

Response: The kappa calculation for data abstraction was clarified as follows. The re-written paragraph now reads as follows.

Following the training phase, two authors (NS and SJ) applied the study inclusion criteria to another randomly selected sample of 23 studies, and kappa was calculated for the decision to include or exclude (yes or no). Both authors extracted data from this validation set using a standardized form. All data extracted by each of the respective authors were then coded and pooled, and kappa was calculated for the pooled results of the data extraction. Subsequently, one investigator (SJ) applied the inclusion criteria to all remaining studies and extracted data from the retained studies.

Major Compulsory Revisions

2. The authors describe that validation studies are characterized by their methods and outcomes, the latter of which includes sensitivity/specificity etc. However, the authors do not include any summary of the validity measures captured in the studies. Depending on the approach used in validation studies, not all measures are able to be calculated. Therefore, the authors should identify whether in fact
measures of sensitivity/specificity/positive predictive value/negative predictive value or agreement measures were calculated.

Response: The validation measures have been added to Table 2.

The last paragraph of the results now reads:

The main diagnosis coding systems that were validated included ICD-9 or ICD-9 CM (28 studies, 75.7%) and ICD-10 or ICD-10-CA (8 studies, 21.6%). The most frequent external data sources used to validate administrative data were medical charts (23 studies, 62.2%) and disease-specific registry data (6 studies, 16.2%). Other validation sources used included clinical databases, laboratory records, and survey data. Validation measures reported include sensitivity (24 studies, 64.8%), specificity (20 studies, 54.0%), positive predictive value (17 studies, 45.9%), and negative predictive value (8 studies, 21.6%).

3. Paragraphs 6 to 8 of the discussion section should not be included in the discussion. These paragraphs highlight two health conditions for which administrative data validation studies have been published in both adult and pediatric populations. The discussion should not be used to report additional study results that are not presented in the results section. For example, Tables 3 and 4 would not be appropriate to include in the discussion. If one of the goals was to compare the pediatric studies identified with the adult studies for the same medical condition then that should be stated in the methods and outlined in the results.

I suggest the following:

3a. Remove paragraphs 6-8 from the discussion

Response: These paragraphs were removed as recommended by the reviewer.

3b. As part of the methods include validity measures for each study as part of the data abstracted

Response: This has been added as described in number 2 above.

3c. Remove Tables 3 and 4 that compare adult validation studies for particular conditions with the included pediatric validation studies

Response: These tables were removed.

3d. Re-focus discussion in this section to address differences in validity measures among the pediatric studies and where there are adult validation studies available for similar conditions, discuss overall the major differences or similarities.
Response: The comparison to specific adult conditions was eliminated, as per comments from both reviewers. Given that a systematic review of the adult literature for similar adult validation studies was out of the scope of this work, a thorough comparison of validation measures was not possible. The discussion has otherwise been shortened and altered to reflect comments from both reviewers as described above.