Author’s response to reviews

Title: Validating surgical procedure codes for inflammatory bowel disease in the Swedish National Patient Register

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Date: 13 August 2019
Dear Editor Modave,

Thank you for your careful review of our manuscript and for the opportunity to re-submit a revised version for your consideration.

We provide below a point-by-point response to all editorial and reviewer comments. Two copies of the manuscript are provided, one with changes highlighted and the other a clean copy.

Sincerely,

Anders Forss

POINT-BY-POINT RESPONSE

In addition to the below point-by-point responses we have discovered a mistake about the changes of regulations on mandatory registration of surgical procedure codes in the National Patient Register in the manuscript. After personal communication with the National Board of Health and Welfare (lawyer Josefin Adlertz, 10-13 August 2019) it has been established that the change was in force already in 1993, not from 2007 and onwards as previously stated in the manuscript. We have made the following change (lines 303-304, page 13):

“In 1993, it became mandatory to register surgical procedure codes (such registration was however done to a considerable extent also before 1993).”

Reviewer 1: William Hogan

This manuscript reports the validity of procedure codes in Swedish National Patient Register for surgical procedures related to inflammatory bowel disease. The results are novel and important. The authors found that these procedures codes have excellent sensitivity, specificity, positive predictive value, and negative predictive value for the surgical procedures they represent. Because the system of procedure codes changed in 1997, the authors also measured the sensitivity and specificity of the codes prior to 1997 and after 1997, which was an important subanalysis that I was pleased to see.

The work reported does have a few limitations that are appropriately acknowledged and discussed by the authors. None of these limitations affect the suitability of the manuscript for publication. Although only a single author reviewed charts to establish the gold standard, this author did consult a surgeon in the case of ambiguities that made it hard to discern presence vs. absence of a particular surgical procedure.

It is not entirely clear what a "transfer error" is.

Do the authors have any idea why sensitivity prior to 1997 is somewhat lower than sensitivity after 1997?

Lastly, it would be useful to know if there are systematic and significant differences in the population
of patients for which requested charts were received vs. those patients for which requested charts were not received. For example, if it were the case that every patient for whom the authors did not receive a requested chart had a surgery for IBD, that could affect the sensitivity and specificity results.

Authors: Please see comments below.

It is not entirely clear what a "transfer error" is.

[1] Thank you for your valuable remarks and questions about our manuscript.

We define a transfer error as an error occurring when the surgical procedure code is transferred from the patient chart to the patient register. In some rare cases technical translation errors occur in this process, such as a swap of letters in the procedure code, for example JFB-- becomes JBF--. In order to clarify the term ‘transfer error’ we have made the following changes (lines 212-216, page 9):

“The two discrepancies between the codes in the charts and the NPR (one registered in 1988 and one in 2000) were both transfer errors (Table S2), possibly technical translation errors occurring when manually transferring the procedure code from the patient chart to the register, for example JFB-- instead registered as JBF--.”

Do the authors have any idea why sensitivity prior to 1997 is somewhat lower than sensitivity after 1997?

[2] We speculate that the new regulations introduced in 1993, making it mandatory for all clinics to report surgical procedure codes to the NPR, may have increased the sensitivity in the second study period (1997-). A chi-square test shows a p-value of 0.02, supporting a statistically significant difference in the sensitivity until 1996 as compared to 1997 and onwards. However, the numbers of missing codes in the NPR are small and the confidence intervals before 1996 (90.6% (95%CI=84.6-100)) and 1997 onwards (98.7% (95%CI=95.0-100)) are overlapping. The difference should be interpreted with caution. In order to clarify the interpretation we have made the following changes (lines 322-324, page 14):

“We speculate that the higher sensitivity 1997 and onwards could be related to the introduction in 1993 of mandatory registration of surgical procedures in the NPR. However, any differences over time should be interpreted with caution due to small numbers.”

Lastly, it would be useful to know if there are systematic and significant differences in the population of patients for which requested charts were received vs. those patients for which requested charts were not received. For example, if it were the case that every patient for whom the authors did not receive a requested chart had a surgery for IBD, that could affect the sensitivity and specificity results.

[3]
Thank you for this very relevant question. As concluded in the limitations we cannot exclude that the charts not received could have biased the result. However, the final sample included in our study represents a nationwide random sample. We received patient charts from almost all clinics requested to provide such. The proportion of patients undergoing surgery among the included is 20% (53/258). This is similar to previous studies which have shown a life-time risk of surgery for IBD-patients between 20 and 50% (see references 2-8 in the manuscript). However, the surgery rates in our study sample do not represent the life time risk of surgery and can be expected to be on the lower end of this range. We find no evidence that the patients we did not receive charts for are significantly different from the included.

We have made the following changes (lines 344-347, pages 14-15):

“However, the patients included still represent a random nationwide sample and our 20% surgery rate (53/258) for the included patients can be compared to an expected lifetime risk of surgery of 20% to 50% for IBD-patients[2-8]. We do not expect the missing charts to be significantly different from the charts included.”

Reviewer 2: Zhaoyi Chen

The authors conducted a very neat analysis on validating the procedure codes for IBD, the overall study design and analysis approach are appropriate. The only concern I have is that the authors did not sufficiently justify what this study contribute.

In the introduction, I would like to see more background on what the validation of this procedure code is needed, and the authors should also extensively discuss what the findings on this study implicate for future.

[4] Thank you for your remarks and suggestions. We believe a validation of procedure codes are highly relevant for future epidemiological studies based on the validated procedure codes. We have added the following, including an additional reference, to the introduction to further elaborate on the urgency of our validation study (lines 94-101, pages 4-5):

“The NPR and quality registers in Sweden provide unique opportunities for systematic collection of medical data at the population and individual level[15]. Through the NPR, health care personnel and researchers can determine the incidence and prevalence of IBD. Based on the procedure codes related to IBD surgery in the NPR the effects and consequences of surgical interventions in IBD patients can be studied, both in large epidemiological and in smaller clinical studies. To ensure high validity and reliability of such future research, IBD related surgical procedure codes needs to be validated. The procedure codes validated in this study include codes also used for similar surgical interventions in other diseases than IBD, such as colorectal surgery in cancer patients.”


[5] To clarify the implications of our study we have made the following additions to the discussion (lines 333-340, page 14):
“The Swedish healthcare system, offering free access to equal care regardless of income and place of residency, provides high external validity as compared with similar healthcare systems such as those of the other Scandinavian countries. The results of this study give an estimate of the validity of surgical procedure codes for IBD related surgery in the NPR previously not known. The results allow future studies to accurately investigate the efficacy of surgery and surgical complications in various subgroups of IBD related surgical procedure codes in the NPR. The overlap of codes between IBD related surgery and other abdominal or perianal surgery lends the results external validity.”