Self-reported awareness and use of the *International Classification of Diseases* coding of inflammatory bowel disease services by Ontario physicians

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RATIONALE: Population and health services research can be performed by linkage analysis of administrative data. However, the robustness of study results is determined by the accuracy of the diagnostic coding.
OBJECTIVES: To estimate the awareness, use and accuracy of the *International Classification of Diseases, Ninth Revision* (ICD-9) coding by physicians providing services for patients with Crohn's disease (CD) and ulcerative colitis (UC).
METHODS: All Ontario gastroenterologists and a 10% random sample of internists, pediatricians, pediatric or general surgeons, and family physicians were surveyed by postal questionnaire to estimate the frequency and 95% CI of using codes 555 or 556 when billing for CD- and UC-related services, respectively. χ^2 tests were used for between-group comparisons.
RESULTS: Of the physicians who were surveyed, 67.7% (416 of 614) responded; 258 of 391 (66%) who were still practising in Ontario saw patients with inflammatory bowel disease (IBD), and 54% had more than 10 IBD patients; 86.5% (95% CI 82.4% to 90.6%) were familiar with ICD-9 codes, and 91.4% (95% CI 88.1% to 95.6%) used the codes 555 (CD) or 556 (UC) for billing. Rates of ICD-9 use did not differ by sex but were used more frequently by those graduating after 1981 ($P<0.02$). Gastroenterologists used ICD-9 IBD codes 555 or 556 significantly more often than all other physicians ($P=0.001$). Most (more than 75%) Ontario physicians used ICD-9 IBD codes always or frequently when billing for IBD-related services. Few (10%) used these codes to bill for non-IBD-related problems.
CONCLUSIONS: These data suggest that there is acceptable use and accuracy of ICD-9 diagnostic coding for CD and UC services – comparable with results from studies of other diseases. Administrative data may thus be used to undertake epidemiological studies in IBD in Ontario.

Key Words: *Accuracy; Crohn's disease; Databases;* International Classification of Diseases, Ninth Revision; *Inflammatory bowel disease; Ulcerative colitis*

Résumé à la page suivante

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Connaissance auto-déclarée et utilisation par les médecins ontariens des codes de classification internationale des maladies pour les services de santé reliés aux MII

JUSTIFICATION : La recherche sur les populations et les services de santé peut être effectuée au moyen de l'analyse des liens entre les données administratives. Par contre, la solidité des résultats d'étude est déterminée par la précision des codes de diagnostic attribués.

OBJECTIFS : Mesurer le degré de connaissances, d'utilisation et de précision de l'attribution des codes de la 9e révision de la Classification internationale des maladies (ICD-9) par les médecins qui soignent les patients atteints de la maladie de Crohn (MC) et de colite ulcéreuse (CU).

MÉTHODES : Tous les gastro-entérologues de l'Ontario et un échantillon aléatoire de 10 % des internistes, des pédiatres, des chirurgiens pédiatriques ou généraux et des médecins de famille ont été interrogés au moyen d'un questionnaire permettant d'estimer la fréquence et les intervalles de confiance à 95 % (IC 95%) relativement à l'utilisation des codes 555 ou 556 lors de facturations pour des services dispensés pour la MC et la CU, respectivement. Des tests du chi carré ont servi pour les comparaisons entre les groupes.

RÉSULTATS : Parmi les médecins interrogés, 67,7 % (416 sur 614) ont répondu, 258 sur 391 (66 %) qui pratiquaient toujours en Ontario ont vu des patients atteints de MII, et 54 % soignaient plus de 10 patients atteints de MII. Parmi eux, 86,5 % (82,4 % - 90,6 %) connaissaient les codes de l'ICD-9 et 91,4 % (88,1 % à 95,6 %) ont utilisé les codes 555 (MC) ou 556 (CU) pour leur facturation. Les taux d'utilisation de l'ICD-9 n'ont pas différé selon le sexe, mais étaient utilisés plus fréquemment par les médecins ayant reçu leur diplôme après 1981 (P < 0,02). Les gastro-entérologues ont significativement plus utilisé les codes 555 ou 556 de l'ICD-9 comparativement à tous les autres médecins (P= 0,001). La plupart des médecins ontariens (plus de 75 %) ont toujours ou souvent utilisé les codes de l'ICD-9 pour les MII au moment de facturer pour des services relatifs à ces maladies. Peu (10 %) ont utilisé ces codes pour des problèmes non reliés aux MII.

CONCLUSION : Ces données suggèrent que l'utilisation et la précision des codes de diagnostic de l'ICD-9 pour les services relatifs à la MC et la CU sont acceptables et comparables aux résultats d'études menées au sujet d'autres types de maladie. Les données administratives peuvent ainsi servir à la conduite d'études épidémiologiques sur le MII en Ontario.

As the global population ages and health expenditures rise, it is critical that estimates of the burden of certain diseases be optimized to improve the allocation of scarce resources. The cost of undertaking such studies can be substantially reduced by linking administrative databases. Health insurance databases, hospitalization files, physician billing files and prescription utilization databases are among those that can be analyzed. Countries that have been most successful in health services and epidemiological research have followed this path, with the diagnosis coded using the *International Classification of Diseases* (ICD) (1) as a critical field. This coding system is now in its 10th revision (ICD-10) (2), although most countries still use the ninth revision (ICD-9) system. Until now, very few countries have considered inflammatory bowel disease (IBD) to be an important condition. Nonetheless, the young age at onset and its considerable impact on health status, with the potential to affect the earning capacity and socioeconomic status of patients and their families, suggest that it imposes a significant health burden. Some countries such as Sweden (3) and Denmark (4) have developed record linkage systems that capture information on all diseases, including IBD. They already consider IBD to be a public health problem and have developed registries to identify all cases prospectively. This approach, however, is more difficult to assume in countries, such as Canada, with a large geographic expanse and heterogeneous health care systems. Bernstein et al (5) have used computerized linkage of existing data from administrative databases to identify patients and estimate the incidence and prevalence rates of IBD in Manitoba. Indeed, they suggest that these prevalence rates are among the highest reported in the world for IBD – at almost 400 per 100,000 person-years.

The validity of conclusions derived from linkage analysis research depends greatly on the accuracy of the data in these databases. Few studies have been undertaken to verify the accuracy of ICD-9 coding in administrative databases, but those that have been done suggest that there is 74% to 81% agreement between the database data and review of the patients' chart for the most responsible diagnosis (6-10). No study has previously evaluated the awareness and accuracy of use by physicians of the ICD-9 coding of services provided to patients with IBD. In the present study, we surveyed Ontario physicians to assess both their familiarity with and current application of ICD-9 coding when billing for Crohn's disease (CD)- or ulcerative colitis (UC)-related services.

METHODS

All gastroenterologists and 10% of all internists, pediatricians, and pediatric or general surgeons were selected randomly from the College of Physicians and Surgeons of Ontario database. Ten per cent of family physicians were also selected from the College of Family Physicians of Ontario database. Each physician was mailed a survey questionnaire (Appendix 1) to evaluate whether they saw IBD patients, their knowledge of ICD-9 codes and self-reported accuracy of using ICD-9 codes 555 and 556 when billing the Ontario Health Insurance Plan for IBD or unrelated services. The ICD-9 codes for CD or UC are 555 and 556, respectively, and the frequency of use and 95% confidence intervals were calculated. χ^2 tests were performed for comparisons between physician groups. $P<0.05$ was considered to be statistically significant for all tests. Data were analyzed using SPSS.pc statistical software (SPSS Inc, USA).

RESULTS

Survey sample

Table 1 shows the number of physicians sampled from each group, and the respective proportions who responded and were in practice at the time. Of the 614 physicians surveyed, 416 (67.7%) completed the questionnaire. However,

TABLE 1
Population of Ontario physicians who were surveyed, by specialty

Specialty	Number sampled	Respondents, n (%)	In practice	Proportion of final sample (%)	Saw IBD patients (%)*
Family medicine	150	88 (58.7)	87	22.2	94.3
Gastroenterology	108	83 (76.9)	79	20.2	100
Pediatric and general surgery	95	60 (63.2)	60	15.3	75.0
Pediatrics	80	68 (85.0)	64	16.3	41.3
Internal medicine	113	43 (38.1)	42	10.7	28.6
Other	68	61 (89.7)	59	15.1	23.7
Total	614	416 (67.7)†	391	100	65.9

**Percentage within each subspecialty who had seen patients with inflammatory bowel disease (IBD) in their practice; †Thirteen moved, 12 were not in practice*

TABLE 2
Practice patterns of surveyed Ontario physicians

	Gastroenterologists		Nongastroenterologists	
Sample	n	% (95% CI)	n	% (95% CI)
Saw IBD patients	79/79	100	179/312	57.3 (51.8-62.8)
Saw >10 IBD patients/year	75/79	94.9 (90.1-99.7)	64/179	35.7 (28.7-42.7)
Saw >50 IBD patients/year	60/79	75.9 (66.5-85.3)	8*/179	4.5 (1.5-7.5)
Secretary or agency bill for services	71/79	89.9 (83.3-96.5)	138/179	77.0 (70.9-83.1)
Know ICD-9 codes	72/79	91.1 (84.5-97.7)	151/179	84.3 (79.0-89.6)
Use codes 555/556 (any time)	69/72	95.8 (91.2-100.4)	135/161	83.9 (78.3-89.5)

**One pediatrician and seven surgeons saw more than 50 patients with inflammatory bowel disease (IBD) each year. ICD-9* International Classification of Diseases, Ninth Revision

13 had moved out of the province and 12 were not in practice. The median year of graduation of respondents was 1981 (range 1951 to 1999), and 292 (72.5%) were male. A significantly greater proportion of female physicians graduated after 1990 (26.4%) than between 1951 and 1970 (9.4%) (P<0.001).

IBD patient exposure

Two hundred fifty-eight respondents (66%, 95% CI 61.3 to 71.7) saw IBD patients and 48% (95% CI 42.0 to 54.0) of those had a solo practice. Table 1 shows the proportion in each specialty who saw IBD patients. Family physicians and surgeons were the nongastroenterologist (non-GI) physicians who reported the highest exposure to IBD patients. Table 2 illustrates the practice patterns of the Ontario physicians who were surveyed, demonstrating that 100% of gastroenterologists, significantly more than 57% (51.8 to 62.8) of the non-GI physicians, saw IBD patients (P=0.001). Of the gastroenterologists, 94.9% (95% CI 90.1 to 99.7) claimed to have 10 or more patients with IBD in their practices.

Familiarity with the ICD-9 code

The majority of participants (81.0%, 95% CI 76.3 to 85.7) who saw IBD patients had a secretary or external billing service submit their claims. There were no significant differences in the rates of awareness (93.9% versus 84.7%, P=0.09) or use (81.6% versus 89.1%, P=0.16) of ICD-9 codes 555 or 556 between physicians who submitted their bills themselves and those who did not. Of the 258 physicians who saw IBD patients, 86.5% (95% CI 82.4% to 90.6%) were familiar with the ICD-9 coding system and 91.4% (95% CI 88.1% to 95.6%) of those reported using ICD-9 IBD codes 555 and 556. There was no significant difference in familiarity by sex (87.4% men versus 83.3% women, P=0.41). Gastroenterologists reported the highest rate of familiarity with the ICD-9 codes 555 and 556 at 91.1% (Table 2).

ICD-9 IBD code use and self-reported accuracy

Gastroenterologists also reported usage of 555 and 556 (Table 2) significantly more than did non-GI physicians (95.8% versus 83.9%, P=0.01). Figure 1 shows the frequency of ICD-9 555 and/or 556 use for IBD services by medical specialty. Physicians who had graduated after 1980 (93%) also used the IBD ICD-9 codes significantly more than those who had graduated before 1980 (P=0.02) (Figure 2). Table 3 illustrates the frequency with which physicians reported using ICD-9 codes 555 and 556 for billing IBD-related services. The majority of physicians stated that they had used ICD-9 codes always or most of the time when billing for IBD-related services. Few physicians

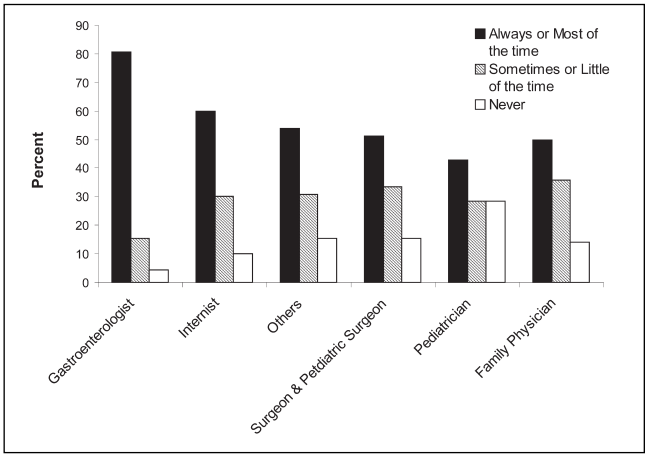

Figure 1) *Frequency of use of* International Classification of Diseases, Ninth Revision *555 and/or 556 codes for inflammatory bowel disease services, by medical specialty*

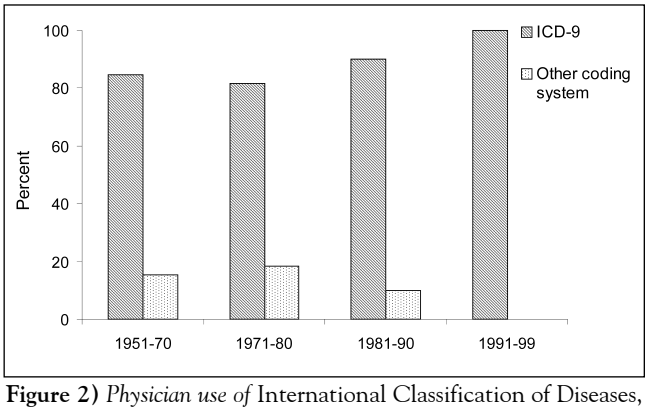

Figure 2) *Physician use of* International Classification of Diseases, Ninth Revision *555 and/or 556 at any time, by decade of graduation*

TABLE 3
Frequency (always or most of the time) of use of the *International Classification of Diseases, Ninth Revision* (ICD-9) codes for billing inflammatory bowel disease-related services

Patient	Reason for service	ICD-9 code billed	% (95% CI)
Crohn's disease	Crohn's disease	555	78.5 (72.9-84.1)
Gastroenterologists	Crohn's disease	555	92.8 (86.8-98.8)*
Nongastroenterologists	Crohn's disease	555	71.3 (63.7-78.9)
Ulcerative colitis	Ulcerative colitis	556	75.1 (69.2-81.0)
Gastroenterologists	Ulcerative colitis	556	85.5 (81.5-89.5)*
Nongastroenterologists	Ulcerative colitis	556	69.9 (62.2-77.6)
Crohn's disease	Not Crohn's disease	555	10.2 (6.1-14.3)
Gastroenterologists	Not Crohn's disease	555	21.7 (12.0-31.9)*
Nongastroenterologists	Not Crohn's disease	555	4.4 (1.0-7.8)
Ulcerative Colitis	Not ulcerative colitis	556	10.2 (6.1-14.3)
Gastroenterologists	Not ulcerative colitis	556	24.6 (14.5-34.7)*
Nongastroenterologists	Not ulcerative colitis	556	2.9 (1.3-4.5)

**P<0.05 gastroenterologists versus nongastroenterologists*

(10%) reported using these codes to bill for non-IBD-related services for their IBD patients. Gastroenterologists were significantly more likely to use the IBD codes for IBD or non-IBD services than non-GI physicians. There were no significant differences in the reported use of codes between men (92.6%) and women (96.4%) (P=0.32).

DISCUSSION

This survey is the first to assess physician self-reported ICD-9 coding for IBD services. Over 85% of Ontario physicians surveyed were familiar with ICD-9 codes, and 91.4% of those reported using ICD-9 codes 555 or 556 for billing when they saw IBD patients. Recent graduates were more likely to use these codes. Not surprisingly, gastroenterologists (91%) were most familiar with the use of ICD-9 555 and 556 codes than other specialists (84%). The self-reported accuracy with which all of the physicians surveyed used 555 or 556 always or most of the time when billing for IBD-related services, irrespective of specialty, was over 75%, while only a few (10%) used these codes to bill for non-IBD-related problems in patients with IBD. The majority of the physicians (81%) who saw IBD patients did not bill for the services themselves, but rather secretaries (64.3%) or an agency (16.7%) performed these tasks. However, there was no significant difference in the awareness of or use of ICD-9 codes between these two groups. Such accuracy would be reasonable for undertaking some epidemiological studies, such as estimating the burden of disease, but might be less acceptable for more specific research questions, such as estimating the resources needed for IBD cancer surveillance. Irrespective of the research question, a key data field for linkage analysis is the disease diagnosis, which in Canada is generally coded using the ICD-9 classification (6).

Bernstein et al (5), in an epidemiological study, examined the Manitoba health care databases to develop valid case definitions for IBD. The accuracy of diagnosis from health care data was compared with two reference measures – a self-report postal questionnaire sent to the IBD patients identified in the databases and a standardized chart review. The database accuracy increased with the consistency of coding, and the number of health contacts, being greatest (approximately 90%) if subjects had been in the system for two or more years and had five or more of the last nine con-

tacts for the same IBD diagnosis. Sensitivity estimates were similar in CD using either self-report (88.9%; 95% CI 87.0% to 90.6%) or chart review (89.2% 95% CI 84.2 to 92.8%) and for UC, were slightly lower, at 87.7% (95% CI 85.8% to 89.5%) for self-report and 74.4% (95% CI 67.3% to 80.5%) for chart review. Our results are predictably less accurate than those derived from the Manitoba database, which is made up of multiple files that are carefully cross-checked. Our survey data represent only physicians' estimates of their billing practices for IBD visits, and suggest an approximate error rate in a single database file. It is, therefore, likely that applying validated criteria and linking multiple files could improve the accuracy of the data obtained from linkage research. Other studies, cited below, have not specifically assessed IBD coding but have evaluated other medical conditions.

In Canadian studies (7-11) that have used provincial databases for assessing the accuracy of diagnosis for a number of medical conditions, the accuracy for the most responsible diagnosis has ranged from 74% to 98%. Discrepancies were attributed to the vagueness of the diagnosis, hospital policy and incomplete diagnostic documentation at the time of coding. Hospital service abstracts were more likely to be accurate than physician claims data because of the detailed documentation required in a hospital compared with an office setting, and because the recording hospital physicians were usually specialists (11). Studies from the United States (12,13) have reported similar diagnostic accuracy from hospital abstracts (76% to 90%) and suggested that further improvements could be achieved by increasing the number of diagnoses abstracted and carefully selecting diagnostic codes of interest.

These studies have also illustrated some potential sources of error when using administrative databases. A major error is the omission of subjects who have not entered the health care system or who have been well and had no visits during the period of interest. A second source of errors is physician or diagnostic test error. In Canadian databases, the accuracy of diagnosis on the medical record appeared to vary with the number of criteria for a specific disease (6). For conditions such as stroke or rheumatoid arthritis, when the diagnosis can be somewhat uncertain, the agreement was 35% to 80% and 45%, respectively. For other conditions, for which diagnostic criteria are more explicit or based on objective evidence, the accuracy rates increased accordingly, to 78% to 94% for myocardial infarction and 93% for diabetes. A third source of error in the diagnosis of hospitalized patients occurs when medical records abstracters identify a secondary diagnosis as the primary diagnosis in patients with multiple disorders or omit a diagnosis if there is a limited number of diagnoses that can be recorded. This could lead to an underestimation of less frequent disorders, particularly in complex cases. Fourth, transcription errors may occur while entering diagnostic codes into the database. In the present survey, secretaries or agencies performed 81% of the billing entries and submissions to the Ontario Ministry of Health. Limited training or supervision of billing staff, substitution of missing codes or inappropriate use of nonspecific codes by the physicians could also lead to undercoding of some diagnoses. Faciszewski et al (14) suggested that other nonrandom sources of error, such as a reimbursement incentives, might cause some billers to favour particular codes or grade certain disorders as more severe.

Our study has several limitations. First, only physicians were surveyed, and results were not compared with those of billing staff, patient or chart data. Second, a restricted group of physicians was assessed, based on pilot data (unpublished), identifying groups that most frequently billed for IBD-related services (internists 39%, family physicians 28.5%, gastroenterologists 15%, general surgeons 13%, others 2.5% and pediatricians 2%). Indeed, physicians who see very few IBD patients are more likely to bill inconsistently than those who see many IBD patients. Third, this was a self-reported survey and, therefore, subject to possible recall or tendency of agreement biases, which could result in an overestimation of the accuracy of use. Nevertheless, our rates of 77% accuracy lie within the range of those of most studies that have reported 50% to 95% accuracy. The aim of our survey was to determine the feasibility of undertaking linkage studies in IBD by assessing sources of error in Ontario administrative databases, which involve a large population (over 12 million subjects) and a large geographic area. We recommend that investigators undertaking linkage research validate the accuracy of their case ascertainment methods during the study. This would require the examination of a random sample of the population of interest (15) and of a sample of patients who might be easily confused with the study population. In the context of IBD, patients with 'infectious colitis' or irritable bowel syndrome could represent 'negative controls', permitting the evaluation of the sensitivity and specificity of case ascertainment. There are also problems of disease reclassification, which occur when a patient's diagnosis is changed from CD to UC or vice versa. This should also be taken into consideration in the case validation process (16). In the present study, physicians were not asked whether they consistently used the same ICD-9 codes over time. This would require a longitudinal assessment of administrative or prospectively collected data.

CONCLUSIONS

The use of data linkage research in IBD in Ontario is feasible. The accuracy of IBD diagnostic coding seems to be comparable with that observed for other important diagnoses. However, it is crucial that the case ascertainment methods be validated in the study population and that accuracy estimates be carefully examined in the context of the research question.

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APPENDIX 1
Questionnaire used to evaluate physicians' knowledge of *International Classification of Diseases, Ninth Revision* (ICD-9) codes, and self-reported accuracy of using ICD-9 codes 555 and 556 when billing the Ontario Health Insurance Plan (OHIP) for Inflammatory Bowel Disease (IBD) or unrelated services

CCFC IBD RESEARCH NETWORK

Study ID # ☐☐☐

Diagnostic Codes Assessment Form

Name (optional) _____ Last

_____ First

1. Today's date ☐☐ ☐☐ ☐☐ DD MM YY

2. City or Town_____ ☐☐

3. Gender Male ☐ Female ☐

4. Year of graduation 19☐☐

5. Medical speciality (Check one only)

- Family Practice ☐
- Gastroenterology ☐
- Internal Medicine ☐
- Paediatrics ☐
- Surgery ☐
- Other _____ ☐

6. Practice Arrangement (Check one only)

- Solo Practice ☐
- GI Group Practice <5 MDs ☐
- GI Group Practice +5 MDs ☐
- Multi-specialty Group Practice <10 MDs ☐
- Multi-specialty Group Practice +10 MDs ☐
- Not in Practice Setting ☐
- Other: _____ ☐

7. Which is your job description? (Check all that apply)

- Research-Basic ☐
- Research-Clinical ☐
- Clinical-Academic ☐
- Clinical-Private Practice ☐
- Other _____ ☐

8. Who does your billing? (Check one only)

- Self ☐
- Secretary ☐
- Other _____ ☐

9. Do you see patients with inflammatory bowel disease?

No ☐ Yes ☐

(If the answer is NO, you are finished the questionnaire)

10. Approximately how many patients with inflammatory bowel disease do you see in a year? (Check one only)

- <10 ☐
- 10-50 ☐
- >50 ☐

11. Are you familiar with the International Classification of Disease (ICD-9) diagnostic codes? (These are the codes for 'diagnosis' or symptoms you fill in when you bill the Ministry of Health)

- No ☐
- Yes ☐

12. When you bill the Ministry of Health, how often do you use each of the following types of coding?

a)- ICD-9 disease specific codes (such as 555 for Crohn's and 556 for ulcerative colitis)

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

b)- Non-specific symptom codes (such as 787 = nausea, vomiting, abdominal pain)

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

c)- Do you use any other method of coding?
Specify_____

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

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APPENDIX 1 (continued)
Questionnaire used to evaluate physicians' knowledge of *International Classification of Diseases, Ninth Revision* (ICD-9) codes, and self-reported accuracy of using ICD-9 codes 555 and 556 when billing the Ontario Health Insurance Plan (OHIP) for Inflammatory Bowel Disease (IBD) or unrelated services

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Study ID # ☐☐☐

Diagnostic Codes Assessment Form

13. Once a patient has a diagnosis of Crohn's disease, do you use the ICD-555 code when seeing them for a Crohn's related problem?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

14. Once a patient has a diagnosis of Crohn's disease, how often do you use the ICD-555 code when seeing them for a non-Crohn's related problem?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

15. When you see a new patient who comes with a diagnosis of Crohn's disease for a Crohn's related problem, do you use ICD-555 code?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

16. When you see a new patient who comes with a diagnosis of Crohn's disease for a non-Crohn's related problem, do you use ICD-555 code?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

17. Once a patient has a diagnosis of ulcerative colitis, how often do you use the ICD-556 code when seeing them for a colitis related problem?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

18. Once a patient has a diagnosis of ulcerative colitis, how often do you use the ICD-556 code when seeing them for a non-colitis related problem?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

19. When you see a new patient who comes with a diagnosis of ulcerative colitis for a colitis related problem, do you use ICD-556 code?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

20. When you see a new patient who comes with a diagnosis of ulcerative colitis for a non-colitis related problem, do you use ICD-556 code?

- Never ☐
- A little of time ☐
- Sometimes ☐
- Most of time ☐
- Always ☐

Thank you for your participation.

CCFC Crohn's and Colitis Foundation of Canada

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