

Title: Clinician administered and self-report survey both effective for identifying fecal incontinence in patients with Inflammatory Bowel Disease

Running head: Asking about bowel control in IBD

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### **Conflicts of Interest**

LD: speaker fees from Janssen, AbbVie and Eli-Lilly; consultancy fees from GL Assessments and Crohn's & Colitis UK

AH: has served as consultant, advisory board member or speaker for AbbVie, Atlantic, Bristol-Myers Squibb, Celltrion, Falk, Ferring, Janssen, MSD, Napp Pharmaceuticals, Pfizer, Pharmacosmos, Shire and Takeda. She also serves on the Global Steering Committee for Genentech.

JD: speaker fees from Warner Chilcott, Dr Falk pharma, Abbvie, Janssen, Takeda, MSD whilst an IBD Nurse Manager at Guy's & St Thomas's Hospitals Trust. Has been fully employed by Takeda UK Ltd since 2018. .

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### **Authors' contributions to the study**

CN: CI, conceived study

CN, LD, JD, AH, CK, HT, AV, SK: study design, funding application

LD: project manager, site set up and oversight, ethics applications, qualitative analysis

DL: PCTU project coordinator

SK: oversight of statistical analysis

VM: reviewed the statistical analysis plan and conducted the data analysis

TW: conducted and analysed qualitative interviews with patient participants, clinicians delivering the intervention, and with project staff

MF: chair of steering group, study review and monitoring

All authors contributed to manuscript writing and / or revising of drafts.

## ABSTRACT

### Objectives

To test two methods for reporting of fecal incontinence (FI) in people with Inflammatory Bowel Disease.

### Methods

Consecutive patients from IBD clinics in six UK hospitals completed a short three item case-finding survey about FI; they either completed the survey themselves or were asked the same questions face to face by a clinician.

### Results

Of 1336 eligible patients with complete data (48% male; mean 43 years; 55% Crohn's disease, 41% ulcerative colitis), 772 were asked about FI face-to-face, and 564 self-completed the survey: FI was reported in 63% and 56% respectively ( $p=0.012$ ). In regression analyses, those aged 51-60, having Crohn's disease and higher disease activity were more likely to report FI. Of all respondents, 38.7% were interested in receiving help for their incontinence.

### Conclusions

Fecal incontinence affects the majority of people with IBD. Although more patients reported fecal incontinence when asked face-to-face than self-reported, routine screening by either method in clinical practice is recommended. Over one third of patients with IBD want help for bowel control problems.

**KEYWORDS:** bowel control, fecal incontinence, inflammatory bowel disease, screening, urgency

## INTRODUCTION

The unpredictable relapsing-remitting nature of Inflammatory Bowel Disease (IBD) causes episodes of bowel urgency and diarrhea. Disease activity, loose stool, female gender, childbirth, a weak or fatigable anal sphincter and previous colorectal surgery are risk factors for fecal incontinence (FI) in IBD [1]. This distressing social and hygiene problem affects 2 -10% of adults in the general population [2,3] and 12.6-76% of people with IBD, depending on definition used [3,4]. Urgency and FI are not confined to episodes of relapse; FI has been reported to persist in at least 10% of patients in remission [4,5] whilst urgency affects up to 66% in remission [6]. Urgency and FI negatively affect quality of life, restrict social activities and limit individuals' wider life and employment opportunities; some may become housebound [7, 8]. Bowel control issues are consistently reported as a top concern of people with IBD [9-11]. Identifying effective treatments is a key research aim [12], yet treatments can only be offered if those who need them can be identified. Despite recommendations by the UK National Institute for Health and Care Excellence (NICE) [13] that clinicians actively ask about FI in at-risk populations, IBD clinicians seldom ask patients about bowel control issues. Patients avoid reporting the problem themselves [7,14], with most preferring that clinicians raise this sensitive topic [7]. Although people with urinary incontinence are more likely to disclose symptoms by postal questionnaire than by face-to-face questioning [15], there is no robust evidence to confirm effective method(s) of active case-finding for FI in people with IBD.

As part of a larger study to trial an intervention for patients with IBD-related FI [16], we first aimed to test two strategies for identifying patients with IBD who experience FI. The research question for this study was: *Does face to face clinician questioning or self-report identify patients with IBD who experience fecal incontinence?*

## **METHODS**

### **Study design**

This cross-sectional active case-finding study used a paper survey to screen participants for bowel control problems including FI, either self-completed by the patient or the same questions asked face-to-face by clinical staff.

### **Study population and sample sizes**

The study population comprised a convenience sample of all consecutive eligible patients with IBD attending outpatient clinics at six general and specialist hospitals in England during the study period.

### **Development of the case-finding survey**

The case-finding survey was developed by the study team and a patient panel, piloted with 10 people with IBD and consequently adjusted slightly. The survey comprised three questions, each with definitions to facilitate consistent interpretation across participants, and with several response options [Table 1]. All participants completed this one survey, whether self-completed or face to face with questions asked by clinical staff.

Demographic data (age, gender, ethnic group) and disease activity scores (Harvey Bradshaw index for CD [17] or Walmsley score for UC [18]) were also collected. A Harvey Bradshaw score of < 5, or a Walmsley Index score of <3 was taken to indicate clinical remission. Participants confirmed whether their current symptoms were or were not usual for them in remission.

## **Ethical permissions**

The study was approved by the UK NHS Health Research Authority National Research Ethics Service (NRES Committee London-Hampstead), Ref: 15/LO/0051.

## **Patient and Public Involvement (PPI)**

The PPI team of six patients with IBD contributed to the funding application, study design, and development of patient-facing materials (consent forms and case-finding survey).

## **Recruitment and data collection**

Consecutive IBD patients attending outpatient clinics who met the study criteria were invited to participate.

### Inclusion criteria:

- Confirmed diagnosis of IBD documented in the patient's medical notes
- Aged 18 - 80 years

### Exclusion criteria:

- Current stoma
- Inability to give informed consent (for example, due to reduced mental capacity)
- Insufficient command of English to understand study documents and procedures

The recruitment and data collection strategy alternated weekly across all participating sites between two strategies:

*Strategy 1* (self-completion): packs containing an introductory letter, study information leaflet, case-finding survey, and pre-paid return addressed envelope were given to eligible patients on arrival in clinic. These were either completed unsupervised and returned on the day



in clinic, posted back later, or not returned. One follow-up postal reminder was sent. Return of the completed survey implied consent to participate.

*Strategy 2 (face-to-face):* on arrival in clinic, eligible patients received the study information leaflet. If willing to participate, they were screened by either the gastroenterologist, IBD clinical nurse specialist, or research nurse following their scheduled appointment. Written informed consent was collected prior to data collection.

### **Data Analysis**

All statistical analyses were carried out using Stata v14.0. The outcome (disclosure of FI) was analyzed using a logistic regression model, with enquiry method (self-completion return; face-to-face) as a predictor variable. Diagnosis (Crohn's disease or Crohn's colitis; Ulcerative colitis or proctitis; IBD unclassified), disease activity categories (remission; mild; moderate or severe), age group (18-30; 31-40; 41-50; 51-60 or 61-80), gender (male or female) and ethnic group category (White; Asian; Black or Other) were also tested as predictor variables. Results are presented as odds ratios and adjusted odds ratios adjusting for all other predictors.

### **RESULTS**

Of 3351 patients, 1464 were invited to participate in face-to-face screening, and 1887 were invited to self-complete the screening form. In total, 1417 (42%) agreed to participate; of these, 1336 (94%) provided complete data. Of these, higher response rates were obtained by face-to-face method of enquiry than self-complete: 53% (772/1464) compared with 30% (564/1887). Of the 1336 with complete data, 693 (51.9%) were female; 547 (40.9%) had ul-

cerative colitis (UC), 740 (55.4%) had Crohn's disease (CD), and 49 (3.7%) had IBD-Unclassified (IBD-U). Ages ranged from 18 to 80 years (mean = 43 years). A range of ethnicities was represented. The two methods yielded comparable groups with respect to demographics and clinical characteristics [Table 2].

Patients were less likely to report FI by self-report than with face-to-face screening; 56.0% versus 62.7%; Odds ratio 0.75 (0.60 to 0.94). Overall 801/1336 (60.0%) reported at least some FI. Older and female patients, and those with more active disease were more likely to disclose FI, while patients of Asian origin were less likely to disclose FI [Table 3]. Likelihood of FI increased with greater disease activity but was not always absent during remission: 2.9% and 5.2% of participants reported daily FI during remission or mild flare respectively, while 0.8% and 4.1% reported FI weekly during remission and mild flare respectively [Table 4]. Only 535/1336 (40%) reported that they never experience FI. After adjusting for all other risk factors female gender was no longer significantly related to disclosure of FI; adjusted odds ratio 1.17 (0.92 to 1.48), and patients with Ulcerative Colitis were less likely to report FI; adjusted odds ratio 0.77 (0.60 to 0.99).

Patients were more likely to report interest in receiving treatment for FI via self-completion than face-to-face; 42.0% versus 36.3%; adjusted odds 1.79 (1.32 to 2.43). However, across all participants, increased disease activity and disclosure of FI were associated with interest in treatment. After adjustment for confounders, those of Asian ethnicity were more likely to want help [Table 5]. Across all participants those aged 41 to 60 were more likely to be interested in treatment than those from other age groups but this difference was explained by co-variates and was not significant in the final model.

## DISCUSSION

Reflecting previous studies reporting rates of FI in people with IBD [1-4, 19], the case-finding survey found that most people with IBD report at least some FI, with many wanting help for this symptom. Although estimating prevalence was not the primary purpose of this study, the case-finding methods enabled this to be determined; results showed that the prevalence of any reported FI was 60% and for 6.6% of participants this occurred at least weekly.

Although participants with UC might be expected to have greater issues with rectal sensitivity and tenesmus, and by association, a higher likelihood of FI, in this study they were less likely to report FI. We did not exclude participants with perianal disease and associated complications since these patients are as likely to want help for their leakage. The purpose of case-finding is to identify patients with FI, who can then be offered specific treatment or intervention appropriate to each patient's situation.

The reasons for the statistically significant difference in disclosure of FI between face-to-face and self-completed survey are unclear. More of those reporting FI face-to-face did not want help for it, suggesting that a self-completed survey may yield a better estimate of who wants help.

Active case-finding is important in populations where there is a high risk of FI [15]. Self-report produces slightly lower disclosure rates than face-to-face screening, but either method is effective and suitable for clinical practice. Face-to-face screening might be easier administratively but would extend consultation time. Whilst IBD specialist nurses may be best placed to conduct case-finding, these clinicians are already overstretched [20]. In very busy clinics, giving the patient the self-report survey on arrival in clinic, so they can complete it whilst waiting for their appointment, may be a more efficient use of resources.

Whilst self-reporting patients are less likely to report FI, they are more likely to want help if they do report FI. It is unclear why those asked face-to-face are less likely to request help, but the difficulty of both admitting a problem and asking for help, may be a factor. Targeted use of either approach may be warranted, according to the predictors of revealing and wanting help reported above, as well as logistical factors in individual clinical settings.

### Strengths and limitations

Case-finding recruitment from multiple participating sites, including general, regional and tertiary (specialist) centers, increased the likelihood that participants reflected the demographic profile(s) of IBD patients in the UK. All age groups were well-represented and whilst most participants were Caucasian, Asian, Black and other ethnic populations were also represented. Although more participants in all stages of the study were female, males were also recruited. There was robust PPI involvement in study design and development of study materials including the case-finding survey. The response rate of 42% suggests a possible self-selection bias: those who responded may have been more likely to have an issue with incontinence which they wished to report. Our definition of FI may have been too strict; using the less restrictive (in terms of number of FI episodes required to fulfill criteria) Rome III criteria<sup>21</sup>, recently reported as more effective than the later Rome IV criteria at detecting people whose quality of life is affected by FI<sup>22,23</sup>, might show whether those with less frequent FI are more likely to seek help. Findings may or may not be transferable internationally. We do not know how many participants had perianal disease.

### CONCLUSIONS

This simple survey, completed either face-to-face with a clinician, or self-completed by the patient can both identify those with FI, many of whom want help. FI is both common in remission and strongly related to disease activity. The brief survey provides clinical services with an easy means of identifying patients who may need help to manage this distressing symptom.

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**Table 1: Screening questions to identify patients with bowel control / incontinence concerns**

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**1. Do you experience bowel incontinence related to your IBD? Please tick one answer only**

*Bowel incontinence means accidental passing of stool, faeces, poo into your underclothes, that you are either unaware of at the time, or unable to control*

Never <input type="checkbox"/>	Rarely <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Weekly <input type="checkbox"/>	Daily <input type="checkbox"/>
<i>Never have incontinence</i>	<i>Incontinence only once, or less than once, in past four weeks</i>	<i>Incontinence more than once in past four weeks, but less than once a week</i>	<i>At least one episode of incontinence per week but less than once per day</i>	<i>One or more episodes of incontinence per day</i>

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**2. Is any bowel incontinence related to flare-up / relapse of your IBD? Please tick one answer only**

Always related <input type="checkbox"/>	Usually related <input type="checkbox"/>	Not related <input type="checkbox"/>	No incontinence <input type="checkbox"/>
<i>Incontinence only occurs during flare-up / relapse</i>	<i>Incontinence mostly occurs during flare-up / relapse but can sometimes occur during remission</i>	<i>I have incontinence whether I am in flare-up / relapse or in remission</i>	<i>I am never incontinent</i>

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**3. Are you interested in receiving help to try and improve your bowel control and reduce your incontinence? Please tick one answer only**

Yes, definitely <input type="checkbox"/>	Yes, possibly <input type="checkbox"/>	No thanks <input type="checkbox"/>	I do not have incontinence <input type="checkbox"/>
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**Table 2: Participant characteristics by method of enquiry**

	Method of enquiry		All respondents
	Face-to-face	Self-completion	
	N=772	N=564	N=1336
<b>Male</b>	382 (49.5)	261 (46.3)	643 (48.1)
<b>Age (years)</b>			
18-30	205 (26.6)	113 (20.0)	318 (23.8)
31-40	203 (26.3)	149 (26.4)	352 (26.4)
41-50	151 (19.6)	96 (17.0)	247 (18.5)
51-60	109 (14.1)	100 (17.7)	209 (15.6)
60-80	104 (13.5)	106 (18.8)	210 (15.7)
<b>Ethnicity</b>			
White	640 (82.9)	449 (79.6)	1,089 (81.5)
Asian or Asian British	73 (9.5)	64 (11.3)	137 (10.3)
Black or Black British	25 (3.2)	15 (2.7)	40 (3.0)
Other ethnic back-ground	34 (4.4)	36 (6.4)	70 (5.2)
<b>Diagnosis</b>			
Crohn's	428 (55.4)	312 (55.3)	740 (55.4)
Colitis	308 (39.9)	239 (42.4)	547 (40.9)
IBD unclassified	36 (4.7)	13 (2.3)	49 (3.7)
<b>Diagnosis confirmed by colonoscopy / endoscopy</b>			

Yes	593 (76.8)	394 (69.9)	987 (73.9)
<b>Disease Activity</b>			
Remission	407 (52.7)	221 (39.2)	628 (47.0)
Mild	179 (23.2)	187 (33.2)	366 (27.4)
Moderate	165 (21.4)	133 (23.6)	298 (22.3)
Severe	21 (2.7)	23 (4.1)	44 (3.3)
<b>Disease activity in-</b>			
<b>dex: mean (SD)</b>			
<b>Ulcerative Colitis</b>	4.2 (3.1)	4.5 (3.1)	4.3 (3.1)
<b>Crohn's disease</b>	4.6 (4.9)	5.8 (5.5)	5.1 (5.2)

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*SD=Standard deviation*

**Table 3: Predictors of disclosure of incontinence**

	<b>Number (%) reporting any faecal inconti- nence</b>	<b>Odds ratio (95% confidence interval)</b>	<b>Adjusted Odds ratio (95% confidence interval)</b>
<b>Method of enquiry</b>			
Face-to-face	485 (62.8)	ref	ref
Self-completion	316 (56.0)	0.75 (0.60 to 0.94)*	0.63 (0.49 to 0.80)***
<b>Age (years)</b>			
18-30	160 (50.3)	ref	ref
31-40	200 (56.8)	1.30 (0.96 to 1.76)	1.45 (1.04 to 2.00)*
41-50	163 (66.0)	1.92 (1.36 to 2.70)***	1.70 (1.18 to 2.46)**
51-60	146 (69.9)	2.29 (1.58 to 3.31)***	2.25 (1.52 to 3.34)***
60-80	132 (62.9)	1.67 (1.17 to 2.39)**	1.71 (1.16 to 2.52)**
<b>Gender</b>			
Male	365 (56.8)	ref	ref
Female	436 (62.9)	1.29 (1.04 to 1.61)*	1.17 (0.92 to 1.48)
<b>Ethnicity</b>			
White	672 (61.7)	ref	ref

Asian	71 (51.8)	0.67 (0.47 to 0.95)*	0.61 (0.41 to 0.91)*
Black	24 (60.0)	0.93 (0.49 to 1.77)	0.84 (0.42 to 1.66)
Other	34 (48.6)	0.59 (0.36 to 0.95)*	0.52 (0.31 to 0.89)*
<b>Diagnosis</b>			
Crohn's	445 (60.1)	ref	ref
Ulcerative Colitis	322 (58.9)	0.95 (0.76 to 1.19)	0.77 (0.60 to 0.99)*
IBD unclassified	34 (69.4)	1.50 (0.80 to 2.81)	1.05 (0.54 to 2.05)
<b>Disease activity</b>			
Remission	300 (47.8)	ref	ref
Mild	214 (58.5)	1.54 (1.19 to 2.00)**	1.70 (1.28 to 2.24)***
Moderate	246 (82.6)	5.17 (3.69 to 7.25)***	5.71 (4.00 to 8.14)***
Severe	41 (93.2)	14.9 (4.58 to 48.8)***	16.93 (5.12 to 55.99)***

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\*  $p < 0.05$ ; \*\*  $P < 0.01$ ; \*\*\*  $P < 0.001$

**Table 4: Relationship between incontinence frequency and disease severity**

Frequency of Incontinence	Severity of disease				Frequency
	Remission	Mild	Moderate	Severe	Totals
	N (%)	N (%)	N (%)	N (%)	N (%)
Never	328 (52.2)	152 (41.5)	52 (17.5)	3 (6.8)	535 (40.1)
Rarely	235 (37.4)	123 (33.6)	87 (29.2)	6 (13.6)	451 (33.7)
Sometimes	42 ( 6.7)	57 (15.6)	84 (28.2)	15 (34.1)	198 (14.8)
Weekly	18 ( 2.9)	19 ( 5.2)	41 (13.8)	10 (22.7)	88 (6.6)
Daily	5 ( 0.8)	15 ( 4.1)	34 (11.4)	10 (22.7)	64 (4.8)

$Chi^2$  12 df = 291.3773  $P < 0.001$

**Table 5: Predictors of interest in treatment**

	<b>Number (%) of patients interested in treatment</b>	<b>Odds ratio (95% confidence interval)</b>	<b>Adjusted odds ratio (95% confidence interval)</b>
<b>Method of enquiry</b>			
Face to face	280 (36.3)	ref	ref
Self-completion	237 (42.0)	1.27 (1.02 to 1.59)*	1.79 (1.32 to 2.43)***
<b>Age (years)</b>			
18-30	103 (32.4)	ref	ref
31-40	124 (35.2)	1.14 (0.82 to 1.56)	0.96 (0.63 to 1.47)
41-50	108 (43.7)	1.62 (1.15 to 1.29)**	1.05 (0.67 to 1.66)
51-60	101 (48.3)	1.95 (1.36 to 2.79)***	1.16 (0.72 to 1.86)
61-80	81 (38.6)	1.31 (0.91 to 1.89)	0.88 (0.54 to 1.42)
<b>Gender</b>			
Male	233 (36.2)	ref	ref
Female	284 (41.0)	1.22 (0.98 to 1.52)	1.01 (0.75 to 1.35)
<b>Ethnicity</b>			
White	415 (38.1)	ref	ref
Asian	57 (41.6)	1.16 (0.81 to 1.66)	1.88 (1.09 to 3.24)*
Black	18 (45.0)	1.33 (0.70 to 2.51)	1.80 (0.74 to 4.36)

Other	27 (38.6)	1.02 (0.62 to 1.68)	1.85 (0.91 to 3.78)
<b>Diagnosis</b>			
Crohn's disease	284 (38.4)	ref	ref
Ulcerative colitis	207 (37.8)	0.98 (0.78 to 1.23)	0.83 (0.61 to 1.13)
IBD Unclassified	26 (53.1)	1.82 (1.02 to 3.24)*	1.58 (0.72 to 3.50)
<b>Disease activity</b>			
Remission	155 (24.7)	ref	ref
Mild	149 (40.7)	2.09 (1.59 to 2.76)***	1.90 (1.32 to 2,73)**
Moderate	180 (60.4)	4.66 (3.47 to 6.25)***	2.40 (1.67 to 3.46)***
Severe	33 (75.0)	9.15 (4.52 to 18.5)***	3.55 (1.59 to 7.92)***

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\*  $p < 0.05$ ; \*\*  $P < 0.01$ ; \*\*\*  $P < 0.001$