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## **The IBD-disk is a reliable tool to assess the daily-life burden of patients with inflammatory bowel disease**

Sara Tadbiri, Maria Nachury, Yoram Bouhnik, Mélanie Serrero, Xavier Hebuterne, Xavier Roblin, Julien Kirchgesser, Guillaume Bouguen, Denis Franchimont, Guillaume Savoye, et al.

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2  
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30 **All of the members of the GETAID-IBD-disk study group are listed in the appendix.**

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6  
7 **Abbreviations:** Crohn's disease: CD; ulcerative colitis: UC; inflammatory bowel disease: IBD;  
8 Groupe d'Etude Therapeutique des Affections du tube Digestif: GETAID; IBD-DI :  
9 Inflammatory Bowel Disease Disability Index: IBD-DI; International Classification of  
10 Functioning, Disability and Health: ICF Core Set; Receiver Operating Curve: ROC; World  
11 Health Organization: WHO.  
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22  
23 Maria Nachury has received consulting and travel accomodation fees from Abbvie, Adacyte,  
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26 Yoram Bouhnik has received lecture and consulting fees from Abbvie, Biogaran, Boehringer-  
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29 UCB and Vifor Pharma. This author has also stock ownership of Inception IBD, San Diego,  
30 CA, USA.  
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39 Melanie Serrero has received lecture or consulting fees from Abbvie, Ferring, Amgen,  
40 Celltrion, Janssen, Ferring, Takeda and Tillotts.  
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43  
44

45 Xavier Hébuterne has received fees and research support from Abbvie, Abivax, Alfasigma,  
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55 Xavier Roblin reported a relationship with MSD, Abbvie, Amgen, Sandoz, Pfizer, Takeda and  
56 Janssen.  
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3 Guillaume Bouguen received lecture fees from Abbvie, Ferring, MSD, Takeda and Pfizer and  
4 consultant fees from Takeda, Janssen.

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6  
7 consultant fees from Takeda, Janssen.

8  
9  
10 Denis Franchimont is research director of FNRS; he has received educational grants from  
11 Abbvie, Takeda, MSD, and has received honoraria fees for lectures or consultancy from  
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13 and Hospira.

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15  
16  
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4 Kabi, Janssen, Mylan, MSD, Pfizer, Takeda

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36  
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38 Matthieu Allez has received honoraria from Novo Nordisk, MSD, Abbvie, Ferring, Genentech,  
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51

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57 Lucile Boivineau has received consulting fees from Abbvie and Tillotts.

58  
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2  
3 Ludovic Caillo received board and lecture fees from Abbvie, Janssen, Pfizer, Takeda, Amgen

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32 Conception and design of the study: AM, MN, DL, LPB

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41 Drafting or revision of the manuscript: ST, MN, YB, MS, XH, XR, JK, GB, DF, GS, AB, EL,  
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## ABSTRACT

**Introduction:** The inflammatory bowel disease (IBD)-disk is a 10-item self-questionnaire that is used to assess IBD-related disability. The aim of the present study was to evaluate this tool in the assessment of IBD daily-life burden.

**Patients and methods:** A one-week cross-sectional study was conducted in 42 centres affiliated in France and Belgium. Patients were asked to complete the IBD-disk (best score: 0, worst score: 100) and a visual analogue scale (VAS) of IBD daily-life burden (best score: 0, worst score: 10). Analyses included internal consistency, correlation analysis and diagnostic performance assessment.

**Results:** Among the 2011 IBD outpatients who responded to the survey (67.8% of the patients had Crohn's disease), 49.9% were in clinical remission. The rate IBD-disk completion was 73.8%. The mean IBD-disk score and IBD daily-life burden VAS were  $39.0 \pm 23.2$  and  $5.2 \pm 2.9$ , respectively. The IBD-disk score was well-correlated with the IBD daily-life burden VAS ( $r=0.67$ ;  $p<0.001$ ). At an optimal IBD-disk cut-off of 40, the area under ROC curve (AUROC) for high IBD daily-life burden ( $VAS>5$ ) was 0.81 (CI95%: 0.79-0.83;  $p<0.001$ ). Using multiple logistic regression, a shortened IBD-disk score including only five items (abdominal pain, regulating defecation, education and work, emotions and energy) from the IBD-disk score had a correlation and diagnosis performance similar to those of the complete IBD-disk score (AUROC=0.82 [0.79-0.83];  $p<0.001$ ) in the assessment of IBD daily-life burden.

**Conclusion:** In a large cohort of patients, the IBD-disk score was well correlated with IBD daily-life burden, and it could be used in clinical practice.

## INTRODUCTION

Inflammatory bowel diseases (IBDs) are chronic inflammatory conditions that negatively affect various dimensions of daily life (1). Therefore, new standards of care taking into account IBD-related disability and daily-life burden are increasingly being incorporated into clinical practice. According to the World Health Organization (WHO), disability is an umbrella term that includes impairments, activity limitations, and participation restrictions. An impairment is a problem with a bodily function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; and a participation restriction is a problem experienced by an individual in achieving full involvement in life situations (2).

IBD can cause physical, psychological, familial and social impairment and self-administered questionnaires that assess patients' quality of life are often too restrictive for the assessment of disability (3–7). To date, there is only one validated tool used to assess IBD-related disability: the IBD Disability Index (IBD-DI) (8,9). Although the IBD-DI is a very informative questionnaire it has to be completed with the assistance of a trained nurse and it is time-consuming.

Based on the principles of the PSO-disk, a validated self-administered tool for assessing the burden of psoriasis (10–12), the IBD Connect group has developed the IBD-disk, a visual self-administered tool based on a Delphi consensus process to measure disability in patients with IBD(13). Ten items were chosen to assess ten dimensions of disability including joint pain, abdominal pain, regulating defecation, interpersonal interactions, education and work, sleep, energy, emotions, body image and sexual functions (1,8,9). The IBD-disk may be useful to assess the IBD daily-life burden in clinical practice.

Therefore, we aimed to assess the correlation between the overall IBD-disk score and the IBD-disk subscores with the IBD-daily-life burden in a large cross-sectional study.

## **PATIENTS AD METHODS**

### **Study population**

A cross-sectional survey was conducted in 42 tertiary centres in France and Belgium affiliated with the Groupe d'Etude Therapeutique des Affections Inflammatoires du tube Digestif (GETAID) in France and Belgium. The survey was conducted from November 26<sup>th</sup> to November 30<sup>th</sup>, 2018. Investigators asked consecutive adult outpatients with a confirmed diagnosis of IBD regardless of any other criteria to complete a standardized self-questionnaire that was given by their treating physicians or IBD nurse.

The study was conducted in accordance with the ethical principles expressed in the Declaration of Helsinki and the requirements of applicable French regulations. The patients' experience study was conducted through the French reference methodology, MR-004, and it was supervised by and registered with GETAID (registration number 2210131). All the authors had access to the study data and reviewed and approved the final manuscript.

### **Survey instrument**

A 4-page, self-administered questionnaire was designed to examine the demographics of the patients, type of IBD, history of surgical treatment of IBD, working status, duration of IBD and current IBD-related treatment (Supplementary Figure S1). An IBD-disk was included in the survey and included 10-point Likert scales (0 = no burden; 10 = maximal burden) assessing each component of the IBD-related disability: joint pain, abdominal pain, body image, education and work, emotions, energy, interpersonal interactions, regulating defecation, sexual function, and sleep (Figure S1). The overall IBD-disk score was calculated as the sum of its 10 components, ranging from 0 to 100. The questionnaire also included two 10-point visual analogue scales (VASs) to assess the IBD daily-life burden and overall health (0 = worst; 10 = perfect). Burden scales have been used to study the burden of many chronic diseases, such as

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2  
3 Crohn's disease, celiac disease, irritable bowel syndrome, diabetes and congestive heart failure  
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5 (14–20). IBD activity was determined by patient self- assessment (yes or no).  
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### 8 **Correlation of the overall IBD-disk score with IBD daily-life burden**

9  
10 A simple linear correlation analysis using Pearson's correlation coefficient was applied  
11  
12 to test the correlation between the overall IBD-disk score and IBD-disk subscores with the IBD  
13  
14 daily-life burden scale. Outliers were detected using a graphical method by excluding values  
15  
16 1.5-fold over the standard deviation. A correlation was considered significant if the Pearson  
17  
18 correlation coefficient  $r$  was strictly superior to 0.5. Discrimination of models was assessed by  
19  
20 the C-statistic (Area Under the ROC Curve). The C-statistics of the models were applied to  
21  
22 assess the accuracy of detecting a high IBD daily-life impact (score >5).  
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### 26 **Reliability**

27  
28 Cronbach's  $\alpha$  coefficient ( $> 0.7$ ) and corrected item-total correlations ( $> 0.4$ ) were  
29  
30 used to assess the internal consistency of the overall IBD-disk score. Cronbach's  $\alpha$   
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32 coefficient with a one-at-a-time deletion procedure was used to assess the impact of the  
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34 items on the internal consistency of the overall IBD-disk score.  
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### 38 **Factors associated with IBD-related disability using the overall IBD-disk score**

39  
40 The overall IBD-disk score was calculated for the overall study population and  
41  
42 compared according to the patients' characteristics using a Mann-Whitney test or an ANOVA  
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44 test followed by a Tukey test for post hoc analysis  
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### 48 **Construction and validation of a shortened IBD-disk score**

49  
50 To improve the accuracy of the IBD-disk in assessing the IBD daily-life burden, a new,  
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52 shortened IBD-disk score was constructed. The relationship between the IBD-disk subscores  
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54 and the IBD daily-life burden scale was based on the correlation coefficient. A multiple linear  
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56 regression method was used to determine the linear combination of subscores that had the  
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58 strongest correlation with the IBD daily-life burden scale. Each of the subscores were  
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3 successively selected by a stepwise regression method, using the F-test at each step.  
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5 Coefficients were standardized and rounded to allow for straight forward calculation of the new  
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7 IBD-disk score. The  $R^2$  of the new model was used to determine the overall association between  
8  
9 the shortened IBD-disk score and the IBD daily-life burden scale. The C-statistics of each  
10  
11 model were compared using a nonparametric test developed by DeLong *et al.* that is appropriate  
12  
13 for non-independent data (21).  
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### 16 17 **Statistical analysis**

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19 The data are expressed as numbers (%) for qualitative data and as the means  $\pm$  standard  
20  
21 deviations (SDs) or medians [interquartile ranges] for quantitative data. Qualitative variables  
22  
23 were compared using Chi<sup>2</sup> test or Fisher's exact test, and quantitative variables were compared  
24  
25 using the Mann-Whitney test or an ANOVA test followed by a Tukey test for post hoc analysis.  
26  
27 The normality of the distribution was verified using the Kolmogorov-Smirnov test, Shapiro-  
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29 Wilk test and visual inspection. A result was considered significant if the p value less than 0.05.  
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31 All the statistics were calculated using SPSS Statistics v23® software.  
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## RESULTS

### Study population

### Study population

During the one-week study period, 2011 outpatients with IBD (47% male; median age of 40.0 [29.0-52.0] years) were included in the 42 centres. The median number of patients recruited at each centre was 46.5 (24.0-63.0). The characteristics of the study population are listed in Table 1. Briefly, 67.8% of the patients had Crohn's disease (CD), and 32.2% had ulcerative colitis (UC). The median duration of IBD was 10.5 [4.5-18.5] years. The majority of the patients were treated with biological agents, including anti-TNF in 56.2%, vedolizumab in 11.1% and ustekinumab in 6.6%; 78.6% of the patients were treated with biological agents alone, and 21.4% of the patients were treated with biological agents in combination with an immunomodulator. According to the patient global assessment, 49.1% of the patients considered themselves to be in clinical remission.

### Overall IBD-disk score and IBD-disk subscores correlation and reliability

Among the 2011 participants, 1484 (73.8%) patients fully completed the 10 items of the IBD-disk score, 220 (10.9%) completed  $\geq 6$  items and 307 (15.3%) completed  $< 6$  items. Considering every items of the IBD-disk questionnaire separately, the completion rate of any item was  $> 80\%$  (Table 2). The IBD-disk questionnaire was considered easy to complete by 1571 (88.4%) patients.

After removing 29 outliers, complete IBD-disk scores with all subscores were assessable in 1455 patients. The overall IBD-disk score and subscores are presented in Table 2. The mean complete IBD-disk score was  $39.3 \pm 23.0$ , and the subscores from its components ranged from 2.4 (interpersonal interactions) to 5.7 (energy).

Cronbach's alpha coefficient calculated with the overall IBD-disk score was 0.89, and this value calculated with the subscores was between 0.87 and 0.89. One-at-a-time deletion of

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3 subscores confirmed the contribution and the unidimensionality of the 10 subscores  
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5 (Cronbach's alpha coefficient between 0.87 and 0.89) (Table 3). All the corrected item-total  
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7 correlations were  $> 0.4$ .  
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10 Assessments of IBD daily-life burden and overall health with the VAS were available  
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12 for 1927 (95.8%) and 1952 (97.1%) patients, respectively. The mean IBD daily-life burden and  
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14 overall health scores were  $5.2 \pm 2.9$  and  $6.6 \pm 2.2$ , respectively.  
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17 The correlation between the complete IBD-disk score and IBD daily-life burden VAS  
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19 was  $r = 0.67$  ( $p < 0.001$ ) and was inversely correlated with the overall health score ( $r = -0.64$ ,  
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21  $p < 0.001$ ). Analysis of the IBD-disk subscores revealed inconsistent correlations; four  
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23 subscores (regulating defecation, abdominal pain, work and study, and energy) had correlations  
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25 with IBD daily-life burden that were over 0.5, and six other subscores had correlations that  
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27 were lower than 0.5, ranging between 0.299 and 0.491 (Table 4).  
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30 The diagnostic performance of the overall IBD-disk score in predicting a high IBD  
31  
32 daily-life burden ( $> 5$ ) was evaluated using a receiver operative curve showing a C-statistic of  
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34 0.81 [0.79-0.83] ( $p < 0.001$ ) with an optimal threshold for the overall IBD-disk score  $> 40$   
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36 (Figure 3).  
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### 39 **Construction and validation of a shortened IBD-disk score**

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42 To construct a simplified, shortened IBD-disk score, multiple linear regression analysis  
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44 was applied to the IBD-disk subscales with IBD daily-life burden as a dependent variable. Five  
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46 IBD-disk subscales were selected by stepwise multiple linear regression: regulating defecation,  
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48 work and study, abdominal pain, energy and emotions. The regression coefficients were  
49  
50 standardized and rounded to generate the shortened score: work and study  $\times 2$  + regulating  
51  
52 defecation  $\times 2$  + abdominal pain + energy + emotions (Table 6). The shortened IBD-disk score  
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54 ranged from 0 to 80. This score was correlated with the IBD daily-life burden scale ( $r=0.68$ ,  
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56  $p<0.001$ ) and was inversely correlated with the overall health scale ( $-0.64$ ). The diagnostic  
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3 performance for a high IBD daily-life burden ( $> 5$ ) was similar between the shortened and the  
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5 overall IBD-disk score (AUROC = 0.82 [0.80-0.84],  $p < 0.001$ ) with an optimal threshold  $> 30$   
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8 for the shortened IBD-disk score.  
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## DISCUSSION

Taking into account IBD-related disability requires validated tools. In the present study, we assessed the performance and internal consistency of the IBD-disk questionnaire in a large population of outpatients with IBD to predict high IBD-related daily-life burden. Our study population encompassed a wide range of patients with long-lasting disease, requirements of immunomodulators and biological agents and a history of intestinal resection, namely, a population highly relevant to the field of patient-reported outcomes (PRO). We demonstrated there was a good correlation of the overall IBD-disk score with IBD daily-life burden. The overall IBD-disk score disclosed a diagnostic performance of 0.81 [0.79-0.83] to predict high IBD daily-life burden  $> 5$  with an optimal threshold for the overall IBD-disk score  $> 40$ . We were unable to construct a better tool by using the IBD-disk subscores.

IBD is a severe, chronic, progressive disease that causes disability and impacts patients' daily-lives (22). The development of biological agents has changed the paradigm of management of IBD from focusing on physician-reported clinical outcomes to implementing mucosal and/or transparietal healing and patient-reported outcomes (23,24). PROs are divided into two categories: those that measure disease activity from the patients' perspective and those that assess IBD-related disability. Although most of the current studies are focusing on PRO measurement of clinical activity, we chose to focus on those that assess IBD-related disability by using the IBD-disk questionnaire. Indeed disability remains poorly studied in IBD compared to other inflammatory diseases such as rheumatoid arthritis, multiple sclerosis or psoriasis (11,25–28).

It should be emphasized that quality of life and disability are two distinct concepts that should both be studied independently (3). Disability is an objective description, unlike quality of life which is the patient's subjective perception regarding a loss of function. For those reasons, we chose to use an auto-administered questionnaire to assess different components of

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3 disability and the IBD daily-life burden scale as a reference of IBD-related disability instead of  
4 quality-of-life scores such as the Short-IBD questionnaire or other tools built by physicians and  
5 not patients to assess IBD-related disability (1,8,29).  
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10 Assessing a tool for IBD-related disability requires clarity, readability and  
11 comprehensiveness of the questionnaire as well as a high completion rate of the whole  
12 questionnaire (30,31). Indeed, it is not conceivable to focus on the small subset of patients who  
13 are willing to complete a complex questionnaire or only those who understand the whole  
14 questionnaire or specific items. In the present study, the IBD-disk questionnaire was considered  
15 easy to complete by 88.4% of patients. Furthermore, the full completion rate for the 10 items  
16 of the IBD-disk was 73.8%. Considering the simplified IBD-disk score we constructed, the full  
17 completion rate for the five items would have been even higher, at 80.2% of patients.  
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28 The simplified IBD-disk score was constructed based on five components of IBD-  
29 related disability, including regulating defecation, abdominal pain, energy, emotions and work  
30 and study. This simplified score ranged from 0 to 80 instead of 0 to 100, and it displayed a  
31 performance similar to that of the overall IBD-disk score, considering its correlation with the  
32 IBD daily-life burden scales and the AUROC to predict high IBD daily-life burden (0.82 [0.80–  
33 0.84]). However, the use of the simplified score may reduce the assessment of the whole IBD-  
34 related disability spectrum, since it does not take into account body image, sleep, interpersonal  
35 interactions, joint pain and sexual function. Furthermore, the introduction of a weighting  
36 coefficient could make it more difficult for physicians to apply in daily practice. Therefore, we  
37 thought that it might be more beneficial to patients to use the overall IBD-disk questionnaire in  
38 daily practice.  
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53 IBD-related disability is a multidimensional concept that includes six main domains:  
54 body functions and structures, activities and participation and personal and environmental  
55 factors (1). The IBD-DI and the IBD-disk questionnaire were developed focusing mostly on  
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3 three domains, bodily functions (abdominal pain, sleep, energy, emotions, joint pain, body  
4 image and sexual functions), activities and participation (regulating defecation, interpersonal  
5 interactions and work and study) (8,13). The IBD-DI is an exhaustive questionnaire that  
6 evaluates different aspects of IBD-related disability. The IBD-DI is not self-administered and  
7 could lead to discrepancies between the patients' experience and the perception of a physician  
8 (32,33). As such, it is mostly used in clinical trials settings (13). It should be emphasized that  
9 the IBD-DI is based on a 0 to 4 Likert scale and does not include sexual functions which is an  
10 important component of disability. Moreover, the IBD-DI includes the number of daily liquid  
11 stools which is more related to the clinical activity of IBD (34,35). In the present study, we  
12 showed that a self-administered questionnaire, such as IBD-disk, that assess all of the  
13 components of disability on a wider scale of severity was also accurate and reliable. However,  
14 we have to highlight the lack of a direct comparison between IBD-disk and IBD-DI in our study.  
15 Indeed, it would have been confusing to reassess the same component of IBD-related disability  
16 with various scales.

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19 We also need to highlight some limitations of the present study. The recruitment was  
20 mainly conducted in tertiary IBD centres with an obvious recruitment bias, and more than two-  
21 thirds of the included patients were treated with biological agents. However, this limitation is  
22 counterbalanced by the size of our study population, which included a large panel of patients  
23 with varied IBD history, demographics and treatment. We did not assess the reliability of the  
24 overall IBD-disk score due to the absence of repeated IBD-disk questionnaire administration.  
25 However, we thought that anonymity was an important prerequisite for this study, which is not  
26 compatible with repeated testing. Last, it is possible that the VAS does not perfectly account  
27 for IBD-related disability. However, this limitation is counterbalanced by the use of the VAS  
28 in many chronic diseases, including IBD, thus proving its reliability (14–19), and by the fact  
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3 that none of the alternate scores available to measure IBD-related disability would have been  
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5 satisfying in this setting.  
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8 In conclusion, the IBD-disk questionnaire is a self-administered questionnaire used to  
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10 evaluate IBD-related disability with a good accuracy and reliability in both UC and CD. We  
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12 validated this questionnaire and provided evidence of internal consistency in a large multicentre  
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14 cohort study of 2011 outpatients with IBD. Further studies are needed to highlight the  
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16 determinants of IBD-related disability and to assess the reliability of the IBD-disk questionnaire  
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18 in longitudinal follow-up.  
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## TABLE AND FIGURE LEGENDS

### TABLE LEGENDS

**Table 1:** Demographic, disease and medication characteristics of 2011 patients with inflammatory bowel disease.

**Table 2:** IBD-disk overall score and subscores in a subset of 1455 patients who completed the 10-item questionnaire according to the patient global assessment of clinical remission

**Table 3:** Cronbach's alpha coefficients assessing the consistency of the IBD-disk subscores with one-at-a-time deletion of subscores contributing to the overall IBD-disk score

**Table 4:** Pearson's correlation coefficient  $R^2$  assessing the convergent validity of the overall IBD-disk score with IBD daily-life burden and overall health

**Table 5:** Multiple logistic regression analysis with IBD-disk subscores as independent variables and daily-life inflammatory bowel disease burden as a dependent variable

### FIGURE LEGENDS

**Figure 1:** Scatter plot (A) and box plot (B) of the distribution of the IBD daily-life burden according to the overall IBD-disk score and predictive accuracy of the overall IBD-score and the simplified shortened IBD-disk score in discriminating patients with high IBD daily-life burden ( $> 5$ ) summarized using ROC curves analysis (C).

### SUPPLEMENTARY FILES

**Table S1:** The IBD-disk questionnaire

**Figure S1:** The IBD-disk scale

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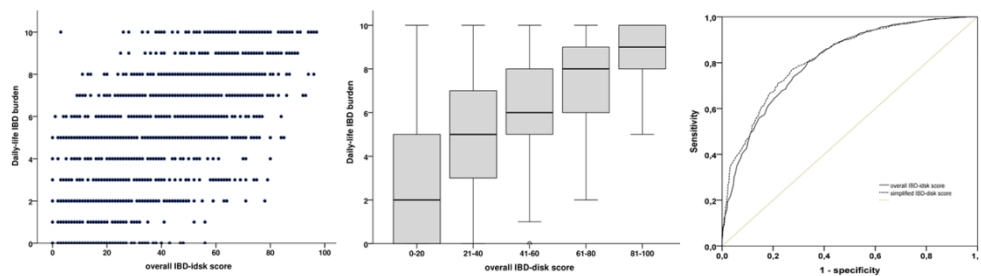
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**Table 1:** Demographic, disease and medication characteristics of 2011 patients with inflammatory bowel disease.

<b>Characteristic</b>	<b>Overall population (n = 2011)</b>
<b>Age at diagnosis, years</b>	40.0 [29.0-52.0]
<b>Male gender, no (%)</b>	53.1%
<b>BMI, kg/m<sup>2</sup></b>	24.4 ± 6.5
<b>Duration of IBD, years</b>	10.5 [4.5-18.5]
<b>Age at diagnosis, no (%)</b>	
A1: ≤16 years	14.2%
A2: 17 – 40 years	67.6%
A3: > 40 years	18.2%
<b>Type of inflammatory bowel disease, (%)</b>	
Crohn's disease	67.8%
Ulcerative colitis	62.2%
<b>History of intestinal resection, no (%)</b>	45.6%
<b>Occupational status, %</b>	
Employed	62.2%
Unemployed	8.6%
Homemaker	8.5%
Student	8.4%
Retired	12.3%
<b>Distance from home, km</b>	46.8 ± 99.6
<b>Current treatment</b>	



None	6.3%
5-ASA	11.6%
Immunomodulator alone	8.5%
Anti-TNF	56.0% (including 14.9% with combination therapy)
Vedolizumab	11.1% (including 1.0% with combination therapy)
Ustekinumab	6.8% (including 0.9% with combination therapy)

5-ASA: 5-aminosalicylic acid; TNF: tumor-necrosis factor; BMI: body mass index; GI: gastrointestinal; IBD: inflammatory bowel disease.

Variables are presented as n (%), mean  $\pm$  standard deviation or median (interquartile range).

**Table 2:** IBD-disk overall score and subscores in a subset of 1455 patients who completed the 10-item questionnaire according to the patient global assessment of clinical remission

	<b>Overall study population (n = 1455)</b>	<b>Presence of clinical remission (n = 648)*</b>	<b>Absence of clinical remission (n = 638)*</b>	<b>Missing values** (%)</b>	<b>p</b>
<b>Joint pain</b>	3.9 ± 3.3	3.5 ± 3.2	4.2 ± 3.2	16.3%	<0.001
<b>Abdominal pain</b>	4.2 ± 3.1	3.5 ± 2.9	5.1 ± 3.0	15.6%	<0.001
<b>Regulating defecation</b>	3.9 ± 3.4	2.9 ± 3.1	4.8 ± 3.5	15.9%	<0.001
<b>interpersonal interactions</b>	2.4 ± 2.9	1.9 ± 2.7	2.9 ± 3.0	18.2%	<0.001
<b>Education and work</b>	4.0 ± 3.4	3.1 ± 3.2	4.9 ± 3.3	16.1%	<0.001
<b>Sleep</b>	5.0 ± 3.4	4.4 ± 3.3	4.7 ± 3.4	15.1%	<0.001
<b>Energy</b>	5.7 ± 3.2	5.1 ± 3.2	6.5 ± 2.9	14.2%	<0.001
<b>Emotions</b>	4.5 ± 3.2	3.8 ± 3.2	5.3 ± 3.2	15.5%	<0.001
<b>Body image</b>	4.0 ± 3.4	3.5 ± 3.3	4.5 ± 3.4	17.0%	<0.001
<b>Sexual functions</b>	2.8 ± 3.2	2.3 ± 3.0	3.4 ± 3.3	19.4%	<0.001
<b>Overall IBD-disk score</b>	39.3 ± 23.0	32.9 ± 21.5	46.7 ± 22.2	26.2%	<0.001
<b>IBD daily-life burden scale</b>	5.2 ± 2.9	4.1 ± 2.8	6.2 ± 2.6	4.2%	<0.001
<b>Overall health scale</b>	6.6 ± 2.2	7.5 ± 1.8	5.7 ± 2.1	2.9%	<0.001

IBD: inflammatory bowel disease.

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3 Variables are presented as mean  $\pm$  standard deviation. Quantative variables between groups  
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5 was compared using Mann-Whitney test.  
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8 \*The patient global assessment of global remission was missing in 169 out of 1455 patients.  
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10 \*\*Missing values are given with respect with the overall study population of 2011 patients.  
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**Table 3:** Cronbach's alpha coefficients assessing the consistency of the IBD-disk subscores with one-at-a-time deletion of subscores contributing to the overall IBD-disk score

	<b>Cronbach's alpha coefficient</b>	<b>Corrected item-total correlation</b>	<b>Cronbach's alpha coefficient if item deleted</b>
<b>Joint pain</b>	0.888	0.492	0.888
<b>Abdominal pain</b>	0.877	0.652	0.877
<b>Regulating defecation</b>	0.880	0.605	0.880
<b>interpersonal interactions</b>	0.879	0.627	0.879
<b>Education and work</b>	0.870	0.740	0.870
<b>Sleep</b>	0.877	0.647	0.877
<b>Energy</b>	0.873	0.709	0.873
<b>Emotions</b>	0.872	0.719	0.872
<b>Body image</b>	0.886	0.525	0.886
<b>Sexual functions</b>	0.883	0.566	0.883

**Table 4:** Pearson's correlation coefficient  $R^2$  assessing the convergent validity of the overall IBD-disk score with IBD daily-life burden and overall health

	<b>IBD daily-life burden</b>	<b>Overall health</b>
<b>Joint pain</b>	0.348	-0.319
<b>Abdominal pain</b>	0.499	-0.490
<b>Regulating defecation</b>	0.535	-.0500
<b>interpersonal interactions</b>	0.438	-0.389
<b>Education and work</b>	0.590	-0.532
<b>Sleep</b>	0.463	-0.419
<b>Energy</b>	0.515	-0.505
<b>Emotions</b>	0.491	-0.454
<b>Body image</b>	0.299	-0.246
<b>Sexual functions</b>	0.371	-0.329
<b>Overall IBD-disk score</b>	0.650	-0.614
<b>New IBD-disk score</b>	0.670	-0.640

P-values for each pearson's correlation coefficient was < 0.001.

**Table 5:** Multiple logistic regression analysis with IBD-disk subscores as independent variables and daily-life inflammatory bowel disease burden as a dependent variable

Independent variables	Coefficient	Standardized and rounded coefficient	P
<b>Abdominal pain</b>	4.485	1	< 0.001
<b>Regulating defecation</b>	7.623	2	< 0.001
<b>Education and work</b>	9.491	2	< 0.001
<b>Energy</b>	5.642	1	< 0.001
<b>Emotions</b>	4.041	1	< 0.001

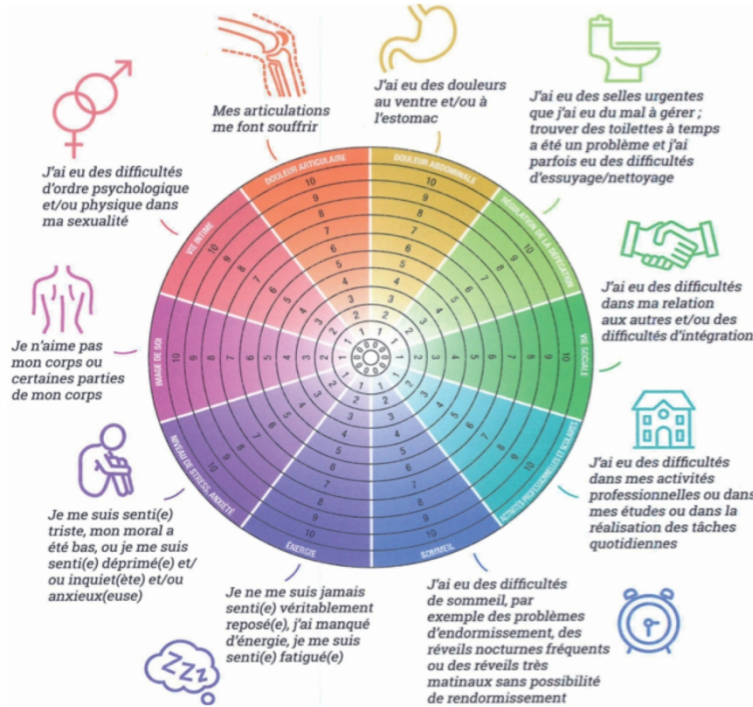
**Table S1 : the IBD-disk questionnaire**

<b>Components</b>	<i>For each of the ten statements below, score your level of agreement on a scale of 0 (Absolutely disagree) to 10 (Absolutely agree). Circle your scores on the coloured disc.</i>
<i>In the last week, because of my inflammatory bowel disease ...</i>	
<b>Abdominal pain</b>	<i>... I have/had aches or pains in my stomach or abdomen</i>
<b>Regulating defecation</b>	<i>... I have/had difficulty coordinating and managing defecation, including choosing and getting to an appropriate place for defecation and cleaning myself afterwards</i>
<b>Interpersonal interactions</b>	<i>... I have/had difficulty with personal relationships and/or difficulty participating in the community</i>
<b>Education and work</b>	<i>... I have/had difficulty with school or studying activities and/or difficulty with work or household activities</i>
<b>Sleep</b>	<i>... I have/had difficulty sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning</i>
<b>Energy</b>	<i>... I have/had not felt rested and refreshed during the day, and have felt tired and without energy</i>
<b>Emotions</b>	<i>... I have/had felt sad, low or depressed, and/or worried or anxious</i>
<b>Body image</b>	<i>... I have/had not liked the way my body or body parts look</i>
<b>Sexual functions</b>	<i>... I have/had difficulty with the mental and/or physical aspects of sex</i>
<b>Joint pain</b>	<i>... I have/had pains in the joints of my body</i>

► Auto-évaluation (« IBD Disk ») de votre état de santé au cours de la semaine qui vient de s'écouler : pour chaque item, entourer le chiffre qui correspond à votre ressenti

Par exemple :

Mes articulations me font souffrir : PAS DU TOUT 0 1 2 3 4 5 6 7 8 9 10 ÉNORMÉMENT



► Avez-vous trouvé cet « IBD Disk » facile à remplir ? .....  oui  non

Merci de votre participation

Ce questionnaire est élaboré par le GETAID dans le cadre d'une enquête concernant les patients atteints d'une MICI, pour mieux comprendre leur maladie et leur prise en charge. Les informations fournies serviront exclusivement à cette enquête. Le GETAID s'engage à assurer la confidentialité des informations fournies.

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