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Should Inflammatory Bowel Disease Clinicians Provide Their Patients with e-Health Resources? Patients' and Professionals' Perspectives

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Abstract

Introduction: The internet is emerging as a source of information for patients with inflammatory bowel disease (IBD). However, it is not always reliable and may cause anxiety. We aim to assess patients' information habits and patients' and professionals' perceptions of a national website integrated as an educational resource for the IBD unit.

Methods: Patients aged 18–65 years, comfortable with the internet, and attending follow-ups at participating IBD units (March–June 2019) and their professionals were invited to evaluate a recommended website through an online survey.

Results: Three hundred eighty-nine patients and 95 professionals completed the survey. The internet (n = 109; 27.4%) was the second preferred source of information after the health care team (n = 229; 57.5%). Eighty percent of patients searched the internet for information on their disease and 28.6% did so at least once a week (n = 114), especially newly diagnosed ones (<2 years). Patients valued a website recommended by their professional (n = 379; 95.2%) and endorsed by the National Working Group (n = 377; 94.7%). They would attend online educational initiatives on the website (n = 279; 70.1%) and complete periodical surveys to improve its usefulness (n = 338; 84.9%). According to IBD professionals, this type of website is the best patient source of supplementary information (n = 76; 80%) and they “prescribe” it to most patients (67.0 ± 25.2%), especially the newly diagnosed patients (52.7 ± 26.5%). It effectively integrates routine face-to-face education (n = 95; 100%).

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Conclusions: *Patients of IBD units, especially newly diagnosed ones, appreciate a trusted e-Health resource to back up professional information. The favorable opinion of patients and professionals will allow its use in training interventions.*

Keywords: *inflammatory bowel disease, patient education, digital health resources, website, digital health, online health, web application, e-Health, telemedicine*

Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), are chronic disabling disorders of the gastrointestinal tract that affect 0.3–0.5% of the population worldwide, impacting on almost aspect of their lives.^{1,2} Patient education and empowerment are paramount in high-quality inflammatory bowel disease (IBD) care.^{3–6}

The ECCO Consensus on IBD patients' needs in health quality of care⁷ stressed that "Quality of Health Care depends on the level of disease information available to the patient"; and more recently, the ECCO position article on the quality of care standards includes the need for educational support in all quality indicators.³ In fact, patient education is associated with better disease coping, improved treatment adherence and disease outcomes, and reduced health care resource use.^{8,9}

Traditionally, patient education has been delivered by the clinician in face-to-face sessions,¹⁰ through information leaflets, or in patients' association meetings. However, these approaches are insufficient to cover current patient educational needs. Recently, in the IBD2020 Global Forum quality of care survey¹¹ carried out in eight European countries, including Spain, patients reported that within 3 months after diagnosis they had not had an in-depth conversation with their health care provider (HCP) about the basic features of their illness, therapeutic goals, or risks and benefits of the treatment options.

They also complained that their last follow-up visit was too short to discuss all relevant issues and they wished their HCP had relied more on new technologies. The internet has opened up new ways to search for information,^{11,12} although it is not always reliable and can even become a source of anxiety.¹²

Thus, there is a need for high-quality websites endorsed by the professional IBD team and scientific organizations providing patient-oriented information^{7,13,14} as a back up to medical visits. Generally, patients prefer the medical information given by their HCP,⁷ but to our knowledge, no published studies have explored perceptions of IBD patients on education actively provided by their IBD team by means of a national specialized web application.

Therefore, we conducted a study aimed at (1) assessing patients' preferences and needs of disease-related education and current sources of information; (2) determining the acceptance level of information obtained from a specific web resource endorsed by the Spanish Working Group on Crohn's Disease and Ulcerative Colitis (GETECCU); and (3) evaluating the utility and acceptability of educational interventions and periodical web-based surveys carried out on this platform, tailoring the information to the real needs of patients.

Methods

In October 2017, GETECCU released a national IBD patient education website, called G-Educainflamatoria.¹⁵ As per recommendations,^{7,14} professionals working in IBD units were directly involved in development of an educational web app that would be easy to understand, regularly updated, and tailored to the real needs of patients. Content web quality scored 70 (excellent) on the DISCERN instrument,¹⁶ and readability, assessed using the Simple Measure Of Gobbledygook (SMOG) test,¹⁷ achieved an approximate SMOG level of 7 (7th grade, junior high school).

This means that over 90% of the website information can be easily understood by the average patient. The website included IBD-related information for patients in the form of written texts, infographics, and educational videos (YouTube channel) and a web forum for patients to ask clinicians questions.

STUDY DESIGN, POPULATION, AND DATA COLLECTION

This was a multicenter, observational cross-sectional study carried out in 33 IBD units across Spain that were invited to use and evaluate the G-Educainflamatoria website¹⁵ as an educational tool to integrate routine face-to-face patient education. The study was approved by the corresponding Clinical Research Ethics Committees.

IBD patients between 18 and 65 years of age, attending routine follow-ups at participating IBD units from March to June 2019, were proposed to participate in the study if they had access to the internet and felt comfortable using it. They were invited to browse the website and fill out an anonymous opinion survey. Upon informed consent signature, participants received a link and a password to the online survey (hosted at SurveyMonkey¹⁸), where they received instructions on how to complete the questionnaire.

SAMPLE SIZE

In Spain, no nationwide IBD prevalence studies were available at the time of sample size calculation, so prevalence was estimated from a study that had been recently published in Catalonia¹⁹ and from European epidemiologic data,²⁰ which indicated that IBD affects 500–600 individuals per 100,000

inhabitants, providing an estimated IBD population in Spain of 300,000 patients. As the proportion of IBD patients who use the internet is currently unknown, we conservatively estimated a 50% prevalence of possible users of an official IBD information website based on the results of a previous study.¹² Thus, to obtain representative results with a 95% confidence level and 5% precision, a sample size of 384 patients was estimated.

About 370 professionals were using G-Educainflamatoria at the time of the survey, so a representative sample of 95 professionals was calculated. Participating professionals are listed in Supplementary Data S1. Surveyed HCPs were not involved in the development of the website.

QUESTIONNAIRE

Two independent survey questionnaires were developed: one aimed at patients and the other at IBD professionals. Both questionnaires were structured in two parts: one recorded characteristics of patients or professionals and the other assessed their perceptions regarding the website (Supplementary Data S2).

The understandability and ease of completion of the questionnaire were first evaluated in a pilot study of 15 subjects (5 research staff members and 10 IBD patients) and subsequently improved.

STATISTICAL ANALYSES

Statistical analyses were performed using SPSS 23 (IBM, Armonk, NY). Continuous data are described using means and standard deviations and qualitative data using frequencies and percentages. Characteristics of the groups were compared using Student's *t*-test or the Mann-Whitney *U* test, depending on whether data were normally distributed. Continuous variables with more than two categories were compared using analysis of variance (ANOVA). Fisher's exact test or the *chi*-square test was used for analysis of categorical variables. A *p*-value of <0.05 was considered statistically significant.

Comparative subanalyses of the patient survey were performed for sex, years since diagnosis (<2, 2–8, and ≥8 years), type of diagnosis (Crohn's or colitis), surgical status (operated vs. nonoperated), treatment (untreated, mesalazine, azathioprine–methotrexate, and biologic), and educational level (elementary school, high school, vocational school, and university). Comparative subanalyses of professionals included sex, years of experience (<2, 2–5, 5–10, and ≥10 years), and role [physician, nurse, or other]).

Results

PATIENTS' SURVEY

Of the 850 patients invited to participate, 462 completed the questionnaire (response rate, 54%). However, 64 patients

started but did not finish the survey and were therefore excluded, so the final sample comprised 398 patients. Patient characteristics are listed in *Table 1*.

SOURCES OF INFORMATION AND FREQUENCY OF INTERNET SEARCHES

Patients preferred to receive information about their illness from their reference HCP (physician or nurse), while the internet was the second preferred choice among the currently available ones (*Fig. 1*), especially among newly diagnosed

Table 1. Patient Characteristics

VARIABLE	GLOBAL (n=398)
Age (in years, mean + SD)	42.9 ± 11.8
Male	45.5 ± 12.0
Female	41.0 ± 11.3
Sex, n (%)	
Male	170 (42.7)
Female	229 (57.3)
Disease, n (%)	
Crohn's disease	232 (58.3)
Ulcerative colitis	166 (41.7)
Time since diagnosis (years), n (%)	
<2	84 (21.1)
Between 2 and 8	133 (33.4)
>8	181 (45.5)
Surgery, n (%)	
Yes	81 (20.4)
No	317 (79.6)
Current treatment, n (%)	
No treatment	45 (11.3)
Mesalazine	95 (23.9)
Azathioprine–methotrexate	105 (26.4)
Biologics	153 (38.4)
Educational level, n (%)	
Elementary	22 (5.5)
Secondary	84 (21.1)
Vocational secondary	168 (42.2)
University	124 (31.2)
Results presented as n (%) unless otherwise stated. SD, standard deviation.	

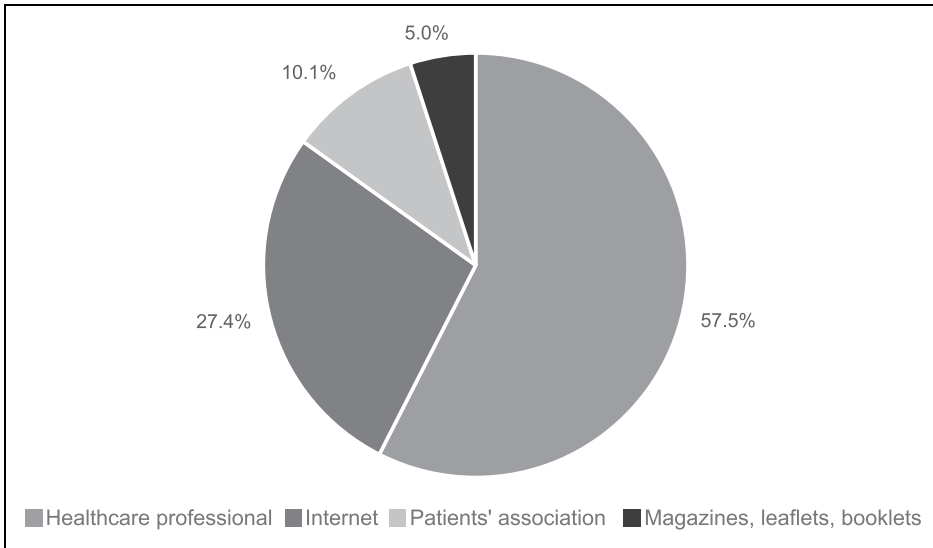


Fig. 1. Overall patients' preferred source of information on IBD. IBD, inflammatory bowel disease.

patients who consult the internet and read written resources significantly more frequently than the other groups, but are less interested in patient associations ($p=0.001$; Fig. 2).

About 80% of patients searched the internet for information on IBD. Almost a third of the sample consulted the internet at least once a week (Fig. 3), with newly diagnosed patients (<2 years) consulting it more frequently, once a week or more (Fig. 4).

TOP TRENDING TOPICS

The topics most searched on the web were treatments ($n=295$; 74.1%), symptoms ($n=261$; 65.6%), nutrition ($n=255$;

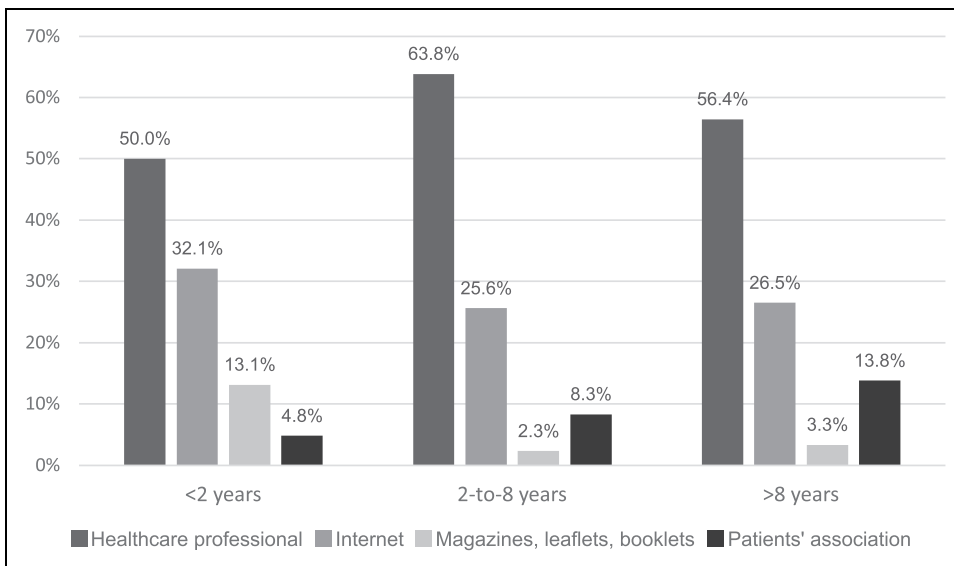


Fig. 2. Patients' preferred source of information by time since diagnosis. Newly diagnosed patients (<2 years) are more inclined to perform internet searches.

64.1%), and IBD extraintestinal manifestations ($n=205$; 51.5%), while <20% of patients searched for information on diagnostic tests, vaccines and prevention, and surgery.

Patient information needs according to patient profile are reported in Supplementary Data S3.

PATIENTS' PERCEPTIONS OF THE EDUCATIONAL WEB APP

The survey comprised a series of questions aimed at investigating patients' views on the website. Results are shown in Table 2.

Almost all respondents agreed on the importance of their care team informing them about a quality web app endorsed by IBD scientific societies (score of 4–5 on a 5-point Likert scale, $n=379$; 95.2%), and this made them feel reassured and confident in the content of the website (scores 4–5, $n=377$; 94.7%). In their opinion, the information was easy to understand (score 4–5, $n=353$; 88.7%), especially for recently diagnosed patients (<2 years) ($n=82$; 97.6%).

Patients would be willing to attend educational initiatives on the website (preferred option over in-person activities) and to answer periodical surveys aimed at investigating their perceptions or assessing their degree of knowledge about different aspects of the disease (Table 2).

Comments and suggestions were also collected (selected comments are reported in Supplementary Data S4). Comments were generally positive, and the web app was perceived to be useful and reliable because it was developed and recommended by IBD professionals. Participants valued the initiative of collecting patients' perceptions, insisting on the need to keep the website updated. The general tone was of gratitude and compliments for a job well done.

PROFESSIONALS' SURVEY

Ninety-five professionals completed the survey (Table 3). According

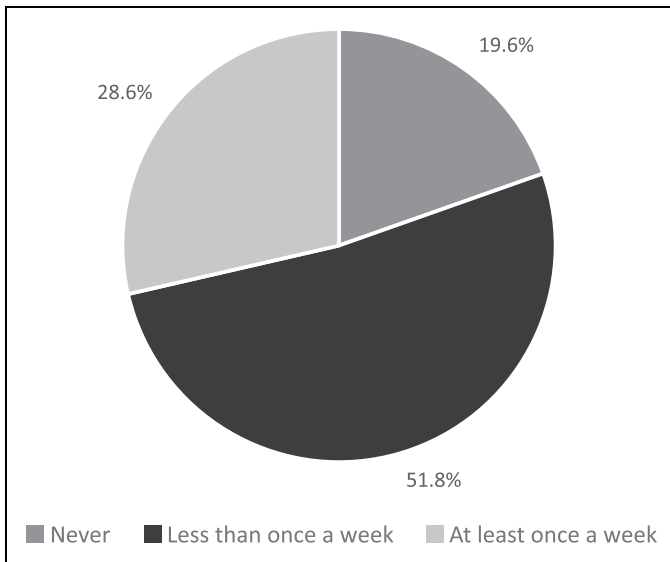


Fig. 3. Overall frequency of internet searches about IBD.

to 80% of respondents, a specialized IBD website endorsed by scientific societies is the most appropriate source of supplementary information for patients among those currently available in the clinical practice, and all participants emphasized that it was crucial to proactively recommend it (Table 4).

Almost all professionals ($n=93$; 99%) agreed on the importance of being able to recommend such an educational instrument to their patients, which would enhance the quality of health care ($n=95$; 100%) (Supplementary Data S5).

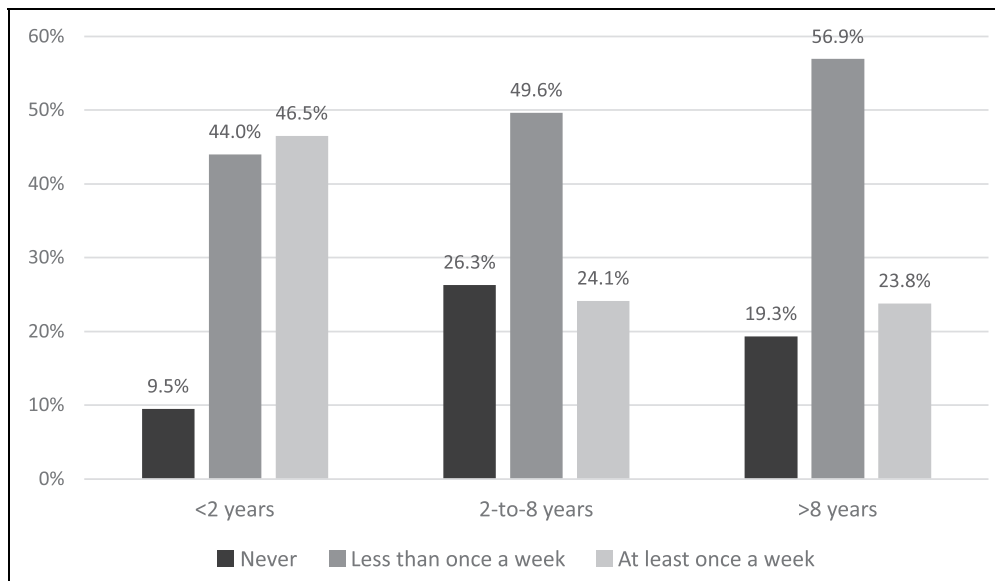


Fig. 4. Frequency of internet searches about IBD by time since diagnosis. Newly diagnosed patients (< 2 years) consulting it more frequently). ($p \leq 0.001$ for all comparisons).

Participants “prescribed” the website to most patients ($67.0 \pm 25.2\%$ doctors’ own estimation) and the main “indication” was recommending it to newly diagnosed patients ($52.7 \pm 26.5\%$ doctors’ own estimation) perceived as a group with greater informational needs (Supplementary Data S5).

Participants considered website content to be of high quality (score 4–5, $n=94$; 99%) and easy for patients to understand (score 4–5, $n=91$; 96%). They agreed on the importance of offering a forum for patients to consult their HCPs (score 4–5, $n=84$; 88%) and nearly 97% ($n=88$) would recommend it to professionals of other IBD units (score 4–5) (Supplementary Data S5).

HCP open-handed comments on G-Educainflamatoria were generally positive, participants found the website useful, the importance of maintaining up-to-date information was stressed, and the importance of collecting patients’ perspectives was appreciated (selected comments are presented in Supplementary Data S4).

Discussion

IBD patients, especially the newly diagnosed patients, have many doubts about their illness; however, time limits imposed by routine health care make it difficult to fully cover patient’s information needs. We proposed that in the internet era, face-to-face education could be integrated with e-Health technologies, so a group of specialists from the IBD National Working Group (GETECCU) developed an IBD patient information website to fulfill this need.

In this study, we found that patients (1) appreciate and rely on information obtained from the website endorsed by the national IBD organization; (2) are willing to respond to surveys on their perceptions or degree of knowledge of topics related to their disease; (3) are interested in participating in web-based educational activities; and (4) are willing to contribute to web content design by giving their feedback.

This can establish a positive web interaction that may empower patients and improve disease control. IBD professionals also believe that an official educational website is an

E-HEALTH EDUCATIONAL RESOURCES IN INFLAMMATORY BOWEL DISEASE

Table 2. Patients' Opinions on the G-Educainflamatoria Website

PATIENTS' PERCEPTIONS OF THE G-EDUCAINFLAMATORIA WEBSITE (n=398)				
Do you think it is important that your doctor or nurse recommends a quality website? (score from 1 to 5, where 1 is "not important at all" and 5 is "very important")				
1	2	3	4	5
0 (0)	2 (0.5)	17 (4.3)	87 (21.9)	292 (73.3)
The G-Educainflamatoria website hosts a forum where patients can ask questions and IBD professionals answer them. Would you use it to consult a specialist if you needed information?				
No			58 (14.6)	
Yes			340 (85.4)	
Do you find the G-Educainflamatoria content easy to understand? (score from 1 to 5, where 1 is "very difficult to understand" and 5 is "very easy to understand")				
1	2	3	4	5
5 (1.3)	8 (2.0)	32 (8.0)	151 (37.9)	202 (50.8)
On the G-Educainflamatoria home page, there is a search engine for searching information. Do you think it is useful? (score from 1 to 5, where 1 is "I do not think it is useful" and 5 is "it is very useful")				
1	2	3	4	5
4 (1.0)	5 (1.3)	43 (10.8)	151 (37.9)	195 (49.0)
Score the usefulness of the G-Educainflamatoria website content from 1 to 5 (where 1 is "it does not seem to be useful at all" and "it seems very useful for learning about my disease").				
1	2	3	4	5
2 (0.5)	4 (1.0)	29 (7.3)	142 (35.7)	221 (55.5)
Score from 1 to 5 the confidence you get from knowing that the G-Educainflamatoria webpage is endorsed by the IBD National Scientific Organization and that it is recommended by your medical team (where 1 is "I do not feel confident at all" and 5 is "I feel reassured and very confident with a website recommended by my medical team").				
1	2	3	4	5
2 (0.5)	4 (1.0)	15 (3.8)	34 (8.5)	343 (86.2)
Would you like to see the website information organized by topic menus, such as a "Newly diagnosed" menu or "Perianal disease" menu or "Disease acceptance" menu?				
No			33 (8.3)	
Yes			365 (91.7)	
Which topic menu would you like to find in G-Educainflamatoria? (Multiple choices were allowed)				
Newly diagnosed			338 (84.9)	
Nutrition and diet			338 (84.9)	
Emotional well-being			318 (79.9)	
IBD follow-up and checkups			239 (60.1)	
Women and IBD			179 (45.0) ^a	
Would you like to take part in virtual educational activities on the G-Educainflamatoria website with the aim of improving aspects related to your disease (adherence, nutrition, healthy lifestyle, etc.) or would you prefer to attend them in person?				
On the online platform			279 (70.1)	
In person			103 (25.9)	
It does not matter to me			16 (4.0)	

continued →

Table 2. Patients' Opinions on the G-Educainflamatoria Website *continued*

PATIENTS' PERCEPTIONS OF THE G-EDUCAINFLAMATORIA WEBSITE (n=398)

Would you be willing to periodically answer questions aimed at assessing your viewpoint or degree of knowledge about specific aspects of your disease?

Yes	338 (84.9)
No	40 (10.1)
It depends on the topics; I would decide on the spot	20 (5.0)

Results presented as n (%) unless otherwise stated.

^aAfter adjusting by sex, 96.6% of women wished a "Women and IBD" menu existed.

IBD, inflammatory bowel disease.

appropriate tool for integrating routine face-to-face patient education and they actually "prescribe" it in their daily routine, especially to newly diagnosed patients.

IBD patients are taking control of their disease, and the demand for information is growing.²¹ A recent study carried out by GETECCU in collaboration with the Spanish Confederation of Associations of Patients with Crohn's and Ulcerative Colitis (ACCU) developed a series of quality indicators also based on patients' perceptions. One of the most important items was acquiring sufficient information about their illness,²² so delivering adequate patient-oriented information should be a priority for IBD units.

IBD e-Health resources are generally part of telehealth programs; however, only a few initiatives are accessible in routine care.¹⁰ The G-Educainflamatoria web app¹⁵ is currently integrated into the routine care of 73 IBD units (Supplementary Data S6), hosting >300 educational entries and self-control tools²³ developed and supervised by GETECCU. It has its own YouTube channel, with about 70 informative videos, many of which are animated presentations on a wide range of topics. Videos of patients communicating positive messages or telling their own experiences are also available.

The website was released in October 2017, 18 months after we surveyed users, both patients and IBD professionals, on their impressions to improve our design and content and adjust them to patients' needs. Collected feedback about web app use and menu organization was subsequently implemented to improve patients' experience. "Prescription" menus were created for special groups, such as "newly diagnosed patients" or "women and IBD," according to patients' wishes and following published recommendations.²⁴ Indeed, a new version of the app has recently been released (Supplementary Data S7). Quality surveys are scheduled periodically to gather users' feedback and consistently update the website in response to patients' needs.

Patients generally prefer receiving information from their IBD team in person, but as the internet is a growing source of information,^{11,25,26} patients have shown in this survey that such an online educational tool is acceptable and appreciated.

Based on our results, we may venture to state that certain features of our educational website foster a positive perception among patients: the IBD National Working Group (GETECCU) is directly involved in the development and promotion of the website; surveys are performed to collect patients' opinions and their feedback is promptly integrated to improve their experience; the level of written comprehension was assessed with validated instruments before the

Table 3. Characteristics of Professionals

VARIABLE	GLOBAL (n=95)
Age, years	43.3 ± 10.1
Sex	
Male	25 (26)
Female	70 (74)
Professional role	
Doctor	64 (67)
Nurse	25 (26)
Other	6 (6)
Experience (n=94)	
<2 years	10 (11)
Between 2 and 5 years	13 (14)
Between 5 and 10 years	24 (26)
>10 years	47 (50)

Results presented as n (%) unless otherwise stated.

Table 4. Professionals' Views on Sources of Information for Patients

SOURCES OF INFORMATION (n=95)				
Choose among the educational methods currently available the option you consider most appropriate for providing extra support to your patients' education				
Leaflets and booklets provided by the IBD unit				4 (4)
Website recommended by the IBD unit and endorsed by IBD professionals who keep it updated				76 (80)
Explanation given by the doctor/nurse at the patient's request				13 (14)
Periodic face-to-face meetings organized by the IBD unit or patients' associations				2 (2)
Score from 1 to 5 the importance of supporting IBD education of patients from their own IBD unit (where 1 is "not important at all" and 5 is "very important").				
1	2	3	4	5
0 (0)	0 (0)	0 (0)	12 (13)	83 (87)
Results presented as n (%) unless otherwise stated.				

contents were made available to ensure that virtually all users understand the information; and a web forum is available for patients and caregivers to ask questions. It is known that there are topics that are embarrassing for patients to talk about,²⁷ thus allowing for anonymous questioning in the web forum may help patients to address these doubts.

Newly diagnosed patients are more inclined to perform internet searches. This is consistent with findings from a study carried out in the United States by Bernstein et al,¹¹ who reported that less than half of patients were completely satisfied with the information they were given at the time of IBD diagnosis and a quarter were clearly unsatisfied. Authors suggest that supplementing physician-patient consultations with well-designed written information or a website recommendation could foster more effective communication and education.

Indeed, in their study, patients rated these sources of information as highly acceptable. This is true for our survey too, and in response, we created an *ad hoc* menu for this patient group, and we will develop future website activities and surveys especially directed to this population.

Access to a quality web app helped foster digital education and patient support especially in the present context of the COVID-19 pandemic, which has reinforced the concept of remote patient care. As routine consultations with IBD professionals were largely replaced by telephone or e-mail contacts during the first year of the pandemic, this web app has acted as an additional powerful patient-oriented tool.

Although pandemic restrictions are relaxing, we firmly believe that new follow-up protocols relying on the internet will be permanently integrated into future routine clinical

practice. Thus, we believe that the use of e-Health educational resources that offer this kind of professional involvement will increase significantly in IBD units in the immediate future.

Our study has some limitations. Collecting data from internet users involves a systematic bias as certain segments of the population do not have internet access, such as those with lower socioeconomic status. Nonetheless, this bias appears to be rapidly reducing: in 2017, 83.4% of Spanish households had internet access.²⁸ Our study did not explore the effect of socioeconomic status.

However, we speculated that there could be a systematic bias toward more highly educated patients. Almost one-third of respondents had a university education, which is comparable with the national rate (30.1%, at the second trimester of 2019). Secondary education levels among our sample are also comparable with the general population rate (63.3% vs. 68.6%),²⁸ so it seems that educational bias is not an issue in our series.

Recruiting patients in IBD units can also introduce a bias as these units concentrate on a selected group of patients who may have more severe disease and are generally more informed and eager to understand their disease compared with patients followed in a gastroenterologist's office or primary care. This may potentially limit the generalizability of our results to an unfiltered patient group. However, we have demonstrated the feasibility of recruiting an online cohort of IBD patients to study relevant patient-reported perceptions.

Recruitment of almost 400 participants from 33 IBD units over a 3-month period provides strong evidence of the interest of the IBD patient community in participating in such a project. Longitudinal follow-up of this large diverse cohort of

participants will help clarify the complex associations between health education and behaviors, medical treatments, and disease course measured by patient-reported outcomes.

Moreover, we have also designed a scalable modular platform, upon which interventional studies and translational studies can be built using the contact information of study participants for future evaluation of health-behavior intervention outcomes.

In conclusion, we strongly believe that e-Health can backup IBD care in the internet era. Patients trust an IBD educational web app recommended by their clinicians and endorsed by scientific societies as very useful and reliable. These e-Health resources may be of particular interest to newly diagnosed patients, given their increased need for information and regular use of the internet for their health searches.

Integrating patients' perceptions and preferences in the design and content of an e-Health portal intended to foster their education may make it more effective. Furthermore, these types of websites are welcomed by IBD HCPs and are routinely "prescribed," especially to newly diagnosed patients. They are also ideal platforms for conducting online educational interventions and studies assessing patient knowledge.

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Authors' Contributions

A.E., M.C., and P.N. were responsible for the study concept and design, survey design, data collection, analysis and interpretation of data, and initial draft of the article. J.L.P., G.M., M.S.A., M.C.M.P., N.M., B.B., N.C., B.C., D.M.R., Y.S.O., P.C., M.C., A.M.L.C., and J.M. were responsible for the study concept and design, interpretation of data, and critical revision of the survey and article.

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Supplementary Material

Supplementary Data S1
Supplementary Data S2
Supplementary Data S3
Supplementary Data S4
Supplementary Data S5
Supplementary Data S6
Supplementary Data S7

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