

COVID-19-related health anxieties and impact of specific interventions in patients with inflammatory bowel disease in the UK

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ABSTRACT

Objective Health-related concerns brought on by the COVID-19 pandemic and the impact of specific local and national interventions have not been explored in patients with inflammatory bowel disease (IBD) in the UK. We evaluated perspectives of patients with IBD on the pandemic and effectiveness of information dissemination in addressing concerns.

Methods We prospectively conducted a survey among patients with IBD during the COVID-19 pandemic to assess concerns, information-seeking behaviours, risk perception, compliance and effect of specific interventions.

Results A total of 228 patients were interviewed of whom 89% reported being concerned about the impact of COVID-19 on their health. Access to at least one IBD-specific clinical interaction during the pandemic (COVID-19 information letter from IBD team, interaction with IBD team or general practitioner, Crohn and Colitis UK website visit) was significantly associated with alleviating concerns (OR 2.66; 95% CI 1.35 to 5.24; $p=0.005$). Seeking health information solely through unofficial channels (search engines or social media) was less likely to ease concerns (OR 0.15; 95% CI 0.03 to 0.61; $p=0.008$). A quarter of patients disagreed with their assigned risk groups, with majority perceiving higher-risk profiles. This discordance was greatest in patients within the moderate-risk group and constituted immunosuppression use. Nearly 40% of patients had ongoing concerns with regard to their medications of whom a third felt their concerns were not addressed.

Conclusion IBD-specific clinical interactions are associated with alleviation of COVID-19

Significance of this study

What is already known on this topic

► COVID-19 pandemic has resulted in significant health anxieties in patients with inflammatory bowel disease (IBD), particularly those on immunosuppression. National policies were introduced during the pandemic clinical services to undertake individual assessment of risk associated with COVID-19.

What this study adds

► Our study is the first to directly evaluate anxieties around the impact of COVID-19 in patients with inflammatory bowel disease (IBD) in the UK and assess the effectiveness of the measures undertaken to protect patients during the pandemic. We were able to demonstrate that IBD-specific clinical interactions were associated with alleviation of COVID-19 health concerns. A significant proportion of patients, however, disagreed with their assigned risk profiles and many had ongoing concerns with regard to their medications.

How might it impact on clinical practice in the foreseeable future?

► As we enter new phases of the COVID-19 pandemic, this study highlights key areas of care delivery that may need to be optimised in order to enhance the quality of care provided to our IBD population. There is both a clear need to maintain accurate local and national disease registries and development of innovative solutions that facilitate effective communication with patients without burdening current services.

health concerns. These findings have wider implications and emphasise importance of innovative solutions that facilitate effective communication with patients without overburdening current services.

INTRODUCTION

COVID-19 is an infectious disease that was first described in December 2019 and rapidly emerged as a global public health crisis.¹ Sweeping changes to elective and emergency hospital services were rapidly enforced resulting in patients facing unprecedented changes to their care.^{2,3} Inflammatory bowel disease (IBD) affects over 600 000 people in the UK⁴. With many patients with IBD requiring immunosuppressive therapies, it is likely that the COVID-19 pandemic resulted in significant anxieties. Following national guidance, the British Society of Gastroenterology COVID-19 IBD Working Group devised a risk grid categorising patients into high, moderate or low-risk groups (as shown in online supplemental document 1).^{5,6} Similar to most IBD centres in the UK, our service sent COVID-19 information letters with specific advice relating to IBD and immunosuppressive therapies to patients on our immunosuppression database prior to the pandemic declaration. This was followed by a letter detailing their assigned level of risk and relevant guidance on their respective degree of isolation. These letters also signposted patients to relevant government websites and the Crohn's disease.⁷

We aimed to evaluate perspectives of patients with IBD on the pandemic and the effectiveness of the rapidly instituted protective measures described above. To achieve this, we conducted a telephone survey of our cohort of patients with IBD assessing their concerns and attitudes to the risk assessment process during the COVID-19 pandemic so far.

METHODS

Study characteristics

A 10-point survey was conducted among patients registered with our IBD service at Heartlands and Good Hope Hospital serving approximately 2500 patients with IBD. Surveys were performed prospectively by specialist nurses or gastroenterologists (consultants and registrars) either over the telephone or face to face during planned and unplanned clinical contact between May and June 2020. The survey assessed onset of health anxieties, primary source of health information during COVID-19 pandemic, impact of specific local and national health interventions, source of COVID-19 risk assessments, perceived risk and concerns around IBD medication use. Baseline data were collected for patient demographics including age, sex, ethnicity, comorbidities, assigned risk groups and medications at the point when risk assessment was conducted. The survey was registered locally as a

clinical audit. A transcript of the survey is provided as online supplemental document 2.

Statistical analysis

Data were analysed using Microsoft Excel 2019 (Microsoft, Redmond, Washington, USA) and Stata V.16. Continuous data were analysed using a Mann-Whitney U test and categorical data using a χ^2 tests. The χ^2 test was used to identify information variables significantly associated with alleviation of COVID-19 concerns and OR was calculated to quantify the corresponding risk. Significant variables, identified by univariate analysis, were used to build a multivariate model to assess the effect of each potential confounding factor and to determine independent and significant factors. All tests were two tailed, a $p \leq 0.05$ was considered statistically significant.

RESULTS

Characteristics of IBD population surveyed

A total of 228 patients were interviewed as part of this survey of which 154 (68%) had Crohn's disease and 32% had UC. Seventy-seven (34%) were assigned as being in the high-risk group, 128 (56%) in moderate risk and 23 (10%) were low risk. There were no significant differences in ethnicity, age, gender or IBD phenotype between risk groups. Detailed demographics are shown in [table 1](#). With regard to IBD medication use, 53 (23%) patients were on oral mesalazine, 94 (41%) on thiopurines, 152 (67%) on biological therapy and 5 (2%) on other forms of immunosuppression. No patients were enrolled in clinical trials. Although there were no significant differences in individual medications between moderate and high risk groups, overall immunosuppression use was significantly greater in the moderate risk group ($p < 0.001$). A greater proportion of patients in the high-risk group had significant comorbidities that met the criteria for high risk stratification. Of the patients surveyed, 20 (9%) believed they had symptoms suggestive of COVID-19 and self-isolated as per guidelines. Only two patients were tested, both were negative.

Temporal onset of health concerns related to COVID-19

Of the patients surveyed, 89% reported being concerned about the impact of COVID-19 on their health in relation to IBD. The onset of anxieties was linked to specific key events in the UK to mitigate against recall bias as shown in [figure 1](#). We found that 27% of patients first became concerned either before or following the announcement of the first case of COVID-19 in the UK (28 February 2020). This followed an increasing temporal trend with 52% of respondents recalling onset of anxieties around 1–2 weeks before or following the announcement of the UK lockdown (23 March 2020). No significant differences in the onset of COVID-19-related health concerns were seen between risk groups or among different ethnic groups.

Table 1 Characteristics of IBD population surveyed in relation to risk groups as per British Society of Gastroenterology COVID-19 IBD guidelines

	Risk groups			Total
	High	Moderate	Low	
Age (years) median (IQR)	41 (28)	34.5 (17.3)	32 (23)	
Gender				
Female	28 (26%)	67 (62%)	13 (12%)	108 (47.3%)
Male	49 (41%)	61 (51%)	10 (8%)	120 (52.6%)
Ethnicity				
Caucasian	48 (33%)	84 (58%)	12 (8%)	144 (63.2%)
South Asian	26 (38%)	34 (50%)	8 (12%)	68 (29.8%)
Black	3 (19%)	10 (63%)	3 (19%)	16 (7%)
IBD phenotype				
CD	52 (34%)	88 (57%)	14 (9%)	154 (67.5%)
UC	25 (34%)	40 (54%)	9 (12%)	74 (32.5%)
Current medical therapy				
Mesalazine	15 (28%)	17 (32%)	21 (40%)	53 (23.2%)
Thiopurine	31 (33%)	63 (67%)	0 (0%)	94 (41.2%)
Methotrexate	2 (100%)	0 (0%)	0 (0%)	2 (0.9%)
Tofacitinib	1 (33%)	2 (67%)	0 (0%)	3 (1.3%)
Infliximab	26 (37%)	45 (63%)	0 (0%)	71 (31.1%)
Adalimumab	12 (31%)	27 (69%)	0 (0%)	39 (17.1%)
Vedolizumab	4 (27%)	11 (73%)	0 (0%)	15 (6.6%)
Ustekinumab	13 (48%)	14 (52%)	0 (0%)	27 (11.8%)
Combination therapy(biologic +immunomodulator)	18 (35%)	34 (65%)	0 (0%)	52 (22.8%)

There were no significant differences in ethnicity, age, gender or IBD phenotype between risk groups. Overall immunosuppression use was significantly greater in the moderate-risk group ($p < 0.001$) compared with the high-risk group. CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

Primary sources of COVID-19-related health information

There were primarily nine sources through which patients sought COVID-19-related health information as shown in figure 2. National Health Service (NHS) or Department of Health websites were accessed by

53% of patients for COVID-19-related health information. In contrast, only 26% of patients visited COVID-19 information pages on Crohn and Colitis UK website, while 24% of patients contacted the IBD Helpline for advice. Only 15% of patients recall receiving COVID-19 information letter from the hospital with 12% contacting their general practitioner (GP) for advice and 7% discussing COVID-19 during a follow-up clinic appointment. Thirty per cent of patients, however, resorted to seeking information via search engines with 12% acquiring information through unofficial websites and 15% via social media. No significant differences were seen based on information seeking behaviour between ethnic groups.

Of the patients with concerns regarding the impact of COVID-19 on their health, 22% in high-risk, 26% in moderate-risk and 48% in low-risk groups found that the information they sought or received did not help address their concerns. Patients in the low-risk group were significantly less likely to have received any IBD specific support ($p = 0.03$) or have their concerns alleviated (OR 0.30; 95% CI 0.11 to 0.89; $p = 0.02$) compared with the other groups. Multivariate analysis revealed that receiving a COVID-19 information letter from the hospital (OR 6.99; 95% CI 1.82 to 26.81; $p = 0.005$), contacting the IBD helpline (OR 3.86; 95% CI 1.54 to 9.65; $p = 0.004$) and using NHS websites (OR 2.91; 95% CI 1.32 to 6.40; $p = 0.008$) was significantly associated with alleviating patient concerns. Furthermore, access to at least one IBD-specific clinical interaction during the COVID-19 pandemic in the form of a COVID-19 information letter from the hospital, interaction with the IBD team (helpline or clinics), GP or access to Crohn and Colitis UK was significantly associated with addressing COVID-19-related patient concerns (OR 2.66; 95% CI 1.35 to

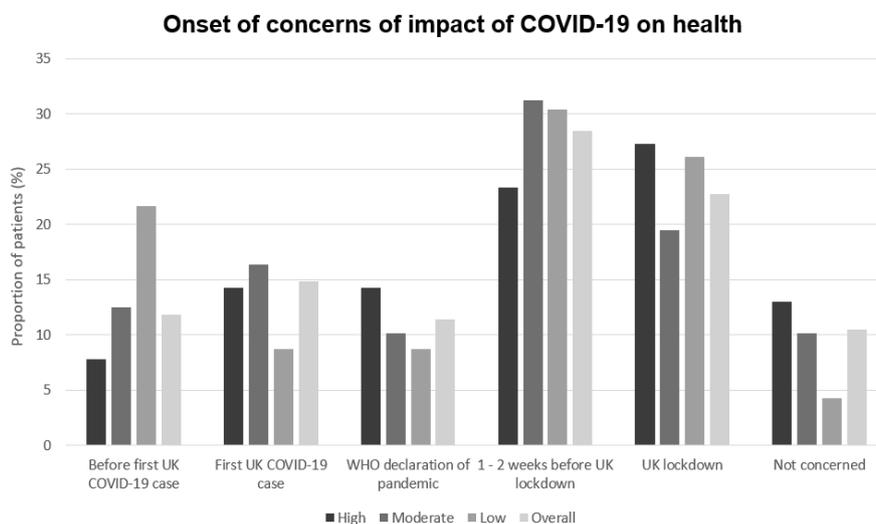


Figure 1 Bar plots demonstrating onset of concerns of impact of COVID-19 on health in relation to public health events between different risk groups. A temporal increase was seen in patient anxieties before the onset of the first COVID-19 case in the UK and peaked around the period of UK lockdown. This trend was similar across all the three risk groups.

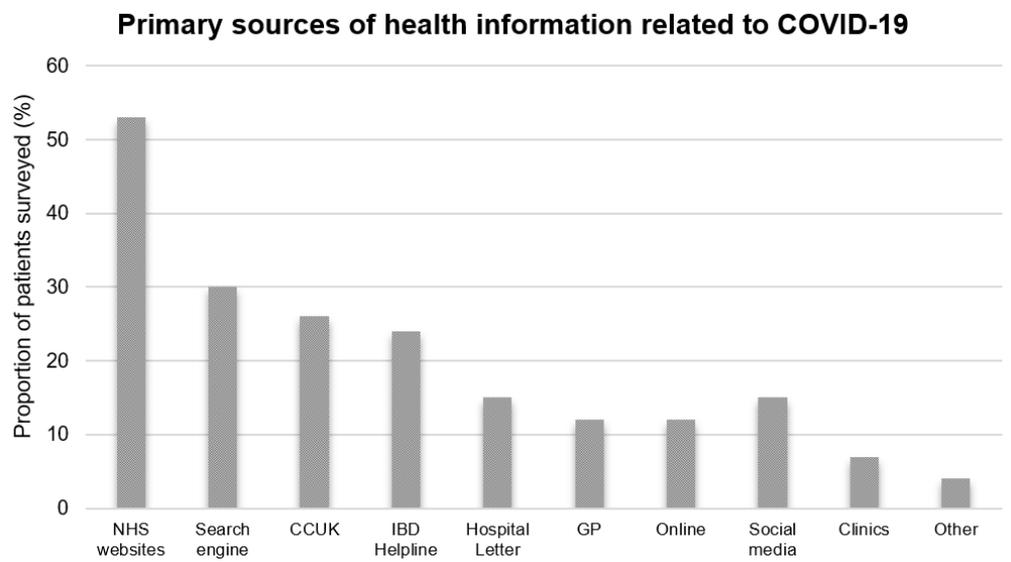


Figure 2 Bar plots showing primary sources of COVID-19-related health information accessed by patients with IBD during the pandemic. Most patients accessed information online via NHS websites and through search engines. IBD-specific information via the Crohn's and Colitis UK website, IBD helpline, COVID-19 information letter from the hospital IBD service were accessed by relatively fewer patients. IBD, inflammatory bowel disease; GP, general practitioner; NHS, National Health Service.

5.24; $p=0.005$). Patients who sought health information solely through unofficial channels including those via search engines and social media were more likely to remain concerned about the impact of COVID-19 on their health (OR 0.15; 95% CI 0.03 to 0.61; $p=0.008$). Alleviation of concerns was not significantly different between disease groups.

Risk assessments

Of the patients surveyed, 197 (86%) had a risk assessment completed with 77 (39%) patients having received this from more than one source (figure 3). Of

these, 79% had received a letter from the IBD service, 23% received a letter or a text message from the Department of Health, 16% of patients via GP, 13% directly during a consultation with the IBD team and only 8% via the IBD UK tool.

Concordance of patient perception of risk with national guidance

Assessing concordance with BSG risk group stratification revealed that 92% of patients within the high-risk group agreed with their risk assessment, with 6% perceiving their risk as being moderate (figure 4).

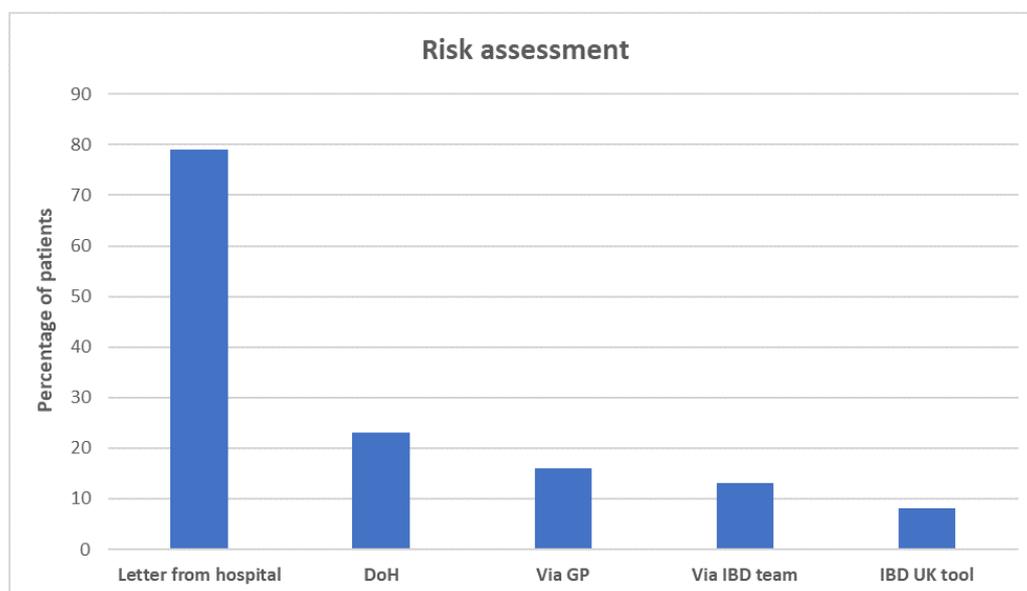


Figure 3 Breakdown of source of risk assessments. Of the patients surveyed, 197 (86%) had a risk assessment completed with 77 (39%) patients having received this from more than one source. IBD, inflammatory bowel disease; GP, general practitioner.

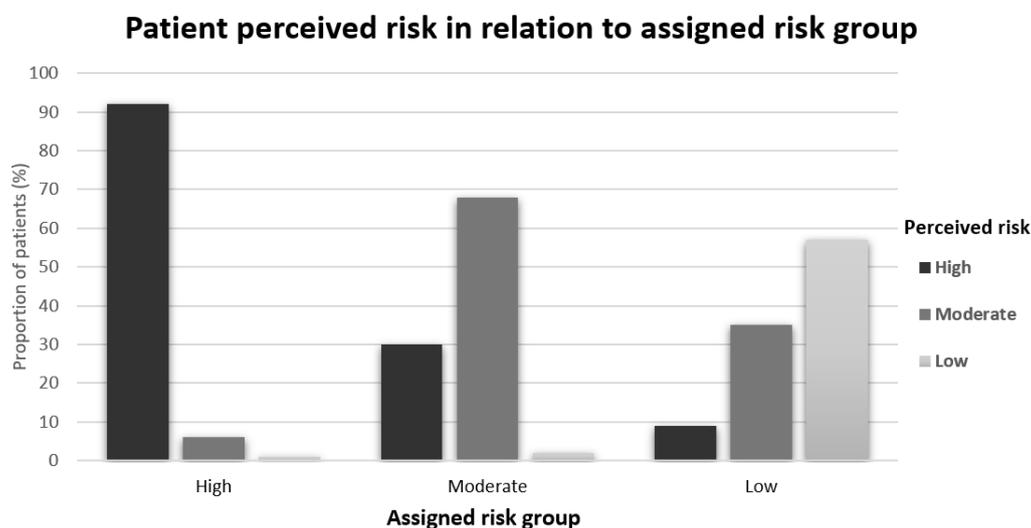


Figure 4 Comparative histograms demonstrating perception of risk in patients assigned different risk groups based on the British Society of Gastroenterology COVID-19 IBD guidelines. The greatest concordance in risk perception was seen within high-risk group. Thirty per cent of patients in the moderate-risk group perceived their risk as being high and 44% of patients within the low-risk group did not agree with their assigned risk profile. IBD, inflammatory bowel disease.

Only 68% of those in the moderate-risk group agreed with their risk group assignment with 30% perceiving their risk as being classed within the high-risk group requiring shielding. These discrepancies between risk assignments and patient perceptions were significantly different between the risk groups ($p=0.001$). There was no significant association between an elevated perception of risk and the use of mesalazine, immunosuppression or combination immunosuppression in this risk group. Within the assigned low-risk group, 57% of patients agreed with their risk stratification with 35% of patients perceiving their risk as moderate and 9% as high. Consistent with the guidance, the lower-risk group were not on any immunosuppressive therapies. However, we did not find a significant association between a perception of a higher risk and mesalazine use in this risk group. A breakdown of risk assessment is shown in online supplemental table 1.

Concerns around IBD medications

Of the patients surveyed, 200 (88%) were on medications with 42% (83/200) concerned about the impact of IBD medications on the risk of acquiring SARS-CoV2 and eventual outcomes associated with COVID-19. Of these, 67% felt their concerns were satisfactorily addressed. These measures were not significantly different between ethnic groups. Multivariate analysis revealed that patients on biologics were significantly more likely to have their concerns addressed than those on immunomodulators or mesalazine (OR 4.2; 95% CI 1.12 to 15.83; $p=0.03$). Eight patients had stopped medications without medical advice with four subsequently developing a flare of their IBD.

DISCUSSION

This survey of 228 adult patients with IBD is the first to evaluate anxieties of patients around the impact of COVID-19 in the UK and effectiveness of the measures undertaken to protect patients in the early stages of the pandemic. Nine of 10 patients with IBD were anxious about the impact of COVID-19 on their health with over a quarter being concerned before our first COVID-19 information letters were sent out to patients. Most patients in the high and moderate-risk groups found that the information they sought or received addressed their concerns. The main sources of information were NHS and Department of Health websites, search engines, the Crohn's and Colitis UK website and the IBD helpline. Many patients were left frustrated by conflicting risk profile assessments from different sources and a significant proportion of patients in the moderate and low-risk groups felt that their assessment underestimated their risk.

We recently demonstrated a correlation between online search trend activity for immunosuppressive drugs and IBD search terms during the COVID-19 pandemic with key public health events and disease-specific interventions in the UK as a surrogate for population/patient-level anxiety.⁸ The present study demonstrates a similar temporal association between patient anxieties and the evolution of the pandemic. Like most other NHS trusts, COVID-19 advice letters were sent to patients on our immunosuppression database. Consequently, patients in the high and moderate-risk groups felt their concerns were more adequately addressed compared with the low-risk group who had little contact with clinical services. We were able to demonstrate that a single clinical intervention, either

through an advice letter from the hospital or contact by the IBD team, significantly reduced anxiety compared with being left unsupported. Despite reassuring reports of outcomes in patients with IBD contracting COVID-19,^{9,10} it is clear that the pandemic has had an immense psychological impact and this has been demonstrated through similar surveys.^{11–14}

The UK government introduced the shielding policy for those ‘extremely clinically vulnerable’ to COVID-19.¹⁵ Patient populations identified through NHS digital coding was far from comprehensive. Consequently working groups developed guides often with conflicting advice between different professional societies.^{5,16} The advice and practical recommendations from the BSG have been commendable particularly given the paucity of clinical data. The identification of patients for risk assessment has been challenging as most services were not equipped with a disease registry. Furthermore, the process of assessments was chaotic, impromptu, poorly understood and often done by multiple sources resulting in conflicting risk assessments.¹⁷ A quarter of the patients surveyed disagreed with their assigned risk groups, a majority of whom perceived themselves to be associated with a higher risk profile. This lack of concordance was greatest in moderate risk group and constituted those on immunosuppressive therapies.

Results of this survey emphasise the need to improve IBD service-patient communication. We found those on biologics were significantly more likely to have their anxieties addressed than those on other medications, possibly due to a greater degree of contact with their IBD teams (via helplines or infusion units). Consistent with the online global survey through EFCCA¹² and the survey from Germany,¹⁴ 4% of patients on medications stopped their immunosuppression with some consequently suffering disease flares. Ensuring there is a channel for prompt communication with our patients is crucial especially at a time when evidence around outcomes with regards to IBD and specific therapies are rapidly evolving.¹⁰

Over one-third of patients included in our study are from Black, Asian and minority ethnic (BAME) backgrounds. It is widely recognised that patients with COVID-19 from BAME backgrounds have worse clinical outcomes and this is likely reflective of existing health and socioeconomic disparities.^{18–20} Moreover, young people from BAME backgrounds have had greater increases in depression, anxiety and self-harm during the COVID-19 pandemic.²¹ Interestingly, our survey did not find any differences in anxiety levels or information seeking behaviour along ethnic lines.

This survey has highlighted several areas to enhance quality of care afforded to our patients with IBD as we enter new phases of the pandemic. The difficulties experienced by our centre and many others in patient identification highlights the urgent need to maintain accurate disease registries.²² Second,

in the face of an ever-evolving situation, there is a need to develop real-time means of communication with our patients regardless of their risk status. In Wuhan, China, a popular social media app has allowed instructional alerts to be disseminated to all patients with IBD.⁹ Third, there is a need to facilitate patient access to IBD-related information from credible sources, particularly since the internet can amplify misinformation.⁹ With resources such as the IBD helpline stretched to the maximum, there is a need to develop innovative solutions using artificial intelligence through collaboration with digital technology partners.²³

Our survey has a few limitations. It is based at a single centre and results may not be fully generalisable to other regions in the UK. However, the study benefits from a varied patient population from a wide range of socioeconomic and ethnic backgrounds. Due to survey methodology, we are not able to calculate a response rate but estimate that less than 10% of patients declined to participate. We did not include a control group of either healthy volunteers or non-IBD high-risk patients. Comparing patients in high, moderate and low-risk IBD groups was able to provide a more meaningful evaluation of the IBD risk stratification process and the information dissemination measures that were instituted.

This survey has emphasised the benefits of IBD-specific clinical interactions in alleviating COVID-19 health concerns as compared with information from untrusted sources. Processes for information distribution should not ignore low-risk patients with IBD as it would seem that they are at least as anxious as those at high risk. Moreover, anxiety levels were heightened in patients with IBD who received differing risk assessments from multiple sources and it is clear that central/locoregional processes for information dissemination should be better aligned going forward.

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