

GASTROENTEROLOGY

Understanding attitudes, concerns, and health behaviors of patients with inflammatory bowel disease during the coronavirus disease 2019 pandemic

Thomas M Goodsall*,[†]  Sangwoo Han* and Robert V Bryant*,[†]*IBD Service, Department of Gastroenterology, The Queen Elizabeth Hospital, and [†]Faculty of Health Sciences, School of Medicine, University of Adelaide, Adelaide, South Australia Australia**Key words**

COVID-19, Crohn's disease, Inflammatory bowel disease, Patient perceptions, Ulcerative colitis.

Accepted for publication 21 September 2020.

CorrespondenceDr Robert V Bryant, IBD Service, Department of Gastroenterology, The Queen Elizabeth Hospital, Adelaide, SA 5011, Australia.
Email: robert.bryant@sa.gov.au**Declaration of conflict of interest:** TMG has received support through the provision of an Australian Government research training program scholarship and grant support from Janssen. SH has no conflict to declare. RVB has received grant/research support/speaker fees (all paid to employer for research support) from AbbVie, Ferring, Janssen, Shire, Takeda, and Emerge Health and is a shareholder in BiomeBank.**Author contribution:** TMG developed the study design, analyzed the data, and was involved in drafting and revising the manuscript for important intellectual content. SH developed the IBD database and was involved in study design and revising the manuscript for important intellectual content. RVB supervised the study designed and was involved in drafting and revising the manuscript for important intellectual content. All authors approve the final version of the manuscript and agree to be accountable for all aspects of the work.**Financial support:** No funding was received for this study.**Introduction**

The severe acute respiratory syndrome coronavirus 2, which causes coronavirus disease 2019 (COVID-19), has emerged as a global health crisis. COVID-19 is characterized by fever, respiratory, and gastrointestinal symptoms and can progress to severe disease with respiratory and organ failure.¹ The current COVID-19

pandemic is associated with a 1–18% hospitalization rate and an estimated infection fatality ratio of 2.7% in the general population.²

The risk of severe disease and death with COVID-19 increases with age, immunosuppression, and chronic disease on the basis of early data and extrapolation from other coronavirus diseases.^{2,3} Inflammatory bowel disease (IBD) is a chronic condition that is

Abstract

Background and Aim: The coronavirus disease 2019 (COVID-19) pandemic has led to a rapid shift in care delivery models for patients with inflammatory bowel disease (IBD); however, little is known about patient perceptions during this period. We aimed to prospectively evaluate the attitudes, concerns, and health behavior of IBD patients during COVID-19.

Methods: An online survey was sent to patients from a tertiary IBD Service. The survey included demographic information and questions about the impact of COVID-19, levels of concern caused by COVID-19, perceived risk of IBD medications, medication cessation, and care delivery preferences.

Results: Of 97 respondents (39%), 95 (98%) reported concern about the impact of COVID-19 on their health, and 43% felt their risk of contracting COVID-19 was above average; 62% reported concern about medication-induced COVID-19 risk, and 11% stopped medications because of COVID-19. Patients considered all medications to increase the risk of COVID-19 susceptibility and severity; 45% preferred telehealth while 16% preferred face-to-face clinic reviews. Preference for IBD monitoring tools in decreasing order was blood testing, stool collection, gastrointestinal ultrasound, magnetic resonance enterography, and then colonoscopy.

Conclusions: Patients with IBD are demonstrated to experience concern related to their diagnosis and medications. The insights provided by the survey are informative for a possible “second-wave” of COVID-19 and routine care, including acceptance of telemedicine, preference for non-invasive investigations, and a need for dissemination of information and education.

frequently associated with relapsing disease or flares requiring immunosuppressive medications.^{4,5} IBD patients are considered at increased risk of COVID-19 related severe disease and mortality, with a standardized mortality ratio of 1.5–1.8 for IBD patients compared with the general population.^{6,7} IBD flare and subsequent use of systemic steroids is considered a greater risk factor for severe COVID-19 disease than other medications used to induce and maintain remission including thiopurines, methotrexate, and monoclonal antibody medications.⁸ An international prospective IBD COVID-19 registry found an adjusted odds ratio for COVID-19 related death of 11.62 for corticosteroid use; however, no other medication was associated with significantly increased odds of death.^{7,9} Notably, 5-aminosalicylates were associated with severe illness but not death in preliminary analysis, but this finding has not yet been replicated, and the significance of this association remains unclear.⁷ Similar findings were demonstrated in another study in which corticosteroids but not immune-mediated therapy was associated with higher risk of severe COVID-19.¹⁰

During this period of uncertainty and changing health advice, citizens in many countries have received directives to self-isolate with quickly evolving policy changes in response to new information. Furthermore, there has been a rapidly implemented shift to digital health-care provision through telemedicine to avoid unnecessary social contact and mitigate the risk of health-care transmission of the virus. In this pandemic setting, patients with IBD may have been burdened by serious health concerns and anxieties, compounded by reduced access to primary and specialist health-care provision. Prior to the COVID-19 pandemic, up to a third of IBD patients were not adherent with prescribed medications.¹¹ Given the propensity for self-initiated medication withdrawal during this period, a far high rate of medication nonadherence may be anticipated, placing patients at increased risk of disease flare and steroid use.

A better understanding of the attitudes of IBD patients toward the COVID-19 pandemic will assist in developing high-quality health care and mitigating risk of IBD complications. This information transcends the current pandemic and has future relevance in the face of a second wave of COVID-19 illness and possible future pandemics. The aim of this study is to prospectively survey patients with IBD to understand their attitudes and concerns regarding COVID-19 relevant to their disease, medications, and care delivery preferences.

Methods

Participants. The participants in this study were sourced from an IBD database of patients known to the Queen Elizabeth Hospital IBD unit, which is a tertiary IBD center caring for >600 patients with IBD, one-third of whom receive biologic therapy. During the COVID 19 pandemic, the Queen Elizabeth Hospital IBD service changed to a default telephone consultation service for all outpatient encounters. A fortnightly newsletter summarizing current society recommendations and guidelines was disseminated electronically to all patients. Endoscopy activity was significantly reduced in March and April of 2020 according to government policy. Point-of-care gastrointestinal ultrasound was provided through the IBD service as a non-invasive IBD activity assessment tool. Gastrointestinal ultrasound is accurate when

compared with ileocolonoscopy and can guide management decisions including medication escalation and de-escalation while avoiding endoscopy in many cases.^{12,13} All patients with available email addresses (42% of cohort) were contacted for inclusion in the study on April 21, 2020. The project was reviewed and approved by the Central Adelaide Local Health Network human research ethics committee prior to commencement.

Survey and distribution. The survey included demographic information, IBD phenotype and medications, and perceived risk of COVID19 including risk associated with IBD and medication use, whether participants had considered or already stopped medications because of COVID19 and who they discussed this with, perceived risk of specific IBD medications for infection and serious illness/death associated with COVID19, current level of social distancing/isolation, employment conditions and preferences for receiving IBD care during the COVID19 pandemic including information distribution, and the use of telehealth and monitoring tools for assessing IBD. Questions used a binary yes/no or Likert scale format. Monitoring tool preference was measured on a 5-point Likert scale. The full list of survey questions is available as a supplementary file (Data S1). The survey was sent to recorded patient email addresses using an online survey platform, and a reminder email was sent to nonrespondents 10 days after the initial invitation to participate.

Statistical analysis. Descriptive and summary statistics were used to describe the demographic and clinical characteristics of respondents. Continuous variables were summarized with mean and standard deviations. The Wilcoxon sign-rank test was used to compare assessment modality preference as normality assumptions have not met any responses. All statistical calculations were performed using STATA V14 (StataCorp, TX, USA).

Results

Participant information. There were 251 email invitations sent to patients with IBD, and 97 responses were received (39%) between April 21 and May 22, 2020. Demographic, phenotypic, and medication data of respondents are presented in Table 1. Eight patients (13%) were taking prednisone at the time of the survey, 40 patients (60%) were on immunomodulator therapy, and 51 patients (53%) were on biologic medications. Nine patients (9%) were not on any IBD medications. All patients reported some level of social distancing as a result of COVID-19; 4 (4%) were avoiding large gatherings, 26 (29%) continued to work but avoided unnecessary social exposure, 54 (60%) were only going out for essential services, and 6 (7%) had completely self-isolated. Of those employed at the time of the survey, 42 (66%) described their employer as extremely supportive of any need to socially distance or isolate because of IBD, 15 (25%) were somewhat supported, and 6 (9%) did not feel supported.

Perceived risk of coronavirus disease 2019. Of the patients, 38 (42%) were very or extremely concerned about the impact of COVID-19 on their personal health while only 2 (2%) were not at all concerned. In those 38 expressing concern, 2 were on no

Table 1 Demographic and clinical characteristics of 97 respondents

Age (median, range)	49, 17–77
Current smokers <i>n</i> (%)	14 (14%)
IBD phenotype	
Crohn's disease <i>n</i> (%)	57 (59%)
Ulcerative colitis <i>n</i> (%)	38 (39%)
Unsure/indeterminate <i>n</i> (%)	2 (2%)
Current medications	
Prednisolone <i>n</i> (%)	8 (13%)
Budesonide <i>n</i> (%)	3 (5%)
5-Aminosalicylates <i>n</i> (%)	35 (49%)
Rectal therapy <i>n</i> (%)	10 (17%)
Thiopurines <i>n</i> (%)	35 (51%)
Methotrexate <i>n</i> (%)	5 (9%)
Infliximab <i>n</i> (%)	19 (30%)
Adalimumab <i>n</i> (%)	6 (10%)
Golimumab <i>n</i> (%)	2 (4%)
Vedolizumab <i>n</i> (%)	14 (23%)
Ustekinumab <i>n</i> (%)	9 (15%)
Tofacitinib <i>n</i> (%)	1 (2%)
Combination medication use	
Thiopurine and biologic agent	18 (19%)
Methotrexate and biologic agent	4 (4%)
Prednisolone and biologic agent	2 (2%)
Prednisolone, thiopurine, and vedolizumab	1 (1%)

IBD, inflammatory bowel disease.

medications, 4 were on aminosaliculates, 11 were on steroids or immunomodulators, 12 were on biologics, and 9 were on combination therapy with a biologic agent and immunomodulatory. Personal risk of catching COVID-19 was considered above average by 39 (43%), average by 32 (36%), and below average by 19 (21%). IBD caused additional concern about COVID-19 a lot or a great deal in 34 (38%), moderately in 27 (30%), and a little or not at all in 29 (32%). Of the patients, 50 (56%) expressed moderate to great concern about a flare of their IBD if they caught COVID-19 while 40 (44%) had little or no concern. In those 50 expressing concern, one was on no medication, 9 were on aminosaliculates, 8 were on immunomodulators, 18 were on biologics, and 14 were on combination therapy. The level of concern

about the effect of medications on the risk of COVID 19 was very high or high in 39 (43%), moderate in 17 (19%), and a little or none in 34 (38%). General stress owing to COVID-19 was considered a lot or a great deal by 20 (22%), moderate by 34 (38%), and a little or none at all by 36 (40%).

Medication risk and cessation. Of the patients, 13 (14%) reported considering stopping their IBD medications because of COVID-19 and 11 (11%) actually stopped medications; one on azathioprine, one on prednisolone and sulfasalazine, three on azathioprine and infliximab, three on ustekinumab, and three on undisclosed medications. Of these 11 patients, three stopped medications themselves (27%), five stopped medications after discussion with their IBD specialist (45%), and three did not specify how they made a decision to stop medications (27%). Three patients who stopped medications without consultation with their physician also expressed moderate to great concern of an IBD flare. When questioned about perceived risk of individual medications for susceptibility to COVID-19, lowest to highest risk was attributed to 5-aminosalicylates, budesonide, tofacitinib, vedolizumab, steroids, ustekinumab, thiopurines, methotrexate, and anti-tumor necrosis factor- α (anti-TNF α) medications (Table 2). For perceived risk of individual medications for severe illness or death from COVID-19, lowest to highest risk was attributed to 5-aminosalicylates, tofacitinib, budesonide, vedolizumab, steroids, thiopurines, methotrexate, anti-TNF α medications, and ustekinumab (Table 3). Of the participants, 65 (73%) indicated that they would like to receive more information about the current understanding of how IBD medications may affect COVID-19 risk.

Care delivery preferences. Of the participants, 74 (82%) indicated that they would like to receive email updates regarding coronavirus and IBD. Preference for care delivery was by telephone or telemedicine in 40 (45%) and face-to-face clinic review in 14 (16%), and no preference indicated by 35 (39%). When questioned about preference for IBD monitoring tools, the mean score (\pm standard deviation) was greatest for blood testing 3.92 (\pm 0.96), stool collection 3.28 (\pm 1.08), and gastrointestinal ultrasound 3.28 (\pm 0.99); all of which were significantly greater than mean score for magnetic resonance enterography 2.95 (\pm 0.97) and colonoscopy 2.75 (\pm 1.16) ($P < 0.002$ for each comparison).

Table 2 Perceived risks ranked 1 (no increase in risk) to 4 (great increase in risk) of inflammatory bowel disease medications for catching coronavirus disease 2019

Medication	No or small increase in risk (1–2)	Moderate or great increase in risk (3–4)	Mean value
5-ASAs	31 (79%)	8 (21%)	1.66 (1.03)
Budesonide	8 (67%)	4 (33%)	2.08 (1.16)
Tofacitinib	6 (60%)	4 (40%)	2.1 (1.1)
Vedolizumab	12 (57%)	9 (43%)	2.15 (1.14)
Steroids	19 (54%)	16 (46%)	2.19 (1.24)
Ustekinumab	10 (56%)	8 (44%)	2.56 (1.10)
Thiopurines	16 (34%)	31 (66%)	2.66 (1.04)
Methotrexate	8 (40%)	12 (60%)	2.8 (1.20)
Anti-TNF α	12 (35%)	22 (65%)	2.85 (1.01)

5-ASA; 5-aminosalicylates, anti-TNF α ; anti-tumor necrosis factor- α medications.

Table 3 Perceived risks ranked 1 (no increase in risk) to 4 (Great increase in risk) of IBD medications for developing severe illness or death from coronavirus disease 2019

Medication	No or small increase in risk (1–2)	Moderate or great increase in risk (3–4)	Mean value
5-ASAs	23 (74%)	8 (26%)	1.74 (0.93)
Tofacitinib	3 (43%)	4 (57%)	2.15 (1.07)
Budesonide	6 (46%)	7 (54%)	2.31 (1.32)
Vedolizumab	9 (47%)	10 (53%)	2.4 (1.07)
Steroids	17 (49%)	18 (51%)	2.51 (1.09)
Thiopurines	14 (36%)	25 (64%)	2.77 (0.93)
Methotrexate	6 (33%)	12 (67%)	2.78 (1.06)
Anti-TNF α	9 (21%)	22 (79%)	2.87 (0.92)
Ustekinumab	5 (31%)	11 (69%)	2.88 (1.02)

5-ASA; 5-aminosalicylates, anti-TNF α ; anti-tumor necrosis factor- α medications.

Discussion

This survey of 97 patients with IBD provides an important insight as to the attitudes, concerns, and health behavior of IBD patients during the height of the COVID-19 pandemic in Australia. Patients with IBD are demonstrated to experience concern related to their diagnosis and medications, which led to self-initiated medication cessation in a proportion of patients, placing them at a potentially increased risk of flare and ensuing corticosteroid requirement. Most patients with IBD preferred telemedicine consultation to maintain continuity of care, along with non-invasive disease monitoring, and provision of accurate COVID-19 and IBD information. The lessons learned during this phase of the pandemic should inform best management during any further waves or outbreak. Furthermore, the insights gleaned may transcend the pandemic period and remain relevant during routine IBD care.

The survey responses expose a perception of heightened personal risk among patients with IBD in the face of the COVID-19 pandemic. Patients with IBD felt vulnerable as nearly half of respondents felt that they had above-average risk of contracting COVID-19. Moreover, most patients felt that contracting COVID-19 would bring about a flare of their IBD. It seems that susceptibility concerns related to prescribed medications for IBD led to medication cessation in 11% of respondents, half of which was self-initiated and not discussed with the treating IBD team. Inappropriate medication cessation without consideration of underlying disease severity is likely to increase the risk of IBD flare and subsequent requirement for escalation of therapy or systemic corticosteroid use.¹⁴ In addition to potential complications associated with IBD flare, the use of systemic corticosteroids is considered to be a greater risk for COVID-19-related morbidity and mortality than any other IBD medication.^{8,15,16} Although understandable, IBD patient fears were out of keeping with evolving evidence during the pandemic, given that the SECURE_IBD (Surveillance Epidemiology of Coronavirus Under Research Exclusion) registry revealed a similar mortality between patients with IBD and the general population.⁷ Provision of accurate and up-to-date information may have reassured patients and avoided inappropriate medication cessation.

Patients with IBD were shown to overestimate risk for most medications in the setting of the COVID-19 pandemic. The risks

of thiopurine therapy, methotrexate, and anti-TNF α agents were overestimated by many respondents as best evidence is that there is no significant increase in risk associated with these agents, aside from when used as combination therapy.^{7,15–19} However, in parallel to routine care, patients tended to underestimate the risks associated with corticosteroid therapy, which has been shown to impart risk of severe COVID-19 disease.^{7,10,16} Although it is acknowledged that a rapidly evolving pandemic situation prevented accurate appraisal of IBD medication risk for COVID-19, survey data illustrate the importance of provision of current and accurate information so as to help mitigate medication-related anxiety and prevent inappropriate medication cessation.

A favorable response by patients toward drastic changes in care delivery during the COVID-19 pandemic was demonstrated, in particular a shift toward telemedicine and non-invasive disease activity assessment. Telehealth consultation was preferred by most but not all patients with IBD during the height of the COVID-19 pandemic. Telehealth has been long proposed as a mechanism for effective delivery of IBD care, particularly for patients in remote settings.²⁰ However, until the advent of the pandemic, delivery of telemedicine has not matched enthusiasm. The rapid increase in delivery and acceptance of telemedicine as an efficient means of achieving safe and convenient care to patients with IBD must be considered a silver lining of the current situation. Indeed, current guidelines support ongoing consultation via telemedicine for at least one-third of patients beyond the COVID-19 pandemic peak.^{21,22} Given that not all patients consider telemedicine favorable, care delivery should be tailored and personalized where possible, so as to ensure the most satisfying outcomes for patients and clinicians. This survey demonstrated a significant preference for non-invasive assessment of IBD, which parallels routine practice.^{13,23} While it is unsurprising that patients prefer monitoring tools that are less invasive and do not require bowel preparation, the finding is in keeping with previous studies and is important to consider when delivering a quality care model.^{23–25} Current expert opinion supports utilization of non-invasive tools for treat-to-target strategy both during and after the initial peak of the COVID-19 pandemic.²¹ Notably, respiratory syndrome coronavirus 2 is detectable in stool in 29% of cases, and fecal viral shedding may persist longer than respiratory shedding.^{26,27} In the current pandemic, stool collection presents a theoretical

increase in risk to patients and laboratory staff not assessed in this survey.

These strengths of this study include the fact that it is the first in Australia to evaluate perceptions of patients with IBD at the height of the COVID-19 pandemic revealing important data as to how to best manage a second wave or future pandemic. The study was limited by the relatively small sample size and risk of responder bias with a response rate of 39%, although this is consistent with many epidemiological survey response rates.^{28,29} The participants all resided in an Australian state with low COVID-19 case numbers, which may limit the generalizability of results to international areas with high prevalence of COVID-19 infection. Furthermore, the survey was administered 4 weeks into the COVID-19 care model meaning that some respondents had already been reviewed by telehealth and provided with electronic information and employer letters while others had not, which may have affected how respondents answered many of the questions.

In summary, this study reveals the health-related concerns experienced by patients with IBD during the height of the COVID-19 pandemic in Australia. The insights provided by the survey are informative for a possible second wave of COVID-19, including acceptance of telemedicine, safe delivery of accessible non-invasive investigations as colonoscopy surrogates, and a need for dissemination of information and education. These lessons learned may well transcend the pandemic period and lead to shifts in care delivery toward a more patient centered and efficient model.

References

- Wang Y, Wang Y, Chen Y, Qin Q. Unique epidemiological and clinical features of the emerging 2019 novel coronavirus pneumonia (COVID-19) implicate special control measures. *J. Med. Virol.* 2020; **92**: 568–76.
- Verity R, Okell LC, Dorigatti I *et al.* Estimates of the severity of coronavirus disease 2019: a model-based analysis. *The Lancet Infectious Diseases*. [https://doi.org/10.1016/S1473-3099\(20\)30243-7](https://doi.org/10.1016/S1473-3099(20)30243-7)
- Prevention CfDCA. Coronavirus disease 2019 (COVID-19) 2020 [Cited 17th Jun 2020.] Available from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html>
- Burisch J, Jess T, Martinato M, Lakatos PL, on behalf of ECCO-EpiCom. The burden of inflammatory bowel disease in Europe. *Journal of Crohn's and Colitis*. 2013; **7**: 322–37.
- Cosnes J, Gower-Rousseau C, Seksik P, Cortot A. Epidemiology and natural history of inflammatory bowel diseases. *Gastroenterology* 2011; **140**: 1785–94 e4.
- Spychalski P, Błażyńska-Spychalska A, Kobiela J. Estimating case fatality rates of COVID-19. *Lancet Infect. Dis.* [https://doi.org/10.1016/S1473-3099\(20\)30246-2](https://doi.org/10.1016/S1473-3099(20)30246-2)
- Brenner EJ, Ungaro RC, Gearry RB *et al.* Corticosteroids, but not TNF antagonists, are associated with adverse COVID-19 outcomes in patients with inflammatory bowel diseases: results from an international registry. *Gastroenterology*. <https://doi.org/10.1053/j.gastro.2020.05.032>
- Gastroenterological Society of Australia. Recommendations for patients with inflammatory bowel disease (IBD) during the covid-19 pandemic 2020 [Cited 17th Jun 2020] Available from: https://www.gesa.org.au/public/13/files/COVID-19/GESA_IBD_Patient_Recommendations_COVID19_26032020.pdf
- Surveillance Epidemiology of Coronavirus (COVID-19) Under Research Exclusion [Internet]. 2020 [cited 17th Jun 2020]. Available from: <https://covidibd.org/>
- Singh S, Khan A, Chowdhry M, Bilal M, Kochhar GS, Clarke K. Risk of severe COVID-19 in patients with inflammatory bowel disease in United States. *A Multicenter Research Network Study. Gastroenterology*. <https://doi.org/10.1053/j.gastro.2020.06.003>
- Shah NB, Haydek J, Slaughter J *et al.* Risk factors for medication nonadherence to self-injectable biologic therapy in adult patients with inflammatory bowel disease. *Inflamm. Bowel Dis.* 2019; **26**: 314–20.
- Bolegala N, Griller N, Bannerman H, Habal M, Nguyen G. Ultrasound vs endoscopy, surgery, or pathology for the diagnosis of small bowel Crohn's disease and its complications. *Inflamm. Bowel Dis.* 2019; **25**.
- Bryant R, Friedman A, Wright E *et al.* Gastrointestinal ultrasound in inflammatory bowel disease: an underused resource with potential paradigm-changing application. *Gut* 2018; **67**: 973–85.
- Torres J, Boyapati RK, Kennedy NA, Louis E, Colombel J-F, Satsangi J. Systematic review of effects of withdrawal of immunomodulators or biologic agents from patients with inflammatory bowel disease. *Gastroenterology* 2015; **149**: 1716–30.
- Tinsley A, Navabi S, Williams ED *et al.* Increased risk of influenza and influenza-related complications among 140,480 patients with inflammatory bowel disease. *Inflamm. Bowel Dis.* 2018; **25**: 369–76.
- Wisniewski A, Kirchgerner J, Seksik P *et al.* Increased incidence of systemic serious viral infections in patients with inflammatory bowel disease associates with active disease and use of thiopurines. *United European Gastroenterology Journal*. 2019; **8**: 303–13.
- Goodsall TM, Costello SP, Bryant RV. COVID-19 and implications for thiopurine use. *Medical Journal of Australia* 2020; **212**: 490 e1.
- Kirchgerner J, Lemaître M, Carrat F, Zureik M, Carbonnel MD, Dray-Spira R. Risk of serious and opportunistic infections associated with treatment of inflammatory bowel diseases. *Gastroenterology* 2018; **155**: 337–46.
- Toruner M, Loftus EV Jr, Harmsen WS *et al.* Risk factors for opportunistic infections in patients with inflammatory bowel disease. *Gastroenterology* 2008; **134**: 929–36.
- Jackson BD, Gray K, Knowles SR, De Cruz P. EHealth technologies in inflammatory bowel disease: a systematic review. *Journal of Crohn's and Colitis*. 2016; **10**: 1103–21.
- Danese S, Sands B, Ng SC, Peyrin-Biroulet L. The day after COVID-19 in IBD: how to go back to 'normal'. *Nat. Rev. Gastroenterol. Hepatol.* <https://doi.org/10.1038/s41575-020-0322-08>
- Holtmann G, Quigley EM, Shah A *et al.* "It ain't over ... till it's over!" Risk-mitigation strategies for patients with gastrointestinal diseases in the aftermath of the COVID-19 pandemic. *Journal of Gastroenterology and Hepatology*. [https://doi.org/10.1016/S1473-3099\(20\)30243-7](https://doi.org/10.1016/S1473-3099(20)30243-7)
- Goodsall TM, Noy R, Nguyen TM, Costello SP, Jairath V, Bryant RV. Systematic review: patient perceptions of monitoring tools in inflammatory bowel disease. *Journal of the Canadian Association of Gastroenterology*. <https://doi.org/10.1093/jcag/gwaa001>
- Buisson A, Gonzalez F, Poullenot F *et al.* Comparative acceptability and perceived clinical utility of monitoring tools: a nationwide survey of patients with inflammatory bowel disease. *Inflamm. Bowel Dis.* 2017; **23**: 1425–33.
- Rajagopalan A, Sathananthan D, An Y-K, Van De Ven L, Martin S, Fon J, *et al.* Gastrointestinal ultrasound in inflammatory bowel disease care: Patient perceptions and impact on disease-related knowledge. *Journal of Gastroenterology and Hepatology* Open doi <https://doi.org/10.1002/jgh3.12268>
- Wang W, Xu Y, Gao R. Detection of SARS-CoV-2 in different types of clinical specimens. *Journal of the American Medical Association*. 2020; **323**: 1843–4.
- Xu Y, Li X, Zhu B *et al.* Characteristics of pediatric SARS-CoV-2 infection and potential evidence for persistent fecal viral shedding. *Nat. Med.* 2020; **26**: 502–5.

- 28 Morton SMB, Bandara DK, Robinson EM, Carr PEA. In the 21st century, what is an acceptable response rate? *Aust. N. Z. J. Public Health* 2012; **36**: 106–8.
- 29 Choung RS, Locke GR, Schleck CD *et al.* A low response rate does not necessarily indicate non-response bias in gastroenterology survey research: a population-based study. *J. Public Health* 2013; **21**: 87–95.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Data S1. Supporting information.