

## Original Research Article

# Patient information on the internet for surgical management of inflammatory bowel disease: is it good enough?

Alex J. Besson<sup>1</sup>, Christy Kei<sup>1</sup>, Belinda Jackson<sup>2</sup>, Trevor M. Yeung<sup>5</sup>,  
Irene Deftereos<sup>1,3</sup>, Justin M. C. Yeung<sup>1,4\*</sup>

<sup>1</sup>Department of Surgery, The University of Melbourne, Western Precinct, Melbourne, Victoria, Australia

<sup>2</sup>Department of Gastroenterology, <sup>3</sup>Department of Nutrition and Dietetics, <sup>4</sup>Department of Colorectal Surgery, Western Health, Footscray, Victoria, Australia

<sup>5</sup>Department of Colorectal Surgery, University of Oxford, United Kingdom

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### \*Correspondence:

Justin M. C. Yeung,

E-mail: [Justin.yeung@unimelb.edu.au](mailto:Justin.yeung@unimelb.edu.au)

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## ABSTRACT

**Background:** Our study aimed to identify the search engines and terms commonly used by inflammatory bowel disease (IBD) patients and aimed to assess the quality and readability of these resources.

**Methods:** Patients attending IBD clinic were surveyed, regarding search engines, terms and number of websites viewed. Websites according to these predetermined criteria were identified. Website content was described and quality was assessed using DISCERN. Readability was graded using the Flesch Reading Ease Score (FRES).

**Results:** From 33 survey responses, Google was universally utilised. Forty-two websites met the inclusion criteria (19 for Crohn's disease (CD), 23 for ulcerative colitis (UC)). Only one website originated from Australia. Websites were infrequently updated (CD 21%, UC 17%) within the previous 12 months. Overall readability was poor with a mean FRES of 35.8 (11.8, range 15.7-57.7) for CD and 35.7 (11.3, range 19.4-54.3) for UC websites. Quality was moderate to poor with only five (12%) websites being rated as high quality (2 CD, 3 UC).

**Conclusions:** There is very little Australian based web information available on IBD surgery and overall, it is of a low readability and poor content quality. There is need for the development of patient targeted health literature to help these patients.

**Keywords:** Inflammatory bowel disease, Crohn disease, Internet, Patient education, Surgery, Ulcerative colitis

## INTRODUCTION

Inflammatory bowel disease (IBD), which encompasses Crohn's disease (CD) and ulcerative colitis (UC), can have a significant impact on patients' quality of life.<sup>1</sup> In Australia, more than 75,000 individuals are living with IBD and it is estimated that up to 5500 new cases are diagnosed every year and this is projected to rise steadily.<sup>2,3</sup>

Despite availability of effective medical therapies, IBD patients remain at high risk for requiring surgical intervention. For patients with UC, it is estimated that the

5 and 10-year cumulative risk of colectomy are both 10-15%.<sup>4</sup> For those with CD, up to 65% will require surgery within 10 years of diagnosis.<sup>5-7</sup>

There is good evidence that patients with IBD often lack complete information about their treatment, which limits their ability to participate in management decisions.<sup>8,9</sup> Many patients are therefore turning to the internet for information in order to understand more about their surgical treatments. A study in the United States (USA) has shown that more than half of IBD clinic patients used internet resources to attain IBD information regarding their condition, being the most trusted source of

information, following health care professional advice.<sup>10,11</sup>

This growing utilization of internet sources necessitates the need for reliable sources which confer accuracy, good quality and readability.<sup>12-17</sup> Moreover, sources must also be relevant to the patient demographic and accurately reflect country-specific practices and guidelines.<sup>18</sup> There have only been a limited number of studies which have investigated the quality and readability of internet resources for IBD patients.<sup>13-17,19-21</sup> Results consistently show poor quality and readability. In addition, no study has investigated resource quality or readability within the Australian IBD context regarding surgery.

The aims of this study were therefore to (1) identify which internet resources Australian IBD patients utilize to help them understand the surgical management of IBD, their origins and inferred relevancy to the Australian population, (2) to assess the quality of identified websites using the DISCERN instrument and (3) to determine the readability of content on these resources using the Flesch Reading Ease Score (FRES).

## **METHODS**

A survey of patients attending a tertiary institution's IBD Clinic was conducted in June 2019 to determine patient preferences when looking for information regarding surgery for IBD. This was carried out as a cross-sectional study in which patients with CD, UC or indeterminate colitis were surveyed regarding how they would construct an internet search for information on the surgical management of their given diagnosis. All patients had not previously had surgery as part of their IBD management. The survey was conducted following ethics approval from our local institution.

Two researchers then performed separate searches using the search engine defined by the patients with the terms 'surgery for Crohn's disease' and 'surgery for ulcerative colitis'. These searches were conducted in September 2019, with the geographical location set to Australia. The two researchers then independently identified the first 25 websites for each search term. The number of websites identified satisfied the number reported by 97% of patients surveyed. These were conjointly examined against the following inclusion and exclusion criteria.

### ***Inclusion criteria***

Websites on Crohn's disease and surgical management or ulcerative colitis and surgical management; Written in the English language.

### ***Exclusion criteria***

Non-informative articles (example- patient experience forums/blogs); advertisement links on Google searches; and duplicate websites.

### ***Quality of content***

Two researchers independently evaluated the quality of each identified website using the DISCERN instrument, a validated tool for analysing health information regarding treatment options.<sup>22</sup> A total of 15 question items were rated on a scale of 1 to 5, and an overall rating was determined for the final question item according to DISCERN scoring guidelines of "high, moderate, or low". This then correlated to an overall quality of "poor, fair or good".

### ***Readability of content***

The Flesch Reading Ease Score was calculated for each website using an online tool (<https://www.webfx.com/tools/read-able>). The FRES is a tool which assesses the "how difficult a passage in English is to read" based on sentence and word length.<sup>23,24</sup> This score is commonly used to assess the readability of written health-care information materials. The score correlates to a level of education required to read the information with lower scores indicating lower readability.<sup>23,24</sup> For materials written with the intent of health education, the recommended level is a maximum of 6-8<sup>th</sup> grade (11-14 years of age) or a FRES of 60-89.<sup>25,26</sup>

### ***Statistical methods***

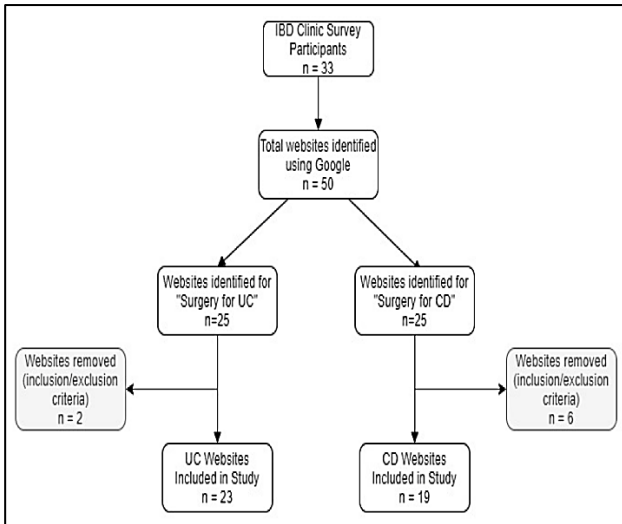
A sample size of greater than 30 patients was determined as the minimum number for results to be appropriately powered for normally distributed data.<sup>27</sup> Demographic results were defined using descriptive statistics. Cohen's Kappa ( $\kappa$ ) coefficient was performed to determine agreement between evaluators following the initial website analysis. Disagreements were resolved through discussion, and a final score and overall rating was agreed upon for each website.

## **RESULTS**

Thirty-three patients, (14 CD, 15 UC, 4 indeterminate colitis), were surveyed. The most common search term was 'surgery for Crohn's disease' or 'surgery for ulcerative colitis' and was used by 88% of patients. The most popular search engine was Google, with 100% of patients indicating they would utilize this search tool first.

Eighty-eight percent of patients indicated that they would not view more than 10 sites, with 97% of responses ranging from one to 20 sites.

Based on this, the initial website search identified 25 websites for CD and UC. After application of the inclusion and exclusion criteria, 19 CD and 23 UC websites were assessed (Figure 1).

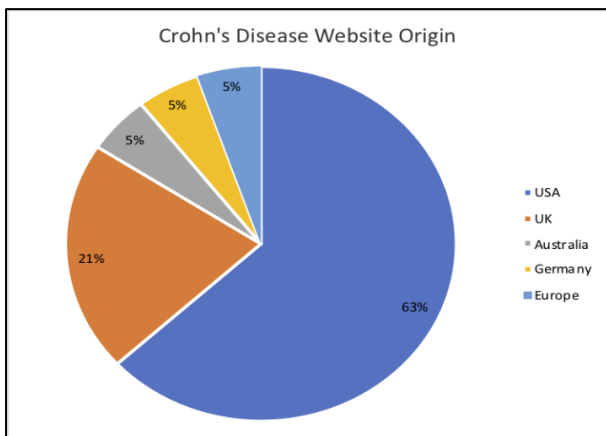


**Figure 1: Flow chart for website selection and inclusion.**

**Website content analysis**

*Crohn's disease*

Of 19 CD websites, 12 (63%) were published in the USA, four (21%) in the UK, the remaining three each from Australia, Germany and Europe respectively (Figure 2). Twelve (63%) websites had been updated more than two years ago or provided no reference to the date of publication or when the information was last updated. Only 7 (37%) websites had been updated in the last two years with 4 (21%) having been updated within the last 12 months.

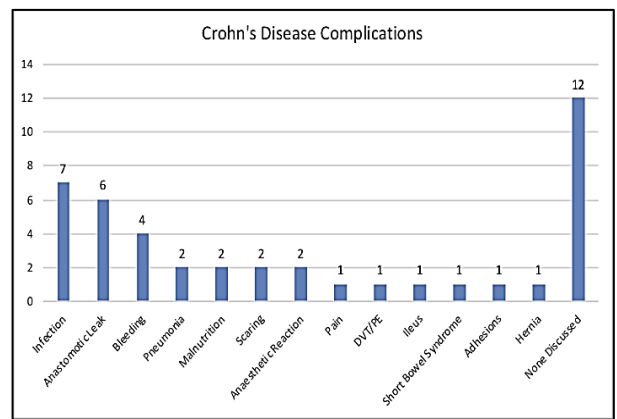


**Figure 2: Crohn's disease website origin when a search is conducted within Australia.**

Seventeen (89%) websites were open access with two (11%) requiring a paid subscription to access. Patients were the target audience of 11 (58%) websites, whilst eight websites (42%) contained medical literature, targeted at clinicians. Two (18%) patient orientated websites had been updated within the last year, four

(36%) were updated within the last two years, and five (45%) were updated more than two years from the search date. Of the medical literature websites, two (25%) were revised within the last year, three (38%) were revised within two years and greater than two years, respectively. No website provided links to patient advocate groups or IBD associations, unless the website was published by one of these support groups.

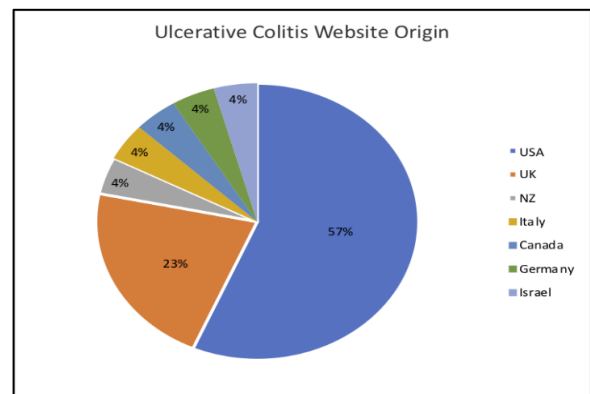
Of the 19 websites reviewed, 12 (63%) did not discuss any of the complications of surgical treatment. When complications were discussed the most commonly mentioned included bleeding, anastomotic leak and infection (Figure 3).



**Figure 3: Crohn's disease complications.**

*Ulcerative colitis*

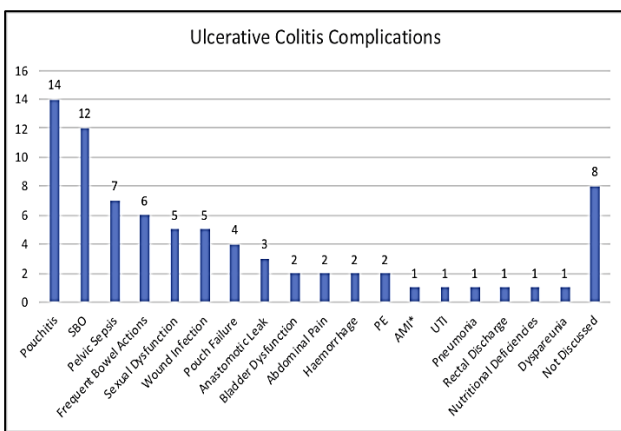
Of the 23 UC websites identified, the majority were published in the USA (13, 57%). A further five (22%) were British. The remainder were published in New Zealand, Italy, Canada, Germany and Israel (Figure 4). Sixteen (70%) websites were last updated more than two years ago or provided no reference to the date of publication or when the information was last updated. Finally, seven (30%) websites were updated within the last two years, resulting in four (17%) websites having been updated within the previous 12 months.



**Figure 4: Ulcerative colitis website origin.**

Twenty (87%) publications were open access, with three (13%) requiring a paid subscription. Patients were the target audience of 14 (61%) websites, whilst nine (39%) targeted clinicians.

Among the 23 websites reviewed, eight (35%) did not outline any complications of treatment. Only 14 (61%) mentioned pouchitis and 12 (52%) discussed small bowel obstruction (SBO). Figure 5 outlines all complications of UC surgery mentioned in the reviewed websites. There was a total of five different operations discussed for UC among the 23 websites reviewed (Figure 6). The two most commonly discussed procedures included restorative proctocolectomy with ileal pouch anal anastomosis (IPAA) (83%) and proctocolectomy with ileostomy (57%).



\*AMI (acute myocardial infarction) in the perioperative or post-operative period.

Figure 5: Ulcerative colitis complications.

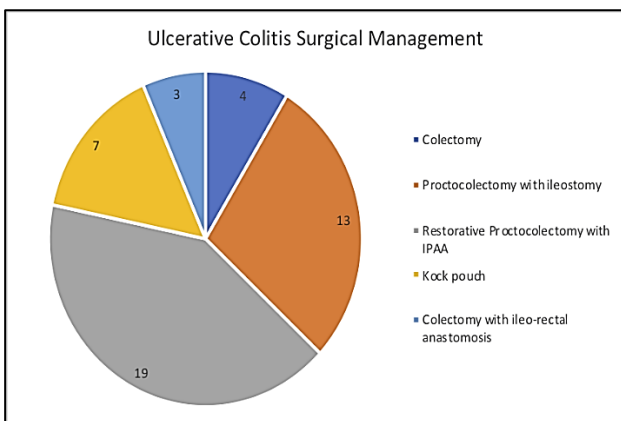


Figure 6: Ulcerative colitis surgical management.

**Readability**

The mean FRES for readability of CD websites was 35.8 ( $\pm 11.8$ , range 15.7-57.7), whilst for UC websites the mean FRES was 35.7 ( $\pm 11.3$ , range 19.4-54.3). Both of these mean scores are considered a difficult reading level.

The readability of websites aimed at patients had an average readability of 41.5 ( $\pm 10.9$ , range 15.7-57.7) and 41.0 ( $\pm 10.0$ , range 20.9-54.3) for CD and UC respectively. Whereas the average FRES for sites containing only medical literature was 25.5 ( $\pm 3.1$ , range 21.9-30.7) and 29.3 ( $\pm 9.6$ , range 19.4-51.4) for CD and UC respectively.

**Quality of information according to DISCERN**

Of the CD websites assessed using DISCERN, two (11%) were rated as being of high quality, whilst 12 (63%) and five (26%) were rated as being of moderate and poor quality, respectively. Three (13%) UC websites were of high quality, with the remaining 14 (61%) and six (26%) being of moderate and poor quality respectively. Detailed score distributions for each of the 15 questions in the DISCERN instrument can be seen in Figure 7 and 8. A Cohen's Kappa value of 0.80 for the CD data set and 0.77 for UC was calculated, indicating substantial agreement between both researchers.

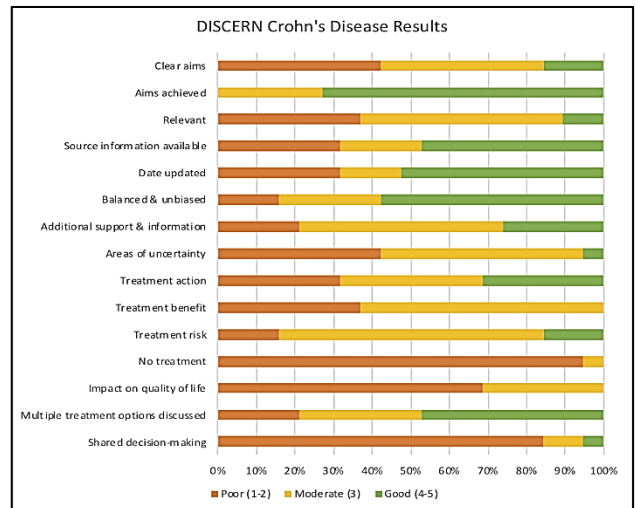


Figure 7: Crohn's disease DISCERN tool results.

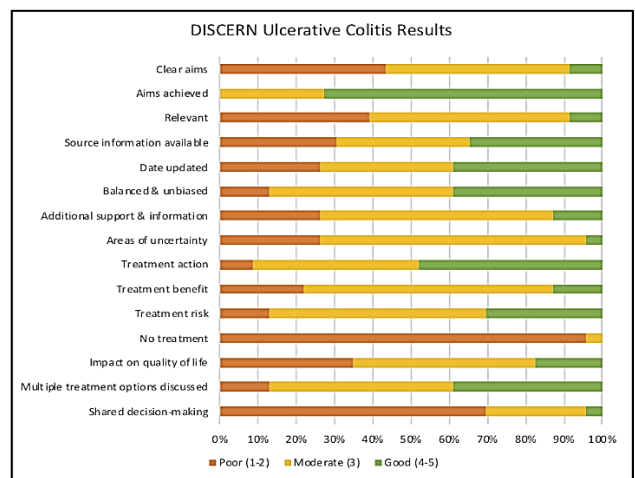


Figure 8: Ulcerative colitis DISCERN tool results.



## DISCUSSION

Patient education is crucial in the management of complex diseases.<sup>28</sup> Consultation time for patients and the provision of multidisciplinary support is limited in our current resource limited healthcare system. As a result, many patients are using the internet to understand more about their surgical management.

From our study, the majority of CD and UC websites originated from the USA and the UK. Only one of the 42 websites was found to be of Australian origin. Up to date information was lacking; 63% of CD and 70% of UC websites had not been updated within two years and provided no publication or review date. This raises concerns regarding the applicability and appropriateness of current information available to Australian IBD patients.

The readability of CD and UC websites were almost identical, with mean scores of 35.8 and 35.7, respectively. When websites were divided by target audience, patient orientated websites were easier to read with mean readability scores of 41.5 and 41.0 for CD and UC respectively. Unsurprisingly, medical clinician websites were harder to read as they were assessed to have lower mean readability scores, (25.5 CD and 29.3 UC respectively).

Forty percent of all websites analysed were medical literature resources, targeted at health care professionals, with the remaining being designed for patients. Despite patient orientated websites being easier to read when compared to medical sites, the average website reviewed in this article was defined as being difficult to understand (FRES score of between 30-50), akin to a college level education material. Furthermore, the website that had the highest FRES (57.7 rated as being fairly difficult), requires a minimum education level of between grade 10-12. It must be noted that the accepted standard reading difficulty for patient centered information is a FRES of 60-89.<sup>25,26</sup>

In our cohort, we found that all websites were all too complex for patients. The evidence in the literature is that only 11-16.9% of IBD patients may have a tertiary level education.<sup>29,30</sup> Similar studies from the UK and US has also found that the readability of sites exceeded the recommended level for internet-based patient information for IBD surgery.<sup>17,21</sup>

With regards to quality of information presented, only five of the 42 (12%) websites reviewed were rated of high quality using the DISCERN tool (two CD and three UC websites). Of these five websites, three were of very difficult readability and the remaining two of a difficult level, potentially inappropriate for our patient population to understand.

There were, however, some notable positive findings on website quality. Websites provided high quality information on summarising that there are multiple treatment options available to patients (47% CD and 39% UC). Similarly, we found that the mechanism of action for each treatment was relatively well explained in 48% of UC websites; however this percentage fell to 32% in CD websites. Of the CD websites, balanced and unbiased information (58%) was frequently scored high quality. Ulcerative colitis websites also outperformed CD websites when discussing the associated risks of each treatment option, with 30% of UC and 16% of CD websites recording high quality scores.

There were areas that consistently received poor or moderate rating on the DISCERN tool. Areas of uncertainty, shared decision making, treatment benefit, effect of no treatment and impact on quality of life were all poorly addressed amongst CD and UC websites. Of these categories, only impact on quality of life amongst UC websites received high quality scores for >15% of websites. No website reviewed in this study resulted in a high-quality score when discussing the effect of “no treatment”. This finding was also reported in two UK studies assessing UC and CD online educational materials.<sup>19,20</sup> Furthermore, no CD website was rated as high quality for the impact on quality of life and treatment benefit, whilst these categories were high quality in 17% and 13% of UC websites respectively.

Post-operative complications (Figures 3 and 5) were poorly addressed in most websites. Surprisingly, 63% of CD websites made no mention of post-operative complications; this reduced to 35% in the UC websites we reviewed. This illustrates a major deficiency in the information provided to the public. Complications and risks associated with surgery needs to be discussed in detail as it is essential information that patients need to understand prior to surgical therapy. This outlines a clear gap in crucial information that could lead patients to not fully comprehending the risks associated with surgical management for IBD.

Poor quality information is a consistent finding in internet-based patient resources for IBD over the past 15 years.<sup>16,19,20,31</sup> Education material development guidelines should be used to help generate patient appropriate information resources. Defining the target audience and using appropriate language, which means targeting to a 6-8<sup>th</sup> grade literacy level are important first steps.<sup>25,26</sup> Other educational techniques shown to promote greater health literacy include the use of positive examples of what patients can do or change, rather than focus on what to avoid or stop. In addition, we need to ensure that health information is culturally appropriate for the given target audience.<sup>24</sup>

This study has several potential limitations. Only a small number of IBD clinic patients at a single centre were surveyed to determine search terms and approximate

number of sites to be assessed. A multi-centre approach (including rural patients from a non-tertiary centre) and a larger sample size may more accurately reflect IBD patient preferences in Australia.

Only websites written in the English language were included. Given the multicultural landscape of Australia, websites in other languages may be utilized by patients and unaccounted for. Furthermore, this study identified the top 25 sites for each search term in September 2019. Given the changing ranking of sites, this study only captures a small number of sites at a specific time point. The quality of websites may also differ with the search set to alternate geographical locations.

In addition, readability tests only measure the complexity and length of words and sentences used within the written text. It does not take into account its organization, syntax, patient familiarity or visual content which may alter comprehensibility.

Whilst the DISCERN instrument used to assess the quality of websites in this study is a validated tool, individual evaluation may be partially subjective. However, agreement between evaluators was accounted for through calculation of the Cohen kappa coefficient.

Finally, this study only evaluated the quality of sites and did not formally assess accuracy.

## CONCLUSION

Given the lack of up to date publications, low readability and website quality overall, there is a great need for the development of patient targeted health literature for the surgical management of IBD. Information should be focused around ensuring these educational aids are designed at a middle school literacy level, allowing for clinicians to direct patients to high quality websites that would aid in patient care.

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