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Variable Quality and Readability of Patient-oriented Websites on Colorectal Cancer Screening

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BACKGROUND & AIMS:

The efficacy of colorectal cancer (CRC) screening is dependent on participation and subsequent adherence to surveillance. The internet increasingly is used for health information and is important to support decision making. We evaluated the accuracy, quality, and readability of online information on CRC screening and surveillance.

METHODS:

A Website Accuracy Score and Polyp Score were developed, which awarded points for various aspects of CRC screening and surveillance. Websites also were evaluated using validated internet quality instruments (Global Quality Score, LIDA, and DISCERN), and reading scores. Two raters independently assessed the top 30 websites appearing on Google.com. Portals, duplicates, and news articles were excluded.

RESULTS:

Twenty websites were included. The mean website accuracy score was 26 of 44 (range, 9-41). Websites with the highest scores were www.cancer.org, www.bowelcanceraustralia.org, and www.uptodate.com. The median polyp score was 3 of 10. The median global quality score was 3 of 5 (range, 2-5). The median overall LIDA score was 74% and the median DISCERN score was 45, both indicating moderate quality. The mean Flesch-Kincaid grade level was 11th grade, rating the websites as difficult to read, 30% had a reading level acceptable for the general public (Flesch Reading Ease > 60). There was no correlation between the Google rank and the website accuracy score ($r_s = -0.31$; P = .18).

CONCLUSIONS:

There is marked variation in quality and readability of websites on CRC screening. Most websites do not address polyp surveillance. The poor correlation between quality and Google ranking suggests that screenees will miss out on high-quality websites using standard search strategies.

Keywords: Worldwide Web; Patient Information; Adenoma; Colonoscopy; Consumer Health Information; Fecal Occult Blood Test.

Screening is effective in reducing the burden of colorectal cancer (CRC) and many countries have implemented CRC screening programs. The success of CRC prevention is highly dependent on participation in the screening program. Initial participation and subsequent adherence to surveillance can be influenced by enhanced knowledge about CRC screening and colonoscopy outcome. As more screening programs are implemented worldwide, providing adequate patient-oriented information is increasingly important. Most organized screening programs approach individuals for screening on a voluntary basis without personal contact with a health professional. Accordingly, these individuals may search for additional information on screening themselves.

The internet is widely regarded as an important channel of health information.^{6,7} In Western countries,

more than half of the population uses a smartphone, allowing instant and rapid access to the World Wide Web.⁸ However, few regulations control the information that individuals or organizations list on their websites. A systematic review reported that 70% of studies identified quality issues with health- and disease-focused internet websites.⁹ Because the efficacy of a CRC screening program is dependent on informed participation, assessing the availability and quality of online information aimed at screenees is of crucial importance.

Abbreviations used in this paper: CRC, colorectal cancer; FOBT, fecal occult blood test; FRE, Flesch Reading Ease score; IQR, interquartile range; r_s , Spearman rho.

2 Schreuders et al

Therefore, the aim of this study was to rate the quality, accuracy, and readability of web-based information on CRC screening from a screenee perspective.

Methods

Internet Search Strategy

Web sites were identified by searching the World Wide Web with Google.com (Mountain View, CA), the most frequently used internet search engine. The search was performed with English settings, with location tracking and search activity history switched off so that search results were not influenced by location or past searches. Searches were performed in 2014, 2015, and 2016. The following search terms were used: "colorectal cancer screening" OR "bowel cancer screening" OR "colon cancer screening" (quotation marks included). The search terms used reflect the most searched terms listed in the statistics provided via Google Trends (Supplementary Figure 1).

It is known that internet searchers do not typically view more than a few search hits and usually choose one of the first results displayed by the search engine. We therefore decided to examine the first 30 hits, corresponding with the first 3 pages of Google searches.

Inclusion and Exclusion Criteria

English websites were included only if the main part of the site dealt with educational information about CRC screening. Websites that merely contained portal links to other sites were excluded, as were duplicate websites, news articles, and sites containing irrelevant information (eg, advertising, retail sites, or patient fora).

Accuracy Assessment

The variability and accuracy of the information provided by each website on key facts about CRC screening and surveillance was investigated. For this purpose a website accuracy score specific for CRC screening was developed (Table 1). In addition, a separate polyp score for colorectal polyps was developed to assess information on important aspects of polyps, colonoscopy outcome, and surveillance guidelines (Table 2). The website accuracy score and polyp score consist of a list of key items deemed relevant for CRC screening and surveillance. They were generated through evaluation of the literature and discussions with key stakeholders. The website accuracy score and polyp score went through 5 iterations and were pretested twice before their final use, using a random selection of websites. The range of scores was 0 to 44 for the website accuracy score and 0 to 10 for the polyp score. If a website did not discuss or name an item of the website accuracy score or polyp score, zero points were awarded for that item. Items had to be presented clearly on the website; the search

Table 1. Colorectal Cancer Screening–Specific Website Accuracy Score Components and Percentage of Websites That Were Awarded Points for These Items

Website information	Websites,
components (maximum, 44 points)	n (%)
CRC general information	
Description of the colon/bowel/large intestine	15 (75)
Image of the anatomy of the intestines	15 (75)
Explanation of polyp as a precursor of	17 (85)
colorectal cancer	` ,
Development of a polyp into malignancy	8 (40)
is a slow process (takes years)	
Colorectal cancer can be prevented by	15 (75)
removing precancerous polyps/adenomas	
Causes of CRC	
Risk factors	0 (45)
Unknown	3 (15)
Age, >50 y Sex, male	13 (65)
History of previous polyps	0 (0) 15 (75)
Family history of colorectal cancer	17 (85)
Hereditary/familial adenomatous	14 (70)
polyposis/Lynch syndrome	()
Lifestyle (2 points possible)	
Unhealthy lifestyle (general)	
Unhealthy diet (low fiber, high fat, red meat)	
Smoking	
Alcohol	
Obesity	
Mentions 1–2 lifestyle factors: 1 point	1 (5)
Mentions ≥3 lifestyle factors: 2 points	13 (65)
Symptoms of colonic polyps/CRC	44 (55)
Most polyps are asymptomatic	11 (55)
Mentions symptom(s) such as: blood in stool/rectal bleeding, change in bowel	13 (65)
habit, unexplained weight loss, tenesmus	
(false urge)	
Recommendation to contact medical doctor in	11 (55)
case of symptoms	()
Screening for CRC	
Mentions that there are different methods of	16 (80)
screening	
The detection and removal of polyps is the	15 (75)
main purpose of the screening program for	
colorectal cancer	7 (05)
Mentions that not all tests have same accuracy	7 (35)
Mentions that not all tests have same patient burden	7 (35)
Colonoscopy is gold standard/most accurate	7 (35)
for diagnosing polyps	7 (55)
Colonoscopy	20 (100)
Explanation of procedure	17 (85)
Explanation of risks (bleeding and perforation	14 (70)
are mentioned)	
Explanation of polypectomy	13 (65)
Explanation of bowel preparation	13 (65)
Mentions flexible sigmoidoscopy	15 (75)
Explanation of procedure	13 (65)
Explanation of risks	8 (40)
Mentions FOBT (immunochemical or guaiac)	20 (100)
Explanation of procedure Has to be repeated every 1-2 years	16 (80) 13 (65)
Stresses importance of repeated screening	7 (35)
Explains possibility of	11 (55)
false-positive/-negative results	(55)
, 3.	

Table 1. Continued

Website information components (maximum, 44 points)	Websites n (%)
Mentions barium enema	9 (45)
Poor detection of (pre)cancer	3 (15)
Mentions CT colonography	11 (55)
Explanation of procedure	10 (50)
Explanation of risks	8 (40)
Mentions that all tests, when positive,	9 (45)
need to be followed by colonoscopy	
Mentions surveillance after colonoscopy in case of adenomas	3 (15)
Mentions that frequency of screening is different per test	7 (35)
Describes possibility of interval carcinomas (CRC after negative test)	4 (20)
Describes limitations of screening such as overdiagnosis and overtreatment	5 (25)

NOTE. The maximum number of points is 1 per item, unless otherwise specified.

function of the website was not used to locate this information.

Quality Assessment

In addition to a website accuracy score and a polyp score, a selection of validated scores was used to assess the website quality and reliability. The overall quality of each website was rated using the global quality score. This is a previously validated 5-point Likert scale to rate

Table 2. Polyp Score Items and Percentage of Websites That Were Awarded Points for These Items

Website information components	Websites, n (%)
Polyp score (maximum 10)	
Description of what a polyp is:	15 (75)
growth/mushroom/lump in the lining of the	
large bowel	
Image of a polyp	9 (45)
Prevalence of people with polyps in population	6 (30)
Explains that there are different types of polyps	9 (45)
Explains that not all polyps have an equal risk of	10 (50)
turning into colon cancer	
Explains differences between adenoma and hyperplastic polyp	4 (20)
Mentions that some polyp characteristics have a	3 (15)
higher risk of malignant degeneration	, ,
(ie, histologic findings) (villous aspect)	
Mentions polyp size is a risk factor of malignant degeneration	3 (15)
Influence of degree of cleanliness of bowel on polyp detection	2 (10)
Explains surveillances intervals after polypectomy	2 (10)

the overall quality of a website (Table 3).^{12,13} It incorporates the accessibility of the information within the website, the quality of this information, the overall flow of information, and how useful the website reviewer thinks the particular website would be to a screenee. The global quality score was assigned by the reviewer after evaluating the entire website.

The LIDA instrument is a validated question-based instrument, assessing the overall score (0-96), accessibility (0-54), usability (0-12), and reliability (0-30) of health care websites. The scores are reported as percentages of the maximum score: overall scores greater than 90% represent good results and scores less than 50% represent poor results. The online LIDA instrument was used for this study.¹⁴

The DISCERN tool is a validated 16-item questionnaire to rate the quality of written information on treatment choices for a health problem. 15,16 The first 8 questions address reliability, dependability, and trustworthiness of a website, the next 7 questions focus on the quality of information on treatment choices, and the last question addresses the overall quality of the site. Each question is rated on a 5-point scale with a maximum score of 80. Questions were answered as if participation in CRC screening was the treatment choice. The total quality of each website was classified as high (\geq 65 points), moderate (33–64 points), or low (16–32 points).

The amount of advertisements on each website was scored as none, little, average, or many, and agreed on through discussion by the 2 reviewers.

Readability Assessment

Readability, referring to the reading difficulty based on word and sentence length, was assessed by the use of 2 readability scores. The Flesch Reading Ease Score (FRE) assigns a value between 0 and 100 whereby a higher value represents a greater ease of reading. A section with a score of 90–100 is considered to be very easily understood, greater than 60 is an acceptable level of difficulty for the

Table 3. Global Quality Score Criteria Used to Score Websites on CRC Screening

Score	Global quality score description
1	Poor quality, poor flow of the site, most information missing, not at all useful for patients
2	Generally poor quality and poor flow, some information listed but many important topics missing, of very limited use to patients
3	Moderate quality, suboptimal flow, some important information is discussed adequately but other information is poorly discussed, somewhat useful for patients
4	Good quality and generally good flow, most of the relevant information is listed, but some topics are not covered, useful for patients
5	Excellent quality and excellent flow, very useful for patients

CT, computed tomography.

4 Schreuders et al

general public, and less than 30 is considered very difficult to read.¹⁷ The Flesch–Kincaid grade level uses the same input variables as the FRE score and outputs a US school grade indicating the average school grade able to read the text.¹⁷ The American Medical Association Foundation states that health-related materials for patients should be written at a level appropriate for those in the sixth grade or below.¹⁸ The FRE score and the Flesch–Kincaid grade level score were calculated using the Microsoft Word 2007 program (Santa Rosa, CA). A random 100-word sample of text was extracted from each website and pasted into the program by both reviewers independently.

Statistical Analyses

The website assessment was performed by 2 independent raters (E.H.S. and E.J.G.). For the website accuracy score assessment, any difference in score between the reviewers was resolved through discussion and by re-review of the website by both reviewers together to generate a single score for each website. Consensus in case of disagreement was achieved through discussion with a third reviewer (S.J.O.V.v.Z.). For other quality parameters, the mean score of both website raters was used. Correlations between different quality parameters were analyzed using the Spearman rank-correlation coefficient because of non-normality of the data. Statistical tests were performed with IBM SPSS software (version 21.0 Armonk, NY) and GraphPad Prism 5. A 2-sided P value less than .05 was considered significant. All authors had access to the study data and reviewed and approved the final manuscript.

Results

The Search

The Google search was performed on April 9, 2014, and resulted in more than 2,000,000 hits. The first 30 results were evaluated, of which 20 websites were included. Two portal websites leading to another site, 1 duplicate site, 1 website with information on insurance reimbursement, 3 news articles, and 3 guidelines and medical articles clearly aimed at health professionals were excluded. All websites were accessed between April 2014 and June 2014. Additional Google searches were performed on August 7, 2015, and February 22, 2016, to evaluate possible changes in Google rank position. Most websites were published by a professional medical society (35%) or a governmental organization (30%) (Figure 1). Almost half of the websites were from the United States (45%), others were from the United Kingdom (25%), Canada (20%), and Australia (10%).

Accuracy and Quality of Website Information

The mean website accuracy score was 26 (range, 9-41). Most websites contained general information on

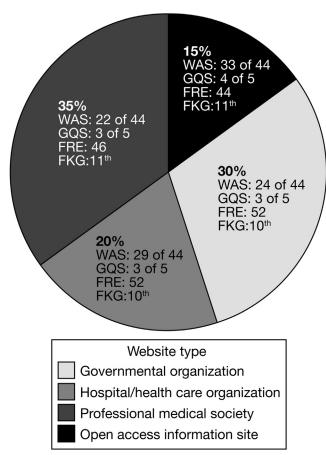


Figure 1. Mean website accuracy score, global quality score, and reading scores per website type. FKG, Flesch–Kincaid grade level; GQS, global quality score; WAS, website accuracy score.

CRC screening, but description and risk of different screening modalities and limitations of screening were not always captured (Table 1). The median global quality score was 3 (range, 2-5). This score indicates that the quality of information of most websites was moderate. On many sites, some information was discussed adequately, whereas other parts of information were missing and the overall flow of information was suboptimal. There was a strong positive correlation between the website accuracy score and the global quality score, with a Spearman rho (r_s) of 0.81 (P < .001) (Figure 2). The median polyp score was 3 (range, 0-10) (Table 2). The polyp score correlated positively with the global quality score ($r_s = 0.81$; P < .001). The median LIDA overall score was 74% (interquartile range [IQR], 11). The median LIDA score for accessibility was 88% (IQR, 8), for usability was 63% (IQR, 22), and for reliability was 52% (IQR, 26). The median DISCERN score was 45 (IQR, 20), indicating moderate quality. Ten percent of websites (2 of 20) were classified by DISCERN as high quality, 80% (16 of 20) were classified as moderate, and 10% (2 of 20) were classified as low quality. Both the validated LIDA and DISCERN had a moderate correlation with the website accuracy score: $r_s = 0.45 \ (P < .05) \ and \ r_s = 0.66 \ (P < .01)$, respectively. There was no correlation between the Google ranks and

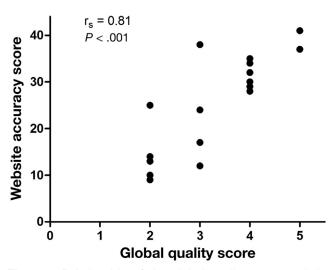


Figure 2. Relationship of the global quality score and the website accuracy score used to evaluate colorectal cancer screening websites.

the website accuracy score ($r_s = -0.31$, P = .18; $r_s = -0.47$, P = .08; and $r_s = -0.31$, P = .25 for the 2014, 2015, and 2016 searches, respectively).

Table 4 lists the top 5 websites as rated by CRC screening-specific website accuracy score and other evaluations of website quality. The complete scores per website are published in Supplementary Table 1. Eight websites had initial inter-rater website accuracy score differences of 8 or greater. Differences in scoring of the website accuracy score or the polyp score between reviewers were caused by oversight or differences in interpretation.

Readability of Websites

The mean FRE score was 48 (range, 27–76), 30% of the websites had a reading level acceptable for the general public defined by a FRE score of greater than 60. The mean Flesch–Kincaid grade level was 11 (SD, ± 2.2 ; range 5–16), indicating that the text would be understandable to an average 11th grade US student. The reading level of health care and governmental websites was the easiest, whereas the reading level of open-access information sites was the most difficult (Figure 2).

Advertisements

When assessing the amount of advertisements, 16 (80%) websites contained none, 2 (10%) websites contained a moderate amount of advertisements, and 2 (10%) websites contained many advertisements. The latter 2 were open-access websites. Websites published by governmental organizations contained no advertisements.

Discussion

This study shows that there is marked variation in the accuracy, quality, and readability of information on CRC screening websites and that most websites do not address polyp surveillance. The best 5 websites as ranked by the website accuracy score are www.cancer. org; www.bowelcanceraustralia.org; www.uptodate. com; www.macmillan.org.uk; and www.nlm.nih.gov/medlineplus. Their corresponding Google rank positions varied over time and some of these websites will be missed by standard Google searches (Table 4).

The poor correlation between website accuracy and Google ranking is especially concerning given the fact that Google is a prominent search engine. Internet users often do not go beyond the first page of a search, which can result in missing websites that provide high-quality information. This problem has been identified before. 12,13,19

Even though surveillance after colonoscopy, especially if adenomatous polyps were found, is important for CRC screening to reach its maximal efficacy, it was mentioned on only 15% of the websites. Surveillance intervals are based on findings during colonoscopy. However, clear and easy to understand information on how findings during a screening colonoscopy (ie, adenomatous polyps) determine the follow-up surveillance recommendations was lacking on most sites. This is reflected in the low overall median polyp score (3 of 10) and the fact that only 2 websites (10%) described the actual surveillance intervals. This is an important information gap because adherence to surveillance is influenced by enhanced knowledge. Previous studies have shown that patients may not be sufficiently aware of

Table 4. Top 5 Websites as Ranked by the Website Accuracy Score With the Corresponding Polyp Score, Quality Scores, Reading Scores, and Google Rank Positions

	Accuracy			Quality		Read	ability	Google rank		
Website	WAS PS		GQS	DISCERN	LIDA	FRE	FKG	2014	2015	2016
www.cancer.org	41	5	5	65	67%	62	9th	6	3	2
www.bowelcanceraustralia.org	38	2	3	35	58%	58	10th	5	Χ	29
www.uptodate.com	37	6	5	69	85%	28	14th	27	13	16
www.macmillan.org.uk	35	5	4	49	69%	48	11th	19	Χ	Χ
www.nlm.nih.gov/medlineplus	34	6	4	57	81%	59	8th	4	4	4

6 Schreuders et al

important endoscopic findings and the consequences this has for subsequent surveillance recommendations.^{3,21} Understanding the need for surveillance likely will motivate participants to adhere to surveillance recommendations.

The reading difficulty of most websites was far greater than the required standard. Only 5% of the websites met the recommended level by the American Medical Association Foundation of 6th grade or below. 18 This suggests that most websites are too difficult for the average reader and this may result in misunderstanding of information. Other studies evaluating patient information websites also documented that the required reading levels were high and above the recommended 6th grade level. 22–24 Our study showed that commercially funded websites were more difficult to read than governmental websites. This is in accordance with previous literature. 22

When evaluating the website accuracy scores, it became apparent that most websites only focused on the predominant screening test used in the country where the website originated, and did not provide information on other options for CRC screening. It is debatable whether it is necessary to inform screenees about all possible screening tests that are available. 25 However, providing information that several different options exist may help individuals, who are interested in screening, to make an informed decision.^{25,26} Colonoscopy and guaiac or immunochemical fecal occult blood test (FOBT) were described on all websites in detail. However, not all websites stressed the importance of the need for repeated screening when FOBT is used. This is despite strong evidence that repeating stool testing at regular intervals is of paramount importance for FOBT-based screening to be effective in the long term. Only 20% of the websites mentioned the possibility of the occurrence of interval carcinomas. This may be explained in part by the fact that this aspect of CRC screening has gained a lot of attention only during the past few years. However, not mentioning potential limitations of screening may stand in the way of informed decision making.27

A strength of this study was that the website accuracy score and the polyp score are CRC screening-specific evaluation tools. These content-specific outcome measures showed moderate to strong correlation with the validated generic outcome measures of the global quality score, LIDA, and DISCERN. This provides further evidence that the use of these CRC screening-specific outcome measures provide meaningful and relevant information. The advantage of the global quality score over LIDA and DISCERN is that it is short and easy to perform. We believe that the global quality score is a good score for overall flow and ease of use of any website providing health information.

This review systematically assessed the quality, accuracy, and readability of patient-oriented websites on CRC screening as well as polyp surveillance. Previous studies have reported on the quality of web-based

information regarding CRC surgery or treatment, but none were systematic reviews of existing websites. ^{23,28,29} Two other publications evaluated CRC screening websites but these did not include detailed information on polyps and surveillance. ^{30,31} An American study focused on the readability and suitability of 12 CRC screening websites. ³¹ However, these sites were self-chosen by the author. Another brief review examined 5 chosen websites and evaluated their content and usability. ³⁰ In both of these publications no apparent selection criteria for quality were used. Most of the listed websites did not appear in our original 2014 search results, or in the first 3 Google pages assessed in 2015 and 2016.

Our study had some limitations. Both the website accuracy score and the polyp score were not validated separately before use on the selected websites. However, the good correlation with other previously validated quality instruments suggests adequate content validity. We only searched using English search terms, thus only English websites were retrieved. Another possible limitation was the fact that quotation-based search terms were used, which require words to appear together in retrieved websites. The omission of quotation marks when searches are performed could lead to different results.

The internet increasingly is used by consumers to find relevant health information. There is evidence that experience and knowledge of internet use has a significant impact on the uptake of CRC screening. Furthermore, the credibility of cancer-related information on the internet is associated with population compliance with CRC screening, indicating the relevance of this study. We believe health care providers interested in developing websites on CRC screening, for example, for their own institutions, can use our approach to evaluate the quality and readability of provided information to develop the content of the site they are creating. Alternatively, they can recommend several of the high-quality websites that we identified, listed in Table 4, to health care consumers.

Physicians should be aware of the limitation of Google searching for CRC screening. Our study may be helpful in that regard because it provides a list of those websites that provide the highest quality information on CRC screening. However, it is important to remember that the internet is continuously evolving and that the quality of websites may change over time or new high-quality websites may be developed.

In conclusion, our study showed that there is marked variation in the overall quality of web-based patient information on CRC screening. Most websites lack important information regarding polyps and their importance for future follow-up surveillance colonoscopies. Several high-quality websites do exist, but poor correlation with Google ranking suggests that these websites may be missed. High-quality and readable websites are essential to provide patients with reliable information to make informed decisions on CRC screening and surveillance participation and to optimize efficacy.

Supplementary Material

Note: To access the supplementary material accompanying this article, visit the online version of *Clinical Gastroenterology and Hepatology* at www.cghjournal.org, and at http://dx.doi.org/10.1016/j.cgh.2016.06.029.

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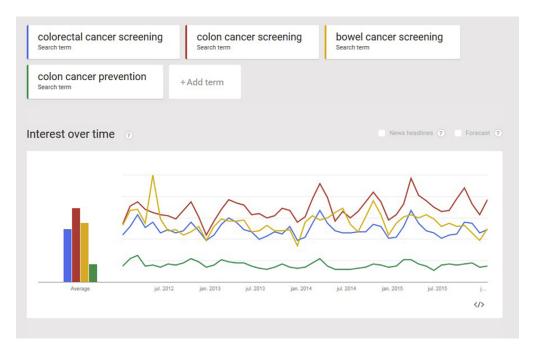
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Conflicts of interest

The authors disclose no conflicts.



Supplementary Figure 1. Interest over time.

Website URL

rank

Google Google

rank

LIDA

accessibility, usability,

LIDA

LIDA

reliability,

FRE

school

grade

FKG

points

Polyp

score

points

WAS

points

rank

GQS

points

DISCERN

points

LIDA

overall, %

Supplementary Table 1. Continued

Website URL	Google rank 2014	Google rank 2015	Google rank 2016	WAS points	Polyp score points	GQS points	DISCERN points	LIDA overall, %	LIDA accessibility, %	LIDA usability, %	LIDA reliability, %	FRE school grade	FKG points
www.bccancer.bc.ca/PPI/Screening/colorectal.htm	23	Х	Х	10	0	2	43	26	0	67	57	13th	33
www.healthpei.ca/colorectal	25	Χ	Χ	9	1	2	29	66	85	42	40	11th	46
www.uptodate.com/contents/colon-and-rectal- cancer-screening-beyond-the-basics	27	13	16	37	6	5	69	88	83	88	97	14th	28
www.asge.org/patients/patients.aspx?id=8074	29	16	17	13	1	2	38	67	88	50	37	11th	42

FKG, Flesch-Kincaid grade level; X, not in the first 3 Google page results.

^aURL changed to https://www.gov.uk/topic/population-screening-programmes/bowel. ^bURL changed to http://patient.info/health/screening-for-bowel-colorectal-cancer.