

# Information on the Internet about colorectal cancer: patient attitude and potential toward Web browsing. A prospective observational study

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**Background:** Patients with colorectal cancer who seek to improve their knowledge of health and treatment options can now access in a few seconds data that would previously have required hours of research. Our aim was to evaluate the attitudes of patients toward Web browsing for information on colorectal cancer.

**Methods:** We surveyed all patients attending a colorectal cancer follow-up clinic between January and August 2007 on their use of the Internet to obtain information on colorectal cancer.

**Results:** In all, 439 patients with mean age of 68.6 years participated in the study. Of these, 24% reported using the Internet to obtain colorectal cancer information. Most participants used the Google search engine. Only 13% of participants confirmed that colorectal cancer information on the Internet was helpful in decision-making. Patients under the age of 65 years were more likely to have Internet access ( $p < 0.001$ ), more likely to use the Internet to find colorectal cancer information ( $p = 0.005$ ) and more likely to access a site recommended by a colorectal specialist ( $p = 0.002$ ). Among Internet users, men were slightly more likely than women to use the Internet, although the difference was not significant ( $p = 0.20$ ).

**Conclusion:** The Internet is a useful tool for disseminating information about colorectal cancer. The best sites are still difficult for patients to distinguish from the thousands of sites returned by search engines. This study demonstrates that the level of potential interest is sufficient to justify the development of a departmental or regional colorectal cancer network of websites and indicates areas of interest for patients.

**Contexte :** Les patients atteints d'un cancer colorectal qui souhaitent à mieux connaître leur état et les possibilités de traitement peuvent maintenant consulter en quelques secondes des données qu'il leur aurait fallu chercher pendant des heures auparavant. Nous voulions évaluer les attitudes des patients à l'égard de la recherche sur Internet d'information au sujet du cancer colorectal.

**Méthodes :** Nous avons sondé tous les patients qui se sont présentés à une clinique de suivi du cancer colorectal entre janvier et août 2007 au sujet de l'utilisation d'Internet pour obtenir de l'information sur le cancer colorectal.

**Résultats :** Au total, 439 patients qui avaient en moyenne 68,6 ans ont participé à l'étude et 24 % d'entre eux ont déclaré avoir cherché sur Internet de l'information au sujet du cancer colorectal. La plupart des participants ont utilisé le moteur de recherche Google. Seulement 13 % des participants ont confirmé que l'information sur le cancer colorectal trouvée sur Internet les a aidés à prendre une décision. Les patients de moins de 65 ans étaient plus susceptibles d'avoir accès à Internet ( $p < 0,001$ ), plus susceptibles d'utiliser Internet pour trouver de l'information sur le cancer colorectal ( $p = 0,005$ ) et plus susceptibles de consulter un site recommandé par un spécialiste du cancer colorectal ( $p = 0,002$ ). Chez les internautes, les hommes étaient un peu plus susceptibles que les femmes d'utiliser Internet, même si la différence n'était pas significative ( $p = 0,20$ ).

**Conclusion :** Internet est un outil utile pour diffuser de l'information sur le cancer colorectal. Il demeure difficile pour les patients de distinguer les meilleurs sites parmi les milliers découverts par les moteurs de recherche. Cette étude démontre que le niveau d'intérêt possible suffit pour justifier la création d'un réseau de sites web sur le cancer colorectal au niveau du département ou de la région et précise les domaines d'intérêt des patients.

The Internet is becoming a widely accepted and accessible medium for the dissemination of information on colorectal cancer among patients, their relatives, the general public, allied health professionals and doctors. In addition, the Internet is continually expanding communication networks for all types of consumers. This expansion has been matched by an increase in the number of individuals using the Internet. The United Kingdom now has an estimated 35 million regular users of the Internet, second only to the United States.<sup>1</sup> Patients with colorectal cancer who seek to improve their knowledge of health and treatment options can now access in a few seconds data that would previously have required hours of research. These patients previously relied heavily on colorectal multidisciplinary teams for information conveyed verbally or through pamphlets, videos or books accessible on an outpatient basis. Those resourceful enough to obtain access to medical libraries and databases could only examine a fraction of the information that is now available on the Internet. The crucial difference between the information provided online and that available in more traditional sources is that the latter is usually subject to some form of peer review. Patients seeking information only through Internet searches may not be aware of the peer review process and the critical assessment to which published medical literature is subjected. The Internet provides no separation of scientifically proven conclusions from anecdotal information or commercially biased reports. Web pages can be set up by anyone and may be altered and/or removed at any time, with no effective way of protecting the general public from misleading medical information on colorectal cancer. A recently published article by our group<sup>2</sup> concluded that more than 50% of websites on colorectal cancer were commercially oriented and contained information on goods or private health services; less than 1% of the information was provided by professional societies like the Association of Coloproctology of Great Britain and Ireland (ACPGBI). Colorectal surgeons are gradually confronting this problem and various instruments have been developed in an attempt to evaluate the accuracy, readability, trustworthiness and credibility of colorectal cancer information on the Internet. We conducted an observational prospective study to assess the extent to which patients with colorectal cancer use the Internet to obtain information about the illness and treatment.

## METHODS

### *Participants*

We recruited participants among consecutive patients who underwent surgical treatment for colorectal cancer in the Worthing Hospital colorectal unit and were attending a colorectal cancer follow-up clinic between January and August 2007. Efforts were made to approach every patient entering the clinic on a given day who had not been previ-

ously approached for participation. A surgical research fellow (M.S.S.) approached patients in clinic, and their willingness to participate in the study was assessed using a scripted dialogue. Eligible participants included patients aged 18 years or older who could communicate sufficiently in English and who were neither medically nor mentally impaired to an extent that would prohibit participation. Patients provided verbal informed consent to participate in this study based on a scripted dialogue and were interviewed immediately after consent was obtained. Patients were told that all answers would be kept confidential and would not affect their care in any way.

### *Interview, interviewer and survey instrument*

Information was obtained from patients via a structured, face-to-face interview lasting 5–10 minutes. We designed the questionnaire, and some questions were adapted from prior studies.<sup>3–6</sup> The criteria used to determine the quality of information gathered from patients during the interview process was arbitrary. During the interview, all questions were read from a standardized questionnaire. Patients' responses were handwritten on the survey form by the surgical research fellow. Numerical codes were assigned to the hand-written responses, and the responses were entered into a database that we created in a Microsoft Excel (Microsoft Excel 2007 for Windows XP) spreadsheet.

The interviewer had a postgraduate medical degree and had attended a week-long training course in medical ethics. Furthermore, the interviewer had prior experience obtaining medical histories and conducting surveys among patients with various surgical conditions and underwent ongoing training in interview techniques at the University of London.

All survey questions were developed by us or adapted from prior studies. A pilot version of the self-designed questionnaire was administered among 20 patients from the same colorectal cancer follow-up clinic. We used those results and our experience to refine some questions to improve understanding. Information obtained from the patients included sociodemographic characteristics and clinical information specific to colorectal cancer. The questionnaire addressed access to computers and the Internet and exposure to Internet information on colorectal cancer and attempted to identify barriers to computers and Internet use. The questionnaire also asked about the type of colorectal cancer information sought on the Internet (if any), search strategies, assessment of the quality of the information obtained from the members of the multidisciplinary team or from the Internet and any discussion about Internet resources on colorectal cancer. We obtained local audit and ethics committee approval before the study began.

### *Statistical analysis*

We performed a  $\chi^2$  test to examine the association between categorical variables and Internet use. If any expected cell

sizes were less than 5, we conducted a Fisher exact test instead of the  $\chi^2$  test. We considered results to be significant at  $p < 0.05$ .

## RESULTS

We approached 489 patients for participation in the study, and the data of 439 patients were analyzed. We excluded 41 patients owing to duplication of clinic appointments during the study period. In addition, 9 patients refused to participate, with the most common reason being not feeling well enough to participate. Demographic characteristics of the patients are provided in Table 1. The mean age of par-

ticipants was 68.6 years. Twenty-four percent ( $n = 106$ ) reported using the Internet directly or through proxies (e.g., friends, family members) to search for colorectal cancer information. Most (39%,  $n = 41$ ) participants used the Google search engine to obtain colorectal cancer information online (Fig. 1). The 8 most common websites accessed to obtain information on colorectal cancer are listed in Table 2. The types of information sought on the Internet were treatment options (80%,  $n = 84$ ), general information on cancer (73%,  $n = 78$ ), ways to live with cancer (45%,  $n = 48$ ), nutrition and cancer (27%,  $n = 28$ ), news about cancer treatment/research (25%,  $n = 27$ ) and alternative therapies (9%,  $n = 7$ ). Overall, participants felt that colorectal cancer information on the Internet was not very helpful (Fig. 2). More than half (58%,  $n = 62$ ) of the participants who used the Internet reported that web-based information was not helpful because of perceived quality, incomprehensibility owing to use of medical terms and volume of information causing confusion. Only 13% ( $n = 14$ ) of participants confirmed that colorectal cancer information on the Internet was helpful in their decision-making. Among non-users of the Internet, 59% ( $n = 197$ ) had access to a computer and 43% ( $n = 143$ ) had access to the Internet. Non-users of the Internet were asked why they did not use the Internet. The most common barriers (Fig. 3) were lack of interest (54%,  $n = 180$ ), no computer access (47%,  $n = 156$ ), no Internet access (39%,  $n = 130$ ), not knowing how to use a computer or the Internet (34%,  $n = 113$ ), not knowing cancer information was available on the Internet or how to

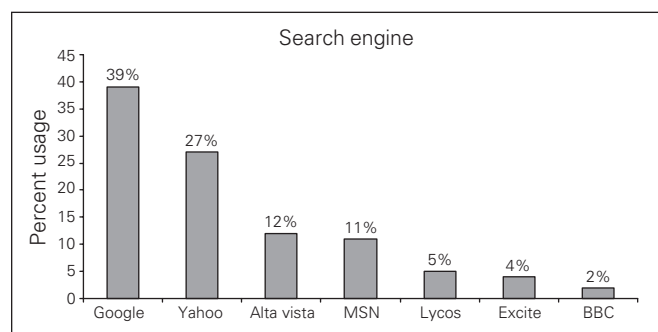
**Table 1. Demographic characteristics of study participants,  $n = 439$**

Characteristic	No. (%)*
Age, mean (range) yr	68.6 (36–93)
Sex	
Male	242 (55.0)
Female	197 (45.0)
Time since diagnosis, mean (range) mo.	71 (3–96)
Location of colorectal cancers	
Rectum	123 (29.0)
Sigmoid tumour	87 (20.0)
Left colon	97 (22.0)
Right colon	126 (29.0)
Procedure	
Open Hartman procedure	6 (1.4)
Laparoscopic Hartman procedure	2 (0.4)
Open anterior resection	29 (6.6)
Laparoscopic anterior resection	75 (17.0)
Open abdominoperineal resection	9 (2.0)
Laparoscopic abdominoperineal resection	7 (1.5)
Open sigmoid colectomy	23 (5.2)
Laparoscopic sigmoid colectomy	61 (13.8)
Open left/extended left hemicolectomy	12 (2.7)
Laparoscopic left/extended left hemicolectomy	84 (19.1)
Open right/extended right hemicolectomy	36 (8.2)
Laparoscopic right/extended right hemicolectomy	92 (20.9)
Total colectomy/proctocolectomy	3 (0.6)

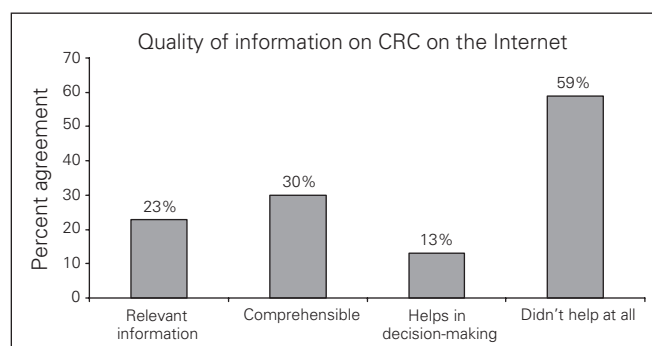
\*Unless otherwise indicated.

**Table 2. Specific websites visited by respondents who reported Internet use**

Website	%
www.colorectal-cancer.net	31
www.cancerbackup.org.uk	20
www.cancerhelp.org.uk	12
www.cancerscreening.nhs.uk	11
www.cancerresearchuk.org	11
www.nlm.nih.gov	7
www.cancer.org	4
www.cdc.gov	4



**Fig. 1.** Search engines used among patients with colorectal cancer to find information on their disease on the Internet.



**Fig. 2.** Quality of colorectal cancer (CRC) information on the Internet.

find it (21%,  $n = 70$ ), and access to a very efficient multidisciplinary team (10%,  $n = 33$ ). Non-users of the Internet who did have a computer and Internet access preferred not to use the Internet because they received enough information from their colorectal multidisciplinary team or because they were not interested in knowing more. In contrast, users of the Internet without access to a computer or the Internet (i.e., users who sought help from proxies to obtain colorectal cancer information) were happy with the performance of the local colorectal multidisciplinary team but wanted to explore more about colorectal cancer treatment options and follow-up protocols. Judgment of the information provided by local colorectal multidisciplinary teams was excellent among 78% ( $n = 342$ ), very good in 10% ( $n = 43$ ), good in 5% ( $n = 22$ ), fair in 4% ( $n = 18$ ) and poor in 3% ( $n = 14$ ) of patients with colorectal cancer.

Patients under the age of 65 years were more likely to have Internet access than those older than 65 ( $n = 359$ , 81.7% v.  $n = 40$ , 9.1%;  $p < 0.001$ ), more likely to use the Internet to find colorectal cancer information ( $n = 314$ , 71.6% v.  $n = 74$ , 16.9%;  $p = 0.005$ ) and more likely to access a site recommended by a colorectal specialist ( $n = 306$ , 69.5% v.  $n = 102$ , 23.3%;  $p = 0.002$ ). Men were slightly more likely than women to use the Internet ( $n = 55$ , 52% v.  $n = 42$ , 40%); however, this difference was not significant ( $p = 0.20$ ).

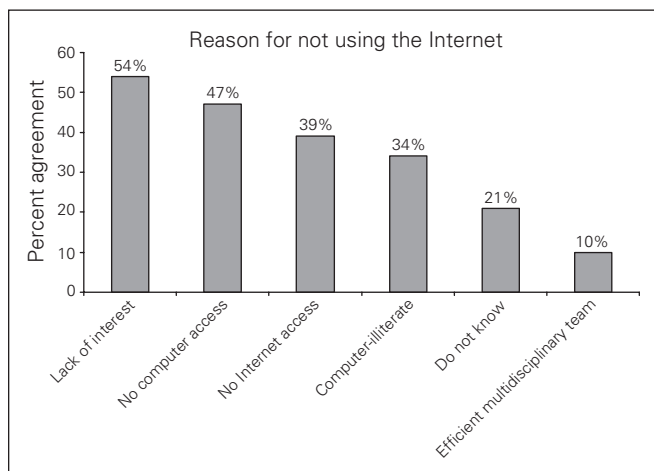
## DISCUSSION

Use of the Internet to obtain health information about colorectal cancer is becoming widespread among individuals seeking medical care, with millions of individuals going online each day to find health care information. Studies of Internet use among cancer patients suggest that 30%–40% of patients seek information about their cancers on the Internet,<sup>5,7,8</sup> although in socioeconomically disadvantaged populations there is evidence that this proportion of patients is lower.<sup>9</sup> To our knowledge, ours is the first study

of a large cohort of patients with colorectal cancer seeking health care information on the Internet. Our cohort is a mixed population, including all types of socioeconomic groups, mixed sex and a wide age range (36–93 yr). The rate of Internet use of 24% is less than previously reported values of 60%–83%.<sup>3,4</sup> The reason for this shortfall is not very clear but may reflect specific local factors, including age range, availability of Internet facilities and up-to-date technology such as broadband (which is known to lag in the United Kingdom compared with the United States and other areas of Western Europe).<sup>4</sup> In addition, greater Internet use was reported only among patients with cancers other than colorectal cancer.<sup>10</sup> Despite these facts, to our knowledge our study still reports the highest percentage of Internet users among patients with colorectal cancer.<sup>3,4</sup>

All patients using the Internet to obtain colorectal cancer information used search engines. These search engines directed them to a number of websites, leaving them vulnerable to misleading or confusing information. Studies have shown that as many as 63% of medical information websites on colorectal cancer were commercial in nature, with 23% of all websites offering unconventional or even misleading information.<sup>2,11</sup> A follow-up of a previous *BMJ* study examining the quality of information on the Internet, showed that, although there has been some improvement over the last few years, serious concerns still exist about many websites.<sup>12</sup> Many instruments have been designed and developed to measure the quality of health care information on the Internet, but their validation is still controversial. In our study, 59% of patients reported that the Internet information on colorectal cancer did not help them at all.

The findings from the present study suggest that patients are not as dependent on the Internet as they are on the colorectal cancer multidisciplinary team for information; our results show that 97% patients with colorectal cancer are happy with the performance of their local source of information. This has already been shown by Baker and colleagues,<sup>13</sup> who reported that



**Fig. 3.** Reasons among patients with colorectal cancer for not using the Internet to find information about their disease.

“approximately 40% of respondents with Internet access reported using the Internet to look for advice or information about health or health care in 2001. Six percent reported using e-mail to contact a physician or other health care professional. About one third of those using the Internet for health reported that using the Internet affected a decision about health or their health care, but very few reported impacts on measurable health care utilization; 94% said that Internet use had no effect on the number of physician visits they had and 93% said it had no effect on the number of telephone contacts. Five percent or less reported use of the Internet to obtain prescriptions or purchase pharmaceutical products.”

Local multidisciplinary colorectal cancer teams are still the major source of colorectal cancer information for patients and the public. It is difficult to conclude from this study why patients with colorectal cancer find local colorectal multidisciplinary teams more helpful in disseminating

colorectal cancer information than the Internet. However, patient–doctor and patient–nurse interaction may be responsible for higher satisfaction.

### Limitations

We recognize several limitations in our study. Although to our knowledge it is the largest study on the use of the Internet conducted exclusively among patients with colorectal cancer to date, it was conducted among a convenience sample within a single district general hospital located on the southern coast of England, and the possibility of cohort bias cannot be excluded. Second, the survey as designed did not delve deeply into the effects of Internet information on patients' decisions and the quality of clinical care provided. This is an area of patient-centred outcomes that needs further study, given the many public and private efforts to provide Internet access to patients with colorectal cancer and given the overall growing use of the Internet to obtain health information. Third, no distinction was made between patients with acute problems (e.g., bleeding per rectum) and those with chronic disorders (e.g., intra-abdominal adhesions). It is conceivable that significant differences may exist between these groups. Finally, no attempt was made to assess satisfaction with information already available from other sources (with the exception of a colorectal cancer multidisciplinary team) such as patient leaflets, packages, videos and support groups.

### CONCLUSION

It seems likely that as Internet use increases with time there will be a corresponding increase in Internet use to obtain colorectal cancer information, especially among older patients (mean age in our group was 69 years). Rather than seeing the Internet as a foe, we could use it as an opportunity to create a partnership with patients. As colorectal surgeons, we must become more proficient in the use of the Internet for disseminating colorectal cancer information, and we must also be able to guide patients to reputable sites, such as the website of the Association of Coloproctology of Great Britain & Ireland, PubMed, the National Library for Health and Cancer Back-up. Reliable information provided via the Internet can actually improve patients' understanding of colorectal cancer and even take some burden off the colorectal surgeon in this environment of increased expectations and reduced consultation times. Actual rates of Internet use by patients to find colorectal cancer information are currently higher in our local population, in keeping with the findings of previous studies. However, this study demonstrates that the levels of poten-

tial interest are sufficient to justify the development of a departmental or regional colorectal cancer network website and indicates areas of interest for patients to be included within the website.

**Competing interests:** None declared.

**Contributors:** Drs. Sajid and Baig designed the study. Drs. Sajid and Shakir acquired and analyzed the data. Dr. Sajid wrote the article, which Drs. Shakir and Baig reviewed. All authors approved its publication.

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