

Your patient information website: how good is it?

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Abstract

Aim The study was designed to evaluate the accessibility, reliability and readability of information on familial adenomatous polyposis (FAP) on the Web.

Method We searched for the keywords 'familial adenomatous polyposis' using the three most popular search engines (Google™ Yahoo™, MSN™) and looked at the first 50 websites. The LIDA tool (an online validation instrument for healthcare websites) was used to assess their accessibility, usability and reliability. The readability of each document was assessed using the Flesch Reading Ease (FRE) score. We also checked whether each site was certified by the Health on the Net Foundation Code of Conduct (HONcode) – the oldest and most trustworthy code for medical and health-related information available on the Internet.

Results Of the 150 possible sites, only 48 were analysed because of repetitions (52), irrelevant content (21) or inaccessible links (29). Nineteen were HONcode-certified. The mean LIDA and FRE scores for all websites

were 62.59% (SD = 10) and 32.9 (SD = 16) respectively. HONcode-certified websites have slightly higher reliability scores than HONcode-uncertified websites (38.5% *vs* 36.2%).

Conclusion Good quality information on patients with FAP is difficult to obtain on the Internet. The websites analysed have alarmingly low reliability scores. The readability of their content is poor and they often do not appear among the top search results. There is a need to develop a clear, easily accessible and authoritative resource for patients with FAP.

Keywords Familial adenomatous polyposis, readability, reliability, internet

What is new in this paper?

The study highlights the poor quality and readability of information on familial adenomatous polyposis available on the Internet – hence the need to develop simple and reliable patient education materials.

Introduction

The Internet is one of the most popular sources of medical information [1]. A recent survey by the Office for National Statistics showed that 70% of households in the UK had Internet access in 2009 and 42% of adults had sought health-related information from the web [2]. A similar survey by the Pew Internet and American Life Project found that 61% of US adults had looked online for health information [3]. There are thousands of websites offering information and advice on health topics [4]. The unregulated nature of the Internet, however, means that the reliability of this expanding volume of information is uncertain. In a systematic review Eysenbach *et al.* [5] reported that 70% of studies contained

poor quality health information on the web. A recent study examining the surgical decision-making experience of patients with familial adenomatous polyposis (FAP) identified families as the primary source of information [6]. Another study identified patients' concerns regarding the lack of healthcare providers with adequate knowledge of this disease [7]. For these patients and their relatives websites and online support groups are a useful source of information and emotional support [4].

Our aim was to evaluate the quality and readability of information available on the World Wide Web for patients with FAP. The International Society for Gastrointestinal Hereditary Tumours (InSiGHT) is an international scientific organization which aims to improve the quality of care of patients affected by any condition resulting in hereditary gastrointestinal tumours. The secondary aim was to evaluate the websites of InSiGHT member institutions (IMI) separately.

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Method

We searched for the term ‘familial adenomatous polyposis’ using Google™, Yahoo!™ and MSN/BING™ [8]. All sites were identified and reviewed in a single search session. Since the majority of Internet users do not search beyond the first 50 websites [9], we only explored the top 50 sites per search engine. The LIDA tool is an online instrument that evaluates the design and content of medical websites and it scores these websites on three broad areas: accessibility, usability and reliability [10].

Web accessibility means that people with any type of disability are able to use the web [11]. Specific guidelines have been produced by the World Wide Web Consortium, the Internet governing body, to improve web accessibility [12]. The accessibility score (0–100%) can be automatically calculated by the LIDA tool using the universal resource locator (URL) of each website, i.e. the web address.

If patients cannot use websites effectively, they are likely to go elsewhere to find the information they need and may not come back [13]. Providing reliable online health information is critical because inaccuracies can have disastrous consequences [1]. The usability and reliability scores consist of several components that can be graded separately (see online tool) [10]. A medical expert (Consultant Colorectal Surgeon, SC) browsed and analysed all relevant websites and marked each component accordingly. The final scores for usability and reliability are generated by the software and range from 0% to 100%. The LIDA score is an average of accessibility, usability and reliability scores.

Flesch reading ease (FRE) score

Readability can be defined as ‘the ease of understanding due to the style of writing’ [14]. The FRE formula is one of the most tested and reliable readability formulae [14]. The FRE score varies from 0 to 100 [15], with low scores indicating complex documents. Scores between 61 and 70 represent a standard readability level. The FRE scores of relevant websites in our study were calculated using Microsoft Word®.

Health on the net foundation code of conduct (HONcode)

The Health on the Net (HON) Foundation is an internationally recognized organization that aims to standardize the reliability of medical and health information available on the web [16]. In order to display the HONcode seal (Fig. 1), subscribing sites have to strictly adhere to eight HONcode principles. We looked for this



Figure 1 HONcode logo (reproduced with kind permission from HON Foundation).

unique dynamic seal on all web pages to identify those medical sites accredited by the HON Foundation.

Statistical analysis

The data gathered from the three search engines were analysed using Microsoft Office Excel® (Microsoft, Washington, DC, USA) and MedCalc® (MedCalc Software, Mariakerke, Belgium). A comparison of means was performed using an independent samples *t* test and the result was considered positive if the *P* value was < 0.05.

Results

In all, 150 sites (50 per search engine) were examined. Only 48 were included in the final analysis because of repetitions ($n = 52$), irrelevant content ($n = 21$) or inaccessible links ($n = 29$). Figure 2 shows a box-and-whisker plot of all the websites analysed. The mean accessibility, usability, reliability, LIDA and FRE scores for all websites were 76.8% (SD = 13), 60.1% (SD = 20.9), 37.8% (SD = 16.9), 62.5% (SD = 10) and 32.9 (SD = 14.9) respectively. The usability, reliability and FRE scores are scattered over a wide range thus indicating the variable nature of online information available to patients. The reading style was classified as ‘very difficult’ for 22 sites (46%) and only two websites presented their material at a standard reading level (St Mark’s Polyposis Registry and MacMillan Cancer Support). Moreover, only seven websites belonging to institutions registered with InSiGHT were identified and they are Mount Sinai Hospital (Canada), Cleveland Clinic (USA), M.D. Anderson Cancer Center (USA), Johns Hopkins Gastroenterology and Hepatology (USA), St Mark’s Hospital Polyposis Registry (UK), Memorial Sloan-Kettering Cancer Center (USA) and Mayo Clinic (USA).

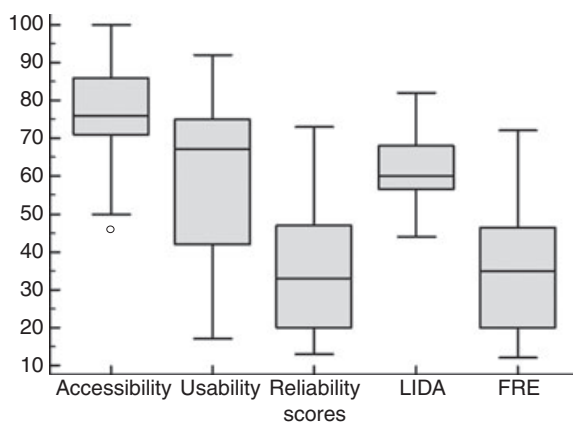


Figure 2 Box and whisker diagram illustrating the range of scores for all websites analysed in this study.

A comparison of scores of IMI websites *vs* other websites is shown in Table 1. Apart from the accessibility score, all other scores were higher for IMI websites (with mean reliability and FRE scores being statistically significant). However, the reading ease score of IMI sites remained low (range 36.4–62.9).

Nineteen of the 48 websites analysed were HONcode-certified. Table 2 shows a comparison of scores according to HONcode status. With the exception of one institution (M.D. Anderson Cancer Centre), no other IMI sites were accredited by HON. HONcode-certified websites tend to be more user-friendly and more reliable, although the differences in the scores were not statistically significant. Interestingly, the information provided by HONcode-certified sites has lower readability scores (range

11.9–54.3); 13 (68%) of those sites contain information classified as ‘very difficult’ to read and comprehend. It should be noted that satisfactory readability is not among the benchmarks proposed by the HON Foundation.

Discussion

It was estimated in 2004 that around 4.5% of all global Internet searches are for health-related information [17]. Unfortunately, the Internet has no boundaries and this expanding repertoire of information is laden with unreliable information [18,19]. In an attempt to solve these problems, organizations have published codes of best practice to help webmasters improve the quality and credibility of medical websites [16,20]. The HON Foundation aims to raise the quality of healthcare information available on the net by critically reviewing the contents of medical websites. These sites can display the HONcode seal provided they comply with the benchmarks proposed by the Foundation. At the end of the certificate validity, HONcode reviewers undertake a re-evaluation process to verify that these sites still respect the HONcode principles.

Saraiya *et al.* [21] found that the majority of participants who attended an FAP patient education conference obtained information pertaining to their condition from the Internet. However, other studies have shown that patients regard healthcare professionals as their preferred source of information [22,23].

Our study shows that FAP-related information is difficult to obtain on the web due to the large number of irrelevant (14%) and inaccessible (19%) websites. The

	IMI websites (<i>n</i> = 7)	Other websites (<i>n</i> = 41)	<i>P</i>
Mean accessibility score (SD)	73.1 (12)	77.4 (13)	0.43
Mean usability score (SD)	70.3 (17.3)	58.3 (20.9)	0.17
Mean reliability score (SD)	56.1 (9.2)	34.6 (15.9)	0.001
Mean LIDA score (SD)	67.6 (8.8)	61.6 (9.9)	0.15
Mean FRE score (SD)	47.3 (7.8)	30.4 (14.5)	0.005

Table 1 Comparison of average scores of IMI *vs* other websites.

	HONcode-certified (<i>n</i> = 19)	Not HONcode-certified (<i>n</i> = 29)	<i>P</i>
Mean accessibility score (SD)	76.9 (13.6)	77.6 (11.6)	0.84
Mean usability score (SD)	64.4 (17.4)	57.5 (22.7)	0.28
Mean reliability score (SD)	38.5 (10.7)	36.2 (19.5)	0.61
Mean LIDA score (SD)	63.3 (8.6)	62.1 (10.9)	0.44
Mean FRE score (SD)	27.2 (13.2)	36.1 (14.9)	0.045

Table 2 Comparison of average scores of websites according to HONcode status.

remaining sites assessed suffer from poor readability and reliability: 83% ($n = 40$) of all websites have FRE scores that indicate a difficult or very difficult readability level. It has been shown that more readable text increases readership and comprehension [15] – hence the need to focus on a different approach to web design. Reader-friendly sites with well structured contents are inherently high value and likely to attract a steady base of repeat visitors and new visitors.

The reliability scores for all sites range from 13% to 87%. This is alarming given that bad information provided by unreliable sites has the potential to cause serious harm to patients [24,25]. Purcell *et al.* [26] also pointed out that users will not trust websites without clear quality control policies. Although IMI websites tend to have better scores compared with other sites, there is still work to be done to improve the readability of information provided to patients. In this increasingly litigious climate, healthcare organizations should minimize their own risk by ensuring that their websites are designed and structured in a clear manner and the quality of their content is robust.

Study limitations

Various online instruments and computer programs can be used to calculate FRE scores. Due to the complex nature of the equation involved, scores will vary depending on the software used. We have chosen Microsoft Word[®] because it is a popular and well established software. Moreover, it should be noted that readability scores do not take into account other factors that affect comprehension such as writing style and explanation of medical jargon [5]. Of the analysed websites 60% (29/48) were not accredited by HON. This does not necessarily imply that these sites do not adhere to the HON principles. It is possible that the sites may not have formally submitted an application for certification. Dozens of instruments designed to assess the quality of medical websites have been identified, many of which have been incompletely developed [27]. Several authors have agreed on key criteria to be used for evaluating health-related websites [28–30]. These include authorship, attribution, disclosure, accessibility, site design, ease of navigation, currency of contents and use of media to communicate material. Although the LIDA instrument is not a validated tool, it uses all the mentioned criteria to assess medical websites.

Proposed solutions

A number of strategies can be pursued to improve the ability of patients to obtain high-quality web-based

education materials. Healthcare providers should ensure their patients are receiving quality material to review and therefore should direct patients to known reputable sites with material written at a suitable reading level. Professional medical societies and other healthcare organizations should advertise Internet sites that provide useful patient-oriented information. Webmasters and site authors should be encouraged to provide links to known good educational sites. Finally, by using a technique called Search Engine Optimization, high-quality medical websites can get ranked near the top of major search engine listings and thus improve their visibility [31].

The Internet is providing an easily accessible but uncontrolled source of consumer health information and it is difficult for patients to judge the accuracy and credibility of such information. Health-related materials are commonly written at a level unsuitable for a diverse audience. Despite these shortcomings, it remains an important and valuable source of information for patients and healthcare providers. Lifelong conditions like FAP can have a significant impact on the quality of life of patients and their relatives. Having supplemental high-quality information is of paramount importance to assist patients in the decision-making process about their management. This study shows that the search for high-quality information about FAP on the Internet is difficult to find – hence the need to develop clear, easily accessible and authoritative resources for patients with FAP and their relatives. As healthcare professionals, it is essential that we help patients identify sources of reliable information written at an appropriate reading level.

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