

# **An Evaluation of Websites Recommended by UK NHS Consultants to Patients with Adolescent Idiopathic Scoliosis at the First Point of Diagnosis**

**Shaun Wellburn, BSc (Hons), Josette Bettany-Saltikov, PhD, and Paul van Schaik, PhD**

**Teesside University**

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## **Introduction**

The use of electronic means to access health information is becoming increasingly more popular as Internet access becomes more widely available. Studies show that one of the most common sources of inquiry on the Web is for the purpose of medical or health-related information, whether it is for an existing health condition or otherwise.<sup>1-3</sup> A recent survey found that 59% of 168 parents attending a scoliosis clinic had searched the Web for information relating to scoliosis.<sup>4</sup>

However, because of the unregulated format of the Web and the availability of Web server software anyone can set up a Website and publish health-related information that is available to everyone. This then questions the availability of access to health-related information produced without structure, education or guidance and whether access to such information is in the best interests of either patients or health-professionals.<sup>5</sup> In some cases, health-professionals are reported

to have expressed a dislike for the Web because they believe it interferes with the traditional patient-doctor relationship. As a result, appointments become extended in order to re-educate a patient due to misunderstood or poor quality information.

A series of standards that could help achieve the production of high-quality health-related information have previously been published in *JAMA*.<sup>6</sup> These were the following:

- authorship: relevant credentials of authors and contributors along with their affiliations should be provided;
- attribution: details of the source/reference of all content should be listed and all information related to copyright should be noted;
- disclosure: Website ownership should be fully revealed as well as any advertising and sponsorship or possible conflicts of interest. This should also be applied to links to other Websites, posted as a result of financial considerations;
- currency: the date that the content was posted and when it was updated should be clear.

Wyatt (1997)<sup>7</sup> added the caveat that even if the content is correct and indeed timely, people must be able to read and understand the information

Recent studies have been conducted in an aim to evaluate the quality and accuracy of information included on scoliosis related Websites.<sup>1,8</sup> These studies analysed Websites identified through the use of a single search term “scoliosis”. The top five most popular search engines, Google, Yahoo, AltaVista, MSN, and Lycos, were identified from the allsearchengines Website. This type of search to access health-related information was criticised by Berland *et al.*<sup>9</sup> in 2001, describing it as

“not efficient”. Furthermore it should be noted that only the Nason *et al.*<sup>8</sup> study used a validated quality rating instrument and as such the analysis of Mathur *et al.*<sup>1</sup> may be less robust. These three studies concluded that the information was of limited quality and poor informational value. Additionally it was suggested that clinicians should assume primary responsibility for educating patients and to direct patients to Websites appropriate to their medical condition. A survey, of a sample of 485 parents of paediatric outpatients, found that 88% of parents thought doctors should recommend suitable Websites.<sup>10</sup>

The aim of this study was to analyse the quality of the content of Websites recommended to patients with adolescent idiopathic scoliosis (AIS) at the first point of diagnosis by UK NHS consultants.

## **Materials and Methods**

### *Instrumentation*

The DISCERN instrument is a validated tool for assessing the reliability of a publication providing information about treatment choices and comprises of sixteen questions.<sup>11</sup> The questions are divided into three sections as described in *Table 1* and are scored on a five-point Likert scale. Thus the maximum score a Website could achieve was 80 and the minimum score was 15 (if question 2 was omitted following a negative answer to question 1). Each question has hints to explain what to look for in order to meet the criteria of the question.

The Health on Net Foundation code (HONcode)<sup>12</sup> is a Website certification which may be awarded, following a voluntary application, after evaluation of the Website by Health on Net experts.

*Table 1: The sixteen questions contained in the DISCERN instrument.*

Section 1. Is the publication reliable?	
1	Are the aims clear?
2	Does it achieve its aims?
3	Is it relevant?
4	Is it clear what sources of information were used to compile the publication (other than the author or producer)?
5	Is it clear when the information used or reported in the publication was produced?
6	Is it balanced and reliable?
7	Does it provide details of additional sources of support and information?
8	Does it refer to areas of uncertainty?
Section 2. How good is the quality of information on treatment choices?	
9	Does it describe how each treatment works?
10	Does it describe the benefits of each treatment?
11	Does it describe the risks of each treatment?
12	Does it describe what would happen if no treatment is used?
13	Does it describe how the treatment choices affect overall quality of life?
14	Is it clear that there may be more than one possible treatment choice?
15	Does it provide support for shared decision making?
Section 3. Overall rating of the publication?	
16	Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices.

### *Sample*

A survey of UK NHS scoliosis consultants was conducted by Bettany-Saltikov *et al.* 2012 (abstract).<sup>13</sup> Two of the questions within this survey asked “Are scoliosis patients and their families referred to any Websites?” and “If so, to specify which ones?” In response to these questions nine Websites were identified. These were, Scoliosis Association UK (SAUK), British Scoliosis Society (BSS), Scoliosis Research Society (SRS), British Scoliosis Research Foundation (BSRF), British Association of Spinal Surgeons (BASS), Eurospine, Medikidz, Spinesurgeons and iScoliosis.

### *Procedure*

Two of the Websites identified, BASS and Spinesurgeons, were found to be different terms for the same Website. The primary function of the BSRF Website is to promote research into scoliosis and was therefore not deemed as a patient information resource. It should however be noted the BSRF Website provides a number of links

to other scoliosis Websites. Subsequently there were seven Websites identified for inclusion in this study. These Websites were independently analysed for reliability of the content by the authors of this paper, a PhD student (reviewer 1), a Research Methods Senior Lecturer (reviewer 2) and a Psychology Professor (reviewer 3), using the DISCERN instrument. Websites were also analysed for the presence or absence of HONcode certification.

### *Statistical analysis*

Statistical analysis was performed using SPSS version 19. Each reviewer's scores for all items of the DISCERN instrument were added together to give a summative score for each Website by each reviewer. The summative scores for all of the Websites were then tested for correlation between reviewers using Kendall's tau ( $\tau$ ). The Websites were ranked (1 being the best) based on the summative score they achieved for all items of the DISCERN instrument. Comparisons were drawn between the ranking derived from the summative score and the rating score given to each Website for Item 16 of the DISCERN instrument.

### **Results**

A significant correlation was found between the summative scores of Reviewers 1 and 2 ( $\tau = 0.878$ ,  $p = 0.006$ ) and also between Reviewers 2 and 3 ( $\tau = 0.732$ ,  $p = 0.029$ ). A moderate correlation ( $\tau = 0.577$ ) was found between the summative scores of Reviewers 1 and 3, approaching significance ( $p = 0.091$ ).

**Table 2: Average scores for each item for Reviewers 1 and 2.**

Question No	SAUK	SRS	BSS	iScoliosis	BASS	Eurospine	Medikidz
1	4.5	3.5	4.5	3.5	3.5	3.5	3
2	4	4	3.5	3.5	3.5	3.5	4
3	4	3	2	3	1.5	3	3
4	1	1	2	1.5	1	2.5	1
5	1	3	1.5	2.5	1.5	2.5	1
6	3	3	2	2.5	1.5	4	2
7	3.5	2.5	4	3	4	1	2
8	2.5	2	2.5	2.5	1.5	1.5	1
9	2.5	2.5	2	3.5	1	2.5	1.5
10	3.5	2.5	1	4.5	1	3	1
11	1.5	1.5	1.5	3	1	3	1
12	2	2	1	2.5	1	2.5	1
13	1	1.5	1	2.5	1	2	1
14	2.5	3.5	4	4	1	4	2
15	3.5	1	1	4	1	1.5	1
16	3.5	2.5	2	3	1	3	1.5
Total	43.5	39	35.5	49	26	43	27
Rank	2	4	5	1	7	3	6

Mean scores were calculated from the analysis of the two reviewers with the strongest correlational value. These mean scores for each item, for each Website and a mean summative score for each Website are shown in *Table 2*. The highest average value was achieved by the iScoliosis Website. No Website achieved a total individual score of more than 50 out of a potential 80 (62.5%). The overall rating score given for item 16 of the DISCERN instrument (and the resultant average) did not always coincide with the summative score for all items. For example the iScoliosis Website achieved a higher summative score than the SAUK Website yet the SAUK Website achieved higher overall rating score for Item 16. Only the iScoliosis Website was found to display a HONcode.

## Discussion

The studies of Mathur *et al.*<sup>1</sup> and Nason *et al.*<sup>8</sup> selected a larger number of Websites (41 and 50 respectively) for analysis than did this study. Despite the larger samples in these previous studies only two (Mathur) and three (Nason) of the Websites reviewed in the current study were reviewed in those previous studies. It could be

suggested that identifying scoliosis Websites via a search engine would be indicative of the way a patient may search for information about a particular condition. The current study evaluated Websites identified through a survey of UK NHS consultants. It could be argued that because a Website was recommended by a consultant, patients may believe it to be a more valid source of information.

The highest individual score achieved by any of the Websites evaluated in this study was 50 (62.5%) which was the iScoliosis Website. It is interesting to note that this was the only Website evaluated in this current study to display a HONcode. The study by Nason *et al*<sup>8</sup> found similarly that Websites displaying the HONcode scored more highly than when the code was absent, though not significantly so. Nonetheless, whilst presence of the HONcode may imply a trustworthy Website, this is only likely to be useful to Internet users if they are aware of its existence, meaning and are actually looking for it. Moreover other Websites evaluated in this study not displaying a HONcode scored similarly poorly.

The implications of this are that the information provided on these Websites may not be evidence based, accurate or trustworthy and may therefore not be meeting patient needs. A problem noted with all of the Websites evaluated was the failure to identify the source of the information contained on the Website and also the date it was produced. These are two of the standards suggested by Silberg *et al.*<sup>6</sup>, attribution and currency of information. It is arguably of similar importance that this information should be evidence based. Moreover the level of quality of the evidence should also be considered.

If the information is from a reliable, credible source then this should be made apparent in order that this may increase users' confidence in what they are reading. Similarly the date the information was produced should be evident so users' can be

confident that they are reading up-to-date, relevant material. No single Website was particularly strong in any section although high scores were achieved on individual questions. For example, most Websites scored well in identifying the aims of the Website.

Websites that scored poorly were particularly weak in Section 2 of the instrument, specifically how treatments work and their associated risks and benefits. At the time that the current study was carried out (May 2011) there was little information to be found relating to conservative management of scoliosis, specifically bracing and physiotherapy based modalities. There are a number of different braces in use therefore descriptions of them may be warranted. Very little information was also found relating to scoliosis specific physiotherapy based exercise programmes, in some cases being described as complimentary therapies. Recent Cochrane reviews found evidence of the successful use of bracing and physiotherapy based modalities albeit of low quality.<sup>14,15</sup> The lack of information surrounding conservative management may be reflective of the differing treatment pathways from centre to centre that are available within the UK. The Website that scored best in section 2 was iScoliosis. It is worth noting, however, that this is an American Website and the information may be reflective of the use of different treatment processes than the UK.

Information relating to the signs, symptoms and aetiology of the condition were generally well presented on all Websites evaluated (Item 3, 'is it relevant?'); this is an area which has been highlighted as being of importance to AIS patients and their families (Wellburn *et al.* 2012). The SAUK and iScoliosis Websites were strong in the provision of links to alternative sources of information and in support for shared decision making. Weak areas that could be improved for all Websites were



the lack of source identification and date, descriptions of how all treatments work, the associated risks and benefits of all treatments and how treatment choices can affect overall quality of life (QOL). This final point, regarding QOL, was an area of weakness noted in all Websites evaluated and yet quality of life is considered to be of great importance to AIS patients and their families.

A potential limitation of the DISCERN instrument may be the use of a single question (Item 16) to summarily evaluate the Website based on the answers to the previous questions. In this study the overall rating (Item 16) did not always correspond to the summative score achieved for the previous 15 items. It could be suggested that a more accurate reflection of the overall rating of the publication/Website be derived from a summative score for the previous 15 Items of the DISCERN instrument. This may remove some of the subjective nature of the overall rating of the publication/Website.

A potential limitation of this study was the limited experience of the reviewers in the use of the DISCERN instrument. However guidelines for each individual question of the DISCERN instrument are provided and were rigorously adhered to by the reviewers.

## **Conclusion**

An alternative methodology to identify Websites for evaluation was used for the current study than the two studies previously carried out in the field of scoliosis. The findings were however similar; despite the reported increase in the number of Websites relating to the field of scoliosis the quality of information on these Websites remains poor<sup>8</sup>. If healthcare professionals are to suggest Websites to patients as a source of further information they should be aware of the content of those Websites

to enable them to make the most appropriate recommendations. Websites designed to act as a source of health-related information should be maintained in such a way that the information contained is up to date, evidence based, impartial and written in plain language. It may be suggested that constructing a Website based on the criteria of the questions on the DISCERN instrument could contribute to the production of a useful, informative, reliable and credible Website. Furthermore the Websites should be designed in such a way that the content is tailored to suit the patients' information needs.

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