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# **Online patient information on Vagus Nerve Stimulation: how reliable is it for facilitating shared decision making?**

## **Introduction**

The internet is one of the most popular sources of healthcare information for patients<sup>1</sup>. Online resources can facilitate the process of informed consent and patient-centred shared decision-making, as they allow patients to gain understanding of their condition, and the treatments available, at their own pace. Information on the internet therefore impacts upon the relationship between physician and patient<sup>2,3</sup>. This means that patient-orientated online information must be monitored for reliability and accuracy<sup>4,5</sup>.

Vagus Nerve Stimulation (VNS) may be considered in the treatment of drug-refractory epilepsy in childhood<sup>6</sup>. Patients and parents may have many questions and reservations about VNS, which may not all be addressed during their consultations with healthcare professionals<sup>7,8</sup>. Therefore the quality of online resources plays an important role in contributing to patients' and their families' understanding of VNS as a treatment option. In this study, patient-orientated websites regarding VNS were evaluated to assess their reliability and relevance<sup>9</sup>.

## **Methods**

To model typical search strategies implemented by patients, key phrases were entered into two popular search engines (Google™, Yahoo™). These phrases were: "Vagus nerve stimulator", alone and in combination with "childhood epilepsy", "paediatric epilepsy" and "epilepsy in childhood". The terms "VNS" and "VNS

epilepsy” were also used. Approximately 26 000 000 websites were retrieved. The first 50 hits per search (n=600) were screened for pertinence and overlap. Duplicated (n=262), irrelevant (n=230) and inaccessible (n=15) web pages were excluded, and thus 93 websites were identified for evaluation (Figure 1).

Three independent reviewers analysed the retrieved websites using the DISCERN questionnaire, a reliable and validated battery of 16 questions to assess factors relating to the quality of online patient information, such as objectivity, reliability, and exhaustivity<sup>8</sup>. Each question in the DISCERN tool requires the website be given a rating from 1-5, (1 = lowest possible score, 5 = highest possible score; see Supplementary Material)<sup>8,9</sup>. Each web page was also allocated a global quality rating out of 80 (Excellent=80-63; Good=62-51; Fair=50-39; Poor=38–27; Very poor=26-

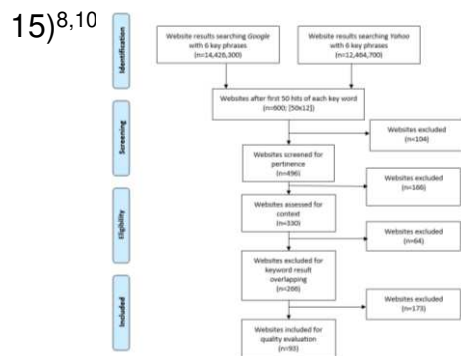


Figure 1: Flow diagram illustrating the

For web pages which incorporated multimedia resources, such as videos or slideshows, (n=3) the DISCERN questions were applied to the information provided in the multimedia elements without the need for any significant modification to the DISCERN tool.

## **Results**

The average DISCERN score for the 93 evaluated websites was 39/80 (49%; SD 13.5; range 20/80-61/80). This equates to Fair (borderline Poor) global quality. None of the analysed sites obtained an Excellent quality rating. 13% (n=12) obtained a Good score, 40% (n=37) obtained an Average score, 35% (n=33) obtained a Poor score, and 12% (n=11) obtained a Very poor score. (Figure 2). A full list of the websites and their DISCERN scores can be reviewed in the Supplementary Material Table. The top five highest scoring websites are listed in Table 1.

When the scores for each individual question of the DISCERN tool were scrutinised, the cohort of websites scored particularly poorly on assessment of whether focussed information was presented, (28%, SD 19) whether reliable sources were used to develop the information provided, (40%, SD 26) and whether alternative treatments were discussed, (31%, SD 14).

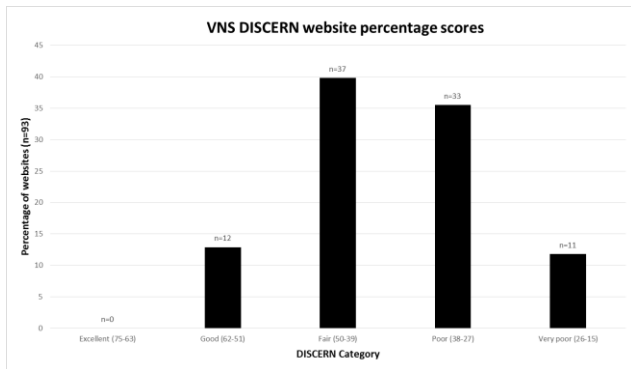


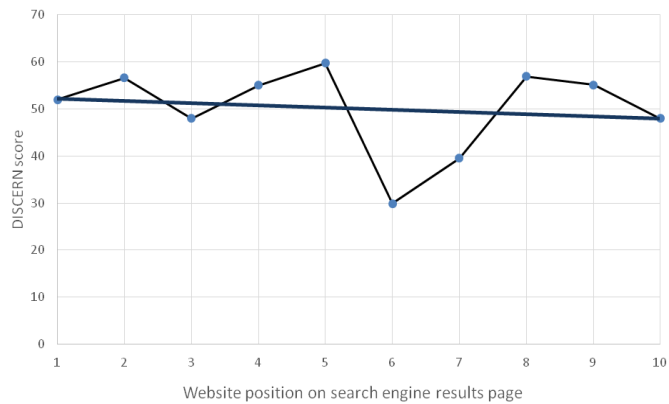
Figure 2: The distribution of analysed

<b>Website authors/institution</b>	<b>URL address</b>	<b>Overall DISCERN score (categorical rank)</b>
<i>The National Health Service (NHS) in partnership with Epilepsy Action</i>	<a href="http://www.nhs.uk/ipgmedia/National/Epilepsy%20Action/assets/Vagusnervestimulation.pdf">http://www.nhs.uk/ipgmedia/National/Epilepsy%20Action/assets/Vagusnervestimulation.pdf</a>	60.8 (Good)
<i>Royal Children's Hospital Melbourne</i>	<a href="http://www.rch.org.au/neurology/patient_information/vagus_nerve_stimulation/">http://www.rch.org.au/neurology/patient_information/vagus_nerve_stimulation/</a>	59.7 (Good)
<i>Uptodate® (Walters Kulwer®)</i>	<a href="http://www.uptodate.com/contents/treatment-of-seizures-in-children-beyond-the-basics">http://www.uptodate.com/contents/treatment-of-seizures-in-children-beyond-the-basics</a>	57.5 (Good)
<i>American Medical Association</i>	<a href="http://www.anthem.com/medicalpolicies/policies/mp_pw_a053286.htm">http://www.anthem.com/medicalpolicies/policies/mp_pw_a053286.htm</a>	56.9 (Good)
<i>Epilepsy Action</i>	<a href="https://www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation">https://www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation</a>	56.6 (Good)

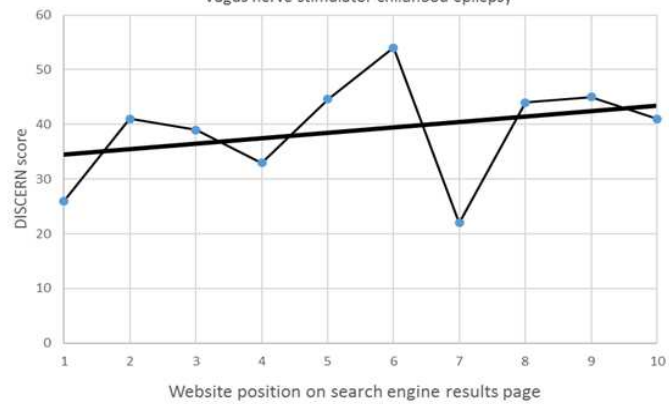
Table 1: The top five highest-scoring websites in the study; overall DISCERN rankings and website authorship are listed.

To assess whether there is any relationship between website quality and its position on search engine results pages, websites DOSCERN scores were compared to their ranking on search engine results pages. Three examples of this analysis are provided in Figure 3.

Website rank on search engine result page Vs website DISCERN score: 'Vagus nerve stimulator'



Website rank on search engine result page Vs website DISCERN score: 'Vagus nerve stimulator childhood epilepsy'



Website rank on search engine result page Vs website DISCERN score: 'Vagus nerve stimulator paediatric epilepsy'

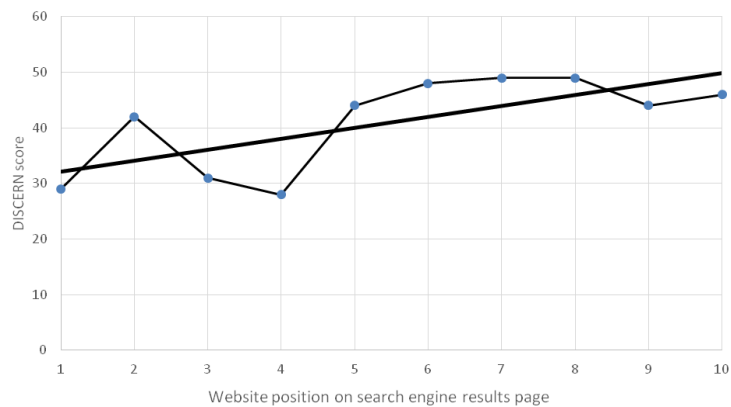




Figure 3: Comparison of websites' rankings on the first search engine results page with each site's DISCERN score. This revealed that there was no consistent relationship between website information quality and its ranking on the search engine results list. Data pertaining to websites

## Discussion

### Shared decision making between patients and

clinicians requires patients to be informed with detailed and accurate information about their conditions and treatment options. It is often unfeasible for patients to assimilate all the information needed to facilitate an informed decision in the time-frame of a clinic appointment. Therefore there is a degree of reliance upon other resources to help patients and families to collate, sieve and assimilate the wealth of information relevant to their personal situation.

The internet is one of the most popular tools utilised by patients to aid in this information-gathering process<sup>4,10,11</sup>. However the unmonitored nature of information posted online means that patients are at risk of being exposed to unreliable and misleading information. This may result in damaged patient-clinician relationships, misinformed patient decision-making, and thus poor clinical outcomes<sup>4,5,6</sup>. This study found that searches for reliable and accurate patient information regarding VNS on the internet generates websites with variable, and ultimately disappointing, levels of informative quality.

Patients using online search engines are exposed to a plethora of information, which is presented in a hierarchical fashion based on hit rate, sponsorship and popularity, rather than the quality or relevance of websites' information<sup>4</sup>. Of the 600 web pages retrieved using our methodology, only 93 (15%) were identified as suitable for analysis. This low proportion is in tune with numbers reported in the literature regarding patient information websites on similar topics<sup>3,4</sup>. This highlights the

intimidating volume of information patients may be faced with when utilising popular internet search engines.

As a response to the plethora of information available when conducting internet searches, most search engine users tend to focus on the first ten websites on the first page of results retrieved by a search engine<sup>12</sup>. This study identified that there appears to be no consistent relationship between the quality of information provided by a website and its hierarchical position in the results list when retrieved by a search engine. That is, some websites ranked at near the top of search engine results pages obtained 'Very poor' or 'Poor' DISCERN scores (26/80; 29/80), and vice versa (Figure 3). This is because search engines utilise multi-faceted algorithms to determine the ranking of websites retrieved during a user search. These variables include popularity, advertising and sponsorship, and typically do not include the determinants of websites' informative qualities assessed in the DISCERN tool<sup>12</sup>. Therefore, it seems that patients and their families are currently at high risk of being exposed to poor quality information regarding vagus nerve stimulation on the internet.

The focus of this study was on the written information provided by the websites. Other work has also identified that patient information websites are also highly variable in terms of general readability<sup>3</sup>, and exhaustivity<sup>4</sup>. In conjunction with our findings, it seems that the abundance of information available to patients on the internet varies not only in informative quality, but also comprehensibility<sup>5</sup>. Unlike previous works, this study evaluated the information presented in multimedia formats within websites, such as videos, slideshows and audio clips. Whilst these elements

were not assessed during the development of the DISCERN instrument<sup>11</sup>, it stands that the same questions can be applied to non-written media, to assess the quality of the information provided therein. A minority of sites in the study cohort made use of such resources (n=3). However, these web pages scored above the cohort average, (mean score 45/80; 56%) and two of the sites obtained a 'Good' overall quality rating (DISCERN score >50/80). Providing information through multiple formats, (e.g. text, video, interactive elements) could facilitate patient engagement with, and hence digestion of, the presented information<sup>6,7</sup>. However definitive conclusions regarding the usefulness of these elements cannot be drawn from the data collected during this study. Furthermore, the information provided, whatever the format, still requires monitoring to ensure accuracy and reliability<sup>6,10,11</sup>.

The internet should be viewed as a useful tool to help inform patients of their disease and the risk-benefit profile of different treatment alternatives. However, the vast quantities of variable information available online means that, for the moment, it must remain an adjunct to information delivered to patients from healthcare professionals directly. The average-to-poor informative quality of VNS-related websites identified in this study demonstrates an opportunity for the creation of reliable, accurate online patient resources regarding VNS. Healthcare professionals could consider signposting websites which deliver the most reliable patient information to families during consultations. Clinicians could also consider empowering patients by educating them to identify red flags of poor-quality websites, such as sites with unidentified authors, without a recent update, or those with secondary financial agendas<sup>6,7,8</sup>.

The methodology of analysing only the first 50 web addresses per search means that a proportion of websites ranked below 50 for each search term were not assessed in this study. However, the aim of this work was to model stereotypical patient search strategies, and it has been shown that patients do not typically search beyond the first 20 sites retrieved by a search engine, with most attention being paid to the first 10 results after input of one to three simple key words<sup>11,12</sup>. Therefore the method utilised models a typical patient search strategy, and in fact analyses more search terms and results than a typical internet user would be expected to view.

An ostensible drawback of the DISCERN instrument is that a degree of subjectivity is required to implement it. However, the tool has been proven as a validated standardised quality index for assessing patient-directed information, with consistent overall inter-rater scores<sup>11</sup>. Inter-rater variability in our study was also confirmed to be minimal; six sites within the cohort were randomly selected for analysis by all three independent reviewers separately. These sites all received such similar scores that they were all rated within the same overall categories by each reviewer, (data not shown).

## **Conclusion**

High quality patient information can shape patient expectations, and may thus improve patient satisfaction and clinical outcomes<sup>4</sup>. In the current era, the internet plays an expanding role in the dissemination of information to patients. This study discovered that the quality of information regarding VNS on the internet is currently suboptimal. There is a need to develop VNS-related web pages delivering higher quality, reliable patient information. Professional societies may also need to direct

patients to the most reliable web resources, whilst also warning them of the presence of inaccurate or biased websites.

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