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Evaluating the quality of internet information for breast cancer

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ABSTRACT

The internet is frequently used by patients for researching information regarding breast cancer. This study aims to assess the quality of these websites using validated tools.

The term 'breast cancer' was searched for in 3 search engines. The top 20 results were selected, and duplicates and irrelevant websites were excluded. 26/34 websites were analysed using the DISCERN Plus tool, HONcode and the JAMA benchmarks. 46% of the websites were classed as 'excellent' when assessed with the DISCERN tool. The range of DISCERN scores was wide (range: 25–74). Nine websites were found to be HONcode certified. Seven websites complied with all four JAMA benchmarks.

This study shows the quality of breast cancer information on the internet is on the whole good; however the range of quality is wide. We recommend healthcare professionals use all 3 tools together to establish which websites are best to advise which websites patients should trust.

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Introduction

The internet has become a source of health information frequently accessed by both patients and healthcare professionals (HCPs), with studies showing that 39% of people in the UK searched the internet for this purpose [1].

Breast cancer affects 45,000 people in the UK per year and is the second commonest cause of cancer deaths [2]. Traditionally patients have received health information directly from HCPs including primary care physicians, oncologists, surgeons and nurses. This would come in the form of direct verbal advice, and also information leaflets designed by the HCPs. Such information is critical to a patient's understanding of their diagnosis, treatment and prognosis, as it provides a reference point once their consultation with a HCP ends. The decision making process that a patient embarks on is not confined to the consultation. In recent decades, the depth of understanding of breast cancer in particular has increased. It is a condition which has numerous subtypes and thus many different treatment options; and therefore discussions regarding prognosis become more complex and nuanced. Now, patients are increasingly using the internet to access this information. The internet is available at all times, and is able to present a range of information, at speed, using a variety of multimedia modalities. Whilst many websites are contemporaneous and unbiased, many are unregulated and of poor quality.

It is important that patients have access to reliable information as they may use this information to inform their decisions on treatment and their understanding of the disease.

To help patients and HCPs evaluate information on the internet, several validated tools have been developed. These include the DISCERN tool, Health on the Net Foundation Code (HONCode) and the JAMA benchmarks. The aim of this study was to assess the quality of information found on the internet using the three aforementioned tools.

Methods

To emulate the real user experience the term 'breast cancer' was searched for in the three most used English language search engines: Google.com, Yahoo.com and Bing.com in July 2014 [3]. The first 20 results from each search engine were used as most people use the first page of the search results. Sponsored links, advertisements, news reports and social media websites were excluded, as were sites that were found to be duplicates or containing no health information on breast cancer (see Fig. 1). The authors erased browser and cookie information prior to conducting the search.

The websites were broadly assessed by all three investigators simultaneously to see what the most common types of websites were. This was performed in order to gain understanding of what kind of organizations were offering information on breast cancer on the internet.

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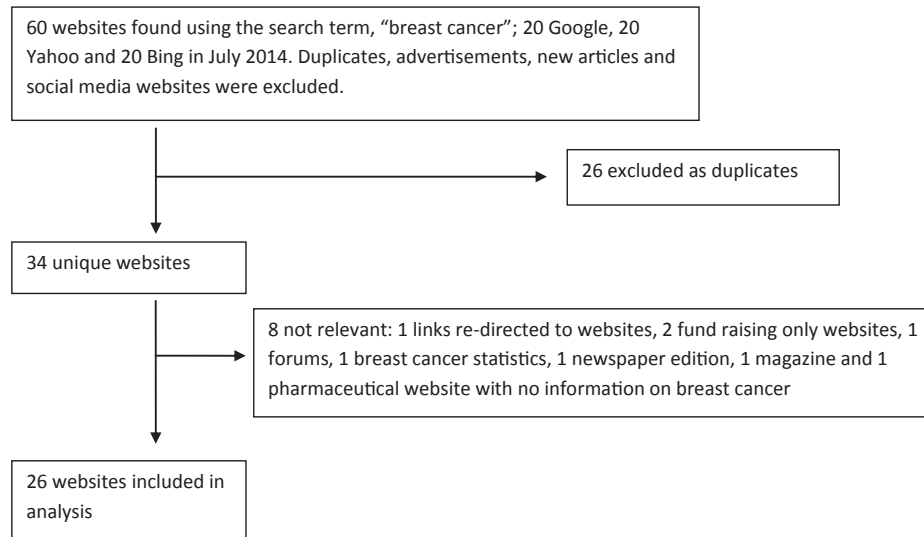E-mail address: allan.nghiem@doctors.org.uk (A.Z. Nghiem).

Fig. 1. Flow diagram to show inclusion and exclusion of websites for evaluation.

The quality of the websites were then evaluated by two investigators (AN and YM) independently of each other using the DISCERN Plus tool, HONCode and JAMA benchmarks.

These three tools were selected because they are some the earliest examples of tools to assess quality of healthcare information; they are also the most frequently used and the authors also have familiarity with these tools.

DISCERN plus

The original DISCERN tool is a validated tool developed in 1998 University of Oxford, UK to help the general public judge the quality of written information specific to healthcare [4]. The tool was developed by an expert panel consisting of clinicians, health journalists, medical publishers and members of the lay public, who subsequently tested it by using it to assess the quality of information on a number of conditions [4]. It uses 15 questions (see Table 1) with the rater giving a score of 1–5 (1 for definite no, 5 for definite

yes and 2–4 partially) for each question and producing a total score out of 75 [4]. The first eight questions address reliability, whilst the next seven refer to details of the treatment being discussed. DISCERN 'Plus' added a 16th question, giving a final score out of 80. As in previous studies [5,6], we rated the websites as 'excellent' (63–80), 'good' (51–62), 'fair' (39–50), 'poor' (27–38) and 'very poor' (15–26).

HONcode

Health On the Net (HON) Foundation is a non-governmental organization that was created in 1995 in Geneva, Switzerland to promote quality health information on the internet [7]. The HONcode is a code of ethics of which there are 8 principles (see Table 2) that promote quality, objective and transparent medical information on the internet and websites can be certified displaying the HONcode logo [7]. Their certification status and the number of principles each site complies with was recorded.

Table 1
Average score per DISCERN question amongst all websites assessed.

	DISCERN questions	Mean score
1	Are the aims clear?	2.88
2	Does it achieve its aims?	4.40
3	Is it relevant?	4.88
4	Is it clear what sources of information were used to compile the publication (other than the author or producer)?	3.04
5	Is it clear when the information used or reported in the publication was produced?	3.08
6	Is it balanced and unbiased?	4.88
7	Does it provide details of additional sources of support and information?	3.50
8	Does it refer to areas of uncertainty?	2.35
9	Does it describe how each treatment works?	4.50
10	Does it describe the benefits of each treatment?	3.77
11	Does it describe the risks of each treatment?	3.31
12	Does it describe what would happen if no treatment is used?	1.15
13	Does it describe how the treatment choices affect overall quality of life?	3.42
14	Is it clear that there may be more than one possible treatment choice?	4.92
15	Does it provide support for shared decision making?	3.85
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?	3.92

Score out of 5; 1 for definite no, 5 for definite yes and 2–4 partially.