Web-based information on oral dysplasia and precancer of the mouth - quality and readability

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Objectives: The numbers of individuals with oral cancer are increasing. This cancer is preceded by oral epithelial dysplasia (OED). There remains no detailed study of the online information presently available for patients with OED or indeed what information such patients may require to be appropriately informed regarding their condition. Hence, the aim of the present study is to assess the patient-oriented web content with respect to OED.

Methods: The first 100 websites yielded from nine searches performed using different search terms and engines were considered. These were assessed for content, quality (DISCERN instrument, Journal of the American Medical Association benchmarks, and Health on Net seal) and readability (Flesch Reading Ease Score and Flesch-Kincaid Grade Level).

Results: There was a general scarcity of OED content across the identified websites. Information about authors, sources used to compile the publication, treatment, and shared decision were limited or absent. Only 6% and 27% of the websites achieved all the four JAMA benchmarks and HON seal, respectively. The average readability level was at 10th grade (US schools), which far exceeds the recommended levels of written health information.

Conclusion: At present patients seeking information on OED are likely to have difficulty in finding reliable information from the Web about this disorder and its possible impact upon their life. Further work is thus required to develop a web-based resource regarding OED that addresses the shortfalls demonstrated by the current study.

Keywords:

Chronic disease

Head and neck neoplasms

Health literacy

Health education

Information seeking behaviour

Internet

Leukoplakia, oral

Mouth neoplasms

Needs assessment

Introduction

Oral epithelial dysplasia (OED) is a histopathological finding associated with an increased risk of malignant transformation of the oral epithelium [1, 2]. The World Health Organisation (WHO) describes dysplasia as an altered epithelium that shows various architectural and cellular changes on the surface epithelial layer as a result of accumulated genetic changes [3]. It is estimated that OED affects 0.25% to 0.5% of populations [4]. Clinically, it can present as white, red, or mixed lesion, categorised under the umbrella of oral potential malignant disorders (OPMD), which precede oral cancers in up to 70% of cases [5].

In 2016, the estimated Internet penetration was at 46% and 92% of the world and UK populations respectively [6]. A US population-based survey showed that around 80% of the web users have searched for online health information (OHI) in the previous year to find information about a medical condition, treatment options, medications, and other topics related to lifestyle [7]. Concerns exist regarding access to online information and also the quality of web-based health information which refers to how reliable, accurate, trustworthy, current [8], and readable the information is. In addition, there may be concerns regarding the subjectivity of commercial bias [9], whether the content is peer reviewed [10], and compliance with rules and regulations [11].

To make the most of their OHI patients require an acceptable level of health literacy. Health literacy empowers individuals by providing the cognitive and social skills needed to *'gain access to, understand and use information in ways which promote and maintain good health'* [12]. Those with poor health literacy are believed to have a reduced awareness of their disease process and management as well as limited appreciation of the way health system work. This makes this group at greater risk of poor health, lower quality of life, and higher mortality than those with good or high health literacy [13-15]. It is thought that health literacy is associated with general literacy, a term which includes the ability of a person to read, write, speak and problem solve [16]. Therefore a key element of general literacy and in turn health literacy is the readability of the text material. Current evidence indicates that the readability scores of various web-based health information are higher than recommended reading levels [17-22], thus making the currently available potentially incomprehensible and unusable.

There is limited knowledge about the patient-oriented web content with respect to OED. The use of validated assessment instruments could ease the identification of search engines and websites with relevant content, higher quality, and recommended readability levels for written health information. The aim of this study is thus to evaluate the content, quality, and readability of web-based information on OED.

Materials and methods

Search strategy

Web searches for the terms ‘oral dysplasia’, ‘treatment of oral dysplasia’, and ‘treatment of precancer of the mouth’ was carried out between February and May 2017 using the most commonly employed search engines in the UK: Google.com, Yahoo.com, and Bing.com [23]. For each term, the first 100 websites per search engine were selected with no refinement.

Exclusion criteria

Links to scientific content (e.g. books or journals), websites that required membership or subscription, websites promoted by search engines, sites that advertise for clinical services or techniques, community-based forums without professional guidance, and websites with only video or audio content were excluded [24, 25].

Content assessment

The content of the included web sites was assessed following the categorisation method used by Ni Riordain and McCreary [26], which grouped the websites according to affiliation (commercial, non-profit organisation, governmental, or university/medical centre), specialisation (the site is entirely or partly related to the searched topic), content type (medical facts, clinical trials, human interest stories, and question and answer), and content presentation (image, video, and audio).

Quality assessment

The DISCERN instrument [27], Journal of the American Medical Association (JAMA) benchmarks [28], and Health on the Net (HON) seal [29] were used to evaluate the quality of identified websites. DISCERN is a validated 16-item tool rated by a 5-point scale (5 = complete fulfilment of the quality criterion and 1= none) that aims to ensure making informed choices based on trusted evidence by evaluating the quality of written health information. It includes questions about the reliability of information (items 1-8), treatment choices (items 9-15), and an overall rating question (item 16). JAMA quality benchmarks ensure the accountability of web-based health information by considering the authorship (authors, their affiliations and credentials), attribution (citations, sources, and copyright), disclosure (acknowledging the ownership, sponsorship, advertising, underwriting, funding and support, and possible conflict of interest), and currency (demonstrate the dates and updates) of the given information. HON is a non-profit foundation that aims to assess the quality and transparency but not the accuracy of web-based health information. HON code of conduct includes eight criteria: authority, complementarity, confidentiality, attribution, justifiability, transparency, financial disclosure, and advertising policy.

Readability assessment

The readability, described as *'the reading comprehension level a person must have to understand written materials'* [30], was assessed using an online tool (https://readable.io) considering two readability formulae: Flesch Reading Ease Score (FRES) [31] and Flesch-Kincaid Grade Level (FKGL) [32]. FRES assesses the readability on a 0-100 scale (0=hardest and 100=easiest), while FKGL estimates the number of years of education in the US needed to understand a passage of written material. There are no available readability guidelines of the patient-related health information in the UK [33]. Therefore, an approach that considers a range of difficulty as easy (4th, 5th, and 6th grade), average difficulty (7th, 8th and 9th grade), and difficult (10th grade and above) was followed [34].

Data analysis and representation

The data was collected using a study specific proforma and recorded in Microsoft Excel to facilitate descriptive statistics. The representation of variables was performed by IBM SPSS (version 22.0). To ensure the intra-rater agreement of DISCERN, one of the identified websites was randomly selected and re-assessed by the same investigator (AA), two months after the initial evaluation and the intraclass correlation coefficient (ICC) was determined [25]. Also, the ICC was calculated to ascertain the level of agreement on DISCERN scores between two investigators (AA and RNR) using one randomly selected site. Ethical approval was not required for this study.

Results

Only 80 out of 900 websites met the inclusion criteria however 36 sites were considered for the summary evaluation after eliminating the duplicates. The screening results for all searches are summarised in Figure 1. For all searches, Google yielded the highest relevant content to patients, with less non-operating and duplicating links than both of Yahoo! and Bing. Regarding the search terms, “treatment of precancer of the mouth” generated the most relevant websites to patients with all search engines (n=35) followed by ‘treatment of oral dysplasia’ (n=23), and ‘oral dysplasia’ (n=20). The categorisation of the identified websites is summarised in Table 1.

The quality assessment of the 36 identified websites by DISCERN showed a mean overall rating of 2.24 (±0.90) out of 5 with no website obtained the highest score (Table 2). The average measure ICC for intra-rater and inter-rater assessment of DISCERN were at 0.789 [95% C.I. = 0.419, 0.925 ($P<0.001$)] and 0.789 [95% C.I. = 0.403, 0.926 ($P<0.001$)], respectively. There is no consensus available to interpret the ICC estimate based on 95% confidence interval, however, a score between 0.75 to 0.90 demonstrates good reliability [35, 36]. HON seal was presented in ten of the identified websites (27%). The number and percentage of websites per obtained JAMA benchmark are demonstrated in Figure 2. With regard to the total number of benchmarks obtained, four benchmarks were met in 2 websites (6%), three benchmarks met in 5 websites (14%), two benchmarks met in 11 websites (31%), one benchmark was met in 14 websites (39%), and no benchmark was found in 4 websites (10%).

With regard to the readability assessment, an analysis with the FKGL showed a range of grade levels from 5th grade to university level (14th grade) with a mean around 10th grade. Using the FRES formula showed a range of scores between 18.1 and 71.9 with a mean of 47.65 (±13.63). The categorisation of the 36 selected websites based on FRES scores is outlined in Figure 3.

4. Discussion

Individuals are motivated to seek health information online in an attempt to seek reassurance, to find alternative opinions on medical interventions and to better comprehend information delivered in the clinical setting [37]. This information-seeking behaviour can aid the 'shared-decision making' model being promoted in healthcare interactions [37]. For example, those affected by OPMD and other potentially malignant conditions frequently use the Internet to obtain information about their condition and treatment options in spite of the potential for unaddressed worries that may arise from the information generated [38]. Although a previous study noted general acceptability of quality of web-based information of OPMD, no validated assessment tool was used in that study [38]. Also, none of the terms searched in the current analysis were considered in the earlier study.

The content of patient-oriented web information related to OED

Nine searches were performed in the current study using different terms and search engines to ensure a thorough web analysis of OED. The results indicate that there is a scarcity of patient-oriented web content of OED as only 36 websites of 900 websites were suitable for patients. Other similar studies had a range 50 to 300 websites in their initial assessment [25, 26, 39-41]. Only 3 of these websites in this study had content specifically devoted to OED with minimal information content in these 3 OED specific sites.

The quality of patient-oriented web information related to OED

Despite the criticism that DISCERN may not comprehensively assess the web content when compared to JAMA benchmarks, a previous study noted its satisfactory internal consistency and inter-rater reliability [42]. The mean of overall rating by DISCERN was at 2.42 out of 5 which is similar to other studies of oral leukoplakia (2.3) [39] and head and neck cancer (2.55) [26]. As with previous studies, questions concerning sources to compile the publication [41] as well as those related to the risks of each treatment, effects of treatment choice on quality of life, and support for shared decision-making [39] had notably low mean scores. Like the findings of DISCERN, the JAMA benchmarks, authorship, attribution, and currency, were only achieved in around one-third of the identified websites - which is low compared to head and neck cancer (66%, 69%, and 84% respectively) [26], oral leukoplakia (50% of each) [39] but similar to the findings reported with oral ulcers (27%, 33%, and 61% respectively) [41]. Given that a website failing to fulfil a minimum of three of these criteria might be considered as suspicious [28] - 80% of the websites included in this analysis would fall in this category. Due to the lack of JAMA benchmarks achieved the information on the majority of these sites may not be trustworthy and may therefore set unrealistic expectations regarding treatment interventions. This could then perhaps adversely influence the patients' ability to make autonomous and informed decisions [39, 43, 44].

Although HON was introduced in 1995, its application is still limited, perhaps due to a lack of awareness of its existence by designers of health information websites. In addition, the certification process can take up to 14 weeks [29] and thus may serve as a deterrent to usage.

This was possibly evident in our study as only 27% of the analysed websites have maintained the HON code seal a rate however that is higher compared to adult orthodontics at 2% [25], oral ulceration at 7% [41], and oral leukoplakia at 17% [39]. Nonetheless, it is important to note that organisations such as the NHS have developed a more sophisticated quality mark called Information Standard, which was not considered in this study due to its very recent introduction [45].

The readability of patient-oriented web information related to OED

Both FRES and FKGL indices used in the present analysis measure the readability by using the word and sentence length but with different formulae. The present analyses showed that only users who at or above 10th grade (US schools) might be likely to comprehend the content of the websites. These levels far exceeded those recommended by the American Medical Association (AMA) for written patient education materials which are at 5th to 6th grade levels or even lower in practices attended by individuals with expected lower literacy [46]. Achieving these recommendations is necessary to enable all readers with different literacy levels to comprehend the information and to enhance the informed decisions about their conditions [25].

The role of information provision in the management of chronic disease such as OED

Living with a chronic and potentially malignant disease such as OED often requires effective health behaviour changes, which necessitate that an individual has an awareness of their disease and is provided with the information and skills necessary to initiate and maintain these behaviour changes [47]. The most important modifiable risk factors for oral cancer are tobacco, excessive alcohol consumption and the use of betel quid [48]. Numerous studies have evaluated the impact of online interventions to change health behaviours including disease management and tobacco smoking cessation [49, 50]. When considering smoking cessation specifically, online interventions are considered to have the potential to increase cessation rates thereby having a positive influence on a key modifiable risk factor in patients with potentially malignant oral disease.

There is limited knowledge of the psychological impact of oral cancer symptoms upon affected individuals [51]. Individuals with other suspected cancer conditions (e.g. breast, lung, and colorectal structures) reported negatively affected quality of life and high levels of anxiety at the pre-diagnostic phase that can remain despite having a later benign outcome [52-54]. The possible reasons why the diagnosis of OED may cause distress may include the perception of threat to life, experienced symptoms including pain and disability, and treatment and its effects on physical and psychosocial well-being. Thus, providing tailored information for patients with longstanding conditions such as OED must acknowledge their information needs and considering the impact of the illness and its treatment on physical and psychological well-being [55-57]. One evolving method is to acquire these aspects by patient-based information needs assessment scales. There are tools available for various chronic disorders, but none of these are known to be suitable to assess the need for information for OED specifically.

Available information on oral dysplasia at health speciality organisations

Since health professional organisations are regarded as reliable sources for health information to patients and public [9], the relevant societies were searched deliberately and a patient information leaflet of OED found at British Society of Oral Medicine (BSOM) website [58]. This leaflet showed good quality by achieving an overall rating of four out of 5 by DISCERN and obtained three out of four JAMA benchmarks. However, it did not provide information about making informed decisions or what sources of information were employed to compile the leaflet. Similarly, the information about how the treatment works, its benefits or risks, and its effect on quality of life was not detailed. Also, its FRES score was at 51 which is fairly difficult to read. Another section about premalignant oral lesions, which was included in the analysis of the current study, is presented on the American Academy of Oral Medicine website [59]. This section obtained a good overall rating by DISCERN (4 out of five) but achieved only 2 out of the 4 JAMA benchmarks (authorship and disclosure). Its readability level was difficult to read (FRES = 45) which is similar to findings from other studies [46]. Through partnerships with medical practices and health speciality organisations, clinicians should consider the imperfections addressed by the current study, acknowledge better the published literature and create credible and user-friendly written health materials to patients and the public [15, 46]. There is also perhaps a need to improve the searching algorithms by Web search engines [9] to ensure finding reliable information sources if other descriptions of OED are being searched (e.g. oral precancer or oral potential malignant disorders).

Patient support groups as a supplementary source of valid and reliable information

Patient support groups can be valuable in patient education by providing a source of informational support, first-hand experience, and positively impacting upon changing an individual’s s attitude toward their chronic illness [58, 60] and precancerous disease [61]. Further to the advantages of face-to-face support groups, online support groups have been extensively developed for numerous conditions to improve access to helpful sources, overcome geographical and time restraints, and yet ensure anonymity [62, 63]. In dental health care, these groups can provide a supportive atmosphere to share previous experiences and concerns about dental management and motivation to dental attendance, particularly across dentally anxious individuals [64, 65]. Anxiety and fear may act as a barrier from attending regular clinic visits [64] and therefore such motivation is necessary especially when it comes to reporting worrying symptoms (e.g. change in appearance or size) of OED to the dental practitioner.

Examples of English language websites providing online support groups that can be suitable for patients with OED include disease-related online support groups such as UK Lichen Planus (https://www.uklp.org.uk) International OLP Support Group (https://dentistry.tamhsc.edu/olp), Lupus Foundation of America (https://www.lupus.org), and rare disease support groups that can be searched at the National Organisation for Rare Disease website (https://rarediseases.org). Other available online sources include cancer [e.g. Mouth Cancer Foundation (http://mouthcancerfoundation.org), Oral Cancer Foundation (https://oralcancerfoundation.org), and Cancer Survivors Network by American Medical Association (https://csn.cancer.org)] as well as alcohol/smoking cessation support groups [e.g. Smokers' Helpline by Canadian Cancer Society (https://www.smokershelpline.ca) and Alcoholics Anonymous (https://www.aa.org)]. Despite its advantages over face-to-face support groups [66], concerns remain toward the accuracy of shared information via online support groups as well as the cost of access to the Internet and shortage of professional facilitators [67, 68].

The limitations and strengths of the study

Aside from limitations of each assessment tool, this study is limited by restricting the search to English websites at a one-time point and considering the initial page of each link. Although 77% of OHI seekers in the US begin the search for information using a search engine, it is important to consider other sources such as general websites (e.g. Wikipedia), medical information websites (e.g. WebMD), social network sites (e.g. Facebook) [7] as well as mobile health applications [69]. Strengths include conducting nine searches of different search engines and terms as well as using more than one assessment tool per criteria (i.e. quality and readability) compared with previous studies that used a single method of each criteria [10, 40, 70].

Conclusion

The available web-based information on OED has little content specifically relating to OED and is generally of low quality. The readability scores, as shown by FRES and FKGL, are well above the recommended levels for written health materials. Thus at present patients seeking online information on OED are likely to have difficulty in finding and understanding reliable information about such disease and its possible impact upon their life. Further work is required to generate a web-based resource for OED that addresses the shortfalls demonstrated by the current study.

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Figure 1 A summary of results for all searches.

Figure 2 The JAMA benchmarks achieved by number and percentage of the 36 identified websites.

Figure 3 The number of websites per reading easiness grade based on Flesch Reading Ease Scores (n=36).

Table 1

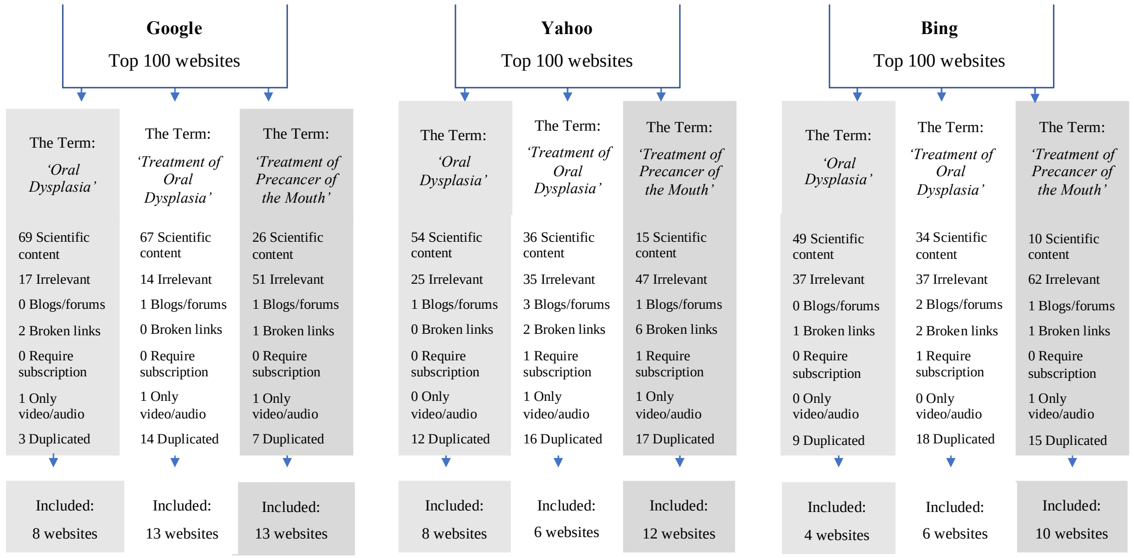
Summary of categorisation of the analysed websites according to affiliation, specialisation, and content type (n=36).

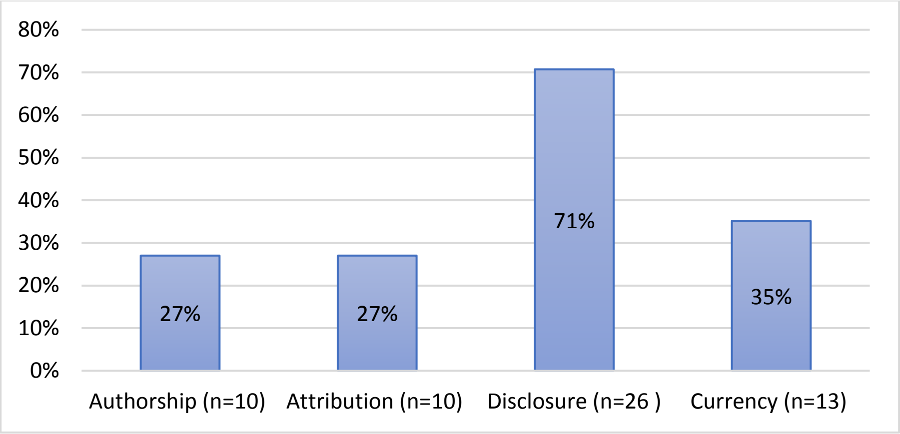
Category	**Criteria**	**Number of websites (%)**
Affiliation	Commercial	12 (33.33%)
	Non-profit organisation	12 (33.33%)
	Governmental	1 (2.77%)
	University/medical centre	11 (30.50%)
Specialisation	Site is entirely related to oral precancer	6 (16.66%)
	Site is partially related to oral precancer	30 (83.33%)
Content type	Medical facts	30 (83.33%)
	Clinical trials	2 (5.55%)
	Human interest stories	2 (5.55%)
	Question and answer	17 (47.22%)
Content presentation	Image	19 (52.77%)
	Video	1 (2.77%)
	Audio	1 (2.77%)

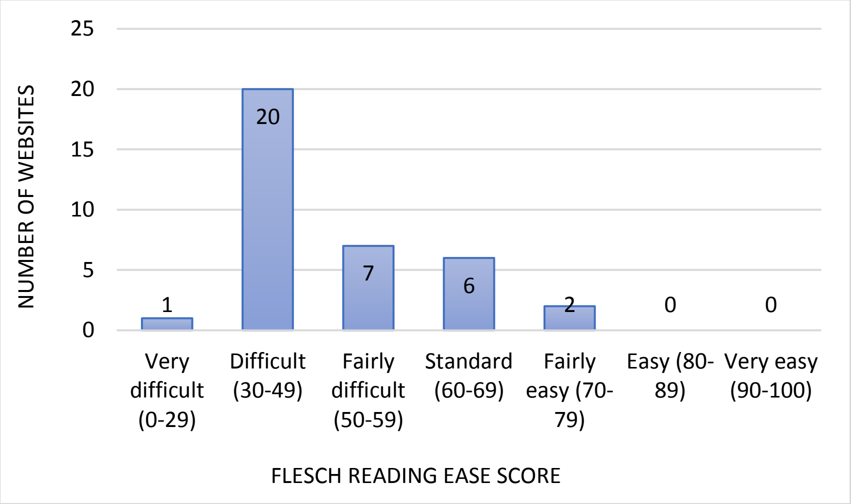
Table 2

The mean DISCERN scores of the 36 selected websites.

Domain	DISCERN question	Mean score (Std. Deviation)
Reliability	Q1. Explicit aims	3.56 (±0.80)
	Q2. Attainment of aims	3.19 (±1.16)
	Q3. Relevance	3.89 (±0.91)
	Q4. Explicit sources	1.86 (±1.22)
	Q5. Explicit date	2.31 (±1.30)
	Q6. Balanced and unbiased	2.97 (±1.02)
	Q7. Additional sources	2.47 (±1.46)
	Q8. Areas of uncertainty	3.08 (±1.18)
Treatment options	Q9. How treatment works	2.25 (±1.15)
	Q10. Benefits of treatment	2.14 (±1.07)
	Q11. Risk of treatment	1.97 (±1.08)
	Q12. Effects of no treatment	2.22 (±1.09)
	Q13. Effects on quality of life	1.92 (±1.10)
	Q14. All alternatives described	3.00 (±1.58)
	Q15. Shared decision	1.86 (±1.17)
Overall rating		2.42 (±0.90)


Google
Top 100 websites
The Term: 'Oral Dysplasia'
69 Scientific content
17 Irrelevant
0 Blogs/forums
2 Broken links
0 Require subscription
1 Only video/audio
3 Duplicated
Included: 8 websites
The Term: 'Treatment of Oral Dysplasia'
67 Scientific content
14 Irrelevant
1 Blogs/forums
0 Broken links
0 Require subscription
1 Only video/audio
14 Duplicated
Included: 13 websites
The Term: 'Treatment of Precancer of the Mouth'
26 Scientific content
51 Irrelevant
1 Blogs/forums
1 Broken links
0 Require subscription
1 Only video/audio
7 Duplicated
Included: 13 websites
Yahoo
Top 100 websites
The Term: 'Oral Dysplasia'
54 Scientific content
25 Irrelevant
1 Blogs/forums
0 Broken links
0 Require subscription
0 Only video/audio
12 Duplicated
Included: 8 websites
The Term: 'Treatment of Oral Dysplasia'
36 Scientific content
35 Irrelevant
3 Blogs/forums
2 Broken links
1 Require subscription
1 Only video/audio
16 Duplicated
Included: 6 websites
The Term: 'Treatment of Precancer of the Mouth'
15 Scientific content
47 Irrelevant
1 Blogs/forums
6 Broken links
1 Require subscription
1 Only video/audio
17 Duplicated
Included: 12 websites
Bing
Top 100 websites
The Term: 'Oral Dysplasia'
49 Scientific content
37 Irrelevant
0 Blogs/forums
1 Broken links
0 Require subscription
0 Only video/audio
9 Duplicated
Included: 4 websites
The Term: 'Treatment of Oral Dysplasia'
34 Scientific content
37 Irrelevant
2 Blogs/forums
2 Broken links
1 Require subscription
0 Only video/audio
18 Duplicated
Included: 6 websites
The Term: 'Treatment of Precancer of the Mouth'
10 Scientific content
62 Irrelevant
1 Blogs/forums
1 Broken links
0 Require subscription
1 Only video/audio
15 Duplicated
Included: 10 websites


80%
70%
60%
50%
40%
30%
20%
10%
0%
27%
27%
71%
35%
Authorship (n=10)
Attribution (n=10)
Disclosure (n=26)
Currency (n=13)


NUMBER OF WEBSITES
25
20
15
10
5
0
1
20
7
6
2
0
0
Very difficult (0-29)
Difficult (30-49)
Fairly difficult (50-59)
Standard (60-69)
Fairly easy (70-79)
Easy (80-89)
Very easy (90-100)
FLESCH READING EASE SCORE