Googling Endometriosis: A Systematic Review of Information Available on the Internet

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Googling Endometriosis: A Systematic Review of Information Available on the Internet.

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Short title: Online Endometriosis Information

Condensation:

Online endometriosis information for patients is of poor quality.

Objective

We aim to evaluate the credibility, quality, readability, and accuracy of online patient information concerning endometriosis.

Data sources

We searched the five popular internet search engines: [1] aol.com; [2] ask.com; [3] bing.com; [4] google.com; and [5] yahoo.com. We developed a search strategy in consultation with patients with endometriosis, to identify relevant websites.

Website eligibility

Websites containing information related to endometriosis for women with endometriosis or the public.

Website appraisal and synthesis methods

Two independent authors screened the search results. Websites were evaluated using validated instruments across four domains, including assessments of: [1] credibility (White Paper instrument; range 0-10); [2] quality (DISCERN instrument; range 0-85); and [3] readability (Flesch-Kincaid instrument; range 0-100). Accuracy was assessed by a prioritized criteria developed in consultation with healthcare professionals, researchers, and women with endometriosis based upon the European Society of Human Reproduction of Endometriosis guidelines (range 0 – 30). We summarized these data in diagrams, tables, and narratively.

Results

We identified 750 websites, of which 54 were included. Over a third of websites did not attribute authorship and almost half the included websites did not report the sources of information or academic references. No websites provided information assessed as being written in plain English. A minority of websites were assessed as high quality. A single website provided accurate information, evidentlycochrane.net. Available information was, in general, skewed towards the diagnosis of endometriosis. There were 16 credible websites, however the content limitations were infrequently discussed. No website scored highly across all four domains.

Comment

In the unlikely event that a website reports high quality, accurate, and credible health information it is typically challenging for a lay audience to comprehend. Healthcare professionals, and the wider community, should inform women with endometriosis of the risk of outdated, inaccurate, or even dangerous information online. The implementation of an Information Standard will incentivize providers of online information to establish and adhere to codes of conduct.

International Prospective Register of Systematic Reviews (PROSPERO): CRD42016036134.

Keywords

[1] Endometriosis
[2] Patients
[3] Accuracy
[4] Credibility
[5] Quality
[6] Readability
[7] Online information
[8] Systematic review

Introduction

Endometriosis is benign gynecological disease which affects one in ten women of reproductive age. It is characterized by pain and subfertility with associated reduced quality of life [1]. The economic burden of endometriosis is of a similar magnitude to other chronic diseases such as diabetes [2]. There is a paucity of high quality research to guide clinical practice, this leads to unwarranted and unjustified variations in patient care [3].

The internet is *the* source of health information as patients can access health information quickly, conveniently and privately. There are an estimated 6.75 million health searches daily in Google representing 4.5% of all searches performed [4]. There has been a rapid growth in the number of websites providing health information with little or no governance [5]. Seven in ten adults regularly search for an explanation and information on a new diagnosis or treatment [6-8]. Information provided is commonly written at a high literacy level compounding the difficulties for patients untrained in establishing whether the information is accurate. Exposure to complex, ungoverned, unfounded health information which lacks expert editorial supervision, could negatively affect patient understanding, compliance, and decision making. This could lead to poorer health outcomes, including harm [9-13]. There are no systematic reviews assessing the quality of online patient information pertaining to endometriosis.

We systematically assessed the accuracy, quality, readability, and credibility of websites providing women with endometriosis and the public information regarding the diagnosis and management of endometriosis.

Materials and Methods

Sources

A protocol with explicitly defined objectives, criteria for website selection, and approaches assessing outcome selection was developed and registered with the International Prospective Register of Systematic Reviews (PROSPERO), Identification number: CRD42016036134. This review was performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement [14].

Website Selection

We developed a comprehensive search strategy in consultation with healthcare professionals, researchers, and women with endometriosis. We used a keyword analytic instrument, SEMrush (www.semrush.com), to inform our selection of search terms. SEMrush provides analytical information related to search terms. We are confident we identified and selected all search terms commonly used by women with endometriosis. We used the following search terms: 1) endometriosis, 4,560,000 searches per annum; 2) endometriosis symptoms, 325,200 searches per annum; 3) endometriosis treatment, 64,800 searches per annum; 4) endometriosis pain, 19,200 searches per annum; and 5) endometriosis diagnosis, 15,600 searches per annum. We searched the most popular search engines including: 1) aol.com; 2) ask.com; 3) bing.com; 4) google.com; and 5) yahoo.com, during March 2016. Individuals rarely examine more than the first three pages of a search [11]. We therefore extracted the websites from the first three pages for each search term within each search engine. Location services were disabled to eliminate geographical bias.

We organized the extracted websites and removed duplicates. Two reviewers (M.H. and S.A.) independently screened the full content of websites to assess eligibility. All data extraction was performed using piloted data extraction instruments. We pilot tested each instrument using a representative sample of the websites to be reviewed. This testing helped identify data that are missing from the form, or likely to be superfluous. This allows authors trialing the form to provide feedback that certain coding instructions are confusing or incomplete (e.g. a list of options may not cover all situations). Any discrepancies between the reviewers were resolved by discussion with a consensus required before the form is modified to avoid any misunderstandings or later disagreements. We repeated the pilot testing on a new set of websites where no major changes were needed after the first pilot testing [15].

We included websites providing health information about endometriosis greater than 300 words in length. We excluded websites for the following reasons; 1) non-English language; 2) inaccessible, for example password restricted; 3) aimed at a professional audience, for example scientific publication; 4) excessive commercial advertising (two or more commercial advertisements); and 5) content related solely to the lived experience of endometriosis, for example a patient’s diary or blog.

Those websites which met the criteria for inclusion were saved as a portable document format for evaluation and data extraction by two independent authors (M.H & S.A). M.H. and J.D. did not assess any websites they had previously contributed too.

Website Characteristics

Two reviewers (M.H. and S.A.) extracted the website characteristics independently using a piloted data extraction sheet. Information extracted from each website included country of origin, disease specific information, listed authors, and privacy statements. Two reviewers (M.H. and S.A.) independently assessed each website using validated instruments including assessments of 1) credibility assessed using the White instrument [16] anchored between 0 (poor) and 10 (excellent) 2) quality assessed using the DISCERN [17] instrument anchored between 0 (poor) and 85 (excellent), and 3) readability assessed using the Flesch-Kincaid [18] instrument anchored between 0 (poor) and 100 (excellent). Discrepancies were resolved by discussion.

Quality Assessment

Two reviewers (MH and SA) underwent training in the use of the quality assessment instruments. We assessed accuracy using a prioritized list of recommendations included within the European Society of Human Reproduction and Embryology endometriosis guidelines (ESHRE) [19]. The ESHRE guideline was selected for comparison as this was objectively assessed to represent the highest quality endometriosis guideline [20]. All recommendations were extracted by two authors independently. Discrepancies were resolved by discussion. In consultation with healthcare professionals, researchers and women with endometriosis, the recommendations were scored as 1) critical for decision making, 2) important but not critical for decision making and 3) not critical and not important for decision making. Fifteen guideline recommendations were selected as statements critical for decision making (appendix 1). The assessment of accuracy was standardized against selected guideline recommendations. This approach has been utilized in similar research studies [21].

Two reviewers (M.H and S.A) independently reviewed each website and using a piloted standardized proforma assessing the accuracy of information. Each recommendation was scored: 0 (if absent or incorrectly described), one (present and incompletely described), or two (present and completely described). Accuracy assessment was anchored between zero and 30. Discrepancies were resolved by discussion. We classified websites with a score greater than or equal to 20 as accurate.

The website's credibility was assessed by two reviewers independently using a validated instrument, White [16]. This instrument, designed for consumers of health information, provides a set of criteria that can be used to accurately and reliably assess the quality of health information on the Internet. Credibility was assessed using a ten point criteria: 1) source; 2) context; 3) currency; 4) utility; 5) editorial review process; 6) hierarchy of evidence; 7) statement of original source; 8) disclaimer, which included ownership, sponsorship, funding and advertising; 9) omissions; and 10) feedback. Each criterion was scored 0 (absent) or one (present) giving a score anchored between 0 to 10 [22]. Discrepancies were resolved by discussion. We classified those websites with a score greater than or equal to seven as credible.

The website's quality was assessed by two reviewers independently using a validated instrument, DISCERN [17], a validated instrument designed to assess the quality of written information on treatment choices which can be applied to any disease [7,17]. The DISCERN instrument offers a framework for the production, evaluation, and screening of written consumer health information. This includes 16 questions assessed using a Likert scale anchored between one (do not agree) and five (agree) [17]. Discrepancies were resolved by discussion. We classified those websites as high (>53), moderate (27-52), and low (<27) quality.

The website's readability was assessed using the Flesch-Kincaid reading-ease test [18]. This formula presents a score as a U.S. grade level, making it easier for teachers, parents, librarians, and consumers of health information to judge the readability level of various texts. The Flesch Kincaid score is generated from the following equation: 206.835 – 1.015 (total words / total sentences) – 84.6 (total syllables / total words) (www.readability-score.com) [18]. The scores were anchored between 0 (complex language) and 100 (simple language) and can be categorized by reading age or educational status: 1) 90-100 (5th grade); 2) 80-90 (6th grade); 3) 70-80 (7th grade); 4) 60-70 (8th and 9th grade); 5) 50-60 (10th, 11th and 12th grade); 6) 30-50 (college); 7) 0-30 (college graduate). Discrepancies were resolved by discussion.

A large-scale national assessment of the average reading level among Americans performed by the National Center for Education Statistics found that the typical

American reads between a 7th and 8th grade level [23]. It is recommended that online health information should not exceed the level of American 7th grade writing and reading [24]. We therefore expected websites to have a readability score at or below the level of American education 7th Grade (>70) to be deemed appropriate for a patient and public audience.

Analysis

The website characteristics and assessments were summarized in tabular form and presented with descriptive statistics within summary tables and diagrams.

Results

The search strategy identified 750 websites which were assessed for eligibility. We screened 211 websites following the exclusion of 539 duplicate websites. Two authors independently applied an inclusion and exclusion criteria when screening the websites. We included 54 websites in our final assessment (figure 1, table 1).

Website characteristics

Twenty-one (39%) websites did not report the authors and 25 (46%) of websites did not reporting sources of information or academic references. The majority of included websites were published in the United Kingdom (25 websites; 46%). All websites presented structured content. Almost two thirds of the websites reported a privacy statement (38 websites; 70%) (table 1).

Accuracy

A single website provided accurate information, *evidentlycochrane.net*. The median accuracy of included websites was 5 (Interquartile range [IQR] 4 – 7). Included websites contained limited information (Table 1), skewed towards the diagnosis of endometriosis. Information pertaining to the medical or surgical management of pain or infertility associated with endometriosis were poorly represented. The most commonly reported recommendation, "*Clinicians should consider the diagnosis of endometriosis in the presence of gynecological symptoms such as: dysmenorrhea, non-cyclical pelvic pain, deep dyspareunia, infertility, fatigue in the presence of any of the above*", was described by four fifths of included websites (43 websites, 80%). The least frequently described recommendations, described by a small minority of included websites (3 websites; 6%) were: 1) "*In infertile women with endometriosis, clinicians may offer treatment with assisted reproductive technologies after surgery, since cumulative endometriosis recurrence rates are not increased after controlled ovarian stimulation for IVF/ICSI.*" 2) "*Clinicians [should] inform women with endometriosis requesting information on their risk of developing cancer that 1) there is no evidence that endometriosis causes cancer, 2) there is no increase in overall incidence of cancer in women with endometriosis, and 3) some cancers (ovarian cancer and non-Hodgkin's lymphoma) are slightly more common in women with endometriosis*". The delivery of inaccurate, outdated or dangerous information remains prevalent in websites. Inaccuracies include: 1) "Your specialist may also suggest flushing out your blocked fallopian tubes. This procedure is an alternative to surgery and is usually successful" website ID 1. Routine tubal flushing is used in diagnostic evaluation of tubal patency and it is not recommended therapeutic approach [25]. 2) "The only reliable way to confirm the presence of the disease is by visually inspecting the abdominal organs by a procedure called a laparoscopy" Website ID 20. There are many difficulties associated with visually confirming endometriosis. The most reliable way to diagnose endometriosis is laparoscopy, biopsy and histopathological examination. Visual diagnosis is no longer recommended [19]. 3)"It is suspected that between 10-20% of reproductive aged women have the disease."

Website ID 20. The estimated prevalence within the general population is up to 10% [19].

Credibility

Credibility was defined as a score equal to or greater than seven. Sixteen websites (29%) were assessed as credible. The median credibility of included websites was 5 (IQR 2 - 8.8). The highest scoring criteria included context relevant to the disease and originality with all websites fulfilling these criteria. The least frequently described area of credibility was the discussion of content limitations which was reported by one website (table 1).

Quality assessment

Thirteen websites (24%) were assessed to be high quality, 40 (74%) websites were assessed to be of moderate quality, and a single website (2%) was assessed as low quality. The highest scoring criteria included describing aims (median = 5; IQR 3-4) and being unbiased (median 5; IQR 4-5). Websites typically did not describe the consequences of no treatment (median 1; IQR 1-1).

Readability

All included websites were assessed as fairly difficult to read (10th, 11th, and 12th grade), difficult to read (college), or very difficult to read (college graduate). The median readability score was 38.2 (IQR 30.7 – 48.0), indicating an average educational status of a college student would be required to understand the written content (table 1 and 2). Forty-five websites (83%) presented written information at a level at or above college standard.

There were no substantial discrepancies between authors in the data extraction of quantitative parameters and we observed very high interrater agreement.

Comment

Summary

There are no websites which provide high quality, accurate, and credible health information pertaining to endometriosis. Currently, websites contain limited amounts of information which are skewed towards the diagnosis of endometriosis. In the unlikely event that a website reports high quality, accurate, and credible health information, it is typically written in language that is challenging for a lay audience to comprehend.

Strengths and Weaknesses

To our knowledge, this is the first study to examine the quality, credibility, accuracy, and readability of patient focused online information pertaining to the diagnosis and management of endometriosis. We followed a robust, prospective systematic review method with validated instruments to assess the information presented. We evaluated individual websites using four validated instruments in a systematic process, independently performing all assessments in duplicate. We involved women with endometriosis, to inform the research question, design and delivery of the research study, and its dissemination. All reviewers underwent recommended training prior to commencing the study.

This study is not without limitations. Limiting the search to the first three pages may have resulted in the exclusion of potentially eligible websites, however only 2.6% of people search past Googles' third page (www.protofuse.com). Included websites were only written in English language, limiting the generalizability of our findings. The search was conducted while computer location services were disabled, however there may have been regional differences in search results, out of the authors control, which account for the predominance of British websites. We designed and registered this systematic review prospectively with a pre-defined inclusion criteria and analysis plan. There are few scientific publications which evaluate online information for patients allowing limited precedent to guide our methods. We observed diminishing returns, however this was not quantified. All websites were designed and managed within high resource countries. This limits the applicability of this research to inform low resource settings. We did not calculate weighted kappa to explore agreement between authors as the statistical level of agreement required in health research is unclear [26]. This evaluation is not currently recommended by the Cochrane Collaboration [15]. We could have conducted in-depth qualitative interviews of women with endometriosis to explore their satisfaction with reading individual websites and evaluate the correlation with accuracy, credibility, quality and readability.

Interpretation

As clinicians we must be aware that patients are increasingly seeking unregulated health information online which shapes opinions and treatment choices. The essence of modern clinical consultations is changing from a reliance on face-to-face interaction to information gathering online prior to seeking professional opinion. In the United States of America, there are over 400,000 endometriosis searches per month in Google alone. We have demonstrated that individual websites are frequently incomplete, inaccurate, and poorly written. This is a barrier to patient education and results in those vulnerable patients who seek reliable information being misinformed. This is of greater importance to non-expert patients (majority) who may be less able to evaluate the reliability of online information and be susceptible to the bias and inaccuracies contained within. These forays into online information gathering can lead to a breakdown in doctor patient relationships. Inaccurate online health information can lead to clinicians advocating guideline-supported recommendations different from those read on “reputable” online sources. This mismatch of information can lead to a breakdown in trust in the clinician-patient relationship.

A review conducted by the United States Office of Disease Prevention and Health Promotion (ODPHP) concluded that the potential for harm from inaccurate online information is significant [27]. Harm can be: 1) physical, from inappropriate treatments, adverse effects, or untreated disease; 2) emotional, from anxiety or false hope arising from inaccurate diagnostic, prognostic, or therapeutic information; 3) financial, costs incurred from unnecessary purchase of ineffective health services or products [27]. The ODPHP concluded that the Internet is critical to disease prevention, health promotion, and health care because of the increasing amount of information and services available via the internet. This included a key objective to increase the quality of online health information [28].

The readability of a website is an essential facet of online information. Information presented at a standard above patients' comprehension will limit its ability to inform the patient. Healthcare professionals should be aware that there is very limited information available to women with endometriosis with basic levels of literacy (indicates skills necessary to perform simple and everyday literacy activities), and therefore directing them to online information is of limited value in informing decision making.

Many online information rating systems use proxy markers for quality that do not consider the needs and opinions of patients and the public. Meric and colleagues [29], determined website popularity did not correlate well with traditional standards of website quality. Quality of online information is crucial as patients want to know about the risks, benefits, and uncertainty associated with diagnostic and therapeutic options. This information must be accurate to ensure that patients seeking information are gaining correct and complete information about the disease from up to date scientific evidence. Without access to good quality information, patients are unable to make informed choices about their treatment.

Recommendation(s)

Healthcare professionals and the wider medical community are increasingly quizzed by patients regarding health information found online. It is essential that healthcare professionals acknowledge their position of responsibility and proactively inform women with endometriosis about the risk of outdated, inaccurate, or even dangerous information online. Interactive consultations using online clinical practice guidelines such as those produced by the American College of Obstetrics and Gynecology [30] or the Society of Obstetricians and Gynaecologists of Canada [31] can provide the basis for clear, concise, evidence based management discussions. Following consultations, patients should be sign posted towards higher quality and more reliable sources of online information to answer questions they may have forgotten to ask during their limited consultation time.

While it may sound unrealistic to regulate health information on the internet, codes of conduct have been developed and implemented. The Health on the Net Foundation, based in the United States, provides accreditation to websites, which meet pre-defined standards related to readability, accessibility, and accuracy [18]. The Information Standard, based in the United Kingdom, assesses online health information to ensure the information is clear, accurate, balanced, evidence-based, and up-to-date. Information produced by the Royal College of Obstetricians and Gynaecologists is accredited by this information standard (https://www.england.nhs.uk/tis/).

We acknowledge that regulating health information on the internet has inherent difficulties as online authors are not bound by the same codes of practice as licensed healthcare professionals. The implementation of a robust Information Standard internationally will incentivize providers of online information to establish and adhere to codes of conduct ensuring an improvement in the quality of online information. Healthcare professionals and professional bodies should direct women with endometriosis towards higher quality, more reliable sources of online information. In general, websites who comply with an Information Standard, should be prioritized.

The internet will continue to increase its role as a provider of online health information. The media by which health information is transferred from source to patient should not compromise the fundamental features of accuracy, credibility, quality and readability. It would not be tolerated if a healthcare professional were delivering sub-standard information in a face-to-face consultation. A strategy is required to improve the standard of online information for women with endometriosis with evident need for the development of patient focused online information with a robust evidence base. The translation of research from trials or systematic reviews into online sources has a direct pathway currently being delivered by Cochrane in the form of Evidently Cochrane summaries. These webpages summarize Cochrane systematic reviews into patient focused bite size pieces of information [32].

Conclusion

In the unlikely event that a website reports high quality, accurate, and credible health information it is typically challenging for a lay audience to comprehend. Healthcare professionals, and the wider community, should inform women with endometriosis of the risk of outdated, inaccurate, or even dangerous information online. Providers of online information should engage with established codes of conduct, such as the Information Standard.

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surgery-friend-foe/

Table Legends

Table 1. Included websites characteristics and summary statistics of quality, accuracy, credibility, and readability of included websites.

Table 2. Readability presented by US reading age.

Table 1. Web site characteristics and a summary of quality, accuracy, credibility, and readability assessment

I.D	Web Domain	Country	Listed Authors	Privacy Statement	Quality[a]	Accuracy[b]	Credibility[c]	Readability[d]
1.	endocenter.org	USA	No	Yes	46	10	4	23.5
2.	endometriosis.org	Global	No	Yes	62	12	7	39
3.	endometriosis.org	Global	No	Yes	50	1	4	34.8
4.	endometriosis.org	Global	No	Yes	50	10	8	55.4
5.	endometriosis.org	Global	Yes	Yes	37	3	3	38.1
6.	endometriosis.org	Global	No	Yes	42	4	5	46.3
7.	home.bt.com	UK	Yes	Yes	46	10	5	49.1
8.	lifestyle.one	UK	Yes	No	48	3	4	38.3
9.	medical-dictionary.thefreedictionary.com	USA	No	Yes	62	10	9	38.3
10.	metro.co.uk	UK	Yes	No	37	5	2	49.3
11.	pain.about.com	USA	Yes	Yes	61	7	6	38.5
12.	patient.info	UK	Yes	No	69	6	7	26.8
13.	shetrust.org.uk	UK	No	No	35	11	8	23.9
14.	sogc.org	Canada	No	Yes	42	6	3	34.9
15.	womenshealth.about.com	USA	Yes	Yes	42	2	8	24.8
16.	activebeat.com	Canada	No	Yes	28	2	7	40.4
17.	babycentre.co.uk	Global	No	Yes	40	6	4	34.2
18.	channel4embarrassingillnesses.com	UK	No	Yes	32	2	5	32
19.	cwhn.ca/node/40781	Canada	No	No	43	3	4	51.7
20.	endo-resolved.com	UK	No	No	35	1	5	44.9
21.	endo-resolved.com	UK	No	No	37	4	4	55.1
22.	endo-resolved.com	UK	No	No	54	10	9	48.1
23.	endometriosis.ie	Ireland	No	Yes	39	6	3	56.8
24.	endometriosisaustralia.org	Australia	No	No	58	10	8	24.3
25.	endometriosisinstitute.com	USA	No	No	50	2	5	49.8
26.	endometriosisinstitute.com	USA	No	No	51	9	4	33.7
27.	evidentlycochrane.net	UK	Yes	No	45	7	8	40.6
28.	evidentlycochrane.net	UK	Yes	No	56	13	6	45.9

29.	healthline.com	USA	Yes	Yes	62	1	5	47.6
30.	hellomagazine.com	UK	No	Yes	38	5	4	53.4
31.	independent.co.uk	UK	Yes	Yes	32	0	5	51.6
32.	livescience.com	Global	Yes	Yes	47	2	4	32.2
33.	medicalnewstoday.com	UK	Yes	Yes	45	8	5	23
34.	netmums.com	UK	No	No	45	8	5	21.3
35.	nytimes.com	USA	Yes	Yes	51	2	6	32.6
36.	nzendo.org.nz	New Zealand	No	No	40	11	8	21.5
37.	pelvicpain.org.uk	UK	No	Yes	57	2	3	61
38.	pelvicpain.org.uk	UK	No	Yes	38	13	9	33.8
39.	prevention.com	USA	Yes	Yes	35	8	7	30.8
40.	students4bestevidence.net	UK	Yes	Yes	47	5	4	47.3
41.	theguardian.com	UK	Yes	Yes	40	6	5	33.6
42.	theguardian.com	UK	Yes	Yes	31	4	7	29.6
43.	uptodate.com	UK	Yes	Yes	64	10	9	30.7
44.	womens-health.co.uk	New Zealand	No	Yes	22	28	7	5
45.	womens-health.co.uk	New Zealand	No	Yes	35	2	5	31
46.	youngwomenshealth.org	USA	Yes	No	61	5	5	38.2
47.	en.wikipedia.org	Global	No	Yes	50	4	3	38.5
48.	health.facty.com	Canada	Yes	Yes	32	2	5	48.3
49.	betterhealth.vic.gov.au	Australia	No	Yes	61	4	5	52.3
50.	endometriosis-uk.org	UK	No	Yes	42	5	4	28.1
51.	endometriosis-uk.org	UK	No	Yes	40	3	4	32.8
52.	endometriosis-uk.org	UK	No	Yes	41	5	8	57
53.	endometriosis-uk.org	UK	No	Yes	53	2	4	23
54.	endometriosis-uk.org	UK	No	Yes	33	1	5	24.8
				Median IQR	44 (37–51)	5 (4-7)	5 (2–9)	38.2 (30–48)

[a] DISCERN tool to assess quality of information (range 16 - 80)
[b] Accuracy assessed using selected criteria from 2013 ESHRE guidelines (range 0 - 30)
[c] Credibility based on ten criteria (range 0 - 10)
[d] Readability assessed using the Flesch Reading Ease tool (range 0 - 100)

Ease of reading	USA educational level	Webpages (n)

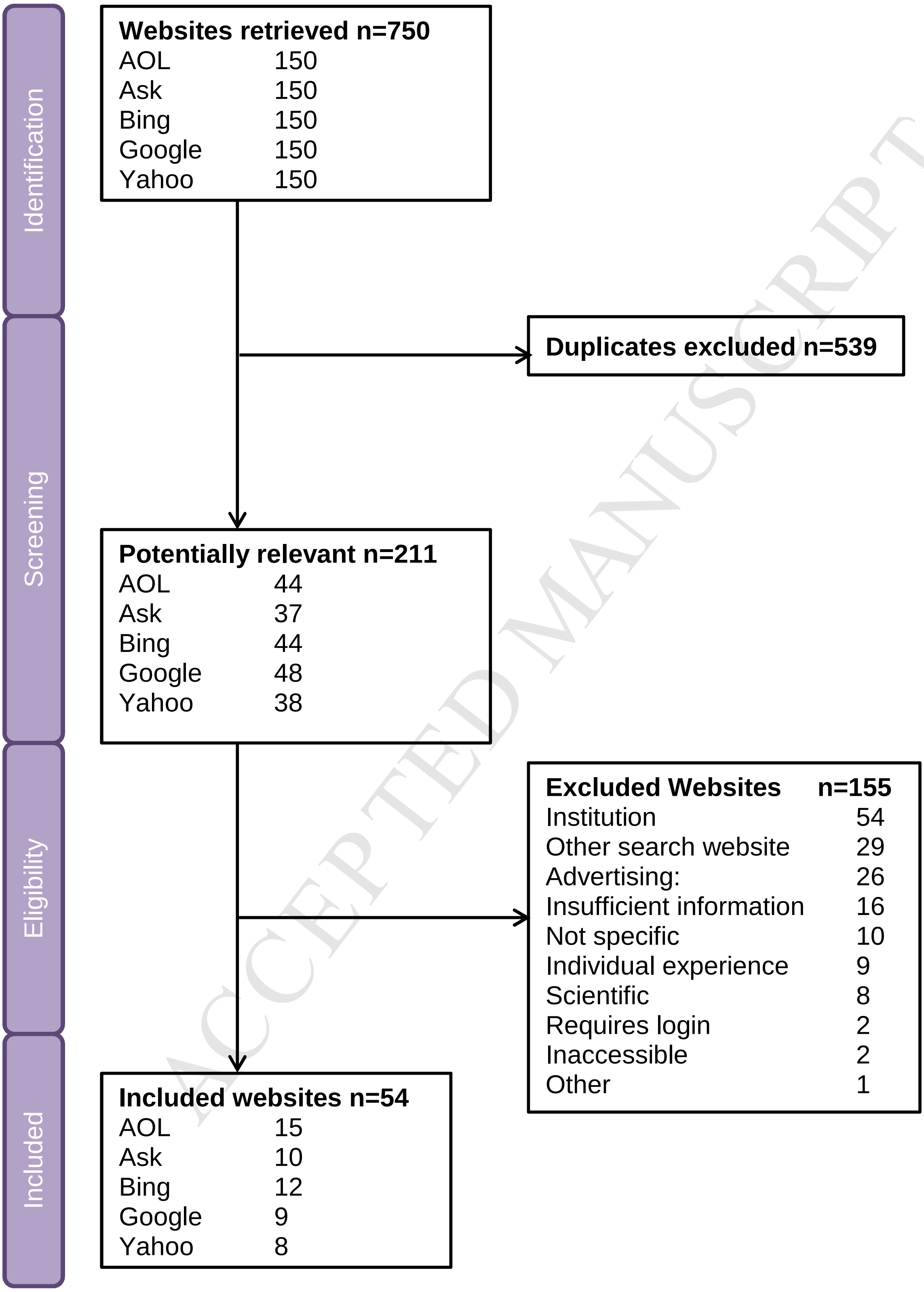
Table 2. Readability

Very easy to read (score 90-100)	5th Grade	0
Easy to read (score 80-90)	6th Grade	0
Fairly easy to read (score 70-80)	7th Grade	0
Plain English (score 60-70)	8th-9th Grade	1
Fairly difficult to read (score 50-60)	10th-12th Grade	8
Difficult to read (score 30-50)	College	32
Very difficult to read (score 0-30)	College Graduate	13

Figure Legend

Figure 1. Flow of included websites.

Figure 1. Flow of included websites.



Appendix 1. Summary of ESHRE Guidelines for Accuracy Assessment

1. The GDG recommends that clinicians should consider the diagnosis of endometriosis in the presence of gynecological symptoms such as: dysmenorrhea, non-cyclical pelvic pain, deep dyspareunia, infertility, fatigue in the presence of any of the above.

2. The GDG recommends that clinicians confirm a positive laparoscopy by histology, since positive histology confirms the diagnosis of endometriosis, even though negative histology does not exclude it.

3. Clinicians are recommended to perform transvaginal sonography to diagnose or to exclude an ovarian endometrioma.

4. Clinicians are recommended not to use immunological biomarkers, including CA-125, in plasma, urine or serum to diagnose endometriosis.

5. The GDG recommends clinicians to counsel women with symptoms presumed to be due to endometriosis thoroughly, and to empirically treat them with adequate analgesia, combined hormonal contraceptives or progestagens.

6. Clinicians are recommended to prescribe hormonal treatment [hormonal contraceptives (level B), progestagens (level A), anti-progestagens (level A), or GnRH agonists (level A)] as one of the options, as it reduces endometriosis-associated pain.

7. When endometriosis is identified at laparoscopy, clinicians are recommended to surgically treat endometriosis, as this is effective for reducing endometriosis-associated pain i.e. ‘see and treat’.

8. When performing surgery in women with ovarian endometrioma, clinicians should perform cystectomy instead of drainage and coagulation, as cystectomy reduces endometriosis-associated pain.

9. The GDG recommends that clinicians refer women with suspected or diagnosed deep endometriosis to a centre of expertise that offers all available treatments in a multidisciplinary context.

10. In infertile women with AFS/ASRM stage I/II endometriosis, clinicians should perform operative laparoscopy (excision or ablation of the endometriosis lesions) including adhesiolysis, rather than performing diagnostic laparoscopy only, to increase ongoing pregnancy rates.

11. In infertile women with ovarian endometrioma undergoing surgery, clinicians should perform excision of the endometrioma capsule, instead of drainage and electrocoagulation of the endometrioma wall, to increase spontaneous pregnancy rates.

12. The GDG recommends that clinicians counsel women with endometrioma regarding the risks of reduced ovarian function after surgery and the possible loss of the ovary. The decision to proceed with surgery should be considered carefully if the woman has had previous ovarian surgery.

13. Clinicians can prescribe GnRH agonists for a period of 3 to 6 months prior to treatment with assisted reproductive technologies to improve clinical pregnancy rates in infertile women with endometriosis.

14. In infertile women with endometriosis, clinicians may offer treatment with assisted reproductive technologies after surgery, since cumulative endometriosis recurrence rates are not increased after controlled ovarian stimulation for IVF/ICSI.

15. The GDG recommends that clinicians inform women with endometriosis requesting information on their risk of developing cancer that 1) there is no evidence that endometriosis causes cancer, 2) there is no increase in overall incidence of cancer in women with endometriosis, and 3) some cancers (ovarian cancer and non-Hodgkin’s lymphoma) are slightly more common in women with endometriosis.