Googling fibroids: A Critical Appraisal of Information Available on the Internet.

Martin Hirsch[a], Alexandra Wojtaszewska[b], Ertan Saridogan[a], Dimitrios Mavrelos[a], Claire Barker[c], James M. N. Duffy[a]

[a]Elizabeth Garret Anderson Institute for Women's Health, University College London, London, United Kingdom.

[b]University College London Medical School, London, United Kingdom

[c]Radcliffe Women's Health Patient and Public Involvement Group, University of Oxford, Oxford, OX1 2JD, United Kingdom

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Corresponding author

Martin Hirsch BM MRCOG MD(Res)

Elizabeth Garret Anderson Institute for Women's Health, University College London, London, United Kingdom.

m.hirsch@nhs.net

+44 (0)7763838460

@martinhirsch100

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Objective

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

Study design

We searched the most popular Internet search engine: Google.com. We developed a search strategy in consultation with patients with fibroids, to identify relevant websites. Two independent authors screened the search results. Websites were evaluated using validated instruments across three domains, including assessments of: [1] quality (DISCERN instrument; range 0-85); [2] readability (Flesch-Kincaid instrument; range 0-100); and [3] accuracy. Accuracy was assessed using evidence-based statements. We summarised this data narratively including the use of figures and tables.

Results

We identified 750 websites, of which 48 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 website provided written patient information in line with recommendations from the American Medical Association. A minority (18%) of websites were assessed as high quality. Twelve webpages provided only accurate statements. Available information was, in general, skewed towards the surgical management of fibroids. No website scored highly across all three domains.

Conclusion

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 Healthcare professionals and the wider community, should inform women with fibroids of the risk of outdated, inaccurate, or even dangerous information online.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

Keywords
[1] Fibroids
[2] Patients
[3] Accuracy
[4] Quality
[5] Readability
[6] Online information

1 Introduction

Uterine leiomyomas (fibroids) are the most common benign tumours in women of reproductive age, affecting up to 80% of females.[1] The prevalence of fibroids increases with age until menopause and are more common in women of Black ethnicity.[2] Fibroids are associated with significant morbidity and a reduction of quality of life, in the domains of pain, heavy menstrual bleeding, and infertility.

The Internet has transformed information delivery with an estimated 3.4 billion people globally accessing online information and 70,000 health searches per minute in Google.com.[3] This facilitates health seeking behaviours with information accessible to patients in a timely, convenient and private manner.[4,5] There is limited regulation of online health information with a rapid expansion of webpages reporting to offer “must know” health information.[6] Patients are commonly untrained in assessing whether online information is accurate. Exposure to ungoverned, inaccurate and complex material can negatively coerce patient decision making, leading to harm.[6]

Previous systematic reviews of online information in areas of women’s health including: endometriosis; obstetric anal sphincter injury; and bladder pain syndrome have revealed poor quality, accuracy, and readability.[7–9] A single systematic review relating to online information of fibroids has been published, however this only assess quality.[10] We systematically assessed the accuracy, quality, and readability of webpages providing information regarding the diagnosis and management of fibroids.

2 Materials and Methods

2.1 Sources

In consultation with healthcare professionals, researchers and women with fibroids, we developed a comprehensive search strategy, criteria for website selection, and approaches assessing outcome selection. This review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement.[11]

2.2 Webpage Selection

In consultation with health care professionals, researchers and women with fibroids, a long list of potential search terms was generated. We used a keyword analytic instrument (https://www.semrush.com/) to select the four most frequently used search terms: “fibroids,” 74,000 searches per month; “uterine fibroids,” 33,100 searches per month; “leiomyoma,” 12 100 searches per month; “fibroid tumours,” 6,600 searches per month. Using these search terms (“fibroids”, “uterine fibroids”, “leiomyoma” and “fibroid tumours”), we performed the search during December 2017. Location services were disabled to ensure no geographical bias. We chose to use Google.com (https://www.google.com) because it is the world's most popular search engine.[12] As most patients are highly unlikely to read beyond the third page of Google.com, only the first three pages of results were screened for eligibility.[13] We excluded the following webpages: non-English language; aimed at a professional audience (scientific publication); sponsored content; content based on individual experience of fibroids (blog); dictionary definitions; and those which were inaccessible (subscription based access).

Fibroids have wide ranging clinical signs and symptoms. In consultation with health care professionals, researchers and women with fibroids, we chose to limit the remaining sources for information to: 1) diagnosis; 2) impact on bleeding, fertility and

pregnancy; 3) medical management; and 4) surgical management. Webpages which did not provide information in these domains were not included in the analysis.

The remaining webpages were converted to PDF documents for independent evaluation and characteristics extraction by two authors (MH and AW). Webpage extraction allowed for mitigation against content updates during the period of analysis.

2.3 Website Characteristics

Two authors (MH and AW) independently extracted webpage characteristics using a piloted data extraction tool. Information extracted from webpages included: authorship, sources, academic references, and country of publication.

2.4 Webpage Assessment

Two reviewers (MH and AW) underwent training in the use of all the assessment instruments. Statements pertaining to the diagnosis, impact and management of fibroids were independently extracted by two authors (MH and AW) and categorised into four domains: 1) diagnosis; 2) impact on bleeding, fertility and pregnancy; 3) medical management; and 4) surgical management. The source of each statement remained identifiable for the purpose of analysis.

Two reviewers independently evaluated each webpage using validated instruments, assessing: (1) quality (DISCERN instrument, anchored between 16 (poor) and 85 (excellent))[14]; (2) readability (Flesch-Kincaid instrument, anchored between 0 (poor) and 100 (excellent))[15]; and (3) accuracy (expert opinion, anchored between 0 (very poor) and 100 (excellent)).

2.4.1 Accuracy

There is no single evidenced based guideline for the management of uterine fibroids. We therefore sought expert opinion to assess the accuracy of extracted statements. The statements were independently evaluated by medical experts in the diagnosis and management of fibroids: Mr. Dimitrios Mavrelos (DM) and Mr. Ertan Saridogan (ES). Statements were classified as “accurate”, “inaccurate” or “unclear”. The accuracy results were anchored between 0% accurate statements and 100% accurate statements. Webpages were categorised as accurate if greater than or equal to 80% of all statements were accurate and inaccurate if less than 80% of all their statements were accurate.

2.4.2 Quality

The quality of the webpages was assessed using a validated instrument – DISCERN.[14] It was designed for patients and information providers to assess the quality of written information on treatment choices and can be applied to any disease. The instrument consists of 16 questions assessed using a Likert scale, anchored between 1 (no) and 5 (yes), with further 5 points added as a reflection of overall quality. High quality webpages were classified as scoring 53 and above, moderate quality as those scoring 27-52 and low-quality scoring 26 or less. This approach was adopted in similar studies.[7]

2.4.3 Readability

The readability of included webpages was measured using the Flesh-Kincaid reading ease test.[15] 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). The reading scores are anchored from 0 (very difficult

to read) to 100 (very easy to read) and were categorised by educational level: 90-100 (Year 6); 80-90 (Year 7); 70-80 (Year 8); 60-70 (Years 9 and 10); 50-60 (Years 11, 12 and 13); 30-50 (university); or 0-30 (university graduate).

The American Medical Association recommends that health information for patients should be presented at a reading level no higher than the American sixth grade level (11-12 years of age).[16] This equates to a Flesch-Kincaid Reading Ease Score of 80-90.[17] We therefore expected websites to have a readability score at or below the level of 6th Grade (>80) American education to be deemed appropriate for a patient and public audience.

2.5 Analysis

The website characteristics and assessments were presented with descriptive statistics and summarised in tabular form.

3 Results

The search strategy identified 205 webpages, which were assessed for eligibility. We screened 166 webpages following the exclusion of 39 duplicates. Forty-eight webpages were included for analysis (Figure B.1, Table A.1). Throughout the review process all disputes were resolved by discussion. In relation to assessment of accuracy, quality, and readability a single score was allocated following discussion.

3.1 Webpage characteristics

The majority of webpages, 25/48 (52%) were published in the United States of America. Eleven webpages (23%) were published in the United Kingdom. The remaining 12 webpages (25%) were published by global organisations with no tie to a

particular country. Authorship of the content was not reported by 34/48 (71%) of included sources. No sources of information or academic references were reported by 26/48 (54%) webpages. (Table A.1)

3.2 Accuracy

The median number of statements provided by a single webpage was 13 (IQR 4-28). The median percentage of accurate statements provided was 84% (IQR 75-96.25%); inaccurate statements 4% (IQR 0-12%); and unclear statements 7% (IQR 0-13%). (Table A.2, Table A.3)

Thirty-one webpages (65%) provided accurate information. Seventeen webpages (35%) provided inaccurate information.

The information extracted from webpages was limited and skewed towards surgical management of fibroids, with 185 (58%) statements pertaining to this domain. We extracted 88 (28%) statements related to medical management, 30 (9%) related to diagnosis, and 15 (5%) related to the effect of fibroids on bleeding, fertility and pregnancy.

Of the 31 accurate webpages, 9 (29%) were of high quality. None satisfied the suggested readability standards.

3.3 Quality assessment

A minority of the webpages (9, 19%), were found to be of high quality. The majority (31, 65%) were of moderate quality, and eight (17%) of low quality. The highest scoring criteria included relevance (median 4, IQR 3-4) and clarity that more than one treatment is possible (median 4; IQR 3-5). The poorest performing categories included

aim clarification (median 1, IQR 1-3), aim achievement (median 1, IQR 1-2.75) and provision of additional sources of information (median 1; IQR 1-3). (Table A.4)

3.4 Readability

Six webpages (13%) were assessed as being very difficult to read; 28 (58%) were difficult to read; nine (19%) were fairly difficult to read; five (10%) were in plain English. No webpage met the suggested readability standard. The median readability of the included sources was 45.5 (IQR 38-51.6), indicating a requirement of an average reading level of a university student to fully comprehend the written text. (Table A.5)

4 Comment

There are no websites which provide high quality, accurate, and comprehensible health information pertaining to fibroids. Currently, websites contain limited information which is skewed towards the surgical management of fibroids. Information is typically written in a language that would be challenging for patients to comprehend.

4.1 Strengths and limitations

This is the first study to examine the accuracy, quality, and readability of patient focused online information relating to fibroids. We followed a robust, prospective systematic review method with use of validated instruments, where available, to assess the information presented. The authorship included women with fibroids. This helped to inform the study design, delivery, and dissemination.

This study is not without limitations. The search was limited to the first three pages of a single search engine; this excludes potentially eligible, less affluent producers of

online information, favouring wealthy ahead of quality webpage developers.[13] Our search was limited to English language webpages. We disabled computer location services, however regional differences in search results occur which are out of the authors control. The systematic evaluation of online information is a new field with limited precedent to guide our methods. All websites were designed and managed within high resource countries limiting the applicability of this research to inform low resource settings.

There is no single evidence-based guideline for management of fibroids. Several small guidelines / practice statements exist that cover limited areas of this review.[18,19] The use of guideline developed recommendations to assess webpage accuracy would convey greater reliability of the results generated.

4.2 Generalisability

The findings of this study are comparable to the study published by Melo et al on the topic of online information relating to fibroids.[10] Webpages providing information pertaining to fibroids use complex language unsuitable for most women. The accuracy and quality of webpages vary. Healthcare professionals must be aware of the potential harms associated with misinformation or misinterpretation of online information. Those responsible for the production of online health information should abide by principles developed by the Health on the Net Foundation. Their principles include standardising the reliability and credibility of medical and health information available on the Internet.

4.3 Relevance

The dissemination of inaccurate health information has been clearly demonstrated in other areas of women's health.[7–9] The implications and sequelae of this information is difficult to quantify.

With the expansion of information available online and the ready availability of modern smartphones to answer impromptu questions, searching for everyday queries now commonly includes health topics.

Online information commonly lacks an evidence base and can fail to reflect current practice without being obvious to the consumer. Many women with fibroids do not have the scientific skills to critically appraise the health information leaving them unable to detect inaccurate, unreliable, and biased information. This can leave women vulnerable to making poor health choices.[6] Influencing health choices has the potential to cause harm. Harm can be defined in three clear parameters:1) financial – inappropriate investigations or treatments; 2) psychological - anxiety or false hope arising from inaccurate diagnostic, prognostic, or therapeutic information 3) physical - from inappropriate treatments, adverse effects, or untreated disease.

4.4 Recommendations

There is no role to be played in limiting the user from performing health related searches. There is a role for standardisation or kite marking of approved health content websites. This challenge currently has no policing or responsible body allocated internationally. The responsibility currently lies with the clinician to inform each patient of the harms associated with online websites until a stage comes when high quality webpages can be easily distinguished from low quality webpages.

A strategy is required to improve the standard of online information for women with fibroids with evident need for the development of patient focused online information

with a robust evidence base. Regulation of health information on the internet is understandably difficult, however codes of conduct have been developed and implemented. In the United Kingdom institutions or websites can apply to The Information Standard which assesses and approves online health information to ensure it is accurate, balanced, clear, evidence-based, and up-to-date. In the United States The Health on the Net Foundation provides accreditation to websites which meet pre-defined standards related to accessibility, accuracy, and readability.[15]

The notion that patients trust online health sources must be acknowledged and addressed publicly at an international level. Governments should work together to encourage large multinational corporations to alter their current search delivery methods when related to health matters. Companies delivering published online health information to the top of an individual's search require regulation by health authorities to ensure they do not cause or contribute to harm through inappropriate prioritisation of inaccurate or inappropriate information in exchange for financial remuneration. Regulating bodies must make a greater effort to provide signposting to high quality online sources of information regardless of finance.

5 Conclusions

Our Google search indicated that there are no websites which provide high quality, accurate, and comprehensible health information pertaining to fibroids. Currently, websites contain limited amounts of information which are skewed towards the surgical management of fibroids. Information is typically written in language that is challenging for a lay audience to comprehend. There is an urgent need to provide consumers of online health information with either high quality information or a clear method to identify reliable sources.

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7 Appendix A

Table A.1. Web site characteristics and a summary of accuracy, quality and readability assessments.

ID	Web Domain	Country	Listed Authors	Accuracy[1]	Quality[2]	Readability[3]
1	americanpregnancy.org	Global	No	83	42	46.9
2	fibroids.co.uk	UK	No	81	41	31.3
3	nezhat.org	Global	No	70	45	29.5
4	obgyn.ucla.edu	USA	No	79	34	39.4
5	alternativesurgery.com	USA	No	50	30	35.0
6	cosmopolitan.com	USA	Yes	67	29	44.8
7	msdmanuals.com	USA	Yes	76	31	21.0
8	netdoctor.co.uk	UK	Yes	100	31	48.3
9	nhsdirect.wales.nhs.uk	UK	No	88	51	46.6
10	draxe.com	USA	Yes	29	35.5	48.7
11	wikipedia.org	Global	No	75	50	31.8
12	fibroids.com	USA	No	75	26	43.3
13	medlineplus.gov	USA	No	82	42	64.9
14	medlineplus.gov	USA	No	100	25	15.1
15	clevelandclinic.org	Global	No	100	41	42.8
16	acog.org	Global	No	93	45	48.1
17	avogel.co.uk	UK	Yes	25	33	52.0
18	babycenter.com	USA	Yes	93	60	52.2
19	babycentre.co.uk	UK	No	95	49	57.1
20	bsir.org	Global	No	85	70	44.7
21	bupa.co.uk	UK	No	88	33	63.8
22	cancer.org	Global	Yes	100	33	42.4
23	cedars-sinai.edu	USA	No	100	35	52.6
24	dfusfoundation.org	Global	No	33	33	35.1
25	guysandstthomas.nhs.uk	UK	No	88	65	61.3

[1] Accuracy assessed though percentage of accurate statements (range 0-100)

[2] Quality assessed using the DISCERN tool (range 16-80)

[3] Readability assessed using the Flesh Kincaid reading ease test (range 0-100)

26	health.ny.gov	USA	No	83	70	58.2
27	healthline.com	USA	No	100	36	49.2
28	imperial.nhs.uk	UK	No	100	20	11.4
29	livescience.com	USA	Yes	92	45	39.4
30	livestrong.com	USA	Yes	100	20	51.5
31	mayoclinic.org	Global	No	75	30	46.2
32	med.unc.edu	USA	No	70	40	47.8
33	medicalnewstoday.com	USA	Yes	79	52	46.9
34	medicinenet.com	USA	No	50	19	37.7
35	medicinenet.com	USA	Yes	78	50	36.3
36	ncbi.nlm.nih.gov	USA	No	82	54	53.2
37	nhs.uk	UK	No	100	26	51.2
38	nhs.uk	UK	No	93	68	44.4
39	nwhn.org	Global	No	89	63	38.1
40	onhealth.com	USA	Yes	80	54	44.5
41	philips.co.uk	UK	No	25	28	36.2
42	radiologyinfo.org	Global	No	85	27	42.1
43	wakemed.org	Global	No	50	29	42.5
44	webmd.boots.com	USA	No	100	28	25.6
45	webmd.com	USA	No	100	18	26.5
46	womenshealth.gov	USA	No	87	57	61.7
47	womenshealthmag.com	USA	Yes	83	38	51.9
48	womenshealthmag.com	USA	Yes	100	20	61.2
	MEDIAN (IQR)			84 (75-96)	35.75 (29-50)	45.5 (38-51.6)

Table A.2. Accuracy results according to domain

Domain	Number of Statements	% accurate (n)	% inaccurate (n)	% unclear (n)
Diagnosis	30	67 (20)	20 (6)	13 (4)
Effect on Bleeding, Fertility and Pregnancy	15	73 (11)	13 (2)	13 (2)
Medical Management	88	64 (56)	18 (16)	18 (16)
Surgical Management	185	74 (136)	12 (23)	14 (25)
Total	318	70 (223)	15 (47)	15 (47)
MEAN	79.5	69 (55.75)	15 (11.75)	15 (11.75)

Table A.3. Accuracy results according to study ID

Study ID	Number of Statements	% accurate (n)	% inaccurate (n)	% unclear (n)
1	12	83 (10)	8 (1)	8 (1)
2	31	81 (25)	16 (5)	3 (1)
3	50	70 (35)	(12) 6	18 (9)
4	14	79 (11)	14 (2)	7 (1)
5	10	50 (5)	20 (2)	30 (3)

6	3	67 (2)	0 (0)	33 (1)
7	42	76 (32)	7 (3)	17 (7)
8	9	100 (9)	0 (0)	0 (0)
9	59	88 (52)	3 (2)	8 (5)
10	14	29 (4)	50 (7)	21 (3)
11	44	75 (33)	9 (4)	16 (7)
12	4	75 (3)	25 (1)	0 (0)
13	17	82 (14)	6 (1)	12 (2)
14	3	100 (3)	0 (0)	0 (0)
15	8	100 (8)	0 (0)	0 (0)
16	14	93 (13)	7 (1)	0 (0)
17	4	25 (1)	50 (2)	25 (1)
18	14	93 (13)	7 (1)	0 (0)
19	19	95 (18)	0 (0)	5 (1)
20	48	85 (41)	6 (3)	8 (4)
21	26	88 (23)	0 (0)	12 (3)
22	4	100 (4)	0 (0)	0 (0)
23	9	100 (9)	0 (0)	0 (0)
24	3	33 (1)	67 (2)	0 (0)
25	57	88 (50)	4 (2)	9 (5)
26	48	83 (40)	4 (2)	13 (6)
27	8	100 (8)	0 (0)	0 (0)
28	1	100 (1)	0 (0)	0 (0)
29	25	92 (23)	0 (0)	8 (2)
30	1	100 (1)	0 (0)	0 (0)
31	8	75 (6)	25 (2)	0 (0)
32	27	70 (19)	22 (6)	7 (2)
33	42	79 (33)	7 (2)	14 (6)
34	2	50 (1)	0 (0)	50 (1)
35	18	78 (14)	17 (3)	6 (1)
36	11	82 (9)	0 (0)	18 (2)
37	1	100 (1)	0 (0)	0 (0)
38	55	93 (51)	4 (2)	4 (2)
39	27	89 (24)	4 (1)	7 (2)
40	41	80 (33)	12 (5)	7 (3)
41	4	25 (1)	50 (2)	25 (1)
42	20	85 (17)	10 (2)	5 (1)
43	4	50 (2)	50 (2)	0 (0)
44	2	100 (2)	0 (0)	0 (0)
45	1	100 (1)	0 (0)	0 (0)
46	45	87 (39)	4 (2)	9 (4)
47	6	83 (5)	0 (0)	17 (1)
48	8	100 (8)	0 (0)	0 (0)
MEDIAN % (IQR)	13 (4-28)	84 (75-96)	4 (0-12)	7 (0-13)

Table A.4. Quality classification

Quality	Webpages, n
Low (score 26 or less)	8
Moderate (score 27-52)	31
High (score 53 or higher)	9

Table A.5. Reading ease classification

Reading ease	UK educational level	Webpages, n
Very easy (score 90-100)	Year 6	0
Easy (score 80-90)	Year 7	0
Fairly easy (score 70-80)	Year 8	0
Plain English (score 60-70)	Year 9-10	5
Fairly difficult (score 50-60)	Year 11-13	9
Difficult (score 30-50)	University	28
Very difficult (score 0-30)	University graduate	6

1
2

8 Appendix B

Figure B.1. Flow diagram of included webpages