Accuracy and reliability of Internet resources for information on idiopathic pulmonary fibrosis

Jolene H. Fisher[1]
Darragh O'Connor[2]
Alana M. Flexman[3]
Shane Shapera[1]
Christopher J. Ryerson[2,4]

[1] Department of Medicine, University of Toronto, Toronto, Canada
[2] Department of Medicine, University of British Columbia, Vancouver, Canada
[3] Department of Anesthesiology, University of British Columbia, Vancouver, Canada
[4] Centre for Heart Lung Innovation, University of British Columbia, Vancouver, Canada

Contact Author: Dr. Christopher J. Ryerson, St. Paul's Hospital, 1081 Burrard St, Ward 8B, Vancouver, BC, Canada, V6Z 1Y6, Ph: 604-806-8818, Fax: 604-806-8839; chris.ryerson@hli.ubc.ca

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Scientific Knowledge on the Subject: Patients commonly use the Internet as a resource for health information, however no studies have evaluated the content and quality of online information on idiopathic pulmonary fibrosis (IPF).
What This Study Adds to the Field: IPF websites are frequently incomplete, inaccurate, and outdated. The low quality of online information on IPF is a significant barrier to patient education. This study emphasizes that IPF stakeholders need to take a more active role in ensuring the accuracy, quality, and readability of online health information.

This article has an online data supplement, which is accessible from this issue's table of content online at www.atsjournals.org

ABSTRACT

RATIONALE: Patients commonly use the Internet as a resource for health information, however no studies have evaluated the online information on idiopathic pulmonary fibrosis (IPF).

OBJECTIVES: We sought to determine the readability, content (compared to established guidelines), bias, and quality of online IPF resources.

METHODS: We analyzed the first 200 hits for 'idiopathic pulmonary fibrosis' in Google®, Yahoo®, and Bing®. Each website was evaluated for content related to IPF features and treatments that are discussed in clinical guidelines. Website quality was assessed using the validated DISCERN instrument.

MEASUREMENTS AND MAIN RESULTS: Eligibility criteria were met in 181 websites. The median reading grade level was 12. More content was provided in scientific resources (academic institutions or governmental organizations) and foundation/advocacy organization sites compared to personal commentary (blog) sites, however most sites provided incomplete and/or inaccurate information. Non-indicated and/or harmful pharmacotherapies for IPF were described as potential IPF treatments in 48% of websites, and were most often recommended in foundation/advocacy organization websites. Azathioprine and corticosteroids were discussed as potential chronic treatments of IPF in 13.3% and 30.6% of the 98 websites that had been updated after publication of data demonstrating harm from these medications. Website quality (DISCERN score) was poor in all sites types, but was worse in news/media reports and personal commentary (blog) sites compared to sites from scientific and foundation/advocacy organizations.

CONCLUSIONS: Patient-directed online information on IPF is frequently incomplete, inaccurate, and outdated. There is no reliable method for patients to identify sites that provide appropriate information on IPF.

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INTRODUCTION

The Internet is a common source for health information. Widespread adoption of the Internet has steadily increased over the past decade, with 84% of all American adults using the Internet in 2015.[1] Approximately 4.5% of all Internet searches are health-related, corresponding to 6.75 million health-related searches occurring daily in Google® alone.[2] The Internet is an attractive resource to patients, as it provides immediate and easily available information on virtually all health-related topics. Despite these advantages, there are concerns regarding the accuracy and reliability of online health information, and there is significant potential for patients to be misinformed.[3,4] In addition, many online resources are written at a high reading level, which negatively impacts patient understanding, compliance, and overall health.[5]

Idiopathic pulmonary fibrosis (IPF) is a chronic, fibrosing interstitial pneumonia of unknown etiology that is characterized by progressive dyspnea, worsening lung function, and poor prognosis.[6] Consensus guidelines on the diagnosis and management of IPF were published in 2011,[6] and were updated in 2015 based on new evidence regarding IPF pharmacotherapies.[7] Despite the existence of these widely read and highly cited guidelines, IPF patients are frequently misinformed by incorrect or out-of-date information obtained from IPF-related Internet resources. The objective of this study was to describe the characteristics of Internet resources available for IPF, and evaluate their readability, content (compared to established IPF guidelines), risk of bias, and overall quality.

METHODS

Data sources and search strategy

We analyzed written online health information on IPF using the three most common Internet search engines. Google®, Yahoo®, and Bing® searches for 'idiopathic pulmonary fibrosis' were performed on June 29th, 2015. Searches were performed using the United States (US) version for each search engine after removal of the web browsers' history and cookies. Country-specific results were standardized using a US Internet Protocol address to specify that searches were conducted in the US.

Study selection

The top 200 hits for each search engine were screened for eligibility criteria. English websites intended to provide IPF information to patients or caregivers were eligible. One author (DOC) systematically determined website eligibility by reviewing the identified site and first-generation links to additional pages that remained within the original domain. A second author reviewed sites with unclear eligibility (CJR). Websites that required registration or enrolment fees to access information, duplicated websites, and scientific journal articles clearly intended for medical/research professionals were excluded.

Data extraction and website evaluation

Characteristics retrieved from each website included continent of origin, dates of publication and most recent update, and textual difficulty (measured using the Flesch Reading Ease Score [FRES] and the Flesch-Kincaid grade level).[8,9] Websites were classified into 5 main categories, including scientific resources (*e.g.* academic

institutions and governmental organizations), foundations/advocacy organizations, news/media reports, industry/for-profit, and personal commentary (*e.g.* personal blogs).

Health on the Net Foundation code of conduct (HON) certification was determined for each website (http://www.hon.ch/HONsearch/Patients/hunt.htm). HON is an independent organization that assesses whether websites provide understandable, accessible, and trustworthy health information. Quality of written information on each website was assessed using the DISCERN instrument and *Journal of the American Medical Association* (JAMA) benchmarks.[10,11] DISCERN is a validated instrument designed to assess the quality of written information on treatment choices, and can be applied to any disease (**Supplementary Appendix Table E1**).[10] Sixteen questions are rated from 1 (low quality/not addressed) through 5 (high quality/fully addressed). Each website was independently scored in duplicate by two authors, including at least one experienced ILD clinician-researcher. Scores within 1 point were considered agreement for each DISCERN question. More significant discrepancies were resolved by re-review of the website and discussion of remaining disagreements between two reviewers. Content scores were similarly produced by two authors using a predefined scoring system based on 25 key IPF features described in established clinical guidelines, including the definition, symptoms, risk factors, evaluation, management, and outcomes of IPF (**Supplementary Appendix Table E2**).[12] Medications described as non-experimental treatment options of chronic IPF were recorded for each website. Additional methodology details are provided in the Supplementary Appendix.

Statistical analysis

Between-group differences were assessed using Chi-square, Fisher's exact, Wilcoxon Rank Sum, or Kruskal-Wallis tests as appropriate. Multivariate linear

regression was used to determine predictors of DISCERN and content scores. Model variables selected *a priori* included website category, HON certification, and source continent. Statistical significance was defined by a two-tailed p-value <0.05. Analyses were performed using SAS software, version 9.4 (SAS Institute Inc., NC) and STATA 11.2 (StataCorp, TX).

RESULTS

Website characteristics

The first 200 results from the 3 search engines yielded 350 unique sites, with 181 websites meeting inclusion criteria (**Figure 1**). A list of the websites analyzed and their rank in each search engine are provided in **Supplementary Appendix Table E3.** Characteristics of eligible websites are summarized in **Table 1**. Yahoo® had the highest number of eligible sites (118 versus 90 in both Google® and Bing®). Scientific resources were the largest category in all search engines. Personal commentary websites were more frequent in Yahoo® and Bing® than Google® (p=0.01), while Google® identified more news/media websites (p=0.04). Most websites were from North America (77.9%) and most did not have HON certification (85.1%). The median reading grade level was 12 (interquartile range [IQR] 9.2-12) and the median FRES was 39.4 (IQR 29.5-58.4), corresponding to difficult readability/easily understood by college students. Average DISCERN total and content scores were higher for the top 10 websites in each search engine as compared to the overall group (p<0.01 for all comparisons). The median time since the last reported website update was 1.3 (IQR 0.7-2.6) years in the 123 (67.9%) websites that reported this date (**Figure 2**).

Website content

Content varied across website categories (**Figure 3**). The definition of IPF (a chronic scarring lung disease of unknown cause) was appropriately described in the majority of websites, but was more often incomplete in news/media sites compared to other categories (p=0.003; **Supplementary Appendix Table E4**). Significant differences were also observed between website categories in the symptoms, risk factors, diagnosis, and management of IPF, with scientific and foundation/advocacy sites generally performing better than news/media and personal commentary sites (**Supplementary Appendix Table E4 and Table E5**). The prognosis of IPF was adequately described in a minority of websites in all categories.

Oxygen and lung transplant were discussed in 57.5% and 63.5% of websites, respectively, and were more likely to be described in scientific and foundation websites (**Table 2**). Nintedanib, pirfenidone, anti-acid therapy, and palliative care were discussed in a minority of websites. Harmful and/or non-recommended treatments were frequently recommended,[6,7] including azathioprine (15.5%), corticosteroids (38.7%), immunosuppressive therapy (14.4%), and n-acetylcysteine (18.2%). Azathioprine and corticosteroids were discussed as chronic treatments of IPF in 13.3% and 30.6% of the 98 websites that had been updated after publication of data demonstrating harm from these medications.[13] Foundation/advocacy organizations were most likely to suggest a role for these harmful and/or non-indicated therapies in IPF, while news/media reports were least likely (p=0.01 for azathioprine and p<0.0001 for corticosteroids; **Supplementary Appendix Table E6**). Wikipedia (https://en.wikipedia.org/wiki/Idiopathic_pulmonary_fibrosis) provided the best balance between accurate IPF content and lack of inappropriate treatment recommendations.

Website content was only modestly estimated by potential predictor variables (R-squared=0.27). Website category was the only independent predictor of content score,

with more content provided in scientific resources and foundation/advocacy organization sites, and less content provided in news/media sites, compared to personal commentary (blog) sites (p=0.009, p=0.007 and p=0.006, respectively; **Supplementary Appendix Table E7**). Higher website rank within Yahoo® and Bing® was independently associated with more overall content in multivariate models constructed for each search engine. Model performance for each search engine was not improved compared to the original multivariate model (R-squared≤0.27).

Website quality

The mean inter-observer agreement for individual DISCERN questions was 85%, with a mean kappa of 0.57. In general, websites scored poorly (mean score≤2) on questions that addressed treatment risks, what would happen without treatment, and the need for shared decision-making between patient and physician (**Figure 4**). DISCERN total score was lower in news/media reports and personal commentary (blog) sites compared to other website categories (p=0.001; **Table 3**). On pairwise comparison, scores for DISCERN total, DISCERN questions 1-8, DISCERN question 16, and the JAMA benchmarks score were significantly higher for scientific resources and foundation/advocacy organizations than for personal commentary (blog) websites (p≤0.01 for all comparisons; **Table 3**). Website category did not predict likelihood of HON certification. Websites with HON certification (15% of total) had higher DISCERN scores compared to those without certification, although scores were poor in both groups (**Table 4**). Wikipedia and Medscape (http://emedicine.medscape.com/article/301226-overview) had the highest website quality measured by DISCERN and JAMA benchmarks.

Higher DISCERN total score was independently predicted by HON certification (p=0.04) and website category, with higher DISCERN scores in scientific resources, foundation/advocacy organizations, and industry/for profit sites compared to personal commentary (blog) sites (p=0.002, p=0.0002, and p=0.02, respectively; R-squared=0.14; **Supplementary Appendix Table E7**). Reliability (DISCERN questions 1-8) was higher in scientific resources, foundation/advocacy organizations, news/media, and industry/for profit sites than in personal commentary (blog) sites (p<0.0001, p<0.0001, p=0.007, and p=0.02, respectively). Higher score for information on treatment choices (DISCERN questions 9-15) was predicted by foundation/advocacy organizations (*vs*. personal commentary [blog] sites) and HON certification (p=0.047 and p=0.03, respectively). Higher website rank was independently associated with higher DISCERN total score in all search engines, with at most a modest improvement in model fit (R-squared≤0.28).

DISCUSSION

Patients with IPF frequently search the Internet for information related to their disease, however there are no previous studies evaluating the content, quality, or readability of these online resources. We applied multiple validated tools and standardized scoring systems to 181 IPF-related websites to demonstrate the overall poor content and quality of patient-directed Internet resources on the topic of IPF. These deficiencies have important implications in an era when patients are increasingly using the Internet to obtain health-related information.

We identified 25 content items that correspond to well established IPF features and therapies, however we were unable to determine a reliable method that predicted website accuracy. Many items were inadequately covered in all sites, including features that are highly relevant to IPF patients and caregivers such as details on diagnostic tests,

management, and prognosis. Scientific resources provided more content than other website categories, but were less likely to discuss recently approved antifibrotic therapies. News/media reports typically focused on a specific news item, including newly approved therapies, but were less likely to provide a general overview of IPF. Nearly half of all websites (48%) suggested a role for at least one unproven treatment, and more than a third of websites suggested a role for medications that were proven harmful in IPF over 3 years before our study was conducted.[13] Foundation and advocacy organizations were most likely to suggest these harmful and/or non-indicated therapies, despite patients likely considering these non-profit organizations a reliable source of information. This unpredictably inaccurate online information results in healthcare providers recommending different therapies than those that are discussed in reputable and reportedly up-to-date online sources, potentially leading to distrust of physicians that are providing appropriate and guideline-supported recommendations.

The impact of the frequently incomplete and inaccurate content is worsened by the poor reliability, quality, and readability that were observed all website categories. These limitations are particularly challenging for a non-expert patient audience that is less able to assess the risk of bias in a specific website, and that has more difficulty incorporating that potential bias when assessing the reliability of that site's content. Previous studies have applied the DISCERN and JAMA instruments to other diseases, suggesting the quality of online information on IPF is similar to breast cancer surgery, but worse than information available for prostate cancer.[14,15] According to the National Adult Literacy Survey, 43% of American adults have basic or below basic literacy (*i.e.* can perform only simple literacy activities),[16] however IPF websites had a median reading grade level of 12 and a FRES score corresponding to a college student level.

The generally poor content, quality, and readability of IPF websites indicate the need for a reliable method for assessing which sites should be targeted by patients interested in learning more about IPF. Although content and quality were higher in scientific and foundation/advocacy sites compared to other website categories, overall scores for content and quality were low in all categories. HON is an internationally recognized independent organization that rates the quality of patient-directed online health information, however few IPF-related resources (15%) have HON certification and certification was associated with only modest improvements in website quality. Importantly, incomplete and incorrect information was frequently provided in HON certified sites, sites from foundation and advocacy organizations, and sites that had been updated since publication of definitive evidence for or against specific IPF therapies. This highlights the challenges faced by patients and other non-experts when attempting to determine the accuracy of health information provided on the Internet.

Despite the variable quality, the Internet will remain a frequent resource for IPF patients given the easy access to information on virtually all health-related topics. The ongoing use of the Internet indicates the need for a strategy that attempts to increase the accuracy of online information, highlights and facilitates access to websites with appropriate content, and supports improvements of websites that contain misinformation. At the time of our search, Wikipedia provided the best balance between content and quality, possibly due to the multi-author iterative approach to Wikipedia updates and site management, and similar approaches may be necessary to address the limitations of other common patient resources. The frequent deficiencies in most other websites suggest that IPF stakeholders need to take a more active role in ensuring the accuracy, quality, and readability of online health information.

In conclusion, this comprehensive and rigorous assessment of patient-directed online health information on IPF demonstrates that websites are frequently incomplete, inaccurate, and outdated, and that there is currently no reliable method for patients to identify sites that provide appropriate information. The low quality of online information on IPF is a significant barrier to patient education and higher standards are required for websites that are intended to provide IPF-related health information to patients with IPF. Managers of all IPF-related websites should review website quality on a regular basis and ensure that provided content is consistent with guideline recommendations and recent advances in the medical literature.

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FIGURE LEGENDS

Figure 1. Search results and study selection.

Eligibility criteria were sequentially applied in a mutually exclusive manner. Websites could be included in the results for multiple search engines.

Figure 2. Cumulative incidence of time since last website update.

Figure 3. Webpage content across website categories.

Each row represents an individual website. The shade of each cell represents the content included in each website, including content that is adequately addressed (dark grey), partially addressed (light grey), and not addressed (white).

Figure 4. DISCERN scores across website categories.

Each row represents an individual website. The shade of each cell represents the DISCERN score, ranging from a low score of 1 (white) to a high score of 5 (dark grey).

TABLES

Table 1. Website Characteristics.

Website Characteristic	Overall (n=181)	Yahoo® (n=118)	Google® (n=90)	Bing® (n=90)	P value
Website Category					
Scientific resource	84 (46.4%)	53 (44.9%)	47 (52.2%)	43 (47.8%)	0.58
Foundation/Advocacy organizations	25 (13.8%)	21 (17.8%)	14 (15.6%)	17 (18.9%)	0.83
News/Media reports	32 (17.7%)	14 (11.9%)	17 (18.9%)	6 (6.7%)	0.04
Industry/For profit	18 (9.9%)	13 (11.0%)	9 (10.0%)	9 (10.0%)	0.96
Personal commentary (blog)	22 (12.2%)	17 (14.4%)	3 (3.3%)	15 (16.7%)	0.01
Host Continent					
North America	141 (77.9%)	95 (80.5%)	68 (75.6%)	72 (80.0%)	0.65
Europe	28 (15.5%)	14 (11.9%)	17 (18.9%)	13 (14.4%)	0.37
Multiple	3 (1.7%)	1 (0.9%)	2 (2.2%)	2 (2.2%)	0.66
Asia	2 (1.1%)	1 (0.9%)	1 (1.1%)	0 (0%)	0.63
Australia	1 (0.6%)	1 (0.9%)	1 (1.1%)	0 (0%)	0.63
Missing	6 (3.3%)	6 (5.1%)	1 (1.1%)	3 (3.3%)	0.29
HON* certification	27 (14.9%)	25 (21.2%)	14(15.6%)	20 (22.2%)	0.47
Flesch Reading Ease Score	39.6 (29.5, 58.4)	38.9 (30.3, 52)	41.2 (29.5, 62.1)	39.4 (30.3, 58.3)	0.87
Flesch-Kincaid grade level	12 (9.2, 12)	12 (9.8,12)	11.8 (8.8,12)	11.9 (9.2,12)	0.52
Content total score	10.9+/–5.6	10.9+/–5.2	11.9+/–5.8	11.7+/–5.2	0.29
Top 10 website hits†	-	17.7+/–3.7	18.0+/–3.1	17.7+/–3.7	0.98
DISCERN total score	2.5+/–0.7	2.5+/–0.7	2.6+/–0.7	2.5+/–0.8	0.87
Top 10 website hits†	-	3.6+/–0.4	3.4+/–0.6	3.6+/–0.4	0.75

Data are shown as number (percent), median (interquartile range) or mean +/– standard deviation. Chi-square or Fisher's exact tests were used as appropriate. Kruskal-Wallis was used as a conservative test when determining significance for continuous variables, given the non-normality of some data. A Flesch reading ease score of 30-50 corresponds to a 'difficult' reading level, or the reading level of an academic article.[8] The Content total score was based on 25 key IPF features described in established clinical guidelines.

*Abbreviation: HON, Health on the Net Foundation code of conduct.
†The Content and DISCERN total scores were calculated for the top 10 websites retrieved in each search engine.

Table 2. Website content on IPF management.

Management topic	Proportion completely addressed by website category						
	Overall (n=181)	Scientific resource (n=84)	Foundation/ Advocacy organizations (n=25)	News/Media reports (n=32)	Industry/ For-profit (n=18)	Personal commentary (blog) (n=22)	P value
Nintedanib	38 (21.0%)	11 (13.1%)	7 (28.0%)	12 (37.5%)	6 (33.3%)	2 (9.1%)	0.01
Pirfenidone	61 (33.7%)	24 (28.6%)	9 (36.0%)	15 (46.9%)	8 (44.4%)	5 (22.7%)	0.23
Anti-acid therapy	4 (2.21%)	2 (2.4%)	2 (8.0%)	0 (0%)	0 (0%)	0 (0%)	0.33
Pulmonary rehabilitation	83 (45.1%)	50 (59.5%)	13 (52.0%)	5 (15.6%)	6 (33.3%)	9 (40.9%)	0.0005
Oxygen	104 (57.5%)	59 (70.2%)	17 (68.0%)	7 (21.9%)	9 (50.0%)	12 (54.6%)	< 0.0001
Lung transplant	115 (63.5%)	61 (72.6%)	17 (68.0%)	12 (37.5%)	10 (55.6%)	15 (68.2%)	0.01
Palliative care	11 (6.1%)	8 (9.5%)	0 (0%)	0 (0%)	1 (5.6%)	2 (9.1%)	0.18

Data are shown as number (percent). Chi-square or Fisher's exact tests were used as appropriate.

Table 3. Website reliability and quality.

Questionnaire Items	Overall (n=181)	Scientific resource (n=84)	Foundation/ Advocacy organizations (n=25)	News/Media reports (n=32)	Industry/ For-profit (n=18)	Personal commentary (blog) (n=22)	P value
Reliability (DISCERN Q1-8)	2.8+/–0.8	3.0+/–0.8	3.1+/–0.8	2.7+/–0.5	2.7+/–1.0	2.1+/–0.5	<0.0001‡‖
Treatment choices (DISCERN Q9-15)	2.0+/–0.8	2.0+/–0.8	2.4+/–0.9	1.7+/–0.6	2.3+/–0.8	1.9+/–0.7	0.07
Overall quality (DISCERN Q16)	2.6+/–1.0	2.8+/–0.9	3.0+/–0.9	2.1+/–0.8	2.6+/–1.3	1.9+/–0.8	<0.0001‡‖
DISCERN total score	2.5+/–0.7	2.6+/–0.7	2.8+/–0.8	2.2+/–0.4	2.5+/–0.8	2.0+/–0.5	0.001*§
JAMA total sore	1.5+/–1.0	1.5+/–0.9	1.8+/–1.1	1.8+/–1.1	1.6+/–1.3	0.9+/–0.6	0.01†§

Data are shown as mean +/– standard deviation. Kruskal-Wallis was used as a conservative test when determining significance across all website categories, given the non-normality of some data. Wilcoxon rank sum testing was used when determining significance on pairwise testing.

*p<0.05 on pairwise comparison of foundation/advocacy organization versus personal commentary websites.
†p<0.01 on pairwise comparison of foundation/advocacy organization versus personal commentary websites.
‡p<0.001 on pairwise comparison of foundation/advocacy organization versus personal commentary websites.
§p<0.01 on pairwise comparison of scientific resource versus personal commentary websites.
‖p<0.0001 on pairwise comparison of scientific resource versus personal commentary websites.

Table 4. Health on the Net Foundation code of conduct (HON) certification.

Variable	HON certification (n=27)	No HON certification (n=154)	P value
Website category			0.32
Scientific resource	17 (42.5%)	67 (63.0%)	
Foundation/Advocacy organizations	4 (14.8%)	21 (13.6%)	
News/Media reports	2 (7.4%)	30 (19.5%)	
Industry/For-profit	1 (3.7%)	17 (11.0%)	
Personal commentary (blog)	3 (11.1%)	19 (12.3%)	
DISCERN total score	2.8+/–0.7	2.4+/–0.7	0.02
JAMA total score	1.6+/–0.8	1.5+/–1.1	0.43
Content total score	12.8+/–4.2	10.6+/–5.7	0.06

Data are shown as number (percent) or mean +/– standard deviation. Wilcoxon rank sum testing was used as a conservative test when determining significance given the non-normality of some data. The Content total score was based on 25 key IPF features described in established clinical guidelines.

Figure 1

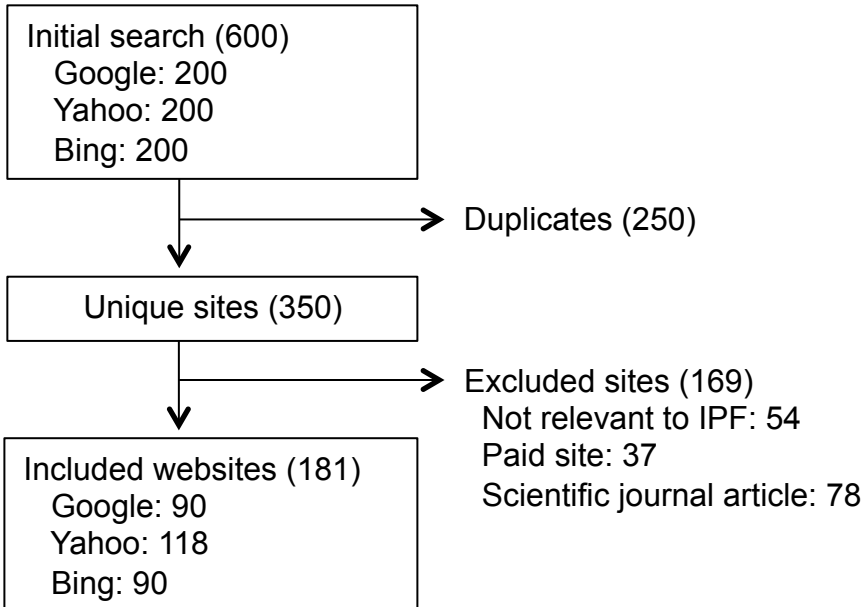
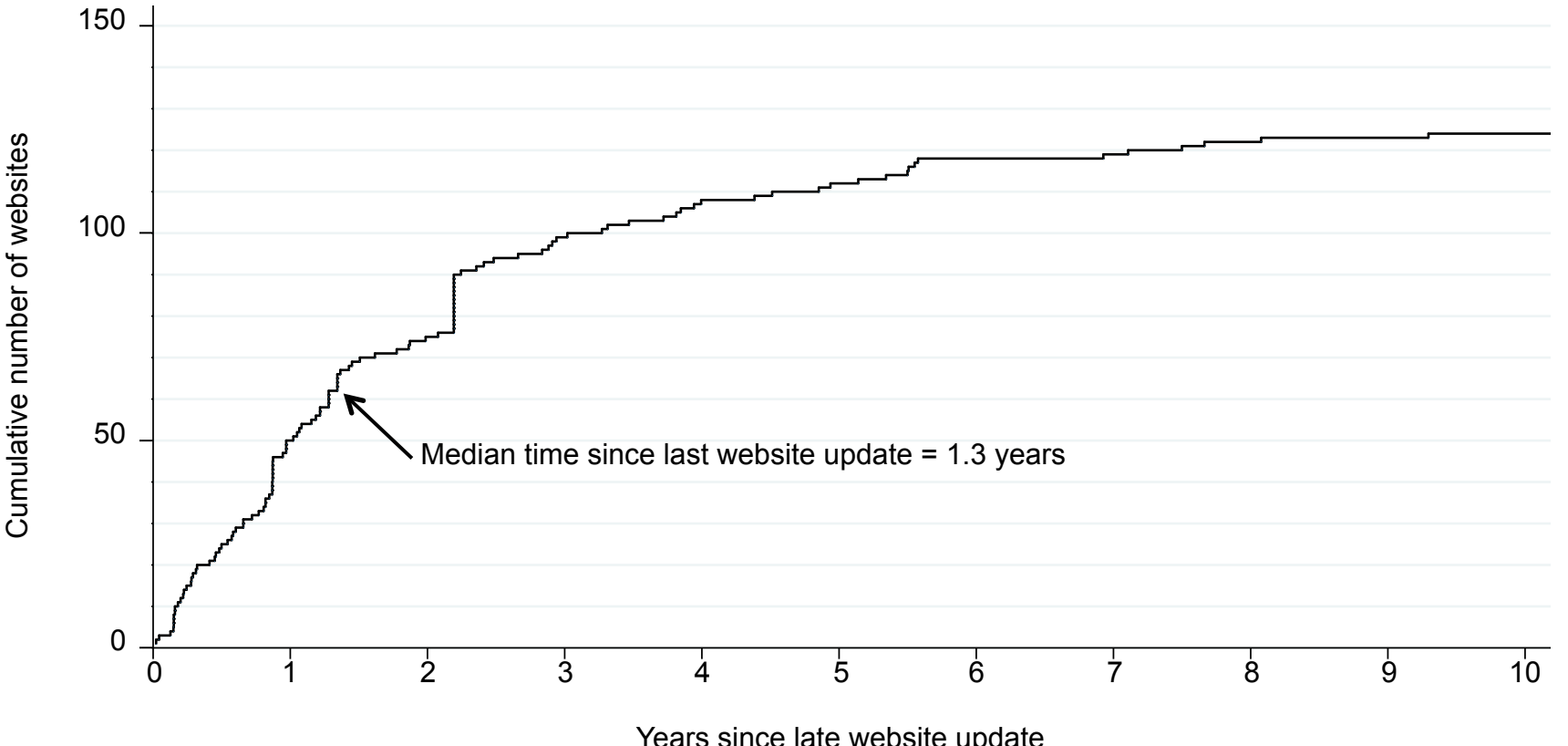

Initial search (600)
Google: 200
Yahoo: 200
Bing: 200
Duplicates (250)
Unique sites (350)
Excluded sites (169)
Not relevant to IPF: 54
Paid site: 37
Scientific journal article: 78
Included websites (181)
Google: 90
Yahoo: 118
Bing: 90

Figure 2


150
100
50
0
Cumulative number of websites
Median time since last website update = 1.3 years
0
1
2
3
4
5
6
7
8
9
10
Years since late website update

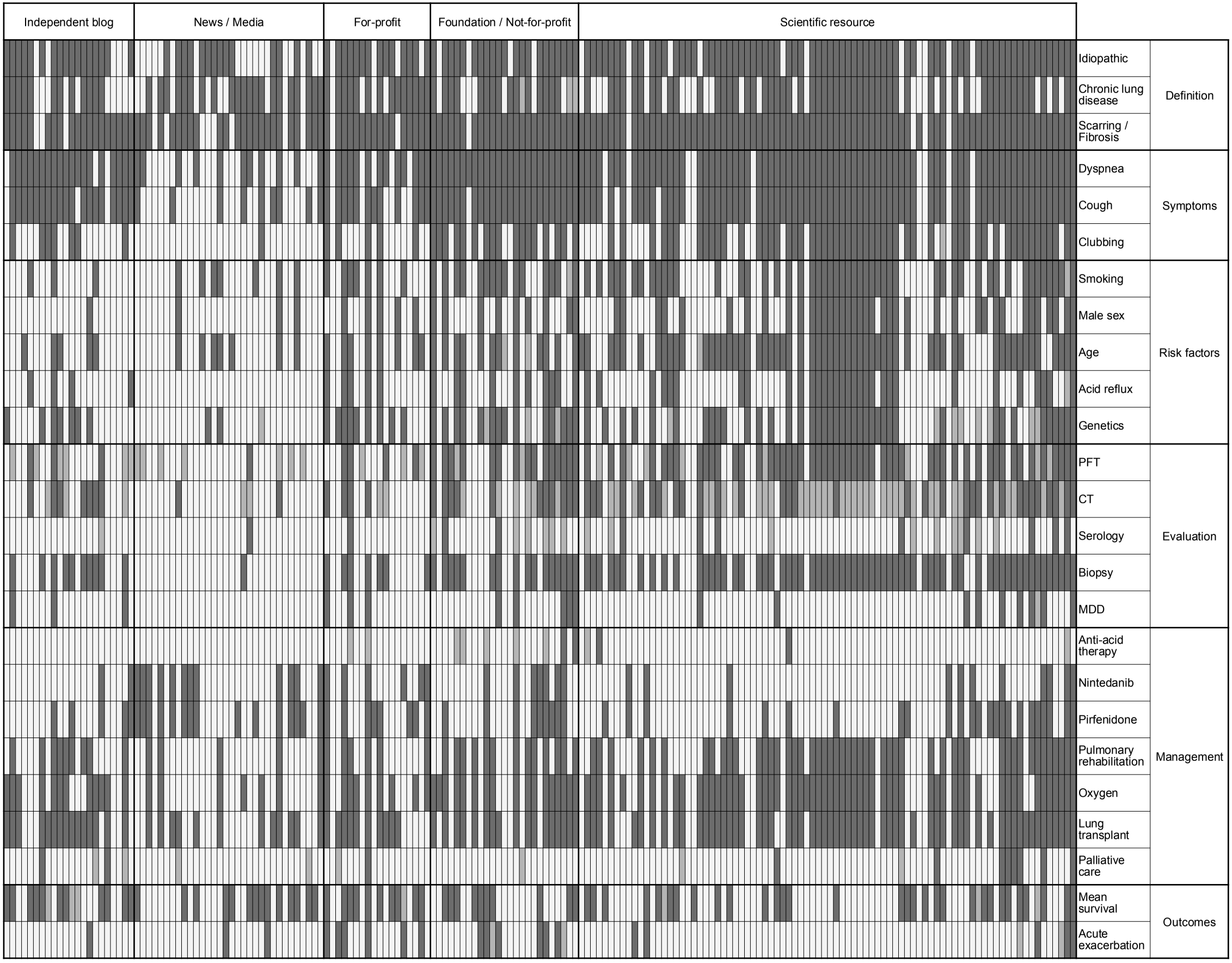
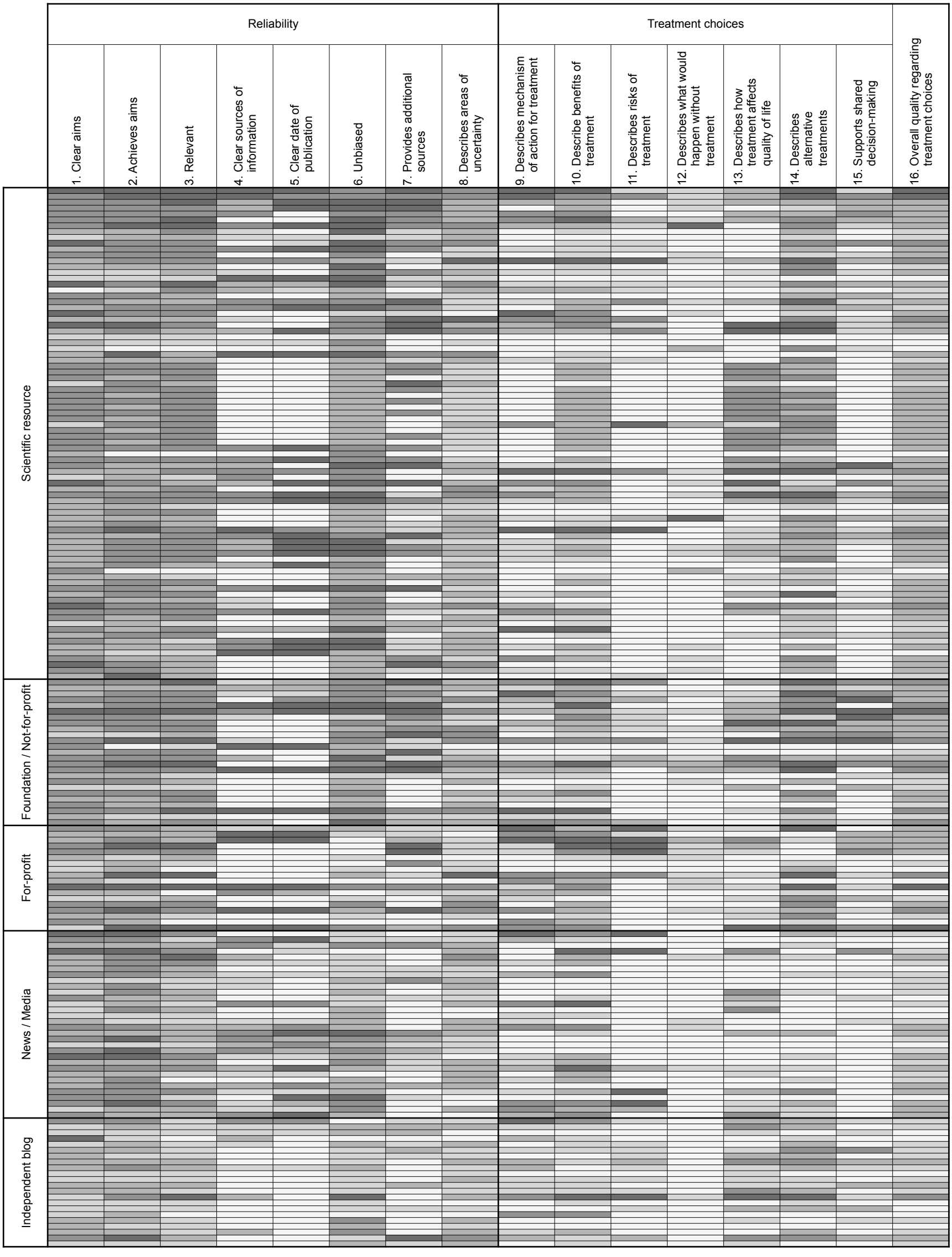

Independent blog
News / Media
For-profit
Foundation / Not-for-profit
Scientific resource
Idiopathic
Chronic lung disease
Scarring / Fibrosis
Definition
Dyspnea
Cough
Clubbing
Symptoms
Smoking
Male sex
Age
Acid reflux
Genetics
Risk factors
PFT
CT
Serology
Biopsy
MDD
Evaluation
Anti-acid therapy
Nintedanib
Pirfenidone
Pulmonary rehabilitation
Oxygen
Lung transplant
Palliative care
Management
Mean survival
Acute exacerbation
Outcomes

Figure 3

Figure 4


Reliability
Treatment choices
1. Clear aims
2. Achieves aims
3. Relevant
4. Clear sources of information
5. Clear date of publication
6. Unbiased
7. Provides additional sources
8. Describes areas of uncertainty
9. Describes mechanism of action for treatment
10. Describe benefits of treatment
11. Describes risks of treatment
12. Describes what would happen without treatment
13. Describes how treatment affects quality of life
14. Describes alternative treatments
15. Supports shared decision-making
16. Overall quality regarding treatment choices
Scientific resource
Foundation / Not-for-profit
For-profit
News / Media
Independent blog

Accuracy and reliability of Internet resources for information on idiopathic pulmonary fibrosis

JH Fisher, D O'Connor, AM Flexman, S Shapera, CJ Ryerson

-- Online Data Supplement --

ADDITIONAL METHODS

Flesch Reading Ease Score [FRES] and the Flesch-Kincaid grade level

The FRES rates reading comprehension difficulty of English text on a 100-point scale, with higher scores indicating material that is easier to read. For example, scores between 60-70 are considered 'standard' and at the reading level of Reader's Digest, while scores between 0-30 are considered 'very difficult' and at the reading level of a scientific journal.[1] The Flesch-Kincaid grade level formula calculates a readability score that corresponds to a US grade level.[2]

DISCERN scoring

DISCERN is a validated instrument designed to assess the quality of written information on treatment choices, and can be applied to any disease (**Supplementary Appendix Table E1**).[3] Sixteen questions are rated from 1 (low quality/not addressed) through 5 (high quality/fully addressed). Questions 1-8 evaluate publication reliability, questions 9-15 evaluate the quality of information regarding treatment options, and question 16 evaluates the overall publication. DISCERN scores ≤2 were considered poor, 3 considered fair, and ≥4 considered good.

JAMA benchmarks

The JAMA benchmarks are 4 basic standards that should be met by Internet sources of medical information,[4] including: 1) Authorship: proper citations used in the website; 2) Attribution: references and sources of information are identified; 3) Currency: the website is updated with the latest information; and 4) Disclosure: website ownership, advertising, and conflicts of interest are disclosed.

Statistical Methods

Date of last update was also specified *a priori* as a potentially relevant predictor variable, however this was excluded from the multivariate analysis since it was not reported in >20% of websites. Website rank within each search engine was tested for association with DISCERN and content scores in separate sensitivity analyses for each of the 3 search engines.

ONLINE SUPPLEMENT REFERENCES

E1. Flesch R. A new readability yardstick. *J Appl Psychol* 1948;32(3):221-233.

E2. Kincaid JP, Fishburne LRP Jr, Rogers RL, Chissom BS. Derivation of new readability formulas (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for Navy enlisted personnel. Memphis, TN*:* Naval Air Station; 1975.

E3. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health* 1999;53(2):105-111.

E4. Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor - Let the reader and viewer beware. *JAMA* 1997;277(15):1244-1245.

Table E1. DISCERN questionnaire.[1]

Question	Score				
Section 1 – Is the publication reliable?					
1. Are the aims clear?	No		Partially		Yes
	1	2	3	4	5
2. Does it achieve its aims?	No		Partially		Yes
	1	2	3	4	5
3. Is it relevant?	No		Partially		Yes
	1	2	3	4	5
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?	No		Partially		Yes
	1	2	3	4	5
5. Is it clear when the information used or reported in the publication was produced?	No		Partially		Yes
	1	2	3	4	5
6. Is it balanced and unbiased?	No		Partially		Yes
	1	2	3	4	5
7. Does it provide details of additional sources of support and information?	No		Partially		Yes
	1	2	3	4	5
8. Does it refer to areas of uncertainty?	No		Partially		Yes
	1	2	3	4	5
Section 2 – How good is the quality of information on treatment choices?					
9. Does it describe how each treatment works?	No		Partially		Yes
	1	2	3	4	5
10. Does it describe the benefits of each treatment?	No		Partially		Yes
	1	2	3	4	5
11. Does it describe the risks of each treatment?	No		Partially		Yes
	1	2	3	4	5
12. Does it describe what would happen if no treatment is used?	No		Partially		Yes
	1	2	3	4	5
13. Does it describe how the treatment choices affect overall quality of life?	No		Partially		Yes
	1	2	3	4	5
14. Is it clear that there may be more than one possible treatment choice?	No		Partially		Yes
	1	2	3	4	5
15. Does it provide support for shared decision-making?	No		Partially		Yes
	1	2	3	4	5
Section 3 – Overall rating of the publication					
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.	Low*		Moderate†		High‡
	1	2	3	4	5

*Serious or extensive shortcomings, †Potentially important but not serious shortcomings, ‡Minimal shortcomings

Table E2. Criteria for content scoring.

Category	Criteria	Additional examples
Definition	Idiopathic	Idiopathic, unknown etiology, uncertain cause
	Chronic lung disease	Chronic, progressive
	Scarring/fibrosis	Scarring, fibrosis
Symptoms	Dyspnea	Shortness of breath, breathing difficulty
	Cough	
	Clubbing	Fingernail changes, curved nails
Risk factors	Smoking	Cigarettes, *smoke* (partial)
	Male sex	
	Older age	
	Acid reflux	Heartburn
	Genetics	Family history, familial, hereditary
Evaluation	Pulmonary function tests	Breathing tests, lung function tests
	Computed tomography	CT scans, HRCT scans, *chest imaging* (partial)
	Serology	Autoimmune disease, connective tissue disease, *blood tests* (partial)
	Biopsy	Lung tissue sample
	Multi-disciplinary discussion	Multi-disciplinary conference, review with multiple specialists
Management	Anti-acid therapy	Proton pump inhibitors, H2 blockers, reflux therapy
	Nintedanib	Ofev
	Pirfenidone	Esbriet
	Pulmonary rehabilitation	Lung rehabilitation, *exercise* (partial)
	Oxygen	
	Lung transplant	
	Palliative care	End-of-life care, *symptom management* (partial)
Outcomes	Mean survival	Survival 2-5 years from diagnosis, *poor survival* (partial) *fatal* (partial)
	Acute exacerbation	Acute worsening, *rapid progression* (partial)

Scoring: addressed = 1 point, partially addressed = 0.5 point, not addressed = 0 point.

Table E3. Website uniform resource identifier.

Website uniform resource identifier	Rank Yahoo®	Rank Google®	Rank Bing®
http://www.nhlbi.nih.gov/health/health-topics/topics/ipf	1	1	1
https://en.wikipedia.org/wiki/Idiopathic_pulmonary_fibrosis	2	2	2
http://www.coalitionforpf.org/facts-about-idiopathic-pulmonary-fibrosis/	14	3	12
http://emedicine.medscape.com/article/301226-overview	6	4	6
http://www.mayoclinic.org/diseases-conditions/pulmonary-fibrosis/basics/definition/con-20029091	3	5	3
http://my.clevelandclinic.org/health/diseases_conditions/hic-idiopathic-pulmonary-fibrosis	5	6	5
http://www.webmd.com/lung/what-is-idiopathic-pulmonary-fibrosis	4	7	4
http://www.nhs.uk/conditions/pulmonary-fibrosis/Pages/Introduction.aspx	54	8	106
http://patient.info/health/idiopathic-pulmonary-fibrosis-leaflet	18	9	16
http://www.ucsfhealth.org/conditions/idiopathic_pulmonary_fibrosis/	16	10	17
http://www.pulmonaryfibrosis.org/life-with-pf	7	11	7
https://www.blf.org.uk/Page/IPF	59	12	40
http://www.orpha.net/consor/cgi-bin/OC_Exp.php?Expert=2032&lng=EN	110	16	109
https://www.nice.org.uk/guidance/cg163	-	17	-
http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm418991.htm	47	19	30
https://www.rareconnect.org/en/community/idiopathic-pulmonary-fibrosis	24	21	19
http://www.sciencedaily.com/releases/2015/06/150608102946.htm	-	22	-
http://www.prnewswire.com/news-releases/new-survey-uncovers-emotional-and-physical-impact-of-idiopathic-pulmonary-fibrosis-a-fatal-lung-disease-300033929.html	-	24	-

https://rarediseases.org/rare-diseases/idiopathic-pulmonary-fibrosis/	-	25	-
http://umm.edu/health/medical/ency/articles/idiopathic-pulmonary-fibrosis	63	27	50
http://www.merckmanuals.com/professional/pulmonary-disorders/interstitial-lung-diseases/idiopathic-pulmonary-fibrosis	-	28	122
https://www.patientslikeme.com/conditions/1954-pulmonary-fibrosis	56	29	-
http://www.modernmedicine.com/tag/idiopathic-pulmonary-fibrosis	-	31	-
http://www.pilotforipf.org/	124	32	104
http://uvahealth.com/services/pulmonary/lung-conditions/idiopathic-pulmonary-fibrosis	-	33	-
https://www.boehringer-ingelheim.com/news/news_topics/idiopathic_pulmonary_fibrosis.html	27	36	57
http://www.medicinenet.com/pulmonary_fibrosis/article.htm	44	37	-
http://pulmonaryfibrosisnews.com/2015/05/19/new-data-genentech-esbriet-idiopathic-pulmonary-fibrosis-presented-2015-ats-conference/	-	38	-
http://www.techtimes.com/articles/18000/20141016/fda-approval-of-roche-boehringer-drugs-for-idiopathic-pulmonary-fibrosis-is-a-big-step-forward.htm	-	39	-
http://medical-dictionary.thefreedictionary.com/idiopathic+pulmonary+fibrosis	15	40	21
http://www.pulmonary-fibrosis.net/	142	41	100
http://www.biosciencetechnology.com/articles/2014/10/reversing-idiopathic-pulmonary-fibrosis	79	43	84
http://www.lung.org/lung-disease/pulmonary-fibrosis/symptoms-diagnosis.html?referrer=https://www.google.com/	34	46	72
http://www.gene.com/media/news-features/medicine-fda-approved-for-idiopathic-pulmonary-fibrosis	40	47	82
https://www.esbriet.com/	114	51	-
http://www.nytimes.com/2014/10/16/business/fda-approves-first-2-drugs-for-treatment-of-a-	-	52	-

fatal-lung-disease.html?_r=0			
http://www3.imperial.ac.uk/newsandeventspggrp/imperialcollege/newssummary/news_8-9-2014-16-36-47	-	55	-
https://www.ofev.com/	-	58	-
http://www.immuneworks.com/autoimmune-lung-diseases/idiopathic-pulmonary-fibrosis-ipf-treatments	41	59	38
http://www.novarepharma.com/disease-applications/idiopathic-pulmonary-fibrosis	-	65	-
http://pulmonaryhypertensionnews.com/tag/idiopathic-pulmonary-fibrosis/	69	66	-
http://www.upmc.com/Services/pulmonology/respiratory/conditions/Pages/ipf.aspx	35	67	190
http://www.drugs.com/condition/idiopathic-pulmonary-fibrosis.html	117	68	64
http://www.breathingmatters.co.uk/idiopathic-pulmonary-fibrosis/	-	70	-
http://www.earthclinic.com/cures/pulmonary-fibrosis-lung-disease-remedies.html	158	71	172
http://www.mountsinai.org/patient-care/health-library/diseases-and-conditions/idiopathic-pulmonary-fibrosis	129	74	76
http://www.newswithviews.com/guest_opinion/guest253.htm	-	75	-
http://lungfoundation.com.au/patient-area/lung-diseases/idiopathic-pulmonary-fibrosis-ipf/	48	76	-
http://www.empr.com/news/two-new-drugs-for-idiopathic-pulmonary-fibrosis-approved/article/377594/	-	78	-
http://www.thestar.com/life/health_wellness/2014/09/18/rose_mcgowan_aims_to_end_idiopathic_pulmonary_fibrosis.html	-	79	-
https://news.brown.edu/articles/2014/06/ipf	-	81	-
http://www.nationaljewish.org/healthinfo/conditions/pulmonary-fibrosis/Familial-Pulmonary-Fibrosis/forms	91	82	61
http://www.waltonpulmonary.com/pdf/idiopathic%20pulmonary%20fibrosis.pdf	-	83	-

http://noairtogo.tripod.com/ild.htm	33	84	34
http://www.pennlive.com/bodyandmind/index.ssf/2012/10/living_with_idiopathic_pulmona.html	-	88	-
http://www.theguardian.com/society/2014/jan/16/campaign-raise-awareness-lung-disease-idiopathic-pulmonary-fibrosis	-	89	-
https://www.lung.ca/lung-health/lung-disease/idiopathic-pulmonary-fibrosis	12	91	11
http://www.transplantliving.org/before-the-transplant/diseases/idiopathic-pulmonary-fibrosis/	50	93	70
http://www.diseaseinfosearch.org/Idiopathic+pulmonary+fibrosis/3756	-	99	-
https://healthunlocked.com/idiopathic-pulmonary-fibrosis	-	104	-
https://www.ucl.ac.uk/nuclear-medicine/research/researchabstracts/IPF	-	106	-
http://www.ersnet.org/news/item/4466-new-insights-into-idiopathic-pulmonary-fibrosis.html	-	107	-
http://www.rightdiagnosis.com/medical/familial_idiopathic_pulmonary_fibrosis.htm	17	110	26
http://www.bionity.com/en/idiopathic-pulmonary-fibrosis.html	-	111	-
https://www.healthtap.com/topics/over-the-counter-treatment-for-idiopathic-pulmonary-fibrosis	84	115	-
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http://tulanehealthcare.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	122	-
https://www.axappphealthcare.co.uk/Health-worries/General-health-worries/Pulmonary-fibrosis-(idiopathic)/	-	125	-
http://www.personalhealthnews.ca/education-and-advocacy/caregivers-of-idiopathic-pulmonary-fibrosis-patients-take-a-breather	-	137	-
http://articles.chicagotribune.com/keyword/idiopathic-pulmonary-fibrosis	-	142	-
http://www.heartofengland.nhs.uk/birmingham-chest-clinic/patient-information-for-idiopathic-pulmonary-fibrosis/	-	145	-

http://portsmouthhospital.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	148	-
http://nfrmc.com/your-health/?/75687/Idiopathic-Pulmonary-Fibrosis	-	153	-
http://www.signs-and-symptoms.org/idiopathic-pulmonary-fibrosis/	121	156	80
http://www.empowher.com/condition/idiopathic-pulmonary-fibrosis	199	160	-
http://swedishhospital.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	162	-
http://doctors-hospital.net/your-health/?/75687/Idiopathic-Pulmonary-Fibrosis	-	163	-
http://sahealth.com/your-health/?/75687/Idiopathic-Pulmonary-Fibrosis	-	164	-
http://frankfortregional.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	167	-
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http://mymidwestphysician.com/your-health/?/75687/Idiopathic-pulmonary-fibrosis	-	172	-
http://www.ehub.cat/the-hub-hosts-an-international-symposium-on-idiopathic-pulmonary-fibrosis/?lang=en	-	178	-
http://www.thefreelibrary.com/Idiopathic+pulmonary+fibrosis.-a0226661194	-	181	-
http://fawcetthospital.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	183	-
http://alaskaregional.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	184	-
http://danvilleregional.com/your-health/?/75687/Idiopathic-Pulmonary-Fibrosis	-	185	-
https://www.semc.org/ebsco/Page.asp?chunkid=75687&lang=&db=	-	186	-
http://www.nuh.com.sg/umc/patients-and-visitors/diseases-and-conditions/throat-and-chest/idiopathic-pulmonary-fibrosis.html	-	188	-
http://texasorthopedic.com/hl/?/75687/Idiopathic-Pulmonary-Fibrosis	-	193	-
http://www.uab.edu/news/innovation/item/6170-study-shows-acute-pulmonary-fibrosis-may-respond-to-autoimmune-disease-therapy	-	200	-
http://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0022934/	9	-	8

http://www.nlm.nih.gov/medlineplus/pulmonaryfibrosis.html	10	-	9
http://www.nytimes.com/health/guides/disease/idiopathic-pulmonary-fibrosis/overview.html	22	-	14
http://lungs.emedtv.com/idiopathic-pulmonary-fibrosis/idiopathic-pulmonary-fibrosis.html	26	-	25
http://www.news-medical.net/health/What-is-Idiopathic-Pulmonary-Fibrosis.aspx	19	-	28
http://www.nice.org.uk/guidance/qs79	55	-	31
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http://bodyandhealth.canada.com/condition_info_details.asp?disease_id=109	31	-	51
https://rarediseases.info.nih.gov/gard/8609/idiopathic-pulmonary-fibrosis/resources/1	65	-	55
http://lunginstitute.com/lung-diseases/pulmonary-fibrosis/	51	-	58
https://answers.yahoo.com/question/index;_ylt=A0SO8xx42JJVu80ADbdXNyoA;_ylu=X3oDMTByN3UwbTk1BGNvbG8DZ3ExBHBvcwM5BHZ0aWQDBHNlYwNzcg--?qid=20080204165249AA7Gbhw&p=idiopathic%20pulmonary%20fibrosis	61	-	60
http://www.healthline.com/health/pulmonary-fibrosis#Overview1	99	-	65
http://www.dailystrength.org/c/Pulmonary-Fibrosis/support-group	72	-	66
http://www.healthboards.com/boards/lung-respiratory-disorders-copd/391679-idiopathic-pulmonary-fibrosis.html	118	-	75
http://www.disabilitybenefitscenter.org/compassionate-allowances/idiopathic-pulmonary-fibrosis-social-security-disability	85	-	77
http://www.pivotalhealth.info/new_pulmonary_fibrosis_page?xtr=xyzbingpulmonaryfibrosis	68	-	83
https://ufhealth.org/idiopathic-pulmonary-fibrosis	86	-	87
http://www.caringvoice.org/2012/04/healthy-diet-for-pulmonary-fibrosis/	132	-	91
http://www2.organizedwisdom.com/medical/terminology/COPD-vs.-Pulmonary-Fibrosis	101	-	93
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http://newnurseblog.com/2011/04/12/end-stage-idiopathic-pulmonary-fibrosis/	107	-	98
http://www.inipf.com/	-	-	99
http://pulmonaryfibrosistreatment.com/	87	-	102
http://www.medhelp.org/posts/Respiratory-Disorders/Idiopathic-Pulmonary-Fibrosis/show/577091	137	-	105
http://www.medic8.com/lung-disorders/idiopathic-pulmonary-fibrosis.htm	49	-	110
http://ic.steadyhealth.com/end-stage-of-lung-fibrosis	-	-	113
http://pulmonaryhealthnow.com/idiopathic-pulmonary-fibrosis	62	-	114
http://www.medhelp.org/tags/show/122351/Idiopathic-pulmonary-fibrosis	-	-	115
https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022420	89	-	116
http://www.carepages.com/forums/health-conditions/topics/210-idiopathic-pulmonary-fibrosis	66	-	117
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http://jerseytribune.com/2015/07/02/cnio-researchers-show-that-telomeres-are-linked-to-the-origins-of-idiopathic-pulmonary-fibrosis/	-	-	126
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http://www.mdguidelines.com/interstitial-pulmonary-fibrosis	-	-	154
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http://www.answers.com/Q/What_is_life_expectancy_for_a_patient_with_pulmonary_fibrosis	-	-	169
http://pennstatehershey.adam.com/content.aspx?productId=117&pid=1&gid=000069	161	-	173
http://www.mcrh.org/Pulmonary-Fibrosis/51472.htm	108	-	174
http://www.utmedicalcenter.org/your-health/encyclopedia/disease/000069/	-	-	176
http://www.nmihi.com/f/ipf.htm	104	-	178
http://www.health-reports.com/pulmonary-fibrosis.shtml	131	-	179
http://www.disability-benefits-help.org/compassionate-allowances/idiopathic-pulmonary-fibrosis-and-social-security-disability	98	-	183
http://www.niaid.nih.gov/topics/asthma/research/Pages/pulmonaryFibrosis.aspx	93	-	185
http://www.boehringer-ingelheim.ca/en/human_health/disease_states/IPF.html	-	-	192
http://symptoms.rightdiagnosis.com/cosymptoms/idiopathic-lung-fibrosis-remove.htm		-	196
http://www.sharecare.com/health/pulmonary-fibrosis	155	-	198
http://www.irishhealth.com/article.html?id=9831		-	199
http://www.disabled-world.com/disability/ipf.php	94	-	200
http://ghr.nlm.nih.gov/condition/idiopathic-pulmonary-fibrosis	13	-	-
http://healthfoxx.com/idiopathic-pulmonary-fibrosis-symptoms-causes-diagnosis-treatment/	52	-	-
http://time.com/104514/idiopathic-pulmonary-fibrosis-treatment/	70	-	-
http://ic.steadyhealth.com/idiopathic-pulmonary-fibrosis-life-expectancy-and-quality-of-life	77	-	131
http://www.coalitionforpf.org/lets-talk-about-idiopathic-pulmonary-fibrosis-comprehensive-information-for-patients-and-caregivers/	78	-	-

http://blogs.fda.gov/fdavoice/index.php/2014/10/two-fda-drug-approvals-for-idiopathic-pulmonary-fibrosis-ipf/	81	-	-
https://www.healthtap.com/topics/cystic-fibrosis-vs-pulmonary-fibrosis	84	-	-
http://www.sciencedaily.com/releases/2014/05/140519110322.htm	109	-	-
http://www.biosciencetechnology.com/articles/2014/08/idiopathic-pulmonary-fibrosis-hope-last	112	-	-
http://pulmonaryhypertensionnews.com/2014/04/18/stem-cell-procedure-for-idiopathic-pulmonary-fibrosis-offers-alternative-to-lung-transplants/	113	-	-
http://healthtips-lifestyle.blogspot.ca/2012/05/pulmonary-fibrosis-life-expectancy.html	115	-	-
http://whatispulmonaryfibrosis.com/	116	-	-
http://www.slideshare.net/biodemiclabs/pulmonary-fibrosis-end-stages	126	-	-
http://www.boehringer-ingelheim.com/content/dam/internet/opu/com_EN/document/01_news/02_Press_and_Information packs/Factsheetipf.pdf	133	-	-
http://www.jwatch.org/fw108844/2014/05/19/new-treatments-idiopathic-pulmonary-fibrosis-help	139	-	-
http://www.on.lung.ca/document.doc?id=1750	140	-	-
http://www.post-gazette.com/news/health/2014/08/05/Walk-run-celebrates-possible-breakthrough-for-pulmonary-fibrosis/stories/201407290009	145	-	-
http://www.medpagetoday.com/Pulmonology/GeneralPulmonary/42997	148	-	-
http://www.dailyrx.com/ofev-and-esbriet-both-approved-treat-idiopathic-pulmonary-fibrosis	150	-	-
http://www.getstemcelltreatments.com/pulmonary-fibrosis/	152	-	-
http://www.lungsindia.com/ild-interstitial-lung-disease/idiopathic-pulmonary-fibrosis/	164	-	-
http://www.healthguideinfo.com/respiratory-conditions/p92459/	168	-	-
http://sites.magellanhealth.com/library/HIE%20Multimedia/1/000069.htm	172	-	-

http://medicalxpress.com/news/2014-09-idiopathic-pulmonary-fibrosis-cases-linked.html	176	-	-
http://pharmexp.blogspot.ca/2013/04/is-idiopathic-pulmonary-fibrosisipf.html	180	-	-
http://pulmonaryfibrosisrelief.com/	181	-	-
http://www.ipfinfo.com/pagethre.html	182	-	-
http://netwellness.org/healthtopics/pulfibrosis/overview.cfm	186	-	-
http://www.mc.vanderbilt.edu/root/vumc.php?site=ipfcenter	188	-	-
http://www.uwmedicine.org/health-library/pages/pulmonary-fibrosis.aspx	189	-	-
http://www.livestrong.com/article/517448-diet-for-idiopathic-pulmonary-fibrosis/	190	-	-
http://www.pharmacytimes.com/product-news/FDA-Approves-Pair-of-Idiopathic-Pulmonary-Fibrosis-Treatments	193	-	-
http://www.pulmonary-fibrosis.org/progression.html	195	-	-
http://meari.blogspot.ca/2014/09/idiopathic-pulmonary-fibrosis.html	196	-	-
https://sites.google.com/a/pulmonaryfibrosis.org.uk/pulmonary-fibrosis-uk/about-pulmonary-fibrosis	197	-	-
http://www.lifewithipf.com/about_ipf/what-is-IPF.html	198	-	-
http://www.fiercebiotech.com/tags/idiopathic-pulmonary-fibrosis-0	57	-	74
http://www.sciencedaily.com/releases/2014/05/140519110322.htm	109	-	-

Google®, Yahoo®, and Bing® searches for 'idiopathic pulmonary fibrosis' were performed on June 29th, 2015. Websites were accessed between June 29th and August 24th, 2015.

Table E4. Content scores by website category.

Content category	Website category						
	Overall (n=181)	**Scientific resources (n=84)**	**Foundation/ Advocacy (n=25)**	**News/Media reports (n=32)**	**Industry/For profit (n=18)**	**Personal commentary (n=22)**	**P value**
Definition (/3)	2.3+/–0.9	2.5+/–0.8	2.5+/–0.8	1.8+/–0.9	2.4+/–0.9	2.2+/–1.0	**0.003**
Symptoms (/3)	2.0+/–1.1	2.4+/–1.0	2.6+/–0.6	0.6+/–0.9	1.7+/–1.1	2.0+/–0.8	**< 0.0001**
Risk factors (/5)	2.0+/–1.8	2.7+/–1.8	2.5+/–1.9	0.6+/–1.1	1.9+/–1.9	0.9+/–1.2	**< 0.0001**
Diagnosis (/5)	1.7+/–1.5	2.3+/–1.3	2.2+/–1.7	0.3+/–0.6	1.2+/–1.5	1.3+/–1.3	**< 0.0001**
Management (/7)	2.3+/–1.7	2.6+/–1.6	2.7+/–2.0	1.6+/–1.7	2.3+/–1.9	2.1+/–1.4	**0.04**
Prognosis (/2)	0.6+/–0.6	0.5+/–0.6	0.7+/–0.7	0.5+/–0.6	0.9+/–0.8	0.6+/–0.5	0.08
Overall (/25)	10.9+/–5.6	12.9+/–4.9	13.3+/–5.5	5.5+/–3.3	10.4+/–6.7	9.1+/–3.9	**< 0.0001**

Data are shown as mean +/– standard deviation. See Figure 3 and Table E2 for details of each content category. Kruskal-Wallis was used as a conservative test when determining significance between website categories, given the non-normality of some data.

Table E5. Selected pairwise comparisons of content scores by website category.

Content category	P value for pairwise comparison			
	Scientific resource *vs* Personal commentary	**Scientific resource *vs* News/Media reports**	**Foundation/Advocacy *vs* Personal commentary**	**Foundation/Advocacy *vs* News/Media reports**
Definition (/3)	0.24	**0.0002**	0.49	**0.005**
Symptoms (/5)	**0.004**	**< 0.0001**	**0.01**	**< 0.0001**
Risk factors (/5)	**< 0.0001**	**< 0.0001**	**0.005**	**0.0002**
Diagnosis (/5)	**0.001**	**< 0.0001**	0.05	**0.0001**
Management (/7)	0.20	**0.004**	0.26	**0.04**
Prognosis (/2)	0.14	0.82	0.94	0.32
Overall (/25)	**0.0006**	**< 0.0001**	**0.008**	**< 0.0001**

Wilcoxon rank sum testing was used as a conservative test when determining significance on pairwise testing given the non-normality of some data. Pairwise comparisons are not shown for Industry/For profit websites since these scores were between those of Scientific resources / Foundation/Advocacy organizations and Personal commentary / News/Media websites.

Table E6. Recommendation of non-indicated therapy by website category.

Non-indicated pharmacotherapy	Proportion recommended by website category						
	Overall (n=181)	**Scientific resource (n=84)**	**Foundation/ Advocacy (n=25)**	**News/Media reports (n=32)**	**Industry/ For-profit (n=18)**	**Personal commentary (n=22)**	**P value**
Azathioprine	28 (15.5%)	16 (19.1%)	8 (32.0%)	0 (0%)	1 (5.60%)	3 (13.6%)	**0.004**
Bosentan	1 (0.6%)	1 (1.2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	>0.99
Chlorambucil	2 (1.1%)	2 (2.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	>0.99
Colchicine	5 (2.8)%	4 (4.8%)	0 (0%)	0 (0%)	0 (0%)	1 (4.6%)	0.58
Corticosteroids	70 (38.7%)	36 (42.9%)	15 (60.0%)	1 (3.1%)	3 (16.7%)	15 (68.2%)	**<0.0001**
Coumadin	1 (0.6%)	1 (1.2%)	0 (0%)	0 (0%)	0 (0%)	(0%)	>0.99
Cyclophosphamide	18 (9.9)%	13 (15.5%)	2 (8.0%)	0 (0%)	0 (0%)	3 (13.6%)	**0.04**
Cyclosporine	6 (3.3)%	5 (6.0%)	1 (4.0%)	0 (0%)	0 (0%)	0 (0%)	0.56
Etanercept	1 (0.6%)	1 (1.2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	>0.99
Imatinib	1 (0.6%)	1 (1.2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	>0.99
Immunosuppressants	26 (14.4%)	17 (20.2%)	5 (20.0%)	0 (0%)	0 (0%)	4 18.2%)	**0.006**
Interferon	5 (2.8%)	3 (3.6%)	0 (0%)	0 (0%)	0 (0%)	2 (9.1%)	0.31
Mycophenolate	3 (1.7%)	2 (2.4%)	1 (4.0%)	0 (0%)	0 (0%)	0 (0%)	0.79
Methotrexate	5 (2.8%)	5 (6.0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.41
NAC*	33 (18.2%)	16 (19.1%)	10 (40.0%)	0 (0%)	4 (22.2%)	3 (13.6%)	**0.001**
NAC* inhaled	1 (0.6%)	0 (0%)	0 (0%)	1 (3.1%)	0 (0%)	0 (0%)	0.54
Nattokinase	3 (1.7%)	0 (0%)	0 (0%)	0 (0%)	2 (11.1%)	1 (4.6%)	**0.008**
Penicillamine	4 (2.2%)	4 (4.8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0.66
Sildenafil	3 (1.7%)	1 (1.2%)	0 (0%)	1 (3.1%)	1 (5.6%)	0 (0%)	0.42
Serrapeptase	3 (1.7%)	0 (0%)	0 (0%)	0 (0%)	2 (11.1%)	1 (4.6%)	**0.008**
Stem cell transplant	4 (2.2%)	0 (0%)	0 (0%)	2 (6.3%)	1 (5.6%)	1 (4.6%)	0.07
Vincristine	2 (1.1%)	2 (2.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	>0.99
Non-indicated pharmacotherapy	**Proportion recommended by website category after publication of data showing harm of prednisone/ azathioprine**						
	Overall (n=98)	**Scientific resource (n=49)**	**Foundation/ Advocacy (n=7)**	**News/Media reports (n=30)**	**Industry/ For-profit (n=5)**	**Personal commentary (n=7)**	**P value**
Azathioprine	13 (13.3%)	8 (16.3%)	3 (42.9%)	0 (0%)	1 (20.0%)	1 (14.3%)	**0.01**
Corticosteroids	30 (30.6%)	19 (38.8%)	5 (71.4%)	1 (3.3%)	1 (20.0%)	4 (57.1%)	**<0.0001**

Data are shown as number (percent). The reported p value is based on Chi-square or Fisher's exact test where appropriate.

*Abbreviations: NAC, n-acetylcysteine.

Table E7. Multivariate models for predictors of website content and DISCERN total scores.

Variables in model	Content total score		DISCERN total score	
	Estimate	P value	Estimate	P value
Website category (*vs*. Personal commentary websites)				
Scientific resource	3.3	**0.009**	8.4	**0.002**
Foundation/Advocacy organizations	4.1	**0.007**	12.4	**0.0002**
News/Media reports	-3.9	**0.006**	3.1	0.29
Industry/For-profit	0.9	0.57	8.0	**0.02**
Host continent (N. Am.* *vs*. other)	-0.28	0.76	-0.6	0.75
HON† certification (yes *vs*. no)	1.0	0.34	4.6	**0.04**
R-squared	**0.27**		**0.14**	

A high content total score and high DISCERN total score indicate higher site quality (content and bias). A positive estimate indicates superior website quality compared to personal commentary websites, and a negative estimate indicates inferior website quality compared to personal commentary websites.

Abbreviations: *N. Am., North America, †HON, Health on the Net Foundation code of conduct.