Assessment of available online educational resources for patients with atrial fibrillation

Melissa E. Middeldorp, PhD,*† Ellen Lyrtzis, BHSc,* Kyle Heath, BSc,* Tanya Hall,‡
Kadhim Kadhim, MBChB,*† Prashanthan Sanders, MBBS, PhD*†

*From the *Centre for Heart Rhythm Disorders, University of Adelaide, Adelaide, Australia, †Department of Cardiology, Royal Adelaide Hospital, Adelaide, Australia, and ‡Heart4Hearts, Melbourne, Australia.*

BACKGROUND A diagnosis of atrial fibrillation (AF) often leads patients to search online for information, which can expose them to information of varied quality.

OBJECTIVE We conducted a qualitative systematic review of websites that contain useful information regarding AF.

METHODS The following terms were searched on 3 search engines (Google/Yahoo/Bing): (Atrial fibrillation for patients), (What is atrial fibrillation), (Atrial fibrillation patient information), (Atrial fibrillation educational resources). Inclusion criteria included websites with comprehensive AF information and information about treatment options. The Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) and PEMAT for Audiovisual Materials assessed understandability and actionability (score range 0–100). Those with a mean PEMAT-P score of >70, meaning acceptable understandability and actionability, underwent DISCERN score assessment of information content quality and reliability (score range 16–80).

RESULTS The search yielded 720 websites that underwent full review. After exclusions, 49 underwent full scoring. The mean overall PEMAT-P score was 69.3 ± 17.2. The mean PEMAT-AV score was 63.4 ± 13.6. Of the websites that scored >70% on the PEMAT-P, 23 (46%) underwent DISCERN scoring. The mean DISCERN score was 54.7 ± 4.6.

CONCLUSIONS There is a wide variation in the understandably, actionability, and quality of websites, many not providing patient-level materials. Knowledge of quality websites could provide an important adjunct for improving patients understanding of AF.

KEYWORDS Atrial fibrillation; Online; Websites; Patient Resources; Educational material

(Heart Rhythm O² 2023;4:187–192) © 2022 Heart Rhythm Society. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Background

Atrial fibrillation (AF) prevalence is on the rise, with treatment options such as medical therapy, procedural techniques, and lifestyle management advancing with time.[1] Patients diagnosed with AF often leave their medical practitioners office overwhelmed and anxious, and many will turn directly to the Internet for further information regarding their diagnosis.[2] Additionally, many patients turn to the Internet to fill in the gaps in what they learnt from their physician.[3] It has been reported that when seeking information about their health, 70% of adults go to the Internet as their first source.[4] In surveys undertaken in the U.S. population, 70% to 80% of individuals had undertaken a search for health or medical information yearly.[5] These searches may be to further their knowledge of their condition or seek understanding of the treatment and management available. One concern with information accessed due to the ability for anyone to create a site on the Internet is that it is can contain information that is not accurate, and additionally, these sites are not peer-reviewed, often providing misleading information.[6] The available information could lead to the "Dr Google" effect, in which patients are then led to increase in anxiety based on information that is not evidence based or medically sound, known as cyberchondria.[7]

Objectives

There is no easy way for AF patients to know the most accurate source of information. We therefore undertook a systematic review of online patient resources to assess the quality of information available to the public, rate available resources for patients, and establish a comprehensive list of recommended websites.

Methods
Data search and selection

A structured online search designed to mimic that of what a patient would perform was undertaken to obtain freely accessible resources designed for patients with AF. An online search was conducted between October and November

Address reprint requests and correspondence: Dr Melissa Middeldorp, Centre for Heart Rhythm Disorders, University of Adelaide & Department of Cardiology, Royal Adelaide Hospital, Port Rd, Adelaide, SA 5000, Australia. E-mail address: melissa.middeldorp@adelaide.edu.au. Twitter: @melissaemm1

2022. Search engines used were Google, Yahoo, and Bing with the following search terms: (atrial fibrillation for patients), (what is atrial fibrillation), (atrial fibrillation patient information), (atrial fibrillation educational resources). Only the first 3 pages were assessed, as prior data demonstrate that most people seeking health information do not move past the first 3 pages when undertaking a search.[3] Websites were assessed by 2 independent reviewers (M.M. and E.L.) with the instruction to clear cache and search history prior to undertaking each search. Disagreement of website inclusion was resolved by consensus. Websites were screened to identify resources that provided comprehensive information about the condition AF and designed at the patient level. A secondary review was undertaken of any audiovisual materials within the websites from the search.

Due to the nature of this study and no patient involvement, ethics approval was not required or sought. We adhered to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines throughout our study (Figure 1).

To be included in the study, websites had to meet the following inclusion criteria: be a patient not healthcare professional website; have an explanation of AF including symptoms, AF types, treatment options, and potential risks; and include downloadable or printable webpages. Downloadable or printable materials had to include websites in which PDF documents were available or in which the content was printable.

Websites were excluded if they were a duplicated website, required a subscription or membership for access, were a news article, were intended for healthcare professionals such as a link to a scientific abstract or manuscript, were corrupt or unable to open, were not specific to AF, or were developed by private clinics.

Assessment tools
Evaluation of the websites accessibility and readability was undertaken through the use of the previously validated Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) and Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-AV).[8] In order to evaluate the content quality, we used the DISCERN instrument.[9] These tools have been previously undergone formal validation studies and have been used to assess websites in a number of other websites evaluation studies.[10,11]

Patient Education Materials Assessment Tool
The PEMAT assessment tool was established to provide a reliable instrument to be able to assess printable and
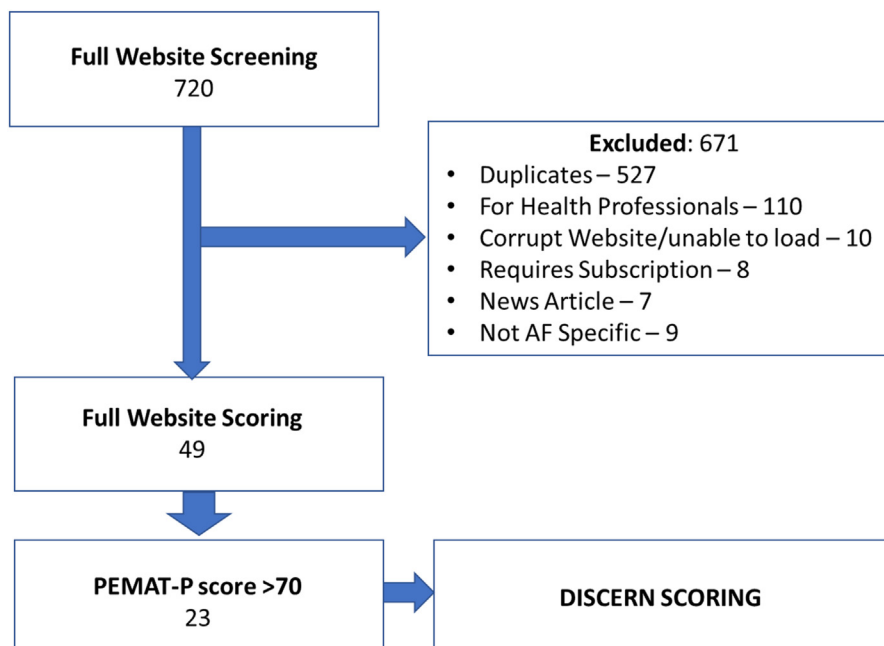

FIGURE 1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart of study screening, inclusion and exclusion, and the final study cohort. Of 720 websites, 49 met inclusion criteria for Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) full review. A further 23 scored the optimal mean score ($\geq$70) and underwent DISCERN scoring for content quality. AF = atrial fibrillation.
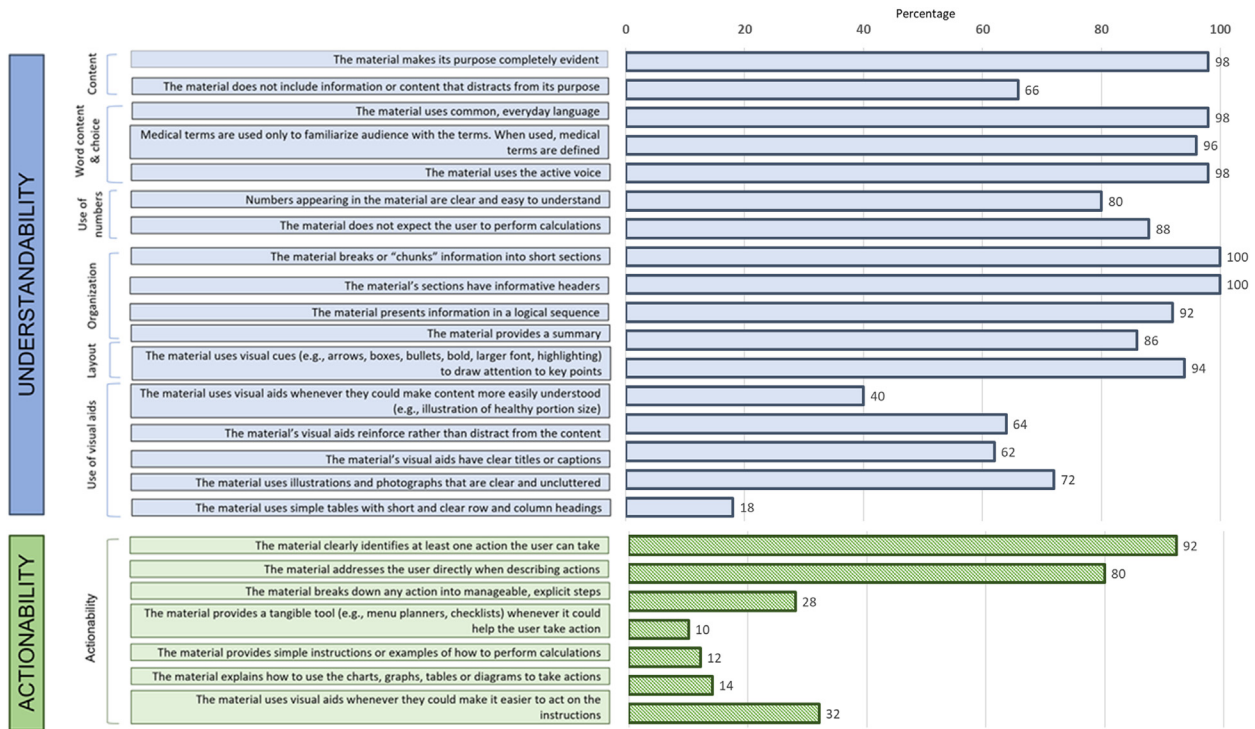
FIGURE 2 Patient Education Materials Assessment Tool for Printable Materials scoring. The percentage of websites that scored points for each item topic: blue is representative of the understandability domain and green is representative of the actionability domain.

audiovisual understandability and actionability. Due to different individuals' levels of literacy and understanding, it is formulated to provide a simple scoring system. The PEMAT-P tool assesses 2 aspects of the materials, understandability and actionability, and is available freely online (Supplemental Figure 1). The PEMAT-AV (Supplemental Figure 2) uses the same principles as the PEMAT-P with 13 understandability items and 4 accountability items (details in the Supplemental Appendix).

To establish if the websites were considered understandable and actionable, they had to reach a total score of ≥70% as previously validated.[10] Following scoring with PEMAT-P, eligible studies with a score of ≥70% underwent further screening with the DISCERN instrument to determine quality of the website content.

DISCERN instrument
The DISCERN instrument was developed to provide a tool to be able to review the quality of information for the consumer particular with a focus on treatment choices in health information (Supplemental Figure 3). The questionnaire is developed to review the evidence of clinical effectiveness by assessment of the most up-to-date and rigorous scientific research (details in the Supplemental Appendix).

Data analysis
For the PEMAT scores, the totals of understandability and actionability are divided by the total possible points and

multiplied by 100 for a score presented as a percentage. For the DISCERN tool, questions are scored using Likert scoring. The scores are then compiled with ranking from 16 (bad quality) to 80 (exceptional quality). A pragmatic approach was undertaken for this qualitative analysis. Scores were obtained independently from each reviewer and the mean score was calculated. Data are presented as continuous with mean ± SD.

Results
The search of the 3 most common search engines yielded full review of 720 websites from 2 reviewers, and each reviewer independently searched the four topics and reviewed the first 3 pages. After removing duplicates and those not meeting inclusion criteria, a total of 49 websites underwent full scoring and were included in the final analysis (Figure 1).

For websites with audiovisual materials available, of the 720, 49 websites included printable and audiovisual material. After review and exclusions, 18 websites underwent scoring using the PEMAT-AV (Supplemental Table 1).

PEMAT-P scoring
Of the 49 websites, 10 (20%) scored 100 in understandability, while only 3 (6%) scored 100 in actionability. Overall PEMAT-P mean score was 69.3 ± 17.2. The mean understandability score was 88.9 ± 8.6 and the mean actionability score was 49.6 ± 25.8. Only 23 (46%) websites had an overall mean score >70% (Supplemental Table 1).

FIGURE 3 Patient Education Materials Assessment Tool for Audiovisual Materials scoring. The percentage of websites that scored points for each item topic: blue is representative of the understandability domain and green is representative of the actionability domain.

For each of the PEMAT-P domains, most websites scored well in understandability domains of content, word content and choice, use of number, organization, and layout. However, for use of visual aids, <72% scored points. Overall actionability was lacking, with most websites not scoring points in each of the domains (Figure 2).

We assessed the audiovisual materials available as part of the search. The mean understandability score was 89.2 ± 10.9 and the mean actionability score was 37.6 ± 23.1. The mean overall PEMAT-AV score was 63.4 ± 13.6. Only 8 (44%) websites had a mean overall score >70%.

As with the PEMAT-P domains, the PEMAT-AV domains scored well for most websites in understandability, except for the domain that was scored for providing a summary and tables. There was no score allocated for any of the websites for both final domains of understandability regarding the use of visual aids and an actionability explanation of how to use charts, graphs, tables, or diagrams, due to no websites having this available. Actionability was also low scoring, with none of the actions scoring >70% (Figure 3).

DISCERN scoring

When scoring the quality of the websites, of the 23 websites with a PEMAT-P score >70%, no websites scored the optimal DISCERN score of 80. The mean DISCERN score was 54.7 ± 4.6, with 7 (30.4%) scoring ≥60. Most of the websites scored well when describing the relevance of the information, with 4 of the questions in this domain scoring >4 points. However, when describing quality of information on

treatment choices, the scores were lower, with only 2 scoring >4 points (Figure 4).

Website overview

Most of websites were based in the United States (n = 22 [46%]). Australia and New Zealand had 12 (24%), and the remainder from the United Kingdom, Canada, Europe and Asia (Table 1). Of the 23 websites that scored >70, most of the major associations were included, such as the American College of Cardiology, the American Heart Association, the Heart Rhythm Society, and the Heart Foundation. There were 4 industry-based websites.

In assessing the content, 48 (98%) websites contained information on the association between stroke and stroke risk. For comprehensive information on AF definition, symptoms, and types, 47 (96%) included this for patients, while 45 (92%) provided information on medication therapies and 44 (89.6%) on procedural treatment options. In contrast, only 37 (74%) provided information on lifestyle factors associated with AF.

Discussion

The primary findings of this study highlight the greater consideration that needs to go into the development of accurate online content for patients with AF. Based on this review, only 46% of websites scored the ideal of >70, with the mean understandability being 88.9 and a low mean score of 49.6 for actionability in the PEMAT-P scores.
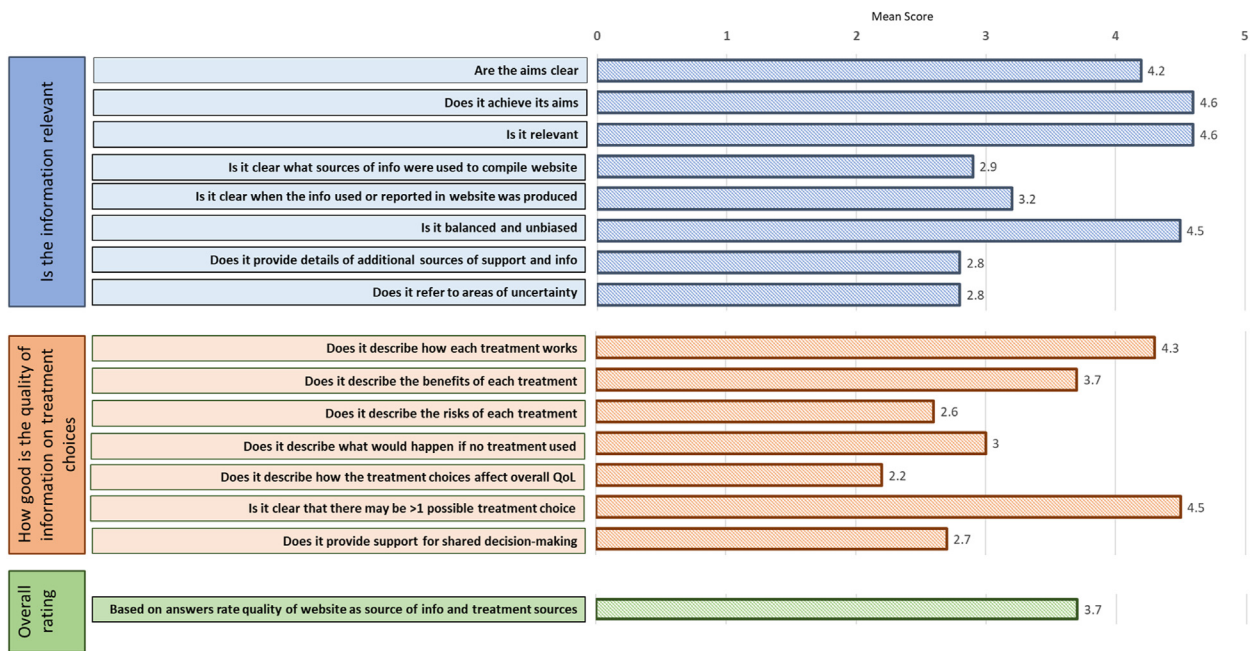
FIGURE 4   DISCERN scoring. Percentage of websites that scored points for each topic item. The blue section is representative of the relevance of the information. The orange section is representative of the quality of the information on treatment choices. The green section is the overall quality rating of the website.

While most of the websites did score reasonably well for understandability, the domain which considers content, use of wording, layout, and visualization, many of the websites did not score well in the use of visual aids. It has been well described that many people often prefer to have visual aids in order provide ease of understanding.[12] A large proportion (92%) scored for at least 1 action, though the delivery of this action was poorly identified. From the audiovisual perspective, again actionability was lacking. Actions such as demonstration of pulse taking and blood pressure taking were shown in some videos but were lacking in majority of the videos.

Due to the nature of the Internet, anyone can create a website, in turn leading to information of varying quality and accuracy. There is no quality control in place, with content not subjected to guidelines, review, or approval, possibly imposing harm if the information is incorrect or unclear. It was reassuring to see that many of the websites scored well for their aims with balanced and unbiased information, highlighting more than one possible treatment and how these treatments work. Conversely, the mean overall score was low, 54.7 of a possible 80. This is of concern, suggesting that the information that patients refer to is often not of the quality required for a full understanding of their condition. The areas that appeared to be most lacking comprised quality descriptions of the information sources, risks of the available treatment options, comprehensive treatment outcomes, quality of life, and support for shared decision making.

The content of the websites in our review varied somewhat, with a strong focus on stroke, which was addressed in most of the websites. Yet, despite providing symptom and treatment options, only 74% provided information on lifestyle factors associated with AF.[13] These key points are imperative to patient care and are important aspects that should be included in websites to support guideline-directed information relevant to AF patients.[14]

We did note that in using the websites, the ease of navigation was at times complicated and not intuitive, such that those who are of an older generation or with a lower literacy level would have had difficulty navigating to all the pages.

Despite the strengths of this review, there are also a few limitations to consider. The search could vary depending on the geographical location and could produce different findings, and similarly only English websites were reviewed. We did undertake the search using 2 independent reviewers, 3 search engines, and using common search terms to capture as many websites as possible to try to minimize this problem. Websites do undergo updates; however, these are infrequent, and often these changes are minor and therefore unlikely to affect the overall score. To mitigate potential validation biases, we did ensure that the information that we reviewed had the ability to be printed. We did not conduct a separate review of audiovisual materials available on sites such as YouTube. This was undertaken so to mimic a search that a patient would run, being a generic Web-based search, providing predominantly website-based information.

Conclusion

The ability to provide comprehensive, accurate information via online resources is key to assisting patients in a better understanding of their condition and treatment options. It is evident that there is need for improvement in the websites

available to patients of all ages, backgrounds, and literacy levels, and this review provides a comprehensive list of websites for recommendation to patients with AF.

References

1. Kirchhof P, Benussi S, Kotecha D, et al. 2016 ESC Guidelines for the management of atrial fibrillation developed in collaboration with EACTS. Eur Heart J 2016;37:2893–2962.
2. Lee ST, Lin J. The influence of offline and online intrinsic motivations on online health information seeking. Health Commun 2020;35:1129–1136.
3. Morahan-Martin JM. How internet users find, evaluate, and use online health information: a cross-cultural review. Cyberpsychol Behav 2004; 7:497–510.
4. Prestin A, Vieux SN, Chou WY. Is online health activity alive and well or flatlining? Findings from 10 years of the Health Information National Trends Survey. J Health Commun 2015;20:790–798.
5. Finney Rutten LJ, Blake KD, Greenberg-Worisek AJ, Allen SV, Moser RP, Hesse BW. Online health information seeking among US adults: measuring progress toward a Healthy People 2020 objective. Public Health Rep 2019; 134:617–625.
6. Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 2002;287:2691–2700.
7. Fergus TA. Cyberchondria and intolerance of uncertainty: examining when individuals experience health anxiety in response to Internet searches for medical information. Cyberpsychol Behav Soc Netw 2013;16:735–739.
8. Shoemaker SJ, Wolf MS, Brach C. Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. Patient Educ Couns 2014; 96:395–403.
9. 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;53:105–111.
10. Vishnevetsky J, Walters CB, Tan KS. Interrater reliability of the Patient Education Materials Assessment Tool (PEMAT). Patient Educ Couns 2018; 101:490–496.
11. Rees CE, Ford JE, Sheard CE. Evaluating the reliability of DISCERN: a tool for assessing the quality of written patient information on treatment choices. Patient Educ Couns 2002;47:273–275.
12. Garcia-Retamero R, Cokely ET. Designing visual aids that promote risk literacy: a systematic review of health research and evidence-based design heuristics. Hum Factors 2017;59:582–627.
13. Middeldorp ME, Ariyaratnam J, Lau D, Sanders P. Lifestyle modifications for treatment of atrial fibrillation. Heart 2020;106:325–332.
14. Chung MK, Eckhardt LL, Chen LY, et al. Lifestyle and risk factor modification for reduction of atrial fibrillation: a scientific statement from the American Heart Association. Circulation 2020;141:e750–e772.