Online information for Spontaneous Coronary Artery Dissection (SCAD) survivors and their families: a systematic appraisal of content and quality of websites.

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ABSTRACT

Background

Spontaneous coronary artery dissection (SCAD) survivors often seek information online. However, the quality and content of websites for SCAD survivors is uncertain. This review aimed to systematically identify and appraise websites for SCAD survivors.

Methods

A systematic review approach was adapted for websites. A comprehensive search of SCAD key-phrases was performed using an internet search engine during January 2023. Websites targeting SCAD survivors were included. Websites were appraised for quality using Quality Component Scoring System (QCSS) and Health Related Website Evaluation Form (HRWEF), suitability using the Suitability Assessment Method (SAM), readability using a readability generator, and interactivity. Content was appraised using a tool based on SCAD international consensus literature. Raw scores from tools were concerted to percentages, then classified variably as excellent through to poor.

Results

A total of 50 websites were identified and included from 600 screened. Overall, content accuracy/scope (53.3±23.3) and interactivity (67.1±11.5) were poor, quality was fair (59.1±22.3, QCSS) and average (83.1±5.8, HRWEF) and suitability was adequate (54.9±13.8, SAM). The mean readability grade was 11.6 (±2.3), far exceeding the recommendations of ≤8. By website type, survivor affiliated and medically peer-reviewed health information websites scored highest. Appraisal tools had limitations, such as overlapping appraisal of similar things and less relevant items due to internet modernity.

Conclusion

Many online websites are available for SCAD survivors, but often have limited and/or inaccurate content, poor quality, are not tailored to the demographic, and are difficult to read. Appraisal tools for health website require consolidation and further development.

1 INTRODUCTION

Spontaneous coronary artery dissection (SCAD) is a distinct non-atherosclerotic cause of myocardial infarction (MI), estimated to account for up to 4% of acute coronary syndromes (ACS) admissions globally [1]. In contrast to atherosclerotic ACS, SCAD occurs in a younger demographic (mean 44-53 years of age) with little to no modifiable cardiovascular risk factors, and predominantly affects women (87-95% of presentations) [1,2]. Recurrence is reported in 10-30% of survivors and is not directly amenable to existing secondary prevention strategies given the typical absence of modifiable risk factors [1,3]. Many of those experiencing SCAD (hereafter SCAD survivors) are misdiagnosed and incorrectly treated in clinical settings [4,5] and information given following SCAD is limited by healthcare professionals' lack of awareness of the condition [5,6,7]. SCAD survivors are provided generic ACS education not relevant to their circumstances and have reported receiving inadequate or conflicting information [4,6]. Uncertainty then results in stress, anxiety, loneliness and feelings of isolation in SCAD survivors [2,6,8] who subsequently report turning to online material for information and peer-support [2,6,7].

The quality of information given during SCAD admission has been described as "insufficient/inadequate" by 82% of SCAD survivors and over half the study participants considered the internet as the most helpful information source following discharge [7]. However, the standard of SCAD related webpages is currently unknown so clinicians may struggle to know where best to direct survivors. It is unclear how many websites exist, how many pages have SCAD content, if the information contained is accurate and comprehensive, and whether information is included that SCAD survivors may value, such as future pregnancy and exercise advice [9]. It is also unclear how many website utilise different modes of delivery such as illustrations, videos, PDFs or survivor stories. Users report judging the quality of health websites based on completeness and understandability of information and these judgements differ with age, gender, education and digital health literacy levels [10]. Some users make quality judgements based on whether online

information is appealing and familiar, thus suitability is an important factor [11]. Cultural and contextual factors are amongst many multifactorial influences on digital health literacy [10] and thus website readability is significant, especially given that higher reading requirements foster misinterpretation of online resources in cardiovascular disease [13].

To date, these factors have not been appraised for SCAD survivors websites. Therefore, this study aimed to ascertain the number and quality of websites for SCAD survivors globally, and the features and resources available. The primary aim was to systematically identify and appraise websites that target SCAD survivors across five domains: accuracy and scope of content, quality, suitability, readability and interactivity.

2 METHODS

2.1 Study Design

A systematic review design was adapted for the review and appraisal of websites. The study was not applicable for registration on PROSPERO.

2.2 Searches and sources

A systematic search was undertaken using an internet search engine on Safari internet browser Version 16.5 throughout January 2023. Twenty individual searches were conducted using different search terms. Search terms/keywords were compiled by entering “SCAD” and “spontaneous coronary artery dissection” into the internet search engine “Google” to identify related searches and were also fielded from closed survivor support groups to identify terms valuable to consumers (Appendix A. Table A.1). We searched the first 30 results of each search given evidence that internet users rarely search beyond the first three pages [14] and to account for minor variations in the order of search results for the same search performed on different days. Different pages from the same website were counted as one. Where present, the search function of each website was used by searching “SCAD” and “Spontaneous Coronary Artery Dissection.” To ensure generalisability, a selection of the

screening was repeated using a Chrome browser but no discernible difference was observed in search results or website speed and function. Cookies and search history were deleted between searches to avoid influencing outcomes.

2.3 Study selection

Websites were included that 1) contained information regarding SCAD, 2) were aimed at survivors or the general public, and 3) were written in English. Websites for SCAD associated conditions, such as fibromuscular dysplasia, were also included providing that they featured SCAD content. Website links directly to PDF documents, such as brochures or booklets were included and counted in all appraisals. Websites were excluded that were 1) non-medical or for medical conditions unrelated to SCAD, 2) related to heart disease but without SCAD specific content, 3) aimed specifically at medical or research professionals, 4) research group pages describing or recruiting for studies, 5) research publications or scientific journal pages, 6) video only pages such as YouTube, 7) social media pages including closed access SCAD survivor groups, and 8) websites requiring subscription or login to access content.

2.4 Data extraction

Websites identified during the search process were recorded in the Research Electronic Data Capture (REDCap) system and duplicates removed [15]. Screening for eligibility was undertaken by two reviewers (JW and ZM) with disagreements resolved by consulting another reviewer (RG). Data extraction and website appraisal were performed by the primary researcher (JW) with 20% of included websites independently appraised by another reviewer (NE) for interrater reliability scores.

Data were collected on the website name, country of origin, URL, number of pages containing SCAD content, presence of internal links for other information (e.g. general heart attack advice or cardiovascular disease in women), illustrations, videos, downloadable PDFs

or brochures, presence of survivor stories and format (text or video), and links to survivor groups. Experiences of SCAD survivors were also assessed, with inclusion of written or video accounts of survivor stories being factored into content appraisal as a way of imparting information. Hyperlinks to external websites were not directly appraised for content but were noted in quality and suitability assessments.

2.5 Appraisal tools

Websites were assessed in five domains: content (accuracy and scope), quality, suitability, readability and interactivity. The methods used for appraisal have been guided by previous website assessment processes, including validated appraisal tools and cut-off thresholds, except the content (accuracy and scope) assessment which was adapted specifically for SCAD while retaining the published scoring system and thresholds [16,17,18,19,20]. Except for readability grade, all raw scores for tools were converted to percentages and categorised as below.

2.5.1 Accuracy and scope of content

The accuracy and scope of website content was assessed using a content appraisal tool, adapted for SCAD from previous studies (Appendix C. Table C.1). As International SCAD guidelines do not currently exist for diagnosis, treatment, management and care, items assessed were based on the 2018 expert consensus statements from the European Society of Cardiology [21] and the American Heart Association [22], and a comprehensive SCAD literature review published in 2020 [1]. Content for each topic in the website assessed was classified (and scored) as “accurate, fully addressed” (+1 points) if the topic was covered with sufficient explanation consistent with the reference documents above; “accurate, partially addressed” (+0.5 points) if content was correct but had superficial or inadequate explanation; “not addressed” if content on the topic was not present (0 points); and “inaccurate” (-1 point) if content was relevant to atherosclerotic ACS rather than SCAD, misleading, outdated, or contradictory of the reference documents. Subtopic scores were

added for a maximum total of 26. Total scores were converted into percentages and categorised as excellent (≥90%), adequate (75-89%) and poor (≤74%) based on previous studies [16]. Higher scores represent wider scope and higher accuracy of content.

2.5.2 Quality

Quality and reliability were assessed using the Quality Component Scoring System (QCSS) and Health-Related Website Evaluation Form (HRWEF) respectively. Both tools have previously been validated for the appraisal of websites for conditions such as cluster headaches [23], retinopathy [18] and health behaviours during infancy [16]. The cut-off scores used in the current assessment were those published previously [16,17]. Higher scores represent higher quality.

The QCSS is a 7-item instrument assessing website ownership, attribution of authorship, qualifications of the authors, purpose, references, interactivity and currency (provision of publication date) [18,19]. All items, with the exception of ownership, are awarded full (2), partial (1) or nil (0) points. Points are totalled for a maximum of 13 and then converted to a percentage, classified as excellent (≥80%), very good (70-79%), good (60-69%), fair (50-59%) and poor (≤50%).

The HRWEF [16,17] is 30-item tool that assesses quality more broadly than the QCSS, taking into account the appropriateness and balance of the website [20]. Factors considered include transparency of funding sources, qualifications of authors and editors, diversity of perspectives in topics of controversy, provision of links to external sources, and targeting to the specific audience. Scores are awarded for agree (2 points) and disagree (1 point), with an option for not applicable, totalled for a potential score of 60. Scores are then converted to a percentage, which is classified as excellent (≥90%), adequate (75-89%) and poor (≤74%).

2.5.3 Suitability

Suitability was appraised using the Suitability Assessment of Material (SAM); a 22-item tool for assessing the suitability of a website for an intended audience's characteristics [16,17]. The SAM appraises content, literacy demand, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness. Items receive points classified as superior (2), adequate (1), not suitable (0), or not applicable. Scores are totalled for a potential 44 points, converted to a percentage, and material classified as superior (≥70%), adequate (40-69%), and not suitable (≤39%). Higher scores represent higher suitability.

2.5.4 Readability

An online readability generator was used to assess readability grade. The readability generator has been used in previous publications and uses a consensus of several reading tools including the Flesch Reading Ease formula, Flesch-Kincaid Grade Level, Fog Scale, Simple Measure of Gobbledygook Index, Coleman-Liau Index, Automated Readability Index and the Linsear Write Formula [24]. For continuity, the entire word content of the landing page of the website was input into the readability generator. For this study, a reading level of grade 8 or below was considered adequate readability, as published previously [16,17]. Lower reading grades indicate writing that is easier to read.

2.5.5 Interactivity

A 15-item adaption of an online interactivity assessment scale [16,17] was used to assess interactivity in terms of user control over what is viewed (active control – 4 items), ability to provide feedback and communicate (two-way communication – 6 items) and responsiveness of the website to input and accessibility of information (synchronicity – 5 items). Each item was scored as agree (2 points), partially agree (1 point) and disagree (0 points). Points were totalled to a maximum of 30, and converted into percentages, categorised as excellent

(≥90%), adequate (70%-89%), and poor (≤69%). Higher scores represent higher interactivity components.

2.6 Data Analysis

Data were extracted, recorded and classified using REDCap. Raw scores were converted to percentages and classified as described above. Data were analysed using IBM SPSS Statistics (Version 27). Descriptive statistics were used according to the variable type as frequencies and percentages or means with standard deviations. Interrater reliability scores were calculated using intraclass correlation coefficients for the two reviewers and these were excellent for content (.96, 95% confidence interval [95%CI] .85-.99) and QCSS (.94, 95%CI.77-.98), good for SAM (.87, 95%CI.55-.97) and acceptable for HRWEF (.76, 95%CI.30-.94) and interactivity (.76, 95%CI.31-.94). Cronbach's Alpha was used to assess internal reliability with the following outcomes: content tool 0.91 (excellent internal reliability), QCSS 0.66 (moderate internal reliability), HRWEF 0.73, SAM 0.77 and interactivity tool 0.78 (acceptable internal reliability). Websites were categorised into one of six website types (Box 1) by two of the researchers and means scores calculated for each area of appraisal by website type.

Website type	Description
National cardiac foundations	The websites of national authorities/charities that are responsible for funding of cardiovascular disease research and development of guidelines.
Hospital groups	Websites for individual or multiple hospital(s), research institutions and government health organisations.
Medically peer-reviewed health information	Websites of independent organisations providing health advice, written by healthcare professionals and peer-reviewed by medical doctors.
Survivor affiliated	Websites created by individuals with lived experience of SCAD (including family members), or charities/organisations/affiliations for SCAD survivors.

Affiliated medical news or blog	Websites using a journalistic or blog style reporting, typically using a featured case-study or reporting findings in layman terms from a recent publication. Affiliated with (but neither linked to nor a feature of) university, hospital or professional association websites. Author may not be a healthcare professional.
Non-medically reviewed health information	Websites providing health advice that is not medically peer-reviewed and is unaffiliated with universities, hospitals, research institutes, governments, survivor groups or national foundations. Author is not a healthcare professional.

Box 1. Definition of website type categories.

3 RESULTS

A total of 600 websites were identified, of which 367 were eligible, 317 removed as duplicates, and 50 were included in the review (Figure 1). The majority of websites were based or created in America (64%), Canada (14%) or Australia (12%) (Table 1). Websites included illustrations (38%), educational videos (34%), downloadable educational material PDFs (16%), links to SCAD survivor peer-support groups (38%) and survivor stories (40%), with approximately half of these in video format (18%).

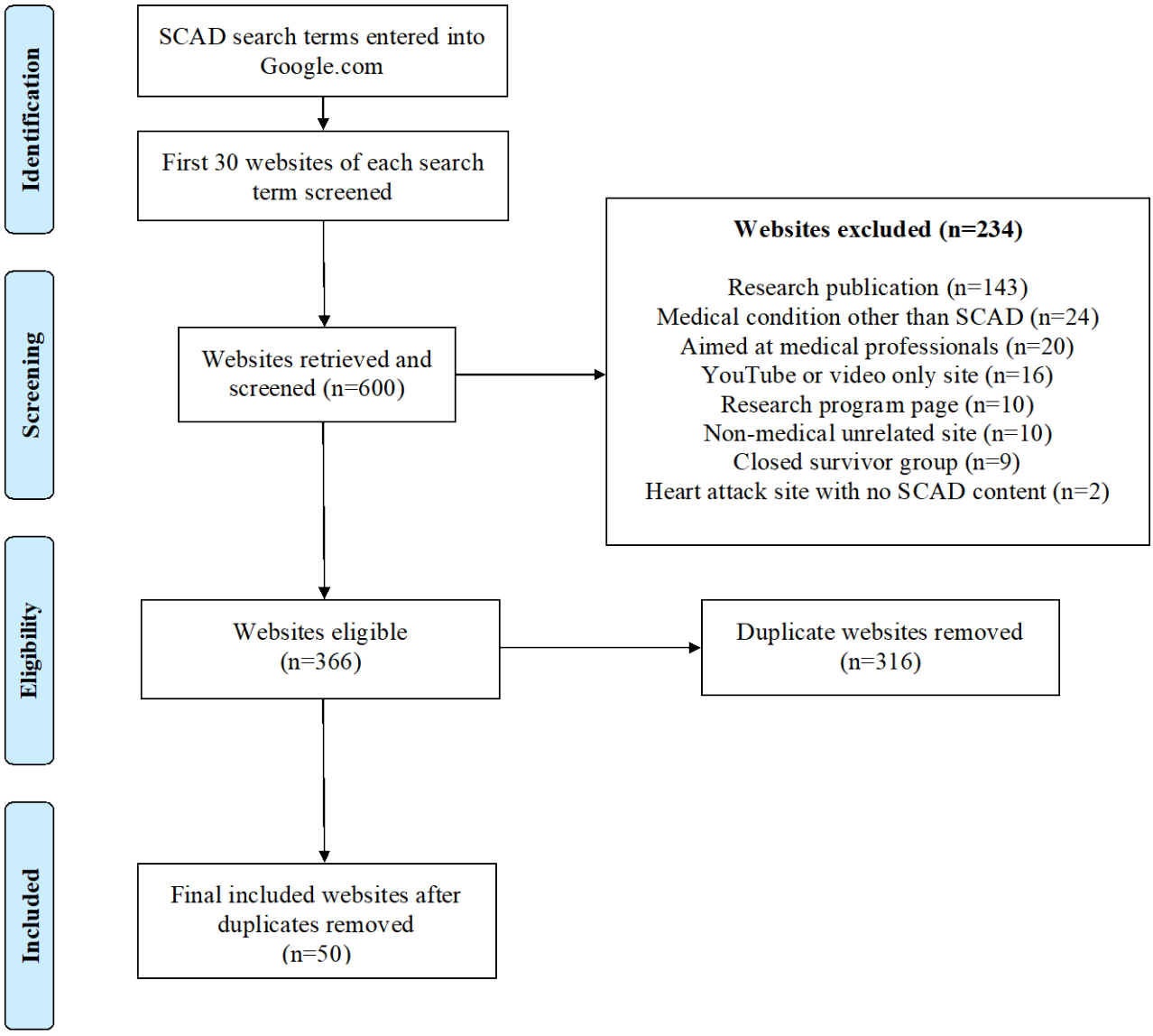

Figure 1. Systematic appraisal search process.

Website name	Website type	Country	Pages of SCAD content	Internal links to information	Illustrations	Videos	PDF or brochures	Survivor stories (format)	Links to survivor group
American Heart Association	NCF	USA	8	✓	✗	✗	✗	Text and video	✗
British Heart Foundation	NCF	UK	7	✓	✗	✓	✗	Text and video	✓
Heart and Stroke Foundation	NCF	Canada	4	✓	✗	✗	✗	Text	✓
Heart Foundation	NCF	New Zealand	6	✓	✗	✗	✗	Text	✓
Cleveland Clinic	Hosp/res	USA	5	✓	✗	✓	✗	✗	✗
Edward-Elmhurst Health	Hosp/res	USA	1	✓	✗	✗	✗	✗	✗
Frankel Cardiovascular Centre	Hosp/res	USA	2	✓	✗	✗	✗	✗	✗
Intermountain Healthcare	Hosp/res	USA	9	✓	✓	✗	✗	✗	✗
Lehigh Valley Health Network	Hosp/res	USA	1	✓	✗	✗	✗	Text	✗
Massachusetts General Hospital	Hosp/res	USA	4	✓	✗	✓	✗	✗	✓
Mayo Clinic	Hosp/res	USA	8	✓	✓	✓	✗	✗	✓

Mount Sinai	Hosp/res	USA	1	✓	✗	✗	✗	Text	✗
Ottawa Heart Institute	Hosp/res	Canada	>10	✓	✓	✓	✓	✗	✓
Saint Luke's	Hosp/res	USA	6	✓	✓	✓	✗	Text and video	✓
Sparrow	Hosp/res	USA	3	✓	✓	✗	✗	✗	✗
St Vincents Heart Health	Hosp/res	Australia	2	✓	✓	✗	✗	✗	✓
Stanford Medicine	Hosp/res	USA	7	✓	✗	✗	✗	✗	✗
Sunnybrook Health Sciences Centre	Hosp/res	Canada	>10	✓	✓	✓	✗	Text and video	✓
Victor Chang Cardiac Research Institute	Hosp/res	Australia	9	✓	✗	✓	✗	Text and video	✓
Drugs.com	Med peer r/v	USA	4	✓	✓	✗	✗	Text	✗
eMedicineHealth	Med peer r/v	USA	1	✗	✗	✗	✗	✗	✗
GoodRx Health	Med peer r/v	USA	1	✗	✗	✗	✗	✗	✗
Her Heart	Med peer r/v	Australia	6	✓	✓	✗	✓	Text and video	✓
Medical News Today	Med peer r/v	USA/UK	3	✗	✗	✗	✗	✗	✗

MedicineNet	Med peer r/v	USA	1	✗	✗	✗	✗	✗	✗
MyHealth.Alberta.ca	Med peer r/v	Canada	1	✓	✓	✗	✗	✗	✗
VerywellHealth	Med peer r/v	USA	1	✗	✗	✗	✗	✗	✗
WebMD	Med peer r/v	USA	3	✓	✗	✗	✗	✗	✗
Beat SCAD	SA	UK	>10	✓	✓	✓	✓	Text and video	✓
FMD-Be	SA	Belgium	1	✓	✗	✗	✗	✗	✗
Heart Sisters	SA	Canada	>10	✓	✗	✓	✗	Text	✓
Irish Heart	SA	Ireland	7	✓	✓	✗	✓	✗	✓
SCAD Alliance	SA	USA	>10	✓	✓	✓	✓	✗	✓
SCAD BC	SA	Canada	>10	✓	✓	✓	✓	Text	✓
SCADresearch.com.au	SA	Australia	>10	✓	✓	✓	✗	Text and video	✓
SCADresearch.org	SA	USA	>10	✓	✓	✓	✓	Text and video	✓
SCAD Research Portal	SA	UK	>10	✓	✓	✓	✓	Text	✓

Chester County Hospital – Health e-Living Blog	Aff news	USA	1	✓	✗	✗	✗	✗	✗
Insight+	Aff news	Australia	1	✓	✓	✗	✗	✗	✗
Mayo Clinic News Network	Aff news	USA	7	✓	✗	✓	✗	Text	✗
Michigan Health	Aff news	USA	3	✓	✗	✗	✗	Text	✗
Penn Medicine News	Aff news	USA	1	✓	✗	✗	✗	✗	✗
UTSouthwestern Medical Centre	Aff news	USA	1	✓	✗	✗	✗	Text	✗
CardioSmart	Aff news	USA	3	✓	✗	✗	✗	✗	✗
Seconds Count	Aff news	USA	7	✓	✗	✗	✗	✗	✗
Dr. Axe	Non-med r/v	USA	1	✗	✗	✗	✗	✗	✗
globalnews.ca	Non-med r/v	Canada	1	✓	✗	✗	✗	✗	✗
PhysioLife	Non-med r/v	Australia	1	✗	✗	✗	✗	✗	✗
Self	Non-med r/v	USA/UK	1	✓	✗	✗	✗	✗	✗
Wikipedia	Non-med r/v	USA	1	✓	✓	✓	✗	✗	✗

Total	-	-	-	86%	38%	34%	16%	40% text 18% videos	38%

Legend: ✓ present on the webpage(s) with SCAD content, ✘ not present on the webpage(s) with SCAD content

Abbreviations: NCF; national cardiac foundations, Med peer r/v; medical peer reviewed health information, Hosp/res; hospital and research groups, SA; survivor affiliated, Aff news; affiliated medical news or blog, Non-med r/v; non-medically reviewed health information.

Table 1. Summary of attributes of n=50 included websites

3.1 Accuracy and scope of content

Accuracy and scope of websites content were rated “poor” (53.3%, SD 23.3) (Table 2). Content topics most often accurate and fully addressed were description of condition (90%) and symptoms (82%), whereas content least often addressed were on-going symptoms of chest pain (70% unaddressed) and family planning/pregnancy (62% unaddressed). Topics that were inaccurate most often were statin therapy use in SCAD in the absence of hypercholesterolemia (16%) and differentiation from atherosclerotic MI (8%) (Figure 2).

Website type	Content	Quality		Suitability	Readability	Interactivity
		QCSS	HRWEF			
	% score (SD)				Grade (SD)	% score (SD)
All websites (n=50)	53.3 (23.3)	59.1 (22.5)	83.1 (5.8)	54.9 (13.8)	11.6 (2.3)	67.6 (11.2)
National cardiac foundations (n=4)	58.9 (16.5)	40.4 (14.6)	83.6 (2.2)	52.1 (16.7)	11.3 (2.1)	63.3 (11.5)
Hospital and research groups (n=15)	40.3 (27.1)	49.0 (21.7)	81.0 (6.5)	51.3 (13.0)	11.1 (2.2)	66.3 (11.1)
Medically peer-reviewed health information (n=9)	63.9 (14.9)	76.9 (22.4)	87.2 (2.9)	61.4 (9.9)	12.3 (3.9)	67.0 (13.3)
Survivor affiliated (n=9)	65.2 (23.4)	54.7 (19.4)	85.4 (5.7)	62.9 (16.4)	11.7 (1.1)	73.3 (10.8)
Affiliated media, news and blogs (n=8)	52.4 (15.8)	71.4 (13.8)	81.6 (5.3)	49.2 (13.0)	11.7 (1.4)	68.6 (9.8)
Non-medically peer-reviewed health information (n=5)	51.2 (21.9)	64.6 (20.1)	79.9 (6.2)	50.9 (10.7)	11.8 (2.0)	64.7 (11.9)

Abbreviations: content, accuracy and scope of content; QCSS, Quality Component Scoring System; HRWEF, Health-related Website Evaluation Form.

Table 2. Mean percentage scores of appraisal tools for n=50 websites and by website type

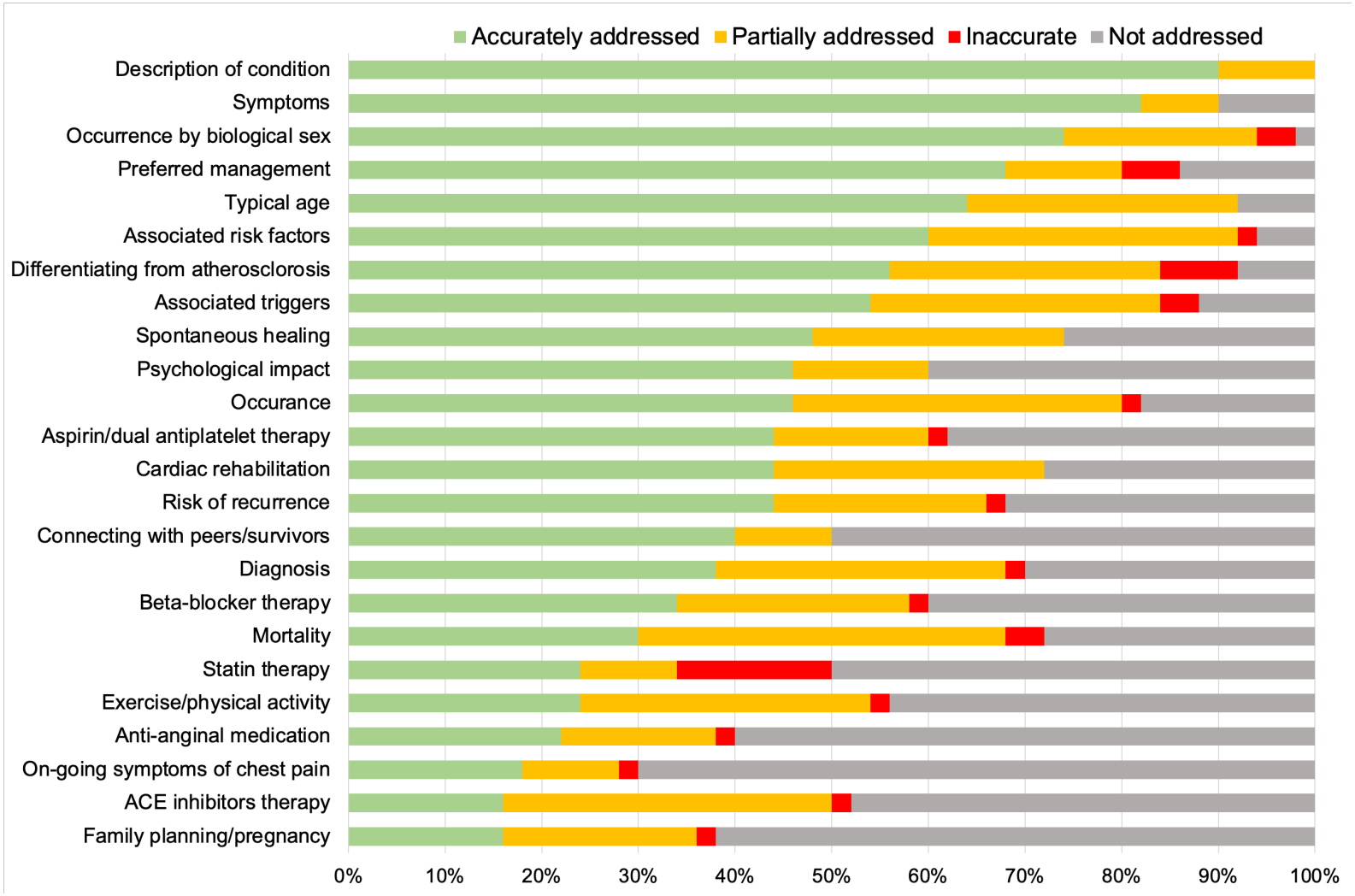

Figure 2: Coverage and accuracy of SCAD content across all websites (%) (print in colour)

3.2 Quality

Quality of websites were rated “poor” using the QCSS (59.1%, SD 22.5) but “adequate” using the HRWEF (83.1%, SD 5.8). Areas that performed well in the QCSS were websites clearly specifying ownership (94%) and purpose (92%). The QCSS areas that performed least well were due to authors lacking or not providing professional experience (64%), not providing any indication of authorship at all (50%) and not for providing attribution of information by referencing sources (40%) (Figure 3).

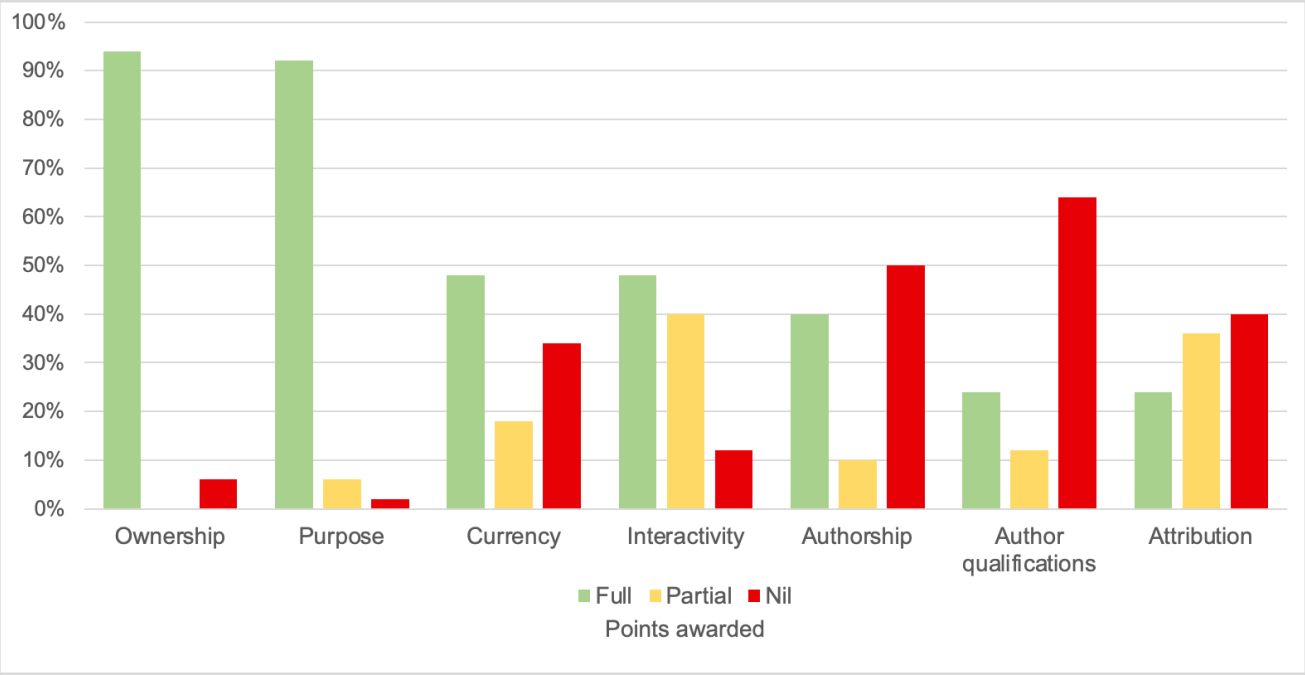

Figure 3. Quality Component Scoring System item scores (%)

Areas where websites performed well most often in the HRWEF were for content that was not obviously an infomercial/advertisement (94%), was unbiased (94%), was voiced at an intended audience (94%), and which had information that was quickly retrievable (96%). Areas where websites performed least well for HRWEF were for covering all aspects of SCAD (18%) and discussing all sides of controversial issues in SCAD (10%). (Table 3).

Content	Agree
Is not an “infomercial” (not an advertisement)	94%
No bias evident	94%
Purpose of site clearly stated	92%
External links given to adequately cover subject	52%
All aspects of the subject are adequately covered	18%
If opinionated, author discussed all sides of issue	10%
Accuracy	
The information is accurate	88%
Sources are clearly documented	50%
The website states that it adheres to HON code	12%
Author	
Site is sponsored by an institution/organisation	84%
Author/webmaster contract information given	74%
Authors/editors credentials are clearly stated	36%
Currency	
Date of publication clearly posted	66%
Revision date recent enough for current literature	50%
Audience	
The intended audience of the website is evident	94%
Level of detail appropriate for the audience	82%
Technical terms are appropriate for the audience	58%
Reading level is appropriate for the audience	30%
Navigation	
Information can be retrieved in a timely manner	96%
Search mechanism provided	92%
Internal links add to the usefulness of the site	86%
Site organised in logical manner for information	84%
Search mechanism necessary to make site useful	4%
Software needed to use the site is downloadable	0%
External links	
Links are operable	98%
Links are relevant and appropriate for this site	92%
Links connect to reliable sources and information	90%
Links are current enough to account for change	84%
Links appropriate (do not lead to technical sites)	66%
Organisations that should be represented have links	44%

Table 3. Health-related Website Evaluation Form content.

3.3 Suitability

Suitability of websites were rated “adequate” (54.9%, SD 13.8) Areas where websites performed well most often were for the use of easily readable typography in a sans-serif font (92%), conveying an evident purpose (80%), and layout of content in a consistent and uncluttered manner with adequate white space (70%) (Table 4). Conversely, the areas where websites performed least well were due to lacking sufficient illustrations (24%), a summary of content (16%) or lists and tables or charts (14%) to convey and summarise information. Approximately half the websites presented material that was culturally appropriate to the typical demographic and experiences of SCAD survivors (48%). Websites occasionally used images that were culturally positive for SCAD (28%), but the majority used neutral stock images, with some using exaggerated or irrelevant imagery.

	Superior	Adequate	Not suitable
Content			
Purpose is evident	80%	20%	---
Limited to essential information	70%	22%	8%
Summary and review	16%	24%	60%
Content is about behaviours	14%	50%	36%
Literacy demand			
` Headers or topics captions	68%	16%	16%
Context given first	36%	58%	6%
Writing style with active voice	6%	70%	24%
Vocabulary uses common words	2%	62%	36%
Reading grade level	---	4%	96%
Graphics			
Purposeful cover graphic*	30%	24%	46%
Relevance of illustration	24%	22%	54%
Appropriate type of illustration*	24%	28%	48%
Captions used*	14%	12%	74%
Lists, tables, graphs and charts*	2%	6%	92%
Layout and typography			
Typography	92%	8%	---
Layout factors	70%	26%	4%
Subheadings used	28%	52%	20%
Learning, stimulation and motivation			
Modelled and specific behaviour	32%	56%	12%
Self-efficacious tasks and behaviour	12%	84%	4%

Interaction with reader	---	32%	68%
Cultural appropriateness			
Cultural match	48%	46%	6%
Cultural images and examples	28%	66%	6%

*Scores will not add up to 100 (%) as some websites scored “not appliable”.

Table 4: Suitability Assessment of Material scores of websites.

3.4 Readability

The mean reading grade of all websites was 11.6 (SD 2.3), exceeded the recommending reading grade of 8 or below. In total, 96% of websites were written at reading grade 9 or higher, signifying high reading proficiency requirements to understand websites (Appendix B. Table B.1).

3.5 Interactivity

Interactivity of websites were rated “poor” (67.1%, SD11.5) Websites featured very little active control (2%), reflecting a largely passive website experience and a lack of interactive features. Websites processed input very quickly and responded swiftly to requests (98%) and provided instantaneous information from clicking on links (96%). Although approximately half the websites made it easy to offer contact (42%), websites scored poorly for facilitating two-way information (14%) and for being effective in gathering feedback (10%) (Table 5).

Interactivity tool items	**Agree**
Active control	
My actions decided the kind of experience I got	4%
I could choose freely what I wanted to see	2%
I had full control over what I could do	2%
I felt that I had a lot of control over my visiting experience	2%
Two-way communication	
Website gives the opportunity to talk back	44%
It is easy to offer feedback	42%
Website makes me feel like it wants to listen to its visitors	32%

Website encourages visitors to talk back	26%
Website facilitates two-way communication	14%
Website is effective in gathering visitors feedback	10%
Synchronicity	
Website processes input very quickly	98%
The website was very fast in responding to my requests	98%
Clicking on the links feels like instantaneous information	96%
Getting information is very fast	92%
I was able to obtain the information I want without delay	84%

Table 5. Interactive scores of websites.

3.6 Appraisal outcomes by website type and by individual website

Websites were classified into national cardiac foundations (n=4), hospital and research groups (n=15), medically peer-reviewed health information (n=9), survivor affiliated (n=9), affiliated media, news and blogs (n=8) and non-medically peer-reviewed health information (n=5). The top two best scoring website types across appraisal domains were survivor affiliated (content, quality - HRWEF, suitability and interactivity) and medically peer-reviewed health information websites (content, quality – both tools, and suitability) (Table 2).

4 DISCUSSION

The internet is an essential resource for SCAD survivors and contemporary research recommends that information should be widely available online [9]. In this review we have adapted a systematic approach to identify and appraise these online resources in the context of low availability of evidence. Website appraisals like this are important to highlight what is being done well, as well as to guide website developers in improving quality in online resources. This review identified that while SCAD information is widely available online, many of these resources provide limited and poor-quality information. For instance, many websites focused on a description of SCAD and its symptoms, and less on the impact,

implications or recovery of the condition, topics which survivors seek [5,6,9]. Most websites had clear ownership and purpose but lacked author credentials, indication of currency and referenced sources, fundamental given the context of rapidly evolving research in SCAD. This is problematic because it does not provide grounds for credible and reliable consensus, noted as the worst aspect of SCAD by survivors [6]. However, further work is needed to develop these appraisal tools given the length of time since development, an overlap of items, and shifting of emphasis on what is important in modern internet usage.

In uncommon health conditions, online information can promote informed decision making, empower consumers and caregivers to become experts in that condition, and help prepare for consultations [25]. This is particularly important in SCAD where healthcare professional knowledge is limited and more dependence is placed on internet resources by survivors and their families [5,6,9]. The same reliance is also observed in healthcare professionals themselves [26]. Even in professionals with experience treating SCAD, paucity of available evidence-based guidance results in feelings of anxiety and frustration in the healthcare provider as well as SCAD survivors [27]. Our review thus identifies a need for more accurate, focused and consistently updated content for SCAD online. Several websites fail to clearly distinguish SCAD from atherosclerotic MI, mirroring public perception and healthcare professional's lack of familiarity [5,6,7,8]. Knowledge deficits of SCAD, combined with often high levels of awareness of atherosclerotic ACS, leads to contradictory information and a lack of clarity [5,6]. Some websites perpetuate this confusion and need to reform content so that this distinction is clear and unambiguous [5,6].

Website information was not always tailored to SCAD or the typical demographic of survivors, for example on-going symptoms of chest pain being common, not necessarily indicating ischemia or recurrence, and occurring cyclically in many premenopausal survivors [1,21,22]. Images used on many SCAD websites were mismatched to the SCAD demographic, often including generic images of older women demonstrating Lavigne's sign.

This is important because isolation and loneliness is exacerbated because of SCAD survivors' younger age, emphasising the need for relevant imagery and peer experience [5]. In this regard, many websites (survivor affiliated in particular) often provided images and stories of survivors, giving a genuine representation of the SCAD demographic and their experiences. Survivor stories, particularly videos, are effective in portraying the emotional impact of unexpectedly diagnosed conditions [28] and are likely to be beneficial given the psychological impact reported in SCAD [2,6,8]. Survivor stories increased content scores because the survivors talked about topics and issues that impacted and mattered to them [2,5,6]. Many of these issues are discussed in the international position papers [21,22] and expert review [1] but were often missing from the content of many websites.

Advice for future pregnancies is an example of an infrequently addressed topic that is an important consideration in SCAD, because motherhood is fundamental to many peoples' identities [29]. To some extent, lack of content in areas like this occurs because there is limited evidence to provide specific advice [1]. For example, a 2020 study did not demonstrate evidence for SCAD recurrence in pregnancy when compared to non-pregnant women with a history of SCAD, although this requires cautious interpretation and guidance remains unchanged [30]. Similarly, avoidance of pregnancy following SCAD is commonly recommended, yet consensus position statements do not expressly prohibit pregnancy, instead providing strategies for risk management [1,21,22]. The desire to have children is an innate human value to many, so women may elect to proceed with pregnancies regardless of recommendations after SCAD [30]. In other cardiac conditions where pregnancy avoidance is recommended, some reported motherhood to be more important than the need for self-care [31]. Information often missing from websites was that careful consideration and counselling is paramount in post-SCAD pregnancy planning [23], and that on-going care needs to involve a multidisciplinary specialist team (including experienced cardiologist) [1,24,36].

Another frequently unaddressed area of importance for SCAD survivors is exercise and physical limitations [5,6]. This is likely because physical activity post-SCAD requires cautious establishing of individual limitations, preferably in the cardiac rehabilitation setting [32]. However, SCAD survivors and treating healthcare professionals report that the generic advice given in cardiac rehabilitation programs is too conservative and not considerate of pre-SCAD fitness levels [27]. Exercise dependence, routine, realise of endorphins, and social interaction are reported as important reasons for regular exercise [33]. Therefore, sudden cessation of exercise, as experienced often after SCAD, can negatively impact fatigue, self-esteem, depressive symptoms, anxiety, social interaction and quality of life [34]. Exercise is also fundamental to many peoples' identity [35], which pre and post SCAD are a challenge to reconcile [5], so lack of physical activity guidance is frustrating [6]. Physical restriction advice on lifting children, redistributing household responsibilities, and recommencing sexual activity are also frequently unaddressed [1,5,9]. Even so, many websites were useful in being able to at least provide some superficial advice and most importantly direction to other peers and professionals for support moving forward.

The findings of this review were consistent with other reviews of online information related to rare conditions that report a lack of credible, high-quality, demographically appropriate, easy to understand online information [36,37]. Only 2 websites were written at the recommended reading grade of level 8 or below. This is consistent with the wider cardiopulmonary literature where online patient information for left ventricular assist devices [38] and pulmonary arterial hypertension [39] are written to a reading level exceeding that of the average and recommended literacy level. However, as 4 in 10 adults struggle to understand public health information, health literacy levels need consideration [40]. Furthermore, issues with memory and thinking are common after ACS which act as a barrier to information uptake [41,42]. Artificial intelligence (AI) has demonstrated the capacity to accurately simplify patient education material to the recommended reading grade for medical information and may play an important role in future website development [43]. A variety of formats that address

different learning styles, cognition and literacy level are also needed [40]. Using videos and illustrations to convey information is an important strategy [44] and may be more informative, memorable, digestible or appealing than written text or verbal information from a healthcare professional [11]. Survivor stories were also important mechanisms to deliver information with the benefit of providing peer support elements to reduce feelings of isolation [2,5,6], because the listener can recall the person telling it, the factors attached, and may consider peer information more trustworthy and pertinent [28,45].

To our knowledge, this review is the first of its kind to appraise websites available to SCAD survivors, however some limitations should be noted. As time has passed since many of these tools were developed, certain items were not as relevant such as synchronicity, which is rarely an issue with modern internet speeds. Similarly, although remaining an item in the HRWEF, the Health On the Net (HON) Foundation has permanently discontinued the HON code as of December 2022, although many websites continue to display the HON code certification [38]. Important features such as survivor videos and text did not factor into suitability appraisal using the SAM, and the HRWEF and QCSS quality scores proved to be uncorrelated which may reflect the currency and applicability of the tools. Several instruments had overlapping items, reducing appraisal efficiency and requiring preparation of assessors to avoid ambiguity. For quality, suitability, readability and interactivity, future research could focus on developing one concise, accurate and comprehensive tool to appraise websites. Content appraisal was based on current international position statements and a recent literature review and will need to be updated regularly. Classification of website type was specific to this review and requires further development.

5 CONCLUSION

In SCAD where public information is lacking, it is reassuring to see there are numerous websites for SCAD survivors to access, all providing, at minimum, rudimentary information. Many of these websites are beneficial, containing useful knowledge for SCAD survivors,

valuable lived experiences and direction to peer-support. However, our review found that the content and quality of these websites are highly variable and often lacking, with high reading requirements which may limit accessibility of information. Areas that could be improved are inclusion of authorship qualifications and references, varied information formats for learning styles, suitable pictures and content, and inclusion of less addressed topics. Co-designing future resources with SCAD survivors is an important step that can help enhance accuracy, scope, quality and suitability of content.

Authors contributions

Joseph Weddell: conceptualization, screening, appraisal, writing, review and editing, Danielle Jawad: methodology, REDCap project set up and support, review and editing, Thomas Buckley: review and editing, supervision, Julie Redfern: review and editing, supervision, Zarin Mansur: screening, editing, Natalie Elliot: appraisal, editing, Coral Hanson: review and editing, Robyn Gallagher: review and editing, consensus, supervision.

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Summary Table

What was already known on the topic:

- SCAD survivors frequently turn rely on the internet for support and information after ACS admission.

What this study added to our knowledge:

- There are many available websites containing information for SCAD survivors to access. This review highlights areas that could be improved and provides considerations for clinicians when directing SCAD survivors to online support.

- The lived experience of SCAD survivors were featured on several websites, providing important and pertinent content in a way that circumvented issues with content, quality and readability.

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APPENDIX A. Search strategy.

N^{O}	Search term	Hits*
1	SCAD	21
2	Spontaneous Coronary Artery Dissection	11
3	Artery dissection	6
4	What is SCAD?	23
5	SCAD heart attack	22
6	SCAD heart	20
7	Life expectancy after SCAD	18
8	How rare is SCAD?	24
9	SCAD symptoms	23
10	SCAD causes	25
11	How is SCAD diagnosed?	21
12	Recurrence after SCAD	5
13	What exercise can be done after SCAD?	13
14	Physical activity after SCAD	16
15	What sport can I play after SCAD?	12
16	Recovery from SCAD	19
17	What to expect after a SCAD	24
18	Can you live a normal life with SCAD?	25
19	Medication after SCAD	19
20	When can I return to work after SCAD?	19
Total hits		366

* Including duplicates (removed post-search)

Appendix table A.1. Search terms and hits

APPENDIX B. Individual website scores.

Content	%	Quality QCSS	%	Quality HRWEF	%	Suitability	%	Readability grade		Interactivity	%
Beat SCAD	96.2	e-MedicineHealth		Sunnybrook Health Sciences Centre	94.8	SCADresearch (.com.au)	80.6	MyHealth. Alberta.ca	7	Beat SCAD	93.3
Irish Heart	93.8	Insight+	100	Beat SCAD		Irish Heart	78.6	UTSouthwestern Medical Centre	8	Insight+	
Wikipedia	89.6	VerywellHealth		Her Heart		SCADresearch (.org)		Sparrow		SCADresearch (.com.au)	86.7
Ottawa Heart Institute	87.5	Medical News Today	92.3	Irish Heart	91.4	Beat SCAD	77.5	Mount Sinai		Her Heart	83.3
SCADresearch (.com.au)	86.5	Sunnybrook Health Sciences Centre	84.6	SCADresearch (.com.au)		Sunnybrook Health Sciences Centre	75	British Heart Foundation		Edward-Elmhurst Health	
Sunnybrook Health Sciences Centre		Irish Heart		VerywellHealth				WebMD	9	Intermountain healthcare	80
								Saint Luke's		VerywellHealth	
								Cleveland Clinic		Sunnybrook Health Sciences Centre	

Note: minimum of top five highest scoring websites presented, some tools contain more when multiple websites achieved the same score.

Appendix table B.1. Top highest scoring websites per appraisal tool

Website name	Content	QCSS	HRWEF	SAM	Readability	Interactivity
	%	%	%	%	Grade	%
Beat SCAD	96.2	46.2	91.4	77.5	12	93.3
Irish Heart	93.8	84.6	91.4	78.6	11	70
Wikipedia	89.6	30.8	79.3	45.5	14	46.7
Ottawa Heart Institute	87.5	38.5	84.5	71.4	11	63.3
SCADresearch.com.au	86.5	53.9	91.4	80.6	14	86.7
Sunnybrook Health Sciences Centre	86.5	84.6	94.8	75	10	80
GoodRx Health	81.3	84.6	86.2	63.9	12	46.7
VerywellHealth	81.3	100	91.4	66.7	14	80
Her Heart	77.1	30.8	91.4	70	16	83.3
Drugs.com	75	61.5	82.7	69.1	10	63.3
Mayo Clinic	75	84.6	87.9	57.1	10	66.7
Heart and Stroke Foundation	73.1	30.8	81	57.5	14	66.7
Heart Foundation (New Zealand)	73.1	38.5	82.8	65	11	66.7
Sparrow	72.9	53.9	86.2	61.9	9	70
SCADresearch.org	71.2	38.5	87.9	78.6	11	60
SCAD Alliance	68.8	38.5	75.9	61.4	12	66.7
Mayo Clinic News Network	66.7	69.2	81	30.6	12	70
Seconds Count	64.6	61.5	82.8	44.4	10	66.7
eMedicineHealth	60.4	100	87.9	41.7	20	66.7
Insight+	58.3	100	84.5	66.7	12	86.7
Michigan Health	58.3	76.9	86.2	58.3	10	66.7
MyHealth.Alberta.ca	58.3	61.5	86.2	71.4	7	76.7
Penn Medicine News	54.2	61.5	71.2	36.1	12	60
Victor Chang Cardiac Research Institute	54.2	30.8	77.6	50	14	70
British Heart Foundation	47.9	30.8	84.5	58.3	9	73.3
Medical News Today	47.9	92.3	84.5	55.6	11	66.7
MedicineNet	47.9	76.9	87.9	61.8	12	73.3
SCAD Research Portal	47.9	53.9	79.3	56.8	12	70
Dr. Axe	45.8	76.9	79.3	64.3	14	66.7
FMD-Be	45.8	30.8	81	41.7	11	63.3
Self	45.8	76.9	86.2	38.1	11	76.7
WebMD	45.8	84.6	86.2	52.5	9	46.7

Chester County Hospital - Health e-Living Blog	43.8	69.2	86.2	58.3	14	73.3
American Heart Association	41.7	61.5	86.2	27.5	11	46.7
Frankel Cardiovascular Centre | University of Michigan Health	41.7	23.1	81	44.4	14	46.7
SCAD BC	40.4	61.5	86.2	40.9	12	73.3
PhysioLife	39.6	76.9	70.4	59.5	10	60
Saint Luke's	39.6	61.5	89.7	57.1	9	76.7
Cleveland Clinic	37.5	69.2	77.6	45	9	46.7
Heart Sisters	36.5	84.6	84.5	50	10	76.7
globalnews.ca	35.4	61.5	84.5	47.2	10	73.3
Mount Sinai	27.1	15.4	77.6	36.1	9	63.3
St Vincent's Heart Health	25	30.8	79.3	59.1	11	76.7
Edward-Elmhurst Health	22.9	61.5	84.5	36.1	12	80
Massachusetts General Hospital	22.9	23.1	70.7	41.7	14	53.3
CardioSmart	20.8	61.5	79.3	50	12	56.7
Intermountain Healthcare	20.8	46.2	77.6	59.5	15	80
Lehigh Valley Health Network	17.3	53.9	75.9	57.1	10	63.3
Stanford Medicine	12.5	38.5	72.4	38.9	13	66.7
UTSouthwestern Medical Centre	2.1	69.2	79.3	30.6	8	56.7

Appendix table B.2. Individual scores for all included websites (n=50).

APPENDIX C. Content accuracy and scope tool.

Occurrence As high as 4% ACS presentations, no longer considered rare [1], [2], [3].	
Fully	either: prevalence is estimated at up to 4% of all ACS (or) statement: SCAD (once considered rare) understood to be less rare.
Partially	SCAD is a rare cause of heart attack.
Incorrectly	SCAD is very rare (or) very common (or) prevalence is not known.
Occurrence by biological sex Women account for 87-95% presentations [1]. Approximately 90% SCAD are women [2]. May be cause of ACS in up to 35% of woman <50 years old [2], [3].	
Fully	woman account for 87-95% of SCAD (or) ~90% (or) SCAD overwhelmingly affects women and is infrequent in men (or) SCAD is estimated to account for up to 35% of ACS in women under 50 years old.
Partially	SCAD is more common in woman (statement that does not indicate how much more common).
Incorrectly	ambiguous or no clear reference to SCAD being more common in women.
Typical age SCAD "typical" demographic is middle-aged woman [1], mean age between 44-52 years [1], [2] or 45-53 years [3].	
Fully	mean age given (44-53 years old) (or) reference to middle-age presentations being typical of SCAD
Partially	SCAD is more common in younger people (or) SCAD affects people younger than the typical age of heart attacks.
Incorrectly	statement that SCAD can occur in any age with no explicit reference to typical younger age presentations.
Risk of recurrence 5-10% extension or recurrent SCAD [3], 4.7%-29.4% various time periods [2]. Review by Hayes et al gives the recurrence estimate at 10-30% [1].	
Fully	reoccurrence estimate is given as 10% - 30% (or) is given at ≥4.7%
Partially	variation of: recurrence can occur (no indication of how frequently).
Incorrectly	definitive statement: recurrence is rare or extremely common.
Description of condition	
Fully	notes a dissection leading to potential heart attack and gives description of what occurs.
Partially	SCAD is a type of heart attack caused by a dissection (no further details or lacking explanation).
Incorrectly	statement that SCAD is a type of heart attack statement with no mention of a dissection (or) no clear differentiation between atherosclerotic ACS and SCAD.
Spontaneous healing	
Fully	variation of: spontaneous "healing" of the dissection typically occurs in most stable presentation (+/-) within a few months. PCI and CABG are given as other treatment options. Optional statement that PCI or CABG (as appropriate) are typically reserved for unstable or high-risk presentations (will not lose or gain points).

Partially	statement makes reference that SCAD can heal by itself but wording such as “sometimes” and mention of PCI or CABG do not make it clear that this is preferable or common in stable presentations.
Incorrectly	descriptions of PCI (and/or CABG) as potential treatment options is given with no content that explains that SCAD is capable of self-healing and being managed conservatively in stable presentations.
Differentiating from atherosclerosis	
Fully	clearly differentiates between atherosclerosis and SCAD as diseases and causes of ACS.
Partially	variation of: SCAD is a different from "normal" (atherosclerotic) heart attacks (content vague, no further information for discernment).
Incorrectly	SCAD and atherosclerotic ACS described in such a way as being indistinguishable from one another (content is confusing or misleading), or not differentiated at all.
Mortality Mortality (long-term) is low following SCAD, although MACE significant [2], in hospital mortality low (although substantial if under/misdiagnosed) [3], substantial in pregnancy [1]. However, can present with ventricular arrythmias, cardiogenic shock, or sudden cardiac arrest.	
Fully	variation of: SCAD has a generally low mortality but in severe presentation can cause cardiogenic shock, cardiac arrest, ventricular arrythmias etc. Optional statement: major adverse cardiac events (MACE) significant in SCAD patients (will not lose or gain points).
Partially	vague statement suggesting: mortality is low (only) (or) SCAD can cause life threatening complications (only)
Incorrectly	definitive statement: SCAD always causes life threatening presentations (or) never causes life threatening complications. Likelihood of death is described as extremely high or low.
Symptoms Chest pain most frequent symptom [1], [2], [3]. Presenting symptoms similar to atherosclerotic ACS [1], a) Chest pain [1], [2], [3]. b) Pain in (or radiation to…) shoulder, arms, back or jaw [3]. c) Palpitations d) Fatigue [3]. e) Shortness of breath/dyspnea [3]. f) Diaphoresis [3]. g) Nausea/vomiting [3]. h) Dizziness/feeling faint/syncope [3]. i) Heartburn j) Headache [3]. k) “Atypical” i.e. burning, pleuritic, tearing, positional [2] l) Ventricular arrythmias, cardiogenic shock, sudden cardiac death [1], [2].	
Fully	at least three or more of the above, must include chest pain (+/-) reference to unpredictability or ambiguity of symptoms.

Partially	one or two of the above symptoms.
Incorrectly	definitive statement: one or more of the symptoms will *always* be present (or) symptoms are not known (or similar statement).

Associated risk factors

Although pathophysiology of SCAD remains unclear, certain predisposing conditions have been associated with precipitation of SCAD [2]. Some associations are less supported by data but have still been reported [3].

a) Migraines [1], [3].
b) Fibromuscular dysplasia and/or other arteriopathies, coronary tortuosity, ectasia [1], [2], [3].
c) Connective tissue disorders: e.g. Marfan's syndrome, Loeys-Dietz syndrome, Ehler Danlos syndrome type IV [1], [2], [3].
d) Genes [1].
e) Hypertension [1].
f) Pregnancy [1], [2], [3],
g) Multiparity [2].
h) Systemic inflammatory conditions: e.g. systemic lupus erythematosus, inflammatory bowel disease, celiac disease, hypothoroidism, Crohns disease, ulcerative colitis, polyarthritis nodosa [1], [2], [3].
i) Coronary artery spasm [1], [3].

Fully	three of more of the above, must include FMD (or CTD) and pregnancy. Optional statement: mechanisms are not well understood (or similar) (will not lose or gain points).
Partially	one or two of the above (+/- mechanism not understood statement).
Incorrectly	"the cause of SCAD is unknown" or similar, with no reference to associations.

Associated triggers

Although pathophysiology of SCAD remains unclear, certain predisposing conditions have been associated with precipitation of SCAD [2]. Some associations are less supported by data but have still been reported [3].

a) Emotional stress [1], [2], [3].
b) Extreme physical exertion (e.g. intense isometric or aerobic exercise) [1], [2], [3].
c) Medications/drugs (including illicit – cocaine and amphetamines) [1], [2], [3].
d) Sex hormones (including oral contraception, hormone replacement therapy, menstruation, polycystic ovarian syndrome, post-abortion, testosterone etc) [1], [2], [3].
e) Labour/delivery [1], [3].
f) Valsalva/straining: including sexual activity, vomiting/retching, coughing, bowel movements etc. [1], [2], [3].
g) Coronary spasm [2].

Fully	two or more of the triggers are mentioned and must at minimum include emotional stressors and physical exertion.
Partially	vague statement: a trigger causes SCAD but ambiguous in terms of what this/these may be

Incorrectly	variation of: the cause of SCAD is unknown (or similar) with no reference to associations or triggers.
Preferred management	
Fully	variation of: preferentially, SCAD is conservatively managed (or similar wording - managed with medications etc) wherever possible. PCI and CABG are also options if required. Optional statement: in high risk or unstable cases, urgent revascularisation with PCI or CABG is typically required (will not lose or gain points).
Partially	SCAD can be conservatively managed, can be treated with PCI or treated with CABG (not clearly stated or implied that conservative management is preferential when possible).
Incorrectly	SCAD is treated by PCI or CABG (conservative management is not mentioned or statement implies that PCI/CABG is always used routinely as first line treatment).
Diagnosis	
Fully	variation of: ECG, troponin (or blood test/cardiac enzyme etc) and coronary angiogram (or heart catheterisation etc) used for diagnosis. Must indicate or imply that coronary angiography is routinely performed. Optional: other diagnostic tests (IVUS, IC nitrates, CTCA, cMRI etc) can be mentioned (will not lose or gain points).
Partially	Non-specific statement (i.e. using the word - may): your cardiologist may perform a coronary angiogram/troponins/ECG etc.
Incorrectly	statements suggesting that SCAD is typically diagnosed without performing coronary angiography (or) coronary angiogram should be avoided on presentation due to risk of further dissection/extension (i.e. differences between angiogram and PCI not explicitly obvious).
Cardiac rehabilitation	
Fully	Variation of: cardiac rehabilitation is beneficial/recommended after SCAD. Optional: limitations (i.e. lack of SCAD specific programs) can also be noted (will not lose or gain points).
Partially	CR is briefly mentioned and is only partially encouraged (or) generic content given on cardiac rehabilitation in general (relevant to all causes of ACS)
Incorrectly	CR is explicitly not recommended or contraindicated for SCAD survivors.
Psychological impact	
Fully	emotional or psychosocial challenges after SCAD is highlighted as common (or) emotional support after SCAD is offered (or) there is content that explores the emotional impact of SCAD (including with examples/lived experiences in survivor stories)
Partially	emotional ramifications of SCAD touched on non-specifically or described in such a way that the reader could interpret as rare or uncommon (or) emotional impact of a heart attack (non-specific to SCAD) is included only.
Incorrectly	misleading or contradictory statements to the above points.
Connecting with peers/survivors	
Fully	readers are made aware that online support groups for SCAD exist (or) engagement with an SCAD online support group is encouraged. Must include either a link to a survivor group(s), or the name of the group(s). (Can achieve

	this score if information contained in lived experience stories). (Will not lose points if generic cardiac support groups included in addition among resources).
Partially	readers are made aware that support groups exist but methods of engaging with support groups (name of group or link) are not given. The context or benefit of why peer support groups are important may be lacking.
Incorrectly	ONLY providing links for non-SCAD specific cardiac support groups (e.g. support groups mainly for atherosclerotic ACS).
Family planning/pregnancy	
Fully	pregnancy is identified as high risk but there is no statement definitively stating as a blanket rule that survivors of SCAD should not get pregnant. Variation of: cautious consideration and counselling is highly recommended if planning for pregnancies after SCAD, [2] and it is important on-going care involves a specialist team including cardiologist experienced in SCAD [1], [3].
Partially	variation of: pregnancy is high risk and not fully understood. (No recommendation or guidance is given for future pregnancies) (or) variation of: if you have had SCAD you may be advised not to get pregnant (non-definitive statement)
Incorrectly	blanket statement: variation of: SCAD survivors should not get pregnant (or) pregnancy after SCAD is an individual choice (with no reference to the high risk of pregnancy or the need for on-going expert care).
Exercise/physical activity As physical activity has been correlated to SCAD onset in up to 32% of presentations [1], concerns about exercise following SCAD exist but there is a lack evidence for benefit or harm [3]. Following SCAD, prolonged high-intensity exercise, contact sports, exercising to exhaustion, elite/competitive sport, endurance training, commencing vigorous physical activity without warm up, physical activity in temperature extremities and Valsalva are recommended to generally be avoided [1], [3]. At the time of publication, the European Society of Cardiology SCAD study group position paper (2018) notes that no study had demonstrated an association between recurrent SCAD and physical activity, but to advise against isometric or extreme exercise [2]. A “full return” to “full activity” is suggested as “reasonable” given the benefits on physical activity [2].	
Fully	variation of: generally, exercise after SCAD is ok (and/or important) but first needs to be discussed with a SCAD specialist or limits need to be established during cardiac rehabilitation. Certain exercises should be avoided (example from list above) including those involving straining or Valsalva.
Partially	variation of: exercise is ok but certain exercises should be avoided (does not name examples, ambiguous, no direction or advice).
Incorrectly	blanket statement: all exercise is ok (or) all exercise should be avoided. (exercise completely restricted or not restricted at all).
On-going symptoms of chest pain Chest pain following SCAD is common: although early reinfarction occurs in 6.1-17.5%, most post-SCAD chest pain is often non-ischemic [1]. Although often associated with hospital admission, chest pain does not necessarily always indicate recurrence, may occur cyclically/premenstrually, or relate to dissection rather than ischemia [2] [3].	
Fully	variation of a statement that indicates that chest pain recurrence is common after SCAD. Optional statement: although often associated with hospital admission, chest pain does not necessarily always indicate recurrence, may

	occur cyclically/premenstrually, or relate to dissection rather than ischemia [2] [3] (will not lose or gain points).
Partially	chest pain after SCAD can be experienced (vague statement that does not indicate that chest pain recurrence is common)
Incorrectly	variation of a statement suggesting that chest pain after SCAD is not commonly experienced.
Beta-blocker therapy There are no randomized controlled trials to guide pharmacological management specific to SCAD [1]. Generally recommended in keeping with current guidelines for left ventricular systolic function [1], [2], [3]. The role of Beta-blockers are more contentious in the management of SCAD without LV systolic function impairment [2]. However, hypertension is associated with recurrent SCAD and requires treatment [1]. Recommendations are mostly based on registry data, clinical experience, empirical evidence (anti-anginals), and extrapolated recommendations for atherosclerotic ACS [1], [2]. One retrospective study found a reduction in SCAD recurrence risk using beta-blockers but this has not been confirmed using a randomized control trail [1], [2].	
Fully	Beta-blockers are named as an example of drug consideration/option for blood pressure control.
Partially	variation of: drugs to control blood pressure may be prescribed by your doctor (no specific drug class named - score both beta-blockers + ACE inhibitors as partially correct)
Incorrectly	variation of a statement implying that beta-blockers are always used for treatment of SCAD, regardless of the clinical context.
Aspirin/dual anti-platelet therapy There are a lack of clinical trials and consensus on the use of DAPT post SCAD [1], [2], [3]. Patients who undergo stenting after SCAD should receive DAPT in line with current ACS guidelines [1], [2], [3]. Some recommend following the ACS therapy guidelines (1-year DAPT then lifelong Aspirin) but others recommend a more conservative approach including monotherapy (Aspirin only) or no early or prolonged DAPT [1], [2]. Another balanced recommendation is 2-4 weeks DAPT and then low dose Aspirin for 3-12 months in consideration of SCAD healing time [1].	
Fully	Aspirin is explicitly named as a medication that may be used in SCAD management. If Clopidogrel is mentioned (or dual anti-platelet therapy) it is noted that this is recommended for use in the context of post-PCI (or) in conservatively managed SCAD (no PCI) there is a lack of evidence and consensus on the use of DAPT.
Partially	Aspirin (not mentioned by name) is referred to in laymen's terms as a "blood thinner/anti-platelet" (or) (when mentioned DAPT) variation of: your cardiologist may consider the use of DAPT/Aspirin and Clopidogrel (or similar) (no specific reference to only using DAPT following PCI)
Incorrectly	statement implying that DAPT is given as standard treatment for SCAD (in the absence of PCI).
ACE inhibitors therapy There are no randomized controlled trials to guide pharmacological management specific to SCAD [1]. Angiotensin-converting enzyme inhibitors should be used to treat left ventricular dysfunction when it occurs after SCAD in accordance with heart failure/post-MI guidelines [1],	

[2]. ACE inhibitors can also be used as an option for concomitant hypertension, but female patients of reproductive age should be made aware of teratogenicity risks [2].	
Fully	ACE inhibitors are named as an example of drug consideration/option for blood pressure control. Optional statement: explaining the use of ACE inhibitors in concomitant hypertension treatment or LV systolic dysfunction (or) warning regarding the use of ACE inhibitors in pregnant or breast-feeding women (teratogenicity warning) (will not lose or gain points).
Partially	variation of: drugs to control blood pressure may be prescribed by your doctor (no specific drug class named - score both beta-blockers + ACE inhibitors as partially correct)
Incorrectly	statement implying that ACE inhibitors are first line treatment for blood pressure control in SCAD (or) that ACE inhibitors should never be used in SCAD.
Not addressed	no mention of blood pressure control (or) if beta-blockers only are mentioned.
Statin therapy	
Fully	variations of a statement that explains in the absence of atherosclerotic disease or hypercholesterolemia, statins do not have a routine role in SCAD treatment and are generally not recommended to be prescribed (or) variation of: SCAD presentations with high cholesterol may be prescribed a statin [1], [2], [3].
Partially	variation of: your doctor may decide to prescribe statins (no explanation that prescription is generally only indicated in SCAD presentations with hypercholesterolemia/atherosclerotic risk factors)
Incorrectly	statements that imply that statins should always be prescribed after SCAD or that statins are routine and effective treatment for SCAD.
Anti-anginal medication There are no randomized controlled trials to guide pharmacological management specific to SCAD [1]. Antianginal therapy often used for the management of post-SCAD chest pain, however recommendation based off empirical evidence [2] and currently does not have a routine role for hospitalisation or long-term treatment [3]. Symptomatic relief may be achieved using nitrates, calcium channel blockers or ranolazine [3]. Antianginal therapy has a variable response, has limited evidence, and may a limited option due to considerations of hypotension and migraines [1].	
Fully	specific mention of nitrates, calcium channel blockers, ranolazine or antianginals to treat symptomatic chest pain. Optional statement: use is limited by inadvertent hypertension and headaches and/or a lack of evidence.
Partially	medication might be prescribed by your physician to control chest pain
Incorrectly	statement implying anti-anginal medication is highly effective for symptomatic chest pain relief following SCAD (or) should be routinely prescribed.

All items guided by the 2020 Journal of the American College of Cardiology state-of-the-art review on SCAD by Hayes et al [1], the 2018 European Society of Cardiology SCAD study group position paper by Adlam et al [2], and the 2018 American Heart Association Scientific Statement on SCAD by Hayes et al [3].

References (Appendix C)

1. Hayes SN, Tweet MS, Adlam D, et al. Spontaneous Coronary Artery Dissection: JACC State-of-the-Art Review. *J Am Coll Cardiol* 2020; 76: 961–984. doi: 10.1016/j.jacc.2020.05.084
2. Adlam D, Alfonso F, Maas A, et al. European Society of Cardiology, acute cardiovascular care association, SCAD study group: a position paper on spontaneous coronary artery dissection. *Eur Heart J* 2018; 39: 3353–3368. doi: 10.1093/eurheartj/ehy080
3. Hayes SN, Kim ESH, Saw J, et al. Spontaneous Coronary Artery Dissection: Current State of the Science: A Scientific Statement From the American Heart Association. *Circulation* 2018; 137: e523–e557. doi: 10.1161/CIR.0000000000000564