

1 **The content and quality of information about hyperacusis presented online**

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20

21 **Abstract:**

22 **Purpose:** Hyperacusis is a disorder characterised by reduced sound tolerance leading to ear
23 pain, emotional distress, and reduced quality of life. Many people with hyperacusis turn to the
24 internet for information and support from online communities to discuss their condition. The
25 purpose of this study was to assess the content and quality of hyperacusis information presented
26 online.

27 **Methods:** The three most used internet search engines were used to identify relevant websites
28 using the single search term 'hyperacusis'. Fifteen websites were selected for analysis. Details
29 of the purpose, audience, and content of each website were extracted using a bespoke data
30 extraction form. The quality of the information on each website was rated using the validated
31 DISCERN questionnaire.

32 **Results:** There was a wide disparity in the quality and content of hyperacusis information
33 across websites. The website Hyperacusis Focus achieved the highest overall DISCERN score.
34 Hyperacusis Focus and UK National Health Service websites were the most comprehensive
35 online resources for health care professionals and patients respectively. Wikipedia was judged
36 useful for both healthcare professionals and patients. In general hyperacusis-related
37 information was accurate. However, no single website provided a complete account of
38 hyperacusis, and some were judged to be selective in the information they provided.

39 **Conclusions:** The internet provides an important source of information for those who have
40 hyperacusis and those who care for them. Revisions to the websites reviewed here are needed
41 for each to provide a complete account of hyperacusis.

42

43 **Introduction**

44 Hyperacusis describes an increased sensitivity to everyday environmental sounds. The
45 condition has also been defined on the basis of decreased or even collapsed tolerance to sound
46 (Fackrell et al., 2017). Sounds that are usually innocuous, such as the rustling of a newspaper
47 or the running of tap water, can be perceived as particularly loud and sometimes painful by
48 sufferers (Tyler et al., 2014). For some people hyperacusis is only a minor disturbance while
49 for others can have a serious detrimental effect on everyday life (Baguley and Hoare, 2018).
50 Physical symptoms of the disorder are often described by its sufferers as ‘discomfort’ or ‘pain’
51 in the ear (Fackrell et al., 2017). In more severe cases, hyperacusis has a deep psychological
52 component and mental-wellbeing can deteriorate. Sound can be ‘disabling’ to an individual,
53 resulting in anxiety or stress when in public places where sound is heightened and
54 uncontrollable. At worst, patients avoid social gatherings altogether leading to social isolation.
55 Hyperacusis is a presenting symptom in numerous conditions such as Williams Syndrome and
56 Multiple Sclerosis (Klein et al., 1990, Weber et al., 2002). In general population the reported
57 prevalence of hyperacusis across different studies varies from 1.9% to 17.1 % (Andersson et
58 al., 2002, Fabijanska et al., 1999, Baguley 2018). One factor contributing to such variability
59 is the lack of an agreed definition of hyperacusis (Fackrell et al., 2017). There is no universally
60 accepted neurophysiological mechanism to explain the symptoms of hyperacusis and many
61 hypotheses have been proposed. One proposed mechanism involves enhanced central gain,
62 whereby to compensate for a reduced sensory input from the auditory periphery to the central
63 auditory system, neural activity in the central auditory system is increased. In theory, this
64 would lower a person’s threshold for noise tolerance (Auerbach et al., 2014).
65 Currently there is no cure available for hyperacusis but a number of management strategies are
66 offered (Fackrell et al., 2017, Pienkowski et al., 2014). For some hyperacusis patients, it is
67 expected that education and reassurance is sufficient for successful management (Aazh et al.,

68 2016). Other treatments that have been used or trialled for hyperacusis include Tinnitus-
69 Retraining Therapy (TRT) (Bright Audiology, 2017), and Cognitive Behavioural Therapy
70 (Aazh and Moore, 2018). There are no clinical practice guidelines on the management of
71 hyperacusis, meaning there is no framework for healthcare professionals. By its nature, many
72 people with hyperacusis avoid noisy situations such as healthcare settings, and instead turn to
73 the internet as a source of information and support from online groups and forums. However,
74 the content or reliability of information on prominent websites has yet to be formally evaluated.

75

76 The purpose of this study was to (1) identify the most commonly accessed hyperacusis-related
77 information online, (2) assess the reliability and quality of that information using the DISCERN
78 tool, and (3) evaluate the hyperacusis-related content using summative analysis.

79

80 **Method**

81 **Selection of websites for evaluation**

82 Websites chosen for evaluation were identified using search engines that can be easily accessed
83 by patients. Google, Bing, and Yahoo made up 97.5% of the search engine market in July 2018
84 (Statista, 2018). Therefore, these were used to perform the searches using the single term
85 'hyperacusis'.

86 It has been determined that 70% of web page clicks occurred on the first page of a Google
87 search results page, with 67% of these clicks within the top five results. The second and third
88 pages of a Google search account for 5.6% of clicks (Leverage Marketing, 2018). Therefore,
89 the first two pages represented the most commonly accessed websites. On this basis, only the
90 results on the first two pages of each search were considered for inclusion. The search resulted
91 in a list of 85 websites. Multiple duplicate were excluded or combined (n = 56). Advertisements
92 (n = 4), results that were direct links to individual scientific publications (n = 8), and results

93 that did not contain any hyperacusis-related information (n=2), were also excluded (Figure 1).

94 The remaining 15 websites were screened and were included when the following criteria were

95 met:

96 1) Website provided information related to the symptoms, causes, diagnosis and/or
97 management of hyperacusis.

98 2) Website provided direct access to the above information rather than access through a
99 list of links or a database of literature on the subject.

100 3) Primary purpose was not commercial (i.e. to sell a product).

101

102 *****ADD FIGURE 1 ABOUT HERE

103

104 **Data Extraction**

105 An electronic data extraction form was developed to systematically extract data from each
106 website. The development of the form was guided by Petch (2004). A draft data extraction

107 form was piloted using the NHS website on noise sensitivity (NHS, 2016) by two authors. The
108 form was then revised before formal data extraction commenced (Supplemental Information

109 1).

110 ***Website details***

111 General information about each website was extracted including: i) Website name; ii) URL
112 address; iii) Producer; iv) Purpose; v) Intended audience; and vi) Accreditation and contact to

113 the producer. In addition, features related to functionality (i.e. number of separate webpages,
114 search function, top three search results for the key word 'hyperacusis', online glossary, errors,

115 mobile functionality, and other) and usability (i.e. text links, use of graphics, colour and
116 background, audio and video clips, drop-down menus, URLs to other pages, adverts on the

117 websites, quality of English) were also extracted. Ease of navigation was rated on a 10-point

118 scale (where a score of 1 = website is broken, all error pages, and a score of 10 = every page
119 works, very intuitive, easy to use).

120 *Content analysis*

121 Content analysis of the websites was informed by a comprehensive scoping review on
122 hyperacusis related literature (Fackrell et al., 2017). Based on the review a list of keys word
123 and phrases was populated related to: i) signs and symptoms; ii) onset/causes; iii) investigations
124 by a healthcare professional; iv) associated conditions; and v) treatments and the context in
125 which they were used and data extracted from all included websites. An option to extract
126 additional terms ('Other') that were not covered by the pre-defined key words and phrases was
127 also included. In addition, data regarding the use of supporting research evidence related to the
128 content were recorded. Data was independently extracted by two authors who then met to
129 discuss the data extraction and agree a final dataset.

130

131 **The DISCERN Questionnaire**

132 The quality of general and health-related information provided on each website was evaluated
133 using the DISCERN questionnaire (Charnock et al., 1999). The DISCERN questionnaire was
134 developed to enable patients and information providers to judge the quality of written
135 information about the treatment choices available. It was developed and refined over time by
136 an expert panel who represented expertise in consumer health information. The questionnaire
137 was tested by a national sample of healthcare providers on a range of consumer health
138 information on treatment choices. The Final iteration of the DISCERN questionnaire was
139 deemed to be a reliable and valid instrument for judging the quality of written consumer health
140 information and can be applied by experienced users and providers of health information to
141 discriminate between publications of high and low quality.

142 The DISCERN is separated into three sections. Section 1 (questions 1-8) addresses the general
143 reliability and trustworthiness of the website. For example, whether there is evidence of bias
144 or the information is based on out of date evidence. Section 2 (questions 9-15) focuses on
145 quality and detail of information related to treatment choices. Section 3 (question 16) asks for
146 single overall quality rating of the resource based on all 15 preceding questions. Questions are
147 rated on a 5-point Likert scale, where a score of '1' indicates that the website has not met the
148 particular criterion and a score of '5' indicates that the website met that criterion in full.
149 Intermediate ratings between 2 and 4 indicate that the website met that criterion to some degree.
150 The ratings for individual questions contribute to a combined score. The DISCERN handbook
151 provided clear guidance on how to rate each question (Charnock et al., 1999). For example for
152 question 1 'Are the aims clear? The handbook states that a good quality publication will have
153 clear aims such as what it is about, what it covers and who the publication is aimed at. If the
154 aims are clearly stated at the beginning it will indicate what aspects of the condition and its
155 treatment will be addressed and help the consumer to judge whether the publication will contain
156 the information required. It is important for the consumer to know what information may not
157 be included as this information may be required from another source before an informed
158 decision regarding treatment can be made. The handbook asks the rater to examine the opening
159 paragraphs for a description of the content, scope and the target audience of the publication
160 and to merit a good rating the aims should be clearly outlined in the text at the beginning. If
161 the publication meets this criteria in full it is awarded a score of 5, if the publication does not
162 include any indication of its aims it is awarded a score of 1. The scores of 2 to 4 are awarded
163 if the publication has aims but they are deemed to be unclear or incomplete, the awarding of a
164 partially met score of between 2 and 4 can be subjective which is why more than one rater is
165 used.

166 Each website was independently rated by two authors who then met to discuss their scores,
167 review any disagreements, and agree a final scores on each question. Inter-rater reliability was
168 calculated using Kappa statistics. Kappa was interpreted as: 0.01-0.20 = slight agreement, 0.21-
169 0.40 = fair agreement, 0.41-0.60 = moderate agreement, 0.61-0.80 = substantial agreement, and
170 0.81-1.00 = almost perfect agreement.

171

172 **Results**

173 **Website details**

174 Fifteen websites met the criteria for inclusion in this study (Table 1.). For detailed information
175 see Supplementary Table 1.

176

177 -----**INSERT Table 1 about here**-----

178 ***Producer***

179 Seven websites were commercially produced, six were not-for-profit, and two were
180 government produced. Of the seven commercial websites, four (Amplifon, Hear.com,
181 Hyperacusic.net, and Hidden Hearing) were involved in the sale of hearing aids or hyperacusic-
182 related products, and two (Dizziness & Balance (D&B), and University of California San
183 Francisco (UCSF)) were for medical practices. The other commercial site, WebMD, did not
184 charge consumers but generated income via corporate sponsorships and advertisements. Both
185 government-produced sites were directly linked to the National Health Service (NHS), and the
186 six remaining sites were not-for-profit charities or information providers.

187 ***Intended audience***

188 Many of the websites did not specify a target audience, so this was assumed based on the
189 content and complexity of that content. Ten were judged to primarily target people with
190 hyperacusic or other auditory complaints. Only three (American Speech-Language-Hearing

191 Association (ASHA), D&B, Hyperacusis Focus) targeted professionals (doctors, audiologists,
192 academic researchers). The remaining two websites (Wikipedia, NHS) were judged to be
193 suitable for both people with hyperacusis and for professionals.

194 ***Purpose***

195 Only two websites (Hyperacusis Focus, Hyperacusis.net) provided explicit details of their
196 purpose, and they were the only sites to focus solely on hyperacusis. A purpose of some
197 websites could be implied from ‘About us’ pages. For example, Amplifon stated that they were
198 a ‘Global Leader in Hearing Healthcare with the aim of improving Hearing Health’.

199 ***Accreditation***

200 Less than half of the websites (7 from 15) featured any evidence of accreditation. Action on
201 Hearing Loss (AOHL) featured accreditation from ‘The Information Standard’, an NHS
202 commissioned certificate that marks website of high quality and best practice (NHS). WebMD
203 had multiple award logos on its website, one of which was as a URAC Accredited Health
204 Website, designed to recognize quality in healthcare-related services (URAC).

205 ***Contact information***

206 All websites contained contact information for various purposes, from general enquiries to
207 freedom of information requests. Many commercial websites gave contact details for booking
208 a hearing test appointment. Website organisations were contactable via phone, live chat, email,
209 fax, and/or postal letter.

210

211 **Functionality**

212 ***Number of separate webpages***

213 Thirteen websites had only one page relevant to hyperacusis. Both Hyperacusis.net and
214 Hyperacusis Focus had over 20 pages of hyperacusis-related information.

215 ***Search Function***

216 Twelve websites had a search function. For the three websites that did not (Amplifon,
217 Hear.com, Vestibular.org), all raters judged hyperacusis information difficult to locate.

218 ***Glossary***

219 Five websites (AOHL, ASHA, D&B, British Tinnitus Association (BTA) and Hidden Hearing)
220 had a glossary, but none were very extensive. The UCSF and WebMD websites contained
221 online dictionaries. The remaining seven websites did not provide a glossary.

222 ***Errors***

223 On the dates the websites were accessed no major errors were noted with the exception of
224 Hear.com where there was a 404 error on the homepage.

225 ***Mobile Functionality***

226 All websites could be accessed via a mobile phone as they had a mobile site, most of the
227 websites adapted for the smaller screen size, with the exception of D&B, and UCSF where the
228 homepage was mobile friendly but the hyperacusis pages were not.

229

230 ***Usability***

231 ***Text Links***

232 Only two websites (Amplifon, South Tees NHS) did not make use of text links to navigate to
233 other parts of their sites. The remaining sites used links to further information such as
234 diagnostic tests (D&B), further treatments such as Cognitive behavioural Therapy (NHS), and
235 information about diseases and drugs which may cause hyperacusis (WebMD)

236 ***Use of graphics, colour and background***

237 Only one website (Hyperacusis Focus) was judged to make good use of images, graphs and
238 flow-charts.

239 ***Audio and video clips***

240 One website (Hyperacusis Focus) made use of audio clips (white noise, pink noise, softened
241 pink noise and brown noise) and linked to video clips on YouTube. Vestibular.org had an
242 option to access the stories of patients with hyperacusis. When this option was selected it took
243 the user to a website (The Mighty) which hosted videos.

244 *Drop-down menus*

245 Only three of the included websites used drop-down menus.

246

247 *Links to other pages*

248 Eight of the sites provided links to further information or support on different websites The
249 BTA and Hyperacusis.net were the most popular websites to be linked to as further sources of
250 information by other websites. Other links included to a donations page for hyperacusis
251 research donations (Hyperacusis Focus)

252 *Adverts on the websites*

253 The majority of the websites did not use advertisements. Notable were Amplifon who
254 advertised their services, Hear.com who displayed adverts to trials and products, and
255 Vestibular.org which included an advertisement for a herbal compound (Inner Ear-Balance
256 formula) which was clearly marked as a paid advertisement.

257 *Standard of English use*

258 For all websites the quality of the English was judged to be good, and appropriate for their
259 target audience. For ASHA, D&B, Hyperacusis Focus, and vestibular.org, the level of English
260 was judged to be good but more targeted to a scientific audience.

261

262 **Ease of navigation**

263 Amplifon, NHS, Wikipedia scored maximally 10 out of 10 for ease of navigation, whereas
264 Vestibular and Hear.com were rated lowest (7 and 6 out of 10 respectively).

265

266 **Content of websites**

267 Signs and symptoms included in our pre-defined list of key words and phrases were generally
268 well reported (Supplementary Table 2), however the variability was observed with 6 websites
269 reporting majority of the symptoms (10 or more) and remainder reporting fewer key terms and
270 phrases. Websites reported between 0 and 7 of the onset/causes included in our pre-defined list
271 of key words and phrases (Supplementary Table 3). All websites contained information about
272 signposting to services such as general practitioner, ear nose and throat, audiologist, or other.
273 Other clinical disciplines such as clinical psychologists or speech and language services were
274 also mentioned. Reporting of associated conditions was sporadic with seven websites reporting
275 less than half of the twelve associated conditions included in our pre-defined list of key words
276 and phrases. Additional conditions not identified prior for content analysis included
277 autoimmune disorders, metabolic disorders, and vitamin deficiency (Supplementary Table 4).
278 The hyperacusis treatments were sparsely reported across the websites. Only one website
279 (Hyperacusis Focus) reported more than half of the treatments according to our pre-defined list
280 of key words and phrases. The treatments mentioned included sound devices, Tinnitus
281 Retraining Therapy (TRT), Cognitive Behavioural Therapy (CBT), alternative therapies
282 including acupuncture, hypnosis, and relaxation, and anti-inflammatory medicines
283 (Supplementary Table 5). Contra-indications for the use of ear plugs were also discussed.

284 **Quality assessment: The DISCERN questionnaire**

285 The DISCERN Questionnaire scores (Section 1, Section 2 and overall score) are given in Table
286 2.

287

288

-----INSERT Table 2 about here-----

289 **Agreement**

290 There was perfect agreement ($\kappa = +1$) between raters on the scores for Hear.com. Almost
291 perfect agreement was reached between raters for Wikipedia, substantial agreement was
292 reached for Amplifon, AOHL, South Tees Health, and Vestibular.org, moderate agreement for
293 ASHA, Hidden Hearing, and UCSF and fair agreement for the BTA. For four websites, there
294 was only slight agreement between raters (Hyperacusis Focus, Hyperacusis.net, NHS and
295 WebMD). Ratings of one website (Dizziness and Balance) had a Kappa score less than 0,
296 indicating a lower level of agreement than one given by chance.

297 Maybe suppl table here

298

299 ***DISCERN SECTION 1: Reliability of the information***

300 Averaged scores for Section 1 questions (out of 5) for the 15 websites ranged from 1.2 (South
301 Tees NHS) to 4.6 (Hyperacusis Focus). The highest scoring website, Hyperacusis Focus, had
302 ‘minimal shortcomings’ according to the DISCERN handbook. For this website, all the
303 information was clearly referenced and it was judged by all raters to be free from bias. Scores
304 on Questions 4 and 5 relating to the sources of information used and the dating of the content
305 were generally scored low; five websites scored over 3 out of 5 (AOHL, ASHA, D&B, NHS
306 and Wikipedia) which suggests that they partially met the quality criterion. The remaining
307 websites scored less than 3 indicating that the websites had potentially serious shortcomings.

308

309 ***DISCERN SECTION2: Quality of the information on treatment choices***

310 The highest score on Section 2 was achieved by Hyperacusis Focus (3.5 out of 5), while the
311 lowest scores were achieved by South Tees NHS and Vestibular.org (1.2 out of 5). All the
312 websites, with the exception of Hyperacusis Focus, scored less than 3 which would indicate
313 potential shortcomings in the quality of information on treatment choices.

314

315 ***DISCERN SECTON 3: Overall quality***

316 Only one website (Hyperacusis Focus) scored the maximum score of 5 for overall quality. Five
317 websites (AOHL, ASHA, BTA, Hear.com, NHS) scored over 3. Nine websites scored less than
318 3 indicating serious shortcomings in the quality of their websites, for example providing limited
319 information on the treatment options, lack of additional sources of information, not reporting
320 treatment uncertainty, or the risks of each treatment.

321

322 **Discussion**

323 This study is the first to assess the content and quality of hyperacusis-related information on
324 websites using content analysis and the DISCERN questionnaire. The main finding from the
325 study is that no single website provides comprehensive information on hyperacusis.

326 Signs and symptoms, of hyperacusis were generally well reported by most websites, however
327 reporting of the onset and causes was mixed with little consistency. Some websites only
328 reported one or two predefined onset and causes, whilst others reported a range of possible
329 onsets or causes. Over twelve conditions were reported as being associated with the onset and
330 cause of hyperacusis. All websites reported associated conditions of hyperacusis. However,
331 again there was little consistency in the conditions reporting across the websites, with a number
332 of different associated conditions reported by some websites. The lack of treatments options
333 reported for hyperacusis is a concern. With the exception on one site Hyperacusis Focus
334 reporting on the variety of treatment options was poor. Similar conclusions have been drawn
335 across other studies which shows that hyperacusis is not the exception to the rule. For instance,
336 a study analysing online information about tinnitus concluded that no website provided a full,
337 informative perspective on the disorder (Fackrell et al., 2012). Other studies also highlight
338 variability in the quality rating of online information for tinnitus, with most being rated as poor
339 or fair quality (McKearney et al., 2018; Laplante-Levesque et al., 2012).

340 However, one important difference currently exists between hyperacusis and tinnitus
341 management in that practice guidelines are published for tinnitus (Cima et al., 2019).
342 Unfortunately, clinical guidelines do not exist for hyperacusis, meaning that clinicians have
343 less information on which to base their management strategies.

344 The treatment options reported by different websites included sound devices, TRT, CBT, ear
345 plugs (mainly contra-indications for using those), several alternative therapies such as
346 acupuncture, hypnosis, and relaxation and anti-inflammatory medicines. A scoping review by
347 Fackrell and colleagues (2017) concluded that most treatments for hyperacusis were evaluated
348 in patients who reported hyperacusis as a secondary complaint or as part of a set of symptoms.
349 In such case no strong conclusions can be drawn based on the published literature as to potential
350 benefits (or harms) of any treatments for hyperacusis, including those mentioned on the
351 websites.

352 The authors also found that most of the websites lacked critical details such as the dates and
353 sources of the published information this lack of transparency is a concern because people with
354 hyperacusis who access these sites may read information and believe it is evidence based
355 whereas this may not be correct and this could significantly affect patient outcomes and quality
356 of life if unreliable information is being presented online.

357 The most comprehensive website in the current study was Hyperacusis Focus. It scored the
358 highest on both sections of the DISCERN questionnaire, and was most comprehensive
359 according to our content analysis. Furthermore, sources of information were provided for all
360 topic areas. Research-focused aspects of this website can be recommended to doctors looking
361 to provide evidence-based management advice to their patients. Action on Hearing Loss also
362 produced a high DISCERN score. Wikipedia provides very useful information that is suitable
363 for both patients and doctors. The most limited website was South Tees NHS as the content
364 was lacking.

365 Another point for discussion was the prevalence of accreditations within the analysed websites.
366 Less than half of the websites had any form of accreditation. Within the wider field of Online
367 Health Information, accreditation is typically associated with a higher quality of content.
368 Previous research has correlated accreditations with higher DISCERN scores than those
369 without accreditation (Bailey et al., 2013). However, the findings in the current study did not
370 conform to this statement. The highest performing website on the DISCERN, Hyperacusis
371 Focus, had no advertised accreditation. On the other hand, WebMD which advertised
372 accreditation from URAC, averaged less than half of the total DISCERN score. The research
373 suggests that at least for hyperacusis websites, accreditation is not sufficient for website
374 recommendation.

375 One likely reason for the disparity in online hyperacusis information is the lack of research and
376 knowledge of the condition (Paulin et al., 2016). It is also agreed by some authors that future
377 research should evaluate the effectiveness of hyperacusis treatments currently available. This
378 resonates with a recent hyperacusis research prioritisation exercise in the UK (Fackrell et al.,
379 2019). Patients and doctors are both increasingly using the internet to source health-related
380 information (Barry et al., 2011). The recommendations of specific websites may provide both
381 patients and doctors with guidance on the newest developments in care also. However, the
382 general quality of websites is still very much guided by the literature, so the latter needs to
383 improve for the former to become more comprehensive and evidence based.

384

385 *Strengths and Limitations of the Study*

386 The use of four independent raters during the data collection and analysis process increases the
387 reliability of the results. Furthermore, consistency of data extraction was ensured by piloting.
388 Meetings were also held at regular intervals to discuss concerns and resolve issues with the

389 study process. Another strength to the study was that it replicated patient online health
390 information seeking behaviour by using results from major search engines (Wang et al., 2012).
391 This study used the well-established DISCERN questionnaire. Although detailed guidance is
392 given in the DISCERN handbook, differences in rating using the tool are inevitable. Four
393 authors (ES and one other author: MS, SS or BA) performed data extraction and ratings
394 according to the DISCERN questionnaire, meaning that different authors, from different
395 backgrounds were involved in ratings of different websites. This could have contributed to the
396 variability of the DISCERN scores. Only one member of the team had extensive knowledge of
397 hyperacusis so they were likely more critical of website quality than the other three raters.
398 Similarly, only one rater had previously used the DISCERN which may have resulted in
399 different applications of the questionnaire. Another limitation of the study is the reliance on
400 basic search results. Some websites may be in more popular use, e.g. recommended within
401 online hyperacusis discussion and support forums. It would be interesting to explore such
402 forums and the resources that are recommended therein.

403 Although it served our purpose, use of a bespoke questionnaire may also be considered a
404 weakness. An alternative would have been to use more established questionnaires for website
405 evaluation such as the WebQual (Barnes and Vidgen 2000) or the website evaluation
406 questionnaire (Elling et al 2012).

407 **Conclusions**

408 Based on the findings in this study, Hyperacusis Focus is recommended as the best online
409 resource for information about hyperacusis. Wikipedia was also judged very useful in
410 providing extensive accessible information. Recommended websites for patients are the BTA
411 and NHS due to their comprehensive information on hyperacusis at a level suitable for the
412 general public. Furthermore, AOHL was judged as providing a useful concise resource for
413 patients. No website is comprehensive on its own. The evaluation of these websites should

414 guide doctors and patients in the management of hyperacusis until national guidelines are
415 produced.

416

417

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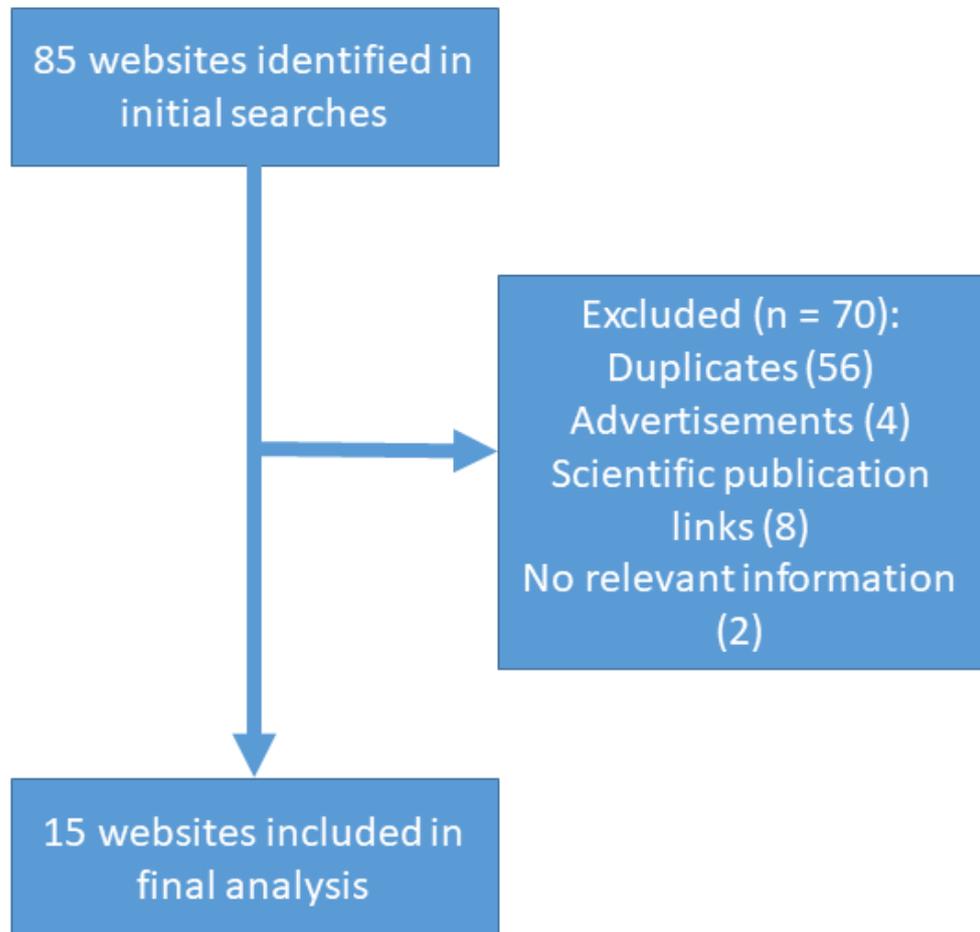
501 **Supplemental information**

- 502 S1. Data Extraction Form
- 503 S2. Detailed Information about the fifteen included websites
- 504 S3. Signs and Symptoms of hyperacusis
- 505 S4. Onset/causes of hyperacusis
- 506 S5. Associated conditions
- 507 S6. Treatments for hyperacusis

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Figure 1.



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516 **Table 1. The fifteen included websites with URL and accessed dates**

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Website	Website Address	Date Accessed
Amplifon	https://www.amplifon.com/uk	23.11.18
Action on Hearing Loss	https://www.actiononhearingloss.org.uk	24.11.18
American Speech-Language-Hearing Association	https://www.asha.org	25.11.18
British Tinnitus Association	https://www.tinnitus.org.uk	24.11.18
Dizziness & Balance	https://www.dizziness-and-balance.com	25.11.18
Hear.com	https://www.hear.com/uk/	24.11.18
Hidden Hearing	https://www.hiddenhearing.co.uk	24.11.18
Hyperacusis Focus	http://hyperacusisfocus.org	25.11.18
Hyperacusis.net	http://www.hyperacusis.net	25.11.18
NHS	https://www.nhs.uk	16.11.18
South Tees NHS	https://www.southtees.nhs.uk	24.11.18
University of California San Francisco	https://www.ucsfhealth.org	25.11.18
Vestibular.org	https://vestibular.org	24.11.18
WebMD	https://www.webmd.com	25.11.18
Wikipedia	https://www.wikipedia.org	23.11.18

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521 **Table 2. DISCERN Questionnaire scores**

522 Section1, Section 2 and Overall score for each website are presented as mean of all questions

523 (8 questions in Section 1, 7 questions in Section 2, 15 questions overall). Values are averages

524 corrected to one decimal place. Websites are listed in alphabetically.

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DICERN Question	Section 1 mean score	Section 2 mean score	Overall score	Question 16
Amplifon	1.9	2.0	2.0	1.5
Action on Hearing Loss	3.9	2.8	3.4	4
American Speech-Language- Hearing Association	3.7	2.9	3.3	3
British Tinnitus Association	2.6	2.0	2.3	3
Dizziness & Balance	3.5	2.9	3.2	3
Hear.com	1.8	2.1	2.0	2
Hidden Hearing	1.3	1.4	1.3	1.5
Hyperacusis Focus	4.6	3.5	4.1	5
Hyperacusis.net	2.3	2.1	2.2	2.5
NHS	3.3	2.7	3.0	3
South Tees NHS	1.2	1.2	1.2	1
University of California San Francisco	1.8	2.1	1.9	2.5
Vestibular.org	2.1	1.2	1.7	2
WebMD	2.6	2.1	2.3	2.5
Wikipedia	3.3	2.1	2.7	2.5

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