

1 Exploring how members of the public access and use health  
2 research and information: A scoping review

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## 29 Abstract

30 **Background:** Making high-quality health and care information available to members of the general  
31 public is crucial to support populations with self-care and improve health outcomes. While attention  
32 has been paid to how the public accesses and uses health information generally (including personal  
33 records, commercial product information or reviews on healthcare practitioners and organisations)  
34 and how practitioners and policy-makers access health research evidence, no overview exists of the  
35 way that the public accesses and uses high quality health and care information.

36 **Purpose:** This scoping review aimed to map research evidence on how the public accesses and uses  
37 a specific type of health information, namely health research and information not including  
38 personal, product and organisational information.

39 **Methods:** Electronic database searches [CINAHL Plus, MEDLINE, PsycInfo, Social Sciences Full Text,  
40 Web of Science and SCOPUS] for English language studies of any research design published between  
41 2010-2022 on the public's access and use of health research or information (as defined above). Data  
42 extraction and analysis was informed by the Joanna Briggs Institute protocol for scoping reviews,  
43 and reporting, the PRISMA extension for scoping reviews.

44 **Results:** The search identified 4410 records. Following screening of 234 full text studies, 130 studies  
45 were included. One-hundred-and-twenty-nine studies reported on the public's sources of health-  
46 research or information; 56 reported the reasons for accessing health research or information and  
47 14 reported on the use of this research and information. The scoping exercise identified a substantial  
48 literature on the broader concept of 'health information' but a lack of reporting of the general  
49 public's access to and use of health research. It found that 'traditional' sources of information are  
50 still relevant alongside newer sources; knowledge of barriers to accessing information focused on  
51 personal barriers and on independent searching, while less attention had been paid to barriers to

52 access through other people and settings, people’s lived experiences, and the cultural knowledge  
53 required.

54 **Conclusions:** the review identified areas where future primary and secondary research would  
55 enhance current understanding of how the public accesses and utilises health research or  
56 information, and contribute to emerging areas of research.

57

## 58 Keywords

59 Health research, health information, public, patients, access, use, scoping review

60

## 61 Background

62

63 Making high-quality health and care information available to members of the general public is crucial  
64 to support populations with self-care and improve health outcomes, as knowledge ‘holds the  
65 potential to change practice and achieve positive clinical, population and other outcomes,’ (1)  
66 (p.524). Minimally, ‘high quality information’ may be understood as information grounded in  
67 primary research, free from commercial sponsorship and other conflicts of interest (2). Additional  
68 criteria such as conciseness, simplicity of design, and continued updating may be required by some  
69 authorities for research-based information to be considered ‘high quality information’ (e.g. (3)).

70 The science of how people access and use health information is not new (e.g. (4)). However, if the  
71 requirement of ‘high quality’ for health information is adopted, that is, that the information be  
72 ‘research’ or ‘research-based’, the existing literature presents a number of shortcomings. Firstly, the  
73 literature that has examined how research is accessed and used has tended to focus on practitioners  
74 and policymakers (e.g. in the emerging field of Research on Research Use (5)), with relatively little

75 attention paid to how members of the public access and use research. Secondly, while a rich  
76 literature exists on how the public access and use health information, it has tended to conflate all  
77 types of health information – including research evidence and information such as personal records,  
78 medication labels and physician’s personal web pages (6). Consequently, little is known about how  
79 the public accesses and uses high quality health information, and there are no summaries or  
80 overviews of this topic.

81 In this light, a scoping review methodology was deemed appropriate as such reviews are intended to  
82 ‘map the literature and provide an overview of evidence, concepts, or studies in a particular field’  
83 and the results may be used to inform priorities for future research on the topic of interest. (8)

84 Accordingly, this review aimed to systematically search for and describe the research evidence on  
85 how members of the public access and use (high quality) health research or information (HRI)  
86 relating to human health and healthcare; the reasons for access and use of HRI and the factors that  
87 may shape how they access and use HRI. In order to approximate the notion of ‘high quality  
88 information’, the review adopted a narrower definition of ‘health information’ than in the broader  
89 literature, excluding personal records, product information, and information on establishments  
90 providing healthcare.

## 91 **Methods**

92  
93 The review was informed by the Joanna Briggs Institute guidance for conducting scoping reviews and  
94 reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-  
95 Analyses (PRISMA) Extension for Scoping Reviews (9, 10). The search was conducted in three steps:  
96 an initial search of a select number of academic databases (CINAHL plus, MEDLINE and Web of  
97 Science) to identify and narrow the range of relevant search terms to inform the final search  
98 strategy; an expanded search of academic databases (CINAHL Plus, MEDLINE, PsycInfo, Social  
99 Sciences Full Text, Web of Science and SCOPUS) with the identified search terms; and manual search

100 of the reference lists of included systematic reviews and meta-analyses. Alongside, experts in the  
101 field were consulted to ensure all relevant studies had been included in the retrieved corpus.

102 This search strategy departed from the current JBI guidance on scoping reviews as neither grey  
103 literature nor manual searching of the reference lists of all included studies was conducted, due to  
104 resource constraints.

105 The protocol was registered with the Open Science Forum (registration DOI:  
106 [10.17605/OSF.IO/RXP39](https://doi.org/10.17605/OSF.IO/RXP39)) on 16/02/2022.

107

## 108 Data Sources

109 Search terms included subject headings, free text and wild-card terms located in the title or abstract  
110 for population of interest (members of the public e.g. general public, public, people, community, lay  
111 public, lay person, patient, carer), concept of interest (access to and use of human health research or  
112 information. e.g. : access\*, utilisation/utilisation, us\*, adopt\*, uptake, engagement; AND research  
113 evidence, research findings, research publications, research articles, research outputs, scientific  
114 evidence, scientific findings, scientific articles, scientific publications, scientific knowledge, research,  
115 information) and context of interest (e.g. health, healthcare).

116 The search was limited to studies published between 01-01-2010 and 18-01-2022. This was informed  
117 by the rapid changes in communications technologies over the last decade and evidence that most  
118 studies on the use in healthcare of social media, a technology able to reach less traditional  
119 audiences (11), were published after 2010 (12) (Table 1). The full electronic search strategy is  
120 presented as Supplement 1.

121

## 122 Study selection

123 Studies were eligible for inclusion in this review if: they investigated the access and use of HRI by  
 124 members of the general public from any socio-cultural background, age, gender and ability, and  
 125 national setting, following any research design, and they were published in the English language in  
 126 peer-reviewed journals. The inclusion of English-language only publications was due to the limited  
 127 availability of resources for translation.

128 Access to HRI was defined as the process of finding and obtaining HRI or physically accessing HRI in  
 129 varied formats. Studies which discussed how information is accessed conceptually only (e.g. National  
 130 Institute of Health Research (NIHR) (13)) were not included. HRI use or utilization was defined as  
 131 what people did with the research or information they had accessed, including how they assessed,  
 132 applied or adapted the research or information to their needs and context (14) rather than their  
 133 intention or stated preference. Studies which discussed ‘access to health information’ where it was  
 134 clear that by ‘health information’ was meant personal health records, information about physicians,  
 135 hospitals or medication labelling or similar types of information (personal, product and institutional  
 136 information) only were not included. Studies in which ‘health information’ included these last types  
 137 of information as well as research evidence and data for each was presented separately, were  
 138 included.

139 *Table 1: Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>- Studies investigating access to and use of health and health care research or information (as defined in this study) by members of the public</li> <li>- Participants from any socio-cultural background, age, gender, ability and profession</li> <li>- Any research design</li> </ul>	<ul style="list-style-type: none"> <li>- Studies that discuss or report access to research or information relating to topics other than health and healthcare.</li> <li>- Studies in which ‘health information’ includes personal records, personal, product or institutional information only or as well as health research evidence, and data on each type of information is not presented separately.</li> <li>- Studies that focus exclusively on health care professionals and students/trainees.</li> <li>- Studies that focus on non-human health (e.g. animal, planetary)</li> <li>- Studies not written in the English language</li> </ul>

- Study dated to from 1 <sup>st</sup> January 2010	- Studies published prior to 2010.
- Published, peer-reviewed, full-text articles.	- Opinion pieces, editorials, protocols, conference abstracts and proceedings, commentaries, books and book chapters, unpublished dissertations, evaluation reports.

140

141

142 **Collating, summarising and reporting the results**

143 Records were exported to Proquest® RefWorks for deduplication and then exported to Rayyan  
 144 (Rayyan <https://www.rayyan.ai/>). Independent (blind) screening of abstract/titles against eligibility  
 145 criteria was completed by two reviewers [CHS, KH]. The two reviewers initially screened 25 records  
 146 independently and then conferred to establish common understanding. Each reviewer screened 50%  
 147 of remaining records and then checked 20% each other’s screening for accuracy. One reviewer  
 148 [CHS] screened all full-texts against the eligibility criteria, and a second reviewer [KH] checked 5%.  
 149 Any disagreements were resolved through discussion. A third reviewer was identified as arbitrator,  
 150 though this was not needed [LB or TV].

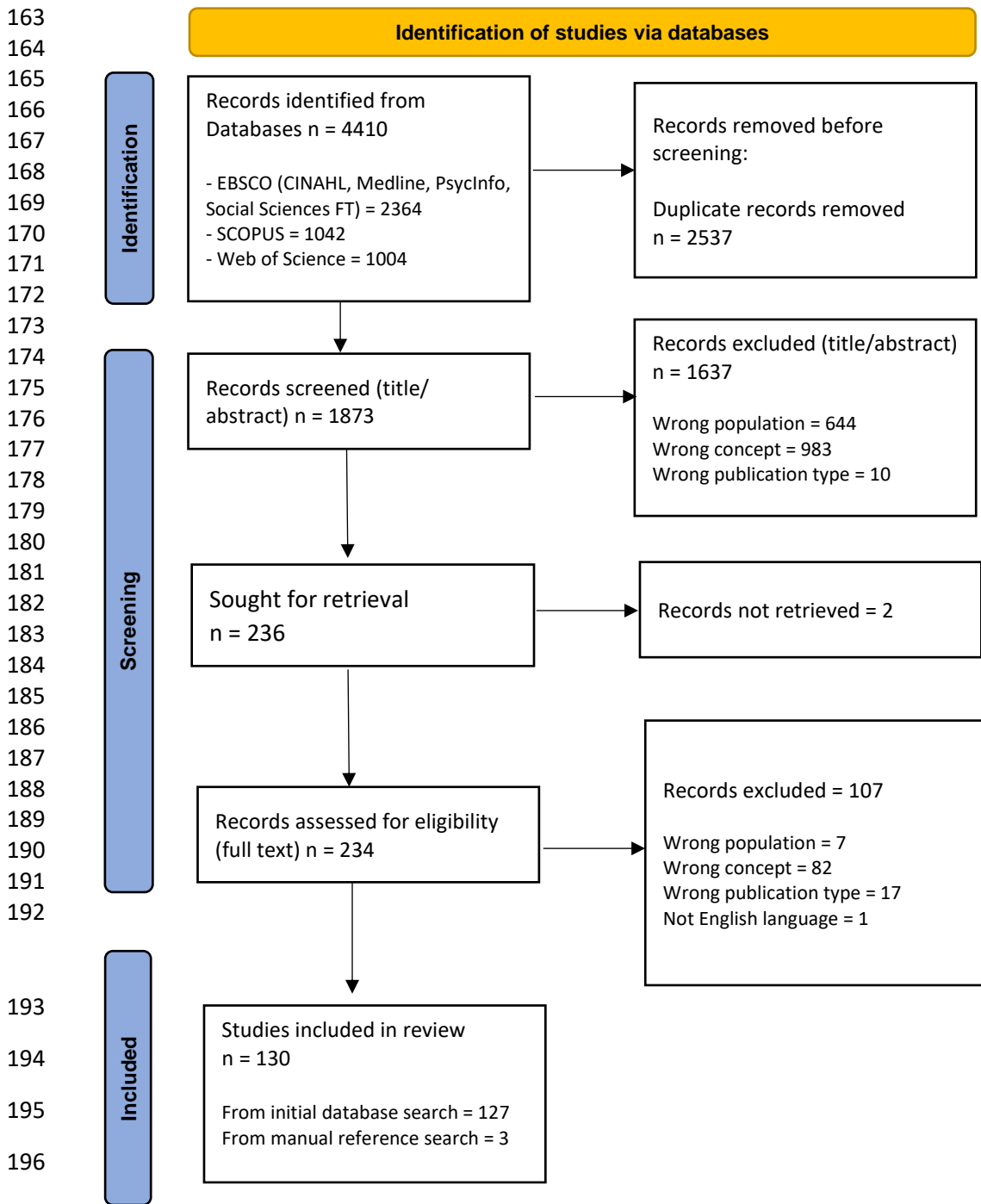
151 A bespoke data extraction tool was developed and piloted on five included studies (See Additional  
 152 File 1). Two reviewers [SQM, CHS] extracted data from included studies, and a third reviewer [ND]  
 153 checked 10% of the extracted data for accuracy.

154 Data were extracted on: study characteristics (author/s, date, title, journal, keywords, study type,  
 155 methodology); population characteristics; reasons/purpose for accessing/using HRI (general interest,  
 156 specific condition); source of HRI; utilization of accessed HRI; condition/aspect of health or  
 157 healthcare to which the HRI accessed relates; and factors facilitating access or barriers to accessing  
 158 the HRI. Data for each category was summarised in table form, accompanied by a narrative.

159 Figure 1 presents a flow diagram for the scoping review process adapted according to the PRISMA  
 160 extension for scoping reviews (PRISMA-ScR) statement (15).

161

162 Figure 1: PRISMA ScR diagram



## 198 Results

### 199 Study characteristics



200 The search produced 4410 records. Following deduplication and title and abstract screening the full  
201 text of 234 studies were screened and 130 studies were included in this review (Figure 1).

202 Two studies investigated access to research by members of the public [(16), (17)]. One hundred and  
203 twenty-eight studies investigated access to health information by members of the public  
204 (Supplement 2).

205 Eighty included studies (62%) applied a quantitative research methodology [ (18), (19), (20), (21),  
206 (22), (23), (24), (25), (26), (27), (28), (29), (30), (31), (32), (33), (34), (35), (36), (37), (38), (38), (39),  
207 (40), (41), (42), (43), (44), (45), (46), (47), (48), (49), (50), (51), (52), (53), (54), (55), (56), (57), (58),  
208 (59), (60), (61), (62), (63), (64), (64), (64), (65), (66), (67), (68), (69), (70), (71), (72), (73), (74), (75),  
209 (76), (77), (78), (79), (80), (81), (82), (83), (84), (85), (86), (87), (88), (89), (90), (91), (92), (93), (94)],  
210 33 studies (25%) followed a qualitative methodology [ (95), (96), (16), (97), (98), (99), (100), (101),  
211 (102), (103), (104), (105), (106), (107), (108), (109), (110), (111), (112), (113), (114), (115), (116),  
212 (117), (118), (119), (120), (121), (122), (123), (124), (125), (126)], 13 studies (10%) were mixed- or  
213 multi-method studies [(127), (128), (17), (129), (130),(131), (132), (133), (134), (135), (136), (137),  
214 (138)], and four (3%) were reviews [(139), (140), (141), (142)].

215 Fifty-nine included studies were conducted in North America (45%) [(18), (95), (96), (16), (129), (97),  
216 (130), (99), (100), (101), (102), (31), (103), (34), (104), (105), (106), (35), (36), (39), (40), (43), (44),  
217 (47), (50), (108), (51), (52), (109), (55), (57), (61), (62), (63), (67), (68), (115), (70), (116), (72), (76),  
218 (117), (77), (79), (80), (119), (120), (83), (121), (84), (85), (88), (137), (122), (123), (89), (125), (138),  
219 (92)], 18 in Europe (14%) [(25), (27), (28), (128), (17), (54), (58), (59), (60), (112), (143), (114), (75),  
220 (118), (78), (86), (87), (126)], 18 in Asia (14%) [(20), (29), (98), (30), (49), (133), (56), (111), (66), (69),  
221 (74), (81), (82), (135), (136), (124), (90), (91)], 11 in Africa (8%) [(21), (26), (127), (32), (46), (131),  
222 (53), (64), (113), (65), (73)], nine in the Middle East (7%) [(19), (23), (24), (33), (144), (48), (110),  
223 (145), (94)], five in Australasia (4%) [(41), (42), (45), (71), (134)] and two in South America (2%) [(38),

224 (107)]. Four studies spanned several continents (3%) [(22), (132), (140), (93)] and another four  
225 studies did not state any specific geographical location (3%) [(139), (37), (141), (142)].

226 The studies included people with specific health conditions (n=33) [(95), (22), (26), (27), (28), (130),  
227 (98), (30), (100), (101), (32), (36), (46), (132), (52), (53), (54), (67), (70), (75), (79), (119), (85), (87),  
228 (91), (126)], hearing or visual impairment (n=4) [(23), (108), (120), (134)], carers (n= 11) [(19), (24),  
229 (100), (105), (38), (132), (51), (52), (110), (133), (92)], the elderly (n=6) [(45), (68), (73), (135), (86),  
230 (88)], youth or teens (n=12) [(95), (130), (33), (36), (131), (65), (68), (141), (120), (83), (136), (138)],  
231 minority populations (n=22) (e.g. ethnic minorities [(97), (99), (102), (34), (106), (39), (40), (43), (62),  
232 (140), (115), (116), (76), (117), (119), (123)], homeless people [(61), (63)] or refugees [(42), (47),  
233 (112), (89)]), and criminalised individuals [(103)]. Twenty-four studies included other populations  
234 (e.g. African American breast cancer survivors [(96)], members of public libraries [(144)], women in  
235 Tanzania [(127)] a rural community [(128)]), students in an ESOL class [(114)] [(18), (96), (127),  
236 (128), (29), (35), (146), (42), (48), (107), (111), (61), (63), (113), (68), (114), (71), (118), (81), (121),  
237 (84), (124), (125), (94)]. Eighteen studies were a sample of the general population [(20), (25), (17),  
238 (129), (44), (49), (50), (109), (57), (59), (145), (69), (74), (78), (80), (82), (122), (93)] and sixteen  
239 studies did not identify the population [(21), (22), (16), (99), (139), (31), (104), (37), (72), (141), (117),  
240 (77), (119), (142), (137), (90)]. Some study populations had several of the characteristics listed  
241 above.

## 242 Access to health research and information by members of the public

243 Sixty-one studies listed healthcare professionals (including GPs, nurses, allied health professionals,  
244 complementary and alternative therapists) as a source of HRI. Sixty studies mentioned informal  
245 sources (friends, work colleagues, families and neighbours); and 18 studies mentioned other types of  
246 professional advisors, such as pastors, educators, governmental officials or charity sector workers  
247 (Table 2).

248 Forty-five studies listed a type of setting (a place or event) as the source of HRI, including medical  
249 settings (n=14), formal community settings such as town hall meetings (n=20), formal educational  
250 settings (n=5), other educational settings (n=14) such as workshops/lectures, and settings such as  
251 bookshops or libraries (n=12) (Table 2).

252 Finally, 83 studies reported on the tools used by members of the public to access HRI. This  
253 comprised: mass media (n=51), printed information (n=48) the internet (n=38). Internet sources  
254 included social media (n= 27); various specialist governmental, non-governmental and personal  
255 websites (n=25); and search engines (n=19). Online communities of various types (platform  
256 unspecified) were mentioned as a way to access HRI in 13 studies. Other sources mentioned among  
257 included studies were scholarly sources such as academic journals, textbooks and encyclopaedias  
258 (n=16), phone services and applications (n=13), and marketing materials (n=3) (Table 2).

259 *INSERT TABLE 2 HERE*

## 260 **Reasons for accessing and using health research and information**

261  
262 Fifty-six studies reported on reasons for seeking HRI by members of the public. The main reasons for  
263 seeking HRI were: (i) to find health-related information for other people and on different topics (n =  
264 46); (ii) to navigate the healthcare system, such as preparing for meetings with healthcare  
265 professionals (HCPs) and advocating on one's behalf, making one's own health decisions, including  
266 whether to seek professional help, and sometimes to avoid going to an HCP, and to verify, clarify or  
267 add to information received from other sources; to manage one's own health (n = 31); and (iii) to  
268 obtain psycho-social support by reading testimonials from other people, gain reassurance and  
269 comfort, and to gain a sense of control over the diagnosis, condition or treatment (n = 9) (Table 3).

270 *INSERT TABLE 3 HERE*

271 Fourteen included studies reported the ways which the HRI accessed was used by members of the  
 272 public (Table 4). Reasons for use included: to improve participants' own health behaviours and/or  
 273 ability to manage their health (n = 4); to support health-related decision making (n = 5); to facilitate  
 274 or enhance conversations or encounters with HCPs (n = 4); to increase people's own understanding  
 275 of a health-related topic (n = 3); to assess the information from another source (n = 2); and to share  
 276 with or educate others in the context of providing psychosocial support (n = 1).

277 *Table 4: Reported use/utilisation of accessed HRI*

	Number of studies	Study number
Improve their own health behaviours or ability to manage their health <sup>a</sup>	4	(145), (143), (65), (126)
Make health decisions <sup>b</sup>	5	(105), (58), (65), (67), (70)
Facilitate / enhance conversations or encounters with HCPs	4	(39), (54), (65), (142)
Increase their own understanding of a health-related matter <sup>c</sup>	3	(105), (145), (126)
Assess the information from another source	2	(109), (133)
Share / educate others in the context of providing psychosocial support	1	(132)
<u>Notes:</u>		
<sup>a</sup> Including, for example, developing better coping strategies or lower thresholds for seeking help.		
<sup>b</sup> This may include decision to change medication without discussing it with HCP.		
<sup>c</sup> Including for example, a dependent's condition; own symptoms, treatment options, best use of insurance		

278

## 279 **Factors influencing access to and use of health research and information**

### 280 *Barriers to accessing and using HRI*

281 Thirty studies reported barriers to accessing and using HRI. The main barriers related to: (i) the  
 282 source characteristics (n=24); (ii) the characteristics of the person accessing or using HI/R (n=12); the  
 283 nature of the condition for which HRI was desired (n=3). Other barriers such as a fear that seeking  
 284 information could be distressing, inability to determine the quality of information appeared in seven  
 285 studies (Table 5).

286 *Table 5: Barriers to accessing and/or using health research or information*

	No. of studies	Study number
Barriers relating to the characteristics of the source (channel, format) (n=24)		
Language <ul style="list-style-type: none"> <li>- Information not in preferred language (including national, local and sign languages)</li> <li>- Information not available in formats suitable for the visually impaired</li> <li>- Terminology / language used by or in channel is difficult to understand</li> </ul>	17	(20), (21), (23), (24), (128), (33), (39), (46), (107), (108), (109), (117), (119), (120), (121), (137), (89)
Channel* availability <ul style="list-style-type: none"> <li>- Expense of channel or cost of using channel</li> <li>- Preferred channel does not exist for specific condition or concern</li> <li>- Preferred channel (e.g. HCP, pharmacist) is not easily available</li> </ul>	11	(20), (21), (32), (33), (46), (113), (73), (117), (119), (122)
Quantity, quality and tone of information <ul style="list-style-type: none"> <li>- Too much information is given</li> <li>- Information is too general, not explicit</li> <li>- Information is too impersonal</li> <li>- Information is inadequate, outdated or irrelevant</li> </ul>	6	(20), (95), (32), (106), (46), (73)
Credibility - Channel is not trusted	1	(141)
Barriers related to the characteristics of the health research or information seeker (n=12)		
Individual lacks personal resources that would enable effective health research or information access and use <sup>a</sup>	8	(20), (46), (107), (112), (113), (114), (70), (73)
Individual's health or other physical characteristics <sup>b</sup>	2	(27), (108)
Age or other characteristic restricts access to sources of health research or information <sup>c</sup>	2	(95), (119)
Lack of awareness of sources of HRI on given condition/health topic	1	(20)
Barriers related to the nature of the condition for which health research or information is desired (n=3)		
Condition is stigmatising or may lead to discrimination, concerns about disclosure <sup>d</sup>	3	(32), (33), (131), (131)
Other barriers (n=7)		
Reluctance to search for information from fear it could be distressing	3	(132), (114), (70)
Inability to determine the quality of information of the source /poor info evaluation skills	3	(21), (33), (73)
Poor experiences with healthcare profession in the past	1	(141)
<u>Footnotes:</u>		
*By 'channel' is meant the medium e.g. journal, website, radio programme, etc		
<sup>a</sup> This includes lack of technical or other skills, language, information retrieval, literacy, health literacy and time.		
<sup>b</sup> This may include, for example, visual impairment, deafness or limb amputation.		
<sup>c</sup> For example, restricted access to internet among youth by parents, or reliance on family members to access preferred channel.		
<sup>d</sup> For example, HIV/AIDS, depression, puberty, menstruation.		

287

288 *Factors that facilitate accessing and using health research and information*

289 Six studies discussed factors that facilitated members of the public access and use of HRI. Six studies  
290 reported factors related to the source of information that facilitated access to HRI. These se included  
291 ease of access [(143), (121), (125)], anonymity [(143), (126)], cost [(143)], format and language in  
292 which HRI was presented [(118), (121)], and quantity and complexity of contents [(129)]. Factors

293 facilitating access were: reports that did not use technical terms and acronyms but ‘sound[ed]  
294 scientific’ [(118)]; on-demand availability of the channel [(143), (121), (125)]; information that was  
295 up-to-date and provided both an outline of the topic and detail [(129)].

#### 296 *Factors influencing choice of source of health research and information*

297 Three studies reported the factors that influenced people’s choice of source of HRI. Two studies  
298 found that the health condition searched for, and how it was perceived (i.e. trivial or stigmatising)  
299 influenced choice of source [(104), (116)]. One study reported that presenting health condition could  
300 influence choice [(126)]; one study noted that the healthcare provision available to study  
301 participants influenced choice of source [(104)]; and one study highlighted that patterns of access  
302 and use of HRI differed according to when in the patient journey this information was sought, and  
303 according to the purpose (for instance, the internet was not considered useful for making health  
304 decisions but it was useful for other health-related reasons) [(116)].

## 305 Discussion

306 This scoping review was the first to be conducted with the aim to identify the extent and nature of  
307 the research literature on how members of the public access and use high quality health research  
308 and information.

309 The scoping review identified 130 studies that investigated how members of the public accessed  
310 HRI. Mass media was the most studied source of information, followed by printed information and  
311 the internet. The reasons for members of the public accessing and using HRI included to improve  
312 health behaviours, and/or ability to manage their health, to help with health-related decision  
313 making, facilitating or enhancing conversations or encounters with HCPs, increasing people’s own  
314 understanding of a health-related topic; assessing the information from another source, and sharing  
315 with or educating others in the context of providing psychosocial support. The factors that

316 constrained access and use of HRI, related to the source characteristics, the characteristics of the  
317 person accessing the HRI and the nature of the condition for which HRI was accessed. Six studies  
318 reported on the factors facilitating access and use of HRI, and three studies discussed factors that  
319 influenced the choice of one source rather than another.

320

## 321 Health information vs health research

322  
323 The review identified a substantial literature on broader concept of 'health information' but a lack of  
324 reporting of the general public's utilisation of health research.

325 Crucially, only two included studies investigated access of health research by members of the public,  
326 and none of the included studies explored the use of health research by members of the public. One  
327 case study conducted in the USA found that a library of brief podcasts on health research (duration  
328 22 minutes each) was feasible to co-produce with local community partners and generated user  
329 views /engagement over 18 months [(16)]. However, this preliminary study, conducted in a single  
330 state in the USA, does not specify the number of study participants and their demographics, limiting  
331 learnings from the study, as well as the generalisability and transferability of its findings. Another  
332 mixed-methods study investigated the relationship between information sources and public trust in  
333 health research in two European countries (Italy, Slovakia) [(17)]. In this study, traditional media (e.g.  
334 television, newspapers) and digital media (e.g. blogs, social networks) were the most widely cited  
335 information channels, followed by personal interaction and exchanges (e.g. family, friends, experts,  
336 people in authority), echoing the overall results of this scoping review. At ten roundtable discussions  
337 participants (n=192) reported obtaining credible health research from a source considered  
338 authoritative and competent (e.g. health professionals). The experts provided the information  
339 needed to help the individual understand and evaluate complex issues via direct interaction. Taken  
340 together, these two studies suggest that the public will engage with health research in diverse ways

341 and that delivery by a source perceived as competent or authoritative may be important to  
342 engagement with health research, whatever the medium.

343 All other included studies centred on the broad concept of 'health information'. This potentially  
344 obscures the interest among the general public in accessing research evidence. For example, 16  
345 included studies reported 'scholarly/academic sources' as a source of HRI, potentially indicating  
346 direct access to health research by members of the public (Table 2). This is supported by a recent  
347 mixed-methods study conducted by the UK's National Institute of Health and Care Research, which  
348 found a strong interest among the general public in being able to access research findings [13].  
349 However, neither the NIHR study nor the majority of studies mentioned scholarly/academic sources  
350 provide demographic data or disaggregated demographic data for the participants accessing and  
351 using these sources. Furthermore, the two included studies that highlight the use of scholarly  
352 sources of HRI and also provide relevant participant data [(122), (123)], suggest that such sources  
353 are more prevalent among more educationally privileged groups: in these two studies, up to 90-  
354 100% of study participants were college or university educated. It does not follow, however, that  
355 only more educated groups tend to access health research through scholarly or academic sources.  
356 Indeed, as studies such as Vandrevalla et al (forthcoming) have shown, information access and use is  
357 often a social act, with members of the public not only seeking information for themselves but  
358 others within their social network. The paucity of research on how members of the public access and  
359 use health research evidence, and the use of the umbrella term, 'health information', without  
360 explicit definition and distinguishing between the types of 'health information' sought, may  
361 underestimate the extent of access and use of research evidence, among the general public. The  
362 issue of paywalls excluding the general public from access to academic or scholarly sources such as  
363 journals was not raised in the retrieved literature.

364 Another issue highlighted by this review concerns the similarities and differences between how the  
365 general public and policymakers and practitioners use health research and HRI, respectively, though



366 this will need further exploration. Like practitioners and policymakers, the general public's uses  
367 included conceptual and instrumental uses of HRI (5). In addition, the general public used HRI to  
368 obtain or provide psychosocial support, a use that was not noted in relation to research use by  
369 practitioners and policymakers.

## 370 A vast diversity of ways of accessing HRI

371 Included studies reported a wide range sources to access HRI, with at least 84 different sources  
372 identified, which were classified into three broad categories: 'other people', 'professional settings'  
373 (medical, community or educational places), and 'independent searches' (that covered all those  
374 tools that people use to do their own 'research' to access the information that they need). The  
375 review found that, even as interest in the internet and social media as means to access or deliver HRI  
376 has increased (e.g. (147), (148)), 'traditional' sources of information such as mass media or printed  
377 material are still relevant. For example, a 2016 survey conducted among Asian American groups in  
378 New York City (n=1373), USA, found that the internet was among the least used sources of HRI, with  
379 print media being the most used source [(47)]. Similarly, a 2021 survey among cancer patients  
380 (n=404) in Japan found the most widely used source of HRI to be newspapers, followed by HCPs, and  
381 that the internet was used by a small proportion of the patients only [(66)]. These examples are not  
382 unique, and hint that *diversification of means of delivering HRI* to support self-care may be a more  
383 suitable approach for delivering HRI, though this conclusion is tentative and will need confirmation  
384 through a more systematic study and further research.

385 Communications technology has advanced rapidly in the past decade, notably through the increase  
386 in the number of internet platforms and the development of new functionalities so that, for  
387 instance, YouTube is no longer just a means to share video material but also features discussion  
388 boards. Instagram as a means to access HRI was mentioned in only one study ((56)), there was an  
389 absence of studies evaluating the role of Tiktok, a popular channel (Zenone et al 2021), and social  
390 media influencers as ways to deliver HRI (e.g. (149)), suggesting that this literature is now dated.

391 Equally, podcasts were infrequently mentioned in the included studies, in spite of their growing  
392 appeal as a way to disseminate medical knowledge ((150)).

393 In addition, many studies lacked detail. For instance, studies reported 'online chatrooms' as a source  
394 of information without specifying the platform for the chatroom, whether social media or a  
395 specialist health organisation. Some sources of information such as social media were insufficiently  
396 distinguished in studies, for example Twitter and Instagram, which tend to favour one or the other  
397 format and may therefore appeal to different audiences. Generally, very few included studies  
398 considered or reported on the format of the HRI accessed.

399

#### 400 **Barriers and facilitators to independent searches vs other sources of HRI**

401

402 Included studies did not generally explore barriers and facilitators to the use of HRI, or, if they did,  
403 they did not report on barriers to use separately from barriers to access. This section focuses  
404 therefore on barriers to and facilitators of access.

405 The studies included in this review described a wide range of factors that shaped how the public  
406 accessed HRI. These were classified into 16 different factors under four overarching categories that  
407 related to personal characteristics, source characteristics and nature of the health condition of  
408 interest or presenting and 'other' factors.

409 Relating these to the sources of HRI identified in this review ('other people', 'professional settings'  
410 and 'independent searches'), included studies provided a detailed understanding of barriers to  
411 access and, in particular, barriers to access through *independent searches*, where major  
412 considerations related to how information is presented, namely: the format, the language used, the  
413 quantity of information and the level of detail provided. There was no consensus among studies,  
414 however, with some identifying as facilitators shorter pieces in simple, non-technical language while

415 others indicated that accessible but ‘scientific-sounding’ (including some level of technical language)  
416 and more detailed information facilitated access to HRI.

417 Only one barrier was identified that related to ‘other people’ as sources of HRI, and that concerned  
418 the availability of the source. None of the studies specifically identified barriers relating to  
419 ‘professional settings’, though conceivably, features of the setting, including its physical features,  
420 may act as a barrier to accessing HRI. One example was provided by a study of people with autism  
421 which reported struggling with the physical environment of specialist clinics ((151)).

422 Studies provided a good understanding of the characteristics of the individual seeking information  
423 that may act as a barrier to accessing HRI, mainly their possession of specific technical skills  
424 (technological, linguistic, information retrieval) and time. However, again, these pertained mostly to  
425 independent searches rather than accessing HRI through other sources. No mention was made of  
426 the cultural knowledge and skills needed to navigate the professional settings or relationships  
427 through which HR/I may be accessed, although it is known that lack of familiarity with healthcare  
428 systems and its norms can be a barrier to accessing these settings (e.g. (152)), and therefore,  
429 potentially, HRI.

430 Another factor shaping how people accessed HRI that was seldom investigated in included studies  
431 was the role of *past experience with healthcare services, either an individual’s own lived*  
432 *experience of these services or that of other members of their community* or social network. This  
433 was reported in one included study only [(141)], and in relation to a specific community (Lesbian,  
434 Gay and Bisexual adolescents). This absence is surprising, given the evidence that negative  
435 experiences with healthcare provision will impact health behaviours (e.g. (153)) and that negative  
436 experiences in the community will impact information seeking generally (e.g. (154)).

437 In a systematic review including 344 studies, Mirzaei et al (2021) (6) identified a total of 1595  
438 significant ‘predictors of health information seeking behaviours’, (defined as the variables affecting  
439 the actions of seeking out information) and classified these into 67 different categories. Although

440 HISB and accessing and using HRI are not identical conceptually, there were parallels between the  
441 current scoping review findings and Mirzaei et al (2021)'s comprehensive typology. In addition, this  
442 scoping review built on Mirzaei et al (2021)'s findings: while Mirzaei et al had identified the role of  
443 previous exposure to a healthcare source of information as a predictor of HISB, this review identified  
444 that past lived experience with healthcare services generally (whether or not it was a source of  
445 information) in shaping how members of the public accessed HRI. Given the differences between  
446 this scoping review and Mirzaei et al (2021)'s systematic review, it is not possible to draw firm  
447 conclusions regarding influences on accessing different types of health information (Mirzaei et al's  
448 definition is broader) or differences across groups (Mirzaei et al include the general public as well as  
449 healthcare practitioners and healthcare students). This will need further detailed exploration.

450

## 451 **Limitations**

452 Due to funding and time constraints this review only included peer-reviewed studies published in  
453 English language between 01/01/2010 and 18/01/2022). No grey literature searches or manual  
454 searching of the reference lists of included studies were conducted. However, we searched the  
455 reference lists of relevant systematic reviews and meta-analysis, and consulted experts in the field to  
456 ensure that very few, if any, relevant studies produced during this period had been overlooked.  
457 Studies published since January 2022, unpublished studies or studies in other languages, though, will  
458 not have been captured.

459 Limiting the review to English language studies may have influenced in the geographical bias of  
460 included literature, with a majority of studies conducted among North American populations.  
461 However, evidence indicates that the conclusions of most systematic reviews are not altered  
462 through the omission of non-English language studies, and the exclusion of non-English language  
463 publications aligns with recommendations from the Cochrane collaboration ((155)).

464 The conclusions from this review were hampered by poor reporting in some included studies  
465 particularly the lack of clear definitions for the term 'health information'. As a result this review may  
466 have included studies with a broader definition of 'health information', though this is likely to apply  
467 in a very small number of cases only.

468

## 469 Implications

470 This scoping review found a lack of research on research use by members of the public. This absence  
471 may not reflect the extent to which the public uses research, given the subset of studies identifying  
472 scholarly sources as a means to access HRI by the general public in this review, and the fact that  
473 people will often access HRI on others' behalf in their communities or social networks. This justifies  
474 more primary research in this area or a detailed review focusing on this subset, including contacting  
475 authors for more information on their study. Research on research access and use by the general  
476 public could also usefully explore the differences in access and use between the general public and  
477 practitioners and policymakers, for instance, through a systematic review including grey literature  
478 and increased number of databases consulted.

479 The review also identified the need for an update on the barriers in accessing HRI, following the  
480 observation that barriers (e.g. cost of internet access) have considerably decreased for some groups  
481 in the last decade. More specifically, it highlighted a need to enrich current knowledge of the  
482 facilitators of both HRI **access and use** and barriers to **use** of HRI, in relation to the following:

- 483 - The factors shaping access to HRI **through 'other people' and 'professional settings'**, with  
484 specific attention to features of the setting and the presence or absence of cultural skills to  
485 navigate the professional settings where HRI is accessed;
- 486 - A better understanding of the role of **lived experience of individuals or communities** with  
487 healthcare providers in shaping access to HRI;

- 488 - A better understanding of person and setting characteristics that **facilitate** access to HRI
- 489 - A better understanding generally of the factors shaping how the public **uses** HRI.

490 Finally, the literature was found to be dated in relation to the sources of HRI explored, underscoring  
491 the need for primary research to update our knowledge of the communications tools currently in  
492 use among different populations, and the formats that are now being adopted by social media  
493 networking platforms (e.g. Instagram in-feed, stories, and reels; YouTube Community Tab).

## 494 Conclusions

495 This scoping exercise, the first to adopt a narrow definition of health information in an attempt to  
496 understand how the public accesses and uses ‘high quality health and care information’, identified  
497 major patterns of access and use and also identified gaps in the existing research literature. Major  
498 patterns included: the use of a wide diversity of sources to access HRI, with traditional sources still  
499 relevant alongside newer sources; access and use for HRI a wide range of reasons, from the  
500 conceptual to the psychosocial, both for self and for others. Barriers to use related to how HRI is  
501 presented (e.g. language, quantity of information and level of detail) and its availability; the skill,  
502 knowledge and time of the person accessing the information, their physical condition and  
503 autonomy; and the perception of a health topic or the personal and social implications of searching a  
504 given topic. Gaps in the evidence included: a limited number of studies focussing on how members  
505 of the public accesses health research and how the public uses health research; the absence of  
506 newer (online) sources of HR/I, and the lack of exploration of the features and functionalities of  
507 online sources. The review also identified that there is a need for more detailed studies on the  
508 factors that shape how the public **access** HR/I through other people and by visiting professional  
509 settings. The factors shaping how the public **uses** health research and information was also a need in  
510 further primary research, notably, by paying more attention to lived experience of healthcare

511 provision generally and the cultural knowledge that is required of the public when attempting to  
512 access certain sources of health information.

513 Finally the review found that, given the challenges around reporting and the lack of precise  
514 definition of the term 'information', identifying how the public accesses and uses high quality  
515 information is not straightforward at present. More precise definitions of the term 'information',  
516 and studies based on these will be needed to find ways for policy-makers to better support self-care  
517 and improve health outcomes among the general public.

518

## 519 [List of abbreviations](#)

520 HCP: healthcare professional or provider

521 HISB: health information seeking behaviour

522 HRI: health research or information

523

## 524 [Declarations](#)

525 Ethics approval and consent to participate

526 Not applicable.

527

528 Consent for publication

529 Not applicable.

530

531 Availability of data and materials

532 The datasets used and/or analysed during the current study are available from the corresponding  
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534

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536 There is no conflict of interest in this project.

537

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543 LB, TV contributed to the study's conception; LB, TV, CHS, KH, contributed to the design of the  
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546 from LB, TV and KH. CHS prepared the final draft of the manuscript. All authors read and approved  
547 the final manuscript.

548

549

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966

Table 2: Sources of HRI for the general public

Source	No. of studies	Study number
<b>Other people as source of HRI</b>		
Healthcare professionals (n = 61)		
Unspecified healthcare professionals	36	(19), (20), (21), (27), (16), (29), (99), (139), (103), (33), (35), (38), (43), (44), (46), (48), (50), (53), (58), (59), (112), (63), (145), (113), (66), (76), (141), (117), (118), (120), (121), (86), (87), (88), (89), (125)
Doctors	33	(24), (26), (127), (28), (128), (129), (99), (102), (34), (105), (38), (43), (52), (109), (54), (58), (59), (145), (113), (143), (114), (70), (73), (76), (78), (119), (82), (134), (136), (89), (124), (91), (94)
Allied Health Professionals	16	(24), (26), (102, 139), (105), (39), (109), (59), (112), (63), (145), (113), (143), (119), (82, 83)
Nurses	8	(24), (26), (102), (46), (145), (113), (119), (82)
Alternative medical practitioners	5	(127), (39), (113), (73), (124), (119)
Informal sources (n = 60)		
Family, friends, and/or colleagues	52	(20) (21), (23), (26), (27), (127), (28), (128), (17), (129), (29), (99), (102), (139), (103) (32), (33), (38), (146), (39), (44), (46), (107), (131), (50), (108), (109), (110), (54), (59), (112), (63), (145), (113), (114), (115), (70), (71), (73), (76), (141), (78), (120), (82), (134), (83), (121), (136), (86), (123), (89), (124)
Peers/people experiencing similar condition	8	(25), (26), (105), (44), (46), (110), (58), (87)
Unspecified	5	(35), (112), (117), (118), (93)
Other professional advisor (n = 18)		
Individuals identified as scientists or having access to scientific knowledge	2	(17), (105)
Religious practitioners	1	(124)
Formal education figures	4	(33), (105), (120), (83)
Government officials (including public health)	4	(17), (32), (73), (78)
Non-government organizations/Charities	4	(127), (32), (63), (73)
Other sources	8	(23), (17), (139), (35), (53), (112), (143), (89)
<b>Specific settings as source of HRI</b>		
Medical (n = 14)		
Primary care	9	(26), (27), (127), (101), (115), (117), (78), (85), (87)
Secondary care	8	(99), (32), (39), (43), (115), (74), (78), (85)
Other	1	(32)

Community (n = 20)		
Town hall meetings	1	(21)
Community meetings/health centres	5	(99), (53), (117), (78), (124)
Age group meetings	1	(73)
Churches/Religious Gatherings	8	(21), (26), (32), (110), (53), (113), (115), (117)
Support groups	9	(96), (99), (100), (101), (34), (104), (132), (145), (114)
Formal education (n = 5)		
Secondary education	1	(131)
Tertiary education	2	(141), (83)
Unspecified education setting	3	(115), (141), (134)
Other training settings (n = 14)		
Conferences/Seminars/Lectures/Workshops, etc	14	(20), (21), (27), (32), (33), (48), (109), (59), (112), (63), (113), (135), (121), (87)
Other (n = 12)		
Libraries/Book shops	12	(21), (26), (33), (144), (46), (52), (63), (114), (118), (122), (89), (125)
<b>Tools used in independent searches for HRI (n=83)</b>		
Social media (n = 27)		
Social media (unspecified)	18	(19), (20), (21), (22), (23), (25), (17), (33), (144), (46), (48), (60), (140), (66), (82), (88), (91), (126)
Facebook	5	(22), (102), (56), (140), (85)
Twitter	3	(22), (56), (140)
Reddit	1	(22)
YouTube	6	(102), (37), (133), (56), (140), (77)
WhatsApp	2	(56), (60)
Instagram	1	(56)
Pinterest	1	(56)
WeChat	2	(56), (90)
MySpace	1	(140)

Telegram channel	2	(110), (56)
Search engine (n= 19)		
Search engine (not specified)	11	(20), (22), (25), (100), (101), (48), (60), (121), (90), (91), (126)
Google	7	(129), (102), (20), (56), (71), (85), (123)
Yahoo	2	(146), (123)
Naver	1	(123)
Database (unspecified)	1	(122)
Websites (n= 25)		
Health/disease/condition-specific websites	15	(20), (25), (29), (100), (101), (102), (146), (48), (107), (56), (63), (72), (90), (91), (94)
Healthcare providers/service-related websites (physician, hospital, pharmacy, etc)	4	(25), (48), (143), (126)
Personal websites	2	(66), (94)
Health insurance websites	2	(143), (87)
Pharmaceutical websites	1	(143)
Government websites	4	(23), (100), (101), (133)
Online Encyclopaedias	2	(90), (126)
Web portal	3	(143), (86), (90)
Other unspecified websites	3	(110), (53), (82), (94)
Online Communities (n= 13 )		
Online discussion forum	9	(20), (100), (101), (146), (48), (58), (145), (85), (90)
Internet communities	1	(143)
Chat rooms	1	(126)
Online Q&A board/Chat reference service	3	(98), (122), (90)
Scholarly/Academic sources (n= 16)		
Medical/Health/Scientific/Academic Journals and/or magazines	13	(20), (21), (24), (28), (129), (100), (146), (47), (114), (70), (118), (137), (122)
Textbooks/Medical Encyclopaedias	3	(16), (99), (118)
Periodicals	1	(123)

Mass media (n= 51)		
TV (satellite, cable, etc )	37	(20), (21), (23), (24), (26), (27), (16), (28), (128), (17), (129), (29), (99), (102), (139), (33), (35), (38), (146), (46), (47), (48), (108), (109), (53), (59), (63), (145), (114), (115), (71), (73), (76), (82), (85), (88), (125)
Radio	26	(20), (21), (24), (27), (16), (28), (17), (139), (33), (35), (38), (46), (47), (109), (53), (59), (63), (145), (113), (71), (116), (73), (76), (82), (85), (88)
Newspapers and/or magazines (print, online)	33	(20), (21), (23), (26), (27), (127), (28), (128), (17), (129), (29), (139), (35), (38), (39), (43), (47), (109), (53), (59), (63), (145), (66), (71), (73), (74), (76), (85), (88), (123), (89)
Other mass media (unspecified)	6	(32), (131), (50), (74), (141), (87)
Phone services and applications (n= 13)		
Landlines	2	(41), (42)
Telephone services	1	(45)
Health help telephone lines	1	(85)
Telephone (with whom not specified)	1	(122)
Telephone information number	1	(89)
Over the phone (type of phone and with whom not specified)	1	(93)
Unsolicited text messages	1	(85)
Electronic devices and applications	9	(25), (127), (33), (41), (42), (60), (121), (87), (90)
Various printed informational materials (n= 48)		
Poster	7	(19), (24), (26), (27), (32), (46), (143)
Pamphlets/Leaflets/Brochures	21	(20), (24), (26), (127), (128), (99), (139), (35), (43), (46), (109), (54), (59), (115), (78), (135), (87), (137), (122), (89), (125)
Books	27	(20), (21), (27), (127), (28), (128), (17), (139), (38), (146), (39), (43), (59), (63), (145), (114), (74), (76), (117), (118), (78), (121), (87), (88), (137), (122), (89)
Print media/materials (type not specified)	6	(50), (52), (120), (82), (85), (123)
Written (e.g. notices to health examination, test results)	1	(112)
Newsletters	1	(66)
Paper based guidelines/materials	3	(115), (118), (93)
Marketing materials (n= 3 )		
Campaign	1	(19)

Commercial marketing	1	(133)
Medical bill board	1	(46)
Other online sources (n = 2)		
Online sources (not specified)	1	(73)
Web-based health info	1	(86)
Other sources (n= 10)		
Local materials and resources (not specified)	1	(96)
Podcast	1	(127)
Films	1	(127)
Non-science resources	1	(105)
Video services	1	(60)
Favourites lists (not specified)	1	(145)
Worksites	1	(115)
Video instructions	1	(135)
Music, dance, drama	1	(85)
Formal education assessments	1	(83)
Postal	1	(122)

**Table 3: Reasons for seeking or accessing HRI**

	Number of studies	Study number
To look for health information for:		
Oneself	4	(18), (45), (51), (94)
Someone else	11	(18), (19), (100), (45), (51), (56), (59), (116), (118), (92), (94)
To look for health-related information on the following topics (n = 46):		
General health information	11	(20), (24), (129), (40), (45), (49), (56), (59), (73), (84), (94)
A specific disease / condition including its <ul style="list-style-type: none"> <li>- symptoms</li> <li>- diagnosis</li> <li>- prognosis</li> <li>- transmission</li> <li>- causes</li> <li>- complications</li> <li>- other/unspecified</li> </ul>	36	(18), (19), (20), (21), (25), (26), (28), (129), (97), (98), (100), (102), (33), (105), (106), (38), (48), (49), (109), (53), (54), (56), (58), (140), (114), (73), (81), (82), (121), (84), (85), (123), (124), (125), (93), (126)
Treatments <ul style="list-style-type: none"> <li>- Medication</li> <li>- Expert-led treatments (conventional and CAM)</li> <li>- Self-care/self-management<sup>a</sup></li> <li>- Other<sup>b</sup></li> </ul>	28	(18), (20), (25), (26), (96), (28), (129), (97), (100), (101), (32), (105), (106), (38), (49), (132), (109), (53), (54), (58), (59), (114), (73), (118), (81), (84), (85), (123)
Screening and testing <ul style="list-style-type: none"> <li>- for a specific condition</li> <li>- general health check</li> </ul>	6	(18), (20), (28), (97), (114), (84)
For other types of health information <sup>c</sup>	4	(73), (118), (84), (123)
To acquire/develop resources for psycho-social support (n = 9)		
To gain reassurance, comfort and support including from others with lived or personal experience of the condition <sup>d</sup>	7	(95), (24), (25), (98), (38), (54), (118)
To gain a sense of control, ability to cope with the diagnosis, condition or treatment	4	(101), (54), (70), (118)
To navigate their own health journeys and the healthcare system (n = 31)		
To find information on or locate appropriate local healthcare providers	15	(18), (20), (21), (25), (28), (129), (32), (49), (132), (54), (69), (73), (81), (84), (126)
To prepare ahead of meeting HCPs / HC institutions <sup>e</sup>	5	(96), (54), (114), (69), (70)
To make health decisions, including whether to seek professional help	8	(20), (96), (129), (39), (54), (69), (73), (118)
To avoid going to a HC provider	1	(106)
To make own diagnosis, prevent or cure or manage disease /condition or maintain health	9	(20), (21), (105), (106), (146), (46), (48), (69), (73)



	Number of studies	Study number
To verify/confirm/clarify or add to information received from another given source including: <ul style="list-style-type: none"> <li>- To verify information from HCP (n=6)</li> <li>- To obtain additional information<sup>f</sup> (n=3)</li> <li>- To clarify/understand info from HCP or medication label or prescriptions (n=4)</li> <li>- General or unspecified (n=1)</li> </ul>	10	(21), (24), (98), (104), (38), (54), (56), (73), (118), (94)

Notes:

<sup>a</sup>This includes, for example, home remedies, tips on what's worked well for someone else with the condition

<sup>b</sup>This includes advice on caring for an elderly person, psychological care or unspecified treatments.

<sup>c</sup>This includes information relating to health insurance, policies, and guidelines.

<sup>d</sup> This may involve seeking support from patient groups, other families with children with a similar problem, or reading testimonials online.

<sup>e</sup> For instance, in order to learn what questions to ask of HCP or how to approach HC providers (e.g. importance of being persistent), to be one's own health advocate.

<sup>f</sup> For example because the individual did not have time to ask during their appointment with a HCP or was afraid to ask.

## Supplementary table 1 – Search strategy

**Databases:** CINAHL Plus, Medline, PsycInfo, Social Sciences Full text Search Strategy (combined on EBSCO platform)

**Abstract and title only**

**Limits:** English only; 01-01-2010 to 18-01-2022 only; academic journals, peer-reviewed articles

**Searches:**

Search 1 - 'health information'

a) "access to health information" OR "use of health information" OR "utilization of health information" OR "accessing health information" OR "using health information" OR "utilizing health information" OR "health information utilization" OR "uptake of health information" OR "health information uptake" OR "adoption of health information" OR "adopting health information" (**1859 hits**)

b) public OR general public OR people OR community (index terms) OR lay public (text words) OR patient OR carer OR lay person (**6,096,162 hits**)

**a) AND b) 1272 hits**

Search 2 - 'health research'

a) "access to health research" OR "use of health research" OR "utilization of health research" OR "accessing health research" OR "using health research" OR "utilizing health research" OR "health research utilization" OR "uptake of health research" OR "health research uptake" OR "adoption of health research" OR "adopting health research" (**92 hits**)

b) public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person"

**a) AND b) 30 hits**

Search 3 - 'Research evidence'

a) "access to research evidence" OR "use of research evidence" OR "utilization of research evidence" OR "accessing research evidence" OR "using research evidence" OR "utilizing research evidence" OR "research utilization" OR "uptake of research evidence" OR "research evidence uptake" OR "research uptake" OR "adoption of research evidence" OR "adopting research evidence" (all text words, except 'research utilization', index term) (**947 hits**)

b) health OR healthcare OR “health care” (exploded MeSH term) **(2,238,037 hits)**

c) public OR “general public” OR people OR community OR “lay public” OR patient OR carer OR “lay person”

**a) AND b) AND c): 302 hits**

Search 4 - ‘Scientific evidence’

a) “access to scientific evidence” OR “use of scientific evidence” OR “utilization of scientific evidence” OR “accessing scientific evidence” OR “using scientific evidence” OR “utilizing scientific evidence” OR “scientific evidence utilization” OR “uptake of scientific evidence” OR “scientific evidence uptake” OR “scientific evidence uptake” OR “adoption of scientific evidence” OR “adopting scientific evidence” **(147 hits)**

b) health OR healthcare OR “health care”

c) public OR “general public” OR people OR community OR “lay public” OR patient OR carer OR “lay person”

**a) AND b) AND c): 52 hits**

Search 5 - ‘research findings’

a) “access to research findings” OR “accessing research findings” OR “use of research findings” OR “utilization of research findings” OR “using research findings” OR “access to scientific findings” OR “accessing scientific findings” OR “use of scientific findings” OR “utilization of scientific findings” OR “using scientific findings” **(470 hits)**

b) health OR healthcare OR “health care”

c) public OR “general public” OR people OR community OR “lay public” OR patient OR carer OR “lay person”

**a) AND b) AND c): 46 hits**

Search 6 - ‘research outputs’

a) “access to research outputs” OR “accessing research outputs” OR “use of research outputs” OR “utilization of research outputs” OR “using research outputs” OR “access to scientific outputs” OR “accessing scientific outputs” OR “use of scientific outputs” OR “utilization of scientific outputs” OR “using scientific outputs” **(5 hits)**

b) health OR healthcare OR "health care"

c) public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person"

**a) AND b) AND c): 1 hit**

Search 7 - research or scientific publications/articles

a) "access to scientific articles" OR "access to research articles" OR "access to research publications" OR "access to scientific publications" OR "accessing scientific articles" OR "accessing research articles" OR "accessing research publications" OR "accessing scientific publications" (**24 hits**)

b) health OR healthcare OR "health care"

c) public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person"

**a) AND b) AND c): 4 hits**

Search 8 – Engagement

a) "engagement with research" OR "research engagement" OR "engagement with science" OR "science engagement" (**1457 hits**)

b) health OR healthcare OR "health care"

c) public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person"

**a) AND b) AND c): 535 hits**

Search 9 – other search terms

a) "access to scientific knowledge" OR "access to research" OR "research accessibility" (**484 hits**)

b) health OR healthcare OR "health care"

c) public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person"

a) AND b) AND c): 122 hits

**Total EBSCO (CINAHL, PsycInfo, MedLine, Social Science Full Text): 2364**

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**Database:** SCOPUS

**Abstract and title only**

**Limits:** English only; 01-01-2010 to 18-01-2022 only; articles only

Search 1 - 'health information'

a) TITLE-ABS({access to health information} OR {use of health information} OR {utilization of health information} OR {accessing health information} OR {using health information} OR {utilizing health information} OR {health information utilization} OR {uptake of health information} OR {health information uptake} OR {adoption of health information} OR {adopting health information}) (**908 hits**)

b) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person}) (**4,691,978 hits**)

a) AND b) **647 hits**

Search 2 - 'health research'

a) TITLE-ABS({access to health research} OR {use of health research} OR {utilization of health research} OR {accessing health research} OR {using health research} OR {utilizing health research} OR {health research utilization} OR {uptake of health research} OR {health research uptake} OR {adoption of health research} OR {adopting health research}) (**17 hits**)

b) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) **10 hits**

Search 3 - 'Research evidence'

a) TITLE-ABS({access to research evidence} OR {use of research evidence} OR {utilization of research evidence} OR {accessing research evidence} OR {using research evidence} OR {utilizing research evidence} OR {research utilization} OR {uptake of research evidence} OR {research evidence uptake} OR {research uptake} OR {adoption of research evidence} OR {adopting research evidence}) **537 hits**

b) TITLE-ABS(health OR healthcare OR {health care}) **1,512,118 hits**

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person}) **4,691,978 hits**

a) AND b) AND c): **148 hits**

Search 4 - 'Scientific evidence'

a) TITLE-ABS({access to scientific evidence} OR {use of scientific evidence} OR {utilization of scientific evidence} OR {accessing scientific evidence} OR {using scientific evidence} OR {utilizing scientific evidence} OR {scientific evidence utilization} OR {uptake of scientific evidence} OR {scientific evidence uptake} OR {scientific evidence uptake} OR {adoption of scientific evidence} OR {adopting scientific evidence}) (**95 hits**)

b) TITLE-ABS(health OR healthcare OR {health care})

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) AND c): **31 hits**

Search 5 - 'research findings'

a) TITLE-ABS({access to research findings} OR {accessing research findings} OR {use of research findings} OR {utilization of research findings} OR {using research findings} OR {access to scientific findings} OR {accessing scientific findings} OR {use of scientific findings} OR {utilization of scientific findings} OR {using scientific findings}) ( **132 hits**)

b) TITLE-ABS(health OR healthcare OR {health care}) (**1,512,118 hits, as above**)

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) AND c): **19 hits**

Search 6 - 'research/scientific outputs'

a) TITLE-ABS({access to research outputs} OR {accessing research outputs} OR {use of research outputs} OR {utilization of research outputs} OR {using research outputs} OR {access to scientific outputs} OR {accessing scientific outputs} OR {use of scientific outputs} OR {utilization of scientific outputs} OR {using scientific outputs}) ( **11 hits**)

b) TITLE-ABS(health OR healthcare OR {health care})

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) AND c): **0 hits**

Search 7 - research or scientific publications/articles

a) TITLE-ABS({access to scientific articles} OR {access to research articles} OR {access to research publications} OR {access to scientific publications} OR {accessing scientific articles} OR {accessing research articles} OR {accessing research publications} OR {accessing scientific publications}) ( **26 hits**)

b) TITLE-ABS(health OR healthcare OR {health care})

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) AND c): **6 hits**

Search 8 – Engagement

a) TITLE-ABS({engagement with research} OR {research engagement} OR {engagement with science} OR {science engagement}) ( **793 hits**)

b) TITLE-ABS(health OR healthcare OR {health care})

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) AND c): **110 hits**

Search 9 – other search terms

a) TITLE-ABS({access to scientific knowledge} OR {access to research} OR {research accessibility}) ( **463 hits**)

b) TITLE-ABS(health OR healthcare OR {health care})

c) TITLE-ABS(public OR {general public} OR people OR community OR {lay public} OR patient OR carer OR {lay person})

a) AND b) AND c): **71 hits**

**Total SCOPUS: 1042**

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Web Of Science search (Editions = Science Citation Index Expanded (SCI-EXPANDED), Social Sciences Citation Index (SSCI), Emerging Sources Citation Index (ESCI))

**Topic only (Title, abstract and keywords)**

**Limits:** English only; 01-01-2010 to 18-01-2022 only; academic journals, peer-reviewed articles

Search 1 - 'health information'

a) TS=("access to health information" OR "use of health information" OR "utilization of health information" OR "accessing health information" OR "using health information" OR "utilizing health information" OR "health information utilization" OR "uptake of health information" OR "health information uptake" OR "adoption of health information" OR "adopting health information") (**725 hits**)

b) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person") (**4,214,173 hits**)

a) AND b) **553 hits**

Search 2 - 'health research'

a) TS=("access to health research" OR "use of health research" OR "utilization of health research" OR "accessing health research" OR "using health research" OR "utilizing health research" OR "health research utilization" OR "uptake of health research" OR "health research uptake" OR "adoption of health research" OR "adopting health research") ( **hits**)

b) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) **8 hits**

Search 3 - 'Research evidence'

a) TS=("access to research evidence" OR "use of research evidence" OR "utilization of research evidence" OR "accessing research evidence" OR "using research evidence" OR "utilizing research evidence" OR "research utilization" OR "uptake of research evidence" OR "research evidence uptake" OR "research uptake" OR "adoption of research evidence" OR "adopting research evidence") (**604 hits**)



b) TS=(health OR healthcare OR "health care") (**1,517,557 hits**)

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **185 hits**

Search 4 - 'Scientific evidence'

a) TS=("access to scientific evidence" OR "use of scientific evidence" OR "utilization of scientific evidence" OR "accessing scientific evidence" OR "using scientific evidence" OR "utilizing scientific evidence" OR "scientific evidence utilization" OR "uptake of scientific evidence" OR "scientific evidence uptake" OR "scientific evidence uptake" OR "adoption of scientific evidence" OR "adopting scientific evidence") (**79 hits**)

b) TS=(health OR healthcare OR "health care")

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **29 hits**

Search 5 - 'research findings'

a) TS=("access to research findings" OR "accessing research findings" OR "use of research findings" OR "utilization of research findings" OR "using research findings" OR "access to scientific findings" OR "accessing scientific findings" OR "use of scientific findings" OR "utilization of scientific findings" OR "using scientific findings") (**98 hits**)

b) TS=(health OR healthcare OR health care)

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **21 hits**

Search 6 - 'research outputs'

a) TS=("access to research outputs" OR "accessing research outputs" OR "use of research outputs" OR "utilization of research outputs" OR "using research outputs" OR "access to scientific outputs")

OR “accessing scientific outputs” OR “use of scientific outputs” OR “utilization of scientific outputs” OR “using scientific outputs”) (**6 hits**)

b) TS=(health OR healthcare OR health care)

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **0 hits**

Search 7 - research or scientific publications/articles

a) TS=(“access to scientific articles” OR “access to research articles” OR “access to research publications” OR “access to scientific publications” OR “accessing scientific articles” OR “accessing research articles” OR “accessing research publications” OR “accessing scientific publications”) (**22 hits**)

b) TS=(health OR healthcare OR health care)

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **3 hits**

Search 8 – Engagement

a) TS=(“engagement with research” OR “research engagement” OR “engagement with science” OR “science engagement”) (**830 hits**)

b) TS=(health OR healthcare OR health care)

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **139 hits**

Search 9 – other search terms

a) TS=(“access to scientific knowledge” OR “access to research” OR “research accessibility”) (**353 hits**)

b) TS=(health OR healthcare OR health care)

c) TS=(public OR "general public" OR people OR community OR "lay public" OR patient OR carer OR "lay person")

a) AND b) AND c): **66 hits**

**Total Web of Science: 1,004 hits**

**Total database search prior to de-duplication: 4410**

Supplementary Table 2 – List of included studies, showing relevance to scoping review objective and evidence

Author & date	Study type	Methodology	Participant numbers	Participant characteristics	Participant location	Reasons for access	Source of HR/I	Format of HR/I	Use of HR/I	Barriers & facilitators
Abara et al 2010	✓	✓	✓	✓	✓	✓	✓			
Afeef et al 2021	✓	✓	✓	✓	✓	✓	✓			
Ahmad et al 2021	✓	✓	✓	✓	✓	✓	✓	✓		✓
Ahola et al 2017	✓	✓	✓	✓	✓	✓	✓			✓
Akidi 2019	✓	✓	✓		✓	✓	✓			✓
AlGhamdi 2012	✓	✓	✓	✓	✓	✓	✓			
Alhuwail et al 2018	✓	✓			✓		✓			
Almusawi et al 2021	✓	✓	✓	✓	✓		✓			✓
Alsaadi 2012	✓	✓	✓	✓	✓	✓	✓			✓
Alvarez-Galvez et al 2020	✓	✓	✓	✓	✓	✓	✓	✓		
Anyaoaku & Nwosu 2017	✓	✓	✓	✓	✓		✓			
Ashing-Giwa et al 2012	✓	✓	✓	✓	✓	✓	✓			
Athanasopoulou et al 2017	✓	✓	✓	✓	✓		✓			✓
Balls-Berry et al 2018	✓	✓			✓		✓	✓		
Benard & Chipungahelo	✓	✓	✓	✓	✓	✓	✓			
Bianco et al 2013	✓	✓	✓	✓	✓	✓	✓			
Blaga et al 2019	✓	✓	✓	✓	✓		✓			✓

Author & date	Study type	Methodology	Participant numbers	Participant characteristics	Participant location	Reasons for access	Source of HR/I	Format of HR/I	Use of HR/I	Barriers & facilitators
Brondi et al 2021	✓	✓	✓	✓	✓		✓			
Bulled 2011	✓	✓	✓	✓	✓	✓	✓			✓
Chae & Quick 2015	✓	✓	✓	✓	✓		✓			
Chavarria et al 2017	✓	✓	✓	✓	✓	✓	✓			
Chisolm et al 2011	✓	✓	✓	✓	✓		✓			
Cho et al 2011	✓	✓	✓	✓	✓	✓	✓	✓		
Chung et al 2020	✓	✓	✓	✓	✓		✓			
Clark et al 2014	✓	✓	✓		✓		✓			
Coffey et al 2017	✓	✓	✓	✓	✓	✓	✓			
Coffey et al 2016	✓	✓	✓	✓	✓	✓	✓			
Colineau & Paris 2010	✓	✓	✓	✓	✓	✓	✓	✓		
Criss et al 2015	✓	✓	✓	✓	✓		✓			
Cutilli 2010	✓	✓					✓			
Das et al 2015	✓	✓	✓		✓		✓			
Donelle & Hall 2016	✓	✓	✓	✓	✓		✓			
Edewor 2010	✓	✓	✓	✓	✓	✓	✓	✓		✓
Esmailzadeh et al 2018	✓	✓	✓	✓	✓	✓	✓			✓
Eysenbach et al 2014	✓	✓	✓	✓	✓		✓			
Faith et al 2016	✓	✓	✓	✓	✓	✓	✓	✓		
Feinstein 2014	✓	✓	✓	✓	✓	✓	✓		✓	



Author & date	Study type	Methodology	Participant numbers	Participant characteristics	Participant location	Reasons for access	Source of HR/I	Format of HR/I	Use of HR/I	Barriers & facilitators
Kelley et al 2015	✓	✓	✓	✓	✓		✓			
Kim 2017	✓	✓	✓	✓	✓		✓			✓
Kim et al 2021	✓	✓	✓	✓	✓	✓	✓			
Kim & Kwon 2010	✓	✓	✓	✓	✓		✓			
King-Shier et al 2018	✓	✓	✓	✓	✓	✓	✓		✓	✓
Koohkan et al 2019	✓	✓	✓	✓	✓		✓			
Kugbey et al 2019	✓	✓	✓	✓	✓	✓	✓			
Lam et al 2015	✓	✓	✓	✓	✓		✓		✓	
Laurent et al 2012	✓	✓	✓	✓	✓		✓		✓	
Lee et al 2010	✓	✓	✓	✓	✓		✓			
Lim et al 2022	✓	✓	✓	✓	✓	✓	✓			
Lustria et al 2010	✓	✓	✓	✓	✓		✓			
Maddock et al 2011	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Maitra & Rowley 2021	✓	✓	✓	✓	✓		✓			
Maraziene et al 2012	✓	✓	✓	✓	✓	✓	✓			
Marco-Ruiz et al 2020	✓	✓	✓	✓	✓		✓			
Martensson et al 2020	✓	✓	✓	✓	✓		✓	✓		✓
Masson et al 2019	✓	✓	✓	✓	✓		✓			
Messias & Estrada 2017	✓	✓	✓	✓	✓		✓			
Mi et al 2014	✓	✓	✓	✓	✓		✓			

Author & date	Study type	Methodology	Participant numbers	Participant characteristics	Participant location	Reasons for access	Source of HR/I	Format of HR/I	Use of HR/I	Barriers & facilitators
Moorhead et al 2013	✓	✓	✓	✓	✓	✓	✓			
Nangsangna & da-Costa	✓	✓	✓	✓	✓		✓			
Neter & Brainin 2012	✓	✓	✓	✓	✓		✓	✓	✓	
Obaremi & Olatokun 2021	✓	✓	✓	✓	✓		✓	✓		✓
Ohlow et al 2013	✓	✓	✓	✓	✓		✓		✓	✓
Osei et al 2017	✓	✓	✓	✓	✓	✓	✓		✓	
Ozaki et al 2021	✓	✓	✓	✓	✓		✓			
Ozkan et al 2016	✓	✓	✓	✓	✓		✓		✓	
Paige et al 2021	✓	✓	✓	✓	✓		✓			
Papen 2012	✓	✓	✓	✓	✓	✓	✓			✓
Parija et al 2020	✓	✓	✓	✓	✓	✓	✓			
Peak et al 2010	✓	✓	✓	✓	✓		✓			
Radina et al 2011	✓	✓	✓	✓	✓	✓	✓		✓	✓
Ragusa & Crampton 2019	✓	✓	✓	✓	✓		✓			
Ramirez et al 2015	✓	✓	✓	✓		✓	✓			
Ray et al 2017	✓	✓	✓		✓		✓			
Reghagwa & Ono 2021	✓	✓	✓	✓	✓	✓	✓	✓		✓
Ren et al 2019	✓	✓	✓	✓	✓	✓	✓			
Renahy et al 2010	✓	✓	✓	✓	✓		✓			
Rooks et al 2012	✓	✓	✓	✓	✓		✓			



Author & date	Study type	Methodology	Participant numbers	Participant characteristics	Participant location	Reasons for access	Source of HR/I	Format of HR/I	Use of HR/I	Barriers & facilitators
Rose & Friedman 2013	✓	✓			✓		✓			✓
Rust & Davis 2011	✓	✓	✓		✓		✓			✓
Scantlebury et al 2017	✓	✓	✓	✓	✓	✓	✓			✓
Schladen et al 2011	✓	✓			✓		✓	✓		
Schmidt et al 2021	✓	✓		✓	✓		✓			
Schrank et al 2010	✓	✓	✓	✓		✓	✓		✓	✓
Seckin 2014	✓	✓	✓	✓	✓		✓			
Seckin 2020	✓	✓	✓	✓	✓		✓			
Shum et al 2014	✓	✓	✓		✓		✓			✓
Smith et al 2015	✓	✓	✓	✓	✓		✓			✓
Soni et al 2017	✓	✓	✓	✓	✓	✓	✓			
Suri et al 2016	✓	✓	✓	✓	✓	✓	✓			
Tan & Goonawardene	✓	✓	✓				✓		✓	
Terry et al 2016	✓	✓	✓	✓	✓		✓			
Turnbull et al 2021	✓	✓	✓	✓	✓	✓	✓	✓		
Vader et al 2011	✓	✓	✓	✓	✓		✓			
Vamos et al 2019	✓	✓	✓	✓	✓	✓	✓			✓
Viswanath et al 2013	✓	✓	✓	✓	✓	✓	✓			
Waldman et al 2018	✓	✓	✓	✓	✓	✓	✓	✓		
Wang et al 2022	✓	✓	✓	✓	✓		✓			

Author & date	Study type	Methodology	Participant numbers	Participant characteristics	Participant location	Reasons for access	Source of HR/I	Format of HR/I	Use of HR/I	Barriers & facilitators
Weber et al 2020	✓	✓	✓	✓	✓		✓			
Wlodarczyk et al 2019	✓	✓	✓	✓	✓		✓			
Yamashita et al 2019	✓	✓	✓	✓	✓		✓			
Yi 2015a	✓	✓	✓		✓		✓	✓		✓
Yi 2015b	✓	✓	✓	✓	✓		✓	✓		✓
Yi et al 2012	✓	✓	✓	✓	✓	✓		✓		
Yoon et al 2017	✓	✓		✓	✓		✓			✓
Yusup et al 2019	✓	✓	✓	✓	✓	✓	✓			
Zach et al 2011	✓	✓	✓	✓	✓	✓	✓			✓
Zaim et al 2021	✓	✓	✓	✓	✓		✓			
Zhang et al 2020	✓	✓	✓		✓		✓	✓		
Zhao et al 2021	✓	✓	✓	✓	✓		✓			
Zulman et al 2013	✓	✓	✓	✓	✓	✓	✓			

Additional file 1 – Data extraction tool

Data Extraction Tool																			
Author(s)	Date	Title	Journal	Study type (e.g. research, review)	Methodology	Intervention or specific product evaluation? Y/N	If intervention / product evaluation add detail	Participant numbers	Participant characteristics	Participant Geographical location	Reasons / purpose for accessing HRI	Communication tool used for accessing HRI	Format of HRI accessed	Use of HRI	Condition/ aspect of health or healthcare accessed	Factors facilitating access/barriers to accessing/using HRI	Study conclusions	Author recommendations	Notes