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Highlights:

- Wide variation in experiences of discussing HPV in the context of **head and neck cancer** (HNC)
- Reliable information about HPV needed for both HCPs and HNC patients
- HCPs vary in confidence in HPV discussions, which is related to HPV knowledge
- Barriers to discussions include the perception in HCPs that HPV is a sensitive topic
- Strategies to facilitate HPV discussions in patient-provider consultations need

Communicating about HPV in the context of head and neck cancer: a systematic review of quantitative studies

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Abstract

Objective: Rising incidence of HPV-positive head and neck cancers (HPV-HNC) means HPV infection is increasingly relevant to patient-provider consultations. We performed a systematic review to examine, in the context of patient-provider HNC consultations: discussions about HPV, attitudes towards discussing HPV and information needs.

Methods: We searched Embase, PsychINFO, and CINAHL+ for studies to August 2018. Eligible studies included: HNC healthcare professionals (HCPs) and/or HNC patients investigated HNC patient-provider communication about HPV.

Results: Ten studies were identified: six including HCPs and four including patients. HCPs varied in confidence in HPV discussions, which was related to their HPV knowledge. Both HCPs and patients acknowledged the need for reliable HPV information. Factors which facilitated HPV discussions included accessible HPV information for patients and HCPs and good HPV knowledge among HCPs. Barriers included the perception, among HCPs, that HPV was a challenging topic to discuss with patients.

Conclusions: Information deficits, communication challenges and barriers to discussing HPV were identified in HNC patient-provider consultations.

Practice Implications: Appropriate HPV information is needed for HCPs and patients. Professional development initiatives which increase HCPs' HPV knowledge and build their communication skills would be valuable.

Keywords: Human papillomavirus; Head and Neck cancer; Healthcare professionals; Patients; Communication; Patient-provider consultations; Systematic review.

1 **1. Introduction**

2 Human papillomavirus (HPV) is a causal agent for cervical, vulvar, vaginal, penile, anal, and
3 some head and neck cancers (HNCs) [1]. Globally, approximately 38,000 cases of head and
4 neck cancers per year are attributable to HPV [2]. In recent decades, North American and
5 European populations have experienced rising incidence of head and neck squamous cell
6 cancers (HNCs) linked to HPV infection [3, 4]. This increased incidence of HPV-positive
7 HNCs (HPV-HNC) has led to new challenges for healthcare professionals (HCPs) in terms of
8 communication with patients around HPV. A broad range of HCPs may be faced with HPV-
9 related questions from patients, ranging from general practitioners (GPs), to dentists who deal
10 with non-cancer patients, as well as surgeons, oncologists and speech and language therapists
11 who see patients diagnosed with HNC. Evidence-based health information can facilitate
12 informed healthcare decision-making by patients [5]. A growing range of health information
13 sources are accessible to patients - both formal and informal- which can vary in quality and may
14 expose them to confusing and conflicting information [6, 7]. Emerging evidence suggests HPV-
15 HNC patients often have specific information needs regarding the origin of their disease, how
16 they acquired the HPV infection and long-term implications [8]. Moreover, they may
17 experience significant psychological distress as a result of their combined cancer and HPV
18 diagnosis [8]. It is clear, therefore, that this patient group requires appropriate communication
19 about HPV and high-quality information from healthcare providers. However, although HPV-
20 HNC patients may consider their doctors as their primary trusted information source about HPV
21 [9], approximately half of patients reported that their oncologist did not discuss HPV-related
22 issues with them [10].

23 Research in the area of cervical cancer screening has established that health professionals can
24 encounter challenges in discussing HPV with patients, mainly because of its sexually

25 transmitted nature and often lack HPV knowledge [11, 12, 13]. Studies in the area of HNC,
26 albeit limited, suggest that while most health professionals are willing to discuss HPV with
27 patients, they have mixed views about explaining the causal role of HPV in HNC [14] and can
28 be uncomfortable in discussing HPV [15].

29 It is important that effective, evidence-based patient-provider HPV communication strategies
30 are developed in the context of HNC. Understanding health-care providers' and patients'
31 perspectives is vital in developing such strategies. We, therefore, performed a systematic review
32 to examine, in the context of HNC, patient-provider consultations, (1) discussions about
33 HPV and attitudes towards discussing HPV and (2) HPV information needs of HCPs and HNC
34 patients.

35

36 **2. Methods**

37 This systematic review was conducted and reported according to Preferred Reporting Items for
38 Systematic Reviews and Meta-Analyses (PRISMA) guidelines [16]. The review protocol was
39 published at PROSPERO (CRD42017058224).

40 *2.1 Search strategy*

41 Eligible papers were identified through searches of three electronic databases from 01/01/2007
42 to 31/08/2018: EMBASE, CINAHL+ and PsychINFO. Search terms were developed by the
43 research team in consultation with a specialist librarian and involved both controlled vocabulary
44 from databases (MeSH) and free text words/phrases (Table 1). The search was restricted to
45 English language and full peer reviewed papers.

46 <<Table 1>>

47 *2.2 Selection criteria*

48 This review set out to investigate HPV communication between HCPs and HNC patients
49 and, specifically, to explore attitudes in both groups towards discussing HPV. It also

50 aimed to identify barriers/facilitators to such HPV discussions and information needs of
51 HCPs and HNC patients. In order to facilitate synthesis of the data in a concise manner it
52 was decided to focus on quantitative studies. Inclusion and exclusion criteria are presented in
53 Table 2. Since the initial search was intended to be sensitive (to identify all relevant literature),
54 no restriction was placed around research design. Editorials, case-reports, case studies, letters,
55 conference abstracts, overviews, reviews or systematic reviews were subsequently excluded on
56 screening. Papers were eligible if they (i) included HCPs or HNC patients/patients with
57 suspected HNC and (ii) presented quantitative data on patient-provider
58 discussions/communication about HPV infection in the context of HNC. Mixed methods studies
59 were also eligible if quantitative data were reported separately. Papers were ineligible if they
60 were (i) related to any cancer other than head and neck, (ii) focused on HPV infection in
61 relation to cervical cancer prevention or (iii) related to HPV vaccination.

62 <<Table 2>>

63 *2.3 Selection procedure*

64 Screening of titles and abstracts was conducted independently by at least two authors (MO'C,
65 BO'D & AÓC). Differences in opinion were resolved by discussion. Papers identified as
66 potentially eligible by at least one author were obtained and underwent independent full-text
67 review by MO'C, BO'D and AÓC. Reasons for exclusion were recorded (e.g. wrong disease,
68 wrong patient population, about HPV vaccination). Reference lists of eligible papers were
69 searched for further relevant papers. Relevant journals (Oral Oncology; Journal of
70 Otolaryngology - Head and Neck Surgery; Papillomavirus Research and BMC Oral Health,
71 Head & Neck) were manually searched.

72 *2.4 Quality Assessment*

73 A revised version of a previously developed quality checklist [18, 19] was used by two
74 reviewers to independently appraise the eligible papers (MO'C & BO'D). This assessed

75 methodological quality across ten parameters, including research design, recruitment, data
76 collection and data analysis. There were three response options for each parameter - “Yes=1”,
77 “No=0” and “Partially=0.5”- which were then summed. Thus, each paper was scored 0-10 with
78 higher scores indicating more robust methodological quality. Any differences between
79 reviewers were resolved through discussion. In order to provide a full overview of the
80 available evidence, papers were not excluded from narrative synthesis on the basis of their
81 scores.

82 *2.5 Data extraction and synthesis*

83 The following information was extracted for each paper: author, year, country of origin and data
84 collection time period; study design; study population, sample size; and method of data
85 collection. Quantitative data related to discussions/communication about HPV infection in
86 the context of HNC were also extracted, specifically: (1) discussions about HPV, (2) attitudes
87 towards discussing HPV and (3) HPV information needs of HNC healthcare professionals, and
88 HNC patients. Data were extracted independently by two reviewers (MO’C and BO’D) with
89 any differences resolved through discussion. The heterogeneous nature of the study designs,
90 populations, outcomes and analyses methods meant that a narrative synthesis was
91 considered the most appropriate approach to combining and summarizing the evidence
92 [17]. This was structured around (i) discussions about HPV (ii) Attitudes of HCPs and HNC
93 patients towards discussing HPV and (iii) HPV information needs of HCPs and HNC patients.
94 It was conducted by two reviewers, and involved three stages: (1) preliminary synthesis,
95 involving grouping of studies, tabulation and examining similarities and/or differences in
96 the data; (2) exploration of relationships within the data using, for example, frequency
97 distributions, spider diagrams, concept mapping and translation; and (3) assessing the
98 robustness of the synthesis, which was done through the quality assessment described

99 earlier. For the purposes of this review dental professionals are defined as dentists and
100 dental hygienists.

101

102 **3. Results**

103 *3.1 Search results*

104 An adapted PRISMA flow diagram is shown in Figure 1. The initial search returned 980
105 citations. After removing duplicates the titles and abstracts of 543 papers were screened. A
106 total of 21 papers were selected for full-text review, 8 of which were eligible on full-text
107 review. An updated electronic search and hand search of relevant journals and reference lists
108 generated additional papers, of which 2 were deemed to be eligible. Thus a total of 10 eligible
109 papers were identified, 9 were quantitative and one a mixed-method study (only quantitative
110 data from the latter was considered).

111 <<Figure 1>>

112 *3.2 Description of the studies*

113 Table 3 summaries the study characteristics. All were cross-sectional with three published
114 2007-2016 and seven published 2017-2018. Seven studies were conducted in the United States
115 [20,24, 25, 26 27, 28, 29] two in Canada [21, 22] and one in the United Kingdom and Ireland
116 [29]. Study populations varied: six included HCPs [, 20, 21, 22, 23, 24, 25] and four included
117 HNC patient studies [26, 27, 28, 29]. Of the six HCP studies, one was with dental hygienists
118 [22], two were with dentists and dental hygienists [, 20, 24] and three were with a range of
119 HCPs who see HPV- HNC patients [21, 23,25]. The four HNC patient studies included three
120 studies with HPV positive (+ve) participants [26, 27, 29]. All ten studies used some type of
121 sampling frame to identify potentially eligible participants (e.g. for health professional studies -
122 the American Head and Neck Society [25], various HNC professional organisations in the UK

123 [23]; for HNC patient studies – lists of patient diagnosed with HPV-HNC within a certain time
124 frame at a specific hospital [26, 27, 28, 29]. Sample sizes varied from 34 to 372 participants.

125 <<Table 3>>

126 All three review topics (discussions about HPV, attitudes towards discussing HPV, and HPV
127 information needs) were investigated in five studies [21, 23, 25, 26, 27] with two topics
128 considered in three studies [24, 28,29] and just one topic explored in two studies [20,
129 22]. Details are presented in Tables 4 and 5.

130 <<Table 4>>

131 <<Table 5>>

132 *3.3 Quality appraisal*

133 When quality was appraised, the studies scored in the range 5-7.5 (mean = 6.7; median = 6.75)
134 out of a possible 10. In general, studies scored poorly (≤ 1) in the areas of documenting
135 eligibility and recruitment, describing non-responders (and non-participants), and
136 appropriateness of statistical methods (Table 6).

137 <<Table 6>>

138 *3.4 Discussions about HPV*

139 HCPs reported discussing or having previous experience of discussing HPV with their
140 patients in four of the six HCP studies; the proportion of HCPs who reported discussing HPV
141 ranged from 17% to 91% [20, 21, 23, 25,]. These proportions varied considerably across the
142 different professions; in two studies of HNC surgeons [21, 25], >80% discussed HPV with
143 patients compared to just 19% of dentists in another study [20]. Many HNC patients –
144 proportions ranging from 45% to 94% - reported HPV discussions with their HCPs in three
145 studies [26, 27, 29]. In two of the three studies of HPV+ve HNC patients, a majority, 90% and
146 94%, reported discussing HPV with their HCP [26, 27]; however this figure fell to 45% in the
147 third study [29]. For both HCPs and HNC patients, the experience of discussing HPV varied

148 across studies. One study indicated that patients were confident they could potentially discuss
149 HPV with their HCPs if they wanted to [28]. However, in another study, many patients reported
150 that their oncologist either did not discuss (39%) or only ‘somewhat’ discussed (45%) HPV and
151 HNC with them [29]. These limited HPV discussions resulted in them seeking information
152 elsewhere [29]. In one study older patients were less likely than younger patients to have been
153 told by their HCPs that their cancer was HPV-related and less likely to know if their cancer was
154 HPV positive [26]. Evidence emerged in two HCP studies that primary care physicians (PCPs)
155 do not usually tell their patients that some HPV strains can cause HNC [21, 24]. Some
156 professional groups - namely surgeons, oncologists & specialist nurses - had more experience of
157 HPV discussions than speech language therapists (SLTs) or other HCPs [23]. Oncologists and
158 surgeons reported that they most often initiated any HPV discussions with patients while, by
159 contrast, SLTs observed that HPV discussions were generally initiated by patients. Patients in
160 two studies reported they were satisfied with their HPV discussions and found them useful [26,
161 27].

162 *3.5 Attitudes of HCPs and HNC patients towards discussing HPV*

163 Nine of the 10 studies reported attitudes towards discussing HPV [21, 22, 23, 24, 25, 26, 27, 28,
164 29]. Five of these explored HCPs’ attitudes to HPV discussions [21, 22, 23, 24, 25] and four
165 explored patients’ attitudes [26, 27, 28, 29]. One study reported that 52% of HCPs felt they had
166 inadequate HPV knowledge [21]. Two studies, on the other hand, reported that HCPs were
167 confident in their HPV knowledge [20, 22]. Confidence in discussing HPV with patients varied
168 and was related to the HCPs’ HPV knowledge in two studies [22, 23]; one of these also found
169 confidence was linked to length of professional practice [23]. Cancer specialists (surgeons,
170 oncologists, specialist nurses) were generally more confident about engaging in such
171 discussions with patients than allied healthcare professionals and non-specialist nurses [23].
172 One study indicated that willingness among HCPs to engage in future HPV discussions was

173 linked to HPV knowledge and overall positive attitudes among HCPs to such discussions [23].
174 The same study also reported cancer nurse specialists had more positive attitudes to discussing
175 HPV with their patients than surgeons, oncologists and allied HCPs [23].
176 In relation to patients' attitudes to discussing HPV, in one study (conducted among a mixed
177 group of HPV-positive and HPV-negative HNC patients), almost all patients (95%) were
178 confident they could talk to their doctor about HPV, but only 53% reported that they had
179 sufficient knowledge about HPV to discuss it. Furthermore, a high proportion of HPV- positive
180 patients in this study (47%) indicated they did not have sufficient information about HPV to
181 engage in discussions with their HCPs [28]. Three HCP studies reported barriers to discussing
182 HPV with patients: these included lack of HCP awareness/knowledge about HPV; HCPs
183 prioritising other health topics; time constraints; lack of privacy; fear of offending patients; and
184 patients' age/gender [21, 23, 24]. Barriers to discussing HPV with HCPs were not explicitly
185 examined in any of the patient studies. One study reported that reasons for HPV-HNC patients
186 not disclosing their HPV status to partners included embarrassment and stigma [29].
187 One study investigated the specific roles of dentists and dental hygienists in discussing HPV in
188 the context of HNC prevention. Most participants (% not specified) agreed that dental
189 professions have a role in discussing HPV with patients [24] and facilitators of such discussions
190 included educational opportunities for HCPs; accessible pamphlets for patients; and
191 technological support materials [24]. In the one study conducted among dental hygienists,
192 participants were confident in conducting oral cancer screenings but did not feel prepared
193 enough or confident to discuss HPV with their patients [22].

194 *3.6 Information needs*

195 Eight studies reported on HPV-related information needs [21, 23, 24, 25, 26, 27, 28, 29], four
196 studies among HCPs [21, 23, 24, 25] and four among HNC patients [26, 27, 28, 29]. Three of
197 the four HCP studies reported that HCPs needed more HPV information, [23, 24, 25]. One

198 study identified a variety of HPV information needs for dental hygienists (and patients) which
199 included communication skills training and pamphlets/videos in practice waiting rooms [24].
200 HCPs were generally supportive of educational opportunities about HPV in HNC for both
201 themselves and patients [24, 25].

202 Two patient studies reported that many patients felt it was important for patients to know about
203 HPV and the most useful HPV information for patients was related to survival and treatment
204 rates [26, 27].

205 Studies indicated that a variety of information sources are accessed by HCPs and patients for
206 information about HPV. HCPs access the internet, medical journals and consult with other
207 colleagues [21]. The internet was also used by HNC patients after diagnosis and many found it a
208 useful source of information on HPV [27]. In terms of trusted sources of HPV information for
209 HNC patients, in one study, doctors/HCPs ranked first but the internet was the most utilised
210 information source (81% used the internet v 38% doctors/HCPs) [28].

211

212 **4. Discussion and conclusion**

213 *4.1 Discussion*

214 This systematic review is the first to examine the emerging literature on HCP and patients'
215 discussions about HPV, and attitudes towards, discussing HPV and HPV information needs in
216 the context of HNC. There was wide variation in experiences of discussing HPV across studies.
217 Among HCPs, the proportion of dental professionals (which here refers to dentists and dental
218 hygienists) and SLTs discussing HPV with patients was lower than HNC surgeons and
219 oncologists. Among HNC patients the experience of discussing HCPs also varied, although,
220 in all studies, the majority reported they had discussed HPV with their HCPs. These
221 discussions may have been initiated by patients or their HCPs. It is noteworthy that some
222 HPV positive HNC patients reported that their oncologist did not discuss HPV with them

223 or only engaged in limited discussions [29]. The prognostic implications of a HPV positive
224 HNC diagnosis suggest that providing HPV-related information to these patients in
225 particular, should be a priority in their healthcare.

226 This review also highlighted that there was variation in confidence in discussing HPV among
227 healthcare professionals. Confidence in discussing HPV with patients was related to the HCPs'
228 HPV knowledge and length of professional practice. A variety of information sources,
229 including the internet, are currently accessed by HCPs and patients, but all stakeholder groups
230 recognised the need for access to further reliable information about HPV. The factors which
231 facilitated HPV discussions included accessible information sources for patients and HCPs and
232 good HPV knowledge among HCPs, while barriers that impeded discussions included the
233 perception of HCPs that HPV is a challenging topic and HCPs' beliefs about their capabilities to
234 initiate HPV discussions.

235 *4.1.2 HPV-HNC discussions – the HCP perspective*

236 This review suggests that there is variation in confidence among HCPs in discussing HPV with
237 their patients [21]. This confidence was linked to HPV knowledge and duration of professional
238 practice [23]. However, HCPs spoke about gaps in knowledge, a finding consistent with
239 previous research in the context of HPV and cervical cancer prevention [12, 13, 33, 34]. This
240 review also suggests that while surgeons and oncologists may readily discuss HPV with their
241 patients, allied HCPs were less likely to discuss HPV with patients and instead refer the patient
242 back to their medical team. Similarly, previous studies in the area of cervical cancer prevention
243 found differences in HPV knowledge between professional groups (e.g. public health
244 nurses/practice nurses compared with GPs) [13, 35]. Compared to other cancers, there is a
245 diverse group of health professionals (including but not limited to surgeons, nurses, dental
246 professionals, and allied health professionals) involved in the diagnosis, treatment and post-
247 treatment recovery of HNC. Therefore, it is important that all HCPs, who may come into

248 contact with patients who want to know about HPV, have the knowledge and skills to be able to
249 have these conversations. Cancer care is multi-disciplinary and HCPs who deal with HNC
250 patients are likely to be particularly diverse - dentists can frequently play a key diagnostic role.
251 Improvements in HCP education should reflect the importance of allied HCPs in HNC care and
252 focused training around HPV-HNC communication skills is likely to be needed.

253 Dental professionals (including dentists and dental hygienists; dental therapists, dental
254 nurses and oral health educators [30]) may be the first health professional point of contact for
255 patients with potential cancers in the oral cavity. In addition, dentists are often involved in the
256 care of HNC patients undergoing radiotherapy. As they generally see their patients more often
257 than other HCPs (with the exception of GPs) they are optimally positioned to discuss HPV with
258 their patients. This review found some evidence for this evolving role of dental professionals,
259 particularly in discussing HPV prevention efforts and increasing patient awareness of HPV
260 infection and its association with HNC. Recent research examined the potential role that
261 dental professionals could have in preventing HPV-related oral cancer. It was suggested
262 that an expansion of prevention strategies used in dental practices is required [31; 32]. It
263 is likely that a multi-level approach would be needed to improve dental providers' self-
264 efficacy to communicate about HPV. Any effective intervention would need to consider the
265 specific environmental context of dental settings, dental training/skills development, and
266 perceptions of professional roles [32].

267 *4.1.3 HPV-HNC discussions – the patient perspective*

268 Qualitative research suggests that patients consider HCPs to be a trusted information source
269 about HPV and that HPV-HNC patients have specific concerns about the origin and long- term
270 effects of their HPV-HNC [8, 9]. This review shows that many HPV-HNC patients engaged in
271 HPV discussions with their HCPs [26, 27, 28, 29] although it should be noted that only 4
272 studies of HNC patients were identified and 3 of these included only HPV positive patients.

273 Moreover, patients reported considerable variation in these discussions and some described
274 limited HCP interactions and inadequate HPV discussions. In particular, patients considered
275 HPV discussions to be inadequate if HCPs did not provide them with information about
276 HPV at diagnosis or did not discuss the link between HPV and cancer or the emotional
277 effects of an HPV associated cancer diagnosis. Many patients felt uninformed and as a result
278 sought information elsewhere. These findings are supported by qualitative research among
279 HPV-HNC patients which found that issues related to HPV were not discussed enough in
280 conversations with their doctors and patients had questions around HPV that remained
281 unanswered [9]. This review also suggests that older HNC patients received information from
282 their HCPs around HPV less often than younger patients. These results are of concern as the
283 population of older patients with HPV-positive tumours is growing [36].

284 *4.1.4 HPV-HNC discussions – barriers and facilitators*

285 A noteworthy finding of this review concerns the factors which facilitate or impede patient-
286 provider HPV communication [21, 23, 24, 25, 26, 28]. Although some environmental barriers to
287 HPV discussions were identified (e.g. time limitations and lack of privacy in the clinical
288 setting); in general, the factors that influenced HCPs willingness to engage in these discussions
289 were HPV knowledge, communication skills, and individual beliefs among HCPs about their
290 capabilities to initiate HPV discussion. Previous research with HCPs in other contexts also
291 identified lack of knowledge, poor communication skills and environmental limitations as
292 barriers to effective HPV discussion [12, 37]. Several studies with GPs and practice nurses
293 highlight a perception among HCPs that HPV could be a challenging or sensitive topic, which is
294 also consistent with research in cervical cancer prevention which identified unease experienced
295 by HCPs when answering HPV-related questions as well as the challenges of communicating
296 HPV-related information to particular patient groups [38,40]. This suggests that professional
297 development initiatives which address HCPs' knowledge gaps, enhance their beliefs about

298 capabilities in discussing HPV with patients, build their communication skills and alleviate
299 concerns about consequences of HPV discussions, would be valuable.

300 Among patients, barriers and facilitators to HPV discussions with HCPs were not explicitly
301 explored in any studies, and this is an important evidence gap. Although SLTs reported that
302 HPV discussions were initiated by some patients [23], additional research is required to
303 determine what support might be needed to assist patients in more routinely initiating such
304 discussions with their HCPs.

305 *4.1.5 HPV-HNC information needs*

306 In healthcare reliable information is considered to be information which is evidence based,
307 and available to patients from credible sources [39]. This review strongly suggests that there
308 is a need for access to reliable information about HPV for both HCP and patients. Unmet
309 information needs for HCPs and HPV-HNC patients were identified in all studies. HCPs
310 highlighted the need for more information and education on HPV; and access to support tools
311 such as journals and mobile apps. Increasingly, HCPs are being faced with patients during
312 consultations who have accessed online health information. Online health information has been
313 shown to be beneficial for patients – it can increase their knowledge of, competence with, and
314 engagement in health decision-making strategies; it allows them to find answers for additional
315 or forgotten questions; and it can offer special insights and reflections from the lived
316 experiences of their specific health conditions, especially when patients access patient-centred
317 websites, blogs, or online support communities [41]. A striking finding of this review concerned
318 a common pattern of internet use for obtaining HPV information across study populations. In
319 one HCP study conducted among a wide range of health professions, the internet was cited by 4
320 out of 5 participants as the main source of information about HPV [23]. These findings contrast
321 with our own qualitative research among women who underwent HPV testing in the context of
322 cervical screening follow-up, and who reported negative experiences of searching for HPV

323 information on the internet, and described the information accessed as being contradictory or
324 exaggerated [19]. Research on accessing health information in other areas found the volume of
325 available information can be overwhelming and/or contradictory, often leading to information
326 overload [42, 43]. In order to mitigate the potential for patients seeking online information on
327 HPV and HNC to access untrustworthy, contradictory or overwhelming information, an open
328 dialogue between HCPs and patients about online health information is needed, as are
329 appropriate and credible HPV information resources.

330 *4.1.6 Strengths and limitations*

331 The review followed the PRISMA guidelines [16]. The search strategy was designed to
332 optimise sensitivity and multiple databases were searched. However, the possibility cannot be
333 entirely excluded that relevant papers may have been missed. We included only papers that
334 were published in English, which meant that any relevant papers in other languages were
335 missed. Moreover, we decided not to search the grey literature and it is possible reports,
336 conferences proceedings and other aspects of the grey literature could contain potentially
337 interesting studies. However, the nature of these studies makes it difficult to include them in a
338 systematic way, and conference abstracts usually do not provide much detail about design,
339 methods and findings. In terms of the evidence-base itself, a major limitation is heterogeneity in
340 design, study population, and, importantly, how the outcomes were assessed. Consequently, the
341 data could not be combined statistically. None of the included studies used validated
342 instruments to assess outcomes – one patient study [27] did incorporate some questions from
343 the validated HPV Impact Profile (HIP) tool [44] to assess HPV information needs. Another
344 limitation of the evidence-base from the perspective of HCPs, is that only one study included
345 GPs (family physicians) [21]. These healthcare professionals are at the coalface of patient care
346 and with the incidence of HPV-HNCs rising worldwide, it is increasingly likely that GPs will be
347 faced with discussing HPV and HNC with their patients during consultations. The purpose of

348 the quality appraisal was to aid critical evaluation of the credibility of the paper's
349 findings; therefore, papers were not excluded from the narrative synthesis on the basis of
350 their scores. However the mean quality score was 6.7 of a possible 10 and no studies
351 scored more than 7.5. The robustness of the studies' findings may be questionable as
352 frequently only descriptive analyses were conducted, recruitment strategies were poorly
353 described and limited (or no) information about non-participants was provided. Additional
354 limitations of the evidence-base not covered in the appraisal of individual studies include: the
355 absence of any longitudinal studies (all were cross-sectional); the relatively small sample sizes
356 of most studies (especially those among HNC patients); and, in the HNC patient studies, the
357 lack of a population-basis and variations in time from diagnosis. Improved methodological
358 rigour in future studies is required to reduce potential for bias and improve generalisability. In
359 particular for HNC patient studies, use of population-based sampling frames and larger sample
360 sizes would improve robustness of findings, while longitudinal research would be valuable to
361 determine whether HPV information needs vary over time from cancer diagnosis.

362 *4.2 Conclusion*

363 The incidence of HPV-HNC is increasing - therefore there is a need to address the specific
364 information needs in HCPs and HPV-HNC patients. This review has identified information
365 gaps, challenges and barriers around HPV communication in the context of the patient-provider
366 consultations. The findings highlight the need for appropriate and credible HPV health
367 information for HCPs and patients. Future research should focus on identifying patient barriers
368 to HPV discussions, reducing the barriers (for both HCPs and patients) to HPV discussions and
369 identifying effective strategies to facilitate (and improve) HPV communication in patient-
370 provider consultations. These could include tailored communication training for HCPs and
371 increasing patient access to reliable HPV information with online resources.

372 *4.3 Practice implications*

373 This review identified the need for appropriate HPV information for HCPs and patients.
374 Professional development initiatives which use accessible support tools to increase HCPs' HPV
375 knowledge and build their communication skills would be beneficial for patient- provider
376 consultations. These could include, for example, continuing education programs for HCPs
377 and the incorporation of HPV as part of HCP's training curricula e.g. a role for dental
378 schools in training dental providers about HPV and improving their capacity to discuss
379 HPV with their patients. HPV discussions can potentially occur in many different contexts
380 with many different HCPs and different types of patients (both HNC patients and non-HNC
381 patients). These interactions can possibly take place between surgeons/oncologists/nurses/SLTs
382 and HNC patients; GPs and non-cancer patients; dentists/dental hygienists and non-cancer
383 patients. Interventions to improve patient-provider discussions about HPV should be tailored to
384 reflect this wide variety of potential patient- provider interactions. There could be a role for
385 professional associations in providing a framework to assist HCPs in these interactions
386 e.g. tailored technological support materials or HPV communication scripts.

387

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391

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396 Conflict of interest

397 None declared.

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Table 1. Search terms and strategy for databases

Databases	Search strategy
EMBASE (2007-2018)	hpv* AND 'head and neck tumour' OR 'oropharyngeal cancer*' OR 'mouth cancer' OR 'oral cancer' OR 'tonsil cancer' OR 'tonsillar cancer' OR 'larynx cancer' OR 'laryngeal cancer' AND experience OR 'information needs' OR information OR 'doctors visit' OR practices OR 'patient education' OR beliefs OR attitudes OR consultation OR counseling OR counselling OR discussion OR communication OR guidance
CINAHL PLUS (2007-2018)	"Oropharyngeal cancer*" OR "Head and Neck tumour" OR "Mouth cancer" OR "Oral cancer" OR "Tonsil cancer" OR "Tonsillar cancer" OR "Larynx cancer" OR "Laryngeal cancer" AND "Papillomavirus infections" OR hpv* AND Experience OR Information OR "Information needs" OR "Doctors visit" OR Practices OR "Patient education" OR Attitudes OR Beliefs OR Consultation OR Counselling*
PsychInfo (2007-2018)	(HPV*) AND (Head and neck tumour OR Oropharyngeal cancer OR Mouth cancer OR Oral cancer OR Larynx cancer OR Laryngeal cancer) AND (Experience OR Information needs OR Information OR Doctors visit OR Practices OR Patient education OR Beliefs OR Attitudes OR Consultation OR Counselling* OR Discussion
Hand searching ^a (2007-2018)	Oral Oncology; Journal of Otolaryngology - Head and Neck Surgery; Papillomavirus Research; BMC Oral Health

^a Relevant journals from reference lists of eligible papers.

Table 2. Inclusion and exclusion criteria

	Inclusion Criteria	Exclusion Criteria
Population	HNC patients (undergoing treatment or undergoing post-treatment followup) Patients with suspected HNC (awaiting diagnosis) Non-patient adult (aged 18+yrs) population ANY Health professional	General population studies
Outcomes	Discussions about HPV, attitudes towards discussing HPV and information needs around HPV in the context of head and neck cancer	HPV infection in the context of cervical cancer/cervical cancer prevention HPV infection knowledge/awareness HPV vaccine knowledge/awareness Attitudes towards HPV vaccine Attitudes towards discussing HPV vaccine
Study design	No limits on study size Qualitative and quantitative studies Mixed methods studies Cross-sectional and prospective studies Longitudinal studies RCTs Structured and semi-structured interviews Postal/online surveys Focus groups	
Reporting	Studies must report sufficient detail on how and what outcomes were assessed Studies must report sufficient detail on results for meaningful data extraction Full-text English language papers that report primary data and are published in peer-reviewed journals	Editorials, case-reports, case studies, letters, conference abstracts, overviews*, reviews* or systematic reviews*, papers that propose 'frameworks' for counselling pts on HPV <i>*Reference lists of these were reviewed for potentially eligible papers</i>

Table 3. Characteristics of included studies (n=10)

Study (author & yr, location, data collection time period)	Study design	Study Population	Method of Data collection
<i>HCP studies</i>			
1. Anderson et al., 2017, Canada Oct 2014-April 2015	Cross-sectional quantitative	N=337 (PCPs, OHNs, OBGYNs, paediatricians)	Self-administered online and paper-based survey questionnaires*
2. Clarke et al., 2017, Canada May-July 2015	Cross-sectional quantitative	N=256 dental hygienists who routinely conducted OCSs	Self-administered online survey questionnaires
3. Daley et al., 2017, USA 2015	Cross-sectional quantitative	N=182; 36 dentists & 146 dental hygienists	Self-administered paper-based survey questionnaires completed at a continuing education course
4. Dodd et al 2017, UK/IRL No dates	Cross-sectional quantitative	N=260 (Surgeons, oncologists, specialist nurses, SLTs, 'Other' ^s)	Self-administered online and paper-based survey questionnaires ^a
5. Kline et al., 2018 ^c , USA 2015 & 2016	Mixed methods - cross-sectional quantitative	N=203 (37 dentists & 166 dental hygienists)	Self-administered paper-based survey questionnaires completed at professional conferences
6. Malloy et al 2013, USA 2011 & 2012	Cross-sectional quantitative	N=297 Head and Neck surgeons	Self-administered online survey questionnaires
<i>Patient/Non patient studies</i>			
7. D'Souza et al., 2016 USA Sept 2014-Feb 2015	Quantitative - computer assisted surveys	N=48 pts with HPV+OPC	Survey questionnaires- computer assisted self interview (CASI)
8. Gallagher et al., 2017, USA No dates	Cross-sectional quantitative	N=34 pts with HPV+OPC	Self-administered online and postal survey questionnaires

9. Inglehart et al., 2016 USA No dates	Quantitative	N= 372 pts with OSCC; HPV+, 188; HPV-, 184	Survey questionnaires- computer assisted self interview (CASI)
10. Milbury et al., 2013, USA No dates	Cross-sectional quantitative	N= 62 pts with HPV+OPSCC	Self-administered postal survey questionnaires

Abbreviations: HCPs=healthcare professionals; PCPs=Primary care physicians; OHNs = Otolaryngology - Head and Neck Surgeon; OBGYNs= obstetrics/obstetrician; OCS oral cancer screening; SLTs = Speech and language therapists; HPV+OPC=HPV-related oropharyngeal cancer; OSCC= squamous cell carcinomas. HPV+OPSCC= HPV-oropharyngeal squamous cell carcinoma. ^anot stated/unclear whether paper-based survey questionnaires were posted/mailed to participants. ^b'Other' includes dieticians, radiographers, staff nurses, research nurses

^cMixed methods paper quantitative data only reported here.

Table 4. Results of HCP studies

Study (author & yr)	Discussions	Attitudes	Information needs
1. Anderson et al., 2017	<p>-91% of PCPs† & 81% OHNs had previously discussed HPV infection & transmission with a patients-68% of PCPs ‘never’ or ‘rarely’ tell pts that a HPV serotype can cause HNC</p> <p>-86% of PCPs ‘never’/‘rarely’ discuss sexual transmission as risk factor for HPV-HNC v 93% who ‘usually’/‘always’ discuss sexual transmission in regards to HPV+ cervical cancer</p> <p>-82% of OHNSs ‘never’/‘rarely’ counseled pts with HPV+ HNC on the potential association with anogenital cancer</p>	<p><i>Barriers to HPV discussion</i></p> <p>-19% HCPs felt other health topics took precedence over HPV discussion</p> <p>-17% HCPs felt there was not enough time to discuss HPV</p> <p>-15% felt HPV-HNC discussion was better addressed by other HCPs</p>	<p>Most common reason reported by HCPs for not engaging in HPV- HNC discussion:</p> <p>-lack of knowledge/awareness on topic (52% of all HCPs)</p>
2. Clarke et al., 2017	N/R	<p>-43% of respondents felt confident in their HPV knowledge and comfortable discussing HPV risk factors with patients</p> <p>-37% felt their education prepared them well to discuss sensitive topics such as HPV</p>	N/R
3. Daley et al., 2017	<p>-47% of dentists & 65% of dental hygienists reported they did not discuss HPV with pts</p> <p>-33% of dentists & 19% of dental</p>	N/R	N/R

hygienists only discussed HPV with some pts

-19% of dentists & 17% of dental hygienists did discuss HPV with pts
-35% of dental hygienists reported 'less discussion' with pts about HPV than dentists (53%)

-Of 65% of dental hygienists who did not discuss HPV had lower knowledge scores than those who did with some or all their pts

4. Dodd et al 2017

- 75% had previous experience of discussing HPV with a pt.

-Surgeons, oncologists & specialist nurses had significantly ($P < 0.001$) more experience of telling their pts that their cancer was caused by HPV

- 68% of oncologists reported initiating HPV discussion with pts vs 55% of surgeons and 26% of specialist nurses

Negative & positive attitudes

-Overall negative attitudes to discussing HPV were low (mean negative attitudes score = 1.93 range 1-5) but there was variation among the different HCP grps; significantly higher scores among surgeons (m=1.98), the 'other' group of HCPs (m = 2.02) and SLTs (m = 2.00) vs specialist nurses (mean score = 1.66)

-Overall positive attitude to discussing scores were high (mean positive attitudes score = 4.22; range 1 to 5);

Barriers to HPV discussion

-Overall mean score for personal barriers to discussing HPV was 2.87 (range 1 to 5),.

- SLTs and the 'other' HCP group reporting significantly higher scores for barriers than specialist nurses (surgeons $P = 0.001$; SLTs $P < 0.001$; 'other' $P = 0.003$) and surgeons reporting significantly lower scores ($P=0.04$) for barriers than SLTs

SLTs had a significantly greater need for information than surgeons ($P < 0.001$), oncologists ($P < 0.001$) and 'other' HCPs ($P = 0.002$).

-94% had sought out information on HPV and HNC

-The Internet (79%), medical journals (74%) & other colleagues (70%) were the top 3 information sources

5.Kline et al., 2018 ^a	N/R	<p>- majority of dentists & hygienists 'agreed' or 'strongly agreed' they had role in discussing prevention of HPV-related cancer</p> <p><i>Barriers to HPV discussion</i></p> <p>-54% dentists; 54% hygienists cited lack of privacy</p> <p>-51% dentists; 59% hygienists cited fear of offending pts</p> <p>-43% dentists cited patient's age & gender</p> <p>-51% hygienists cited lack of time</p> <p><i>Facilitators of HPV discussion</i></p> <p>89% dentists; 90% hygienists cited waiting room patient information pamphlets</p> <p>-57% dentists; 56% hygienists cited office posters for patients</p> <p>-46% dentists; 57% hygienists cited waiting room videos for patients</p>	<p>-95% dentists; 84% hygienists cited journals as opportunities for continued education on HPV</p> <p>-73% dentists; 70% hygienists cited technology support materials (e.g. mobile apps)</p> <p>-54% dentists; 52% hygienists cited interview training</p> <p>-49% dentists; 48% hygienists cited building communication skills</p>
6.Malloy et al 2013	-309 (90%) currently mention HPV as a risk factor for HNC cancer	<p>-Only 31% felt their pts are sufficiently informed of the risks of becoming infected with HPV and the potential consequences of such an infection</p>	<p>- The majority of respondents (96%) were in support of future efforts to educate clinicians about HPV-HNC link. Most were also in support of increase public awareness (92%) re HPV and educating pts.</p>

Abbreviations: HCPs=healthcare professionals; PCPs=Primary care physicians; OHNs= Otolaryngology - Head and Neck Surgeon; OBGYNs= obstetrics/obstetrician; HPV-HNC=HPV-related head and neck cancer; pt=patient.
^aMixed methods paper quantitative data only reported here.

Table 5. Results of patient/non patient studies (n=4)

Study (author & yr)	Discussions	Attitudes	Information needs
1. D'Souza et al., 2016	<p>-90% were told by doctors HPV could have caused their cancer</p> <p>-77% told that tumour was HPV+ at diagnosis.</p> <p>-Older pts (> 65 yrs) less likely than younger pts (≤ 65 yrs) to have been told by doctors their cancer HPV+ (50% vs 84%, <i>P</i>=0.03)</p> <p>-5% pts reported tension with partners/family following HCP discussion on HPV and HNC</p>	<p>-92% of those who were told they had a HPV+ tumour believed discussion on their status was adequate</p>	<p>-Of the 77% pts (n=37) who were told their tumour was HPV+, the most useful HPV-related info given at diagnosis was: cure/survival & treatment rates (55%), HPV acquisition & transmission (18%); HPV prevalence (15%); & HPV was cause of their cancer (12%)</p>
2. Gallagher et al., 2017	<p>-94% (32) were told they had a HPV+ cancer</p>	<p>-All participants (n=34) felt knowing about HPV was important</p> <p>-72%(23) indicated they were somewhat/very satisfied with the amount of HPV education they received</p>	<p>-63%(20) were not given information about HPV at diagnosis</p> <p>-75%(24) had researched HPV after diagnosis</p> <p>-92% (22/24) used the Internet to look for HPV information; 79%(19/24) found Internet very helpful</p>
3. Inglehart et al., 2016	N/R	<p>95% confident they could discuss HPV with doctor if they wanted</p>	<p>-53% of HPV+ cases reported they knew 'enough' about HPV to discuss with their doctor</p> <p>-56% of HPV+ cases felt they had enough HPV information to discuss it with their sexual partner</p> <p>-64% of all OSCC cases sought information about OSCC (average = 2 sources)</p> <p>-Internet most commonly used source by all OSCC cases – 81%^a utilised the internet and ranked 8th in trust levels (out of 15 possible info sources)</p> <p>-Doctors/HCPs trusted by majority 96%</p>

4. Milbury et al., 2013

-39% of pts reported their oncologist did not discuss HPV & HNC with them; 45% reported only 'somewhat' discussed
-58% of pts sought information elsewhere

-14% pts intended to keep their HPV status secret from their partners (3% did not tell partners)
- reasons for secrecy included embarrassment 25%; stigma 38%; no one else's business 25%

of all OSCC cases (1st in trust ranking) but was the 2nd most commonly used source by all OSCC cases -38^a% utilised doctors/HCPs
-Pts with HPV+ OSCC used significantly more information sources for OSCC info than HPV- OSCC patients (P <0.01)

Abbreviations: HCP = health care professional; HNC = head and neck cancer; N/R = not reported; OSCC= oral squamous cell carcinoma

^a % include HPV+ and HPV—OSCC pts.

Table 6. Quality appraisal of eligible papers^a (n=10)

Domains/questions ^b	Anderson et al. 2107	Clarke et al. 2017	Daley et al., 2017	Dodd et al. 2017	D' Souza et al. 2016	Gallagher et al. 2017	Inglehart et al.2016	Kline et al. 2018	Malloy et al. 2013	Milbury et al. 2013
1. Clearly stated aims	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Participant eligibility and recruitment strategy clearly documented	P	N	P	P	Y	Y	P	Y	N	N
3. Main features of population (and participants) and study design described	Y	P	Y	Y	Y	Y	Y	Y	Y	Y
4. Non-responders (and non-participants) described	N	N	N	P	N	P	N	P	N	N
5. Main limitations identified	Y	Y	Y	Y	Y	Y	P	Y	N	P
6. No evidence of selective reporting of results ^c	P	Y	P	P	Y	P	P	N	P	Y
7. Statistical methods described	Y	Y	Y	Y	Y	N	Y	Y	Y	P
8. Statistical methods appropriate ^d	N	Y	N	N	P	N	P	P	P	N
9. Outcome measures relevant and described adequately	P	N	Y	Y	N	Y	Y	P	N	Y
10. Results discussed adequately ^e	Y	Y	Y	Y	Y	Y	Y	P	Y	Y
Total score	6.5	6.5	7	7.5	7.5	7	6.5	7	5	6

^aQuality appraisal adapted from 'The pocket guide to critical appraisal' by Crombie, 1996 and Jefferies et al., 2012 and O' Connor et al., 2015.

^bThe range of possible responses to each domain/question was "Yes (Y)", "No (N)", "Partially (P)". Questions were only assigned a "Yes" (and a score of 1) if the detail necessary to fully answer the question was provided in the article; where the domain/question was dealt with to some extent, we assigned a response of "Partially" (and a score of 0.5). "No" was assigned a score of 0. ^ce.g. non-significant results described and discussed sufficiently. ^de.g. multivariate analysis conducted where possible and appropriate. ^ee.g. inconsistencies in results explained, all relevant important outcomes considered.

Figure 1. Flow diagram of study identification and selection process

