

**Encouraging a Patient-Centred Approach to Education,
Designing an eLearning Platform to Enhance Knowledge of
HPV Positive Head and Neck Cancer: A Delphi Consensus
Study**

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Citation:

JOPSON, Rebecca and APPLEYARD, Robert (2026). Encouraging a Patient-Centred Approach to Education, Designing an eLearning Platform to Enhance Knowledge of HPV Positive Head and Neck Cancer: A Delphi Consensus Study. *Journal of Cancer Education*. [Article]

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Encouraging a Patient-Centred Approach to Education, Designing an eLearning Platform to Enhance Knowledge of HPV Positive Head and Neck Cancer: A Delphi Consensus Study

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Received: 24 November 2025 / Accepted: 28 March 2026
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Abstract

A significant global rise in head and neck cancer (HNC) has been recorded, with Human Papillomavirus (HPV) now responsible for most oropharyngeal squamous cell carcinomas (OPSCC) in the USA and UK [1]. The UK introduced prophylactic HPV vaccination for adolescent boys in 2019, adopting a gender-neutral prevention strategy [2]. However, vaccine uptake remains below target nationally and internationally, particularly among males, a recognised high-risk group for HPV-positive OPSCC [3]. This highlights the need for clearer, more accessible educational resources to improve early detection, prevention, and support the management of this patient group. By recruiting a panel of 16 experts with personal/professional experience in the field of head and neck oncology, education, virology and cancer awareness and prevention, the Delphi method was employed to reach a consensus on areas of priority, key target audiences and the accessibility and delivery in order to aid the design of an eLearning platform on this topic, with experts being provided with 3 rounds of e-questionnaires. Response rates were 100% in rounds 1 and 2 (n=16) and 93% in round 3 (n=15). Thematic analysis of round 1 generated three themes: purpose and content of the eLearning resource, accessibility and delivery, and audience. By round 3, consensus (>70% agreement) was achieved on 9 of 10 items. One item, whether to include all HPV-related cancers, reached 73% agreement (n=11). Participants identified priority areas as awareness and prevention, support during and after an HPV+HNC diagnosis, and resources for healthcare professionals working with this population. The Delphi process provided a robust method of identifying the scope available to design and produce an eLearning platform on topics related to HPV+HNC. The expert panel highlighted that multiple resources would be required to address all areas of priority. Accessibility and was fundamental, bridging the gap on health inequality by utilising the interactivity and accessibility an eLearning resource could offer.

Introduction

As healthcare professionals (HCPs), there is a fundamental responsibility to engage in continuous education and professional development to ensure patients receive the highest

standard of care. Beyond clinical responsibilities, HCPs are expected to raise societal awareness by serving as role models, promoting health, and educating interprofessional peers. This is particularly crucial in complex patient treatment pathways requiring multimodal care approaches [4].

Head and neck cancer (HNC) exemplifies such complexity. Over the past two decades, global rates of HNC have significantly risen, with Human Papillomavirus (HPV) identified as a major contributor. HPV now accounts for 71% of oropharyngeal squamous cell carcinomas (OPSCC) in the USA and 51.8% in the UK [1]. This marks a pivotal aetiological shift, as HPV is now recognised as an independent risk factor distinct from smoking and alcohol consumption [5]. The World Health Organization [6] acknowledges the HPV-positive (HPV+) subset as a biologically and clinically distinct entity from HPV-negative disease.

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HPV is a small, complex, double-stranded DNA virus transmitted through skin-to-skin contact, affecting approximately 80% of individuals during their lifetime [7, 8]. First identified by Dr. Harald zur Hausen in the 1970s, HPV types 16 and 18 were linked to an increased cancer risk, leading to zur Hausen's groundbreaking discovery of HPV's oncogenic potential [9]. Today, over 200 strains of HPV are categorised as low or high risk based on their carcinogenic properties [10]. HPV infection, the most common sexually transmitted infection worldwide, is linked to cancers of the cervix, vagina, vulva, penis, anus, and head and neck [8].

HPV+ OPSCC typically affects males and females aged 40–60, who often present with no significant comorbidities [10, 11]. Although this subset has a better prognosis, patients face unique challenges, including psychological distress, financial difficulties, and anxiety about recurrence [12]. Anatomical considerations often result in long-term physical and functional impairments, such as changes in breathing, eating, speaking, and appearance [13]. Furthermore, HPV+ patients, often younger, must navigate the psychosocial complexities of a sexually transmitted aetiology, which can lead to self-blame and anxiety [14–16].

Despite advancements, gaps persist in early detection and prevention. While HPV vaccines have reduced infection rates, uptake among males remains suboptimal [2, 3]. The literature in this area provides sociodemographic predictors relating to health inequalities as a significant contributing factor to this. Moreover, there is a critical lack of resources and training for HCPs to effectively support HPV+ patients [17, 18]. Addressing these deficiencies, this study hoped to gather insights from service users and educators to design an accessible eLearning platform, enhancing knowledge and support for HPV + HNC.

Methods

This study employed the Delphi method, a structured process for gaining consensus among experts, particularly useful in clinical settings to develop standards and guidelines [19]. The Delphi method systematically collects expert opinions over multiple rounds, allowing anonymity and minimising bias while identifying areas of agreement.

Sample Size

Delphi studies typically require 10–30 participants, ensuring manageable data collection and diversity of expertise while avoiding diminishing returns beyond 30 [20]. This study targeted 10–30 experts, recognising potential participant attrition across rounds.

Recruitment

Participants were recruited based on expertise and relevance to HPV+HNC, this included Therapeutic Radiographers, Head and Neck Oncology Dietitians, Consultant Head and Neck Oncologists, Advanced Speech and Language Therapists, Head and Neck Oncology Research Nurses, an Associate Professor in Cellular and Molecular Biology with a research interest in HPV+HNC, a University Lecturer specialising in Head and Neck Oncology, patient advocates who have experience of undergoing treatment for HPV+HNC, representatives from HNC patient support groups and charities, and the founder of a global coalition focused on HPV prevention. Recruitment strategies included direct contact, patient support group postings, and snowball sampling. Experts received a briefing pack detailing study objectives, ethical considerations, and timelines, along with a participant information sheet and consent form.

Inclusion and Exclusion Criteria

Inclusion criteria focused on individuals with direct experience in HPV+HNC. Eligible participants included HCPs, educators, patient advocates, and representatives from charities and support groups working with individuals who have undergone diagnosis and treatment. Organisations involved in HPV awareness and prevention, as well as experts in HPV virology, were also included. Exclusions included individuals affected by HPV-negative disease, those undergoing treatment, or unrelated professionals.

Questionnaire Tool and Dissemination

The Jisc online questionnaire [21], which is General Data Protection Regulation (GDPR) compliant, enabled anonymous dissemination and response tracking. Midpoint reminders enhanced response rates. Challenges, such as missed emails or technological barriers, were mitigated with support materials like briefing packs, ensuring participants understood the study's purpose and timelines.

Delphi Rounds

Round 1: Open-Ended Questions

Participants completed an open-ended questionnaire, allowing them to share insights and priorities based on their experiences. This qualitative data provided a foundation for understanding the expectations and needs for an eLearning platform. The questionnaire was concise to maintain

engagement, with thematic analysis identifying key themes: platform purpose, accessibility, and audience.

Round 2: Simplified Questions

Based on Round 1 themes, the second questionnaire included simplified yes/no and multiple-choice questions to streamline responses and clarify priorities. Consensus was defined as $\geq 70\%$ agreement. This round further refined focus areas while addressing time constraints.

Round 3: Refinement and Feedback

In Round 3, all questions were revisited to validate consensus. Feedback included results from previous rounds, highlighting agreement levels and unresolved areas. Revised questions incorporated majority selections to achieve final consensus. Responses were analysed statistically, with consensus criteria including $\geq 70\%$ agreement and a coefficient of variation < 0.35 .

Data Analysis

Thematic analysis of qualitative data identified shared priorities, while quantitative analysis employed descriptive and inferential statistics. Consensus thresholds, including $\geq 70\%$ agreement, were applied consistently across rounds. Yes/no responses were numerically coded for analysis (YES=1, NO=2).

Ethical Considerations

Ethical approval was granted by the University Research Ethics Committee. Participants provided informed consent, and anonymity was maintained through quasi-anonymity, where individual responses were anonymised, but participation was monitored. Sensitive topics related to cancer experiences were addressed by signposting participants to appropriate support resources. Participants were advised not to participate if the topic posed emotional risks.

Results

Round 1

Thematic analysis of the responses from ‘round 1’ revealed 3 main themes aligning to the objectives of this study: Purpose and content of the eLearning resource, accessibility and method of delivery and audience.

Due to the qualitative nature of ‘round 1’ each theme is illustrated through direct quotations from the expert panel (Table 1).

From the responses received in ‘round 1’ it was evident that the content of the resource was determined by its purpose with a significant emphasis on public awareness and both clinical and patient communities. Participants clearly highlighting that there was a gap in knowledge and even with the resources available, sometimes the wording used failed to answer the questions of the person acquiring it. All participants felt that the resource should provide fundamental information surrounding the virus, transmission and cancer development, including highlighting how common the virus is and that most people are able to clear the virus without knowing they have contracted it.

Wording seemed to be a significant issue amongst experts, specifically in relation to the transmission of HPV being primarily through sexual contact. Some participants responses suggested that this contributed to the stigma surrounding HPV. There were suggestions that there needed to be more information surrounding a HPV+HNC diagnosis, treatment and survivorship, supporting the carers and relatives of those diagnosed. This was a very specific suggestion, as a resource including this information would be directed at somebody working with this patient group, somebody who may have received a diagnosis and be anticipating treatment or their caregiver/relative, especially including detail surrounding the late effects of HNC treatment. This is less generalisable to the public from an awareness perspective and was the first indication that multiple resources should be considered and an area to be put to the experts in the following round.

Another indication that separate resources should be considered was that participants felt that there was an obligation to raise awareness from a prevention perspective amongst the general public and professionals who may be seen as being in a prime position to be asked questions including general practitioners and high school teachers. High school children and parents who may have a child of vaccination age were also seen as a target audience. Participants highlighting similar points to that raised in the literature on this topic, surrounding the requirement for gender awareness, with HPV being primarily associated with cervical cancer. This was identified by the researcher as an area of interest, as with a broader target audience should HPV awareness be limited.

Comments indicated a strong emphasis on a patient-centred, interactive approach to the resources. Videos presented by healthcare professionals and true recollections provided by patients and their relatives were also key suggestions to take forward into the following round of questions.

The accessibility of the resources was also highlighted by experts, specifically indicating the need to support those with

Table 1 Direct quotations from free-text comments made by participants in ‘Round 1’

Purpose	Accessibility	Audience
<i>“Why HPV develops into a cancer. The fact that a lot of people clear the virus and it never turns into a cancer”</i>	<i>“Short videos/concise test/real life experiences”</i>	<i>“All staff working to support those patients would benefit from education on HPV, particularly in view of its increasing prevalence. In my experience, questions about HPV can arise at any time in the patient’s journey...as a mother of a 13-year-old son who just received the HPV vaccination, I was shocked to hear that his teacher told him that he didn’t really need the vaccination and it was to protect girls”</i>
<i>“How Common HPV is. That it is not a sexual disease and not only promiscuous people get it”</i> <i>“...transmission of disease and role of immune system overcoming virus and how there is now vaccine roll out”</i>	<i>“Areas for improvement- Accessibility: No easy read material for patients that don not or struggle to read. Some patients struggle with the volume of written information, or do no comprehend information by reading/ watching a video alone. Information to be given in different formats- easy read/bite size information, would be more beneficial”</i>	<i>“Pubic, high schools and newly diagnosed patients”</i>
<i>“...what HPV is; that it causes head and neck cancer; that it affects men as well as women; that the incidence of head and neck cancer is rising rapidly”</i>	<i>“An interactive platform with linked focus areas”</i>	<i>“Patients, loved ones, carers and to an extent clinicians”</i>
<i>“Lots of language in literature that could stigmatise patients - ie sexually transmitted”</i>	<i>“Clear language with good case studies”</i>	<i>“GPs, general public”</i>
<i>“We need to stop patients feeling that they have an STI or feeling that they their partner has cheated.”</i>	<i>“Patient narratives are really powerful and videos are easier to access, but would be also useful to have a jargon free paper resource to accompany this as not everyone has internet (health literacy). Patients are often processing lots of information so being succinct will be key”</i>	<i>“Educators”</i>
<i>“How to talk to patients and patient support resources. We need to demystify the stigma”</i> <i>“Clarity regarding the potential cause of this type of cancer. The stigma attached to a patient’s fear that the cause may be linked to a sexually transmitted disease can be very stressful, on top of the stress of receiving a diagnosis”</i>	<i>“...I just want an educational video”</i> <i>“Animation/videos- real life experience, explanation from doctor/consultant/ nurse”</i>	<i>“Patients/carers, Dentists, GPs, District/Community Nurses”</i>
<i>“High Schools to help them understand the importance of getting boys vaccinated and awareness to parents”</i>	<i>“Real-life, some educational references, different languages, YouTube/videos- help address those literacy needs”</i>	<i>“Those wishing to know more and understand their cancer diagnosis”</i>
<i>“GPs - that the presenting individual may not meet the “traditional” risk factors of smoking/drinking...”</i>		<i>“All Oncology HCPs working within the head and neck pathway”</i>
<i>“How HPV is transmitted linking information regarding cervical HPV which is not stigmatised as H&N is”</i>		<i>“I think we have different audiences here.”</i>
<i>“...Patient awareness of all known potential long term side effects of surgery and radio/chemotherapy e.g.: - Reduced saliva gland function. Damage to thyroid Hypertension / increased blood pressure due to post diagnosis/ treatment stress”</i>		<i>“Need to aim material at the following audience. 1. Parents of young boys 2. General public 3. Newly diagnosed patients.”</i>

protected characteristics, with a clear emphasis on bridging the gap on health inequality with respect to information provision. This was something taken forward in to ‘round 2’.

Round 2

Round 2 responses from the panel were 100% $N=16$ as seen in Table 2. Good consensus (>70%) was reached for most

questions except for whether the eLearning resource should discuss other cancers HPV relates to which was met with 50% agreement.

Round 3

Round 3 saw a 94% response rate with one expert unable to respond due to being on annual leave, despite this,

Table 2 Responses from 'Round 3'

Question	Yes responses (N)	% Agreement (Yes)
There should be 3 eLearning packages. One focusing on public awareness and prevention. The second focusing on diagnosis, treatment and support (including support for carers/relatives). The third aiming to support healthcare professionals whose job includes supporting the HPV+H&N patient group, including how to answer specific questions. (Q2)	15	100
Each of the 3 eLearning packages should target a specific audience including; the general public, young people eligible for the HPV vaccine and their parents/guardians, primary care e.g. GPs, teachers and school nurses, healthcare professionals who are likely to play a role in the care of this patient group, those directly affected by a diagnosis and their carers and relatives. (Q3)	15	100
Should the eLearning packages discuss other cancers caused by HPV? (Q5)	11	73
There should be supplementary resources available to accompany the eLearning package(s), with the content being relevant to each potential audience e.g. public, patients, relatives and carers, healthcare professionals. (Q6)	15	100
The eLearning package and related resources should be available in the following formats: Different language options (e.g. top 5 UK spoken languages English, Polish, Romanian, Punjabi, Urdu and Bengali), Braille and moon and British Sign Language. (Q7)	13	87
The resource should include information on research in this area, for example, what clinical trials are ongoing but that this was not necessary for all audiences. (Q9)	15	100
The head and neck cancer pathway should be discussed, including possible healthcare professionals involved in the care of this patient group? (Q10)	14	93
Representation of lived experience is completely necessary and would help to remove the stigma around HPV and a head and neck cancer diagnosis. (Q11)	15	100
Including the lived experience of a relative or partner would be beneficial (Q12)	15	100
Should the eLearning package discuss acute and late effects of head and neck cancer treatment, both physical and psychological but have a specific focus on HPV? Eg. stigma/psychological impact. (Q13)	13	87

consensus criteria was not altered. Round 2 responses were modified and repeated in round 3 to ensure validity of those responses where consensus had already been reached. Responses from the multiple-choice selection questions which failed to reach over 50% majority in round

2 were eliminated in round 3. There was one question which provided a free text option which requested further information if the experts disagreed with the accessibility selections filtered from round 2. Two experts selected no to this question and suggested adding video options and an aphasia/dementia friendly version.

Discussion

This study used the Delphi method to achieve consensus across four key objectives: identifying priority areas for an eLearning resource on HPV and HNC, determining the depth of knowledge required, and establishing the pedagogical approaches appropriate for various target audiences.

Areas of Priority and Target Audience

Rather than evaluating the experts' personal knowledge, which could have been subjective and self-reported, the study leveraged the Delphi method to gather insights on existing resources, gaps, and areas requiring prioritisation. Experts highlighted the importance of foundational knowledge, emphasising the link between HPV transmission and cancer as a critical starting point for any educational tool.

Throughout the rounds, perspectives evolved on the depth and focus of the content. Initially, 38% of participants suggested a single resource might suffice; however, by round three, consensus (100%) was reached that three distinct eLearning packages would better address the unique needs of specific audiences: patients and caregivers, healthcare professionals (HCPs), and broader public awareness. This division would allow tailored learning outcomes and address topics like stigma, survivorship, and the cancer pathway in appropriate depth.

Participants recognised the importance of addressing frequently asked questions from caregivers, emphasising emotional and psychological impacts, lifestyle changes, and relationship dynamics. Previous research [22] similarly highlighted caregivers' struggles with altered lifestyles and unspoken concerns about infidelity linked to HPV+ diagnoses. This aligns with the study's findings on the psychological toll of stigma and embarrassment, which act as barriers for both patients' seeking information and HCPs providing it.

A consensus (100%) was also reached on the need for supplementary materials to enhance accessibility and extend reach, underscoring the value of collaborative efforts to host multiple resources on a centralised platform. The suggestion for a national awareness campaign reflects a broader need to enhance HPV education and combat misinformation. Government campaigns have historically improved HPV awareness, particularly regarding vaccination and cervical cancer

prevention [17–23], suggesting that similar initiatives could elevate understanding of HPV's role in HNC.

Public Awareness and Prevention

An unexpected but significant finding was the prioritisation of educating key groups like school nurses, teachers, general practitioners (GPs), and dentists on HPV vaccination and its prevention of HNC. Current vaccination campaigns predominantly focus on cervical cancer prevention, with limited emphasis on other HPV-related cancers. Official statistics from 2022 to 2023 indicate declining vaccination uptake, particularly among males, which may stem from the public's limited awareness of HPV's broader links to cancers beyond the cervix [24].

Despite the vaccine's demonstrated effectiveness against HPV-16, a leading cause of HPV+HNC, the multifactorial nature of HNC may complicate public health messaging. Nonetheless, educational initiatives could benefit from integrating evidence-based information on HPV-related cancer risks, survivorship concerns, and the potential for second HPV-associated cancers post-treatment.

Gaps in Resources and Communication

The study revealed inconsistencies in resources used by participants, with some HCPs relying on journal articles and digital resources from charities while others reported no formal resources. These disparities highlight the need for standardised, accessible, and patient-friendly educational tools. One participant noted the limitations of online searches, underscoring the importance of accurate and trustworthy information delivery by HCPs.

Research suggests that patients benefit from full disclosure of diagnoses, treatments, and causes of their cancer [25]. Equipping HCPs with the knowledge and tools to provide this information fosters trust, enhances patient compliance, and promotes informed health decisions. Additionally, the evolving roles of HCPs provide opportunities for more patient-centred approaches to education and care.

Pedagogical Approach

The expert panel emphasised that an eLearning resource must cater to diverse audiences with varied needs. Digital learning offers an accessible, cost-effective solution that supports continuous professional development and accommodates different learning styles through interactive and self-paced features [26].

Accessibility emerged as a key theme, with experts advocating for adaptations to meet the needs of individuals with protected characteristics. Recommendations included

translating content into the top five UK languages (e.g., Polish, Punjabi) and incorporating resources in Braille, Moon, and British Sign Language. Suggestions also included creating dementia- and aphasia-friendly versions, given the overlap between the median age of HPV+HNC diagnosis and dementia onset.

Interactivity and gamification were highlighted as effective methods to enhance engagement and retention, particularly for younger audiences. Patient and caregiver stories were also recommended to provide authentic, impactful learning experiences that align with patient-centred care principles [27].

Future Research

This study establishes a foundation for developing three eLearning packages tailored to distinct audiences. Future research could focus on refining the content with input from specialist groups, implementing the resources, and evaluating their effectiveness in enhancing knowledge, skills, and user satisfaction.

Notably, the experts' enthusiasm for awareness and prevention highlights the potential impact of targeting teachers, school nurses, and parents. Prioritising the development of a prevention-focused resource could serve as a pilot, informing the broader rollout of the other packages.

Limitations

Round two of the Delphi process relied on yes/no responses, potentially limiting the depth of insights. Additionally, while the expert panel offered valuable perspectives, a larger sample including more service users and caregivers could provide a broader understanding of the issues.

Conclusion

This Delphi study underscores the critical need for education on the connection between HPV and HNC. eLearning offers a scalable, standardised, and adaptable solution to address the diverse needs of patients, caregivers, HCPs, and the public. Priority areas identified include raising awareness and prevention, supporting patients and relatives through treatment, and equipping HCPs with tools to deliver patient-centred care.

While the current campaigns focus on cervical cancer prevention, this study emphasises the importance of expanding educational efforts to cover all HPV-related cancers, particularly HNC. A collaborative, multi-platform approach, possibly accompanied by a national awareness

campaign, could significantly enhance public understanding and uptake of preventative measures like vaccination.

The findings provide a strong foundation for the development and implementation of eLearning resources, with the potential to improve knowledge, reduce health disparities, and foster better outcomes for HPV+HNC patients and their caregivers.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s13187-026-02870-9>.

Declaration

Statements and Declarations All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

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