

# Exploring Opinions and Concerns about the Human Papillomavirus Vaccine on a United Kingdom Online Discussion Forum

## Abstract

**Background:** In September 2008, the United Kingdom introduced a national human papillomavirus (HPV) vaccine program to all girls aged 12–13 years, which was later extended to boys, in September 2019. **Aim:** This study aims to explore and identify opinions and concerns about the HPV vaccine and to generate recommendations to address these for the uptake of the vaccine to remain high. **Methodology:** Using Mumsnet, a popular online discussion forum, 162 HPV vaccine-related threads were identified between 2005 and 2016. Seven threads, with over 100 posts each, were selected for detailed analysis using a thematic approach (Ritchie and Spencer 1994). Main outcome measures were to identify themes regarding the opinions and concerns about the HPV vaccine, and identify potential barriers to vaccine uptake. **Results:** Advocates of the vaccine posted factual evidence and personal experiences of HPV-related diseases. Opponents of the vaccine included posts about negative personal experiences of the vaccination process, side effects attributed to the vaccine, as well as quoting media articles. Posts explored concerns surrounding the lack of evidence about the length of protection of the vaccine and the possibility of sexual disinhibition among vaccinated adolescents. **Conclusions:** The results of our study suggest that some parents who decline the vaccination for their children share common concerns and uncertainties regarding the vaccine. Finding ways to address these may be beneficial in alleviating concerns and thus potentially increasing the vaccine uptake.

**Keywords:** Attitudes, health knowledge, papillomavirus vaccines, practice, social media, uterine cervical neoplasms/prevention and control

## Introduction

In 2008, the United Kingdom (UK) introduced a national human papillomavirus (HPV) vaccine program to girls aged 12–13 years, which was later extended to boys, in September 2019. A successful vaccination program depends on high acceptability and coverage, and thus it is imperative to identify causes that reduce vaccine uptake.<sup>[1]</sup> This was seen in Japan, with a drop from 74% initial completion rate to 0.6%<sup>[2]</sup> and Ireland, with a drop from 86.9% to 72.3%,<sup>[3]</sup> following negative media coverage.<sup>[2,3]</sup> This study aims to explore opinions and concerns about the HPV vaccine and to generate recommendations for these.

## Methodology

### Use of internet forums in research

Online discussion forums have become a place for people to share information,

experiences, discuss problems and ask questions, as well as gain support. They have been likened to “large virtual focus groups,”<sup>[4]</sup> as they allow the collection of data in a similar style to standard focus groups, but on a Larger Scale.

### Identification of discussion forums for this project

Mumsnet is a UK online discussion forum and is one of the largest parenting websites with a discussion board receiving over six million monthly visitors.<sup>[5]</sup> This forum was selected as it is freely accessible and, therefore does not require a subscription or registration to view active or archived threads. Other sites identified were evaluated and not selected for analysis as the information was not freely accessible, representative of the population or did not meet the aims of the study. For example, Jo’s Trust explored opinions surrounding vaccination as a treatment of cervical cancer, rather than prevention.

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## Selection of posts for detailed analysis

Mumsnet was searched for HPV vaccine-related threads within the “Vaccinations” category and across the “Talk” section generally, using various keywords [Figure 1] to encompass all related threads. Between 2005 and 2016, 162 threads were identified which mentioned the HPV vaccine. Inclusion criteria [Figure 1] were used to select threads with the richest data for analysis. In addition, threads generated by other researchers or health-care workers were excluded, as the study was only concerned with naturally occurring data.

Eleven threads met the inclusion criteria and seven of those (from August 19, 2008, to July 24, 2016) were selected for analysis. This was done to obtain at least one thread for each year since the vaccination was introduced, to identify changes in concerns over time, which may have been affected by various factors, including changes in vaccination schedule, dosage, as well as media reports. Data collected over 8 years, following the introduction of the HPV vaccination in 2008, were deemed to capture the changes and attitudes triggered by the new vaccination, before changes reflected by extending the vaccination to boys.

## Analysis

Descriptive and thematic analysis was used to analyze the seven threads.<sup>[6]</sup> A framework approach to analysis was used, which comprised a five-step process of familiarization of data, coding, thematic framework, charting, and interpretation [Figure 2].

## Ethics

The Medical Research Council toolkit “do I need National Health Service (NHS) Research Ethics Committee (REC) review?” indicated NHS REC review is not required for this research. Naturally occurring data were collected, with the researcher acting as an observer and therefore conducting passive data collection, rather than active data collection where the researcher becomes involved in the online discussion. As was suggested by Robinson,<sup>[7]</sup> it was not necessary to obtain informed consent from the users, as by posting on a freely available forum it is assumed that the users are aware that their posts will be read by others.

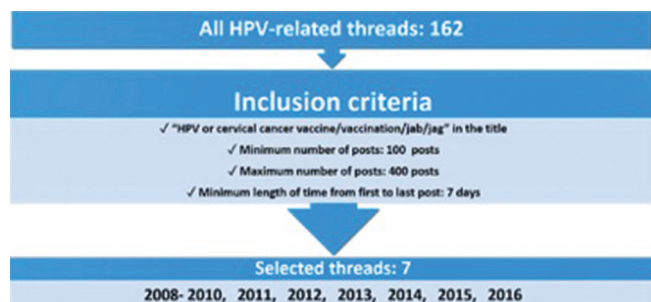


Figure 1: Flow chart of selection process of data

No ethical approval was required for this project as the information on Mumsnet is freely available to the public. Mumsnet discussions can be viewed by visitors and a Mumsnet profile is only required for those who wish to contribute to discussions. Users are also informed of this in the “Terms of Use” when they join Mumsnet. In addition, users post anonymously under their chosen username and are encouraged not to use identifiable information. We further anonymized the usernames for the preparation of this manuscript, numbering the Mumsnet users in order that they appear in the manuscript, followed by the year posted.

## Results

### Characteristics of Mumsnet users

Comprehensive sample characteristics cannot be provided, as only a username is required to join Mumsnet, however, it can be inferred from the discussions and information disclosed the majority of Mumsnet users were females, based in the UK.

### Characteristics of the discussions

Three broad categories of Mumsnet users were identified: vaccine supporters, vaccine opponents, and information seekers. Mumsnet users validated their viewpoint through various ways, including scientific literature, personal or media anecdotes as well as opinions of health-care professionals.

The characteristics of the seven threads were analyzed [Table 1]. The number of Mumsnet users in each thread varied, from 21 to 93, where the total number of users from all threads was 416. In total, the seven threads yielded 1343 posts, however, 44 of those were deleted, by the user of Mumsnet, leaving 1299 posts available for analysis.

Results were divided into five categories as summarized in Table 2.

### Individual concerns for child

Individual concerns for children included concerns over vaccine efficacy with a degree of protection offered, as well as its ingredients, safety, and side effects. There were also questions over the appropriate age for the HPV vaccination.

### Vaccine efficacy and safety

Two of the main concerns expressed were surrounding vaccine efficacy and safety, with worries that the vaccine is new and under tested. In addition, there were concerns regarding the lack of information about the long-term effects of the vaccine and the possibility of it having undesirable effects and causing diseases, such as cancer.

*“HPV vaccination is currently in an experimental phase-we don’t know about long term effects, population wide effects, affect on the virus strains themselves” (Mumsnet user 8, 2014).*

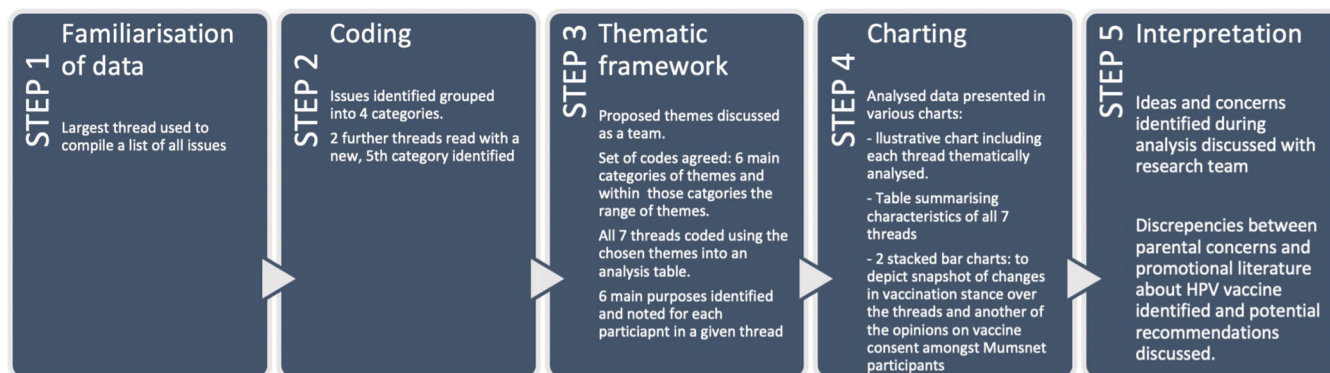


Figure 2: Flow chart of framework approach

Table 1: Summary of characteristics of the seven threads analyzed

Thread (year of commencement)	Total number of posts	Number of users contributing to thread	Mean number of posts by each person	Range of number of posts in a thread by a single contributor	Duration of thread	Trigger opening post
2008	129	57	2.26	1–13	August 19, 2008– June 12, 2010	“New vaccination against cervical cancer for girls – what are general thoughts on it.” (Mumsnet user 1)
2011	326	47	6.94	1–70	September 20, 2011–October 14, 2011	“What are your thoughts/ research on this (HPV Vaccine)?” (Mumsnet user 2)
2012	305	93	3.28	1–37	July 09, 2012– July 16, 2012	“to change my mind and tell the school I don’t want dd to have cervical cancer jab?” (Mumsnet user 3)
2013	111	21	5.29	1–27	October 10, 2013–March 19, 2014	“I am alarmed having read the side effects and personal experience comments at the bottom of the HPV side effects page on the NHS website ... does anyone have any views?” (Mumsnet user 4)
2014	209	54	3.87	1–42	September 24, 2014–October 06, 2014	“HPV Vaccine should i consent for my 12 year old to be given this?” (Mumsnet user 5)
2014	229	86	2.66	1–31	September 20, 2014–February 09, 2016	“I have declined the HPV vaccine for my daughter – school nurse demands I give reasons why – is this legal?” (Mumsnet user 6)
2016	125	58	2.16	1–11	June 24–July 24, 2016	“H.P.V - Decided not to immunise 12 year old – Am I alone in this decision?” (Mumsnet user 7)

HPV: Human papillomavirus, NHS: National Health Service

Mumsnet users were concerned over the side effects of the vaccine, which ranged from general to specific, including chronic fatigue syndrome and postural tachycardia syndrome, as well as HPV vaccine-related deaths, quoting personal, familiar or media accounts. There was worry expressed surrounding the lack of information provided by the NHS regarding those side effects and support for those

allegedly affected. Users also shared public or personal stories of girls suffering side effects after receiving the vaccine, ranging from arthritis to kidney failure and even death.

“I have worked with a teenage girl who has suffered irreversible damage from that particular vaccine” (Mumsnet user 9, 2016).

**Table 2: Summary of results**

Key themes	Sub-themes
Individual concerns for child	Vaccine efficacy and safety Long-term effects Side effects Limited degree of protection Perceptions of own child's vulnerability
Broader societal concerns	Appropriate age for vaccination Marketing the vaccine Credibility of information sources Other countries perceptions of the HPV vaccine
Persuading to have the HPV vaccine	
Vaccination consent	
Herd immunity and HPV vaccination for boys	
HPV: Human papillomavirus	

*"2 cases where young women have died a short while after having the vaccine" (Mumsnet user 10, 2008).*

The limited degree of protection conferred by the vaccine, only protecting against a few strains of HPV was raised, with concern that other strains may become more dominant or new strains may emerge, as a result.

*"offers limited cover" (Mumsnet user 11, 2014).*

### Perceptions of own child's vulnerability

A less common concern was the issue regarding the child's personal or family medical history, where some users felt that certain conditions, including genetic and autoimmune conditions, as well as allergic reactions, would predispose the child to an adverse reaction to the vaccine.

*"Concerned of possible affects on her eczema of adding the vaccination to her system" (Mumsnet user 12, 2014).*

### Appropriate age for vaccination

The appropriate age for the HPV vaccination was a popular topic among Mumsnet users. Overall, out of a total of 65 users who discussed the age dilemma, 75% were supportive of the target age for vaccination and 25% disagreed with the young age for vaccine administration, refusing the vaccine altogether or delaying it. There were many reasons behind the age dilemma, including the duration of protection conferred by the vaccine, with concerns the effectiveness may wear off before sexual debut, as well as worries surrounding sexual disinhibition. A stereotype of a "typical" woman who would contract HPV, with early sexual debut and multiple sexual partners, was discussed and some expressed sexual education alone and other preventative measures could minimize the risk or even prevent virus infection. However, opposing views

mentioned uncontrollable factors such as a partner's sexual history, infidelity, and sexual assault. Mumsnet users were concerned the vaccine may encourage sexual disinhibition and girls may become sexually active earlier, in false belief that no barrier protection is necessary, thus putting themselves at risk of other sexually transmitted infections (STIs) and pregnancy. These issues are specific and unique to the HPV vaccine, as no other routine vaccine protects against STIs and as such involve personal, cultural, and religious views.

*"I think the "sexual" aspect clouds the issue, I suspect there would be less debate about a vaccine to prevent colon cancer." (Mumsnet user 13, 2014).*

*"Condom use, care with partners and frequent smears all seem to me to be a rational alternative to a vaccine" (Mumsnet user 14, 2011).*

*"If there is only a short period of efficacy (you suggested 5 years) then that is extremely worrying as I guess most women are at their most sexually active and promiscuous in their late teens/early 20s, precisely when the efficacy is wearing off" (Mumsnet user 15, 2011).*

### Broader societal concerns

#### Marketing the vaccine

Some users feared girls would become complacent of full protection from the vaccine against cervical cancer, with worries that vaccinated girls will no longer attend routine cervical screening, as a result. Both those in favor and those against the HPV vaccine agreed about the importance of providing adequate sexual education, including reiterating the continued importance for all vaccinated girls to attend regular cervical screening, with the use of examples of celebrities affected by HPV.

*"My concern is that young women will think "I've had the vaccine, so I don't need the smear test"" (Mumsnet user 16, 2012).*

*"remember the Jade Goody effect--an awful lot of young women just don't like the thought of smear tests and don't go unless somebody dies, very publically" (Mumsnet user 17, 2011).*

#### Credibility of information sources

Mumsnet users cited and referred to various sources. These ranged from opinions of healthcare professionals, scientific papers and NHS-endorsed websites, through to newspaper articles and "alternative" media, which included anti-vaccine websites. These sources were usually used to back up the users' point of view of the vaccine, with the majority holding a positive value judgment of both scientific literature and healthcare professional opinion.

*"Unless you have read the peer reviewed papers published in medical journals, then you haven't done research" (Mumsnet user 18, 2016).*

### *Other countries' perceptions of the human papillomavirus vaccine*

Users discussed the policies and negative perceptions of the HPV vaccine in other countries, mainly Japan, with its astonishing effects of anti-vaccine propaganda and the subsequent effect on the vaccine uptake, and to a lesser extent Denmark and the United States of America.

*"Japan no longer routinely vaccinate" (Mumsnet user 19, 2013).*

### *Persuading to have the human papillomavirus vaccine*

A number of Mumsnet users shared personal experiences of suffering with the effects of HPV, from the stigma it carries, through to living with cervical cancer, recovering from treatment and the long-term physical and emotional effects of the disease. A few also shared personal or familial stories of dying of cervical cancer and leaving their children motherless. These were highly emotive and powerful accounts, expressing great regret at the vaccine not being available when they were young and making a number of Mumsnet users reconsider their decisions to vaccinate.

*HPV was viewed as "life destroying" (Mumsnet user 20, 2016), it "basically eats you alive" (Mumsnet user 21, 2012), while the HPV vaccine was seen as "potentially life saving" (Mumsnet user 22, 2016).*

*"Im now dying. of (cervical) cancer, its horrible and painful. Ill be leaving my dd of 11 without a mum. I wish I could have had the injection" (Mumsnet user 23, 2016).*

Some users also discussed the vaccine, in a risk versus benefit approach, where they appreciated the vaccine's potential side effects and unknowns, however deemed the magnitude of the effects of HPV a far greater danger and risk to take.

*"It's a risk/benefit analysis and vaccination always comes out on top." (Mumsnet user 24, 2014).*

### *Consent: Who should consent for the vaccine? The parent or the child?*

There were mixed views expressed amongst Mumsnet users, with the majority of an opinion it should be the daughter's decision, given it is her body. However, others thought it should be a joint decision, of both the parents and the daughter and these users highlighted the importance of good communication with one's children to enable such a discussion on sensitive matters, such as sexual activity. There were other parents who were of an opinion that their daughters are not mature enough to decide and the decision should be made by the parents. Others chose to wait until their daughter was at the age 16 or older to make the decision herself.

*"your daughter has the right to choose for herself. it's their body they aren't babies" (Mumsnet user 25, 2012).*

*"How can they (12 year olds, consent for themselves), when they don't have access to or let's face it the interest in such information?" (Mumsnet user 14, 2011).*

### *Herd immunity and human papillomavirus vaccination for boys: Should boys also receive the human papillomavirus vaccine?*

The topic of herd immunity provided by the HPV vaccine was discussed. Some in favor of the HPV vaccine expressed aversion toward parents not vaccinating their children but relying on herd immunity for protection. The minority who disagreed with herd immunity as a general concept, held a belief they should not risk their children's health in being vaccinated, to protect the health of the population. The concept of herd immunity also brought up the question whether boys should receive the HPV vaccine, with an overwhelming majority stating boys should be vaccinated as well as girls. The main reason behind this was the concerning rise in the incidence of HPV-related cancers in men with some sharing personal accounts of their male relatives suffering from these.

*"DH (dear husband) has had a throat cancer scare, and I would prefer to do what I can to protect my sons." (Mumsnet user 26, 2014).*

## **Discussion**

### **Summary of key findings**

The most common concerns identified across all threads in our study were surrounding the lack of, or negative information about, the safety, efficacy, and side effects of the vaccine, the appropriate age for vaccination and the fear of complacency of being fully protected against cervical cancer.

Concerns surrounding vaccine safety and efficacy were in line with other studies, including those using focus groups and questionnaires,<sup>[8]</sup> as well as those online, on online forums,<sup>[9]</sup> online comments<sup>[10]</sup> and social media platforms such as Twitter.<sup>[11]</sup> One study showed the UK had the highest proportion of tweets expressing concerns, compared to Canada and Australia, at 22.6%.<sup>[11]</sup> These concerns were also seen in studies from more economically developed countries and less economically developed countries and interestingly among both parents<sup>[9]</sup> and adolescents.<sup>[8]</sup> Some studies have highlighted particular concerns over side effects,<sup>[12]</sup> with a study from rural South Florida showing 80% of parents believed the HPV vaccine would leave their child sterile.<sup>[13]</sup>

The concern over appropriate age for vaccination was in line with a Canadian study,<sup>[10]</sup> and was also associated with apprehension of the vaccine increasing sexual promiscuity. There was also some variation in concerns seen between our study and others. The concern over potential reduced cervical screening rate as a result of HPV vaccine uptake was also expressed in a study of Australian General

Practitioners,<sup>[14]</sup> however not a common concern in other studies which may be associated with no national screening program available in those countries.<sup>[9]</sup>

With the recent extension of the vaccine program to boys, it is encouraging that our results showed the majority thought boys should be vaccinated as well as girls. Some of those, in our study, who disagreed with vaccinating boys did not perceive the prevalence of HPV-related cancers in men to be high enough to warrant the risk of vaccinating. This is in line with a Swedish study, where parents expressed a low awareness about the health benefits of male HPV vaccination.<sup>[15]</sup>

### Through the eyes of a parent

Available online resources about the HPV vaccine were reviewed by the authors to identify if there was easily accessible information to address concerns raised by Mumsnet users. Responses to certain concerns were not readily identifiable, for example, both the NHS and Immunization Scotland websites give vague information about possible side effects, and the NHS website can be seen as difficult to navigate for information on specific concerns such as the rationale for vaccinating at the age of 12 years. The above discrepancies highlight the need for traditional health services to provide easily accessible information online and on social media platforms, where the public increasingly seeks information.

### Strengths and limitations

Our study benefits with the use of online forums, compared to traditional focus groups, as they are easily accessible and a free resource, which enabled us to collect naturally occurring data, without interference or interviewer bias. Further, an online setting allowed for a collection of a larger sample from a wider geographical area,<sup>[16]</sup> as well as collection of views and opinions expressed over eight years, without any recall bias.<sup>[17]</sup> The findings of this study may be specific to users of online discussion forums and not representative of the general population.<sup>[16]</sup> It can be inferred from discussions that the majority of Mumsnet users are female, whereas it may be useful to include more fathers and parents from a variety of ethnic and socioeconomic backgrounds for a more general representation of opinions and concerns.

### Conclusion

#### Interpretation and implications

Based on our findings, it may be beneficial to supplement current promotional vaccine literature with a few significant points. This could be presented under a section titled “some parents worry...” listing a number of parental concerns and re-assurances in a conversation-like style, including highlighting evidence that the vaccine does not increase sexual activity and has in fact been shown to increase cervical smear attendance. The use of links or summaries to simplify up to date research on the vaccine, as well as a diagrammatic portrayal of the vigorous process

the vaccine goes through prior to approval being granted, may be useful. Current resources could be improved, and new ones developed, with a representative panel of parents, teenage girls as well as clinicians to discuss the type of information, format and language that would be most useful and using a qualitative tool such as HPV Adolescent Vaccine Intervention Questionnaire<sup>[18]</sup> to assess and further improve the effectiveness of the resources. With an increasing use of social media, creating HPV vaccine and screening campaigns on these platforms<sup>[19]</sup> may have far reaching effects on the current generation and enable us to monitor the public response to HPV vaccine,<sup>[20]</sup> using a Vaccine Sentimeter.<sup>[21]</sup>

Finally, as some Mumsnet contributors highlighted, providing more school-based education about HPV and the vaccine could be beneficial. In addition, further education on HPV-related cancers affecting men is important, as with a potential feminization of HPV and HPV vaccines, some still view HPV as a “female disease.”<sup>[22]</sup>

### Future research

Research into opinions of adolescent girls and boys on the HPV vaccine, and using these to inform future campaigns, would be beneficial. It may also be useful to target men, as well as women, and personalize campaigns to vulnerable groups,<sup>[23]</sup> such as women from socially deprived areas, where cervical cancer rates are highest, thus narrowing the health equality gap.

Research has shown that vaccine hesitancy has risen to higher levels around the COVID-19 pandemic and vaccination.<sup>[24]</sup> It appears fluctuations in hesitancy surrounding vaccination often mirror policy changes, new information, or newly reported vaccine risks.<sup>[24]</sup>

Between 2021 and 2022 in England, the rate of completion of the HPV vaccination schedule in girls was 67.3%, which is 20% lower than prepandemic (2018–2019).<sup>[25]</sup> It will be important to monitor trends and levels of abnormal cervical smears and cervical cancer rates, in relation to this. Despite HPV vaccination coverage rates remaining relatively good, there have been reports that concerns about one vaccine may promote hesitancy regarding other vaccines; in Denmark, MMR vaccination levels decreased following negative media reports surrounding the HPV vaccine.<sup>[24]</sup>

With concern over general anti-vaccine issues worldwide, the World Health Organization (WHO) highlighted it as one of the top 10 global threats. It is important to keep vaccine conversations open and respond to evolving concerns early.<sup>[24]</sup> It seems that campaigns that promote vaccines in general may be beneficial, as a study has shown general belief in vaccines is associated with a higher acceptance of the HPV vaccine.<sup>[4]</sup>

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## Conflicts of interest

There are no conflicts of interest.

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