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## HPV vaccination and cervical screening: the knowledge and attitudes of mothers of adolescent girls

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#### **ABSTRACT**

**Objective:** Mothers play a significant role in decision making about human papillomavirus (HPV) vaccination for their daughters and about cervical screening attendance for themselves. This study had three objectives, to explore: (1) mothers' knowledge and attitudes about HPV and HPV vaccination, (2) their knowledge and attitudes about cervical cancer and screening, and (3) whether their daughter's HPV vaccination invitation was an opportunity to nudge mothers to attend screening.

**Design:** 138 women from North Staffordshire completed a cross-sectional survey and 15 took part in follow-up focus groups. **Results:** Despite high self-reported engagement with both the cervical screening and HPV vaccination programmes, relatively low levels of knowledge and some uncertainty were evident. There was mixed opinion about the potential of using the vaccination invite as an opportunity to nudge mothers to attend cervical screening.

**Conclusion:** Even amongst women who do engage positively with the programmes, knowledge is not as complete and certain as it could be. Further research is needed with women who are less likely to accept the vaccination for their daughters. Women need to be better informed, which may go some way to reversing the decline in screening and maintaining high levels of vaccination.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Cervical screening; cervical cancer; human papilloma virus; HPV vaccination

#### Introduction

In the UK, there are around 3,200 new diagnoses and 900 deaths from cervical cancer every year (Cancer Research UK, 2017). Human papillomavirus (HPV) is a common sexually transmitted infection responsible for 99.7% of cases of cervical cancer. It causes changes to the cells in the cervix which, if left untreated, can turn into cancerous cells. The NHS cervical screening programme (NHSCSP) is estimated to save 4,500 lives every year in England alone by detecting pre-cancerous changes or early stage cervical cancer (Peto et al., 2004). Women aged 25–49 years are invited to attend screening every three years, while women aged 50–64 years are invited every 5 years. Since 2013, the cervical screening programme has trialled and then rolled out HPV

primary testing (to replace cytology) across England, Scotland, and Wales, with the rollout completed by the end of 2019. With HPV primary testing, a sample of cells is still taken from the cervix, but this sample is first tested for HPV and only if the test is positive, does it then undergo cytology. Despite the effectiveness of screening at reducing the incidence of cervical cancer, in recent years, the number of women who take up their invitation has fallen across all age groups, for example in 2004 80.6% of eligible women were recorded as up to date with screening in England (HSCIC, 2005), whilst in 2018 this figure had fallen to 71.4% (NHSCSP, 2018), considerably lower than the national cervical screening target of 80%.

In 2008 the HPV vaccination programme was introduced in the UK for girls aged 12 to 13. The HPV vaccine is a quadrivalent vaccine currently given in two doses, with the second dose delivered 6 to 12 months after the first. Uptake of the vaccination among girls has been stable for the two years before the COVID-19 pandemic, with an uptake rate of 83.9% for both doses by the end of the school year 2018–19 and of 83.8% by the end of 2017–18 (Public Health England, 2019). Although it meets the 80% target coverage, this figure is down from 2013–14 when 86.7% completed the then-three dose schedule, and further decline needs to be avoided.

Despite the causal role that HPV plays in cervical cancer and the comprehensive vaccination programme, knowledge about HPV and cervical cancer is still relatively low. Marlow et al. (2013) conducted an international online survey to explore levels of HPV knowledge and HPV vaccination knowledge in 2409 men and women across the UK, Australia and the US. 62% of UK women (mean age 41.8) had heard of HPV meaning that over a third of women had not heard of HPV. Furthermore, when those who had heard of HPV were asked 15 knowledge questions, they achieved on average 8.53 or 57% correct responses. In particular, fewer than 50% of UK women knew that there are many types of HPV, that HPV can cause genital warts, that it cannot be cured with antibiotics and crucially, only 24.9% of women who had heard of HPV knew that most sexually active adults will get HPV at some point in their lives. More recently, Sherman and Nailer (2018) explored knowledge about HPV in a sample of parents of teenage boys in the UK and found that 63.6% of parents who also had daughters had previously heard of HPV. Parents who had heard of HPV achieved a median score of 14 correct answers to 21 questions about HPV, suggesting some gaps in their knowledge. Consistent with Marlow et al., only 32.3% of those parents knew that most sexually active adults will get HPV.

Research conducted in the US, suggests that mothers' lack of knowledge may be a barrier to educating daughters and it is mothers who are either the primary decision makers or who assist their daughters in making the decision to have the vaccine or not (Griffioen et al., 2012). Previous research in the UK exploring the impact of mothers' attitudes on HPV vaccination uptake has focused on screening history (e.g. Spencer et al., 2013), ethnicity and other sociodemographic factors (e.g. Marlow et al., 2009; Spencer et al., 2014) or was conducted prospectively prior to the introduction of the HPV vaccination programme to the UK (e.g. Waller et al., 2006). Studies have also highlighted the significant influence that mother-daughter communication can have on vaccine uptake, with Roberts et al. (2010) in the US finding that communication about sex and the daughters' perceptions of their mother's approval were positively associated with having the HPV vaccine. At the same time, open lines of

communication about the HPV vaccine between mother and daughter can provide opportunity for important conversations about sex and sexual health more generally (McRee et al., 2011).

Given the increased role that HPV is playing in the prevention of cervical cancer through HPV vaccination and now primary screening, it is important that women (older and younger) are well informed about HPV and the role it plays in cervical cancer. In addition, although there is high uptake of the vaccination programme, cervical screening attendance is declining. As such, we wanted to consider mothers' HPV knowledge and awareness from the perspective of their daughters' vaccination uptake and their own cervical screening engagement as well as considering whether there was an opportunity to link the two events. Our research aims were thus: (1) to find out what mothers of girls age 11-18 (eligible, or nearly eligible for the HPV vaccination) know and think about HPV and HPV vaccination; (2) to find out what mothers know and think about cervical cancer and cervical screening; and (3) to explore whether the vaccination invitation is a good opportunity to nudge mothers to attend cervical screening. We used a survey which included questions based on previous research (Marlow et al., 2007; Sherman et al., 2016) to gather quantitative responses to questions about HPV, HPV vaccination, cervical cancer, and cervical screening and followed this up with focus groups to explore these issues in more depth along with whether the vaccination invitation might represent a screening nudge opportunity.

#### **Methods**

#### **Participants and procedures**

Survey participants were 138 mothers of female pupils aged 11-18 from six schools in North Staffordshire, UK, aged between 28 and 60 years (M=45.22, SD = 6.340). Participants completed either a paper survey sent home from school with female pupils (2 schools), or an online survey (4 schools) emailed directly to parents by the school or posted on the school website or social media page. An information sheet accompanied the paper survey and was the first page of the online survey. Participants provided informed consent and then completed the survey, which took approximately 5-15 minutes. At the end they were invited to provide their contact details if they were interested in taking part in a follow-up focus group. Participants were offered the opportunity to be entered into a draw to win a £100 prize.

Seventy-three mothers who had indicated their interest in taking part in a follow-up focus group were contacted by telephone or email depending on the details they had included. Four focus groups and one semi-structured interview were conducted by the first author (see results section for demographics). Focus groups were chosen as the main method because of their ability to stimulate discussion and interaction, especially useful for exploring the beliefs, attitudes and feelings of multiple individuals in relation to a specific topic (Howitt, 2010). On one occasion, only one mother attended, hence the one interview. The focus groups ranged in length from 45-60 minutes, took place at the schools or the campus of the last author's institution and were recorded using a digital audio recorder and attached microphone. Focus groups were conducted until data saturation where no new, additional information addressing the aims of the research, was being revealed (Fusch & Ness, 2015).

#### Survey measures and focus group schedule

A self-report survey was used to assess knowledge of cervical cancer, HPV and personal engagement with cervical screening and HPV vaccination. The survey consisted of 5 sections. Section A asked for basic socio-demographic information and asked if participants had experience of cancer through themselves, a close family member or a close friend. Section B consisted of two open-ended questions adapted from Marlow et al. (2007) asking participants about their knowledge of the cause of cervical cancer. The first question asked what the participant considered to be the main cause of cervical cancer. The second question asked the participant to list as many other causes as they could think of. Section C examined HPV knowledge and began with a filter question asking participants if they had heard of HPV. Those that responded 'yes' or 'don't know' went on to answer subsequent questions in the section taken from Sherman et al. (2016). These consisted of four knowledge questions asking what the letters HPV stand for, what HPV is, how HPV is contracted and what the relationship is between HPV and cervical cancer. These items, along with one further HPV knowledge item from section E, were used to give a knowledge score out of 5. Section D referred to personal engagement with and knowledge of cervical screening and asked participants to indicate when they last been for cervical screening (had a smear test). Those that indicated that they had not had one recently or ever were asked by an open question to indicate their reasons for this whilst women who were up to date with screening were asked an open question about their motivation to keep attending. All participants were asked whether they think cervical screening helps to prevent cervical cancer and, if yes, how it might do so. Section E asked about engagement with the HPV vaccination programme and knowledge of vaccination. Specifically, participants were asked how many daughters they have, how old they are, and whether they have had or will have the HPV vaccination. They were also asked an open question about their reasons for either having or not having their daughters vaccinated. Two further questions asked participants whether vaccinated girls will need to attend cervical screening in the future and whether they think the HPV vaccine will prevent all cases of cervical cancer, the latter of these being used as the final question in the HPV knowledge score. Finally, one question asked participants to indicate sources of information about HPV and cervical cancer and an open question asked whether there was anything else they'd like to add.

A flexible question schedule was created by the research team and used to guide the discussions. The schedule covered three main areas; cervical cancer (e.g. 'what do you know about cervical cancer), the HPV vaccination (e.g. 'how effective do you think the vaccine is in preventing cervical cancer?' and cervical screening (e.g. 'how important do you think cervical screening is?'). We also asked: 'Do you think it would be useful for the information sent home about the HPV vaccine for your daughter(s) to include a prompt about your cervical screening attendance?' The questions were partly informed from the survey responses to explore and delve deeper into the mothers' attitudes and knowledge and additionally, to explore whether the HPV vaccination letter was an opportunity to

encourage women to attend cervical screening. The question schedule was used flexibly to guide the discussions, not to be restrictive. The research team had also included some pre-planned prompts for each question which were used when appropriate; if, for example, the mothers seemed hesitant or unsure of what was being asked.

#### Ethical considerations

Ethical approval for this study was obtained from the School of Psychology Ethics Committee at Keele University. Participants were provided with detailed information sheets and given the opportunity to ask questions, before being asked to provide their informed consent to participants. The mothers taking part in the focus groups were additionally asked to provide their consent for the anonymous use of any quotes from their responses.

#### **Data analysis**

Descriptive statistics were calculated for the survey data. Due to the homogeneity of the sample, no meaningful inferential statistics were possible. The focus groups (and one interview) were transcribed and analysed thematically using the guidelines set out by Braun and Clarke (2006). The analysis was conducted by the first author (JT) who familiarised themselves with the data by listening to the audio recordings, as well as reading and re-reading the transcripts. An inductive approach was taken with transcripts being systematically coded line by line, with a few words or a phrase being used to capture the essence of the particular segment of data it referred to (e.g. 'early detection of cancerous cells', 'going with the flow'). Codes were then sorted into potential themes and the relevant data extracts collated into separate Word processing documents. Underpinned by a realist epistemology, the coding and theme searching was conducted at the more semantic level of the spectrum, with themes being identified within the surface level of the data. Consistent with this position, the analysis was focused on identifying and describing what was considered to be the 'reality' of the mothers' attitudes and knowledge with regards to this specific topic.

Once initial themes had been identified, time was spent refining and ensuring coherence amongst each theme, as well as in making sure there were sufficient distinctions between them. Time was then spent by the first and second authors in naming the final themes, as well as selecting illustrative quotes. At this stage, analysis did progress to a more interpretative level although the themes remained grounded in the semantic content of the data.

#### Results

#### Survey

Demographic characteristics are shown in Table 1.1 The majority of participants were white (93.5%), married (75.4%), Christian (84.8%) with English as a first language (95.7%). Most had a degree level qualification (57.2%), were in some form of employment (88.4%) and reported an annual household income of £30,000 or more (75.3%). Most participants also reported close personal experience of cancer (82.6%).

Table 1. Demographic characteristics.

Table 1. Demographic characteristics.	
Characteristic	(n = 138); %
Ethnicity	
White	93.5
Asian/Asian British	1.4
Black/African/Caribbean/Black British	2.2
Mixed/Multiple Ethnic	0.7
Missing	2.2
Religion	
Christian	84.8
Muslim	0.7
No religion	14.5
Education level	
First degree or postgraduate degree	57.2
College qualification (below degree)	15.2
A-levels or equivalent	10.1
Vocational qualifications	7.2
GCSEs/O-levels/CSE or equivalent	8.0
No formal qualifications	1.4
Missing	0.7
Employment status	
Employed full-time	45.7
Employed part-time	35.5
Self-employed	7.2
Student	2.2
Full-time homemaker	5.8
Unemployed	2.2
Disabled or too ill to work	0.7
Missing	0.7
Annual household income	
£0 to £9999	4.3
£10,000 to £19,999	8.7
£20,000 to £29,999	11.6
£30,000 to £39,999	11.6
£40,000 to £49,999	18.1
£50,000 or more	42.8
Missing	2.8
Marital status	
Married	75.4
Divorced/Separated	9.4
Cohabiting	8.7
Single	5.1
Widowed	0.7
Missing	0.7
English first language	
Yes	95.7
No	4.3
Close personal experience of cancer	
Yes	82.6
No	16.7
Missing	0.7

#### **Cervical screening**

Most participants reported being up to date with their cervical screening (92.8%) and a further 1.4% reported that they no longer needed to attend after having a hysterectomy. Almost a third of participants who were up to date with screening (30.5%) described their reasons for attendance as being because screening is 'routine', 'precautionary', 'common sense' or 'to check I'm healthy'. The need to identify abnormalities, cell changes or signs of cancer was cited by 42.2% with most of these specifically mentioning the importance of early detection and treatment (25.8% of all up-to-date

participants) and prevention of health problems such as cancer was given as a reason by 12.5%. A fifth of up-to-date participants (19.5%) described previous related health problems as their reason for attending and 3.9% said family history motivated them. Cues to action, such as invitation letters, reminders from health professionals and media coverage were cited as reasons for attending by 11%.

Of the remaining participants, 4.3% had not had cervical screening in the last 5 years and 1.4% were not sure how long it had been since their last test. Reasons for not attending recently included being unable to arrange an appointment at a convenient time (n=2), not knowing where to go for screening (n=1), forgetting (n=2) and being nervous or embarrassed about it (n=1).

Most participants (79.7%) correctly responded that cervical screening helps to prevent cervical cancer, and of these, 69.1% described this as being through the identification of early or pre-cancerous cell changes in the cervix.

#### **HPV** vaccination

All participants had at least one daughter aged 11-18 years. Most had one daughter (65.9%), 22.5% had two daughters, 10.1% had three and 1.4% had four. Of the 100 participants who had a daughter aged 12 or over who had been offered the HPV vaccination, 85% had accepted the vaccination, 6% had not and 9% didn't know if their daughter had received it or not. Of the 78 participants who responded to the question 'If you have a daughter who is 11 or 12 and has not yet had the HPV vaccination, do you intend to allow her to have it?', 84.6% responded yes, 3.8% responded no and 11.5% didn't know.

For those participants whose daughters either had or would be vaccinated (n=124), 61.3% gave reasons focusing on 'protection' or 'preventing cervical cancer'. Smaller numbers gave reasons indicating that they accept all available vaccines or medical interventions (4.8%), that they felt the vaccine is well-researched (3.2%), that the decision was made following discussion with their daughter (3.2%), that it was based on family history of related medical problems (2.4%) or that their decision was based on advice from a medical professional (1.6%).

Reasons for not getting daughters vaccinated or being unsure about whether to get them vaccinated (n=14) included not knowing enough about the vaccination (n=6)or there not being enough research (n=3). Three participants were concerned about side-effects with one participant reporting problems after a previous child's HPV vaccination and one participant worried about side-effects they had heard about in the media. One participant did not believe in giving any vaccinations to their children and one participant's daughter felt it was unnecessary as she intended to abstain from sex.

For the question, 'Do you think the HPV vaccination will prevent all cases of cervical cancer?', 58.7% of participants responded 'no', 7.2% answered 'yes' and 31.9% were unsure. When asked, 'Do you think girls who are vaccinated will need to go for cervical screening in the future?', 89.1% responded 'yes', 0.7% said 'no' and 9.4% were unsure.

The most common sources of information about HPV and cervical cancer were information from school/college/university (63.8%), doctor/nurse/other health professional (37.7%), and newspapers/magazines (31.2%). A guarter of participants also got information from the internet (25.4%) or television/radio (25.4%). Only 16.7% of participants reported getting information from friends or family.

#### Causes of cervical cancer

Responses to the two open questions about the causes of cervical cancer were combined. Close to half of participants (44.2%) were aware of a link between HPV or sexually transmitted infection/disease (STI/STD) and cervical cancer with a third of participants (31.9%) naming HPV as the cause and 15.2% naming an unspecified STI/STD as a cause. A small number of participants named genital warts as the cause (2.2%) and 2 participants named other STI/STDs as a cause (HIV and herpes).

At least one sexual behaviour (e.g. multiple partners, sex at a young age, sexual activity and unprotected sex) was named by 44.2% of participants. Almost half of participants (46.4%) named at least one other biological factor, the most common being genetics or inheritance (28.3%), genetic/cell mutations (11.6%) and unspecified infections/viruses (8.0%). Over a third of participants (37.7%) named at least one lifestyle factor. The highest of these were smoking (30.4%), poor diet/obesity/lack of exercise (10.1%) and contraception (10.1%). Participants who either didn't respond or answered 'don't know' to both questions was 13.0%.

#### Awareness and knowledge of HPV

Overall, 79.7% of participants reported that they had heard of HPV. Of those that reported having heard of HPV (n=110), 58.2% scored at least 4 out of 5 (M=3.32, SD = 1.533). Approximately two thirds correctly identified what the letters HPV stand for (67.3%), that HPV is a virus or STI/STD (70.0%) and that it is contracted through sex or sexual contact (66.4%). Slightly lower numbers correctly described the relationship between HPV and cervical cancer as being a causal one (64.5%) and correctly responded that the HPV vaccine will not prevent all cases of cervical cancer (63.6%).

Some misconceptions were apparent in participants' responses to some of the knowledge items. For example, five participants responded to the question 'What is HPV?' with the answer 'vaccine', and for the question, 'How does someone get HPV?' three responses included the suggestion that males are simply 'carriers' of HPV who then pass it on to women.

#### **Focus groups**

Fifteen mothers took part in the focus groups, aged between 35 and 51 years (M=45, SD = 4.5). All identified being of British ethnicity and indicated that they were educated to a first degree or postgraduate level. All but two indicated that they, a close family member or a close friend, had had cancer. 13 of the 15 mothers said that they had a daughter(s) who had received or that they intended for them to receive the HPV vaccination. Two indicated that their daughter(s) had not yet had the vaccination and they indicated in the survey that they were unsure if they intended to allow them to have it. Two themes captured the mothers' attitudes and knowledge with regards to HPV and the HPV vaccination, cervical cancer and cervical screening: (1) Limited knowledge and uncertainty; although not a distinct theme in itself, the importance of education and communication was something that was embedded within this theme, and (2) Trusting and unquestioning. A third theme captured aspects

of the mothers' communication with their daughters about HPV related topics. The analysis is presented under sub-headings, with illustrative quotes accompanied by participant pseudonyms in parentheses. The qualitative data in relation to our specific research aim 3 are also discussed.

#### Theme 1—Limited knowledge and uncertainty

Although knowledge inevitably varied, and the mothers certainly had some knowledge of HPV and cervical cancer, it was, often by their own acknowledgement, limited. The knowledge that they did have was saturated with uncertainty. Some acknowledged that they did not know anything about the link between HPV and cervical cancer other than what they had read in the materials they were given to look at during the focus group. Others were aware of the connection but lacked detailed knowledge and were uncertain about the specifics, for example: 'I'm not sure if it's a direct cause, or whether it's associated with being more likely to get it' (Kate, FG3). Kate went onto attribute her uncertainty to a lack of clarity in terms of the communication about the link from external sources: 'Is it a contributory factor or does it cause it? For me, I've not heard... I've not heard a clear message on the news or in the newspapers' (Kate, FG3). Claire was uncertain where her limited knowledge had come from: 'I think I assumed it's a bit like HIV; you can have it forever and still not get cervical cancer, like you can get HIV and never get AIDS. I think that but I don't know why I think that' (Claire, FG1).

Uncertainty and a lack of specific knowledge were similarly evident with regards to cervical cancer more generally. Belinda, for example, when asked what she knew about cervical cancer said: 'I've got patchy bits of knowledge and I don't even know if what I know is right. I just think I know some things' (FG1). Uncertainty about cervical cancer was particularly apparent in the following exchange, when the mothers were asked to discuss what they knew about it:

Maureen: And you're more likely to get it if you've had genital warts and stuff aren't you, from what I believe.

Nicola: Or sex early on, somebody told me or I've read it somewhere. The earlier you have sex, the increased risk. I've got it in my head from somewhere.

Maureen: Right.

Lauren: I don't know (laughs).

Maureen: (laughs) I might have just made that up. (FG4)

Limited knowledge and uncertainty were most evident with regards to the HPV vaccination itself, with several of the mothers acknowledging that they knew very little about it: 'All I really knew was that it was a couple of injections over a period of time. That was about it really' (Isobel, FG3). Whilst some attributed their lack of knowledge to not having researched the vaccine sufficiently themselves, for example: 'I haven't even looked at it to be honest. I know it comes in an injection form as a vaccine but that's it really' (Grace, FG2), one mother, Andrea (INT1), held external sources responsible. Andrea, whose daughter had not yet had the vaccination, spoke about her expectations for receiving adequate information from the school:

INT: So, would you prefer to have had some information by now knowing that it's going to be something that your daughter's going to have fairly soon?

Andrea: Yes, either from the doctor's surgery or school, just a letter. They get weighed in Year 6, the children are weighed and measured to keep an eye on obesity. You'd have thought at that point that... because then you get a letter at home. You'd have thought at that point maybe something about the immunisation programme for the next two or three years might have... it's not that hard to do really is it, yes, if you're already putting letters in envelopes. (INT1)

Although the mothers whose daughter(s) had already received the HPV vaccination acknowledged that they had received information from the schools, their recollection of the literature was vague, encapsulated particularly well in the following extract when asked to describe what they remembered about it:

Nicola: I have no idea (laughs)

Lauren: I can't remember

Nicola: I've slept since then (laughs). I can't remember it

Lauren: It was definitely a letter from the school because obviously we had to give consent form for them to be able to do it. I can't remember if it was like a threefold leaflet. I've got a feeling in my head.

Nicola: (laughs) I've just got a vague, a very vague recollection. (FG4)

Most of the mothers said that they would have preferred to have received more information. Despite their uncertainty and lack of detailed knowledge about the vaccine, it was something that all the mothers really valued and emphasised the importance of.

The mothers were much more informed about the benefits of, and purpose of, cervical screening, with all emphasising its importance, for example, Hannah commented 'I think it's massively important' (FG2) and 'It's life-saving isn't it?' (Grace, FG2). All spoke about cervical screening being used preventatively for the early detection of precancerous cells, although uncertainty was expressed by a couple of the mothers as to the extent of its preventative capabilities and a lack of knowledge of the symptoms:

Alice: I would like to know if it's more preventative than going with symptoms. I mean, it isn't, is it because if you've got a symptom you go and I'm sure that must be more preventative then mustn't it?

Belinda: I wouldn't know what the symptoms are.

Despite their knowledge about cervical screening, gaps and uncertainty were still evident. Alice, for example, was uncertain of the distinction between precancerous and cancerous cells, asking 'What is the difference? I don't understand' (FG1), and others expressed uncertainty as to the age women are invited for screening: 'I don't know what the age is though' (Belinda, FG1).

#### Theme 2—Trusting and unquestioning

Despite some uncertainty and gaps in knowledge (illustrated in the previous theme), a trusting and unquestioning attitude towards cervical screening and the HPV vaccine was evident across the data. The majority of mothers expressed their dislike for cervical screening, mainly because of it being an uncomfortable, unpleasant experience.

Regardless of this, all of the mothers attended screening because of its considered importance, with several expressing the opinion that it is something they had to do, for example: 'You just know you have to do it. Like having your eyes checked' (Kate, FG3), 'I just think you probably wouldn't not go would you?' (Debbie, FG1), and 'You know you've got to do it' (Penny, FG4). One mother, Andrea, talked about how she attributed this attitude to an unquestioning trust in the importance of cervical screening:

I always go, I've trusted that someone's worked out the numbers and said that it's important that... it's sensible that we're all screened, that it saves lives at some point for some person. And that it is worth... the benefits outweigh the, sort of, the costs of screening the entire population [laughs]. (Anthea, INT 1)

Although knowledge was limited and uncertain, the majority of the mothers spoke about how they unquestioningly 'went with the flow' (Debbie, FG1) and 'rolled along with it' (Claire, FG1) when it came to making the decision about their daughter(s) having the HPV vaccination. Belinda explicitly described her unquestioning attitude towards it: 'I didn't really question it, I just assumed it was a good thing to do' (FG1). Two mothers talked about their trust in the NHS with regards to the HPV vaccination; they did not believe that the NHS would invest in something if it 'wasn't effective' (Grace, FG2). Claire, described how she felt there was a sense of apathy amongst parents when consenting to the vaccine, attributing this to the fact that they have already had to consent to numerous other vaccinations, such as the MMR: 'I think we're just so used to giving consent for MMRs or tetanus, your school nurse visits and everything else that you just didn't question it at all' (FG1). Similarly, Isobel said: 'I think when they're babies and you've had them vaccinated for other things it just becomes a follow-on' (FG3). Several of the mothers thus regarded the HPV vaccination as something that was 'no different' (Andrea, INT1), and as a natural follow-on to other vaccinations that their children have already had.

Most of the mothers spoke positively about not only the HPV vaccine, but vaccinations more generally, in terms of their protective, potentially life-saving qualities (many acknowledged that vaccinations were not completely effective). Mothers spoke about the HPV vaccination as being a 'privilege' (Fiona, FG1), 'logical' (Penny, FG4) and Kate commented that she was 'glad it's there' (FG3). It was its protective, preventative potential that made the decision to consent to the HPV vaccine, for some, a simple and unquestioning one, as articulated by Alice:

I just think that with vaccines if you've been offered it, because there are loads of vaccines that you are not offered, aren't there? And I just think if you're being offered it and you didn't have it and you got something like this, well, that would just be dreadful, wouldn't it? So, I think I probably would always say yes to vaccinations. (FG1)

Anticipated regret as to what could potentially happen if they did not consent to their daughter(s) having the vaccine, referred to here, appeared to be a driving force for a few of the mothers.

#### Theme 3—Mothers' communication with their daughters about HPV related topics

A trusting, unquestioning attitude (discussed in theme two) towards the HPV vaccine, and vaccinations more generally, led many of the mothers to not discuss these topics at any length and/or in any depth with their daughter(s). The decision, for some, was not open to debate, particularly illustrated in the following extract when asked whether they had spoken to their daughter(s) about it:

Isobel: No. I don't... I don't think we did discuss it that much. We just went...it's here, you're having it, get on with it (laughs)

Kate: Yes. You're having the injection [name of daughter]. Oh alright okay.

Kate: It wasn't optional so it was just... She never wanted...

Isobel: We did put it on the calendar so I was able to, you know, remind her the day before or whatever in case she was nervous or wanted to talk about it. (FG3)

Some of the mothers talked about how they would have made the decision for their daughters(s) to have the vaccination, despite what the literature they had received from the schools said, for example: '... so I don't think it mattered what the literature would have said, I probably would have still done it' (Penny, FG4) and: 'It'd have to be something pretty bad to deter me from not having it' (Isobel, FG3). One mother described how she had already made up her mind despite not knowing much about the vaccination, admitting she had probably 'dismissed' any 'bad bits' about the vaccine in the literature (Isobel, FG3). Belinda, whose daughter had not yet had the vaccination, mentioned how even her concerns about it would not stop her from wanting her daughter to have it: 'I suppose my biggest concern is that it's a very new vaccine... But I don't think that means I won't do it' (FG1). As well as their own unquestioning and trusting attitude, Kate talked about how her daughter had not gueried the decision: 'She just relied on me to say [name] you should have this. So, she didn't really question it' (FG3). This was echoed by Penny (FG4) when talking about her daughter's awareness of the vaccine: 'I don't think she would have called into question if we said well, you're having you know, you're getting this.' On reflection, one mother wondered whether she should have talked to her daughter more about the vaccination beforehand, questioning whether this made her 'a bad mother' (Kate, FG3).

Despite the lack of communication between the mothers and their daughters about the vaccine, several talked about how they believed their daughters should be informed about these topics. In relation to the vaccine, for one mother this was about helping her daughter understand their decision for them to have the vaccine, rather than for the daughter to make their own decision:

It's part of the process of giving them the responsibility to look after themselves. If you just dictate all the time, they don't understand all the reasons behind, whereas if you give the information to them, even if you are telling them they have got to and it's not optional, but they start to see why you're saying that. (FG1)

Although this view was expressed by one of the mothers, some felt as though their daughters were too young to understand all the details when it came to the vaccine and in particular, what this was for. A barrier to communicating between mothers and their daughters was the mothers' perceived embarrassment of talking about these topics, with mothers talking about potential strategies that they used to facilitates these conversations; some mothers talked about the importance of normalising these topics so embarrassment was not so much of a barrier. Several of the

mothers talked about how their daughters were educated about these topics at school, although their knowledge of the content and the extent of this education was uncertain. There was mixed opinion as to whether it was the school or parent's responsibility to educate their daughters about these topics, with the acknowledgement that sometimes the parents 'don't know' (FG4) and that 'children don't always listen to their parents' (FG4).

Mothers were asked how important they felt it was for those who have been vaccinated to still attend future cervical screening appointments. Despite their uncertainty and lack of specific knowledge about the HPV vaccine, discussed in theme one, the mothers in all but one of the focus groups were certain their daughters, even after receiving the HPV vaccine, would still need to attend cervical screening, attributing this to a range of reasons, mainly their acknowledgement that vaccines are never one hundred percent effective. In one focus group however, some mothers were uncertain as to whether this was the case.

Alice: That is something I do not know about. I thought maybe they wouldn't even have to go...I was thinking that might be phased out, I don't know.

Debbie: HPV is not the only way you can get cervical cancer though is it.

Fiona: I didn't know that you see. I was hoping that would be it; they would be protected and not need it but that's wrong. (FG1)

The general consensus was that despite their view of the importance of future cervical screening, this information needed to be emphasised more to their daughters; some thought that this could be highlighted more in the literature received regarding the vaccine whereas others felt as though it would be more beneficial for this reminder to be incorporated into the cervical screening invites when their daughters get to the age when this applies to them: 'But maybe when they're 25 and they get this they will get the information saying you may have had the vaccine but you will still... Perhaps that's the time to bring it up' (FG1). Some mothers talked about how they 'hoped' that the importance that they placed on cervical screening themselves was something that would be shared by their daughters: 'I always tell the nurse how much I hate having it done when I go. But, you know, you have to do it. And I hope my daughter believes that' (FG3).

#### Research aim 3—HPV invite—an opportunity to nudge mothers about cervical screening?

All mothers in our focus groups were asked their opinions about whether the HPV vaccination invite could be used as an opportunity to remind mothers about the importance of cervical screening. Responses were mixed; some mothers articulated their strong support of this, for example, when asked this question, some mothers replied 'definitely' (FG2) and 'Absolutely' (FG2), whilst others were against it. The main reason that appeared to be behind those in support of the suggestion was that 'it wouldn't do any harm' (Claire, FG1) and more specifically the opinion that it is 'better than doing nothing I suppose isn't it?' (Jackie, FG3). One mother talked about how their daughter's vaccine invitation was comparable to pregnancy in being one of those 'key moments' when a reminder about the importance of cervical screening could be beneficial. Despite this view, there was unease about a reliance on this:

I mean, it wouldn't hurt, I guess, to have the paragraph in here. I mean, we all think that paragraph is important in here, but it seems daft to rely on something that goes home with your daughter to get the adult to go for the smear test. (FG1)

The main concern articulated from those who were against the idea was that it might detract attention from the intended focus of the vaccine invite being about their 'daughter's moment' (FG5), for example: 'I can see why it might be useful to get two messages across. But it might complicate the matter. They might think, is this for me? Or my daughter?' (Kate, FG3) and 'I would write to them directly. Rather than use the daughter's HPV vaccine' (Fiona, FG1).

#### **Discussion**

This study drew upon both quantitative and qualitative methods to explore three main areas: (1) adolescent girls' mothers' knowledge and attitudes towards HPV and the HPV vaccination, (2) their knowledge and attitudes towards cervical cancer, cervical screening, and (3) whether their daughters' vaccination invitations might be an opportunity to nudge mothers to attend cervical screening. Our participants represented a homogenous group of predominantly white, middle class, educated women. Their self-reported uptake of cervical screening (92.8%) was considerably higher than the national average (71.4%, NHSCSP, 2018) and they reported a slightly higher engagement with the vaccination programme for their daughters (85%) than the national average (83.9%, Public Health England, 2019). Despite these characteristics, findings from the quantitative survey linked to aims 1 and 2, revealed that the mothers still displayed relatively low levels of knowledge about the causes of cervical cancer as well as gaps in their knowledge about HPV. In addition, there was some confusion about the purpose of cervical screening. These findings were supported by qualitative insight from the focus groups, where mothers talked about their limited knowledge and uncertainty about the link between HPV and cervical cancer, the HPV vaccination, and about certain aspects of cervical screening (e.g. difference between cancerous and pre-cancerous cells). The limited knowledge and uncertainty indicated and expressed by the mothers in our study echoes findings from previous research in this area (e.g. Marlow et al., 2013; Sherman & Nailer, 2018).

Previous research (e.g. see Brewer and Fazekas, 2007 for a review) has shown that vaccine acceptability can be high despite low levels of knowledge about HPV and so the finding that these women were engaging with the vaccination program on behalf of their daughters, despite displaying relatively low levels of knowledge about HPV in the survey and uncertainty and limited knowledge about HPV and the vaccination in the focus groups, is not unexpected. Our second theme from the focus group data (trusting and unquestioning) goes some way to explaining why engagement is still happening in the absence of detailed or confident knowledge. For both screening and vaccination, mothers reported trust in the NHS and clinical opinion. Furthermore, for the vaccination programme a reported 'going with the flow' revealed the free

school programme in the UK may remove some of the barriers to vaccination that other countries may experience (namely cost and arranging an appointment for the vaccination to take place). Previous research (e.g. Marlow et al., 2007) has shown that trust in doctors and the government has emerged as a significant predictor of HPV vaccine acceptance amongst mothers. The idea of the HPV vaccine being 'no different' and as a natural follow-on to other vaccinations that children have already had, also echoes findings from previous literature which indicates that mothers are more likely to accept the HPV vaccine if their children have received all of the previous vaccinations offered to them (e.g. Marlow et al., 2007).

The findings reported in our third theme that a trusting, unquestioning attitude towards the HPV vaccine, and vaccinations more generally, led many of the mothers to not discuss the topic at any length and/or in any depth with their daughter(s), contradicts existing research (e.g. McRee et al., 2011) which indicated that most mothers reported talking to their daughter about the HPV vaccine. The current findings are of concern given McRee et al. highlighted that such discussion, between mother and daughter, could provide opportunities for more open lines of communication about sex and sexual health more generally. Anticipated regret about their daughter's future health emerged as a driving force for some of our mothers in their unquestioning decision to consent to their daughters having the HPV vaccine, echoing previous literature which has found this to play an important role in caregivers' decision-making process surrounding the HPV vaccine (e.g. Ziarnowski et al., 2009).

Although two thirds of mothers report school/college/university as a source of information about HPV and cervical cancer, our sample had mixed feelings about whether the HPV vaccination letter might be an opportunity to nudge mothers to attend cervical screening. Furthermore, as the focus groups revealed, even when the mothers receive information from school, they do not always attend to it or remember it as well as they might. In light of this lack of engagement with information contained in the vaccination invitation letters on behalf of their daughters, there is no reason to think that this would be any more effective as a method of encouraging mothers to attend screening than the actual screening invitation letters themselves.

Our findings highlight how useful it is to draw upon both quantitative and qualitative methods, with qualitative data capturing some of the subtler nuances and complexities in attitudes and understanding, which may otherwise have been missed. Whilst women, for example, might be aware that the aim of cervical screening is to identify pre-cancerous cells (as correctly indicated by nearly 70% of survey respondents), the focus group data indicates that women may not necessarily understand what this means. One mother, for example, expressed her uncertainty about the difference between cancerous and pre-cancerous cells. Similarly, whilst survey responses indicated a certain degree of uncertainty (31.9%) about whether the vaccine prevents all cases of cervical cancer, focus group data was able to shed some light on this, with uncertainty being expressed about whether there were causes of cervical cancer, other than HPV.

Although most mothers (89%) in the survey felt that it was important for girls, despite having the vaccine, to still go for future cervical screening, there was still some uncertainty (9.4%). This uncertainty, further demonstrated by mothers in one of the focus groups, supports previous research (e.g. Henderson et al., 2011) which indicated there might be a misunderstanding amongst some parents and girls that the vaccine provides complete immunisation against cervical cancer. Since the quadrivalent vaccine provides protection against two HPV types that are responsible for most but not all cervical cancers, it is important that the HPV vaccination programme is not seen as a replacement for the cervical screening programme. This research further illustrates the importance of ensuring that women and girls are aware of this.

The decision many of the mothers in our study had made to engage in cervical screening can be explained to some extent by the Health Belief Model (HBM) (Becker & Rosenstock, 1984). According to the HBM, there are five constructs which influence whether an individual will engage in a protective health behaviour; perceived susceptibility, perceived severity, perceived benefits of engaging in the behaviour, perceived barriers, and cues to action (e.g. reminders to engage in the behaviour). The mothers in our study particularly highlighted the perceived severity of cervical cancer by talking about cervical screening, for example, as being 'important' and 'lifesaving'. The perceived barriers (i.e. it being an uncomfortable, unpleasant experience) were outweighed by the perceived benefits and importance of cervical screening. Several of the women in the focus groups also talked about receiving reminders (cues to action) to attend their cervical screening appointments. Whilst some of the HBM constructs can be drawn upon to explain women's engagement in cervical screening and, to an extent their decision to engage in the HPV vaccination programme, the model does not account for the unquestioning trust that was evident in the mothers' responses in the focus groups. This emerged as a very important, powerful influence on women's decision to engage in the programmes despite, by their own acknowledgement, their limited knowledge and uncertainty.

Our study has some limitations. We have a relatively low sample size and due to the method of sampling, we are unable to determine a response rate, however it is likely to be quite low, which raises the possibility of a biased sample. As we have already indicated, our sample is not a diverse one. Additional research is needed to explore what those women from different socio-demographic groups, who do not report such high engagement with the screening and vaccination programmes, understand about HPV and its relationship with cervical cancer. However, as our research demonstrates, even amongst those women who do engage with the programmes, knowledge is not as complete as it might be. Now that HPV primary screening has been rolled out across the UK, the public needs to be better informed about HPV, cervical screening and cervical cancer. In particular, women need to be clear that their daughters still need to attend cervical screening, despite having had the vaccine. Daughters also need to be aware of this for when they come to the age of being invited for cervical screening. Women need to be encouraged to talk to their daughters about the HPV vaccination to keep lines of communication open about HPV, cervical cancer, cervical screening and sexual health more generally. Our findings indicate that the unquestioning trust of the mothers may prevent this communication from occurring; strategies to avoid this need exploring. The mixed response to the suggestion that the HPV invite being used as an opportunity to nudge mothers to attend cervical screening, also warrants further investigation.



#### Note

We are unable to provide a response rate for the survey. For the online study, we have no way of knowing how many mothers would have seen or read the link to the survey since schools varied in texting the link or hosting it on their website. For the paper survey, we cannot be certain how many surveys were actually sent out by the schools since only 13 were returned.

#### **Data availability**

The survey is available here: https://osf.io/h953r/. The data are available on request from the corresponding author for five years post publication.

#### **Disclosure statement**

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