A qualitative study to assess the potential of the human papillomavirus vaccination programme to encourage under-screened mothers to attend for cervical screening

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ABSTRACT

Background Coverage of the UK National Health Service Cervical Screening Programme is declining. Under-screened women whose daughters participate in the human papillomavirus (HPV) vaccination programme could be stimulated to attend. We investigated whether factors associated with the vaccination programme changed mothers' intentions for future screening.

Methods Questionnaires were sent to mothers of girls aged 12–13 years across two North West primary care trusts (n=2387) to assess the effect of the HPV vaccination programme on screening intentions. This identified mothers whose intentions had changed. Consent was sought to contact them for a semi-structured interview to discuss their screening intentions. Key themes were identified using framework analysis.

Results 97/606 women responding to the questionnaire had changed their views about cervical screening. 23 women were interviewed, 10 of whom expressed a positive change and 13 no change. Most had discussed the vaccine information, including cervical screening, with their daughters. Mothers who made a positive change decision recognised their daughters' risk of cervical cancer, the need for future screening, and the importance of their own example. In this way daughters became 'significant others' in reinforcing their mothers' cervical screening motivation.

Conclusions A daughter's invitation for HPV vaccination instigates a reassessment of cervical screening intention in some under-screened mothers.

Key message points

- Information provided with the human papillomavirus vaccination programme promotes mother–daughter communication.
- This results in a reassessment of the relevance of cervical screening in some under-screened mothers, and reinforces the importance of setting a good example for daughters.
- There should be a more coordinated delivery of information between the two cervical cancer prevention programmes to enhance the connections made and maximise participation.

INTRODUCTION

Coverage of the UK National Health Service Cervical Screening Programme (NHSCSP) has been declining since the mid-1990s.[1] There are many reasons why women fail to attend cervical screening, such as practical barriers around access and appointment times, negative previous experience, and feelings of embarrassment and fear. Poor knowledge about the purpose of screening and cause of cancer are also known barriers.[2–7] Yet women are now more likely to come into contact with information about the role of human papillomavirus (HPV) in cervical cancer than previously. HPV testing has

been incorporated into the UK NHSCSP,[8] providing an opportunity for information transfer among eligible women. With routine HPV vaccination of girls aged 12–13 years, information about the virus, its mode of transmission and link with cervical cancer is usually provided so that parents and girls can together make an informed decision about participation.[9 10]

Research has suggested that mothers' cervical screening history influences the decision to vaccinate daughters, with screened women more likely to have vaccinated daughters.[11–17] The information provided within the HPV vaccination programme could, in turn, serve as a reminder for mothers who have failed to attend for screening. We have previously reported a significantly higher screening return rate in the current vaccination year for lapsed and never-screened mothers [odds ratio 1.05 and 1.16, respectively].[18] As this result was based on an analysis of data records it did not allow further interpretation. Information associated with the vaccination programme was a possible factor but other influences may also have prompted women's decision to return to the cervical screening programme.

The purpose of this qualitative study was to investigate what mothers learn about cervical cancer prevention from their daughters' vaccine literature and whether daughters' vaccination influences mothers' motivation for cervical screening.

METHODS

Study population

The study was conducted in two primary care trust (PCT) areas within Greater Manchester, UK. PCTs at that time were the NHS bodies responsible for commissioning cervical screening and delivering HPV vaccination. One PCT had a relatively low cervical screening coverage of 76.8% and the other was relatively high at 80.3% (2010/2011).[19]

Study design

Questionnaires were sent to all mothers or female guardians of 12–13-year-olds girls eligible for vaccination in the school year 2010/2011 in the two PCTs (n=2387). The sample size considerations can be found in the online Supplementary Material. Data collection took place in November 2010 following the first vaccine dose. The questionnaire sought information on mother's screening history and consent for HPV vaccination as well as future screening intentions. The responses formed the basis for recruitment for a semi-structured interview on PCT premises to assess the views of women who did and did not indicate a change in future screening intentions as a result of contact with the vaccine programme. Written consent was obtained from participants at the time of interview.

The theory of planned behaviour[20] provided a framework for considering whether the intended behaviour (cervical screening) was perceived to be desirable and thus necessary and also the severity or consequences of not attending for screening. Other important aspects of this theory are the impact of subjective norms, such as an individual's perception of what significant others (friends or family) think about cervical screening. The delivery of HPV information in the context of mother–daughter communication was relevant to this analysis. Behavioural control or self-efficacy could include perceptions of difficulty in attending screening or having a smear. As the theory anticipates rational decision-making, mothers might be expected to consider their own, as well as their daughters', cervical cancer risk. The interview schedule covered: mother's screening history – influences on attendance or barriers, future cervical screening intentions; daughter's HPV vaccination – reasons for consent/no consent, discussion of HPV information. Participants were shown a number of Department of Health (DH) leaflets during the interview[21–23] to see if any were recognised as part of the information sent to them.

Data handling

The number and percentage responding to the questionnaire were summarised by PCT and demographic characteristics. Women expressing an interest in attending for interview were purposefully sampled utilising questionnaire responses to stated intentions to change screening behaviour or change in screening views as well as by daughter's vaccination status, PCT and ethnic background.

During their interviews some women indicated different future screening intentions from those indicated on their questionnaire and were reclassified. This included one woman whose questionnaire response indicated her screening intentions negatively changed following the vaccination programme. It became apparent in the interview that she was more likely to attend for screening in the future.

Women who completed interview were classified as either:

- *No Change – Always Attend (NCA):* Have always attended cervical screening in the past and intend to continue in the future.
- *Positive Change – Lapsed Attendance (PCL):* Have previously lapsed from screening but have attended at least once in the past. Expressed intentions to attend more frequently in the future
- *No Change – Lapsed Attendance (NCL):* Have previously lapsed from screening but do not see their screening behaviour changing in the future

Attempts were also made to contact women who had never attended for cervical screening. Unfortunately we were unsuccessful in recruiting these women to interview.

All interviews were audio-recorded and transcribed verbatim. Two researchers (AMS and AV)

Table 1 Demographic characteristics of questionnaire respondents and for women attending interview

Characteristic	Questionnaires		Interviews	
	n	%	n	%
PCT				
1	333	28	13	57
2	273	23	10	43
Age (years)				
25–34	74	12	3	13
35–49	484	80	19	83
50+	46	8	1	4
Unknown	2	0.3		
Ethnicity				
White	560	92	20	87
Non-white	40	7	2	9
Unknown	6	1	1	4

Twenty-four questionnaires were excluded due to duplicate responses or as a result of father or daughter responding.
PCT, primary care trust.

independently read the transcripts, with AMS undertaking detailed coding, facilitated by the NVivo10™ computer programme (QSR International, 2012). Key themes and subthemes within and across the interviews were agreed utilising framework analysis.[24 25] The analysis focused on a comparison of the three change groups to understand how attitudes had altered.

When reporting direct quotation minor grammatical errors have been corrected and identifiable information excluded. An ellipsis […] within speech marks indicate that text has been removed. Quotations are referenced to include the classification of participants (as above) and the interview number.

RESULTS

Numbers of women changing screening intentions

The response rate to the questionnaire was 25.6% (n=606). The majority of respondents were aged between 35 and 49 years (n=484) and over 90% were white (Table 1). Sixteen per cent of mothers stated that their views about cervical screening had changed as a result of the vaccination programme (Table 2). Over 50% (n=311) of respondents expressed an interest in participating in an interview. A total of 41 women were contacted, with 23 attending for interview. Of these, 10 lapsed attenders expressed intentions to attend more frequently in the future (PCL), six of whom had gone on to attend for cervical screening prior to the interview. In contrast, two women remained disinclined to attend regularly (NCL). Eleven women were interviewed who had always attended cervical screening in the past and intended to continue in the future (NCA), two of whom did not provide vaccination consent. Nine of the women attending for interview came from health service backgrounds or had links with schools or teaching.

Factors affecting change/no change decisions of mothers in the context of a HPV vaccination programme

Table 3 summarises the main themes arising during interviews with the three categories of respondents. In discussing reasons for cervical screening there were

Table 2 Questionnaire responses (%) for all respondents (n=606) and for women attending interview (n=23)

Question	Questionnaire responses		Interviewee responses	
	N	Yes [*n* (%)]	*N*	Yes [*n* (%)]
1 Have you consented to allow your daughter to have the HPV vaccine?	604	566 (94)	23	21 (91)
2 Did you discuss the vaccine information with your daughter?	605	559 (92)	23	21 (91)
3a Have you received a smear test in the last 5 years?	560	514 (92)	21	16 (76)
3b Have you received a smear test in the last 3 years?	543	448 (83)	22	13 (59)
4 How often do you attend for a smear test?				
Always		526 (88)	23	8 (35)
Sometimes	600	60 (10)	23	14 (61)
Never		14 (2)	23	1 (4)
5 How often do you intend to go for a smear test in the future?				
Always		501 (93)	23	15 (65)
Sometimes	537	25 (5)	23	6 (26)
Never		11 (2)	23	2 (9)
Positive change in screening intentions	606	27 (4)	23	7 (30)
Negative change in screening intentions	606	2 (0.3)	23	1 (4)
6 Did receiving the HPV vaccine information change your views about cervical screening?	594	97 (16)	23	11 (48)

Not all questionnaire respondents completed all the questions hence the denominator (*N*) for individual questions is also provided. In the case of Questions 3, 4 and 5, missing responses include those stating 'Not Applicable' due to hysterectomy or other related health issues. Positive and negative changes in screening intentions were inferred from the responses to Questions 4 and 5.
HPV, human papillomavirus.

Table 3 Main themes and subthemes

Theme	Subtheme	Participant classification: No Change – Always Attend	Positive Change – Lapsed Attendance	No Change – Lapsed Attendance
Past cervical screening				
Barriers	Access – time, appointments	✓	✓	✓
	Embarrassment		✓	✓
	Procedure – uncomfortable, painful	✓	✓	✓
	Fear, guilt	✓	✓	
	Not a priority – family, work commitments		✓	
	Knowledge – lack of information		✓	
Facilitators	General prevention beliefs	✓		
	Cancer awareness	✓		
	Family/friend cancer history	✓	✓	
	Aging		✓	✓
	Encouragement from significant others – own mother, husband	✓	✓	
	Opportunistic screening – postnatal check-up		✓	
	Time available			✓
	Jade Goody	✓	✓	
Daughters' HPV vaccination				
Information provision	Consent form/invitation letter	✓	✓	✓
	Department of Health leaflets – received	✓	✓	✓
	Would have been useful	✓	✓	
	Own research carried out:	✓	✓	
	Internet	✓	✓	
	Discussion with others (friends, family, health professionals)	✓	✓	
	Media – news, TV, magazines	✓		
Knowledge	HPV link to cervical cancer	✓	✓	✓
	Link to herpes/wart virus	✓	✓	
	Number of doses	✓	✓	
	Sexual transmission	✓	✓	✓
	Screening and vaccination interlinked	✓	✓	✓
	Purpose of screening – early detection of abnormalities	✓	✓	✓
Barriers to vaccination consent	Not enough information on side effects	✓	✓	
	Daughter fear of the needle	✓	✓	
	Lifestyle implications – sex	✓		
Facilitators to vaccination consent	General prevention beliefs	✓	✓	✓
	Cancer awareness	✓	✓	✓
	Family/friend cancer history	✓	✓	
	Free and available	✓		
	Part of a national programme	✓	✓	
	Others having it – follow the crowd	✓	✓	
	Youth promiscuity		✓	✓
	Jade Goody	✓	✓	
	Mothers' cervical screening history		✓	
Vaccination discussion with daughter	Daughters' concerns	✓	✓	
	Cancer prevention	✓	✓	
	Family/friend cancer history	✓	✓	
	Jade Goody	✓	✓	
	Sex – safe sex, relationships,	✓	✓	✓
	Cervical screening	✓	✓	✓
Influence of HPV vaccination on future cervical screening intentions	Reminder		✓	
	Realisation of sexual transmission of virus – reassessment of risk	✓	✓	
	Setting an example for daughter		✓	
	To be there for her family in the future		✓	
	Daughter now prompts mother for cervical screening		✓	✓
	Learning about cervical screening from discussion with others	✓	✓	

HPV, human papillomavirus.

themes common to women who were already screening and intended to screen in future that contrasted with mothers who held negative views on screening. As general factors influencing screening have been well described, they are briefly summarised in the online Supplementary Material.

HPV vaccination information

Mothers across all groups reported having received a small amount of information with the consent form, including "what the vaccine was" (NCA11) and that it was "to do with cervical cancer" (PCL15). A number of participants did not recognise the DH leaflets even though nearly half of the women said they had looked for other sources of information, including NHS material on the internet. Much of this research was in the context of vaccine safety in a '*new*' programme. Women across all groups, with the exception of No Change – Lapsed women, undertook some form of discussion, with health professionals, friends, husbands and/or their own mother. Feeling the need in "following the crowd" (PCL1) was an important element in considering vaccination consent. This sometimes led to questions on screening and resulted in one Positive Change – Lapsed woman learning "how often you should go, or how often other people were going for cervical screening" (PCL10). For those generally acceptant of vaccines, research was more superficial being "more or less a yes anyway" (PCL18) or "just an extra one" (NCL16).

Most women were to some extent aware of how HPV is transmitted, though some women remained oblivious to the fact that the virus is sexually transmitted including one of the No Change – Lapsed women who admitted "I don't know anything about it" (NCL16). For some lapsed attenders, making the link with sexual transmission made screening "more relevant" (PCL19) and reinforced the importance of screening for those who already attended (NCA). The realisation that men can carry the virus and that "sexual contact with another person, you know, how you can be infected and so on and you think OK maybe!" (PCL15) rather than just sexual intercourse can transmit the virus, led to a reassessment of risk in both these groups because "you are sure of yourself but you are not sure about your partner" (NCA20). For one woman confirmation of this link from reading the DH information leaflet *Your Guide to the HPV Vaccination*[22] during the interview was influential in her changing her future screening intentions.

For always-attenders, sexual transmission was something they "didn't think about" (NCA21), particularly as they felt they were at low risk attending "screening regularly and I only have one partner now" (NCA11) or "because I am married and … sort of in a settled relationship it hasn't really entered my head" (NCA21). The two women who failed to consent to the vaccination were keen to emphasise lessons in "lifestyle" (NCA21) to their daughters such as "not lots of sexual partners" (NCA 21) and not having "unprotected sex" (NCA23) but did not necessarily feel the risk of contracting HPV was relevant to them. "I just think that it is so unlikely to happen to me" (NCA21). This was echoed by one of the No Change – Lapsed women who saw the vaccination programme as being particularly '*useful*' for young people who are "becoming more promiscuous" (NCL17). This subset of always attenders who didn't consent to the vaccine and No Change – Lapsed women also appeared to be unsure as to whether cervical cancer "runs in the family" (NCL17). For one non-consenter this misconception was one of the reasons leading to her decision not to vaccinate her daughter whereas her screening attendance was "out of habit … I don't think I gave it an awful lot of thought now" (NCA21).

For those expressing a positive change in screening intentions, daughter's vaccination invitation itself was seen as a '*reminder*' for screening but "more so than actual reminders you get because that's addressed to me it's nothing to do with anybody else and it goes straight in the bin and nobody else needs to know except me whereas this is my family" (PCL18).

Importance of mother–daughter communication

All but two of the women interviewed undertook some form of discussion with their daughter about the HPV vaccination. Women who accessed the DH information leaflet *Your Guide to the HPV Vaccination*[22] prior to their daughter's vaccination identified it as being particularly useful in facilitating discussion. Mothers found the vaccination programme gave opportunity to "open communication" (PCL15) with their daughter, with mothers across all groups including safe sex, contraception and cervical screening when discussing the vaccination.

> *"…since they started with the injections at school she wanted to know why and what it was all about* [cervical screening] *and I thought well now is the perfect time to sit down and explain all about it".* (PCL14)

For No Change – Lapsed women, discussion with one daughter focused more on "where the cervix is as part of their biology information" (NCL17) with the other simply aware that her daughter had "read the leaflet" (NCL16).

Positive Change – Lapsed women were most likely to reflect on past screening experiences. For these women, recounting previous abnormalities, painful experiences or worry from failing to attend, assisted in forming a decision to consent for the vaccination programme as "they're both like me, they both worry so much … I didn't want them to go through the same thought process" (PCL3). In turn these women were more likely to discuss their own experience of cervical screening with their daughters. Discussion enhanced a mothers' role to "lead by example"

(PCL3) for her daughter's future screening attendance. "When the next appointment comes it will be more 'I will do that right now' and I will tell the girls" (PCL12). This in turn gave daughters insight into mothers' screening attendance, such that they could be actively encouraged to attend.

> *"Yes I felt very hypocritical and I was going to get it, yeah and they nag me now they nag me and say I see you got a letter the other day mum."* (PCL10).

Another woman acknowledged that if her daughter '*nagged*' her "she would have more influence than my husband" (PCL18). This was not expressed by No Change– Lapsed women who did not include their own experiences in discussions with their daughter. These women did not acknowledge that they might play a role in encouraging their daughter's future screening.

> *"No I think she will go herself, she won't need the reminder from me."* (NCL16).

Mothers frequently expressed feelings of "wanting to be there as they're growing up" (PCL3) or "when they get married" (PCL14), emphasising their sense of responsibility because "they need me as much as I need them" (PCL3). Some women utilised stories of friends and family members affected by cancer or Jade Goody "in focusing their (daughters') minds on the realities of what cancer could do … People don't know when people could be struck down and at what time – I'm gonna go for my smear test now!" (PCL10). As the No Change – Lapsed women "don't really have anyone in the family who's had it" (NCL17) this could not be a reinforcement factor.

DISCUSSION

A daughter's participation in the HPV vaccination programme seems to result in a reassessment of cervical screening motivations for some under-screened mothers, as well as for those who regularly attend. Previous research has shown a 5% increase in mothers returning to screening in the year of their daughter's vaccination.[18] In this study 16% of questionnaire respondents stated that the vaccination programme had changed their views about cervical screening. Common barriers to screening such as embarrassment, pain of the procedure, and service access[2–7] are not necessarily overcome; but for some mothers, exposure to the HPV vaccination programme, alongside family or friends' experience of cancer and Jade Goody's death, caused them to challenge their own screening behaviour. Exposure to the vaccination programme also led to more discussion with family or friends. Lapsed women who indicated positive future cervical screening intentions were more likely to make a connection between their own screening behaviour and their daughter's HPV vaccination than those who did not demonstrate a change in screening intentions or always attended. The realisation that cervical cancer presented a future risk for their daughter challenged these mothers to set an example for their daughters to follow since the latter would now be aware that the risk of cervical cancer also demanded action from their mothers. Such daughters are "significant others" who can provide an active role in influencing mothers' screening attendance, thereby enhancing or altering subjective norms towards cervical screening.[20] Mothers realised that the omission of screening would impact on their family should any cervical abnormalities remain undetected, facilitating their revaluation of behavioural attitudes and the consequences of not attending screening.[20]

For some mothers this was the first time cervical screening was openly discussed with family or friends. The vaccination programme allowed them to open a dialogue not only about vaccination and screening but also about safe sex. More awareness that the HPV virus responsible for cervical cancer is sexually transmitted resulted in a reconsideration of whether screening was necessary in the light of their own risk behaviour.[20] Reassuringly the always-attenders interviewed who made this link did not express any negative change in intended screening behaviour. This has been a concern for experts who have worried that women who associate HPV transmission with promiscuity will fail to see a need for screening if they are monogamous[26] and a fear that attribution of blame to cervical cancer patients could result in ambivalent attitudes towards screening.[27] Some women did not recognise that HPV is a sexually transmitted disease, which may have been a consequence of not receiving sufficient information, not reading the information they did receive, or of failing to understand the information provided. As HPV testing in the UK is now embedded within the cervical screening programme, with the programme piloting switching from cytology to HPV testing as the primary screening method,[28] it is possible that this will further enhance awareness amongst mothers and heighten the connection made between the two screening programmes.

Strengths and limitations

A key strength of the study was the use of the questionnaire, which enabled a sufficient number of women who had changed screening intentions as a result of the vaccination programme to be identified. Despite this, it remained very difficult to recruit for interview many of the women who had agreed to be contacted, with particular difficulties faced in the recruitment of women with negative attitudes to cervical screening. The nine women interviewed from health service or school backgrounds may be expected to have a greater knowledge of the HPV vaccination programme and cervical screening than the general population. However, it became apparent that overall awareness was still lacking.

The interview itself and the questionnaire asked directly about the influence of the HPV vaccination on cervical screening intentions. This may have instigated a more conscious awareness of the connection between the two preventions. The study was conducted in the UK during the early years of the national HPV vaccination programme and in the year following the death of Jade Goody, a British reality-television personality who died of cervical cancer at the age of 27 years. This corresponded with an increased media interest in HPV vaccination. At that time PCTs were responsible for the commissioning of cervical screening and delivery of HPV vaccination. Further work is required to understand how generalisable these findings are to current vaccination practice and information provision. It is also important to investigate the health literacy of women and girls to understand how the provided information is interpreted. This is especially important with the NHS HPV vaccination programme's change from a bivalent to a quadrivalent vaccine in 2012, which draws more attention to sexual transmission and genital infections.

CONCLUSIONS

The views and opinions of the women interviewed in this study demonstrate that there can and should be more coordinated delivery of information for both the HPV vaccination and cervical screening programmes. Although cervical screening is briefly mentioned in the HPV vaccination information, vaccination is not currently included in information provided in the cervical screening programme. Information provided with both programmes should incorporate the cause of cervical cancer and methods to prevent it, including both cervical cancer prevention programmes. Information provided in the context of a daughter's HPV vaccination has the potential to promote mother–daughter communication, reinforcing the relevance and value of cervical screening attendance in lapsed mothers as well as their daughters.

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Supplementary online material:

Sample size considerations

The sample size for the questionnaire was based on consideration of parental vaccine acceptance of dose 1 HPV uptake for the NW in 2008/09 at ~90% and cervical screening uptake at ~80%. Using the 2009/10 cohort of 12-13 year olds eligible for the vaccine as an estimate, approximately 2500 questionnaires were to be sent in total. Based on a conservatively estimated 20% response rate taken from a previous study investigating parental attitudes to the HPV vaccine [29], 500 questionnaires would be returned.

Data were not available to allow estimation of mothers' intentions to change screening behaviour. 100 returns from non-screened women would allow the proportion of women changing attitudes to be determined with 50% relative accuracy if 15% reported such changes (based on the binomial two sided 95% confidence interval).

It was planned that a pragmatic sample of 20-30 mothers, who had agreed on their questionnaire to be contacted for interview, would be selected. It was anticipated that this would be an adequate number to understand how perceptions of cervical screening are modified by HPV vaccination.

Supplementary results from semi-structured interviews:

Factors affecting cervical screening intentions unrelated to HPV vaccination

Having the time or convenient access to services was an issue for women across all three groups, as was the *'uncomfortable'* nature of the *'procedure itself'*. Those who had lapsed attendance (PCL and NCL) discussed barriers but declared fewer reasons for attendance in the past. Reasons for past screening included increased contact with the health service when pregnant and during the post-natal check-ups. Even so, as children got older and contact with the health service reduced, being a mother for lapsed women meant, screening was *'not a priority'* making *'the children the priority rather than myself'* (PCL15) with particular difficulties identified for working mothers *'with kids to balance around and a job'* (NCL17). One of the No Change-Lapsed women missed the *'structure'* of the *'health service system'* in the process of *'having children'* which *'keeps you on the screening pathway'* (NCL16). Poor access and lack of availability of convenient appointments remained a major barrier to screening for those lapsed women who expressed no change in future screening intentions

(NCL), even following their daughters' vaccination. Also some mothers were *'still really none the wiser as to where..to go to have it completed'* (NCL17).

Always attenders (NCA) more frequently expressed a general belief in *'prevention rather than cure'* (NCA5) and *'early diagnosis'* (NCA8). Such beliefs were made *'more prominent because someone in the family'* (NCA9) or a *'friend'* had been affected by cancer or a related illness. Knowing and hearing of people affected by cancer was a reason many lapsed women returned to screening (PCL), with the increased realisation '*as you get older it does affect people's lives'* (PCL12). Jade Goody, the reality television star who died from cervical cancer further enhanced the relevance of screening to always attenders and lapsed attenders expressing a positive change. As a *'young'* woman, she was a *'popular figure'* they *'could identify with'* (PCL10). They *'empathised with her situation because she had two young children'* (PCL1). Neither of the lapsed women who expressed no change (NCL) could recall any friend or family member being affected by a related disease or expressed an influence from Jade Goody's death.