Title: HPV PRIMARY CERVICAL SCREENING IN ENGLAND: WOMEN’S AWARENESS AND ATTITUDES

Running Title: AWARENESS OF PRIMARY HPV SCREENING IN ENGLAND

Authors
Hersha Patel\textsuperscript{a}, Esther L Moss\textsuperscript{b}, Susan M Sherman\textsuperscript{c},

Affiliations
\textsuperscript{a} Department of Health Sciences, University of Leicester, University Road, Leicester, LE1 7RH, UK
\textsuperscript{b} Leicester Cancer Research Centre, University of Leicester, University Road, Leicester, LE1 7RH, UK
\textsuperscript{c} School of Psychology, Keele University, Staffordshire, ST5 5BG, UK

Corresponding Author
Dr Esther Moss
Leicester Cancer Research Centre, University of Leicester, University Road, Leicester, LE1 7RH, UK
Email-em321@le.ac.uk
Tel: +44 300 303 1573
Fax: +44 116 258 8210
ABSTRACT
Background
Primary HPV cervical screening is due to be implemented in England within the next 2 years however, the acceptability of HPV testing as the primary screening test is unclear. This study explores women’s awareness and attitudes towards HPV testing/screening.

Methods
Qualitative interviews (semi-structured and focus group) were conducted with forty-six women (aged 25-65 years) from community and secondary care settings. Data was analysed using the inductive-framework method.

Results
Women were unaware that cervical screening currently includes HPV testing and lacked HPV-related knowledge. Emotions of shock, fear and anxiety were reported upon receiving a positive HPV result. For women in long-term relationships, the realisation that HPV is a sexually transmitted infection (STI) was seen as a barrier to primary HPV testing. Knowledge that HPV testing is a screening test to prevent cervical cancer did not change their attitudes. Women debated the need for continued screening following a negative result. Women feared judgement by the community if they participated with primary HPV screening because they were being tested for an STI, with the possible attendant perception that they had adopted a high-risk lifestyle in comparison to non-attenders.

Conclusions
The acceptability of HPV testing may be a limiting factor in encouraging participation with screening in the future.

Keywords
Cervical cancer, cervical screening, HPV attitudes, HPV testing, Primary HPV screening
BACKGROUND

Persistent infection with high-risk human papillomavirus (hrHPV) sub-types has been identified as the main aetiological cause of cervical cancer (CC)\(^1\). In England, HPV features in two components of CC prevention: HPV vaccination (introduced in 2008); and HPV triage and test of cure (TOC) (introduced in 2011). With HPV triage women with low-grade cytology undergo reflex hrHPV testing and those found to be positive are referred for colposcopic examination whereas those who are negative return to routine recall. Following a review of the results from six pilot sites for primary HPV testing in England and the adoption by other countries, such as Australia and the Netherlands, the UK National Screening Committee in January 2016 announced that it should be adopted nationally\(^2\), with plans for national implementation in England by 2019\(^3\).

The benefits of primary HPV testing include: significantly higher sensitivity than cytology at detecting cervical intraepithelial neoplasia\(^4,5\); automated testing resulting in higher throughput of specimens and fewer human resources, and potentially increasing the screening interval from 3 to 5 years\(^6\). However, the specificity of HPV testing is lower than cytology due to the high prevalence of hrHPV in the young sexually active population\(^7,8\); positivity rates of 34.6% have been reported in women aged 16-24 years in England\(^9\), although this projected to fall when the vaccinated cohort commences screening\(^10\).

The acceptability to women of HPV testing in the context of cervical screening (CS) is not clear. Hendry et al., found that HPV testing in the form of HPV triage and TOC were acceptable in hypothetical situations but concerns were still raised over receiving a positive result\(^11\). Having an hrHPV diagnosis has been found to result in increased anxiety and distress levels\(^12\). It is unclear whether the associated negative emotions are long lasting\(^13\) and Irish studies have suggested that it is an abnormal result rather than the HPV test itself which results in heightened anxiety levels\(^14,15\). Australian and Canadian studies have shown that a high percentage of women (78% and 84% respectively) are willing to accept the change to primary HPV testing from cytology\(^16,17\), but both studies found that acceptance rates reduced significantly with the proposed extended screen intervals. Knowledge of HPV and the natural history of CC will be central in influencing not only the acceptance of the hrHPV test but the
accompanying changes in the screening programme. HPV knowledge levels in the general population have been shown to be poor\(^\text{18}\). The introduction of primary HPV screening will result in a dramatic increase in the number of women receiving a positive HPV result and without adequate knowledge to interpret it there is the potential for greater numbers of women to experience adverse psychological reactions.

This study provides an update on the attitudes of English women towards HPV infection and more specifically in the context of primary HPV testing, prior to the planned changes to the English CS programme.

The aim of this study was to explore women’s awareness and attitudes towards current HPV testing and primary HPV screening in England.

**METHODS**

Ethical approval for the study was obtained from the London Bromley research ethics committee (15/LO/0249). Participants were recruited from two settings, colposcopy clinics and the community (to sample both women who had and had not experienced abnormal smear results), from across the Midlands (Leicester, Northampton and Birmingham), between April 2015-December 2016. The women were asked to participate as part of a larger study exploring CS behaviours and attitudes in English-born and Eastern European migrant populations. A snowballing approach was adopted to recruit women from community groups/centres, for example neighbourhood groups. Only women of CS age in England (25-65 years) were included in the study.

The women were given the option of participating in a one-to-one semi-structured interview or a focus group session, preliminary work suggested that some women would be more comfortable discussing this topic in a group setting. Written consent was obtained from all participants. The same interview guide (online supplementary material) and interviewer (HP) were used for both. Interviews were conducted until data saturation was achieved.
The interviews were audio recorded and transcribed verbatim. Inductive framework analysis was used, with the aid of NVivo software to analyse the data. Two reviewers (HP, SS) reviewed the initial two transcripts independently and agreed on an extensive list of codes. HP reviewed the remaining transcripts to which the codes were applied. New emerging codes were added to the analytic framework and the final framework was applied to all the transcripts. The final set of codes were grouped into themes19.

RESULTS
Forty one-to-one semi-structured interviews (mean length 30 minutes, range 17-58 minutes) and one focus group session (38 minutes) consisting of six community participants who were unknown to each other, were conducted. Participant characteristics are presented in Table 1, no differences were noted between the two ethnic groups, therefore this is not referred to further in the results. Details in parentheses following quotes represent the participant's identification number, recruitment setting (PC=Community, PH=Colposcopy clinic), and age (in years).

Awareness and attitudes towards current HPV testing
Most women were not aware that HPV testing was incorporated into the current NHS CS programme. One participant believed it to part of a routine sexually transmitted infection (STI) screen that her daughter had been tested for. Some women were only aware that they had been tested when they received the results letter with a positive HPV result.

“My daughter’s been tested for it and so have all her friends, they’re all quite into being tested for that.” (PC13, 56)

“I had a positive HPV and abnormal cells, so at the doctor’s, like, I wasn’t told, or the nurse, I wasn’t told what HPV would mean” (PH7, 25)

The women held contrasting opinions regarding if they would still attend for screening knowing it involved HPV testing. Several women compared it to pregnancy when you are happy to undergo tests for conditions that you know you are unlikely to have. Women who were in long-term relationships had polarised attitudes, either they
would not mind attending as they were confident that “nothing would be found” or that they would no longer feel the need to attend as HPV would not affect them.

“As in I was positive she wasn’t going to find anything.” (PC7, 30)

“I’m a bit more like, “oh why am I going?”” (PC22, 31)

**Positive HPV result**

Women who had not received a positive HPV result, hypothesised that they would handle it in very pragmatic terms. For those who had actually tested positive for HPV it was a different scenario. A few women were only concerned about the fact that they had an “abnormal” result not the HPV status specifically. However, the majority of women expressed emotions of shock, fear and embarrassment. These were coupled with an element of self-blame for putting themself into a “high-risk” situation. The women explained how it had not been present on previous smears tests and attempted to identify when or how they could have acquired the infection. Could they have made different lifestyle choices? Was it something they had done? Processing the connotations of a positive result was especially difficult for those women who were in committed long-term relationships. The main trigger for their emotional responses was the fact that they were either not aware that were being tested for HPV and/or they did not have adequate information about it.

“I spent a lot of my time thinking, I don’t get it, I don’t get how I could have avoided it, I don’t think I could have been any safer in any of my activities..” (PH7, 25)

“..it was almost three years back when I had a long-term partner and when I think oh my God, yes, at that time we were not using condoms, we were using contraceptives but not condoms..” “I mean it was a big hurdle to overcome I suppose because then you suddenly realise oh my God, you start blaming yourself, because yes it’s your fault” (PH13, 36)

**Participation with primary HPV testing**

Some of the women who were willing to accept that primary HPV testing was CS and for the benefit of their own health anticipated that they would still participate. This group were very matter of fact about it, commenting that they were sexually active
and therefore at potential risk of acquiring the infection and this was a test for cancer, which could be life threatening.

“No because they are still checking for cancer so it doesn’t bother me, I would still go” (PC26, 35)

The views of women in committed long-term relationships were split; some believed that they might have acquired the infection from a previous relationship and therefore would not mind participating. Whereas others considered that testing for HPV in any form was not applicable to them, as their self-perceived risk of acquiring the infection was believed to be non-existent.

“I think because I’m married and I know that we don’t sleep with other people I wouldn’t think there’s any chance of me getting an STI so I would think oh well there’s no point in me having that..” (PC10, 33)

Women who had previously had an abnormal smear result claimed that they would have no objection to primary HPV screening, for them it was more important that the abnormality was detected and treated rather than what was actually being tested. When the same women who were initially in agreement with participating in primary HPV testing, thought more in depth about HPV testing and the implications it may have on their relationship, they started to question if they would participate. For this group of women being tested for an STI, even if was a screening test for the prevention of CC, was not as simple as it had initially appeared. If the women had only had one sexual partner they believed that they were not at risk and their partner’s previous relationships did not appear to be of concern. Those who were religious also felt that if this was now a test for an STI it would not be of relevance to them, in view of their religious beliefs and subsequent lifestyle choices.

“...just because you believe in a kind of monogamous marriage, relationships and that being the correct way to have sex, that’s what I believe now, but I didn’t right until university and then even then, mine is because of my faith..” “..I am neither sleeping with other partners nor is my husband and I am confident of that. So actually why would I get tested for HPV?” (PC9, 33)
**Improving participation with primary HPV testing**

Some women thought that normalising HPV testing would reduce the stigma attached to it, “I guess because you’re not being targeted, it’s almost all women isn’t it, I guess it would become normal wouldn’t it I suppose if all women are having it, maybe that will help..” (PC11, 36). In addition, having “more information, you know what it was for and why, rather than just sexual...” (PH9, 52) was believed to help.

The wording of the smear invitation letter for primary HPV testing was considered important. If it was worded for example as, “you are being invited for a cervical screening test”, it may not be viewed any differently to how it is currently. However if it mentioned that screening would involve being tested for HPV and then somewhere in the letter it was mentioned that HPV is an STI, this could deter women from attending. Even if in the letter it did not explicitly state that HPV is an STI, the women were concerned that as soon as the word HPV is entered into an internet search engine, this would be the first piece of information to appear. Currently having a smear test is not associated with an STI.

It emerged that the information leaflet, which accompanies the smear invitation, is rarely read; therefore the role it would play in providing information and reassurance would be limited. The stigma of being tested for HPV was thought to be lessened if men were also offered routine testing, as is the case for other STIs.

“Yeah, I think some people would not feel comfortable being tested for a sexually transmitted disease, you know having a smear test is not linked with that as far as people are aware, all they’re going for is a routine smear test.” (PC18, 40)

**Division into two groups**

There was a fear that primary HPV testing might result in women being divided into two groups by society, those who attend for screening will be thought of as having adopted a more high-risk lifestyle compared to non-attenders. There was concern that having CS would be viewed as synonymous with being screened for an STI. This was thought to be more of a concern for the younger generation.
“Some people who think that their husbands are unfaithful or are promiscuous and people who aren’t, yes...” (PC9, 33)

**Partner feelings**
The actual or hypothesised feelings of their partners regarding HPV testing in general or about receiving a positive HPV result were discussed. Some women found that their partners were very supportive and were only concerned about the wellbeing of the women. These partners did not question previous relationships. Other women believed that their partner’s reaction to a positive HPV result would be to start questioning the faithfulness of the woman. One lady who had previously had a positive HPV result became distressed during the interview discussing her partner’s response to it. She felt that since the diagnosis he was distant from her. The partners were felt to have very little knowledge about HPV and how it affects them. The male partner in some instances was thought to be a barrier to participation with primary HPV testing whereas others believed it was not their decision to make.

“oh you have done something, the partner has done something wrong. That’s like maybe you have been somewhere else with somebody else. I think that’s the first thought what man would think.” (PH11, 30)

“Perhaps if the men found out... they might think that the women might have been... Unfaithful, yeah.” (PH10, 63)

“He’d probably be like, “you don’t need to... why are you going?”” (PC22, 31)

**Need for continued screening following a negative smear result**
The women questioned the need for continued screening following a negative HPV result, if they were in a monogamous relationship. Further if they did attend would it imply lack of trust in their relationship and what would be the implications of a subsequent positive result? The participants thought that this might cause confusion and that women might start to question their need for repeated screening.
“...if you only go for one and you’ve got the same sexual partner you don’t need to go for any more smears..” (PC22, 31)

DISCUSSION

The women in this study were all of screening age and all reported participating in the screening programme. Despite this, their responses reveal misunderstandings with HPV testing and very real concerns with the implications of HPV testing.

Crucially, most of the women in our study were unaware that hrHPV testing is currently part of the screening process. Therefore, the question of whether HPV testing is acceptable in its current form is difficult to answer. The issue of consent comes into question in this situation, if women are not aware what they are being tested for are they providing informed consent? HPV-related information is provided in the leaflet that accompanies the smear invitation letter, our study would suggest that either women are not reading the leaflet or they are not retaining the information. The medium through which information is shared is important, leaflets in isolation have been found to be of little benefit but in combination with verbal communication can improve patient experience\textsuperscript{20}. One solution to ensure informed consent might be through verbal communication of HPV related-information at the time of the smear test. Knowledge of HPV/HPV testing in practice nurses in England (who perform majority of the smear tests) has been found to be poor\textsuperscript{21} and therefore healthcare professionals themselves will have to be educated about HPV first.

The question of if women would still attend for screening knowing that it might include a HPV test related back to their self-perceived risk of testing positive for HPV and/or their understanding of the test. In common with other studies a positive HPV result was associated with anxiety and distress\textsuperscript{12}, embarrassment and concerns about past and future sexual relationships\textsuperscript{22}. Knowledge of HPV, which is poor amongst the general population\textsuperscript{18}, was vital in calculating self-perceived risk and in the interpretation of a positive result. The influences of religious and cultural beliefs were not specifically explored in this study, however for women from particular cultural
and religious backgrounds, HPV testing does represent a conflict\textsuperscript{23}. Participants in this study alluded to the fact that their lifestyle choices, i.e. being in a monogamous relationship, were determined by their religious beliefs and as a result believed that HPV testing was not pertinent to them. This is of great concern as the change to primary HPV screening might result in women from particular religious backgrounds opting out of screening. Participation with primary HPV testing was discussed in hypothetical terms. For women who had had an abnormal smear result (with or without HPV) and/or undergone treatment, the fear of developing cancer was worse than the screening test. Anxiety associated with abnormal cytology and/or treatment has been shown to outweigh any concerns regarding HPV status specifically\textsuperscript{14}. Primary HPV testing will result in a greater number of women receiving what might be considered an “abnormal” result, i.e. a positive HPV result. In England between 2015-2016 93.8% of all smear samples were classified as negative cytology, whereas the prevalence of hrHPV has been shown to be 27% in women aged 20-30 years\textsuperscript{24} and 34.6% in 16-24 year olds\textsuperscript{9}. Consequently more women might experience adverse psychological effects and will women who are cytology negative but HPV positive be content to wait 12 months without any treatment, as proposed in the primary HPV screening protocol\textsuperscript{25}? If HPV is considered to be the same as other STIs will there be an expectation to receive treatment for it. The aforementioned practice nurse study showed that 63% believed that HPV infection requires treatment\textsuperscript{21} and unpublished data from another study we have conducted indicated that 76% (n=158/208) of women share the same belief.

The marketing of primary HPV testing will be vital; this study cohort considered focusing on the prevention of CC rather than testing for HPV would help increase participation and others have found that this may similarly reduce adverse psychological effects associated with HPV testing\textsuperscript{26}. The difficulty will be achieving the right balance between ensuring that the women are fully aware of what they are being tested for in order to obtain informed consent but not taking the focus away from CC prevention.

Anticipated or experienced impact of disclosure of HPV status to their partners varied in the current study; negative partner responses may worsen adverse psychological effects experienced by women by removing their normal source of support. Women
have dealt with this by focusing on the abnormal cytology rather than the HPV status, when disclosing results to their partners. However, with primary HPV testing this will not be possible for women who are hrHPV positive but cytology negative.

Women in monogamous relationships questioned the need for continued screening following a negative HPV result. If they do continue to attend for screening, what would be the implications for their relationships? What advice should healthcare professionals provide these women? Once again, careful consideration is needed as to how information on HPV is conveyed, since even those in committed relationships or who are not currently sexually active might be at risk of a reactivated infection from previous exposure.

Clinical Implications
In England no sudden decline in screening coverage was noted following the introduction of HPV triage and TOC, this study would suggest that this is because women are not actually aware that HPV is currently being tested for. When women were informed of the nature/transmission of HPV, not all were keen on participation with HPV testing. Therefore it is possible that the introduction of primary HPV screening might result in a significant fall in screening coverage. To combat this potential decline in participation with CS, healthcare professionals will need to provide the women with adequate counselling about HPV testing, for example informing them that HPV is a very common infection. Additionally to minimise the adverse social and/or psychological response to receiving a positive result or even just participating with primary HPV testing clinicians will need to ensure that they provide an opportunity for patients to raise their concerns. They might even as a routine need to initiate such conversation and offer support, therefore taking away the onus from the patient who might not be comfortable broaching the subject.

Limitations
Attitudes towards and acceptability of primary HPV testing are explored in hypothetical terms only and it might be that once primary HPV testing is universal for all women, their opinions may differ. This study provides an insight into some of the barriers and challenges, which might be encountered on the introduction of primary HPV testing. In doing so it presents an opportunity for healthcare professionals and
programme implementers to be prepared and possibly even devise solutions. This study did not specifically explore the effect of culture and religion, however other studies have explored the impact of this on attitudes towards HPV testing in the form of HPV triage and TOC\textsuperscript{23,27}. It is likely that the barriers noted in these studies will be amplified with primary HPV testing as all women will undergo HPV testing compared to the current screening protocol where only a limited number of women are tested. Similar to other qualitative studies the importance and/or the generalizability of the emergent themes is not clear. Using a snowballing technique to recruit community participants might have resulted in women with similar characteristics and attitudes being recruited, however different geographical locations were sampled in attempt to combat this.

**CONCLUSIONS**

Current awareness of HPV is poor\textsuperscript{18,30} and this may be contributing to the negative attitudes towards HPV and the associated stigma. Educating women on the nature of HPV might alleviate the stigma and increase the acceptability of HPV testing. It is not yet clear if primary HPV testing will be an acceptable test or if women are ready to accept that CC is caused by an STI\textsuperscript{1}.

**Acknowledgements**

We would like to acknowledge the contributions made by Mr Charles Redman and Professor Douglas Tincello in their role as supervisors. We would like to thank everyone who helped with recruitment and all the women who participated in the study.

**Funding**

This study was funded by the Leicester Hospitals Charity

**Disclosures**

The authors have no conflict of interest.
References


Table 1: Participant Characteristics

<table>
<thead>
<tr>
<th>Recruitment Setting</th>
<th>Colposcopy clinic</th>
<th>14(30)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n(%)</td>
<td>Community</td>
<td>32(70)</td>
</tr>
<tr>
<td>Age (median/range)</td>
<td></td>
<td>34(25-63)</td>
</tr>
<tr>
<td>Relationship status</td>
<td>Married</td>
<td>24(52)</td>
</tr>
<tr>
<td>n(%)</td>
<td>In a relationship</td>
<td>12(26)</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>10(22)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White British</td>
<td>20(43)</td>
</tr>
<tr>
<td>n(%)</td>
<td>White Eastern European</td>
<td>26(57)</td>
</tr>
</tbody>
</table>