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## ORIGINAL ARTICLE

# Exploring the acceptability of two self-sampling devices for human papillomavirus testing in the cervical screening context: a qualitative study of Muslim women in London

Anne Szarewski, Louise Cadman, Lesley Ashdown-Barr and Jo Waller

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**Objectives** We explored Muslim women's attitudes to self-sampling for human papillomavirus (HPV) in the context of cervical cancer screening and their responses to two self-sampling devices.

**Setting** A Muslim community centre in north-east London.

**Methods** Following a talk given on the subject of cervical cancer and HPV at the community centre, 28 women were recruited to take part in three focus group discussions. The discussion covered cervical screening, self-sampling and HPV testing. Women were also asked for their responses to a swab self-sampling kit and a cervico-vaginal lavage device. Discussions were recorded and transcribed verbatim and the qualitative data were analysed using Framework Analysis.

**Results** Participants were generally positive about cervical screening but acknowledged that some women in their community were reluctant to attend because of embarrassment, language difficulties, fear or because they were unmarried and did not want to communicate implicit messages about being sexually active. Self-sampling met a mixed response – women were concerned about not doing the test correctly, but thought that it might overcome barriers to screening for some women. HPV testing itself was thought to raise potentially difficult issues relating to trust and fidelity within marriages. Although most women said they would prefer to continue to have screening by a health professional, if they were to perform self-sampling, there was overwhelming preference for the swab over the lavage kit.

**Conclusions** There was limited enthusiasm for self-sampling in this group of Muslim women who had mostly attended for cervical screening, but a clear preference for a swab rather than a cervico-vaginal lavage.

## INTRODUCTION

In the UK, the NHS Cervical Screening Programme (NHSCSP) has stated that its target is to ensure that 80% of eligible women are screened.<sup>1</sup> Coverage has been falling in the last few years, with the latest figures (2007–2008) once again showing a drop, to 78.6%.<sup>2</sup> It is recognized that uptake is not consistent throughout the population. In particular, women in inner city areas and from certain ethnic minority groups have lower levels of attendance.<sup>3–5</sup> In addition, women from lower socioeconomic groups tend to have lower attendance rates than women from more affluent backgrounds.<sup>6,7</sup> In recent years it has been shown that attendance rates among women aged between 25 and 29 years have also dropped.<sup>2,8</sup> Among the reasons cited for the refusal to accept smear tests is the nature of the gynaecological examination itself, which may be embarrassing and unacceptable to some women. Specific concerns are that male staff may be present and that the examination will be painful or embarrassing.<sup>9–14</sup>

These issues need to be addressed if uptake of screening is to be improved. A screening programme can only be

successful if it achieves high population coverage, and it is well documented that those who do not attend are at higher risk of developing cervical cancer.<sup>15,16</sup> Therefore any measure which would encourage such women to take part would have the potential to save lives and could also save the NHS money, by reducing costs of invasive cancer treatment.

One possibility is to test for human papillomavirus (HPV). HPV is a common sexually transmitted virus, high-risk types of which, if persistent, can cause cervical cancer.<sup>17</sup> Testing for HPV is being incorporated into the cervical screening programme in a number of ways, and may be a feasible primary screening tool in the future.<sup>18</sup> One advantage of HPV testing is that it can be done using a sample collected by a woman herself, in her own home, removing the need for her to go to the surgery or clinic for the test. This potentially avoids the embarrassment and concerns about discomfort that can put women off attending for smear tests. It has been shown to have similar specificity and sensitivity to clinician sampling<sup>19–21</sup> and is always more sensitive than cytology.<sup>22</sup> We have previously shown that women in England find self-sampling, by which the need for a speculum examination

carried out by a health-care professional is eliminated, to be an acceptable procedure.<sup>21,23</sup> Across studies of self-sampling, a common concern among women appears to be about whether they would use the test properly and therefore whether the result would be accurate.<sup>23–25</sup> A British focus group study has suggested that women from ethnic minority groups may be more willing to carry out self-sampling than attend for a smear test, but Indian and Pakistani women were less certain that they would try self-sampling than white British women.<sup>26</sup> In addition to issues of self-sampling, HPV testing itself raises particular concerns, due to the fact that HPV is a sexually transmitted infection (STI). It may be less acceptable to women from some ethnic backgrounds because of religious beliefs about the unacceptability of sex outside marriage.<sup>27</sup>

Although it is intuitively likely that self-sampling would be more attractive to non-responders in the screening programme than attending for cervical smear tests, there has been only one previous study testing this hypothesis, carried out in the Netherlands.<sup>28</sup> Screening non-attenders were randomized

to receive either a self-sample kit or a further invitation to attend for screening. Of those who received the self-sample kit, 34% sent it back, compared with 17% who attended for a smear following a further invitation. No such study has been performed in a UK population and it is essential that such interventions should be acceptable to women across different socio-economic and ethnic groups to ensure that their introduction would not widen existing health inequalities.

In our previous studies on HPV self-sampling,<sup>21,23</sup> we used a testing kit (manufactured by Qiagen; Germantown, MD, USA) which consists of a sterile Dacron swab for insertion into the vagina and a small plastic tube containing specimen transport medium in which to place the swab. This study aimed firstly to identify barriers to attendance at conventional cervical screening among Muslim women, and secondly to assess the acceptability of self-sampling for HPV using a new cervico-vaginal lavage self-sampling device (the Pantarhei Sampler; Zeist, Netherlands) and to compare attitudes to this new device with women's feelings about the Qiagen kit.

### Box 1 Topic guide for discussion

#### Welcome and introductions

Moderator recaps on HPV and cervical cancer information and answers women's questions

#### Cervical screening

- What is understood by the term smear test?
- Why is the smear test done? Is it important? For whom?
- Would anything make one woman more likely to get cervical cancer than another? (age, sexual activity, smoking status)
- Your experience of going for a smear – reasons for going/not going

#### Barriers to uptake of smear test and possible solutions

Reasons why some Muslim women do not come for smears. Prompts:

- fear of being told have cancer
- worried about test being painful
- embarrassment
- thinking women only need a smear test if there is a problem
- thinking they are too old/young to get cervical cancer
- transport problems
- appointment times not being suitable/convenient
- don't realize that it is important
- don't know about it
- language barriers
- child care problems
- cultural norms and values
- personal beliefs

Ways of overcoming barriers?

#### Service delivery

Where do Muslim women prefer to go for a smear test? (FPC, health centre, GP, somewhere else?)

#### Preferred sources of information

Where would you like to get information about cervical screening?

- Leaflets, Letters, Posters, GP, Nurse, Health visitor, Friend, Community worker, Religious sites, Talks/workshops

#### HPV self-sampling

Moderator introduces idea of self-sampling and shows the Pantarhei device.

Women respond:

- willingness to use it
- concerns
- benefits of self-sampling
- what might their friends/family think
- what would their husbands/partners think
- clarity of instruction sheet – would they feel confident doing it?

Moderator shows the cotton bud self-sampling device.

Women respond:

- willingness to use it
- concerns
- clarity of instruction sheet
- comparison with the Pantarhei kit

#### HPV testing

Benefits and barriers to HPV testing – would anything put women off?

Acceptability within the community

Concerns.

#### Close of discussion

Final questions from participants

Thanks; reassurance about confidentiality

## METHODS

### Participants and recruitment

Women were recruited from the Noor Ul Islam Trust (a Muslim organization in Leyton, north-east London, where about 15% of the population are Muslim) after discussions with the Chairman of the Noor Ul Islam Trust. Initially a talk about cervical cancer and HPV was given to women at the Noor Ul Islam community centre by Dr Anne Szarewski. This was advertised in the Trust's newsletter and in flyers sent out to the local community in the area, resulting in an attendance by about 40 women. Women who had attended the talk were invited to take part in focus group discussions at a later date, and additional women were recruited using snowballing techniques.

The study was approved by the UCL Research Ethics Committee and all participating women provided written consent.

### Procedure

Three focus groups were held on the Noor Ul Islam premises, each lasting approximately 45–60 minutes. Prior to participation, all women completed a short demographic questionnaire assessing their age, ethnic background, number of children and previous attendance for cervical screening. The groups were facilitated by one researcher (LAB) and structured around a topic guide that was developed based on the aims of the study and previous literature in this area (see Box 1). Although English was the language used in the groups, women translated for each other from Urdu, as necessary. Prior to the groups, women expressed a preference for this kind of informal translation rather than having a designated translator present. A researcher (AS) took notes during the discussion groups, which were also audio recorded (by LC). Towards the end of the discussions, women were shown two self-sampling kits: a Qiagen kit containing a Dacron swab and specimen transport medium, and a Pantarhei cervico-vaginal lavage device.

Women were given £10 as a contribution towards their time and travel costs, and a donation was made to the Noor Ul Islam Trust to acknowledge the time and work put in by their staff in organizing the talk and discussion groups.

### Analysis

The discussions were transcribed (by LC) and the transcripts and notes were used for analysis. After familiarization with the data, thematic analysis was used to identify recurrent themes and these were organized using a matrix-based approach (Framework Analysis<sup>29</sup>). All the authors took part in the analysis and disagreements about the thematic structure were resolved by discussion. Data from each group were summarized under each of the thematic sub-headings using Excel. One row was allocated for each group with a column for each subtheme.

## RESULTS

### Sample

Twenty-eight women took part in the focus groups. They were aged between 21 and 65 years with a mean age of 50

(only one woman was under 30 years). The majority were from Pakistani ( $n = 15$ ) or Indian ( $n = 9$ ) backgrounds, most had children, and only one woman in the screening age range reported never having had a smear test. Due to difficulties with organizing the groups, they were of varying sizes: Group 1 included three women; Group 2 had eight women and Group 3 included 17 women, although not all took an active part in the discussion. One woman, who had been active in helping to recruit participants, was present in both Group 2 and Group 3.

### Understanding cervical screening

Women in all the groups were generally in favour of screening as a way of preventing cancer: 'If they catch it in the beginning there is more chance of them treating it' (Group 1), regarding it as 'life-saving' and believing that 'everyone should go'. In Group 1, it was noted that screening would not be available 'back home' and women were happy that it is offered in the UK.

There was confusion about the age range within which women were invited and whether, having had a normal result, it was necessary to go for further tests. There was an underlying assumption that unmarried women are not sexually active and a belief that they therefore might not need to go for screening: 'You have to be married to have a smear test?' (Group 1). But it was acknowledged that some unmarried women were sexually active, often without their parents' knowledge, and that fear of parental disapproval could be a barrier to attending for screening: 'There are some girls, they are sexually active but they are keeping it away from their parents ... so just because of that reason they don't want to go to the doctor's' (Group 2). This issue of sexual activity in relation to screening attendance was not raised in Group 3 but was mentioned spontaneously by women in Groups 1 and 2 in response to probing about whether there are particular women who need to attend for screening.

### Barriers to attendance for screening

Across the groups, embarrassment was a dominant theme in discussing barriers to attendance at screening, although often not actually for the women taking part in the discussion: 'I have one of my friends and I keep telling her to go. I think she feels embarrassment' (Group 1); 'I think embarrassment is quite an important issue for a lot of women, especially those who are not married and the young ones as well' (Group 2).

There was particular concern that the doctor carrying out the test might be male. Fear of pain and discomfort were also cited as reasons not to attend, as well as time pressures, and not prioritizing one's own health: 'Being an Asian woman, being any woman, you never make time for yourself' (Group 1). Language was also raised as a problem, even among women who were born in the UK. The language used in screening materials and letters was thought to be difficult to understand, even for fluent English-speakers, and women whose first language was not English would have to rely on family members to translate. Women suggested displaying information in doctors' surgeries in non-English languages. In addition to Urdu, one woman suggested: 'There are Somalis

around here . . . and Polish around here. Whatever language the majority is, and then looking round the room, the doctor's surgery, they might come across it' (Group 1).

Provision of materials in non-English languages, evening clinics to fit in with work or child-care commitments, and advertising the presence of a female practitioner were all thought to be possible ways of increasing attendance at screening within the Muslim community. Some women thought that screening materials should make it clear that women who are not sexually active need not attend.

### Acceptability of HPV self-testing

Regarding the idea of the self-test itself, there were conflicting views. Across all three groups, women expressed unprompted concern that they would not take the sample correctly and many preferred to continue to go to the doctor for screening: 'If you do it at home you are not satisfied because you do not get the correct result. If you go to the doctor you get the correct result' (Group 3). Some women felt uncomfortable about carrying out the test: 'I wouldn't use either of them. I would be frightened' (Group 1). For some, the experience would be less unpleasant at the doctor's surgery: 'I think I'd rather go to the doctor. I'm quite scared. I'd rather go to the nurse. They talk to you while they're doing it. Your mind's not on it. This way [with self-sampling] your mind would be on it as well' (Group 2).

There was, however, an acknowledgement that for women who would not attend the doctor's surgery for screening, the self-test might be helpful and it was seen as a way for unmarried, sexually active women to have screening without their parents' knowledge: 'It would be good for the ones who were shy or embarrassed' (Group 3), and: 'For the "unmarrieds", it is hiding their sexual activity from the parents. It is better they do the same thing at home' (Group 2).

Despite the fact that some of the women who took part in the study had attended a talk by one of the authors (AS) on HPV and cervical cancer, there was poor understanding of the link between the two, and more explanation was needed during the discussions about what the results of the HPV test would mean. Once women understood that the self-test would be for HPV, a sexually transmitted infection, additional concerns arose, related to testing positive. Women talked about the fact that an HPV-positive result would imply infidelity on the part of the husband ('She would kill him', Group 1), or the wife ('These days you can't trust people, even ladies', Group 1). The consequences of perceived infidelity were seen to be worse for a woman: 'If a man does it, they turn a blind eye. A woman – they would chop her up' (Group 1). Because both partners are expected to be virgins until marriage, an HPV-positive result could lead to a breakdown of trust and the effects were thought to be 'devastating'. This was seen by one group as being an 'Asian' rather than a 'Muslim' attitude (i.e. cultural rather than religious).

There was a tension, though, between the 'rights' of a woman to have the test and the possible implications of a positive result, as illustrated by this excerpt from Group 2. As can be seen, the women did not immediately seem to understand the implications of a positive result:

AS: Now what we are really asking is, in your community, where as you say, the women mostly have one partner, if such a woman was found to be positive for a virus that is known to be transmitted through sex, do you think there would be implications for her, from her husband for example?

P1: Because of exposure?

AS: Well, what would the assumptions be, or what would happen to such a woman who tested positive for a virus that is known to be . . .

LC: Or to her husband?

P2: The husband. He the one who did to me.

P1: It is her right, isn't it?

P3: Yes, it is her right.

P1: All the more reason why she should have it done, you know.

P4: It would have implications.

AS: What sort of implications?

P4: It's a [unclear] thing, that you lose the trust, don't you? Ours is a lot based on trust, isn't it? If you lose that trust, you probably start getting such divorce rates. These things can get out and it can be quite devastating.

In Group 3 which, because of the large number of women, proved particularly difficult to moderate, women did not discuss issues related to sexual transmission, perhaps because with so many people in the room, it did not feel like a comfortable environment within which to talk about these sensitive issues.

### Acceptability of the self-sampling devices

Overall, women felt that the Qiagen kit was preferable to the Pantarhei device. They thought it looked 'easy', 'more friendly' and 'smaller', and felt that it was more hygienic than the Pantarhei device because the swab could be placed immediately into the transport medium liquid. There were concerns that the Pantarhei device was 'too big' and that it might be contaminated if it was put down on a surface:

'My concerns are I might put it somewhere, I don't know, just say on a dirty surface or something that could tamper with the results due to the fact it's not covered. This one [Qiagen], you put it in there and break it in the liquid and it is covered. This one [Pantarhei], I would be concerned it would not be accurate because it's not covered' (Group 1).

Some women likened its appearance to sealant: 'like Polyfilla . . . to put around the bath tub'; to others, the shape felt familiar as it was similar to a vaginal ultrasound.

At the end of the sessions, the women were asked to vote (by a show of hands) whether they would prefer a self-sample test or a test done by the doctor. Around two-thirds preferred to have the test performed by the doctor. They were then asked to choose which of the two self-sampling devices they would be willing to use. All of them preferred the Qiagen device, and only two said they would be willing to use either device.

## DISCUSSION

This is the first study looking specifically at the attitudes of Muslim women in the UK to the idea of self-sampling for

HPV in the context of cervical screening. Little work has been carried out overall with Muslim women in Britain, who are a particularly hard to reach group. Our collaboration with a Muslim community organization enabled us to access women from the local Islamic community; despite this, those who took part in the study were mostly women who had in fact attended for screening (see the Limitations section for more discussion of this). However, they were able to highlight issues that they perceived as barriers to screening uptake within their community, and these were broadly consistent with the findings from previous research with ethnic minority and white British women.<sup>7,30</sup> Their general enthusiasm for screening was also consistent with previous work with ethnic minority groups in the UK.<sup>30</sup> Simple practical steps could be taken to address some of the barriers raised, especially advertising the availability of a female practitioner to carry out screening, and making information available in appropriate languages.

The women often seemed to find it difficult to understand the relationship between HPV, an STI, and cervical cancer, and to imagine the possible impact of a positive HPV result. However, in Groups 1 and 2 where the link was successfully communicated, women highlighted problematic issues around the sexually transmitted nature of the infection and the implications for them of testing positive. These echoed the concerns previously expressed by Indian and Pakistani women in the study by Forrest *et al.*<sup>26</sup> and indeed the view was expressed that this was generally an 'Asian' rather than a 'Muslim' issue. Strong norms around women not engaging in sexual activity prior to marriage were expressed, and the possibility of testing positive for an STI was thought to have potentially devastating effects on relationships. This calls into the question the appropriateness of testing for HPV in this community.

The women were not entirely enthusiastic about the idea of self-sampling, even though it would avoid the acknowledged problems of having to attend a clinic, where there might be issues of privacy, male staff and language problems. They were concerned that they might not carry the test out correctly and many preferred the reassurance of knowing it was being done properly by a doctor. However, when it came to the choice of self-sampling device, they were unanimous in their preference for the Qiagen swab, rather than the Pantarhei device. This contrasts with a recent study in the Netherlands which suggested that the Pantarhei device was acceptable in a group of screening non-attenders.<sup>31</sup> However, that study was not targeted specifically at women from ethnic minorities, and the profile of non-responders in the Netherlands may not be similar to that in the UK. This underlines the importance of carrying out acceptability studies in different populations and gives a clear indication that any study trialling self-sampling for HPV in this community would be better using a swab test kit rather than a lavage device.

### Limitations

The study had a number of limitations. Due to logistical problems, the groups varied widely in size, and one was much larger than is ideal for a focus group discussion. Moderation of this group was particularly difficult and not all the women

were able to express their views. The responses reported here are therefore likely to be those of the most confident and vocal women, and may not be representative of the wider group. The lack of discussion of issues relating to the sexual transmission of HPV in this group indicates that it was not a suitable forum for exploring sensitive issues.

Translation was also a difficult issue. Women mainly spoke fluent English but at times they translated for each other from Urdu, for the benefit of the moderator, so the flow of the discussion was sometimes interrupted. Ideally, the groups should have been carried out by a bilingual moderator, in the preferred language of the participants, and then been translated and transcribed afterwards. Unfortunately our resources did not allow this.

In terms of our sample, the women had mainly attended for screening, so were not drawn from the non-attender group at whom home-based self-sampling might be targeted. This is perhaps not surprising as one might expect that women who do not attend for screening would be reluctant to take part in this type of research. This meant we had to rely on reports of what others in the community might think, to gain any insights into the beliefs of non-attenders, which is less than ideal. More work is needed to try to recruit Muslim women who have never been for screening into research studies, and this could be facilitated by having Muslim researchers on the team who might be more able to reach out into the community beyond those who attend centres such as the one with which we worked during this study. In addition, the mean age of the women was 50 years, so our findings may not apply to younger women. This is important given the falling uptake of cervical screening generally among women aged 25–29 years.<sup>2</sup> Although one might expect the beliefs and attitudes of second and third generation Muslim women to be more similar to those of broader population-based samples, they are an important group to include in future research, especially given the issues raised in this study about young women needing to hide the fact that they are sexually active from their parents.

Because they were self-selected, following a talk about cervical cancer and HPV, it is possible that the participants held more positive attitudes to screening than other women in the community. Finally, women only looked at the self-sampling devices and did not try using them. Although this provides useful information on women's responses to the look of the devices, it may not accurately reflect how they would feel and respond if they received the kits in the post and were asked to use them at home.

### CONCLUSION

The Muslim women who took part in this study held positive attitudes towards cervical cancer screening, and attended for smear tests. They acknowledged that self-sampling might overcome barriers to participation for some women in their community, although when shown two self-sampling kits, there was little enthusiasm for using them, with most women preferring to see a clinician. This highlights the need for thorough evaluation of acceptability of HPV self-sampling across different socio-cultural groups prior to consideration of its use in the cervical screening

programme, to avoid inequitable uptake and widening health disparities.

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