

Women's experiences of repeated HPV testing in the context of cervical cancer screening: A qualitative study

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Abstract

Objective: To evaluate the psychosocial impact of taking part in repeated testing for human papillomavirus (HPV) in the context of cervical cancer screening.

Methods: In-depth interviews were carried out with 30 women who were HPV positive with normal cytology at trial baseline, and attended for a repeat HPV test 12 months later. Interview transcripts were analysed qualitatively using Framework Analysis to identify emergent themes.

Results: Although women often experienced serious negative emotional consequences at the time of their first positive result, these did not generally last during the year between tests once questions about HPV had been resolved. The emotional impact of testing positive a second time was greater for many women, sometimes causing them to overcome their embarrassment about having a sexually transmitted infection in order to disclose their result and seek support. Among the women interviewed there was an overwhelming preference for immediate colposcopy rather than continued surveillance for persistent HPV. This was associated with the desire for a speedy resolution, and fears about progression to cancer.

Conclusions: Although most women did not appear to suffer on-going anxiety while waiting for a second HPV test, this seemed contingent on their information needs being met. Women appeared to be more distressed by a second HPV positive result than a single one, and expressed a clear preference for immediate colposcopy over continued surveillance. This finding might have implications for the way in which HPV testing could be used in cervical cancer screening programmes.

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Introduction

There is growing interest in the possible uses of testing for high-risk types of human papillomavirus (HPV) in cervical cancer screening and the management of cervical intraepithelial neoplasia (CIN). HPV testing is now approved in the US [1,2] and its role is being evaluated in several studies in the UK. Alongside clinical and economic considerations, it has been argued that psychosocial issues also need to be taken into account when deciding whether and how to introduce HPV testing [3,4]. A few studies have indicated that testing positive for HPV may impose a significant psychological burden on the women taking part in screening, over and above the impact of an abnormal smear result [5–7]. This seems to be due, at least in part, to the fact that as a sexually transmitted infection (STI), HPV

carries connotations of stigma and raises issues for relationships that are not commonly experienced when receiving an abnormal smear result. Anxiety is further exacerbated by a lack of understanding of HPV. But so far no studies have evaluated the impact of participation in repeated HPV tests. If HPV testing is used as a surveillance tool for women with mildly abnormal cytology, or as a primary screening test, many women may undergo repeated tests, and the impact of this must be evaluated. This study takes a first step towards this evaluation using qualitative methods to explore women's experiences and concerns.

The study addresses three aspects of responses to repeated testing for HPV. Firstly we investigated whether women experience long-term anxiety and distress about being HPV positive while waiting for their second test. On-going anxiety has been found

in some women with mildly abnormal cytology who are managed by surveillance [8–10] and it is possible that this could be more severe among women who are HPV positive, as the psychosocial burden of testing positive for HPV seems to be greater than the impact of an abnormal smear result [5–7]. There is currently no effective means of treating HPV, so women may face on-going positive status without resolution.

Secondly, we examined women's responses to their second HPV result. Two aspects of their responses were explored: (i) emotional responses to testing either positive or negative for the virus; (ii) the impact of the second result on disclosure behaviour. For each of these aspects, changes between the first and second HPV test result were explored.

Finally we were interested in women's choice of management of persistent HPV infection. In general, women have been found to express a preference for colposcopy over cytological surveillance for the management of mildly abnormal smear results [9,11]. However this was not the case in a recent trial in which women given the option of immediate colposcopy or cytological surveillance were fairly evenly divided in their management choices [12]. We explored the reasons for women's preferences for either immediate colposcopy or repeated HPV testing after 12 months.

As the study addressed questions that are sensitive in nature and about which little is currently known, in-depth interviews and qualitative analysis methods were used to ensure that the findings were grounded in the accounts of the participants [13].

Methods

Sample

With the approval of the North West Multi-centre Research Ethics Committee, 30 women were recruited from the ARTISTIC trial of HPV testing in Manchester, UK (see http://www.nchta.org/projectdata/1_project_record_notpublished.asp?PjtId=1162). This sample size was adequate to ensure inclusion of women with a range of experiences and from a range of backgrounds, while still being small enough to allow in-depth analysis of the data. All women in this study were selected having tested HPV positive with normal cytology at the trial baseline. The recommended follow-up in the trial for such women was a repeat HPV test at 12 months. Women were recruited to the interview study following participation in the second HPV test, and the sample included those who were reported both positive and negative at the second test (see Figure 1). Approximately 40% of women tested positive at follow-up (unpublished

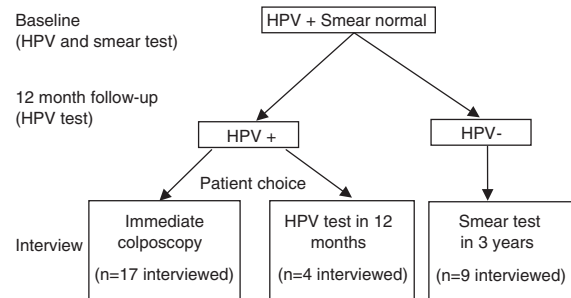


Figure 1. Management of women within the ARTISTIC trial and recruitment for interview

data), although without typing data, it is impossible to differentiate between new and persistent infections. Within the positive group, women were given a choice of management: immediate colposcopy versus repeat HPV testing in a further 12 months. The study aimed to include women from both management option groups.

Women were selected using purposive sampling to ensure a heterogeneous sample in terms of age, marital status and socio-economic background. Although we ensured that women from both management option groups were included, we could not include equal numbers because very few women opted for repeat HPV testing. The vast majority of women opted for immediate colposcopy, so we decided to concentrate on this group.

Procedure

Women were sent a letter informing them about the study, and were given the opportunity to opt out if they did not wish to participate. Those who had not opted out were contacted by telephone and invited to take part. In-depth, semi-structured interviews were carried out in women's homes (or places of work if this was preferred) by the first and second authors or a trained freelance interviewer. The interview was structured using a topic guide covering general background, the two HPV tests, emotional responses to the tests, differences between the impact of the two tests, disclosure of results, decisions about follow-up and feelings about future screening.

With the consent of participants, interviews were recorded and transcribed verbatim. The transcripts were analysed using Framework Analysis to identify emerging themes and to organise the data [14]. This is a matrix-based approach, with themes making up the columns and cases making up the rows of the matrix. The thematic framework is developed through familiarisation with a sub-set of transcripts. All data are summarised within the framework and this organisation facilitates examination of both themes and cases, allowing relationships between themes and explanations for patterns within the data to be explored.

Results

Sample

Demographic characteristics of the sample are shown in Table 1.

The sample was well-distributed across the age groups. Two-thirds were married or cohabiting. Of the 21 women with persistent HPV, 17 opted for immediate colposcopy rather than waiting for a third HPV test 12 months later.

Emotional impact of being HPV positive over the year between tests

The first aim of the study was to examine the way in which anxiety and concern about being HPV positive played out over the course of the 12 months between the two tests. Three main patterns of anxiety were described.

Initial anxiety that was then resolved

Feelings of shock, confusion and distress about testing HPV positive were common. These feelings frequently related to the sexually transmitted nature of HPV and concerns were articulated about where the virus had come from. Anxiety about the health implications of HPV was also expressed. Anxiety was often compounded by lack

of knowledge about HPV. These responses are consistent with results from an earlier study [7,15].

Initial anxiety was often followed by seeking further information about HPV from the internet, the ARTISTIC trial helpline, or a GP. Once some of the confusion had been resolved, women seemed able to put the result to the back of their mind until the next test. Particularly reassuring was the knowledge that the virus could lie dormant for a long time, so exposure was not necessarily recent and its presence did not mean that a partner had been unfaithful.

I mean if he'd had an affair with somebody then I would have been angry and upset. As it is ... it's something that I think he's had before our relationship, I trust him a hundred per cent. (F5)

Women were also reassured by the fact that HPV does not have symptoms, is highly prevalent and can clear spontaneously without treatment.

The pattern of initial anxiety followed by information seeking and reassurance is illustrated by the following quotation from a woman who was upset to be diagnosed with an STI, but whose distress lessened after receiving reassurances from the trial helpline.

I was quite annoyed, couldn't really believe it that it happened to me. And because it was sexually transmitted, and because I haven't had a lot of partners. Yeah wasn't very happy at all really. ... I phoned the [ARTISTIC Trial] helpline and they reassured me, they really did reassure me so I felt quite happy after talking with them. ... I would say it [the anxiety] lessened over the year because of the chat I had with the helpline ... I thought well if I hadn't taken part in that test I would never have known I had it and I knew I was going to have further tests. (F21)

On-going anxiety

This theme was characterised by the experience of anxious thoughts about HPV on and off throughout the year. The thoughts usually focused on unanswered questions and confusion about certain aspects of the virus. Women describing this experience had usually not sought additional information about HPV, or had not found satisfactory answers to their questions, and so seemed to dwell on the confusing and worrying aspects of the virus, unable to resolve their concerns. The need for a coherent model of the infection was expressed, but it was often difficult to develop such a model from the information available. For example, one woman had phoned the ARTISTIC trial helpline, but still had questions about HPV which she reported thinking about on a weekly basis.

Table 1. Demographic characteristics of the sample

	HPV positive at follow-up (n = 21)	HPV negative at follow-up (n = 9)	All (n = 30)
Age			
20s	7	1	8
30s	5	2	7
40s	6	3	9
50 and over	3	3	6
Relationship status			
Single	4	0	4
In relationship	4	2	6
Married/cohabiting	12	7	19
Divorced	1	0	1
Education			
Left school before 16/no qualifications	1	2	3
Left school at 16 (GCSEs, CSEs, O levels)	7	2	9
A levels	3	0	3
Further education (diploma, BTech etc.)	5	2	7
Higher education (degree)	4	3	7
Missing data	1	0	1
Choice of follow-up			
Colposcopy	17	n/a	17
Repeat HPV test	4	n/a	4

Like I say, the only thing that I do go back on is like what is it? If I keep carrying on, how long will I have it? What will they do for it? What will the long term effects be for me? They're the questions that go over a lot. The other things are just fleeting thoughts like now I sit and think about it. Could it be that? Could it be this? ... Every now and again I'll think about it for whatever the reason and they're my thoughts that I always have. (F9)

In addition to telephoning the trial helpline, this woman had tried to obtain information from her doctor but her concerns seem not to have been taken seriously. She reported being told 'It's just a study we're doing. It's nothing to worry about'. The explanations she had received were not clear enough for her to understand:

No one has actually, in my terms, made me understand what it is. They kind of give me long words and terms that go a bit over my head. (F9)

Another woman had a similar experience. She worried about when she had caught HPV and from whom, and was concerned about whether her long-term partner might have been unfaithful. She was also concerned about her risk of cancer. When she attended for colposcopy, she tried to talk to a doctor about it and reported:

She wasn't prepared to discuss anything with me. She just said go on the internet (F28)

This woman did not have access to the internet at home, and also felt scared about what she might find out if she looked.

Women in this group tended to have few educational qualifications and to be from lower socio-economic backgrounds. This may have contributed to their difficulty in accessing adequate information about HPV, though this hypothesis needs further empirical examination.

No anxiety

A third group of women were unconcerned about their HPV positive result and claimed to have forgotten about it completely between the two tests. Even some of the women who had strongly negative initial reactions then forgot about HPV until they were recalled for the second test. This response seemed to be associated with understanding that HPV could clear up on its own over the year, that it was not serious or life-threatening, and that their smear test result had been normal. The asymptomatic nature of HPV was also cited as a reason for being able to forget all about it. Sometimes anxiety increased immediately prior to the second test, as women wondered what the result would be.

I think to be honest I probably forgot about it most of the time until, I think, August when I realised I had to go for another one [test]. Then I got a bit anxious. How will it go? Will I still be positive? (F10)

Impact of the second HPV result

The impact of a second HPV result was explored and themes emerged relating to women's emotional and behavioural responses. Particular attention was paid to the ways in which these differed from responses to the first HPV result.

Emotional responses

Not surprisingly, emotional responses following the second HPV test varied greatly by whether or not that test was positive.

HPV positive at follow-up

Many women in the study described experiencing similar feelings when they received their second HPV positive result, as have been found in women receiving a first HPV positive result [7]. These included fear and anxiety about cancer and becoming ill, concerns about fertility, feelings of being unclean because of the sexually transmitted nature of HPV, concerns about transmission and sexual relationships, a negative impact on feelings about sex, and relationship issues including blaming a partner for the infection.

There was some variation from the initial result though, with concern often being greater after the second test. This was partly related to having a greater understanding of HPV the second time around, and may also have been linked to the fact that a colposcopy was offered after the second test, making it seem more serious.

The first one you don't know what it's about whereas with the second one it's important to you. When you find out you're positive again ... you're like ahh! (F18)

There was a sense that something that 'isn't going away' must be more serious and more of a threat to health than the first result. After the second test, fears about cancer and progression seemed to be more of an issue than they had been initially.

I didn't really know what HPV meant and then when I worked it out and I thought God, what if I can't have children or something? Or I have got cancer or something? (F13)

Hopes or expectations that the result would be negative led to feelings of disappointment when the virus had not been cleared. This was associated with the belief that a strong immune system would

fight off the virus, and that this could be hampered by stress or an unhealthy lifestyle. In some cases, a second HPV positive result led to a sense of failure, or of one's body letting one down.

You know, when you're thinking oh God my body can't fight it off itself, my body can't get rid of it itself, it's not good. (F18)

This negative impact was not universal though. In some cases, the offer of a colposcopy and additional monitoring led to feelings of reassurance. This was especially true if women knew that cervical abnormalities could be treated easily if they developed. Sometimes taking part in the trial and receiving the offer of regular testing and colposcopy was seen as preferable to the standard three year recall system, which was regarded by many as too infrequent.

Another response was to regard the test as part of research, and not something that was of personal relevance. This enabled women to distance themselves from the result and avoid experiencing any negative impact. This response highlights the importance of the trial context in shaping women's experiences.

I just understood that it was one of these things that women get and that's what the whole research was about—trying to find out how and why, and why some clear up and some don't and all the rest of it. That it was really just a piece of research rather than anything that was threatening to me personally. (F2)

HPV negative at follow-up

Testing negative was generally associated with feeling 'pleased', 'glad' or relieved, as if a 'big weight [had been] lifted off your shoulders'. The relief was connected with not needing further tests or treatment and, for some, with a reduced risk of cervical cancer.

[HPV] was something that was gone that was possibly some kind of a risk, I don't know. If it's something that it's better not to have than to have, then I'm glad I haven't got it. (F6)

One woman was especially pleased about her negative result as she interpreted it as meaning that the HPV could not have come from her current partner. She believed that if it had come from him, he would have re-infected her during the year, so her result would still have been positive.

There were some lingering concerns about future fertility or about recurrence of the infection. There was also uncertainty about whether a negative test could be an indication that the virus was still lying

dormant and might reappear at a later date. This was linked with a 'herpes' model of viral infections.

Among women who had expected still to be positive, there was shock and surprise about the negative result, but this was usually associated with feelings of relief as well.

I just had a feeling it would still be there. I was quite surprised when it said it was negative. I was glad but ... I was just surprised that it would have just gone on its own. (F7)

The negative result was also welcomed as evidence of the effective functioning of the immune system.

I thought oh my body must be working then because it's fought it off now, it's disappeared for now. (F29)

Behavioural impact

In an earlier study, disclosure was found to be an important coping response to testing HPV positive, and was indicative of women's emotional response [7]. Most women in this study reported a consistent pattern of disclosure across their two HPV results, talking to the same people about their second as their first result. Some, though, did not talk to anyone about their first result, often because of the perceived stigma associated with STIs, but were so upset or worried about their second result that they either felt the need to seek support and reassurance, or were forced to explain to work colleagues or their family what they were upset about. This woman described telling her father about her second positive result.

I think I wouldn't have bothered [to tell my father] if it wasn't for the fact that I was so upset 'cause I didn't bother the first time round but second time I was so upset and needed to get it off my chest that I told him. It was quite difficult! (F10)

In addition, some women chose to disclose following a second positive result because they wanted information or support about the colposcopy procedure and possible treatment. This provides further evidence that the emotional impact of the second test was more negative and severe than the first result, and that some women were motivated to overcome feelings of embarrassment about the sexually transmitted nature of HPV in order to gain information and support.

The relationship between anxiety and disclosure was not straightforward. For some women, feeling anxious led them to disclose their result and this helped lessen their concerns when friends and family were reassuring and supportive. For others, disclosure was unhelpful because friends and family had not heard of HPV and so were not

able to provide the support that had been hoped for. Because awareness of HPV is generally low, some women chose not to talk about it, especially if they lacked confidence in their own ability to explain it to someone else.

I haven't really mentioned it at all I suppose 'cause, I don't know, I'm hopeless at explaining things. (F16)

Sometimes disclosure added to the burden of anxiety because women then had to deal with the concerns of others. One woman's partner felt guilty about having given her the virus, whereas she was relatively unconcerned about it.

He [partner] just felt guilty. I think really what scared him was the cancer thing with it. If he thought that I had cervical cancer I don't know what he'd have done, I think he'd have just had a nervous breakdown because he just would have felt just so guilty about that. (F26)

Choice of follow-up among HPV positive women

The third aim of the study was to explore women's reasons for choosing each management option for persistent HPV. As shown in Table 1, the majority of women interviewed opted for colposcopy rather than waiting another 12 months for a third HPV test. Only four women in the sample decided to wait, which reflected the pattern of choices in the trial population as a whole (unpublished data). Three women were unaware of having been offered a choice. Among those who had actively chosen a particular management option, the reasons for the choice were explored.

Reasons for choosing colposcopy

Anxiety was one reason for choosing to have a colposcopy immediately. Some women were worried and upset by their second HPV positive result and were not prepared to continue to worry for another 12 months.

Well I thought maybe there was something a bit wrong, I don't know. To have two tests come back that say positive I think then you start thinking well what is it? What is wrong? I just would rather if there was something wrong for it to be found really. . . . I'd prefer to be looked at and examined and be told everything's fine rather than for another year to worry about yeah I'm positive again, what does that mean to me? I'd rather be checked really. (F9)

As the example illustrates, this was associated with concerns about the meaning of a second positive result, and fears about what might be wrong. Other

women exhibited less anxiety, but nevertheless expressed a desire for immediate resolution and reassurance, rather than a further period of uncertainty. This was often associated with an understanding that treatment might be offered if abnormalities were picked up during the colposcopy.

'Cause I'm the sort of person that I need to get things sorted now. I'm a bit of a fix-it person. . . . So in that way I would have gone as far down the line as I could have done before people said there's nothing more we can do. That was why I chose the colposcopy. (F20)

There was widespread understanding that the colposcopy was a more 'thorough' test, and many women welcomed the opportunity to have further investigation and reassurance, even if they were not particularly concerned about anything being wrong.

I think because that was the next piece in the jigsaw. It was OK I've been here and it's still showing up as positive, a colposcopy now so we'll investigate it a bit further. Well go along and make sure that there's nothing there untoward. . . . I saw it more as an investigation and quite probably nothing would show up. (F19)

There was a sense among some women that waiting 12 months might allow something to develop which could otherwise be dealt with now. This was associated with the general belief that cancer is a disease that can progress rapidly and therefore any early detection or treatment must be important.

You nip things in the bud with cancer. The sooner you get treatment the better it is. (F5)

Despite the general feeling that a colposcopy was preferable to waiting for a year, concerns were expressed about the procedure itself.

I was more worried about the procedure I think. At that moment in time I was worried about the procedure, I hadn't thought past the result. I thought more about how much it was going to hurt and whether I'd have to take time off work all that kind of stuff. (F1)

Reasons for choosing a repeat HPV test

Of the four women opting for a repeat test, only three were aware of having done so. The fourth woman was, in fact, unaware of having tested positive for HPV, and thought that annual screening for HPV was the standard trial protocol. Among the other three women, two decided not to go for the colposcopy because this was the easiest option, and they were not concerned about

their HPV results. Practical barriers to attending for colposcopy outweighed any perceived benefit associated with attending.

If anyone gives me a choice of having treatment or not if it's not necessary, I mean if they said oh yes it is necessary you have to go then I would go. But if you're giving me an easy way out then I'll take the easy way out. It's the convenience I think. I wasn't quite sure how I would have it done, how I'd get there. (F15)

When women were offered a choice, some of those who were not worried about their result interpreted the colposcopy as not being essential and therefore chose to avoid this additional procedure.

The third woman in this group displayed a more avoidant response towards the colposcopy, and described fear about what might be found. She preferred to wait, and hoped that the problem might go away.

I was quite tempted to go for the examination but then I think fear and ... I'm a bit scared about what might be found and it got the better of me. That sounds awful ... but I think it's a lot of case of just ignore it, it might go away. (F23)

Discussion

Women in this study had received a positive HPV result and then been re-tested a year later as part of the ARTISTIC trial of HPV testing in cervical cancer screening. The study found that although many women reported distress, anxiety and confusion following their first HPV result, this usually resolved and did not lead to on-going anxiety in the period between the two tests. The negative emotional impact of a second HPV positive result was often reported to have been greater than the first, sometimes motivating women to overcome the shame and embarrassment associated with having an STI in order to mobilise social support through disclosure of their result. This greater impact encompassed both the issues relating to the sexually transmitted nature of the virus and fears about the health implications and cancer risk associated with persistent infection. Women who tested negative for HPV at follow-up reported feeling happy and relieved.

In contrast to a recent study of patient choice in the management of mild dyskaryosis [12], women with persistent HPV in this qualitative study opted overwhelmingly for an immediate colposcopy rather than a third HPV test in a further 12 months. There is a variety of possible explanations for this. As HPV is unfamiliar and poorly understood, women are motivated to seek further testing and, if necessary, treatment. This may have been

associated with a lack of understanding of the very slow progression of HPV to CIN and cancer. Secondly, the study took place in the context of a clinical trial. This might mean that participants differed from the general screening population, and were probably more in favour of testing in general. This is reflected in some of the comments that women made—they were generally inclined to take up any test that was offered and were keen to be monitored more frequently than every three years. The findings are consistent with US research which shows enormous enthusiasm for frequent screening despite the risk of false positives and unnecessary investigation and treatment and perhaps represents an assumption that any early detection must be a good thing [16,17]. However, more research is needed to see how pervasive the attitudes of the women who opted for repeat testing are in the wider UK population.

HPV testing identifies individuals with an infection that puts them at risk of a more serious condition, but no immediate intervention is recommended. This is in contrast to risk factors such as high blood pressure or cholesterol which are often treated in their own right, so when diagnosed, people immediately receive medication or advice to change their lifestyles. Receiving risk information without being given any advice about reducing risk might be expected to cause anxiety. However, experimental studies have indicated that people receiving positive (unfavourable) test results downplay the threat compared with those receiving a negative (favourable) result [18]. This denial effect seems to be strongest when, as in the case of HPV, there is no recommended behaviour change to reduce the threat [19]. This might explain why, in most cases, the women in our study did not experience ongoing anxiety after their HPV diagnosis. In the absence of any behavioural recommendations, denial can be seen as an adaptive response to a health threat. There is also evidence from experimental studies that common conditions are seen as less serious than rare ones [20], so the provision of prevalence information about HPV may have been important in reducing anxiety.

As medical technology advances, it is likely that increasing numbers of people will have to deal with risk information for which there are no behavioural changes that reduce the threat of serious disease (e.g. testing for prostate specific antigen). This study suggests that such risk labelling is not necessarily anxiety-inducing, and that ensuring that prevalence information is widely disseminated might be a means of reducing any possible negative psychological consequences.

It is interesting that anxiety did not seem to have a straightforward relationship with management preference. Some women who were not anxious about HPV still opted to have a colposcopy, and one woman who was very anxious about it chose to

wait, and hoped that the virus would go away on its own. The need for a speedy resolution of the problem seemed to be a strong motivating factor for many women, but more research with larger samples is needed to explore this. It is also possible that if women had a better understanding of the low disease risk associated with their HPV positive status, they would be more willing to undergo conservative management.

In line with other studies, information provision emerged as an important means of reducing the anxiety and confusion associated with testing positive for HPV. Women who experienced on-going anxiety between the two HPV tests were frequently those who had unanswered questions relating to the virus, and had not been able to develop a coherent model of HPV. Providing information addressing women's concerns at the time of the first test might help to resolve confusion more rapidly, but this hypothesis needs to be tested empirically.

The findings of this study should be treated with some caution as the HPV test results at baseline coincided with a normal cytology result. If HPV testing were the sole screening test then the significance of the test result could be greater. This could have implications not only for the psychological impact of testing but also for adherence to recommended follow-up. Women therefore need to be fully informed and comfortable with HPV testing. There needs to be consideration of the emphasis on HPV as an infection and HPV as an indicator of cancer risk.

Conclusions

The study indicates that most women do not experience on-going anxiety between a first HPV positive result, and a second test a year later. This suggests that annual recall could be an acceptable form of management for women with normal cytology but HPV positive results. However, the more serious negative impact of a second HPV positive test compared with the first, and the overwhelming desire among the women we selected for interview for an immediate colposcopy, may indicate that on-going monitoring using HPV testing might be less acceptable to some women than immediate referral for colposcopy if the infection is persistent. This finding needs to be tested among representative samples of women undergoing HPV testing, but if found to be robust, might have implications for the development of screening policy for HPV testing.

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