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Communicating the changes to cervical cancer screening in England: The choice to have an HPV test

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Scientific understanding of the role of HPV in cervical cancer increased dramatically through the 1990s. The last seven years have seen the introduction of HPV vaccination for young women in many developed countries. In parallel, the potential for HPV testing to improve current cervical screening practices is being explored. Primary HPV testing in the cervical screening context involves testing the cervical sample for the presence of HPV DNA. Many studies have shown that compared with cytology, HPV testing has improved sensitivity for detecting high-grade disease [1]. HPV-based screening would therefore detect pre-cancerous lesions that would have progressed sooner than cytology. In the US, combined HPV and cytology is recommended for women over the age of 30 who wish to lengthen the screening interval [2]. A UK-based randomised trial (ARTISTIC) found that primary HPV testing with cytology triage, was the superior option, benefiting from a high negative predictive value permitting longer intervals between screening invitations. The automated process of HPV DNA testing also offers high throughput [3]. Primary HPV testing is now being piloted in the UK [101]. Decisions about how best to use HPV testing for the prevention of cervical cancer are likely to vary by country, depending on the current provision for cervical screening [4]. But whatever way HPV testing is introduced, these changes will need to be effectively communicated to the women who are invited to participate.

The importance of informed choice

Supporting women to make an informed choice about cervical screening is important. It respects their autonomy and acknowledges that screening can have harms and benefits. The importance of patient involvement in decision making has recently become recognised in service provision policy in the UK both generally [5] and in cancer screening specifically [102]. According to Marteau et al. an informed choice is one that is “based on relevant knowledge, consistent with the decision maker’s values and behaviorally implemented” (adapted from O’Connor and O’Brien-Pallas, page 100)[6]. They propose that a good level of relevant knowledge about a screening test is a pre-requisite for informed choice. Once knowledge is deemed ‘good’, positive or negative attitudes can be formed, and behaviour should be consistent with these attitudes; those who have positive attitudes about cervical screening should attend and those who have negative attitudes should not attend.

Good knowledge of HPV and cervical screening

Ensuring that women have sufficient knowledge about HPV and cervical cancer screening is a challenge. Lay understanding of HPV has lagged behind scientific understanding. While more people have now heard of HPV (attributed largely to the introduction of the vaccine), knowledge of some important aspects is still poor. For example, in a study of 18-70 year olds in the UK, US and Australia, a third of women who had heard of HPV before did not know that ‘condoms reduce the risk of getting HPV’, half did not know that ‘most sexually active people will get HPV at some point in their lives’, and nearly all did not know that ‘HPV usually doesn’t need any treatment’ [7]. In the same study, knowledge about HPV testing was even poorer, with only 21% of women who had heard of HPV testing aware that ‘If a HPV test shows that a woman does not have HPV, her risk of cervical cancer is low’ [8].

More worryingly, a fifth of women who had heard of HPV testing could not identify the statement 'If a woman tests positive for HPV, she will definitely get cervical cancer' as false.

HPV and its relationship with cervical cancer can be difficult to understand and aspects of the infection are potentially frightening [9]. HPV is sexually transmitted, it is a common infection, and it is untreatable, but it is not serious and will often clear spontaneously. If it progresses there is the potential for it to cause cancer, but in many cases it does not progress, and there are several treatable stages before a cancer diagnosis. In addition, women will likely have their own representations of cervical cancer, how it develops, and how screening plays a role in early detection. Women need to incorporate information about HPV into their existing knowledge of cervical cancer screening. This could be particularly difficult for many women who misunderstand the purpose of cervical screening and terms such as pre-cancer [10]. Recent work in the US suggests that although most women think the Pap test screens for cervical cancer, many also think it can detect other types of cancer, as well as sexually transmitted diseases. For a long time, patient information leaflets have failed to include adequate information about HPV, particularly at the screening invitation stage [11].

Improving knowledge of HPV among women may help to ensure the choice to be screened is informed, but could also have benefits later in the screening process if women are diagnosed with HPV. Qualitative studies with women undergoing HPV testing in the context of cervical screening have suggested that a lack of prior awareness of HPV contributes to feelings of anxiety and shock following a diagnosis [12]. Conversely, understanding the meaning of their results was associated with reduced anxiety in HPV-positive women [13]. A recent review concluded that despite acknowledging past misunderstandings and confusion, women want to know they were being tested for HPV, and want to give informed consent [14].

Can one size ever fit all?

An understanding of HPV testing and the role it can play in cervical cancer screening would help women to understand the purpose of screening and reduce the possibility of anxiety following HPV positive results. Following an informed choice approach would also require individuals to have sufficient understanding of research-based information about the benefits and harms of a screening test, including positive and negative predicative values. One way to satisfy this is to encourage use of decision aids in screening. Decision aids can successfully increase the proportion of people making an informed choice [15], albeit sometimes at the risk of reducing screening uptake [16]. An alternative option is to encourage women to *consider an offer*. This approach involves a recommendation to attend from trusted sources, alongside open discussion of why the recommendation has been made and provision of sources of further information for women who want it. This approach may be more appropriate when expert committees have reviewed the research data and endorse the screening programme (as with HPV testing in the context of cervical screening). Recent work in the context of colorectal cancer suggests that the majority of adults in Britain want a recommendation to participate in screening, although most also want access to full information about the risks and benefits of screening [17].

Conclusion

Changing the English cervical screening programme to use primary HPV screening with follow-up cytology for an HPV-positive result is subtly but importantly different from using cytology alone. Women will be tested for HPV, and some will ultimately be told they have an HPV infection. In the context of primary screening, many women will be told they are HPV-positive but cytology-normal. These women will need to understand that they are at greater risk than an HPV negative woman, so it is important that take up the subsequent screening invitation, but that they need not be anxious because it is likely HPV will regress and any

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persistent infection could be detected at the next screen. There are clear benefits to good communication about the changes in cervical screening including reduced anxiety if abnormal results are found.

In 1999, Braun & Gravey [18] raised concerns about how information on sexual risk factors for cervical cancer were suppressed in order to encourage uptake of cervical screening, citing a 1988 report that stated “It is of critical importance, if a woman is to co-operate in a screening programme, that she does not gain the impression that the risk of contracting this disease is somehow linked to promiscuity on her part. If she gains this impression and is monogamous, she will not accept the need for screening readily” (page 1467). We are now a long way from the ‘protectionism’ approach to screening. However the purpose of cervical screening continues to be misunderstood by many and changes to cervical screening offer an opportunity to address this and ensure all women have a basic knowledge of HPV, cervical screening, and what it means to them.

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