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Research findings: Women's views on HPV and cervical screening



The research was for NHS Health Scotland.



The research was undertaken by ResearchScotland



The research involved discussions with 100 women across Scotland

About this report

This is a summary of research which explored women's understanding of the introduction of HPV testing to the cervical screening programme (smear testing) in Scotland. This research was for NHS Health Scotland.

The full research report is available here:

www.healthscotland.scot
(search cervical screening)

Awareness of HPV

Many women had not heard of HPV or had heard of it only vaguely

There was a lot of worry and confusion about HPV.

Even when women had heard of HPV they did not always know it was linked with cervical cancer.

When women had heard of HPV it was often because of the HPV vaccination that girls aged 11 to 13 get at school.



I've never heard of HPV so I've never heard about any link with cancer.

Participant: 25 - 35 years

That's quite scary, that you can just pick it up.

Participant: 35 - 44 years

It gives me a wee bit of hope that they might be able to catch things earlier.

Participant: 45 - 54 years

Researchers talked to women about HPV and gave some facts and figures about it. Some women found it shocking, scary and worrying that nearly everyone gets HPV at one point in time.

Women were pleased that the new test would focus on HPV - which causes 99% of cases of cervical cancer. However, women were also concerned about the other 1% of cases and how they would be picked up.

Women were pleased that there was research showing the HPV test was a better way of identifying those at risk of cervical cancer. Women were glad that research was being done on women's health and causes of cancer. Some were particularly pleased to hear that other countries which had used similar approaches - such as Australia - now thought it was possible to eradicate cervical cancer.

For a few lesbian women, the message that HPV is spread through skin to skin intimate contact was important, confirming the importance of them taking part in the cervical screening programme.

Information about the new test



I would worry that you would develop it within the five years and you wouldn't know...

Participant: 35 - 44 years

I don't know what would be high risk or low risk.

Participant: 25 - 34 years

It's all about education, people need to know about HPV.

Participant: 55 - 65 years

Information

The women involved in this research felt there were gaps in information about both cervical screening generally and HPV in particular.

Women wanted to get information through trusted places and people, including the NHS website, GP practices, and health centres and clinics.

Women also expected to see information in the letters they received about cervical screening – the invitation and results letters.

Test frequency

Researchers explained to women that because the new test is better, women who don't have HPV will be invited to a cervical screening test every five years. This is a change for women under 50 who used to be invited every three years.

Many were very concerned about this change, worrying that they may contract HPV and develop cancer within the five year period.

Language

Researchers asked women what they thought about a few words and phrases related to HPV and cervical screening. Overall, women did not particularly like the terms:

HPV positive and negative – some found these scary, confusing and likely to attract stigma

High-risk HPV – some were confused about what the risk was, and what level of risk there was.

Women generally preferred clear, simple language such as 'HPV was found' or 'No HPV was found'.

Recommendations

The researchers suggested that NHS Health Scotland should:

Provide clear information

Women need to understand that:

- HPV is common
- It usually clears from the body on its own
- It rarely leads to cervical cancer
- Cervical cancer usually develops slowly, over 10 to 20 years
- Women with HPV will be called back for regular re-testing
- If HPV developed it would cause cell changes – which would be picked up in the cervical screening test
- Cell changes can normally be treated

Women also need to understand that anyone who has ever had skin to skin, intimate contact is at risk of developing HPV – regardless of who this is with (man or woman), how long ago this was, how many different people this is with, or how often it is.

Focus on preventing cervical cancer

NHS Health Scotland should be clear that:

- It wants to eliminate cervical cancer in Scotland Cervical cancer is one of the most preventable cancers

To do this, NHS Scotland is:

- Vaccinating all young girls and boys to protect against cervical cancer
- Moving to a new, better way of testing cervical screening samples
- Making sure all women know how to identify signs of cervical cancer

If you'd like to find out more...

If you want to find out more about HPV and cervical cancer, please go to:

www.jostrust.org.uk - Jo's Trust supports women, their families and friends affected by cervical cancer and provides information on cervical screening and HPV

www.nhsinform.scot/cervicalscreening - information from the NHS on cervical screening