

Women's understanding of the introduction of HPV testing to the cervical screening programme in Scotland

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Executive summary

About this research

This research explored women's understanding of the introduction of HPV testing to the cervical screening programme in Scotland. It explored:

- women's understanding of HPV and links with cervical cancer
- perceived benefits of and barriers to participation in the cervical screening programme brought about by the changes
- learning to improve information provided to women on cervical screening and HPV testing in the future.

The research is for NHS Health Scotland and the HPV Implementation Board. The findings from this study will be used to inform a communications and engagement plan for the change in the cervical screening programme. This will include developing a set of clear messages that can be used consistently across various communications channels. It will also inform the updating or refreshing of the current suite of information materials which support the cervical screening programme, including the information pack sent to women inviting them to participate.

Method

This research was entirely qualitative. It involved group or individual discussions with 100 women across Scotland. Women were approached to participate through the researchers working with trusted third sector groups and organisations across Scotland. A guide outlining all the necessary areas of questioning was used in each discussion.

There was a strong focus on involving women in areas of deprivation, with 38% of participants coming from the 20% most deprived data-zones in Scotland. Women were involved from five different NHS Health Board areas – Ayrshire and Arran, Grampian, Greater Glasgow and Clyde, Lothian and Tayside. The range of women involved included women with additional support needs, minority ethnic women and lesbian and bisexual women. There was a mix of women who attended cervical screening regularly, irregularly and never.

Using an informed consent process, participants signed a written consent form before the discussion confirming their willingness to take part. Participants were offered £30 to thank them for their contribution.

Key findings

Awareness of HPV

This research highlighted that many women had not heard of HPV or had heard of it only vaguely. It also highlighted high levels of worry and confusion about HPV. Even women who had heard of HPV were not always aware of the link with cervical cancer. This research supports other research which shows that awareness of the link between HPV and cervical cancer is relatively low¹.

¹ <https://www.jostrust.org.uk/node/1074526>

The HPV vaccine appears to have played a role in raising awareness of HPV. It is likely that as the HPV vaccination programme continues, awareness of HPV will continue to increase.

NHS Scotland has been working for some time to raise awareness of the importance of cervical screening. With so much confusion and worry about HPV, it is important to ensure that any awareness raising around HPV does not detract from the core message that cervical screening is about preventing cervical cancer.

Messages about HPV and cervical cancer

The research tested women's reactions to a series of messages about HPV. The most positively received messages were:

- **Research shows the HPV test is a better way of identifying those at risk -** Women felt this was a positive message and were pleased that research was being done on women's health and the root causes of cancer. This was a particularly strong message for women when accompanied with the statement that Australia is on track to eradicate cervical cancer because of a similar approach.
- **If high risk HPV is treated it is unlikely to lead to cervical cancer -** This was a reassuring message which could impact positively on screening attendance. However, a few participants found it confusing.
- **HPV causes 99% of cases of cervical cancer -** Women felt that this was a positive message and felt that this would mean the test could catch cervical cancer at an earlier stage. Women felt it emphasised the importance of the test and may make people more likely to attend. However, women were concerned about the other 1% of cases and how they would be picked up.
- **HPV is spread through skin to skin, intimate contact –** This message did not influence many women, but for a few lesbian women it confirmed the importance of them taking part in the cervical screening programme.

Women's views were mixed on two messages:

- **Nearly everyone gets HPV at one point in time –** Some women found this shocking, scary and worrying. Levels of awareness of HPV were relatively low, and people generally did not find this information influenced their views on cervical screening. Participants indicated that it was important to give the message that 'HPV is common', which may be a more useful way to provide this information.
- **Most of us can get rid of HPV like a common cold –** While some women felt this was reassuring, some felt it didn't really reflect how serious it could be. Women would welcome information on what they can do to help HPV to clear from the body as well as what, if anything, they can do to reduce their risk of HPV.

Two statements had potentially negative impacts:

- **HPV can stay in the body un-noticed for a long time – up to 20 years –** Mostly, this message did not impact on women's views on cervical screening. However, it is very important to consider if and how this message is conveyed. This message was a key factor in three women out of the 100 involved in the research saying they would be less likely to attend the screening test as a result of the changes. This message may have an impact on women with long term partners, of more than 20 years, who may believe their risk had reduced and they no longer needed to attend cervical screening.
- **Because the test is better, women who don't have HPV will be invited for a test every 5 years** – Many were very concerned about this change – although they did not feel it would impact on their attendance at screening. It is important that women understand that this change is 'because the test is better', which many women did not pick up from this statement.

Language

This research found that there were some phrases that should not be used to describe test results:

- **HPV positive and negative** – Some found these terms scary, confusing and likely to attract stigma. Instead the term 'HPV was found' could be used, as most found this clear and simple.
- **High risk HPV** – Some were confused about what the risk was, and what level of risk there was. A plain English alternative may be 'The type of HPV which can cause cervical cancer', or similar. However it is worth noting that this may also cause alarm. The simple statement 'HPV was found' may be most appropriate.

Within letters providing results, women were comfortable with the sentences:

- Your recent smear test shows that further investigation is required.
- Treatment at this stage can prevent the development of cervical cancer.
- No HPV was found, so no further testing is needed – with an addition to describe that this is for another five years, or until your next smear test.

Information provision

A wide range of information is currently available on cervical screening and HPV, but the women involved in this research felt there were gaps in information about both topics. Women are particularly keen to access information through trusted places and people, including through the NHS website, through GP practices, health centres and clinics, and in invitation and results letters and leaflets.

Research shows that minority ethnic women and disabled women face particular barriers to cervical screening. This research highlighted that there is some demand for face to face information provision with these groups, talking through the changes and the key messages they need to know about HPV and cervical screening.

Conclusions

Many women had not heard of HPV and there were high levels of worry and confusion about HPV. Even those who had heard of HPV were not always aware of the link with cervical cancer.

Women reacted positively to messages which emphasised that the new HPV test is better at identifying those at risk of cervical cancer. There was a particularly positive reaction when women understood that there was research showing the test was better. However, there was some concern about how the new approach would catch the small proportion of cases of cervical cancer not caused by HPV.

Most women were worried about the planned changes in frequency of screening. However, most did not understand the likely timelines for the development of HPV through to cervical cancer, or the detailed process that would be in place for testing and re-testing for women identified as having HPV (including cytology).

The message that HPV is spread through skin to skin intimate contact was particularly important for some lesbian women, and helped to confirm the importance of them taking part in the cervical screening programme.

The message that HPV can stay in the body for a long time (up to 20 years) did not have an impact on most women's views on cervical screening. However, this research highlighted that a few women who have been with their partners for more than 20 years may use this information to decide that they are at reduced risk of cervical cancer and decide not to attend cervical screening appointments.

The research found that the terms 'HPV positive', 'HPV negative' and 'high-risk HPV' were not well received. Instead, the term 'HPV was found' was generally seen as clear and simple.

Women participating in this research were keen to access information about cervical screening and HPV through trusted places and people, including through the NHS website, GP practices, health centres and clinics. Women would also expect to see information in their invitation and results letters, and in information leaflets.

Recommendations

Recommendation 1: Providing timely information

NHS Health Scotland should consider when women need information about HPV.

The main group of women who will need detailed information are women who have HPV found in their sample (but no cell changes). These women will need clear messages that:

- HPV is common
- Your immune system normally clears HPV from your body on its own
- HPV rarely leads to cervical cancer
- Cervical cancer usually develops slowly – over 10 to 20 years
- They will be called back for regular re-testing

- If HPV develops, this causes cell changes – which would be picked up in the smear test
- Cell changes can normally be treated.

Women would welcome being able to speak to a medical professional at this stage, and it is important that they are able to provide clear, consistent and supportive messages to reassure women.

Women who do not require another smear test appointment for five years should also get clear information that explains the rationale for 5 yearly testing. This should stress that they are at very low risk for cervical cancer and cervical cancer usually develops slowly (over 10 to 20 years). However, it should make clear that women should visit their GP in the meantime if they have any symptoms of cervical cancer – and provide an explanation of what these are.

Recommendation 2: Language in test results letters

Test results letters should avoid the terms HPV positive, HPV negative and high-risk HPV. Clear and simple terms should be used, including:

- Your smear test sample was tested for HPV.
- HPV was found/ No HPV was found.
- No further testing is needed, for another five years.
- Further investigation is required.
- Treatment at this stage can prevent the development of cervical cancer.

Recommendation 3: Ambition of eliminating cervical cancer in Scotland

The focus of wider awareness raising work with women should cover the changes in the cervical screening programme collectively – including the HPV vaccination, improved test focusing on the root cause of cervical cancer, the fact that cervical cancer is preventable, the ambition of eliminating cervical cancer in Scotland and the fact that research underpins this approach. Key messages should include:

- We want to eliminate cervical cancer in Scotland.
- It is one of the most preventable cancers.
- To do this, we are: vaccinating all young girls and boys to protect against cervical cancer; moving to a new, better way of testing smear test samples; and making sure all women know about how to identify signs of cervical cancer at an early stage.

Recommendation 4: Raising awareness of the risk of cervical cancer

NHS Health Scotland should continue to provide information about who is at risk of cervical cancer, making clear that anyone who has ever had skin to skin, intimate contact is at risk of developing HPV, regardless of who this is (man or woman), how long ago this was, how many different people it is with, or how often it is.

1. Introduction

1.1 About this report

This report sets out findings from research into women's understanding of the introduction of HPV testing to the cervical screening programme in Scotland. The report will cover:

- women's understanding of HPV and its links with cervical cancer
- women's reactions to exploring more detailed information about HPV, and how these influence perceptions of cervical screening
- women's views on the perceived benefits and potential barriers to introducing HPV testing into the cervical screening programme
- women's views on the information that they need about the introduction of HPV testing, and how and where they would like to access this.

1.2 Research context

1.2.1 Cervical screening

Cervical cancer is the most common cancer in young women aged 25 to 35. Six women are diagnosed with cervical cancer every week in Scotland.

Cervical screening was introduced in Scotland in the 1960s, with a national programme introduced in 1988. Cervical screening helps prevent cervical cancer from developing by identifying changes in the cells of the cervix, which could develop to become malignant, in women who otherwise have no symptoms.

Importantly, the cervical screening programme plays an active part in preventing cancer in the first place. Cervical screening prevents eight out of ten cervical cancers from developing and saves around 5,000 lives in the UK every year².

NHS Health Scotland is a national special NHS Board with a remit for improving health and reducing health inequalities. The Screening & Immunisation programme at NHS Health Scotland is responsible for overseeing the development of a range of information materials (invitation letters and leaflets, website information) to support informed uptake of the national immunisation and screening programmes in Scotland. This is done in partnership with Scottish Government, NHS National Services Scotland, Health Protection Scotland, NHS Boards and third sector partners.

1.2.2 Understanding of cervical screening

Recent research conducted by Jo's Cervical Cancer Trust and Scottish Government³ found that many women in Scotland did not have good awareness or understanding of the importance or relevance of cervical screening. Two thirds were unaware that not attending cervical screening was one of the biggest risk factors for developing cervical cancer. A high proportion were not aware of what the test was for. Over half of the women involved in the research did not know that HPV was a risk factor for cervical cancer. Almost a quarter thought it was to check the health of the womb and almost a quarter thought it was to find ovarian cancer.

² Cancer in Scotland (April 2017): Information Services Division, NHS National Services Scotland

³ <https://www.jostrust.org.uk/node/1074526>

NHS Health Scotland has undertaken previous insight gathering exploring the barriers and benefits of cervical screening. It is responsible for producing an information leaflet – A Smear Test Could Save Your Life⁴ - on the importance of cervical screening, which is posted with the invitation letter issued to all eligible women. NHS Health Scotland and Scottish Government also run an award winning awareness raising campaign – the Flower⁵ – to raise awareness of cervical screening among those aged 25 to 35.

1.2.3 Uptake of cervical screening

More than one in four women does not take part in the cervical screening programme, and uptake has fallen in the past decade. Uptake is lower in the most deprived areas, at 67%, compared with 78% in the least deprived areas⁶. Women under 30 are also less likely to attend their screening test⁷. There is also evidence that participation is lower among women with a learning or physical disability, minority ethnic women, lesbian and bisexual women and the transgender community.

1.2.4 Changes in the cervical screening programme

The UK National Screening Committee advises ministers and the NHS in all UK countries about all aspects of population screening. In 2016 the age range and frequency for cervical screening were changed in line with the National Screening Committee recommendations. The age range was adjusted from 20 to 60, to 25 to 64. Women on non-routine screening (where changes or abnormalities in cells have been identified) are now offered tests up to 70 years old.

There were also some changes to frequency of tests. The frequency for women aged 25 to 49 remained the same at every three years. However, women aged 50 and over are now offered tests every five years.

In addition, the Scottish Government's Beating Cancer strategy⁸ committed to introducing Human Papilloma Virus (HPV) testing as a first line test in the cervical screening programme. This approach was intended to come together with the HPV vaccination programme, which began in 2008.

From early 2020 the first line cervical screening test will be adapted. It will shift from cytology (the study of cells) to a targeted test for high-risk HPVs.

HPV testing aims to identify and treat cervical cancer earlier. Evidence shows that HPV testing is a better way of identifying women at risk of cervical cancer. This is partly because the HPV vaccination should offer prevention of HPV and result in a falling number of women who remain at risk of catching HPV and developing cervical cancer. The test also has higher sensitivity for certain high-risk factors, and a lower false negative rate than cytology.

⁴ <http://www.healthscotland.com/documents/24327.aspx>

⁵ <http://www.healthscotland.com/documents/28923.aspx>

⁶ Scottish Cervical Screening Programme Statistics, 2017/18 (Table 1), Information Services Division, September 2018

⁷ Scottish Cervical Screening Programme Statistics, 2017/18 (Figure 1), Information Services Division, September 2018

⁸ Beating Cancer: Ambition and Action, Scottish Government, March 2016

The new HPV testing will not result in changes for women regarding how the test is performed. However, it will be important for women to understand the changes in the tests and what the results mean.

1.2.5 HPV and cervical cancer

HPV is the main risk factor for cervical cancer. Almost all cervical cancers are caused by HPVs, and most (75%) are caused by just two types of high-risk HPVs^{9, 10, 11}.

Since 2008, girls aged 11 to 13 years old have been offered a vaccine designed to protect against HPV. This vaccine protects against the two types of HPV that cause around three quarters of cases of cervical cancers. Recently, the Scottish Government announced its commitment to also extending the HPV vaccine to young men in early secondary school.

HPV immunisation rates for young women are high, at over 80%¹². However, uptake rates are lower in the most deprived areas. While the HPV vaccine protects against most types of cervical cancer, cervical screening is also still required.

1.3 Research aims

The overall aim of the research is to:

- explore women's understanding of the introduction of HPV testing to the cervical screening programme
- explore the potential barriers and facilitators to participation that the changes may bring
- gain user insight into how the changes should be communicated to maximise attendance.

The specific objectives are to:

- explore women's understanding of HPV and links with cervical cancer
- explore factors that might improve women's understanding of HPV and engagement with the cervical screening programme to maximise uptake
- identify perceived benefits of introducing HPV testing into the cervical screening programme – and describe how these might be utilised to encourage uptake
- identify potential barriers to participation in the cervical screening programme, brought about by the change – and describe how these might be overcome
- identify any learning to further improve information provided to women on cervical screening and HPV testing in the future.

1.4 Research purpose

An HPV Implementation Board will govern the introduction of HPV testing in Scotland (reporting to the Scottish Screening Committee). An important workstream of this Implementation Board relates to Communications. This Board is responsible for ensuring successful delivery of the change to HPV testing and is chaired by NHS

⁹ [http://www.who.int/news-room/fact-sheets/detail/human-papillomavirus-\(hpv\)-and-cervical-cancer](http://www.who.int/news-room/fact-sheets/detail/human-papillomavirus-(hpv)-and-cervical-cancer)

¹⁰ <https://www.nhs.uk/conditions/cervical-cancer/causes/>

¹¹ <https://www.jostrust.org.uk/about-cervical-cancer/hpv/hpv-and-cervical-cancer>

¹² HPV Immunisation Statistics Scotland, School Year 2017/18, November 2018

Health Scotland. The Communications Group will develop a detailed plan for communication and engagement with members of the public, and relevant health care professionals.

The findings from this study will be used by the HPV Implementation Board and the Communications Group to inform a Communications and Engagement Plan for the change in the cervical screening programme. This will include developing a set of clear messages that can be used consistently across various communications channels. It will also include updating or refreshing the current suite of information materials which support the cervical screening programme, including the information pack sent to women inviting them to participate.

2. Methodology

2.1 About this chapter

This chapter sets out the methodology for this research. All research tools used are included at Appendix One.

2.2 The research method

This research was entirely qualitative. It involved group or individual discussions with 100 women across Scotland. Women were approached to participate through the researchers working with trusted third sector groups and organisations across Scotland.

A qualitative method was used as it enabled in-depth exploration of understanding, views and attitudes. A mix of group and individual discussions were used to enable different types of reflection and discussion.

Group discussions were used to allow participants to reflect on issues jointly and develop their thinking based on the responses and issues raised by others. This can indicate how discussions about the topic may develop between women in other environments beyond the research, and the types of issues, concerns and views that may emerge. Participants can also be more comfortable in group discussions, as it allows them to participate in discussion about a complex and challenging topic alongside their peers.

Individual discussions were used to allow participants to take part on their own. This can be the preferred method for some, when covering relatively personal and complex discussion points. The individual discussions provided more time for individual exploration of views. They also provided an opportunity to hear individual views when participants were not influenced by hearing the views of other participants. The individual interviews also allowed women who were unable to attend group discussions to participate in the research.

2.3 Sampling

The first stage of the research involved agreeing a sampling framework, setting out the broad mix of women to be involved in the research. This matrix helped to guide targets for participation, enabling the researchers to approach the right mix of organisations likely to work with this range of women.

Deprivation and age were identified as key priorities.

For deprivation, the Scottish Index of Multiple Deprivation (SIMD) was used to assess levels of deprivation among participants. The SIMD is the Scottish Government's official tool for identifying concentrations of deprivation in Scotland. It incorporates several different aspects of deprivation, and combines these into a single index. Concentrations of deprivation are identified at a small geographical level, called a data-zone.

There was a strong focus on involving women in areas of deprivation, with the study aiming for approximately:

- 40 participants in the most deprived areas of Scotland (the 20% most deprived data-zones, based on the Scottish Index of Multiple Deprivation)
- 50 participants in areas which are neither most or least deprived (the 60% of data-zones in the middle)
- 10 participants in the least deprived areas of Scotland (the 20% least deprived data-zones).

For age, the study aimed to include women aged between 25 and 65 (the current age range for the cervical screening programme) with a good spread across the age range. The aim was for a quarter of the participants to fall into each of the following age bands - 25 to 34 years, 35 to 44 years, 45 to 54 years and 55 to 65 years.

Secondary priorities were also identified, with the aim of involving a mix of people such as women with additional support needs; lesbian or bisexual women; minority ethnic women; and a small proportion of transgender men with a cervix. It was also agreed that the participants would come from more than one health board, from a mix of geographical locations, and should include some young women who had been offered the HPV vaccine, women who attended cervical screening regularly, irregularly and not at all, and women who are parents and who are not.

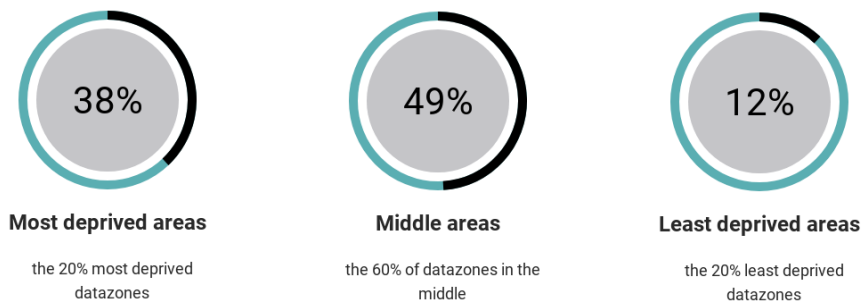
However, from the outset it was recognised that personal characteristics are multiple and overlapping, and that it was unlikely the study would achieve this precise mix within the women participating in the study.

2.4 Participant profile

2.4.1 Deprivation

All 100 participants were asked to provide their full postcode, but three provided postcodes not recognised by the Scottish Index of Multiple Deprivation (SIMD). The final profile of the 97 participants for whom postcode was recognised was:

Figure 1: Profile of participants by deprivation

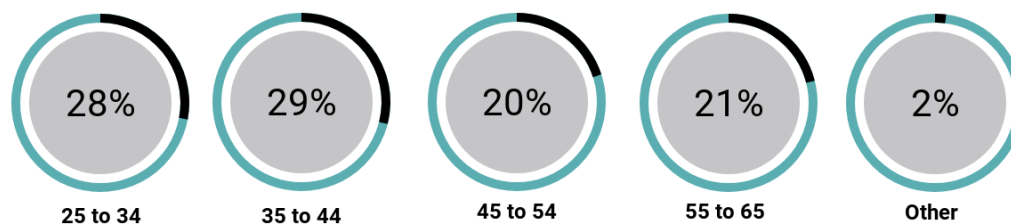


Throughout the report, comparison of views and tagging of quotes is undertaken using SIMD deciles. This is a way of grouping levels of multiple deprivation into ten categories. SIMD decile 1 covers the ten per cent most deprived data-zone areas of Scotland, based on the SIMD. SIMD decile 10 groups together the ten per cent least deprived data-zones of Scotland.

2.4.2 Age

The final profile of the 100 participants was:

Figure 2: Profile of participants by age



Two participants who did not fall into the 25 to 65 age group attended group discussions. Both were under 25. This was raised with NHS Health Scotland, and it was agreed that both participants should be included within the research as their experiences were relevant and informative for the study.

2.4.3 Personal characteristics

It was important that the research involved a mix of women with different characteristics, including women who may be less likely to attend cervical screening such as:

- participants with additional support needs
- minority ethnic participants
- lesbian or bisexual participants
- transgender participants.

The profile of the final 100 participants included:

Figure 3: Profile of participants by personal characteristics



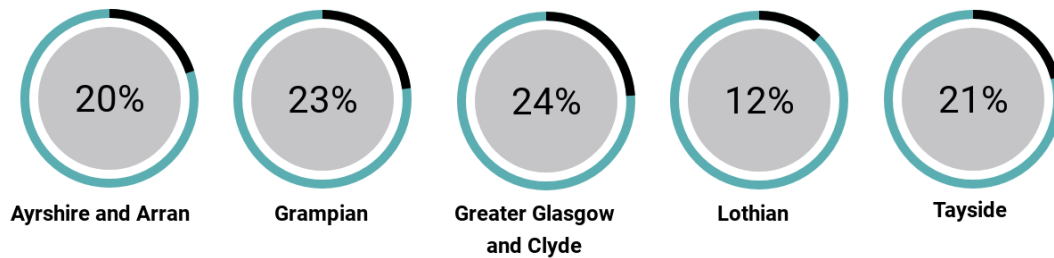
2.4.4 Wider mix

The researchers also aimed to ensure that the mix of participants included women:

- from across at least four Health Board areas
- from a mix of geographies including rural, mixed and urban
- who had been offered the HPV vaccine (as part of the catch up programme, when the HPV vaccine was introduced)
- who attended cervical screening regularly, irregularly or not at all.

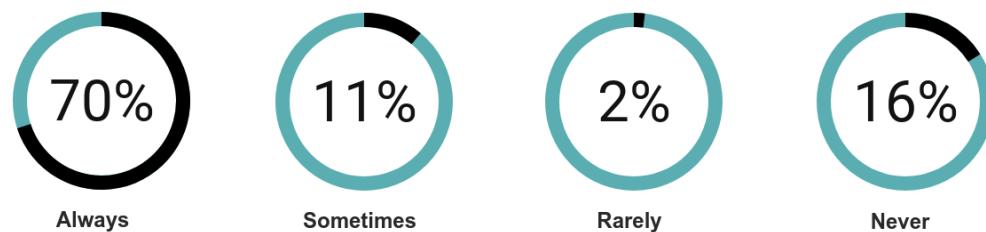
The 100 participants within this research study included:

Figure 4: Profile of participants by Health Board



All participants were asked if they attended cervical screening (their smear test). One did not know, and the profile of the remaining 99 participants was:

Figure 5: Profile of participants by attendance at screening



Most participants were from large urban or other urban areas, with 10% coming from small towns and rural areas. This analysis was undertaken by correlating participant postcode with the Scottish Government Urban Rural Classification (Six Fold Measure).

The final profile of participants also included a few women who had been offered the HPV vaccine, or whose relatives had been offered the vaccine. It was agreed with NHS Health Scotland that the number of participants being offered the vaccine would not be recorded formally through a participant screening survey, but instead would be explored through qualitative discussion with participants within the groups and interviews.

2.5 Recruitment

Participants were recruited through approaching trusted organisations, which already worked with women in Scotland. The researchers developed a matrix setting out the Health Board areas to be covered, the characteristics of participants, and the groups working with women in these areas. Groups were identified through online searches and researcher knowledge of the third sector in Scotland.

A total of 25 organisations were approached. Initial discussions with these organisations highlighted that some were not working with women with the characteristics sought – for example with women who did not fall into the age band for the study. Some were unable to help within the timescales. A total of 11 organisations were able to assist with the study. This included women’s organisations, equality organisations, childcare organisations and community, social and activity groups.

The lead from each organisation able to assist with the study took part in a detailed telephone discussion about the research, and also received an organisation information sheet setting out what would be involved from the organisation's perspective. This explained that the researchers would like to invite women who are involved in the organisation to take part in the research study. This could include women they supported, worked with, provided services for or who volunteered within the organisation. It also explained that organisations would receive £75 to recognise their time in helping with the study, regardless of how many participants came to the research through their organisation.

Organisations then explored the opportunity with the women they worked with. Each organisation had a participant information sheet to provide to potential participants, to help them decide whether to take part. This made very clear that participation was voluntary, and it was up to each individual to decide. It provided a phone number for women to contact the researchers if they had any questions in advance. In two areas, an easier to read version of the participant information sheet was used. This was offered following discussion with the organisations about the profile of participants likely to take part in the research, and their needs.

Women had the opportunity to be involved in a group discussion or individual discussion. When organisations discussed the opportunity with the women they worked with, many indicated that they would prefer to take part in a group discussion. A total of 82 women took part in group discussions, and 18 took part in individual interviews. Each participant was offered £30 as a thank you to recognise the time involved in taking part in the research. All participants were offered the same incentive regardless of whether they took part in a group or individual discussion.

2.6 Focus groups and interviews

Each discussion group lasted for 90 minutes. The first 30 minutes were set aside for the consent process, and to allow participants to ask any questions about the research. Participants were asked if they had any questions about the research and completed a consent form in writing to state that they were happy and willing to take part in the study before the discussion group began.

Each individual interview lasted approximately 45 minutes. Consent for individual interviews was gained in advance, with participants emailing a completed consent form, or dropping this into the office of the participating organisation for forwarding on to the researchers.

The discussion groups and individual interviews followed the same discussion structure. The full discussion guide can be found in Appendix One. Researchers took notes during the discussions.

Before any information was provided about cervical screening, any planned changes to screening, or HPV, the discussions explored:

- women's understanding of the purpose of cervical screening
- whether they had heard of HPV
- whether they had heard anything about a link between HPV and cervical cancer

- how they would feel if the results of a cervical screening test told them they had HPV.

After this, the researchers provided some information on the planned changes to how cervical screening samples are tested in the screening laboratory, and some basic information about HPV. Discussions then explored:

- whether the change would affect how they felt about the test or how likely they were to attend it
- whether different facts and statements about HPV affected how they felt about the test
- where women would go to find out about cervical screening
- how they felt about different words and phrases to describe the changes
- what other information they would want to know.

Finally, the discussions explored:

- now, having had this discussion, how women would feel if the results of a cervical screening test told them that they had HPV
- whether there was anything about the changes that made them feel more positive or more negative about cervical screening, and why
- what they thought the most important message was for women about these changes.

Participants were also provided with further information on HPV and cervical screening in the form of leaflets from Jo's Cervical Cancer Trust which also included details of their website and helpline. At discussions held during cervical cancer awareness week – 21 – 27 January - further materials from Jo's Trust were also available for participants to take away with them if they wished.

2.7 Analysis

We undertook a robust analysis of all the data gathered using a process of 'manual thematic coding'. This is an effective approach to interpreting rich, complex data. It involved taking each question in turn, carefully reading each response and manually identifying key themes emerging to code the data. Data was then sorted into themes and assessed for any patterns in the profile of participants commenting on these themes. The coding and analysis process was led by one senior researcher, to ensure consistency, with findings discussed and developed jointly with all researchers involved in the project.

As part of this process verbatim quotes and examples were identified, to help demonstrate key points made. Quotes are used to express the balance of opinion – and are not highly unusual or outlying in terms of the views expressed.

Although the report is qualitative, throughout this report a consistent scale is used to describe the broad proportion of participants giving a certain viewpoint:

- all – all 100 participants
- almost all – all but up to five participants
- most – more than half of the participants
- some – more than five but less than half of the participants
- a few – two to five participants

- one/ an individual – just one person.

Where bullets are used to summarise responses, points are listed in order of frequency mentioned.

2.8 Ethics approval

Following a review of the NHS assessment criteria for research ethics it was confirmed that the study did not require formal NHS research ethics committee approval. However, the study was reviewed and approved by the NHS Health Scotland Research Development Group.

2.9 Study limitations

This research was qualitative and focused on exploring individual views and attitudes in some depth. It involved 100 participants and provided significant detail on their views and how these changed as HPV and cervical screening were discussed throughout the groups and interviews.

However, qualitative research explores the experiences of the individuals involved in the research. It cannot be extrapolated or assumed that another 100 women would have the same views and attitudes.

It is also important to recognise that women needed to be informed what the study was about, in order to make an informed decision about whether to participate. Before coming to the discussions, women knew they were going to be talking about cervical screening. It is likely that some women informed themselves about the broad subject area before attending the discussion.

The research involved a mix of individual and group discussions. The group discussions gave women the chance to exchange ideas and responses. However, it is possible that in the group settings, some women could have been influenced by the views and concerns of others in the group, as they explored the subject.

Finally, the research gave women between 45 minutes and one hour to explore complex issues. The discussions introduced lots of new ideas that perhaps people hadn't considered before, and women were providing their initial responses on ideas that were completely new to them. It was clear that their thinking was developing as the discussions progressed and it is likely that their thinking will have continued developing as women reflected on the information received.

3. Understanding of cervical screening and HPV

3.1 About this chapter

This chapter explores women's understanding of:

- the purpose of cervical screening
- HPV in general
- HPV and the link with cervical cancer.

It also explores how women would feel if the results of a cervical screening (smear) test told them that they had HPV.

These discussions were held without women being given any information about the planned introduction of HPV screening to the cervical cancer programme, or any information about HPV.

3.2 Understanding of the purpose of cervical screening

All participants were asked an open question exploring what they felt the overall purpose of cervical screening (the smear test) was.

Most participants indicated that the purpose of cervical screening was to pick up any abnormalities or changes in the cells of the cervix. Some highlighted that it was specifically to detect cervical cancer.

'To look for abnormal cells which could potentially become cancer.' (35 – 44 years, always attends screening, SIMD decile 1)

Just a few women indicated that it was to prevent cervical cancer. This was most commonly mentioned by participants who always attended cervical screening.

'To check the cells in the body, to prevent rather than treat.' (35 – 44 years, always attends screening, SIMD decile 3)

However, a few were unsure how to describe the precise function of screening in relation to cervical cancer.

'Mmm... it's to prevent... not to prevent but to... not predict, prescribe, detect... diagnose if you have signs of cervical cancer.' (55 – 65 years, always attends screening, SIMD decile 10)

'It's to check for changes... cancer cells... other... I don't know.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

A few women described the purpose of screening more generally as to look after women's wellbeing, check for any abnormal cells throughout your body, or rule out anything sinister. This included women who did and did not attend screening. One, who always attended cervical screening felt that it was to do with the lining and behaviour of the womb.

One participant highlighted that the test was for anyone with a cervix, whether they would define as a woman or not.

3.3 Awareness of HPV

Participants were asked if they had ever heard of HPV or human papillomavirus. Half of the participants said that they had heard of HPV and half said they had not. There were no clear patterns in terms of level of awareness by level of deprivation. However, participants aged 25 to 34 were more likely than other age groups to have heard of HPV.

Most women who had heard of HPV indicated that they had heard about the HPV vaccine. Most of those who had heard of HPV said they knew of it because their younger sisters, daughters or nieces had received or been offered the HPV vaccine. One had heard about it through her sons, who mentioned that girls in his class were 'getting a jag'.

'The young ones get immunised.' (55 – 65 years, always attends screening, SIMD decile 4)

'Vaguely. I know that there's a vaccine that girls get in high school.' (35 – 44 years, always attends screening, SIMD decile 1)

'Yes. I wouldn't have known what it stood for, but it was in my head somewhere. It's what teenage girls are vaccinated with.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

'Yes, I've heard of HPV. I got it at school.' (25 – 34 years, never attends screening, SIMD decile 3)

A few participants were aware of HPV because they had been offered the HPV vaccination themselves. One had received the vaccine, and one participant was unable to receive the vaccination because she was pregnant at the time.

One participant indicated that she had not allowed her daughter to have the vaccine, as she didn't feel she had received enough information about it. Another mentioned her daughter had refused the vaccine due to having a phobia of needles. One participant remembered the vaccine being introduced and said there was a lot of misinformation about it, with a lot of people associating it with promiscuity.

In two areas, a few participants mentioned that they had heard about the HPV vaccine on the news.

'There's been a lot on the news about it.' (55 – 65 years, always attends screening, SIMD decile 9)

One participant indicated that she was aware of HPV because of her experience when living in another country.

'I know that in Brazil teenagers – both girls and boys – can get a vaccine against HPV at school.' (45 – 54 years, always attends screening, SIMD decile 10)

A few participants in one discussion group initially said that they were not aware of HPV. However, after discussion, these women mentioned that they had heard of a vaccine to prevent cervical cancer (through their daughters) but not specifically of the term HPV.

3.4 Awareness of the link between HPV and cervical cancer

Participants were asked if they had heard anything about a link between HPV and cervical cancer. Overall, around a third of the women had heard of some link between HPV and cervical cancer.

'Yes. I can't remember what the percentages are, but I know that a high percentage of cervical cancer is caused by it [HPV].' (35 – 44 years, always attends screening, SIMD decile 4)

'I think I have, but I've just not taken it in.' (25 – 34 years, never attends screening, SIMD decile 3)

'I know that if you get the infection very often, you may get cervical cancer. Most women get the virus but they can cure it themselves.' (25 – 34 years, always attends screening, SIMD decile 4)

A few indicated that they were aware of the link because of information they received in school when they were receiving the HPV vaccine, or information provided to partners, siblings and wider family members at the time of the HPV vaccine.

'I got the HPV vaccine at school. Before the girls were given the vaccine, they talked with the boys and girls about why the girls were getting the vaccine.' (under 25 years, doesn't know if attends screening, SIMD decile 6)

'Both of my daughters have had the vaccine. They went to a talk about it first.' (34 – 44 years, always attends screening, SIMD decile 6)

A few participants were aware of the link because of their own or family health experiences. One participant was aware of HPV because she had pre-cancerous cells on her vulva caused by HPV. Another was aware of HPV as her daughter had been recalled following a smear test and was told she had abnormal cells that were due to HPV. This participant felt that HPV had not been clearly explained by her GP, and she was concerned that HPV 'sounds like a sexually transmitted disease' and was associated with stigma. Another had learned from her sister's experience of HPV.

'My sister had HPV, and my doctor explained the link between this and cervical cancer to me.' (25 – 34 years, always attends screening, SIMD decile 10)

A few women had heard of HPV through their own work, or a friend's work. For example, one participant worked in a dental practice and was aware of the link between HPV and different types of oral cancer. Another was a speech and language therapist and had experienced issues relating to HPV and oesophageal cancer.

'My friend works with teenagers and they discuss this with them as part of health awareness.' (45 – 54 years, sometimes attends screening, SIMD decile 3)

Participants who had never heard of a link between HPV and cervical cancer came from all age groups, all levels of deprivation and included people who always attended, sometimes and never attended screening. In three discussion groups none of the women had heard of a link – these groups were in an area of deprivation, a mixed urban area, and with a group of disabled women in a rural area.

'I've never heard of HPV, so I've never heard about any link with cancer.'
(25 – 34 years, always attends screening, SIMD decile 7)

However, in one discussion group with minority ethnic women, a particularly high proportion of women were aware of the link between HPV and cervical cancer.

3.5 Feelings about having HPV

Before being given any more information about HPV, participants were asked how they would feel now if the results of a cervical screening (smear) test told them that they had HPV.

Most participants indicated that they would feel unsure or confused. Some participants started asking the researchers questions at this stage, about the consequences of having HPV. Some said that they would need to find out more, or ask their GP.

'What is it?' (45 – 54 years, always attends screening, SIMD decile 1)

'Could it be called pre-cancerous cells?' (35 – 44 years, always attends screening, SIMD decile 1)

'I'm not quite sure. I'd wonder could I get the vaccination? Is it treatable? Is it the early stages of cancer?' (45 – 54 years, always attends screening, SIMD decile 10)

'I don't know anything about it. What does it mean?' (25 – 34 years, always attends screening, SIMD decile 4)

'I don't know about HPV, I want to find out what it is.' (45 – 54 years, never attends screening, SIMD decile 5)

Most participants also said that they would be worried, anxious or scared. Some participants said they would be worried because they didn't know what HPV was, what could be done about it and what the possible outcomes were. One participant

said they would be suspicious if a test told them they had HPV, as they had never heard of it before now.

'I'd freak out because I don't know what it is.' (45 – 54 years, always attends screening, SIMD decile 1)

Some indicated that they would be worried that they would get cancer.

'Scared, because it's linked to cancer isn't it?' (45 – 54 years, always attends screening, SIMD decile 4)

'Because you know the next step might be cancer.' (35 – 44 years, sometimes attends screening, SIMD decile 4)

The degree of concern varied between participants. A few said that they would panic or freak out, while a few said they would be a little concerned. While responses were varied, the participants who never attended screening tended to express more shock and worry about the result than those who attended.

'Stunned.' (35 – 44 years, never attends screening, SIMD decile 9)

'Em... probably quite upset, maybe a bit shocked. It's quite a bad thing to deal with.' (25 – 34 years, never attends screening, SIMD decile 3)

'It would raise some sort of alarm. It is not a neutral or run of the mill result.' (25 – 34 years, never attends screening, SIMD decile 9)

'I'd feel a bit concerned, but I'd go and see my doctor. I know it can be treated if it is caught early enough.' (35 – 44 years, always attends screening, SIMD decile 5)

Two participants said that they would specifically be worried about fertility.

A few participants felt that HPV sounded a bit like HIV, which had a negative connotation for them.

'It sounds similar to HIV, it makes me feel worried.' (35 – 44 years, always attends screening, SIMD decile 4)

One participant said that they would be disgusted by this result, as they would be worried this meant there had been new sexual partners in their relationship.

'I'd feel disgusted, as it could either mean that I had been promiscuous, or my husband had been cheating.' (35 – 44 years, always attends screening, SIMD decile 3)

One participant mentioned that they would be concerned about passing HPV on to others.

'I would be scared about passing the virus on to someone else.' (25 – 34 years, always attends screening, SIMD decile 10)

One participant said that she would be surprised because of her lifestyle.

'I guess I would be very surprised, because I haven't slept with men.' (25 – 35 years, always attends, SIMD decile 7)

One participant felt that awareness of HPV was particularly low among older women.

'Older women don't have an understanding of HPV.' (55 – 56 years, rarely attends screening, SIMD decile 1)

Just four participants said that they would not be particularly worried if this was the result of their test. One participant said that while she understood people's concerns, it might not be anything to worry about. She equated it to feeling a lump which could be cancer, but could also be benign and nothing to be worried about. Another felt well informed as her cervical screening results had shown abnormal cell changes in the past, and she had been through a cycle of additional tests and felt well informed. Another felt it would be useful to understand if she had HPV.

'I wouldn't be bothered either way. I might want to check in case it's a false positive, because I know that false positives can be a thing.' (35 – 44 years, always attends screening, SIMD decile 4)

'I don't think it's a negative thing.' (25 – 34 years, always attends screening, SIMD decile 1)

'Mmm... It would be a benefit if the test was going to tell me something else, in addition to what it already does.' (55 – 65 years, always attends screening, SIMD decile 10)

4. Improving understanding of HPV testing

4.1 About this chapter

This chapter explores whether and how a series of facts and statements may influence how participant's felt about the cervical screening (smear) test. The key messages provided were:

- HPV causes 99% of cases of cervical cancer.
- There is research showing the HPV test is a better way of identifying those at risk.
- Nearly everyone gets HPV at one point in time (4 out of 5 women).
- Most of us can get rid of HPV, like we do with a common cold.
- You cannot prevent HPV.
- HPV is spread through skin to skin, intimate contact.
- HPV can stay in the body un-noticed for a very long time – up to 20 years.
- Because the test is better, women who don't have HPV will be invited for tests every five years.

This chapter also explores how women would feel if the results of a cervical screening (smear) test told them that they had HPV, having had this information.

These discussions were held after the researcher provided some basic information about HPV. The explanation is below, for information.

Researcher explanation:

There is a new way of testing smear test (cervical screening) samples that is better at identifying those at risk. So the NHS is changing the way the sample taken from cervical screening is tested. The process of taking the sample will stay the same, so women's experiences won't change. But the way the cells are tested in the lab will change.

The first thing the lab will do is test for the human papilloma virus (HPV). HPV causes 99% of cervical cancer cases. Only if certain high-risk types of HPV are found, will they then check the cells for abnormalities by looking at the cells through a microscope.

The HPV virus is very common and has no symptoms. Most of us will have it at some point (4 out of 5 people). You are at risk as soon as you are sexually active. Mostly the body clears it like a common cold. But in some cases, if your immune system can't clear it, it can cause changes in the cells of the cervix. If these are left untreated, these cell changes can develop into cervical cancer.

4.2 Reactions to key messages

Participants were asked whether any of the following facts and statements would influence how they felt about the cervical screening (smear) test, and in what way.

4.2.1 HPV causes 99% of cases of cervical cancer

Overall, participants were interested in this information. A few participants did not know or were unsure whether this information influenced how they felt about smear testing.

Some felt positive that the test was able to focus on the main cause of cancer, and perhaps catch cervical cancer at an earlier stage.

'It gives me a wee bit of hope that they might be able to catch things earlier.' (45 – 54 years, always attends screening, SIMD decile 1)

These participants felt it made it even more critical for women to attend cervical screening. This view was largely expressed by women who always attended screening. A few said it would reinforce the importance of attending screening for them.

'It would encourage me to go for my smear.' (35 – 44 years, always attends screening, SIMD decile 5)

'This doesn't change how I feel about the test, just reinforces it.' (55 – 65 years, always attends, SIMD decile 10)

'It wouldn't put me off, it still needs to be done.' (55 – 65 years, always attends, SIMD decile 9)

However, participants who never or sometimes attended also indicated interest in the information. One indicated that it may encourage women to attend screening and one lesbian woman said it would make her more likely to attend.

'Eh... I suppose it just makes me more likely to go and get tested.' (35 – 44 years, sometimes attends, SIMD decile 6)

'I think it would provide a shock factor.'
(55 – 65 years, sometimes attends screening, SIMD decile 1)

However, another lesbian women said that she felt that she was at lower risk of having HPV since she hadn't slept with men, and she might feel slightly less worried about cervical cancer.

One participant said it wouldn't influence her views on cervical screening as she already knew this. Another participant who never attended cervical screening said they would only attend if there was a different way of doing the test.

One participant felt it was important to make sure that young women who had the HPV vaccine still understood they needed to attend their cervical screening appointments.

'They need to explain to young girls who have been vaccinated that they still need to go for screening.' (35 – 44 years, always attends, SIMD decile 3)

Some participants indicated that they were concerned about what causes the other 1% of cases of cervical cancer, and whether these cases may not be picked up through the new test. Participants asked what caused this other 1% of cases, and how this cancer would be identified. Some expressed concern that the changes were due to seeking efficiencies or cost savings, and that some women might be missed as a result.

'If 99% of cases are caused by the virus, that's what they should be testing for, isn't it... It's just the 1% that I might think about.' (35 – 44 years, always attends screening, SIMD decile 1)

'I guess it's good that they can just test for HPV, before spending time, money and effort on the other test.' (35 – 44 years, always attends screening, SIMD decile 7)

This discussion also raised questions for some women around whether men got HPV, how it was transmitted, and how women could explain HPV to their partners.

4.2.2 There is research showing the HPV test is a better way of identifying those at risk

Almost all participants said that they were pleased that research had been undertaken in this field. They were positive that the NHS was researching women's health and acting on the root cause of cancer. Some said that they felt reassured by this information.

'This can only be a positive thing.' (55 – 65 years, always attends screening, SIMD decile 1)

'That's good that they've done the research and found a link and can now make changes.' (35 – 44 years, always attends screening, SIMD decile 1)

'It's encouraging to know that we've moved on and can test for these things.' (35 – 44 years, always attends screening, SIMD decile 10)

A few mentioned that they felt this would lead to more accurate, timely and efficient testing.

'The faster it's found the faster it is to treat.' (25 – 34 years, always attends screening, SIMD decile 4)

'Yes. I think anything that's more accurate is better. That is progress.' (45 – 54 years, always attends screening, SIMD decile 10)

'Yes, that's great that they have found that out. It means they can limit the amount of work they have to do.' (35 – 44 years, always attends screening, SIMD decile 7)

A few said that they were so committed to attending cervical screening, that no information relating to the change in the test would make any difference. A few said that they may feel slightly more positive about attending the test, and a few felt that it

may make people more likely to attend. Conversely, a few said that they had never been for the test and none of this information would make any difference.

A few felt that they would want to know more about the research, to see if it influenced their views. For example, one would want to know more about the different types of HPV.

One participant indicated that using the concept of risk was a good way of encouraging people to attend cervical screening, without it being too scary.

4.2.3 Nearly everyone gets HPV at one point in time (4 out of 5 women)

Participant views were mixed on how this information influenced their thinking. Some women felt that it was helpful to understand that HPV was common, with a few saying it was reassuring as it made them feel that it is just a virus. A few mentioned it helped them understand that HPV develops into cervical cancer for some, but not for others. A few felt it was interesting but didn't influence their views on cervical screening either way. One participant felt that the statistic used in the statement was good, and light enough to be accessible.

'Mmm... I just think it is the kind of viral thing that we are living with. I didn't know that, but it doesn't change how I feel about it. [screening]' (35 – 44 years, sometimes attends screening, SIMD decile 6)

A few participants felt that this information emphasised the importance of getting tested, and said it would motivate them to attend screening. Generally these were women who already attended cervical screening regularly.

'It shows you should get tested to see if anything needs further looked at.' (35 – 44 years, always attends screening, SIMD decile 7)

'That's a new point for me. I think we need to raise awareness about it. I think if people know more they'll understand more and take it seriously.' (35 – 44 years, always attends screening, SIMD decile 10)

However, some women found this information scary and shocking. Some found it scary because they didn't know a lot about the virus. Some found it scary because you could have HPV and not know. A few said this information was too scary and hard hitting.

'It's scary that you can have it and not know.' (45 – 54 years, always attends screening, SIMD decile 3)

'That's quite shocking. And you have no symptoms as such... your body would fight it off?' (45 – 54 years, always attends screening, SIMD decile 1)

At one discussion group, some participants were concerned that HPV sounded like a sexually transmitted disease. At another group, there was concern that people might worry about having sex because they might get HPV. However, a few participants

felt that having access to information about HPV status may help reduce stigma and taboo.

One participant who had never had sex felt it was important to be clear that this statement only applied if you were sexually active. Another participant felt that it was important to focus on how to avoid HPV.

'I don't like how this statement is worded. The focus should be on how to avoid getting HPV.' (55 – 65 years, never attends screening, SIMD decile 6)

A few participants felt that there was a risk of worrying people.

'I suppose there is a risk attached that not everyone will go on to have cervical cancer. Do you alarm someone? But it wouldn't stop me having the test.' (55 – 65 years, always attends screening, SIMD decile 10)

'This is quite a scary thought, but... if it can resolve on its own... I suppose it could pick up HPV in people when it could just go away, and may cause unnecessary concern.' (25 – 35 years, always attends screening, SIMD decile 7)

A few participants wondered if men could also have HPV. These participants wanted to know more about how HPV was spread, who carried it, and whether it could be tested for in men.

'The other thing I'd wonder is whether males carry it?' (45 – 54 years, always attends screening, SIMD decile 10)

4.2.4 Most of us can get rid of HPV, like we do with a common cold
Participants had mixed views on this information. Some said that it didn't make any difference to how they felt about cervical screening.

Some indicated that they found this information reassuring. This was because it indicated that HPV was relatively easy to get rid of and made them feel that it was 'less of a big thing' and not as scary.

'It's just one of the marvellous things that our bodies do.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

However, some felt it did not reflect how serious HPV could be. A few were worried that people would not go for their smear tests when they heard this information. A few felt it was confusing and contradictory, as although HPV was as common as getting a cold, the consequences could be much worse.

'The message is too simplistic. We need to ensure that our children and others protect themselves against HPV.' (45 – 54 years, always attends screening, SIMD decile 10)

'I think it's worrying that people might think because it's common they don't need to go for smears.' (35 – 44 years, always attends screening, SIMD decile 2)

A few participants simply expressed their surprise at this information.

'I'm quite surprised at that... because it seems like some people can get rid of it, but for others it can become cancer.' (35 – 44 years, always attends screening, SIMD decile 1)

A few participants wondered how you get rid of HPV, and who would not be able to clear HPV from their body. A few wondered if people with lower immunity would be less able to clear HPV from their body.

'But does it depend on if you have a strong immune system – like on your age or health conditions?' (45 – 54 years, always attends screening, SIMD decile 1)

4.2.5 You cannot prevent HPV

Most women felt that this statement had no real impact on their feelings towards cervical screening. A few said it was part of life that there were viruses that you could not prevent.

'I'm not really surprised by that, because I guess you can't prevent a cold or the flu either.' (35 – 44 years, always attends screening, SIMD decile 1)

'There's a lot of things you cannae prevent in life. We are living organisms. It's part of being human. Obviously, you have things that you carry on your body.' (45 – 54 years, always attends screening, SIMD decile 10)

Some women were surprised that HPV was not preventable. For example, one participant said she felt out of control and another felt angry on hearing this information. Another said there should be information about how to reduce your risk of contracting HPV. Two participants were concerned that practicing safer sex would not protect you from HPV. One lesbian woman who sometimes attended cervical screening said she would be more likely to go for the test knowing this.

'Mmm... I don't know. Can you not prevent it through wearing a condom? Maybe I'm more at risk than I thought.' (25 – 35 years, always attends screening, SIMD decile 7)

One participant found the message within this information a bit confusing and wondered about how this was best conveyed to women.

'It's a bit of an odd one. All the other messages around sexual health do tend to be around preventative, avoidance.' (55 – 65 years, always attends screening, SIMD decile 10)

Some participants discussed whether abstaining from sexual activity could protect you from contracting HPV. This was raised in four discussion groups and in a few individual interviews. Some felt the statement was incorrect, as they believed that abstaining from sexual activity or skin-to-skin intimate contact would mean that you could not contract HPV. A few felt that the information should be clear that you can prevent HPV if you are not sexually active.

'It can be in your body, unless you are not sexually active.' (55 – 65 years, always attends screening, SIMD decile 7)

However, one participant (aged 45 to 54) said that cervical cancer used to be directly attributed to being promiscuous and felt that focusing strongly on the facts around HPV would be a good thing. Another felt that knowing you can't prevent HPV might reduce any stigma or taboo around having the virus, and might reassure people that getting it is not a personal failing and they couldn't have prevented it – unlike other sexually transmitted infections.

A few women thought that attitudes to HPV may vary depending on people's age, believing young people to be more aware of their sexual health.

4.2.6 HPV is spread through skin to skin, intimate contact

Views on this information were mixed. Some women felt that this had no real impact on their views on cervical screening, with some stating that it was useful to know, and important that people knew this.

Two participants said that this information would make them more likely to want to go to their cervical screening test.

'I suppose that would make me think you want to go for your tests.' (25 – 35 years, always attends screening, SIMD decile 7)

'Mmm... That would probably make me want to go.' (25 – 34 years, never attends screening, SIMD decile 3)

However, some were surprised and a few said they were shocked.

'That's quite scary, that you can just pick it up.' (35 – 44 years, always attends screening, SIMD decile 1)

'It feels like HPV is an STI, and this gives a different connotation to the cervical screening test.' (55 – 65 years, never attends screening, SIMD decile 6)

A few assumed safe sex practice would protect them from HPV – and participants asked about whether using condoms would prevent HPV. Some discussed what type of contact spread HPV and wanted more clarification on exactly what was meant by intimate contact. One wondered if you could contract HPV if you only had one partner. A few wondered if it could be passed on through kissing or oral sex.

'Yeah well... I take it... I would be asking if there are any preventative measures.' (45 – 54 years, always attends screening, SIMD decile 10)

One participant (45 – 54 years) felt that the description was too vague, as different age groups may interpret this differently. She highlighted that people used to think that if you touched someone with AIDS you could get AIDS. Another (55 – 65 years) felt it was important to stop 'any silly non sense' or myths that may come about around how you pick up HPV. However, one woman liked the use of the term skin to skin intimate contact because it was ambiguous, which she felt was good for people who identify as fluid sexuality or non-binary.

In one discussion group, the participants discussed whether men were 'carriers' of HPV. Another participant wondered whether there could be a sense of blame on your partner, even though it is not their fault.

'This means you have to be very careful when you choose your partner.'
(25 – 34 years, always attends screening, SIMD decile 10)

A few wondered if personal hygiene was a factor, and whether it could be contracted from using toilets.

4.2.7 HPV can stay in the body un-noticed for a very long time – up to 20 years
Views on this information were mixed. Some participants felt that this information was useful to know, but that it didn't really change how they felt about the test. A few mentioned that it was important to ensure women were aware of this, as they may not believe they are at risk – for example if they are in a long-term relationship. A few wanted to know more information – like how is it known that HPV stays in the body for up to 20 years, and what would happen if HPV was picked up through the smear test? One participant felt that it was reassuring to know that you could have HPV but it might not be harmful.

However, some found the information concerning or frightening. The main concern was that HPV could bring about changes that develop into cervical cancer. However, a few women expressed a general unease about the idea of a virus lingering in the body for a long time. A few were worried that they wouldn't know they had HPV, as there were no signs. One participant was worried that there would be stigma attached to HPV, and another was worried they could pass it on to someone they loved.

'If it's in you, it has the potential to become cancerous.' (35 – 44 years, sometimes attends screening, SIMD decile 1)

'It's like a secret or silent cancer.' (45 – 54 years, always attends screening, SIMD decile 1)

'It makes me feel dirty.' (25 – 35 years, sometimes attends screening, SIMD decile 7)

A few participants found this information confusing. These participants found it hard to understand this information alongside the information that most people could get rid of HPV like the common cold.

'This makes me confused and anxious that you can't get rid of HPV.' (25 – 34 years, always attends screening, SIMD decile 4)

A few compared it to other viruses or illnesses that can stay in your body that don't affect you, but were worried that HPV could have more serious consequences.

'I mean it disnae surprise me. Lots of viruses do that already. But I wouldn't have connected that to the end point of cancer.' (45 – 54 years, always attends screening, SIMD decile 10)

'It's interesting that it can kill you or lie dormant.' (45-54 years, never attends screening, SIMD decile 3)

A few women wondered if there were comparable viruses. For example, one wondered if it was a bit like shingles – but it could lead to something bigger. One participant mentioned that in this way, HPV is not like the common cold.

In terms of impacting on cervical screening attendance, a few participants who never or sometimes attended screening said that this information would make them more likely to view the test as important, and/ or attend the test.

'Yeah, that would make me want to go.' (25 – 34 years, never attends screening, SIMD decile 3)

'Yes, so I guess if it's not got any symptoms and you have got it, it's important to get checked.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

One participant who never attended cervical screening had significant concerns and anxieties about the test. This participant had previously said nothing would change their perception of the test, but when considering this information did feel that it might slightly change their views on the smear test.

'That's pretty horrifying... That might change... a little bit.' (25 – 34 years, never attended, SIMD decile 9)

A few who always attended their smear test said that this information emphasised the importance of the test.

'If you go for your screening it'll be fine.' (25 – 34 years, always attends screening, SIMD decile unknown)

'This makes me a little bit concerned, but I go for my smear test regularly so it should get picked up.' (35 – 44 years, always attends screening, SIMD decile 5)

4.2.8 If high risk HPV is treated it is unlikely to lead to cervical cancer
Most participants found this information reassuring.

‘It makes you have a wee bit of hope. If you get it you get it, but it is treatable.’ (45 – 54 years, always attends screening, SIMD decile 1)

Most felt that this was an important message, which would help to encourage attendance at smear testing.

Two participants who sometimes or never attend their smear test said they would be more likely to attend, knowing this.

‘That’s really good. I’d be more likely to go for testing and keep getting checked.’ (35 – 44 years, sometimes attends screening, SIMD decile 6)

‘Yeah, that would make me willing to go.’ (25 – 34 years, never attends screening, SIMD decile 3)

Some women said that they would use this information to encourage others – such as their daughters or sisters – to attend the test.

‘If you know all these facts, you would definitely go. There’d be no messing about.’ (25 – 34 years, always attends screening, SIMD decile unknown)

A few felt it helped back up rationale for the test.

‘This is really good. It backs up the reason for this type of testing.’ (25 – 35 years, always attends screening, SIMD decile 7)

However, some women found this information contradictory or confusing, as earlier information provided as part of the research made clear there was no treatment for HPV. One wanted more information to fully understand the changes taking place.

‘I’m not sure because I’m not yet convinced... I’m still not seeing that pathway. I’ve grown up with having a full smear test to detect the changes.’ (55 – 65 years, always attends screening, SIMD decile 10)

4.2.9 Because the test is better, women who don’t have HPV will be invited for tests every five years. This is a change for women under 50 who used to be invited every three years.

Most participants felt worried and concerned about this change, feeling that five years was a long time between tests. In particular, some were worried that they could catch HPV and that this would develop into cervical cancer in the gap between tests. A few were also worried about the impact of this timescale on the small proportion of cervical cancer cases not caused by HPV.

‘I would worry that you would develop it within the five years and you wouldn’t know, and then you’d be waiting a few years before your next test.’ (35 – 44 years, always attends screening, SIMD decile 1)

Some just felt that five years seemed too long, without giving a specific reason why. A few also felt that three years was quite a long time and wanted tests to be even more frequent.

'Honestly, I would prefer every three years. Five years seems quite a long time. Personally, I would rather go more often.' (45 – 54 years, always attends screening, SIMD decile 1)

'How do they know if the new test will be more effective? I think they should still do three year testing for women under 50 and then review this, rather than jumping to five year testing.' (45 – 54 years, never attends screening, SIMD decile 5)

Some participants felt that women with more sexual partners may be at more risk of HPV, and may need tested more often. A few wondered if younger women were more at risk, believing they may have more sexual partners. One participant wanted to know if you could request a screen more frequently if you believe you are high risk because of levels of sexual activity. Another wondered if family history should be taken into account.

'Because HPV is something that can be picked up at any time, I think that this is quite a negative thing. It's too long... Especially for younger women who may have more sexual partners... Maybe it should be based on your lifestyle?' (25 – 35 years, always attends screening, SIMD decile 7)

A few participants said they felt suspicious about the reasons for this change, and wondered if it was to save money. One participant highlighted that the three year test also gave women the chance to talk about sexual health, and would be a shame to lose this opportunity.

Some participants welcomed the change, and a few could see both positive and negative impacts. The participants who welcomed the change indicated that they felt comfortable with this approach, felt it made sense and a few felt it may encourage more women to attend if the test is less frequent. None of these participants were in the most deprived areas.

'I'm over 50 and I wish it had come in before. If the test is more accurate it seems fine. I always find that it is not that pleasant an experience.' (45 – 54 years, always attends screening, SIMD decile 10)

'This is good news. It seems reasonable, but I'd still have some concern about the 1% of cases not caused by HPV.' (35 – 44 years, always attends screening, SIMD decile 5)

'I think that's a fair enough approach, if somebody is considered low risk then there's no point repeating it so often.' (35 – 44 years, always attends screening, SIMD decile 10)

'Eh well in one sense it makes me feel better if I don't have to get a smear test so often. But on the other, it's an extra two years and the risk

increases, that's a bit of a concern.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

A few women in older age groups were less concerned about the change, indicating that it was not a change for them. However, a few wondered if younger women would worry about it.

Finally, a few felt they would need more information and evidence to understand this change before giving a view. For example, participants felt they needed to understand how long after contracting HPV it would take to cause abnormal cells, and then to develop into cancer.

4.2.10 Australia is on track to eradicate cervical cancer because of a similar approach (HPV testing, similar age range and test periods)

In early discussion groups, researchers let women know that Australia had taken a similar approach in terms of HPV testing, with a similar age range and test intervals – and there was a hope of eradicating cervical cancer in Australia over the next 20 years. This was not a formal question within the discussion guide, but researchers found this information was very helpful in helping people to reflect on the five year testing period.

It was agreed that this information would be introduced to a small number of discussion groups and interviews – where appropriate - and the responses to this information analysed.

Where this information was introduced, participants were very positive about it. A few had heard that Australia hoped to eradicate cervical cancer, while the information was new to most. Participants were very hopeful about this message, and hoped that Scotland was learning from Australia. A few participants felt that this helped to convey the message that the changes are being made because the test is better.

'Wow, my goodness... If that's true, fabulous, it's definitely good that you can stop things and prevent cancer.' (45 – 54 years, always attends screening, SIMD decile 1)

'This makes me feel a wee bit better, if you knew you were going to get rid of it.' (25 – 34 years, always attends screening, SIMD decile 4)

4.3 Feelings about having HPV

Having heard these messages and discussed them with other participants and/ or the researcher, participants were then asked again how they would feel now about the result of a cervical screening (smear) test telling them they have HPV.

Most participants indicated that they would feel slightly less worried, nervous and anxious than they did before the discussion. This was because they felt more informed, confident and aware of what HPV was.

'I would be thinking, ok, it could be nothing, it could be low risk or high risk. I'd feel better informed.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

'Now I'd know what it is and I wouldn't worry about it.' (45 – 54 years, always attends screening, SIMD decile 5)

Some said that they understood HPV was common, so they wouldn't feel too worried. A few said they felt more equipped to get knowledge about HPV, and would feel more confident to discuss HPV with their GP. A few said they would be less likely to panic than before the discussion.

'The information is now clearer. I feel more confident to discuss things with my GP.' (45 – 54 years, always attends screening, SIMD decile 10)

'I wouldn't be as scared. I wouldn't be worried.' (25 – 34 years, always attends screening, SIMD decile 1)

'I think I would feel slightly better. But in the same breath I would be worried.' (25 – 34 years, always attends screening, SIMD decile 4)

However, most participants said they would still feel worried, and would feel a bit confused over what happened next. Most wanted more information on what having HPV would mean for them, and what the next steps would be – for example repeating the test, having more frequent screening.

'I don't think I'd be worried. I would want to know what the next steps are in terms of follow up and monitoring. Is there a distinction between something benign and passive, or that can lead to something more serious?' (55 – 65 years, always attends screening, SIMD decile 10)

'It would make me really inquisitive about what would be done. I'd still be nervous, but not panicked.' (55 – 65 years, always attends screening, SIMD decile 9)

'I would worry. I would want to find out about treatment and what could be done so that it doesn't develop into cancer.' (35 – 44 years, always attends screening, SIMD decile 1)

A few said they would want to know whether they had high risk HPV. One participant would want to know if anything was prohibited if you have HPV (such as sex or kissing) and what the re-transmission rate is.

5. Impact on the cervical screening programme

5.1 About this chapter

This chapter explores women's views on how the introduction of HPV testing may influence how they felt about cervical screening.

5.2 Overall impact on attendance

Participants were asked whether the planned changes would affect how likely they were to attend the cervical screening test.

Participants who always attended their cervical screening test said that the planned changes would not impact their attendance. However some of these women said that the new approach would give them further motivation to attend, and they may prioritise making their appointment. A few felt that they would be more likely to encourage others to attend their smear test, and a few felt that the planned changes may encourage other women to go.

'... it may encourage more women to go, if it is less frequent and more accurate.' (45 – 54 years, always attends screening, SIMD decile 10)

'It reinforces my thoughts on it and makes me sure that I would encourage my child to go when she comes of age, and I would recommend it to other women as well.' (35 – 44 years, always attends screening, SIMD decile 10)

A few participants who never or sometimes attended their screening appointments said that they would now be more likely to attend.

'Yes, I'd be more likely to go. Now I know more about it, the specifics and stuff. It could identify you maybe have the HPV virus, which could then be treated.' (25 – 34 years, never attends screening, SIMD decile 3)

'It makes it very important to go.' (35 – 44 years, sometimes attends screening, SIMD decile 1)

'I haven't been for a smear test. My husband said I should go, but I didn't. I now know that I should go and I will go.' (25 – 34 years, never attends screening, SIMD decile 2)

However, a few women in the one discussion group all said they would be less likely to attend as the focus of the test was screening for HPV, which they saw as being an STI which had negative connotations for them. These women suggested it may put other women off too.

'Now that the test is screening for an STI, I would be less inclined to go as I've only had one partner.' (35 – 44 years, always attends screening, SIMD decile 8)

Three participants who never attended their smear test appointments for very specific reasons said that the changes would not influence their views.

5.3 Perceived benefits of HPV testing

Most participants could see some benefits to HPV testing.

Some felt more positive as the test would be better at identifying women who are most at risk of developing cervical cancer and focused on identifying the root cause of cervical cancer. Participants felt that this was positive as the cause of cervical cancer could be identified earlier, and tracked, helping to catch pre-cancerous cells at an early stage.

Some felt less worried about attending cervical screening because they felt more informed about the process after the discussion, making it seem less daunting. Some felt less worried about attending cervical screening because they knew there was treatment available.

Some participants felt it was positive generally that health research was being undertaken which then improves practice – and may continue to improve practice in the future. Some participants felt particularly positive about the message from Australia that it may be possible to beat cervical cancer and reduce the number of cases in Scotland.

‘Yeah... The research that’s gone into it. It is really positive to start to reduce the number of people who actually have cervical cancer.’ (45 – 54 years, always attends screening, SIMD decile 10)

‘It’s good to know that there are developments like this in medical research.’ (35 – 44 years, always attends screening, SIMD decile 2)

One participant who never attended cervical screening felt slightly more positive because they felt that it showed research was ongoing, and it may be possible to develop a different way of taking the sample in the future.

‘Because if they are looking at ways to test samples, maybe overall they will look at changing the actual method.’ (25 – 34 years, never attends screening, SIMD decile 9)

One felt more positive because she felt the information justified her decision not to attend screening.

‘Yes, because I know that I have made the right decision, and I don’t need to go for screening because I’m not sexually active.’ (45 – 54 years, never attends screening, SIMD decile 5)

Some participants did not identify any potential benefits. Some felt that they were already positive about cervical screening, and the proposed changes did not affect this. A few were more focused on their concerns about the change, as explored below, and did not identify any positives.

5.4 Perceived barriers to HPV testing

Participants were asked whether there was anything about the changes that made them feel less positive about cervical screening and why.

Some indicated that they had no concerns and that the planned changes sounded positive.

Some had concerns. The main concern was the introduction of five yearly testing for under 50s. Participants felt that this was a long time, and were concerned that it would be possible to contract HPV and develop cervical cancer within this time period. A few felt that it was a particularly long time period if women had different partners over this time.

Some participants felt that the planned changes may appear to be cost saving measures. They felt it was important to communicate very clearly that the change is being made because this is a better test.

A few were concerned about how the small proportion of cervical cancer which is not caused by HPV would be identified.

A few were worried that they may feel negatively knowing that they have HPV and it could lead to something more serious.

Two women said they may not now go for screening as they didn't think they were high risk as they had been with the same partner for over 20 years¹³.

A few women felt that the actual process of taking the sample is probably what puts people off the most, and that if there was an easier way to obtain the sample it would encourage uptake.

¹³ The researcher facilitating this discussion group made clear that it was still important that everyone attended cervical screening tests.

6. Improving information provision

6.1 About this chapter

This chapter explores women's views on the language used to describe HPV testing. Women were asked for their views on the use of a series of phrases and sentences; whether they understood them; and how they made them feel. These were:

- HPV positive/ negative
- High-risk HPV
- Your smear test sample was tested for HPV
- No high-risk HPV was found so no further testing is needed
- HPV was found
- Your recent smear test shows that further investigation is required
- Treatment at this stage can prevent the development of cervical cancer.

6.2 Views on language

6.2.1 HPV positive/negative

Some women felt that these terms were clear, understandable and fine to use. In one discussion group, a few participants felt that it was quite blunt, but they felt it was best to be clear.

'It's quite simple, isn't it? You either have it, or you don't.' (35 – 44 years, always attends screening, SIMD decile 1)

A few women said they liked it better than the current language which includes the term 'abnormalities'. One participant liked the terms because she felt they would be easy to search for on the internet as they were simple. One participant said that having had the discussion in the group, she felt fine about the terms as she had some background information and knowledge.

Participants who were comfortable with these terms often stressed that there would need to be information about HPV in the results letter, to help people understand the terms and what they meant for them. However, a few participants said that they wouldn't like to hear they had HPV through a letter and would prefer to hear this from their GP.

However, some women did not like these terms.

The main concern was that HPV sounded very like HIV. Some felt that this would cause confusion. Some women were worried that this made the terms sound very scary. One participant felt it also sounded similar to hepatitis results, which may cause confusion.

'HPV... I just want to put an 'i' in there. I get a pure feeling of (*gasp!*). It isn't really widely used... Initially it would give me a fright.' (45 – 54 years, always attends screening, SIMD decile 1)

'HIV is the first thing that comes to mind. It doesn't have the same magnitude as HIV – so it's important to use more calming words.' (55 – 65 years, never attends screening, SIMD decile 3)

'I've got no feelings really about them. But some might associate them with HIV positive and negative.' (25 – 35 years, always attends screening, SIMD decile 7)

Some women were concerned that there may be stigma, as the term was so close to HIV. A few worried there may be a judgemental feeling about being HPV positive – that you have somehow been negligent about your health.

In one discussion group, the participants suggested using the term human papilloma virus in full to avoid any stigma or confusion.

A few women expressed other concerns:

- Two women didn't like the use of the word negative, as they felt this sounded like it was a bad result.
- Two women wanted more information about the intensity or type of HPV and the level of risk
- A few women just said they felt the terms weren't very clear.

'If I see 'negative', I think it is a bad thing.' (25 – 34 years, always attends screening, SIMD decile 10)

In the first interview, when the guide was being piloted, the phrases HPV positive/ negative/ infection were tested. The participant said that they did not fully understand, and was unsure what was more worrying – being HPV positive or having an HPV infection. After this, the discussion guide was amended to only explore responses to HPV positive/ negative.

6.2.2 High-risk HPV

Most participants indicated that they found this term scary, alarming or confusing. Most simply said that they found the term scary and they would feel worried. A few said it sounded dangerous. A few said that they would automatically assume they had cancer if they were told they had high-risk HPV.

'You might think - it's high risk, I've got cancer.' (25 – 34 years, never attends screening, SIMD decile 1)

'It's alarming – it's too harsh. I would panic.' (35 – 44 years, always attends screening, SIMD decile 1)

Some said that they didn't really understand what the term meant. A few women were not sure if it meant that they were at high risk of developing cervical cancer, or if the virus was a high risk strain of HPV.

'Eh... I don't know. It makes me less uncomfortable than HPV positive and negative. But it would make me think what does that mean high risk

or low risk? Am I the high risk, is the virus high risk?' (35 – 44 years, sometimes attends screening, SIMD decile 6)

'I don't know what would be high or low risk.' (25 – 34 years, always attends screening, SIMD decile 7)

Some women felt better about the term when they heard it used in context, or when the term was explained in more detail by the researcher (in basic terms - as the type of HPV that may cause cervical cancer, as opposed to a type that might cause warts). This explanation was given with the clear caution that the researchers are not medical professionals. However, some still felt very scared and concerned by the term, and appeared confused by some of the messages given in the discussion.

'It sounds like a death sentence, if there is no treatment for HPV.' (35 – 44 years, always attends screening, SIMD decile 8)

Some women said that they would want to know what the treatment pathway was, and be reassured that they would receive regular checks on their health.

'High-risk for what? This needs more explanation and the next steps need to be clearly set out in the letter.' (25 – 34 years, always attends screening, SIMD decile 10)

'I'd want confirmation that I would be getting checked routinely and frequently.' (55 – 65 years, never attends screening, SIMD decile 6)

In contrast, some women felt that the term was clear. A few felt that it was clearer and more accurate than the use of the terms HPV positive and negative. Those who felt the term was clear stated that it was important to understand the term in context, and to have information on the level of risk, how likely it was to develop into cervical cancer and what the follow up or treatment plan would be. A few made suggestions to make the phrase clearer – perhaps describing it as a high-risk strain of HPV, or the type of HPV that can lead to cervical cancer. Participants from SIMD deciles 9 and 10 were more positive about the use of this term than those in other SIMD deciles.

'It is clearer and more accurate than being told you are HPV positive.' (55 – 65 years, always attends screening, SIMD decile 9)

'My understanding is that this means I am more prone to getting it, that I have a higher risk of cancer.' (35 – 44 years, always attends screening, SIMD decile 10)

'For me, it that's what it is, it is good to say that. Say what you mean.' (45 – 54 years, always attends screening, SIMD decile 10)

A few women highlighted that they would definitely want to know if they had high-risk HPV. For example, one woman said she was already high-risk for breast cancer, and would want to know if she had high risk HPV.

'As shocking as it is, I would like to know.' (55 – 65 years, sometimes attends screening, SIMD decile 1)

6.2.3 Your smear test sample was tested for HPV

Almost all participants felt that this sentence was clear, simple and made sense to them. Most participants said that the statement made sense to them now, having had a discussion about HPV, but that before the discussion they may not have understood it. Most said that this sentence would only work if it sat alongside information about HPV – explaining what HPV was and why the sample was tested for HPV. A few also said it was important to give women information about HPV in advance of the results letter – so that they understood what would happen at the test and why the sample would be tested for HPV.

'It's all about education, people need to know about HPV.' (55 – 65 years, always attends screening, SIMD decile 1)

At this stage, a few participants said that they would prefer that the full term human papilloma virus was used. One participant said she would prefer the full term because she generally doesn't like the use of abbreviations, and a few said the full term should be used to reduce confusion or association with HIV.

One participant who never attends her cervical screening test said that she didn't understand this sentence and would need more information.

6.2.4 No high-risk HPV was found so no further testing is needed

Most participants felt that this was a reassuring, positive and clear sentence that they would be happy to see in their letter. A few said that while it was clear, they would welcome more information on why no further testing needed, and some information and reassurance around the five year wait for their next test.

However, some participants wondered if this sentence might make people think that they didn't need to go for screening any more. A few suggested adding 'on this occasion' or 'for five years' or 'until your next smear is due' so that people knew they need to go back for their next regular test.

'It implies that there is no need to go for your smear test.' (35 – 44 years, always attends screening, SIMD decile 6)

'It sounds like you don't have to come back again.' (25 – 34 years, sometimes attends screening, SIMD decile 7)

A few women were unsure about the use of the term 'high-risk HPV' in this sentence. A few wondered if they would be told if any form of HPV was found. And a few wondered whether they could still develop cervical cancer from low risk HPV.

'I don't know. Does it need to be high-risk HPV? Does that mean you could have HPV? Could you just say no HPV was found?' (45 – 54 years, always attends screening, SIMD decile 1)

'Ok. That would make me think there is low risk HPV. What is the impact of that? Am I not being told something?' (35 – 44 years, sometimes attends screening, SIMD decile 6)

'If I have low risk HPV, do I still have a chance of getting cervical cancer?' (25 – 34 years, always attends screening, SIMD decile 10)

In one discussion group, a few participants were worried about the potential of developing cervical cancer which is not linked to HPV and how this would be picked up.

One individual was concerned about wider women's health and felt that the focus of the smear test should not only be on cervical cancer, but a wider gynaecological check. This opinion was influenced by her personal experiences.

'The smear test might say that your cervix is fine, but the areas round about that might not be and won't get picked up at the smear test.' (35 – 44 years, always attends screening, SIMD decile 4)

One participant felt that starting the sentence with no was confusing and it might be better to say something like 'The test shows that there was no sign of HPV'.

6.2.5 HPV was found

Some participants felt that this was a clear statement, which they would be happy to receive. However, these participants also said that they would be concerned about what would happen next, and that there needed to be information about what to do, what the next steps would be and where to access support. One participant felt that this was particularly important for women with mental health issues.

'There is a need for emotional support for people who suffer from anxiety and depression to back up the facts.' (25 – 34 years, sometimes attends screening, SIMD decile 7)

'I would be slightly concerned, but only mildly. It's quite common. I wouldn't be too worried.' (35 – 44 years, always attends screening, SIMD decile 7)

A few participants felt that the statement was too ambiguous and vague. A few felt that there should be more information on the type of HPV (whether high or low risk) with an explanation of what this meant for them.

A few participants simply said that this would make them feel scared.

'It would fill me with dread. I would be absolutely horrified.' (45 – 54 years, always attends screening, SIMD decile 1)

One participant said that they did not feel they should be getting this information in a letter, and that they would prefer to hear it over the phone.

'I wouldn't say that was appropriate in a letter, it would be better to phone someone.' (35 – 44 years, always attends screening, SIMD decile 1)

6.2.6 Your recent smear test shows that further investigation is required

Most participants felt that this sentence was clear and easy to understand. However, most also wanted the letter to say what they have found from the test, why further testing is needed, what to do next, timescales for further investigation, and who to speak to about this.

'That would make me think there is some abnormality, something is inconclusive, something is not quite right.' (25 – 34 years, never attends screening, SIMD decile 9)

A few stressed the importance of something happening quickly. One participant wanted the letter to include a date for a follow up appointment. A few said they would prefer if the results went to their GP, who could call them to talk about the results and next steps.

'I would want to speak to a human.' (35 – 44 years, always attends screening, SIMD decile 2)

'It would put me in a state of anxiety. I'd want it done yesterday.' (45 – 54 years, always attends screening, SIMD decile 1)

Some participants said this sentence reminded them of the phrasing of the current letter and that women would be familiar with this kind of message.

Some women said that they would panic if they heard this news and that they would find it very worrying.

6.2.7 Treatment at this stage can prevent the development of cervical cancer

Most participants felt that this sentence was clear. Participants described feeling reassured, hopeful and happier as a result of this information.

'Oh, so that's a bit reassuring that at the moment you don't have cancer.' (35 – 44 years, sometimes attends screening, SIMD decile 6)

A few participants stressed that this was a really important message to get out to women, to encourage them to take action.

'I think that's quite an important statement to make. I suppose that's the point.' (25 – 34 years, never attends screening, SIMD decile 9)

'It would get me into action so I get the treatment... because the 'C' word has come in.' (35 – 44 years, always attends screening, SIMD decile 10)

Most women would also want to know what the treatment was. However, a few indicated that they were confused as earlier in the discussion group the researchers had made clear that HPV could not be treated. A few felt that there needed to be

more clarity on whether it was the HPV being treated, or the abnormalities resulting from HPV.

A few participants indicated again that they would feel better talking to a GP about this rather than seeing it in a letter. A few also raised wider concerns about having to wait for treatment, and how anxious and worried that could make them

6.3 Accessing information

Participants were asked where they would go to find out information about cervical screening. In order of frequency, the places that were mentioned were:

- the internet - some said they would use the NHS website, and some said they would search for terms online
- their GP practice – some said they would speak to their GP and a few said they would speak to a nurse at their GP practice
- another health information centre or sexual health clinic - with the Sandyford specifically mentioned by a few participants
- the letter they receive about cervical screening
- friends or word of mouth.

While many women would use the internet, a few mentioned that you had to be careful which sites you used otherwise you could get misinformation. A few said they would only use NHS websites. One participant said she would not go online at all for information about cervical screening for this reason.

‘I wouldn’t go online, you can get scared if you get the wrong information.’
(45 – 54 years, never attends screening, SIMD decile 5)

A few women said that if they were going to speak to someone at their GP practice, they would do this at their smear test appointment.

A few minority ethnic women indicated that they could sometimes find it hard to access interpretation support when visiting their GP. One minority ethnic woman felt that information was not always accessible in a range of languages and felt that awareness raising through visiting communities would be useful to get important messages across.

One blind participant indicated that receiving information digitally would help, as she could access information more easily on her computer compared to a printed letter. However, she cautioned that everyone had different needs, and stressed the importance of accessible information in a range of formats. One deaf participant highlighted that it was important to ensure that deaf people were able to access the same information as everyone else.

One participant who had been through gender reassignment would go to specialist services such as the Chalmers Centre to access information, as the service they provide is LGBT friendly. A few participants in one discussion group said that it was not easy to access sexual health clinics in their local area because they had closed.

A few participants indicated that they didn’t always read the letters that came through the post.

'I normally just get whatever comes through the door, but I don't always read it.' (35 – 44 years, always attends screening, SIMD decile 1)

A few women said that most of the information they received about cervical screening was through friends and family. One said her mum was her main source of information for this. A few said they didn't think there was much information available about cervical screening.

'Everything I knew was from word of mouth.' (25 – 34 years, always attends screening, SIMD decile 1)

'I personally don't feel there is a lot of information about smear tests just now. It is important, but it kind of puts me off going because I don't know.' (25 – 34 years, never attends screening, SIMD decile 3)

6.4 Information requirements

Participants were asked what other information they would want to know about the introduction of HPV testing, who from and when.

A few didn't need any more information at the moment – but said they would need more information if they found out they had HPV and would wish to have a discussion with their GP at this stage. A few said that because the procedure for collecting the sample wasn't changing, they didn't really need much more information.

'No, I don't think so. As long as you are getting the information you need through health professionals, when your appointment is due.' (45 – 54 years, always attends screening, SIMD decile 1)

Some participants gave suggestions about how they would want to hear information, and who this should come from. Suggestions included:

- a clear information leaflet - available alongside the next invitation to a smear test, and also through organisations women know and trust
- at smear test appointments – so that information can come from a trusted source or someone you have a relationship with
- a national awareness raising campaign – to reduce stigma and worry around HPV, using social media, TV and other media
- targeted visits to explain the changes – for example at schools, or through visits to organisations working with minority ethnic women and disabled women
- information on HPV and cervical screening included along with sanitary products.

'I would like to see the information everywhere.' (25 – 34 years, always attends screening, SIMD decile 1)

While some women felt that information should be available in GP practices, a few said they didn't think that posters and leaflets in GP practices had an impact. A few women mentioned that they didn't really read the letters they received about cervical screening and would need information to be provided in another way as well. A few

mentioned it was important that it was easy to find information about HPV and cervical screening on the internet.

'A letter can put you uneasy, because of the big words they are using.' (45 – 54 years, always attends screening, SIMD decile 1)

Most participants said that this information should be available before the change takes place, and then for each woman in advance of their smear test appointment and at smear test appointments. A few said it was important to provide messages as often as possible, so they stick in your head.

'I don't want to wait – I want information now.' (25 – 34 years, always attends screening, SIMD decile 7)

Some women stressed that the information provided needed to be clear, simple and factual. One participant said that it would be important to avoid information overload.

'You have to explain HPV in the simplest possible terms.' (35 – 44 years, always attends screening, SIMD decile 10)

The types of information that participants suggested should be conveyed about HPV testing included:

- HPV is common
- you can recover from HPV
- HPV is the main cause of cervical cancer
- having HPV does not mean that you have cervical cancer
- the rationale and reason for testing for HPV
- how the immune system fights HPV
- when the change in testing is being introduced
- whether the approach will be piloted
- whether women who have had the HPV vaccine have the same test
- rates of HPV in young women who have had the HPV vaccine
- whether and how the introduction of HPV testing is linked to changes in the age range for cervical screening.

'I think people need to know just that everyone carries it. They need the full background on that it's there and they can have it, and recover from it.' (45 – 54 years, always attends screening, SIMD decile 10)

'Because the test is new, there needs to be more information about it. The research should be made public, and there should be a national campaign to raise awareness of HPV and the link with cervical cancer.' (55 – 65 years, always attends screening, SIMD decile 7)

'Lots of women like me really appreciate being spoken to like an adult. Is it budgetary, is there a key driver clinically?' (55 – 65 years, always attends screening, SIMD decile 10)

Some participants also felt wider messages should be conveyed around cervical screening and cervical cancer including:

- cervical screening can prevent cervical cancer
- how to spot cervical cancer.

'It would be good to know how to look out for any changes, would you see any changes if you had cervical cancer?' (25 – 34 years, always attends screening, SIMD decile 4)

6.5 Critical messages

At the end of the discussion, participants were asked what they thought was the most important message for women to hear about these changes. There were different views on the main messages that women needed to hear.

Some women felt it was important to focus on the main message that the ultimate aim of cervical screening is preventing or reducing cervical cancer. These women felt it was important to raise awareness of cervical screening, be clear cervical cancer is preventable and make clear it is very important to attend your appointment.

'That there is still a commitment to prevent or reduce cases of cervical cancer. A virus is a key factor, and it is fine to be aware of it – but the aim is ultimately avoiding cervical cancer.' (55 – 65 years, always attends screening, SIMD decile 10)

'It could save your life.' (45 – 54 years, always attends screening, SIMD decile 2)

A few felt that the message that it may be possible to eradicate cervical cancer was an important one to convey. And a few felt that it was important that women knew that this was a better test.

'That it's a development, not a step back.' (35 – 44 years, always attends screening, SIMD decile 7)

Some women said that there should be limited focus on the changing test, as it did not impact on women's experience of the sample being taken. This included women in the most and least deprived areas of Scotland, and across different age groups and characteristics.

Conversely, some felt that it was very important to raise awareness of HPV, and reiterated messages previously mentioned including:

- HPV is very common
- HPV causes almost all cervical cancer
- HPV can be treated.

A few felt that it was important to make clear that HPV was not 'dirty'.

'It's common – it's not dirty.' (35 – 44 years, rarely attends screening, SIMD decile 2)

'HPV is not a dirty word, sex is not dirty.' (35 – 44 years, always attends screening, SIMD decile 6)

However, a few were concerned about too much focus on HPV due to potential stigma because of it being transmitted through intimate contact.

A few felt it was very important to make sure younger women knew that if they had their HPV vaccine, they still needed to attend screening. And one participant felt it was important that women knew to approach their GP if they saw signs of cervical cancer between cervical screening tests.

'Obviously a big thing for people would be, you know, the every five years. But don't wait those five years if you spot any signs.' (25 – 34 years, always attends screening, SIMD decile 4)

Finally, some women said there should be more support to help women to go for screening. This included women living in a disadvantaged area, disabled women and minority ethnic women.

'My first smear test was very embarrassing. I didn't know what I was supposed to do. It would be good to have a diagram to look at when you go for the test, especially if you do not understand English.' (25 – 34 years, always attends screenings, SIMD decile 4)

A few disabled women said it was particularly important to support women with physical disabilities to attend their test, as this could be a challenge. One suggested there should be an option to have the test at home.

7. Discussion

7.1 About this chapter

This chapter discusses the findings, and develops the ideas emerging from the research.

7.2 Understanding of cervical screening

Existing research shows that many women in Scotland do not have a good awareness or understanding of the importance of cervical screening, and a high proportion were not aware of what the cervical screening test was for¹⁴.

This research supports the finding that many women do not understand the purpose of cervical screening. There is more work to be done to make sure that women understand the core purpose of cervical screening, as preventing cervical cancer.

7.3 Understanding of HPV

This research highlighted that many women had not heard of HPV or heard of it only vaguely. It also highlighted high levels of worry and confusion about HPV.

The HPV vaccine appears to have played a role in raising awareness of HPV. Young women aged 25 to 35 – who could have fallen into the HPV catch up programme or had friends and sisters in the programme - were more likely than other age groups to have heard of HPV. It is likely that as the HPV vaccination programme continues, awareness of HPV will continue to increase.

However, even those women who had heard of HPV were not always aware of the link with cervical cancer. This research supports other research which shows that awareness of the link between HPV and cervical cancer is relatively low¹⁵.

NHS Scotland has been working for some time to raise awareness of the importance of cervical screening. With so much confusion and worry about HPV, it is important to ensure that any awareness raising around HPV does not detract from the core message that cervical screening is about preventing cervical cancer.

7.4 Messages about HPV and cervical cancer

The research tested women's reactions to a series of messages about HPV.

7.4.1 Positive messages

The most positively received messages were:

- **Research shows the HPV test is a better way of identifying those at risk**
 - Women felt this was a positive message and were pleased that research was being done on women's health and the root causes of cancer. When reflecting at the end of the discussion, three of the four main benefits that women highlighted relating to the new test related to research. These three research related benefits were that:
 - it was better at identifying women at risk

¹⁴ <https://www.jostrust.org.uk/node/1074526>

¹⁵ <https://www.jostrust.org.uk/node/1074526>

- the root cause of cervical cancer would be identified at an earlier stage
- research was being done in this field

This is clearly an important message to convey to women.

- **Australia is on track to eradicate cervical cancer because of a similar approach** – Although this concept was introduced briefly in discussion groups, initial reactions from participants were very positive. This was identified by women as one of the main benefits of the new way of testing. There is scope to introduce a message along the lines of:
 - We want to eliminate cervical cancer in Scotland.
 - It is one of the most preventable cancers.
 - To do this, we are: vaccinating all young girls and boys to protect against cervical cancer; moving to a new, better way of testing smear test samples; and making sure all women know about how to identify signs of cervical cancer at an early stage.
- **If high risk HPV is treated it is unlikely to lead to cervical cancer** – This was a reassuring message which could impact positively on screening attendance. However, a few participants found it confusing. It is worth reviewing this statement to make sure it is accurate, as HPV cannot be treated. A range of related messages may be more useful and accurate, such as:
 - High risk HPV rarely leads to cervical cancer.
 - Cervical cancer usually develops slowly – over 10 to 20 years.
 - If HPV develops, this causes cell changes – which would be picked up in your smear test.
 - Cell changes can normally be treated.
- **HPV causes 99% of cases of cervical cancer** – Women felt that this was a positive message and felt that this would mean the test could catch cervical cancer at an earlier stage. Women felt it emphasised the importance of the test and may make people more likely to attend. However, women were concerned about the other 1% of cases and how they would be picked up. It will be important to reflect on whether:
 - it is possible to provide clear information on what causes the remaining 1% of cases – so that women can understand their level of risk
 - it can be made clear that (like the existing test) the new test won't pick up absolutely all cases of cervical cancer – so that women understand that there is still a very small chance that they could have cervical cancer if they don't have HPV, and can be alert to signs of cervical cancer.

7.4.2 Messages important for certain groups

- **HPV is spread through skin to skin, intimate contact** – This was a particularly important message for lesbian women, confirming the importance of them taking part in the cervical screening programme. Generally, a few women thought that men were carriers of HPV. This message did not influence many women but building understanding of HPV and how it is

spread may help some lesbian women to understand their risk of cervical cancer.

7.4.3 Mixed views

Women's views were mixed on two messages:

- **Nearly everyone gets HPV at one point in time** – Some women found this shocking, scary and worrying. Levels of awareness of HPV were relatively low, and people generally did not find this information influenced their views on cervical screening. Later in the discussion, participants indicated that it was important to give the message that 'HPV is common', which may be a more useful way to provide this information.
- **Most of us can get rid of HPV like a common cold** – While some women felt this was reassuring, some felt it didn't really reflect how serious it could be. Women would welcome information on what they can do to help HPV to clear from the body.

Women felt that the statement that they cannot prevent HPV had no real impact on their views on cervical screening – although some wanted to know if there was anything they should be doing to reduce the risk.

Overall, women would welcome the message that HPV is common along with information about what, if anything, they can do to reduce their risk of HPV and their likelihood of clearing it from the body effectively.

7.4.4 Potential negative impact

- **HPV can stay in the body un-noticed for a long time – up to 20 years –** Mostly, this message did not impact on women's views on cervical screening. However, it is very important to consider if and how this message is conveyed. This message was a key factor in three women out of the 100 involved in the research saying they would be less likely to attend the screening test as a result of the changes. This message may have an impact on women with long term partners, of more than 20 years, who may believe their risk had reduced and they no longer needed to attend the test.
- **Because the test is better, women who don't have HPV will be invited for a test every 5 years** – Many were very concerned about this change – although they did not feel it would impact on their attendance at screening. It is important that women understand that this change is 'because the test is better', which many women did not pick up from this statement. This change could be best explained in the context of the wider, critical messages for women – that research shows the test is a better way of identifying those at risk, and there is a chance of eliminating cervical cancer in Scotland. It may also be important to stress:
 - the way cervical cancer develops (HPV – cell changes – cancer)
 - the fact that all HPV positive tests will be looked at under a microscope to check for cell changes
 - the re-call testing and timescales for women with HPV
 - the timescales over which cervical cancer normally develops.

7.5 Language

This research found that there are some phrases that should not be used to describe test results:

- **HPV positive and negative** – Some found these terms scary, confusing and likely to attract stigma. Instead the term ‘HPV was found’ could be used, as most found this clear and simple.
- **High risk HPV** – Some were confused about what the risk was, and what level of risk there was. A plain English alternative may be ‘The type of HPV which can cause cervical cancer’, or similar. However it is worth noting that this may also cause alarm. The simple statement ‘HPV was found’ may be most appropriate.

Within letters providing results, women were comfortable with the sentences:

- Your recent smear test shows that further investigation is required
- Treatment at this stage can prevent the development of cervical cancer
- No HPV was found, so no further testing is needed – with an addition to describe that this is for another five years, or until your next smear test.

7.6 Information provision

A wide range of information is currently available on cervical screening and HPV, but the women involved in this research felt there were gaps in information about both topics. Women are particularly keen to access information through trusted places and people, including through the NHS website, through GP practices, health centres and clinics, and in invitation and results letters and leaflets.

Research shows that minority ethnic women and disabled women face particular barriers to cervical screening. This research highlighted that there is some demand for face to face information provision with these groups, talking through the changes and the key messages they need to know about HPV and cervical screening.

8. Conclusions and Recommendations

8.1 Conclusions

Many women had not heard of HPV, and there were high levels of worry and confusion about HPV. Even those who had heard of HPV were not always aware of the link with cervical cancer. Some found it scary and worrying that nearly everyone gets HPV at some point of time, particularly if they had never heard of it. While some felt it was reassuring that most of us can get rid of HPV like a common cold, some felt this message didn't really reflect how serious it could be.

Women reacted positively to messages which emphasised that the new HPV test is better at identifying those at risk of cervical cancer. There was a particularly positive reaction when women understood that there was research showing that the test was better, and that there was evidence from Australia highlighting that it is on track to eradicate cervical cancer because of a similar approach. However, there was some concern about how the new approach would catch the small proportion of cases of cervical cancer not caused by HPV.

Most women were worried about planned changes in frequency of screening. However, most did not understand the likely timelines for the development of HPV through to cervical cancer, or the detailed process that would be in place for testing and re-testing for women identified as having HPV (including cytology).

The message that HPV is spread through skin to skin, intimate contact was particularly important for some lesbian women, and helped to confirm the importance of them taking part in the cervical screening programme.

Overall, the message that HPV can stay in the body for a long time did not impact on women's views on cervical screening. However, this research highlighted that a few women who have been with their partners for more than 20 years may use this information to decide that they are at a reduced risk of cervical cancer, and do not need to attend their screening appointments.

The research found that the terms 'HPV positive', 'HPV negative' and 'high-risk HPV' were not well received. Instead, the term 'HPV was found' was generally seen as clear and simple.

Women participating in this research were keen to access information about cervical screening and HPV through trusted places and people, including through the NHS website, GP practices, health centres and clinics. Women would also expect to see information in their invitation and results letters, and in information leaflets.

8.2 Recommendations

Recommendation 1

NHS Health Scotland should consider when women need information about HPV.

The main group of women who will need detailed information are women who have HPV found in their sample (but no cell changes). These women will need clear messages that:

- HPV is common
- Your immune system normally clears HPV from your body on its own
- HPV rarely leads to cervical cancer
- Cervical cancer usually develops slowly – over 10 to 20 years
- They will be called back for regular re-testing
- If HPV develops, this causes cell changes – which would be picked up in the smear test
- Cell changes can normally be treated.

Women would welcome being able to speak to a medical professional at this stage, and it is important that they are able to provide clear, consistent and supportive messages to reassure women.

Women who do not require another smear test appointment for five years should also get clear information that explains the rationale for 5 yearly testing. This should stress that they are at very low risk for cervical cancer and cervical cancer usually develops slowly (over 10 to 20 years). However it should also make clear that women should visit their GP in the meantime if they have any symptoms of cervical cancer – and provide an explanation of what these symptoms could be. It should be made clear that women should be alert to these symptoms even though HPV was not found in their test.

Recommendation 2

Test results letters should avoid the terms HPV positive, HPV negative and high risk HPV. Clear and simple terms should be used, including:

- Your smear test sample was tested for HPV.
- No HPV was found.
- No further testing is needed, for another five years.
- HPV was found.
- Further investigation is required.
- Treatment at this stage can prevent the development of cervical cancer.

Recommendation 3

The focus of wider awareness raising work with women should cover the changes in the cervical screening programme collectively – including the HPV vaccination, improved test focusing on the root cause of cervical cancer, the fact that cervical cancer is preventable, the ambition of eliminating cervical cancer in Scotland and the fact that research underpins this approach. Key messages should include:

- We want to eliminate cervical cancer in Scotland.
- It is one of the most preventable cancers.
- To do this, we are: vaccinating all young girls and boys to protect against cervical cancer; moving to a new, better way of testing smear test samples; and making sure all women know about how to identify signs of cervical cancer at an early stage.

This information should be available through national media, on the NHS website, in GP practices and health centres, in invitation and results letters and leaflets. It is important to note that most women wanted information through formal and trusted channels, and any social media campaign should be clearly identified as an NHS campaign.

Recommendation 4

NHS Health Scotland should continue to provide information about who is at risk of cervical cancer, making clear that anyone who has ever had skin to skin, intimate contact is at risk of developing HPV, regardless of who this is (man or woman), how long ago this was, how many different people it is with, or how often it is.

Appendix 1: Research tools

- 1a) [Discussion guide](#)
- 1b) [Organisation information sheet](#)
- 1c) [Participant information sheet](#)
- 1d) [Participant consent form](#)

1a) Discussion guide

Understanding of the purpose of cervical screening

1. **Overall, what do you think the purpose of cervical screening (the smear test) is?**

At end of discussion, facilitator explains - the main purpose of cervical screening (smear testing) is prevention of cervical cancer.

Current understanding of HPV (10 minutes)

2. **Have you ever heard of HPV or human papillomavirus?**
3. **Have you heard anything about a link between HPV and cervical cancer?**
 - If yes, what do you know about it? How/ where did you hear about it?
 - Have you been offered (if relevant), or heard of, the HPV vaccine for young girls?
4. **Just now, how would you feel if the results of a cervical screening (smear) test told you that you had HPV?**

Exploring HPV in more detail (15 minutes)

Facilitator explains - There is a new way of testing smear test (cervical screening) samples that is better at identifying those at risk. So the NHS is changing the way the sample taken from cervical screening is tested. The process of taking the sample will stay the same, so women's experiences won't change. But the way the cells are tested in the lab will change.

The first thing the lab will do is test for the human papilloma virus (HPV). HPV causes 99% of cervical cancer cases. Only if certain high-risk types of HPV are found, will they then check the cells for abnormalities by looking at the cells through a microscope.

The HPV virus is very common and has no symptoms. Most of us will have it at some point (4 out of 5 people). You are at risk as soon as you are sexually active. Mostly the body clears it like a common cold. But in some cases, if your immune system can't clear it, it can cause changes in the cells of the cervix. If these are left untreated, these cell changes can develop into cervical cancer.

The NHS wants to make sure women can understand the changes, and that you get the information you need.

5. **Would the change – from looking at cells to testing for a virus – affect how you felt about the cervical screening (smear) test? In what way?**

6. Would any of the following bits of information influence how you felt about the cervical screening (smear) test? For each, explore in what way?

- a) HPV causes 99% of cases of cervical cancer.
- b) There is research showing the HPV test is a better way of identifying those at risk.
- c) Nearly everyone gets HPV at one point in time (4 out of 5 women).
- d) Most of us can get rid of HPV, like we do with a common cold.
- e) You cannot prevent HPV.
- f) HPV is spread through skin to skin, intimate contact.
- g) HPV can stay in the body un-noticed for a very long time – up to 20 years.
- h) If high risk HPV is treated it is unlikely to lead to cervical cancer.
- i) Because the test is better, women who don't have HPV will be invited for tests every five years. This is a change for women under 50, who used to be invited every three years.

7. Would these changes affect how likely you were to attend the cervical screening (smear) test? In what way?

Information provision (10 minutes)

The main way that women will find out about this change is through the letter inviting you to take part, through a conversation with the nurse doing the smear test, and through your results letter. The NHS wants to make sure it describes the changes well.

8. Where would you go to find out information about cervical screening / smear tests?

9. How do you feel about the use of these words/ phrases in describing the changes to you? Do you understand them? How do they make you feel?

- a) HPV positive/ negative
- b) HPV clears from your body – a bit like a cold
- c) High-risk HPV

- d) Your smear test sample was tested for HPV
 - e) No high-risk HPV was found so no further testing is needed
 - f) HPV was found
 - g) Your recent smear test shows that further investigation is required
 - h) Treatment at this stage can prevent the development of cervical cancer
- 10. What other information would you want to know about the introduction of HPV testing? Who from? When?**

And finally (10 minutes)

Bearing in mind everything we have talked about today:

- 11. Having had this discussion, how would you feel if the results of a cervical screening (smear) test told you that you had HPV?**
- 12. Is there anything about these changes that makes you feel more positive about cervical screening (smear testing)? Why?**
- 13. Is there anything about these changes that makes you feel less positive about cervical screening (smear testing)? Why?**
- 14. What do you think is the most important message for women about these changes?**

Thank you very much for your time. Your views will influence how NHS Health Scotland and its partners develop information for women about cervical screening.

Offer of signposting for any women seeking further support following issues arising during the group.

1b) Organisation information sheet

Women's understanding of changes to cervical screening Organisation Information Sheet October 2018, Version 1

Invitation to take part

We would like to offer the women your organisation supports the opportunity to take part in a research study. We would like to work with you to invite women to take part in a discussion group (which would take place in or near your premises) or individual discussions to inform this research.

The study involves exploring women's understanding of planned changes to smear testing (cervical screening) in Scotland. This is to inform how NHS Health Scotland develops the information it provides to women about these changes. The research is important so that women can understand the smear test process and the results they receive.

The study is being carried out by Research Scotland on behalf of NHS Health Scotland.

Who will be involved?

The study will involve about 100 women aged 25 to 65 across Scotland. We are working with organisations across the country to try to involve a good mix of women with different experiences and backgrounds. We want to involve a range of women whether they have previously attended cervical screening or not. We are not looking for women to discuss their personal experience of cervical screening (either positive or negative).

We would like to invite up to ten women who are involved in your organisation to take part in this research study. This could include women you support, work with, provide services for or who volunteer with your organisation.

Taking part is totally voluntary. Women can choose to take part or not, and can choose how they would like to take part.

What does taking part involve?

Taking part involves either coming to:

- **A discussion group** – This would be one hour long and involve up to eight women. Ideally it would take place in your premises – or nearby.
- **An individual interview** – This would take approximately 45 minutes. It can be face-to-face or over the phone. It can take place in your premises or at a nearby venue trusted by the individual.

Discussions will be welcoming and informal, with refreshments provided. Women can choose what suits them best.

The discussions will explore:

- views on the purpose of smear testing (cervical screening);
- views on the planned changes to smear testing (cervical screening) – after these are explained; and
- how the NHS can best tell women about these changes.

All views would be reported completely anonymously.

Potential participants will receive an information sheet in advance, which we would ask you to distribute to them. They would also have the chance to ask us any questions about the research. When they meet with Research Scotland, researchers will explain the process again in detail, check that participants are content to continue, and ask participants to sign a consent form. Participants can change their mind and withdraw at any stage, without giving a reason. Participants can choose not to answer a question if they don't want to.

Benefits of taking part

The research will help to make sure the information women in Scotland receive about smear testing is useful and easy to understand.

We recognise that taking part will mean extra work for your organisation. We will offer a donation of **£75** to your organisation to thank you for your time, regardless of how many women take part through your organisation.

We recognise that women taking part have busy lives and will need to dedicate time to taking part. We will offer an incentive of **£30** to each woman taking part in a discussion group or interview, to thank them for their time.

Find out more

If you are interested in helping with this research study, please contact:

Ann Elliott, Research Scotland

0141 428 3972

ann.elliott@researchscotland.org

Ann will work with you to explore the profile of the women you work with and agree how best to involve the women you support in the research. Ann will provide you with the participant information sheet to help you to inform potential participants. Ann will also answer any questions that you have.

1c) Participant information sheet

Women's understanding of changes to cervical screening Participant Information Sheet October 2018, Version 1

Invitation to take part

We would like to invite you to take part in our research study. Taking part is entirely up to you. Before you decide whether to take part or not, we would like to explain why the study is being done and what it would involve for you.

Please read this information sheet carefully. Discuss it with others if you wish.

If you have any questions, or if anything is unclear, please contact Ann or Katy at Research Scotland. Our contact details are at the end of the document.

What is the study about?

We are exploring women's understanding of planned changes to smear testing (cervical screening) in Scotland. This is to inform how NHS Health Scotland develops the information it provides to women about these changes.

The research is important so that women can understand the change to the smear test (cervical screening) process and the results they receive. Your views will help NHS Health Scotland to know what it needs to explain to women about the changes, and how to do this in a way that women will understand.

The study will take place between October 2018 and March 2019. It will involve about 100 women across Scotland.

Who is organising and funding this study?

This study is being carried out by Research Scotland on behalf of NHS Health Scotland who are funding the study. NHS Health Scotland produces information about the smear testing (cervical screening) programme.

All research involving people is looked at by an independent group to protect your interests. This study has been reviewed and approved by the NHS Health Scotland Research Development Group.

Why have I been invited to take part?

You've been invited to take part as you are eligible for, and may previously have attended, the cervical screening programme. We want to involve a range of women from across Scotland. You are eligible to take part if you are between 25 and 65 years old. We have worked with organisations across Scotland to try to involve a good mix of women with different experiences and backgrounds.

What does taking part involve?

Taking part involves coming to an hour-long discussion group or taking part in a 45 minute individual interview. You can choose which suits you best.

The discussion group will involve a chat with a group of up to eight women. The group will be held in a familiar, local venue. Discussions will be welcoming and informal, with refreshments provided.

Individual interviews can be face-to-face or over the phone. Face-to-face discussions would be in a suitably private space, for example in private space within a venue that you are familiar with, to make sure what you say remains confidential. For a phone interview, you would be asked to find a suitable private space.

The discussions will explore:

- your views on the purpose of smear testing (cervical screening);
- what you think about the planned changes to smear testing (cervical screening) – after we explain these to you; and
- how the NHS can best tell women about these changes.

The researcher will take notes during the discussion. There will be no pressure to answer any question, and you can stop the discussion or leave at any time without giving us a reason.

The discussions are exploring topics which are new to everyone. There is no right answer. We are interested in your views whether you've ever been for a smear test or not.

At the beginning of the discussion, we will also ask you to complete a short equal opportunity form which asks for some details like your age, postcode, ethnic origin and whether you have been to a smear test before. Each will have the option to tick 'prefer not to say'. You don't have to fill in any of the survey questions if you prefer not to.

Do I have to take part?

No, it is entirely up to you. Participation is voluntary. You do not have to participate if you do not want to. If you decide to take part, you will be asked to sign a consent form before the discussion group or interview to confirm that you are happy and willing to take part.

Even if you tell us you want to take part or sign the consent form, you're still free to withdraw from the study at any time, without giving a reason.

What are the possible benefits of taking part?

Taking part may be of no direct benefit to you. But the research will help to make sure the information women in Scotland receive about smear testing (cervical screening) is useful and easy to understand.

To thank you for your time, you will be offered £30 for taking part. If you are interviewed face-to-face you will receive this in cash at the beginning of the discussion. If you are interviewed by telephone, we will ask you for a postal or email address so that we can send you a voucher. Posted vouchers will be sent in a plain envelope within five working days of the interview. Your address or email address will be stored securely until we have sent you the voucher, and then we will delete it from our records.

What are the possible risks of taking part?

We hope that taking part will not cause you any harm. But you might be asked questions you find difficult to answer or upsetting or you might find out information that causes you some concern.

You do not have to answer any questions you do not wish to answer. If you get upset, the researcher will check whether you wish to continue the discussion and make sure that you are able to speak to someone if you want to. Details are at the end of this information sheet.

Will my taking part in this study be kept confidential?

Yes, all information collected from and or about you will be kept confidential, except in circumstances where there is a serious and immediate concern that you might hurt yourself or someone else. In this situation the researcher has a legal duty to tell someone.

If you attend a discussion group session, the other people in the group will know what you have said but all group participants are asked to respect each other's privacy.

We will store notes of our discussion and the equal opportunities form in our IT system in an anonymised way, without your name or any other details about you. Your consent form, which includes your name, will be stored separately from the notes and equal opportunities form.

You will not be identifiable in any study outputs, such as reports or presentations. We may use some direct quotes from what you say in study reports and presentations but where we do this, we will make sure we do not include information that may identify you.

Where required, your address or email is only collected for the purposes of sending you a voucher, and will be deleted once we have done this. We won't pass any identifiable information on to anyone else.

What will happen to the results of this study?

Your anonymous data will be combined with that of other participants and this will be used to produce a research reports and presentations to be shared with NHS Health Scotland. Selected findings may also be presented at conferences. At the end of the project, the research report will be available on NHS Health Scotland's website. The report is expected to be available in April 2019. You can also ask for a free copy from the NHS Health Scotland study lead – Nuala Healy. Nuala's contact details are at the end of this information sheet.

Details on data protection

NHS Health Scotland is the Data Controller for the research study, which means that they are responsible for looking after your information and ensuring it is used properly. Information collected from you as part of the study will be processed by Research Scotland. The information collected will only be used for the purposes of this specific study.

Personally-identifiable information is used to help us conduct research to ultimately improve health, care and services. As a publicly-funded organisation, NHS Health Scotland has to ensure that it is in the public interest when it uses personally-identifiable information from people who agree to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your data will be processed only so long as is required for this study.

In order to collect and use your personal information as part of this research, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

As we will be collecting some data that is defined in the legislation as more sensitive (information about your health), we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

During the study, your data will be stored in secure, locked cabinets or secure password protected servers for electronic data with access limited to the research team at Research Scotland. To safeguard your rights, we will try to minimise the processing of personal data wherever possible. If we are able to anonymise or pseudonymise the personal data you provide, we will do this at the earliest opportunity. This means that personal details such as your name and contact details will be removed from the data, and a number will instead be assigned to it. That number will then be used whenever referring to it.

Once the research is completed, Research Scotland will pass **anonymised** equal opportunities forms and interview notes to NHS Health Scotland using an encrypted device or courier. There will be nothing in this information that would identify you, ever. The information will never be passed to anyone else. The information will be held securely on password protected servers or locked cabinets with restricted access for a minimum of three years from study completion, and then securely destroyed. One month after the research is completed, Research Scotland will delete all the personal information from its systems.

Taking part in the research

If you would like to take part in the research, please speak to Ann (see below) who will explain what happens next:

Ann Elliott
Research Scotland
0141 428 3972
Ann.elliott@researchscotland.org

Withdrawing from the research

If you decide you don't want to take part before or after the interview or discussion group, please contact the research team (details below). We'd appreciate it if you could give us as much notice as is possible. If you decide you don't want to take part

during the interview or discussion group, simply let the researcher know you'd like to stop.

Please note that we will not be able to exclude the information you have provided after it has been combined with that of other people taking part and we will need to keep the information you've already provided. Your rights to access, change or move your information will be limited as we need to manage your information in specific ways for the research to be reliable and accurate. To safeguard your rights, be assured we will use the minimum amount of personally-identifiable information possible.

Contact details

If you have any concerns or questions at all about taking part in the study, please contact Katy MacMillan at Research Scotland on 0141 428 3972 or katy.macmillan@researchscotland.org

If you are still concerned or are unhappy about any aspect of the study, please contact the NHS Health Scotland study lead, Nuala Healy on 0131 5367 or nualahealy@nhs.net

If you wish to raise a complaint on how your personal data has been handled please contact NHS Health Scotland's Data Protection Officer, Duncan Robertson on 0131 314 5436 or duncanrobertson@nhs.net

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). For information on how to make a data protection complaint you can visit their website (<https://ico.org.uk/concerns/>) or contact their helpline (telephone: 0303 123 1113).

If you would like support or advice after taking part in the study, please contact:

Jo's Cervical Cancer Trust Helpline
0808 802 8000

Thank you for taking the time to read this and considering taking part. Please take this sheet away with you

1d) Participant consent form

Women's understanding of changes to cervical screening Participant Consent Form October 2018, Version 1 – Discussion Group

Study number: 2018/19 RE003

Project title: Women's understanding of changes to cervical screening

Participant Identification Number for this study: _____

Name of researcher: _____

Please read each of the statements below. If you have any questions please ask a member of the research team at Research Scotland. Please initial to confirm that you've done this and only sign the form when you are happy with ALL statements.

This consent form is to ensure that you understand the nature of this research and have given your consent to participate. Your participation is entirely voluntary and you are free to change your mind about taking part at any time. Just tell a member of the research team at Research Scotland if you wish to do this.

By signing this form, you agree to take part in a discussion group to share your views on planned changes to cervical screening.

Please initial box

	Statement	Initial
1.	I confirm that I have read and understand the participant information sheet dated October 2018 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.	
2.	I understand that my participation is voluntary and that I am free to withdraw from the study at any time, either during the discussion group or afterwards (up to the point my information has been combined with that from other people) without giving a reason and without there being any negative consequences.	
3.	I understand that direct quotations from my discussion may be used for research purposes (e.g. research presentation, publications and reports) but my identity will not be revealed.	
4.	I give permission for members of the research team to have access to my anonymised responses.	
5.	I understand my anonymised responses will be transferred to NHS Health Scotland at the end of the study.	
6.	I understand that I do not need to answer any questions that I do not wish to.	
7.	I agree to take part in the above study.	

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

