

# **Awareness of cervical cancer and prevention among women eligible for cervical screening in Scotland**

A project funded by the Scottish Government Screening  
Inequalities Fund

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## 1. Background

### *About cervical screening and cervical cancer*

In the UK, over 3,000 women are diagnosed with cervical cancer each year, with six women diagnosed every week in Scotland alone. The NHS Cervical Screening Programme helps to reduce the risk of cervical cancer and saves 5,000 lives each year. However, attendance of this life-saving test is falling year on year and incidence of cervical cancer is worryingly high, with nine women diagnosed every day in the UK.

This report sets out to better understand awareness of cervical cancer and prevention in Scotland, with a focus on barriers to cervical screening. The data collected through this survey, which was generously funded by the Scottish Government Inequalities Fund, will add valuable insight to the evidence base and inform the Screening Inequalities Strategy in Scotland.

Recent statistics show cervical screening coverage in Scotland has fallen across every age group and health board, and is now at a 10 year low. This trend urgently needs to be addressed if we are to see fewer women diagnosed and dying from this devastating disease.

- In 2014, incidence of cervical cancer increased 22% compared to the year before. In 2015 numbers were at a similar level and the third highest since 1996. Adding to this concern, deaths from cervical cancer have sharply risen, with 32% more women losing their lives to the disease in 2015, the highest since 2005.
- Incidence and mortality figures show severe health inequalities in Scotland, with 2012 figures showing diagnoses in the five most deprived areas more than twice as high as the least deprived (490 compared to 241), and a mortality rate that is 163% higher (161 compared to 61).

Previous research by Jo's has heightened knowledge gaps in awareness of cervical cancer, with many women unaware how they can reduce their risk of the disease or what cervical screening is. Among 25 to 29 year olds, over a quarter (26.7%) are too embarrassed to attend cervical screening and over two thirds (70%) don't think they reduce a woman's risk of cervical cancer. For women over 50, one in three (32%) do not think cervical screening is a part of the healthy upkeep of a woman's body and almost one in four (22%) do not think they are important to have regularly. A worrying one in three (33%) women have delayed or not attended this potentially life-saving test, with an average delay of 26 months, while one in 10 (10%) women delay for over five years. Symptom awareness is also low with women are more likely to visit a GP about a cold than if they had gynaecological symptoms<sup>1</sup>.

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<sup>1</sup> Jo's Cervical Cancer Trust 2012. Cervical cancer symptoms awareness among women – an area in need of more education. Accessed December 2017: <https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/symptoms-awareness>

## 2. Methodology

In early 2018, Jo's Cervical Cancer Trust commissioned a survey of 3,000 Scottish women aged 25-64 to understand Scottish specific barriers to attending cervical screening and canvas attitudes to cervical cancer prevention. The survey, which was conducted by Censuswide and consisted of 20 questions covering all aspects of cervical cancer and prevention, was carried out between the 1<sup>st</sup> and the 14<sup>th</sup> of June 2018.

The questions targeted three main areas:

1. Knowledge and understanding of cervical cancer, including how it develops and manifests, and how it can be prevented.
2. Practical barriers and women's feelings around screening
3. The way forward: trying to find ways to improve uptake by asking women how they would like to access screening and what would encourage them to attend the test.

The survey also collected biographical data including age (divided in four age groups: 25-34, 35-44, 45-54, and 55+), nearest city of residence (Aberdeen, Dundee, Edinburgh, Glasgow, Inverness, Perth, Stirling) and ethnicity.

### 3. Key Findings

#### 3.1 The knowledge gap - What do women know about cervical cancer prevention?

Nine out of 20 survey questions aimed to understand what women know about aspects of cervical cancer prevention, from risk factors to signs and symptoms.

##### Key stats

- One in five (22%) don't know what puts them at risk of cervical cancer, with over one in four (30%) wrongly believing the disease is hereditary
- Almost two thirds (60%) weren't aware that HPV infection puts them at risk of cervical cancer
- Almost one in four (24%) wrongly believe that condoms/dental dams fully protect against HPV
- 95% were unaware that HPV infection usually goes away by itself
- A worrying 5% think the HPV jag is unsafe and 4% would never let anyone have the HPV jag
- 13% think there is no relationship between the HPV jag and cervical cancer
- Half (50%) are unable to identify abnormal bleeding as a symptom of cervical cancer, with a third (31%) not knowing any symptoms of cervical cancer

While the majority of women (70%) were aware that cervical screening is a test to find changes to the cells of the cervix (cervical abnormalities), an almost equally high percentage (68.8%) also thought it is a test to find cervical cancer. This reveals a misunderstanding of the role of cervical screening as a preventative test.

Other answers that signal confusion around cervical screening include thinking it's a test to check the health of the womb (23%) or to find ovarian cancer (22.6%).

Interestingly, despite most women knowing what cervical screening is for, almost half (45%) are unsure of what happens if abnormal cells are found, with only 15.3% feeling confident about next steps. Further almost half of the women surveyed (42.6%) neither agreed nor disagreed when asked whether an abnormal test result means having cancer.

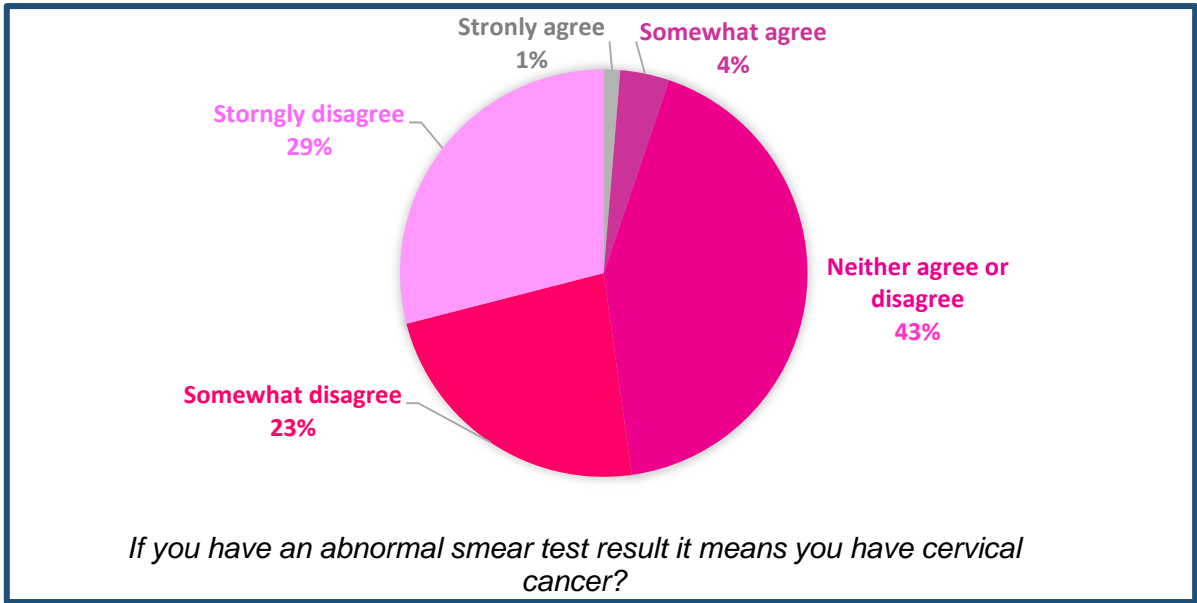


Table 1. To what extent women agree with the question on abnormal smear test results as a sign of cervical cancer

Another gap in understanding concerns risk factors for cervical cancer. Survey participants were asked to select the factors they thought increased someone’s risk of cervical cancer. Only a third knew an infection with HPV (39.7%) or not attending cervical screening (38.3%) are risk factors. Under a fifth selected smoking (17.9%). Of concern is the percentage of women who put bad luck as a risk factor (16.4%), a belief that was strongest among those aged 25 and 34. A third of the women from the same age group also wrongly believes cervical cancer is hereditary.

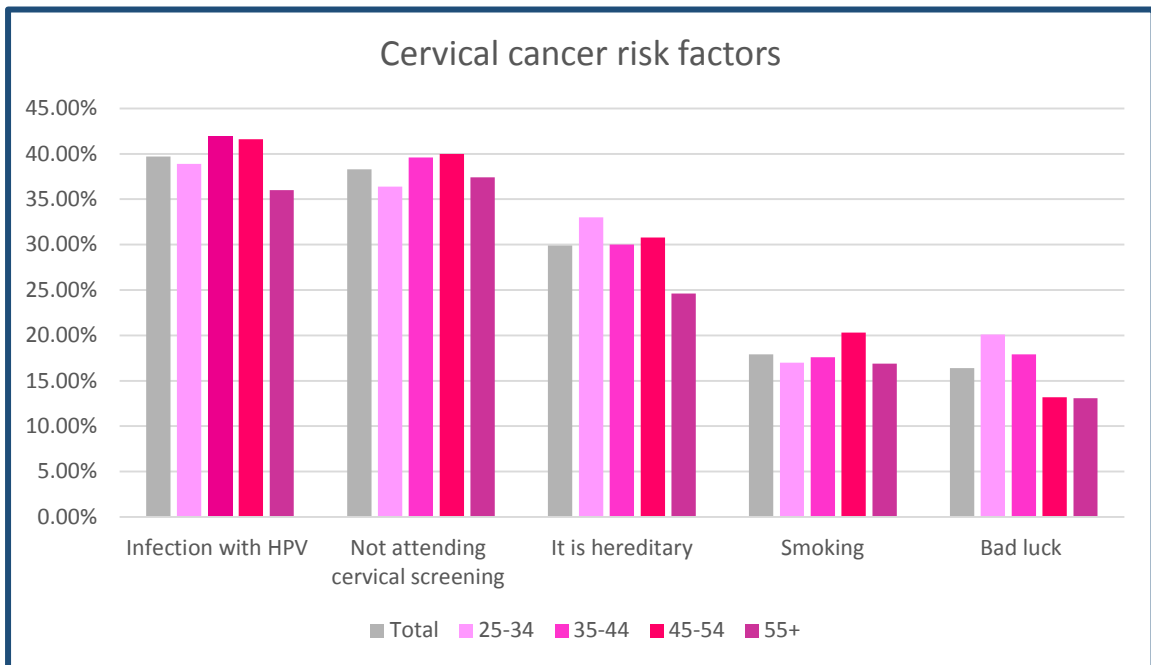


Table 2. Some of the options identified as risk factors for cervical cancer, divided by age group

While a high percentage identified infection with HPV as the most prominent risk factor, when asked if they had heard of HPV less than half (41.1%) said they had however yes they did not know what it was. One in five had never heard of HPV.

There was lots of uncertainty around HPV including how it is contracted, spread and how it develops with over half (55.7%) unsure whether someone will get cervical cancer if they have HPV.

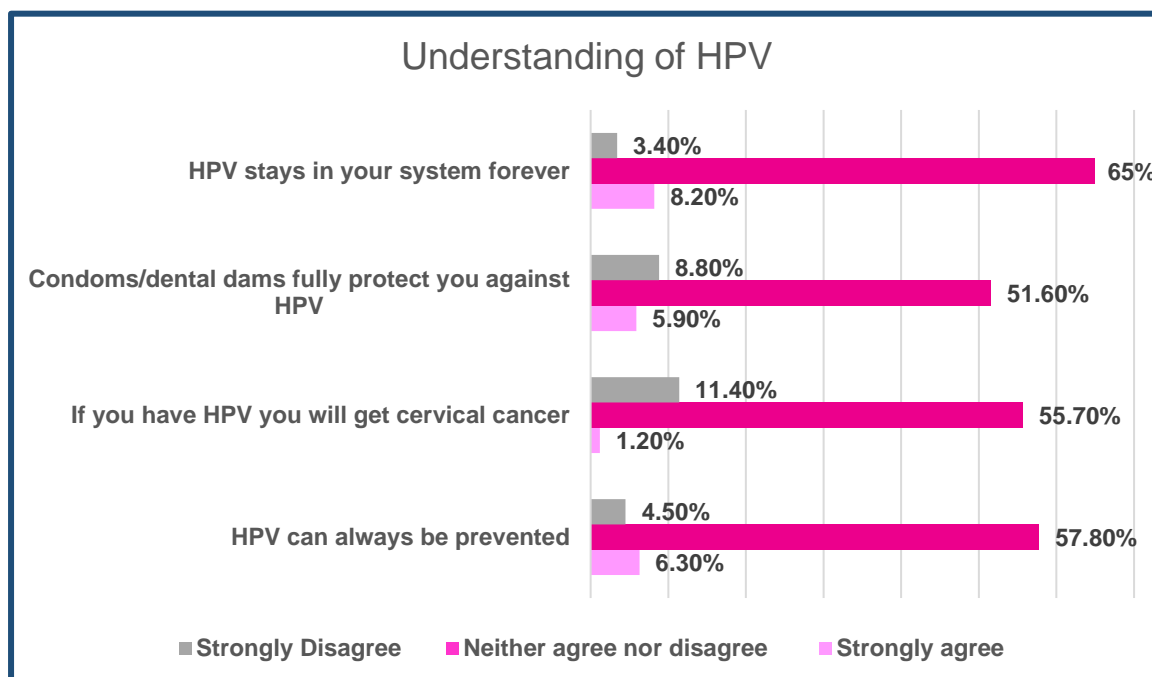


Table 3. Women's opinion on HPV facts and prevention

The survey uncovered a worryingly lack of understanding and even trust in the HPV vaccination. A high percentage (88.5%) did not disagree that the HPV vaccination is unsafe.

### 3.2 Barriers to screening - Who is delaying and why?

The NHS cervical screening programmes saves thousands of lives every year however we have seen a decline in the number of women attending with uptake in Scotland at a 10 year low. Understanding barriers to attendance is essential if we are to turn around declining uptake of this potentially life-saving test.

Almost half (46.3%) of the women surveyed said they had previously delayed cervical screening for more than 3 months. Significantly, 41.1% have delayed between over 3 months and up to 2 years and, although the percentage of women delaying for over 2 years is relatively small (see table below), 10.5% of women living in Dundee (against 5% of the total) delayed for over 7 years, and 17% of women over 55 do not recall or are unsure about how long they delayed their test for.

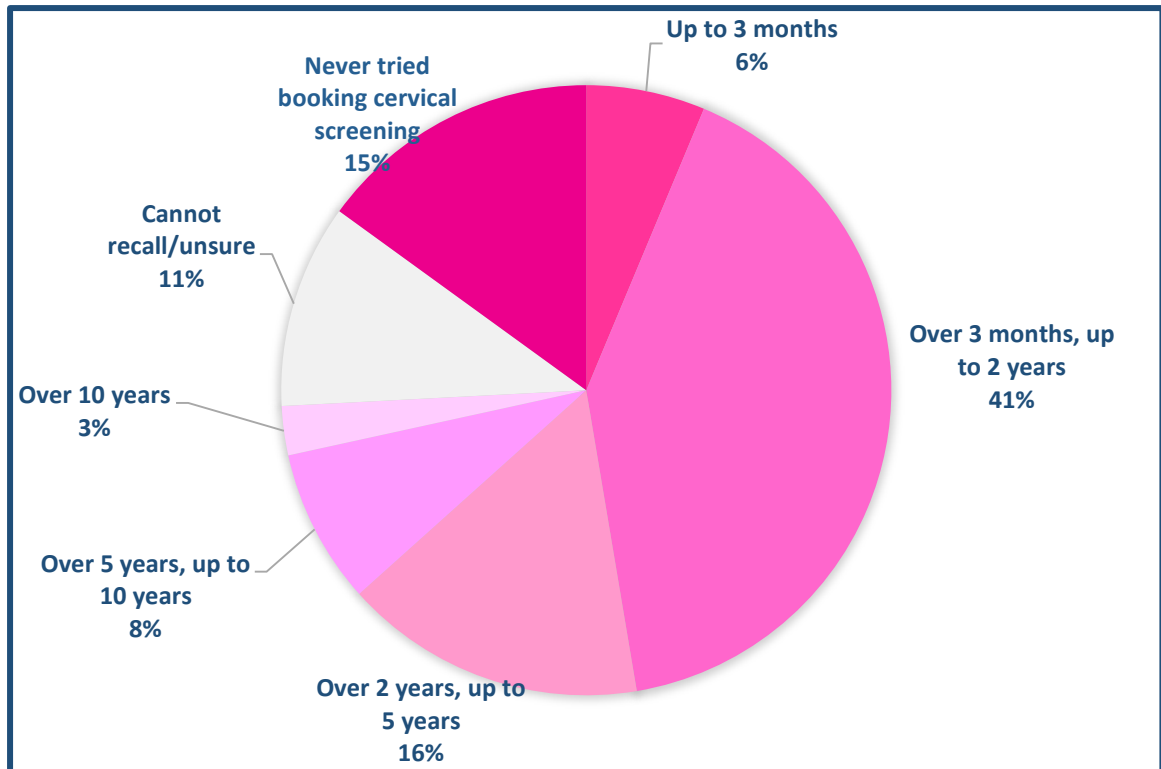


Table 4. Delays in attending cervical screening

When asked to choose which reasons caused them to delay their screening test, a third (33.5%) simply kept putting it off, with the second most common cause (19.9%) being worrying that it could be embarrassing. The latter seems to be a bigger concern for younger women (23.6% of women aged 25-34, versus 11.9% of women aged 55+).

Interestingly, White British women seem to be the most embarrassed (21%), compared to White-European (14.9%) and White-American (12.5%) - with the only exception of women of mixed descent White and Black African (33.3% - this data, however, is less significant since only 3 women answered this question compared to 1186 White British).

When we further analyse this data, findings from Perth are varied from the total and other cities' figures, as table 5, below, illustrates. Perth, together with Dundee, falls within the NHS Board of Tayside where uptake is above the national average. The causes for delaying given by women living in Dundee however, are different from those given by the women of Perth.



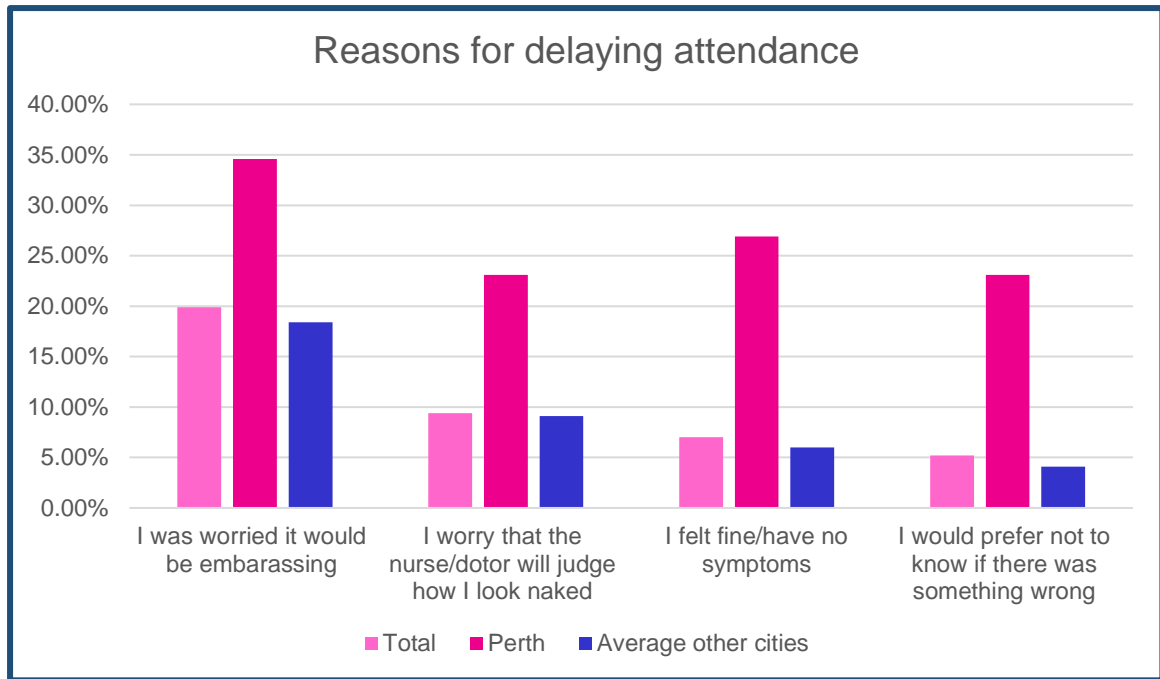


Table 5. Some of the reasons why women say they delayed their cervical screening. A comparison between responses in Perth and other cities in Scotland

When we focus on physical barriers, barriers over which women do not have control - for instance, the availability of appointments at GPs surgeries - more expected data emerge. Although 44% have never had a problem in getting an appointment, this seems to be less true for women aged 25-34 (32.7%) than older women (54.4% of women aged 55+). This could be due to work or childcare commitments.

Indeed, when women were asked what would encourage them to attend regular cervical screening, not having to take holiday from work to attend an appointment was selected by 19.4% of younger women (25-34), versus 8.5% of women above 55. The percentage of women thinking that not enough appointments are offered was the highest among younger women (11.4% of women aged 25-34), whereas fewer older women (above 55) are concerned with that (4.7%).

### 3.3 A way forward (possible solutions to improve cervical screening attendance)

#### Cervical Screening Programme – the facts

The UK National Screening Committee advises on screening policy across the UK but the commissioning and delivery of the structures for cervical screening are different in each country.

The National Services Division commissions and co-ordinates the cervical screening programme in Scotland. Health Boards decide where screening can take place, which is primarily through GP services and some sexual health services. In April 2018, the new Scottish GP Contract came into force which removed the quality and outcomes framework (QOF).

From Monday June 6 2016, the age range for cervical screening changed from ages 20-60 years, to ages 25-64 years plus 364 days. Women are invited every three years from 25 to age 49, and every five years for women from age 50 to 64 plus 364 days of age.

As we have just seen, 44% of the women surveyed state they have not had a problem booking their cervical screening at their GPs and almost half (49%) chose their own GP as the preferred place to have their screening done. However, different needs and preferences emerge from different age groups.

In general there seems to be a divide between women age up to 44, and those above 45 years old, with the former group showing the desire to try different options, such as taking their own sample at home without a speculum, going to a different GP practice, or booking an appointment at a sexual health clinic.

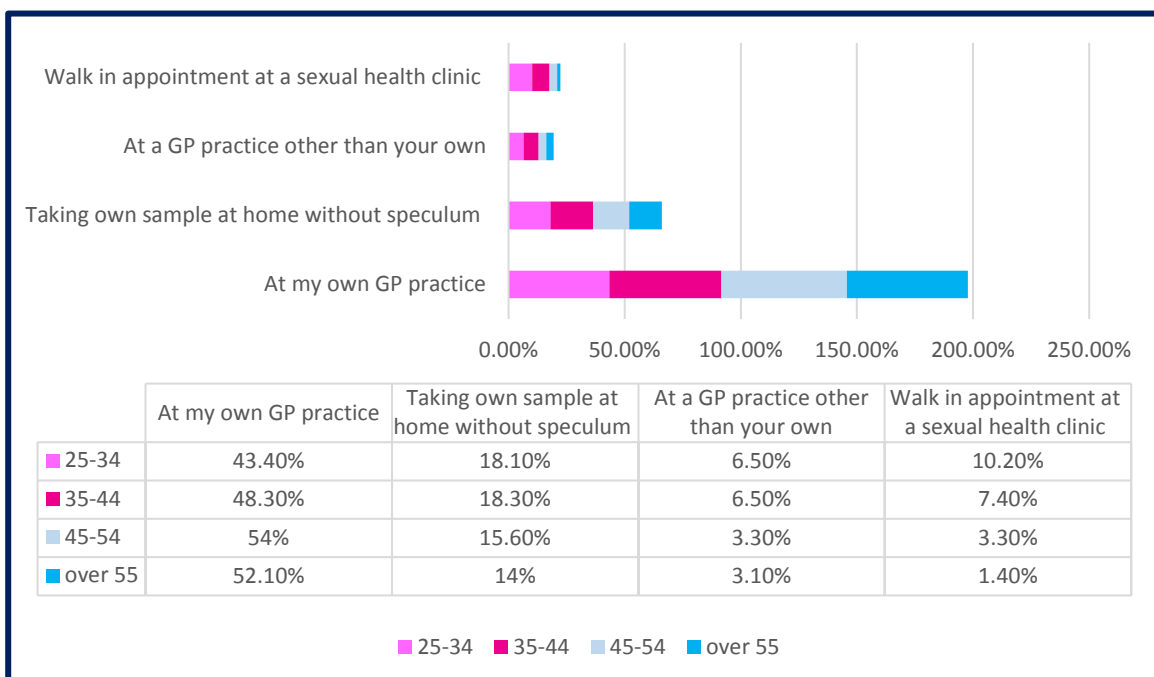


Table 6. How would you prefer to have your cervical screening (smear test)?

Younger women aged 25-34 were keener on combining screening with other tests with 10.2% keen to have it done at the same time as an appointment about their contraception, and 7.1% at the same time as a sexual health check at a sexual health clinic. Although relatively low, this percentage becomes more meaningful when compared to the percentage of women from the other three age groups (35-44, 45-55, 55+) who picked the same choices (2.6% and 1.6% average, respectively).

Interestingly, when asked if they would prefer an alternative test that they could do at home without a speculum which was just as accurate as a cervical screening, the majority (86.3%) responded positively - with 47.5% being definitely sure and 38.8% saying it would be a possibility. An even higher majority (91.5%) who said to have previously delayed or to be currently overdue their cervical screening, would welcome it.

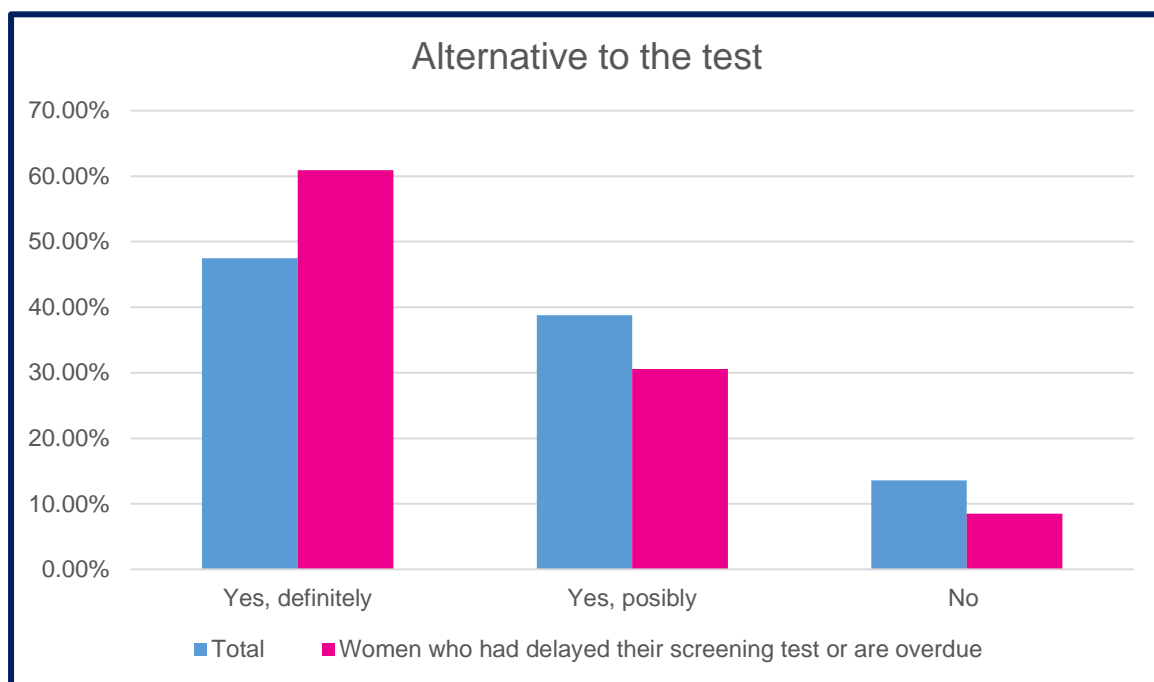


Table 7. Answer given to the question "If there was an alternative test that you could do at home without a speculum which was just as accurate as a cervical screening (smear test), would you prefer to use it over having a test with a speculum?"

The survey also asked how they would prefer to receive their cervical screening invitation. Although the preferred option was by a letter asking to call the GP to book an appointment (29.7%), one in four (25.3%) would like the letter to state an appointment date and time.

Receiving the invitation by email was more popular among younger women (24% and 22% of women aged 25-34 and 35-44 respectively), but not particularly favoured compared to other means by those who had previously delayed or are currently overdue screening (23.3%). A high percentage (40%) who have never attended say they have no preferences when it comes to receiving their cervical screening invitation.

Embarrassment is a significant barrier with 41.2% saying they would go if there was a less embarrassing or intrusive way to get the test done. 16.9% said that they will never attend if they have to visit a doctor.

Almost 1 in 10 women (9.5%), and 33.1% who have never attend screening, admitted that nothing would encourage them to have regular cervical screening when invited.

**Among women who have never attended cervical screening:**

- 41.2% would go if there was a less embarrassing or intrusive way to get the test done
- 5% don't want to delay attending but feel they have no choice as they can't get a suitable appointment
- 16.9% will never attend if they have to visit a doctor
- 3.5% have a physical disability which makes it hard/impossible to get to a doctor
- 3.1% want go but can't [not specified why]

#### **4. Conclusion**

The cervical screening programmes saves thousands of lives every year however uptake in Scotland is in decline. It is currently at 72.8% meaning over one in four women are not taking up their invitation. Understanding and actively addressing barriers to attendance is essential if we are to turn around declining uptake of this potentially life-saving test and address the health inequalities that exist.

This research highlights clear gaps in awareness of cervical cancer and prevention among women of eligible age for cervical screening in Scotland. It provides an insight into factors preventing women from taking up their screening invitation and highlights ways in which women may be more encouraged to attend.

The data collected will hopefully help inform further targeted work in Scotland to address declining cervical screening attendance and help reduce incidence of cervical cancer in the country.