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Evidence Briefing

Why is cervical screening coverage falling in the UK and what has primary care done to increase uptake of cervical screening?

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Why is cervical screening coverage falling in the UK and what has primary care done to increase uptake of cervical screening?

Question

This briefing summarises the evidence on barriers to cervical screening uptake in the UK and what has been done to increase the uptake of cervical screening for women – due to the amount of literature identified between January 2011 and January 2018, the primary research included has been restricted to UK only.

Key messages

- cervical cancer costs the NHS £21 million a year and £9 million tax is lost from women who stop work, or die, as a result of cervical cancer
- in 2016, cervical screening coverage in England dropped to 72.7% and only 62% of 25-29 yr olds were screened
- many barriers to uptake of cervical screening were identified including access to services, discomfort, pain, embarrassment, anxiety, fear, low education, lack of awareness or knowledge, relevance, no time and lack of symptoms
- younger women had low awareness of the purpose of cervical screening, were demotivated, viewed screening as a test for older women and raised practical barriers as the reason for not attending
- non-attenders who had made an active decision not to take part tended to be older and had more negative attitudes to screening
- language, culture and religion commonly affected ethnic minority women's screening behaviour; embarrassment and shame may contribute to lower screening rates among Asian women; a quarter of women from Black, Asian and Minority Ethnic (BAME) backgrounds were ‘disengaged’ from screening and were more likely to be from lower socioeconomic backgrounds
- human papillomavirus (HPV) vaccination is not associated with reduced attendance for screening in Scotland; unvaccinated women in the UK were less likely to attend cervical screening and socially deprived women were less likely to be vaccinated or attend cervical screening
- parents and girls had limited understanding and knowledge of HPV vaccination – many did not know that vaccination was not 100% effective, and that cervical screening was still necessary after vaccination
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- recommendations to increase uptake include offering on-the-spot screening, having an option to have screening done by a woman, a 'mums and daughters' campaign, and young female celebrities acting as 'cervical cancer ambassadors'

- effective interventions to increase uptake include pre-screening reminders, personalised reminders, timed appointments, HPV self-testing, media/celebrity endorsements, GP endorsements and GP positive attitudes, and daughter's invitation for HPV vaccination

- uptake amongst young women remains relatively low despite the widespread use of invitations and reminders, so use of these letters is not the solution for all women; HPV self-sampling kits and the opportunity to book appointments had the largest effect in improving cervical screening uptake for young women

- learning disability (LD) nurses perceive that they can help to prepare LD women psychologically for screening

- Mexico and the Netherlands have piloted alternative screening methods, including HPV self-testing and urine testing
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**Background**

Cervical cancer costs the NHS £21 million a year, while the state loses £9 million in tax revenue from women who stop work, or die, as a result of cervical cancer (1). It has been calculated that with 100% coverage of screening, costs to the NHS would halve, costs to the state would reduce by a third, and total costs to women diagnosed with cervical cancer would fall by around 40% (1).

It has been shown that in the absence of screening, cervical cancer deaths would be four times higher for women aged 35 to 49 yrs and five times higher for women aged 50 to 64 yrs (2). This analysis concluded that "a further 347 deaths per year could be prevented if everyone attended screening regularly between ages 25 and 64 years".

In 2016, cervical screening coverage in England dropped to 72.7% (1.12 million/4.2 million women invited for screening did not attend) (3) and in young women aged 25-29 yrs, only 62% of women were screened (4). Women with negative screening at age 50-64 yrs had one-sixth of the risk of cervical cancer at age 65-83 yrs compared with women who were not screened (5). Cervical screening coverage is lower for younger women, non-Caucasian individuals and those living in socioeconomic deprivation (6).

**Barriers to cervical cancer screening**

Many barriers to uptake of cervical screening were identified from the research literature. These are:

- Access to services and facilities (7) (8) (9) (1) - facilities with flexible appointment times and reminders had higher test uptake (9)
- Physical experiences (10)
  - Discomfort (11)
  - Pain (11)
- Emotional experiences (10)
  - Embarrassment (11) (8) (1)
  - Anxiety (10) (12)
  - Sexual abuse (13) (1) - women who have experienced sexual abuse are less likely to attend for regular cervical screening (13)
  - Mental health (14)
  - Fear (12) (8) (1)
- Personal characteristics (7)
- Social factors (7) (1)
  - Inequalities (14) (8) – socially deprived women described negative feelings of 'fear', 'embarrassment' and feeling 'stigmatised', and had practical issues such as timing of appointments and child care (8)
  - Ethnic group (15)
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- Education - women with highest education were more likely to adhere to cervical cancer screening (16)
- Awareness (17) (18) (15) (1)
- Knowledge (18) (12) (8) (1) - awareness of HPV testing among people who have heard of HPV is higher in the USA than in the UK, but overall knowledge is low (18); there is a lack of understanding about HPV with participants struggling to interpret limited information (12)
- Relevance (10)
- Value (10)
- Health literacy/reading (19) (20) - evidence supports a positive link between health literacy and cervical cancer screening (20)
- Relationships – women were concerned about the effects an HPV test may have on their relationship e.g. partner might have been unfaithful or that they themselves would be accused of infidelity (12)
- GP visits – visiting the GP enhanced the uptake of a cervical cancer screening examination (21)
- Time factors (8)
- Sexual partners - women with more than 10 sexual partners in their lifetime were more likely to participate in the cervical screening programme (15)
- No symptoms - screening was less likely among women who believed that screening in the absence of symptoms is unnecessary (15)
- Learning disabilities – there was a low uptake of cervical cancer screening among women with a learning disability (22)

A systematic review identified 53 psychosocial barriers to cervical screening – the % of studies indicating type of barrier were 9.5% facilities (transportation, appointments), 67.9% personal characteristics (time, childcare, no symptoms, lack of information, discomfort) and 22% social factors (lack of social support, unsatisfactory contact with physicians) (7).

The most common reasons for women not attending cervical screening in a survey of 188 women were embarrassment (35%), no time/too busy (17%) and the test being painful (15%) (1). One study found about a quarter of eligible women did not go for a cervical screening test, either because they were unaware of screening or that they intended to go, but were overdue (17).

Women reported feeling disappointed with how the procedure was conducted and suggested that practitioners’ attempts to normalise the interaction actually made them feel more uncomfortable (11).

As there are a number of reasons why women may not attend cervical screening, non-attenders should not be viewed as a homogenous group (10).
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Ethnicity, age factors or learning disabilities

Additional barriers for ethnic minorities, younger/older women or those with learning disabilities:

- **Age factors** - younger women had low awareness of the purpose of cervical screening, were demotivated by reports of bad experiences, thought it was unnecessary as they had no symptoms and viewed screening as a test for older women (23); non-attenders who had made an active decision not to take part tended to be older and had more negative attitudes to screening, and those who intended to be screened but did not attend were mainly younger women, who raised practical barriers as the reason for not attending (24)
- **Country of birth** - older and Indian-born women were less likely to attend for screening (25)
- **Self-collected HPV sampling** - women were not confident that their sample would be as good as a clinician sample and were concerned about the impact a positive HPV result might have on their relationships (25)
- **Culture and religion** - language, culture-related factors and religion commonly affected ethnic minority women's screening behaviour (26); among Black women, those from African backgrounds and those who attend religious services could be the most likely to delay attending cervical screening (27)
- **Interactions with health professionals** – negative experiences were well remembered by ethnic minority women and could be a barrier to repeat attendance (28)
- **Emotional barriers** – embarrassment and shame may contribute to lower cervical screening rates among Asian women (28) (29)
- **Disengagement** - a quarter of women from BAME backgrounds were ‘disengaged’ from screening and these women were more likely to be from lower socioeconomic backgrounds, more likely to have migrated to the UK as adults and not speak English well (29)

Barriers to uptake for women with learning disabilities are a lack of easy read invitations, difficulties using appointment systems, mobility issues, communication barriers, attitude and knowledge of professionals, fear, anxiety, consent issues and understanding of the importance of screening (30).

Screening after HPV vaccination

The NHS introduced the HPV vaccination programme for girls aged 12-13 in 2008; the first girls to be vaccinated against HPV 16/18 are now approaching age 25. As the vaccination is not 100% effective, vaccinated women are still advised to be screened regularly (1). Using a model, it was predicted that HPV screening could mean women vaccinated against HPV 16/18 only need three cervical screening tests in their lifetime (31).
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Could the recent fall in cervical screening be because young people vaccinated against HPV think they don’t need to undergo cervical cancer screening?

- Attendance
  - unvaccinated women were less likely to attend cervical screening (32)
  - HPV vaccination is not associated with reduced attendance for screening in Scotland; immunised women in the catch-up cohorts appear to be more motivated to attend than unimmunised women (33)
  - mothers are central to health interventions to promote both cervical screening and HPV vaccination, as daughter's HPV vaccination uptake was associated with mother’s cervical screening attendance (34)
  - socially deprived women were less likely to be vaccinated or attend cervical screening compared to those who lived in the least deprived areas (32)

- Uncertainty
  - parents and vaccination-aged girls were uncertain about the level of protection offered by the HPV vaccine (35)

- Knowledge and understanding of HPV and screening attendance
  - parents and girls had a lack of understanding that cervical screening would be required irrespective of HPV vaccination; some parental decisions to accept the vaccine were made on the misunderstanding that vaccination provided complete protection against cervical cancer - future invitations for cervical screening should stress the necessity to attend regardless of HPV vaccination status (35)
  - a lack of knowledge and understanding of HPV-related issues was exhibited among the public; many girls and their parents are poorly informed and have limited understanding about HPV vaccination, which could impact on future uptake of cervical screening (36)
  - many girls linked HPV to cancer, only half specifically associated it with cervical cancer and most girls had no idea how long the vaccine would offer them protection; 50% of the girls were aware that in the future they would need to attend for cervical screening (37)

A modelling study concluded that “focus should be placed on scenarios that offer less intensive screening for vaccinated women and more on increasing coverage and incorporation of new technologies to enhance current cervical screening among unvaccinated women” (38).

Increasing uptake for cervical screening

The evidence base for interventions designed to increase cervical screening uptake is small, but growing - a summary of some published UK projects has been produced by Cancer Research UK (39) including interventions such as invitation letters, telephone interventions, education and self-sampling.
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A report commissioned by Jo’s Cervical Cancer Trust outlined interventions in the UK and internationally that have had an impact on cervical screening uptake, including public role models and the ‘Jade Goody effect’, developing a ‘screening habit’, GPs as gatekeepers, stating the risks and HPV self-testing (1). This report recommends offering on-the-spot screening and an option to have screening done by a woman; a ‘mums and daughters’ campaign, where young women reaching screening age and their mothers remind and encourage each other to attend screening; and young, female celebrities to act as ‘cervical cancer ambassadors’ and raise awareness and reduce embarrassment (1).

Many effective interventions were identified from the research literature:

- **Reminders, recall, invitations** (25, 40-43) (44-49)
  - a single reminder letter sent around the time of a person’s birthday was not as effective as a reminder letter just before a woman is due (40)
  - non-responders to invitations are significantly more likely to respond to a postal invitation for HPV self-testing than a further invitation for cytology screening (50)
  - pre-screening reminders and more personalised reminders increased attendance for non-participants (44)
  - there is evidence to support the use of invitation letters to increase uptake (45)
- **Timed appointments** (49, 51)
- **Education** (41, 42, 45, 47, 49)
  - one-on-one education is an effective population-based intervention to increase uptake (41)
  - a Cochrane view found limited evidence for educational interventions but it was unclear what format is most effective (45)
- **Access, facilities** (41, 42, 49)
  - reducing structural barriers is an effective intervention to increase community access to screening services (41)
- **Sampling technique** (49)
- **HPV self-testing** (50) (44, 48, 51-56)
  - HPV self-sampling raised participation rates by around 10% (44)
  - offering an in-home HPV self-sampling kit is more effective and cost-effective than a recall letter in increasing participation (48)
  - HPV self-sampling kits and timed appointments achieved a small but significant increase in the uptake of screening (51)
  - 50% of cervical screening non-attenders present to their GP at least once a year, in over 75% of practices, representing a good opportunity to offer HPV self-sampling (53)
  - HPV self-testing significantly improved the participation of women who did not routinely attend cervical cancer screening programs (54)
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- HPV self-testing can improve uptake among lower socioeconomic groups (55)
  - Media/celebrity endorsements (57, 58)
    - over 33,000 more cervical screening tests than expected were carried out in Wales 2008/9, 11,539 (35%) of which were in the month of Jade Goody's death (58)
    - half a million extra cervical screening attendances occurred in England between mid-2008 and mid-2009, the period during which Jade Goody was diagnosed and died, peaking in March 2009 at 70% higher than expected (59)
    - the 'Jade Goody Effect' was more pronounced among young women and those from lower socioeconomic backgrounds (60)
    - an EastEnders storyline seemed to have no effect on interest in cervical cancer or screening, but the AdWords campaign may have had some effect (61)
  - GP endorsement/motivation/programmes (44, 46, 62)
    - general practice endorsement were found to improve participation in cancer screening, including in underserved populations (44)
    - population-based programs are more effective than spontaneous screening in obtaining higher testing uptake (46)
    - GPs influence women's screening behaviours and can have a positive or negative impact on women's participation - a positive attitude by their GP towards cervical screening strongly influenced a woman's likelihood of having a smear (62)
  - Lay-health advisors (55)
    - there is varying success using lay health advisors, but some evidence of a statistically significant increase in screening uptake (55)
  - Mothers-daughters (34, 63)
    - daughters are 'significant others' in reinforcing their mothers' cervical screening motivation, and a daughter's invitation for HPV vaccination instigates a reassessment of cervical screening intention in some under-screened mothers (63)
    - daughters' HPV vaccination uptake was associated with mother's cervical screening attendance - daughters of mothers who are not engaged with preventive services are less likely to be vaccinated and may be less likely to engage with screening (34)
  - Text-messaging - SMS text messaging interventions can moderately increase screening rates for cervical cancers (64)
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Two case studies on increasing uptake were published in “Health Matters: making cervical screening more accessible” (65):

- Improving cervical screening in Trafford: One Minute campaign - intensive work to create awareness about the need for cervical smear tests, especially in those practices and groups of women where uptake was lowest, led to an increase in the number of women having the test
- GP surgery initiatives boost cervical screening uptake - an ‘In the Pink’ surgery campaign increased awareness of cervical screening and encouraged patients to attend

**Age factors**

Older women more often had misconceptions about smear tests and more often perceived they had a lower risk of getting cervical cancer. Older women more often agreed that: "women only need smears if they have problems like bleeding" and "women should start having smear tests after giving birth to their first child". They were also more likely to believe that cervical cancer is easy to treat. These findings may inform initiatives to improve screening uptake among older women (66).

A systematic review of intervention studies for improving cervical screening uptake could not conclusively determine which interventions are effective amongst younger women (aged ≤ 35) (67). As the uptake amongst young women remains low despite the widespread use of standardised invitation and reminder letters, it is apparent that the use of these invitations and letters is not the solution for all women.

HPV self-sampling kits and the opportunity to book appointments had the largest effect in improving cervical screening uptake for young women (aged 25 in Manchester and aged 20 in Grampian, Scotland), not responding to initial prompts (56).

Advising younger women to book an appointment when convenient rather than in the middle of their menstrual cycle, offering appointments up to 7pm and contacting older women personally with advice had all been effective in getting more women to come for smear tests (24).

**Ethnicity**

Effectiveness of cervical screening for Asian women may hinge on a variety of social-and cultural factors, such as the type of intervention and study population characteristics, and the large cultural diversities within Asian women should be considered (68).
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**Learning disabilities**

Learning disability (LD) nurses state that motivational and skills-based factors appear to impact on LD women’s attendance at and ability to tolerate cervical screening; they perceive that they can help to prepare LD women psychologically for screening and manage the challenges associated with supporting women with more complex needs (69).

**Future research**

Other countries (e.g. Mexico and the Netherlands) have piloted alternative screening methods, including HPV self-testing and urine testing; the UK could follow their lead and discover whether these methods could potentially be used in future for cervical screening (1).
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Endnote database matrix showing the highly relevant papers with key information

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This database can be obtained on request.
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References

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