Development of a pre-notification leaflet to encourage uptake of cervical screening at first invitation: a qualitative study

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Abstract

Cervical screening attendance among women aged 25–29 years in England is lower than at older ages. There is some evidence that pre-notification leaflets motivate women who have not yet considered their response to a health intervention. We aimed to identify key information to motivate young women at their first cervical screening invitation. Six focus groups were conducted, five with young women aged 17–25 registered with a General Practice in Manchester, UK, and one with Practice nurses. Some women took part in two further groups to discuss leaflet design. There was low awareness of the purpose or procedures of cervical screening, and most women were de-motivated by reports of bad experiences. Some intended to be screened, but not immediately after invitation. Screening was viewed as a test for a cancer that affected older women. Since none of the participants believed that they had cervical cancer, screening seemed unnecessary. We conclude that the perception that screening is unimportant when you are young needs to be challenged. Women also need to be better informed of screening procedures. A pre-notification leaflet incorporating key information was designed and will be tested in a randomized trial of complex interventions within the routine cervical screening programme.

Introduction

Cervical cancer mortality in the UK declined following the introduction of the cervical screening programme [1]. Yet, in recent years, attendance among the female population has dropped to <80% [2], and in England, among young women aged 25–29 years, it is consistently lower than at older ages [3]. At the same time, incidence of cervical cancer among the under-30s has been increasing [4]. Attendance could further decrease if future cohorts of women vaccinated against human papillomavirus (HPV) perceive themselves to be at low risk of cervical cancer and do not attend for screening [5]. The National Institute for Health Research Health Technology Assessment Programme recently approved funding for a randomized controlled trial to develop and test interventions to address this problem in Manchester and Aberdeen [6]. One of the interventions to be evaluated is a pre-notification leaflet, aimed to sensitize women to the need for cervical screening before they receive their first invitation letter. The leaflet will be one of several interventions offered to women in this trial. Research conducted amongst women older than 25 years indicates that single solutions are unlikely to have sufficient impact, given the multitude of perceived barriers to screening [7–9]. A particular problem is the lack of evidence on which to base strategies for young women aged 20–25 years. This article therefore reports qualitative research
undertaken to develop a pre-notification leaflet that would appeal to this younger age group. The research addressed key messages, as well as how to increase the chances that an unsolicited mailed leaflet on cervical screening would be opened and read. The latter required finding a presentational style that might appeal to women in their early 20s.

The transtheoretical model (TTM) provides a useful framework for understanding short- and long-term behaviour change [10]. It suggests that there are steps in adopting a behaviour involving progression from pre-contemplation (not engaging, or planning to engage with an action), to contemplation (not engaging in it, but considering it), preparation (taking steps towards engagement) and action (beginning to engage). In the context of cervical screening, most women before their first invitation will probably be at the pre-contemplation stage. The TTM model anticipates that at the pre-contemplation stage people perceive that the negative aspects of an action outweigh the positives. They may have heard about cervical smears but the majority will not know much about the programme or have given serious thought to being screened. Women do receive factual information with their formal screening invitation but it is relatively complex and unappealing [11], to the point of being non-motivational [12]. Providing written information to women smokers about the link between smoking and cervical cancer, for example increased women’s readiness to stop smoking [13]. The smoking study compared two leaflets and the briefer of the two proved more effective, perhaps because some women found concepts in the detailed explanation too difficult to grasp. Our objective was to identify information that was particularly relevant for young women called for cervical screening for the first time. This information was incorporated in a pre-notification leaflet to be evaluated in a randomized trial.

Methods

Study design

The study design was consistent with the recommended phased approach for developing and evaluating components within a complex trial that typically involves a number of interventions [14], as will be the case in the HTA trial [6]. In Phase 1 of this trial, the leaflet is sent to young women ~6 weeks before their first invitation, at age 24 years in Manchester and age 19 years in Aberdeen. This is facilitated by the local screening agencies, which maintain the population-based registers for the cervical screening programme. Some of the women will also be offered the option of a booked internet appointment. During Phase 1, a Discrete Choice Experiment, using interview and survey methods, will also be conducted to pilot and select proposed interventions for non-attenders (Phase 2). The purpose of the trial is to determine whether a range of complex interventions designed to improve uptake of cervical screening are successful when embedded within routine cervical screening programme practice.

Ethics

The development of the leaflet was undertaken prior to the start of the randomized controlled trial and ethical approval was granted by North West 8 Research Ethics Committee–Greater Manchester East.

Setting and participants

Young women aged 17–25 years, registered with the Robert Darbishire General Practice in Manchester, were contacted. This Practice is part of Manchester Medical School at the University of Manchester and its population profile represents a broad mix of ethnicities, students and other mobile groups.

Data collection

Four focus group discussions (FGDs) took place with 21- to 25-year old women who did not qualify for catch-up HPV vaccination, while a fifth recruited registered 17- to 20-year old women who had been offered routine HPV vaccination. A sixth focus group was held with cervical screening nurses at the Practice, but since it covered all the proposed trial interventions, it is only briefly reported here. The Practice first contacted registered individuals
for whom it held e-mail addresses. As this resulted in an over-representation of students, for two FGDs, a healthcare assistant contacted non-students by phone. Women who expressed an interest in the research were followed up by L.S., but many did not attend the scheduled FGD, despite reminders and the offer of a £15 High Street voucher.

FGDs took place at the convenience of the participants, either at the Practice or on the Research floor of St. Mary’s Hospital, which is a short distance away. Written consent was requested for digital recording. For the young women’s groups, two facilitators who were a similar age to the participants (L.S. and R.A.) used a discussion guide which covered the following topics: (i) What did they know about the cervical screening programme? (ii) Did they feel at risk of cervical cancer? (iii) What explanation would they offer for declining screening coverage? (iv) How important would it be for them to go for screening at their first invitation? At each session, participants indicated their HPV immunization status and completed a few written questions on date of birth, ethnicity and postcode sector to monitor the diversity of those interviewed. In their FGD, practice nurses were asked their views on the problem of declining screening coverage and how the Practice dealt with this. Time was given at the end of each session to answer participants’ questions and clarify factual points.

Data analysis and selection of leaflet format

Digital recordings were transcribed verbatim by an independent agency but each transcription was carefully checked and corrected for errors. The analysis and development of the leaflet were carried out by the authors. Important themes and sub-themes were identified using framework analysis [15]. Two researchers (L.S. and L.B.) manually read and coded the data independently, and then re-assessed the transcripts to agree the thematic framework. The analysis was intended to identify specific information likely to positively influence women’s reactions to their first screening invitation, and which, if absent, might constitute a barrier to timely acceptance (Fig. 1). Quotations have been corrected conservatively for readability.

Following initial data analysis, two further FGDs were conducted with previous participants who had indicated willingness to give their views on a suitable leaflet style. A copy of the proposed text was presented to the groups together with four possible designs. These included a leaflet folded like a card, with a birthday cake on the front cover, a six page folded leaflet with mobile phone text and ‘to-do’ list images, an A4 information sheet with coloured border and a six page folded leaflet featuring a picture of a bin with the slogan, ‘Don’t throw this away, it might just save your life…’ Their views on content, sequence of information and illustrations, length and general design and the varying viewpoints were analysed and summarized as mentioned earlier. This lead to selection of one of the leaflet designs (Figs 2 and 3) for use in the main trial. Further adjustments were made to the text after piloting at a local sexual health clinic.

Results

In all, 31 women attended the five FGDs for young women (Table I), of whom 20 were at school or in further education, while the remainder were employed (6), non-working mothers (4) or unemployed (1). Of those who reported their ethnicity (18), eight were non-white and two were white non-British. Four women had been invited for cervical screening and two had attended. Four participants had received two or three HPV vaccine doses.

What was known about the cervical screening programme?

General awareness

The majority had low awareness of cervical screening, including the vaccinated participants. Very few remembered being given information in school or through the NHS, although they acknowledged seeing leaflets and posters in hospital or at the GP
surgery. A typical response was

I only knew it because I’ve got friends that have been invited. . . . . I wouldn’t have known it otherwise. (FG1)

Screening invitation

Being younger than 25 years, most had not considered future screening although there was some awareness of the public debate about lowering the age of first invitation. Most were unclear about how you were called for screening or where you went. They mostly assumed they would get a letter, but did not know who sent it, and some expected to be asked to attend a hospital or a genitourinary medicine clinic. There was a view among some women that if you were not sexually active, you did not need to attend.

Purpose of screening

A few women stated that they had ‘not got a clue’ (FGD4) why they needed to go for screening. A common notion was that screening detected cancer. Some women accurately described the test as a collection of cells from the cervix, but others were unfamiliar with the term ‘cervix’. ‘Smears’ and swab tests for detection of sexually transmitted infections (STIs) were easily confused and led to perceptions that screening tested for HPV, DNA mutations, pelvic cancer and bacteria in the uterus and could itself introduce bacterial infection. In trying to relate their interpretation of these various tests to cervical screening, they tended to conclude that ‘there’s no definite test really is there?’ (FG3).

Details of the procedure

Most information came from friends and family, who conveyed their feelings about the test, rather than the procedure. As a result the majority view was that screening was ‘painful’, ‘unpleasant’, ‘uncomfortable’, ‘scary’, ‘intimidating’, ‘daunting’,
‘exposing’ and ‘intrusive’ and possibly required removing body hair. In short,

It’s something I feel a lot of people feel really awkward talking about...you wouldn’t really want to have a conversation, I mean, even with your mom it would be embarrassing. (FG1)

or

I think if anyone was trying to tell me I wouldn’t be listening... It’s just not nice to hear about. (FG5)

This reluctance to discuss intimate details with others included doctors and nurses.

**Did they feel at risk of cervical cancer?**

Perceived risk was low because they believed that cervical cancer was uncommon, predominantly affected older women and, from family experience, was often treatable. A typical view of cancer risk was that

it’s really very remote—in my opinion I wouldn’t truly think I would get it. (FG1)

All the vaccinated women assumed that vaccination reduced their cancer risk and had not given much thought to the level of protection it offered. One stated, when asked what the vaccine prevented,

I don’t know whether it was a bacteria or something that causes the cancer. I don’t know, I can’t remember what it was, but it stops that thing. (FG5)

Vaccinated and unvaccinated, women were generally unaware that HPV was a sexually transmitted virus.
I really wouldn’t never have thought you can get cancer from sex. (FG4)

One asked whether it could be transmitted through unclean hospitals during childbirth. They did not know that HPV was common in women of their age, or that it caused the cell changes that could be detected at screening. Most thought that cancer is caused by ‘multiple factors’ (FG2).

**Is screening important?**

When asked why they thought young women were not going for screening, the discussion touched on most of the barriers known to deter women such as lack of knowledge, fear, embarrassment, being busy, difficulty with making appointments, reduced trust in health recommendations and disgruntlement with previous health care. They also reflected on their own attitudes to screening, such as

We think we are young and we won’t get it (cancer). I think a lot of people think this. (FG1)
It’s worse than some STIs but people probably would be more likely to go for a STI test. (FG2)

When asked whether they will prioritize screening when invited, some responded that they did not ‘feel the need’ (FG3) or ‘think of it as necessary’ (FG1), at least not until after marriage or if they had symptoms. The low priority was reflected in the following statement:

I smoke, I drink like... I think cervical cancer isn’t something that’s on my radar as being concerned with. I am far more worried about other health issues than that. (FG2)

They would ‘try and make it’ (FG2) but typically, ‘it probably would get put on the backburner for quite a while.’ (FG1) One participant summed up the two aspects that most influenced women’s attitudes as follows:

In terms of actually being bothered, I think that is more related to how at risk you feel. If you are going to go, then it would be kind of down to whether you are... put off by the whole idea. (FG1)

Other women reinforced this view asking,

Why would I want to do that, like? I don’t have cancer. (FG2)

Yet, some women in all groups, and all women in FG4, were strongly motivated for screening, partly fearing regret should they later develop cancer. Young parous women were most anxious.

I don’t sleep about and that, no I’m not one of them, but it’s just I got kids int’it? I’ve got to think about me kids. (FG3)

and

I feel like I’ve waited that long. I mean I had my first daughter at 18 and since then I’ve been wanting to have one done, and I’m having to wait till I’m 25. So I think it will be the first thing I will do. (FG4)

Could a leaflet motivate them to attend?

After receiving corrected information from the facilitators, participants were able to identify some factual information that was key to their risk perceptions. One stated:

You know how you said there is a 10 to 15 year period, like a latency period like, between the changes and it becoming cancer... if the peak age is in your thirties, why is it a risk now? But now I understand that is when the changes start. (FG2)

Another said,

I don’t think you necessarily have to know all the details as long as you know the main point—that it is important to go for screening because it catches it early. At the end of the day that is the main thing. (FG2)

The deterrent effect of the procedure was emphasized, and they wanted ‘less medically written’ (FG1) information about what would happen, as well as reassurance. None of the vaccinated girls had been told about screening by the vaccinating nurse. They needed something that ‘actually helped link it together and stuff, cus otherwise you’d think, I actually thought, it was kind of two different things.’ (FG5)

Views of cervical screening nurses (FG6)

This session confirmed that the most common questions they answered related to smear procedures and pain, that it was much easier to take smears from parous women, and that women did not always distinguish a cervical smear from infection screening. Their experience suggested that women who delayed screening for years were fearful of the result rather than the procedure. When asked if they had received more screening requests when HPV vaccination was introduced they replied that they had queries about the vaccine but not smears, ‘never in the same conversation, they never related the two actually, which is strange.’ They spontaneously classified women into three groups: those who say no to cervical screening and ‘won’t enter
The goal with contemplators is to get them to think about the problem [16]—in this case, to motivate them towards positive action at their first cervical screening invitation. This requires them to reassess their thoughts, feelings and knowledge about the recommended behaviour and to become more aware of the health threat of failure to act. This study described a spectrum of young women, some of whom will attend screening regularly, not necessarily because they are better informed or more thoughtful, but because they generally accept health recommendations. Even these women may delay first attendance because they have a low perceived risk of cervical cancer at this stage of their lives.

Their perception of low cervical cancer risk at the Table II. Views on cover designs and presentation of information proposed for a pre-notified leaflet

<table>
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<tr>
<th>Reinforcing important messages</th>
<th>Age relevance</th>
<th>Readability</th>
<th>Motivational</th>
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<td>Highest cancer risk among women who do not attend is a key statement. Screening is not a cancer test (Needs stating but not as the opening statement as it may detract from its importance). Avoid cancer incidence statistics (encourages low risk perception). Overuse of statistics gives an impression that the reader needs to be convinced. Attach an NHS logo. Simple medical terms provide weight to the argument. Avoid anything that trivializes the topic (e.g. cartoons, clip art)</td>
<td>HPV is sexually transmitted. Justify contact at age 25. Provide a link paragraph to explain the birthday card cover. Draw a clear distinction between leaflet and first invitation letter. Use ‘you’ rather than ‘women of your age’ to personalize. State that screening is required by HPV vaccinated women. Only need to know that young women are invited every 3 years.</td>
<td>Remove terms ‘asymptomatic’ and ‘high grade changes’. Highlight important text because some women will skim read. Question and answer format preferred. Graphs and statistics generally difficult to interpret. Simple diagram of the cervix located in lower body preferred (did not want ‘a biology lesson’). Mixed views on including case histories/personal experiences. HPV types do not need to be given. Simple font preferred.</td>
<td>Message that screening saves lives is motivational. Contact your doctor if you do not receive your invitation. Get more information on line. Birthday cake design with ‘25’ on it gets positive attention. Leaflet should be less formal/detailed than the first screening invitation. Yellow is a happy colour. Provide reassurance that the test is quick and not painful. Avoid stressing that the reader has to make a ‘decision’ as this is confrontational.</td>
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The age of 25 years is, in fact, correct [17]. The most important information to convey, therefore, would be that persistent cervical changes occurring as a result of exposure to HPV infection have to be monitored when women are much younger and most at risk of contracting the virus that causes cervical cancer. Second, young, non-parous women are thoroughly deterred by what they have heard about the screening procedure even though, in some cases, they had undergone pelvic examinations to investigate STI symptoms. As they reassessed their cancer risk some participants were willing to contemplate cervical screening but others clearly remained opposed.

Although general reasons for the reluctance of women older than 25 years to take up screening in the UK are well documented [7, 18, 19], this study is novel because it focuses on messages most relevant to younger women just before their first screening decision. At this time, women have very confused and patchy knowledge about HPV and cervical cancer. This is not surprising—such poor knowledge is now well described, not only among women attending screening programmes [20] but also among girls who have been vaccinated [21]. Mothers are the key decision makers for vaccination of young school-aged girls in the UK, and while girls are often involved in the vaccine decision, this may not involve much discussion [22]. School nurses no longer have sufficient time for comprehensive health promotion in the classroom [23]. As a result, even vaccinated girls do not see HPV vaccination and screening as representing different stages of cervical cancer prevention. This is a gap that might be filled by a pre-screening leaflet, at least until a time when HPV vaccinated girls are better prepared to expect post-vaccination cervical screening or HPV testing. Better preparation would be preferable to relying on a leaflet that necessarily has to be short, read, understood and not offend. Practice nurses were generally sceptical that a leaflet would be read but its development was encouraged by women in their early twenties in this study, many of whom had not been eligible for HPV vaccination.

Experience of pre-screening notification in the context of the colorectal screening programme has been encouraging, albeit in a much older population. In Scotland, a trial of a pre-screening notification letter led to a modest uptake of colorectal cancer screening (OR, 1.24; 95% CI: 1.193–1.294) among all sociodemographic groups [24]. In England, a pre-notification letter sent 6 weeks before the scheduled invitation increased participation by ~6% [25]. Neither study specified which attitudes or barriers were modified by the intervention. Attitudes and beliefs are not easily changed, but some participants in our study signalled that they would reappraise their screening intentions now they understood their current risk of cervical cell abnormalities due to a STI.

As focus groups were the only method used to assess information needs, some caution should be exercised in simply relying on what women have said about their intentions and motivations. One advantage of focus groups is that participants not only present their own views and experiences but also hear from other people, which may lead them to reassess their standpoint [26]. Some of the participants returned to discuss the format of the leaflet, by which time their opinions were more considered and they could identify what had changed their own views. This also made them active participants in the research process. In principle therefore, this theoretically based pre-notification leaflet should be effective [27]. Evaluation within a randomized trial, however, is the most reliable way to determine whether a pre-notification leaflet of this type is useful and can, together with interventions for women who consistently ignore their screening reminders, significantly increase overall uptake at first invitation.

**Contribution to authorship**

L.S. helped to design the study, collected the data and analysed the results; R.A. co-facilitated the focus groups and corrected the final draft; R.S. organized data collection and participated in one of the FGDs; H.C.K. conceived the idea of including a pre-notification leaflet within the HTA trial, commented on the design and reviewed the manuscript;
L.B. designed the study, analysed the data and wrote the manuscript.

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Conflict of interest statement

None declared.

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