

# VALUING THE NHS CERVICAL SCREENING PROGRAMME AND ACCEPTABILITY OF THE INCLUSION OF HPV TESTING.

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Z Philips<sup>1</sup>, D Whynes<sup>2</sup>, M Avis<sup>3</sup> and S Johnson<sup>3</sup>

The notion of informed consent has been rehearsed repeatedly within the NHS including the participation in the cervical screening programme. However, previous studies have found that women's knowledge about cervical cancer and screening for the disease is poor, with many having unrealistic expectations of the screening programme. Despite this apparent misplaced knowledge-base of the female population, the current coverage of the English screening programme is around 84%.

There is now a strong possibility that HPV testing could be added to the NHS cervical screening programme. Studies from the USA suggest knowledge of HPV and its relation with cervical carcinogenesis is poor. The acceptability and value that women place on adding a test for a sexually transmitted disease that cannot be treated into a regular surveillance programme is unknown.

This paper presents pilot results in terms of women's responses to abnormal smear results, and their knowledge and understanding of cervical cancer, screening and HPV. The pilot work serves as a prerequisite to a large questionnaire survey and interview study which will seek to:

- 1) ascertain women's knowledge and understanding of cervical cancer and the NHS cervical screening programme and understand how women currently value the programme.
- 2) identify how adding HPV testing to the current screening programme might change women's valuations.
- 3) understand women's motivations for screening and their potential acceptability of routine HPV testing.

The survey instruments and outline interview schedule are presented as an appendix to this short paper, which provides a background and framework for this research. The purpose of this paper is to obtain comment upon the questionnaire and the theoretical context in which this study is being undertaken.

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<sup>1</sup> Centre for Health Economics, University of York. Corresponding author: E-mail znp2@york.ac.uk.

<sup>2</sup> Department of Economics, University of Nottingham.

<sup>3</sup> Postgraduate School of Nursing, University of Nottingham.

## Introduction

The aim of the NHS cervical screening programme is to reduce the incidence of, and mortality from, invasive cervical cancer in women. This has been achieved by regularly screening women using cervical cytology or the Pap smear test, in order to detect and treat cervical abnormalities before invasive cancer occurs.

There is evidence that the screening programme has been successful. There has been a 26% fall in the incidence of the disease over the last five years and rates are now as low as 9.3 new cases per 100,000 [1]. Mortality from the disease is also falling at a rate of 7% per year and current mortality from the disease is around 3.7 per 100,000 per year [2]. It has been estimated that the programme prevents around 3900 cases of cervical cancer each year [3] and that approximately 6000 deaths from the disease have been prevented over the past decade [4].

However, mass screening has not been accomplished without social and psychological costs. Invitation for screening itself has been found to cause anxiety in some women, which is not always allayed by a normal result [5, 6]. Moreover, the effectiveness of the programme has been achieved by a system geared toward high sensitivity. This inevitably results in large numbers of women being followed-up after abnormal smears. For minor cervical abnormalities, which represent the majority of abnormal smear results, follow-up may be of no clinical benefit - either because abnormalities are not truly pre-cancerous, or because they may regress spontaneously. The psychosocial effects associated with the receipt of an abnormal result are well documented (see [7] for a review), in particular the uncertainty and anxiety caused by follow-up and treatment [8], [9]. Moreover, there is always a proportion of women who will receive a false positive result, leading to increased worry and unnecessary treatment [10]. This is pertinent because the number of abnormalities detected on smears has increased in recent years [3] and is predicted to rise further [11].

The notion of informed consent has been rehearsed repeatedly within the NHS [12] [13], including the participation in the NHS cervical screening programme [14] [15]. Informed participation in cervical screening should ensure all women are fully aware of the purpose of the screening programme and its mechanics, as well as the benefits, potential limitations and current uncertainties. However, previous studies have found that women's knowledge about cervical cancer and screening for the disease is poor [16, 17], with many having unrealistic expectations of the smear test. There is a perception that the disease is more prevalent than it is, perhaps due, in part at least, to the social amplification of the risk of disease through constant media and primary care attention [18]. Risk factors for the disease are also mis-understood [19] [20]. Understanding of the purpose and the meaning of the results of screening tests are inaccurate - that the test aims to detect cancer and that an abnormal result means cancer [7]. There is also a perception that the test is infallible. The case at Kent and Canterbury [21] and the more recent findings from an audit at Leicestershire [22] [23] are cases in illustration. It is unsurprising therefore, that normal smear results are perceived to represent a situation of "all clear", and of no risk of disease [24]. Media focus on such cervical screening "mistakes" [25] has led the NHS to re-iterate the purpose of cervical screening to ensure accurate information is conveyed to women about the limitations of the programme [26, 27].

Despite this apparent misplaced knowledge-base of the female population, the current coverage of the English screening programme is around 84% [28]. However, this has probably as much to do with the efficiency of the call-recall system and primary care incentives (target payments to general practitioners), as it has “informed choice” on the part of the subjects. The call-recall system, which is based on a series of invitation and reminder letters, places emphasis on the 'normality' of cervical screening for women, adopting what might be referred to as an 'opt out' system [29]. It has been suggested that many women participate in cervical screening out of a sense of obligation and duty rather than an accurate perception of the costs and benefits [30] [31]. Expert assessment of risk, and paternalistic expectations that all eligible women should participate in screening, may be in conflict with an increasing emphasis on information for informed participation.

There is reason to believe that the screening programme itself generates both process and outcome utility, i.e. that there is value attached to the results of screening interventions by way of information, and also through the act of participating in the screening process itself. Indeed, routine and regular surveillance through screening appears to bring re-assurance to women [32], and has been described as an element of the definition of femininity [29].

At present, therefore, we remain unclear about women's motivation for participation in cervical screening, the meaning they attach to the information obtained from screening, and the value that they place on it.

### **Potential adjuncts to the screening programme**

At present the NHS cervical screening programme is unable to distinguish between minor cervical abnormalities that are likely to progress to more severe disease and those which will not. It is now understood that certain strains of the Human Papillomavirus (HPV), which are normally transmitted sexually, are central to the aetiology of cervical cancer. Over 90% of invasive cervical cancer is caused by HPVs [33]. Accordingly, there has emerged an interest using supplementary HPV testing, as a means of improving both the accuracy and the cost-effectiveness of the existing screening programme [34]. However, HPV infection is very common - lifetime risk of infection is of the order of 50% [35]. Very few HPV infections actually lead to cervical dysplasia. In many cases, infection is transient, short, has no symptoms and does not cause any lasting cervical pathology [36]. Moreover, there is no treatment for these strains of HPV infection. HPV testing methodology has improved tremendously in recent years, but there still appears a problem with low specificity (in relation to cervical abnormalities), especially in younger women [36] [37].

Clinical trials are currently under way in both the UK (TOMBOLA) and the USA (ALTS), to establish both the precise nature of HPV-cancer relationship and the cost-effectiveness of using supplementary HPV testing as a screening technology. In addition, pilot studies are being undertaken in three sites across the UK to assess whether liquid-based cytology and HPV testing as a form of triage for mildly abnormal smears can reduce the number of repeat smears and colposcopy referrals.

Research from the USA suggests that knowledge-base among young people about HPV infection is insubstantial, with the great majority appearing never to have even heard of HPV [38] [39] [40] [41]. The relation between HPV and cervical cancer also appears ill-understood [20]. Not surprisingly, risk perceptions are wildly inaccurate [42]. Indeed, there is evidence that HPV and sexual risk information might be suppressed deliberately by health care professionals, for fear of deterring women from attending for routine screening [43]. In the UK, there are no studies which assess HPV knowledge specifically, but studies relating to women's understanding of abnormal smear results have shown the mention of HPV to cause considerable uncertainty [9], in particular by generating feelings of guilt and blame [44].

The acceptability and potential value placed on adding HPV testing to the NHS cervical screening programme has not yet been evaluated. HPV testing focuses attention on aspects of *lifestyle* as a risk factor in cervical cancer (early sexual activity, multiple partners), which may both stigmatise the detection of cervical abnormalities and transform the meaning of cervical screening. Individual decisions to attend for cervical screening which include HPV testing would need to take account of the risk of acquiring a stigmatised lifestyle.

The new screening technology has the potential to influence perceptions of risk and indeed, control over that risk. Moreover, the results of HPV testing provides information on the presence (or absence) of certain virus types, which may provide risk information about the progression of cervical abnormalities. It cannot provide information about how to manage that risk, or indeed, how to minimise that risk. These HPV infections cannot be treated, and HPV test status can, at best, be seen as a secondary source of information for the prognosis of progression of cervical dysplasia. The effect of this uncertain information on women is unknown. The technology itself may therefore become a source of danger, through the delivery of information that promotes dependence, powerlessness and individual blame without control [45].

### **Aims of research**

The ultimate aim of the research will seek to establish how the introduction of Human Papillomavirus (HPV) testing as part of cervical screening affects women's perceptions of risk, the meaning and value of information obtained from screening, and consequences for health-related behaviour. More specifically we aim to:

1. ascertain women's knowledge and understanding of cervical cancer and the NHS cervical screening programme and understand how women currently value the programme.
2. identify how adding HPV testing to the current screening programme might change women's valuations.
3. understand women's motivations for screening and their potential acceptability of routine HPV testing.

### **A framework for analysis**

The theoretical context of the research question concerns the impact that a new screening technology will have on health behaviour, by investigating its consequences for social construction of risk, perceptions of medical authority and individual responsibility. As an initial framework, we take the perspective of an (economically) rational decision-maker where the decision to participate

in screening will be based on a rational response to cost/benefit evaluation. We hypothesise that the utility obtained from screening and the value placed on it will be a function of personal disposition toward medical authority and peers, perception of risk, and knowledge or information about the screening process and beliefs about the disease. Moreover, we see this process as cyclical with participation in screening generating experience and knowledge about the process and disease, conceivably updating individual preferences and value. Transmission of information therefore, is pivotal to this decision-making process. Our framework is summarised in figure 1.

Our pilot work has taken two of the elements of this framework independently to begin to understand the decision-making process and the elements that may effect the value of screening.

### **Pilot study 1: Transmission - communicating mild and borderline smear abnormalities.**

The aim of the study was to investigate women's responses to detection of mild or borderline abnormalities, to audit the methods by which abnormal smear results are communicated to women; and to assess the content of these communications.

The research design employed two focus groups of women who had received abnormal smear results, together with a questionnaire survey and follow-up telephone interviews with general practices in Nottingham. Figure 2 summarises the main themes and inter-relationships which emerged from the focus groups. The data suggested that the immediate response to an abnormal result is alarm, rapidly giving way to a range of individually-induced concerns. It was clear these concerns were only partially alleviated by the support provided by health care practitioners. Uncertainty about the result and the reasons for surveillance remained. Understanding the notion of cervical pre-cancer and receiving answers to their more detailed questions, such as those relating to viral infections, evidently posed some problems, and a feeling of isolation was frequently expressed by the focus group participants, who felt themselves to be "different" or unusual by virtue of their abnormal results. Within this perceived isolation, an explanation for their result would be constructed on the basis of their own beliefs or understandings, by self-education and speaking to family and friends. Apportioning blame was common, along with feelings of guilt. But, despite these emotions, the women consistently felt it inappropriate to approach their general practice for assistance. Whilst this individual perception was evidently a barrier to the resolution of the women's concerns, inherent system shortcomings were also perceived. The information leaflets issued by GPs were believed to be out of date and were too general to address specific worries or concerns. The women had evidently identified a paternalistic attitude on the part of care professionals, but had also expressed confusion about the language employed. Other cited inhibitions to consulting were a fear of being labelled as a "complainer", embarrassment and the feeling that one would be treated impersonally.

The questionnaire survey to general practices showed that transmitting mild or borderline abnormal smear results is typically the responsibility of the practice nurse, either by standard letter or telephone call. However, upon detailed analysis of the standard letters, it was clear that they varied tremendously in both informational and emotive content. Although in 1997 the NHS CCP has issued guidelines about the written content of information conveyed to women (ref), none of our sample appeared to adhere to them. The most common type of information communicated was

that the result did not indicate cancer, and the management protocol to follow. Few offered an explanation of the meaning of the result.

The clearest message to emerge from this pilot study was that, even within a single city, there exists wide variations in both method and content in communicating mild and borderline smear results, including the personnel principally involved. Each practice had evidently routinised, to its own satisfaction, a communication protocol. Template letters, which displayed variations in content and which were often accompanied by information leaflets, were the means most frequently used to communicate results, but these were seen as inadequate by women. Information on future management and attempts to allay the fear of cancer were commonly included in communications from most practices, although only a minority addressed the HPV issue. This appeared to leave women with persistent uncertainty about the nature of the result, yet there was a self-imposed barrier gaining further information.

### **Pilot study 2: Willingness to pay for a cervical smear test.**

The aim of this study was to obtain estimates of the value of cervical screening and to rehearse the hypothesis that knowledge-base and perception of risk effects valuation. Although there are previous studies which indicate that women's knowledge of cervical cancer is poor, none of these examined the effect this has on value. As a supplementary aim, we also wanted to examine the potential acceptability of introducing HPV testing into the current screening programme.

A questionnaire was constructed, piloted for ease of completion and subsequently sent to a sample of 500 female university students at the university of Nottingham. Knowledge of cervical cancer and of screening were assessed by multiple choice questions - for example subjects were asked to identify an annual population risk from a range of 1 in 100 to 1 in 15,000. They were also provided with an un-labelled bar chart, indicating the number of annual female deaths arising from breast, bowel, cervical and lung cancer, and were required to label the bars on the basis of their beliefs as to the identity of each. They were offered a list of eleven potential risk factors for cervical cancer, and asked to identify those which represented true risks. Knowledge of the screening programme was assessed from questions pertaining to the organisation of the screening protocol, the accuracy of the test, abnormality detection rate and estimated number of cases prevented by screening. In addition, individual risk assessments were obtained (in the form higher, lower or the same as someone of your own age) and basic socio-economic/demographic characteristics.

The value place on a smear test and attitudes towards HPV testing were gauged by using the willingness-to-pay (WTP) method [46]. To obtain a baseline value, subjects were requested to supply a WTP valuation for a single Pap test, using a payment scale ranging from zero to £100. Thereafter, they were required to augment this valuation under two sets of circumstances. As it has been suggested that HPV testing might be able to target the screening programme more effectively, subjects were asked to indicate how much extra they would be prepared to pay for a 10 per cent increase in screening accuracy. They were then invited to revise this estimate if such increased accuracy also entailed testing for a sexually-transmitted disease. By hypothesis, subjects' valuation of increased accuracy would be influenced, *inter alia*, by their knowledge of cancer and of the capabilities of the screening test. We accordingly formulated a simple OLS regression model with WTP for increased accuracy as the dependent variable.

The response rate to the questionnaire was 45%. In terms of knowledge-base, there was a consistent over-estimation of the prevalence of disease, with many believing the disease was more common than bowel cancer. Knowledge of risk factors was good, yet many (over 80%) cited family history as a significant risk. Knowledge of the screening programme itself was mixed, with virtually all responders being aware of the screening protocol (i.e. every 3-5 years between the ages 20-64), but the majority under-estimating the abnormality rate and over-estimating the age at which abnormal results occur. The baseline mean WTP was £24.80 (SD 22.1) and the mean increment for increased accuracy was £15.30 (SD 18.00).

The regression model explaining WTP for increased accuracy included six independent variables. These were, first, baseline WTP for Pap screening, second, whether the subject perceived herself as facing higher than average risk and, third, whether the subject was a smoker. We predicted a positive coefficient in the first case, on the grounds that a higher baseline value would be expected to generate a higher incremental value. Similarly, women perceiving themselves to be at higher risk would be expected to value accurate screening more highly. A negative coefficient was predicted for smokers, on the grounds that smokers are likely to possess a lower health motivation generally and thus a reduced interest in screening. Such a negative association has already been detected in other forms of cancer screening [47, 48]. The three remaining independent variables were knowledge-based. First, we should expect that women who under-estimate the proportion of abnormal smears routinely detected would place a lower incremental value on increased accuracy, because a belief that abnormalities are rare implies that the test's information content would be, to them, minimal. Second, women who over-estimate the accuracy to the existing smear test, i.e. perceive it to be high already, would presumably attach lower values to further increases in accuracy, *ceteris paribus*. Finally, women who believe that most abnormalities occur in a proximate age group should place a higher value on accuracy than those who believe that abnormalities are more common in an age group distant from them.

Table 1 displays the regression model and the signs for all coefficients are consistent with the above hypotheses. Only three of the coefficients, achieve statistical significance. With respect to the second WTP augmentation – valuation for a more accurate test which also identified STDs – over half of the sample (55.2 per cent) provided precisely the same value as for the first augmentation. Around one third (36.5 per cent) were actually willing to pay more, whilst only a minority (8.4 per cent) revised their estimate downwards. The mean WTP for increased accuracy including the STD test was £18.3 (SD 20.8). This was significantly higher than for the mean value of increased accuracy alone ( $t=-4.0$ ,  $p<0.01$ ) and implies a modest positive valuation on STD testing *per se*.

As this sample was confined to university students, generalisations as to the female population as a whole are problematic, although such a limitation also confers advantages. First, the sample is, in comparison with the population, homogenous, with many potentially confounding variables, such as age, income and educational level, being implicitly controlled. Second, our restricted sample makes our findings directly comparable with those of studies of university populations in the USA ([42] [38] [40] [41]). These studies also show that only a minority of women has any knowledge or awareness of HPV. Only one of these studies [42] addressed the valuation issue specifically and discovered that the majority of its subjects would regard the HPV test negatively, in view of its

sexual connotations. In contrast, this appeared to be an obstacle for only a small minority in our study, presumably implying a less alarmist attitude towards STDs.

The general over-estimation of cervical cancer risk exhibited by our sample is consistent with the social amplification hypothesis, namely, that repeated attention via the media and primary care makes individuals believe that the likelihood of an event is considerably higher than it really is [18]. The hypothesis also explains the failure of our sample to identify bowel cancer as a major risk, as mass screening for this disease has only been contemplated in England in the past few years [49].

### **Lessons from the pilots**

Our two pilot studies have shown firstly, that information transmitted to women at the time of a mild or borderline smear result is variable. Although an immediate fear of cancer is allayed, uncertainties remain about the meaning of the result. However, women also appear reluctant to approach health care professionals with questions, and formulate their own beliefs on the basis of speaking to friends and relatives, and taking information from media sources.

We have also demonstrated a relationship between knowledge, perception of risk and value, and that behaviour appears consistent with the traditional rational response model. It is interesting to note that our respondents over-estimated the prevalence of cervical cancer. We explain this with the social amplification hypothesis. Social amplification is particularly valuable in maintaining high compliance with screening, because individuals will be better disposed towards screening if they believe the disease to be widespread and the screening method effective.

It follows from this however that, were our sample to be *correctly* informed, their individual valuations of screening would fall, as would the overall compliance rate [50].

### **The next stage**

The next stage of this research is to initiate a Trent-wide study to understand in more detail, the relationships in the feedback mechanism between transmission of information, knowledge and value. In response to the complex objectives, a combination of quantitative and qualitative instruments (a community-based questionnaire survey and semi-structured in-depth interviews) are being used.

The study population will be women of screening age (i.e. aged 20 - 64). Two recruitment avenues will be pursued in order to obtain a sample for this research: the Trent Focus Collaborative Research Network (CRN), which provides an infrastructure for research in general practice and their populations, alongside screening invitations from Nottingham Health Authority. 8000 questionnaires will be distributed in total. Two versions of the questionnaire will be administered in a random order. Version one contains questions about cervical cancer and screening (enclosed) and version two contains information about cervical cancer and screening. The questionnaires have been developed in response to the pilot studies and have undergone thorough piloting (questionnaire administration with follow-up interview). We welcome all comments.

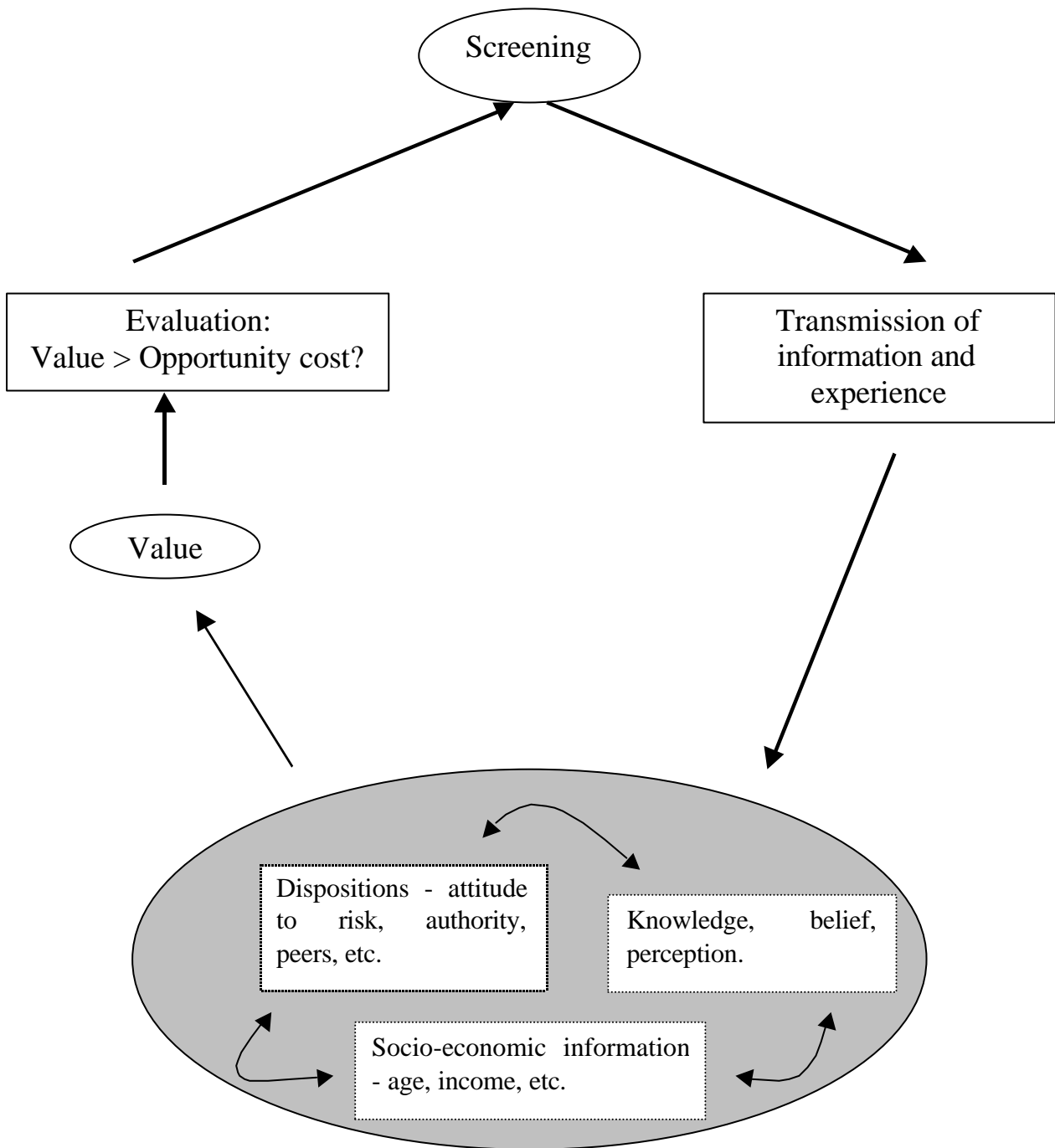


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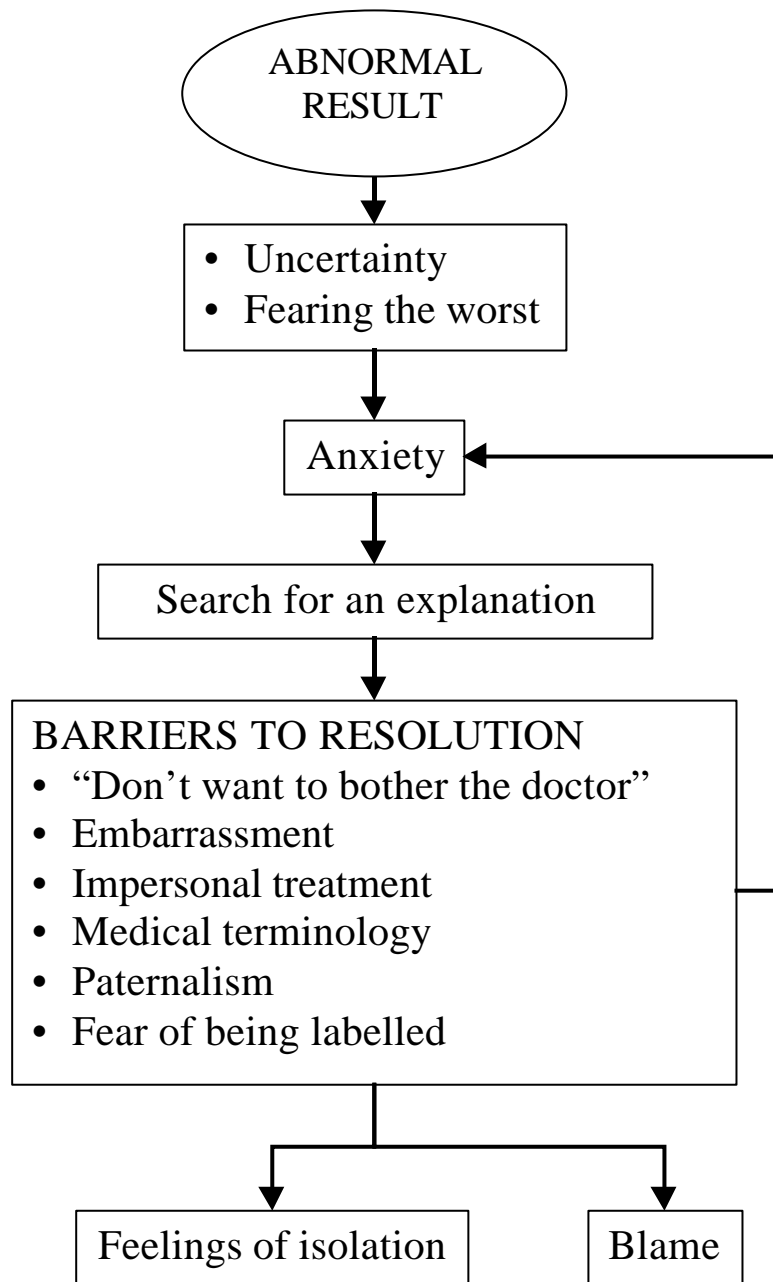
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Figure 1 Framework for analysis



**Figure 2** Thematic summary of focus group data



**Table 1 Regression results: WTP for increased test accuracy**

	<b>Beta</b>	<b>SE</b>	<b>t-ratio</b>	<b>p</b>
Constant	7.77	2.22	3.49	0.00
WTP for routine smear test (£)	0.45	0.04	10.61	0.00
Proportion of smears testing normal ( 1 = under estimate)	-4.67	1.89	-2.47	0.01
Accuracy of smear test ( 1 = over estimate)	-3.65	2.33	-1.56	0.12
Age where most abnormal results occur ( 1 if age estimated at >35 years)	-2.08	1.92	-1.08	0.28
Current smoker (1 = yes)	-5.75	2.50	-1.64	0.10
Perceived personal risk above average ( 1 = yes)	12.46	4.39	2.84	0.00

Adjusted  $r^2 = 0.39$

**Appendix Questionnaire (preamble not included and font size reduced due to space constraints)**

**Section 1: Your experiences with the NHS cervical screening programme**

*For each question, please place a cross ✕ in the most appropriate box or write your answer in the space provided.*

- |   |  |  |  |
|---|--|--|--|
| <b>1. Do you attend for regular cervical smear tests?</b>   | Yes always<br><input type="checkbox"/> | Yes<br>sometimes<br><input type="checkbox"/> | Never<br><input type="checkbox"/>          |
| <b>2. Have you ever had a 'technically unsuitable' or 'inadequate' smear (i.e. the laboratory was unable to analyse the smear)?</b> | Yes<br><input type="checkbox"/>        | No<br><input type="checkbox"/>               | Not applicable<br><input type="checkbox"/> |
| <b>3. Have you ever had an abnormal smear?</b>  | Yes<br><input type="checkbox"/>        | No<br><input type="checkbox"/>               | Not applicable<br><input type="checkbox"/> |
| <b>4. Please explain, in your own words, your understanding of the meaning of an <i>abnormal</i> cervical smear result?</b>         |  |  |  |

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Please consider the following statements and indicate your strength of agreement or disagreement. *Please circle the appropriate number on the scale from 1 - "strongly disagree"; 2 - "disagree"; 3 - "neutral"; 4 - "agree"; to 5 - "strongly agree".*

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
<b>5. I think the cervical smear test is uncomfortable.</b>	1	2	3	4	5
<b>6. I think the cervical smear test is embarrassing.</b>	1	2	3	4	5
<b>7. The main reason I attend for cervical smear tests is because my doctor tells me to.</b>	1	2	3	4	5
<b>8. I think the cervical smear test is painful.</b>	1	2	3	4	5
<b>9. I think it is my duty to attend for regular cervical smear tests.</b>	1	2	3	4	5
<b>10. I am re-assured to know that I will be called for a smear test at regular intervals.</b>	1	2	3	4	5
<b>11. All women ought to attend for cervical smear tests.</b>	1	2	3	4	5
<b>12. I am satisfied with the NHS cervical screening programme.</b>	1	2	3	4	5
<b>13. I would prefer to have a cervical smear test every year.</b>	1	2	3	4	5

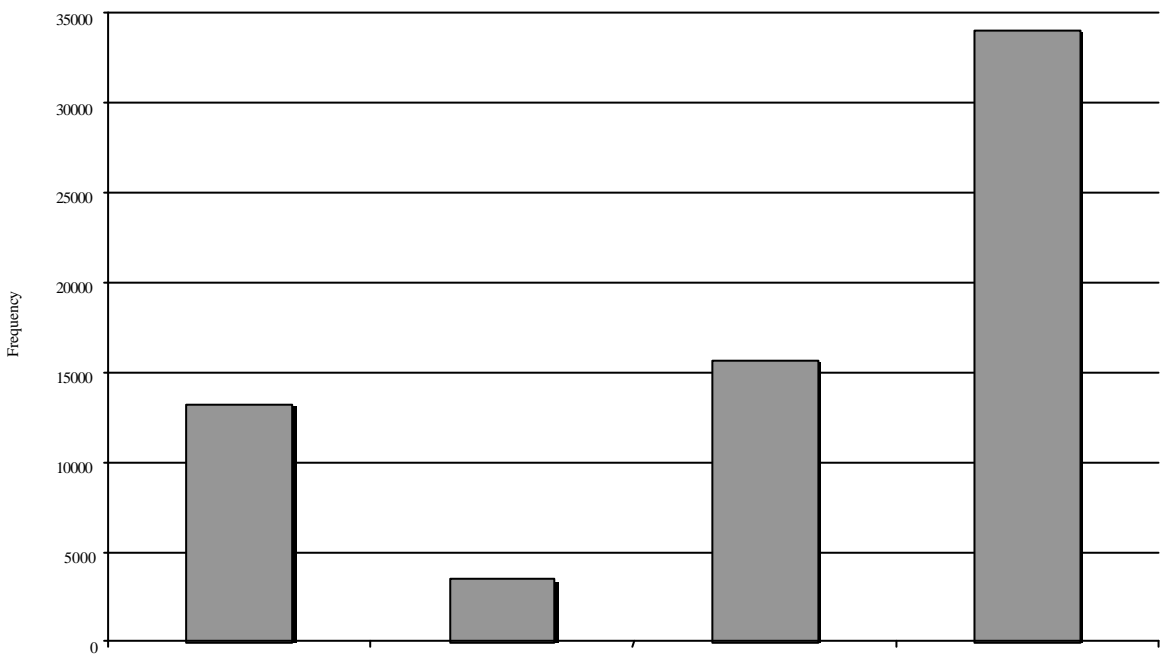
**Section 2: Your awareness of cervical cancer and the NHS cervical screening programme.**

For each question, please place a cross ✕ in the most appropriate box or write your answer in the space provided. Please do not leave any questions blank - if you are not sure of the answer, have a guess.

**14. How common do you think cervical cancer is in the UK?**

- 1 in 100 women get cervical cancer each year
- 1 in 1 000 women get cervical cancer each year
- 1 in 5 000 women get cervical cancer each year
- 1 in 10 000 women get cervical cancer each year
- 1 in 20 000 women get cervical cancer each year

**15. The bar chart below details the estimated *annual number of newly diagnosed cases* of four different cancers in *women in the UK*. The bars represent breast cancer, lung cancer, colorectal cancer and cervical cancer, but not necessarily in that order. Please label the graph. For example, if you think the first bar represents breast cancer, write breast above the first bar.**



**16. How accurate do you think the cervical smear test is?**

- 99% or better
- Between 75% and 98%
- Between 50% and 74%
- Less than 50%

**17. Which of the following do you think are risk factors for cervical cancer?  
(Please respond to each option)**

	Major risk	Minor risk	No risk	Don't know
Unprotected sex (not using a condom)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of pregnancies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Multiple sexual partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Excess weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Early first intercourse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Human papillomavirus infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Early first pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chlamydia infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetic factors (i.e. a family history)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Contraceptive pill usage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**18. Approximately how many cases of cervical cancer In the UK do you think are prevented by the NHS cervical screening programme each year?**

- Less than 1000
- Between 1 000 and 4 000
- Between 4 000 and 9 000
- Over 10 000

**19. At what ages are women most likely to have an abnormal cervical smear result?**

- 18-25
- 25-35
- 35-50
- Over 50

**20. Approximately what proportion of women in the UK receive an abnormal cervical smear result each year?**

- 1%
- 5%
- 10%
- 20%
- 30%



### Section 3: Valuing the NHS cervical screening programme

We would like to know your opinions about the value of the current cervical screening programme and your views on introducing additional testing.

One way of measuring the value of the NHS screening programme is to ask people how much they would be prepared to give up (pay) in order for the service to be provided. In other words, how much is the screening programme worth?

**It is important to remember that the NHS cervical screening programme is provided free of charge and will continue to be provided free of charge. Also, if any additional tests were to be introduced into the cervical screening programme, these would also be provided free of charge.**

**We believe that people should not have to pay for their health care.** The following questions are simply a method of measuring how strongly you value the service and how you might value the introduction of additional testing.

There are no right or wrong answers. The amounts you say can be small or large. It all depends on how much screening is worth to you.

#### **Current follow-up procedures for abnormal smears.**

*(Please read before answering question 21.)*

- As part of the cervical screening programme, some women are followed-up because they have an abnormal smear.
- At present, women who have minor abnormalities detected on their smear are asked to have a repeat smear every six or twelve months.
- This is because the majority of minor abnormalities will clear up on their own.
- Women with more severe abnormalities, and women whose minor abnormalities do not disappear over time or worsen are usually referred for colposcopy.
- A colposcopy is performed by specially trained clinicians at an outpatient appointment.
- A colposcope is a low-powered microscope.
- It is used to examine the woman's cervix to assess the extent and severity of any problem and to determine appropriate treatment.

**21. What is the maximum amount of money you would be willing to pay for having the complete series of cervical smear tests every 3-5 years between the ages of 20-64, which would include the current follow-up procedures for abnormal smears?**

*Please circle around the maximum amount you would pay. (PAYMENT CARD PRESENTED BETWEEN £0 - £1000. Space for respondent to write amount more than £1000)*

**22. Please can you explain in the space below how you arrived at your answer to Q21?**

## The proposed changes to the follow-up of abnormal smears.

*(Please read before answering question 23.)*

- There is a possibility that the screening programme may introduce additional testing for women who have minor abnormalities detected on their smears.
- It is hoped that the new test will be more accurate in being able to distinguish women whose abnormalities are likely to disappear from those whose abnormalities will not.
- Those women who have a negative test would be re-assured more quickly that their smear abnormality is likely to go away without treatment, and would have reduced follow-up (instead of having smears every 6-12 months, they would return more quickly to 3-5 yearly screening).
- Women who have positive test would be referred for colposcopy more quickly.
- Women would find the test rather like a smear test as it involves taking a sample from the cervix. This sample would be analysed in a different way to a smear test.

**23. In the light of your answer to Q21, how much extra would you be prepared to pay for the cervical screening programme if it included the new test (as detailed in the box above) as part of the follow-up for abnormal smears? (your answer can be any amount, including zero)**

£.....

## Further information about the new test.

*(Please read before answering the next questions)*

- The additional test will detect certain types of human papillomavirus (HPV).
- This is a very common virus, which is usually transmitted sexually.
- Around half of all women will get an HPV infection at some point in their life.
- It is more common in younger women.
- Most HPV infections have no symptoms, they pose no risks and go away of their own accord within about 12 months.
- There are a small percentage of HPV infections that are persistent
- It is thought that persistent HPV infections may lead to more severe cervical abnormalities at some time in the future.
- The new test would not be able to tell if the HPV infection is a persistent infection.
- Over 95% of women with cervical cancer have HPV, but only a small percentage of HPV infections could lead to cancer.
- There is no treatment for these types of HPV infection.

**24. In the light of this further information about the new test, would you like to make any changes to the value that you placed on the additional test (i.e. your answer to Q23)?**

Yes, I would pay more than I specified in Q23

Yes, I would pay less than I specified in Q23

No, I do not want to change my value

25. If YES, please write your new valuation in the space provided.

£.....

**Section 4: About you**

Questions asked here: age, ethnic group, marital status, employment status, occupation, household income, smoking status, worries about cervical cancer, personal risk perception about cervical cancer, family history (cancer generally and cervical cancer).