

**PROMOTING INFORMED CHOICES ON CANCER SCREENING
IN A DIVERSE COMMUNITY**

Guidance for service providers and health promoters

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The author would also like to acknowledge the kind permission granted by Dr Cynthia Stein to reference the table of modifiable risk factors for cancer that appeared in her journal article.

INTRODUCTION

What informed the writing of this guidance?

This guidance is based on the work of a participatory action research project entitled Informed Choice For All: Communicating Risk Information about Breast and Cervical Cancer and Cancer Screening to Women from Minority Ethnic and Low Income Groups.* This ran between 2005 and 2008 and was funded by the NHS Cancer Screening Programmes. This guidance reflects the experiences gained through the project and the contributions of the participants.

Who is the guidance for?

This guidance is intended to support health promoters working for healthcare organisations and service providers who are involved in breast and cervical cancer screening to facilitate informed choice in a diverse community. They can be professionals who work in the primary care setting, practice nurses and general practitioners, health visitors, Macmillan nurses, hospital and community midwives, breast care nurses, community health workers or health trainers. They can also be community (lay) health educators who work in the NHS setting or voluntary sector setting.

How can the guidance help?

The guidance can help health promoters to:

- understand the parameters of and limits to a health promoter's role in promoting informed choice
- understand the risk communication process for planning conversations about cancer and cancer screening risks with women
- understand the need to have reference materials and resources to hand to enhance communications
- design health interventions for groups or individuals to encourage dialogue with women about cancer risks, particularly those who are most vulnerable
- stimulate women's interest and reinforce their understanding of some of the crucial messages that might play a role in helping them to make choices by using the accompanying toolkits.

The structure of the guidance

The guidance is written in five parts:

Part 1: Knowledge informing risk communication and informed choices – presents some of the key findings of the project that supported the writing of this guidance, and highlights the types of opinions that were found, with a view to helping health promoters to understand what their clients/patients might bring to the risk communication encounter.

Part 2: Concepts – presents the current understanding of the concept of informed choice and its related concepts of risks and risk communication in the context of cancer screening.

* The full research report is published by the NHS Cancer Screening Programmes (*Communicating Risk Information about Breast and Cervical Cancer and Cancer Screening to Women from Minority Ethnic and Low Income Groups*. NHS Cancer Screening Programmes 2009 (Cancer Screening Series No 5)). Available from www.cancerscreening.nhs.uk.

Part 3: Issues and context – highlights the issues surrounding the promotion of informed choice in a diverse community and provides examples of good practice around the country.

Part 4: Effective risk communication – provides general guidance for service providers on how informed choice can be promoted through effective risk communication about cancer and cancer screening.

Part 5: Resources – is a list of resources that professionals can access to facilitate the communication of risks about cancer and cancer screening.

The accompanying toolkits

Accompanying this guidance is a risk communication tool that was developed in response to the finding that some women, particularly those who are vulnerable or have low literacy skills or whose first language is not English, do not have adequate knowledge about the risks that are associated with breast cancer and what the screening programmes can realistically achieve. The toolkit is available as a PDF to download from the NHS Cancer Screening Programmes website. It can help women to discuss their perceptions of cancer and cancer screening risks. A risk modification table developed by Dr Cynthia Stein of Harvard University can be downloaded by following the reference.¹

What this guidance is not

This guidance document is not an expert document on the topic of cancer or cancer screening.

It does not offer a comprehensive and definitive view on risk communication and informed choice but rather suggestions based on results from the Informed Choice For All project.

Risk information about breast and cervical cancer and cancer screening contained in this document is limited to relevant information retrieved during the period of our research between 2005 and 2008. The author is not responsible for information updated subsequent to the accessing of sources.

PART 1: KNOWLEDGE INFORMING RISK COMMUNICATION AND INFORMED CHOICES

1.1 Research methods employed

The aims of the Informed Choice for All project were:

- to investigate, using a participatory action research approach, how the risks and benefits of existing screening programmes (cervical and breast) are understood by health professionals and minority ethnic and low income groups, and to determine the mechanisms by which risk information can be effectively communicated to facilitate informed choice
- based upon the above, to produce guidance for services providers and health promoters on informed choice in the context of cancer screening.

We used mixed methods including focus groups, Q-methodology and consensus forums at different stages of the project to engage stakeholders and members of the target communities to explore what might be the issues involved in promoting informed choice. A quasi-experimental trial was also conducted to test the effectiveness of the risk communication tool developed based on results obtained in earlier stages of the project.

Figure 1 shows how these methods were applied at each stage. Details about each method are presented in the research report.[†]

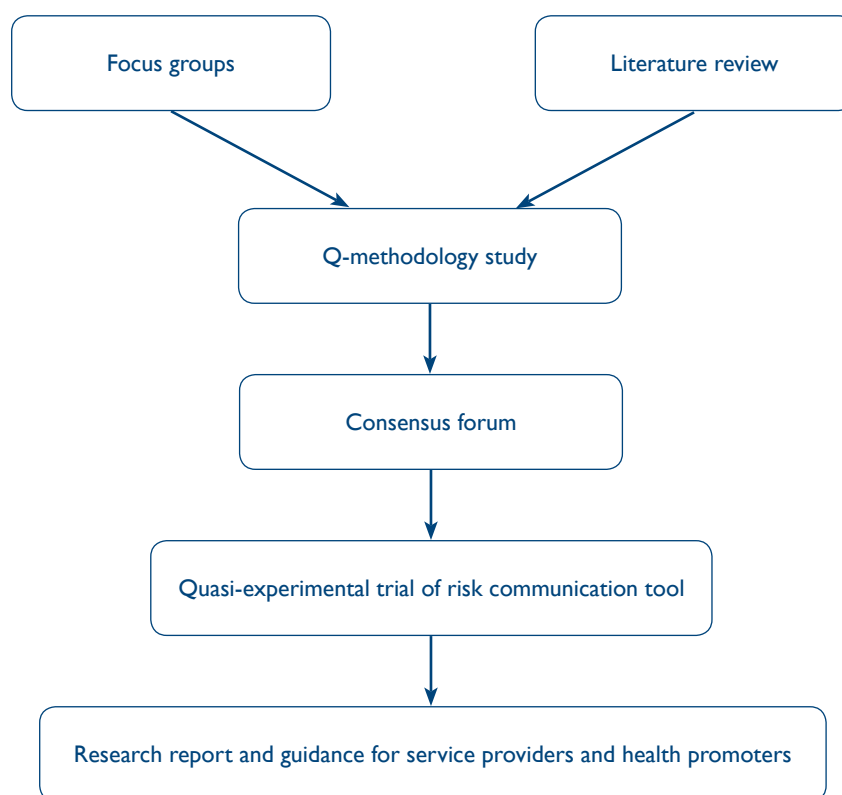


Figure 1 Research methods employed in the Informed Choice for All project.

[†] The full research report is published by the NHS Cancer Screening Programmes (*Communicating Risk Information about Breast and Cervical Cancer and Cancer Screening to Women from Minority Ethnic and Low Income Groups*. NHS Cancer Screening Programmes 2009 (Cancer Screening Series No 5)). Available from www.cancerscreening.nhs.uk.

1.2 Managing and presenting relevant knowledge

One of the key features of the participatory action research approach is that analysis of research data takes place at two different levels. On one level, results of different stages of the project are fed back to participants so as to engage them in further actions. For example, the results of the literature and information review and focus groups were used to prepare the Q-methodology study, which is a method to investigate the diversity of opinions held by individuals. The Q-results were then fed back to the consensus forums to generate communication solutions, leading to the production of the draft guidance and risk communication tool. Upon the completion of the project, all the results are subject to analysis and reanalysis. This final level of analysis aims to produce a deeper understanding of the theoretical and practical implications of the project.

In relation to this guidance, the conceptual understanding of the relationship between risk communication and informed choice was derived from insights gained from literature and information reviews of the subject matter and focus group discussions. This understanding has formed the backbone of the guidance within which detailed content about risk communication could be framed. Thus, the results of the Q-methodology study provide, for the first time, good insights into the perception of risks by both the public and health professionals.

1.3 Key results

- Almost all women interviewed perceived that they might have a chance to develop cancer and that cervical and breast cancer screening are positive health protection programmes.
- There is a clear difference of opinion about risks of cancer and cancer screening between lay people and health professionals.
- Statements of risk factors and statistical information about what cancer screening programmes could achieve appear to have little significance for the majority of participants, including the health professionals. This might be due to the lack of accurate understanding of the risk factors involved by lay participants. For the health professionals, this might be a response to the uncertainties surrounding the scientific evidence about these risk factors.
- For some lay participants the emotional and social impacts of the chance of being diagnosed with cancer are seen as most significant. These participants tend to be of the anxious type.
- Although many professional participants are aware of the screening risks, eg ‘screening is not perfect’, most lay participants appear to be unaware of what the screening programmes can achieve, and appear to have little understanding of the concepts of ‘false positive’ and ‘false negative’, and the other consequences of screening apart from detecting cancer early.

1.4 Highlighting different opinions about risks

Three distinctive viewpoints emerged from the factor analysis performed on Q-sorts of breast and cervical cancer and screening. These were labelled medico-official view; moderately informed and pro-screening; and uninformed, anxious and fatalistic. These are labelled here types A, B, and C.[‡] On the topic of cervical cancer and screening, the medico-official view dominated – in technical terms, had the highest loading factor in the Q-analysis. However, on the topic of breast cancer and cancer screening, this view was overtaken by the moderately informed and pro-screening view.

[‡] For easy reading, these types of opinions on the two topics (breast and cervical) are labelled here according to their characteristics rather than in the order of the factor loading obtained from the outputs of factor analysis using PQmethod software. For details of the Q-results, please refer to the research report.

Health professionals represent a majority of the people who clustered around the medico-official view (type A). It is important to recognise that the medico-official view is not held exclusively by professionals – a few lay individuals also held such views. The lay participants make up the majority of the other two clusters of opinions, ie moderately informed and pro-screening (type B) and uninformed, anxious and fatalistic (type C).

A smaller number of participants in clusters means that opinions are more diverse. The practical implication of this is that the case for basing strategy on the types of opinions that emerged from the Q-sorts for cervical cancer and screening to interventions might not be so strong. Generally, the higher the controversy about a subject, the more polarised are the opinions. The fact that opinions about cervical cancer and screening are diverse might indicate the lack of discussion and communication about the subject as a whole. The taken-for-granted nature of cervical cancer and screening might mean as a result that the need to provide information and support for informed choice for this procedure is being neglected. While this might not matter for much of the population, vulnerable groups such as the older age group and the low-literacy, migrant and minority ethnic groups might be adversely affected.

1.5 Types of opinions: breast cancer and screening

For presentation purposes, the results of the Q-sorts are constructed as opinion profiles voiced by different individuals. It is important to bear in mind that these profiles do not represent any particular individuals but a possibility of someone holding opinions about cancer and screening that are associated with one (or a mixture) of these types. It is also important to recognise that each type of opinion does not directly relate to a particular ethnic group although our results indicate that one or other type of opinion might be more common amongst certain ethnic groups. For example, for both topics (breast and cervical), more participants of African-Caribbean origin appear to fall into type C, characterised as uninformed, anxious and fatalistic, whereas very small numbers of individuals from other ethnic groups were found to hold opinions of this kind.

It is important to note that the differences between professionals and lay opinions are clearly marked. However, the type A opinion (medico-official) is not exclusively held by professionals; a few lay participants are also found to hold such a view.

1.5.1 Type A: medico-official view

The risk of developing breast cancer increases with age; the older you are (after 40), the more likely you are to develop breast cancer. That is why women who are over 65 are invited for screening now – because they are more at risk. Breast cancer risk increases when a woman has close relatives, ie her mother or sisters, who are diagnosed with cancer before the age of 40. Using hormone replacement therapy (HRT) increases the risk of developing breast cancer. Breast lumps can be caused by hormones and infection cannot cause breast cancer. Therefore, I don't think breastfeeding can have a protective effect, helping to reduce risk because it helps to get rid of lumps. I am not sure whether alcohol is associated with increased risk of breast cancer.

Breast screening cannot prevent breast cancer. In fact, having a mammogram would expose me to radiation. Breast screening may cause anxiety among women but I am not anxious or embarrassed when I go for a mammogram. I don't think the disease is talked about in the community, so if I see someone diagnosed with breast cancer who was successfully treated it would make me more ready to accept screening.

I would never think 'breast cancer would not happen to me'. There is always a chance.

1.5.2 Type B: moderately informed and pro-screening

I would never think 'breast cancer would not happen to me' – there is always a chance. If I am diagnosed with breast cancer, I would fight the disease all the way, and accept every treatment they offer me. However, prevention is better than cure. Therefore, although having a mammogram can be a bit painful and uncomfortable, it will help me to find out about my illness sooner. I don't think screening will cause anxiety among women. I am not anxious nor embarrassed about having a mammogram. I am not so concerned about exposing myself to radiation and I don't think the procedure [squeezing my breasts too hard] will harm me.

Women who breastfeed long term have a reduced risk of breast cancer; this may be because sometimes women take pills to stop breast milk [when they are lactating]. This is an 'unnatural way of stopping the production of breast milk and might cause blockage' and thus put you at risk of cancer [focus group comments]. Breastfeeding may be a more natural way and it helps to get rid of lumps. Women who have a history of breast problems are at risk and age comes into this too, as the older you are (after 40), the more likely you are to develop breast cancer. However, I don't think screening is less effective for younger women. The food that you eat plays a part in the development of cancer. I believe alcohol is associated with breast cancer and consuming a high fat diet when you are young increases your risk. I am unsure whether drinking soya milk can prevent breast cancer.

I am not fatalistic [nothing can make you live longer, you go when your time is up], and would not be terrified if I knew someone who has breast cancer. I do not know whether middle-class women are more likely to be diagnosed with breast cancer but working-class women are more likely to die from it.

1.5.3 Type C: uninformed, anxious and fatalistic

Breast cancer is a big problem in this country. The disease is not talked about very much in the community. Screening may cause anxiety among women, as it is not perfect; some people can be misdiagnosed. However, if a woman is found to have breast cancer early through x-rays, the survival rate is at least 50%. Although I might agree that breast screening saves lives, nothing can make you live longer, you go when your time is up.

I don't believe that breast screening can detect cancers early. Having a mammogram can cause pain and discomfort. If I go, I'll run the risk of being anxious and embarrassed. There is a risk that a mammogram can harm you when they squeeze your breast too hard but I don't think it would expose me to radiation.

In terms of whether I am at risk or not, I think all women, whatever the ethnic group, are at risk of developing breast cancer and there is a chance that I might develop it too.

I don't think the risk of developing breast cancer increases with age and that the older you are (after 40) the more likely you will develop the disease. Therefore I don't think screening is less effective for young women. The food you eat does not play a significant part in the development of the disease. I don't believe that being overweight, particularly after the menopause, increases my risk of developing breast cancer, nor do I believe obesity (at whatever age) makes me slightly more prone to the disease. Drinking alcohol would not increase my risk. Breastfeeding long term does not reduce breast cancer risk and it cannot protect us although it might help to get rid of lumps. I don't think the fact that a woman's family has had cancer will mean she is more likely to develop the disease..

However, it is difficult to know what to look for and how to bring your suspicions to the attention of the doctor. Knowing someone who has breast cancer would terrify me. I think if I am diagnosed with breast cancer, it will terrify my family.

1.6 Types of opinions: cervical cancer and screening

1.6.1 Type A: the medico-official view

Cervical screening is not a cancer test; just because a woman is called back for a repeat test, it does not mean that she will have cancer. Since cervical cancer can happen to all women, there is no reason to believe that cervical cancer is more common in the north of England. Those women who have had a partial hysterectomy (which left all or part of the cervix) should be screened.

Cervical cancer is not hereditary and irregular periods have nothing to do with cervical cancer. The risk of developing cervical cancer is due to viral infection (HPV) that causes cell changes and is usually passed on during sexual intercourse. Therefore, you might be at risk if you are having sex early in life and have had many sexual partners and/or with a partner who has had several other partners. In terms of age, I know that younger women are not more at risk than older women. Therefore, it is difficult to say screening could do more harm than good to younger women [under 25].

The screening programmes can prevent cervical cancer in up to 4500 cases per year and it is effective for the older age group at a five-year interval. I would keep my right to have a smear test and would not sign away this with a disclaimer. However, women can choose not to be screened if they are not sexually active, or have had a total hysterectomy. Women over 65 who have had three normal test results in a row will be unlikely to develop cell changes, therefore they can also choose not to be screened.

Cervical cancer is not a form of punishment. Even if one develops cervical cancer, if detected early, it can be easily treated. It is not true that how long we have to live is determined by God [fate], and that screening cannot change it. The smear test is safe; it does not cause infertility. Damage done to the cervix during childbirth cannot put women at risk of cell changes. Young women are not more at risk than older women. Taking contraceptive pills cannot cause cervical cancer, nor can having a weaker immune system put you at risk.

Although, on the whole, this view reflects most of the official and medical messages about cervical cancer and cancer screening, and it displays a good understanding of the risk factors that are involved in the development of cervical cancer, the understanding of population risks is unclear. The statements ‘Since cervical cancer can happen to all women’ and ‘there is no reason to believe that cervical cancer is more common in the north of England’ indicate that better understanding of population risks would be useful.

1.6.2 Type B: moderately informed and pro-screening

Although I am unsure of how many lives the screening programme saves each year, regular screening is a form of protection and everyone should take advantage of this service. Screening is ‘having regular checks, like an MOT’; it can ‘put my mind at rest’. I am not at all worried that this will lead to unnecessary treatment; neither would I be put off going just because I do not know about the procedure. However, I do know it can be uncomfortable. Indeed, I will put myself at bigger risk if I do not undergo screening regularly, because I think the chances for recovery depend on the stage of the cancer when it is detected.

Although I don’t discuss [or I cannot discuss] this with my doctor/nurse, I know not all women are at risk of cervical cancer. I do not think it is more common in the north of England. I believe that having many sexual partners and/or if my partner has had several other partners can put me at risk. Women’s physical state of health, eg poor nutrition or a weak immune system, can place them at higher risk. External causes such as an infection in the reproductive organ and taking the contraceptive pill can also put me at risk. Using a condom during sex may [or may not] help to prevent viral (HPV) infection.

There are a few myths around; for example, that having regular period [stomach] pains is a sign of cervical cancer. I don't believe that screening may do more harm than good to women younger than 25. I am not convinced that women who are not sexually active should choose not to be screened. I think women with a total hysterectomy might need to be screened too. I am not sure that women over 65 who have had three normal results in a row will be unlikely to develop cell changes, and therefore not undergo screening.

I am not fatalistic. If I am so unlucky as to be diagnosed with cervical cancer, even if the treatments are horrific, I will accept them as they will help me to recover. I am concerned that if diagnosed with my cancer, my relationship with my family will change. I am also worried that a woman will not have a normal sex life after she has had cervical cancer.

1.6.3 Type C: uninformed and fatalistic view

I believe cervical cancer can happen to all women and that how long we have to live is determined by God [fate], screening cannot change it. If a woman smokes, it doubles her risk of developing cell changes. If I undergo screening and am called back to repeat the test, it does not mean I will have cancer, but they might have found that I have other gynaecological problems. A negative smear means that I am clear of cancer.

I don't think where you live will affect your risk and I don't think if my partner has had several other partners that it would put me at risk. I don't think women are at higher risk if they have weak immune systems. I disagree that women should choose not to be screened if they are not sexually active, nor do I think over 65s who have had three normal tests results in a row will be unlikely to develop cell changes.

I don't think age is relevant. I think screening is effective for the younger age group at a three-yearly interval. If screening is good, how can it do more harm than good to women younger than 25?

1.7 Summary

It appears that differences of perception about risks of cancer and cancer screening do exist between lay participants and professionals, but the gulf between them is wider on the topic of cervical cancer and cancer screening. The other insight that is important for health providers and promoters is that specific attention may need to be paid to ensure clear communication to the African-Caribbean group in which Type C – uninformed, anxious and fatalistic – was dominant in respect of both topics.

On the whole, the findings suggest that those participants who are in a better position to make an informed choice about screening will be those who have a more accurate understanding of the causes of the disease and their risk of developing the disease as well as a realistic expectation of what the screening programmes can achieve. However, some lay participants and a surprising proportion of health professionals appeared to view screening as a form of protection in itself and to be oblivious to the issue of risks and consequences of screening.

PART 2: CONCEPTS

2.1 What is informed choice?

The National Screening Committee's second report of 2000 states:²

There is a responsibility to ensure that people who accept an invitation do so on the basis of informed choice, and appreciate that in accepting an invitation or participating in a programme to reduce their risk of a disease there is a risk of an adverse outcome.

The NHS Cancer Screening Programmes produces information leaflets in 19 languages that are designed to inform women of the benefits and limitations of screening. Apart from information about the programmes and procedures, these leaflets also contain information about the risk that the screening procedure might, on some occasions, call women back for further investigations which turn out to be unnecessary (false positives). Screening may also miss some women who should be called back (false negatives).³

The provision of risk information is important for the concept of informed choice. This implies that women will be able to make a genuine choice based on an understanding of the pros and cons of the screening programmes, including the knowledge that a degree of risk is associated with screening.

2.2 What is risk?

Risk is to do with chance or likelihood of undesirable consequences associated with any given activity. Different disciplines have different ways of talking about risks.⁴ In medicine and health, risks are often presented by epidemiologists as the probability that a health problem will occur.

In the context of cancer screening, in order to facilitate informed choice, we have to communicate to women two different kinds of risks, ie cancer risk and cancer screening risk, and help them to familiarise with the terminology used in risk communication, eg risk factors, population risks and personal risks.

Risk factors are things that increase the chances of an individual's development of the disease.

2.3 Cancer risk

Understanding cancer risk is about understanding what influences the development of cancer. Different diseases will have different risk factors – things that increase the chances of an individual developing the disease. For example, **age** is an important risk factor in breast cancer. The much quoted breast cancer risk message '1 in 9 women will develop breast cancer in her lifetime' presents the example of the lifetime risk of a woman who is born today and lives to be 90. This message is often accompanied by another message that presents the probability of women developing breast cancer at a certain age (Table 1), which can be qualitatively summarised as 'the older you are, the higher the chance that you will develop breast cancer'.⁵

Table 1 The lifetime risk of women developing breast cancer

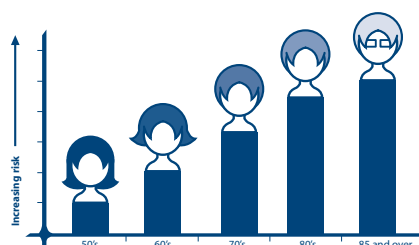
Age	Risk of breast cancer
Up to age 25	1 in 15 000
Up to age 30	1 in 1900
Up to age 40	1 in 200
Up to age 50	1 in 50
Up to age 60	1 in 50
Up to age 70	1 in 11
Up to age 80	1 in 10
Lifetime risk	1 in 9

However, this kind of statistic is quite difficult for people to interpret and relate to. In discussing risk with women, graphic illustration of lifetime risk may be more useful (Figure 2). Also, an individual’s (personal) risk of developing breast or cervical cancer is unique; it depends on a great number of things, some of which are beyond the control of individuals. Women’s responses to risk messages are often affected by the beliefs that they hold about these risk factors. For example, women might rightly question whether ‘age’, ‘sex’, ‘age at first and last periods’ and ‘ethnicity’ are something they can alter or have control over. Some would also doubt they have control over ‘the number of children that they have’, ‘when they have them’, ‘how long they breastfeed them’ and the circumstances under which they decide to take contraceptive or hormone pills. Moreover, women’s beliefs about the consequences of being diagnosed with the disease are also important. For example, can the cancer be detected early by screening? Would the illness then be treatable? Is it life-threatening?⁶ Therefore, communicating risk factors to women is not a simple exercise, as it may cause great anxiety to the individual if it is not done with empathy, understanding and sensitivity.

Your risk of breast cancer increases as you get older...

Keep going for screening if you are over 50.

Over 70? Contact your local screening centre for an appointment.



Report any changes to your breasts to your GP.

www.cancerscreening.nhs.uk  Cancer Screening Programmes

Figure 2 A graphic illustration of lifetime risks of women developing breast cancer.

2.4 Cancer screening risk – choices and consequences

When women receive an invitation for screening, they are immediately faced with a choice – whether to accept it or refuse it. Their understanding of how susceptible they are to developing the disease will play an important part in their receptivity to information and, in turn, their readiness to consider accepting screening. In addition, women’s understanding of the chances of obtaining different outcomes, eg a true or false positive or true or false negative, and how these are weighed with the consequences will help them to make an informed choice. The following figures illustrate the choices and consequences facing women when they are invited for breast (Figure 3) and cervical screening (Figure 4).

2.5 What screening results mean to women

In order for women to understand what risks are associated with cancer screening, they should be able to know what their screening results mean to them.

Terms such as ‘positive’, ‘negative’, ‘abnormal’ and ‘all clear’ are often used by health professionals to describe screening results.⁷ These terms may not be so helpful for women who have no knowledge of the procedure of reaching a diagnosis. Some might interpret ‘positive’ to mean ‘the detection of cancer’ rather than ‘detection of something that is suspicious needing further assessment and investigation’.

To avoid women overinterpreting their screening results, a clear explanation should be given to them as to why they are being recalled for further tests, what it means to their health status and what may happen to them if they are diagnosed or mis-diagnosed (Table 2).

They need to be informed that screening is not perfect. There is a small possibility that screening will ‘see’ a cancer that is not there, and a small likelihood that screening will miss a real cancer. In the context of cancer and cancer screening, an ‘all clear’ can only be provisional.

Table 2 A summary of the explanation of results

Technical terms used for screening results	Explanation	Health status	Consequences
True positive	Women who have been recalled for further tests and subsequently found to have cancer	Diagnosed with cancer	Treatment – better prognosis – better chance of survival
False positive	Women who have been recalled for further tests and subsequently found not to have cancer	Clear of cancer	Unnecessary investigation and/or treatment
False negative	Women who might be developing cancer but the screening misses the cancer	Cancer may appear during the interval between screening tests	Treatment may be delayed, resulting in a poor prognosis. This happens very rarely (approximately 1 in 1000 ¹ breast screenings)
True negative	Women who are given a ‘normal’ result and continue not to develop cancer	Clear of cancer	Continue to undergo screening every three years

¹<http://info.cancerresearchuk.org/cancerstats> (accessed 24 April 2008).

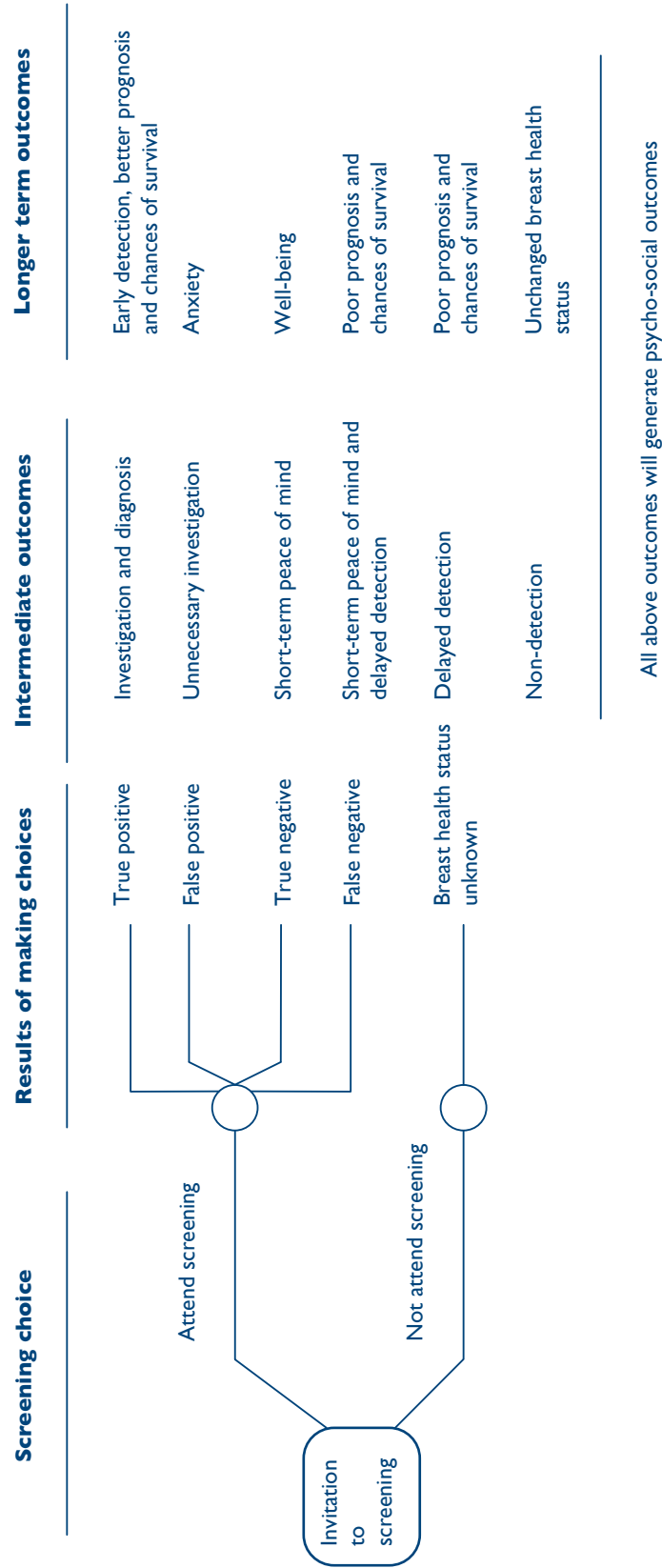


Figure 3 The decision facing women when invited to breast screening.

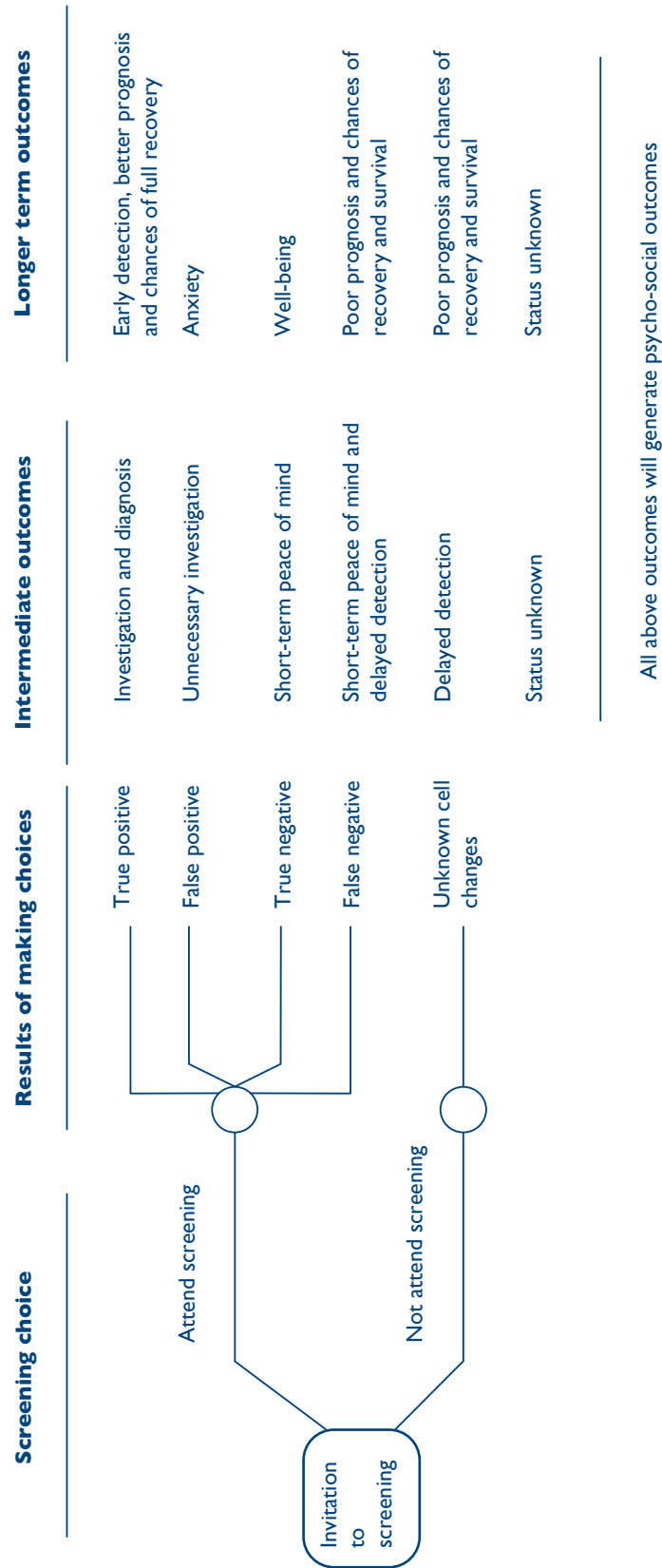


Figure 4 The decision facing women when invited to cervical screening.

In reality, many women may both lack a full understanding of their personal risk and have little or no information about the medical procedures that ensue after screening in order to reach a diagnosis. Few will have a clear understanding of the efficacy of screening and its consequences. Without a clear explanation and discussion with women about their results, they may overestimate their risks and suffer unnecessary anxiety over the chances of being diagnosed or underestimate them based on an unrealistic expectation of the efficacy of the screening programme.

2.6 A conceptual map for understanding risk communication and informed choice

Currently, many initiatives to promote screening tend to focus on disseminating information. Much of the information provided is piecemeal and oversimplified. Moreover, the format of some of this information is not conducive to dialogue and exploration of risks. For real informed decision-making to take place, women first and foremost need good enough knowledge about the extent to which they are at risk of developing breast or cervical cancer and the efficacy of the screening programme to enable them to weigh up the risks and consequences of their acceptance or refusal of the screening invitations.

We have developed a conceptual model for risk communication on cancer and cancer screening which we apply to breast and cervical cancer screening (Figures 5 and 6). The model gives an overview of the issues that we have discussed in this section and how these issues are involved when women make decision on screening. This model acknowledges the complexity of the subject matter, and takes lay people's perspectives of risks into account. A strategy for communicating risk information to women, particularly those from minority ethnic and low income groups, based on this model is more likely to be successful.

2.7 Risk communication tools

The toolkit (breast cancer and screening) which accompanies this guidance has been developed to help women to discuss risk factors and to understand the efficacy of screening. The interactive element of the question and answer sheets and graphic presentation of the statistical risks of breast screening will increase women's understanding not only of the chances of being called back for further tests, and their chances of being diagnosed with breast cancer, but also of the chances of misdiagnosis. This might help them to understand the meaning of the message that 'screening is not perfect'.

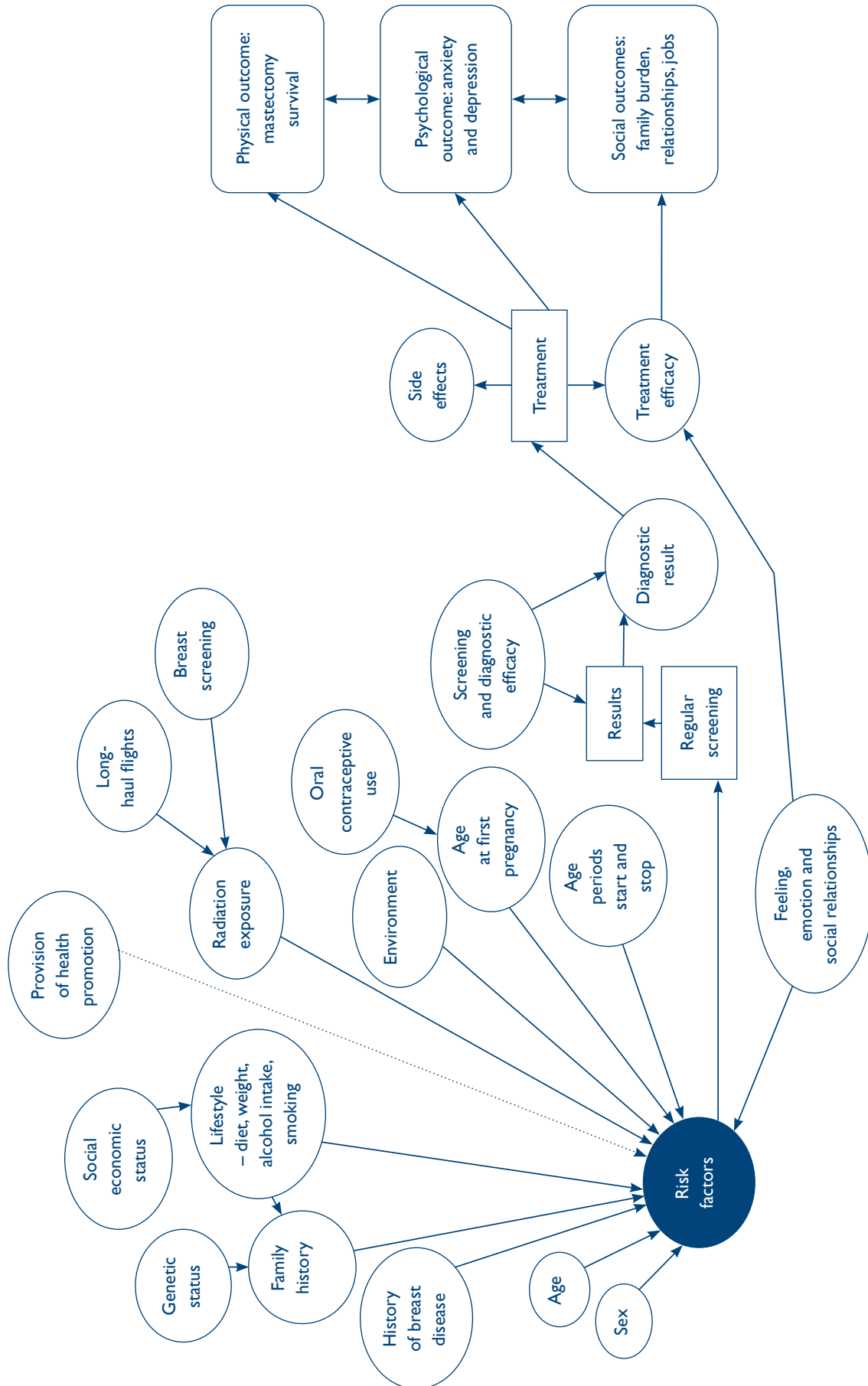


Figure 5 A conceptual map for understanding breast cancer and screening risks and informed choice.

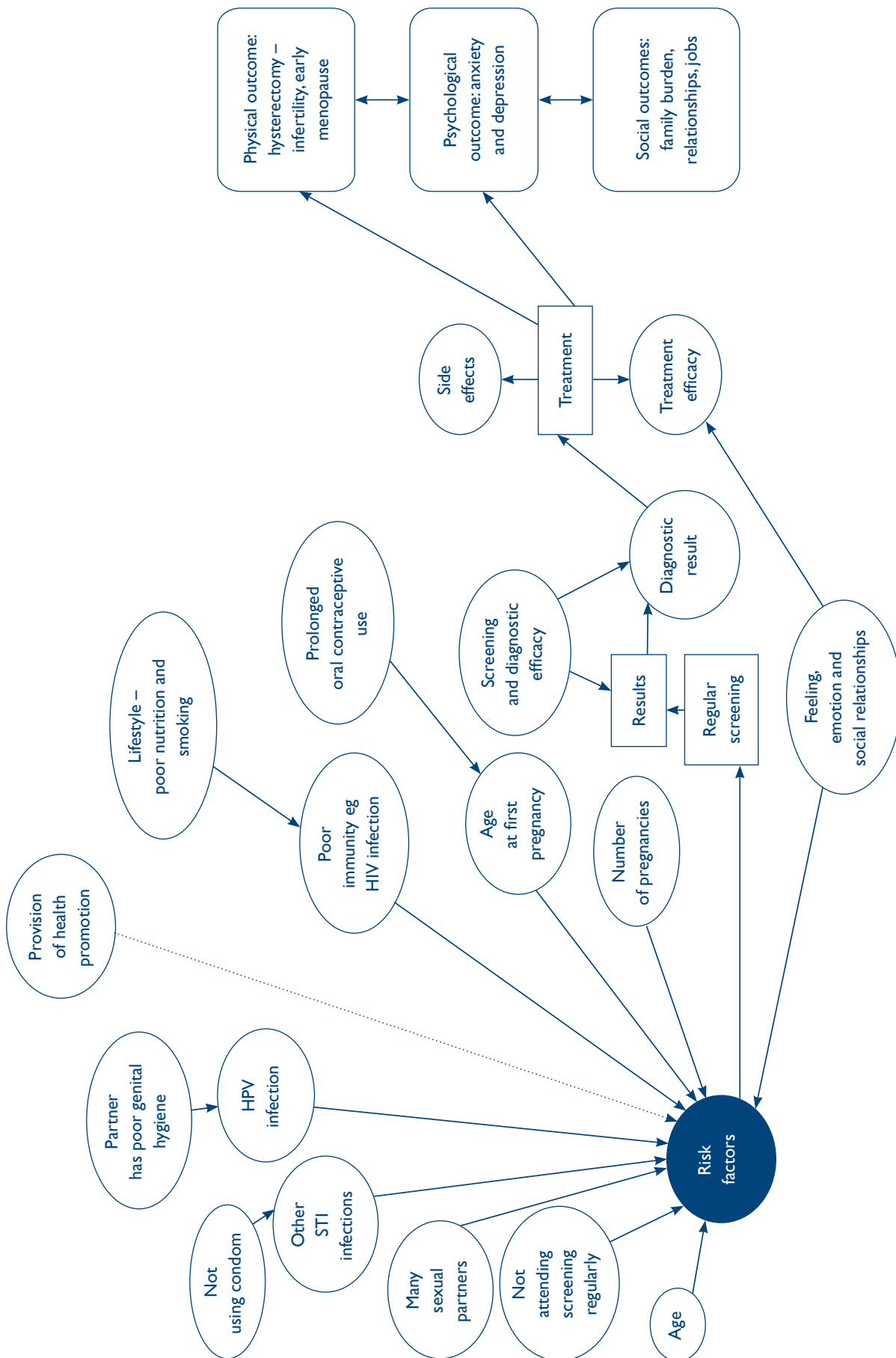


Figure 6 A conceptual map for understanding cervical cancer and screening risks and informed choice.

PART 3: ISSUES AND CONTEXT

3.1 Communicating risks to vulnerable groups

Effective communication of risks must be realistic about 'where people are at' and how far they can be taken.

There is some evidence to suggest that women's screening decisions are influenced by their concerns about cancer and their knowledge of risk factors.⁸ This has led many healthcare providers to focus only on the provision of information. However, merely providing information may not necessarily lead to informed choice. Information needs to be communicated in a way that can be easily understood, and the recipient of the information must be able to choose from available options freely.⁹ Sometimes, depending on how professionals frame or construct messages, it might appear to the individual that there is a 'right' and a 'wrong' choice. This may result in people feeling obliged to comply rather than making a genuine choice.¹⁰

Communicating risk information is a complex issue and the act of communication is a complex process as it typically involves both the sender and the receiver. Effective communication of risk information requires the communicators first and foremost to understand their audience and the parameters and limits that circumscribe the communicative act. In other words, whilst the sender (health promoter) must decide what is most worth discussing, the receiver (the woman) must integrate the incoming messages with her own understanding of risks. This means that we not only have to select the most crucial and critical messages that will enhance the ability of women to make decisions about screening, but also to take care to adapt the messages to the varying needs of recipients.¹¹

3.2 Understanding lay beliefs

People's beliefs about whether they are susceptible to developing cancer or not influence their preventive behaviour.¹² Culture, religion and social and family relationships often play a part in forming these beliefs.¹³ We have found in our study that some beliefs about the causes of cancer amongst women in minority ethnic communities are likely to inhibit information-seeking behaviours, eg that infections/irregular periods cause cervical cancer, that cervical cancer is a form of punishment, or that a stigma is attached to being diagnosed with cervical cancer as it is related to sexual promiscuity.¹⁴

The discrepancy between professional and lay beliefs about risks is well established¹⁵ and is borne out by our own study.¹⁴ Without the knowledge base required for the understanding of the efficacy and management of a screening programme, women often question the reasons for setting a screening age. Women believe that the screening age limits (50–70 for breast cancer screening and 25–64 for cervical screening) are more likely to be based on lack of finance than on the effectiveness of screening based on epidemiological evidence. **Therefore, it might be necessary to explain to women not only why they are invited, but also why other age groups are left out.**

Promoting Informed Choices

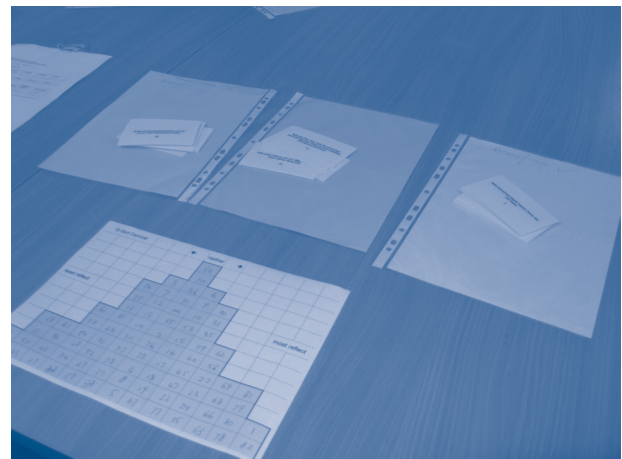
Women in our study are also confused by some risk messages which are typically derived from scientific studies, and which often require cautious interpretation. However, through the media the results of these studies often become so simplified that they do not add much to the individuals' understanding of cancer risks. For example, when the following risk statements were presented to our participants in the Q-sort exercise, both professionals and lay participants questioned what exactly 'long-term' breastfeeding means and how hormones (contraceptive pills), pregnancy and childbirth could be risk factors for cell changes in the cervix (see Appendices for the full set of statements used in Q-sorts).

Women's beliefs about what causes cancer and what screening can achieve are not likely to disappear right away when they are presented with statistical or 'scientific' facts. Professionals need to acknowledge that these beliefs are socially constructed through culture and media, and have a currency of their own.

Women who breastfeed long term have a reduced risk of breast cancer

Hormonal influences of pregnancy are a risk factor for cervical cancer

Having three or more pregnancies can increase the risk of cell changes in the cervix





3.3 Understanding diversity

We have acknowledged that, although women are identified by virtue of their sex, they are not a homogeneous group. Individual women differ according to their socio-cultural backgrounds (ethnicity, occupation, marital status and education) and their personal attributes (cognitive and emotional).

3.3.1 Age

Ageing is another process that separates women. While much information about breast and cervical cancer lists age as the major risk factor, there is not enough attention paid to how information is communicated to different age groups. Terms such as ‘younger’ or ‘older age group’ are often used without being clearly defined. Participants rightly asked ‘how young is younger?’ and ‘how old is older?’.



A study published in 2000 concluded that it is unjustifiable to exclude women from [routine invitation for] breast screening on the basis of assumed low uptake rates. The programme has now extended the age range for routine invitation to include women between 65 and 70.¹⁶ However, participants in our study who were within or above this age group were unaware that they would be invited or that they could ask for a mammogram to be taken. Older women may face subtle discrimination and may be inadvertently excluded from services due to many health and social problems associated with ageing. Older women are at higher risk of breast cancer and, according to epidemiological evidence, are more likely to die than younger women if they are diagnosed with cervical cancer.¹⁷ Older women should then be one of the prime targets for risk information.

3.3.2 *Ethnicity and social backgrounds*

There is plenty of evidence to show that minority ethnic and low income groups suffer from health disparities and unequal access to health services.¹⁸ One-size-fits-all messages are seldom effective in redressing these disparities. Even when translated into different languages, such messages might not be culturally sensitive or tailored to individuals' needs.

Diversity does not mean that we put women in ethnic and cultural boxes. It is about respecting individuals and where they are coming from: socially, culturally, cognitively and emotionally. Our research has demonstrated how different views about cancer risk and cancer screening are held by groups of individuals from different backgrounds, ie professional, lay and ethnic. Some views are held predominantly by members of a particular group, eg the medico-professional view is held by all the professional groups together with a few individuals from two other minority ethnic groups. Our results suggest that some women's views can closely align with professionals and that they are keen to seek information to help themselves in making choices while others, such as those from the African-Caribbean communities in our study, might be anxious, fearful of pain and discomfort, and uncertain about the efficacy of screening. Religion might also play a part in influencing their views. It is important to recognise that these views might well be present among all ethnic groups to a greater or lesser degree.¹⁴

3.4 **Overcoming institutional barriers**

Informed choice means more than just getting risk messages across to women. For women to have a genuine choice, they need to be able to access their chosen options. This means that we need to break down not just information barriers but also service barriers. We have learnt from our previous initiative¹⁹ that a community based initiative without the commitment and involvement of health professionals is likely to mean frustration for women.

It is useful to check whether the appointment system of the screening services is sensitive to the religious and cultural needs of community groups, eg avoiding issuing appointments on days of religious observance to Muslim women or introducing flexible opening hours of clinics/general practices that are suitable for low income groups and shift workers. It is not surprising that women from low income groups often fail to attend screening, as they might find it difficult to take time off work and are reluctant to lose pay or precious annual leave.

Participants in our study who are over 70 reported that they knew very little about their eligibility for screening. Subtle barriers can also be created by general practitioners or health promoters, who might make subjective judgements regarding the benefits of screening for women who are above the age for routine invitation for breast screening. For example, a woman in our study reported that when she went to her GP to discuss her anxiety about developing breast cancer due to her family history, she was told that she 'had other more serious problems to worry about than breast screening'.

3.5 Ensuring accessibility

Consideration will need to be given to how physically accessible the screening service is. For some women, in the case of breast screening, visiting the mobile screening van might mean two bus journeys. Some women might need to rely on spouses or relatives to take them there. This will mean that spouses or relatives also need to take time off work.

Although, increasingly, most screening services arrange special sessions for women with severe physical disabilities, the needs of some women who have mild mobility problems are often overlooked. These women have found it an effort and an embarrassment to climb up the steep stairs of screening vans and consequently do not consider screening a pleasant experience. The difficulty of these women could be easily solved by encouraging them to express their needs and issuing appointments for them to have their mammogram taken at breast screening centres.

3.6 Building on examples of good practice

Public health now has a commissioning and/or providing role. Depending on local structures and strategies, public health departments across the UK are taking different approaches to tackling the issues of inequalities of access and to supporting informed choice in relation to cancer screening services. These strategies range from broad communication initiatives via the media to intensive community health development programmes. For example, Leeds Primary Care Trust (PCT) has decided to launch health information initiatives using a social marketing model to help to raise the awareness of screening (Box 1).

Other organisations, such as Blackburn PCT, are working in conjunction with general practices and communities to commission organisations in the local voluntary sector, such as healthy living centres, to implement the Community Health Educator programme (Box 2). Whether the initiative resides with local primary care trusts, general practices or local voluntary organisations, lay people are increasingly involved in these initiatives as peer educators or community health educators. It is important to bear in mind that the Community Health Educator model has been systematically developed over the past decade and a half. Training materials have been produced through participatory action research projects.¹⁹⁻²² Some of these materials are still available from the NHS Cancer Screening Programmes (see Part 5).

Champions of promoting informed choice among vulnerable groups can also come from the breast screening services themselves. For example, some breast screening centres, such as the Dudley Breast Screening Service, have employed a dedicated health promotion specialist to promote awareness of and access to cancer screening (personal communication) (Box 3). In addition, service providers can adopt a community based intervention approach in which PCTs, breast screening services and local authorities work collaboratively to promote informed choice.

Box I Social marketing – Leeds Primary Care Trust

To tackle the continual falling of coverage for cervical screening, particularly among younger age groups (under 35), and to improve uptake to reach the Department of Health 80% target, Leeds PCT, in conjunction with South Yorkshire and North Yorkshire and York PCTs, has taken a social marketing approach to promote cervical screening. This approach is being supported by the Yorkshire and the Humber Strategic Health Authority and Quality Assurance Reference Centre.

Social marketing in health is 'the systematic application of marketing, alongside other concepts and techniques, to achieve specific behavioural goals to improve health and to reduce inequalities'.* The following diagram illustrates the approach schematically.



The project is in its early stages. A steering group will be set up to define the scope of the project and its aims and objectives. Research will be conducted in understanding the demographics and barriers of the consumer; consumer relevant strategies will be then be developed. These strategies will be implemented through the most appropriate communication channels. The project will then be evaluated and follow-up will take place to refine the strategies based on the evaluation learning approach.

For more information contact Kate Jacobs, Screening Programme Lead, Leeds PCT.
E-mail: k.jacobs@nhs.net

* National Social Marketing Centre (www.nsms.org.uk).

Box 2 Blackburn Primary Care Trust

This pilot project for 12 months is a four stage model based on the Woman to Woman project (see Part 5). The four stages are as follows:

- problem identification – map current issues, identify GP practices
- solution generation – targeted training for GP practices, recruit community health educators and a coordinator
- implementation
- evaluation.

The pilot project will target practices with low uptake of cervical cytology in four or five GP practices in Blackburn with Darwen. A community and voluntary organisation, Blackburn Healthy Living Centre, will be commissioned to carry out the project. A coordinator will be appointed to manage and supervise the whole project. The project plans to recruit local black and minority ethnic (BME) community women and train them to become community health educators (CHEs), who will then work with GP practices to improve access to the cervical cytology service. The GP practices will draw up a 'DNA smear' list for the CHEs, who will visit the women at home. They will carry out pre-screening health education sessions using audio, written and visual promotion materials with women and offer them an opportunity to make an appointment for the smear test. If further support is needed, CHEs will also offer to accompany women for the smear test. The role of the CHE will also include working with local communities and raising awareness of sexual health issues, in particular the cervical cytology programme.

Cultural awareness/cultural competence training will be provided for GP practices to help raise awareness of the key barriers and issues affecting local BME communities.

The project will be evaluated using qualitative and quantitative information.

For more information contact Shahida Hanif.

Email: shahida.hanif@bwdpct.nhs.uk

Box 3 Dudley Breast Screening Service

To promote access to the breast screening service among women with learning disabilities, Dudley Breast Screening Service worked with the learning disability community teams and social services. This relationship had helped the service to gain access to information about women with learning disabilities from the Special Needs Register. The screening office can now identify women with learning disabilities who are eligible for screening. Prior to invitation, women's communication needs were assessed using the NHSBSP Learning Disability leaflet and a breast awareness video. In collaboration with the PCT Speech and Language Department, invitation letters to women with learning disabilities were redesigned using symbols as well as simplified language. Instead of the standard six minutes' appointment, every woman with a learning disability is now also given a 20-minute appointment and support. Since this change, the uptake of breast screening by women with learning disabilities has increased from 41% in the first-round length (1989–1991) to 73% (2006). Four breast cancers have been detected and treated. This service works in a person-centred way to support individuals in making genuine choices about their care.

Dudley Breast Screening Service has also worked with the health improvement teams to research into the needs of other minority groups, eg Yemeni, Chinese, African-Caribbean, Indian and Pakistani. Workshops and dramas were used to raise awareness among these groups.

Dudley Breast Screening Service has produced a pictorial leaflet to target women with learning disability. This leaflet has also been used with minority ethnic groups.

Rosemary Isaac, a health promotion specialist who is also a breast screening radiographer, is employed to promote breast screening in Dudley. With her practical experience in breast screening, she has developed good insights into the barriers that prevent women from minority ethnic and other vulnerable groups accessing the screening service.

For more information contact Rosemary Isaacs.
Email: rosemary.isaacs@btinternet.com

PART 4: EFFECTIVE RISK COMMUNICATION

4.1 Designing a risk communication programme

Because of the complexity involved in the delivery of risk messages to promote informed choice, it is important that service providers and health promoters have a good understanding of what constitutes an effective intervention. Figure 7 shows a logical framework for the design, implementation and evaluation of an intervention for the communication of risk to vulnerable groups.

4.2 Assessing communication needs

Assessing communication needs involves systematically collecting information about the needs of the communities that the intervention seeks to address, and information about the capacity of the organisation to deliver the intervention.

To use allocated resources effectively, service providers will need to have information on the health education and communication needs and the socio-cultural characteristics of the population group at which intervention is targeted.

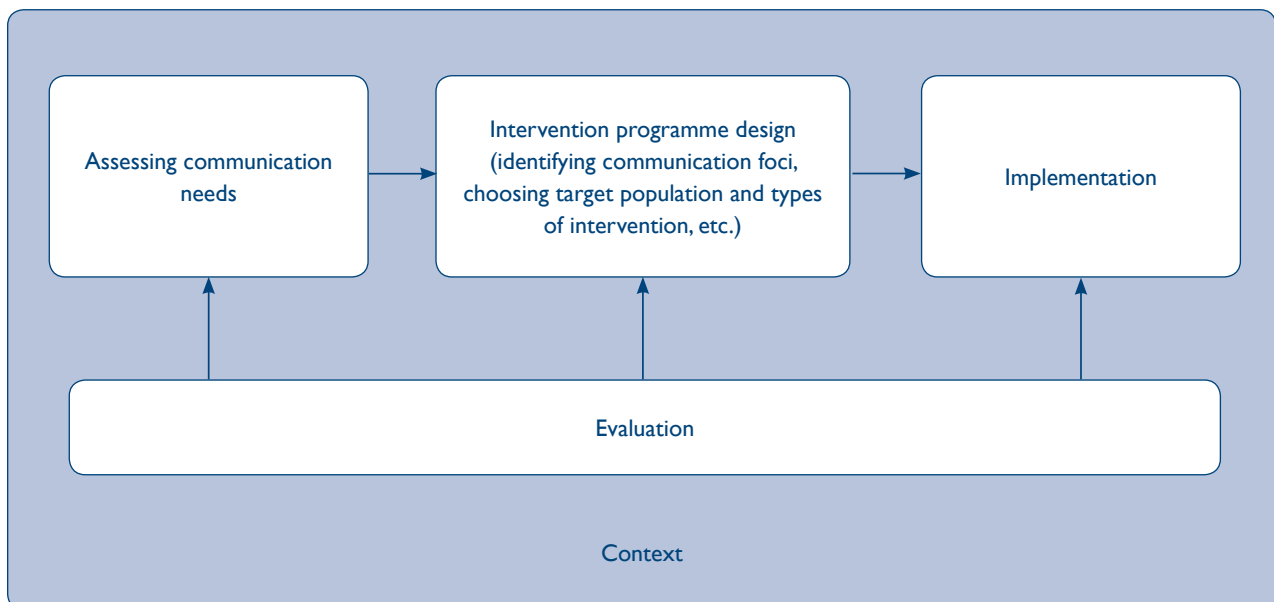


Figure 7 A logical framework for risk communication intervention.

4.2.1 Questions to ask about the community

- 1 What are the key demographic characteristics of the communities?
 - a) ethnicity
 - b) age
 - c) income
 - d) education
 - e) language spoken (primary or preferred)
 - f) geographic distribution of different communities.
- 2 What is the profile and distribution of cancer mortality and morbidities?
- 3 What is the current level of access of different communities to cancer screening services?
- 4 What local factors affect their access and what impact would these have on their health outcomes?
 - a) employment
 - b) level of poverty and income
 - c) physical neighbourhood characteristics, eg type of housing and local services
 - d) transport
 - e) social networks.
- 5 What do people see as their information and communication needs?
- 6 Is addressing inequalities of access to and informed choice on cancer screening a local priority?

4.2.2 Questions to ask about your organisation

- 1 Do you know the needs of the diverse population that you serve?
- 2 How do you know about the disparities in accessing the cancer screening services that you provide?
- 3 How effectively do your staff deal with a diverse population?
- 4 Do you have effective communication strategy and cancer information services for people from different ethnic and social backgrounds?
- 5 How does the concept of inequalities fit in with the organisation's goal and objectives?
- 6 Do you provide adequate language access for members of the population with limited English proficiency through multilingual staff or access to translation and interpreting services?

The above will enable service providers to identify and locate channels for communication, recruiting health educators or volunteers.

Additional quantitative and qualitative information about the environment in which the programme operates can be generated through a participatory approach, eg by involving the community in focus group discussions, interviews and mapping.

4.2.3 What is the information telling you?

The information collected needs to be analysed, so that the results of the analysis can support the way how you plan your intervention.

Steps to make sense of the information:

- 1 Convene a stakeholders' group and distribute the collected information amongst group members. Ask stakeholders to read the information as a whole and identify significant issues related to risk communication.
- 2 Compare current information about morbidity and mortality of cancer in different geographical locations and previous years to identify distributions and trends over time.
- 3 Compare and contrast key demographic characteristics of your target communities with those of the general

population to ascertain the exact nature of diversity among them, eg languages spoken in communities, age structure, educational and employment levels.

- 4 Relate the information about the communities to the cultural competency or diversity policy and staff capacity of the organisation.
- 5 Identify significant gaps in the information.
- 6 Identify and look for positive strengths of your communities, your own organisation and stakeholder organisations, as these can form the building blocks of your engagement.

The results of your analysis will help to determine the appropriate resources level for the communication intervention and to identify appropriate methods for implementation and evaluation. For example, health literacy research has established that conventional written information such as leaflets, booklets or pamphlets is ineffective for low literacy or no literacy (in English) groups²³ and that more intensive education, counselling and developmental methods might produce better results. However these latter methods require higher levels of funding and better trained staff, such as community health educators or volunteers.

4.3 Choosing the types of risk communication intervention

Having analysed the needs of the communities and the capacity of your organisation and stakeholder organisations, you will be in a better position to consider the feasibility of implementing different types of intervention.

4.3.1 Risk awareness campaign

A risk awareness campaign, eg cancer awareness, is a common type of intervention that uses the social marketing model as described in Box 1. This type of intervention is best for those communities that have easy access to the general media, eg television broadcasts and radio. However, service providers can also run campaigns targeting segments of the population. This type of intervention usually takes a shorter period of time to accomplish, involves fewer stakeholder organisations and engages a smaller section of the communities during its operation. It is more successful in communicating simple rather than complicated messages. Therefore, developing the focus of the intervention and messages is its major task. The National Social Marketing Centre's website contains some useful information about how such interventions could be run (<http://www.nsmcentre.org.uk>).

4.3.2 Clinical risk communication intervention

To implement a clinical risk communication intervention using a patient/client education approach, the service providers would normally be health centres or general practices. This type of intervention is useful for tackling patients/clients who might have different opinions about cancer and cancer screening risks as described in Part 1 of this guidance. We have found that some professionals are reluctant to broach the subject about cancer risks to their clients. Skills in communication and counselling about risks are required for staff who will be carrying out the intervention. Appropriate health education information and materials are needed to support interventions.

4.3.3 *Complex developmental intervention*

To implement more complex and developmental interventions, ie dialogic and interpersonal approaches using the Community Health Educator model, to which identifying and locating channels of communication, and recruiting health educators or volunteers are key, service providers will need to:

- ensure someone at executive level champions the approach
- allow enough time for planning and preparing the implementation of the project e.g. writing a project proposal, recruiting and training community health educators
- involve stakeholders and communities
- have experienced and committed staff who can tackle diversity issues
- have the project supported by appropriate communication resources e.g. screening education materials.

4.4 Implementation

The following intervention components need to be considered in programme implementation.

4.4.1 *Settings*

Communicating cancer risks and cancer screening risks to facilitate informed choice can take place in many settings. The setting in which you choose to implement your intervention will influence your choice of intervention methods (Table 3).

Depending on the settings of the programme, service providers will need to ensure that resources and materials are available to support communications.

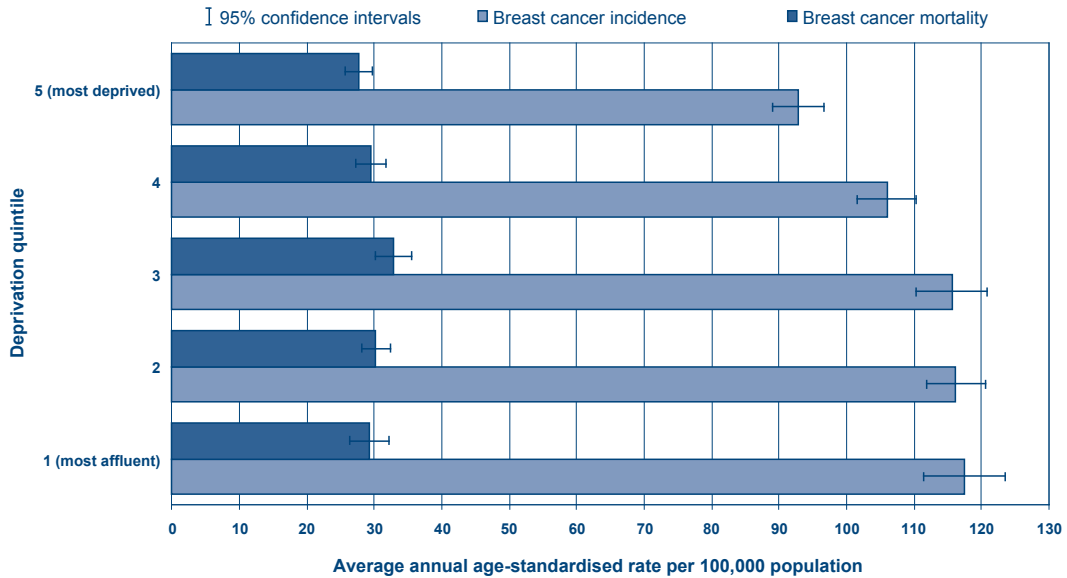
4.4.2 *Having up-to-date information*

Service providers will benefit from having access to up-to-date information about cancer in general and inequalities suffered by vulnerable social groups in particular. This information will be useful in helping to determine the size of the cancer burden and in mobilising resources to tackle the problem. When presented in an appropriate format, this kind of information will also help health promoters locate women's personal risks in a broader context, helping both professionals and women in the localities to see the impact of the environment upon their chances of developing, being diagnosed with and surviving the disease.

Table 3 Intervention settings and methods

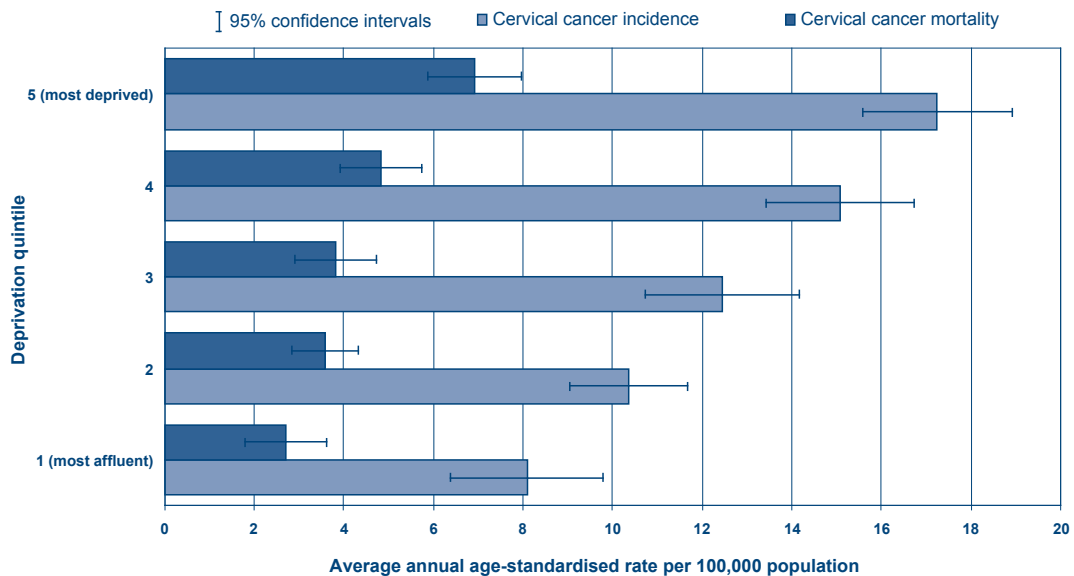
Setting of intervention	Most useful method
Clinics	One to one consultation
Community centres	Health education group sessions
Schools, colleges or universities	Counselling or group settings
Hospitals	One to one counselling

For example, there is evidence to suggest that women who live in deprived areas have poor chances of survival if they are diagnosed with cancer.²⁴ The lower survival rate experienced by women from most deprived areas may be the result of delayed diagnoses due to a number of psychosocial and personal factors and possibly poor access to information and services. Figures 8 and 9 and Table 4 show statistical information taken from Leeds and Bradford between 1990 and 2005 to illustrate the kind of background information that may help health promoters who support women from deprived areas to understand that economic and social conditions can contribute to cancer risks.



Ward-based deprivation quintile based on Income Domain of IMD2004 (quintiles from whole country)
Source: NYCRIS 2008

Figure 8 Female breast cancer incidence and mortality 1990 to 2005 – data from Northern and Yorkshire Cancer Registry and Information Service.



Ward-based deprivation quintile based on Income Domain of IMD2004 (quintiles from whole country)
Source: NYCRIS 2008

Figure 9 Cervical cancer incidence and mortality 1990 to 2005 – data from Northern and Yorkshire Cancer Registry and Information Service.

Table 4 Female breast cancer five-year survival (1997 to 2001) cohort – data from Northern and Yorkshire Cancer Registry and Information Service

Deprivation quintile	Five-year relative survival		
	%	Lower 95% confidence limit	Upper 95% confidence limit
1 – Most affluent	86.3	81.7	89.9
2	89.1	86.0	91.6
3	82.8	78.5	86.3
4	82.5	78.5	85.8
5 – Most deprived	79.4	75.3	82.9

Ward-based deprivation quintile based on income domain of IMD 2004 (outliers from whole country).

Source: Northern and Yorkshire Cancer Registry and Information Service 2008.

4.4.3 Identifying communication foci

A comprehensive understanding of the risks of cervical and breast cancer and screening would include knowledge about the nature, causes, development and consequences of these diseases. Such an understanding would allow a person to weigh the risk information against the cost and benefits of screening and what the screening programme could achieve, and to make an informed decision about accepting or declining the invitation to screening. However, if this were the only way to make such a decision, most people would be paralysed by the sheer volume of information that was needed. It is unrealistic to expect lay people to make a decision on this basis. In addition, there are still uncertainties surrounding evidence of the strength of some risk factors, eg diet. However, in order for women to make decisions about whether they would wish to accept screening or not, women need, at a minimum, information about:

- the nature and likelihood that they will develop these diseases
- the risk factors that influence their susceptibility
- the possibility of reducing these risks.

They will also need information about what screening is, what it can achieve, and what the consequences are likely to be for them personally. This information will serve as a starting point to help women to confront their own opinions about risks.

4.5 Presenting risks to lay people

Health promoters need to ensure that the representation of risks is clear and understandable by people with little statistical training. For example, health promoters should have the basic knowledge to explain in lay terms that risk information is often presented in terms of a population – which means that the proportion of people at risk of a disease is calculated on the basis of the population as a whole.

It is important to present risk information in different ways as this will make it easier for different people to assess the size of risk for themselves.

Population risks

Age-related risk (relative risk) = the chance of an individual developing the disease when the age group she is in compared with other women in different age groups.

Lifetime (absolute risk) = the chance of an individual developing the disease over her whole lifetime (assuming she lives to 90 years of age).

Personal risks and risk factors

Personal risk is the chance of an individual developing the disease, taking into account her age, other scientifically known factors and those risks related to individual lifestyle choices, e.g. smoking, taking alcohol, high consumption of fat and low fibre diet. For cervical cancer, 'not going to screening regularly' is also considered to be a risk factor.

There are a few websites that offer calculations of personal risks (see websites listed in Part 5). These should only be used by service providers if professional counselling is also available.

4.5.1 *Methods of talking about risk factors*

It is important to help people to understand that all risk factors do not have the same value. Some risk factors would have a stronger influence than others. For example, 'age' and 'family history' would be considered as stronger factors than 'diet'. However, as more research evidence comes forth about the relationship between diet and cancer, the strength of diet as a risk factor for breast cancer might well increase. When presenting these risk factors, not only should different levels and strengths of risks be structured in the presentation but also the methods of presentation should include ways in which these risks could be understood through dialogue.

There is some evidence to show that visual and graphical presentations are better than verbal and numeric formats in helping people with low literacy and poor numerical skills.^{25,26} The toolkit developed with this guidance is intended to help presenters and health promoters to stimulate conversations about risks with women.

4.5.2 *Exploring beliefs about risks through dialogue*

Communication that improves women's ability to make decisions will involve exploring the different beliefs held by individuals. Sometimes, health promoters might need to challenge erroneous beliefs by describing the strength of relationships between risk factors and diseases. Some examples are given below.

- (i) *Diet and breast cancer.* Diet is only weakly associated with development of breast cancer. The underlying causalities behind strong or weak relationships might need to be explained. For diet, we might say '... the body has a complex metabolic process mediated by genetics, activity, family practice and environment, making it hard to tell exactly what difference diet might make to the development of the disease'. However, it is always prudent to encourage women to adopt a healthier diet for their general health and well-being.

- (ii) *HPV infection and cervical cancer*: Because HPV infection is strongly associated with cervical cancer, we might need to point out that unprotected sex with multiple partners would increase the chance of HPV infection that leads to cell changes in the cervix.
- (iii) *Reproductive patterns and breast and cervical cancer*: Different reproductive patterns, i.e. having no children, the age at having the first child and having many children, carry different risks for breast and cervical cancers. The relationships between these patterns and risks of different types of cancer appear not to be well understood by women.

Health promoters will need to take care to explain these risk factors to women. It is understandable that middle-aged women may seemingly pay no attention to these risks as they are no longer in a position to change their reproductive patterns. For some women, knowledge of these risks could cause anxiety. It is important to be sensitive when discussing risk factors that are beyond women's control.

- (iv) *Breastfeeding behaviours as a protective factor against breast cancer*: Presenting breastfeeding behaviours as a risk factor can be problematic for some women. According to recent research carried out by Cancer Research UK, after taking into account women's age, menopausal status, ethnic origin, number of births and their age at the birth of their first child, it was found that the longer women had breastfed during their lifetime, the less likely they were to get breast cancer. Breastfeeding lowered breast cancer risk by 4.3% for every year of feeding. The protective benefit of breastfeeding is also cumulative with each child born.

Some of the risk factors are biologically and socially determined and in many cases beyond women's control, e.g. being tall or having children late or no children. These factors would be better highlighted in discussion groups rather than with individuals.

- (v) *Dealing with emotions*: In communicating breast or cervical cancer risks to women, we need to be aware that most women react emotionally rather than rationally to these diseases. Although emotional reactions may signal concern and anxiety, some health promoters think anxiety will motivate women to accept screening. In fact, anxiety may have the opposite effect. It is important that these emotions are dealt with before proceeding to information-giving.

It would also be helpful to offer information that addresses the underlying anxiety related to uncertainties surrounding cancer risks. For example, the truism 'everyone has a chance of developing cancer' might induce anxiety in women; health education efforts can help women to recognise whether their chances of developing these diseases are more or less than the norm.²⁷ In particular, if age is a major risk factor (eg in breast cancer) understanding of lifetime risk (*absolute risk*) and the increased risk associated with growing older (*relative risk*) is of vital importance.

Contrary to the common belief that minority ethnic women perceive themselves as having a lower risk of developing breast cancer, our study has shown that they often overestimate their risks and are more anxious. It is, therefore, important to provide opportunities for minority ethnic women to explore these risks through dialogue and conversations with health promoters, so that their fears can be allayed.

4.5.3 Providing an opportunity to discuss the modification of risks

Providing opportunities for women to explore the real chances of developing these diseases based on the knowledge about risk factors might be more useful as women will then have a more realistic understanding of the extent of benefits of screening, and consider adopting risk reduction behaviours.

Although some of the risk factors of cervical or breast cancer, eg age and genetics, are beyond women's control, discussion of how risks can be reduced or modified by changing lifestyle and following doctors' recommendations for screening might help to relieve the anxiety triggered by a conversation about personal risks. This is especially important for those who are anxious, fatalistic and sceptical about the efficacy of screening (people who hold type C views as described in Part 1).

For service providers who are interested in promoting cancer awareness and communicating key cancer prevention messages, the list of modifiable risk factors developed by Dr Cynthia Stein may be useful.¹

It is also important to ensure that breast awareness messages are communicated as a way of reducing the risk of delaying a diagnosis due to false negatives. A more detailed list of recommendations on how certain risk factors can be modified is included in the toolkit.

4.6 Evaluation

4.6.1 Why evaluate?

Evaluation can both support accountability and allow service providers to achieve greater programme effectiveness. It is useful to know whether your risk communication intervention is working; whether it is going in the right direction; and whether it has achieved the desired effects, ie women are informed of cancer risks and cancer screening.

Risk communication and informed choice are complex social phenomena. Any intervention designed to communicate cancer and cancer screening risks is influenced by a constellation of factors that are fluid, interactive and changeable. In the earlier section, three types of interventions were suggested: (1) a risk awareness campaign; (2) clinical risk communication intervention; and (3) complex developmental intervention. Below is some guidance on how each type of intervention can be evaluated.

4.6.2 Evaluating a risk awareness campaign

Assessing the effectiveness of risk awareness campaigns is essential for ensuring continued success and improving subsequent campaigns. Promptly addressing on-going issues covered in the campaigns is also important.

Service providers should involve stakeholders and communities in the evaluation and invite them to contribute to the improvement of the communicability of risk messages as a continuing endeavour. To help achieve these basic objectives, service providers should conduct risk awareness campaigns on a regular basis. In addition, service providers should formulate evaluations and follow-up plans according to local situations. This could include:

- conducting surveys based on focus groups
- distributing evaluation forms to, and collecting them from, participants in all public awareness events
- comparing the results from campaign events with relevant data that were collected previously to identify campaign successes and to address target populations requiring further risk education
- assessing changes in public attitudes and knowledge of cancer and cancer screening issues for future follow-up campaigns
- implementing outreach programmes designed to build a broader community of those interested in cancer and cancer screening
- utilising the resources provided by the NHS Cancer Screening Programmes' websites in order to highlight and share information related to successful risk awareness campaigns, such as survey data, campaign approaches and promotional materials.

4.6.3 Evaluating a clinical risk communication intervention

Assessing the effectiveness of clinical risk communication is essential for ensuring that women are fully informed of cancer and cancer screening risks through improving the confidence of health professionals to conduct a dialogue with women about cancer and cancer screening risk.

First and foremost, service providers should ensure that all health promoters who are responsible for delivering the intervention are trained. The components of the training will normally include risks explanation, checking of understanding, discussing risk reduction and dealing with emotions. The evaluation should include:

- conducting before and after training evaluation of risk communication skills of health promoters
- assessing qualities of communication resources and tailoring messages
- assessing changes in clients'/patients' perceptions of cancer and cancer screening risks.

4.6.4 Evaluating a complex developmental intervention

Risk communications need to address the issue of diversity, context and the availability of a variety of communication approaches and more sophisticated and complex programmes of risk communications. In recent years, interventions which have taken a participatory approach have become increasingly popular. By its very nature, participatory intervention will involve a range of actors, organisations and activities. This complexity will affect the design and implementation of evaluation. A conventional evaluation approach that highlights certain criteria as scientific rigour is often inappropriate for participatory intervention. A participatory action research approach to evaluation is recommended.²⁸

Effectiveness of complex developmental intervention about risks focuses not on the achievement of programme objectives as a set of predetermined outcomes set by an evaluator but on an optimal level of achievement of a set of objectives determined by all those people involved. What kind of indicators and how this information is collected are decided collectively. Other forms of evidence that will improve learning and development will also be collected both throughout and at the end of the implementation process. The analysis of evidence collected (quantitative and qualitative) should be used to support the development and learning of good risk communication practice.

4.7 Instituting a cancer risk communication programme

Service providers might wish to put together a cancer risk communication programme that incorporates all the above types of interventions. Risk communication should be an on-going two-way process between the service providers and the public. Apart from following the above guidance to evaluate different types of interventions within the programme, an overall assessment of the programme is necessary to support these interventions. Assessment of the programme will need to address three basic questions:

- what are the strengths and weaknesses of the programme?
- how should these weaknesses be addressed and strengths be harnessed to improve the programme?
- what are meaningful measurements for the design of different interventions within the programme?

4.7.1 *Evaluating the strengths and weaknesses of the programme*

The evaluation questions should relate to the original communication needs assessments, ie the assessment of the capacity of the service providers and the needs of the communities. The capacity and resources of the providers and the strategy and design of the intervention that seek to meet the needs of the communities need to be well matched. Any programme that overstretches the capacity and resources of the service providers and their staff will be inherently unstable, and activities are likely to be disrupted or aborted. For example, implementing clinical risk communication intervention without rigorous training of communication skills of health staff would be unacceptable as these might impact on clients'/patients' anxiety.

Failing to identify the strengths and weaknesses of the intervention will lead to the development and use of inappropriate evaluation methods and indicators, which in turn will lead to wrong conclusion or judgement about programme effectiveness,²⁹ thus producing evaluation errors that are likely to cause the premature termination of some worthwhile interventions.

4.7.2 *Addressing weaknesses and harnessing strengths*

Achieving a perfect design for risk communications may not always be possible as many of the situations and conditions are less than perfect. Service providers can respond to this by taking an action learning approach, allowing weaknesses to be identified at the outset and addressed. For example, if in implementing a developmental risk communication intervention a lack of community infrastructure (in terms of both human resources and communication channels) is identified, service providers might wish to team up with local authorities to first and foremost develop such an infrastructure. The other weakness could be the lack of understanding of diversity and the vulnerability of socially disadvantaged groups. Service providers might decide to address such a weakness by instigating primary research into these groups to inform planning of any interventions.

In term of strengths, service providers might decide that one of the strengths of the programme stems from the fact that the organisation has adopted and implemented a cultural competence policy. An organisation that strives for cultural competence will be more willing to seek the collaboration and involvement of committed stakeholders, thus providing conditions that are conducive to dealing with diversity in the population. Other strengths could be good leadership, presence of identified community leaders and the availability of experienced staff and staff from diverse ethnic and social backgrounds. These strengths will help to mobilise resources and risk communication 'know-how' for the implementation of the programme.

4.7.3 Deriving meaningful measurements for the programme

It is important to decide collectively at the outset what outcomes are expected from the intervention. It seems obvious that the terminal goal of any risk communication programme would be an increased awareness of cancer risks and the risks and benefits associated with screening among women exposed to the screening programme. It is, however, important to recognise that the exact mechanisms of communicating risks to women to produce informed decision and behaviours are not well understood. What outcomes can be measured often depends on the overall scope, size and details of the interventions within the programme. It would be unrealistic to expect interventions that involved only simple activities, eg making a leaflet available in GPs' surgeries, to produce a behavioural outcome such as 'informed choice'.

Equally, the outcomes of a complex developmental intervention often involves a range of actors, acting on different levels. Deriving meaningful measurements from such intervention would inevitably be complex and service providers should seek expert support from academic institutions.

4.7.4 Embedding good risk communication practice

No matter what types of risk communication intervention or what level of complexity of the risk communication programme that service providers decide to implement, it is essential to ensure the development and embedding of good risk communication practice.³⁰

This will include

- having clear risk communication policies and procedures
- involving target communities in interventions
- engaging in a dialogic relationship with communities
- seeking to understand communities' opinions and preference
- having foci of risk communication based on needs
- tailoring risk messages paying attention to language and cultural sensitivity
- monitoring and evaluating interventions to provide feedback and learning.

The evaluation of a complex programme or a single simple intervention needs to be carried out systematically. If service providers take an action learning approach to evaluation, the results would be unlikely to pronounce a programme a complete success or failure. Service providers should identify the good elements of programme and build upon them, and eliminate or seek to improve the bad. Lessons learnt from programme evaluation should be used to guide programme improvement or planning of future programmes.

PART 5: RESOURCES

Some of the key information and materials available to help health promoters to inform, educate, communicate and encourage women to make informed choices about cancer screening are listed below.

NHS Cancer Screening Programmes website

Information about both cervical and breast cancer and cancer screening is available on the website of the NHS Cancer Screening Programmes. There are also reference materials and educational resources that have been specifically developed for women from minority ethnic and low income groups.

Straight Talking: Communicating Breast Screening Information in Primary Care

Available in PDF at: <http://www.cancerscreening.nhs.uk/breastscreen/publications/pc-06.html>

Woman to Woman: Promoting Cervical Screening Amongst Minority Ethnic Women in Primary Care

Available in PDF at: <http://www.cancerscreening.nhs.uk/breastscreen/publications/pc-04.html>

Breast Screening: Your Health, Your Choice

DVD developed with CHEs and women from Chinese and South Asian communities. Details and ordering information on the website at <http://www.cancerscreening.nhs.uk/breastscreen/publications/dvd-yourhealth-yourchoice.html>

Other websites

<http://www.cancerscreening.nhs.uk/>

<http://www.cancerresearchuk.org/>

<http://www.cancerbackup.org.uk/>

<http://www.breakthrough.org.uk/>

<http://www.nhs.uk/>

Report

Cancer Atlas of the UK and Ireland 2005. ONS.

Journal papers about risk factors or breast and cervical cancer

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Boyd NF, Stone J, Vogt KN, Connelly BS, Martin LJ, Minkin S. Dietary fat and breast cancer risk revisited: a meta-analysis of the published literature. *British Journal of Cancer*, 2003, 89: 1672–1685.

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APPENDIX 1: Q-SORT (BREAST) PILOT STUDY

Below is a set of 61 statements which were used in the Q-sort. These statements are derived from professional and lay sources. The first 29 statements are distilled from literature identified by a web search of scientific journals and official websites of cancer organisations including the NHS. The rest of the statements are derived from focus group discussions with four ethnic/language groups (African-Caribbeans, Bengali, Chinese and Pakistani) and a professional group.

In order to refine our understanding of professional and lay perceptions of cancer risks and the risks and benefits of screening, we conducted a Q-study in which individuals from lay and professional groupings were asked to sort the 61 statements into a grid that has a structure based on the normal distribution (see example below).

Least reflect						Most reflect						
-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6
53	51	49	44	16	20	26	42	28	35	38	8	21
	41	47	31	2	10	4	30	45	25	19	1	
		56	52	23	9	14	59	15	24	43		
			54	34	37	46	39	33	6			
			48	5	27	60	29	13	3			
				61	7	17	18	32				
				12	36	57	22	58				
					55	50	11					
						40						

In the study, the following briefing was given to help each individual perform the sort.

Briefing

This is not a test but an exercise to see how you think and feel about breast cancer and breast screening. You are *not* being asked to assess whether these statements are true or false. These statements represent the facts, beliefs and attitudes to breast cancer and screening circulated currently in our society. You are asked to sort these statements into those that most reflect and least reflect what your thoughts and feelings are about the subject matter.

Which of these statements most reflect what you think and how you feel about breast cancer and breast screening?

When I think about breast cancer and screening	Source
1 The risk of breast cancer is increased when a woman has close relatives (mother/sister) who are diagnosed with cancer before the age of 40	Cancer Research UK (2004)
2 1 in 10 breast cancers are in women with a genetic susceptibility	Cancer Research UK (2004) NHS Direct (2006) Breast Cancer Care (2005) Cancer BACUP (2005)
3 All women, whatever the ethnic group, are at risk of developing breast cancer	Breakthrough, BBC McCormack VA, Mangtani P, Bhakta D, McMichael AJ, dos Santos Silva I. Heterogeneity of breast cancer risk within the South Asian female population in England: a population-based case control study of 1st generation migrants. <i>British Journal of Cancer</i> , 2004, 90: 160–166
4 Middle class women are more likely to be diagnosed with breast cancer but working class women are more likely to die from it	Cancer Research UK (2004)
5 Breast cancer is overwhelmingly a female disease; the chance of men developing breast cancer is very low (though not zero)	Cancer Research UK (2004) Breakthrough (2006)
6 The risk of developing breast cancer increases with age	Cancer Research UK (2004) Cancer BACUP (2005)
7 Being tall and overweight will increase the risk of developing breast cancer	Cancer Research UK (2004) Van Den Brandt PA, Spiegelman D, Yaun SS et al. Pooled analysis of prospective cohort studies on height, weight, and breast cancer risk. <i>American Journal of Epidemiology</i> , 2000, 152: 514–527 Rapp K, Schroeder J, Stoehr, S et al. Obesity and incidence of cancer: a large cohort study of over 145 000 adults in Austria. <i>British Journal of Cancer</i> , 2005, 93: 1062–1067 NHS Direct (2006) Cancer BACUP (2005)
8 Being overweight particularly after the menopause will increase the risk of developing breast cancer	Cancer Research UK (2004) Van Den Brandt PA, Spiegelman D, Yaun SS et al. Pooled analysis of prospective cohort studies on height, weight, and breast cancer risk. <i>American Journal of Epidemiology</i> , 2000, 152: 514–527 Rapp K, Schroeder J, Stoehr, S et al. Obesity and incidence of cancer: a large cohort study of over 145 000 adults in Austria. <i>British Journal of Cancer</i> , 2005, 93: 1062–1067 NHS Direct (2006) Cancer BACUP (2005)
9 Starting periods early and stopping periods late increase the chance of developing breast cancer	Clavel-Chapelon F. Differential effects of reproductive factors on the risk of pre-and postmenopausal breast cancer. Results from a large cohort of French women. <i>British Journal of Cancer</i> , 2002, 86: 723–727 NHS Direct (2006) Cancer BACUP (2005)

10	Having no children or having children in later-life can increase a woman's risk of developing breast cancer by one-third	<p>Cancer Research UK (2004) NHS Direct (2006) Cancer BACUP (2005) Netdoctor.co.uk (2005) CRD (2002) Collaborative Group on Hormonal Factors in Breast Cancer. Breast cancer and breastfeeding: collaborative reanalysis of individual data from 47 epidemiological studies in 30 countries, including 50,302 women with breast cancer and 96,973 women without the disease. <i>Lancet</i>, 2002, 360: 187–195</p>
11	Women who breastfeed long term have a reduced risk of breast cancer	<p>Cancer Research UK (2004) NHS Direct (2006) Cancer BACUP (2005) CRD (2002) Collaborative Group on Hormonal Factors in Breast Cancer. Breast cancer and breastfeeding: collaborative reanalysis of individual data from 47 epidemiological studies in 30 countries, including 50,302 women with breast cancer and 96,973 women without the disease. <i>Lancet</i>, 2002, 360: 187–195</p>
12	Hormone replacement therapy (HRT) increases the risk of women developing breast cancer	<p>Cancer Research UK (2004) Beral V. Breast cancer and hormone-replacement therapy in the Million Women Study. <i>Lancet</i>, 2003, 362: 419–427 NHS Direct (2006) Cancer BACUP (2005) Netdoctor.co.uk (2005) CRD (Centre for Review and Dissemination); Greiser CM, Greiser EM, Doren M. (2006) Menopausal hormone therapy and risk of breast cancer: a meta-analysis of epidemiological studies and randomized controlled trials. http://www.crd.york.ac.uk/ Li CI, Malone KE, Porter PL, et al. Relationship between long durations and different regimens of hormone therapy and risk of breast cancer. <i>Journal of the American Medical Association</i>, 2003, 289: 3254–3263</p>
13	Exposure to radiation increases the risk of developing breast cancer	<p>Breakthrough (2006) Michels KB, Rosner BA, Chumlea WC, Colditz GA, Willet WC. Preschool diet and adult risk of breast cancer. <i>International Journal of Cancer</i>, 2006, 118: 749–754</p>
14	Consuming a high fat diet in early years increases the risk of developing breast cancer	<p>Breakthrough (2006) Michels KB, Rosner BA, Chumlea WC, Colditz GA, Willet WC. Preschool diet and adult risk of breast cancer. <i>International Journal of Cancer</i>, 2006, 118: 749–754</p>
15	Women who have a history of breast problems are at risk of breast cancer	<p>Cancer Research UK (2004) NHS Direct (2006) Cancer BACUP (2005)</p>
16	Exposure to light at night may increase the risk of developing breast cancer	<p>Breakthrough (2006) Megdal SP, Kroenke CH. Night work and breast cancer risk: a systematic review and meta-analysis. <i>European Journal of Cancer</i>, 2005, 41: 2023–2032</p>

17	Alcohol intake is associated with increased risk of breast cancer	Cancer Research UK (2004) CRD (2004) Collaborative Group on Hormonal Factors in Breast Cancer. Alcohol, tobacco and breast cancer. Collaborative reanalysis data from 53 epidemiological studies, including 58,515 women with breast cancer and 95,067 women without the disease. <i>Lancet</i> , 2002, 87: 1234–1245 NHS Direct (2006) Cancer BACUP (2005) Netdoctor.co.uk (2005)
18	Eating soya products in place of dairy products can reduce the risk of breast cancer	Breakthrough (2006) Cancer Research UK (2004)
19	Breast screening (mammography) can detect cancers early	NHS leaflet <i>Breast Screening: The Facts</i> (2006) Cancer BACUP (2006) NHS Breast Screening Programme Review (2005) Cancer Research UK (2004)
20	For 1000 women screened, seven would on average be found to have cancer	Cancer Research UK (2004)
21	Women who have their breast cancers detected early by mammography will have a better chance of survival than women whose breast cancer is detected by other methods	Joensuu H, Lehtimaki T, Holli, K et al. Risk for distant recurrence of breast cancer detected by mammography screening or other methods. <i>Journal of the American Medical Association</i> , 2004, 292: 1064–1073
22	Breast screening saves lives	NHS leaflet <i>Breast Screening: The Facts</i> (2006)
23	Breast screening cannot prevent breast cancer	Cancer BACUP (2006) NHS leaflet <i>Breast Screening: The Facts</i> (2006)
24	Having a mammogram could be painful/uncomfortable	NHS leaflet <i>Breast Screening: The Facts</i> (2006) Cancer Research UK (2005) Sapir R, Patlas M, Strano SD Hadas-Halpern I, Cherny NI. Does mammography hurt? <i>Journal of Pain Symptom Management</i> , 2003, 25: 53–63
25	Having a mammogram would expose you to radiation	Cancer Research UK (2004)
26	Breast screening may cause anxiety among women	Brett J, Bankhead C, Henderson B, Watson E, Austoker A. The psychological impact of mammographic screening: a systematic review. <i>Psychooncology</i> , 2005, 14: 917–938 Watson EK, Henderson BJ, Brett J, Bankhead C, Austoker J. The psychological impact of mammographic screening on women with a family history of breast cancer: a systematic review. <i>Psychooncology</i> , 2005, 14: 939–948
27	Screening is less effective for younger women	Berrington de Gonzales A, Reeves G. Mammographic screening before age 50 years in the UK: comparison of the radiation risks with the mortality benefits. <i>British Journal of Cancer</i> , 2005, 93: 590–596
28	Breast screening is not a perfect way to detect cancer. Some cancers may be missed by this method	Cancer BACUP (2006) NHS leaflet <i>Breast Screening: The Facts</i> (2006)

29	Some people will be called back but most of them will not have cancer	Cancer BACUP (2006) NHS leaflet <i>Breast Screening: The Facts</i> (2006)
30	The older you are (after 40) the more likely you will develop breast cancer	Focus group
31	Breast cancer leads to mastectomy and horrific death	Focus group
32	The food you eat plays a part in the development of breast cancer	Focus group
33	If you are screened you will find out about your illness sooner	Focus group
34	If a woman is found to have breast cancer early through x-rays, the survival rate is at least 50%	Focus group
35	A woman is more likely to develop breast cancer if someone else in her family has had it	Focus group
36	Breast lumps can be caused by hormones	Focus group
37	Taking hormone pills could cause breast cancer	Focus group
38	If a woman is diagnosed with breast cancer, it will terrify her family	Focus group
39	Knowing someone who has breast cancer would terrify me	Focus group
40	Infection can cause breast cancer	Focus group
41	If breast cancer is mentioned to me I just think 'that's not me'	Focus group
42	Screening is not perfect, some people can be misdiagnosed	Focus group
43	Obesity at whatever age makes you slightly more prone to developing breast cancer	Focus group
44	Apart from finding cancer early, a mammogram can check out other breast problems	Focus group
45	Mammograms can cause pain and discomfort	Focus group
46	Taking pills to stop breast milk can put you at risk of breast cancer	Focus group
47	Breast cancer is a big problem in this country	Focus group

- | | | |
|----|--|-------------|
| 48 | There is a risk that a mammogram can harm you when they squeeze your breasts too hard | Focus group |
| 49 | The disease is not talked about very much in the community | Focus group |
| 50 | Prevention is better than cure | Focus group |
| 51 | Women who are over 65 are not invited for screening because they are not at risk | Focus group |
| 52 | Nothing can make you live longer, you go when your time is up | Focus group |
| 53 | It would never happen to me | Focus group |
| 54 | You run the risk of anxiety and embarrassment when you go for a mammogram | Focus group |
| 55 | Soya milk can prevent breast cancer | Focus group |
| 56 | I would fight the disease all the way, and accept every treatment they offered me | Focus group |
| 57 | Smoking and drinking alcohol [lifestyle] can cause breast cancer | Focus group |
| 58 | Stress can contribute to the development of breast cancer | Focus group |
| 59 | Seeing someone diagnosed with breast cancer who was successfully treated would make you more ready to accept screening | Focus group |
| 60 | It is difficult to know what to look for and how to bring your suspicion to the attention of the doctor | Focus group |
| 61 | Breastfeeding can protect us from developing breast cancer as it gets rid of lumps | Focus group |

APPENDIX 2: Q-SORT (CERVICAL) PILOT STUDY

Below is a set of 82 statements which was used in the cervical Q-sort. These statements are derived from professional and lay sources. The first 39 statements are distilled from literature identified by a web search of scientific journals and official websites of cancer organisations including the NHS. The rest of the statements are derived from focus group discussions with four ethnic/language groups and a professional group.

In order to refine our understanding of professional and lay perceptions of cancer risks and the risks and benefits of screening, we conducted a Q-study in which individuals from lay and professional groupings were asked to sort the 82 statements into a grid that has a structure based on the normal distribution (see example below).

In the study the following briefing was given to help each individual to perform the sort.

Least reflect													Most reflect	
-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6		
38	44	66	8	4	50	29	28	11	7	73	56	78		
25	42	60	53	10	9	32	24	23	72	26	63	65		
	49	52	54	5	27	3	58	13	41	82	37			
	39	51	77	43	61	6	35	18	45	16	20			
			70	48	62	12	40	59	46					
			67	75	74	14	34	2	1					
				19	76	15	33	36						
				68	81	30	57	17						
				32	31	55	71	21						
					64	69	80							
						79								
						47								

Briefing

This is not a test but an exercise to see how you think and feel about cervical cancer and smear testing. You are *not* being asked to assess whether these statements are true or false. These statements represent the facts, beliefs and attitude to cervical cancer and screening circulated currently in our society. You are asked to sort these statements into those that most reflect and least reflect your own thinking and feelings about the subject matter.

Which of these statements most reflect what you think and how you feel about cervical cancer and smear tests?

When I think about cervical cancer and smear test ...	Sources
1 Not going for screening will run the risk of not finding cell changes early enough to stop them developing into cancer	Cancer Research UK (2004) NHSCSP leaflet (2005) BUPA's Health Information Team (2003)
2 Viral infection (HPV) that causes cell changes is passed on during sexual intercourse	BUPA's Health Information Team (2003) Cancer Research UK (2005) NHS Direct (2006) Women's Health website Schlecht NF, Kulaga S, Robitaille J, et al. Persistent human papillomavirus infection as a predictor of cervical intraepithelial neoplasia. <i>Journal of the American Medical Association</i> , 2001, 286: 3106–3114 Reported in Gottlieb, S. (2002). Persistence of HPV increases risk of cervical cancer. <i>British Medical Journal</i> , 2002, 324: 69b A Cochrane review published in 1999 found that health education can help women reduce their risk of cervical cancer Home Health UK
3 Cervical screening saves up to 4500 lives each year in England	Cancer BACUP (2006) BBC <i>The NHS Cancer Plan and the New NHS</i> (DH 2004) Peto J, Gilham C, Fletcher O, Matthews FE. The cervical cancer epidemic that screening has prevented in the UK. <i>Lancet</i> , 2004, 364: 249–256 NHS leaflet (2005) <i>Cervical Screening: The Facts</i>
4 Cervical cancer is the second most common cancer in women aged under 35	Cancer Research UK (2005)
5 Regular screening can prevent 75% of cervical cancer	Cancer BACUP (2006)
6 Women with a weak immune system are at higher risk	BUPA's Health Information Team (2003) Cancer Research UK (2005) NHS Direct (2006)
7 Women living in deprived neighbourhoods are at a higher risk	<i>Cancer Atlas of the UK and Ireland</i> . ONS, 2005 Coleman MP, Rachet B, Woods LM, et al. Trends and socioeconomic inequalities in cancer survival in England and Wales up to 2001. <i>British Journal of Cancer</i> , 2004, 90: 1367–1373 Parikh S, Brennan P, Boffetta, P. Meta-analysis of social inequality and the risk of cervical cancer. <i>International Journal of Cancer</i> , 2003, 105: 687–691
8 A woman should be screened if she only had a partial hysterectomy (which has left all or part of the cervix)	NHS Direct Online Health Encyclopaedia
9 Genital warts can cause cell changes in the cervix	BUPA's Health Information Team (2003) Cancer Research UK (2005) NHS Direct (2006)
10 Women with poor nutrition are less able to fight infection therefore they have a greater risk	Cancer Research UK (2005) BUPA's Health Information Team (2003)

11	Women over 65 who have had three normal tests results in a row will be unlikely to develop cell changes	NHS Direct Online Health Encyclopaedia
12	Using a condom during sex may help to prevent viral (HPV) infection	Cancer Research UK (2005) Cancer BACUP (2006) NHS leaflet <i>Cervical Screening: The Facts</i> (2005) NHS Direct (2006)
13	Between 10 and 30% of smear tests fail to detect cell changes	NHS leaflet <i>Cervical Screening: The Facts</i> (2005) Cancer BACUP (2006)
14	The cervical screening programme can prevent cervical cancer in up to 4500 cases per year	Bray F, Loos AH, McCarron P, et al. Trends in cervical squamous cell carcinoma incidence in 13 European countries: changing risk and the effects of screening. <i>Cancer Epidemiology Biomarkers and Prevention</i> , 2005, 14: 677–686
15	Being called back to repeat the test does not mean a woman will have cancer	Marteau TM, Senior V, Sasieni P. Women’s understanding of a “normal smear test result”: experimental questionnaire based study. <i>British Medical Journal</i> , 2001, 322: 526–528
16	Smoking or oral contraceptives can also put you at risk of cell changes	Ylitalo N, Sørensen P, Josefsson A, et al. Smoking and oral contraceptives as risk factors for cervical carcinoma in situ. <i>International Journal of Cancer</i> , 1999, 81: 357–365
17	Prolonged use of contraceptive pills and having an viral (HPV) infection will increase the risk of developing cell changes	Moreno V, Bosch FX, Muñoz N, et al. (2002). Effect of oral contraceptives on risk of cervical cancer in women with human papillomavirus infection: the IARC multicentric case–control study. <i>Lancet</i> , 2002, 359: 1085–1092. Reported in Dyer, O. WHO links long term pill use to cervical cancer. <i>British Medical Journal</i> , 2002, 324: 808
18	Finding that women have the (HPV) virus could cause relationship difficulties	McCaffery K, Forrest S, Waller J, M Desai, A Szarewski, J Wardle (2003) Attitudes towards HPV testing: a qualitative study of beliefs among Indian, Pakistani, African-Caribbean and white British women in the UK. <i>British Journal of Cancer</i> , 2003, 88: 42–46.
19	Screening can be uncomfortable	NHS leaflet <i>Cervical Screening: The Facts</i> (2005) Cancer BACUP (2006) NHS Direct Online Health Encyclopaedia
20	Smoking doubles a woman’s risk of developing cell changes (CIN)	Ylitalo N, Sørensen P, Josefsson A, et al. Smoking and oral contraceptives as risk factors for cervical carcinoma in situ. <i>International Journal of Cancer</i> , 1999, 81: 357–365
21	Women with a total hysterectomy (womb and cervix removed) will not need to be screened	NHS Direct Online Health Encyclopaedia
22	Chlamydia infection increases the risk of cervical cancer	Josefson, D. Chlamydia increases risk of cervical cancer. <i>British Medical Journal</i> , 2001, 322: 71 Infection with certain subtypes of chlamydia, a bacterium which is commonly transmitted sexually, greatly increases the risk of cervical cancer, according to a new report (<i>Journal of the American Medical Association</i> , 2001, 285: 47–51)
23	Damage to the cervix during childbirth can put women at risk of cell changes	<i>Cancer Atlas of the UK and Ireland</i> . ONS, 2005

24	If a woman is not sexually active she can choose to not be screened	NHS Direct 2006
25	Genital cleanliness of a woman's partner will help to reduce risk	Cancer BACUP Castellsagué X, Bosch FX, Muñoz N, et al. Male circumcision, penile human papillomavirus infection, and cervical cancer in female partners. <i>New England Journal of Medicine</i> , 2002, 346: 1105–1112
26	Having three or more pregnancies can increase the risk of cell changes	Muñoz N, Franceschi S, Bosetti C, et al. Role of parity and human papillomavirus in cervical cancer: the IARC multicentre case-control study. <i>Lancet</i> , 2002, 359: 1093–1101
27	For women aged 50 or over, a 'normal' result means a low risk for developing cancer in the next five years	Marteau TM, Senior V, Sasieni P. Women's understanding of a "normal smear test result": experimental questionnaire based study. <i>British Medical Journal</i> , 2001, 322: 526–528
28	Cervical cancer is more common in the North of England	<i>Cancer Atlas of the UK and Ireland</i> . ONS, 2005
29	Screening may do more harm than good to women younger than 25	NHS Direct Online Health Encyclopaedia
30	Regular screening can prevent cervical cancer	NHS leaflet <i>Cervical Screening: The Facts</i> (2005) Cancer BACUP (2006) NHS Direct Online Health Encyclopaedia
31	Getting pregnant at an early age can increase the risk of cell changes	NHS Direct 2006
32	Having sex early in life can increase the risk of developing cervical cancer	Parazzini F, Chatenoud L, La Vecchia C, Negri E, Franceschi S, Bolis G. Determinants of risk of invasive cervical cancer in young women. <i>British Journal of Cancer</i> , 1998, 77: 838–841
33	Having more partners increases the risk of cervical cancer	Bosch FX, Iftner T. (2005) <i>The Aetiology of Cervical Cancer</i> . NHS Cancer Screening Programmes, 2005 (NHSCSP Publication No 22)
34	Hormonal influences of pregnancy are a risk factor	<i>Cancer Atlas of the UK and Ireland</i> . ONS, 2005
35	Receiving an abnormal result can cause anxiety	Maissi E, Marteau TM, Hankins M, Moss S, Legood R, Gray A (2004) Psychological impact of human papillomavirus testing in women with borderline or mildly dyskaryotic cervical smear test results: cross sectional questionnaire study. <i>British Medical Journal</i> , 328: 1293
36	Screening may lead to unnecessary treatment	Raffle AE, Alden, B, Quinn M, Babb PJ, Brett MT. Outcomes of screening to prevent cancer: analysis of cumulative incidence of cervical abnormality and modelling of cases and deaths prevented. <i>British Medical Journal</i> , 2003, 326: 901
37	Screening is effective for the younger age group at a three year interval	Sasieni P, Adams J, Cuzick J. Benefit of cervical screening at different ages: evidence from the UK audit of screening histories. <i>British Journal of Cancer</i> , 2003, 89: 88–93
38	Screening is effective for the older age group at five year intervals	Sasieni P, Adams J, Cuzick J. Benefit of cervical screening at different ages: evidence from the UK audit of screening histories. <i>British Journal of Cancer</i> , 2003, 89: 88–93

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39	If your partner has had several other partners, it might put you at risk	Bosch FX, Iftner T. (2005) <i>The Aetiology of Cervical Cancer</i> . NHS Cancer Screening Programmes, 2005 (NHSCSP Publication No 22)
40	Knowing what is a risk to my health will help me keep things in perspective	Focus groups
41	I am a worrier, so I'd rather not know very much	Focus groups
42	When I go for my health check (or contraceptive pill) I use the opportunity to discuss cervical cancer risks with my doctor/nurse	Focus groups
43	I would like to sign a disclaimer and refuse the smear test	Focus groups
44	Not knowing about the procedure could put me off going to screening	Focus groups
45	Although cancer is scary, I would rather find out early enough for it to be treated	Focus groups
46	How long we have to live is determined by God [fate], screening cannot change it	Focus groups
47	The disease is not talked about very much in the community	Focus groups
48	I don't know much about cervical screening, therefore I cannot make a choice about whether to accept or refuse it	Focus groups
49	Cervical cancer can lead to infertility because your womb might be taken out	Focus groups
50	Cervical cancer is a form of punishment	Focus groups
51	It would never happen to me	Focus groups
52	The treatments for cancer are horrific but I'll accept them as they will make me better	Focus groups
53	Having too many children can lead to abnormal cell changes in the cervix	Focus groups
54	Contraceptive pills can cause cervical cancer	Focus groups
55	Cervical cancer can happen to all women	Focus groups
56	Having many sexual partners can lead to cervical cancer	Focus groups
57	Smoking can increase your risk of developing cervical cancer	Focus groups
58	Cervical cancer is passed down from your parents	Focus groups

Promoting Informed Choices

59	Infection in the reproductive organs can cause cervical cancer	Focus groups
60	Irregular periods can cause cervical cancer	Focus groups
61	It is a matter of chance whether you develop cervical cancer or not	Focus groups
62	The biggest risk of developing cervical cancer is not going to screening regularly	Focus groups
63	Regular screening is a form of protection	Focus groups
64	Young women are more at risk than older women	Focus groups
65	Having regular period [stomach] pain is a sign of cervical cancer	Focus groups
66	A smear test is so embarrassing and uncomfortable, it puts me off going	Focus groups
67	Knowing someone with cancer made me more aware of my own risks	Focus groups
68	A positive smear means that you are diagnosed with cervical cancer	Focus groups
69	A negative smear means that you are clear of cancer	Focus groups
70	A positive means that you will need to be tested every year	Focus groups
71	A positive means that you will have to undergo treatment or surgery	Focus groups
72	A smear test can cause infertility because it may cause internal damage	Focus groups
73	If I am diagnosed with cervical cancer, this will change my relationship with my family	Focus groups
74	A woman will not be able to have a normal sex life after she has had cervical cancer	Focus groups
75	Because cervical cancer is related to sex and promiscuity, it is very embarrassing to be diagnosed with it	Focus groups
76	Treatment means drugs, surgery and hospital stay	Focus groups
77	Other people might know that you are going for this test	Focus groups
78	If I were called back by the screening programme, I would go immediately	Focus groups

Promoting Informed Choices

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|----|---|--------------|
| 79 | Screening can help to detect cancer earlier, so that the chance of a cure is higher | Focus groups |
| 80 | Screening can help to detect other gynaecological problems | Focus groups |
| 81 | The chances of recovery depend on the stage of the cancer when it is detected | Focus groups |
| 82 | Screening can put your mind at rest | Focus groups |

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