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What Women Know

Report on Awareness Levels of Cervical Cancer amongst Women in England

The Eve Appeal
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Foreword...

The Eve Appeal is delighted to publish this report – "What Women Know – Report on Awareness Levels of Cervical Cancer amongst Women in England". The report gives findings of the most comprehensive face to face survey ever conducted in England on what women do and do not know about cervical cancer.

The survey shows awareness levels of cervicalcancer amongst nearly 1400 women of 16 and over in England and was conducted at the end of 2009.

Key findings of the survey show that despite extensive media coverage on the topic, much of it predicated by Jade Goody's sad death in March 2009, women's knowledge of cervical cancer symptoms and risk factors for the disease remains woefully low.

There also remains a strong embarrassment factor associated with cervical cancer with one in four women finding talking about gynaecological symptoms embarrassing even with friends and family.

We know that earlier diagnosis of cervical cancer can help save lives so our message to women is to start talking, spread the word about signs and symptoms of cervical cancer and help break down the wall of embarrassment that could put their lives at risk.

With support from the Department of Health The Eve Appeal is working to raise awareness of the signs and symptoms of cervical cancer. To find out more please visit **www.eveappeal.org.uk** or call the charity on **0207 299 4430**.

Jane Lyons
CEO

Executive Summary

Background

- This survey was designed to benchmark current levels of knowledge about cervical cancer among women in England.
- The survey will allow an evaluation of the success of the Department of Health's key messages on cervical cancer in raising cervical cancer awareness.

Methods

- The survey was carried out in November-December 2009, prior to the launch of the Department of Health's key messages on cervical cancer in January 2010.
- A sample of 1392 women aged 16 years and over completed a questionnaire on a laptop, in their own homes. The sample was selected using random location sampling, and was weighted to ensure that it was representative of women in England.
- The questionnaire included the Cervical Cancer Awareness Measure and additional items, and covered awareness of the symptoms and risk factors for cervical cancer, knowledge of the cervical screening and HPV vaccination programmes, anticipated barriers to seeking medical help with a possible cervical cancer symptom, and beliefs about screening and other protective behaviours. This report focuses particularly on awareness of facts that are included in the cervical cancer key messages, and reports significant age, socioeconomic status (SES) and ethnic differences in knowledge.

Key Findings

- When asked to think of possible symptoms of cervical cancer, 40% of women were unable to name any.
- When prompted, around two-thirds of women were able to recognise each of the three symptoms highlighted in the cervical cancer key messages: vaginal bleeding after the menopause (66%), vaginal bleeding during/after sex (64%) and persistent vaginal discharge that smells unpleasant (62%). Only 39% recognised all three of the key symptoms.
- The majority of women (80%) said they would seek help within a week if they had a symptom they thought might be cervical cancer.
- The most endorsed barrier to help-seeking for a cervical cancer symptom was worry about what the doctor might find (38%), followed by difficulty making an appointment (29%). There was higher endorsement of barriers in young women.
- Over half the sample were unable to recognise HPV as a risk factor for cervical cancer, and only 51% believed that being a smoker could increase the risk. These beliefs translated into low awareness that stopping smoking and using condoms can reduce the risk of cervical cancer.
- Most women were aware of the cervical screening programme, believed that it is effective, and intended to accept future invitations to attend. There was also high awareness of the HPV vaccination programme. Women from lower social grades had lower awareness of both the screening and vaccination programmes.
- Overall, knowledge tended to be poorest in the youngest age group, in women from lower social grades, and in women from non-white ethnic backgrounds.

Implications for Policy

- Work must be done to raise awareness of the early signs and symptoms of cervical cancer.
- Service delivery and emotional barriers to seeking help for a possible cervical cancer symptom must be addressed e.g. ensuring women can easily make an appointment to see a female doctor, and providing reassurance that symptoms are unlikely to be cancer.
- Most women believe that early diagnosis increases the chances that cervical cancer will be cured, and reinforcing this message may encourage women to seek help with possible symptoms.
- Women need to be made aware of the link between HPV and cervical cancer so that they can understand the relationship between sexual activity and cervical cancer risk, and can make informed choices about condom use.
- Prevention, including stopping smoking and condom use should be emphasised.
- Messages about cervical screening should continue to emphasise that attending screening is the best way to reduce the risk of cervical cancer and should build on the widespread positive attitudes to screening identified by this survey.
- Information should be targeted at women of all ages in all social groups and especially women from lower social grades as many aspects of cervical cancer knowledge are lower in this group.
- Television was the route by which most women had heard about cervical cancer symptoms in the last six months, and is likely to be the most effective tool for communicating to a wide audience.

Introduction

Cervical cancer can affect women of all ages but is most common in women between 30 – 45 years of age. It is rare in women under 25. Cervical cancer kills around 900 women a year in England and many additional deaths are prevented by an effective national screening programme. The risk of dying from cervical cancer increases as a woman ages.

Women aged 25 to 49 are invited for screening every 3 years, and screening continues every 5 years for women aged 50 to 64. Uptake of screening is high, at just under 80%,[1] but the number of women attending has been falling in recent years, especially in the youngest age-group invited to take part - the number of women aged 25-29 screened within the last 5 years fell from 78% in 1999 to 66% in 2009[2].

In 2009, the Advisory Committee on Cervical Screening (ACCS) reviewed the evidence on cervical cancer risk in women aged under 25 and concluded that, in line with current guidelines, women should be screened from 25 years rather than any younger.

This issue ties in with the aims of the National Awareness and Early Diagnosis Initiative (NAEDI),[3] a collaboration between the Department of Health, the National Cancer Action Team and Cancer Research UK, aimed at improving cancer outcomes by promoting early diagnosis.

One of the NAEDI work streams focuses on developing key messages about cancer, and aims to produce clear and consistent information for the public. Ahead of the launch of the cervical cancer key messages in January 2010,[4] the Department of Health commissioned a benchmarking survey to assess knowledge about cervical cancer among women in England. The aim of the survey was to collect baseline data against which the impact of the key messages could be measured, and to identify areas of awareness and particular demographic groups that need to be targeted in public education campaigns.

The survey made use of the Cervical Cancer Awareness Measure (Cervical CAM), which arose from another of the NAEDI work streams – measuring public awareness of cancer. The Cervical CAM was developed by the Cervical Cancer Awareness and Symptoms Initiative (CCASI), a tripartite collaboration between the Department of Health, The Eve Appeal, and UCL's Health Behaviour Research Centre.[5]

Research Objectives

The survey aimed to measure cervical cancer knowledge across the female population in England, specifically in terms of the following:

- Ability to recognise warning signs of cervical cancer
- Understanding of the importance of seeking medical help early for symptoms
- Recognising the age group most at risk of cervical cancer
- Ability to recognise the risk factors for cervical cancer
- Awareness of the NHS cervical cancer screening and HPV vaccination programmes
- Barriers to seeking help with a possible cervical cancer symptom
- Beliefs about the screening programme and other protective behaviours

We were particularly interested in differences between women of different ages, and in differences by socio-economic status (SES) and ethnic group.

[1] *See http://www.ic.nhs.uk/webfiles/publications/cervscreen0809/Cervical_%20Screening_Programme_Report_2008_09_%28revised%29.pdf*
[2] *See http://www.ic.nhs.uk/webfiles/publications/cervscreen0809/Cervical_Screening_Programme_2008_09_Data_Tables_%28revised%29.xls*
[3] *See http://info.cancerresearchuk.org/spotcancerearly/naedi/index.htm for information on NAEDI*
[4] *Cervical cancer key messages are available at http://www.nhs.uk/conditions/cancer-of-the-cervix/pages/keymessages.aspx*
[5] *See http://www.eveappeal.org.uk/our-work/campaigns/cervical-cancer-awareness-and-symptoms-initiative.aspx*

Methodology

Fieldwork for the study was carried out between 26 November and 11 December 2009, in two consecutive rounds of the British Market Research Bureau's (BMRB) Omnibus survey. The omnibus survey uses random location sampling to ensure that respondents are representative of the broader population. This sampling method allows weights to be applied to the data to correct for biases (see Appendix 1 for BMRB's information on sampling and weighting).

A total of 1392 interviews were conducted with women aged 16 years and over in England. All the women were interviewed in their own homes, using Computer Assisted Personal Interviewing. Because of the personal nature of some of the questions, it was felt to be appropriate for women to read and complete the questions themselves, rather than having to speak to an interviewer. A trained interviewer was with them in the room to answer queries, and demonstrated how to move through the survey on a laptop computer.

The survey included questions from the newly developed and validated Cervical Cancer Awareness Measure (Cervical CAM). The Cervical CAM is based on the CAM, a generic measure of cancer awareness developed as part of the NAEDI work stream on cancer knowledge.[6] The measure assesses knowledge of the warning signs of cervical cancer, the peak age of incidence, possible barriers to help-seeking, knowledge of risk factors and awareness of the cervical screening and HPV vaccination programmes. The survey also included additional questions on screening attendance, beliefs about cervical screening and other protective behaviours, and demographic information.

Results

The demographic characteristics of the sample are shown in Appendix 2. Women were well distributed across the age groups (mean age = 47 years, range 16-94). Most were from white backgrounds (91%), 60% were married and the majority had taken part in cervical screening within the last 5 years (82% of women aged 25-64 years).

Responses to each of the questions in the survey are presented below. Significant age, socio-economic status (SES) and ethnic differences are highlighted, particularly with respect to information in the key messages. For most analyses, age was divided into six groups, as shown in Appendix 2. Social grade was used to categorise women by SES, and is broken down into five groups: AB (high or intermediate managerial, administrative or professional), C1 (supervisory, clerical, or junior managerial, administrative or professional), C2 (skilled manual workers), D (semi and unskilled manual workers) and E (state pensioners, casual or lowest grade workers, unemployed or on state benefits). Because the sample was population representative, only a small proportion (9%) were from non-white backgrounds and we were therefore unable to break the sample down into more specific ethnic groups. Analyses by ethnic group compared white with non-white respondents. Summary profiles of women across four different age groups are presented at the end of the Results section.

[6] *See http://info.cancerresearchuk.org/spotcancerearly/naedi/naedi_cam/index.htm for information on the CAM*

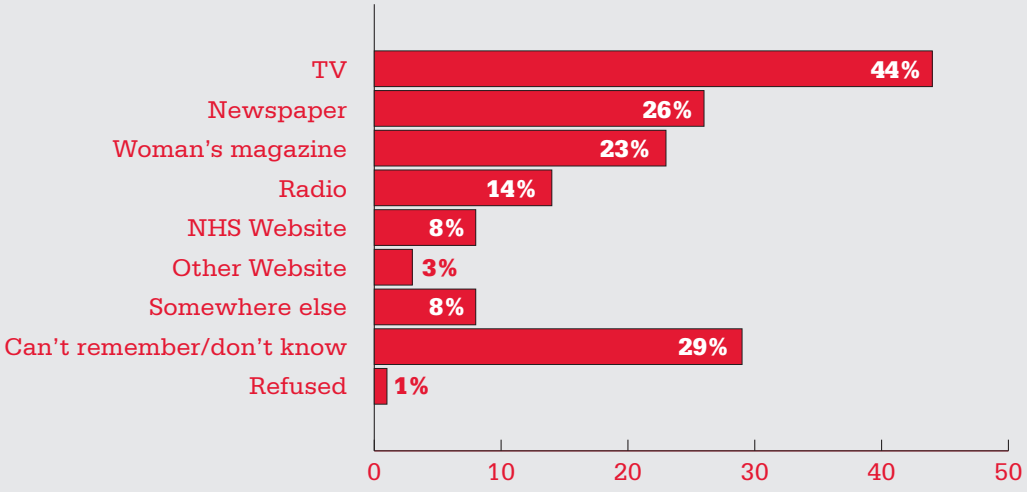
Awareness of Cervical Cancer Symptoms in the Media

In the last 6 months can you remember seeing or hearing anything about the signs and symptoms of cervical cancer?

The majority of women (70%) remembered seeing or hearing something about the signs and symptoms of cervical cancer in the last 6 months. Sources of information included television (44%), newspapers (26%), women's magazines (23%), radio (14%), the NHS website (8%) and other websites (3%). These figures are illustrated in Figure 1 and indicate the sorts of media that could be useful in disseminating the cervical cancer key messages. The very high level of awareness of this information is likely to be related, at least in part, to the media coverage of Jade Goody's illness and death from cervical cancer in March 2009 (just over 6 months before the survey was carried out).

Women aged 65 and over were significantly less likely to have heard anything about the symptoms of cervical cancer than the younger groups. There was no social gradient in having heard something about cervical cancer symptoms, but women from lower social grades were more likely than women in the higher groups to have seen something on television, while women in the highest social groups were more likely to have heard something on the radio, or seen information on the NHS website than those in grades D and E. Respondents from white backgrounds were significantly more likely than non-white respondents to have read about cervical cancer symptoms in a newspaper (27% compared with 15%) but non-white respondents were more likely to have seen something on the NHS website (14%, compared with 8% of white respondents).

Figure 1. Sources of information about cervical cancer symptoms in the last 6 months



Awareness of Cervical Cancer Symptoms

There are many warning signs and symptoms of cervical cancer. Please type in as many as you can think of.

Women were asked to think of as many signs and symptoms of cervical cancer as they could, without prompting. In this question, 40% were unable to name any. The most commonly cited symptoms were bleeding (21%), unusual vaginal discharge (15%), and pain (13%). All other symptoms were mentioned by fewer than 10% of women. In terms of the three warning signs highlighted by the cervical cancer key messages, 15% mentioned vaginal discharge, fewer than 1% specifically mentioned bleeding after the menopause (0.3%) and only 2.3% mentioned bleeding during or after sex.

Do you think [symptom] could be a sign of cervical cancer?

Following the open-ended question, women were prompted with a list of 11 possible signs and symptoms and asked to say whether each one could be a sign of cervical cancer. The order in which the symptoms were presented was randomised. All 11 were correct, although some (e.g. lower back pain and persistent diarrhoea) are signs of late stage cancer rather than early warning signs (see Figure 2 for the 11 symptoms).

The three main symptoms of cervical cancer included in the cervical cancer key messages were recognised by around two thirds of women, these three main symptoms were: vaginal bleeding after the menopause (66%), vaginal bleeding during or after sex (64%), and vaginal discharge that smells unpleasant (62%). Only 39% were able to recognise all three. Just under 30% were able to recognise two out of three, 16% recognised one and 15% did not recognise any of the three.

Key messages summary Box 1

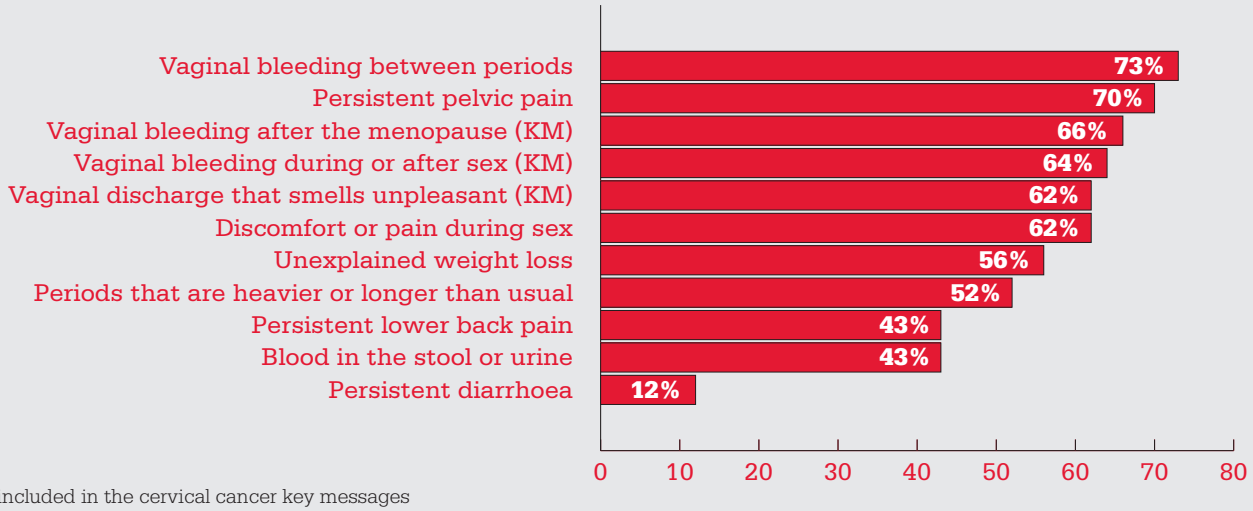
The cervical cancer key messages include the following information:

- The following are the most common symptoms of cervical cancer
  Any unusual bleeding from the vagina particularly:
  o after sex
  o after the menopause when your periods have stopped
- Persistent vaginal discharge that is blood stained or smells unpleasant

These symptoms were recognised 66% (bleeding after menopause), 64% (bleeding after sex) and 62% (vaginal discharge). Only 39% of women were able to recognise all three of these key symptoms.

The most commonly recognised symptom was ‘vaginal bleeding between periods’ (73%). The least recognised symptoms were those of late-stage disease: ‘blood in the stool or urine’ (43%), ‘persistent lower back pain’ (43%) and ‘persistent diarrhoea’ (12%). In this format, 21% of women were able to recognise 9-11 of the symptoms as correct, 29% recognised 7-8 symptoms, 24% recognised 5-6 symptoms and 25% recognised 4 or less.

Figure 2. Recognition of warning signs for cervical cancer (prompted format)



KM=included in the cervical cancer key messages

Older women were more likely to recognise 'bleeding after the menopause' than younger women, and there was also a social gradient in recognition of this symptom, with 72% of women in social grade AB recognising it, compared with 56% of women in grade E. A similar pattern was observed for 'persistent vaginal discharge, with lowest recognition for this symptom in social grade D. Recognition of 'bleeding during or after sex' was highest in women aged 35 to 64 years, and lower in the older and younger age groups. Once again, there was a social gradient, with 73% of women in grade AB recognising the symptom, compared with 53% of women in grade E.

With the exception of persistent diarrhoea, respondents from white backgrounds were significantly more likely than those from non-white backgrounds to recognise all of the symptoms, e.g. bleeding after the menopause (68% vs. 51%), bleeding after sex (65% vs. 49%), vaginal discharge (64% vs. 45%).

Early Presentation and Barriers to Help-Seeking

How confident are you that would notice a cervical cancer symptom?

Women rated their confidence about noticing a symptom of cervical cancer. Most were very (13%) or fairly (42%) confident that they would notice a symptom, with only 10% saying that they were not confident at all. Women in the 16-24 age group were less confident than women in any of the other groups. There was no clear pattern between confidence and social grade but white respondents were more confident than those from non-white backgrounds (56% vs. 44% were very or fairly confident of noticing a symptom).

If you had a symptom that you thought might be a sign of cervical cancer, how soon would you contact your doctor to make an appointment to discuss it?

Women generally reported that they would contact the doctor within a week if they had symptoms they thought might be cervical cancer (80%). Only 3% said they would wait 3 months or more, and 1% said that they would never go to the doctor. This indicates that the vast majority of women would present with appropriate speed if they had a symptom that they recognised to be potentially serious. There was little difference across age groups, but women in social grades C2, D and E were more likely than women in group AB to say that they would seek help within 1 to 3 days (72% in grade E compared with 56% in grade AB). This indicates that raising awareness of the symptoms in lower SES groups may be key to promoting early presentation – awareness of the importance of swift help-seeking already seems to be high. There were no differences between white and non-white groups.

Key messages summary Box 2

The cervical cancer key messages include the following advice:

If you have any of these symptoms, tell your doctor, even if you have been for screening. The chances are that they are not due to cancer, but it is important to have them checked.

Most of the women in the sample (80%) said that they would contact their doctor within a week to discuss a symptom they thought might be cervical cancer

What factors might put you off going to the doctor if you had a symptom you thought might be cervical cancer?

Endorsement of barriers to going to the doctor with a potential cervical cancer symptom are shown in Table 1, and differences between women under 25 and those aged 25 years and over are shown. Barriers were divided into emotional barriers, practical barriers and service barriers. Overall, worry about what the doctor might find was the biggest anticipated barrier to help-seeking, endorsed by 38% of the sample.

Service barriers were also important, with 29% saying it would be difficult to make an appointment, and 26% saying they might be put off by not being able to see a female doctor. Around 20% said that embarrassment would be a barrier, but this rose to almost 40% in the younger age group. All the barriers were significantly more endorsed by younger women, apart from transport difficulties.

There were also some differences in barrier endorsement by social grade. Women in the highest SES group (grade AB) were more likely to worry about wasting the doctor's time and to be too busy to go than women in the lowest group (social grade E). Women in grade E were more likely than those in the highest groups (AB and C1) to say that it would be difficult to arrange transport to the surgery. There were few ethnic differences in barrier endorsement, but those in non-white groups were more likely worry about not being taken seriously by the doctor (35%, compared with 23% of white respondents).

Table 1. Anticipated barriers to seeking medical help for a possible cervical cancer symptom (% responding 'yes sometimes' or 'yes often')

	Whole sample (n=1392)	Under 25 years (n=208)	25 years and over (n=1185)
Emotional barriers			
I would be worried about what the doctor might find	38%	49%	37%*
I would be too scared	26%	42%	23%*
I would worry about not being taken seriously	24%	35%	22%*
I would be too embarrassed	19%	39%	16%*
I would not feel confident talking about my symptom	18%	33%	15%*
Practical barriers			
I have too many other things to worry about	21%	29%	20%*
I would be too busy to make time to go to the doctor	20%	26%	19%*
It would be difficult for me to arrange transport	6%	9%	6%
Service barriers			
It would be difficult to make an appointment	29%	39%	27%*
I might not be able to see a female doctor	26%	37%	24%*
I would be worried about wasting the doctor's time	21%	29%	20%*
My doctor would be difficult to talk to	18%	31%	15%*

* Significant difference between the age groups at the .05 level

Cervical Cancer Risk Factors

In the next year, who is most likely to get cervical cancer in the UK?

A third of respondents (34%) correctly identified the peak age of incidence of cervical cancer as 30-49 years. 23% believed that women in their 20s were most at risk, 12% thought older women aged 50-69 were more at risk, and 27% believed that cervical cancer is unrelated to age. There were no differences in response by social grade or ethnic background but there were some age differences - women aged 16-24 were significantly more likely than any other group to think that the risk was greatest for women in their 20s. This may partly be due to the highly publicised death of Jade Goody at the age of 27.

Key messages summary Box 3

The cervical cancer key messages include the following information on age and risk:

> Cervical cancer can affect women of all ages but is most common in women between 30 – 45 years of age. It is very rare in women under 25.

34% of women thought that women aged 30-49 were more at risk than younger or older age groups. Almost a quarter (23%) believed that women in their 20s are most at risk.

What things do you think affect a woman's chance of getting cervical cancer?

As with the question about warning signs, women were first asked an open question about possible risk factors for cervical cancer and had to respond without prompts. Overall, 38% of women could not name any risk factors. The most common responses are shown in Table 2.

Table 2. Responses to the open question on risk factors for cervical cancer (n=1392)

Risk factor	n	%
Having many sexual partners	272	20%
Genes/heredity	177	13%
Being a smoker	121	9%
Having sex at a young age	111	8%
Having unprotected sex	101	7%
Not going for regular screening	78	6%
Poor diet	60	4%
Being sexually active	46	3%
Nothing	37	3%
Infection with HPV	15	1%

Although there was some awareness of the sexual behavioural risk factors for cervical cancer (e.g. 'Having many sexual partners' – 20%), very few people were able to name HPV as the main cause (1%), and the second most commonly mentioned factor was heredity, which is not considered to be a risk factor for cervical cancer. Fewer than 10% of women were able to recall smoking as a risk factor in this unprompted format.

How much do you agree or disagree that [risk factor] can increase the chance of getting cervical cancer?

Women were then given a list of risk factors - all of which were correct - and asked to indicate how much they agreed that each could increase the risk of cervical cancer, on a scale of 1 (strongly agree) to 5 (strongly disagree). The list was presented in random order. The number of women who agreed or strongly agreed with each risk factor is shown in Figure 3.

In line with responses to the open question, awareness of sexual behavioural risk factors was reasonably high, but the relatively low acknowledgement of the role played by HPV (46% agreed) indicates that most people don't understand the mechanism by which sexual activity increases the risk of cancer. Encouragingly, most women (75%) recognised that not attending for cervical screening has an impact on cervical cancer risk.

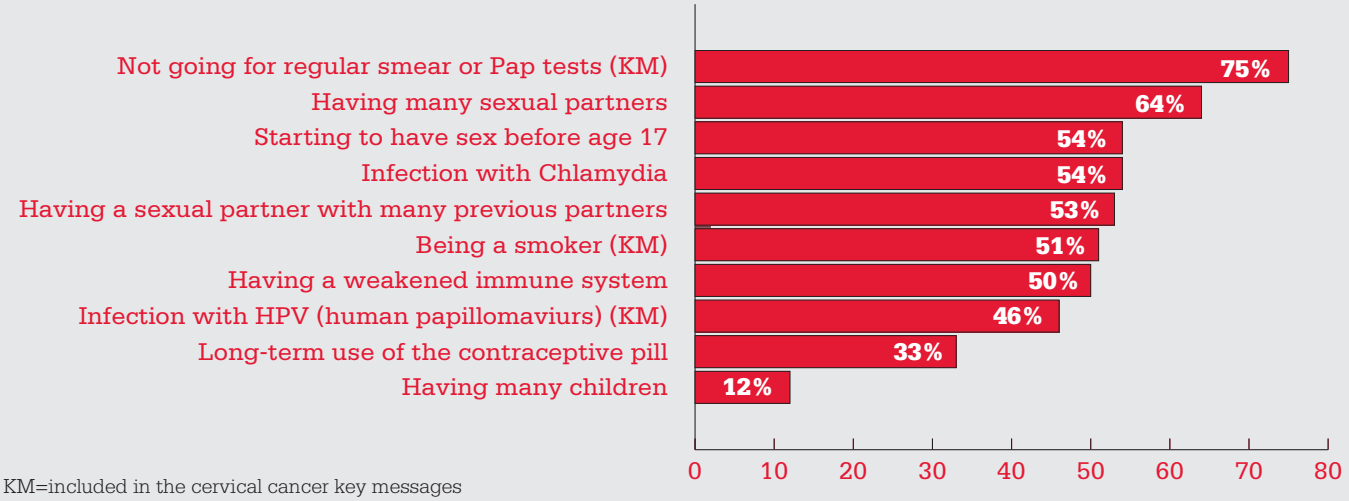
Recognition of HPV as a risk factor was highest in women in the middle age-groups (35-54 years) and in the higher social grades (54% in grade AB compared with 38% in grade E).

Women in grade E were significantly less likely than women in grades AB, C1 and C2 to agree that being a smoker increases the risk of cervical cancer, which is concerning given the social gradient in smoking behaviour – these women are more likely to have been smokers, although smoking status was not measured. Fewer of the oldest age group endorsed smoking compared with the middle age groups.

There was no social gradient in awareness of not going for screening as a risk factor, but awareness was highest in the 35-44 year age group (83% compared with 69% in the oldest and youngest groups).

There were no ethnic differences in recognition of most of the risk factors, but those from non-white groups were more likely to agree that having a weakened immune system could increase the risk (61% compared with 49% of white respondents).

Figure 3. Recognition of risk factors for cervical cancer (prompted format) – percentage responding 'agree' or 'strongly agree'



KM=included in the cervical cancer key messages

Key messages summary Box 4

The cervical cancer key messages include the following information on risk factors:

Nearly all cervical cancers are caused by a common sexually transmitted infection called human papillomavirus (HPV).

They also include the following advice on reducing the risk:

Go for cervical screening when you are invited
If you smoke, try to stop

In our sample, 46% recognised HPV as a risk factor, 75% recognised not going for screening and 51% recognised being a smoker.

Awareness of the NHS Screening and Vaccination Programmes

As far as you are aware, is there an NHS cervical cancer screening programme?

Most women were aware that there is an NHS screening programme for cervical cancer (85%). This ranged from 91% in the highest social grade (AB) down to 74% in social grade E. Awareness was lowest in the youngest (72%) and oldest (65+; 76%) age groups. Younger women being less aware of screening is probably not surprising. Women under 25 are not eligible for screening and may therefore be less aware of the screening programme until it becomes relevant for them. It is perhaps more surprising that women over 65 were less aware when most would probably have been eligible for and may have been screened as younger women. There was no difference in awareness between white and non-white groups.

At what age are women first invited for cervical screening?

Of the women who knew that there is a screening programme, 31% were aware that screening begins at age 25 years. 13% believed that screening starts at age 20 or 21, and 8% thought that it begins at 30. Encouragingly, women in the 16-24 year age group were most aware of the correct age (45% of them said 25 years, compared with 16-36% in the other age groups).

As far as you are aware, is there an NHS Vaccination programme?

There was high awareness of the HPV vaccination programme, considering that it only began just over a year before the survey was carried out, with 69% agreeing that there is an NHS vaccination to protect against cervical cancer. It should be noted that a far greater proportion of the sample were aware of the vaccination programme than recognised HPV as a cause of cervical cancer. Awareness was significantly lower in women aged 65 and over than the other age groups (49%), and in women in social grade E (56%), compared with those in AB, C1 or C2 (78% in grade AB). Women from non-white backgrounds were less aware of the vaccination programme than white women (57% vs. 70%).

At what age is the vaccination offered?

The majority (87%) of those aware of the NHS vaccination believed that it is offered at ages between 12-18 years. All these ages are currently correct as a 'catch-up' programme is being offered to girls up to 18. The main vaccination programme is aimed at girls in school Year 8, aged 12-13 years, and these ages were chosen by 37% of those who knew about the programme. About 19% said 14 years, 10% said 15 years and 17% said 16 years.

Key messages summary Box 5

The cervical cancer key messages include the following information on screening and vaccination:

Cervical screening – previously known as a smear test - can prevent cervical cancer and saves thousands of lives each year.

The best protection against cervical cancer if you are over 25 is attending cervical screening when invited.

In the future, most cervical cancers will be prevented by HPV vaccination.

If aged 12-18, you can reduce your risk of developing cervical cancer in the future by being vaccinated against HPV, and then attending screening from age 25.

85% of women were aware that there is a cervical screening programme. Of those who were aware, 31% knew that screening begins at 25 years.
69% knew about the vaccination programme, and 87% of those who knew about the programme believed that the vaccine is offered between 12 and 18 years.

Attitudes Towards Screening and Other Protective Behaviours

How much do you agree or disagree with each of the following statements? (see Figure 4)

Respondents were asked how much they agreed or disagreed with a list of statements about cervical cancer prevention and cervical screening (see Figure 4). Responses were on a five point scale from 'strongly agree' to 'strongly disagree'.

There was very high endorsement of the importance of early detection in cervical cancer prognosis – 92% agreed[7] that 'the chances of curing cervical cancer are better when the disease is discovered at an early stage'. Women in social grade E were significantly less likely to agree with this statement (84% compared with over 90% in all the other social grades), as were women in the youngest age group (86% compared with 98% for women aged 45-54 years) and those from non-white backgrounds (83% compared with 93% of white women).

Almost as many women (86%) agreed that 'cervical screening can pick up cell changes that may go on to become cervical cancer', indicating an awareness of the preventive nature of screening. Women aged between 35 and 64 years were more likely to agree with this statement than younger or older women, and there was a social gradient, with 93% of women in grade AB agreeing, compared with 78% of women in grade E. Agreement was significantly lower in non-white than white women (65% compared with 88%).

Three quarters of women (76%) agreed that screening is effective in preventing cervical cancer, a belief which was broadly consistent across age, social grade and ethnic groups.

Only a small minority of women (12%) said that they would rather not know if they had cervical cancer. As has been found in other studies, this fatalistic attitude was more common in women from low social grades (19% of women in social grade E agreed, compared with 10% of women in grade AB). Although women from non-white backgrounds were no more likely to agree with this statement, they were less likely to disagree with it, and a large proportion said that they neither agreed nor disagreed (20% of the non-white group compared with 7% of white women).

In line with the high screening participation in this sample, 79% said that they intended to accept future invitations for screening (see Table 3 for an age break-down). Older women were less likely to agree, reflecting the fact that many of them would no longer be invited to take part in the national screening programme. Women in social grade AB were significantly more likely to intend to go for future screening than women in social grade E (84% compared with 68%). There were no ethnic differences in intention to attend.

Awareness of other protective behaviours was less widespread than knowledge about screening. Only around half of respondents agreed that stopping smoking (54%) can reduce the risk of cervical cancer. The youngest age group was least likely to believe that stopping smoking could be protective (43%), and there was a significant social gradient, with women in grade AB most likely to agree (63%) and women in grade E least likely (45%). This reflects the pattern of awareness that being a smoker increases the risk of cervical cancer seen earlier. There was some evidence of a stronger belief that stopping smoking reduces the risk among non-white women – 29% of this group strongly agreed with this statement, compared with 20% of white women.

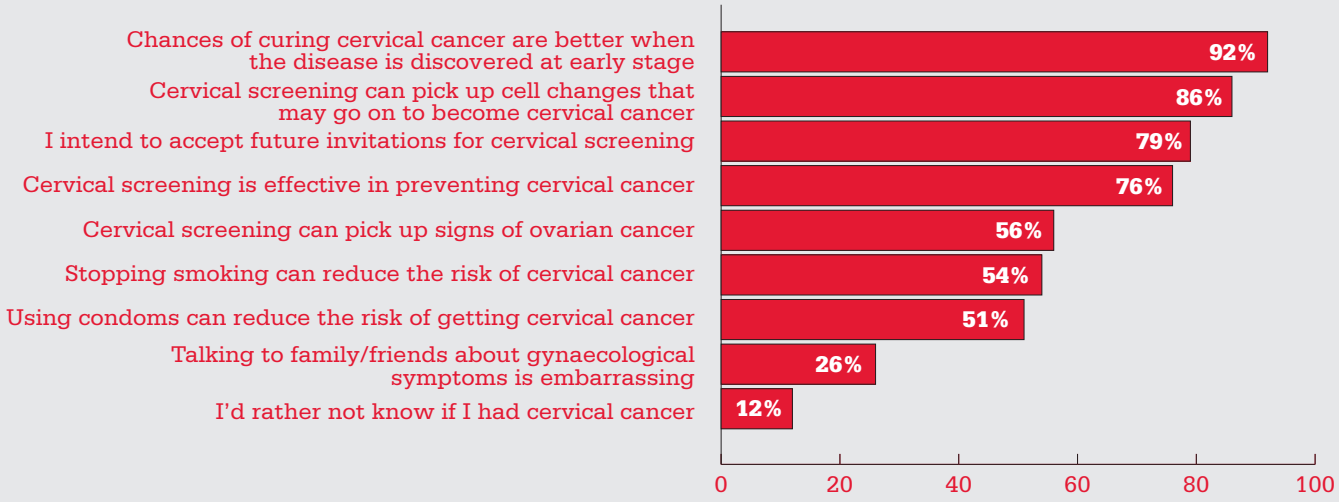
When asked about the efficacy of condom use in reducing the risk, 51% agreed that using condoms could reduce the risk of cervical cancer. Young women were least likely to agree (33% compared with over 60% in the 45-64 year age group). Women in grade AB were significantly more likely than women in the other social groups to agree with this statement (59% compared with 45-49% in the other groups). Women from non-white backgrounds were less likely to agree that condoms could reduce the risk (41% compared with 52% of white women).

[7] *For the purposes of analysis, the categories 'agree' and 'strongly agree' were combined, and the categories 'disagree' and 'strongly disagree' were combined.*

In relation to early presentation with symptoms, a quarter of the sample (26%) agreed that talking about gynaecological symptoms is embarrassing and, as can be seen in the age profiles below (see Table 3), this seemed to be particularly true for young women. There were no significant differences by social grade or ethnic group.

We identified one common misconception – 56% of women incorrectly believed that cervical screening can also pick up signs of ovarian cancer. This may reflect confusion about the different gynaecological cancers and reproductive anatomy, and indicates that many women believe that cervical screening is a more general check-up than is actually the case. There were no age or ethnic differences in this belief but women from lower social grades were more likely to (incorrectly) agree (63% in grade E compared with 52% in grade AB).

Figure 4. Percentage agreeing with the following statements



Age Profiles

To assist with targeting the key messages appropriately, knowledge of the specific information provided in the messages was examined by age group (see Table 3).

Again, it should be remembered that cervical cancer can affect women of all ages but is most common in women between 30 – 45 years of age. It is rare in women under 25. The risk of dying from cervical cancer rises with age

Women aged 16-24 years had relatively poor awareness of warning signs of cervical cancer, with fewer than 60% recognising each of the three symptoms highlighted in the key messages and only 26% recognising all three. Only a third were confident that they would notice a symptom of cervical cancer if they had one.

Importantly, these youngest women in the group surveyed were unlikely to believe that using condoms or stopping smoking could reduce the risk of cervical cancer.

Almost a third in this age group agreed that talking about gynaecological symptoms with family or friends is embarrassing.

Encouragingly, beliefs about screening were more positive, with 70% believing it to be effective in preventing cervical cancer, and 87% intending to accept screening invitations in the future. Although 71% were aware of the vaccination programme, only 40% of the youngest women surveyed agreed that HPV is a risk factor for cervical cancer.

Women aged 25-39 years had very positive beliefs about the importance of screening and early detection, but they had low awareness of the role of HPV in causing cervical cancer, and only half believed that being a smoker could increase the risk.

Although two thirds agreed that bleeding during or after sex could be a sign of cervical cancer, fewer than 60% recognised persistent vaginal discharge as a possible symptom and only 36% recognised all three warning signs.

Only half were fairly/very confident that they would notice a symptom of cervical cancer if they experienced one. This is of concern given that many of these women are in the age of peak incidence of cervical cancer.

Women aged 40-59 years had reasonably good awareness of the warning signs – each sign was recognised by at least two-thirds of women. However, even in this, the best-informed group, only 45% were able to recognise all three of the key warning signs.

Just over half of these women were aware that HPV and smoking contribute to cervical cancer risk and the majority agreed that stopping smoking, using condoms and going for screening could reduce the risk of cervical cancer.

A quarter found talking about gynaecological symptoms embarrassing, but almost all (96%) believed that early diagnosis was important in maximising the chances of cure.

Women aged 60 years and over had similar symptom recognition to the 40-59 year-old group but they were less able to recognise HPV and smoking as risk factors.

Only half believed that stopping smoking could reduce the risk of cervical cancer, and 56% believed that condom use could be protective.

Awareness of the vaccination programme was lowest in this group, probably due to their being less likely to have daughters in the vaccination age-group.

Although their attitudes to screening were positive, and 74% believed it to be effective in preventing cancer, intentions to participate it the future were low, at 56%, and this is likely to be because many of the women in this group were outside the screening age range and probably knew that they would no longer be invited to take part.

Table 3. Summary profiles of 4 age-groups of women

	16-24 (n=208)	25-39 (n=343)	40-59 (n=431)	60 and over (n=410)
Recognition of cervical cancer symptoms				
Persistent vaginal discharge	51%	59%	66%	66%
Bleeding after menopause	57%	62%	69%	72%
Bleeding during/after sex	52%	65%	72%	60%
Recognition of all three Key Messages symptoms	26%	36%	45%	43%
Confident of noticing a sympton of cervical cancer	34%	52%	61%	62%
Aware that women aged 30-49 are most at risk	29%	38%	34%	32%
Risk factors recognised (% agreeing)				
HPV	40%	46%	54%	42%
Smoking	51%	53%	56%	44%
Not having regular screening	69%	79%	77%	74%
Beliefs about protective behaviours (% agreeing)				
Condoms reduce the risk	33%	42%	62%	56%
Screening is effective	70%	77%	80%	74%
Stopping smoking reduces the risk	43%	59%	60%	50%
Beliefs about early diagnosis (% agreeing)				
Talking about gynaecological symptoms is embarrassing	32%	27%	25%	23%
Early detection means a better chance of cure	86%	90%	96%	92%
Awareness of screening and vaccination				
Aware of cervical screening programme	73%	88%	92%	79%
Aware of cervical cancer vaccination programme	71%	77%	76%	54%
Intend to go for screening	87%	90%	87%	56%

Conclusions and Implications

The overall picture presented by this survey is of patchy knowledge. There was good awareness of the screening programme, strong belief in its efficacy and high intention to participate in the future, including in the youngest age-group. This is encouraging and suggests that messages about screening are reaching women.

There was much lower awareness of the other things women can do to reduce their risk of cervical cancer i.e. using condoms and stopping smoking.
Awareness of HPV was higher in this sample than has been found in previous surveys, suggesting that the HPV vaccination programme may be having an impact on public understanding, but over half of the sample did not agree that HPV increases the risk of cervical cancer. Lack of awareness of HPV feeds into a lack of understanding of the sexually transmitted nature of the disease, and so it is perhaps not surprising that women do not know that condoms can reduce the risk.

Similarly, there was low awareness that smoking increases the risk. This is consistent with previous studies which have found that women are unable to conceptualise how smoking could affect the cervix (unlike lung cancer which has a more intuitive link). More work is therefore needed to disseminate messages about the role that both smoking and HPV infection play in cervical cancer development.

In terms of symptoms, a sizable minority of women, and particularly young women, were unable to recognise the three symptoms highlighted in the key messages, even in the prompted question format. Without prompting, 40% of women were unable to think of any symptoms of cervical cancer. This is worrying and suggests that many women could dismiss potentially serious symptoms because they do not realise that they could be cancer.

Work is needed to raise awareness of the signs and symptoms of cervical cancer, particularly those of early-stage disease highlighted in the key messages. Information especially needs to be targeted at women from low social grades and non-white ethnic groups, as symptom awareness was lower among these women.

Encouragingly, most women said that if they had a symptom that they thought could be cervical cancer, they would seek medical help within a week. This points to the need for increasing symptom recognition, rather than promoting quick help-seeking once a symptom has been identified. However, when asked about potential barriers to help-seeking, concerns about what the doctor might find was most commonly endorsed. This presents a communication challenge – we need to raise symptom awareness without raising anxiety so much that women are too afraid to seek appropriate help.

Service-level barriers must also be addressed. Many women said they might be put off seeking help by the difficulty of making an appointment, and by the possibility of not being able to see a female doctor. These service provision issues should be easier to tackle than the emotional barriers. All the barriers were endorsed more by younger women, with emotional barriers such as embarrassment particularly high in this group. Work needs to be done to empower this group of women to seek help if they experience gynaecological symptoms.

Key Recommendations

- Continue to disseminate messages about the importance and efficacy of cervical screening
- Provide women with a causal model of cervical cancer which allows them to understand how sexual activity, condom use and smoking can influence cancer risk
- Raise awareness of HPV and continue to disseminate information about the vaccination programme
- Increase women's knowledge of the signs and symptoms of cervical cancer and encourage them to have symptoms checked by a doctor, while reassuring them that in most cases, the symptoms won't be cancer
- Remove service barriers to help-seeking and ensure that it is easy for women to make an appointment to see a female doctor for gynaecological symptoms
- Promote more open discussion of gynaecological symptoms to minimise the role that embarrassment plays in preventing early diagnosis
- Target information particularly at young women and lower SES and non-white ethnic groups who generally have lower cervical cancer awareness which would encourage screening and vaccination
- Use television, newspapers and women's magazines to disseminate messages, to ensure that they reach women in lower social grades

Appendix 1

Sampling Method

The sampling technique used in this survey is a tightly controlled form of random location sampling developed within BMRB, and is the basis of most consumer surveys which BMRB conducts.

The aim of random location sampling is to eliminate the more unsatisfactory features of quota sampling without incurring the cost and other penalties involved in conducting surveys according to strict probability methods. One of the principal advantages of probability techniques of sampling is that selection of respondents is taken from the hands of interviewers. In conventional quota sampling, on the other hand, interviewers are given quotas to fill, usually from within specified administrative areas. When, for example, an interviewer is asked to complete a quota of AB respondents, she will tend to go to a part of the district where she knows such individuals to be available. AB individuals living in mixed social class areas will have little chance of inclusion. This and similar defects lead to biases which are concealed by superficial agreements between sample profiles and accepted standard statistics.

The principal distinguishing characteristic of random location sampling, as operated by BMRB, is that interviewers are given very little choice in the selection of respondents. Respondents are drawn from a small set of homogenous streets, selected with probability proportional to population after stratification by their ACORN[8] characteristics and region. Quotas are set in terms of characteristics which are known to have a bearing on individuals' probabilities of being at home and so available for interview. Rules are given which govern the distribution, spacing and timing of interviews.

The sample of areas takes as its universe all sample units (groups of Census 2001 Output Areas, on average, 300 households) in Great Britain. Output areas are stratified in the following manner:

(i) Standard Region

(ii) Within Standard Region - by ACORN type

(iii) Within Standard Region by County and ITV Region

Thus, the design is single stage, using direct selection of appropriate groups of Output Areas, rather than taking streets at random from larger units such as wards or parishes.

[8] *See http://www.caci.co.uk/acorn/whatis.asp for information on ACORN*

Weighting Procedures

The data is weighted to ensure that demographic profiles match those for the women aged 16 and over in England. A rim weighting technique is used in which target profiles are set for five separate demographic variables. The computer system then allocates a weight to each individual such that the overall composition of the sample is balanced in terms of the targets set.

The actual weights applied thus vary slightly between surveys; precise figures for specific cases are available from BMRB if required.

Sex 1	
Women working at all	48.05%
Women not working	51.95%
Sex 2	
Women without children	63.21%
Women with children	36.79%
Age	
16-24	14.93%
25-34	15.11%
35-44	18.04%
45-54	16.01%
55-64	14.42%
65+	21.49%
Social grade	
AB	26.06%
C1	30.97%
C2	18.89%
D	14.96%
E	9.12%
Standard region	
North West	12.53%
North	6.05%
Yorkshire and Humberside	10.11%
East Midlands	8.65%
East Anglia	4.60%
South East	22.79%
Greater London	14.57%
South West	10.31%
West Midlands	10.39%

(Source of profile data: BMRB Target Group Index, 2009 and NRS, 2009)

Appendix 2

Demographic characterisics of the sample (n=1392)

	n (weighted)	% (weighted)
Age		
16-24	208	14.9
25-34	210	15.1
35-44	251	18.0
45-54	223	16.0
55-64	201	14.4
65 and over	299	21.5
Social grade		
AB (Managerial/professional)	363	26.1
C1 (Supervisory/clerical)	431	31.0
C2 (Skilled manual)	263	18.9
D (Semi/unskilled manual)	208	15.0
E (State pensioners, unemployed, lowest grade workers)	127	9.1
Working status		
Full time	317	22.8
Part time	352	25.3
Not working	368	26.4
Retired	355	25.5
Ethnic group		
White	1261	90.6
Non-white	128	9.2
Marital status		
Married	833	59.8
Single	282	20.3
Other	276	19.9
Cervical screening status		
Had screening <3 years ago	664	47.7
Had screening 3-5 years ago	187	13.4
Had screening >5 years ago	163	11.7
Never been screened	139	10.0
Have had a hysterectomy	101	7.2
Never been invited	65	4.7
Never heard of cervical screening	61	4.4

About The Eve Appeal

The Eve Appeal was publicly launched in 2005 to help save women's lives by funding research into gynaecological cancers and raising awareness of the diseases.

Around 18,000 women annually in the UK are diagnosed with a gynaecological cancer and nearly 7,500 die.

The charity is well on its way to meeting its original fundraising target of £5 million and by June 2010 had donated £3.7 million to research.

The excellent progress of both The Eve Appeal and the Gynaecological Cancer Research Centre at UCL was recognised in June 2009 by an international review panel chaired by Sir John Pattison.

But there is still much to do. Much of the research work now under way will not be completed for some years and continued funding is essential if its early promise is to be fulfilled.

For the future The Eve Appeal continues to work towards its vision of a world where fewer women develop and more women survive gynaecological cancers, and in the shorter term to fulfill its ambition to become the national gynaecological cancer charity by 2012.

About the Author

This report has been written by Dr Jo Waller, a Senior Research Associate at Cancer Research UK's Health Behaviour Research Centre (HBRC) at UCL. She is a health psychologist, with a particular interest in public understanding of cancer and the psychosocial aspects of cancer screening. Dr Waller leads the HBRC's contribution to CCASI.

About the Cervical Cancer Awareness and Symptoms Initiative

The **What Women Know** report is one output of the Cervical Cancer Awareness and Symptoms Initiative (CCASI), a collaborative partnership, established in September 2009, with the Department of Health, UCL Health Behaviour Research Centre and The Eve Appeal.

By the end of 2010, the initiative aimed to;

1. Develop Cervical Cancer Key Messages on signs and symptoms of cervical cancer for women
2. Develop a Cervical Cancer Awareness Measure
3. Use the Cervical CAM as basis for benchmarking and follow up survey on levels of awareness of key facts about cervical cancer amongst UK women
4. Undertake a dissemination programme for key messages and the survey findings
5. Work in partnership as appropriate with other organisations with shared aims

By June 2010 aims 1, 2 and 3 were complete.

The Eve Appeal received a grant from the Department of Health in March 2010 to ensure dissemination work (aim 4) is undertaken to support awareness raising work for the key messages. This programme is now (June 2010) well under way.

For copies of all the materials produced by CCASI to date, please contact The Eve Appeal on **020 7299 4430** or email **ccasi@eveappeal.org.uk**

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