Cervical Cancer Awareness Measure (Cervical CAM)

Toolkit

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

Working in partnership with

Toolkit contents

TERMS OF USE FOR THE CERVICAL CANCER AWARENESS MEASURE

Please find enclosed/attached the Cervical Cancer Awareness Measure (Cervical CAM) a validated survey instrument enabling you to gather cancer awareness data and guidance for its use.

As you can appreciate with a tool such as this it is vital that consistency of approach to data capture is maintained.

Please ensure that your use of the Cervical CAM complies with our guidance notes.

Please do not alter the Cervical CAM or any of the guidance supplied.

Please ensure that the following notice is included on any copies or partial copies that you make of the Cervical CAM or any of the guidance supplied, and in any publication based wholly or partly on its use;

'This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.'

You may use the data collected for your own non-commercial purposes.

We would like to see all Cervical CAM data lodged in one place for ease of reference to researchers in the future. To facilitate this we have made arrangements with the UK Data Archive, www.data-archive.ac.uk to provide a repository for this. Please ensure that you lodge the data you gather there (see page 56 for guidance).

If you have any queries please contact naedi@cancer.org.uk

Cervical Cancer Awareness Measure (Cervical CAM)

Background information and instructions

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

the eve appeal
gynaecology cancer
research fund

Working in partnership with

UCL

DH Department of Health

Introduction and purpose of the Cervical CAM

In 2007, the NHS Cancer Reform Strategy published by the Department of Health[1], emphasised the importance of raising awareness of cancer early warning signs and risk factors within the general population. The National Awareness and Early Detection Initiative (NAEDI) has been set up with this in mind. It comprises nine work streams, one of which has been to develop a measure of general cancer awareness (Stubbings et al., 2009) called the Cancer Awareness Measure (CAM). The CAM was developed so that researchers could systematically assess the impact of interventions designed to target gaps in public awareness of cancer either in whole populations or specific sub-groups. The CAM enables both researchers and campaigning groups to evaluate and compare the impact of their activities. In addition to the generic version of the CAM, there is a need to develop site specific modules for cancers where early detection is likely to impact survival, as is the case with cervical cancer. This document provides information about the use of the cervical specific version of the CAM – the Cervical CAM.

The Cervical CAM comprises 9 questions with a total of 31 items:

- Warning signs (12 items) (Q1 + Q2)

- Delay in seeking medical help (1 item) (Q3)

- Age at risk of cervical cancer (1 item) (Q4)

- Risk factors (12 items) (Q5 + Q6)

- Confidence detecting cervical cancer symptom (1 item) (Q7)

- NHS cervical cancer screening programme (2 items) (Q8)

    - Knowledge (1 item)

    - Age of first invitation (1 item)

- NHS vaccination programme (2 items) (Q9)

    - Knowledge (1 item)

    - Age offered (1 item)

Evaluation and psychometric status

Psychometric evaluation of the Cervical CAM (paper in preparation) indicates that it has satisfactory internal reliability with Cronbach's alpha above 0.7 for all components. Test-retest reliability over a 1 week interval was found to be good, with all correlations above 0.7. Item difficulty (Kline, 1993[2]) was assessed and the majority of items in the Cervical CAM were answered correctly by more than 20% and less than 80% of respondents. Those items that did not meet these criteria were retained on the basis of content validity (e.g. persistent diarrhoea being a symptom of cervical cancer, long term use of the contraceptive pill, having a sexual partner who is not circumcised, having many children and not going for regular smear tests as risk factors for cervical cancer, and knowledge of the NHS cervical screening programme). Item discrimination analyses showed item-to-total correlations greater than 0.2

---

[1] Department of Health (2007). Cancer Reform Strategy.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_081006.

[2] Klein, P (2000). The Handbook of Psychological Testing. Routledge: London.

for the majority of items with the exception of the warning sign 'vaginal bleeding after the menopause'. This item was retained to ensure content validity. In order to ensure construct validity the Cervical CAM was completed by 19 cervical cancer experts (gynaecologists and colposcopists) and 25 university administration staff and students. Cervical cancer experts obtained significantly higher scores than the university administration staff and students, which indicates that the Cervical CAM is capable of discriminating between those who have high and low levels of cervical cancer awareness. We also carried out an intervention study in which participants randomly received either an intervention leaflet ("Cervical Cancer: The Facts") or a control leaflet ("Recycle to save the environment") to read prior to completing the Cervical CAM. Participants who received the intervention leaflet consistently obtained higher scores than those who received the control leaflet. This demonstrates that the Cervical CAM is sensitive to increases in cancer awareness.

Administration

The Cervical CAM was designed to be administered as an interview either face-to-face or over the telephone and this delivery method will yield the best quality data. If it is not possible to use either of these methods we advise using a supervised self-complete method where individuals are asked to complete the measure but under supervised conditions with someone available for guidance. It is possible to use the Cervical CAM on the internet, or as a 'self complete' survey that is not supervised (e.g. postal) but this will provide lower quality data.

Face-to-face

Ideally, the Cervical CAM should be administered by one trained interviewer in an environment where there will be little distraction.

The internet

Using the Cervical CAM on the internet is often a cheaper and more practical option, but there are several things you should consider before using this option. For example, you should be aware that not everybody will have internet access, and in particular those from lower socio-economic groups may not have access. So using the Cervical CAM in this way could introduce some inequality and not provide total coverage. It is also worth considering participants familiarity with using the internet. Conducting the survey on-line is also a 'less controlled' environment, for example, it is possible that participants could look up the correct answers while completing the survey or consult with others to help them answer the questions.

If you plan to use an on-line version you should ensure that participants cannot return back to previous questions. For sections where there are lists e.g. symptoms or risk factors, it is best to present these as one item per screen, rather than a long list. You could also consider monitoring the time it takes for participants to complete the survey because this could help pinpoint participants who may have less reliable responses.

If you go ahead with an online version you may want to do a quick pilot to make sure that it is being used appropriately and that you aren't suddenly getting 'odd' responses e.g. if someone can't go back and change their answers, but they didn't understand the response options 'first time' this may result in some errors.

Telephone

The telephone offers a good alternative to face-to-face interviews. You should ask respondents to ensure that they are not to be distracted by anyone while completing the survey.

Self-complete or postal

If you would like to administer the Cervical CAM as 'self-complete' or postal survey you must either remove Q1 and Q5 or Q2 and Q6. Q1 and Q5 are 'unprompted' questions which ask respondents to recall warning signs or risk factors from memory. Q2 and Q6 are 'prompted' questions asking respondents to respond to a prompted list of warning signs and risk factors. If both sets of unprompted and prompted questions are included in the survey respondents could go back and change their answers to Q1 and Q5 as a result of being prompted in Q2 and Q6.

You should consider the aims and objectives of your study and the analyses that you plan to carry out to help you decide which questions to keep in the survey. If you are interested in what people actually 'know' you should keep the unprompted questions. But if you would prefer to assess respondent's ability to 'recognise' signs or risk factors, you should keep the prompted questions. You may also find that the unprompted questions are more difficult to code and use in analyses because they generate a larger variety in responses and so this represents are more difficult option for less experienced researchers.

Recruitment considerations

For information about sampling methods and sample size for your Cervical CAM survey please see page 73. Once you have recruited your participants please record the sampling methods using the relevant form (see 'Recruitment Record' on page 25) and submit this to the UK Data Archive together with your data when you have completed your research (for further advice about how to access or upload data in the UK Data Archive see page 56).

Ethical approval

Before you start recruiting your sample, please consider whether you need to obtain ethical approval, this is usually stipulated by the organisation that is funding the research. Regardless of the type of research you are doing it is always appropriate to consider the ethical implications.

Research which falls under the remit of Department of Health approved ethics committees, which abide by governance arrangements for NHS research ethics committees; Department of Health, July 2001, para 3.1, are detailed below:

If the research involves:

- the use of patients and users of the NHS;
- individuals identified as potential research participants because of their status as relatives or carers or patients and users of the NHS;
- access to data, organs or other bodily material of past and present NHS patients;
- the recently dead in NHS premises;
- fetal material and IVF involving NHS patients;
- the use of, or potential access to, NHS premises and facilities;

- NHS staff recruited as research participants by virtue of their professional role, then the ethics of such human research must be referred to the appropriate Department of Health approved ethics committee.

Further details and information on how to apply is available from the Central Office for Research Ethics Committees (COREC): www.corec.org.uk

Informed consent

It is important that you gain consent from the people that you ask to complete a Cervical CAM survey. This is especially important when you are asking people for identifiable information such as their postcode. We have developed an example information sheet and consent form that you can use and modify to your own needs (see page 11).

Please see the UK Data Archive website for more information on consent procedures: http://www.data-archive.ac.uk/sharing/confidential.asp

Data protection

Please make sure that your consent and data management procedures are in line with the Data Protection Act (1999).

For more information see: http://www.ico.gov.uk/what_we_cover/data_protection.aspx

Demographics

Please ensure that all participants complete the 'demographics questions' at the end of the interview. This information is needed to ensure that comparisons of different groups, such as different age groups can be made.

Coding

Instructions are provided about how to code Cervical CAM survey data (see 'Coding Sheet' on page 42). All Cervical CAM data will need to be uploaded in to the UK Data Archive using the coding frame that has been provided. For instructions about how to access or upload data see 'How to access and deposit CAM data' on page 56.

Ensuring quality

Whether you plan to carry out the survey using volunteers or by commissioning an external agency you should ensure that the research is good quality. The Social Research Association (SRA) and the MRS provide professional standards and guidelines about best practice across all aspects of carrying out research;

SRA: http://www.the-sra.org.uk/guidelines.htm#public

MRS: http://www.mrs.org.uk/standards/mrs_guidelines.htm

Cervical CAM Questions

Q1 – Open warning signs (unprompted)

"There are many warning signs and symptoms of cervical cancer. Please name as many as you can think of …"

This is an open question designed to measure how many cervical cancer warning signs a respondent can recall unaided. In face to face interviews this Q1 is always printed on a separate page to Q2 to ensure that respondents answers are their own and not taken from the list for Q2. Please ensure that the respondent does not see Q2 before they have completed Q1.

Q2 – Closed warning signs (prompted)

"The following may or may not be warning signs for cervical cancer. We are interested in your opinion …"

These closed questions are designed to measure how many warning signs a respondent can recognise when prompted. The warning signs were collected from scientific literature and from cancer information websites.

Q3 – Delay in seeking medical help

"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"

This question can be used to assess when an individual would seek help for a symptom that they thought could be a sign of cervical cancer.

Q4 – Age at risk of cervical cancer

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

This question explores the public's knowledge of how age is related to cervical cancer risk.

Q5 – Open risk factors (unprompted)

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

This is an open question designed to measure how many cervical cancer risk factors a respondent can recall unaided. In face to face interviews Q5 is always printed on a separate sheet to Q6 in order to ensure that respondents' answers are their own and not taken from the list given for Q6. Please ensure that the respondent does not see Q6 before they have completed Q5.

Q6 – Closed risk factors (prompted)

"The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?"

These closed questions are designed to measure a respondent's level of agreement with the risk factors. The risk factors for cervical cancer were collected from scientific literature and from cancer information websites.

Q7 – Confidence detecting cervical cancer symptom

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

This question explores women's confidence in detecting cervical cancer symptoms.

Q8 – NHS Cervical cancer screening programme

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

"If yes, at what age are women first invited for cervical cancer screening in England?"

These questions assess awareness of the NHS Cervical Screening Programme, and the age at which women are first invited for screening.

Q9 – NHS vaccination programme

"As far as you are aware, is there an NHS vaccination to protect against cervical cancer?"

"If yes, at what age is this offered?"

These questions assess awareness of the NHS HPV vaccination programme, and the age at which women are first invited for the vaccination.

Cervical Cancer Awareness Measure (Cervical CAM)

Information sheet & consent form

the
eve
appeal
gynaecology cancer
research fund

Working in partnership with

UCL   DH Department of Health

Information sheet for [name of project]

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

[organisation name] is carrying out a survey to assess awareness of cancer risk factors, and signs and symptoms. The results will be used to develop better and more effective NHS communications and services to help increase the early diagnosis of cancer.

Why have I been invited to take part?

[sampling methods, e.g. 'You have been chosen at random' or 'we are asking everyone aged over 50 to complete this survey in xx area].

Do I have to take part?

It is up to you to decide whether or not to take part, taking part is voluntary. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What would I have to do?

If you decide to take part, the survey will take approximately [xx] minutes to complete.

Confidentiality

All the information that is collected will be anonymous and kept strictly confidential. Your personal data will be held in accordance with the Data Protection Act 1998.

What happens to the information that is collected?

All details that can identify you will be removed before storing the data. All the information collected in this survey (although not your name), will be stored in the UK Data Archive, which is a secure national bank where the results of many surveys are kept.
In the future, researchers will be able to download the information from the UK Data Archive and analyse it in new ways. This will help us to build an understanding of public awareness of cancer so that we can develop ways to improve cancer services. More information about the archive can be found here:
http://www.data-archive.ac.uk/Introduction.asp

Thank you for taking the time to read this information sheet.

[Insert lead researcher's signature]

Consent form for [name of project]

Please tick the appropriate boxes

I have read and understood the project information sheet dated DD/MM/YYYY. ☐

I have been given the opportunity to ask questions about the project. ☐

I agree to take part in the project. Taking part in the project will include completing a survey/being interviewed [Other forms of participation can be listed]. ☐

I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked any questions about why I no longer want to take part. ☐

I understand my personal details such as phone number and address will not be revealed to people outside the project. ☐

I understand that my words may be quoted in publications, reports, web pages, and other research outputs but my name will not be used unless I requested it above. ☐

I agree for the data I provide to be archived at the UK Data Archive. ☐

I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of that data and if they agree to the terms I have specified in this form. ☐

I understand that other researchers may use my words in publications, reports, web pages, and other research outputs according to the terms I have specified in this form. ☐

I agree to assign the copyright I hold in any materials related to this project to [name of researcher]. ☐

_____   _____   _____

Name of Participant   Signature   Date

_____   _____   _____

Researcher   Signature   Date

[Contact details for further information: Names, phone, email addresses, etc]

Cervical Cancer Awareness Measure (Cervical CAM)

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

the
eve
appeal
gynaecology cancer
research fund

Working in partnership with

UCL   DH Department of Health

1. There are many warning signs and symptoms of cervical cancer. Please name as many as you can think of:

2. The following may or may not be warning signs for cervical cancer. We are interested in your opinion:

	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?	☐	☐	☐
Do you think persistent lower back pain could be a sign of cervical cancer?	☐	☐	☐
Do you think a persistent vaginal discharge that smells unpleasant could be a sign of cervical cancer?	☐	☐	☐
Do you think discomfort or pain during sex could be a sign of cervical cancer?	☐	☐	☐
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?	☐	☐	☐
Do you think persistent diarrhoea could be a sign of cervical cancer?	☐	☐	☐
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer?	☐	☐	☐
Do you think persistent pelvic pain could be a sign of cervical cancer?	☐	☐	☐
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?	☐	☐	☐
Do you think blood in the stool or urine could be a sign of cervical cancer?	☐	☐	☐
Do you think unexplained weight loss could be a sign of cervical cancer?	☐	☐	☐

3. 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?

4. In the next year, who is most likely to develop cervical cancer in the UK?

a) A woman aged 20 to 29 years	☐
b) A woman aged 30 to 49 years	☐
c) A woman aged 50 to 69 years	☐
d) A woman aged 70 or over	☐
e) Cervical cancer is unrelated to age	☐

5. What things do you think affect a woman's chance of developing cervical cancer?

]

6. The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Infection with HPV (human papillomavirus)	☐	☐	☐	☐	☐
Smoking any cigarettes at all	☐	☐	☐	☐	☐
Having a weakened immune system (e.g. because of HIV/AIDS, immunosuppressant drugs or having a transplant)	☐	☐	☐	☐	☐
Long term use of the contraceptive pill	☐	☐	☐	☐	☐
Infection with Chlamydia (a sexually transmitted infection)	☐	☐	☐	☐	☐
Having a sexual partner who is not circumcised	☐	☐	☐	☐	☐
Starting to have sex at a young age (before age 17)	☐	☐	☐	☐	☐
Having many sexual partners	☐	☐	☐	☐	☐
Having many children	☐	☐	☐	☐	☐
Having a sexual partner with many previous partners	☐	☐	☐	☐	☐
Not going for regular smear (Pap) tests	☐	☐	☐	☐	☐

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

Not at all confident	Not very confident	Fairly confident	Very confident
☐	☐	☐	☐

	Yes	No	Don't know
8a. As far as you are aware, is there an NHS cervical cancer screening programme?	☐	☐	☐
8b. If yes, at what age are women first invited for cervical cancer screening in England? _____			☐

	Yes	No	Don't know
9a. As far as you are aware, is there an NHS vaccination to protect against **cervical cancer**?	☐	☐	☐
9b. If yes, at what age is this offered? _____			☐

Cervical Cancer Awareness Measure (Cervical CAM)

Demographic Questions

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

the
eve
appeal
gynaecology cancer
research fund

Working in partnership with

1. What is your age? ☐☐   Prefer not to say

☐

2. What is your gender?

☐ Male   ☐ Female   ☐ Prefer not to say

3. Which of these best describes your ethnic group?

White	Mixed	Asian or Asian British	Black or Black British	Chinese/other
☐ White British	☐ White and Black Caribbean	☐ Indian	☐ Black Caribbean	☐ Chinese
☐ White Irish	☐ White and Black African	☐ Pakistani	☐ Black African	☐ Other………
☐ Any other White background	☐ White and Asian	☐ Bangladeshi	☐ Any other Black background	☐ Prefer not to say
	☐ Any other Mixed background	☐ Any other Asian background		

4. What is the main language spoken at home?

☐ English   ☐ Sylheti

☐ Urdu   ☐ Cantonese

☐ Punjabi   ☐ Other………………………………………………….

☐ Gujarati   ☐ Prefer not to say

5. What is your marital status?

Single/never married	Married/living with partner	Married separated	Divorced	Widowed	Civil partnership	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

6. What is the highest level of education qualification you have obtained?

☐ Degree or higher degree	☐ O Level or GCSE equivalent (Grade A - C)
☐ Higher education qualification below degree level	☐ O Level or GCSE (Grade D - G)
☐ A-levels or highers	☐ No formal qualifications
☐ ONC/BTEC	☐ Other ………………………….
☐ Still studying	☐ Prefer not to say

7. Please tick the box which best describes your living arrangement:

Own outright	Own mortgage	Rent from Local Authority/Housing Association	Rent privately	Squatting	Other (e.g. living with family/friends)	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

8. What is your postcode?   Prefer not to say   ☐

9. How many years have you been living in the UK? ☐☐   Prefer not to say   ☐

10. Are you currently:

☐ Employed full-time	☐ Full-time homemaker
☐ Employed part-time	☐ Retired
☐ Unemployed	☐ Still studying
☐ Self-employed	☐ Disabled or too ill to work
	☐ Prefer not to say

11. Does your household own a car or van?

No	Yes, one	Yes, more than one	Prefer not to say
☐	☐	☐	☐

12. Have you, your family or close friends had cancer?

	Yes	No	Don't know	Prefer not to say
You	☐	☐	☐	☐
Partner	☐	☐	☐	☐
Close family member	☐	☐	☐	☐
Other family member	☐	☐	☐	☐
Close friend	☐	☐	☐	☐
Other friend	☐	☐	☐	☐

Optional items:

Are you registered with a GP?

Yes	No	Don't know	Prefer not to say
☐	☐	☐	☐

If you plan to use the following question we advise piloting it first with the target group to ensure that it is not off-putting.

What is your sexual orientation?

Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/ straight	Other	Prefer not to say
☐	☐	☐	☐	☐	☐

Cervical Cancer Awareness Measure
(Cervical CAM)

Recruitment Record

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

the eve appeal
gynaecology cancer research fund

Working in partnership with

UCL   DH Department of Health

Introduction

It is important to make your sampling and recruitment methods transparent because it gives people an idea of how representative your sample is and how many factors could have influenced respondent's answers, such as noise levels or confidentiality. This information will influence how the data are analysed and interpreted.

It is also important that you provide us with all the data you receive, so even if people miss out some of the questions, we would like any information they provide.

Purpose and sampling methods

Please outline the purpose of the survey (e.g. to explore awareness of cervical cancer risk factors and signs and symptoms in women aged over 50 years living in x).
Sampling frame(s) (e.g. electoral registers, postal address file, GP lists, telephone directory, all women over 50 years living in x).
Target population(s) (e.g. gender, age, geographical area)
Please describe the methods you used to recruit participants (e.g. flyers, leaflets , posters, newspaper adverts, letter, face-to-face)
Please describe the method(s) of administration of the Cervical CAM (e.g. face-to-face, telephone, internet, other) and complete the number of surveys completed using each method below:

Face to face ☐ Number of surveys…………

Over the telephone ☐ Number of surveys…………

Internet ☐ Number of surveys…………

Other ☐ Number of surveys…………

If the surveys were administered face-to-face:

Please describe the environment(s) in which the surveys were completed (e.g. closed office with one interviewer, communal coffee area, a busy street)
How many other people were present while the interview was being carried out? 0- 1 ☐ More than 1   ☐

If the surveys were administered in a different way:

Please describe how the surveys were distributed (e.g. by post, left on a counter, sent by email)
Please describe the environment(s) in which the surveys were completed (e.g. closed office with one interviewer, communal coffee area, a busy street, at home)

In what language were the interviews carried out?		
☐	English	☐ Sylheti
☐	Urdu	☐ Cantonese
☐	Punjabi	☐ Other……………………………………………
☐	Gujarati	

Sample characteristics

How many participants were recruited? _____
Did you carry out any power or sample size calculations? (If so, please provide details)
How many people were approached/contacted to complete the Cervical CAM? _____
How many people agreed to complete the Cervical CAM? _____

How many people refused to complete the Cervical CAM?   _____
How many participants started to complete the Cervical CAM but did not complete it?   _____
Over what time period were the interviews carried out?   From: _____(dd/mm/yyyy) to: _____(dd/mm/yy)

Cervical Cancer Awareness Measure (Cervical CAM)

Script

Working in partnership with

Introduction

This script is intended for use **during training** of how to administer the Cervical CAM. It should not be necessary to use this script once the interviewer is familiar with the questionnaire and these guidelines.

Instructions:

- Before starting the interview record whether the interview was carried out 'face-to-face', over the telephone etc, where the interview took place and what language the interview was carried out (see the 'Recruitment Record' for more information).

- Read out the questions **exactly** as it is written for each question.

- The text that is written in the shaded boxes is what you should read out.

- If a respondent asks for more details or help, please state that for the purposes of the study you cannot give any prompts or explanations (other than those permitted), remind the participant that we are interested in their own thoughts and beliefs and if necessary repeat the question.

- You may discuss queries once the interview is complete, including providing the correct answers where appropriate.

- Do not discuss the correct answers to the Cervical CAM if it is being used to evaluate the effectiveness of an intervention aimed to improve knowledge in which the same individuals are being interviewed at different times.

- Do not return to previous questions to amend answers.

- For each question it is possible to record if the respondent refuses or does not wish to answer the question or does not know the answer.

- If the respondent has any questions about symptoms they have had or other questions about cancer, please advise them to speak to their GP.

If you are interviewing people face-to-face it may be useful to use 'prompt cards' for some of the questions (e.g. ethnicity).

The interview

QUESTION 1 – OPEN WARNING SIGNS

The following questions are all about cervical cancer, which is cancer of the cervix (sometimes called the neck of the womb).

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

Prompt with 'anything else?' until the respondent can not think of any more signs. If the person says they do not know any, prompt with 'are you sure?' and if necessary 'take a minute to think about it'.

Write down all of the warning signs or symptoms that the person mentions exactly as they say it.

QUESTION 2 – CLOSED WARNING SIGNS

> *The following may or may not be warning signs for cervical cancer. We are interested in your opinion.*
>
> **Do not prompt**
>
> If the respondent asks for clarification about certain items within this set of questions, please refer to the clarifications written below. Please only read these out if necessary.
>
> *Do you think a persistent pain in your abdomen could be a sign of cervical cancer?*
>
> Repeat the above format for each subsequent question in this group.

Clarifications:

Please only read these out if necessary.

> *'Persistent' in reference to any of the warning signs refers to 3 weeks or longer*
>
> *Do you think vaginal bleeding after the menopause could be a sign of cervical cancer? [POINT OF CLARIFICATION]: The menopause is when periods permanently stop.*
>
> *Do you think persistent pelvic pain could be a sign of cervical cancer? [POINT OF CLARIFICATION]: the pelvic area is between the hips and at the bottom of the spine*
>
> *Do you think blood in the stool or urine could be a sign of cervical cancer? [POINT OF CLARIFICATION]: blood in your poo or wee*

QUESTION 3 – SEEKING HELP

> *The next question is about seeking help*
>
> *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?*
>
> Record the response verbatim

QUESTION 4 – CERVICAL CANCER AND AGE

The next question is about age and cervical cancer.

In the next year, who is most likely to develop ovarian cancer?

A woman aged 20 to 29 years

A woman aged 30 to 49 years

A woman aged 50 to 69 years

A woman aged 70 or over

Cervical cancer is unrelated to age

QUESTION 5 – OPEN RISK FACTORS

The next set of questions is about risk factors for cervical cancer

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

Prompt with 'anything else?' until the respondent can not think of any more signs. If the person says they do not know any, prompt with 'are you sure?' and if necessary 'take a minute to think about it'.

Write down all of the risk factors that the person mentions exactly as they say it.

QUESTION 6 – CLOSED RISK FACTORS

These are some of the things that can increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?
Do NOT prompt
Infection with HPV (human papillomavirus)
Strongly disagree
Disagree
Not sure
Agree
Strongly agree
Repeat the above format for each subsequent question in this group.

Clarification:

Please only read this out if necessary

Having many children [POINT OF CLARIFICATION]: Having more than 7 children

QUESTION 7 – CONFIDENCE

The final question is about cervical cancer symptoms
How confident are you that you would notice a cervical cancer symptom?
Not at all confident
Not very confident
Fairly confident
Very confident

QUESTION 8 – NHS SCREENING PROGRAMMES

Do NOT prompt
The next set of questions are about NHS screening programmes
As far as you are aware, is there an NHS cervical cancer screening programme? You may answer: 'Yes', 'No', 'Don't know'
[IF YES] At what age are women first invited for cervical cancer screening in England?
[IF NO] Go to next question

QUESTION 9 – NHS SCREENING PROGRAMMES

Do NOT prompt
The final question is about NHS vaccination programmes *As far as you are aware, is there an NHS vaccination to protect against cervical cancer? You may answer: 'Yes', 'No', 'Don't know'*
[IF YES] If yes, at what age is this offered? *[IF NO] Go to demographic questions*

Demographic questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey. The data collected will help us to identify specific age or demographic groups of people who are in need of more information about cancer. You will not be asked your name and all of your answers will be kept strictly confidential and anonymous. Your personal data will be held in accordance with the Data Protection Act 1998. Your details will not be passed onto your GP and will not affect your medical care in any way.

Could you tell me your age? ☐☐   Prefer not to say
☐

What is your gender?

☐ Male	☐ Female	☐ Prefer not to say

Which of these best describes your ethnic group?

White	Mixed	Asian or Asian British	Black or Black British	Chinese/other
☐ White British	☐ White and Black Caribbean	☐ Indian	☐ Black Caribbean	☐ Chinese
☐ White Irish	☐ White and Black African	☐ Pakistani	☐ Black African	☐ Other………
☐ Any other White background	☐ White and Asian	☐ Bangladeshi	☐ Any other Black background	☐ Prefer not to say
	☐ Any other Mixed background	☐ Any other Asian background		

What is the main language spoken at home?

☐ English	☐ Sylheti
☐ Urdu	☐ Cantonese
☐ Punjabi	☐ Other……………………………………………………….
☐ Gujarati	☐ Prefer not to say

What is your marital status?

Single/never married	Married/living with partner	Married separated	Divorced	Widowed	Civil partnership	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

What is the highest level of education qualification you have obtained?

☐ Degree or higher degree

☐ Higher education qualification below degree level

☐ A-levels or highers

☐ ONC/BTEC

☐ Still studying

☐ O Level or GCSE equivalent (Grade A - C)

☐ O Level or GCSE (Grade D - G)

☐ No formal qualifications

☐ Other …………………………..

☐ Prefer not to say

Which of these best describes your living arrangement?

Own outright	Own mortgage	Rent from Local Authority/Housing Association	Rent privately	Squatting	Other (e.g. living with family/friends)	Prefer not to say
☐	☐	☐	☐	☐	☐	☐

Could you tell me your postcode?

	Prefer not to say	☐

How many years have you been living in the UK?

	Prefer not to say	☐

Are you currently:

☐ Employed full-time

☐ Employed part-time

☐ Unemployed

☐ Self-employed

☐ Full-time homemaker

☐ Retired

☐ Still studying

☐ Disabled or too ill to work

☐ Prefer not to say

Do you or does anyone living with you own a car or van?

No	Yes, one	Yes, more than one	Prefer not to say
☐	☐	☐	☐

Have you, your family or close friends had cancer?

	Yes	No	Don't know	Prefer not to say
You	☐	☐	☐	☐
Partner	☐	☐	☐	☐
Close family member	☐	☐	☐	☐
Other family member	☐	☐	☐	☐
Close friend	☐	☐	☐	☐
Other friend	☐	☐	☐	☐

Optional items:

Are you registered with a GP?

Yes	No	Don't know	Prefer not to say
☐	☐	☐	☐

What is your sexual orientation?

Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/ straight	Other	Prefer not to say
☐	☐	☐	☐	☐	☐

Thank you for taking time to answer my questions.

Now that the interview is over, would you like to ask any questions? Or do you have any comments?

Cervical Cancer Awareness Measure (Cervical CAM)

Answer Sheet

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

Working in partnership with

This booklet is intended for use in training only. Respondents should not see this booklet. The following gives the correct answers to the questions asked in the Cervical CAM.

Q1. *There are many warning signs and symptoms of cervical cancer. Please name as many as you can think of.*

The correct answers to this question are listed in question 2, although there are other warning signs and symptoms and none of the signs and symptoms listed would necessarily be caused by cancer.

Q2. *The following may or may not be warning signs for cervical cancer. We are interested in your opinion?*

The correct answer for this question is that all of the warning signs and symptoms listed could be (but are not necessarily) warning signs for cervical cancer.

Q3. *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?*

There are no correct answers to this question.

Q4. *In the next year, who is most likely to develop cervical cancer in the UK?*

A woman aged 30 and 49 years old is most likely to get cervical cancer.

Q5. *What things do you think affect a woman's chance of developing cervical cancer?*

The correct answers to this question are listed in question 6, although there are other risk factors and none of the risk factors listed would necessarily lead to cancer.

Q6. *The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?*

All of the items listed are risk factors for cervical cancer.

Q7. *How confident are you that you would notice a cervical cancer symptom?*

This is an attitudinal question with no right or wrong answer.

Q8. *As far as you are aware, is there an NHS Cervical cancer screening programme?*

There is a NHS cancer screening programme for cervical cancer.

At what age are people first invited for cervical cancer screening in England?

People are first invited to attend cervical cancer screening at age 25 in England.

Q9. *As far as you are aware, is there an NHS vaccination programme to protect against cervical cancer?*

There is a NHS vaccination programme for cervical cancer.

At what age is this offered?

Girls aged between 12 and 18 are offered the vaccination.

Cervical Cancer Awareness Measure (Cervical CAM)

Coding sheet
(for use with SPSS or EXCEL)

the eve appeal
gynaecology cancer
research fund

Working in partnership with

UCL

DH Department of Health

Background and purpose

The coding guidance set out below ensures that data from the CAM is suitable for depositing in the UK Data Archive.

You can see that as well as numbers for coding the data, we are also providing a set of correct variable names which are highlighted in bold (e.g. **Cervical_vaginalbleedC**). Please use these variable names when recording your data.

For every question it is possible to code data as 'refused' ('98'). Use this code when the respondent actively chooses not to respond. Where appropriate there are also codes for 'don't know' ('99'). For all other missing data just leave a blank.

Please store the data in either EXCEL or SPSS for transfer to the archive. There is a template EXCEL and SPSS data file available, if you require it.

We have not provided guidance about how the CAM should be scored, but we are happy to give advice and can provide syntax files for coding in SPSS.

Contact details: naedi@cancer.org.uk

First of all, please create a participant ID number and describe the method of survey administration.

Participant ID Number **ID**	

Please indicate whether this interview was held face-to-face, over the telephone, via the internet or other. **InterviewMethod**

If 'Other' (code 4) create an additional variable **'InterviewMethodOther'** and write the response verbatim.

Face-to-face **1**	Telephone **2**	Internet **3**	Other **4**

Please indicate where the survey was completed.

InterviewSetting

If 'Other' (code 3) create an additional variable **'InterviewSettingOther'** and write the response verbatim.

Health service **1**	Home **2**	Other setting **3**

Please indicate which language was used to administer the interview.

InterviewLanguage

If 'Other' (code 7) create an additional variable **'InterviewLanguageOther'** and write the response verbatim.

English	**1**	Sylheti	**5**
Urdu	**2**	Cantonese	**6**
Punjabi	**3**	Other………………………………………………	**7**
Gujarati	**4**		

CAM questions

1. OPEN WARNING SIGNS

Create 17 variables labelled **Cervical_symptom01** etc up to **Cervical_symptom11**. Each symptom must be recorded as a new variable using the coding frame below. For example if the first response is 'vaginal bleed between periods' code as '1' in **Cervical_symptom01**. If the second response is 'vaginal discharge' code as '3' in **Cervical_symptom02** etc.

To code a variable that is not on the list code as 'Other' (code 12) create additional variables e.g. **Cervical_symptom14**, **Ovarian_symptom15** etc and write the response the participant has given verbatim.

Warning sign	Code
Vaginal bleed between periods	1
Low back pain	2
Vaginal discharge	3
Pain during sex	4
Heavy periods	5
diarrhoea	6
Bleeding menopause	7
Pelvic pain	8
Bleed during/after sex	9
Blood in stool	10
Weight loss	11
Other	12
Nothing	13
Refusal	98
Don't know	99

2. CLOSED WARNING SIGNS

The following may or may not be warning signs for cervical cancer. We are interested in <u>your</u> opinion:

Question followed by corresponding	Scoring		
	Yes	**No**	**Don't know**
SPSS/Excel Variable Name			
Do you think vaginal bleeding between periods a sign of cervical cancer? **Cervical_vaginalbleedC**	**3**	**2**	**1**
Do you think persistent lower back pain could be a sign of cancer? **Cervical_lowbackpainC**	**3**	**2**	**1**
Do you think a persistent vaginal discharge a sign of cervical cancer? **Cervical_vaginaldischargeC**	**3**	**2**	**1**
Do you think discomfort or pain during sex a sign of cervical cancer? **Cervical_painduringsexC**	**3**	**2**	**1**
Do you think menstrual periods that are heavier or longer than usual a sign? **Cervical_heavyperiodsC**	**3**	**2**	**1**
Do you think persistent diarrhoea is a sign of cervical cancer? **Cervical_diarrhoeaC**	**3**	**2**	**1**
Do you think vaginal bleeding after the menopause is a sign of cervical cancer? **Cervical_bleedingmenopauseC**	**3**	**2**	**1**
Do you think persistent pelvic pain could be a sing of cervical cancer? **Cervical_pelvicpainC**	**3**	**2**	**1**
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer? **Cervical_bleedduringaftersexC**	**3**	**2**	**1**

Question followed by corresponding	Scoring		
SPSS/Excel Variable Name			
	Yes	**No**	**Don't know**
Do you think blood in the stool or urine could be a sign of cervical cancer? **Cervical_bloodinstoolC**	**3**	**2**	**1**
Do you think unexplained weight loss could be a sign of cervical cancer? **Cervical_weightlossC**	**3**	**2**	**1**

3. SEEKING HELP

. 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?"

Cervical_CancerSignTime

4. CERVICAL CANCER AND AGE

In the next year, who is most likely to develop cervical cancer?	
Variable	**Scoring**
A woman aged 20 to 29 years	**1**
A woman aged 30 to 49 years	**2**
A woman aged 50 to 69 years	**3**
A women aged 70 or over	**4**
Cervical cancer is unrelated to age	**5**
Refusal	**98**

5. OPEN RISK FACTORS

Create 17 variables labelled **Cervical_riskO1** etc, up to **Cervical_risk17.** Each risk factor must be recorded as a new variable using the coding frame below. For example if the first response is 'infection with HPV' code as '1' in **Cervical_riskO1**. If the second response is 'smoking' code as '2' in **Cervical_riskO2** etc.

To code a variable that is not on the list code as 'Other' (code 12) create additional variables e.g. **Cervical_riskO14**, **Cervical_riskO15**, etc and write the response the participant has given verbatim.

Risk Factor	Code
Infection with HPV (human papillomavirus)	1
Smoking any cigarettes at all	2
Having a weakened immune system (e.g. because of HIV/AIDS, immunosuppressant drugs or having a transplant)	3
Long term use of the contraceptive pill	4
Infection with Chlamydia (a sexually transmitted infection)	5
Having a sexual partner who is not circumcised	6
Starting to have sex at a young age (before age 17)	7
Having many sexual partners	8
Having many children	9
Having a sexual partner with many previous partners	10
Not going for regular smear (Pap) tests	11
Other	12
Nothing	13
Refusal	98
Don't know	99

6. CLOSED RISK FACTORS

The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?

Question followed by **SPSS/Excel variable name**	**Strongly disagree**	**Disagree**	**Not sure**	**Agree**	**Strongly agree**
Infection with HPV (human papillomavirus) **Cervical_HPVC**	1	2	3	4	5
Smoking any cigarettes at all **Cervical_smokingC**	1	2	3	4	5
Having a weakened immune system (e.g. because of HIV/AIDS, immunosuppressant drugs or having a transplant) **Cervical_weakimmuneC**	1	2	3	4	5
Long term use of the contraceptive pill **Cervical_contraceptivepillC**	1	2	3	4	5
Infection with Chlamydia (a sexually transmitted infection) **Cervical_chlamydiaC**	1	2	3	4	5
Having a sexual partner who is not circumcised **Cervical_notcircumcisedC**	1	2	3	4	5
Starting to have sex at a young age (before age 17) **Cervical_youngsexC**	1	2	3	4	5
Having many sexual partners **Cervical_manysexualpartnersC**	1	2	3	4	5
Having many children **Cervical_manychildrenC**	1	2	3	4	5

Question followed by **SPSS/Excel variable name**	**Strongly disagree**	**Disagree**	**Not sure**	**Agree**	**Strongly agree**
Having a sexual partner with many previous partners **Cervical_partnerpreviouspartnersC**	1	2	3	4	5
Not going for regular smear (Pap) tests **Cervical_notregularsmearC**	1	2	3	4	5

7. CONFIDENCE

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

Variable name; Cervical_symptomConfidence

Not at all confident	Not very confident	Fairly confident	Very confident	Refusal
1	2	3	4	98

8. NHS CANCER SCREENING PROGRAMMES

As far as you are aware, iIs there an NHS Cervical cancer screening programme? **Variable name: CervicalScreening**	**Yes** 3	**No** 2	**Don't know** 1
If yes, at what age are people first invited for Cervical cancer screening? _____ For the **age** component of this question, please record the **actual age** the respondent gave as the answer in the variable name **Variable name CervicalAge**	**Age in years**	**Refused** 988	**Don't know** 999

9. NHS VACCONATION PROGRAMMES

	Yes	No	Don't know
As far as you are aware, is there an NHS cervical cancer vaccination programme? **Variable name: Cervical_vaccination**	**3**	**2**	**1**

	Age in years	Refused	Don't know
If yes, at what age are people first invited for Cervical cancer vaccination _____			
For the **age** component of this question, please record the **actual age** the respondent gave as the answer in the variable name **Variable name Cervical_agevaccination**		**988**	**999**

Demographic Questions

1. What is your age?		Prefer not to say
Age		**98**
Record actual age		

2. What is your gender?
Gender

1 Male	**2** Female	**98** Prefer not to say

3. Which of these best describes your ethnic group?

EthnicGroup

To code an ethnic group that is not on the list code as 'Other' (code 16) and write the ethnicity verbatim in '**OtherEthnic**'

White		Mixed		Asian or Asian British		Black or Black British		Chinese/other	
1	White British	4	White and Black Caribbean	8	Indian	12	Black Caribbean	15	Chinese
2	White Irish	5	White and Black African	9	Pakistani	13	Black African	16	Other………
3	Any other White background	6	White and Asian	10	Bangladeshi	14	Any other Black background	98	Prefer not to say
		7	Any other Mixed background	11	Any other Asian background				

4. What is the main language spoken at home?

Language

To code a language that is not on the list code as 'Other' (code 7) and write the language verbatim in '**OtherLanguage**'

1	English	5	Sylheti
2	Urdu	6	Cantonese
3	Punjabi	7	Other……………………………………………………………
4	Gujarati	98	Prefer not to say

5. What is your marital status?

MaritalStatus

Single/never married	Married/living with partner	Married separated	Divorced	Widowed	Civil partnership	Prefer not to say
1	2	3	4	5	6	98

6. What is the highest level of education qualification you have obtained?

HighestEducation

To code an education that is not on the list code as 'Other' (code 9) and write the education verbatim in **'EducationOther'**

1	Degree or higher degree	6	O Level or GCSE equivalent (Grade A - C)
2	Higher education qualification below degree level	7	O Level or GCSE (Grade D - G)
3	A-levels or highers	8	No formal qualifications
4	ONC/BTEC	9	Other …………………………
5	Still studying	98	Prefer not to say

7. Please tick the box which best describes your living arrangement:

LivingArrangement

To code an education that is not on the list code as 'Other' (code 6) and write the education verbatim in **'LivingArrangementOther'**

Own outright	Own mortgage	Rent from Local Authority/Housing Association	Rent privately	Squatting	Other (e.g. living with family/friends)	Prefer not to say
1	2	3	4	5	6	98

8. What is your postcode?   [|]   Prefer not to say   **98**

Postcode

Record actual postcode

9. How many years have you been living in the UK?   [|]   Prefer not to say   **98**

Years UK

Record actual years

10. Are you currently:

Employed

1	Employed full-time	**5**	Full-time homemaker
2	Employed part-time	**6**	Retired
3	Unemployed	**7**	Still studying
4	Self-employed	**8**	Disabled or too ill to work
		98	Prefer not to say

11. Does your household own a car or van?

Car

No	Yes, one	Yes, more than one	Prefer not to say
1	**2**	**3**	**98**

12. Have you, your family or close friends had cancer?

	Yes	No	Don't know	Prefer not to say
You **CancerYou**	1	2	3	98
Partner **CancerPartner**	1	2	3	98
Close family member **CancerCloseFamily**	1	2	3	98
Other family member **CancerOtherFamily**	1	2	3	98
Close friend **CancerCloseFriend**	1	2	3	98
Other friend **CancerOtherFriend**	1	2	3	98

Optional items:

Are you registered with a GP?			
GP			
Yes	No	Don't know	Prefer not to say
1	**2**	**3**	**98**

What is your sexual orientation?					
SexualOrientation					
To code a sexual orientation that is not on the list code as 'Other' (code 5) and write the sexual orientation verbatim in **'SexualOrientationOther'**					
Bi-sexual	Gay man	Gay woman/lesbian	Heterosexual/ straight	Other	Prefer not to say
1	**2**	**3**	**4**	**5**	**98**

Cervical Cancer Awareness Measure (Cervical CAM)
UK Data Archive

How to access and deposit CAM data

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

Working in partnership with

Background information

The UK data archive is hosted by the University of Essex, please contact Susan Cadogan for any queries (see contact details below). We ask that anyone who collects data using any of the Cancer Awareness Measures to deposit their data into the archive. This will allow us to build up an evidence base that can be accessed by all.

Contact information:	Susan Cadogan
	Senior Acquisitions Officer
	Economic and Social Data Service (ESDS)
	University of Essex,
	Colchester, CO4 3SQ, UK
Phone:	+44 1206 872572
Emails:	susan@essex.ac.uk; acquisitions@esds.ac.uk
Web General:	http://www.data-archive.ac.uk
Web Economic and Social Data service:	http://www.esds.ac.uk

How to access CAM data

Access to the Data Catalogue, including online documentation such as questionnaires, does not require registration. However, to download any CAM data you must register.

1. Go to: http://www.data-archive.ac.uk
2. Go to 'How to register' and follow the appropriate steps

Once you have registered and have a username and password you can access CAM data. To do so:

1. Go to: http://www.data-archive.ac.uk
2. Login via 'UK Federation'
3. Select 'UK data archive' as your home institution (unless you are an academic in which case select your university)
4. Type in your username and password
5. Use the 'Data Catalogue' to search for 'cancer awareness'. This should bring up all the CAM data that is currently held in the archive
6. Click on 'Download/order'
7. When prompted to provide details on how you will use the data, ensure that you select 'non-commercial' purposes.

Please note that if you would like access to identifiable information in the data, such as postcodes, you will be required to agree to the terms of our 'Special Licence'. The Special Licence asks for details about the person(s) or organisations wishing to access the data and a signed declaration that he/she understands the confidentiality obligations owed to those data including its physical security.

How to deposit your data

If you are commissioning your CAM survey please ensure that you specify responsibilities for uploading the data collected using the CAM.

To deposit your data into the archive you will need to complete three basic tasks:

1. Complete a set of deposit forms
2. Provide the data with supporting documentation
3. Complete the licence agreements

These tasks are detailed on the following pages.

Helpful Hints

- Remember to hit 'save' before switching between the different steps, or the information will not be recorded
- There is a 'help' button at the top of the form which links you to online guidance.

Next steps

Once you have sent your data to the UKDA, they should acknowledge receipt of your data via email. They will then review your submission and create a 'report' based on the documents you have provided. You should check this report as it will be held alongside your data in the archive. You should make any changes to the report and then confirm that you are happy with a final version. Your data will then be transferred to the archive and available on the web to other interested researchers.

Help

Please contact NAEDI if you have any queries about this process: naedi@cancer.org.uk

Step 1

Title should reflect the nature of and subject of the data collection and include a date e.g. General Household Survey, 2001-2002

Provide the format of the supporting documentation such as recruitment record etc.

In the box called 'Title of the data collection' please write in: "Cancer Awareness Measure", followed by the local designation, as appropriate. Alternatively, if Cervical CAM was used, write in: 'Cervical Cancer Awareness Measure'.

Give the details of the data collected. For each data file attached, list the name of the files, formats and contents.

NB. If you have collected postcode data, please indicate this here.

Data Collection Deposit Form

EXIT

example.xml

Preview | Submit | Help

Step 1 | Step 2 | Step 3

*Weighting information

○ A: Weighting is covered in documentation.
◉ B: Weighting is not covered in documentation.
○ C: Weighting is not applicable.

Provide details below.

Variable name	File name	Variable description

This information is crucial for secondary analysis. Please indicate whether different weights were assigned to the different cases in the analysis file. Weighting is usually used to correct skewness in a sample that is meant to

Edition/extract/version

Is this a new edition, extract or special version of the data collection?

○ Yes. Provide details below   ◉ No

Please indicate whether this is a new edition, extract or special version of the data collection.

Confidentiality/anonymisation

Has the data collection been anonymised?

○ Yes. Indicate additional anonymisation or confidentiality issues concerning this data collection   ◉ No

Please indicate whether data that includes confidential or sensitive data has been anonymised so that individuals, organisations or businesses cannot be identified from the data, NB. If your data includes postcodes, select 'no'.

Data Collection Deposit Form

EXIT

example.xml

Preview   Submit   Help

Step 1   Step 2   Step 3

Transfer medium

If any files are compressed (e.g. zipped), name the compression programme.

Provide details of the medium used to send the data collection to the UK Data Archive.

Floppy disk:	Number of diskettes	
CD-ROM/DVD:	Number of discs	
ZIP/JAZ or other cartridge:	Number of cartridges	
Other medium:	Specify medium, having first contacted the UK Data Archive to check that it is supported	

Data collections less than 10 megabytes in total may be sent as an attachment via email to acquisitions@esds.ac.uk

Attached files may be zipped or unzipped.

Number of files attached

Date email sent

Note that files with a .exe or .jpg extension will be stripped out due to the University of Essex's email security system.

If sending the data by FTP:

UKDA prefer to 'pull' the data for FTP transfers. If you wish to 'push' the data, an account can be set up for you. Contact help@esds.ac.uk. Once you have transferred the files, list the following:

Directory and path ---- if not the default directory

File name(s) :

Save

The UK Data Archive acknowledges receipt of all materials upon arrival. If you have not received an acknowledgement letter within ten working days, contact acquisitions@esds.ac.uk to make sure that the materials have arrived.

Provide the details of medium used to send the data to the UK Data Archive (by email, by FTP, CD/DVD etc.)

NB. If your data includes postcodes please do not send by email but use an FTP transfer, or send an encrypted CD-ROM/DVD or memory stick. More information about data formats, data transfer and encryption is available here: http://www.data-archive.ac.uk/sharing/acceptable.asp

Step 2

This section of the form asks for information about the funder(s) of the research and contact details of the data creator(s) depositor(s), data collector(s) and any other persons involved in the project.
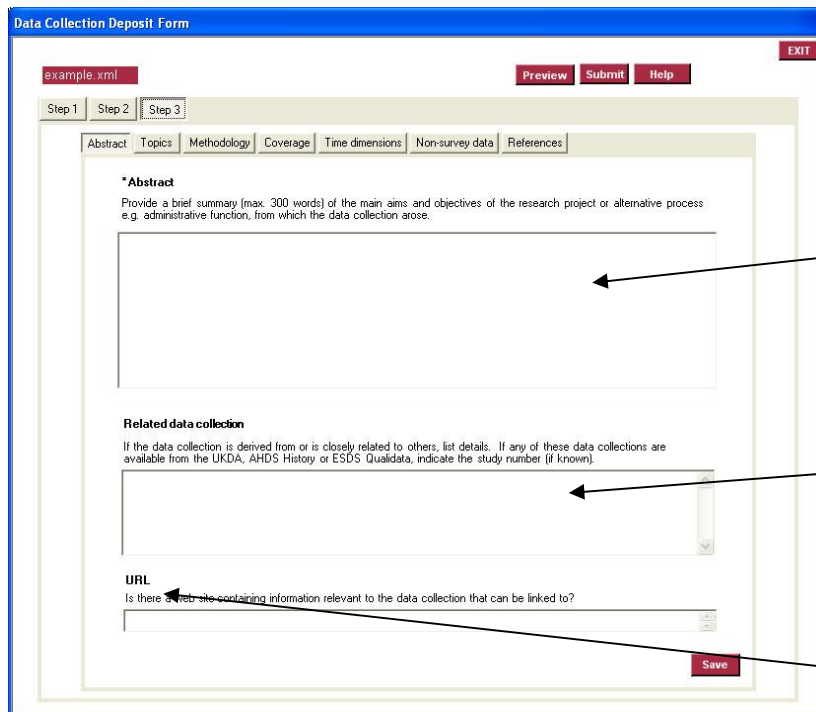

Depositor(s) is (are) person(s) and organisation(s) who deposited the data collection, usually, but not always, the License Agreement signatory.

Data creator(s) - sometimes referred as principal investigator(s) and can be person(s) or organisation(s)

This field should be used for names of individuals or organisations which should be acknowledged as having some input into the data collection.

Data collector(s): person(s) or organisation(s) who collected the data.

Step 3

Data Collection Deposit Form

EXIT

example.xml | Preview | Submit | Help

Step 1 | Step 2 | Step 3

Abstract | Topics | Methodology | Coverage | Time dimensions | Non-survey data | References

*Abstract

Provide a brief summary (max. 300 words) of the main aims and objectives of the research project or alternative process e.g. administrative function, from which the data collection arose.

The abstract covers the general aims, purpose and background to the data collection (use max. 300 words).

Related data collection

If the data collection is derived from or is closely related to others, list details. If any of these data collections are available from the UKDA, AHDS History or ESDS Qualidata, indicate the study number (if known).

If derived from or related to existing data collections, list details.

URL

Is there a web site containing information relevant to the data collection that can be linked to?

If there is a website containing information relevant to the data collection, please provide a link.

Save

In the box 'Main topics' please list the following:

- cancer awareness
- cancer symptoms
- cancer risk factors
- cancer patient delay
- cancer knowledge

In the box 'Main subject categories' please write the following:

- Specific diseases and medical conditions -Health
- Psychology
- Health services and medical care- Health
- Social attitudes and behaviour - Society and Culture

Data Collection Deposit Form

EXIT

example.xml   Preview Submit Help

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

* Population

* Observation units

☐ Administrative units (geographical/political)   ☐ Individuals
☐ Families/households   ☐ Institutions/organisations
☐ Groups   ☐ Text units (documents/chapters/words)

* Method of data collection   *** Sampling Procedures**

☐ Clinical measurements   ☐ Convenience sample
☐ Compilation or synthesis of existing material   ☐ Multi-stage stratified random sample
☐ Diaries   ☐ No sampling (total universe)
☐ Educational measurements   ☐ One-stage cluster sample
☐ Face-to-face interview   ☐ One-stage stratified or systematic random sample
☐ Observation   ☐ Purposive selection/case studies
☐ Physical measurements   ☐ Quasi-random (e.g. random walk) sample
☐ Postal survey   ☐ Quota sample
☐ Psychological measurements   ☐ Simple random sample
☐ Self-completion   ☐ Volunteer sample
☐ Simulation   ☐ Other
☐ Telephone interview
☐ Transcription of existing materials
☐ Other

Save

Provide information about the characteristics of the group or units studied e.g. single mothers in Yorkshire.

Categorise the characteristic of the population studied using the options provided.

Select an option from the list provided or enter additional information by selecting 'other'.

From the list, select one or more methods used in the research or select 'other' and use free text entry box.

65

Data Collection Deposit Form

EXIT

example.xml   Preview Submit Help

Step 1 Step 2 Step 3

Abstract Topics Methodology Coverage Time dimensions Non-survey data References

*Geographical   **Other**

	Country	Region/Town
*		

*Spatial units

Is the data collection geo-referenced ?

○ Yes. Provide the names of the spatial variables.   ◉ No

* Indicate the lowest level of spatial units

Administrative Postal Census 1991/2001 Electoral Education Health Other / Historical

- Unitary Authorities
Northern Ireland
- District Council Areas
- Electoral Wards
Scotland
- Communities
- Council Areas
- Electoral Wards
Wales
- Communities
- Electoral Divisions

Save

This element can include multiple entries. For some data collections geographical coverage is not categorised by country/region/town e.g. for a computer program or a bibliography. In these cases use the 'other' free text box to provide details.

Geo-referenced data consist of measurements or observations taken at specific locations. If the research has been geo-referenced, select 'Yes' and provide the names of the spatial variables, if not select 'No' and proceed to complete the remaining elements of the form.

Data Collection Deposit Form

example.xml

Preview Submit Help EXIT

Step 1 Step 2 Step 3

Abstract | Topics | Methodology | Coverage | Time dimensions | Non-survey data | References

*Dates of fieldwork Date format is MM/YYYY

From
To
Other

Time period covered Date format is MM/YYYY

From
To
Other

Time dimensions

Save

This relates to the date(s) the data were collected. The format of the From: and To: elements is MM/YYYY e.g. 02 1999 denotes February 1999

This relates to the time period covered by the data, if different from the dates of fieldwork. The format of the From: and To: elements is MM/YYYY e.g. 02 1999 denotes February 1999

Select an option from the drop down list.

Data Collection Deposit Form

EXIT

example.xml

Preview Submit Help

Step 1 Step 2 Step 3

Abstract | Topics | Methodology | Coverage | Time dimensions | Non-survey data | References

Details of computerisation or transcription

Sources used

Source location and access

Save

If the data collection was derived in whole or in part from other published or unpublished sources, indicate the methodology used for digitising the original source materials and whether the data represent a complete or partial transcription/copy.

If the data were derived in whole or in part from other published or unpublished, printed or electronic sources, give references to the original material e.g. Enumerators' books; probate records; court materials; newspapers; parliamentary records.

Give details of where the sources described in 'sources used' are held, how they are documented and how they can be accessed.

Data Collection Deposit Form

EXIT

example.xml

Preview　Submit　Help

Step 1　Step 2　Step 3

Abstract　Topics　Methodology　Coverage　Time dimensions　Non-survey data　References

Provide full references to any publications about or based on the data collection.

Save

In the box called 'References' please include the following:

- Stubbings S, Robb KA, Waller J, Ramirez A, Austoker J, Macleod U, Hiom S, Wardle J (2009). Development of a measurement tool to assess public awareness of cancer. British Journal of Cancer, 101, S13–S17
- Robb KA, Stubbings S, Ramirez A, Austoker J, Macleod U, Waller J, Hiom S, Wardle J (2009) Public awareness of cancer in Britain. British Journal of Cancer (in press)
- Waller J, Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Hiom S, Jane Wardle J (2009) Awareness of cancer symptoms and anticipated help-seeking among ethnic minority groups in England British Journal of Cancer, 101, S24-S30

Cervical Cancer Awareness Measure (Cervical CAM)

Flexibility in using the Cervical CAM

the
eve
appeal
gynaecology cancer
research fund

Working in partnership with

≜UCL

DH Department of Health

Introduction

It is important to promote the use of the Cervical CAM and make it as accessible and easy to use as possible. The Cervical CAM includes eight questions and fourteen demographic questions and takes between 15-20 minutes to complete. Many researchers will need to shorten the Cervical CAM, prioritising some of the questions over others and may want to ask additional questions of their own. This brief guide outlines how this can be possible while retaining the validity and reliability of the Cervical CAM questions. .

CAM modules

It is possible to separate the questions in the Cervical CAM into distinct 'modules' that can be used on their own, in conjunction with other items from the Cervical CAM or elsewhere. However it is extremely important that all the items in the modules are retained, removing items could result in reduced reliability or validity of the measure. The modules are listed below.

Module 1. Q1 - Open warning signs (1 item)

Module 2. Q2 - Closed warning signs (11 items)

Module 3. Q3 – Seeking help (1 item)

Module 4. Q4 – Cervical cancer age (1 item)

Module 5. Q5 - Open risk factors (1 item)

Module 6. Q6 - Closed risk factors (11 items)

Module 7. Q7 – Confidence detecting a cervical cancer symptom (I item)

Module 8. Q8 – NHS cancer screening programmes (2 items)

Module 9. Q9 - NHS vaccination programme (2 items)

Ordering of CAM questions

It is possible to change the order of the Cervical CAM modules, for example, you can ask about confidence in detecting ovarian cancer symptoms first and warning signs last. There is one exception to this; closed or prompted questions such as 'The following may or may not be warning signs for ovarian cancer. We are interested in <u>your</u> opinion', should always be asked <u>after</u> open or unprompted questions such as 'There are many warning signs and symptoms of ovarian cancer. Please name as many as you can think of'. This is because the closed/prompted questions essentially provide the answers to the open/unprompted questions.

Taking this into account, it is possible to ask the Cervical CAM modules in any order you like. It is also possible to change the ordering of items within modules. You may wish to counterbalance or rotate the order to see if this has any affect on people's responses.

You can also to ask additional questions alongside the Cervical CAM questions. For example, if you're using the Cervical CAM to assess the impact of an intervention you will want to ask some more specific questions about the intervention itself. In doing so, you should consider how these questions could affect the respondent's response to the Cervical CAM. For example, you should avoid asking questions that could increase the participant's knowledge about cancer.

Additional modules from the CAM

Additional modules from the generic CAM can be added to the Cervical CAM. For example, Module 4 on barriers to help-seeking, or Module 9 on NHS Cancer Screening Programmes.

Demographic questions

It is also possible to include fewer demographic questions. We have outlined the essential demographic items below and these questions must be included in the survey. All other items are optional and you are welcome to add any additional questions if you have more specific needs.

Essential demographic items:

- Age
- Gender
- Ethnicity
- Experience of cancer
- At least one indicator of deprivation[3], e.g. education, employment, living arrangement, car/van ownership, postcode

---

[3] We advise using an individual level of deprivation such as education or employment AND an area-level indicator of deprivation such as postcode.

Cervical Cancer Awareness Measure (Cervical CAM)

Sampling

the eve appeal
gynaecology cancer research fund

Working in partnership with

▲UCL

(DH) Department of Health

Introduction

Your sampling method and your sample size determine the 'generalisability' of your results, in other words, the extent to which you can claim that your findings are an accurate reflection of the population of interest.

If you have access to public health expertise, we suggest you involve them in developing your sampling strategy. There are a number of methods of sampling that you may consider:

Simple random sampling – whereby each individual has an equal chance of being selected. This method is the best way of generating representative samples. To do random sampling you must have a list (sampling frame) of all the people of interest, from which you may randomly sample. A sampling frame of individuals may be a GP list, the electoral register, or a list of church members, for example.

A commonly used sampling frame is the Postal Address File, which does not list individuals but lists addresses. Commonly addresses are randomly drawn from the list and visited; one person is selected to take part in the survey using a method called a Kish Grid. This technique does not strictly randomly sample individuals because the probability of being selected is influenced by the number of people living at an address. Nevertheless, this method, which is used in many national surveys e.g. Health Survey for England, is a good way of selecting representative samples.

Stratified sampling – whereby you randomly select individuals to take part from subgroups (e.g addresses in particular electoral wards or super output areas, people attending particular schools or registered with particular GP practices) of your sampling frame. These subgroups may be selected systematically (e.g. to represent areas with a range of deprivation levels) or randomly. This method is efficient because data collection can be limited to a small number of areas than in simple random sampling. Stratified sampling is a reliable method of generating representative samples and is commonly used in national surveys, for example, the Health Survey for England.

Random digit dialling – for telephone surveys.

Quota sampling – whereby you decide in advance how many people of different age or sex groups you would like to have in your sample and continue to sample by any method until you fill the "quota" for those groups. You may also define the quotas by other characteristics such as socioeconomic status or ethnicity. A quota sample is a convenience sample and is less likely to be truly representative of your population than a sample generated by one of the random sampling methods.

Points to consider when deciding on sampling methods and sample size:

- Funding.
- The target group of interest (e.g. all men over 50 years living in x).
- Method of data collection: face-to-face interviews, telephone interviews, internet or postal?
- Aims and objectives – do you want to simply measure cancer awareness or to evaluate the impact of an awareness raising initiative?
- Generalisability of the sample – do you want to be able to generalise your results to a wider population? If so, which population?
- Which comparisons you wish to make e.g. between which ethnic or socioeconomic groups?

- The likely response to the questionnaire. It is wise to assume that response is likely to be fairly low (e.g. 50% for a postal survey).
- The strategy for maximising response (e.g. repeat visits, postal reminders)
- The margin of error - for example, if you selected a margin of 5% and 40% of respondents said they thought a lump could be a sign of cancer then you would expect (if you'd asked everyone in your sampling frame) that the correct answer would fall between 35-45% (40±5).
- Statistical level of confidence - usually set at 95%. This means that you have 95% chance of your results being true and 5% chance your results will be due to chance/not representative.
- The likely response to the questionnaire. It is wise to assume that response is likely to be fairly low (e.g. 50% for a postal survey).
- The strategy for maximising response (e.g. repeat visits, postal reminders)
- Level of 'unusable' questionnaires (e.g. those that are returned but not valid or incomplete).

Obtaining a baseline of awareness of cancer in your region/locality

The gold standard approach to measuring awareness would be to get a 'population representative' sample using random sampling. True random sampling means that each person in your target group (e.g. the UK population) has an equal chance of being asked to take part. In reality this is nearly impossible to do because you would need to access the details of all the people in the target group in order to randomly select from them, e.g. a list of all the people that live in the area, their contact details and other demographic information. It is possible however to randomly select addresses instead of individuals, e.g. the Office for National Statistics use the Royal Mail's Postcode Address File (PAF) of 'small users':
 http://www.royalmail.com/portal/rm/content1?mediaId=56000706&catId=400085
The ONS methods are described here:
http://www.ons.gov.uk/about/who-we-are/our-services/omnibus-survey/index.html

If random sampling is not feasible the next best option would be to randomly sample locations across your locality or target areas and then carry out quota sampling within each location.

Other options include selecting areas or wards which result in a range of social economic deprivation according to area-based indicators like the Index of Multiple Deprivation (available on the National Statistics website) and then quota sampling within those areas to ensure you have a proportional number of males/females, ethnic groups etc.

Assessing the impact of an awareness-raising initiative

If you are using the CAM as a way of assessing the impact of an initiative designed to increase awareness you will want to ensure that the people who complete the CAM have been exposed to that initiative, or at least have had an opportunity to be exposed to it. In this case your sample should be representative of those targeted by the awareness raising initiative. For example, if the project you would like to assess aimed to increase awareness of cancer in a specific locality then your gold standard approach would be randomly sample from within that locality. If the initiative aimed to raise awareness of a specific type of cancer you should consider whether there is a 'site specific CAM' that is available for this purpose (we have currently developed CAM's to measure awareness of cervical, bowel, breast, lung and ovarian cancer).

Cancer Research UK
Cancer Awareness Measure (CAM)

Glossary

Cervical Cancer Awareness Measure (Cervical CAM)

Cervical CAM glossary of terms

Cancer screening – Testing large groups of apparently healthy people for early signs of certain types of cancer. Screening for a specific cancer can only be carried out when there are good enough tests available and studies have shown that screening will do more good than harm.

Cancer screening programme – Invites certain sections of the population to screening at regular intervals over a period of years.

Closed question – A query that requires the respondent to answer using given options.

Incidence – The number of people newly diagnosed with cancer.

Interviewer – The person giving the questionnaire to respondents.

Open question – A query that allows the respondent to answer freely.

Risk factor for cancer – Something about us or our lives that increases our chances of developing cancer.

Respondents – The people giving the answers to the Cervical CAM.

Seeking help – Visiting a doctor in regards to a suspected warning sign or symptom.

Symptom of cancer – A feeling of illness, or physical or mental change, caused by cancer.

Warning sign of cancer – A feeling of illness, or physical or mental change, that may or may not be caused by cancer.