Together we will beat cancer

CANCER RESEARCH UK

# Breast Module of the Cancer Awareness Measure (Breast-CAM)

## Toolkit

The Breast-CAM was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

# Contents

# Introduction

## *Background to the development of the Breast-CAM*

In 2007, the NHS Cancer Reform Strategy highlighted the importance of raising awareness of cancer as part of the drive to improve cancer survival and reduce inequalities in cancer survival. Following this, a validated survey instrument has been designed (the Cancer Awareness Measure or CAM) to help us measure levels of cancer awareness, explore risk factors for poor cancer awareness, and develop and evaluate interventions to promote cancer awareness. The Breast Module (Breast-CAM) is a validated survey instrument designed to measure breast cancer awareness specifically. There are other modules available to measure awareness of cancers in other sites.

## *What does the Breast-CAM collect data on?*

The Breast-CAM collects data on breast cancer awareness in women within seven domains:

1. Knowledge of symptoms
2. Confidence, skills and behaviour in relation to detecting a breast change
3. Anticipated delay in contacting the doctor
4. Barriers to seeking medical help
5. Knowledge of age-related and lifetime risk
6. Knowledge of the NHS Breast Screening Programme
7. Knowledge of risk factors

## *How was the Breast-CAM validated?*

The Breast-CAM has been found to be a valid and reliable instrument for measuring breast cancer awareness in women (Linsell L et al. Validation of a measurement tool to assess awareness of breast cancer. European Journal of Cancer, 2010). Test-retest reliability is moderate to good for most items. The Breast-CAM detected increases in breast cancer awareness after an intervention to promote breast cancer awareness, and scores were higher with a more intensive than a less intensive intervention, suggesting good sensitivity to change. The Breast-CAM successfully discriminated between women known to have higher breast cancer awareness (senior cancer doctors) and other women of a similar level of education (non-medical academics).

## *Purpose of this document*

This document provides guidance for the use of the Breast-CAM, including:

- Terms of use
- Instructions for use
- A sample participant information sheet and consent form
- A description of the questions with the correct answers, where appropriate
- Data entry and coding instructions
- The script and data collection instruments (both interview and self-complete version)
- How to access and deposit Breast-CAM data in the UK Data Archive.

## Terms of use

With an instrument such as this it is vital that consistency of approach to data capture is maintained. Please ensure that your use of the Breast-CAM complies with this guidance.

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

Please ensure that the following notice is included on any copies you make of the Breast-CAM or the guidance, and in any publication based wholly or partly on its use:

*"The Breast-CAM was developed by Cancer Research UK, King's College London and University College London in 2009. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer."*

The following reference should be included in any publication reporting data gathered using the Breast-CAM:

*Linsell L, Forbes L, Burgess C, Kapari M, Thurnham A, Ramirez A (2010). Validation of a measurement tool to assess awareness of breast cancer. European Journal of Cancer, 46, 1374-1381.*

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

All Breast-CAM data must be archived with the UK Data Archive for ease of reference to researchers in the future.

# Instructions for using the Breast-CAM

## *Administration of the Breast-CAM*

The Breast-CAM may be administered in a face-to-face interview, over the telephone or on the internet (Appendix A). A self-complete version is also available (Appendix B). The main difference between the self-complete and the interview versions is that the self-complete version does not include an open question about symptoms. This is because if the open question were present, women might go back and amend their answers having seen the subsequent closed question about symptoms.

The Breast-CAM has been designed to measure breast cancer awareness in women. A version to measure men's awareness of breast cancer in women is currently under development.

Ideally, the Breast-CAM should be administered in a private setting (away from other members of the family, for example) to maintain confidentiality, and to ensure that the presence of others does not influence how respondents answer the questions.

Researchers collecting data using face-to-face or telephone interviews should follow the script word for word. When completing the Breast-CAM, please record how it was administered (i.e. face-to-face or by telephone), whether others were present, when it was administered, and the language in which it was administered. A place to record these is included in the instrument (Appendix A).

Please ensure that all respondents complete the demographic questions as well as the Breast-CAM. This is to ensure that comparisons of breast cancer awareness between different groups can be made.

When administering the Breast-CAM face-to-face, please do not show the respondent the questionnaire. We recommend using a clipboard. For two of the questions (lifetime risk and ethnic group), the interviewer will need to show the respondent prompt cards to help her answer (a picture to support the question about lifetime risk, and a list of possible ethnic groups). We suggest that the interviewer keeps these separately to show respondents when appropriate.

Although we have plans to translate the Breast-CAM, it is only available in English at present.

## *Ensuring quality of delivery of the Breast-CAM Interview version*

If you plan to administer the Breast-CAM using face-to-face interviews, you should ensure that the interviews are delivered to a high standard. The Social Research Association and the MRS (the body that promotes good practice in market research) provide professional standards and guidelines about best practice across all aspects of carrying out research:

Social Research Association: http://www.the-sra.org.uk/guidelines.htm#public

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

## *Sampling*

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 –** where each individual has an equal chance of being selected. This is the best way of generating a representative sample (as long as you achieve a good response from potential participants you approach). To do random sampling you must have a list (sampling frame) of all the potential study participants of interest, e.g. a GP list, the electoral register, or a list of church members, you can then randomly sample participants from this list.

A commonly used sampling frame is the 'Postal Address File', which actually lists addresses rather than individuals. Addresses are randomly drawn from the list and then one person from the household is selected to take part in the survey. A tool called a 'Kish grid' is commonly used to select the individual. Strictly speaking, this technique does not randomly sample individuals because the probability of being selected is influenced by the number of people living at an address. Nevertheless, this method is used in many national surveys, e.g. the Health Survey for England, and is a good way of selecting representative samples.

**Stratified sampling** – where you randomly select individuals to take part from subgroups (e.g electoral wards or census 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 smaller number of areas than in simple random sampling. Stratified sampling is a reliable method of generating representative samples (as long as you achieve a good response from potential participants you approach) and is commonly used in national surveys, for example, the Health Survey for England.

**Random digit dialling –** used for telephone surveys. This is a form of random sampling and can be simple or stratified by area code. Telephone directories can be used as a sampling frame from which to draw participants, but many people in the UK elect not to have their number listed in the directory, and increasing use of mobile phones means that this method is less likely to generate a representative sample.

**Quota sampling –** where 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 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, telephone, 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 sexes, ethnic or socioeconomic groups?
- The likely response to the questionnaire, i.e. the number of people who complete the survey out of the number you approached (e.g. 50% for a postal survey).
- A 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).
- 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 the response being true and 5% chance the response is due to chance/not representative.

## Recruitment record

For the purposes of data storage over the long term, please record how the sample was selected on the Recruitment Record. You will need to provide this information when you submit the data to the UK Data Archive.

Please write down on the Recruitment Record:

- the name of your organisation
- the purpose of the survey (for example, to evaluate an intervention to promote breast cancer awareness, to explore ethnic differences in breast cancer awareness)
- the sampling frame (for example, electoral register, postal address file, general practice lists, telephone directory, all women living on one street, all women attending a general practice over the period of one week)
- a description of the target population (for example, by age group, place of residence, ethnic group, socioeconomic status)
- how the respondents were recruited (for example, invited using posters or flyers, invited by post, approached in the street or a health service waiting room, invited door-to-door)
- how many women were asked to complete the Breast-CAM
- how many women agreed to complete it
- how many women refused to complete it
- how many women started but did not complete it.

## *Flexibility in using the Breast-CAM*

The Breast-CAM takes between 15 and 20 minutes to complete as an interview. Some researchers may wish to shorten the Breast-CAM or to ask additional questions of their own. We ask as a minimum that all researchers ask these three questions:

- knowledge of breast symptoms using the closed questions i.e. "Do you think ….. could be a sign of breast cancer?"
- knowledge of age-related risk i.e. "In the next year, who is most likely to get breast cancer?"
- frequency of breast checking i.e. "How often do you check your breasts?"

Researchers may alter the order in which questions are asked with the exception of questions about symptom knowledge where the unprompted symptom knowledge question must be asked before the prompted symptom knowledge questions to avoid priming respondents with the answers.

Researchers may also wish to ask fewer or different demographic questions. Researchers may modify these as appropriate to their population of interest. We ask that all researchers gather the following demographic information:

- Age
- Ethnicity
- At least one indicator of deprivation e.g. age at leaving full-time education, employment, housing tenure, car/van access, household source of income, postcode (so that an index of multiple deprivation of area of residence can be assigned)

## *Ethical and data protection issues*

### Ethical approval

It is always appropriate to consider the ethical implications of any survey. However, before you start recruiting women, please consider whether you need to obtain formal ethical approval.

Certain types of research fall 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). This includes research involving:

- 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 women that you ask to complete a Breast-CAM survey. We have developed an example information sheet and consent form that you may use and modify to your own needs.

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

## *Coding and data entry*

We provide instructions for coding and data entry in the relevant section. All Breast-CAM data must be submitted to the UK Data Archive using the coding frame provided (either Microsoft Excel or SPSS).

## *Data analysis*

If you require guidance on analysing data collected using the Breast-CAM, please contact King's College London Promoting Early Presentation Group at b-cam@kcl.ac.uk.

## *Archiving Breast-CAM data*

All Breast-CAM data must be archived in the UK Data Archive (www.data-archive.ac.uk) so that they can be downloaded in future for new analyses. Please see Appendix C for instructions for archiving the data.

# Example information sheet and consent form

## **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 breast 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 |

## Description of the Breast-CAM

This section provides a description of the Breast-CAM questions and the correct answers where appropriate. This is intended:

- to provide information for people designing surveys using the Breast-CAM
- to support training of interviewers to administer the Breast-CAM
- to help interviewers answer questions that respondents may have at the end of the interview.

Please see Appendix A for the script and response sheet to use when administering the Breast-CAM.

Interviewers should read out each question to the respondent in a similar manner exactly as it is written. The text written in the shaded boxes in the script and response sheet (see Appendix A) indicates what the interviewer should read out to the respondent.

If a woman asks for more details or help, the interviewer should say that for the purposes of the study s/he cannot give any prompts or explanations (other than those permitted), tell her that we are interested in their own thoughts and beliefs and if necessary repeat the question. The interviewer may discuss queries once the interview is complete, including providing the correct answers to the questions where appropriate. Interviewers should not, of course, provide the correct answers to the Breast-CAM if it is being used to evaluate an intervention to promote breast cancer awareness in which the same individuals are tested at different timepoints.

The interviewer should not return to previous questions to amend answers. S/he should not allow the respondent to see the questions – a clipboard may be helpful.

If collecting data face-to-face, there are two prompt cards to show the respondent during the interview: one is to help them answer the question about lifetime risk and the other is a list of ethnic groups. We provide these at the end of the script and response sheet. We suggest that each interviewer has a laminated copy of each of these to show each woman.

### THE QUESTIONS

The first question is about the woman's personal experience of breast cancer. This helps to ensure that the interviewer can show appropriate sensitivity while talking about breast cancer to a woman with personal experience of it. Also, it is likely that women with breast cancer experience would have greater breast cancer awareness, so it may be considered important to examine this in the analysis.

**Have you ever had breast cancer?**

If YES: **I am sorry to hear that. As this interview is about breast cancer awareness, are you happy for me to continue?**

If YES: **go to Domain 1**

If NO: **stop the interview**

**DOMAIN 1 KNOWLEDGE OF SYMPTOMS**

This question is an open question aiming to find out how many early warning signs of breast cancer the woman can think of without specific prompting.

| **First of all, please would you name as many early warning signs of breast cancer as you can think of:** |
|---|

The interviewer may prompt "*Anything else*" until the woman can think of no more warning signs or symptoms. If a woman says that she does not know or cannot think of any signs or symptoms for breast cancer, the interviewer may prompt with *"Are you sure?"* and if necessary "*Take a minute to think about it"*.

Following this, there is a series of closed questions about the early warning signs of breast cancer. The interviewer may provide further explanation for three of the questions as shown below, if the woman says she does not understand what the interviewer means by the question.

| |
|---|
| **Do you think a change in the position of your nipple could be a sign of breast cancer?**<br>*[Explanation]: such as pointing up or down or in a different direction to normal* |
| **Do you think pulling in of your nipple could be a sign of breast cancer?**<br>*[Explanation]: where the nipple no longer points outwards but into the breast* |
| **Do you think pain in one of your breasts or armpit could be a sign of breast cancer?** |
| **Do you think puckering or dimpling of your breast skin could be a sign of breast cancer?**<br>*[Explanation]: like a dent or orange peel appearance* |
| **Do you think discharge or bleeding from your nipple could be a sign of breast cancer?** |
| **Do you think a lump or thickening in your breast could be a sign of breast cancer?** |
| **Do you think a nipple rash could be a sign of breast cancer?** |
| **Do you think redness of your breast skin could be a sign of breast cancer?** |
| **Do you think a lump or thickening under your armpit could be a sign of breast cancer?** |
| **Do you think changes in the size of your breast or nipple could be signs of breast cancer?** |
| **Do you think changes in the shape of your breast or nipple could be signs of breast cancer?** |

All of these may be early warning signs of breast cancer, although most may also indicate other, less serious conditions.

**DOMAIN 2 CONFIDENCE, SKILLS AND BEHAVIOUR IN RELATION TO BREAST CHANGES**

These questions aim to measure confidence, skills and behaviour to detect breast changes and act upon the findings. The first question asks about frequency of breast checking, the second about confidence to detect a breast change and the third asks about reporting a breast change to a doctor. The interviewer should not prompt the answer to either of these questions, but should read out the possible responses as shown here.

| **How often do you check your breasts?** |
|---|
| Rarely or never/At least once every 6 months/At least once a month/At least once a week |
| **Are you confident you would notice a change in your breasts?** |
| Not at all confident/Slightly confident/Fairly confident/Very confident |
| **Have you ever been to see a doctor about a change you have noticed in one of your breasts?** |
| Yes/No/Not noticed a change in one of my breasts |

The current Department of Health recommendations on breast checking are as follows:

> "It is important to be aware of how your breasts normally look and feel at different times. You will then notice if something is different or if you develop any of the signs and symptoms listed above.
>
> You can become familiar by looking and feeling your breasts from time to time in any way that is best for you.
>
> You can feel your breasts in the bath or shower using a soapy hand or lying down in bed. Using body lotion can help. It is important to feel the whole breast including the armpit.
>
> You can look at your breasts in the mirror. Move your arms (above your head, on your hips or by your sides) so that you can see your breasts from every angle, including the underside.
>
> As older women are at greater risk of breast cancer, it is very important to be aware of any unusual changes after the menopause, when your periods have stopped.
>
> Breasts may change with age and life events, such as pregnancy, breastfeeding, at different times of the month if you still have periods and after the menopause. This is why it is important to know what is normal for you so you will recognise any changes."

The Department of Health does not provide any firm recommendations on the frequency with which women should check their breasts, because there is no clear evidence that any particular frequency is appropriate.

**DOMAIN 3 ANTICIPATED DELAY IN CONTACTING THE DOCTOR**

This question aims to find out how long women think they will delay before seeking medical help after discovering a breast change. The interviewer should record the response verbatim.

| **If you found a change in your breasts, how soon would you contact your doctor?** |
|---|

Women, particularly those over the age of 50, should contact their doctor's surgery within a few days of discovering a breast change. We know that the sooner breast cancer is diagnosed, the better the outcome is likely to be. The risk of a breast symptom indicating breast cancer is much higher in an older than a younger woman.

**DOMAIN 4 BARRIERS TO SEEKING MEDICAL HELP**

This set of questions aims to find out which barriers women experience when seeking medical help with breast symptoms. They are asked to answer 'yes, often', 'yes, sometimes' or 'no' to each statement. The interviewer should not prompt.

| |
|---|
| **Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. These are some of the reasons people give for delaying. Could you say if any of these might put you off going to the doctor?** |
| **Too embarrassed to go and see the doctor** |
| **Too scared to go and see the doctor** |
| **Worried about wasting the doctor's time** |
| **I find the doctor difficult to talk to** |
| **Difficult to make an appointment with the doctor** |
| **Too busy to make time to go to the doctor** |
| **Too many other things to worry about** |
| **Difficult to arrange transport to the doctor's surgery** |
| **Worrying about what the doctor might find may stop me from going to the doctor** |
| **Not feeling confident talking about my symptom with the doctor** |
| Additional question for people conducting the interview in language other than English |
| **My doctor does not understand my language or culture** |
| |
| **Is there anything else that you can think of that might put you off going to the doctor?** |

**DOMAIN 5 KNOWLEDGE OF AGE-RELATED AND LIFETIME RISK**

These questions aim to find out whether women know that the risk of breast cancer increases with age, and the overall lifetime risk of developing breast cancer. The interviewer should not prompt, but should read out the possible responses as shown.

| |
|---|
| **In the next year, who is most likely to get breast cancer?** |
| A 30 year old woman/A 50 year old woman/A 70 year old woman/A woman of any age |

The correct answer to this question is 'a 70 year old woman'. The risk of breast cancer increases with increasing age. Most women who get breast cancer are past their menopause (change of life), but around one in five women diagnosed each year are under 50 years old.

| |
|---|
| **How many women will develop breast cancer in their lifetime?** |
| 1 in 3 women/1 in 9 women/1 in 100 women/1 in 1000 women |

The correct answer is that about one in eight women will develop breast cancer during their lifetime.

**DOMAIN 6 KNOWLEDGE OF BREAST SCREENING**

These questions aim to assess women's knowledge of the NHS Breast Screening Programme and whether they have had mammograms on the NHS Breast Screening Programme. The interviewer should not prompt.

| **Is there an NHS Breast Screening Programme?** | |
|---|---|
| IF YES: | **At what age are women first invited to the NHS Breast Screening Programme?** |
| | **At what age do women receive their last invitation to the NHS Breast Screening Programme?** |
| | **Have you ever been invited for breast screening on the NHS Breast Screening Programme?** |
| | **Have you ever had breast screening on the NHS Breast Screening Programme?** |
| IF NO or DON'T KNOW: | go to demographic questions |

Women are currently invited for breast screening between the ages of 50 and 70 and are offered mammograms every three years. From 2009, this age range began to be extended. Women in their late forties and up to the age of 73 are also starting to be invited. It will take a few years for this to happen everywhere in England. NHS breast screening is not usually available for younger women as mammograms are not as effective on younger breasts. Women over 70 can ask for free breast screening every three years, by contacting their local breast screening unit.

**DOMAIN 7 RISK FACTORS**

This question aims to assess women's knowledge of risk factors for breast cancer. The most important risk factor, increasing age, has been included as a separate question in Domain 5, so is not repeated here. The interviewer should not prompt, but should read out the possible responses: Strongly disagree, disagree, not sure, agree or strongly agree

| **How much do you agree that each of these can increase the chance of getting breast cancer?** |
|---|
| **Having a past history of breast cancer** |
| **Using HRT (Hormone Replacement Therapy)** |
| **Drinking more than 1 unit of alcohol a day** |
| **Being overweight (BMI over 25)** |
| **Having a close relative with breast cancer** |
| **Having children later on in life or not at all** |
| **Starting your periods at an early age** |
| **Having a late menopause** |
| **Doing less than 30 mins of moderate physical activity 5 times a week** |

All of these increase the risk of breast cancer

HRT does increase the risk of getting breast cancer; however, if women only take it for a short time the increased risk is small. The longer you take HRT, the more your breast cancer risk increases. The risk goes back to normal within five years of stopping taking it. If a woman is worried about taking HRT or any of the other risk factors mentioned here, please recommend that she talks her doctor about the benefits and risks in her individual situation.

## Recruitment record

When you have completed your survey, please complete the following and send to b-cam@kcl.ac.uk along with your data files.

| |
|---|
| Name of organisation |
| Please briefly outline the purpose of the survey (for example, to evaluate an intervention to promote breast cancer awareness, to explore ethnic differences in breast cancer awareness, to establish baseline levels of breast cancer awareness) |
| Sampling frame (e.g. electoral registers, postal address file, general practice lists, telephone directory, all women living on one street, all women attending a general practice over the period of one week) |
| Target population (e.g. general population, women living on a particular street or an ethnic group) What was the geographical area? Which age group did you include? |
| Please record the methods you used in the space below (e.g. electoral register, door–to–door, approaching people in shopping centre, GP practice list, GP waiting room, using posters and flyers) to recruit women: |
| How many women did you approach to complete the Breast-CAM? _____ |
| How many women agreed to complete the Breast-CAM? _____ |
| How many women refused to complete the Breast-CAM? _____ |
| How many women started to complete the Breast-CAM but did not complete it? _____ |
| Over what time period were the interviews carried out?<br>From: _____(*dd/mm/yyyy)* to: _____(*dd/mm/yyyy)* |

## Data entry and coding

For every question it is possible to code data as 'refused' or 'don't know'. For all other missing data just. Please store the data in either EXCEL or SPSS for transfer to the archive. There is a template EXCEL and SPSS data file available. Please contact: b-cam@kcl.ac.uk

| | |
|---|---|
| Participant ID Number<br>*Create one variable* **id** | |

| | | |
|---|---|---|
| Please indicate whether this interview was held face-to-face, over the telephone or via the internet.<br>*Create one variable* **interv** | | |
| Face-to-face 1 | Telephone 2 | Internet 3 |

| | | |
|---|---|---|
| Please indicate if in a health service setting, a home setting or elsewhere.<br>*Create two variables* **setting** *and* **othsett** | | |
| *If you code* **setting** *as 3, please type the response verbatim in* **othsett** *e.g. work, café.* | | |
| Health service 1 | Home 2 | Other setting 3 |

| | | |
|---|---|---|
| How many other people were present while the interview was being carried out?<br>*Create one variable* ***othpeop*** | | |
| 0 0 | 1 or more 1 | |

| | |
|---|---|
| Please indicate which language was used to administer the interview.<br>*Create two variables* **lang** *and* **othlang** | |
| *If you code* **lang** *as 2, please type the language the interview was delivered in verbatim in* **othlang** *e.g. Urdu.* | |
| English 1 | Other language 2 |

Variables names provided in **bold**.

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Have you ever had breast cancer? **everhad** | | Yes 1 | No 2 | Don't know | -99 | Refused | -98 |
| If yes | As this interview is about breast cancer awareness, are you happy for me to continue? **continue** | Yes 1 | No 2 | | | | |

Please name as many warning signs of breast cancer as you can think of:

*Create 13 variables labelled from* **symp01** *to* **symp11,** *plus* **othsym01** *and* **othsym02.** *Each symptom named must be recorded using the coding frame below. For example, if the respondent names 'pain in the breast' and 'bleeding from nipple', code* **symp01** *as 3 in* **symp02** *as 5.*

*After coding and entering the symptoms named from the list below, code for any symptoms not on the list. To do this, code the next blank variable (***symp01** *to* **symp11***) as 12. Then type the symptom verbatim into* **othsym01***. You may do this for up to two additional symptoms e.g. If the respondent names three possible symptoms from the list, plus 'chest pain' and 'tiredness', enter 12 in* **symp04** *and type 'chest pain' in* **othsym01** *and 'tiredness' in* **othsym02***.*

*If the response to this question is 'Don't know', or the respondent refuses to answer, code* **symp01** *-99 or -98 as appropriate, and move on to the next question (***position***).*

| | |
|---|---|
| Nipple position | 1 |
| Pulling in of nipple | 2 |
| Pain breasts/armpit | 3 |
| Puckering/dimpling | 4 |
| Discharge/bleeding nipple | 5 |
| Lump/thickening breast | 6 |
| Nipple rash | 7 |
| Redness breast skin | 8 |
| Lump/thickening armpit | 9 |
| Change size breast/nipple | 10 |
| Change shape breast/nipple | 11 |
| Other | 12 |
| Refused | -98 |
| Don't know | -99 |

| Can you tell me whether you think any of these are warning signs of breast cancer or not? | | | | |
|---|---|---|---|---|
| *Create 11 variables as shown below.* | Yes | No | Don't know | Refused |
| Do you think a change in the position of your nipple could be a sign of breast cancer? **position** | 1 | 2 | -99 | -98 |
| Do you think pulling in of your nipple could be a sign of breast cancer? **pullin** | 1 | 2 | -99 | -98 |
| Do you think pain in one of your breasts or armpit could be a sign of breast cancer? **pain** | 1 | 2 | -99 | -98 |
| Do you think puckering or dimpling of your breast skin could be a sign of breast cancer? **pucker** | 1 | 2 | -99 | -98 |
| Do you think discharge or bleeding from your nipple could be a sign of breast cancer? **disch** | 1 | 2 | -99 | -98 |
| Do you think a lump or thickening in your breast could be a sign of breast cancer? **lump** | 1 | 2 | -99 | -98 |
| Do you think a nipple rash could be a sign of breast cancer? **rash** | 1 | 2 | -99 | -98 |
| Do you think redness of your breast skin could be a sign of breast cancer? **redness** | 1 | 2 | -99 | -98 |
| Do you think a lump or thickening under your armpit could be a sign of breast cancer? **armlump** | 1 | 2 | -99 | -98 |
| Do you think changes in the size of your breast or nipple could be signs of breast cancer? **size** | 1 | 2 | -99 | -98 |
| Do you think changes in the shape of your breast or nipple could be signs of breast cancer? **shape** | 1 | 2 | -99 | -98 |

| How often do you check your breasts? **check** | Rarely or never | At least once every 6 months | At least once a month | At least once a week | Don't know | Refused |
|---|---|---|---|---|---|---|
| | 4 | 3 | 2 | 1 | -99 | -98 |

| Are you confident you would notice a change in your breasts? **confid** | Not at all confident | Slightly confident | Fairly confident | Very confident | Don't know | Refused |
|---|---|---|---|---|---|---|
| | 4 | 3 | 2 | 1 | -99 | -98 |

| Have you ever been to see a doctor about a change you have noticed in one of your breasts? **doctor** | Yes | No | Never noticed a breast change | Don't know | Refused |
|---|---|---|---|---|---|
| | 1 | 2 | 3 | -99 | -98 |

| If you found a change in your breast, how soon would you contact your doctor? **delay** | |
|---|---|
| Don't know -99 | Refused -98 |

| Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. These are some of the reasons people give for delaying. Could you say if any of these might put you off going to the doctor? You may answer 'yes often,' 'yes sometimes' or 'no'. | | | | | |
|---|---|---|---|---|---|
| *Create 13 variables: the 11 variables shown below plus* **othdoc01** *and* **othdoc02** | | | | | |
| *Question followed by* **variable name** | Yes often | Yes some-times | No | Don't know | Refused |
| Too embarrassed to go and see the doctor **embarras** | 1 | 2 | 3 | -99 | -98 |
| Too scared to go and see the doctor **scared** | 1 | 2 | 3 | -99 | -98 |
| Worried about wasting the doctor's time **waste** | 1 | 2 | 3 | -99 | -98 |
| My doctor is difficult to talk to **difftalk** | 1 | 2 | 3 | -99 | -98 |
| Difficult to make an appointment with the doctor **diffappt** | 1 | 2 | 3 | -99 | -98 |
| Too busy to make time to go to the doctor **busy** | 1 | 2 | 3 | -99 | -98 |
| Too many other things to worry about **worry** | 1 | 2 | 3 | -99 | -98 |
| Difficult to arrange transport to the doctor's surgery **trans** | 1 | 2 | 3 | -99 | -98 |
| Worrying about what the doctor might find may stop me from going to the doctor **worrfind** | 1 | 2 | 3 | -99 | -98 |
| Not feeling confident talking about my symptom with the doctor **notconf** | 1 | 2 | 3 | -99 | -98 |
| For women completing questionnaire in language other than English | Yes | No | Not applic-able | Don't know | Refused |
| My doctor does not understand my language or culture **underst** | 1 | 2 | 3 | -99 | -98 |
| | | | | | |
| Is there anything else that you can think of that might put you off going to the doctor? **othdoc01** *and* **othdoc02** | | | | | |
| *Type in verbatim, up to two reasons.* | | | | | |

| In the next year, who is most likely to get breast cancer? | A 30 year old woman | A 50 year old woman | A 70 year old woman | A woman of any age | Don't know | Refused |
|---|---|---|---|---|---|---|
| **agerisk** | 4 | 3 | 2 | 1 | -99 | -98 |

| How many women will develop breast cancer in their lifetime? | 1 in 3 women | 1 in 9 women | 1 in 100 women | 1 in 1000 women | Don't know | Refused |
|---|---|---|---|---|---|---|
| **lifetime** | 4 | 3 | 2 | 1 | -99 | -98 |

| *Create 5 variables as shown below.* | | Yes | No | Don't know | Refused |
|---|---|---|---|---|---|
| Is there an NHS Breast Screening Programme? **screening** | | 1 | 2 | -99 | -98 |
| IF YES: | At what age are women first invited to the NHS Breast Screening Programme? **firstage** | Age in years | | -99 | -98 |
| | At what age do women receive their last invitation to the NHS Breast Screening Programme? **lastage** | Age in years | | -99 | -98 |
| | Have you ever been invited for breast screening on the NHS Breast Screening Programme? **invite** | 1 | 2 | -99 | -98 |
| | Have you ever had breast screening on the NHS Breast Screening Programme? **attend** | 1 | 2 | -99 | -98 |

| How much do you agree that each of these can increase the chance of getting breast cancer? | | | | | |
|---|---|---|---|---|---|
| *Create 9 variables as shown below* | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
| Having a past history of breast cancer **pasthist** | 1 | 2 | 3 | 4 | 5 |
| Using HRT (Hormone Replacement Therapy) **hrt** | 1 | 2 | 3 | 4 | 5 |
| Drinking more than 1 unit of alcohol a day **alcohol** | 1 | 2 | 3 | 4 | 5 |
| Being overweight (BMI over 25) **bmi** | 1 | 2 | 3 | 4 | 5 |
| Having a close relative with breast cancer **famhist** | 1 | 2 | 3 | 4 | 5 |
| Having children later on in life or not at all **nokids** | 1 | 2 | 3 | 4 | 5 |
| Starting your periods at an early age **periods** | 1 | 2 | 3 | 4 | 5 |
| Having a late menopause **menopaus** | 1 | 2 | 3 | 4 | 5 |
| Doing less than 30 mins of moderate physical activity 5 times a week **exercise** | 1 | 2 | 3 | 4 | 5 |

| Could you tell me how old you are? **age** | Type in age at last birthday in years |
|---|---|
| Don't know -99 | Refused -98 |

| Could you tell me your postcode? **postcode** | Type in postcode |
|---|---|
| Don't know -99 | Refused -98 |

| Are you registered with a GP? **gpreg** | Yes 1 | No 2 | Don't know -99 | Refused -98 |
|---|---|---|---|---|

| What is the main language spoken at home? *Create two variables* **langhome** *and* **othhome** | | | |
|---|---|---|---|
| *To code a response that is not on the list, code* **langhome** *as 8 and type the language verbatim in* **othhome** | | | |
| 1 | English | 5 | Sylheti |
| 2 | Urdu | 6 | Bengali |
| 3 | Punjabi | 7 | French |
| 4 | Gujarati | 8 | Other (please write name of language) |
| -99 | Don't know | -98 | Refused |

| Were you born in the UK? **ukborn** | Yes 1 | No 2 | Don't know -99 | Refused -98 |
|---|---|---|---|---|

| Could you tell me which of these best describes your living arrangements? *Create two variables* **living** *and* **othliv** | | | |
|---|---|---|---|
| *To code a response that is not on the list,* code **living** *as 4 and type the response verbatim in* **othliv** | | | |
| 1 | Own outright or have a mortgage | 3 | Rent from private landlord |
| 2 | Rent from Council/Housing Association | 4 | Other (please describe) |
| -99 | Don't know | -98 | Refused |

| Could you tell me, who do you live with? *Create two variables* **livewith** *and* **othlivw** | | | |
|---|---|---|---|
| *To code a response that is not on the list, code* **livewith** *as 3 and type response verbatim in* **othlivw** | | | |
| 1 | Husband/partner | 3 | Other (please describe |
| 2 | Live alone | -99 | Don't know |
| | | -98 | Refused |

| | | | | |
|---|---|---|---|---|
| Does anyone living in your home have a car or van available for use? **vehicle** | Yes 1 | No 2 | Don't know -99 | Refused -98 |

| Could you tell me what age you left full time education? **educate** | Type in age left full time education in years |
|---|---|
| Don't know -99 | Refused -98 |
| No full time education -97 | Currently in full time education -96 |

Please would you look at this list *(on separate page)*. Which one best describes your ethnic group?

*Create two variables* **ethnic** *and* **otheth**

*To code a response that is not on the list, code* **ethnic** *as either 4, 8, 13 16 or 18 as appropriate and type response verbatim in* **otheth**

| **White** | **Mixed/multiple ethnic groups** | **Asian/Asian British** | **Black/African/ Caribbean/ Black British** | **Chinese or other** |
|---|---|---|---|---|
| 1 English/Welsh/ Scottish/ Northern Irish/ British | 5 White and Black Caribbean | 9 Indian | 14 African | 17 Arab |
| 2 Irish | 6 White and Black African | 10 Pakistani | 15 Caribbean | 18 Any other ethnic group |
| 3 Gypsy or Irish Traveller | 7 White and Asian | 11 Bangladeshi | 16 Any other Black/African /Caribbean background | (please describe) |
| 4 Any other white background | 8 Any other Mixed background | 12 Chinese | -99 Don't know | -98 Refused |
| | | 13 Any other Asian background | | |

| Could you tell me, where does your household get most of its income from?<br>*Create two variables* **income** *and* **othinc** | |
|---|---|
| *To code a response that is not on the list, code* **income** *as 4 and type response verbatim in* **othinc** | |
| 1 Wages or salary | 3 Benefits (including unemployment or sickness benefit) |
| 2 Pension | 4 Other (please describe)…… |
| -99 Don't know | -98 Refused |

| Could you tell me what is your sexual orientation?<br>*Create two variables* **sexorien** *and* **othsexor** | |
|---|---|
| *To code a response that is not on the list, code* **lseorien** *as 3 and type response verbatim in* **othsexor** | |
| 1 Heterosexual/straight | |
| 2 Gay/lesbian | -99 Prefer not to say/refused |
| 3 Bisexual | -98 Don't know |
| 4 Other | |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | |

Participant ID number or sticker

# Appendix A: Script and response sheet for the Breast Module of the Cancer Awareness Measure (interview version)

The Breast-CAM was developed by Cancer Research UK, King's College London and University College London in 2009. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

## Instructions

- Please read out each question to the woman in a similar way exactly as it is written

**The text written in the shaded boxes is what you should read out to the woman.**

- If a woman asks for more details or help, please say that for the purposes of the study you cannot give any prompts or explanations (other than those described), tell her that we are interested in her own thoughts and beliefs and if necessary repeat the question.
- You may say that you can discuss queries once the interview is complete (if appropriate to the study design).
- Do not return to a previous question.
- Do not allow the woman to read the questions on this form. It would be helpful to have a clipboard for this purpose.
- It is possible to record the response as 'refused'. Record 'refused' when the woman actively chooses not to respond.

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

| | | |
|---|---|---|
| Please indicate whether this interview was held face-to-face, over the telephone or via the internet. | | |
| **Face-to-face** ☐ | **Telephone** ☐ | **Internet** ☐ |
| Please indicate if in a health service setting, a home setting or elsewhere. | | |
| **Health service setting** ☐ | **Home** ☐ | **Other setting (please describe)** …… |
| How many other people were present while the interview was being carried out? | | |
| **0** ☐ | **1 or more** ☐ | |
| Please indicate which language was used to administer the interview. | | |
| **English** ☐ | **Other language (please describe)** …… | |

## Start of interview

**Note:** If necessary please insert text giving your own explanation of why you are using the Breast-CAM, e.g. 'I am asking these questions on behalf of x PCT as we are trying to find out the level of breast cancer awareness in x.'

We are asking these questions to find out more about breast cancer awareness. It should take around 15 minutes. It is not a test. We are interested in your thoughts and beliefs so please answer the questions as honestly as you can. All your answers will be treated as strictly confidential. I am unable to answer questions during the interview, but there will be time at the end to discuss any questions you might have. I can not go back to a question that has already been asked as we are interested in your first response and later questions may give clues to the right answers.

**QUESTION TO FIND OUT ABOUT PERSONAL EXPERIENCE OF BREAST CANCER**

The first question is about any experience you may have had about breast cancer.

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Have you ever had breast cancer? | | Yes ☐ | No ☐ | Don't know ☐ | Refused ☐ | | |
| **If YES:** | I am sorry to hear that. As this interview is about breast cancer awareness, are you happy for me to continue? | Yes ☐ | No ☐ | | | | |
| | **If NO stop the interview. If YES go to Domain 1.** | | | | | | |

**DOMAIN 1 KNOWLEDGE OF SYMPTOMS**

| |
|---|
| First of all, please would you name as many early warning signs of breast cancer as you can think of: |
| **Prompt "*anything else*" until the woman can think of no more warning signs or symptoms. If a woman says she does not know or cannot think of any signs or symptoms for breast cancer, please prompt with *"Are you sure?"* and if necessary "*Take a minute to think about it"*.**<br>**Please write down all of the warning signs and symptoms of breast cancer that the woman mentions in the box below** |
| |
| Anything else? |

| Can you tell me whether you think any of these are warning signs of breast cancer or not? | | | | |
|---|---|---|---|---|
| **Do not prompt. If the woman asks for explanation, please read out the relevant 'Explanation' where available. Please only read these out if necessary.** | | | | |
| Tick the appropriate boxes | Yes | No | Don't know | Refused |
| Do you think a change in the position of your nipple could be a sign of breast cancer?<br>*[Explanation]: such as pointing up or down or in a different direction to normal* | ☐ | ☐ | ☐ | ☐ |
| Do you think pulling in of your nipple could be a sign of breast cancer?<br>*[Explanation]: where the nipple no longer points outwards, but into the breast* | ☐ | ☐ | ☐ | ☐ |
| Do you think pain in one of your breasts or armpit could be a sign of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think puckering or dimpling of your breast skin could be a sign of breast cancer?<br>*[Explanation]: like a dent or orange peel appearance* | ☐ | ☐ | ☐ | ☐ |
| Do you think discharge or bleeding from your nipple could be a sign of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think a lump or thickening in your breast could be a sign of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think a nipple rash could be a sign of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think redness of your breast skin could be a sign of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think a lump or thickening under your armpit could be a sign of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think changes in the size of your breast or nipple could be signs of breast cancer? | ☐ | ☐ | ☐ | ☐ |
| Do you think changes in the shape of your breast or nipple could be signs of breast cancer? | ☐ | ☐ | ☐ | ☐ |

**DOMAIN 2 CONFIDENCE, SKILLS AND BEHAVIOUR IN RELATION TO BREAST CHANGES**

The next three questions are about finding changes in your breasts.

| How often do you check your breasts? | |
|---|---|
| **Tick one box only.** | |
| Rarely or never | ☐ |
| At least once every 6 months | ☐ |
| At least once a month | ☐ |
| At least once a week | ☐ |
| Don't know | ☐ |
| Refused | ☐ |

If the respondent gives an answer that falls between two categories, please tick as the most conservative response, in other words, less frequent breast checking.

| Are you confident you would notice a change in your breasts? | |
|---|---|
| **Tick one box only.** | |
| Not at all confident | ☐ |
| Slightly confident | ☐ |
| Fairly confident | ☐ |
| Very confident | ☐ |
| Don't know | ☐ |
| Refused | ☐ |

| Have you ever been to see a doctor about a change you have noticed in one of your breasts? | |
|---|---|
| **Tick one box only. Do not prompt.** | |
| Yes | ☐ |
| No | ☐ |
| Never noticed a change in one of my breasts | ☐ |
| Don't know | ☐ |
| Refused | ☐ |

**DOMAIN 3 ANTICIPATED DELAY IN CONTACTING THE DOCTOR**

| | |
|---|---|
| The next question is about seeking help | |
| If you found a change in your breasts, how soon would you contact your doctor? | |
| Record the response verbatim | |
| Don't know | ☐ |
| Refused | ☐ |

**DOMAIN 4 BARRIERS TO SEEKING MEDICAL HELP**

| | | | | | |
|---|---|---|---|---|---|
| The next set of questions is about what might stop you from going to the doctor.<br>Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor? You may answer 'yes often,' 'yes sometimes' or 'no'. | | | | | |
| **Tick the appropriate boxes** | Yes often | Yes some-times | No | Don't know | Refused |
| Too embarrassed to go and see the doctor | ☐ | ☐ | ☐ | ☐ | ☐ |
| Too scared to go and see the doctor | ☐ | ☐ | ☐ | ☐ | ☐ |
| Worried about wasting the doctor's time | ☐ | ☐ | ☐ | ☐ | ☐ |
| I find my doctor difficult to talk to | ☐ | ☐ | ☐ | ☐ | ☐ |
| Difficult to make an appointment with the doctor | ☐ | ☐ | ☐ | ☐ | ☐ |
| Too busy to make time to go to the doctor | ☐ | ☐ | ☐ | ☐ | ☐ |
| Too many other things to worry about | ☐ | ☐ | ☐ | ☐ | ☐ |
| Difficult to arrange transport to the doctor's surgery | ☐ | ☐ | ☐ | ☐ | ☐ |
| Worrying about what the doctor might find may stop me from going to the doctor | ☐ | ☐ | ☐ | ☐ | ☐ |
| Not feeling confident talking about my symptom with the doctor | ☐ | ☐ | ☐ | ☐ | ☐ |
| For women completing questionnaire in language other than English | Yes | No | Not applic-able | Don't know | Refused |
| My doctor does not understand my language or culture | ☐ | ☐ | ☐ | ☐ | ☐ |
| | | | | | |
| Is there anything else that you can think of that might put you off going to the doctor? | | | | | |
| **Record verbatim** | | | | | |
| | | | | | |

**DOMAIN 5 KNOWLEDGE OF AGE-RELATED AND LIFETIME RISK**

| The next question is about who you think is most likely to get breast cancer. | |
|---|---|
| **Tick one box only. Do not prompt** | |
| In the next year, who is most likely to get breast cancer? | |
| A 30 year old woman | ☐ |
| A 50 year old woman | ☐ |
| A 70 year old woman | ☐ |
| A woman of any age | ☐ |
| Don't know | ☐ |
| Refused | ☐ |

| The next question is about how many women you think will develop breast cancer in their lifetime. Please look at these pictures/imagine groups of 3, 9, 100 and 1000 women. | |
|---|---|
| **Tick one box only. Do not prompt. If it is a face-to-face interview, please show the respondent the prompt card associated with this question (found at the end of this script and response sheet). If the interview is over the telephone, please ask the respondent to imagine a group of 3/9/100/1000 people.** | |
| How many women will develop breast cancer in their lifetime? | |
| 1 in 3 women | ☐ |
| 1 in 9 women | ☐ |
| 1 in 100 women | ☐ |
| 1 in 1000 women | ☐ |
| Don't know | ☐ |
| Refused | ☐ |

**DOMAIN 6 KNOWLEDGE OF BREAST SCREENING**

| The next set of questions is about breast screening. | | | | | |
|---|---|---|---|---|---|
| **Tick one box only. Do not prompt.** | | Yes | No | Don't know | Refused |
| Is there an NHS Breast Screening Programme? | | ☐ | ☐ | ☐ | ☐ |
| **If NO or DON'T KNOW** | **go to the Domain 7** | | | | |
| | | | | Don't know | Refused |
| **If YES** | At what age are women **first** invited to the NHS Breast Screening Programme? | Write age ☐☐ | | ☐ | ☐ |
| | At what age do women receive their **last** invitation to the NHS Breast Screening Programme? | Write age ☐☐ | | ☐ | ☐ |
| | | Yes | No | Don't know | Refused |
| | Have you ever been invited for breast screening on the NHS Breast Screening Programme? | ☐ | ☐ | ☐ | ☐ |
| | Have you ever had breast screening on the NHS Breast Screening Programme? | ☐ | ☐ | ☐ | ☐ |

**DOMAIN 7 RISK FACTORS**

| The next set of questions is about what might increase the chances of getting breast cancer. | | | | | |
|---|---|---|---|---|---|
| How much do you agree that each of these can increase the chance of getting breast cancer? You may answer Strongly disagree, Disagree, Not sure, Agree, or Strongly agree. | | | | | |
| **Tick one box only. Do not prompt.** | | | | | |
| | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
| Having a past history of breast cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Using HRT (Hormone Replacement Therapy) | ☐ | ☐ | ☐ | ☐ | ☐ |
| Drinking more than 1 unit of alcohol a day | ☐ | ☐ | ☐ | ☐ | ☐ |
| Being overweight (BMI over 25) | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having a close relative with breast cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having children later on in life or not at all | ☐ | ☐ | ☐ | ☐ | ☐ |
| Starting your periods at an early age | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having a late menopause | ☐ | ☐ | ☐ | ☐ | ☐ |
| Doing less than 30 mins of moderate physical activity 5 times a week | ☐ | ☐ | ☐ | ☐ | ☐ |

**DEMOGRAPHIC QUESTIONS**

Now I have a few questions about yourself.

Could you tell me how old you are? ☐☐ Don't know ☐ Refused ☐

Could you tell me your postcode? ☐☐☐☐☐☐☐ Don't know ☐ Refused ☐

Are you registered with a GP? Yes ☐ No ☐ Don't know ☐ Refused ☐

What is the main language spoken at home?

**Do not read out the names of the languages. Allow the respondent to answer.**

- ☐ English
- ☐ Urdu
- ☐ Punjabi
- ☐ Gujarati
- ☐ Refused
- ☐ Sylheti
- ☐ Bengali
- ☐ French
- ☐ Other (please write name of language) ……

Were you born in the UK? Yes ☐ No ☐ Don't know ☐ Refused ☐

Could you tell me which of these best describes your living arrangements?

- ☐ Own outright or have a mortgage
- ☐ Rent from Council/Housing Association
- ☐ Don't know
- ☐ Rent from private landlord
- ☐ Other (please describe)……
- ☐ Refused

Could you tell me, who do you live with?

- ☐ Husband/ partner
- ☐ Live alone
- ☐ Prefer not to say
- ☐ Other (please describe)……

Does anyone living in your home have a car or van available for use? Yes ☐ No ☐ Don't know ☐ Refused ☐

Could you tell me what age you left full time education? ☐☐ Don't know ☐ Refused ☐

No full time education ☐ Currently in full time education ☐

Please would you look at this list *(on separate page)*. Which one best describes your ethnic group?

If the interview is over the telephone, please read these aloud.

| White | Mixed/multiple ethnic groups | Asian/Asian British | Black/African/ Caribbean/ Black British | Other |
|---|---|---|---|---|
| ☐ English/Welsh/ Scottish/ Northern Irish/ British | ☐ White and Black Caribbean | ☐ Indian | ☐ African | ☐ Arab |
| ☐ Irish | ☐ White and Black African | ☐ Pakistani | ☐ Caribbean | ☐ Any other ethnic group |
| ☐ Gypsy or Irish Traveller | ☐ White and Asian | ☐ Bangladeshi | ☐ Any other Black/African/ Caribbean background | Record here …… |
| ☐ Any other white background | ☐ Any other mixed background | ☐ Chinese | | |
| | | ☐ Any other Asian background | ☐ Don't know | ☐ Refused |

Could you tell me, where does your household get most of its income from?

| | |
|---|---|
| ☐ Wages or salary | ☐ Benefits (including unemployment or sickness benefit) |
| ☐ Pension | ☐ Other (please describe)…….. |
| ☐ Don't know | ☐ Refused |

Could you tell me, what is your sexual orientation?

| | |
|---|---|
| ☐ Heterosexual/straight | ☐ Gay/lesbian |
| ☐ Bisexual | ☐ Prefer not to say |
| ☐ Don't know | ☐ Other (please describe)…… |
| ☐ Refused | …….. |

| |
|---|
| Thank you for answering these questions. As I said before, all your answers will be treated with the strictest confidence.<br><br>Now that the interview is over, do you have any questions you would like to ask?<br><br>Have you any comments on the questions I have been asking you? |
| **Please record any further information here** |

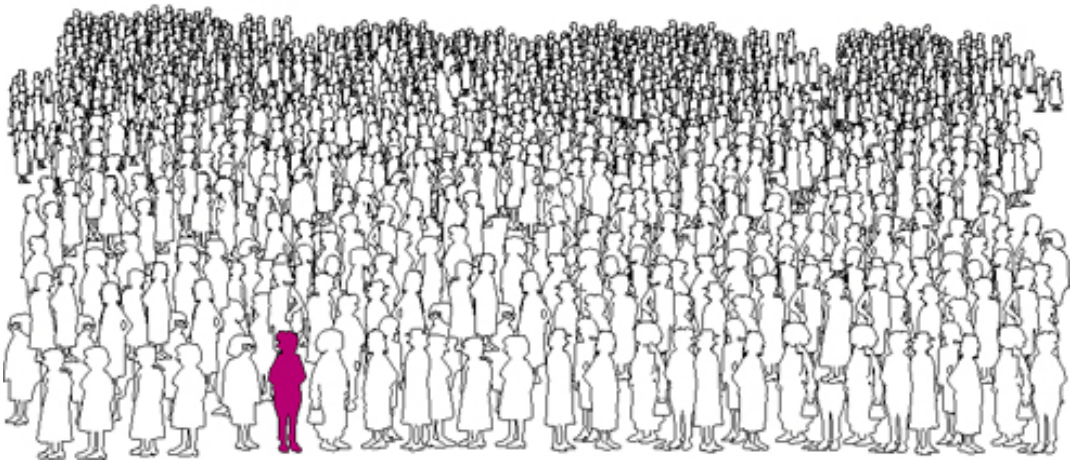
***If a respondent has any questions about symptoms they have had or other questions about breast cancer, please advise them to speak to their GP.***

**This picture is for use when asking the question about lifetime risk**

**1 in 3**

**1 in 9**

**1 in 100**



**1 in 1000**

**This list is for use when asking the question about ethnic group**

## Ethnic groups (Census 2011 classification)

| White | Mixed/multiple ethnic groups | Asian/Asian British | Black/African/ Caribbean/ Black British | Other |
|---|---|---|---|---|
| ☐ English/Welsh/ Scottish/ Northern Irish/ British | ☐ White and Black Caribbean | ☐ Indian | ☐ African | ☐ Arab |
| ☐ Irish | ☐ White and Black African | ☐ Pakistani | ☐ Caribbean | ☐ Any other ethnic group |
| ☐ Gypsy or Irish Traveller | ☐ White and Asian | ☐ Bangladeshi | ☐ Any other Black/African/ Caribbean background | |
| ☐ Any other white background | ☐ Any other mixed background | ☐ Chinese | | |
| | | ☐ Any other Asian background | | |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | |

Participant ID number or sticker

# Appendix B: Self-complete version of the Breast Module of the Cancer Awareness Measure

We are asking these questions to find out more about breast cancer awareness. This questionnaire should take around 15 minutes to complete. It is not a test. We are interested in your thoughts and beliefs so please answer the questions as honestly as you can. All your answers will be treated as strictly confidential.

| | Yes | No |
|---|---|---|
| **1. Have you ever had breast cancer?** | ☐ | ☐ |

**2. Do you know any of the warning signs of breast cancer?**

Yes ☐ No ☐

**If yes, please circle the signs you know below.**

Change in position of your nipple

Pulling in of your nipple

Pain in one of your breasts or armpit

Puckering or dimpling of your breast skin

Discharge or bleeding from your nipple

A lump or thickening in your breast

Redness of your breast skin

Nipple rash

A lump or thickening under your armpit

Changes in the size of your breast or nipple

Changes in the shape of your breast or nipple

**The next four questions are about finding changes in your breasts.**

**3. How often do you check your breasts?**

Please tick one box only.

- Rarely or never ☐
- At least once every 6 months ☐
- At least once a month ☐
- At least once a week ☐
- Don't know ☐

**4. Are you confident you would notice a change in your breasts?**

Please tick one box only.

- Not at all confident ☐
- Slightly confident ☐
- Fairly confident ☐
- Very confident ☐
- Don't know ☐

**5. Have you ever been to see a doctor about a change you have noticed in one of your breasts?**

Please tick one box only.

- Yes ☐
- No ☐
- Never noticed a change in one of my breasts ☐
- Don't know ☐

**6. If you found a change in your breast, how soon would you contact your doctor?**

Write how soon you would contact your doctor here ☐

Don't know ☐

**7. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to the doctor?**

| | Yes often | Yes sometimes | No | Don't know |
|---|---|---|---|---|
| Too embarrassed to go and see the doctor | ☐ | ☐ | ☐ | ☐ |
| Too scared to go and see the doctor | ☐ | ☐ | ☐ | ☐ |
| Worried about wasting the doctor's time | ☐ | ☐ | ☐ | ☐ |
| I find my doctor difficult to talk to | ☐ | ☐ | ☐ | ☐ |
| Difficult to make an appointment with the doctor | ☐ | ☐ | ☐ | ☐ |
| Too busy to make time to go to the doctor | ☐ | ☐ | ☐ | ☐ |
| Too many other things to worry about | ☐ | ☐ | ☐ | ☐ |
| Difficult to arrange transport to the doctor's surgery | ☐ | ☐ | ☐ | ☐ |
| Worrying about what the doctor might find may stop me from going to the doctor | ☐ | ☐ | ☐ | ☐ |
| Not feeling confident talking about my symptom with the doctor | ☐ | ☐ | ☐ | ☐ |

**Please write here anything else that you can think of that might put you off going to the doctor**

**8. In the next year, who is most likely to get breast cancer?**

Please tick one box only.

- A 30 year old woman ☐
- A 50 year old woman ☐
- A 70 year old woman ☐
- A woman of any age ☐
- Don't know ☐

**9. How many women will develop breast cancer in their lifetime?**

Please tick one box only.

1 in 3 women ☐

1 in 9 women ☐

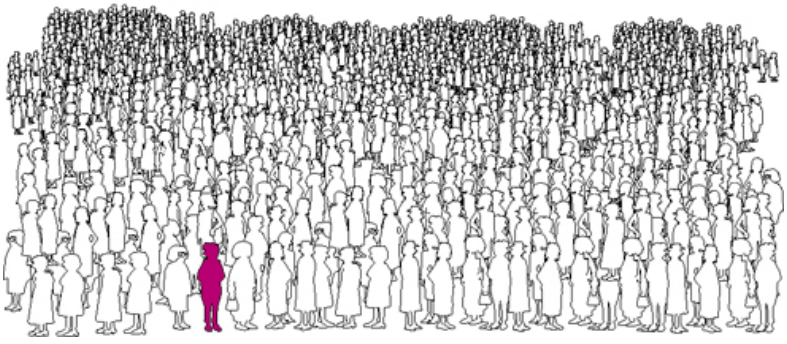
1 in 100 women ☐

1 in 1000 women ☐

**1 in 3**

**1 in 9**

**1 in 100**



**1 in 1000**

**The next set of questions is about breast screening.**

**10. At what age are women *first* invited to the NHS Breast Screening Programme?**

Write age here ☐☐ Don't know ☐

**11. At what age do women receive their *last* invitation to the NHS Breast Screening Programme?**

Write age here ☐☐ Don't know ☐

| | Yes | No | Don't know |
|---|---|---|---|
| **12. Have you ever been invited for breast screening on the NHS Breast Screening Programme?** | ☐ | ☐ | ☐ |
| **13. Have you ever had breast screening on the NHS Breast Screening Programme?** | ☐ | ☐ | ☐ |

**14. How much do you agree that each of these can increase the chance of getting breast cancer?**

| | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|---|---|---|---|---|---|
| Having a past history of breast cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Using HRT (Hormone Replacement Therapy) | ☐ | ☐ | ☐ | ☐ | ☐ |
| Drinking more than 1 unit of alcohol a day | ☐ | ☐ | ☐ | ☐ | ☐ |
| Being overweight (BMI over 25) | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having a close relative with breast cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having children later on in life or not at all | ☐ | ☐ | ☐ | ☐ | ☐ |
| Starting your periods at an early age | ☐ | ☐ | ☐ | ☐ | ☐ |
| Having a late menopause | ☐ | ☐ | ☐ | ☐ | ☐ |
| Doing less than 30 mins of moderate physical activity 5 times a week | ☐ | ☐ | ☐ | ☐ | ☐ |

**Please answer the following questions about yourself**

**Please tell us, what is your age?** ☐☐ years

**Please would you write your postcode here** ☐☐☐☐☐☐☐ Don't know ☐

**Are you registered with a GP?** Yes ☐ No ☐ Don't know ☐

**What is the main language spoken at home?**

- ☐ English
- ☐ Urdu
- ☐ Punjabi
- ☐ Gujarati
- ☐ Sylheti
- ☐ Bengali
- ☐ French
- ☐ Other (please write name of language)

……

**Were you born in the UK?** Yes ☐ No ☐ Don't know ☐

**Which of these best describes your living arrangements?**

- ☐ Own outright or have a mortgage
- ☐ Rent from Council or Housing Association
- ☐ Don't know
- ☐ Rent from private landlord
- ☐ Other (please describe)……
  ……..

**Who do you live with?**

- ☐ Husband/partner
- ☐ Live alone
- ☐ Other (please describe)……
  ……..

**Does anyone living in your home have a car or van available for use?** Yes ☐ No ☐ Don't know ☐

**What age were you when you left full time education?** ☐☐

- ☐ Currently in full time education
- ☐ No full time education

**Which of the following best describes your ethnic group?**

| White | Mixed/multiple ethnic groups | Asian/Asian British | Black/African/ Caribbean/ Black British | Other |
|---|---|---|---|---|
| ☐ English/Welsh/ Scottish/ Northern Irish/ British | ☐ White and Black Caribbean | ☐ Indian | ☐ African | ☐ Arab |
| ☐ Irish | ☐ White and Black African | ☐ Pakistani | ☐ Caribbean | ☐ Any other ethnic group |
| ☐ Gypsy or Irish Traveller | ☐ White and Asian | ☐ Bangladeshi | ☐ Any other Black/African/ Caribbean background | (please describe) …….. |
| ☐ Any other white background | ☐ Any other mixed background | ☐ Chinese | | |
| | | ☐ Any other Asian background | | |

**Would you please tell us, where does your household get most of its income from?**

- ☐ Wages or salary
- ☐ Pension
- ☐ Don't know
- ☐ Benefits (including unemployment or sickness benefit)
- ☐ Other (please describe)……

**What is your sexual orientation?**

- ☐ Heterosexual/straight
- ☐ Bisexual
- ☐ Don't know
- ☐ Gay/lesbian
- ☐ Prefer not to say
- ☐ Other (please describe)……

The Breast Cancer Awareness Measure was developed by Cancer Research UK, King's College London and University College London in 2009. It was validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

# Appendix C: Depositing and accessing Breast-CAM data with the UK Data Archive

**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 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<br>Senior Collections Development and Rights Officer<br>Economic and Social Data Service (ESDS)<br>University of Essex,<br>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 deposit your data**

If you are commissioning your CAM survey please ensure that you specify responsibilities for uploading the data collected using the CAM.
When you are ready to deposit your data, complete the following process:

1. Complete the Data collection deposit form and submit the two XML files created in the process electronically to acquisitions@esds.ac.uk (instructions about how to complete the data deposit form 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.*
2. Prepare data and documentation according to best practice guidance on how to manage and share data
   ***Note. Please include any methodological, technical or end of project reports that will be of use to future researchers as part of the materials being deposited.***
3. Submit data files in any of the following ways:
   ***Note: If data files contain sensitive or personal information, they should be encrypted before submitting.***
   - via the University of Essex Dropbox Service, addressing the deposit to email account "acquisitions@essex.ac.uk" and noting study title or depositor surname in the dropbox description
   - by CD/DVD/memory stick
   - via secure electronic transmission - contact acquisitions@esds.ac.uk
4. Print, sign and date the Licence Agreement, keep a copy for your records and send the original to:
   Acquisitions
   UKDataArchive
   UniversityofEssex
   WivenhoePark
   Colchester
   CO4 3SQ

*Next steps*

The acquisitions team will confirm receipt of all materials associated with the data collection. After administrative checks, the data collection will be prepared for release, see processing data at the UK Data Archive for further information.

*Help*
Please contact NAEDI if you have any queries about this process: naedi@cancer.org.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. Go to: http://www.data-archive.ac.uk/sign-up/credentials-application

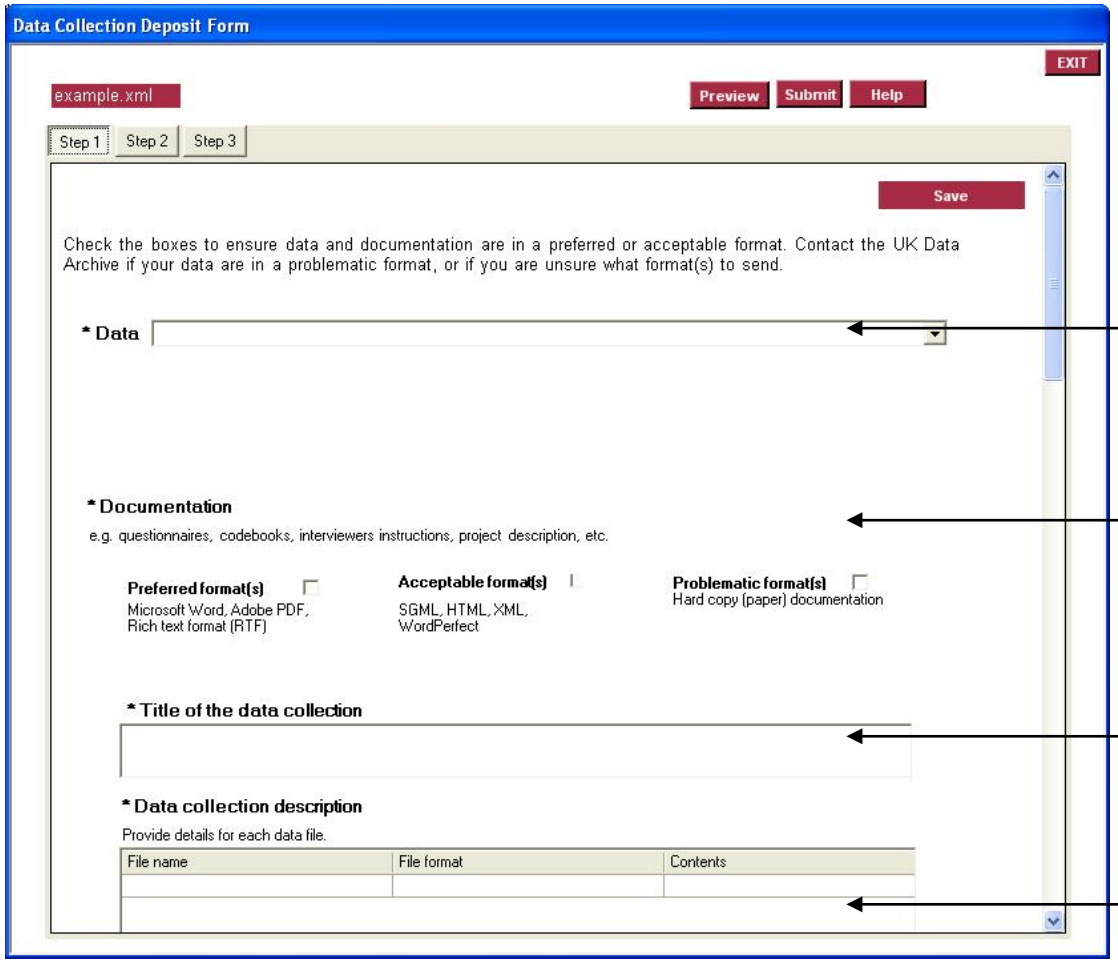
Once you have registered and have a username and password you can access CAM data. To do so:

1. Go to: http://www.esds.ac.uk/newRegistration/newLogin.asp
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. Click on 'Data Catalogue' and go to 'data catalogue search'
6. Type in 'cancer awareness' and this should bring up all the CAM data that is currently held in the archive
7. Click on 'Download/order'
8. 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: Instructions for completing the data deposit form**

## Step 1



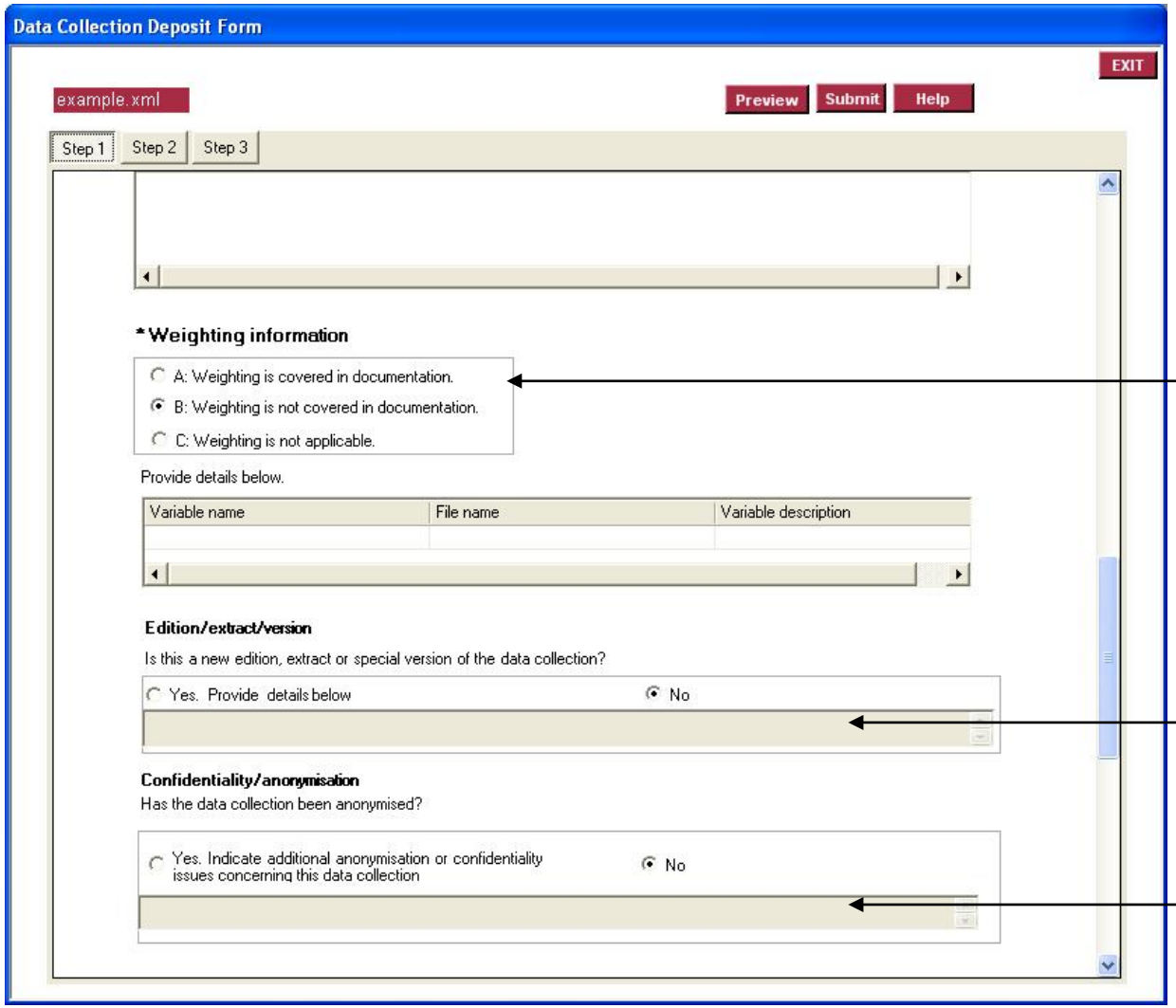

Title should reflect the nature of and subject of the data collection and include a date e.g. General Household Survey, 2001-2002

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 Lung CAM was used, write in: 'Lung Cancer Awareness Measure'.

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

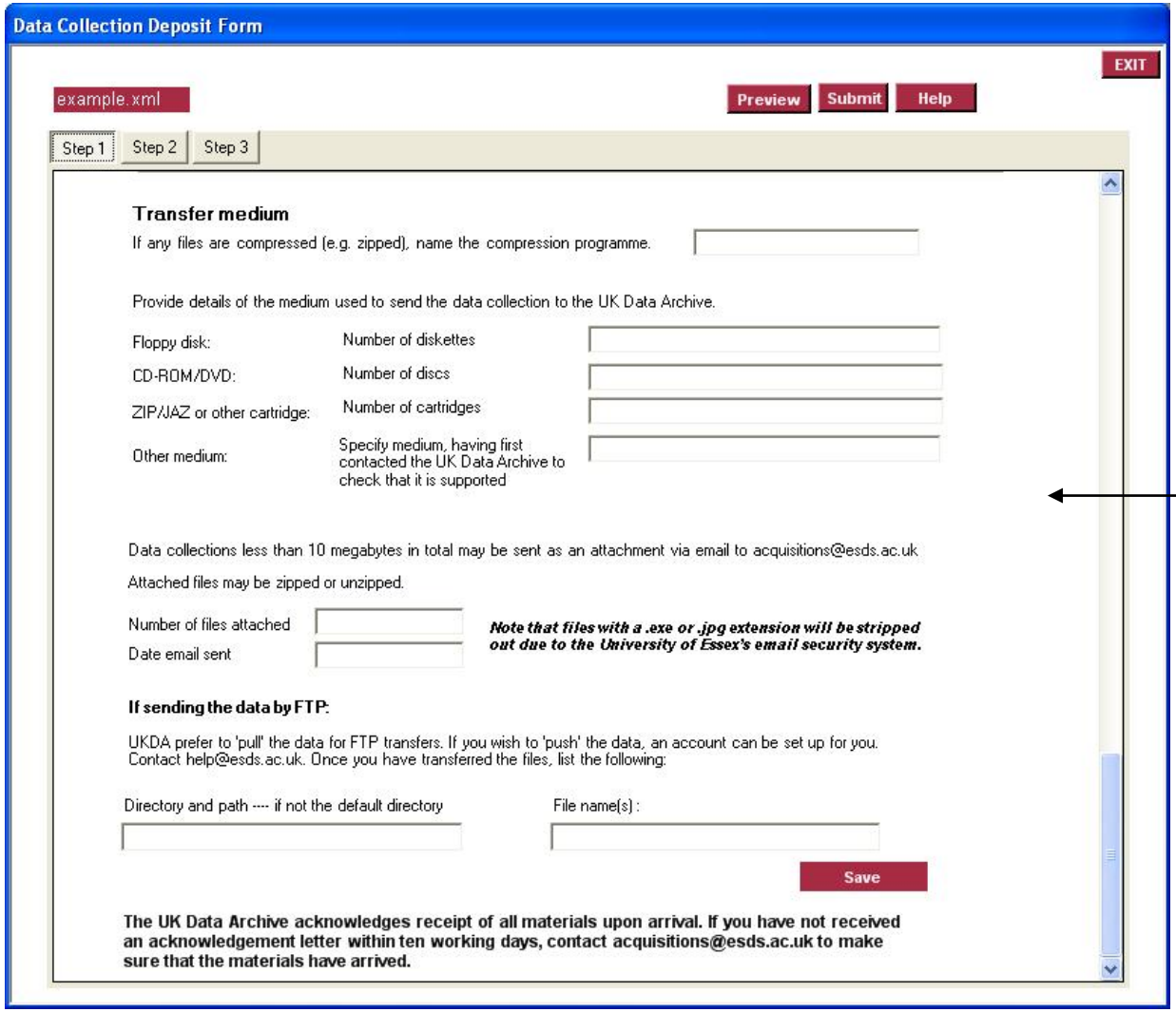
**NB. If you have collected postcode data, please indicate this here.**




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 represent a particular population.

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

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’.

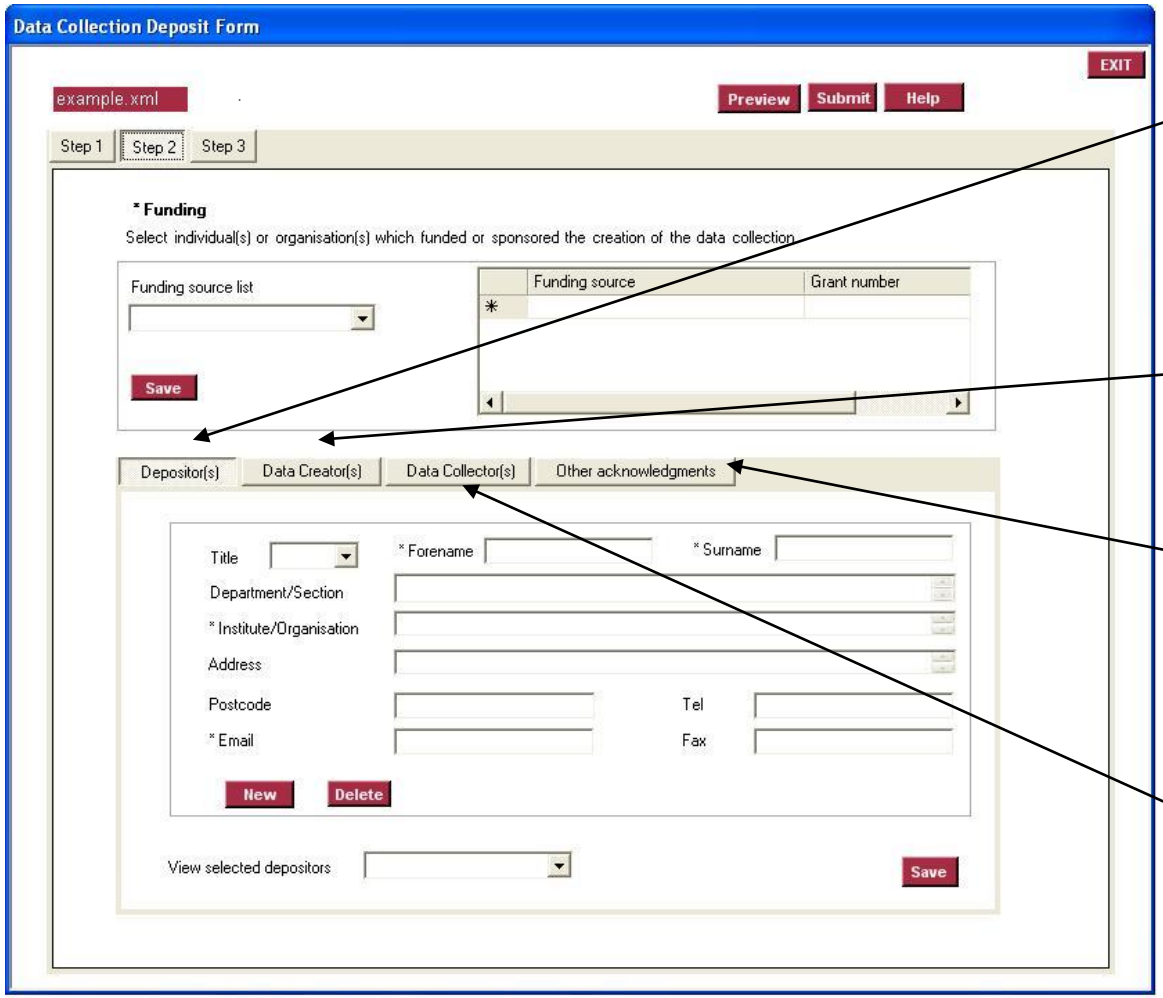



Provide the details of medium/method used to send the data to the UK Data Archive.

NB. **Please do not send by email**. Refer to: http://www.esds.ac.uk/aandp/create/ukdadeposit.asp for further information about how to transfer your data.

## 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.



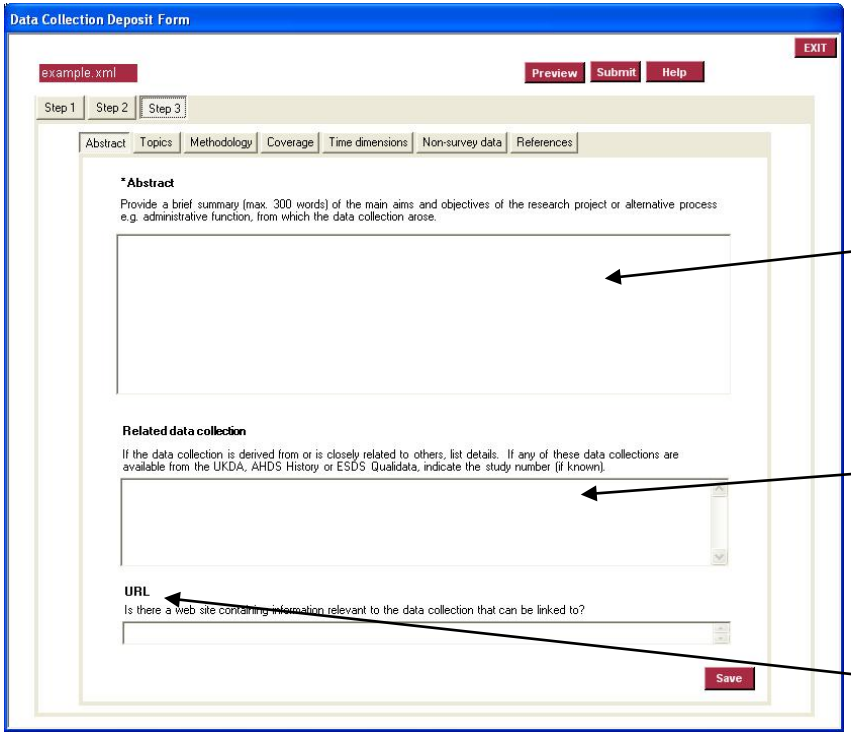

Depositor(s) is (are) person(s) and organisation(s) who deposited the data collection, usually, but not always, the License Agreement signatory.

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.

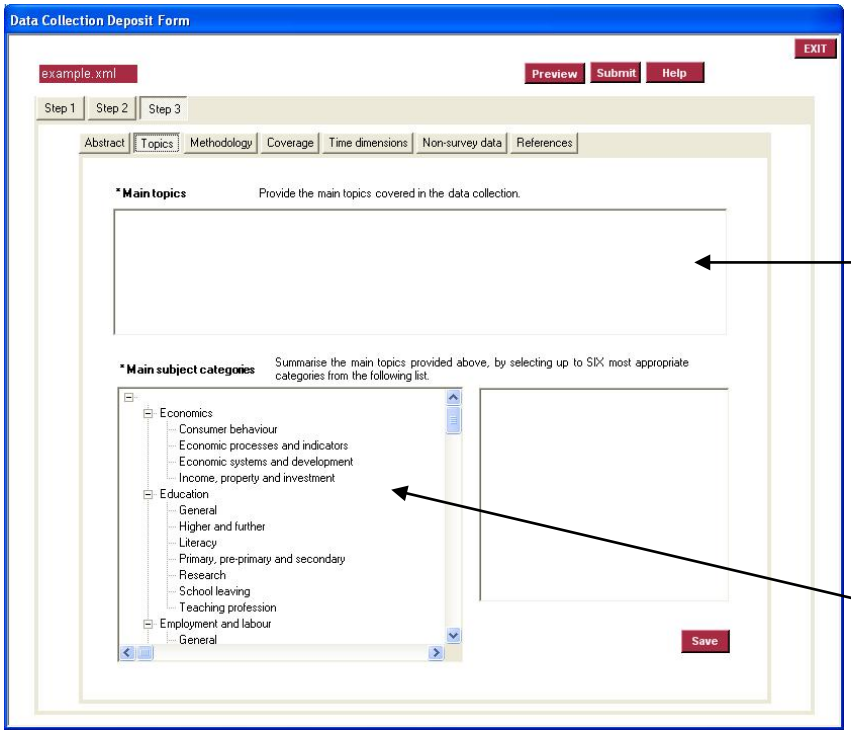
# Step 3




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

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

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

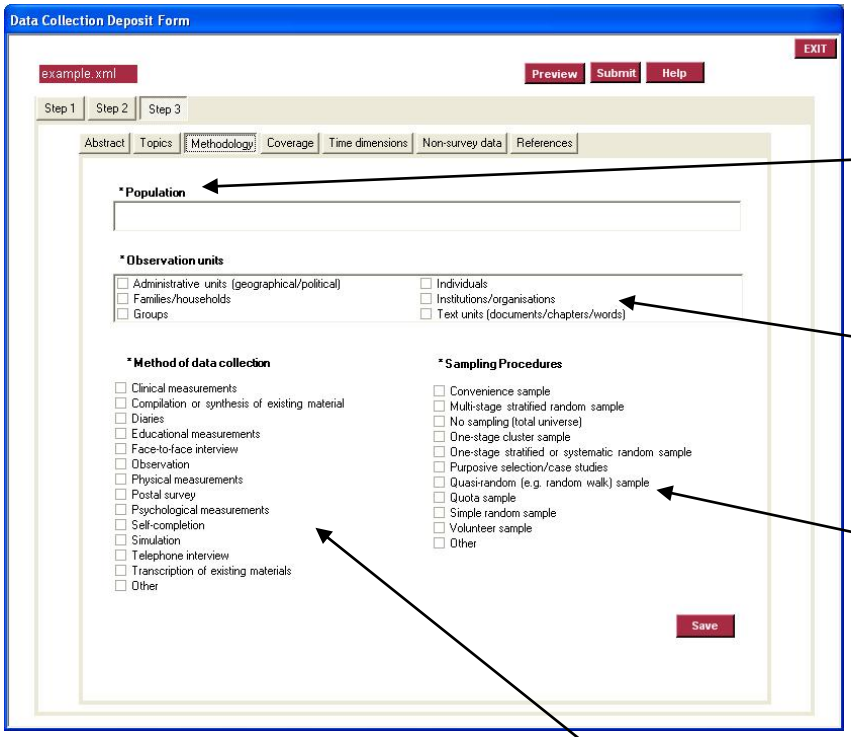



In the box 'Main topics' please list the following:

- 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

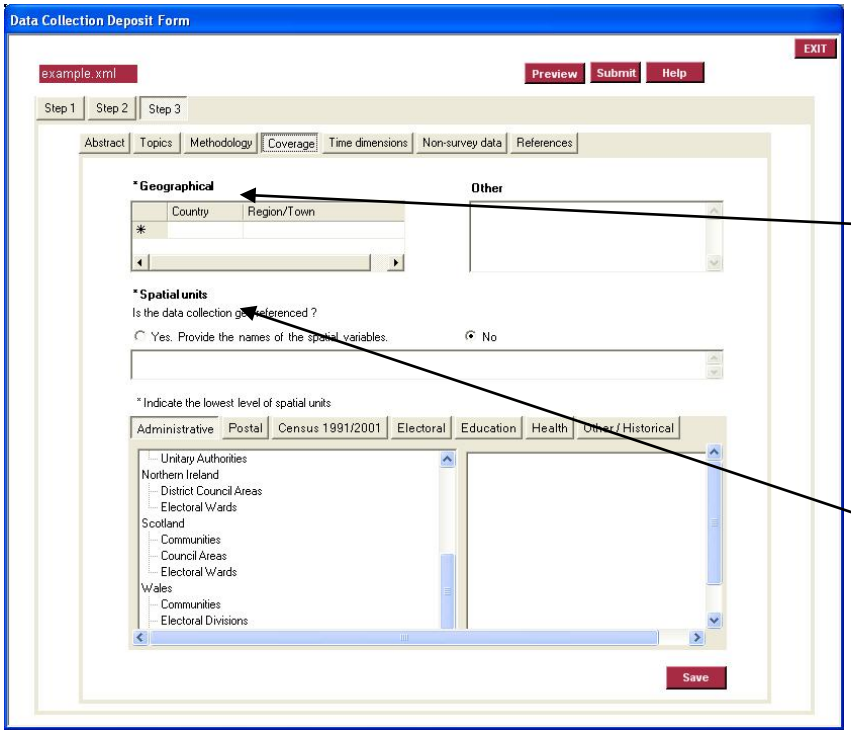



Provide information about the characteristics of the group or units studied e.g. single mothers in Yorkshire.

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

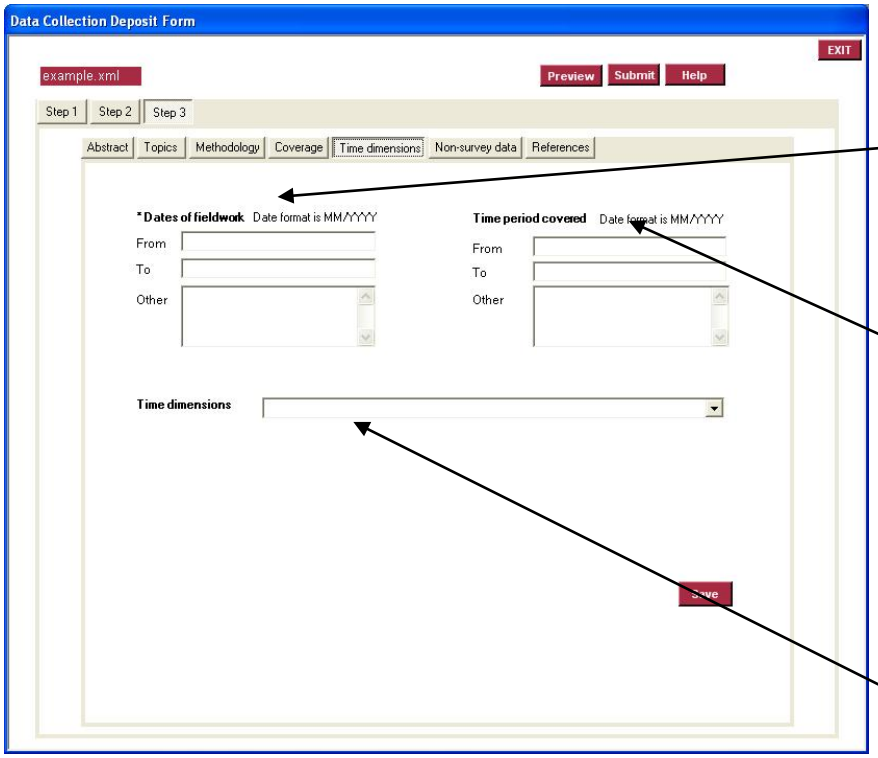
Select an option from the list provided or enter additional information by selecting ‘other’.

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




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.

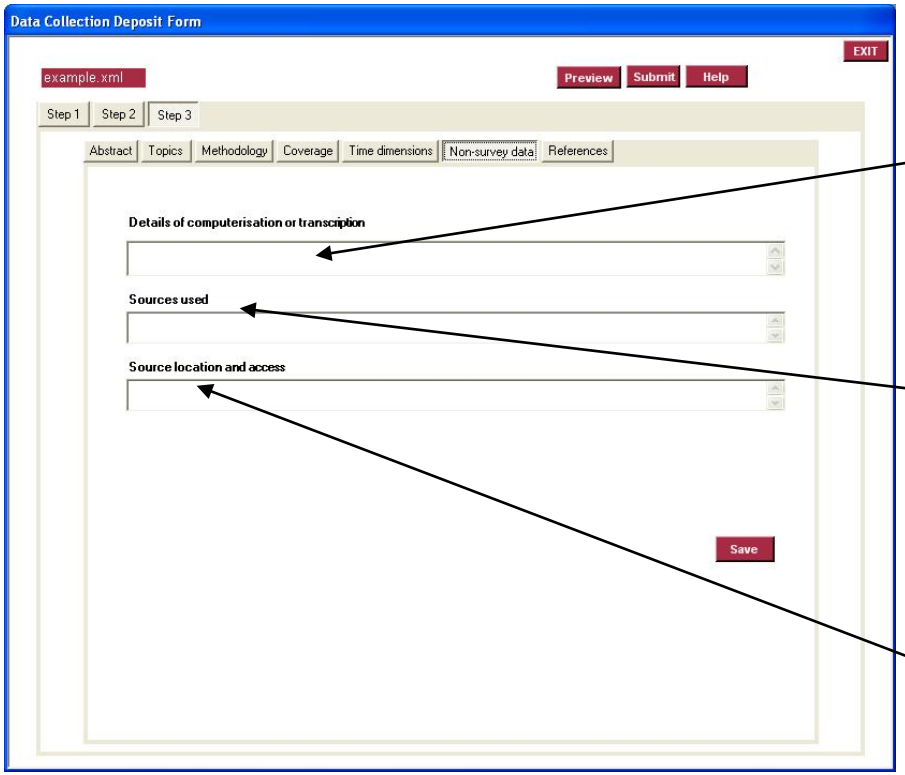
Geo-referenced data consist of measurements or observations taken at specific locations. If the research has been geo-referenced, select 'Yes' and provide the names of the spatial variables, if not select 'No' and proceed to complete the remaining elements of the form.




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

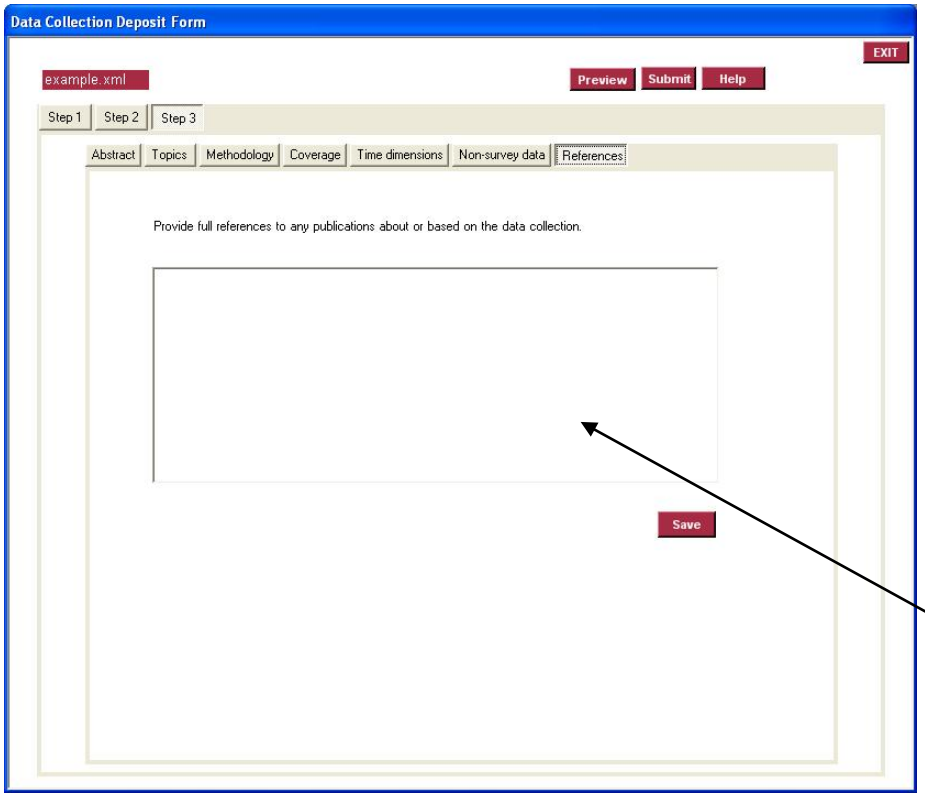
Select an option from the drop down list.




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.




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

Please also add any references for publications that have resulted directly from your own data