International Agency for Research on Cancer
World Health Organization

Centre for Childhood Cancer Survivor Studies
UNIVERSITY OF BIRMINGHAM

strictly private and confidential

STUDY OF WOMEN WHO HAD CANCER, LEUKAEMIA, TUMOUR OR SIMILAR ILLNESS DURING CHILDHOOD

Questionnaire for telephone interview

LABEL: NAME, DOB, STUDYID

Please telephone the Study Centre on **0800 328 9419** if you wish to participate. A research officer will answer your call and will arrange a time that is convenient for you to answer the telephone interview.

This questionnaire is enclosed to show you what questions will be asked during the interview. It would be helpful if you could go through it before the telephone interview takes place. Thank you.

Thank you for participating in this important international study.

1. General information

1.1 Your full name:

last name: _____

first name: _____

maiden name (if changed): _____

1.2 Date of birth: day |__|__| month |__|__| year 19 |__|__|

1.3 Current address:

Street _____

City _____ postcode |__|__|__|__|__|__|

1.4 Telephone number: home |__|__|__|__|__|__|__|__|__|__|__|__|__|

Work |__|__|__|__|__|__|__|__|__|__|__|__|__|

1.5 How many years of schooling (including professional training, technical or university studies) have you completed starting from when you first started school? |__|__|

1.6 To which ethnic group do you consider you belong? (Indicate more than one if applicable)

|__| White |__| Black |__| Chinese

|__| South Asian (India, Pakistan etc) |__| South East Asian (Thailand, Indonesia etc)

|__| Jewish – Ashkenazi |__| Jewish Sephardi

|__| Other (*specify*)_____

2. Reproductive History

It is important to know whether some forms of medical treatment during childhood or young adulthood have an effect on women's natural periods (natural menstrual bleeds).

2.1 At what age did you have your first period?

|__| I have never had a period (*go to question 2.4*)

|__| don't know (*go to question 2.7*)

|__|__| age at first period

2.2 How old were you when you started to have regular periods? Regular periods occur approximately once a month in a predictable way.

|__| I have never had regular cycles

|__| don't know

|__|__| age when you started to have regular periods

2.3 Did they later stop or become irregular (excluding pregnancies)?

|__| no *(go to question 2.4)*

|__| don't know *(go to question 2.4)*

|__| yes

If yes:

If your periods <u>stopped for 3 months or more</u>, when did this occur and for how long? If there was more than one such episode please enter the information for each episode on a separate line.

Age when periods stopped for at least 3 months	Total number of months without a period in this episode	OR	My periods did not restart
|__|__|	|__|__|	OR	|__|
|__|__|	|__|__|	OR	|__|
|__|__|	|__|__|	OR	|__|
|__|__|	|__|__|	OR	|__|

If the periods stopped completely, why did your periods stop?

|__| they stopped on their own at age *(in years)* |__|__|
|__| after surgery to remove the uterus at age *(in years)* → |__|__|
|__| after surgery to remove the ovaries at age *(in years)* → |__|__|
|__| after radiotherapy at age *(in years)* → |__|__|
|__| after chemotherapy at age *(in years)* → |__|__|

What was the reason for the surgery/radiotherapy/chemotherapy?

|__| cancer
|__| dysplasia
|__| polyps
|__| excessive bleeding
|__| other *(specify)* ____________________

2.4 Have you ever been pregnant (include all pregnancies regardless of outcome)?

|__| yes, *specify* how many times have you been pregnant? |__|__|
|__| no *(go to 2.6)*
|__| don't know *(go to 2.6)*

2.5 For each pregnancy (whether it resulted in a live birth or not), indicate in the following table:

Month/year of end of pregnancy	Outcome of pregnancy: 1=live birth 2=miscarriage before 5 months 3=induced abortion 4=stillbirth 5=ectopic pregnancy 9=don't know	How many babies were conceived in this pregnancy?	If the baby was born alive: Did you breastfeed? 1=yes 2=no 9=don't know	If yes, for how many months did you breastfeed?
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|
|__|__|/|__|__|	|__|	|__|	|__|	|__|__|

(for twins or other multiple conceptions please use a separate line for each)

2.6 Have you used the pill (oral contraceptives), injections (of hormones), implants, or patches to avoid getting pregnant for at least 12 months?

|__| yes

|__| no *(go to question 2.7)*

|__| don't know *(go to question 2.7)*

For **each type of contraceptive used** please give age started and age stopped:

Brand name (if remembered) and type of contraceptive (pill, implant etc)	Age at start	Age last used	Total duration of use in months
_____	|__|__|	|__|__|	|__|__|
_____	|__|__|	|__|__|	|__|__|
_____	|__|__|	|__|__|	|__|__|
	|__|__|	|__|__|	|__|__|

2.7 Did you ever use hormones (hormone replacement therapy or estrogens) to induce menstrual bleeding
or alleviate menopausal symptoms or to prevent osteoporosis (fragile bones) or for some other reason?

|__| yes

|__| no *(go to section 3)*

|__| don't know *(go to section 3)*

If yes, specify:

Brand name (if remembered) and type (pill, gel, patch, etc.)	Age at start	Age at stop	Total duration of use in months	Reason for treatment
	|__|__|	|__|__|	|__|__|	
	|__|__|	|__|__|	|__|__|	
	|__|__|	|__|__|	|__|__|	
	|__|__|	|__|__|	|__|__|	

3. Medical History

3.1 Have you ever had breast surgery or a breast biopsy for lumps before this past year?

|__| yes

|__| no *(go to question 3.2)*

|__| don't know *(go to question 3.2)*

If yes, what was the reason for the surgery/biopsy?

|__| benign breast disease:
specify age at first surgery for benign breast disease |__|__|

|__| breast cancer *specify* age at first surgery for breast cancer |__|__|
If you had surgery for more than occurrence of breast cancer please specify age for each surgery
second breast cancer |__|__|
third breast cancer |__|__|

|__| other *(specify)* _____, at which age? |__|__|

Did any of the surgical procedures on your breast(s) involve a radical mastectomy?

|__| yes

|__| no

|__| don't know

3.2 Before age 40 did you ever have radiotherapy, that is, treatment involving radiation?

This treatment may be given for several reasons including such conditions as: benign diseases (of the breast, such as mastitis), ankylosing spondylitis, hormonal infertility, gynaecological disorders, tinea capitis (ringworm of the scalp), acne, haemangioma or for benign or malignant tumours?

|__| no *(go to question 3.3)*

|__| don't know *(go to question 3.3)*

|__| yes

If yes*:* Please list for each course of radiation treatment you have received:

Age	Part of body treated 1=head, 2=neck, 3=chest 4=abdomen, 5=pelvis, 6=arms-upper extremities, 7=legs-lower extremities	Reason for radiotherapy: 1=benign breast disease (specify) 2=ankylosing spondylitis 3=cancer (specify) 4=other (specify)	Name and address of treatment centre. If you do not have the precise address please note the city or town in which it was located	Name of the doctor who was treating you at the time
|__|__|	|__| |__| _____ _____	_____ _____	_____
|__|__|	|__| |__| _____ _____	_____ _____	_____
|__|__|	|__| |__| _____ _____	_____ _____	_____
|__|__|	|__| |__| _____ _____	_____ _____	_____
|__|__|	|__| |__| _____ _____	_____ _____	_____

Age	Part of body treated 1=head, 2=neck, 3=chest 4=abdomen, 5=pelvis, 6=arms-upper extremities, 7=legs-lower extremities	Reason for radiotherapy: 1=benign breast disease (specify) 2=ankylosing spondylitis 3=cancer (specify) 4=other (specify)	Name and address of treatment centre. If you do not have the precise address please note the city or town in which it was located	Name of the doctor who was treating you at the time
		_____	_____	
|__|__|	|__|	|__| _____	_____	_____
		_____	_____	
|__|__|	|__|	|__| _____	_____	_____
		_____	_____	
|__|__|	|__|	|__| _____	_____	_____
		_____	_____	
|__|__|	|__|	|__| _____	_____	_____
		_____	_____	

At the age when you first received radiotherapy had you started to wear a bra regularly?

|__| no *(go to question 3.3)*

|__| don't know *(go to question 3.3)*

|__| yes

If yes, what size bra did you wear? *size* |__|__|__| *cup* |__|__|

Mammograms

3.3 Have you ever had a mammogram?

|__| no *(go to question 3.4)*

|__| don't know *(go to question 3.4)*

|__| yes

If yes*:* at what age did you have your first mammogram? |__|__|

What was the reason for this **first** mammogram?

|__| routine screening

|__| as a result of a lump found on a doctor's or self-examination of the breast

|__| preventive screening because of a family history of breast or ovarian cancer

|__| following symptoms or complaints

|__| other (specify) _____

How many mammograms in total have you undergone in your life? |__|__|

How old were you when you had your last mammogram? |__|__|

In the grid below please mark the number of mammograms you had in each of three periods: up to age 19, between age 20 and 29, between age 30 and 39.

Note: If you had no mammograms at all in an age period, please fill in '0'.

	up to and including age 19	between age 20 and 29	between age 30 and 39
Number of mammograms	_____	_____	_____

Fluoroscopy

From the 1930s and in particular after the Second World War, large groups of the population (nursing staff, educational staff and students) had fluoroscopies taken for tuberculosis.
During a fluoroscopy several images are taken during which the person moves slowly to the left and right.
Note: during a chest X-ray you are asked to stand still. Chest X-rays are not to be taken into account here.

3.4 Have you ever had a fluoroscopy?

|__| no *(go to question 3.5)*
|__| don't know *(go to question 3.5)*
|__| yes

if yes*:* at what age did you have your first fluoroscopy? |__|__|

In the grid below we have listed the most important reasons for having fluoroscopy. Please find the reason that applies to you and mark the number of times you had fluoroscopy in each of three age periods.

***Note**: If you had no fluoroscopy at all in an age period, please fill in '0'.*

Reason for fluoroscopy	Up to and including age 19		number	Between age 20 and 29		number	Between age 30 and 40		number
Example: routine chest examination	|_X|	no		|__|	no		|__|	no	
	|__|	yes	0	|_X|	yes	3-8	|_X|	yes	1
Routine chest examination (include tuberculosis screening)	|__|	no		|__|	no		|__|	no	
	|__|	yes	_____	|__|	yes	_____	|__|	yes	_____
Abdominal pain (including suspected peritonitis)	|__|	no		|__|	no		|__|	no	
	|__|	yes	_____	|__|	yes	_____	|__|	yes	_____
A spot found on a chest X-ray	|__|	no		|__|	no		|__|	no	
	|__|	yes	_____	|__|	yes	_____	|__|	yes	_____
Pneumothorax (collapsed lung)	|__|	no		|__|	no		|__|	no	
	|__|	yes	_____	|__|	yes	_____	|__|	yes	_____
Other, namely ……..	|__|	no		|__|	no		|__|	no	
	|__|	yes	_____	|__|	yes	_____	|__|	yes	_____
I do not recall the reason	|__|	no		|__|	no		|__|	no	
	|__|	yes	_____	|__|	yes	_____	|__|	yes	_____

*A*t what age did you have your last fluoroscopy? |__|__|

X-rays

3.5 Before age 40 did you ever **regularly** have x-rays to the upper part of your body (above the abdomen) as part of a routine screening program at work or school, or for continued monitoring of a chronic condition such as scoliosis or tuberculosis: **Exclude routine dental x-rays**

|__| yes
|__| no *(go to question 3.6)*
|__| don't know *(go to question 3.6)*

If yes*:* In the grid below we have listed the most important reasons for having more than one X-ray as a routine. Please find the reason that applies to you and mark the number of x-rays in each age period.

Note*: If you had no x-rays at all in an age period, please fill in '0'.*

Reason for repeated X-rays	Up to and including age 19		number	Between age 20 and 29		number	Between age 30 and 39		number
Example: routine chest examination	|_X|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|_X|	yes	3-8	|_X|	yes	1
Diagnosis of cancer before age 30	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|
Follow-up of cancer which occurred before age 30	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|
Routine chest examination (include tuberculosis screening)	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|
Scoliosis	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|
Pneumothorax (collapsed lung)?	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|
Other, namely ……..	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|
I do not recall the reason	|__|	no		|__|	no		|__|	no	
	|__|	yes	|__|__|	|__|	yes	|__|__|	|__|	yes	|__|__|

CT Scans

3.6 Before the age of 40 did you ever have a CT examination?
(In this procedure the patient lies down and a round part of the machine moves around the patient. It does not involve being in an enclosed space. In this technology transverse cuts of the body are being filmed and processed by a computer.)

|__| no *(go to question 3.7)*

|__| don't know*(go to question 3.7)*

|__| yes

if yes, please specify the CT scans you have undergone in the past (first to last).

Age	(or) Year	Part of the body scanned: 1=head, 2=neck, 3=chest, 4=abdomen, 5=pelvis, 6=arms-upper extremities, 7=legs-lower extremities	Reasons for CT scan	Name and address of treatment centre. If you do not have the precise address please note the city or town in which it was located
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____
|__|__|	|__|__|__|__|	|__|	_____	_____

Radionuclide/radioisotope scans

3.7 Before the age of 40 did you ever have a radionuclide/radioisotope scan (for example, of the bone, thyroid, liver, heart, etc.)?

|__| no *(go to question 4.1)*

|__| don't know *(go to question 4.1)*

|__| yes

if yes, please list for all such scans:

Age	(or) Year	Reason for radionuclide/radioisotope scan	Name and address of treatment centre. If you do not have the precise address please note the city or town in which it was located
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____
|__|__|	|__|__|__|__|		_____ _____

4. Family history

4.1 Do you have or had any (alive or deceased) sisters or half-sisters (exclude step sisters)?

|__| no

|__| don't know

|__| yes, how many? ⟶ |__|__|

4.2 Did your biological mother, sister(s), half-sister(s) or either of your <u>biological</u> grandmothers ever have breast cancer?

|__| no *(go to question 4.3)*

|__| don't know *(go to question 43)*

|__| yes

If yes, please specify:

Relationship: 1= sister 2= half-sister 3= mother 4= maternal grandmother 5= paternal grandmother	Year of birth	At which age was the breast cancer diagnosed (if known)?	Was this before age 50? 1= yes 2= no 9= don't know
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|

4.3 Did your biological mother, sister(s) or either of your biological grandmothers ever have ovarian cancer?

|__| no *(go to question 5.1)*

|__| don't know *(go to question 5.1)*

|__| yes

If yes, please specify:

Relationship: 1= sister 2= half-sister 3= mother 4= maternal grandmother 5= paternal grandmother	Year of birth	At which age was the ovarian cancer diagnosed (if known)?	Was this before age 50? 1= yes 2= no 9= don't know
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|
|__|	|__|__|__|__|	|__|__|	|__|

5. Physical activity

5.1 Did you engage regularly in any of the following activities? Regularly means more than an hour a week for a period of one year or more?

*If no, please check "never or rarely". If yes, H*ow many hours per week did you spend, on average, engaged in physical activity – when you were an adolescent, when you were a young adult, and in the more recent past?

		From 12-19 years of age	**From 20-39 years of age**	**Since age 40**
		On average	*On average*	*On average*
	Never or rarely	*Number of hours per week*	*Number of hours per week*	*Number of hours per week*
Walking (including to school, work, shopping or as a leisure activity)	|__|	|__|__|	|__|__|	|__|__|
Cycling (including to school, work, shopping or as a leisure activity)	|__|	|__|__|	|__|__|	|__|__|
Gardening	|__|	|__|__|	|__|__|	|__|__|
Housework (cooking, cleaning, childcare)	|__|	|__|__|	|__|__|	|__|__|
Non-competitive sport such as swimming, aerobics, tennis, skiing etc (specify) _____	|__|	|__|__|	|__|__|	|__|__|
Competitive sport or dance (specify) _____	|__|	|__|__|	|__|__|	|__|__|
Other (specify) _____	|__|	|__|__|	|__|__|	|__|__|

6. Tobacco

6.1 Have you ever regularly smoked cigarettes for at least a year? By regularly we mean: *at least 1 cigarette per day OR at least 5 cigarettes per week OR at least 1 pack per month*

|__| yes
|__| no *(go to question 7.1)*
|__| don't know *(go to question 7.1)*

6.2 At what age did you start to smoke regularly *(in years)*? ⟶ |__|__|

6.3 Do you still smoke regularly?

|__| yes
|__| no*:* at what age did you stop? ⟶ |__|__|
|__| don't know

6.4 On average, how many cigarettes do/did you smoke per day? ⟶ |__|__|

6.5 What was the maximum number you ever smoked per day if different from above? |__|__|

6.6 For how long did you smoke this many? ⟶ |__|__| months *or* |__|__|years

7. Alcohol

7.1 We are aware that consumption of alcohol may vary over time. Try to remember average amounts consumed.

	Beer or cider	Wine	Fortified spirits (vodka, brandy etc)
Has there ever been a time when you drank beer, cider, wine, or spirits at least once a week?	|__| yes; |__| no; |__| don't know)	|__| yes; |__| no; |__| don't know)	|__| yes; |__| no; |__| don't know)
If yes: at what age did you start to drink at least once a week?	|__|__|	|__|__|	|__|__|
Do you still drink at least once a week?	|__| yes; |__| no; |__| don't know)	|__| yes; |__| no; |__| don't know)	|__| yes; |__| no; |__| don't know)
If No: at what age did you stop drinking at least once a week?	|__|__|	|__|__|	|__|__|

7.2 On average, how much did you drink per week at the following ages

Age	Beer or cider	Wine	Fortified spirits (vodka, whisky, brandy etc)
	Glass (300 ml)	*Glass (100 ml)*	*Shot*
20 years old	|__|__|	|__|__|	|__|__|
30 years old	|__|__|	|__|__|	|__|__|
40 years old	|__|__|	|__|__|	|__|__|

8. Anthropometry

8.1 At the time you were diagnosed with a malignant disease during childhood or adolescence was your weight:

|__| same as other girls/women your age
|__| less than other girls/women your age
|__| more than other girls/women your age

8.2 What is your current height in cm (in bare feet)?: |__|__| feet |__|__| inches OR |__|__|__|cm

8.3 What is your current waist size in cm: |__|__| inches OR |__|__|__|cm
If unknown, what is your current dress size |__|__|

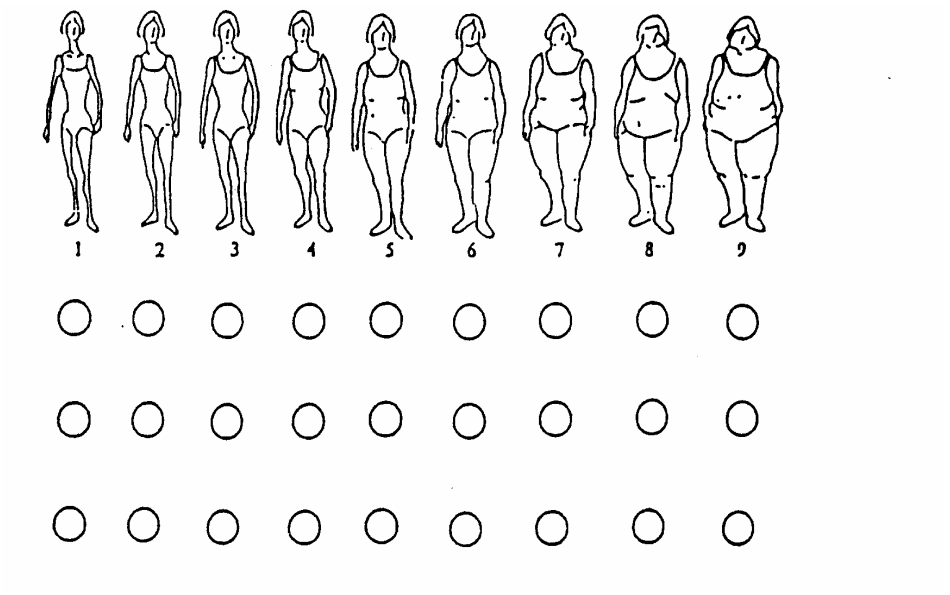
8.4 What is your current hip size in cm *(measure at widest part of hip)*: |__|__| inches OR |__|__|__|cm

8.5 How much did you weigh at age 20? |__|__| stones |__|__| pounds OR |__|__|__|kg

8.6 How much did you weigh at age 30? |__|__| stones |__|__| pounds OR |__|__|__|kg

8.7 How much did you weigh at age 40? |__|__| stones |__|__| pounds OR |__|__|__|kg

8.8 Body size in different periods of life (pictogram): please mark how you think you looked at different ages:



At around age 10

At around age 20

Now

9. Conclusion

This concludes the questionnaire. We would like to thank you very much for your time and effort in answering these questions. Is there any comment you would like to make or any information, which you think is relevant?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Time interview ended: hour |__|__| minutes |__|__|