

General instructions

Thanks for your support to CanScreen5 project. This form is to collect quantitative data on breast cancer screening in the country/regions you are reporting for. The quantitative data mainly focuses on the target population, screening test outcomes, further assessment outcomes, cancer staging and treatment. **Terms in bold and underlined among the text have a definition at the end of the corresponding page.** If you require assistance in filling any of the data forms, please contact us by email at canscreen5@iarc.fr

We would prefer to receive the programme annual screening data (inclusion of participants during a one year period, e.g. 01/01/2017 to 31/12/2017, which will be considered as index year 2017; alternatively, 01/04/2018 to 31/03/2019, which will be considered as index year 2018). Otherwise, you can submit the data for one round of screening that extends over a few years.

CanScreen5 will prefer to get the data stratified by 5-year age groups. However, this is not mandatory, and data without age stratification can also be submitted.

Please fill in the general information as below:

1.	General information	
1.1	Country: _____	
1.2	Reporting for: (1. national programme; 2. sub-national programme ; 3. a pilot programme only; 4. a demonstration project only; 5. a research project only; 6. other _____) (If you are reporting for the national programme, please go to Q1.3 directly)	[]
1.2a	If you are not reporting for a national programme, please name of the geographic area(s) : _____	
1.3	Source:(1. directly from programme (managed by Health Ministry/Health Authority); 2. official report (published by programme or Health Ministry/Health Authority); 3. peer-reviewed publication; 4. other reports (published by NGO/academic institutions); 5. other _____) (Please provide link (if available) or email the document to canscreen5@iarc.fr): _____	[]
1.4	The period of reporting? (From mm/yyyy to mm/yyyy): [] []/[] [] [] [] to [] []/[] [] [] []	
1.5	What's the primary screening test that is used in screening protocol you are reporting for? (1. mammography (Mx) or digital breast tomosynthesis (DBT); 2. (Mx or DBT) and (clinical breast examination (CBE) or ultrasound (US)) (co-testing); 3. CBE + US; 4. US; 5. CBE) Please provide the criteria to consider a case suspicious for cancer based on the primary test _____ (If you want to submit data for programmes that use different screening tests, please fill in different forms for each test)	[]
1.6	Are you reporting data stratified by age group? (1. yes, this form is for 5-year age groups; 2. yes, this form is for 10-year age groups; 3. no age stratified data)	[]

Sub-national programme: A screening programme implemented at sub-national level is sub-national programme. Sub-national level indicates any government entity below the national level, regardless of the political, financial and administrative design of the country (e.g. province, state, cantonal level, etc.).

Pilot programme: Pilot programme is a small-scale implementation of screening programme to assess feasibility, impact on health services, barriers and facilitators of participation, etc. The Ministry of Health/Health Authority is already committed to implement a screening programme and has a well-defined plan to scale up the programme based on the lessons learnt from the pilot. All the elements of screening programmes are fully functional in the area under consideration at the time of implementing the pilot.

Demonstration project: Demonstration project is defined as screening implemented by or in collaboration with the Ministry of Health/Health Authority on a small scale to address one or several implementation issues. There is no documented policy or a commitment to scale up.

Research Project: In a research project screening is conducted by an entity (usually an academic body) to address a specific research question. Sometimes it is difficult to differentiate between demonstration and research projects. A research project more focusing on implementation and with active involvement of the Ministry of Health/Health Authority should be considered as a demonstration project.

Screening protocol: The protocol is a detailed documented plan on how to deliver the screening activities. As a minimum, the screening protocol should include clear information on the eligible women, target age, screening test, examination intervals, further assessment, referral system, and quality assurance.

This section concerns the invitation and screening.

- **Column A: Screening interval (in months):** What's the screening interval as per the protocol?
 - **Column B: Target population:** How many age-eligible women (obtained from official statistics, irrespective of the screening interval) are there?
 - **Column C: Invitation:** How many women were invited during the reporting period? (**leave blank if there is no invitation**).
 - **Column D: Participation:** How many women were screened of those invited during the reporting period? (**leave blank if there is no invitation**).
- As a note, women who received the invitation during the reporting period (e.g. from 1 Jan 2018 to 31 Dec 2018) and received the screening testing during the first 6 months of next time period (e.g. by 30 Jun 2019) should be included in the total screening of invited for the reporting period.
- **Column E: Screened:** How many women were screened in total during the reporting period, **irrespective of invitation**? This is applicable if there is no system of invitation or if women have been screened without being invited (opportunistic screening). Please note that the numbers in this column may be the same as the numbers in column D, if women were screened after invitation only.
 - * For all the data outside the indicated age group or without age information, please fill in the "Other" row **and** add description in the "Any other information" box.

2. Invitation and screening					
Are women personally invited? [] <i>(1. yes; 2. no (keep the column C, D blank))</i>					
Age group (years)	A	B	C	D	E
	Interval	Population	Invitation (if applicable)	Participation (if applicable)	Screened
	Screening interval (in months)	Nº of women in the target age	Nº of women invited during the reporting period	Nº of women screened among invited	Nº of women screened
Stratified by 5 yrs					
40-44					
45-49					
50-54					
55-59					
60-64					
65-69					
70-74					
75-79					
*Other					
Stratified by 10 yrs					
40-49					
50-59					
60-69					
70-79					
*Other					
No age stratification					
All in target age					
Any other information related to invitation and screening: _____					

Screening interval: The interval between two screening episodes (rounds), within a screening programme or in an opportunistic setting.

Target population: Total number of women eligible for screening (usually by age, but the screening programme may have additional criteria) obtained from official statistics residing in the catchment area of a screening programme (national or subnational) as defined by the screening policy.

Invitation: An individual invitation (by letter, email, SMS, phone calls, home visits, or other methods) to the eligible women in the eligible target population to participate in the screening programme is sent by the coordination team, by primary health centres, or by general practitioners.

This section concerns the screening test results.

- **Columns F, G, H, I: Screening test results:** Out of those women screened, how many had:
 - A screen positive result (suspicion of cancer requiring further assessment) ?
 - A screen negative result or suspicious for benign lesion (includes BIRADS 2)?
 - An inconclusive/unsatisfactory screen test result (includes BIRADS 0) ?
 - The screen test result is unknown (missing information)?
- * For all the data outside the indicated age group or without age information, please fill in the “Other” row and add description in the “Any other information” box.

3. Screening test results				
Age group (years)	F	G	H	I
	Nº of women with screen positive result	Nº of women with screen negative result	Nº of women with inconclusive/unsatisfactory screen test result	Nº of women for whom screen result is unknown
Stratified by 5 yrs				
40-44				
45-49				
50-54				
55-59				
60-64				
65-69				
70-74				
75-79				
*Other				
Stratified by 10 yrs				
40-49				
50-59				
60-69				
70-79				
*Other				
No age stratification				
All in target age				
Any other information related to screening test results:				

This section concerns the **further assessment (diagnostic mammography/USG/others) status**.

- **Column J, K, L: Further assessment (diagnostic mammography/USG/others) information:** Out of the screen positive women:
 - How many had further assessment performed?
 - How many did you know that further assessment was not performed, including those who refused?
 - For how many you don't have information on further assessment status (missing information)?
- * For all the data outside the indicated age group or without age information, please fill in the "Other" row **and** add description in the "Any other information" box.

4. Further assessment (diagnostic mammography/USG/others)			
Age group (years)	J	K	L
	Nº of women with further assessment performed	Nº of women with further assessment not performed	Nº of women for whom further assessment status is unknown
Stratified by 5 yrs			
40-44			
45-49			
50-54			
55-59			
60-64			
65-69			
70-74			
75-79			
*Other			
Stratified by 10 yrs			
40-49			
50-59			
60-69			
70-79			
*Other			
No age stratification			
All in target age			
Any other information related to further assessment:			

Further assessment: Additional diagnostic techniques (either immediately after screening or postponed in a referral setting) performed to confirm the nature of a perceived abnormality detected at the screening examination. Example: diagnostic mammography for a woman with abnormal screening mammography.

This section concerns the final diagnosis.

- **Column M, N, O, P, Q: Outcomes of final diagnosis:** Out of those women with further assessment performed:
 - How many was detected to have no lesion/benign diagnosis?
 - How many was detected to have histopathology confirmed carcinoma *in situ* (CIS)?
 - How many was detected to have histopathology confirmed invasive cancer?
 - If you only have aggregated information for CIS and invasive cancer, please fill the **P** column **and** make a note in the “Any other information” box below.
 - For how many you don’t have information on final diagnosis outcome (missing information)?
- * For all the data outside the indicated age group or without age information, please fill in the “Other” row **and** add description in the “Any other information” box.

5. Final diagnosis					
	M	N	O	P	Q
Age group (years)	Nº of women with final diagnosis <u>no lesion/benign</u>	Nº of women with histopathology confirmed <u>CIS</u>	Nº of women with histopathology confirmed <u>invasive cancer</u>	Nº of women with histopathology confirmed cancer “NOS” (<u>Not Otherwise Specified as CIS or invasive</u>)	Nº of women with final diagnosis <u>unknown</u>
Stratified by 5 yrs					
40-44					
45-49					
50-54					
55-59					
60-64					
65-69					
70-74					
75-79					
*Other					
Stratified by 10 yrs					
40-49					
50-59					
60-69					
70-79					
*Other					
No age stratification					
All in target age					
Any other information related to final diagnosis:					

This section concerns the cancer staging information.

- **Column R, S, T, U, V, W: Cancer staging outcomes:** Provide the distribution of staging as follows, which should be based on the TNM/AJCC system:
 - Stage 0
 - Stage I
 - Stage II
 - Stage III
 - Stage IV
 - Staging not done/unknown
- * For all the data outside the indicated age group or without age information, please fill in the “Other” row **and** add description in the “Any other information” box.

6. Cancer staging						
Age group (years)	R	S	T	U	V	W
	Stage 0	Stage I	Stage II	Stage III	Stage IV	Staging not done/unknown
Stratified by 5 yrs						
40-44						
45-49						
50-54						
55-59						
60-64						
65-69						
70-74						
75-79						
*Other						
Stratified by 10 yrs						
40-49						
50-59						
60-69						
70-79						
*Other						
No age stratification						
All in target age						
Any other information related to cancer staging:						

This section concerns the treatment information.

- **Column X, Y, Z: Treatment status:** Out of the women with diagnosis of CIS/invasive cancer,
 - How many initiated treatment?
 - How many did not initiated treatment?
 - For how many you don't have information on treatment status (missing information)?
- * For all the data outside the indicated age group or without age information, please fill in the "Other" row and add description in the "Any other information" box.

7. Treatment			
	X	Y	Z
Age group (years)	Nº of women initiated treatment	Nº of women not initiated treatment	Nº of women for whom treatment status unknown
Stratified by 5 yrs			
40-44			
45-49			
50-54			
55-59			
60-64			
65-69			
70-74			
75-79			
*Other			
Stratified by 10 yrs			
40-49			
50-59			
60-69			
70-79			
*Other			
No age stratification			
All in target age			
Any other information related to treatment:			