General instructions

Thanks for your support and collaboration to CanScreen5 project. The present document will guide you to collect and submit 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, treatment, etc. It will be convenient to collect data using this quantitative data collection form before submitting the same to the online platform of CanScreen5. **Terms in bold and underlined 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 for primary screening test, e.g. 01/01/2017 to 31/12/2017 with index year 2017 or 15/04/2018 to 14/04/2019 with index year 2018), which might be not the current or the last year, as it takes time to get further assessment information and to be completed and validated(meaning data checked for missing values, discrepancy, etc.). Otherwise, you can submit the data for the most recent round of screening.

Please fill in the general information as below:

1.	**General information**	
1.1	Country: _____	
1.2	Reporting for: *(1. national; 2. **sub-national**)*	[ ]
1.3	Name of the geographic area(s) if not reporting for entire country: _____	
1.4	If you are reporting not for entire country, are you reporting for a **pilot programme**, **demonstration project** or a research study? *(1. pilot programme; 2. demonstration project; 3. research study; 4. other_____)*	[ ]
1.5	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): _____*	[ ]
1.6	The period of reporting? (From mm/yyyy to mm/yyyy): [ ][ ]/[ ][ ][ ][ ] to [ ][ ]/[ ][ ][ ][ ]	
1.7	The **screening protocol** you are reporting for: *(If you want to submit data for programmes that use different screening protocols, please fill in different forms reporting for each protocol).* Primary screening tests: *(1. mammography (Mx) or digital breast tomosynthesis (DBT); 2. (Mx or DBT) + (clinical breast examination (CBE) or ultrasound (US)); 3. CBE + US; 4. US; 5. CBE)*	[ ]
1.8	Data by age group: *(1. 5 years age group; 2. 10 years age group; 3. no age stratification)*	[ ]

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Sub-national: 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: 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 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 at the time of implementing the pilot.

Demonstration project: The project is implemented to test a hypothesis (e.g. mammography-based screening is feasible and cost-effective in a specific setting) and there is no commitment to scale up the screening services.

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 individuals, target age, screening test, examination intervals, further assessment, referral system, and quality assurance. It should be integrated into the screening policy.

From here on, you will provide specific data about breast cancer screening and should fill out just one section of the table best representing the age-grouping data from the programme you are reporting. If the data is not stratified by age group, please fill out the last row only. CanScreen5 will prefer to get the data stratified by 5 yearly age groups. However, this is not mandatory. If you have no data for some specific age group, please leave it blank.

Are women personally invited? [ ]

1. yes (complete the column C, D); *2. no (keep the column C, D blank);*

Age group (years)	A	B	C	D	E
	Interval	Population	Invitation (if applicable)	Participation (if applicable)	Examination
	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					

- **Column A: Screening interval (in months):** What's the screening interval as per the protocol?
- **Column B: Target population**: What's the total target population of the programme?
- **Column C: Invitation**: How many women were invited during the reporting period? Only the primary screening invitations were considered (**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**).
- **Column E: Examination**: How many women were screened during the reporting period, **irrespective of invitation**? 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.

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

Target population: Total number of age-eligible individuals obtained from official statistics (irrespective of the screening interval) residing in the catchment area of a screening programme as defined by the screening policy).

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

For how many individuals can you provide test outcomes? [ ]

1. for all individuals screened during the index year (keep the column F blank);
2. for a subset of individuals screened (complete the column F);

Age group (years)	F	G	H	I
	Screening test outcomes			
	If a subset, Nº of women screened with test outcomes known	Nº of women with positive test outcomes	Nº of women with negative test outcomes	Nº of women with inconclusive test outcomes
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				

- **Column F: Number of women screened for whom the test outcomes are known:** Out of the women screened, for how many do you have test results available (including the inconclusive results)?
  The numbers in Column F may be: i) the same as the numbers in Column E, if this is the case, please leave it blank, ii) a subset of the numbers in Column E, for which the test results are available.
- **Columns G, H, I: Number of women with different test outcomes:** Out of those women screened and with results available, how many had:
  - A positive testing result? (BIRADS 3,4,5 for mammography and ultrasound)
  - A negative testing result? (BIRADS 1,2 for mammography and ultrasound)
  - A inconclusive/unsatisfactory testing result? (includes BIRADS 0)

For how many individuals with positive results can you provide further assessment performance? [ ]

1. for all individuals screened positive during the index year (keep the column J blank);
2. for a subset of individuals screened (complete the column J);
3. none (stop filling the form)

Age group (years)	J	K	L
	Further assessment		
	If a subset, Nº of women with positive test outcomes with further assessment outcomes	Nº of women with further assessment performed	Nº of women without further assessment performed
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			

- **Column J: Number of women with positive test outcomes for whom the <u>further assessment</u> outcomes are known**: Out of the women with a positive screening test as mentioned above, for how many do you have information of further assessment, including further assessment performed and not performed women? *The numbers in Column J may be: i) the same as the numbers in Column G, if this is the case, please leave it blank, ii) a subset of the numbers in Column G, for which the test results are available.*
- **Column K, L: Further assessment information:** Out of the screen positive women with information of further assessment available,
  - How many had a further assessment performed?
  - How many did not have any further assessment performed?

<u>Further assessment</u>: 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. Further assessment may take place on the same day as the screening examination or on recall. Examples: repeat smears, HPV testing, colposcopy, histology, ultrasonography, and colonoscopy.

For how many individuals can you provide histopathology outcomes? [ ]

1. for all women with further assessment performed with distinct CIS and Invasive cancer data (use column N and O);
2. for all women with further assessment performed with indistinct CIS and Invasive cancer data (use column O only);
3. for a subset of women with further assessment performed with distinct CIS and Invasive cancer data (use column M, N and O);
4. for a subset of women with further assessment performed with indistinct CIS and Invasive cancer data (use column M and O);
5. none (stop filling the form)

Age group (years)	M	N	O
	Outcomes of histopathology		
	If a subset, Nº of women with histopathology outcomes known	Nº of women with carcinoma in situ (CIS)	Nº of women with invasive breast cancer
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			

- **Column M: Number of women with known histopathology outcomes**: Out of the women with further assessment as mentioned above, for how many do you have information on histopathology?
  The numbers in Column M may be: i) the same as the numbers in Column K, if this is the case, please leave it blank, ii) a subset of the numbers in Column K, for which the test results are available.
- **Column N, O: Outcomes of histopathology information**: Out of those women further assessed and for whom you have **histopathology** results available, how many were
  - Detected to have CIS?
  - Detected to have invasive breast cancers?

For how many individuals can you provide stage outcomes? [ ]

1. for all individuals with CIS and/or invasive cancer (keep the column P blank);
2. for a subset of individuals with CIS and/or invasive cancer (complete the column P);
3. none (stop filling the form)

Age group (years)	P	Q	R	S	T	U	V
	Stage						
	If a subset, № of women with stage information known	Stage 0	Stage I	Stage II	Stage III	Stage IV	Stage not done
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							

- **Column P: Stage information**: Out of the women with CIS/invasive cancer, for how many do you have information on stage, which should be based on the TNM system?
- **Column Q-V: Different Stage**: Out of the women with stage information the distribution of stage was as follows:
  - Stage 0
  - Stage I
  - Stage II
  - Stage III
  - Stage IV
  - Stage not done

For how many individuals can you provide information on whether they have initiated cancer directed treatment or not? [ ]

1. for all individuals with CIS and/or invasive cancer (keep the column W blank);
2. for a subset of individuals with CIS and/or invasive cancer (complete the column W);
3. none (stop filling the form)

Age group (years)	W	X	Y
	Treatment		
	If a subset, Nº of women initiated treatment or not	Nº of women initiated treatment	Nº of women not initiated treatment
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			

- **Column W: Treatment information**: Out of the women with CIS/invasive cancer, for how many do you have information that the women initiated cancer directed treatment or not?
- **Column X, Y: Treatment status**: Out of those women with information on initiated cancer treatment or not, how many were
  - initiated treatment?
  - not initiated treatment?