World Health Organization

# **General instructions**

Thanks for your support to CanScreen5 project. This form is to collect quantitative data on colorectal 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 <u>canscreen5@iarc.fr</u>

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 sex and by 5-year age groups. However, this is not mandatory, and data without sex and/or 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. <u>sub-national programme</u> ; 3. a <u>pilot programme</u> only; 4. a <u>demonstration project</u> only; 5. a <u>research project</u> 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 <u>screening protocol</u> you are reporting for? (1. FIT; 2. gFOBT; 3. stool DNA; 4. flexible sigmoidoscopy; 5. colonoscopy; 6. virtual colonoscopy ) If applicable, please provide the cut-off value for considering the FIT test positive (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)	[]
1.7	Are you reporting data stratified by sex? (1.yes, this form is for females; 2.yes, this form is for males; 3. no sex stratified data) (If you have data stratified by sex, please use separate forms for females and males)	[]

<u>Sub-national programme</u>: 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.

**<u>Research Project</u>**: 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.

**<u>Screening protocol</u>**: 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.

World Health Organization

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 individuals (obtained from official statistics, • irrespective of the screening interval) are there?
- Column C: Invitation: How many individuals were invited during the reporting period? (leave blank if there is no invitation).
- Column D: Participation: How many individuals were screened of those invited during the reporting period? (leave blank if there is no invitation).

As a note, individuals 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 individuals were screened in total during the reporting period, irrespective of invitation? This is applicable if there is no system of invitation or if individuals 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 individuals 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 individuals personally invited? [ 1 (1. yes; 2. no (keep the column C, D blank)) В С D Е А Invitation Participation Population Screened Interval Age group (if applicable) (if applicable) (years) Nº of individuals Nº of individuals Nº of individuals Nº of Screening interval in the invited during the screened among individuals (in months) target age reporting period invited 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 individuals 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 individuals 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 individuals screened, how many had:
  - > A screen positive result?
  - A screen negative result?
  - An inconclusive/unsatisfactory screen test result?
  - > 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 re	sults			
	F	G	Н	Ι
Age group (years)	№ of individuals with screen <u>positive</u> result	№ of individuals with screen <u>negative</u> result	№ of individuals with <u>inconclusive/unsat</u> isfactory screen	№ of individuals for whom screen result is <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 informat	ion related to screenin	g test results:		

World Health Organization

This section concerns the <u>further assessment</u> (colonoscopy) status.

- Column J, K, L: Further assessment (colonoscopy) information: Out of the screen positive individuals:
  - 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.

Age group Nº of individuals with Nº of individuals with Nº of individuals for who	4. Further assessme	· · · · ·	К	
by 5 yrsImage: style st		further assessment	Nº of individuals with further assessment	Nº of individuals for whom further assessment status
40-44Image: selection of the sel	Stratified			
45-49Image: selection of the sel	by 5 yrs			
50-54Image: selection of the sel	40-44			
55-59Image: state of the state o	45-49			
60-64    65-69    70-74    75-79    *Other    Stratified    by 10 yrs    40-49    50-59    60-69    70-79    *Other    No age	50-54			
65-69    70-74    75-79    *Other    Stratified    by 10 yrs    40-49    50-59    60-69    70-79    *Other    No age	55-59			
70-74Image: statistic	60-64			
75-79Image: stratified by 10 yrsImage: stratified by 10 yrsImage: stratified by 10 yrsImage: stratified by 10 yrs40-49Image: stratified bigImage: stratified bigImage: stratified big50-59Image: stratified bigImage: stratified bigImage: stratified big60-69Image: stratified bigImage: stratified bigImage: stratified big70-79Image: stratified bigImage: stratified bigImage: stratified bigNo ageImage: stratified bigImage: stratified bigImage: stratified big	65-69			
*OtherStratified by 10 yrs40-4950-5960-6970-79*OtherNo age	70-74			
Stratified by 10 yrsStratified componentStratified component40-49ImageImage50-59ImageImage60-69ImageImage*OtherImageImageNo ageImageImage	75-79			
by 10 yrs   Image: Marcine State     40-49   Image: State   Image: State     50-59   Image: State   Image: State   Image: State     60-69   Image: State   Im	*Other			
50-59    60-69    70-79    *Other    No age				
60-69    70-79    *Other    No age	40-49			
70-79      *Other      No age	50-59			
*Other No age	60-69			
No age	70-79			
	*Other			
All in target age	All in target age			

**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: colonoscopy for a FIT or gFOBT positive individual.

# This section concerns the final diagnosis.

- Column M, N, O, P, Q, R: Outcomes of final diagnosis: Out of those individuals with further assessment performed:
  - How many was detected to have no lesion/benign diagnosis?
  - How many was detected to have histopathology confirmed adenoma?
  - How many was detected to have histopathology confirmed advanced adenoma?
  - If you only have aggregated information for histopathology confirmed adenoma, please fill the P column and make a note in the "Any other information" box below.
  - How many was detected to have histopathology confirmed invasive cancer?
  - 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.

	М	Ν	0	Р	Q	R
Age group (years)	Nº of individuals with final diagnosis <u>no</u> lesion/benign	Nº of individuals with histopathology confirmed <u>adenoma</u>	Nº of individuals with histopathology confirmed <u>advanced</u> adenoma	№ of individuals with histopathology confirmed adenoma "NOS" ( <u>Not Otherwise</u> )	Nº of individuals with histopatholog y confirmed <u>invasive</u> <u>cancer</u>	Nº of individuals 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						

### This section concerns the cancer staging information.

- Column 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 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.

	S	Т	U	V	W
Age group (years)	Stage I	Stage II	Stage III	Stage IV	Staging <u>not</u> <u>done/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					

#### This section concerns the treatment information.

- Column X, Y, Z: Treatment status: Out of the individuals with diagnosis of advanced adenoma /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.

	Х	Y	Z
Age group (years)	№ of individuals <u>initiated</u> treatment	№ of individuals <u>not</u> <u>initiated</u> treatment	№ of individuals for whom treatment status <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			
	tion related to treatment:		1