

General instructions

Thanks for your support and collaboration to CanScreen5 project. The present document will guide you to collect and submit 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, 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. <i>national</i> ; 2. <i>sub-national</i>) | [] |
| 1.3 | Name of the geographic area(s) if <u>not</u> reporting for entire country: _____ | |
| 1.4 | If you are reporting <u>not</u> for entire country, are you reporting for a pilot programme, demonstration project or a research study? (1. <i>pilot programme</i> ; 2. <i>demonstration project</i> ; 3. <i>research study</i> ; 4. <i>other</i> _____) | [] |
| 1.5 | Source: (1. <i>directly from programme (managed by Health Ministry/Health Authority)</i> ; 2. <i>official report (published by programme or Health Ministry/Health Authority)</i> ; 3. <i>peer-reviewed publication</i> ; 4. <i>other reports (published by NGO/academic institutions)</i> ; 5. <i>other</i> _____) (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. <i>FIT</i> ; 2. <i>gFOBT</i> ; 3. <i>stool DNA</i> ; 4. <i>flexible sigmoidoscopy</i> ; 5. <i>colonoscopy</i> ; 6. <i>virtual colonoscopy</i>) | [] |
| 1.8 | Data by age group: (1. <i>5 years age group</i> ; 2. <i>10 years age group</i> ; 3. <i>no age stratification</i>) | [] |
| 1.9 | Data by gender group (please fill in different forms for different gender): (1. <i>women</i> ; 2. <i>men</i> ; 3. <i>all</i>) | [] |

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 colorectal 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 individuals 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 individuals in the target age | Nº of individuals invited during the reporting period | Nº of individuals screened among invited | Nº of individuals 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 individuals 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 individuals were screened of those invited during the reporting period? (**leave blank if there is no invitation**).
- **Column E: Examination:** How many individuals 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 individuals 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, N° of individuals screened with test outcomes known | N° of individuals with positive test outcomes | N° of individuals with negative test outcomes | N° of individuals 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 individuals screened for whom the test outcomes are known:** Out of the individuals 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 individuals with different test outcomes:** Out of those individuals screened and with results available, how many had:
 - A positive testing result?
 - A negative testing result?
 - A inconclusive/unsatisfactory testing result?

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, N ^o of individuals with positive test outcomes with further assessment outcomes | N ^o of individuals with further assessment | N ^o of individuals 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 | | | |
| 55-59 | | | |
| 70-79 | | | |
| Other | | | |
| No age stratification | | | |
| All in target age | | | |

- Column J: Number of individuals with positive test outcomes for whom the further assessment outcomes are known:** Out of the individuals 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 individuals?
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 individuals with information of further assessment available,
 - How many had a further assessment performed?
 - How many did not have any further assessment performed?

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. 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 individuals with further assessment performed with distinct CIS and Invasive cancer data (use column N and O);
2. for all individuals with further assessment performed with indistinct CIS and Invasive cancer data (use column O only);
3. for a subset of individuals with further assessment performed with distinct CIS and Invasive cancer data (use column M, N and O);
4. for a subset of individuals 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, N ^o of individuals with histopathology outcomes known | N ^o of individuals with carcinoma in situ (CIS) | N ^o of individuals with invasive colorectal 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 individuals with known histopathology outcomes:** Out of the individuals 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 individuals further assessed and for whom you have **histopathology** results available, how many were
 - Detected to have CIS?
 - Detected to have invasive colorectal 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, N° of individuals 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 | | | | | | | |
| 55-59 | | | | | | | |
| 70-79 | | | | | | | |
| Other | | | | | | | |
| No age stratification | | | | | | | |
| All in target age | | | | | | | |

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