

General instructions

Thanks for your support and collaboration to CanScreen5 project. To explain each query in a clear, precise and unambiguous manner, a guide was designed (pages 3-9). After reading the guide, if you still require assistance in filling any of the form, please contact us by email at canscreen5@iarc.fr

1.	General information	
1.1	Country: _____	
1.2	Reporting for: (1. national; 2. sub-national)	[] []
1.3	Name of the geographic area(s) if <u>not</u> reporting for entire country: _____	
1.4	Index year (use <u>current year</u> unless you are reporting from a published report):	[] [] [] [] [] []
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 applicable) or email the document to canscreen5@iarc.fr): _____	[]
2.	Organization of screening	
2.1	Is there an individual/team/institution responsible for management/coordination of the cancer screening activities? (1. yes; 2. no; 3. unknown)	[]
2.1.1	If yes, please provide name of team/institution or the designation of the individual: _____	
2.2	Does the Health Ministry/Health Authority allocate a budget to cancer screening? (1. yes; 2. no; 3. unknown)	[]
2.3	Is there a policy document from the Health Ministry/Health Authority that recommends cancer screening? (1. yes; 2. no; 3. unknown)	[]
2.3.1	If yes, how is the policy documented? (1. law; 2. notification (from Health Ministry/Health Authority); 3. recommendation (from public institution/professional organization/association and endorsed by the Health Ministry/Health Authority)) (Please provide link (if available) or email the document to canscreen5@iarc.fr): _____	[]
2.4	Year screening programme was initiated: (9999. if no programme; 0000. if unknown)	[] [] [] [] [] []
2.5	Was a pilot implemented before introduction of the screening programme or is a pilot ongoing? (1. yes; 2. no; 3. unknown)	[]
2.5.1	If yes, has the pilot programme been evaluated? (1. pilot ongoing; 2. evaluated and report published; 3. evaluated but no report published; 4. not evaluated; 5. unknown)	[]
2.6	Are the screening tests available free of charge to the eligible population? (1. yes; 2. no; 3. unknown)	[]
2.6.1	If the screening tests are not free, is the cost reimbursed from any source? (1. yes, fully reimbursed; 2. yes, partially; 3. no; 4. unknown)	[]
2.7	Are the diagnostic tests available free of charge to the screen-positive individuals? (1. yes; 2. no or partially; 3. unknown)	[]
2.8	Are treatment services available free of charge to individuals with a diagnosis of precancer/cancer? (1. yes; 2. no or partially; 3. unknown)	[]
2.9	Any other information related to screening organization: _____	
3.	Information system and data collection	
3.1	Is there a computerized information system that collects screening-related data on individual basis? (1. yes; 2. no; 3. unknown)	[]
3.1.1	If yes, for which purpose? (1. identify and invite eligible population; 2. collect screening participation; 3. collect screening test results; 4. collect info on diagnosis; 5. collect info on stage; 6. collect info on treatment)	[] [] [] [] [] [] [] [] (multiple responses)
3.1.2	If yes, at which level does this computerized information system exist? (1. national; 2. sub-national; 3. both national and sub-national; 4. unknown)	[]
3.2	Is there a system (computerized or paper-based) that gathers aggregated data on screening activities? (1. yes; 2. no; 3. unknown)	[]
3.2.1	If yes, for which purpose? (1. report number screened; 2. report number of screen positive; 3. report number further assessed; 4. report number treated)	[] [] [] [] [] [] (multiple responses)
3.2.2	If yes, at which level does this computerized or paper-based information system exist? (1. national; 2. sub-national; 3. both national and sub-national; 4. unknown)	[]
3.3	Is there a system to collect information on screening outside the programme (opportunistic screening/private sector)? (1. yes; 2. no; 3. cannot differentiate; 4. unknown)	[]
3.4	Are screening data linked with population-based cancer registries (PBCR)? (1. yes; 2. PBCR exists but is not linked; 3. no PBCR; 4. unknown)	[]
3.5	Any other information related to information system (e.g. quality control of data collection, etc.): _____	

General instructions

Thanks for your support and collaboration to CanScreen5 project. The guide is designed to facilitate collection and submission of information/data for CanScreen5 project using the standardized data collection tools. The guide aims to explain each query in a clear, precise and unambiguous manner so that they are interpreted in the same way by everyone collecting and providing data as well as by those studying and interpreting the results. After reading this document, if you still require assistance in filling any of the data forms, please contact us by email at canscreen5@iarc.fr

Terms in bold and underlined have a definition in Appendix I (pages 7-9).

1. General information

For this part, you will provide general information for cervical cancer screening you are reporting for, including country, index year, data source, etc.

1.1 Please indicate the country, which the following report refers to.

1.2 If you report for the national level, you will report for the entire country. If you report for the **sub-national** level, you need to indicate the specific geographic area under consideration (1.3).

1.3 Please indicate all the specific geographic areas if you are reporting at sub-national level.

1.4 If you are reporting current data directly from programme managed by Health Ministry/Health Authority, please indicate the current year. If you are extracting data from a report published earlier, please indicate the corresponding year of data collection from most recent published reports/peer-reviewed publications. All of the items below should correspond to this index year.

1.5 Please select “directly from programme”, if you are involved in implementing, supervising or reviewing the screening activities on behalf of or in collaboration with the Ministry of Health or other Health Authorities. For other options, if the information is available in any published report/guideline document, including the official report published by programme or Health Ministry/Health Authority, peer-reviewed publication, and other reports published by NGO/academic institutions, please provide the link (if available) or email the electronic document to canscreen5@iarc.fr

Please note that all documents provided on a voluntary basis would also be most encouraged. The core objective of the requested document, link for download or electronic document, is for the quality assurance of the CanScreen5 project. Please rest assured all documents will not be shared or available for public use.

2. Organization of screening

For this section, you will provide the overview of cancer screening organization (including who is responsible for implementation, public funding, an explicit policy, etc.).

2.1 In the country/region you are reporting for, is there specific individual/team/institution/ responsible for management/coordination of cancer screening activities? If no, please go to Question 2.2 directly.

2.1.1 If yes, please indicate the specific team/institution responsible for the cancer screening activities. For individual, please indicate his/her job position.

2.2 Is specific funding from Health Ministry/Health Authority allocated to the cancer screening activities? The response will be ‘yes’ even if the budget for screening is part of the overall budget for cancer control or NCD control programme.

2.3 Is there a **screening policy** document recommending cervical cancer screening? Such a document is issued by the Health Ministry/Health Authority specifying their commitment to provide cancer screening to the target population. If no, please go to Question 2.4 directly.

2.3.1 If yes, please indicate if the policy document is in the form of a legislation or an official notification from the Ministry/Authority. The notification/decreed from the Health Ministry/Health Authority should be published in the government official publication (official journal, official gazette, official newspaper, official bulletin, etc.). Sometimes the recommendations (e.g. screening guidelines) could be developed by a public institution (including National

Cancer Institute)/professional organization/association and endorsed by the Health Ministry/Health Authority. Please provide the link (if available) or email the electronic document to canscreen5@iarc.fr

2.4 Please indicate the specific year when the [screening programme](#) was initiated. If no cancer screening programme, please indicate 9999. Please indicate 0000 if the initiation year is unknown.

2.5 Before the cancer screening implementation across the country/region, was a [pilot programme](#) implemented previously or is the pilot ongoing recently? If no, please go to Question 2.6 directly.

2.5.1 If yes, please indicate the status of the evaluation of the pilot programme. Ideally, a pilot programme should be evaluated and the report should be published before scaling up the programme. Respond “pilot ongoing”, if the pilot is ongoing recently. Respond “evaluated and report published”, if the pilot programme has been evaluated and the report has been published.

2.6 For the eligible population for cancer screening, is the screening test administered [free of charge](#), meaning no immediate payment by the individual for availing the screening services? If yes, please go to Question 2.7 directly.

2.6.1 If no, is the cost reimbursed from government/local government, health insurance company or any other sources, fully or partially?

2.7 For screen-positive individuals needing [further assessment](#), are the diagnosis tests available [free of charge](#), meaning no immediate payment by the individual for availing the diagnostic services?

2.8 For individuals with diagnosis of cervical precancer/cancer, are the treatment services available [free of charge](#), meaning no immediate payment by the individual for availing the treatment services?

2.9 If there is other information related to screening organization, please indicate here.

3. Information system and data collection

In this section, please provide information on cancer screening information system and data collection.

3.1 Is there a computerized information system to collect data related to some or all services related to screening (invitation, screening test administration, diagnosis and treatment of screen positives) on individual basis, the [individual basis data collection](#)? The most organized form of such information system is a [screening registry](#) that collects data on each individual participating in screening.

If no, please go to Question 3.2 directly.

3.1.1 If yes, please indicate for which purpose the information system exists. You may enter multiple responses.

3.1.2 If “yes” for question 3.1, please indicate whether the information system is a unified one covering the screening programmes of the entire country (national) or covers only the sub-national programme (sub-national)? If there are separate information systems at national level and also at sub-national levels please select “both national and sub-national”.

3.2 Is there a computerized or paper-based system that collects [aggregated data](#) (grouped collection instead of individual data collection enabling an overall view of the programme)? The paper-based system works through maintaining registers of the screened individuals at different levels of facilities. If no, please go to Question 3.3 directly.

3.2.1 If yes, please indicate for which purpose the information system exists. You may enter multiple responses.

3.2.2 If “yes” for question 3.2, please indicate whether the information system is a unified one covering the screening programmes of the entire country (national) or covers only the sub-national programme (sub-national)? If there are separate information systems at national level and also at sub-national levels please select “both national and sub-national”.

3.3 Is there a system collecting screening information outside the screening programme (e.g. [opportunistic screening](#) activities, etc.)? If the information can't be differentiated from opportunistic screening or from population-based screening, please select “cannot differentiate”.

3.4 If [population-based cancer registries \(PBCRs\)](#) exist, are the screening [data linked with PBCR](#) via a matching criterion (e.g. national identity number or nominal data)?

3.5 If there is other information related to information system and data collection, please indicate here (e.g. quality control of data collection, the progress of the linkage between PBCR and screening registry, etc.).

4. Screening protocol

In this section, please provide some information on [screening protocol](#) (including screening test, screening interval etc.).

4.1 Please indicate if there is a screening protocol or not. If you have a documented screening protocol, please provide the link (if available) or email the electronic document to canscreen5@iarc.fr. If no screening protocol, please leave the section blank, go to Question 5.1 directly.

4.2 Please indicate the specific year when the current protocol was developed or last updated (indicate the most recent year). If no documented protocol, please indicate 9999. If unknown, please indicate 0000.

4.3 Please provide information on the screening protocol in the field of 4.3.1-4.3.4. Cervical cancer screening may have different protocols using different primary screening tests (or their combinations) targeting different age groups. If there is a single protocol enter it in the field 4.3.1. If there are multiple protocols targeting the same or different age groups, please provide this information in fields 4.3.1-4.3.4 as appropriate. If there is no upper age limit, the upper age should be marked as 99. Please indicate the [screening interval](#) (in months) between routine rounds of screening as specified in the screening programme policy (12 = 1 year, 24 = 2 years, etc.) accordingly.

4.4 After primary screening, is triaging test(secondary test) used for the positive primary women? If you have different triage test for different primary screening, please indicate in “other” to add the notes.

4.5 If HPV test is used as per the screening protocol, is self-collection of samples by women themselves recommended?

4.6 Is ‘[screen and treat](#)’ (individuals with a positive screening test receive immediate treatment) included in the screening protocol?

4.7 If there is other information related to screening protocol uncovered by the section 4, please indicate here (e.g. a different screening protocol not based on age, but for selected population –familial history, high risk population etc.).

5. Invitations for screening and further assessment

In this section, you will provide information on screening invitation and further assessment.

5.1 To improve population awareness, are there any education initiatives conducted by Healthy Ministry/Health Authority, including [mass media campaign](#), [small media campaign](#), [group education](#), [one-on-one education](#)?

If no, please go to Question 5.2 directly.

5.1.1 If yes, please indicate the specific education initiative(s). You may enter multiple responses.

5.2 For [individual invitation](#), is there a system to invite (by letter, email, SMS, phone calls, home visits, or other methods) all the eligible individuals to screening? If no, please go to Question 5.3 directly.

5.2.1 If yes, please indicate how the eligible individuals are identified, from a population register, the electoral roll, the list of General Practitioner (GP) or Primary Health Center (PHC), a list of an insurance company or others. You may enter multiple responses.

5.2.2 If “yes” for question 5.2, please indicate how the eligible women are invited to screening. You may enter multiple responses.

5.2.3 If “yes” for question 5.2, is the [screening kit included](#) in the invitation?

5.3 Some programmes may invite only women not screened in the round to improve compliance or only a selected population (high-risk or vulnerable) rather than all eligible individuals. If the programme invites only the selected women, please provide the criteria for it.

5.4 Is there the [active contact of screen-positive cases](#) to ensure compliance with further assessment? If all screen positive women are actively contacted as a routine, please select “yes, systematically”. If no such system exists or if women may be contacted occasionally, please select “no or sporadically”.

5.5 Is there the [active contact of cancer cases](#) to ensure compliance with further management? If all such women are actively contacted as a routine, please select “yes, systematically”. If no such system exists or if women may be contacted occasionally, please select “no or sporadically”.

5.6 Does the programme also collect information on stage of the cancers detected through the programme? If the programme collect information on stage for all women diagnosed with cancer within the programme, please select “yes, systematically”. If no information on stage is collected (or just for part of those women), please select “no or sporadically”.

5.7 Does the programme also collect information on treatment (surgery, radiotherapy, chemotherapy, etc) of the precancers/cancers detected through the programme? If the programme collect information on treatment for all women diagnosed with cancer within the programme, please select “yes, systematically”. If no information on treatment is collected (or just for part of those women), please select “no or sporadically”.

5.8 Please indicate any other information related to invitation and further assessment(e.g. women were provided the written information on benefits and harms of screening at the time of invitation; invitation include a fixed appointment date; invitation system excludes cases already diagnosed with cancer; etc.).

6 Quality Assurance (QA) of screening activities

In this section, you would provide information about [Quality Assurance](#) of screening activities.

6.1 Is there a document (may be a standalone document or part of protocol or action plan for the programme) indicating the specific actions to be undertaken by the programme managers and the service providers to assure quality of the screening programme?

If yes, please provide the link (if available) or email the document to canscreen5@iarc.fr

6.2 Is there a person/team/institution responsible for quality assurance of the screening service delivery?

If no, please go to Question 6.3 directly.

6.2.1 If yes, please indicate the name of the specific team/institution responsible for the cancer screening activities. For individual, please provide his/her job position.

6.3 Please indicate if there is a system of [accreditation](#) for HPV tests.

6.4 Please indicate if there is a system of [accreditation](#) for pathology services.

6.5 Is there a list of [performance indicators](#) (e.g. screening coverage, participation rate, further assessment rate, detection rate, positive predictive value, etc.) specified by the programme to assess the performance of screening activities and are these indicators used to systematically evaluate the performance?

If no, please go to Question 6.6 directly.

6.5.1 If yes, are the [reference standards](#) defined for some of the indicators? (e.g. examination coverage to be achieved).

6.6 Was the performance report of the screening programme published in last five years?

If yes, please provide the link (if available) or email document to canscreen5@iarc.fr

6.7 If there is other information related to quality assurance not covered by this section, please indicate here (e.g. the key performance indicators and their standards).

Appendix I

Definitions

Sub-national

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.).

Screening policy

A policy for a specific screening programme that specifies the government's commitment to provide screening services and defines the targeted age group and sex group, the geographical area, and other eligibility criteria; the screening test and interval; and requirements for payment or co-payment, if applicable. As a minimum, the screening protocol and repeat interval and determinants of eligibility for screening are stated.

Pilot programme

Pilot programme indicates 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.

A pilot programme should be differentiated from a *demonstration project*. A demonstration 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 programme

Defined as cancer screening performed in the framework of a publicly mandated programme. To be considered a 'programme' there has to be a commitment from the government to provide the screening services free of charges to the eligible population as defined by laws, statutes, regulations, or official notifications. In such cases, the eligible population, the screening test, and the screening interval, at a minimum should be defined and there should be some mechanism for monitoring and supervision.

Screening test, diagnosis, treatment free of charge

Public funding (with or without co-payment by insurance) to ensure no immediate payment by the individual for availing the screening, diagnosis, treatment services.

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.

Individual basis data collection

An information system that enables the follow-up of the care path and history of each individual enrolled in the programme (data from screening, diagnosis, and treatment).

Screening registry

The Cancer Screening Registry is any type of information system (computerized or paper-based) for the collection, storage, analysis and reporting of cancer screening programme data.

The registry supports the screening programmes by:

- Maintaining a database of screening records of individuals;
- Holding a single, consistent, national screening history for each participant;
- Inviting eligible persons to commence screening;
- Reminding participants when they are due and overdue for screening;
- Providing a 'safety net' for participants who are at risk and have not attended further testing, by prompting them (and the healthcare providers) to have follow-up tests.

Aggregated data

Grouped collected data that enable an overall view of the programme activity but do not include the individual details of the care path.

Opportunistic screening or non-population based screening

Screening can be population-based or non-population based, which is also known as opportunistic screening. Ideally screening should be provided through a population-based programme, in which there is a mechanism to identify each individual eligible to screening and invite them to undergo the tests. Screening outside a population-based screening programme, as a result of a recommendation made by a health-care provider during a routine medical consultation, or by self-referral of individuals is known as opportunistic screening. Such examinations can be performed according to the public screening policies, where they exist.

Population-based cancer registries (PBCRs)

A PBCR systematically collects information from multiple sources on all reportable neoplasms occurring in a geographically defined population. The purpose of a PBCR is to provide information on cancer burden and to assess possible causes of cancer in the community, as well as to carry out studies on prevention, early detection and screening, and cancer care. The registry provides a profile of the cancer burden in the population and how it changes over time, and therefore plays a unique role in the planning and evaluation of cancer control programmes.

Data linked with cancer registries

Data of individuals enrolled in the programme linked with the cancer registry data using the matching criteria (national identity number or nominal data).

Screening protocol

A screening 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.

Screening interval

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

Screen and treat

Individuals with a positive screening test receive immediate treatment.

Mass media campaign

Informational or motivational messages delivered to large audiences through broadcast and print media (television, radio, billboards, magazines, newspapers and internet).

Small media campaign

Informational or motivational messages delivered to individuals through brochures, leaflets, newsletters, letters, flip-charts, videos, social media, mobile phone, text message, short message service (SMS).

Group education

Informational or motivational messages delivered to an assembled group in lecture or interactive format by trained lay people or health professional.

One-on-one education

Informational or motivational messages delivered by one individual to another, either in person or by telephone. Maybe supported by small media or client reminders.

Individual invitation

An individual 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.

Screening kit included

A sampling kit is provided with the invitation to a vaginal sample for HPV testing for cervical cancer screening.

Active contact of screen-positive cases

Screen-positive individuals are actively contacted to ensure compliance with further assessment.

Active contact of cancer cases

Individuals with a diagnosis of precancer or cancer are actively contacted to ensure compliance with further management.

Quality assurance

Quality assurance encompasses activities intended to assure and improve quality at all levels of the screening process in order to maximize benefits and cost-effectiveness while minimizing harms. The concept includes the assessment or evaluation of quality, identification of problems or shortcomings in the delivery of care, the design of activities to overcome these deficiencies and follow-up monitoring to ensure effectiveness of corrective steps. Quality assurance of the screening process requires a robust system of programme management and coordination, assuring that all aspects of the service are performing adequately.

Accreditation

Accreditation is important for ensuring safety, quality and consistency of cancer screening activities. A series of initiatives are made to ensure cancer screening under a common set of standard, such as the peer review and evaluation of facility's staff qualifications, equipment performance, laboratory, pathology, endoscopy, radiology quality control and quality assurance programmes, image quality, dose and processor quality control.

Performance indicator

Performance indicators (PI) are measurable values that demonstrate how effectively a cancer screening programme is achieving its main objectives. The aim purpose of PI is to assess and monitor the quality and the possible impact of a cancer screening programme. These PI include screening coverage, participation rate, further assessment rate, detection rate, positive predictive value, etc.

Reference standards

The reference standards for indicators should be based on the achievable performances of well-established screening programmes (e.g. the acceptable level, the desirable level). Enlisting the minimum acceptable standards for the core indicators will greatly help the new programmes to organize their strategies and quality assurance plan. It is also essential to score the harms (and not achieved benefits), which are associated with poor performance.