

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 4-11). 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)	LJ
	(Please provide link (if applicable) or email the document to canscreen5@iarc.fr):	
2.	Organization of screening	T
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:	l
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 that recommends cancer screening? (1. yes; 2. no; 3. unknown)	ΪÎ
2.3.1	If yes, how is the policy documented? (1. law (signed by the president or approved by the parliament); 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)	LJ
2.5.1	If yes, has the pilot programme been evaluated?	гэ
	(1. pilot ongoing; 2. evaluated and report published; 3. evaluated but no report published; 4. not evaluated; 5. unknown)	LJ
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?	ГЪ
	(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?	[]
2.0	(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?	[]
2.9	(1. yes; 2. no or partially; 3. unknown) 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?	
3.1	(1. yes; 2. no; 3. unknown)	[]
3.1.1	If yes, for which purpose? (1. identification of eligible population; 2. screening participation; 3. screening [].[].[].[].	.[].[]
0.1.1		le 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)	LJ
3.2	Is there a system (computerized or paper-based) that gathers aggregated data on screening activities?	гэ
	(1. yes; 2. no; 3. unknown)	[]
3.2.1	If yes, this system collects aggregated data on? (1. screened individuals; 2. screening test results; [].[].[]	.[].[]
	3. further assessment; 4. final pathology diagnosis; 5. cancer staging; 6. treatment) (multiple	le 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)	L J
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)	L J
3.4	Are screening data linked with population-based cancer registries (PBCR)?	[]
2.5	(1. yes; 2. no; 3. unknown)	
3.5	Any other information related to information system (e.g. quality control of data collection, etc.):	

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4.	Screening protocol		
4.1	Is there a screening protocol or guideline? (1. yes; 2. no; 3. unknown) (If yes, please provide link (if available) or email the document to canscreen5@iarc.fr):	[]	
4.1.1	If yes, does the protocol describe monitoring and evaluation of the performance indicators?		
	(1. yes; 2. no; 3. unknown)		
4.2	If yes, year when the current protocol was developed/last updated: (9999 if no documented protocol;0000 if unknown)	[][]	
4.3	If yes, please provide information on the screening protocol (list of screening tests provided below)		
4.3.1	Primary screening test [] Target age ([] [] - [] []) Screening interval ([] [] month		
4.3.2	Primary screening test [] Target age ([] []- [] []) Screening interval ([] [] months)	
4.3.3	Primary screening test [] Target age ([] []- [] []) Screening interval ([] [] months)	
4.3.4	Primary screening test [] Target age ([] []- [] []) Screening interval ([] [] months)	
	Primary screening tests: 1. FIT; 2. gFOBT; 3. stool DNA; 4. flexible sigmoidoscopy; 5. colonoscopy; 6. virtual colonoscopy		
4.4	Any other information related to screening protocol (e.g. a different screening protocol not based on ag	e, but	
	for selected population, etc.):		
5.	Invitations for screening and further assessment		
5.1	Are there any initiatives to create population awareness by the Health Ministry/Health Authority?	[]	
	(1. yes; 2. no; 3. unknown)		
5.1.1	If yes, what are the approaches: (1. mass media campaign; 2. small media campaign; 3. group education; 4.	.[].[].	
		e responses)	
г э	(If 5 and/or 6, please provide link of the website and/or platform):	гэ	
5.2	Is there a system to send individual invitations to the eligible population? (1. yes; 2. no; 3. unknown)	LJ	
5.2.1	(If yes, please leave Q5.3 blank) If yes, from which source are the eligible individuals identified? (1. population register; [].[].[].	Г 1Г 1	
3.2.1	, ,	·L J·L J	
5.2.2	If yes, what is the method of inviting the eligible individuals? [].[].[]	e responses)	
5.2.2		e responses)	
5.2.3	If yes, does the invitation include screening kit? (1. yes; 2. no; 3. unknown)	[]	
5.3	Is there a system to invite selected populations only? (1. not screened in the round; 2. high risk populations []	. 1. 1	
		e responses)	
5.4	Are the screen-positive individuals actively contacted if they have not undergone further assessment?		
	(1. yes, systematically; 2. no or sporadically; 3. unknown)	[]	
5.5	Are the individuals with a precancer/cancer diagnosis actively contacted for compliance to further	[]	
	management? (1. yes, systematically; 2. no or sporadically; 3. unknown)	LJ	
5.6	Does the programme collect data on the stage of the cancers detected through the programme?	[]	
	(1. yes, systematically; 2. no or sporadically; 3. unknown)	LJ	
5.7	Does the programme collect data on the treatment of the precancers/cancers detected through the	[]	
- 0	programme? (1. yes, systematically; 2. no or sporadically; 3. unknown)		
5.8	Any other information related to invitation and further assessment (e.g. invitation system excludes cand	er cases,	
(etc.):		
6. 6.1	Quality Assurance (QA) of screening activities Is there a documented guideline/policy for quality assurance of the screening service delivery?		
0.1		гэ	
	(1. yes; 2. no; 3. unknown) (If yes, please provide link (if available) or email the document to canscreen5@iarc.fr):	[]	
6.2	Is there an individual/team/institution responsible for quality assurance of the screening service	гэ	
	delivery? (1. yes; 2. no; 3. unknown)	[]	
6.2.1	If yes, please provide name of team/institution or the designation of the individual:		
6.3	Is there a system of accreditation of endoscopy units? (1. yes; 2. no; 3. unknown)	[]	
6.4	Is there a system of accreditation for pathology services? (1. yes; 2. no; 3. unknown)	[]	
6.5	Does the colorectal cancer screening programme undergo audit? (1. yes; 2. no; 3. unknown)	[]	
6.5.1	If yes, please provide the reference for the audit document and /or information on which processes of		
	the screening pathway are covered in the audit:	[]	
6.6	Is there a national/regional strategy/recommendation/guideline for training and capacity building for	[]	
	providers of colorectal cancer screening services? (1. yes; 2. no; 3. unknown)	L J	
6.6.1	If yes, please specify who is responsible for organizing such training:	[]	

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6.6.2	If yes, is training provided as?: (1. Initial training for newcomers; 2. Continuous/update training; 3. Highly specialised training on selected topics)	[].[].[] (multiple responses)
6.7	Are there specified performance indicators to assess the performance of screening? (1. yes; 2. no; 3. unknown)	[]
6.7.1	If yes, are the reference standards defined for the indicators? (1. yes; 2. no; 3. unknown)	[]
6.8	Were the performance reports of screening programme published in the last five years? (1. yes; 2. no; 3. unknown) (If yes, please provide link (if available) or email the document to canscreen5@iarc.fr):	[]
6.9	Any other information related to quality assurance (e.g. the key performance indicators and their etc.):	standards,

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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 10-11).

1. General information

For this part, you will provide general information for colorectal 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 <u>sub-national</u> 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 <u>screening policy</u> document recommending colorectal 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 law should be signed by the president or approved by the parliament or a similar of executive or legislative body of government. The notification/decree 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

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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 <u>screening programme</u> 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 <u>pilot programme</u> 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 <u>free of charge</u>, 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 <u>further assessment</u>, are the diagnosis tests available <u>free of charge</u>, meaning no immediate payment by the individual for availing the diagnostic services?
- **2.8** For individuals with diagnosis of colorectal precancer/cancer, are the treatment services available <u>free of charge</u>, 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 <u>aggregated data</u> (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. <u>opportunistic screening</u> activities, etc.)? If the information can't be differentiated from opportunistic screening or from population-based screening, please select "cannot differentiate".

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- **3.4** Are screening registry data linked to <u>cancer registry data</u> (e.g. with a national identification number or personal 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 <u>screening protocol</u> (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.
- **4.1.1** Please indicate whether your protocol describes the monitoring and evaluation of performance indicators.
- **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. Colorectal 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** 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 <u>mass media campaign</u>, <u>small media campaign</u>, <u>group education</u>, <u>one-on-one education</u>, dedicated website, social media platform?

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 <u>individual invitation</u>, is there a system to invite (by letter, email, SMS, phone calls, home visits, or other methods) the eligible individuals to screening? If yes, please leave Question 5.3 blank. 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 individuals are invited to screening. You may enter multiple responses.
- **5.2.3** If "yes" for question 5.2, is the <u>screening kit included</u> in the invitation?
- **5.3** Some programmes may invite only individuals 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 individuals, please provide the criteria for it.
- **5.4** Is there a system to contact screen-positive individuals to undergo further assessment if they have not undergone further assessment? If those individuals are actively contacted as a routine, please select "yes, systematically". If no such system exists or if individuals may be contacted occasionally, please select "no or sporadically".

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- **5.5** Is there a system to contact individuals with a precancer/cancer diagnosis for compliance to further management? If those individuals are actively contacted as a routine, please select "yes, systematically". If no such system exists or if individuals may be contacted occasionally, please select "no or sporadically".
- **5.6** Does the programme also collect information on cancer staging of the cancers detected through the programme? If the programme collect information on stage for all individuals diagnosed with cancer within the programme, please select "yes, systematically". If no information on stage is collected (or just for part of those individuals), 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 individuals diagnosed with cancer within the programme, please select "yes, systematically". If no information on treatment is collected (or just for part of those individuals), please select "no or sporadically".
- **5.8** Please indicate any other information related to invitation and further assessment (e.g. individuals 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 endoscopy services.
- **6.4** Please indicate if there is a system of accreditation for pathology services.
- **6.5** Is there a quality assurance audit of the cancer screening program?

If no, please go directly to question 6.6.

- **6.5.1** If yes, please provide the reference of the audit document and/or information on the processes covered by the screening audit.
- **6.6** Please indicate if there is a national/regional strategy/recommendation/guide for training and capacity building of colorectal cancer screening service providers?

If no, please go directly to question 6.7.

- **6.6.1** If yes, can you specify who is responsible for organizing these training activities?
- **6.6.2** If yes, how are training activities delivered?
- **6.7** Is there a list of <u>performance indicators</u> (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.

- **6.7.1** If yes, are the <u>reference standards</u> defined for some of the indicators? (e.g. examination coverage to be achieved).
- **6.8** Was the performance report of the screening programme published in last five years?

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

6.9 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).

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Appendix I Definitions

Screening programme

It is 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 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.

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.).

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.

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.

Screening policy

It is 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.

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.

Screening interval

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

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.

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 positive individual or diagnostic mammography for a woman with abnormal screening mammography, for cervical cancer it means performing a colposcopy.

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.

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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.

Screening test, diagnosis, treatment free of charge

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

Screening kit included

A sampling kit is provided with the invitation to screening, e.g. a kit for HPV testing for cervical cancer screening or a kit for FIT test for colorectal cancer screening.

Screening registry

The Cancer Screening Registry is an information system (computerized or paper-based) that collects, utilizes and stores cancer screening data on individual basis for programme management and reporting.

The registry supports the screening programmes by:

- Maintaining a database of screening records of individuals;
- Holding a single, consistent, 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.

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 to be documented.

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.

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).

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

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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.

Performance indicator

Performance indicators (PI) are measurable values that demonstrate how effectively a cancer screening programme is achieving its main objectives. The main 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.

Audit

A healthcare audit is defined as a quality improvement cycle or process for measuring the effectiveness of healthcare services against agreed, proven, evidence-based and recognized standards, in order to improve the quality of care and outcomes.

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