ANNEX 1.

Questions about prioritization of barriers to the cancer screening pathway

Adapted from supporting information in Mosquera I et al., Assessment of barriers to cancer screening and interventions implemented to overcome these barriers in 27 Latin American and Caribbean countries. © 2024 World Health Organization; licensed by UICC. International Journal of Cancer published by John Wiley & Sons Ltd on behalf of UICC.

1. What are the barriers to the development and implementation of protocols and guidelines, and capacity-building? Please select up to five barriers that are the most relevant.

a. Screening guidelines are not regularly developed or adopted.
b. Screening guidelines do not cover further management.
c. Screening protocols and guidelines are not regularly updated.
d. Screening guidelines are not disseminated, or no training on them is provided.
e. Compliance with screening guidelines is not regularly monitored and evaluated.
f. Complex and/or unclear administrative procedures delay amendment of the screening protocol.
g. Inadequate national governance structure responsible for assessing training needs.
h. Insufficient number of professionals trained on the screening protocols and guidelines.
i. Screening providers do not follow protocols and procedures.
j. Lack of consensus among key stakeholders on the screening guidelines.
k. Other; please specify.

2. What are the barriers to identifying and inviting the eligible population to screening? Please select up to five barriers that are the most relevant.

a. There is no contact information for the eligible population (not related to data protection regulations).
b. Data protection regulations prevent access to contact information for the eligible population.
c. Population register is not accurate or complete (including, but not limited to, migration, even within the country).
d. Population register is not updated in a timely manner with changes of contact information (address, phone number, etc.).
e. Some eligible patients are not included in the population register (immigrants, individuals who are homeless, etc.).
f. Eligibility criteria vary from a defined protocol according to location.
g. No follow-up of non-responders after the initial screening invitation.
h. Other; please specify.

3. What are the barriers to maximizing informed participation in screening? Please select up to five barriers that are the most relevant.

a. Appointments for screening make it difficult for people to attend (getting an appointment, day/time of appointment, long waiting time for an appointment [not related to insufficient availability of services]).
b. Primary care physicians and other health professionals are not disseminating information about or promoting screening.
c. Health professionals' attitudes and established patterns of practice prevent screening.
d. Inadequate system for monitoring screening participation.
e. Insufficient monitoring of the quality of screening experiences.
f. Inadequate responsiveness by management to problems found in monitoring participation and giving feedback to health professionals.
g. Significant amount of opportunistic testing occurs outside of the routine screening programme.
h. Some people lack knowledge (limited health literacy) or have beliefs and values that lead to non-participation.
i. Some people distrust the health-care system for participating in screening.
j. The screening centre is far.
k. Some people have competing priorities (e.g. care of dependents) and/or physical/social barriers (e.g. disability, language).
l. There is no financial coverage (total or partial) of the direct costs of screening (cost of appointment, cost of collection of test, cost of test analysis, etc.).
m. Indirect costs of screening are not affordable (cost of travel, loss of a day's wages, cost related to care of dependents, etc.).
n. Expected barriers (not financial) in access to cancer diagnosis in case of a positive screening result.
o. Expected barriers (not financial) in access to cancer treatment in case of a cancer diagnosis.
p. Consent prevents screening.
q. Other; please specify.

4. What are the barriers to successful operation of the programme? Please select up to five barriers that are the most relevant.

a. Private ownership of screening facilities hinders optimal screening practices.
b. Limited capacity of screening programme (e.g. insufficient infrastructure and/or financial resources).
c. Limited capacity of screening programme not related to finances (e.g. insufficient trained human resources).
d. Inadequate planning and/or logistics to deliver screening services.
e. Monitoring and evaluation are inadequate and insufficient.
f. Issues with establishing protocols, processes, and legal frameworks.
g. Insufficient information technology (IT) systems resources (computer, Internet).
h. Inadequate information technology (IT) solution for running screening (software/application).
i. Poor interoperability between information technology (IT) systems.
j. Inadequate organizational/administrative support for clinical professionals.
k. Providers do not always work to agreed protocols and guidelines.
l. Outcome data from opportunistic testing (screening without an invitation and based on self-referral or the advice of health providers) is not collected.
m. Outcome data from opportunistic testing (screening without an invitation and based on self-referral or the advice of health providers) is not shared.
n. Opportunistic testing does not follow the same evidence-based screening policy.
o. Out-of-protocol opportunistic testing causes additional costs for the overall health-care system or limits the availability of resources for an organized programme.
p. Limited public promotion of the screening programme.
q. Other; please specify.

5. What are the barriers to follow-up (further assessment)? Please select up to five barriers that are the most relevant.

a. Poor laboratory quality resulting in a high rate of false-negatives/false-positives or mistrust in test results affecting the efficacy of further assessment.
b. No well-defined organizing body or system in place to ensure that the screen-positive individuals are appropriately managed (fail-safe mechanism).
c. Insufficient monitoring and evaluation of non-responders to follow-up.
d. Insufficient infrastructure and/or financial resources for further assessment.
e. Insufficient human resources for further assessment (shortage of trained personnel not related to finances).
f. System-level delays for diagnosis after screening (getting an appointment, day/time of appointment, long waiting time for further assessment [not related to insufficient availability of services], long waiting time for test results).
g. Poor adherence by providers to guidelines on follow-up management (further assessment, change in follow-up, or access to next level of care).
h. Providers are not sharing information about or promoting further assessment.
i. Clinicians' attitudes and established patterns of practice prevent follow-up.
j. Current system does not address personal beliefs about follow-up (e.g. fatalism).
k. Some people have beliefs and values that lead to not undergoing further assessment.
l. Some people distrust the health-care system for undergoing further assessment.
m. Difficulties sharing data due to inadequate linkage between clinics regionally and nationally.
n. Difficulties sharing data due to data protection regulations between clinics regionally and nationally.
o. Poor communication/difficulties sharing data due to inadequate linkage (flow of information) between the screening registry, primary care, and patients for the screening organization.
p. Poor communication/difficulties sharing data due to data protection regulations between screening organizations, primary care, and patients.
q. Insufficient evaluation of the objective obstacles faced by patients requiring follow-up.
r. There is no financial coverage of direct costs of the diagnostic workup (cost of appointment, cost of procedure, cost of test analysis, etc.).
s. Indirect costs of diagnosis are not affordable (cost of travel, loss of a day's wages, cost related to care of dependents, etc.).
t. There is partial financial coverage (either co-payment or full coverage only for certain populations) for the diagnostic workup (cost of appointment, cost of procedure, cost of test analysis, etc.).
u. The information system does not collect follow-up data on the screened population.
v. Other; please specify.

6. What are the barriers to effective treatment? Please select up to five barriers that are the most relevant.

a. Insufficient monitoring is done of individuals diagnosed with precancer or cancer.
b. The treatment centre is far.
c. Delays in initiation of treatment not related to availability of health services (e.g. getting an appointment, day/time of appointment, long waiting time for initiation of treatment, long waiting time for test results).
d. Effective treatment is not available to all who require it.
e. No systematic monitoring or evaluation of treatment outcomes.
f. Information about the management chain (case management) is not tracked systematically.
g. There are difficulties sharing and accessing data across different regions.
h. Patients do not undergo treatment because of a variety of personal beliefs.
i. Some people distrust the health-care system for undergoing treatment.
j. There is no financial coverage (total or partial) of the direct costs of treatment (medical bill including cost of surgery/chemotherapy/radiotherapy, hospital costs, etc.).
k. Indirect costs of treatment are not affordable (cost of travel, loss of a day's wages, cost related to care of dependents, etc.).
l. Other; please specify.