



# Improving EU cancer screening policies: A framework for identifying barriers of screening programs with monitoring data

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## ABSTRACT

Cancer remains a leading cause of mortality in the European Union. The European Beating Cancer Plan and updated screening guidelines emphasize the importance of population-based, organized screening for cancers such as breast, cervical, and colorectal cancer. However, many programs struggle with low participation rates, fragmented data systems, and insufficient quality monitoring. In this paper, we review existing efforts to harmonize the data collection and monitoring activities across Europe, discuss barriers to organized cancer screening programs identified in previous initiatives, and propose a framework linking monitoring indicators with potential barrier domains. We highlight that robust and standardized data collection is crucial for transparent evaluation and barriers assessment, while also emphasizing the need for updated quality indicators. These efforts lay the groundwork for harmonized data collection that can inform barrier identification and drive continuous improvement of screening programs. The insights gained are directly relevant to EU cancer policy, supporting the implementation of the European Beating Cancer Plan and helping member states strengthen organized, equitable screening strategies.

## 1. Introduction

Cancer remains a leading cause of mortality in the European Union (EU). In 2019, almost 1.2 million people died from cancer across member states, representing more than one in four deaths, and a considerable share of these deaths is regarded as preventable [1]. To address this burden, the European Beating Cancer Plan was launched as a cornerstone of the European Health Union [2].

Within this plan, the European Commission announced a new cancer screening scheme with two main objectives: to raise participation in breast, cervical, and colorectal cancer screening by 2025, and to gradually implement organized programs for prostate, lung, and gastric cancer.

The objective of offering breast, cervical, and colorectal cancer screening to 90% of eligible citizens by 2025 is very ambitious [3]. However, the emphasis on prevention and early detection is not new; the 2003 Council Recommendation on cancer screening [4] had already urged member states to implement or expand population-based, organized screening programs for these cancers. Since then, the EU has updated its screening guidelines to reflect a broader approach that integrates early detection with prevention, embeds evidence-based practices, and emphasizes equity in access [5]. However, participation rates remain suboptimal and vary widely between countries. In 2022, average uptake across the EU was 42% for colorectal screening, 56% for breast cancer, and 55% for cervical cancer, with Nordic countries and Slovenia achieving the highest levels, while several Eastern and Southern

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countries, including Hungary, Poland, Portugal, and Romania, reported much lower engagement [6].

A further barrier lies in the organization of screening activities. Although the 2003 EU Recommendation emphasized organized rather than opportunistic screening, this transition remains incomplete. Organized programs proactively invite eligible populations, apply standardized protocols, and incorporate quality assurance mechanisms, thereby improving coverage and reducing inequalities. In contrast, opportunistic screening depends on individual healthcare encounters, often excluding vulnerable groups and delivering inconsistent quality [7]. Many countries therefore continue to face gaps in practical guidance for identifying barriers and using monitoring data to optimize program performance.

Against this backdrop, this paper presents ongoing efforts to harmonize cancer screening data collection and monitoring across Europe, reviews previous work on barrier analysis, and proposes a hypothesis-generating framework linking monitoring indicators with barrier domains. Its novelty lies in connecting two strands of work that have largely developed in parallel: performance monitoring and structured barrier assessment. By showing how routinely collected indicators may signal specific system-level obstacles, the framework aims to support more targeted policy responses and contribute to the implementation of the European Beating Cancer Plan.

## 2. Efforts to harmonize cancer screening data collection and monitoring in the EU

High-quality cancer screening programs require continuous monitoring, quality assurance, and long-term evaluation.

A Delphi study among European experts identified a core set of indicators, including interval cancer rate, detection rate, screening attendance and coverage, cancer incidence, cause-specific mortality, proportion attending further assessment after a positive test, proportion starting treatment after diagnosis, invitation coverage, and distribution of cancers by detection mode [8]. Similarly, the European Commission Initiative on Breast Cancer identified essential performance indicators — most notably screening coverage and detection rate — to assess the impact of breast cancer screening on mortality [9].

The European Cancer Inequalities Registry (ECIS) project has also played a key role in monitoring disparities in cancer prevention, diagnosis, treatment, and outcomes across EU countries. ECIS identified a comprehensive set of Quality Indicators (QIs) to guide policy, support evidence-based improvements, and promote equitable cancer care [10]. Countries without systematic monitoring should prioritize capturing these indicators, alongside those from EU Commission initiatives on breast, cervical, and colorectal cancer. For those with existing systems, this combined checklist can be used to verify and update procedures. To aid implementation, the Finnish Cancer Registry, through the CanScreen-ECIS project, developed an online learning program to support data submission to ECIS and strengthen capacity in screening evaluation [11].

EU reports on cancer screening have also emphasized the importance of population-based approaches and continuous monitoring. The first report found that only half of member states conducted peer reviews or promptly reported results [12], while the second reinforced the need for regular monitoring and updates [13]. Going forward, establishing EU-level reference standards for quality and process indicators, strengthening population-based screening registries, and integrating prevention strategies are critical to maximize effectiveness, minimize harm, and address the growing cancer burden.

## 3. Barriers of effective and equitable screening

Several EU-level initiatives have been launched to harmonize screening data collection and quality assurance, while complementary tools have been developed to assess barriers systematically. These initiatives differ in scope and methods but collectively demonstrate how

monitoring infrastructures and barrier assessment frameworks can be aligned. Table 1 summarizes key examples.

Michie et al.'s implementation model highlights broad categories of barriers, including health-system constraints, capability-related barriers, and intention or motivation-related barriers [14]. Previous work applying health systems and implementation research frameworks to cancer screening has shown that implementation is affected by barriers among both clients and providers, including knowledge, beliefs,

**Table 1**  
Examples for monitoring initiatives and existing barrier assessment tools in Europe.

| Examples of European initiatives                                             |                                                                                                                                                                                                                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Project                                                                      | Monitoring initiative                                                                                                                                                                                                                                                                                                            | Features of the monitoring platform                                                                                                                                                                                                                                                                                                                                                                                                |
| EUTOPIA                                                                      | EU-TOPIA provides a dedicated monitoring tool, building upon the experience of the second EU screening report, collecting and analyzing a set of aggregated standardized data, which can be used to monitoring key QIs of screening performance. The initiative also fosters collaboration with screening and cancer registries. | Data collection templates feeding the monitoring and the evaluation tools<br>Interactive tool to analyze and visualize cancer screening performance indicators,                                                                                                                                                                                                                                                                    |
| CanScreen-ECIS                                                               | The CanScreen-ECIS initiative has developed and piloted a robust, privacy-compliant data management system integrated into the European Cancer Information System (ECIS) to collect and monitor data about performance indicators for breast, cervical, colorectal, and lung cancer screening across Europe                      | ECIS Data Submission Portal – a secure platform for uploading screening data from participating countries.<br>ECIS Data Warehouse – a structured database where the submitted data are stored, processed, and maintained.<br>ECIS dashboard - Web Application for Visual Analytics – an interactive tool to analyze and visualize cancer screening performance indicators, including coverage, participation, and detection rates. |
| European Commission Initiative on Cervical Cancer                            | To establish EU-wide monitoring of cervical cancer screening performance and quality assurance, with a focus on HPV-based screening and outcome tracking.                                                                                                                                                                        | Development of quality assurance indicators, harmonized European guidelines, and integration with cancer registries and national program databases.                                                                                                                                                                                                                                                                                |
| European Commission Initiative on Breast Cancer                              | To monitor breast cancer screening programs across Member States against evidence-based guidelines and QA standards covering the full care pathway.                                                                                                                                                                              | European QA scheme and indicator framework (covering screening, diagnosis, and treatment) supported by JRC platforms for data reporting and benchmarking.                                                                                                                                                                                                                                                                          |
| European Commission Initiative on Colorectal Cancer                          | To ensure consistent monitoring of colorectal cancer screening performance and outcomes across the EU, enabling evaluation of organized vs opportunistic programs.                                                                                                                                                               | Follows the ECIBC/EC-CvC model: guideline-based indicator sets + data templates for standardized program monitoring (integrated into EU cancer screening reports).                                                                                                                                                                                                                                                                 |
| Prostate Cancer Awareness and Initiative for Screening in the European Union | To pilot risk-based early detection strategies and measure cost-effectiveness, feasibility, and uptake, while reducing overdiagnosis/overtreatment.                                                                                                                                                                              | National pilot registries, KPIs, and data collection frameworks feeding into a central evaluation tool; governance boards for program monitoring.                                                                                                                                                                                                                                                                                  |

resources, and service organization [15]. Similarly, the PRECEDE-PROCEED model distinguishes predisposing, enabling, and reinforcing factors that shape health behavior and program implementation. These frameworks are useful for interpreting why barriers occur, but they are not specific to the organization of cancer screening pathways.

Evidence from EU-TOPIA showed that experts consider up-to-date, evidence-based guidelines, systematic monitoring of screening uptake, comprehensive population registers, and long-term outcome tracking to be among the most important elements of successful screening programs [16]. Building on this work, the Barriers to Effective Screening Tool (BEST) was developed to assess barriers across the screening pathway, including knowledge generation, identification of the eligible population, maximization of uptake, program operation, follow-up, and treatment [17]. Previous applications of BEST in European screening contexts have shown that barriers such as incomplete population registers, opportunistic screening, resource limitations, and insufficient follow-up monitoring vary across countries and health systems [18,19]. This pathway-based structure is particularly suitable for linking monitoring indicators to potential barrier domains because it corresponds to the operational steps of organized screening programs.

Other tools, such as PRECEDE-PROCEED and INTERVENER, can complement this approach by helping program managers interpret the behavioral, organizational, or access-related causes behind underperformance once a specific pathway domain has been identified. In this way, the proposed framework does not add another conceptual layer, but uses BEST to locate where barriers occur and broader implementation frameworks to support interpretation of why they occur. Table 2 summarizes the main barrier tools and frameworks discussed in this section.

Barrier assessment tools have traditionally relied on qualitative and semi-qualitative methods. Understanding barriers is essential for sustainable implementation, operation and further development of impactful screening programs. Even in countries with extensive screening histories, challenges related to access, knowledge of invitees, and resource allocation persist, demonstrating that historical experience alone cannot overcome these obstacles. There is therefore a growing need to complement qualitative insights with quantitative monitoring indicators. Together, these sources can provide a more robust, evidence-based foundation for prioritizing barriers and guiding policy and practice.

**Table 2**  
Barrier tools and frameworks with short descriptions.

|                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                     |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| EUTOPIA - Barriers to Effective Screening Tool (BEST) <a href="https://eu-topia-east.org/downloads/">https://eu-topia-east.org/downloads/</a>                                                                                               | BEST helps identify barriers to effective screening specifically for breast, cervical, and colorectal cancers, considering six sub-systems of the screening pathway. Provides the pathway-based structure for locating where barriers occur across the screening process, including population identification, uptake, program operation, follow-up, and treatment. |
| PRECEDE-PROCEED model <a href="https://www.ruralhealthinfo.org/toolkits/health-promotion/2/theories-and-models/precede-proceed?utm">https://www.ruralhealthinfo.org/toolkits/health-promotion/2/theories-and-models/precede-proceed?utm</a> | Framework for planning and evaluating health promotion programs, integrating patient- and system-level barriers. Helps interpret behavioral and contextual causes of underperformance, including predisposing, enabling, and reinforcing factors.                                                                                                                   |
| INTERVENER <a href="https://learning.iarc.fr/edp">https://learning.iarc.fr/edp</a>                                                                                                                                                          | IARC interactive tool for assessing and prioritizing screening barriers and linking them to relevant interventions. Supports prioritization of identified barriers and selection of possible interventions across the screening continuum.                                                                                                                          |

4. Linkage between monitoring and barriers

Building on this gap, we propose a conceptual, hypothesis-generating framework that links selected monitoring indicators to potential barrier domains across the screening pathway. While qualitative and semi-qualitative methods for barrier identification provide valuable insights into social, cultural, and organizational challenges, they also have drawbacks, including potential bias, context-specific findings, and resource-intensive data collection. The impact of each barrier on screening effectiveness varies across countries. A previous survey using the BEST tool showed that, on average, more barriers were reported at the national than at the regional level, suggesting that different stakeholders perceive priorities differently and underlining the need for approaches that can reconcile these views.

Involving multidisciplinary stakeholder groups in barrier assessment and prioritization may reduce such variability. Using quantitative monitoring data alongside qualitative findings can provide objective, representative measures of barriers, helping to select those most relevant in each domain. This requires defining plausible links between barriers and performance indicators. Establishing these links supports the choice of effective interventions, informs roadmap design, and identifies indicators to monitor intervention impact. The barrier assessment process can also align perceptions of barriers among stakeholders, creating a starting point for engagement in developing and implementing solutions.

Integrating quantitative methods within a mixed-methods framework thus offers a more robust understanding of barriers, strengthening both roadmap development and monitoring. We propose a framework that connects specific screening performance indicators with system-level barriers, using the BEST instrument as a foundation (see Table 3). The practical feasibility of the framework is illustrated through a short EU-TOPIA-EAST mini-case from Montenegro, presented in the Appendix. Monitoring and barrier analysis identified six domains, five of which can be linked to specific performance indicators.

In the identification of population at risk, challenges include incomplete or outdated registers, absence of follow-up for non-responders, missing eligible individuals, and limited organizational capacity to invite all eligible participants. Quality indicators therefore focus on comparing registry data with local population estimates and measuring invitation coverage.

For maximization of uptake, barriers include opportunistic screening outside organized programs, cultural or personal beliefs discouraging participation, limited promotion by primary care physicians, and logistical difficulties. Weak monitoring systems, inadequate responsiveness to participant feedback, and appointment-related barriers further reduce uptake. Indicators in this domain include participation, retention, and opportunistic screening rates.

In maximization of follow-up, common issues are insufficient

**Table 3**  
Linking key barrier domains of barrier assessment with monitoring indicators.

| Domains                              | Indicator                                                                                                                                                                                   |
|--------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Identification of population at risk | <ul style="list-style-type: none"><li>• Invitation coverage</li><li>• Alignment of target population with official registry data</li></ul>                                                  |
| Maximization of uptake               | <ul style="list-style-type: none"><li>• Participation rate</li><li>• Retention rate</li><li>• Proportion of opportunistic screening</li></ul>                                               |
| Maximization of follow-up            | <ul style="list-style-type: none"><li>• Compliance with referral to assessment</li><li>• % of early recall</li><li>• Outcome of the assessment (histology, protocol requirements)</li></ul> |
| Ensuring effective treatment         | <ul style="list-style-type: none"><li>• Referral to treatment</li><li>• Compliance with referral to treatment</li></ul>                                                                     |
| Operation of the program             | <ul style="list-style-type: none"><li>• Positivity rate</li><li>• Invalid or inadequate screening test rate</li><li>• Cancer and precursor detection rate</li></ul>                         |

monitoring of non-responders, poor data sharing across clinics, and weak adherence to guidelines. Indicators include compliance with referrals, early recall rates, and assessment outcomes.

For ensuring effective treatment, barriers relate to patient management and data gaps, such as inadequate monitoring of outcomes, poor information on care pathways, and limited tracking of positive screening results. Indicators include compliance with referral to treatment and management of screen-detected lesions.

Finally, under operation of the program, challenges include lack of data from opportunistic screening, fragmented IT systems, and limited resources. Opportunistic testing outside evidence-based protocols increases costs, while organizational and legal issues, poor adherence to guidelines, weak monitoring, insufficient public promotion, and low administrative support impede delivery. Private ownership of facilities can further fragment practices. Quality indicators include inadequate test rates, positivity/recall rates, and detection of cancer and precursors, which reflect both program quality and access barriers.

The proposed integrated approach has been developed as a conceptual and hypothesis-generating framework. A single indicator may reflect multiple interacting barriers, and the same barrier may influence several indicators. The framework should therefore be used to prioritize areas for further investigation rather than to assign causality. The identification of areas of underperformance, quantified using the indicators results, can orient the contextual analysis and qualitative assessment of the role of specific barriers influencing the performance domain measured by that indicator, informing the choice of the interventions aimed to overcome the identified barriers, through stakeholder engagement. The impact of the interventions adopted will be reflected in the changes in the quality of the performance measured by the indicator linked to the targeted barrier. Although the Montenegro case illustrates how monitoring indicators can be linked to barrier assessment and action planning in practice, the framework has not yet been fully validated as a decision-making tool. Further testing across different screening programs, cancer types, and national health system contexts is needed to confirm its validity, feasibility, and usefulness for policy and program management.

## 5. Conclusion and future perspectives

Assessing cancer screening programs requires combining quantitative monitoring data with qualitative insights into participant experiences, service organization, and implementation barriers. The added policy value of the proposed framework is that it helps translate monitoring results into structured questions for action: where in the screening pathway does underperformance occur, which barrier domains may explain it, which is the quantitative impact of that barriers (loss of effectiveness related to the decreased quality), which stakeholders need to be involved, and which interventions should be prioritized. Rather than treating low participation or delayed follow-up as isolated performance problems, the framework supports a pathway-based interpretation of indicators. This can help program managers distinguish between barriers related to population identification, uptake, follow-up, treatment linkage, program operation, or data infrastructure. It can also provide a shared structure for stakeholder dialogue, helping align the perspectives of policymakers, screening coordinators, clinicians, registries, primary care providers, and community representatives.

Systematic monitoring and barrier analysis should therefore be integrated into the implementation of the European Beating Cancer Plan and future EU cancer screening policy. Harmonized indicators remain essential, but their value depends on whether they are used to guide prioritization, accountability, and corrective action. Linking monitoring to barrier assessment can help member states move from measurement to targeted policy response, supporting more equitable, organized, and effective cancer screening programs.

## CRedit authorship contribution statement

**Marcell Csanádi:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Methodology, Formal analysis, Data curation, Conceptualization. **György Széles:** Writing – review & editing, Validation, Supervision, Methodology. **Eveline A M Heijnsdijk:** Writing – review & editing, Validation, Supervision, Methodology. **Urška Ivanuš:** Writing – review & editing, Validation, Resources, Methodology. **Carlo Senore:** Writing – review & editing, Writing – original draft, Visualization, Formal analysis, Conceptualization. **Orsolya Varga:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Conceptualization. **Gianluigi Ferrante:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Zoltán Vokó:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

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## Declaration of Competing Interest

We have nothing to declare.

## Appendix

### *Illustrative application: colorectal cancer screening in Montenegro*

The EU-TOPIA-EAST roadmap process for colorectal cancer screening in Montenegro illustrates how linking indicators to barrier domains can support decision-making. Montenegro introduced organized colorectal cancer screening in 2013 and reached national coverage of the target age group in 2019. The roadmap identified three key barriers: limited colonoscopy capacity in the northern part of the country, inadequate IT systems, and insufficient public promotion.

For example, indicators related to referral to assessment, colonoscopy completion, and timely colonoscopy can signal problems in the follow-up domain. In Montenegro, contextual assessment showed that follow-up problems were partly linked to service capacity: more than 85% of screening-related colonoscopies were performed in Podgorica, while several hospitals lacked trained gastroenterologists or adequate equipment. This shifted decision-making from general efforts to improve follow-up towards targeted actions on workforce training, equipment needs, financing, and expansion of colonoscopy capacity. Follow-up of the roadmap reported the opening of a new colonoscopy center in the northern part of the country and the engagement of trained staff, although data on improved access and waiting times were not yet available.

The case also illustrates how invitation coverage and data completeness indicators can point to barriers in population identification and program operation. The screening program relied on Health Insurance Fund data and was not fully linked to the central population register, limiting identification and invitation of all eligible individuals. This led to actions aimed at registry development, data linkage, standardized reports, and improved IT functions. The example demonstrates that indicators do not identify barriers by themselves; rather, they help locate underperformance in the screening pathway and guide further contextual assessment and action planning.

Source: <https://cordis.europa.eu/project/id/965014/results>

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