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Title:

Identifying the barriers to effective breast, cervical and colorectal cancer screening in thirty one European countries using the Barriers to Effective Screening Tool (BEST)

Key words: Cancer screening; health systems; barrier analysis

Abstract

The aim of this study was to identify barriers to effective breast, cervical and colorectal cancer screening programmes throughout the whole of the European region using the Barriers to Effective Screening Tool (BEST). The study was part of the scope of the EU-TOPIA (TOwards imProved screening for breast, cervical and colorectal cancer In All of Europe) project and respondents were European screening organisers, researchers and policymakers taking part in a workshop for the project in Budapest in September 2017. 67 respondents from 31 countries responded to the online survey. The study found that there are many barriers to effective screening throughout the system from identification of the eligible population to ensuring appropriate follow-up and treatment for the three cancers. The most common barriers were opportunistic screening, sub-optimal participation, limited capacity (including trained human resource), inadequate and/or disjointed information technology systems and complex administration procedures. Many of the barriers were reported consistently across different countries. This study identified the barriers that, in general, require further investment of resources.

# Introduction

The European Union (EU) has issued recommendations for population-based breast, cervical and colorectal cancer screening programmes but a recent review of their performance found that most are not functioning optimally(International Agency for Research on Cancer, 2017). As part of the EU-TOPIA (TOwards imProved screening for breast, cervical and colorectal cancer In All of Europe) project, we developed the Barriers to Effective Screening Tool (BEST). The instrument includes two sections evaluating the components of and barriers to an effective screening system. In each section, the format of the tool was based on a conceptual model that divided the cancer screening system into six sub-systems: knowledge generation, identification of the eligible population, maximising uptake (informed participation), successful operation of the programme, adequate follow-up and effective treatment for those who need it. A pilot exercise applied the instrument separately to breast, cervical and colorectal cancer screening programmes in the six core countries in the EU-TOPIA project: Estonia, Finland, Hungary, Italy, the Netherlands and Slovenia. The results of this pilot are reported in the accompanying papers(Turnbull et al. 2018, and Turnbull et al. 2018) and the results of the pilot were used to compile a list of barriers to include in the tool. This paper aimed to apply the BEST instrument to additional countries throughout the European region to gain a wider view of the barriers to effective screening and validate the list of barriers from the pilot.

# Methods

For this study we used an online version of the BEST instrument. A copy of the instrument is included in Appendix A. We updated the instrument following the pilot to include structured answers, based on the barriers highlighted in the pilots. This was to make the survey simpler to complete and analyse. However, we also allowed free text answers to enable us to capture any new barriers.

We circulated the instrument to all workshop participants prior to an EU-TOPIA meeting in Budapest in September 2017. Respondents accessed the survey via a link in the email that connected to an online portal where they could complete the survey and the authors could access the data. Most attendees were representatives from national or regional screening organisations, and researchers and policymakers from throughout the European region (including non-EU countries). All were experts in screening programmes for breast, cervical and/or colorectal cancer in their country.

To avoid repetition, the instrument was applied once for all three cancer types. The pilot had shown many barriers to be similar across breast, cervical and colorectal programmes. At the end of the survey, we asked respondents to highlight any differences between cancer types. There was no time limit for completion although all surveys were completed within two weeks. Due to the diversity of the sample and practical difficulties for many respondents of meeting face-to-face, we did not require collated responses per country as we had done in the pilot.

# Results

## Sample characteristics

The study included 67 respondents from 31 countries in the European region. The included countries were as follows (including the number of responses, if more than one): Albania, Austria, Belgium (3), Croatia (4), Cyprus, Czech Republic (3), Denmark (3), Estonia, Finland (2), France (5), Georgia, Germany, Hungary, Iceland, Ireland (2), Italy (2), Latvia (3), Luxembourg, Malta, Montenegro (2), Netherlands (4), Norway (2), Poland (2), Portugal, Romania, Serbia, Slovenia (6), Spain (4), Sweden (3), United Kingdom (3) and Switzerland. The response rate was 81% from 83 attendees, excluding individual members of the EU-TOPIA consortium who were also in attendance. The primary analysis included all barriers mentioned by any respondent in each country and results presented first exclude duplicate answers from the same country. The results by number of respondents are also included for information.

Of the roles specified in the tool, the largest group of respondents included representatives from national screening organisation (n=29). The next largest group was researchers (n=12) followed by policymakers (n=9). Representatives from regional screening organisations (n=6) were the largest group of ‘others’. ‘Other’ roles (n=11) specified by respondents included researcher AND policy maker combined, national screening *evaluation* (3), cancer registry, epidemiologist, coordinator in the national public health institute, program coordinator, representative from the Ministry of Health, quality assurance and commissioner, and obstetrician/gynaecologist.

## Components of the screening programmes

In the first section of the survey, we collected information on the components of the screening systems in each country. The description of the components of the screening systems included in this study were generally in line with those previously reported from the pilot in the accompanying papers(Turnbull et al. 2018 and Turnbull et al. 2018) and other reports describing the status of screening systems in Europe(International Agency for Research on Cancer, 2017). In brief, national health authorities (or ministries of health) and, to a lesser extent, national screening organisations or regional/municipal health authorities are responsible for assessing cancer screening needs, evaluating evidence and system design. This is also the case for protocol and process design, based primarily on European guidelines for cancer screening. Sources to identify the eligible population include population registers, health insurance registers or primary care registers. In most countries, programmes send a letter to invite eligible people for screening and appointments can be pre-allocated, with an option to change or made using the contact details provided or according to other local arrangements. Participation is most commonly monitored at a national level by the national health authority or screening organisation unless the programmes operate at a regional level. How quality is assessed varies by country. The responsibility for adequate follow-up and effective treatment for those that need it is split between national, regional and local organisations, and individuals.

Number of barriers reported per respondent

The average numbers of barriers reported per respondent for each of the sub-systems were: knowledge generation (2.4), identification of the eligible population (1.9), maximising uptake (informed participation) (3.4), successful operation of the programme (4.6), adequate follow-up (2.5) and effective treatment for those that need it (2.0). This totalled an average of 16.9 barriers reported per respondent, without rounding, for the breast, cervical and colorectal cancer screening systems overall. On average, respondents from a national screening organisation reported 18 barriers, respondents from regional organisations reported 13.5 barriers, policy-makers reported 16.6 barriers and researchers reported 14.3 barriers in total.

## Reported barriers to effective screening

We identified the barriers to effective screening for each of the components of a cancer screening system: a.) knowledge generation, b.) identification of the eligible population, c.) maximising uptake (informed participation), d.) successful operation of the programme, e.) adequate follow-up, and f.) effective treatment for those that need it. Descriptions of each of these section headings are included in the survey in Appendix A. Given the small numbers of respondents per country, we conducted subgroup analyses by European region (North, East, South and West). **Figure 1** shows the average number of barriers reported by region, **Figure 2** shows the ten most commonly reported barriers from the BEST tool and **Table 1** shows the percentage of countries overall and in each region reporting each barrier by sub-system. The results for each sub-system are discussed further below. Further subgroup analyses by survival for breast, cervical and colon cancer reported in the CONCORD-3 study for each country(Allemani et al., 2018) are included as supplementary material (Supplementary Figures S1-S6).

Figure 1, Figure 2 and Table 1 about here

### Knowledge generation

The three most common barriers to knowledge generation, each reported in over half of countries, were insufficient numbers of trained professionals with knowledge of screening programmes, complex administrative procedures delaying protocol amendments, and insufficient monitoring of screening programmes (uptake, acceptability and outcomes). In the North and South, insufficient trained professionals and inadequate governance structures were particular issues whereas in the West, complex administrative procedures, insufficient monitoring and delays updating guidance were commonly reported.

### Identifying the eligible population

Overall, the three most commonly selected barriers to identifying those to be screened were the population register is not updated with changes of address, some eligible patients are excluded, and there is no follow-up of non-responders after initial screening invitations. The South and East, in particular, reported issues with the correctness and completeness of the population registers and the East and West frequently reported issues relating to eligible patients not being in the register or follow-up of non-responders.

### Maximising uptake (informed participation)

In the vast majority of countries an important barrier to uptake is the existence of opportunistic screening occurring outside of the routine programme. The other three most common barriers, also in over half of countries, are that some people have beliefs and values that lead to non-participation, some people experience practical issues that lead to non-participation, and primary care physicians are not sharing information or promoting screening. Failure by primary care staff to promote screening and non-participation were a particular issue reported commonly in the West whereas opportunistic screening was a frequent issue in the South, and to a lesser extent in the West. The North, South and East all highlighted issues relating to the monitoring of screening.

### Successful operation of the programme

The topmost barriers to operation from those reported, each in over two thirds of countries, are inadequate and/or disjointed information technology (IT) systems, data from opportunistic screening not being collected or shared, opportunistic testing failing to adhere to the same evidence-based screening policy, and limited capacity of screening programmes (insufficient human, physical and financial resources). The East generally reported many operational issues relating opportunistic screening, scarce resources, problems establishing protocols and inadequate IT systems. The South also commonly reported opportunistic screening, logistical and monitoring issues whereas the North were mainly concerned with IT systems. Countries in the West were concerned by provider adherence and opportunistic screening, which may have related to private ownership.

### Adequate follow-up

The barriers to follow up are much more diverse, but insufficient monitoring and evaluation of non-responders, lack of an organisation to monitor follow-up, and difficulties sharing data between clinics regionally and nationally are the most common. Many in the East reported barriers throughout all aspects of this sub-system and in the West many reported issues with organisation, data sharing, provider adherence to recommendations, evaluation and addressing obstacles to participation.

### Effective treatment for those that need it

The three most frequently mentioned barriers to treatment, from all reported, were a lack of systematic monitoring or evaluation of treatment outcomes, failing to track information along the patient journey, and difficulties sharing and accessing data across different regions. The East and West, in particular, highlight issues with monitoring, tracking information and sharing data, as well as non-treatment due a variety of personal and practical issues.

### Other new barriers identified

The survey allowed respondents to describe additional barriers not previously identified by the pilot, although the vast majority had already been identified. However, a few new ones were mentioned and applied across sub-systems: the need for comprehensive IT systems or equipment; insufficient capacity to ensure adequate coverage and minimise waiting times; and the requirement for additional payments by patients in some countries. For the generation of knowledge and effectiveness, slow and inadequate change to guidelines was also reported, albeit for different reasons among countries, including: competition from other or changing political priorities, divisions of responsibility between national and regional organisations, general health system change from public to private sector and reluctance to change traditional practice. Had these barriers been included as a choice response, more countries may have reported these barriers.

## Differences between breast, cervical and colorectal programmes

In certain countries, not all of the three cancer programmes are fully implemented at a population level. In Denmark, colorectal screening has only recently been rolled out, breast screening is new in Slovenia, and in Spain European guidance on population-based screening is not implemented for cervical cancer screening (screening being opportunistic). Germany and Sweden also note that not all programmes are running, Sweden only having mammography, and in Poland breast and cervical screening programmes have recently been stopped. Even in those countries where programmes are implemented, there is still need for a legislative basis for some programmes (Slovenia for breast and cervical screening), larger supported implementation (Albania for cervical cancer), or development of protocols (Hungary for cervical screening).

Opportunistic screening is noted as an issue for cervical cancer screening (Belgium, Croatia, Hungary, Netherlands, Poland, and Spain) and breast cancer screening (France, Hungary, Luxembourg, and Netherlands). Participation seems a particular issue for colorectal cancer screening (Croatia, France, Italy, Malta, Poland, Spain). Low participation may be related to lack of awareness (Croatia, Italy, Malta) and populations including males being less likely to attend than exclusively female populations (Slovenia, Sweden). Different risk perceptions (Sweden, UK) and attitudes (Portugal) to different programmes are also reported. Different levels of participation across programmes are also noted in other countries (Latvia, Portugal and Slovenia) with particular mentions of Romania (low intensity and information for cervical) and Serbia (mammography having the highest attendance). Whilst not a system factor, information on barriers to participation is useful as it can inform system factors such as communication of information and appointment systems.

Examples of differences between programmes relating to the different types of tests used were reported in response to this survey. As noted in Denmark, screening for each of the programmes is operated by different categories of health professionals. In Belgium, appointments must be made for mammography, in Norway cervical screening appointments have to be made with one’s own general practitioner or gynaecologist, whereas colorectal cancer screening with tests such as faecal immunochemical test (FIT) is self-sampling/by post (Belgium, Sweden).

Resource allocation also differs between programmes according to survey respondents. In Italy it is noted that, whilst FIT has enabled the first stage to be operated at low cost, the bottleneck has moved to the second level, colonoscopy. Lack of colonoscopy capacity is also reported elsewhere (Netherlands, Romania, Spain, UK). In Portugal, access to colonoscopy screening is the major constraint, but Serbia reports availability of iFOB (immunochemical faecal occult blood) tests to be an issue. Shortages of mammography facilities (Serbia) and radiologists (Romania, UK) also highlight differences between programmes in different countries.

Finally, monitoring of performance also varies between programmes and countries. Romania reports particular problems while, in the UK, IT issues have created difficulties.

## Overall findings

While noting the considerable national variations reported above, it is also interesting to look at all responses, wherever they came from as results were generally similar with and without duplicate responses from the same country (**Table 2**).

Table 2 about here

# Discussion

## Summary of the evidence

## There was broad consistency across countries in terms of the most common barriers reported. 19 barriers were each reported by over half of countries. The most common barrier was opportunistic screening outside of the population-based programme, not only being selected as a barrier to informed participation but also in terms of successful operation (data collection and sharing, adherence to evidence-based policy and increased cost). The vast majority of countries highlighted non-participation by individuals, mainly due to personal beliefs and values but also practical reasons. The most common barriers relating directly to health services organisation were limited capacity (human, physical and financial resource for successful operation as well as trained staff for knowledge generation), inadequate and/or disjointed IT systems and complex administration procedures delaying knowledge generation. All European regions reported barriers in all sub-systems but patterns varied considerably in different parts of Europe. However, proportionally more countries in the East tended to highlight barriers to identifying eligible patients through accurate registers, following-up non-responders or those requiring more treatment, opportunistic screening, operational issues such as inadequate resources, organisation, protocols, and monitoring. Countries in the North tended to highlight issues such as lack of trained professionals and weak governance, IT, and monitoring. The countries in the West were particularly concerned by administrative procedures delaying updates to guidance, non-participation, lack of follow-up of non-responders and non-adherence to recommendations by providers. In the South, opportunistic screening, problems identifying eligible patients, lack of trained staff, weak governance and logistics, and inadequate monitoring were frequently reported. There were some differences between breast, cervical and colorectal programmes, mainly relating to stage of implementation, level of opportunistic screening and participation, type of test and resource allocation even though, on the whole, there were more similarities than differences.

## Strengths and limitations

The sample covered 31 countries from the European region, thereby providing a wide perspective on current breast, cervical and colorectal cancer screening programmes in Europe. The sample included attendees at a workshop of the EU-TOPIA project who were experts in their national screening programmes. There was a high response rate; for all sub-systems, barrier data was provided for all countries in all but a very small number of cases (were individual respondents had not completed the form, other representatives from their country had largely provided data). The results of this study were generally consistent with the previous pilot study. No issues relating to the tool were reported and the structured answers added to the BEST tool after the pilot were appropriate.

The selection of participants means that they likely had particular characteristics (e.g. being supportive of organised screening) that could bias the results compared with a broader sample, although it would then be necessary to recruit enough and to find ways to resolve disputes. The sample was not large enough to do sub-group analysis by role or country which would have required an identical quota of respondents by role for each country, hence we grouped countries by region and survival of those with the three cancers. Some countries had more respondents than others that may have influenced the overall results. A larger sample could also incorporate other stakeholders from the screening process including members of the screening population, local service providers and health professionals to widen the perspective further.

Due to the time limitations in conducting the survey prior to the workshop, we did not apply a rating or ranking exercise to evaluate the importance of each barrier relative to the other reported barriers. Moreover, we did not apply the CATWOE (Clients, Actors, Transformations, Weltanschauung, Owners, and Environmental) instrument as the pilot had indicated the need for specialists in health systems research to be involved in this analysis. Even though the structured nature of this version of the survey made the exercise quicker to complete and analyse, it may lead to some qualitative elements or subtle differences between countries being lost. This leaves a gap for future barrier research incorporating rating/ranking and the CATWOE approach, as well as further stakeholders. On average, more barriers were identified by respondents working at a national level compared with those working at a regional level. This may be because the national level organisations have more of an oversight of all the components of the system whereas regional organisations focus on certain aspects.

## Comparison with the literature

This study, which uses a soft (health) systems approach and explores the views of expert representatives from screening organisations, researchers and policy-makers, gives a fresh perspective on barriers to organised cancer screening in Europe. Much of the existing literature has been focused on barriers to individual participation from the individual’s perspective. It did not identify any similar studies examining all three cancer screening programmes across Europe, including non-EU states.

The piloting of the BEST instrument compared its results with the EU report(International Agency for Research on Cancer, 2017) on the status of all three cancer programmes. Whilst comprehensive in terms of data, this report is not focused on health service, particularly soft system, barriers. The EUROCHIP study(Drs Paolo Baili, 2012) went some way to evaluating barriers from a health systems perspective, focusing on cervical cancer screening in Eastern Europe(Anttila et al., 2010). This was added to by a survey of screening policies and coverage(Anttila et al., 2009, Nicula et al., 2009) (similar to the BEST tool evaluation of components of the system) and a process performance analysis(Ronco et al., 2009). In addition, other publications highlighted the lack of organised programmes in old member states(Arbyn et al., 2009). Evaluations have found that the performance of screening programmes and the barriers that give rise to inequalities are influenced by a complex system of factors(Dobrossy et al., 2014, Dobrossy et al., 2015). Despite the eight years that have since passed, many of the barriers highlighted in these older studies (e.g. non population-based screening, non-participation, inadequate legislation, disjointed information systems, and lack of resources) are still prevalent today, as highlighted by our study, in many countries across Europe.

Altobelli and Lattanzi(Altobelli and Lattanzi, 2014) have noted the diversity in EU countries in terms of target population coverage and age and in the techniques deployed, but with all constrained by inadequate participation. More recent publications concur that breast cancer programmes are in place in most EU member states but there are still differences, and inadequacies, in terms of implementation and participation(Deandrea et al., 2016). Inequalities in participation in breast and cervical cancer screening programmes, based on socioeconomic status, have been shown to be higher in countries without population-based cancer screening programmes compared with countries with these programmes(Palencia et al., 2010). However, while much research on participation has concentrated on the characteristics of individuals invited for screening, such as age, education, and health status, these do not explain cross country differences in screening performance(Wubker, 2014). This highlights the importance of examining system-level characteristics. Moreover, where individual characteristics, such as socioeconomic position, do have an impact, it is greater with opportunistic than population-based programmes(Walsh et al., 2011).

There is a particular lack of data on health system barriers to effective colorectal cancer screening in Europe. This could be explained, in part by the use of self-sampling at home using FIT which eliminates the need to attend an appointment for an invasive test in the first instance (although colonoscopy is still used at a later stage). A key focus of the evidence is for participation and factors influencing this(Honein-AbouHaidar et al., 2016). According to West et al.(West et al., 2009), whilst there may be differences in approach to colorectal screening, there are similar barriers to overcome in Europe.

## Implications

There is a paucity of data focusing on the health systems aspects of barriers to effective cancer screening programmes. This study goes some way to filling the gap in the evidence. This study provides useful insights to national and regional-level policy-makers so that they can better understand where investment is needed to develop more effective screening programmes. However, more research is still needed to understand the importance of each of the barriers and which should be prioritised in terms of investment of resources. Moreover, the views of local providers, health professionals and the eligible population from the general public should be consulted.

# Conclusion

This study shows that, despite much progress in implementing population-based programmes, there are still considerable barriers to their effective operation, throughout the European region, indicating that, whilst investing resource in some areas for improvement is important, this needs to go hand in hand with an in-depth soft-system analysis of the screening system, identifying barriers to be overcome.

# List of tables and figures

*Table 1: Percentage of countries reporting barriers from each sub-system in BEST tool (all and by European region)*

*Table 2: Number (percentage) of all respondents (and countries) reporting barriers from each sub-system in BEST tool*

Figure 1: Average number of barriers from each BEST sub-system reported in each European region

Figure 2: Percentage of countries in each European region reporting top ten most reported barriers from BEST (all countries)

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