

Title page

Title:

Results of a Health Systems Approach to Identify Barriers to Population-Based Cervical and Colorectal Cancer Screening Programmes in Six European Countries

Conflict of Interest statement:

None

Key words: Cancer screening; health systems; colo-rectal cancer; cervical cancer

Abstract

The aim of this study was to identify barriers to effective cervical and colorectal cancers screening programmes in Europe. The Barriers to Effective Screening Tool (BEST), based on a health systems approach, was completed by teams of three to six experts on cancer screening in each of the six countries involved in leading the EU-TOPIA project (TOwards imProved screening for breast, cervical and colorectal cancer In All of Europe). While the basic components of screening systems and the challenges they face, such as low participation, are similar, there are also many differences, both in the structures underpinning particular functions, such as maintenance of population registers and monitoring outcomes, and the ways that they operate. Many of these lie outside the strict organisational boundaries of screening programmes. BEST offers a means to identify and prioritise issues for further detailed exploration. The holistic health systems approach to assessing barriers differs from previous approaches. Those focus on individual characteristics that determine participation. The approach described here provides additional opportunities to improve outcomes with measures that are largely within the control of those managing the health system.

Introduction

There is now considerable evidence that population-based screening programmes for cervical and colorectal cancers can be effective in reducing incidence and mortality. However many such programmes fail to achieve their full potential, as demonstrated by core performance indicators (International Agency for Research on Cancer, 2017). There are many reasons for this, some lying within the screening programme and others beyond it (Lynge et al., 2012). In the accompanying paper (ref. Turnbull et al 2017, submitted for publication), we described the Barriers to Effective Screening Tool (BEST) that allows the holistic analysis of cancer screening systems, including all those components, or sub-systems, required to achieve optimal outcomes. These sub-systems range from ensuring that the appropriate people are invited for screening through to the effective follow-up of people with detected lesions to confirm that all are appropriately treated. This approach differs from previous research on barriers to cancer screening that has focused on individual characteristics that influence participation in screening programmes. This approach also acknowledges the complexity of the health system and that the success of the programme depends upon how these sub-systems interact.

The first section of BEST, described here, evaluates the various sub-systems of the screening system including generation of knowledge, maximising informed participation, operation of the programme, maximising follow-up and ensuring effective treatment. The second section of the tool explores in more detail the barriers to effective screening programmes and seeks to understand the human factors behind these barriers. It uses a soft systems framework. Soft systems analysis was developed by Checkland (Checkland, 1981) to address the challenges of understanding complex adaptive systems, of which this is an example. Such complex systems, such as the overall screening system, have sub-systems nested within them, each defined by its Clients, Actors, Transformations, Owners, Weltanschauung (vision of the world necessary for its operation) and Environment (CATWOE) influenced by, and interacting with other systems. Humans, unlike the mechanical devices in a hard systems framework, interact with their environment and behave in ways that are complex and often difficult to predict. A soft systems approach can help identify critical challenges to the optimal performance of a screening system and focus attention on the stakeholders whose actions or decisions are key to finding contextually appropriate solutions.

Methods

The accompanying paper described the methodology of the tool in detail, examining breast cancer screening programmes in six European countries who constitute the consortium leading the EU-TOPIA (TOWards imProved screening for breast, cervical and colorectal cancer In All of Europe) project: Estonia, Finland, Hungary, Italy, The Netherlands and Slovenia. The BEST tool was developed by the participating consortium members and was completed by teams of three to six experts on cancer screening in each of the six countries in the first part of 2017. In this paper, we apply this tool to cervical and colorectal cancer screening programmes in the same countries, based on findings obtained using the first part of the tool. The second part involves in-depth analyses, including documentary analysis and interviews with multiple stakeholders, to identify nuanced differences between programmes in terms of how the different sub-systems interact and the outcomes that flow from this process in each country. Due to scale and complexity of these analyses, they will be reported elsewhere in the form of individual case studies.

This paper examines factors that influence operation of screening programmes for both cervical and colorectal cancer. Obviously, there are important differences in the detailed operation of these

programmes, as well as in the stage of implementation. The evidence base for organised colorectal cancer screening is much more recent (Brenner et al., 2014) and it has only been implemented at a population level in three of the countries (Italy, The Netherlands, Slovenia) and in Italy this is only in some regions while, in The Netherlands, progressive roll-out is ongoing (Toes-Zoutendijk et al., 2017). Only pilot programmes are in place in the other countries. In Finland it now covers only about half of the population and in Estonia it has only just started. Self-evidently, many practical and operational differences flow from the nature of the tests used. Cervical cancer screening (Pap smear or liquid cytology/ human papilloma virus testing) involves an examination by a trained professional in a medical facility, while colorectal cancer screening usually involves, at least initially, a faecal sample that can be collected by the individual at home). As we will show, many of the wider systems issues affect both types of screening but, where they differ, this will be noted.

Results

Sub-systems of a cancer screening programme

Figure 1 describes the top-level system components within each sub-system reported by the six countries for their cervical and colorectal cancer screening programmes. There are many similarities, at least superficially, in the overall organisation of both population-based cervical and colorectal programmes in all six countries. For example, the responsibility for cancer screening programmes is at a national level in most cases and most of those invited for screening are identified using population registers. There were also some major organisational differences among countries, for example, whether population registers are maintained at a national, regional or municipal level and the length of time taken before reminders are sent to those eligible for screening.

[Figure 1 about here](#)

Barriers to effective cancer screening programmes

A summary of the key barriers from each sub-sub-system is included in Box 1. Further details of the barriers in each sub-system are presented below.

Box 1: Overview of barriers to effective cervical and colorectal cancer screening programmes

Generation of knowledge	→ Delays to implementation/updates
Identification of the eligible population	→ Incomplete/inaccurate/out-dated population registers
Maximise uptake (informed participation)	→ Opportunistic screening
Operation of the programme	→ Inadequate resources
Maximise follow-up	→ Limited monitoring of long-term follow-up
Ensure effective treatment for those that need it	→ Limited monitoring of long-term treatment

Generation of knowledge

Although guidelines for population-based cancer screening exist in most countries for both types of screening programmes, each of the respondent countries cited certain barriers to their ongoing development and effective implementation. In Hungary, guidelines for population-based colorectal cancer screening are still in development (although guidelines for screening outside the organised programme are available). Delay in publication is, in part, due to complex administrative and legal procedures. A lack of resources and the private ownership of some cytopathology laboratories in Finland is reported to have held back the introduction of new methods of cervical screening. In Slovenia, whilst detailed guidelines exist for colorectal screening, it was reported that providers do not strictly adhere to them. Some general practitioners do not encourage non-responders to participate and there is a general lack of information for patients about colonoscopy.

Identification of eligible screening population

All population-based screening programmes use some form of population register, typically maintained by bodies outside the screening programme. Several issues arise depending on how such registers operate. First, certain groups may be excluded from the register by design, such as undocumented immigrants, temporary residents, and those in secure institutions (e.g. prison). For example, it is estimated that 1% of the resident Dutch population are not included in the register used. In Hungary, data from the National Health Insurance Fund are used so anyone lacking health insurance coverage will not receive an invitation. Second, it is necessary to keep registers up to date. Thus, in Estonia, which has a nationwide population register, it is only updated every three months. The Slovenian respondents noted the challenge of tracking people, especially recent migrants, in temporary accommodation who may move frequently. The challenges may be exacerbated where screening is organised regionally, as in Italy, Finland.

Maximise uptake (informed participation)

Once individuals are correctly identified and invited for screening, they may or may not participate. Consistent with findings elsewhere, respondents noted that certain groups within the population are less likely to participate, especially those of lower socioeconomic status and ethnic minorities (Hungary, Italy, The Netherlands), although there are limited detailed data on differential participation. Thus, there have been a few surveys of non-participation and participant experiences, mostly conducted by screening staff or independent research institutes (Italy, The Netherlands, Slovenia) or from phone and email helplines (Slovenia) but these are usually *ad hoc*. Notably, there is a lack of routine data in terms of whether participation and non-participation is informed, based on an understanding of risks and benefits, as monitoring data are based on uptake rates.

Several countries report limited human and financial resources to promote uptake (especially Hungary, in relation to the colorectal screening pilot) and to follow up queries from individuals seeking clarification or reassurance. For example, a study in Hungary found that the organised cervical screening programme had little impact on women not already attending for opportunistic screening (Gyulai et al., 2015). The system design may introduce barriers, as in Slovenia, where the individual must follow a two-stage process, first completing returning a consent form before being sent a self-test kit. Elsewhere, the two are sent together.

Participation is one area where the nature of the test does matter. Thus, it was reported that some women undergoing cervical screening had concerns about privacy and confidentiality (Estonia) or reluctance to be examined by male doctors/gynaecologists (Slovenia and the Roma population in Hungary). Whilst initial testing for colon cancer using self-tests such as faecal immunochemical tests

(FIT) may not be invasive, there may be a fear of subsequent colonoscopy (Estonia, Slovenia). Fear of cancer was reported as a barrier for both screening tests (Italy).

All countries described organisational factors that acted as barriers to participation, including difficulty scheduling an appointment (Finland, Italy), and long waiting times (Slovenia). In Hungary, there is limited capacity in the official cervical screening programme, which lacks staff and funding.

Opportunistic cervical screening was highlighted as a concern in all countries, although the scale and nature of the problem varied considerably. This is less of a problem with colorectal screening. The most obvious systems factor is the existence of financial incentives that encourage clinicians to offer opportunistic screening, seen as a major issue especially in Hungary. It is, however, difficult, without further research to disentangle the many other factors that play a role, especially as beliefs and attitudes, even those that are longstanding, may themselves be shaped by such incentives but they may also reflect other social and cultural norms. Thus, it was reported that factors encouraging opportunistic screening included perceived higher quality of care (The Netherlands), preference for a physician rather than a nurse (Slovenia), established relationships or a tradition of routine examinations by gynaecologists (Hungary, Italy) and poor knowledge of organised screening programmes (Estonia). Opportunistic screening is a problem; it undermines participation in organised programmes and duplicates efforts with no additional benefit (Makkonen et al., 2017). Simultaneous opportunistic screening hinders data collection; data from opportunistic testing are not usually captured by the screening programme organisers (e.g. in Hungary, from private providers). Opportunistic screening can be conducted outside the recommended age limits, using unapproved methods, and at different intervals from national screening programmes, while lacking appropriate quality assurance (Finland, Hungary).

All countries invite individuals by letter, sometimes followed up by phone calls, but a range of other interventions have been devised to maximise informed participation. However, their use varies across countries and screening programmes. Some emphasise convenience of appointments around work and other commitments (Italy) or enabling choice of appointment (Hungary), while others have improved the availability of female health professionals in designated areas (Italy, Slovenia, Hungary). In Hungary, public health nurses were trained to offer cervical screening opportunities for individuals of lower socioeconomic status and from ethnic minorities. In some countries, it was reported that extending communication through multiple channels and providing good, culturally acceptable information has improved participation (Estonia, Finland, Hungary).

Operation of the programme

Despite the successful implementation of organised screening programmes for cervical and, where population-based programmes have been fully implemented, colorectal cancer, there remain provider-related barriers to their effective operation. In Estonia, Finland and Hungary colorectal pilots are identifying issues that need to be addressed in future scale up.

The under-provision of resources is an issue for all programmes and countries, although the extent to which programmes are affected varies. Human resource requirements include management expertise, organisational skills, administrative support, and sufficient capacity. Financial resource needs include investment into research and development, quality assurance and education on effective screening. Insufficient human and financial resources were reported to limit the scope to undertake quality assurance (Hungary) and improvement (Finland). In Hungary, despite public health nurses having received training in cervical screening, only a small proportion wish to perform the task. Estonian respondents identified a need for greater investment in quality assurance. Italian respondents saw a need for more organisational and administrative support. There was also

reluctance from some health professionals, as well as from the public, to believe in population-based screening in some countries.

Maximisation of follow-up

Despite reminders of the need to follow-up abnormal screening results with diagnostic tests and treatment, people with positive screening test results may still decline to participate. This was attributed to lack of confidence in the diagnostic examinations (Italy), mistrust of evidence-based treatment compared to alternative treatment options (Slovenia), denial of the risk to health (Slovenia for cervical cancer screening), fatalism (that treatment won't work) attitudes (Estonia, Italy), comorbidities or feeling healthy (The Netherlands for colorectal cancer screening). It was also reported that those with other medical conditions may be less likely to attend follow-up (The Netherlands).

There were also numerous barriers at the systems level impeding those requiring further investigation from being followed-up. One issue, particularly noted for cervical cancer screening, is a break in the flow of information in de-centralised systems where there may be poor communication between the screening centres, regions, and providers (The Netherlands, Italy, Finland) so the original screening centre loses track of those screened, particularly if patients move or go elsewhere for treatment (Slovenia). In Hungary, follow-up procedure is not considered as concern of the cervical screening programme. In the Netherlands, the cost of further investigations or treatment is reported as a barrier (even with mandatory health insurance cover, the individual is responsible for a first specified amount spent on specialist treatment each year)(Kroneman et al., 2016). Lack of transportation to facilities for cervical cancer screening, follow-up, and treatment is reported as a barrier for those living in remote areas or for people who are disabled in Slovenia. In Slovenia, 7% of (self-sampling) test positive patients do not attend for colonoscopy, attributed by respondents to the presence of other medical conditions, fear of the examination, or fear of the results. In Estonia, long delays for subsequent investigations and treatment were issues for both programmes.

Ensure access to effective treatment for those that need it

In most countries, any long-term monitoring that does take place is sparse and unsystematic. In Finland for cervical cancer screening, for example, the national screening centre can only monitor up to the primary operation. Information on subsequent management, including oncological treatments, recurrence, metastases, costs, and adverse effects is not tracked systematically. In Estonia, data on additional investigations and treatment are collected, but are sent to the screening registry in free text format. Given the registries' limited resources, this information is not further analysed. In Hungary, screening centres are not informed about subsequent diagnostics and treatment of patients with positive screening tests. In Italy, for both programmes, informants report inadequate data sharing between screening facilities and other healthcare providers and monitoring is constrained by the regional nature of cancer registries. In Italy and Slovenia there is limited data sharing between screening and clinical facilities, exacerbated by insufficient resources. In Slovenia, histology reports are recorded by screening registries, which are linked to the national cancer registry. For colorectal screening, clinicians and pathologists enter data directly into the screening registry and the cervical cancer screening registry is currently in the process of being renewed to include new functionalities for data sharing. In The Netherlands, the gastroenterology association has established a national colonoscopy database to allow future linkage with the screening database but this is not currently implemented. Cancer treatment data are not systematically collected as part of the screening programme, but can be retrieved through linkage with the cancer registry. Provider and patient barriers to treatment uptake were reported as lengthy waiting times for operations (Estonia (cervical cancer screening), Slovenia), poor adherence to guidelines and poor laboratory

quality (Estonia). In Italy, it was reported that women receiving positive screening results and their physicians may have fatalistic attitudes, hindering subsequent treatment.

Discussion

Main findings

All six countries have implemented organised population-based screening programmes for both cervical and colorectal cancer. However, some colorectal cancer programmes are still in the pilot or roll-out phase. Several are organised regionally, with varying degrees of collaboration. Superficially, there are many similarities, in terms of top-level components, identified by the BEST instrument, across countries and for both cancer types. In brief, most programmes are national initiatives (although sometimes implemented at a regional level), population registers are used to identify eligible individuals and follow-up diagnostics are triggered and monitored by screening organisations.

The major barriers for screening are similar across countries and cancer sites, i.e. incomplete, inaccurate, or outdated population registers, the existence of opportunistic screening, inadequate resources, and limited monitoring of long term follow-up and treatment. The extent that each barrier impacts on effectiveness of the screening programme differs widely between countries. It is beyond the scope of this paper to describe in detail why these differences exist, their impact on the performance of screening programmes, and how these various factors play out in each country; this will be described in subsequent publications. However, these differences are likely to be influenced by specific characteristics of the countries in terms of how the screening programme is arranged, the organisation of the health system as a whole (e.g. funding mechanisms or the importance of private providers), screening heritage (i.e. a history of opportunistic screening), the culture of professional practice in relation to screening, and social attitudes to prevention and treatment), as well as the extent to which problems have been recognised and responded to.

Existing literature

The available literature on barriers to screening echoes the findings from our survey that, whilst population-based screening programmes have been implemented for both cervical and colorectal cancer in Europe, they often vary (Basu et al., 2018) and many factors prevent these programmes from functioning optimally. The 2nd European report (International Agency for Research on Cancer, 2017) on the implementation of organized cancer screening programmes across Europe reports that, in 2013, performance was poor, using two common measures, coverage by invitation (the proportion of the subjects in the target age range who received a screening invitation within the scheduled interval in the index year, divided by the total number of eligible subjects) and coverage by examination (the proportion of subjects in the target age range who had a screening test within the scheduled interval over the total number of subjects in the target population). For colorectal cancer, coverage by invitation was 33% and coverage by examination was 14%. Cervical cancer screening programmes achieved invitation and examination coverage rates of 59% and 53% respectively. The report supposes, but does not measure, the possibility that suboptimal coverage of screening for different cancer sites may reflect low levels of acceptance of screening by the population, inadequate engagement by policy-makers and health professionals with quality, socioeconomic inequalities, and the need for adequate resources. However, a key message is that these problems can be overcome. Thus, for cervical screening, coverage by invitation (aged 30-59) ranged from 15.2% (Hungary) to 97.9% in Finland and by examination, from 4.6% in Hungary to

64.4% in Finland, among the countries surveyed in this paper. For colorectal cancer (aged 50-74, although not all countries target all of this age group), coverage by invitation ranges from 2% (Hungary) to 80% (Slovenia) and by examination, from 1% (Hungary) to 41% (Slovenia) respectively (International Agency for Research on Cancer, 2017).

As noted above, it is beyond the scope of this paper to seek to explain how the various barriers identified impact on the performance of screening systems and, in many cases, poor performance is likely to result from a complex of factors. Nor does it propose solutions. Even where they may seem self-evident, such as population registers that are infrequently updated, it is necessary to understand in detail the reasons why they are not. This may relate to, for example, constraints on the organisations that maintain them and a solution will require a detailed assessment of how such constraints can be overcome. This is done to some extent by the second part of BEST, digging down into the sub-system concerned, in this case the maintenance of a population register, seeking to understand who is in ultimate control (ownership), the actors involved, and the Weltanschauung, which covers issues such as attitudes to data sharing and confidentiality.

We hope that our tool will be applied more widely, especially in countries where there have been few evaluations of cancer screening programmes. An initial scoping review that informed our work found that much of the available evidence is focused on reasons why individuals do not participate rather than systems factors, and is from North America. It does identify many of the barriers we found in our study. A systematic review (Chorley et al., 2017) of barriers to cervical cancer screening found that, whilst individual knowledge and perceptions drive intentions to participate, practical issues are important in the decision to translate that intention into action. Other systematic reviews (McLachlan et al., 2012, Honein-AbouHaidar et al., 2016) of barriers to colorectal cancer screening, whilst focused on individual participation, demonstrated a link between awareness and health system factors such as public education and primary care physician efforts.

Strengths and weaknesses of the study

The whole health systems methods used here offered a holistic approach to identify the barriers to effective organized screening programmes. This differs from previous approaches to barriers to screening that focus on identifying population groups who are less likely to participate and explaining the reasons for non-participation. This holistic approach identifies health system barriers. Some are within the control of those managing screening programmes but others require action at a higher level to address factors that apply to the health or other systems more generally, such as co-ordination between the screening programme and clinical providers or cancer registries, or rules of entitlement to services. In addition, although not included in this approach, there are many specific measures that can be done at the level of service delivery, such as creating a welcoming environment with short waiting times, and engagement between staff undertaking screening and those being screened to ensure shared decision-making. However, this level of detail is beyond the scope of this tool which would otherwise be unmanageable.

Experts in cancer screening programmes from across Europe contributed to its design and the six countries included covered geographically diverse regions of Europe with different socioeconomic, political and healthcare settings. This was a survey of professionals involved in planning and governing screening programmes whereas most previous surveys have targeted subjects invited for screening and, on occasion, providers. Professionals organising screening are aware of patient-related barriers as well as organisational barriers.

Ultimately, a more extensive survey, including other countries and a wider range of stakeholders (including health professionals directly involved in screening and the local organisation of services), will be required to obtain a full picture of the barriers to effective screening programmes for breast, cervical and colorectal cancer screening in Europe. Due to the complexity of these screening programmes, there may have been some barriers that this tool did not identify. However, no survey such as this can fully capture the impact of the barriers identified and how to overcome them. That will require targeted evaluative research.

Implications

The approach we have described offers a systematic means to understand the interlinked elements of a screening system and to identify the barriers that exist to its optimal functioning. However, it can only be a first step. Additional research, often involving mixed methods, will be necessary to understand the barriers and, while in many cases, the measures required will be obvious, in some cases there will have to be further evaluative studies to ascertain what works in each context. The detailed analysis of each phase of the screening process, referring to existing constructs, allows the consideration of issues that are not often highlighted. This will be necessary, for example, in finding solutions to low participation due to cultural norms and beliefs, or the existence, within the health system, of competing incentives that are kept hidden by key actors.

Whilst we did not investigate the incidence and impact of each barrier reported, the survey highlighted barriers that were evident in the vast majority of countries. This may provide some indication of where to invest resources to improve screening implementation. Interventions that improve the accuracy of population registers, minimise opportunistic screening, connect information systems and improve communication between policy makers, organisers, providers and the population at risk are essential.

Conclusions

This study showed that many of the barriers to population-based screening are common across breast, cervical and colorectal cancer screening programmes, and across the six countries surveyed, although their scale, nature, and impacts vary considerably. The barriers arise in different elements, or sub systems of the overall screening system, including inadequate information systems, opportunistic screening, factors leading to non-participation, financial and human resource constraints, and inadequate communication between organisations and individuals. The tool reported in this paper, based on the soft systems approach, provides an analytical approach that incorporated all these issues.

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Figure 1: System components of a cervical or colorectal cancer screening programme in six European countries

