

Title page

Title:

A Health Systems Approach to Identifying Barriers to Breast Cancer Screening Programmes. Methodology and Application in Six European Countries

Key words: Cancer screening; health systems; breast cancer

Conflict of Interest statement:

None

Abstract

The benefits of population-based screening for breast cancer are now accepted although, in practice, programmes often fail to achieve their full potential. In this paper, we propose a conceptual model that situates screening programmes within the broader health system to understand the factors that influence their outcomes. We view the overall screening system as having multiple sub-systems to identify the population at risk, generate knowledge of effectiveness, maximise uptake, operate the programme, and optimise follow-up and assurance of subsequent treatment. Based on this model we have developed a Barrier to Effective Screening Tool (BEST) for analysing government-led, population-based screening programmes from a health systems perspective. Conceived as a self-assessment tool, we piloted the tool with key informants in six European countries (Estonia, Finland, Hungary, Italy, The Netherlands and Slovenia) to identify barriers to the optimal operation of population-based breast cancer screening programmes. The pilot provided valuable feedback on the barriers affecting breast cancer screening programmes and stimulated a greater recognition among those operating them of the need to take a health systems perspective. In addition, the pilot led to further development of the tool and provided a foundation for further research into how to overcome the identified barriers.

Introduction

The benefits of organised, population-based screening programmes for breast cancer for women of a certain age are now widely established (Independent UK Panel on Breast Cancer Screening, 2012, Siu and Force, 2016). Yet, in practice, cancer screening programmes often fail to achieve their full potential (Waller et al., 2009, Williams et al., 2014, International Agency for Research on Cancer, 2017). This is not, primarily, because of ignorance about how to screen for breast cancer. The European Union (EU) has made clear recommendations, based on robust evidence, on organised screening for breast cancer (European Council, 2003, European Commission, 2013). Rather, it is because screening, as implemented, falls short of the ideal (European Commission, 2008, International Agency for Research on Cancer, 2017). There are many reasons for this. Some relate to technical aspects of screening activities, such as inappropriate equipment or poorly trained staff, but others lie outside the organisational boundaries of screening programmes, relating to the ability to engage with target populations or health system characteristics that make it difficult to translate early detection of disease, if achieved, into health gain (Altobelli et al., 2017, Rahal et al., 2017, Sankaranarayanan, 2014). These latter barriers may not always be appreciated, especially where assessments are focused on narrow definitions of the screening process.

Breast cancer screening is not unique in this respect. There are many well-established treatments, such as the management of diabetes (Nolte et al., 2006) or control of hypertension (Palafox et al., 2016), where there are clear evidence-based pathways but, in reality, outcomes vary greatly. Recognition of these obstacles to effective implementation has encouraged the growth of health systems research, seeking to understand the barriers to achieving optimal outcomes and how they can be addressed. Health systems have elements that are hard systems, where the components are mechanical and, crucially, usually behave in ways that are entirely predictable, but mostly they involve soft systems (Jacobs, 2004, Checkland and Scholes, 1999) whereby the system in question is populated by humans who act in ways that achieve change, in the face of constraints, while influenced by their environment and values (Rose and Haynes, 1999, Midgley, 2006, Checkland, 1981). Soft (and some hard) systems exist within and contain other systems, each interacting with each other, and with properties that emerge at each level (Checkland, 1981). For example, a screening system will usually be embedded within a health system, and should contain within it a system for identifying the target population.

In this paper, we apply a health systems approach to identifying barriers to breast cancer screening. Our starting point is that outcomes are optimised where government-led, population-based screening programmes are organised rather than opportunistic, where they include all those for whom the benefits outweigh the harms, where they deliver coordinated, evidence-based screening, and where they ensure those identified as requiring further follow up and treatment receive it (Senore et al., 2015, Arbyn et al., 2010). However, we recognise that there are many reasons why it may be difficult to achieve these goals. For example, data protection provisions may make it difficult to identify those who can benefit (Arbyn and Van Oyen, 2000). Systems for paying healthcare providers may fail to incentivise physicians to engage in organised screening and mitigate against the development of integrated pathways (Fabrizio and Shea, 2014). Health care financing systems may impede access to treatment (Wolff et al., 2003). On the other hand, even where these barriers exist, there may be mechanisms by which they can be overcome. Thus, in the area of cancer care, where integrated care

pathways are also important, countries such as France, with a multiplicity of public and private providers, are able to bring them together within regional plans (Voidey et al., 2014, Sommelet and Bey, 2006).

The European Union funded EU-TOPIA (Towards improved screening for breast, cervical and colorectal cancer in all of Europe) project aims to improve health outcomes and equity of breast, cervical and colorectal cancer screening programmes in ways that take full account of the different demographical, medical, political, economic and cultural contexts across Europe. The project aims to do so by providing national, regional, and local policymakers with tools to evaluate and quantify their cancer screening programmes. One part of this project is to identify barriers, explain inequities in cancer screening programmes between European countries and demographic groups and explore ways to overcome these barriers.

This objective of the analysis presented in this paper is to identify barriers to effective breast cancer screening in Europe by piloting a new evaluation tool created for this purpose using health systems methodology. We first propose a conceptual model for analysing population-based screening programmes within the health system. Going beyond the conventional approach, which focuses on those elements internal to the screening programme, we explore the way in which the broader health system, and the context within which it is embedded, influence the outcomes of cancer screening. Secondly, to operationalise these findings, we present a tool based on the conceptual model for the evaluation of barriers to optimal population-based screening programmes from a health systems perspective and report the results of a pilot exercise with key informants in six European countries. A similar exercise for cervical and colorectal cancer, and other countries, is reported in two further publications in this series (Turnbull et al., 2018 and Prialux et al. 2018, accepted for publication).

Materials and methods

We began with Wilson and Jungner's long-established criteria for establishing a screening programme (Wilson and Jungner, 1968, Andermann et al., 2008) which was used to inform a scoping review of policy documents and published literature, followed by discussions with experts in cancer screening. Drawing on literature on barriers to effective cancer screening (**Box 1**), research on system-level barriers to other forms of healthcare (Maimaris et al., 2013) and previous reports on the successful implementation of population-based screening programmes (Lynge et al., 2012, Anttila et al., 2015), we identified a series of sub-systems of an overall screening system, each defined by its functions (Nolte et al., 2005). We presented them to a meeting of experts in cancer screening from across Europe in early 2017 to ensure that they had face and content validity. We recognised that the organisational boundaries of these sub-systems and the actors involved would vary among countries, reflecting factors such as the organisation of public administration, the degree of physician autonomy, and the system for financing health care.

This led us to create a conceptual model in which we identify six interlinked sub-systems. The first is a system of knowledge generation, using research to identify which conditions should be screened for and how screening should be undertaken, both technically and organisationally, with provision for incorporating emerging evidence. The second is a system to identify the entire population at risk and to present information to those operating the system. This will normally take the form of a population register. The third seeks to maximise informed participation, identifying those who are less likely to

undergo screening and, where appropriate, to devise interventions to overcome this. The fourth is a managerial system, designed to ensure the sustainable operation of the screening programme. The fifth seeks to ensure that those identified as requiring further investigation are followed up adequately. The final sub-system ensures access to effective treatment for those who need it.

From the conceptual model we then developed the Barrier to Effective Screening Tool (BEST), a series of questions to define how each sub-system can optimise health gain from screening in each country and the barriers to doing so (**Table 1**). In a pilot exercise conducted from January to June 2017, the BEST tool was then completed by key informants knowledgeable about screening programmes in six European countries: Estonia, Finland, Hungary, Italy, The Netherlands and Slovenia, seeking information on screening programmes for breast cancer. Selected data on screening activity in each country is presented in **Table 2**. More detailed information for all EU Member States can be found in the most recent European Commission report on the implementation of cancer screening (International Agency for Research on Cancer, 2017). Following the pilot, feedback on the tool was obtained from participants and the tool was updated accordingly.

Informants were selected using snowball sampling, starting with the partners from the EU-TOPIA project countries. However, as no one person can be expected to have detailed knowledge of all aspects of the screening system, each then identified individuals knowledgeable about other aspects of the screening programmes and related activities. It should be emphasized that the barriers are the opinion of the respondents and that the impact of barriers varies, depending in part on measures taken to mitigate their effects. The countries (and numbers of respondents contributing to the single collated response in each country) were: Finland (6); Hungary, (4); The Netherlands (6); Slovenia (4); Italy (3), and Estonia (3). Respondents included experts working within the breast screening programme (Estonia, Finland, Italy, Slovenia) and researchers (Hungary, Italy, The Netherlands) who then contacted experts within the national screening programmes (Hungary) and independent monitoring organisations (Netherlands).

Results

Figure 1 brings together all barriers identified from any of the countries included, showing the sub-system in which they occur. In the remainder of this section we summarise the processes involved in each sub-system and how it relates to the identified barriers for that sub-system.

Generation of knowledge and effectiveness

Few barriers in this sub-system were identified. In all countries, the EU guidelines for implementing breast cancer screening form the basis of local policies, either as they are (Finland) or adapted by committees of national experts (Estonia, Slovenia) or by National Institutes (The Netherlands, Italy, Hungary). The Ministry of Health (or equivalent) is responsible for assessing screening needs and evaluating programmes in The Netherlands, Italy and Estonia, with other national organisations responsible in Hungary, Finland and Slovenia. Only Hungary and The Netherlands report barriers in this sub-system. In The Netherlands, when implementing the new, national breast cancer screening protocol, this was a slow process as, when programme adjustments are needed, many parties are involved. In Hungary, guidelines are not updated regularly because the Ministry of Human Resources,

part of the Department of Health, needs to publish the document which is a very slow process. The Breast Cancer Screening Workgroup completed the National Breast Cancer Screening Protocol but there has been no further activity and it has not been updated.

Identification of population at risk

Whilst all countries have a process for identifying women who are eligible for breast cancer screening, barriers to identification exist due to out-of-date, incorrect or incomplete information in the source register. All six countries identify women eligible for breast cancer screening using population registers that are maintained by national authorities within government in Estonia and Slovenia, by regional or municipal authorities in The Netherlands, Finland and Italy, and by the National Health Insurance Fund in Hungary. When the register is not updated in real time, out-of-date data in the register may lead to eligible women not being identified and ineligible women being incorrectly invited. Registers in Finland (used by 90% of municipalities using the invitation service), The Netherlands, Slovenia and Hungary are updated in real time, as individuals register changes of addresses or their deaths are registered, at least every month in Italy and every three months in Estonia. All countries have mechanisms in place for ruling out those ineligible for screening, such as post-mastectomy or deceased women but inaccurate data can be an issue. For example, in Hungary, data entry errors and limited data cleaning lead to ineligible women receiving invitations and invitations being sent to wrong or incomplete addresses. The latter can also be the case when women relocate and postal addresses are not simultaneously updated in the registry. Specific problems include difficulties linking data across regions (Italy) and capturing details of those in temporary accommodation (Slovenia). In The Netherlands and Finland, where screening is operated by regional authorities (albeit coordinated nationally in The Netherlands), intervals between invitations may not be co-ordinated when people move between regions. This is particularly relevant for immigrants who may move multiple times. In Estonia, as previously mentioned, the register is updated only every three months to capture changes.

Another barrier to identification is when eligible people are excluded from or are never registered on the population register and are therefore not invited for screening. The groups affected vary by country, but generally include undocumented migrants and non-permanent residents. This is estimated to include 1% of the population in The Netherlands. Where health insurance registers are used, those without coverage are excluded, as in Slovenia, where 0.3-1% of the population are uninsured. Even where those lacking insurance coverage are included, they may be less likely to attend, as in Estonia, where an estimated 3-5% of the population lack coverage. In Finland, an estimated 2% of the target population do not receive an invitation, mainly women who have been resident for under twelve months, but also those in institutions or under a protection order as their addresses are withheld. Other barriers to identifying the population requiring screening and subsequent invitation include insufficient human and financial resources to follow up queries in Hungary; and organisational weaknesses in some Finnish municipalities, reflecting the highly decentralised system.

Maximise uptake (informed participation)

Barriers to informed participation can include practical issues, lack of awareness, beliefs and values. Practical issues mainly relate to organising and attending mammography appointments. Most countries offer all eligible women a pre-allocated, modifiable appointment, although Hungary

provides two alternative appointments, and Estonia provides contact information for all screening clinics, leaving the onus on the woman concerned. Non-attendance may be associated with the characteristics of the service. Distance to clinics can hinder attendance in Finland and Estonia, although in Estonia this is addressed using two mammography buses. Women may also forget to attend these appointments (Finland, Slovenia). Repeat letters are always sent but the interval differs considerably, with Slovenia sending a repeat letter after three weeks and Estonia waiting until the end of the calendar year.

Lack of access to health services can be a barrier to informed participation, influenced by the characteristics of service users and providers. Informants described a lack of awareness of the objectives of screening or of its relevance to the target population (Estonia) particularly those who are younger, those of low socioeconomic status, and ethnic minorities (The Netherlands, Italy). Most countries use one invitation letter for all ethnicities (Estonia (Estonian and Russian), Finland (in Swedish and Finnish), Hungary, The Netherlands, Slovenia), although some information is translated into other languages for ethnic minorities (Finland (in development), The Netherlands, Slovenia). Beliefs and values such as privacy and confidentiality concerns (Estonia); lack of time (Finland, Slovenia); fear of being diagnosed with cancer and believing screening to be ineffective (Italy) can also be obstacles to uptake.

The main barrier to the compilation and analysis of data on informed participation, including information on sociodemographic inequalities is the existence of opportunistic screening, reported as a major problem by all countries. Whilst organised programmes monitor uptake among those invited, co-existing opportunistic screening is not systematically monitored. The survey identified a variety of incentives for opportunistic screening. In Slovenia, the national health insurance institute is not paying for opportunistic screening for women aged 50-69, although it happens that clinicians perform preventative mammography outside organised screening, listing other reasons for doing it. Elsewhere it is the women being screened who are incentivised, as in The Netherlands where opportunistic screening is perceived to be of higher quality by some women. In Slovenia, it is reported that women prefer opportunistic screening by a doctor over routine screening by a radiographer (Slovenia). In Finland, private providers promote their service by advertising. The random nature of opportunistic screening means it often fails to comply with guidelines and policies on, for example, age limits, intervals, procedures, or quality control, and data are not routinely provided to those responsible for the organised screening programme. Opportunistic screening may be performed by service providers who are not accredited for mammographic screening (Hungary).

Lack of interest among system owners/actors to overcome barriers to screening uptake in Hungary is, in itself, an obstacle to maximising informed participation. There is no formal system for evaluating levels and patterns of informed participation and uptake is based on individual responsibility. Consistent with this view, there is no system in place to follow up patients requiring further treatment, as this is viewed as lying outside the purview of the screening programme.

Operation of the programme

Several countries identify private ownership of screening facilities as a barrier to ensuring optimal screening practices. This is particularly so in Finland, where those with national responsibility for the screening programme only have basic monitoring and evaluation mechanisms. Private operators are

reluctant to invest resources in research and development. In Hungary, limited capacity in facilities within the formal programme means that many women use non-accredited mammography centres, where regional screening coordinators cannot monitor practices. Several countries also identify public and professional beliefs as a barrier to optimising screening. In Slovenia and Italy, many providers implement opportunistic screening outside the programme at longer (three years) or shorter (18 months) intervals. Informants from Italy describe a lack of professionals with adequate organisational skills, while clinicians struggle to provide screening without the necessary administrative support. Lastly, respondents in Finland noted the practical challenges of screening disabled women who are not able to stand for mammography and who may not get invitations if living in institutions.

Poor quality or inappropriate services leading to bad experiences of screening can be a barrier to the successful operation of a programme. Inconvenient appointment times, male health professionals and being screened in an environment alongside cancer treatment can be a deterrent to participation for some women. However, in the included countries, this barrier is less acute as authorities and screening organisers monitor and act on experiences of those undergoing screening, to ensure quality, maximise informed participation and maximise acceptability of the screening programme.

Maximisation of follow-up

Although all countries, except Hungary, have procedures in place to ensure that those who are identified as requiring further investigation are followed up, it is still the case that some people do not respond. Screening providers use phone calls, letters or a combination of both for informing and reminding people who need follow-up investigations in Estonia (including e-mail), The Netherlands, Finland and Italy. Non-responders are reminded by letter in Finland, The Netherlands and Italy. In Slovenia, screening providers ring all patients personally whilst in Estonia they send out initial results letters to patients (additional investigations are carried out by the same unit as the screening mammogram) but non-responders are contacted by phone. In Italy, for example, an information technology (IT) programme includes a fail-safe system prompting screening staff to contact subjects who do not respond. All those who do not attend within a given interval (usually three months) are sent a letter explaining the rationale for follow-up, including their results and inviting them to seek care outside the screening programme. Yet despite these interventions, there are still women who decline follow-up. Informants identify a lack of confidence in the effectiveness of preventive examinations (Italy), a mistrust of the treatment options (Slovenia), denial of the severity of their health situation (Slovenia) or fatalistic attitudes (Estonia, Italy).

Even when women do seek follow-up, they may face practical barriers to doing so. These include insufficient radiographers and radiologists (Italy), long waiting times for additional investigations and treatment (Estonia), difficulties accessing clinics because of poor transportation (Slovenia) and financial concerns. In The Netherlands, for example, some patients may decline further diagnostics or treatment because of the cost involved (although health insurance is mandatory, an initial co-payment has to be made by the individual). Difficulties may also arise if patients move house after screening or choose to go elsewhere for further assessment. In countries with decentralised systems, there are concerns about poor communication and data sharing between regions and providers (The Netherlands, Italy, Finland) meaning that the original screening centre does not have access to results and treatment. Lastly, in Finland and Slovenia, informants report that clinicians might deem further

assessment and/or treatment inappropriate or recommend postponement for some patients with serious comorbidities.

Assurance of effective treatment

An absence of monitoring and evaluation of treatment of those diagnosed with breast cancer as a result of screening can be an impediment to an effective screening system. If health gains are to be maximised, it is important that those requiring treatment receive it. However, in both Hungary and The Netherlands, this is considered the responsibility of the woman herself and is outside the responsibility of the screening programme. In Slovenia, there are links to the national cancer registry. Elsewhere, any monitoring that does take place is sparse and unsystematic. In Finland, for example, the screening organisation can monitor only up to the primary operation. Information on subsequent management, for example, oncological treatments, possible recurrence/metastasis, costs, adverse effects of management, etc. is not tracked systematically. In Estonia, data on additional investigations and treatment are collected, but are sent to screening providers in free text format. Given their limited resources, this information is not further analysed. In Italy, informants describe inadequate data sharing between screening facilities and other healthcare providers, while monitoring is constrained by cancer registries only covering part of the country.

Provider and patient barriers to treatment uptake include lengthy waiting times for operations (Estonia, Slovenia), insufficient radiographers and radiologists (Italy), concerns from providers about the benefit-harm ration of treatment (Estonia) and, from the patient's perspective, fatalistic attitudes and lack of confidence on the effectiveness of preventive examinations (Italy).

Feedback from those using the tool

Those using the tool, all experts in operation of screening programmes, welcomed the opportunity to look holistically at the screening system, something that they report is rarely done. The tool was well received by respondents, in part because it has enabled them to identify barriers that they were previously unaware of, both through contact with other experts or analysing known problems from a new perspective. This has prompted them to see their screening programme in a different light, allowing them to identify areas needing improvement.

Respondents reported that 'questions were comprehensive and triggered valuable discussions on our programmes and the need to develop them'. However, they also provided valuable critique of the tool: an overarching concern was that the survey did not elicit background information about the health system (e.g. services provided, legal framework, and financing), the organisation of screening services and the variety of possible relationships between the screening organisation and the country's health system. As this emerged during our initial review of survey responses, we subsequently requested all countries provide an in-depth description of the process of identifying invitees, now incorporated in the revised tool. A further suggested addition was for a sub-system focusing entirely on quality assurance and monitoring, since respondents felt that programme evaluation was not adequately covered. The piloting also allowed us to identify some questions in the initial version that we could remove in order to minimise the time and resource required to complete the survey (e.g.: "Are processes to create guidelines consistent with best practice (e.g. advancing guideline development, reporting and evaluation in health care(AGREE Enterprise, 2017). Finally, although the tool identified many barriers, it could not quantify the impact they had on screening

outcomes. This is something that we plan to examine in the future, when we have more data, drawing on methods such as quantitative comparative analysis, which use Boolean algebraic techniques to identify those factors that are necessary and those that are sufficient for a programme to operate effectively (Rihoux and Grimm, 2006).

There was a large discrepancy in time taken to complete the tables of the survey (**Table 1**). This may be due to the different ways screening programmes are organised among countries, meaning that some respondents were responsible for most aspects of the screening programme whilst other respondents needed to contact the relevant screening institutes and stakeholders to answer the questions; a much lengthier process. It may also relate to level of detail provided. This prompted discussion on the comparability of results between countries since some respondents may have understood questions differently or found it easier to think of more potential barriers than others. Respondents called for simplification with a more structured tool that included both free text space to describe the background of each sub-system with prompting questions and standardised options (e.g. a list of all potential barriers to prompt responders to think of additional barriers). This has now been developed (see web **Appendix**).

Discussion

The BEST tool is specifically oriented to screening, but it has relationships with other conceptual frameworks, adopting a system-wide approach to understanding barriers to effective preventive interventions, or cancer care, such as the PRECEDE-PROCEED (Green, 2005, Green and Kreuter, 2005) and the National Cancer Institute (NCI) continuum in Cancer Care models (Division of Cancer Control and Population Sciences (DCCPS), 1970). Maximisation of uptake and of follow-up, as well as assurance of subsequent treatment, relate to the transitions of the NCI model. However, the BEST approach differs in its comprehensiveness and ability to consider multiple screening sub-systems. This directs attention to organisational modalities, including programme infrastructure, or governance, which are rarely evaluated in other approaches.

Using the BEST approach, we showed that barriers could be identified at every step of the screening process in all countries, with a surprisingly large number uncovered within the subsystem, 'identification of the population at risk'. This may be the most critical aspect of a screening programme since, if the right women are not being invited, there is little that can be done at subsequent stages in the screening process to compensate. Barriers to maximising participation are also a key concern and links to the previous sub-system as the nature of invitations, the arrangement of appointments and the information provided alongside invitations may affect informed participation.

Many of the barriers are common to different countries, such as women seeking and being offered screening opportunistically outside of the routine programme and non-participation in either screening or follow-up due to beliefs, values or practical issues, although some issues are country specific. For example, capacity and resource issues vary by country, as do obstacles for updating protocols and processes, which are more of an issue in some countries more than others.

Conclusion

This process has provided valuable feedback on the use of the BEST tool. It highlighted the need to begin with a clear description of the health system within which screening takes place. The first part of the tool, defining the sub-systems and identifying the barriers, can be undertaken as a self-assessment by those operating screening programmes, albeit if accompanied by appropriate explanation. In addition, we have further developed our survey tool (see web appendices) to include, as suggested, a mixture of open-ended questions to describe each subsystem and a checklist of all potential screening programme barriers. We are now in the process of gaining further experience with this approach in other European countries. This will also pave the way for further health systems research into how to overcome these barriers.

List of figures

Figure 1: Flow chart of all identified barriers to breast cancer screening programmes in six European countries.

Table 1: Pilot version of the Barriers to Effective Screening Tool (BEST)

We are writing to seek your assistance with an initial analysis of the systems in your country for screening for breast, cervix and colorectal cancer. We are asking you to use your own knowledge of your systems to characterise the key elements (or sub-systems) that make up the overall cancer systems. Given your expertise, we hope that this will be relatively easy, although we appreciate that the approach that we are taking may require some thought to apply.

We are defining each screening system (not programme) as “those activities that are undertaken in each country with the primary intention of diagnosing cancer early”. We realise that, in some countries, screening does not take place within an organised programme and, even where there is a programme, some activities may take place outside it; at this stage that is not a problem as we want to get a picture of the overall system.

We have identified a number of sub-systems that, ideally, would be in place to ensure the optimal operation of the overall cancer system. These are:

1. a sub-system to identify the entire population at risk and to present information to those operating the system. This will often take the form of the population register.
2. a sub-system to generate knowledge, to identify which conditions should be screened for and how screening should be undertaken, both technically and organisationally
3. a sub-system designed to maximise uptake, identifying those who are less likely to undergo screening and, where appropriate, to devise interventions to improve their uptake
4. a managerial sub-system, designed to ensure the sustainable operation of the screening programme.
5. a sub-system to ensure that those who are identified as requiring further investigation are followed up adequately
6. a sub-system that ensures access to effective treatment for those who need it

Sub-system	Initial questions
Generation of knowledge and effectiveness	<ul style="list-style-type: none"> • Who is responsible for assessing needs, evaluating evidence, system design? • What skills do they have access to? • What linkages do they have to other sources of expertise (universities, European collaborators etc.)?
Identification of population at risk	<ul style="list-style-type: none"> • Who is included (citizenship, geographical coverage, insurance status etc.)? • What data items are held? • To what extent can data provide a denominator by, e.g. ethnicity, socioeconomic status (including via record linkage)? • We are looking for a level of details as follows: <ul style="list-style-type: none"> • This register is maintained by XX • Using information from the XX • New information is updated in the population registry by XXX • The registry does not include XXX • Evaluations/assessments of the completeness of the registry and how accurate/up to data they are conducted on a XX basis by XX authority • Barriers to this system are XXX • Eligible women are informed about the need for screening by XXX • The screening invitation letter gives XXX information • Follow up of the screening invitation letter is XXX • Monitoring of numbers of attending screening/making appointment after receiving invitation letters is done by XXX

Maximisation of uptake (informed participation)	<ul style="list-style-type: none"> • Who is responsible for monitoring uptake? • What population sub-groups (e.g. ethnicity) do they monitor? • What problems have they identified? • What have they done to overcome them?
Operation of the programme	<ul style="list-style-type: none"> • Who sets guidelines for screening processes, and how? • Are processes to create guidelines consistent with best practice (e.g. AGREE)? • Who monitors quality of the screening process (e.g. experience of screeners, technical quality, management of positive/negative results, overview of positive predictive value, specificity, interval cancers etc.)? • What quality assurance systems are in place (including critical incident reporting)? • How are the experiences of those undergoing screening monitored, and what steps are taken to remedy problems?
Maximisation of follow-up	<ul style="list-style-type: none"> • Who is responsible? • What measures are taken to ensure follow up of screen positive cases? • What is done in respect of non-responders?
Assurance of subsequent treatment	<ul style="list-style-type: none"> • Who is responsible? • Who monitors uptake and outcomes of treatment? • What links are in place to cancer registration?

Table 2 Selected characteristics of screening activity in the included countries

Country	Year initiated	Screening interval (years)	Target age (years)	Target population in population-based Screening programmes
Estonia	2003	2	50-64	141,000
Finland	1987	2	50-69	761,000
Hungary	2001	2	45-64	1,045,000
Italy	1990	1 (45-49); 2 (50-74)	50-69 *	8,269,000
The Netherlands	1989	2	50-75	2,276,000
Slovenia	2008	2	50-69	283,000

Source: European Commission. Cancer screening in the European Union 2017

* 45-74 years in Piemonte and Emilia Romagna

Box 1 Previous research on barriers to effective screening

Much research has focused on barriers at the individual level (Pasick and Burke, 2008, Curry and Emmons, 1994). These include the health belief model (HBM) (Janz and Becker, 1984, Beckers, 1974, Rahman et al., 2005, Johnson et al., 2008), trans-theoretical model (Prochaska, 1991, Prochaska et al., 1994, Spencer et al., 2005), theory of planned behaviour (Ajzen, 2011, Ajzen, 2015), social support theory (Ashida and Heaney, 2008, House et al., 1988, Umberson et al., 2010, Umberson and Montez, 2010) and social cognitive theory (Bandura, 1989, Bandura, 1998), theory reasoned action (Michels et al., 1995, Cooke and French, 2008) and prospect theory (Curry and Emmons, 1994, Ackerson and Preston, 2009). However, these models tend to say little about the screening system itself or its social, cultural or environmental context (Pasick and Burke, 2008) and evidence associating model constructs to screening behaviour or interventions is limited except for the HBM (Kiviniemi et al., 2011). Recognising the multi-dimensional and multi-disciplinary structure of screening settings, there have been several attempts to take a system-wide approach to understanding barriers to effective cancer screening.

The PRECEDE-PROCEED model (Green and Kreuter, 2005, Green, 2005) has been used widely to assess the importance of factors affecting preventive and health promotion interventions, including cancer screening (Garbers et al., 2003, Senore et al., 2015, Tejada et al., 2009, Ogedegbe et al., 2005, Giorgi Rossi et al., 2017). In Italy, the Ministry of Health has funded a project to implement a tool, based on PRECEDE-PROCEED, to assess barriers and to support planning of interventions aimed to enhance uptake of regional screening programmes by addressing identified barriers (Bellentani and Regionali., 2012). The model includes two components, the second one (PROCEED) including the design, implementation and evaluation of the interventions based on the multilevel diagnosis of barriers (PRECEDE). The application of the full model has proven very resource intensive and it has often only been applied partially mainly for the assessment of influential barriers and of the understanding of their relationship (Pasick and Burke, 2008).

The Cancer Control Continuum model from the National Cancer Institute (Division of Cancer Control and Population Sciences (DCCPS), 1970) also provides a framework to describe various phases in the process of care including cancer prevention, early detection, diagnosis, treatment, survivorship, and end-of life care. It aids understanding of transitions across and within these phases, although as understanding of cancer has evolved there is now more recognition that these phases overlap. Although simplified, the model can be useful to assess plans, progress, and priorities for cancer screening programmes, as well as identify gaps in evidence and resources (Anhang Price et al., 2010).

Models that emphasise multiple strategies to address inefficiencies in population-based cancer screening include the Cancer Screening Health Promotion Model (Alberta Health Services et al., 2010) which combines the population health promotion model and the PRECEDE-PROCEED model with the Ottawa Charter for Health Promotion.

Web Appendices

- Amended barrier analysis tool

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- Screening guidelines/ protocols not regularly updated

- Population register not complete or regularly updated
- Eligible women not included in register
- Access limited by health insurance
- Capacity of screening organisation

- Screening providers do not follow protocol/standard operating procedures
- Private ownership of screening facilities
- Limited capacity of screening programme
- No shared outcome data from opportunistic screening
- Opportunistic screening does not keep the same evidence-based screening policy as programme recommendations

- Insufficient monitoring and evaluation:
- screening programme outcomes
 - follow-up for further investigation
 - treatment outcomes

Generation of knowledge and effectiveness

Identification of population at risk

Maximisation of uptake (informed participation)

Operation of the programme

Maximisation of follow-up

Assurance of subsequent treatment

- Eligible women not invited for screening
- Insufficient capacity to identify and invite all eligible women for screening

- Women don't attend because:
- screening appointments unacceptable
 - opportunistic screening
 - personal beliefs
 - objective obstacles

- No follow up of non-responders needing further investigation
- Personal beliefs or objective obstacles mean women choose not to have further examination or treatment
- Insufficient capacity means some patients requiring follow-up do not receive it

- Insufficient monitoring and evaluation:
- screening uptake
 - screenee experiences
 - personal beliefs
 - objective obstacles

- Assuring treatment is not the responsibility of the screening programme
- Effective treatment is not available to all
- Information on management chain not systematically tracked
- Difficulties sharing and accessing data across different regions