

## Title page

### 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](#)

#### a.) 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.

#### b.) 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.

#### c.) 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.

#### d.) 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.

#### e.) 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.

#### f.) 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 (where 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)*

## References

- ALLEMANI, C., MATSUDA, T., DI CARLO, V., HAREWOOD, R., MATZ, M., NIKSIC, M., BONAVENTURE, A., VALKOV, M., JOHNSON, C. J., ESTEVE, J., OGUNBIYI, O. J., AZEVEDO, E. S. G., CHEN, W. Q., ESER, S., ENGHOLM, G., STILLER, C. A., MONNEREAU, A., WOODS, R. R., VISSER, O., LIM, G. H., AITKEN, J., WEIR, H. K., COLEMAN, M. P. & GROUP, C. W. 2018. Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *Lancet*, 391, 1023-1075.
- ALTOBELLI, E. & LATTANZI, A. 2014. Breast cancer in European Union: an update of screening programmes as of March 2014 (review). *Int J Oncol*, 45, 1785-92.



- ANTTILA, A., ARBYN, M., VEERUS, P., VIBERGA, I., KURTINAITIENE, R., VALERIANOVA, Z., APOSTOL, I., BAILI, P. & MICHELI, A. 2010. Barriers in cervical cancer screening programs in new European Union member states. *Tumori*, 96, 515-6.
- ANTTILA, A., VON KARSA, L., AASMAA, A., FENDER, M., PATNICK, J., REBOLJ, M., NICULA, F., VASS, L., VALERIANOVA, Z., VOTI, L., SAUVAGET, C. & RONCO, G. 2009. Cervical cancer screening policies and coverage in Europe. *Eur J Cancer*, 45, 2649-58.
- ARBYN, M., REBOLJ, M., DE KOK, I. M., FENDER, M., BECKER, N., O'REILLY, M. & ANDRAE, B. 2009. The challenges of organising cervical screening programmes in the 15 old member states of the European Union. *Eur J Cancer*, 45, 2671-8.
- DEANDREA, S., MOLINA-BARCELO, A., ULUTURK, A., MORENO, J., NEAMTIU, L., PEIRO-PEREZ, R., SAZ-PARKINSON, Z., LOPEZ-ALCALDE, J., LERDA, D. & SALAS, D. 2016. Presence, characteristics and equity of access to breast cancer screening programmes in 27 European countries in 2010 and 2014. Results from an international survey. *Prev Med*, 91, 250-263.
- DOBROSSY, L., CORNIDES, A., KOVACS, A. & BUDAI, A. 2014. Implementation status of cervical screening in Europe. *Orvosi Hetilap*, 155, 1975-1988.
- DOBROSSY, L., KOVACS, A. & BUDAI, A. 2015. [Inequalities in cervical screening practices]. *Orv Hetil*, 156, 955-63.
- DRS PAOLO BAILI, C. A. 2012. EUROCHIP-III, European Cancer Health Indicator Project-III, Common Action, DELIVERABLE 10 - FINAL REPORT, . Descriptive Studies and Health Planning Unit, Fondazione IRCCS "Istituto Nazionale dei Tumori" (INT), .
- HONEIN-ABOUHAIDAR, G. N., KASTNER, M., VUONG, V., PERRIER, L., DALY, C., RABENECK, L., STRAUS, S. & BAXTER, N. N. 2016. Systematic Review and Meta-study Synthesis of Qualitative Studies Evaluating Facilitators and Barriers to Participation in Colorectal Cancer Screening. *Cancer Epidemiology Biomarkers & Prevention*, 25, 907-917.
- INTERNATIONAL AGENCY FOR RESEARCH ON CANCER 2017. Cancer Screening in the European Union (2017) - 2nd Report on the implementation of the Council Recommendation on cancer screening. In: EUROPEAN COMMISSION (ed.). Lyon, France.
- NICULA, F. A., ANTTILA, A., NEAMTIU, L., ZAKELJ, M. P., TACHEZY, R., CHIL, A., GRCE, M. & KESIC, V. 2009. Challenges in starting organised screening programmes for cervical cancer in the new member states of the European Union. *Eur J Cancer*, 45, 2679-84.
- PALENCIA, L., ESPELT, A., RODRIGUEZ-SANZ, M., PUIGPINOS, R., PONS-VIGUES, M., PASARIN, M. I., SPADEA, T., KUNST, A. E. & BORRELL, C. 2010. Socio-economic inequalities in breast and cervical cancer screening practices in Europe: influence of the type of screening program. *Int J Epidemiol*, 39, 757-65.
- RONCO, G., VAN BALLEGOIJEN, M., BECKER, N., CHIL, A., FENDER, M., GIUBILATO, P., KURTINAITIS, J., LANCUCKI, L., LYNAGE, E., MORAIS, A., O'REILLY, M., SPAREN, P., SUTEU, O., REBOLJ, M., VEERUS, P., ZAKELJ, M. P. & ANTTILA, A. 2009. Process performance of cervical screening programmes in Europe. *Eur J Cancer*, 45, 2659-70.
- WALSH, B., SILLES, M. & O'NEILL, C. 2011. The importance of socio-economic variables in cancer screening participation: A comparison between population-based and opportunistic screening in the EU-15. *Health Policy*, 101, 269-276.
- WEST, N. J., BOUSTIERE, C., FISCHBACH, W., PARENTE, F. & LEICESTER, R. J. 2009. Colorectal cancer screening in Europe: differences in approach; similar barriers to overcome. *Int J Colorectal Dis*, 24, 731-40.
- WUBKER, A. 2014. Explaining variations in breast cancer screening across European countries. *Eur J Health Econ*, 15, 497-514.

## **Cancer screening systems survey**

We are writing to seek your assistance with an analysis of the systems for screening for breast, cervical and colorectal cancer in Europe. We are asking you to use your own knowledge to characterise the key elements that make up the overall cancer screening system in your country. 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 screening system. These sub-systems are:

1. to generate knowledge that can assist in deciding which conditions should be screened for, among which groups (e.g. by age) and how screening should be undertaken, both technically and organisationally
2. to identify the entire population at risk and to provide their details to those operating the system
3. to ensure the best possible uptake, identifying those who are less likely to undergo screening and, where appropriate, to devise interventions to improve their uptake
4. to ensure the sustainable operation of the screening programme.
5. to ensure that those who are identified as requiring further investigation are followed up adequately
6. to ensure access to effective treatment for those who need it

In the following survey we would like you to describe the key elements of each subsystem for your country and identify any known barriers to an effective cancer screening system. Please respond to the questions for breast, cervical, and colorectal cancer as a whole and highlight any specific differences for each particular cancer type in the final section.

### **Which country are you from?**

Choose

Albania

Austria

Belgium

Bulgaria

Croatia

Cyprus

Czech Republic

Denmark

Estonia

Finland

France  
Georgia  
Germany  
Hungary  
Iceland  
Ireland  
Italy  
Latvia  
Lithuania  
Luxembourg  
Malta  
Montenegro  
Netherlands  
Norway  
Poland  
Portugal  
Romania  
Serbia  
Slovenia  
Spain  
Sweden  
Switzerland  
Tunisia  
United Kingdom  
Other

**What is your job role?**

National screening organisation  
Policy maker  
Researcher  
Other:

## Knowledge generation

In this section we aim to identify how it is determined which conditions should be screened for and how screening should be undertaken, both technically and organisationally.

### **Who is responsible for assessing cancer screening needs, evaluating evidence and system design?**

National health authority / Ministry of Health

National screening organisation

Regional/municipal health authority

Local centres

Professional body

Other:

### **What skills and expertise do they have access to?**

Access to clinical experts

Access to health system/health policy experts

Link to universities

Links to national institutes

Links to other European collaborators

Links to other international collaborators

Other:

### **What are the barriers to knowledge generation? Please check all that apply and add any further barriers.**

Screening guidelines and protocols are not regularly updated

Complex administrative procedures delay protocol amendment

Inadequate national governance structure responsible for assessing needs

Insufficient number of trained professionals with knowledge of screening programmes

Screening providers do not follow protocols and procedures

Insufficient monitoring of screening programmes (uptake, acceptability and outcomes)

Other:

## Identification of the eligible population

In this section we would like to understand how the populations eligible for breast, cervical and colorectal cancer screening are identified and informed, including the level of participation achieved.

### **Which register is used to identify those requiring screening?**

Population register

Health insurance register

Primary care register

Other:

### **Which authority maintains this register?**

National authority

Regional/municipal authority

Health insurance fund

Screening programme

Other:

### **How is the register updated with change of address, death and other criteria?**

Updated in real time / weekly

Updated every 2-3 weeks

Updated every 1-3 months

Updated every 4-6 months

Updated every 6+ months

Ad hoc updates

No organisation of regular updates

Other:

### **Who is missing from the register? (Examples might include homeless people, migrants etc.)**

Free text

### **How are eligible patients invited for screening?**

Letter

Phone call

Email

At visit to primary care physician

Other:

**How are screening appointments arranged?**

Schedule appointment provided - no option for change

Scheduled appointment provided - option to change

Choice of several scheduled appointments

Contact details provided for invitee to ring and book appointment

Other:

**What are the follow-up procedures after screening invitation?**

Reminder letter sent after 0-3 months

Reminder phone call after 0-3 months

Reminder letter sent after 4-6 months

Reminder phone call after 4-6 months

Reminder letter sent after 6+ months

Reminder phone call after 6+ months

Other:

**How is attendance at screening monitored?**

All invitees monitored at a national level

All invitees monitored at a regional/municipal level

All invitees monitored at a local level

Ad hoc monitoring

No monitoring

Other:

**What are the barriers to identification? Please check all that apply and add any further barriers.**

Population register is not accurate or complete

Population register is not sufficiently updated with changes of address

Some eligible patients are not included in the population register

Screening organisation has insufficient capacity to invite all those who are eligible

Eligibility criteria vary according to location

No follow-up of non-responders after initial screening invitation

The cost of screening is not covered by health insurance funds

People who are invited for screening may not have health insurance

Incomplete consent prevents screening

Other:

## Maximising uptake (informed participation)

In this section we aim to understand those who are less likely to undergo screening, despite being informed, and how this is monitored.

### **Who is responsible for monitoring participation?**

National health authority/Ministry of Health

National screening organisation

Regional/municipal health authority

Local centres

Ad hoc research by various organisations

No monitoring

Other:

### **What population sub-groups do they monitor?**

Ethnicity

Gender

Age

Socioeconomic status

Religion

Language

Other:

Do not know

**What are the barriers to maximising informed participation? Please check all that apply and add any further barriers.**

Appointments for screening make it difficult for people to attend

Primary care physicians are not sharing information or promoting screening

Inadequate system for monitoring levels and patterns of screening participation

Insufficient monitoring quality of screening experiences

Inadequate responsiveness to problems found in monitoring and feedback

Opportunistic screening occurs outside of the routine screening programme

Some people have beliefs and values that lead to non-participation

Some people experience practical issues that lead to non-participation

Other:

## Operation of the program

In this section we aim to understand how the screening programme operates and the barriers to the effective management of screening programs.

**Who establishes protocols and processes for screening?**

National health authority / Ministry of Health

National screening organisation

Professional body

Regional/municipal health authority

Local guidelines committees

Other:

**How are protocols and processes established?**

European guidelines for screening are adopted as they are

Amended from European screening quality guidelines

Based on a review of the available evidence

Following an internationally accepted development process such as 'AGREE'?

Other:



### **How is quality of the screening process monitored?**

Comprehensive quality assurance system, looking at all aspects of screening, in place

Monitoring of technical quality of the process of screening (e.g. quality of Pap smears)

Regular monitoring of the experiences of those undergoing screening

Critical incident reporting

Regular monitoring of positive/negative results, positive predictive value and/or specificity

What steps, if any, are taken to remedy problems?

### **What are the barriers to successful operation of the program? Please check all that apply and add any further barriers.**

Private ownership of screening facilities hinders optimal screening practices

Limited capacity of screening programme (insufficient human, physical and financial resources)

Monitoring and evaluation is inadequate and insufficient

Significant organisational and logistical problems

Issues with establishing protocols, processes and legal frameworks

Inadequate and/or disjointed information technology (IT) systems

Inadequate organisational/administration support for clinical professionals

Providers don't always work to agreed guidelines and protocols

Outcome data from opportunistic screening is not collected and shared

Opportunistic testing does not keep the same evidence-based screening policy

Opportunistic testing causes additional costs for overall healthcare system

Limited public promotion of the screening programme

Other:

### **Follow-up**

This sections evaluates what is being done to ensure that those who are identified as requiring further investigation are followed up adequately.

Who is responsible for ensuring follow-up of those requiring further investigation?

National health authority/Ministry of Health

National screening organisation

Regional/municipal health authority

Other:

**What measures are taken to ensure the follow-up of screen positive cases?**

Free text

**What is done in respect of non-responders?**

Reminder letter

Phone call

Contact primary care physician

Other:

**What are the barriers to follow-up? Please check all that apply and add any further barriers.**

Poor laboratory quality results in false negative results and patients not followed up

No well-defined organising body or system in place for follow-up activities

Insufficient monitoring and evaluation of non-responders

Insufficient resources for follow-up activities

Poor adherence by providers to guidelines on follow-up investigations

Clinician's attitudes and established patterns of practice prevent follow-up

Difficulties sharing data between clinics regionally and nationally

Poor communication between screening organizations, primary care and patients

Current system does not address personal beliefs about follow-up (e.g. fatalism)

Insufficient evaluation of the objective obstacles facing patients requiring follow-up

Other:

## Treatment

This section investigates who ensures access to effective treatment for those who need it

**Who is responsible for ensuring those screened get treatment, if required?**

National health authority/Ministry of Health

National screening organisation

Regional/municipal health authority

Local centres

Individual physicians/healthcare professionals

The individual

Other:

**Who monitors uptake and outcomes of treatment?**

National health authority/Ministry of Health

National screening organisation

Regional/municipal health authority

Local centres

Individual physicians/healthcare professionals

The individual

Other:

**What links, if any, are in place to link screening data to cancer registries?**

Free text

**What are the barriers to effective treatment? Please check all that apply and add any further barriers.**

Insufficient monitoring is done on those testing screening positive

Effective treatment is not available to all who require it

No systematic monitoring or evaluation of treatment outcomes

Information on the management chain is not tracked systematically

There are difficulties sharing and accessing data across different regions

Patients do not undergo treatment because of a variety of personal beliefs

Patients do not undergo treatment because of a variety of objective obstacles

Other:

## Differences between breast, cervical and colorectal cancer screening systems

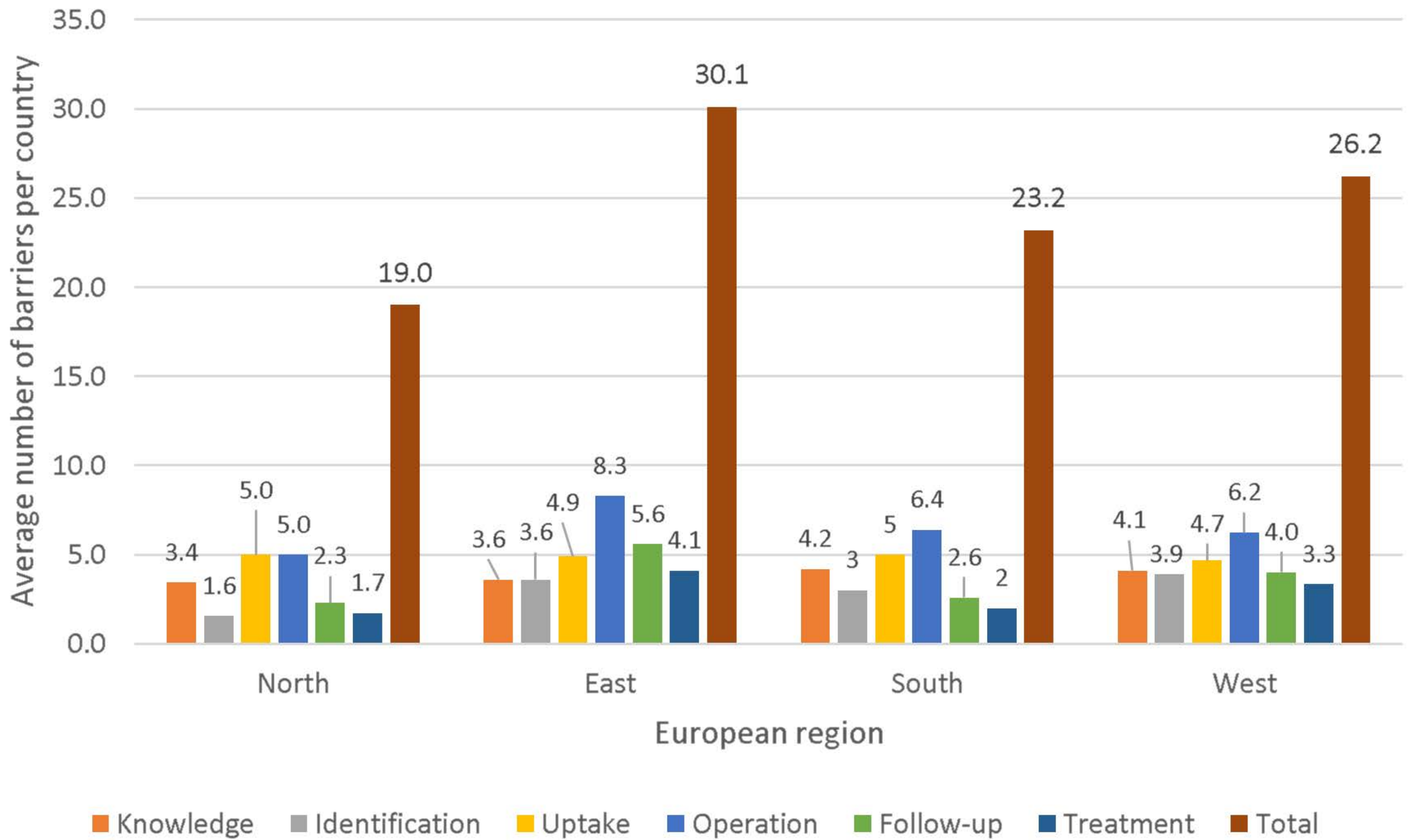
In this section, we would like to identify any differences in the way the programmes are organised for breast, cervical and colorectal cancer and any differences in the barriers experienced in your country. Please refer back to your previous answers.

**What, if any, are the main differences between the three cancer screening systems in your country?**

Free text

**In terms of barriers to effective screening, what, if any, are the differences between the three cancer screening systems in your country?**

Free text



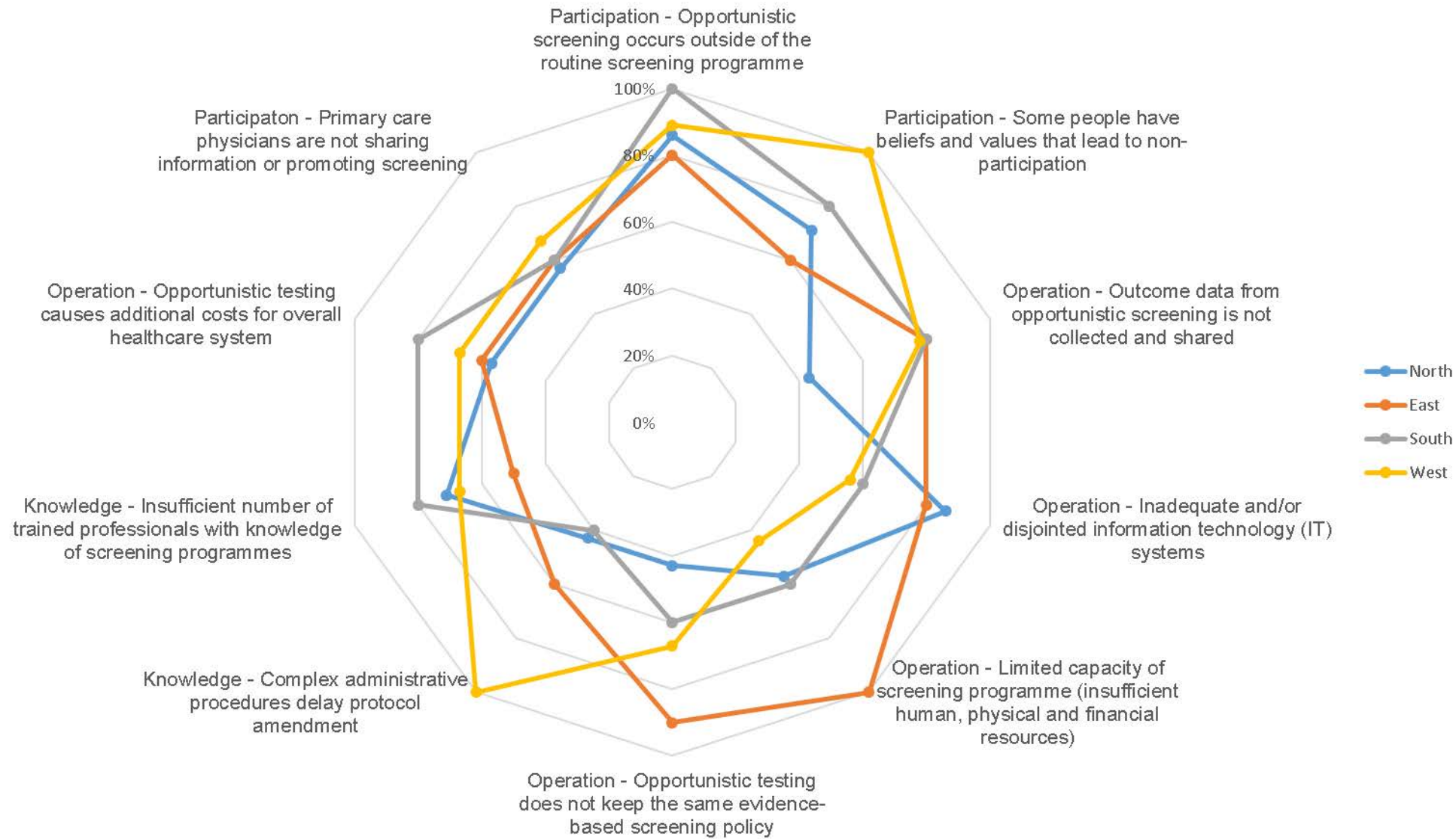


Figure S1: Percentage of countries reporting barriers to knowledge generation (by survival subgroup)

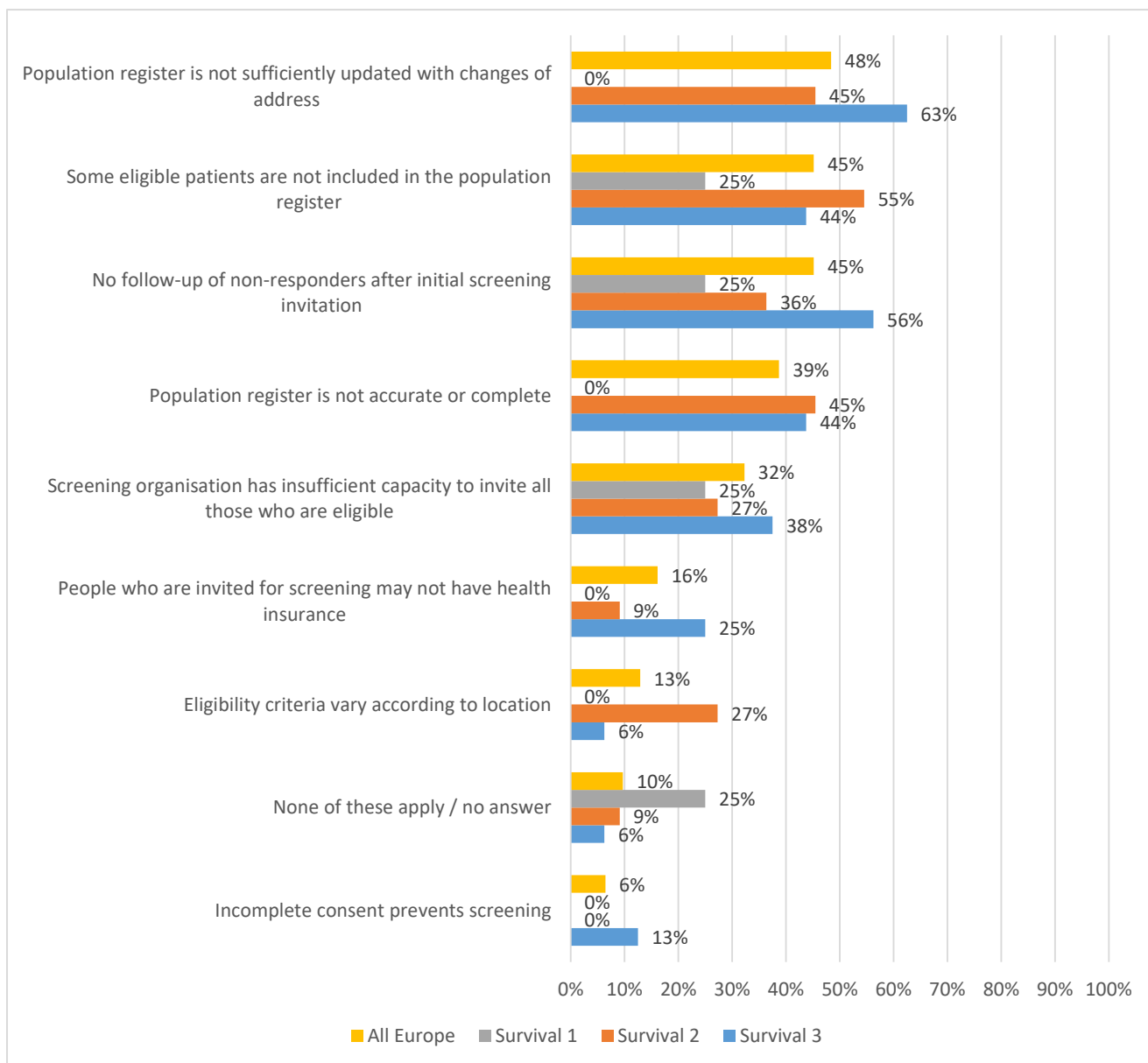


**Key to subgroups:**

All Europe: all countries included in study (n=31). Survival group 1 (n=4): Scandinavia (Finland, Iceland, Norway and Sweden). In the CONCORD-3 study report (Allemani et al. 2018), overall these countries had the best cancer survival in Europe. For breast, cervix and colon cancer, all four countries were in the top seven best European countries in terms of in terms of age-standardised five-year net survival (%) in adults 15-99 years using 2010-2014 data. Survival group 2 (n=11): Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland and United Kingdom. In the CONCORD-3 study report (Allemani et al. 2018), these countries all had survival of 60-69% (colon), 85% or higher (breast) and 60% or higher (cervix). Survival group 3 (n=16): all countries included in this study not in groups 1 or 2. Ref: Allemani C, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018; 391: 1023–75.

The BEST tool asked the following multiple choice question for each sub-system: “What are the barriers to knowledge generation/ identification (of the eligible population)/maximising uptake (informed participation)/successful operation of a programme/(adequate) follow-up/effective treatment (for those that need it)? Please check all that apply and add any further barriers”

Figure S2: Percentage of countries reporting barriers to identifying the eligible population (by survival subgroup)



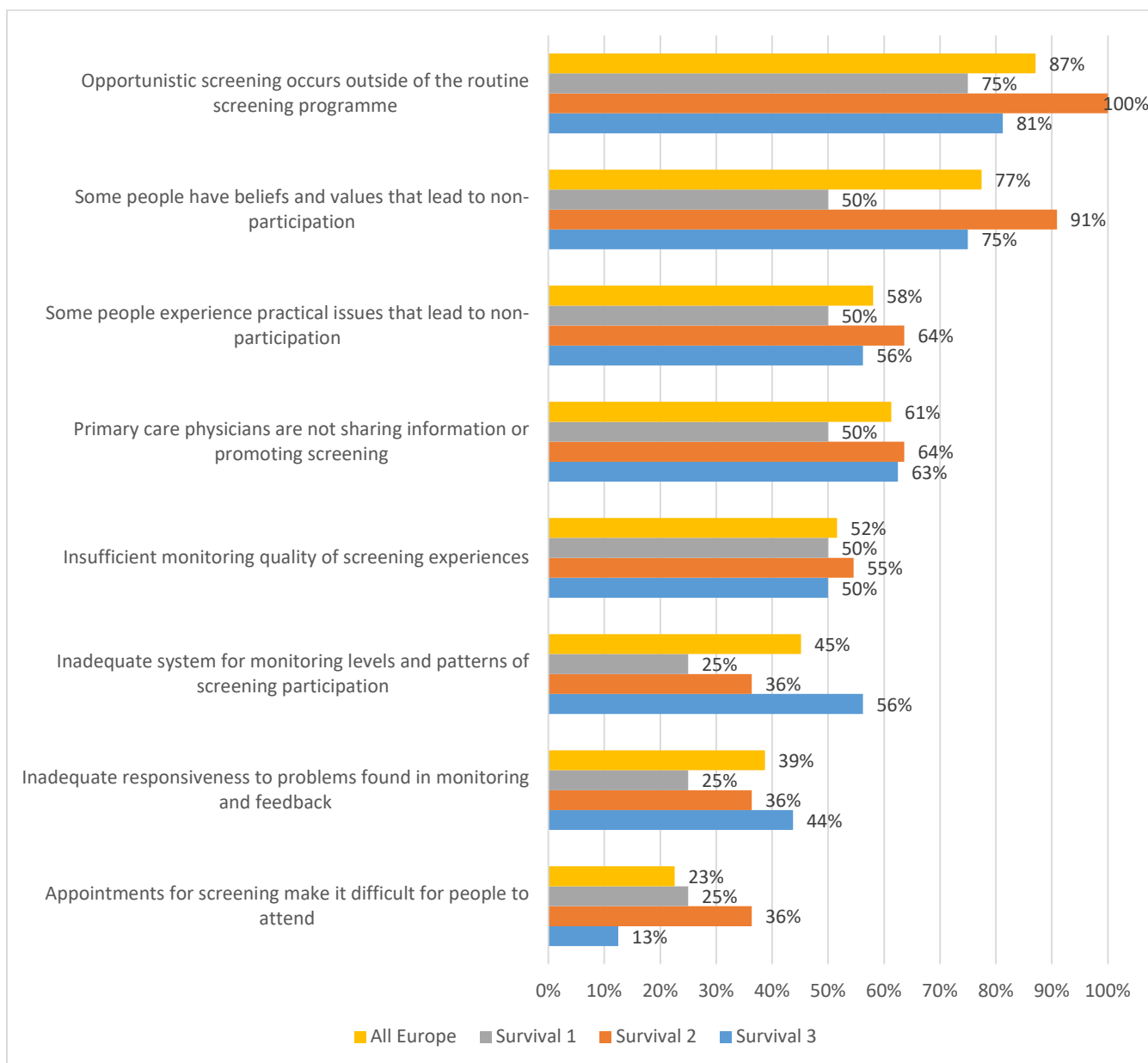
**Key to subgroups:**

All Europe: all countries included in study (n=31). Survival group 1 (n=4): Scandinavia (Finland, Iceland, Norway and Sweden). In the CONCORD-3 study report (Allemani et al. 2018), overall these countries had the best cancer survival in Europe. For breast, cervix and colon cancer, all four countries were in the top seven best European countries in terms of in terms of age-standardised five-year net survival (%) in adults 15-99 years using 2010-2014 data. Survival group 2 (n=11): Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland and United Kingdom. In the CONCORD-3 study report (Allemani et al. 2018), these countries all had survival of 60-69% (colon), 85% or higher (breast) and 60% or higher (cervix). Survival group 3 (n=16): all countries included in this study not in groups 1 or 2. Ref: Allemani C, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018; 391: 1023–75.

The BEST tool asked the following multiple choice question for each sub-system: “What are the barriers to knowledge generation/ identification (of the eligible population)/maximising uptake (informed participation)/successful operation of a programme/(adequate) follow-up/effective treatment (for those that need it)? Please check all that apply and add any further barriers”



Figure S3: Percentage of countries reporting barriers to maximising uptake (informed participation) (by survival subgroup)

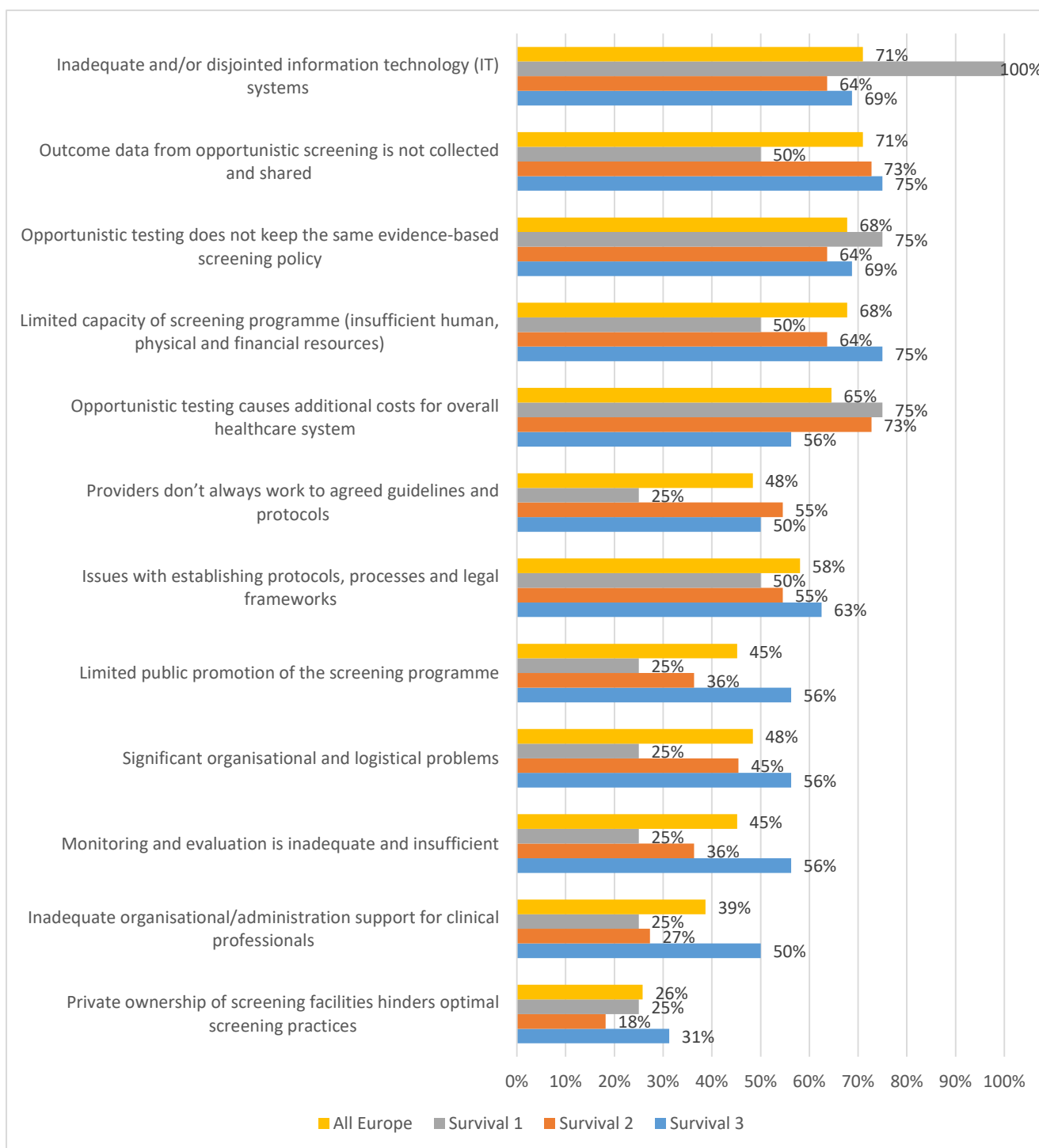


**Key to subgroups:**

All Europe: all countries included in study (n=31). Survival group 1 (n=4): Scandinavia (Finland, Iceland, Norway and Sweden). In the CONCORD-3 study report (Allemani et al. 2018), overall these countries had the best cancer survival in Europe. For breast, cervix and colon cancer, all four countries were in the top seven best European countries in terms of in terms of age-standardised five-year net survival (%) in adults 15-99 years using 2010-2014 data. Survival group 2 (n=11): Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland and United Kingdom. In the CONCORD-3 study report (Allemani et al. 2018), these countries all had survival of 60-69% (colon), 85% or higher (breast) and 60% or higher (cervix). Survival group 3 (n=16): all countries included in this study not in groups 1 or 2. Ref: Allemani C, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018; 391: 1023–75.

The BEST tool asked the following multiple choice question for each sub-system: “What are the barriers to knowledge generation/ identification (of the eligible population)/maximising uptake (informed participation)/successful operation of a programme/(adequate) follow-up/effective treatment (for those that need it)? Please check all that apply and add any further barriers”

Figure S4: Percentage of countries reporting barriers to successful operation of a programme (by survival subgroup)

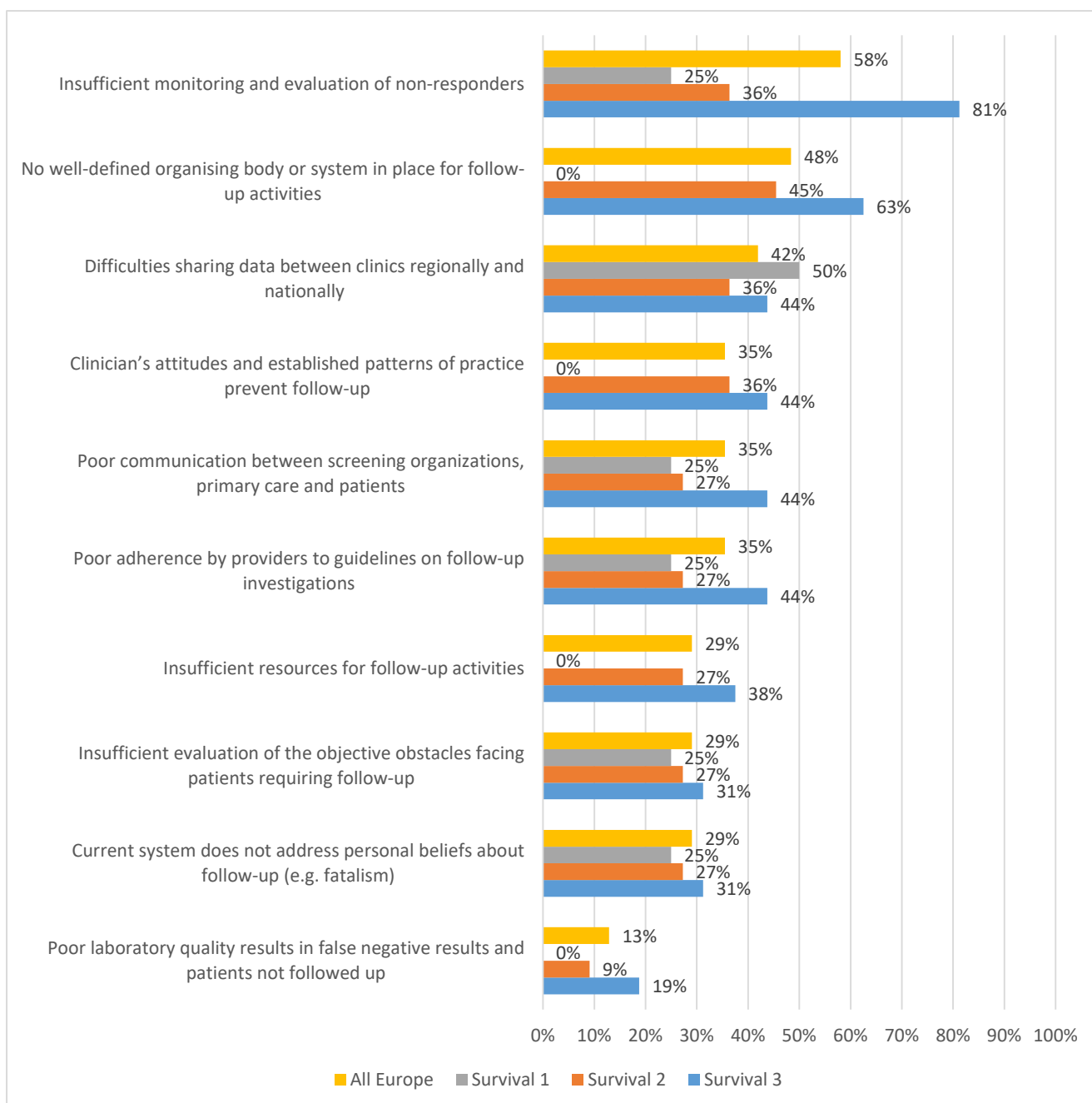


**Key to subgroups:**

All Europe: all countries included in study (n=31). Survival group 1 (n=4): Scandinavia (Finland, Iceland, Norway and Sweden). In the CONCORD-3 study report (Allemani et al. 2018), overall these countries had the best cancer survival in Europe. For breast, cervix and colon cancer, all four countries were in the top seven best European countries in terms of in terms of age-standardised five-year net survival (%) in adults 15-99 years using 2010-2014 data. Survival group 2 (n=11): Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland and United Kingdom. In the CONCORD-3 study report (Allemani et al. 2018), these countries all had survival of 60-69% (colon), 85% or higher (breast) and 60% or higher (cervix). Survival group 3 (n=16): all countries included in this study not in groups 1 or 2. Ref: Allemani C, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018; 391: 1023–75.

The BEST tool asked the following multiple choice question for each sub-system: “What are the barriers to knowledge generation/ identification (of the eligible population)/maximising uptake (informed participation)/successful operation of a programme/(adequate) follow-up/effective treatment (for those that need it)? Please check all that apply and add any further barriers”

Figure S5: Percentage of countries reporting barriers to effective follow-up (by survival subgroup)

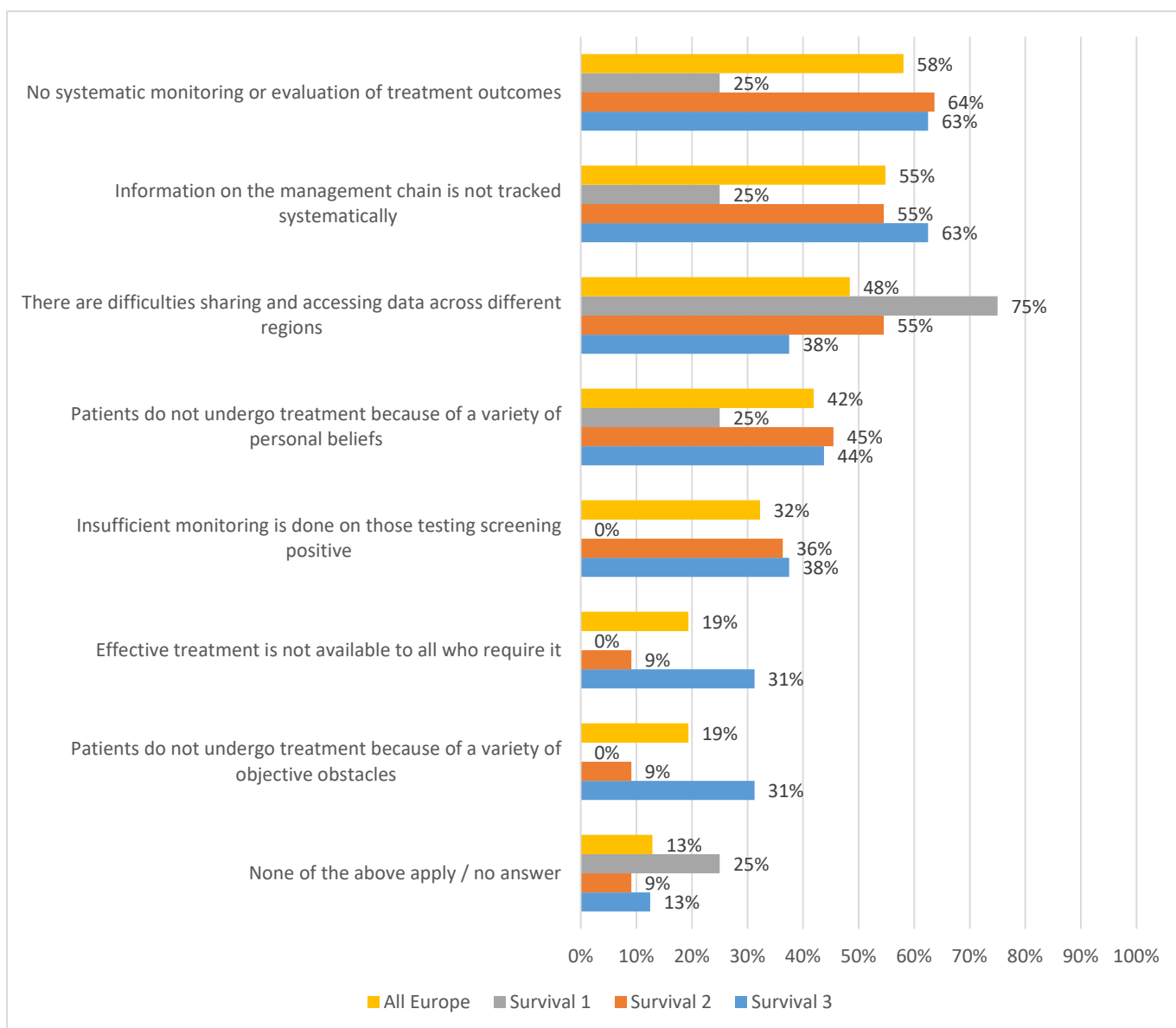


**Key to subgroups:**

All Europe: all countries included in study (n=31). Survival group 1 (n=4): Scandinavia (Finland, Iceland, Norway and Sweden). In the CONCORD-3 study report (Allemani et al. 2018), overall these countries had the best cancer survival in Europe. For breast, cervix and colon cancer, all four countries were in the top seven best European countries in terms of in terms of age-standardised five-year net survival (%) in adults 15-99 years using 2010-2014 data. Survival group 2 (n=11): Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland and United Kingdom. In the CONCORD-3 study report (Allemani et al. 2018), these countries all had survival of 60-69% (colon), 85% or higher (breast) and 60% or higher (cervix). Survival group 3 (n=16): all countries included in this study not in groups 1 or 2. Ref: Allemani C, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018; 391: 1023–75.

The BEST tool asked the following multiple choice question for each sub-system: “What are the barriers to knowledge generation/ identification (of the eligible population)/maximising uptake (informed participation)/successful operation of a programme/(adequate) follow-up/effective treatment (for those that need it)? Please check all that apply and add any further barriers”

Figure S6: Percentage of countries reporting barriers to effective treatment (by survival subgroup)



**Key to subgroups:**

All Europe: all countries included in study (n=31). Survival group 1 (n=4): Scandinavia (Finland, Iceland, Norway and Sweden). In the CONCORD-3 study report (Allemani et al. 2018), overall these countries had the best cancer survival in Europe. For breast, cervix and colon cancer, all four countries were in the top seven best European countries in terms of in terms of age-standardised five-year net survival (%) in adults 15-99 years using 2010-2014 data. Survival group 2 (n=11): Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Portugal, Spain, Switzerland and United Kingdom. In the CONCORD-3 study report (Allemani et al. 2018), these countries all had survival of 60-69% (colon), 85% or higher (breast) and 60% or higher (cervix). Survival group 3 (n=16): all countries included in this study not in groups 1 or 2. Ref: Allemani C, et al. Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. Lancet 2018; 391: 1023–75.

The BEST tool asked the following multiple choice question for each sub-system: “What are the barriers to knowledge generation/ identification (of the eligible population)/maximising uptake (informed participation)/successful operation of a programme/(adequate) follow-up/effective treatment (for those that need it)? Please check all that apply and add any further barriers”

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

	<b>Barriers from BEST sub-system</b>	<b>All</b>	<b>North</b>	<b>East</b>	<b>South</b>	<b>West</b>
	<b>Number of countries in region</b>	<b>31</b>	<b>7</b>	<b>10</b>	<b>5</b>	<b>9</b>
<b>Knowledge</b>	Complex administrative procedures delay protocol amendment	65%	43%	60%	40%	100%
	Insufficient number of trained professionals with knowledge of screening programmes	65%	71%	50%	80%	67%
	Insufficient monitoring of screening programmes (uptake, acceptability and outcomes)	58%	57%	50%	60%	67%
	Inadequate national governance structure responsible for assessing needs	55%	71%	40%	80%	44%
	Screening guidelines and protocols are not regularly updated	48%	57%	50%	20%	56%
	Screening providers do not follow protocols and procedures	39%	43%	50%	40%	22%
<b>Identification</b>	Population register is not sufficiently updated with changes of address	48%	29%	60%	80%	33%
	No follow-up of non-responders after initial screening invitation	45%	29%	50%	40%	56%
	Some eligible patients are not included in the population register	45%	14%	50%	40%	67%
	Population register is not accurate or complete	39%	0%	50%	80%	33%
	Screening organisation has insufficient capacity to invite all those who are eligible	32%	14%	40%	40%	33%
<b>Participation</b>	Opportunistic screening occurs outside of the routine screening programme	87%	86%	80%	100%	89%
	Some people have beliefs and values that lead to non-participation	77%	71%	60%	80%	100%
	Primary care physicians are not sharing information or promoting screening	61%	57%	60%	60%	67%
	Some people experience practical issues that lead to non-participation	58%	57%	60%	60%	56%
	Insufficient monitoring quality of screening experiences	52%	57%	60%	60%	33%
	Inadequate system for monitoring levels and patterns of screening participation	45%	57%	60%	40%	22%
	Inadequate responsiveness to problems found in monitoring and feedback	39%	43%	50%	60%	11%
	Appointments for screening make it difficult for people to attend	23%	29%	20%	0%	33%
<b>Operation</b>	Outcome data from opportunistic screening is not collected and shared	71%	43%	80%	80%	78%
	Inadequate and/or disjointed information technology (IT) systems	71%	86%	80%	60%	56%
	Limited capacity of screening programme (insufficient human, physical and financial resources)	68%	57%	100%	60%	44%
	Opportunistic testing does not keep the same evidence-based screening policy	68%	43%	90%	60%	67%
	Opportunistic testing causes additional costs for overall healthcare system	65%	57%	60%	80%	67%
	Issues with establishing protocols, processes and legal frameworks	58%	43%	70%	60%	56%
	Significant organisational and logistical problems	48%	29%	70%	60%	33%
	Providers don't always work to agreed guidelines and protocols	48%	29%	50%	40%	67%
	Monitoring and evaluation is inadequate and insufficient	45%	29%	50%	60%	44%
	Limited public promotion of the screening programme	45%	29%	70%	40%	33%
	Inadequate organisational/administration support for clinical professionals	39%	14%	70%	40%	22%
	Private ownership of screening facilities hinders optimal screening practices	26%	14%	30%	20%	33%
	<b>Follow-up</b>	Insufficient monitoring and evaluation of non-responders	58%	29%	90%	60%
No well-defined organising body or system in place for follow-up activities		48%	29%	60%	40%	56%
Difficulties sharing data between clinics regionally and nationally		42%	43%	50%	20%	44%
Poor adherence by providers to guidelines on follow-up investigations		35%	29%	50%	0%	44%
Poor communication between screening organizations, primary care and patients		35%	29%	60%	0%	33%
Clinician's attitudes and established patterns of practice prevent follow-up		35%	0%	60%	40%	33%
Current system does not address personal beliefs about follow-up (e.g. fatalism)		29%	29%	40%	0%	33%
Insufficient evaluation of the objective obstacles facing patients requiring follow-up		29%	14%	40%	0%	44%
Insufficient resources for follow-up activities		29%	14%	50%	40%	11%
<b>Treatment</b>	No systematic monitoring or evaluation of treatment outcomes	58%	43%	70%	40%	67%
	Information on the management chain is not tracked systematically	55%	14%	90%	40%	56%
	There are difficulties sharing and accessing data across different regions	48%	43%	50%	20%	67%
	Patients do not undergo treatment because of a variety of personal beliefs	42%	14%	50%	40%	56%
	Insufficient monitoring is done on those testing screening positive	32%	29%	40%	20%	33%

**Key to subgroups:** *All Europe: all countries included in study (n=31). North (n=7): Denmark, Estonia, Finland, Iceland, Latvia, Norway and Sweden. East (n=10): Albania, Croatia, Czech Republic, Georgia, Hungary, Montenegro, Poland, Romania, Serbia and Slovenia. South (n=5): Cyprus, Italy, Malta, Portugal and Spain. West (n=9): Austria, Belgium, France, Germany, Ireland, Luxembourg, Netherlands, Switzerland and United Kingdom.*

**Notes:** \* *The Barrier to Effective Screening Tool (BEST) asked the following multiple choice question for each sub-system: "What are the barriers to [sub-system]? Please check all that apply and add any further barriers". The six sub-systems are as follows: knowledge generation, identification (of the eligible population), maximising uptake (informed participation), successful operation of a programme, adequate follow-up, and effective treatment (for those who need it). Only barriers reported by over 20% of all countries reported above.*

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

	<b>Barrier from BEST sub-system</b>	<b>Number of all respondents</b>	<b>% of all respondents</b>	<b>Number of countries</b>
	<b>Number of respondents / countries</b>	<b>67</b>	<b>67</b>	<b>31</b>
<b>Knowledge</b>	Complex administrative procedures delay protocol amendment	32	48%	20
	Insufficient monitoring of screening programmes (uptake, acceptability and outcomes)	26	39%	18
	Insufficient number of trained professionals with knowledge of screening programmes	25	37%	20
	Inadequate national governance structure responsible for assessing needs	25	37%	17
	Screening guidelines and protocols are not regularly updated	20	30%	15
	Screening providers do not follow protocols and procedures	20	30%	12
<b>Identification</b>	Population register is not sufficiently updated with changes of address	26	39%	15
	Some eligible patients are not included in the population register	21	31%	14
	No follow-up of non-responders after initial screening invitation	17	25%	14
	Population register is not accurate or complete	16	24%	12
	Screening organisation has insufficient capacity to invite all those who are eligible	12	18%	10
<b>Participation</b>	Some people have beliefs and values that lead to non-participation	47	70%	24
	Opportunistic screening occurs outside of the routine screening programme	43	64%	27
	Some people experience practical issues that lead to non-participation	33	49%	18
	Primary care physicians are not sharing information or promoting screening	32	48%	19
	Insufficient monitoring quality of screening experiences	21	31%	16
	Inadequate system for monitoring levels and patterns of screening participation	19	28%	14
	Inadequate responsiveness to problems found in monitoring and feedback	14	21%	12
<b>Operation</b>	Outcome data from opportunistic screening is not collected and shared	36	54%	22
	Limited capacity of screening programme (insufficient human, physical and financial resource)	32	48%	21
	Inadequate and/or disjointed information technology (IT) systems	31	46%	22
	Opportunistic testing does not keep the same evidence-based screening policy	31	46%	21
	Opportunistic testing causes additional costs for overall healthcare system	29	43%	20
	Providers don't always work to agreed guidelines and protocols	28	42%	15
	Significant organisational and logistical problems	26	39%	15
	Issues with establishing protocols, processes and legal frameworks	22	33%	18
	Limited public promotion of the screening programme	21	31%	14
	Monitoring and evaluation is inadequate and insufficient	20	30%	14
	Inadequate organisational/administration support for clinical professionals	15	22%	12
Private ownership of screening facilities hinders optimal screening practices	11	16%	8	
<b>Follow-up</b>	Insufficient monitoring and evaluation of non-responders	30	45%	18
	No well-defined organising body or system in place for follow-up activities	22	33%	15
	Difficulties sharing data between clinics regionally and nationally	20	30%	13
	Insufficient resources for follow-up activities	16	24%	9
	Poor communication between screening organizations, primary care and patients	15	22%	11
	Poor adherence by providers to guidelines on follow-up investigations	15	22%	11
	Clinician's attitudes and established patterns of practice prevent follow-up	13	19%	11
	Insufficient evaluation of the objective obstacles facing patients requiring follow-up	12	18%	9
<b>Treatment</b>	No systematic monitoring or evaluation of treatment outcomes	30	45%	18
	Information on the management chain is not tracked systematically	23	34%	17
	Patients do not undergo treatment because of a variety of personal beliefs	22	33%	13
	There are difficulties sharing and accessing data across different regions	20	30%	15
	Insufficient monitoring is done on those testing screening positive	12	18%	10

**Key:** Number of respondents selecting no barriers in each sub-system (n=67) – knowledge (6), identification (10), uptake (1), operation (5), follow-up (10), treatment (10). Number of respondents selecting 'other' barriers in each sub-system (reported in section above, n=67) – knowledge (13), identification (18), uptake (13), operation (9), follow-up (14), treatment (10).

\* The Barrier to Effective Screening Tool (BEST) asked the following multiple choice question for each sub-system: "What are the barriers to [sub-system]? Please check all that apply and add any further barriers". The six sub-systems are as follows: knowledge generation, identification (of the eligible population), maximising uptake (informed participation), successful operation of a programme, adequate follow-up, and effective treatment (for those who need it). Only barriers reported by over 10% of all countries reported above.