This item is the archived peer-reviewed author-version of:

How is informed decision-making about breast cancer screening addressed in Europe? An international survey of 28 countries

Reference:
Ritchie David, Van Hal Guido F., Van den Broucke Stephan.- How is informed decision-making about breast cancer screening addressed in Europe? An international survey of 28 countries
Health policy - ISSN 0168-8510 - Clare, Elsevier ireland ltd, 124:9(2020), p. 1017-1031
Full text (Publisher's DOI): https://doi.org/10.1016/J.HEALTHPOL.2020.05.011
To cite this reference: https://hdl.handle.net/10067/1709300151162165141
How is informed decision-making about breast cancer screening addressed in Europe?  
A cluster analysis of results from an international survey of 28 countries

Abstract

. The aim of this study was to develop a typology of approaches towards the facilitation of informed decision-making about mammography screening in Europe. All countries collaborating in the European Commission Initiative on Breast Cancer were approached to participate. Experts from 28 European countries responded to a web-based survey providing data on key organisational and policy characteristics of breast screening at the national or regional level. Overall, 35 responses were received including data from regionally organised breast screening in several countries. 27 respondents, covering 21 countries, reported the existence of a policy towards informed decision-making and stated they communicated to women about the benefit and harms associated with participation. However, few countries had attempted to measure the proportion of women making an informed choice. The cluster analysis identified three emerging categories: programmes distinguished mostly by reporting a policy specific to mammography screening with administrative support to monitor implementation; programmes with a general policy, applicable to other screening programmes, with a lack of administrative support to monitor implementation; and programmes without a policy and limited information provided to women regarding the benefits and harms. To the best of our knowledge, this study is the first to investigate the key policy and organisational characteristics of approaches taken to facilitate informed decision-making in Europe. The results demonstrate a broad adoption of the principle of enabling informed decision-making but indicate heterogeneity of implementation.

Introduction

With 626,679 deaths (15.1% of all cancer deaths) attributed to breast cancer globally in 2018, breast cancer remains the leading cause of cancer mortality in women [1][2]. Organised breast cancer screening has been implemented in many European countries to reduce the burden of breast cancer mortality [3][4]. The 4th edition of the European Code against Cancer advises women in the European Union (EU) to participate in breast cancer screening programmes after being invited by the national or regional programme [5]. This advice was made following a thorough review of the evidence, showing a 25-31% mortality reduction amongst women invited to screening in population-based breast screening programmes [6][7]. However, as with other forms of organised screening, participation in breast screening carries certain risks or harms in addition to the potential benefit of decreased mortality risk, including the risk of overdiagnosis of breast cancer [8][9][10]. Consequently, the general principle is that organised breast cancer screening should only be offered to fully informed women who are asymptomatic at the time of invitation to screening [11].

In accordance with this principle, the World Health Organization affirms that achieving a high uptake of screening should not take precedence over the fact of women making informed decisions about screening participation, grounded in evidence and in line with their individual values and preferences [12][13]. Consequently, if making an independent decision is the main ethical consideration, women who are invited to screening must be provided with suitable information to enable them to make an informed decision [14][15]. An informed decision is most commonly defined as being an active choice that is made by a decision-maker consistent with the individual’s values, attitudes and personal preferences [16]. Moreover, knowledge is an essential cognitive component of informed decision-making about mammography screening. In order to make an informed decision about participation, knowledge about benefits and risks of mammography screening must be present [13]. In attempts to measure informed choice about screening participation, decisions have been classified
as informed if adequate knowledge about the screening was demonstrated and consistency was present between the attitudes and preferences of the individual and their behaviour [17]. Nevertheless, decisions about participation in screening are not based solely on the information provided but also take account of a variety of personal and social factors [13]. Knowledge as an indicator of informed choice is also influenced by health literacy as this demonstrates the ability of an individual to understand and apply information. Consequently, women with lower health literacy skills may have greater difficulties to exercise an informed decision in comparison to women with high health literacy skills [18]. In respect of these factors, the new European Guidelines for quality assurance in breast cancer screening, updated under the auspices of the European Commission Initiative on Breast Cancer (ECIBC), issued a strong recommendation that all women invited to breast screening should receive sufficient information about the desirable and undesirable effects in order to make an informed choice [19].

Whilst research into the effect of specific interventions that are designed to facilitate informed decision-making in breast cancer screening are well reported in the literature [20][21][22][23], to the best of our knowledge, no systematic report has been produced with regard to the key policy and organisational characteristics of approaches taken to facilitate informed decision-making in Europe.

The aim of this paper is to address the gap in the literature by mapping the responses taken at national and regional level in Europe and develop a typology of approaches towards the facilitation of informed decision-making about mammography screening in Europe.

Materials and methods

Setting and participants

The study follows a web-based survey designed aimed at experts who have been national contact points for the European Commission Initiative on Breast Cancer (ECIBC) or have provided data to the second implementation report in cancer screening in the EU [24]. Expert contacts were identified following a snowball sample procedure, beginning with the designated national contact points established for each Member State of the European Union and associated countries participating in ECIBC. The ECIBC was used as the basis for selecting the contacts as this initiative is mandated by the European Commission to update the European guidelines for quality assurance in breast cancer screening [25][26]. Plus each participating country in the ECIBC has nominated a national contact point as a referent to provide feedback and advice based on their expertise regarding their national context.

In the event of non-response or non-completion by ECIBC contact points, a secondary contact list was established for each country. These contacts were either nominated by the ECIBC via direct communication with the authors (in circumstances were the ECIBC contact point felt that a colleague is more qualified to provide the data) or were derived from the data providers to the second report on the implementation status of cancer screening in European Union (hereafter, ‘EUSR’) published in 2017 [26]. The EUSR is a comprehensive report on the status of cancer screening across the entire EU, containing data on the organisation and performance indicators of organised breast, cervical and colorectal cancer screening programmes. Data for the report was provided by cancer screening programme coordinators with access to the necessary planning, monitoring, and evaluation data for the respective screening programmes [4]. Consequently, data providers to EUSR would be well placed to respond with accurate data. It is important to note that for some countries included in the ECIBC the responsibility for breast screening programme can be held by the regional or local authority level [4]. For instance, in the United Kingdom, in practice four screening programmes for breast cancer are in operation, reflecting the four nations of the United Kingdom. The same is true regarding the regions of Belgium, as a further example. This situation has been widely acknowledged.
as creating difficulties in obtaining comparative data [13]. Consequently, in such instances, it is more appropriate to collect data from the sub-national level. Therefore, regional or local expert contacts derived from data providers to the EUSR were specifically included for countries with sub-national responsibilities for breast screening, as described in the EUSR [27].

**Data collection**

Data was collected via an online questionnaire developed using the Qualtrics survey platform. Survey questions were derived from the typology established in the EUSR and followed the definitions for screening programme coordination outlined in the report [26]. To facilitate an objective and comparable analysis of the data, most questions were closed-ended with categorical variables per question, for example, “Yes/No/Not Applicable.” Open-ended comments were available in order to allow the respondent to provide further data or clarify their response. Survey questions were organised into three distinct sections relating to: (i) policies that are in place to facilitate informed decision-making (e.g. “Does your country/region have a policy in place for the facilitation of informed decision-making for women offered mammography screening?”); (ii) enabling informed decision-making in practice (e.g. “Is the information on the benefits and harms of mammography screening communicated via decision aids?”); and (iii) evaluating the process for supporting informed decision-making (e.g. “Which, if any, of the following cognitive variables are measured in your country?”). The survey flow function of Qualtrics was used to define the sections and apply both skip and branch logic to allow respondents to provide data relevant to their context of their screening programme. As a result, certain questions were only available to responders depending on their answers to preceding questions. For instance, if respondents answered “Yes” to “Does your country/region provide written information to women about the benefits and risks of mammography screening ...,” further questions would become available to provide additional information about this question. The additional questions would not be available if the respondent answered “No” or “Not Applicable”. Consequently, no respondent could answer every possible question within the survey.

The initial draft, comprising all possible survey questions, was pre-tested with three external experts in breast cancer screening: a breast screening programme coordinator, an academic with international knowledge in breast screening policy, and a breast cancer patient representative. Following the pre-testing, questions were amended or excluded based on the feedback given by the experts.

The finalised version of the survey questionnaire was then distributed to contacts via the email function within Qualtrics.

[insert supplementary file 1 – copy of web-based survey instrument]

This provided recipients with a structured email invitation with a unique link to complete the survey online. The email invitation explained the aims and objectives of the survey with brief definitions of the key concepts. It also informed the contacted experts that it was possible to refer a more suitable colleague to provide the data. In those circumstances, the expert contacts were asked to inform the authors directly. Additionally, contacts were informed that it was possible to collect a response based on the inputs of a group of colleagues with expertise on the status in their respective country or region. However, a lead respondent would be required to submit their personal information and be contactable for follow up or further enquires. Overall, one respondent per country or region was sought.

**Data analysis**
A descriptive study of the main variables included in the questionnaire was performed. Data was transferred from Qualtrics to SPSS (version 24.2) and cleaned for missing values and input errors. Frequencies and percentages of data responses were calculated within SPSS and custom pivot tables developed for each section of the survey.

To identify groups with common organisational characteristics towards enabling informed decision-making, a Hierarchical Cluster Analysis (HCA) of the survey data was performed. HCA groups together objects into distinct, separate clusters according to their similarity. This method was used as HCA has an advantage over other clustering methods in that the HCA does not require a pre-defined number of clusters, thus, it can facilitate a more organic method of developing the typology of approaches to informed decision-making [28]. As categorical data cannot be used directly for the HCA, a Multiple Correspondence Analysis (MCA) was computed as an intermediary step in order to enable the HCA. MCA identifies inherent structures in nominal or categorical data by visualising the data as points in a low-dimensional space and, as a result, infers relationships between the data providing the numerical values required for the HCA [29]. As the survey flow prohibits respondents from providing data for each question of the survey, specific questions answered by >50% of respondents were selected and used to provide the underlying data for the MCA. The 11 questions included in the MCA, described in supplementary file 1, covered characteristics of informed decision-making policy (n=7), and implementation and evaluation factors (n=4).

Following the MCA computation, the relationship between countries (or regions, in cases were the respondent was active at the regional or local level) was visually represented on a factor map depicting the distance along two dimensions. Joint plots of the variables from the survey questions were produced on independent factor maps to represent the distance between the categories according to the individual survey responses. The factor maps were then compared to assess the underlying values contributing to the distance countries or regions for whom an expert submitted data to the survey. Using the object scores produced by the MCA, the HCA was performed using the Ward Agglomerate method to produce clusters of countries and regions. Chi-square tests were applied to assess differences between the clusters.

A total of 85 individual expert contacts from 36 countries received an email invitation with a unique individual link to complete the survey. This included all 35 countries participating in the ECIBC (27 EU member states and Iceland, Montenegro, North Macedonia, Norway, Serbia, Switzerland, Turkey and the United Kingdom) plus Israel, which had been an observer but not direct participant country of the ECIBC [30]. The survey required a lead respondent who would submit the data and provide their specific contact details and information about their professional profile.

Results

A total of 35 responses were received from experts representing 28 independent countries. 13 responses were received from experts active at the regional or local level in six different countries. As 85 individual experts were invited to provide data, the participation rate for the survey is 41.18%. Lead respondents per country or region were most frequently a coordinator of the breast screening programme (48.57% of respondents) working within a cancer-specific institute (37.14%). While 40% of respondents were national contacts points for the ECIBC, the majority of respondents had also provided data for the EUSR. Further characteristics of the respondents to the survey questionnaire are shown in Table 1.
An overview of the general characteristics of the countries and regions represented in the survey is provided in Table 2.

Countries who had been contacted but no response was obtained were Bulgaria; Estonia; Latvia; Poland; The Netherlands; Serbia; Sweden; Turkey; and, from within the UK, England, Scotland and Northern Ireland. A private communication was received from the contact point in Bulgaria stating that they were not able to provide data as mammography screening has not yet been introduced in the country.

The survey completion ranged from 20% to 60%, with a median of 40% completion. Due to the survey flow, questions were posed to respondents based on previous gateway answers, which prevents 100% completion of the survey. Lower completion rates were obtained for countries that do not have widespread systematic breast screening due to insufficient data available at the country level to respond to the questions. Overall, when an answer was asked and expected of the respondent, data was provided 90.25% of the time. Further details on the missing values are provided in annex.

Table 3 summarises the data collected regarding the country or region’s policies to enable informed decision-making in breast cancer screening. Of the respondents, 27 (77.1%) reported that a policy is in place for enabling informed decision-making for women about mammography screening. The year of initiation of the policy ranged from 1992 to 2017, with the most frequent year of initiation being 2015 (n=4). Ten respondents indicated that in their country or region the policy regarding informed decision-making applies to mammography screening specifically. For the remaining 17 respondents, the policy also applies to cervical (n=15) and colorectal (n=12) cancer screening, and in a few cases, is applied to non-cancer screening programmes (n=3). Amongst the eight respondents who stated their country or region is without a policy towards informed decision-making, three reported that their country or region plans to introduce such a policy in the future.

Table 4 presents the data relating to implementation factors surrounding the informed decision-making process in respect of breast cancer screening. As with the presence of a policy for informed decision-making, 27 respondents (77.1%) indicated that their country or region currently provides information to women on the benefits and harms of mammography screening in written form. For those respondents whose country or region does not communicate on the benefits and harms of mammography screening, explanations offered as to why this is the case focused mostly on structural factors, such as the lack of a systematic organised mammography screening programme in place. Nonetheless, four respondents indicated that they are considering communicating information on benefits and harms in the future. As this survey consulted experts in breast screening at the national or regional level, the data reported concerns the information provided directly by a screening programme or other official sources, such as a Ministry of Health. Nevertheless, there exist various other sources of information about breast screening are available to women in Europe.
Advocacy groups and non-governmental organisations in particular play a leading role in providing information in both offline and online formats [31].

Eight respondents indicated that their country or region had performed an evaluation of the information that is provided to women about the benefits and harms of mammography screening. This evaluation most frequently covers factors such as women’s perception of bias \( n = 7 \), and satisfaction with the information \( n = 6 \). Eight respondents indicated that women who had been offered screening were involved in the evaluation, in addition to health professionals \( n = 5 \) and women in lower socio-economic groups \( n = 5 \). Only one respondent, Switzerland (Valais), indicated that their programme had measured the proportion of women who have made an informed decision. This was performed in 2017, with 62% of women reported to have made an informed choice about mammography screening.

In respect of how the information on benefits and harms is communicated, ten respondents reported that a decision aid designed to help women make an informed choice about mammography screening was in use in their country or region. These decision aids are mostly in the format of hard copies, i.e. brochures and leaflets \( n = 10 \) but are also provided online \( n = 7 \). None of the decision aids that were used had the capacity to include an interactive component allowing women to enter their personal details. Reasons provided by the respondents as to why specific decision aids for mammography screening were not developed included concerns about the effectiveness of decision aids as a tool to enable informed decision-making \( n = 2 \), and the lack of standardised best practice \( n = 2 \). At the time of data analysis, respondents in Italy were awaiting the outcome of local investigative trials in which decision aids are compared to standard practice. Consequently, a decision had not yet been taken about this methodology.

**Cluster analysis**

The results of the MCA and HCA support the differentiation of countries according to how their approaches to the policy towards, and implementation of, informed decision-making in breast cancer screening. The model summary of the MCA indicates that the two dimensions accounted for a mean variance of 52.90% (Dimension 1: 72.24%; Dimension 2: 33.55%). Discrimination measures of each category from the survey data were calculated for both dimensions. The presence of an administrative team responsible for the oversight of the policy towards informed decision-making and a team responsible for its implementation have the largest values on both dimensions (team responsible for oversight, dimension 1 = .939; dimension 2 = .684; team responsible for implementation, dimension 1 = .947; dimension 2 = .825). For dimension 1 additional key discriminating variables included the presence of a policy for informed decision-making, whether this policy is specific to breast cancer screening, and whether the policy was developed in consultation with stakeholders. For dimension 2, the development of the policy in consultation with stakeholders was also an important factor, along with the level of governance (i.e. regional or national) of the administrative teams responsible for the oversight and implementation of the policy.

[insert Figure 1]

Figure 1 shows the factor map produced as an output from the MCA. The factor map facilitates the identification of clusters of approaches to supporting informed decision-making in breast cancer screening. Dimension 1 on the map clearly distinguishes between countries and regions that have adopted a policy and communicate actively on the benefits and potential harms, with the screening programmes in the bottom left quadrant being those without policies for enabling informed decision-making. Dimension 2 helps a develop a typology amongst the countries and regions that have a policy for informed decision-making by demonstrating the discriminating value of
organisational characteristics such as the existence of an administrative team for the oversight and/or implementation of the policy to enable informed decision-making.

Using the object scores from the MCA a HCA was performed. Following an iterative process to arrive at the optimal number of clusters informed by a visual inspection of the dendrogram, depicted in supplementary file 4, three clusters of programmes were retained.

[insert supplementary file 4 – results of hierarchical clustering of screening programmes]

Table 5 compares three clusters derived from the hierarchical clustering process. Significant differences between clusters were reported in respect of each variable used for the multiple correspondence analysis.

[insert table 5]

Cluster 1 is by far the largest cluster, containing 19 countries and regions, all of which have a policy for enabling informed decision-making. For most of the countries or regions in this cluster the policy was implemented in the 2010s. These countries also have teams that are responsible for the oversight and implementation of the policy and are predominantly operating at a national scale. All but one of the countries and regions in this cluster provide written information on the benefits and harms of mammography screening, with eight doing so via decision aids.

Cluster 2 contains 8 countries and regions that also have a policy in place for enabling informed decision-making. This policy is not designed solely for breast cancer screening but is oriented towards other screening programmes, such as cervical cancer screening. Unlike cluster 1 these countries and regions do not have specific teams in place to monitor and oversee the policy. All but one of the countries and regions in this cluster communicate to women in the target group about the benefits and harms of mammography screening, but only two use specific decision aids as tools to facilitate informed decision-making in practice.

Cluster 3 contains 8 countries and regions that have no policy for enabling informed decision-making. Nevertheless, two of the countries and regions in this cluster do attempt to communicate about the benefits and harms of mammography screening and use a decision aid to do so. This cluster includes one of the two countries participating in the survey that had no organised programme at the time of data completion, and where the programmes were still in a pilot or rollout phase.

Discussion

The aim of this study was to develop a typology of approaches towards the facilitation of informed decision-making about mammography screening in Europe. To enable this process, an online survey was developed to gather data from key informants, at the national or regional level, on the organisational characteristics of how countries and regions in Europe approach the issue of informed decision-making.

Based on the data provided by 35 respondents from 28 countries, a cluster analysis reported three distinct groups: those countries or regions without a defined policy towards informed decision-making; those countries or regions which do have a policy but it tends not to be specific to breast screening and without a team to oversee or implement the policy; and those who do have a policy that is often specific to breast screening and possess a team responsible for the oversight and implementation.

Results in context
To date, screening for breast cancer is one of only three tumour sites (alongside cervical and colorectal cancer) recommended in Europe, provided that the screening is offered as part of an organised programme with sufficient resources to ensure high quality [32]. Despite this fact, the debate continues regarding the balance of benefits and harms in breast cancer screening, which emphasises the importance of providing women with necessary information in order to make an informed decision about screening participation [33][34].

The WHO position paper on mammography screening recommends that breast cancer screening programmes should, therefore, take measures to privilege informed choice over achieving high participation rates [12]. Subsequently, addressing informed decision-making about participation in breast cancer screening has become a priority issue [35]. The corollary of this is the need for a screening programme to define and implement specific policies and initiatives to facilitate informed decision-making in practice. To the best of our knowledge, no systematic overview has yet been performed on how breast screening programmes in Europe address this issue, thus, this study aims to fill an important gap in the literature. The results from the survey data demonstrate that policies (explained to survey respondents as including statutory instruments, official recommendations, or specific guidelines for professionals) to facilitate informed decision-making are being put in place by many countries in Europe. Each country or region for whom the expert respondent reported the existence of a policy also noted that their country or region seeks to implement this by communicating the benefits and harms of mammography screening to invited women. The cluster analysis indicates two emergent categories for facilitating informed decision-making: countries or regions with a specific policy and organisational resources towards monitoring and implementing the policy (cluster 1), and countries or regions with a general policy and without organisational resources to oversee and implement the policy (cluster 2).

No statistically significant differences in participation rates could be found amongst the two clusters with a policy. The survey data also reveals that the nature of the format of the policy adopted by the countries and regions is divergent between and within clusters, including within countries for whom regional data was provided. The formats cover, on the one hand, specialist guidelines directed at healthcare professionals implicated in mammography screening, whilst on the other, documented principles codified in law or established as non-binding directives. Survey respondents described how the policy can take the form as part of a regional comprehensive cancer plan (Spain [Valencia]); is documented in law through statutory instrument (Germany); or is in practice the aggregation of a “suite of information and consent form” (Ireland). This heterogeneity of formats may reflect the variety of organisational characteristics of health systems in Europe. Within cluster one, the respondents from two countries (Ireland and UK [Wales]) reported that the policy towards informed decision-making was also directed at non-cancer screening programmes. This result may be an outcome of the application of the ‘consider the offer’ approach that is used in other screening programmes, such as prenatal screening [36].

Figure 1 demonstrates how the category of screening programme status is distributed along the factor map and is closely bound along dimension 1 of the chart. This category was a supplementary variable to the cluster analysis, which is included to inform the interpretation of the outcome of the cluster analysis rather the assignment of the clusters themselves. ‘Roll-out complete’ is the only variable of programme status that appears with a positive value along dimension 1. As this dimension measures principally the presence of a defined policy to facilitate informed decision-making, this result suggests a close association between programme status and the presence of policies towards informed decision-making. Several noticeable exceptions are present in the data, namely Czechia, Iceland and Spain (Basque Country), who are all categorised in cluster 3. The respondent from Czechia noted that the breast screening programme behaves differently to other established
programmes in Europe. The Czech programme was described as more “client-oriented” as women are referred to certified screening centres, of the woman’s choice, via GPs and gynaecologists, with personal invitations reserved to women not participating in the past three years. The respondent noted that this entails information about mammography to enable informed choice can be enacted in the face to face discussion between women and their healthcare providers. Thus, this scenario would be more typically categorised as facilitating a shared decision-making approach, which may help distinguish the countries and regions in cluster 3 from the other clusters.

In order to enable women to make an informed decision about mammography participation, decision aids have been developed and widely reported in the literature as a suitable tool for facilitating an informed choice. Decision aids have been defined as evidence-based tools aiming to support people in making specific and deliberated choices among different options in a healthcare setting, such as participation in organised cancer screening [37]. The recently updated European guidelines on breast cancer screening and diagnosis suggest that for informing women about the benefits and harms of breast cancer screening, a decision aid explaining the benefits and harms of screening is preferred over a standard invitation letter [38].

Amongst the screening programmes included in this study, the use of decision aids to communicate the benefits and harms of mammographic screening was reported as being used by ten countries or regions, mostly appearing in cluster 1. Several aspects could elucidate why a minority of countries reported the use of decision aids. Whilst many examples of decision aids for breast cancer screening have been developed in research studies, the reported outcomes on women’s decision-making confidence is not certain [39][40]. Decision aids, as tools to facilitate decision-making about choices about participation in mammography screening, should increase ideally increase knowledge and reduce decisional conflict. However, a recent systematic review on the effects of decision aids about breast screening reported uncertain results regarding the impact of decision aids on the cognitive components of decisional conflict and decision-making confidence. It was noted that the review evaluated examples of decision aids used in a research context. Thus, the participants may not be representative of the wider population as they may possess greater commitment towards screening than a typical citizen, thus limiting further the ability to generalise the results to the wider population [39]. Moreover, the lack of widely available best practices for decision aids in use for mammography screening, which the new European guidelines on breast cancer screening and diagnosis identified as a research priority [41].

Additionally, the dependency on quantitative information in decision aids to support an informed decision remains a key issue, especially where the objective to avoid exacerbating health inequalities is concerned. A recent clinical trial in Spain noted that providing quantitative information on the benefits and harms of breast screening produces a substantial increase in knowledge and informed choice [23]. However, concern remains about the ability of the decision aid format to reflect cultural and other intangible factors, which women take account of during their decision-making [42]. The presentation of information provided can also influence the extent to which women may be able to make an informed choice. Regarding the presentation of quantitative evidence, the use of probabilistic or absolute information can lead diverging assessment of risk by women, thereby influencing the ultimate decision of the woman [13]. In the United Kingdom, the review of information provided to women in the target age group concluded quantitative data can included in the form of absolute risk reduction [36]. Consequently, considering the ongoing debate about the effectiveness of mammography screening, deciding upon the appropriate form for quantitative data remains open for further investigation [43]. Aside from decision aids, programmes typically inform women via the invitation letter or information leaflet. The distinction between a decision aid and an information leaflet is often not clearly delineated and may lead to ambiguity when identifying the
communication tools used by the programmes [35]. For example, in the United Kingdom, invited women receive a leaflet with ‘balanced information’ in order to ‘consider the offer’ of screening [36]. One subtle difference between an information leaflet and decision aid may be the use of pictorial information in place of text. This ambiguity requires further investigation to clarify the terminologies and arrive at best practices for use by women in Europe considering cultural factors and varying levels of health literacy.

The results demonstrate that whilst most countries and regions in cluster 1 and 2 have taken steps to facilitate informed decision-making in mammography screening, few have made attempts to evaluate the effects of the information on benefits and harms. Moreover, only one respondent (Switzerland, Valais) reported that they had tried to measure the proportion of women who made an informed decision. Given the prioritisation afforded to informed choice ahead of achieving high uptake, the rate of women making an informed choice has been proposed as a key performance indicator for breast cancer screening [14]. Many studies have attempting to measure informed choice in cancer screening by focusing on measuring knowledge, values and behaviour [44]. However, as yet, consensus on the measures and methods to enable the measurement of informed decision-making, and arrive at informed choice is lacking [45]. Recent studies have indicated that women appear to over-estimate the benefits of breast screening [46]. Consequently, further research is required to examine the impact of methods to communicate the benefits and harms of mammography screening in respect of informed decision-making.

The cluster analysis also reported a third category in the form of countries and regions that have not yet adopted a policy on informed decision-making and mostly do not communicate the benefits and harms of mammography screening (cluster 3). Reasons given included concerns about the potential impact on the uptake on the screening programme, and insufficient evidence to support the development of a policy. The results also suggest that structural issues, at the national and regional level, may act as barriers to providing information on benefits and harms. One respondent observed that, whilst this survey concerns the provision of information from the screening programme or national and regional authorities, information leaflets can be “provided randomly NGOs and patient support associations, professionals with insufficient knowledge or communication skills.” This can lead to conflicting or confusing information for women eligible for mammography screening.

One respondent indicated that the lack of consensus on how to respond to an ongoing negative campaign against mammography screening in their country inhibited the development and implementation of information on the benefits and harms. In other countries, women are invited only if they have visited a family doctor, so that the provision of information comes through primary care, rather than from the programme itself. However, respondents in cluster 3 were mostly ambivalent about informed decision-making, which may explain why several countries and regions with established programmes appear in this cluster. One respondent noted that attendance at screening itself was considered informed consent. Whilst another respondent reported that their women in their country are provided with “partial information on the benefits of screening”. This highlights the importance of countries and regions learning from others within the cluster as they possess a similar stage of adoption regarding informed decision-making about mammography screening. Therefore, breast screening in Europe would benefit from a range of options and best practice examples that are tailored towards organisational characteristics.

**Limitations**

There are several important limitations to be noted regarding this study. Firstly, countries with important experience, notably the Netherlands and Sweden, did not respond to the survey, despite multiple attempts to engage with the relevant data providers in the respective programmes. In
those countries that did respond, the programmes are sometimes de-centralised (e.g. Italy, Spain and the United Kingdom) and not all regions or nations of these countries were reached by the survey.

A key limitation of the survey is that most country or regional responses are the result of the input of a single expert contact. Moreover, as the survey was directed towards experts who in many cases are directly responsible for existing or nascent programmes, a caveat of seeking responses from such professionals is that there could be a professional interest to portray the country or region in a certain direction.

Many of the questions used in the survey questionnaire were closed questions in order to facilitate manageable data gathering and analysis. This may have had the effect of artificially limiting the responses to the questions by the data provider. However, open-ended comments sections were provided for respondents to feedback more qualitative information.

The potential for ambiguity of interpretation by the respondents may have occurred in respect to the definitions of such concepts as ‘policy’ and ‘decision aids’. To mitigate ambiguity, commonly accepted terms and definitions adopted in the second report on the implementation status of cancer screening in European Union were used and explained the introductory email and in the text of the online survey itself. Nonetheless, the possibility that respondents conflated terms such as informed decision-making and informed consent cannot be ruled out.

**Added value**

The key strength of this study is that it provides a much-needed overview of the current approaches to facilitate informed decision-making in Europe. That this data was provided by professionals from within the respective screening programmes covering most countries implicated in the ECIBC adds to its value and relevance. Moreover, a high response rate from the competent and qualified professionals working with screening programmes was reported. This demonstrates the interest and relevance of the topic and data provided. Additionally, the cluster analysis of the data provides a basis to promote knowledge exchange between countries and regions with comparable characteristics. Furthermore, this data can be used by programmes and researchers to propose evidence-informed policy and practice that is tailored to the organisational aspects reflected in the typologies.

**Conclusions**

This study has found that many countries in Europe have adopted a policy to facilitate informed decision-making about mammography screening and make efforts to communicate to women about the benefits and harms associated with participation.

The cluster analysis determined two broad categories of approaches towards facilitating informed decision-making in practice. The largest cluster typically has a policy specific to mammography screening, and organisational structures in place, in the form of specific teams with the responsibility for the oversight and implementation of the policy. The remaining cluster has a general policy and is without the organisational teams. A third category emerged of countries and regions without any policy towards informed decision-making and who tend not to communicate about the benefits and harms of mammography screening.

The study showed that countries had not yet adopted decision aids to inform women despite this tool now being recommended by the European guidelines on breast cancer screening and diagnosis over a conventional invitation. Reasons provided for this situation include the lack of validated best practices and the need for results of ongoing research from the field.
Finally, the study also found that the measurement of informed decision-making is rarely conducted in practice, and thus, remains an area in need of further investigation. Consequently, validated best practices on how to develop, implement and evaluate policies to facilitate informed decision-making, with culturally appropriate and responsive tools for measurement of informed choice, would provide much needed support to help women make an informed decision about mammography screening.
References


