TITLE

Information needs perceived by women regarding the breast cancer screening leaflet: A mixed-methods study

Running Head: Evaluating cancer screening leaflets

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Acknowledgments

To all the women who participated in this research and the Health council of the Principality of Asturias for their support during this study, especially, to Ana García Fernández and Miguel Prieto García

Conflicts of Interest and Source of Funding:

None declared.

Funding statements

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Authorship

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/ethical_1author.html)].

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Information needs perceived by women regarding the breast cancer screening leaflet: A mixed-methods study

Abstract

Objective: To obtain feedback regarding the comprehension and acceptability of an information leaflet on breast cancer screening (BCS) among women.

Methods: A mixed-methods study was conducted among 41 women aged between 40 and 60 years old in the north of Spain. The breast cancer screening leaflet evaluated included information about breast cancer (BC), BCS, benefits/risks of attending BCS, and the BC mortality and survival rates in relation to screening. Three methods were used to assess the leaflet: a readability assessment (Flesch Index) and two comprehension assessments (the Cloze test and multiple response questions). In addition, 26 semi-structured interviews were conducted to explore the women's opinions regarding comprehension, acceptability, and the contribution of the leaflet as a decision-aid.

Results: Overall, women found the leaflet quite easy to read and most understood the content however, for some women, the information on mortality was considered more difficult to comprehend, too alarming and a cause for rejection. The leaflet was viewed as a decision-aid although further information was requested on mammograms, the need for complementary tests and the risks and symptoms of BC.

Conclusion: Overall, the target population for BCS understood the leaflet, however some terms were considered to be overly complex, which impacted the acceptance of BCS.

Keywords: Early Detection of Cancer; Breast Cancer Screening; Leaflet; Patient Satisfaction; Qualitative research; Mammography

INTRODUCTION

Breast cancer screening (BCS) programmes are the main strategy for the early detection of breast cancer (BC) in developed countries. Although certain differences exist between BCS in terms of the age screening starts or the periodicity of the same, all women resident in Spain aged between 50 and 69 years receive an invitation to undergo a population-based screening programme every two years (Ballesteros Peña & Gavilán-Moral, 2018). This invitation is usually accompanied by a leaflet with information on BC, BCS and mammography exams.

More recently, however, women are being encouraged to decide for themselves whether they wish to participate in BCS programmes, by offering accurate and comprehensive information concerning the entire process (Gummersbach et al., 2015; Hersch et al., 2015, Pérez Lacasta et al., 2019). For example, a study on the information materials for BCS conducted in Spain found that there is a tendency to highlight the benefits of BCS rather than its risks, and no information is provided regarding the emotional impact of screening tests or the confirmatory diagnostic tests related with a false positive (Ballesteros Peña & Gavilán-Moral, 2018).

Recommendations given by health professionals have been reported to be more determinant in a woman's decision to attend a BCS, compared to the effects of information leaflets (Gummersbach et al., 2015). However, another study (Perez Lacasta et al., 2019) demonstrated that providing information on the benefits and drawbacks of BCS contributes towards women making an informed decision and improving their knowledge on BCS. In Spain, a positive attitude towards this screening test exists even though many women have limited knowledge regarding BCS (Baena Cañada et al, 2014). Furthermore, the number of mammograms performed in Spain has increased between the years 2006 and 2014, associated with receiving the invitation letter to participate in BCS and/or the recommendation by a health professional (Carmona-Torres et al., 2014)

In our region, high levels of attendance have been registered since the implementation of BCS. More specifically, in 2014, 95% of women aged between 50 and 70 years old underwent a mammogram (Carmona-Torres et al., 2014) with the satisfaction rates among these women being reported as high (Fernández-Feito et al., 2015).

Local health authorities have revised the information to be included in the leaflets on BCS so that it is relevant for women of the target population and can be used as a decision aid. Previous initiatives have taken place in Europe to design and evaluate material providing direct information on the benefits and risks of BCS (Gummersbach, in der Schmitten, Abholz, Wegscheider & Pentzek, 2013) and colorectal screening (Dreier et al., 2014). Although there is widespread social awareness regarding BCS, the first contact and initial information on BCS is usually via a leaflet which the women receive in the post, an approach that is implemented both in Spain (Ballesteros Peña & Gavilán-Moral, 2018) and in other countries (Gummersbach et al., 2015). When evaluating this material, it is important to not only consider the understanding of the text, but also other aspects, such as acceptability. This is a complex concept which may be interpreted as the degree to which the people who receive a health intervention consider that this is appropriate, based on the cognitive and/or emotional responses to an intervention (Sekhon, Cartwright & Francis, 2017). Thus, the evaluation of the leaflet is influenced by the assessment of BCS and the expectations associated with this strategy (Whelehan, Evans & Ozakinci, 2017).

To date, numerous publications exist on the role of information in BCS and its contribution towards helping with decision-making and/or the intention of participating in this screening, however, less research has focused on the demands for information and contents of these leaflets from the perspectives of the women to whom these programmes are targeted.

OBJECTIVE

To obtain feedback regarding the comprehension and acceptability of an information leaflet for breast cancer screening among women in Northern Spain.

METHODS

A mixed-methods study.

Participants and settings

This study included 41 women, aged between 40 and 60 years. Women who had not yet been included in the BCS were incorporated to analyse their opinion regarding a leaflet that was unknown to them and to gather their feedback.

Convenience sampling was used, seeking the participation of women from different educational profiles, professional backgrounds and residential contexts, as the leaflet had to be understandable and useful for women of different profiles. Snowball sampling was used to complete the sample based on recommendations from initial participants. Sociodemographic variables were gathered, such as the age, educational level, profession and women's place of residence (urban/semi-urban/rural). Thus, urban referred to financial cities with more than 200.000 habitants, semi-urban referred to satellite towns of urban areas with 10.000-50.000 habitants and rural was the term used for towns with less than 10.000 habitants. The women's personal and family history of BC was gathered, as well as any history of previous mammograms. The study took place between January and April, 2018.

Leaflet

In parallel to our study, a separate work team from the Department of Health was designing a new leaflet on BCS, with two differentiated sections (Appendices A and B). The draft of this new leaflet was the written material evaluated in this study. The first section (Part A) (1000 words) featured general information on BC (risk factors, symptoms, etc.) and on BCS in our region (Appendice A). This section aimed to offer women all the available up-to-date information on BC and BCS so they could make an informed decision on whether to participate in the screening, or not.

The second section (Part B) (740 words) featured information on the benefits-risks/inconveniences of attending/not attending a BCS appointment, the influence of participation on mortality and survival after the diagnosis of BC and the mortality data after the BC diagnosis. The information in this section is based on the data on BCS in our region. This data was presented both numerically and using graphs (Appendice B).

Procedures and Measures

The readability of the leaflet was analysed using the INFLESZ 1.0 computer program. This program uses the Flesch Index, or Flesch-Szigriszt Index (IFSZ). This is currently considered the tool of reference for analysing the reading ease of texts in Spanish (Barrio-Cantalejo et al., 2008). The readability of a text is acceptable when the IFSZ index is greater or equal to 55. This section was only assessed by the research team and was the initial analysis performed.

The Cloze test was used to evaluate comprehension of the texts. During this assessment, words are randomly removed and the subject must then supply words to fill in the blank spaces with the most appropriate word in each case, using their own vocabulary. The level of comprehension is determined according to the hit ratio: (>56%) the person understands

the text on his/her own, (44-56%) additional help is needed to understand the main ideas and (<44%) the text is too difficult to understand. Four different modalities of the Cloze test were designed: two modalities for part A and two modalities for part B (Assessment tool 1). In the first modality, one out of every 10 words was removed, whereas, in the second modality, one out of every 15 words was removed. Furthermore, to verify understanding, six multiple-choice questions were included with four response options (with a single valid response) (Assessment Tool 2). The questions concerning part A referred to aspects of BCS and individual characteristics of women (three items), and those for part B addressed understanding of the purpose of the leaflet and information about the women who participate in BCS (three items). A pilot study was performed with eight women using the Cloze test and the multiple-choice questions. These two tools for evaluating comprehension (Assessment Tools 1 and 2) were applied during interviews with women.

Semi-structured interviews

Qualitative methods were used based on a phenomenological approach, and 26 semi-structured interviews were conducted within the total sample of women. The research team was formed by a nurse from the Health Department, a nurse from the University Department and a male nursing student). The nurse from the Health Department had extensive experience on BCS in Asturias. The nurse from the Faculty of Medicine and Health Sciences is a doctor and her PhD thesis was performed on the effectiveness of an intervention to decrease pain during mammograms (Fernández-Feito et al., 2015). In addition, she was the tutor of the final degree project of the nursing student who collaborated in this study on this subject. Each interviewer previously knew the women who participated.

An interview guide (Table 1) was used, which covered the comprehension and acceptability of the leaflet, usefulness of the same as a decision-aid, proposals for changes and aspects on BCS. In addition, field notes were taken to record the sociodemographic variables, their relationship with BCS, the characteristics of the meeting (physical setting, non-verbal communication, duration), the researchers' perceptions and a summary of the interview. Data collection was concluded following the criteria of data saturation and after incorporating women from different educational profiles and residential contexts. The face-to-face interviews took place at the homes of women or at previously agreed locations. The duration of the interviews ranged from 15 and 30 minutes and all interviews were audio recorded after obtaining informed consent. The Giorgi's proposal was followed to process the data (Giorgi, 1997). Thus, after collecting the information and reading the verbatim transcripts of each interview, the text was divided into fragments by identifying the meaningful units. Subsequently, these units were grouped into common meanings, forming groups of meaning. Lastly, the information was summarised into the most relevant themes. The following previously established categories were addressed: comprehension and acceptability of the leaflet, aid decision-making and proposals for improvement. The initial analysis on the verbatim transcripts of all the interviews was performed by same the two researchers who were trained in qualitative methods. Each interview was analysed by both the person who conducted the same and by another person in the research team, through a process of triangulation. Each member of the team analysed 8-10 interviews and the findings were discussed in pairs. Finally, a researcher integrated all results into groups of common meanings and dimensions.

Ethical aspects

This study was approved by the Research Ethics Committee of the Principality of Asturias

(186/17) and by the Health Department. All the women accepted to voluntarily participate in the study by signing an informed consent form, without receiving any financial compensation for their participation. The interview transcripts assigned a code to each participant to preserve their confidentiality.

RESULTS

The sociodemographic and clinical characteristics of participants are presented in Table 2. In total, 41 women participated in this study, however not all women participated in the same study phases as the duration of the assessment of both parts of the leaflet, the Cloze test, the multiple-choice questions and the interviews combined was considered too time-consuming. The distribution of participants for each test was as follows: Cloze test (n= 21), multiple-choice questions (n=28) and semi-structured interviews (n=26). Approximately half of the women had not yet been invited to participate in the screening test as they were under the age of 50, therefore they had no previous contact with any other BCS leaflet. Most of the women had a mid or high level of education (university studies) and lived in an urban environment. Women from different work sectors were included with a high representation of non-health professionals. Over half of women had already received a previous mammography and some had personal or family experience of breast cancer.

Readability of the leaflet

Regarding the readability based on the INFLESZ test, part A obtained an index of 75.7 and part B obtained an index of 77.0. Thus, in both cases, the leaflet was considered quite easy to read.

Comprehension of the leaflet (quantitative analysis)

In total, 21 women completed the Cloze test to evaluate comprehension of the leaflet. For part A, 75% of the women understood the text on their own, and 8.3% required help, whereas for 16.6% the text was too difficult. In part B, this was understandable for 81.2%, 12.5% required help, and it was too difficult for 6.25% of participants. Regarding the comprehension of the leaflet based on the multiple-choice questions, this was evaluated in 28 women (21 women evaluated part A and 24 women evaluated part B). The most general part of the leaflet, which refers to BCS and the purpose of this leaflet received the highest level of understanding. However, in the case of aspects concerning mortality, the percentage of correct answers decreased (Table 3).

Assessment of the new leaflet (qualitative analysis)

During the semi-structured interviews (26 women) four categories were intentionally addressed in order to examine the usefulness of the leaflet (Table 4). In terms of comprehension, the leaflet was considered clear and correctly organised, using simple language. Nonetheless, other aspects were still considered to be quite complex, such as the benefits/risks of BCS and mortality due to breast cancer in relation to BCS. The ability to understand data and graphs was difficult for some women and was specifically related to the women's age and educational level. The acceptability of the leaflet was positively related with comprehension; thus, if the material was easily understood, acceptance of the same increased. Overall, there was good acceptability for the more general information about BC, BCS and the decision of whether to participate. However, the information regarding mortality was deemed as being too alarming, generating

feelings of rejection among some women. The use of graphs in the second part of the leaflet was enlightening for some women, however others also described these as being "mere" statistics and revolving around mortality. Most women considered that this material was useful for making the decision of whether to attend BCS, and spontaneously commented what their decision would be if they were to receive this information. Regarding the proposals for improvement, overall, the women expressed the need for further information on mammography, the possibility of performing complementary tests and also the risks and symptoms of BC. They also stated that they would appreciate a more visual format, simplifying certain sections on the leaflet, especially the table on risks/benefits.

In addition to the previously defined categories, three new categories emerged: beliefs, previous experiences and feelings (Table 5). These three emerging themes intermix concepts on BCS and BC. In general, erroneous beliefs on BC and BCS were detected which, in many cases surfaced upon reading this leaflet. Their participation in this study also enabled them to describe their previous personal experience with benign lesions (e.g. fibrocystic breast disease) or regarding the BCS screening procedures. Lastly, there was a certain duality regarding the emotions and feelings when talking about BC and BCS. Some women appreciated being informed and the efforts of screening programmes for their own health, however, at the same time, a significant negative emotional burden was detected surrounding BC and BCS.

DISCUSSION

This study presents the analysis of the readability and comprehension of a BCS leaflet and the perspectives of women regarding the necessary information and the most appropriate format for this leaflet. The health information material was considered

comprehensible and easy to read, with a high level of acceptability by future participants in this strategy. In addition, this material can aid decision-making. However, some concepts still appeared too complex and women requested further information, displayed in a more visual and simplified manner.

The type of methods applied (mixed-methods) has enabled us to evaluate different technical aspects, such as the readability and understanding of the leaflet using quantitative procedures which have also been explored with women using qualitative methods based on semi-structured interviews and in-depth interviews. In addition, different triangulation processes were performed. Thus, the assessment of materials was triangulated from different perspectives (legibility, comprehensibility, acceptability). In addition, the methods were triangulated (INFLESZ test, Cloze test, semi-structured interviews), together with the researchers who analysed the interviews.

This research has also enabled those responsible for the BCS to design a leaflet that was closer to the target population by incorporating balanced information on the benefits and risks of BCS, while providing useful information for women, independent of whether they decided to attend these screenings. This strategy represents an attempt to abandon the paternalistic approach of intentionally promoting participation, in favour of supporting a more responsible attitude, by providing accurate information (Ballesteros Peña & Gavilán-Moral, 2018, Forbes & Ramírez, 2014;Toledo-Chávarri et al., 2017)

Considering the results of the INFLESZ test, the reading capabilities necessary to understand the new leaflet will be similar to those necessary for understanding primary education books, novels, or gossip magazines, with some text being similar, in literacy levels, to secondary education books or the general press/sports. In our region, among those women who will attend a BCS either this year or in the upcoming years, over half have university studies, followed by those with an intermediate educational level (Álvarez

Martín, 2017). Faced with this reality, we believe that the readability of the leaflet is guaranteed. This is important, especially if we consider that certain authors have already reported readability limitations when analysing internet-based education materials available on the internet on mammography and BCS (Alkhalili , Shukla , Patel, Sanghvi, & Hubbi, 2015) and also regarding other contents (e.g. education materials in ophthalmology) (Williams, Muir & Rosdahl, 2016)

In terms of comprehension, according to the results of the Cloze test, part B was easier to understand. However, when comparing this with the results of the multiple-choice questions, this part of the leaflet obtained the poorest results. Faced with this data, we paid particular attention to the comprehension evaluated during the interviews. This approach revealed which sections were easier or harder to understand, together with the reasons behind this perception and the relationship between comprehension and other dimensions, such as acceptability or beliefs. The results obtained are reasonable, with a greater comprehension of general aspects on BC and BCS, however, understanding was hampered in the case of more complex content, such as mortality data. Appropriate comprehension of the text was related with a greater acceptability and also related with receiving interesting and useful information. We observed a relationship between a greater frequency of the word “death” and a decreased acceptance of the material. It is essential to offer the general population understandable information on screening. Nonetheless, some authors (Sadigh et al., 2016) have detected that most of the information on BCS provided on the webpages of hospitals in the USA are understandable to less than 1% of the American population while only 28 % provided information to enable people to make their own decisions.

It is necessary to reflect on the use of certain terms. For example, this study identified rejection towards terms related to death and mortality. In addition, it is important to find

the appropriate formula to provide information without including words that are difficult to understand (e.g. over diagnosis). In relation to this risk within BCS, some authors have already detected difficulties with the understanding of this term (Toledo-Chavarri et al, 2017) or it was unknown to women (Henriksen, Guassora & Brodersen, 2015). However, according to a previous study, women appreciate and request information on this term, being able to understand this concept after an appropriate explanation is provided (Hersch et al.,2013)

A certain variability was observed among the women's understanding of texts, numbers and graphs, and there was no consensus regarding the preferences regarding how the information should be presented, although participants demanded a more simplistic and visual presentation. Undoubtedly, it is essential to provide accurate data on BCS and BC, as this information faces women with their beliefs on the perception of risks and other aspects regarding BC and BCS. Furthermore, ambivalence was detected regarding BCS. Some women considered this preventive strategy as something positive and they felt "cared for", as has been reported in other studies where there was a sense of gratefulness that these programmes existed (Whelehan, Evans & Ozakinci, 2017). However, some women also commented that they felt concerned or discouraged in terms of their decision to attend such programmes as attendance was not a guarantee of surviving BC.

This study also enabled the possibility of exploring the feelings and beliefs regarding BC and on health in general, an interesting perspective which has been less explored. It is undeniable that many women have expectations and beliefs regarding BCS even before being included on this programme. This can influence the interpretation of the information that is included in the leaflets, especially if it contradicts their prior convictions (Henriksen et al., 2015).

In the future, it would be interesting to approach the information needs on BC and BCS presented by women who are not included in BCS, i.e. women under the age of 50 and over the age of 69. Likewise, it is important to examine the perception on BCS, and factors involved with attendance, information received, etc. according to aspects such as the social class, as the experiences and opinions of other close women can influence a woman's decisions (Henriksen et al., 2015). Lastly, we feel it is necessary to explore the experience of women who attend BCS programmes who receive a false positive result.

Limitations

This study has several limitations. First, the people conducting the interviews previously knew the women. This approach was selected for practical reasons as it facilitated access to women, geographically speaking, as they often lived in the same neighbourhood etc., and also because of trust issues, as we interpreted that it is easier to establish a favourable atmosphere to approach these subjects if the women previously knew the interviewer. Another limitation is not having included women with specific information requirements (collectives of people with difficulty understanding the language or specific ethnic groups). This aspect should be improved in the assessment of the final leaflet, evaluating whether there are understanding difficulties on behalf of these women or whether they require another type of information.

CONCLUSIONS

Overall, the target population for BCS understood the BCS leaflet, however certain terms were considered complex and can condition the acceptance of BCS. The information regarding the benefits and risks of BCS, together with data on mortality rates among the

women who attend BCS programmes and those who do not, represents a potential decision-aid tool. The process of revising the material with the participants is a very enlightening procedure which has enabled the ability to prioritize and improve the contents and format of the leaflet.

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Table 1. Semi-structured interview guide

Thematic area	Questions
Comprehension of the leaflet	Do you think the content is easy to understand? Do you think that the information is better understood using text or using figures, tables, etc.? Is there any aspect which you feel is missing?
Acceptability of the leaflet	What is your opinion regarding the information on this leaflet? What did you find most interesting? How has this information made you feel?
Decision aid	In order to decide whether or not to participate in BCS, what other information would you like to receive? What factors do you believe influence a women's decision to have a mammography within the BCS? Regarding the leaflets which accompany the invitation letter to participate in BCS, do yo think that the leaflets factors do you think determine this participation?
Proposals for improvement (contents/images)	What would you improve from this leaflet and how? Would it be a good idea to include photos?
Experience within BCS	What do you believe the women feel/what have you felt upon receiving the letter of invitation and information on BCS?

BCS: Breast Cancer Screening

Table 2: Characteristics of participants

Age (years)	n=41
40-49	20
50-60	21
Education level	
Primary Education	4
Secondary Education	20
University Degree	17
Residential setting	
Urban	25
Semi-urban	9
Rural	7
Profession	
Not a health sciences professional	33
Health sciences professional	8
Personal history of breast cancer	4
Family history of breast cancer	10
Previous mammography experience	30

Table 3: Comprehensibility evaluated using multiple-choice questions.

Question	Response options	Correct response
PART A		
1. What does BCS offer?	a) It offers the performance of a digital ultrasound of women's breasts. b) It offers the possibility of performing a digital mammography in women aged between 40 and 60 years once in life. c) BCS has qualified professionals for the performance of mammographies. d) It offers the performance of a free mammography every 2 years to women aged between 50 and 69 years old.	100%
2. What should a woman do if she notices a change in her breasts?	a) It is advised that she should consult her doctor as soon as possible. b) She should wait for her next mammography because she is protected with the previous one. c) She should only go to her doctor if the change is a lump. d) She should call her Unit for Early Detection to request a new appointment.	89%
3. What does the leaflet ask a woman to do, if she does not want to be given an appointment for BCS?	a) She should inform her doctor at the health centre. b) She should inform the Unit for Early Detection of BCS. c) It is not necessary for the woman to inform that she does not want to participate in BCS. d) She should obtain a discharge form for BCS available at www.astursalud.es	84%
PART B		

1. What is the main purpose of the leaflet?	a) Provide information that is useful so that women can decide whether they wish to participate in BCS. b) Encourage women with BC to attend BCS. c) Encourage women without BC to attend BCS. d) Provide information on what a mammography test is.	96%
2. Women from 50 to 69 years old who have been diagnosed with breast cancer via a BCS mammography.	a) 33% have ganglions affected in the axilla. b) Can continue to attend BCS. c) The probability of surviving is greater than if BC appears between two BCS mammography. d) Must consult the internet to stay informed.	61%
3. Women aged between 50 and 69 years who do NOT participate in BCS:	a) Have a lower risk of being diagnosed with BC. b) Can choose the Unit of Early Detection where they should participate. c) Have a lesser risk of dying because of BC in the event of being diagnosed. d) Almost never have affected ganglia in the axilla when they are diagnosed with BC.	39%

Table 4. Coding table of initial categories of the study

Meaningful units	Common groups of meaning	Thematic area
Clarity of information. Structured information. Clear and simple language, with an absence of technical/medical terms. Difficulty "oestrogens" term. Appropriate understanding BCS. Need to better explain the purpose of the mammography. Different understanding benefit/risks table. Difficulty understanding data and graphs. Individualized perception on the format of data (text, graph or both). Comprehension related with age and educational level of BCS participants. Doubtful understanding section on mortality because of breast cancer in relation to BCS.	Characteristics of the leaflet Difficulty understanding complex information Factors related to understanding	Leaflet understanding
Acceptance linked to good acceptance: interesting material, relevance, usefulness. Mutual positive relationship between understanding and acceptability. Good acceptance risks, symptoms of BC, BCS, and the information regarding whether or not to attend screening programmes. Duality part B: Positive getting to know the reality and objective data of BCS but also confusion, information that is too alarming. Variable acceptance table benefits/risks of screening, deemed as very interesting but also generating rejection. Mortality after BC diagnosis, duality between acceptance versus rejection/concern speaking directly about mortality. Data presented in graphs variable acceptance, clarifying for some and helpful for understanding, for others, a cause of rejection as these are statistics or mention deaths.	Acceptance of the format Relation with comprehensibility Duality acceptance between objective information on BCS and emotional rejection of BC	Acceptance of the leaflet

The information on the leaflet is useful for deciding whether or not to attend BCS (especially part B). Confusion regarding the information presented in graphs to help decision making. Spontaneous mention of attendance to future screens.	Intention to attend BCS	Decision-making
Need for further information regarding mammography (periodicity, radiation, appointment, duration of appointment…) and the assessment appointment to rule out BC. Need for further information on the risks and symptoms of BC. Simplifying the table of risks/benefits. Need to improve the visual format. Proposals: pleasant images/relaxed images or also informative images related with the subject (e.g. a woman undergoing a mammography). Proposal combined leaflet part A and part B and shorter.	Expand information Formatting proposals	Proposals for improvement (contents/images)

BC: Breast Cancer BCS: Breast Cancer Screening

Table 5. Coding table of the emerging thematic areas.

BC: Breast Cancer BCS: Breast Cancer Screening

Meaningful units	Common groups of meaning	Thematic area
Erroneous beliefs on BC: protective factors, prevalence, prognosis linked to early diagnosis. Beliefs on benefits of BCS which overcome risks and inconveniences. Objective information BCS data in our region, Asturias, is faced with their own beliefs or perceptions on the benefits of BCS. Belief that BCS is "infallible" protecting and ensuring that women do not have cancer. Opinions regarding the reasons for not participating in BCS. Erroneous beliefs on mammography. Own and generalizable belief of society on the incorrect association between cancer and death. Conflicts between understanding the information of the leaflet and previous beliefs (e.g. the screening enables the ability to diagnose and treat some BC without improving life expectancy) Belief that performing tests in general is good for your health "best to prevent than to regret"	Erroneous beliefs BC and BCS Dissonance between information on the leaflet and personal beliefs General beliefs regarding early detection	Beliefs
Previous personal experience of benign lesions. Own lack of knowledge regarding self-examination. Previous personal experience with BCS. Previous experience of knowing other women who do not participate for fear of radiation. Communicating information from BCS to women. Information on functioning of BCS for women who have still not agreed.	Personal experience regarding BC Personal experience regarding BCS	Previous experiences
Negative feelings regarding BC. Ambivalent feelings related with the sample: Positive sensations linked with being informed, cared for, tranquillity versus concern, confusion, rejection of words such as mortality, fear of breast cancer. Feeling discouraged as attending screening does not imply being cured of BC. Importance of not dramatizing, generating excessive fear of BC with the leaflet.	Positive feelings linked to BCS Negative feelings related with BC, BCS and some sections of the leaflet	Feelings*

Appendix 1. Part A of the Breast Cancer Screening Information Leaflet

INFORMATION MATERIAL FOR THE BREAST CANCER EARLY DETECTION

This programme offers all women between 50 and 69 years who live in Asturias a free mammography every 2 years, to identify women who may have this illness.

This information can help you to decide whether or not you attend the programme, according to what is best for you.

Should you require further information to make a decision, we can help you at your health centre. You can also find further information on the web page: www.astursalud.es

This programme follows the recommendations of the European Council and the Ministry of Health.

Breast cancer is the growth of malignant cells in the breast. These cells can travel to other parts of the body and cause severe problems.

A **mammography** is an x-ray of the breast.

XXX

Why does breast cancer appear?

Currently, the causes of breast cancer are unknown.

- Most often, it is related with certain sexual hormones, especially oestrogens. Therefore, it almost exclusively affects women.
- Sometimes it is related with genetic disorders.

Although it is the most common cancer in women, seven out of every eight women never develop cancer.

What can we do?

It is necessary to continue to research the causes of this illness to understand what we can do to avoid the development of breast cancer.

What is the risk of developing breast cancer?

Currently, the risk each woman has is unknown.

Some circumstances increase the risk and cannot be changed:

- Ageing.
- Having family members with breast or ovarian cancer, due to genetic causes.
- Injuries to the breasts, now, or in the past.

The age of the first and last period, pregnancies and breastfeeding also influence the risk of breast cancer, however these factors are not changed to decrease this risk.

Some treatments with hormones can increase the risk, therefore, like in all types of treatment, it is necessary to assess the advantages and inconveniences of the same.

What can I do?

Decreasing exposure to oestrogens may be difficult.

Avoiding being overweight, not consuming alcohol, not smoking and doing sports, are measures which decrease your risks and that of many other illnesses, but they do not guarantee that you will be able to avoid having breast cancer.

If you think that you have a greater risk than most women, we recommend that you consult with your health centre.

Is it possible to have breast cancer without knowing so?

Yes, often, breast cancer has few symptoms. Some tumours may even not ever produce any symptoms.

Most women have the tumour for some time before developing symptoms. the first thing they often notice is a hard lump in the breast or in the armpit which doesn't hurt, but this is not always the case.

What can I do for early detection of cancer?

If you are aged between 50 and 69 years old, you can have a mammography every two years. If you live in Asturias, we recommend that you have this test for free, via the programme.

For your own health, it is important to know what is normal in your body, also in your breasts, this way you can notice when there are changes.

What should I do if I have symptoms?

If you notice changes in your breasts that are not due to your menstrual cycle, we recommend that you consult this with your health centre as soon as possible.

These changes may be due to benign problems. Before thinking and assuming that you have a severe illness, consult with your doctor and wait for the results of the tests.

If you have cancer, an early diagnosis and treatment can increase your chances of surviving breast cancer.

This is important for all women, whether or not they have ever had a mammography:

- Neither the mammography nor any other test is perfect.
- A mammography does not protect you from cancer.

On occasion, breast cancer is diagnosed during the period between two mammographies.

What does the Early Detection Programme for Breast Cancer consist of?

If you decide to attend the Programme, you may be interested to know that:

Appointment. Between the age of 50 and 69 years, every 2 years you will receive a **letter with an appointment** to have a mammography. If you do not wish to be given an appointment, you must notify your Early Detection Unit.

Location. In Asturias there are 8 Units of Early detection, one in each Health Area.

The Unit which you are appointed to, depends on your address. In your letter with the appointment, the address and telephone number of your unit is shown.

Health Area I **Telephone number**	Health Area II **Telephone number**
Health Area III **Telephone number**	Health Area IV **Telephone number**
Health Area V **Telephone number**	Health Area VI **Telephone number**
Health Area VII **Telephone number**	Health Area VIII **Telephone number**

Preparation. In your appointment letter you will find all the information necessary to prepare for the test.

Test. Two different mammographies of each breast are performed at each visit. For a good quality mammography, it is necessary to squeeze the breast with the mammograph. Sometimes, this is painful for some women.

Results. In approximately 15 days you will have the results of the mammography. If you need to perform further tests, you will be called by telephone in order to give you an **assessment appointment**.

Each time 1,000 women attend the Programme in Asturias:

- Between 900 and 950 women have a **normal result**.
  The Programme gives them a new appointment after 2 years, except if they are aged 70 or older.
  Of these, 1 woman is diagnosed with breast cancer before the next mammography.
- Between 50 and 100 women need **complementary tests**.
  Of these, 3 are diagnosed with breast cancer.

Appendix 2. Part B of the Breast Cancer Screening Information Leaflet

INFORMATION MATERIAL FOR THE BREAST CANCER EARLY DETECTION PROGRAMME IN ASTURIAS

The Breast Cancer Early Detection Programme is for women aged between 50 and 69 years old who live in Asturias.

Most women will never have breast cancer, however, the women who do develop the illness can improve their quality of life and their possibilities of surviving the illness if they are diagnosed and treated promptly.

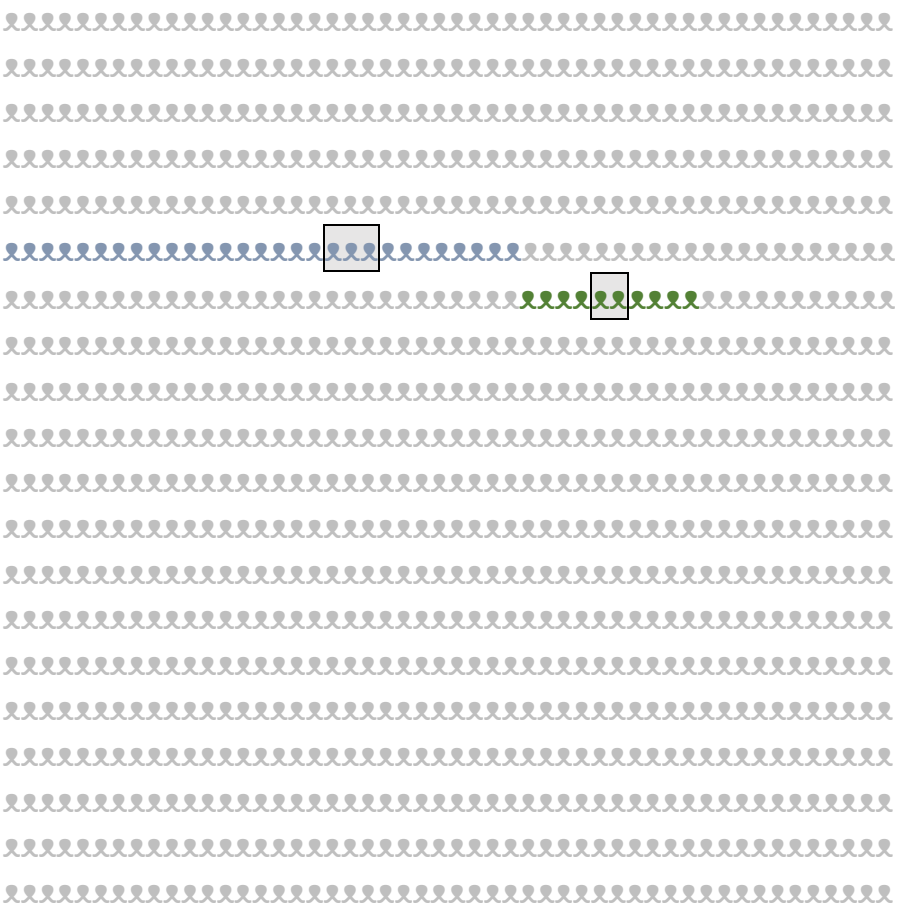
There are many reasons why a woman may decide to have a mammography or not. We have included information which we hope will help you to assess the possible benefits and risks of attending the Programme and those of not doing so.

	Possible benefits	Risks
NOT attending the Programme	Not attending the programme does not have any benefits.	If I have breast cancer, it is likely that when it is diagnosed, it will be more advanced than if I had attended the Programme: - I may need a more complex treatment and have a worse quality of life. - I have a greater risk of dying by cancer than if I had attended the Programme.
ATTENDING the Programme	If I have breast cancer, I have greater possibilities of surviving than if I do not attend the Programme. If I do not have breast cancer, I will be reassured by confirming this with a mammography every two years.	If I have breast cancer, I may receive a diagnosis and a treatment without improving my life expectancy. If I do not have breast cancer, I will be given tests I do not need: a mammography every two years and perhaps an ultrasound exam or a biopsy.

Should I attend the Breast Cancer Early Detection Programme?

We cannot know if having a mammography every 2 years between the ages of 50 and 69 will be beneficial or harmful for you. What we can say is what happens to the women invited to attend the Programme, based on past data.

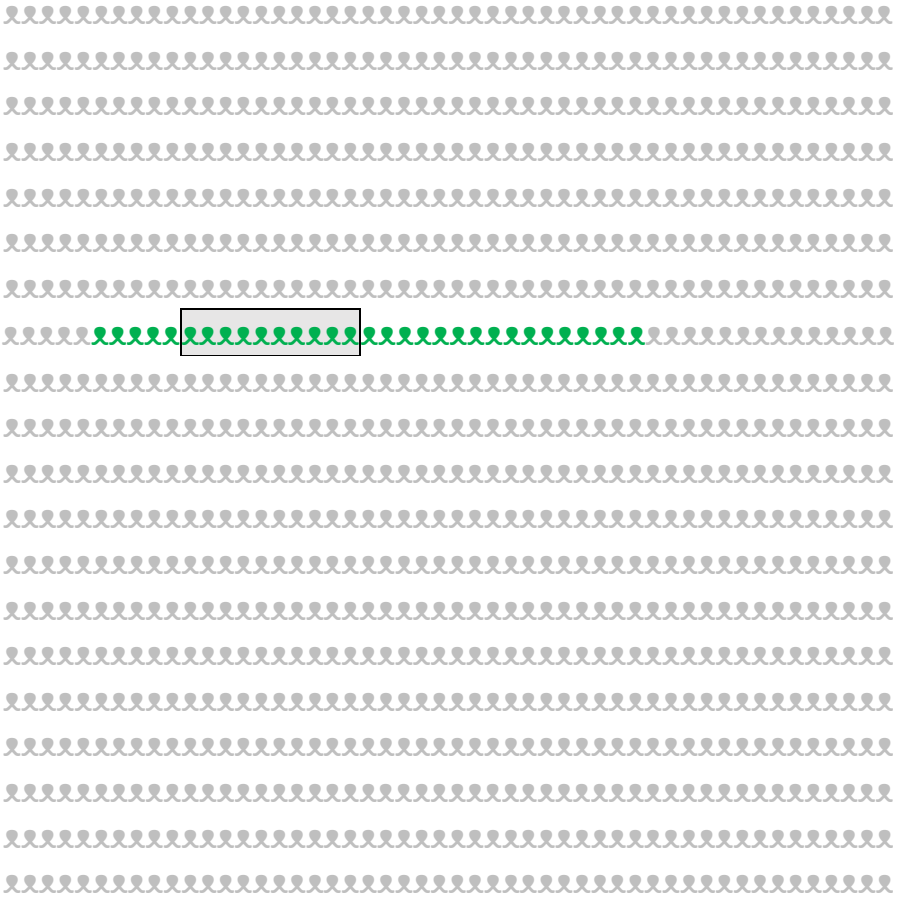
What happens to women between 50 and 69 years old who DO attend the Programme?



Out of every 1,000 women who DO attend the Programme:

- 39 women are diagnosed with breast cancer.
  - 29 women are diagnosed after the mammography they received in the Programme.
  - 10 women are diagnosed in between two mammographies.
- 5 die because of breast cancer in the following 10 years.

What happens to women aged between 50 and 69 years old who are invited and who do NOT attend the Programme?



Out of every 1,000 women invited who do not attend the Programme:

- 31 women are diagnosed with breast cancer.
- 10 die because of breast cancer in the following 10 years.

Of every 1,000 women who attend the Programme every 2 years, between the age of 50 and 69:

- 5 women less die of breast cancer in the 10 years following the diagnosis.
- 8 women are diagnosed and treated of breast cancer, who would not have been diagnosed between the age of 50 and 69 had they not attended the Programme.

What can happen if I am diagnosed with breast cancer?

When a person is diagnosed with cancer, the two greatest concerns are how this is going to affect them in their daily life and if they are going to die from this illness. This is related with the characteristics of the cancer, the treatments received and personal circumstances.

Women aged between 50 and 69 years old who are invited to participate in the Programme and who are diagnosed with breast cancer in Asturias, **will die in the 10 years following the diagnosis, as follows**:

1 out of every 10 women diagnosed based on the mammography given in the Programme.

2 out of every 10 women who are diagnosed between two mammographies in the Programme.

3 out of every 10 women who do not participate in the Programme, among those in

Most women with breast cancer survive this illness.

We hope you find this information useful.

Should you have any questions when reading this leaflet or if you wish to know more about breast cancer before deciding whether or not to attend the Breast Cancer Early Detection Programme in Asturias, you can contact your health centre.