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María José Hernández Leal

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Shared Decision-making in breast cancer screening programmes: Contributions to its implementation

Doctoral Thesis

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Departament of Economic
University of Rovira i Virgili

Reus, Spain – 2022

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Shared Decision-making in breast cancer screening programmes: Contributions to its implementation

Ph.D. Dissertation

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FAIG CONSTAR que aquesta traball, titulat ***Presa de Decisions Compartides als programes de càncer de mama: Contribucions per a la seva implementació***, que presenta **María José Hernández Leal** per a l`obtenció del título de Doctor, ha estat realizat sota la meva dirección al **Departament d` Economia** d`aquesta universistat.

HAGO CONSTAR que el presente trabajo ***Toma de Decisiones Compartidas en los programas de cáncer de mama: Contribuciones para su implementación***, que presenta **María José Hernández Leal** para la obtención de grado de Doctor, ha sido realizada bajo mi dirección el el **Departamento Economía** de esta universidad.

I STATE that the present study, entitled ***Shared Decision-making in breast cancer screening programmes: Contributions to its implementation***, presented by **María José Hernández Leal** for the award of the degree of Doctor, has been carried out under my supervision at the **Department of Economic** of this university.

Reus, 3 de març 2022/ Reus 3 de marzo 2022/ Reus, March 3th 2022

Els directors de la tesis doctoral
Los directores de la tesis doctoral
Doctoral Thesis Supervisors

Dra. Misericòrdia Carles Lavila

Dra. María José Pérez Lacasta

A mi madre, quien soy se lo debo más a ella que a mis méritos.

A mi hermana, por estar aquí a pesar de la distancia.

A todos los pacientes y sus familias que he conocido en mi carrera, que persisten en sus batallas.

Y a todos los profesionales de salud que siguen creyendo en sus pacientes.

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Este capítulo he decidido escribirlo en español, con el fin de que este sea comprensible para quienes está destinado.

Con esta tesis culmina un período de aprendizajes, y por lo tanto, para evaluar todo lo transcurrido desde mi llegada al programa de doctorado. Es inevitable no volver a recordar mis primeros pasos en la investigación, al inicio como ayudante de la Dra. María Teresa Urrutia de la Pontificia Universidad Católica de Chile (PUC), en donde adquirí el amor por la ciencia, lo cual me llevó a decidir realizar el magister de Enfermería en la PUC, y así nutrirme de conocimientos metodológicos en compañía de mis profesoras. Esto me llevó a descubrir un mundo nuevo sobre la forma de relacionarme con mis pacientes: La Toma de Decisiones Compartidas.

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Ambas fueron impulsoras para decidir profundizar en estos conocimientos y aplicar a este programa de doctorado que buscase mejorar la participación de las mujeres en el screening de cáncer de mama.

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De esta formar inicio mis estudio en el Departamento de Economía de la Universitat Rovira i Virgili. Aquí son muchas las personas que han sido un apoyo, tanto académico como emocional, ya que de una u otra forma, se convierten en tu familia cuando se está lejos de casa.

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“There is no such thing of choice unless is freedom to refuse”

David Hume

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ABSTRACT

Since patients' awareness increases, they are being users of the National Health System, a more satisfying health care is demanded. An awareness which relates not only to solve their problems in a proper way, but also to be considered by health professionals in their care. In this way, being listened to, receiving understandable information, being treated empathically, and getting involved in decisions affecting their health seem to be important elements to be considered by health services. This has been understood by different health systems, which have declared patients as the center of the model, even though it may be a challenge when putting it into routine practice during the appointment. Shared Decision-making (SDM) could be an alternative for more participatory and patient-centered care, in the same way models, such as The Three-talk model, would simplify its implementation in either specific health situations.

In this context, women taking breast cancer screening seem to have a very low involvement in the decision of their intention to participate, since they do not have a physical space in which to express their fears, doubts, or preferences to a health professional, and besides, they have not received any balanced information about either the benefits or adverse effects of participating in the screening. Even worse, they do not see those as necessary, since the early-detection benefit is really

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internalized as the only possible result and, they do not either know, or minimize the adverse effects they may suffer due to the screening: false positives, false negatives or overdiagnosis.

This thesis aims to contribute to the development of a more participatory health model in the context of breast cancer screening using the SDM model.

As a result, three studies were obtained, which sought: 1) to know the barriers and facilitators for the implementation of the SDM from the health professionals' perspective; 2) to create two documents -manual and guide- giving practical support to health professionals in order to involve women in the screening decision; 3) to know about women's preferences between the conventional health model and one with the characteristics of the SDM.

The results obtained can be generalized in order to move forward on concrete strategies to improve women's participation in preventive health contexts, especially in breast cancer screening.

Key words: Shared Decision-making; Breast cancer screening; Mammography; Preventive care; Stated preferences

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CHAPTER 1

INTRODUCTION

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1.1 MOTIVATION

This research was born from the Ph.D. candidate's experience as a nursing student and later in her career, taking care of patients. It has been complemented by her joining the Department of Economics of the URV, which meant including a new perspective on her research objectives.

Nurses are in permanent contact with both healthy and sick patients who expect high-quality care, and therefore a humane treatment. Thus, one of the key elements is informing both patients and their supportive network about therapeutic options or care actions; nevertheless, it is no longer enough and therefore, incorporating context and patients' unique personal experiences is necessary to respond to their real needs. In this sense, Shared Decision-making (SDM) unites both elements -information and participation- in health decisions.

On the other hand, the cancer diagnosis has a highly emotional burden, both for the patient herself and for her relatives. Therefore, a screening could be the beginning of a complex pathway and consequently, it requires an accompanying process from the very beginning of her decision to make -or not- to the examination through the SDM.

Finally, it must be considered that the allocation of scarce resources in the health field is a challenge for the different health

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systems. A change in the organizational paradigm of this programme undoubtedly entails a necessary economic analysis to obtain greater satisfaction for its target population.

1.2 SHARED DECISION-MAKING

Throughout the latest decades, health services in many countries, especially occidental ones, have declared their intention to promote more patient-centered care, in which users are the protagonists of health decisions[1]. Thus, in Spain Law 21/2000 on the Rights of the Patient and Clinical Documentation is committed to protect the users' right to make decisions after having received some information[2].

From 1970s onwards, patient-centered care is fundamentally based on the SDM model[3,4]. It seeks to abandon paternalistic relationships, in which the professional or the health system make the health decisions they consider appropriate for the population and incorporate a model in which both actors -the health professional and the patient- become experts from their own perspectives[5]. The former providing available information, scientific evidence, and options, while the latter does so from her personal experience of illness based on her own values, beliefs and preferences[5]. In this way, through a deliberative process in a conversation -not only information delivering- and a care plan -not only alternatives- they jointly decide the therapeutic path to follow according to the particular realities of each clinical appointment[6].

The SDM model not only encourages the patients' autonomy but also promotes various benefits related to self-management and commitment to their health care[5,7], which translates to more efficient health systems in resource management[8]. Despite the benefits mentioned here, there are a few barriers to implementation in general health contexts, it being the lack of time in clinical meetings to deliberate with patients the most reported one[8]. This will be explained in detail in chapter 2.

The main objective is consistency of the decision making within the patient's preferences based on an informed decision. Its implementation reduces decisional conflict; early repentance for making or not a choice; anxiety, concern for a possible disease, etc[10]. It is not a question of the patient deciding for herself on a test or treatment, nor that she should analyze parametric changes of analysis, but that she participates in the decision and treatment[11]. This will get greater satisfaction, and it has been shown that most patients involved in decisions tend to choose appropriate and less invasive treatments to their needs[10].

SDM has been studied within different health contexts, especially those in which therapeutic decisions are complex due to their effects on life quality, such as oncological therapies[12]. It also relates to scenarios where there is great uncertainty in the choice due to the pros and cons of the risks and benefits; situations in which the professional and the patient's values may not be fully aligned; or, where a problematic human situation and the humanity or identity is compromised or in transition[10]. This has led not only to research on curative programs, but also on preventive ones.

1.3 SHARED DECISION-MAKING IN SCREENING

In preventive programmes, research has been developed mainly in the screening of colorectal, prostate and breast cancer[10]. The latter being of great interest since it represents the first cause of women mortality and, in Spain it is the equivalent to 25% of cancers at a national level, and it being mammography the recommended screening for its early detection, having an adherence of 81,5% in the target population[13]. Evidence shows that, if 200 women whose mammograms are performed every two years between the ages of 50 to 69 and, followed up until the age of 80, one is saved thanks to an early detection, whereas 40 will need additional tests (false positives)[14]. However, it is also known that mammography can be harmful, as it can provide adverse effects such as overdiagnosis and consequently over-treatment[15]. Nowadays, official information campaigns for women do not balance information on the benefits and adverse effects of screening, which could explain women's ignorance about these effects[16]. So far, SDM has shown it increases awareness among women who have mammograms[17]. Nevertheless, efforts are required for its implementation on all the actors involved in the programm and in its organization:

1) In regard to health systems, breast cancer screening is organized under age standards in most countries, where women between the ages of 50 to 69 are sent a schedule letter every two years[18]. This schedule letter prevents them from discussing with a professional, elements such as fears, beliefs, or women's preferences regarding mammography. In addition, balanced information materials such as Decision Support Tools (PtDAs) are not incorporated, which would help improve the understanding of medical terms[16].

2) In regard to health professionals, they need to improve their interpersonal communicative skills, especially in risk communication[19]. Finally, they also need, and so make it explicit, greater knowledge on how to incorporate patients' experiences into scientific evidence and make the decision jointly[20]. All this requires training in more participatory care methodologies, interpersonal skills, and evaluation of patients' autonomy.

3) In regard to patients' perspective, they positively value being listened to by professionals[21] and are increasingly more predisposed to be committed to their health decisions, which paves the way to implement SDM. However, there are sociodemographic variables that can diminish this interest, and these groups become population groups who require greater attention[9].

For the local context, in Spain studies have been carried out on the SDM in breast cancer screening, especially in the creation and evaluation of the PtDAs[14,22-24]. However, there is also lack of literature on: the determinants -facilitators and barriers- for their implementation in these contexts, specific information for professionals, and the characterization of a more participatory system that considers women's preferences.

Finally, this thesis seeks to answer the question: How to apply a Shared Decision-making in breast cancer screening programme in a context of National Health System be implemented? The general objective is to determinate the acceptability by health professionals and women of Shared Decision-making and evaluate the possibilities of implementation in breast cancer screening programmes. And in this way, help professionals have the tools to make care provision more participatory and make those women feel empowered in their role as patients.

This thesis was approved by the Medicinal Ethics Committee Product Research Ethics Committee (CEIm) of the Institut d'Investigació Sanitària Pere Virgili (Pere Virgili Health Research Institute).

1.4 CONTENTS

This book presents the results obtained in the development of a doctoral thesis structured in six chapters. Below you can read a brief description of each of them which will be further discussed.

The first one is the Introduction -you are reading-, which explains the most relevant elements about a SDM in the context of a breast cancer screening program, covering both a general and particular perspective in the Spanish context together with its current application, which constitutes the context and supports the motivation for the development of these studies.

Chapter two presents the article: **Health professionals´ behavior regarding the implementation of shared decision-making in screening programs: A systematic review**[25], published in Patient Education and Counseling Journal (2021). This chapter aims to explore, from the health professionals' perspective, the barriers and facilitators for the implementation of the SDM in different screening programs, and thus, identify differences between their implementation in both curative and preventive programs with sick and healthy population groups respectively. A systematic review (SR) was carried out in four databases: PubMed, Cochrane Library, CINHAL, and PsyscInfo, which included qualitative and quantitative papers that mentioned barriers and/or facilitators from professionals' perspective. For the selection of the articles five peer-blind reviewers initially read the titles, the abstracts, and then the complete articles selected from the first choice; if no agreement was reached, a third reviewer would be consulted. The articles included in the SR were classified according to whether the barriers or facilitators came from the same healthcare professional's perceptions and beliefs, the patient's values and variables or the organization and structure of the health system.

As a result, eight screening studies on prostate, breast, colon, cervical and Down syndrome were included in three countries: the USA, Austria, and Canada. Professionals have a clearer perception of barriers than facilitators for the implementation of SDM. They detect the level of literacy and patients' willingness in getting involved in the decision as the main facilitator. Meanwhile the barrier is the available time; since this time may raise a legal conflict in case of negative consequences on the patient's health related to decision making and the lack of remuneration for professionals for performing this task, together with the inflexibility of clinical guidelines and protocols.

Other findings showed that professionals require tools to involve the patient in health decisions, which led to the creation of a Manual and Practical guide that implements the SDM in a simple way during the clinical appointment, as it is explained in chapter 3. In addition, the SR mentions as facilitators the fact that patients prefer a more active role in decision making in preventive programmes. Yet, it was unknown whether this also occurs in breast cancer screening, which led to the development of chapter 4, and thus, get to know women's preference in two types of health care -the usual one and that with SDM-.

Chapter three corresponds to the article **Development of support material for health professionals who are implementing Shared Decision-making in breast cancer screening: Validation using Delphi technique**[26] published in BMJ Open Journal (2022), which responds to the need identified in the previous chapter -the disinformation and lack of tools health professionals must include patients in screening decisions-. The Delphi methodology was used for this purpose as it allows experts to agree on a specific subject. Three rounds of questions were conducted on the relevance of the content and design of a Manual and Practical Guide to facilitate the implementation of SDM in breast cancer screening to two groups of respondents: international Spanish-speaker researchers in SDM, and primary care professionals.

Both documents were designed and prepared by the Ph.D. candidate, adapting the Three-talk model to breast cancer screening. Both researchers and professionals' responses in the Delphi rounds served to concretize the contents of a first draft to remove specific information from the local programme (Catalonia), making the documents more general, and incorporating exemplary dialogues, limitations of the SDM model, and additional references on PtDAs. Most participants agreed that the documents incorporated were necessary since the Three-talk model properly responded to the implementation context and addressed content in terms of quantity and quality as well.

As a result, according to our knowledge, the first Manual and Guide -*Participation of Health Professionals in Shared Decision-making in Breast Cancer Screening*- was created for health professionals in the context of mammography, focusing its content on explaining what a SDM is in a generic context of preventive benefits, and specifically breast cancer screening. In addition, a self-assessment scale was incorporated to enable professionals measure women's participation in decisions made at the clinical appointment. These documents can be found in the annexes to this chapter.

Chapter four, **Women's Preference to apply Shared Decision-Making in Breast Cancer Screening: A Discrete**

Choice Experiment[27], corresponds to an article under review in the Patient Education and Counseling Journal. This chapter aims to analyze women's declared preferences on the attributes of a more participatory care of SDM, in contrast to the usual care for breast cancer screening.

The Discrete Choice Experiment (DCE) methodology was used for it allows, according to Lancaster's discrete utility model, to calculate the relative importance of attributes which characterize each proposed alternative and identify how useful each attribute is for women. For this purpose, women from three screening programs in Catalonia, between 50 and 69 years of age, were invited to participate in the DCE (which consisted of 12-choice-task). Each task includes two hypothetical care scenarios in the context of breast cancer screening, each characterized by specific attributes of both models: the usual one and the one corresponding to a SDM: 1) If the information of benefits and adverse effects are received by a healthcare professional or through a leaflet, 2) if ,when programming a mammography, women's preferences are taken into account or it is the health system which does so on age criteria basis 3) who makes the decision whether -or not- to attend mammography: the woman herself, the professional, or jointly.

A mixed-effect-conditional logit model was made for the analysis of the responses. The results obtained out of the 65

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women who answered the survey showed that the only important attribute for women is `who makes the decision´; being 20% more useful in doing so themselves than in taking it jointly with the healthcare professional, yet, discarding anyway a paternalistic model in which the professional decides for them. The 52.3% of those women were willing to pay for a participatory screening model, 38.5% were willing to pay between €10 and €30 and 13.8% more than €40. No significant differences were detected with respect to the relative valuation and significance of attributes between the responses of women subgroups who were willing to pay and those unwilling to.

Chapter five corresponds to **General Conclusions**, the importance and implementation according to the results obtained: how to continue to enhance participatory health, with recommendations for decision makers in public policies based on healthcare professionals' perceptions and women's preferences. The results obtained in the articles, can be extended to breast cancer screening programmes in other autonomous communities or countries with similar characteristics in their structure and working/functioning health system.

Chapter six refers to **Other Research Activities** carried out by the Ph.D. candidate, prior to starting her studies in the doctoral programme and her collaboration with other research teams in Spain, The United States and Chile while developing their doctoral thesis.

Finally, I hope you enjoy reading these results and expect them to be a contribution to the discussion of this topic in the academy, as well as for professionals who provide daily clinical care and women concerned about their health.

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CHAPTER 2

HEALTHCARE PROFESSIONALS' BEHAVIOUR REGARDING THE IMPLEMENTATION OF SHARED DECISION-MAKING IN SCREENING PROGRAMMES: A SYSTEMATIC REVIEW[1]

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2.1 BACKGROUND

The chief function of screening programmes is the early detection of diseases[1]. Nevertheless, the unwanted effects of screening programmes have been dealt with in scientific discussions over the past few decades. The most discussed effects include overdiagnosis, false positives, false negatives, and over-treatment[2–4]. This increasing emphasis in literature is associated with an increase in the uncertainty of screening programmes, which arises the need for a change in the decision-making model. This need could be satisfied by Shared Decision-making (SDM), which allows healthcare professionals and patients to arrive at a joint decision based on the knowledge of the risks and benefits of screening programmes also considers the patient's values and preferences[5].

SDM has been employed since the 1970s, especially in European countries, Canada, and the United States[6,7]. Elwyn et al. (2010) defined SDM as a model in which 'professionals and patients share the best available evidence when making a decision. Patients are supported to consider the options available, and thus be able to make an informed decision[8]. In other words, it seeks to improve people's participation in the health-disease process through a horizontal relationship between patients and healthcare professionals[9]. In contrast to the paternalistic model, in which the patient plays a passive role, and the interventions are proposed by the healthcare

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professional[10]. The SDM approach considers the patient's values, beliefs, and preferences as well as the risks and benefits associated with therapeutic options[11]. Evidence supports the fact that patients prefer to be active participants in the conversation in which healthcare professionals provide the necessary information; patients report greater satisfaction with the care process when effective and reliable communication is established[12,13].

Based on the previous literature, the main barriers to the implementation of SDM from the perspective of professionals include deficiency of time during healthcare professionals' behavior in screening programmes clinical encounters, and patient's characteristics and current health situation. The factors that facilitate SDM include professionals' motivation and the belief that SDM can have a positive impact on specific health outcomes[14]. However, the use of SDM has not been generalised in the clinical context[15] or screening programmes[12].

SDM has been studied in various health contexts[14], from therapeutic -patients who are sick and seek, their disease to be treated- to preventive -people who are in a healthy condition and seek to avoid falling into disease[16]-. Preventive activities include actions to adopt healthier lifestyle changes, consumption of drugs to reduce the risk of some diseases -such as statins[17]- and screening. The Systematic Review (SR) of Gravel, et al.[6]

includes some of these scenarios, even though a specific study for screening has not been carried out. Having specific studies in this area is important since in recent decades, experts have discussed the difficulty of knowing the magnitude of overdiagnosis, which causes uncertainty about one of its main adverse effects. In other words, the main adverse effect of screening involves treating a disease unnecessarily, while in other preventive activities the adverse effects are different and are focused on those derived from the medication. Therefore, barriers and facilitators other than those derived from already studied in other SR[6].

Moreover, there is evidence from the SDM professionals` perspective also in various health contexts[18], but it has not been done exhaustively in screening contexts either, as this is an increasingly frequent practice within the actions of their profession. In this context, the decision does not include discussing various options, but rather participating -or not- in the screening, which sometimes means that this discussion can be confused with Informed Consent[19].

Thus, for example, other countries have focused on the implementation of SDM in screening programmes through patient decision aids (PtDAs) with the collaboration of public and private institutions[14,20-22]. Examples include Canada, Germany, the United Kingdom, and the United States[23]. Specifically, the

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Swiss Medical Association in Switzerland contends that SDM is the ideal model for a preventive approach[7] and has conducted research on colon cancer screening programmes[24-26].

Despite the aforementioned research, we have no knowledge about other SR which has emphasised healthcare professionals' perspectives regarding the application of SDM in screening programmes and the possibility of overcoming barriers. Accordingly, this SR explored the barriers to and facilitators of healthcare professionals' implementation of SDM in the context of screening programmes.

2.2 METHODS

2.2.1 STUDY DESIGN

A SR was conducted based on the recommendations of the Cochrane manual for systematic reviews of interventions, version 5.1.0 [updated march 2011][27].

2.2.2 LITERATURE SEARCH AND DATA SOURCES

The search was performed between April and May 2019 in four databases—PubMed, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature, and PsycInfo, using the keywords 'shared decision-making', 'screening', 'health personnel', 'barriers', and 'facilitators' with their variants in each database. The search was not limited by language or year (Figure 1.1).

Figure 1.1. Search strategy

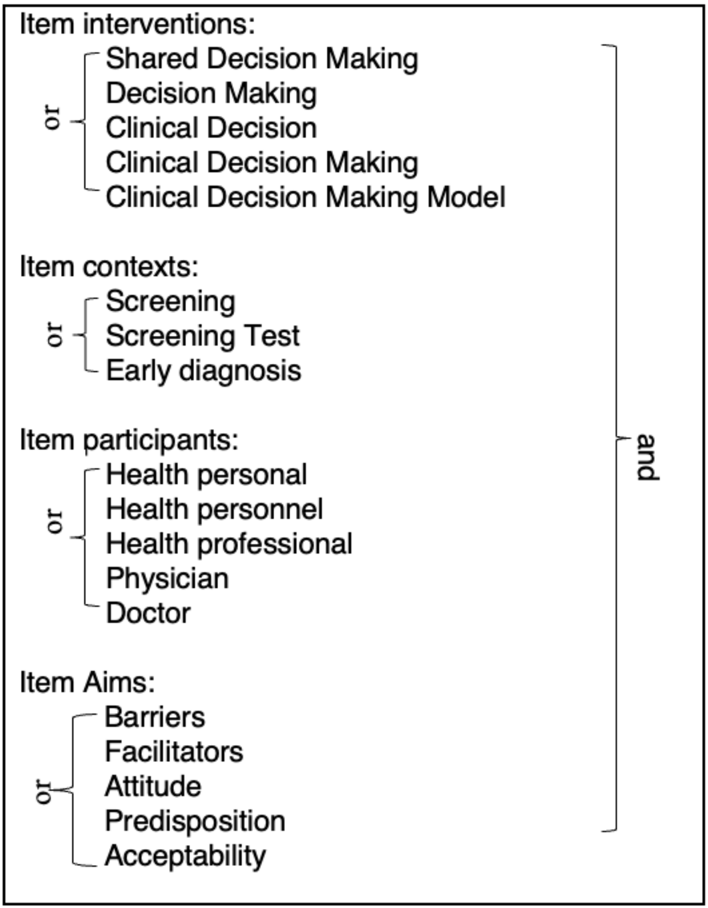

Figure 1.1. Each item was combined with the Boolean term Or and amoung item with the Boolean term AND.

2.2.3 INCLUSION AND EXCLUSION CRITERIA

Original research articles with quantitative, qualitative, or mixed methodologies that referred to the facilitators of and barriers to SDM in the context of screening by healthcare professionals who performed direct clinical care were included. We also included studies that did not explicitly define SDM but incorporated involving patient and a balanced discussion of the

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benefits and adverse effects of screening programmes to facilitate an informed decision.

Some publications were excluded, for example, those combined perceptions of professionals and patients, and which lacked clarity regarding the person who issued the answers.

2.2.4 STUDY SELECTION

The database search was conducted by three teams of researchers (MJH-MJP, MC-MF, and MJH-VR), each of which applied the inclusion and exclusion criteria in the three phases of the process: reading the title (n=977), reading the abstract (n=748), and reading the full text of each article (n=106). Duplicate studies (n=128) and studies that did not report original research, such as SRs, bulletins, theses, posters, and conference or dissertation documents (n=101), were excluded. Other studies were excluded: studies on the perceptions of administrative personnel, students, or patients (n=315); studies pertaining to person-centred medicine (n=123); studies that did not assess screening programmes (n=204) and studies that, while encompassing SDM did not delve into its barriers and facilitators or only evaluated the implementation of PtDAs (n=98).

Disagreements concerning the inclusion and exclusion criteria were resolved through discussion with another researcher pair (MC-MJP).

2.2.5 DATA EXTRACTION AND QUALITY APPRAISAL

One researcher (MJH) extracted the following data from the selected articles: title, authors, year of publication, journal of publication, country of study, type of study, study methodology, participants` characteristics, study screening type, degree of acceptance of SDM, and evidence quality (Table 1.1).

Two researchers (MJH-MC) independently used the QualSyst tool[37] to determine the quality of the studies. The studies were assigned values between 0 and 1, with lower numbers representing poor quality study. The corresponding author of the study was contacted in case of methodological doubts. Discrepancies in evaluation were resolved by a third researcher (MJP).

Table 1.1. Characteristics of the articles (N = 8)

Title	Authors	Year	Journal	Country	Aim / purpose	Type of study	Methodology	Participants (n)	Screening	Acceptability SDM **	Qualsyst
Are Physicians Discussing Prostate Cancer Screening with Their Patients and Why or Why Not? A Pilot Study[28]	Guerra C., Jacobs S., Holmes J. & Shea J.	2007	Journal of General Internal Medicine	USA	To identify factors that either facilitate or prevent discussion about prostate cancer screening	Qual	In-depth, semi-structured interviews. The Walsh and McPhee Systems Model of Clinical Preventive Care as a conceptual framework	Health professionals (18) = internal medicine (14) and family medicine (4) physicians	Prostate cancer	Indifference toward SDM	0,75
Physicians' attitudes about shared decision making for prostate cancer screening[29]	Davis K., Haisfield L., Dorfman C., Krist A. & Taylor K.	2011	Family Medicine	USA	To assess both attitudes and factors which influenced on the	Quant	Surveys	Health professionals (135) = primary care physicians; academic clinicals (16), internes/residents (84),	Prostate cancer	Indifference toward SDM	0,72

					SDM process for primary care providers (PCPs) using participative practices in prostate cancer screening			community clinicians (35)			
Prenatal screening for Down syndrome: a survey of willingness in women and family physicians to engage in shared	Légaré F., St-Jacques S., Gagnon S., Njoya M., Brisson M., Frémont P. &	2011	Prenatal Diagnosis	Canada	To assess both women and their family physicians' willingness (FPs) to engage in	Quant	Surveys. Control-Preference Scale based on OPTION scale, and the degree to which family physicians involved women in	Participants (50) = pregnant women (9) and family medicine physicians (41)	Prenatal screening for Down syndrome	Mild support for SDM	0,77

decision-making[30]	Rousseau F.				shared decision-making (SDM) in prenatal Down-syndrome screening and the factors that might influence on their willingness to do so		shared-decision making related to prenatal screening				
Early detection of prostate cancer by PSA testing: the results of a qualitative study on barriers caused by physicians in	G. Malli	2013	Das Gesundheitswesen	Austria	To explore factors which help to know GPs' counselling about the prostate	Qual	Focus group and deep/further interviews	Health professionals (42) = general (38) and internal medicine (4) physicians	Prostate cancer	Not reported	0,7

Austria implementing informed decision making*[31]					specific antigen test						
Physician decision making for colorectal cancer screening in the elderly[32]	Lewis C., Esserman D., DeLeon C., Pignone M., Pathman D. & Golin C.	2013	Journal of General Internal Medicine	USA	To analyze whether physicians engage elderly patients in individual decision making for colorectal cancer screening assesssment	Quant	Surveys by a research team. Not validated	Health professionals (276) = family medicine (158) and internal medicine (118) physicians	Colon cancer	Indifference toward SDM	0,53
Primary care physicians' use of an informed	Volk R., Linder S., Kallen	2013	Annals of Family	USA	To examine the use of prescreen	Quant	Surveys. Beliefs related to cancer screening and	Health professionals (246) = family	Prostate cancer	Strong support in favor of SDM	0,86

decision-making process for prostate cancer screening[33]	M., Galliher J., Spano M. Mullen P. & Spann S.	Medicine	ing and discuss on potential benefits and harms of prostate cancer screening by primary care physicians. Analise the role of physicians' beliefs in prostate cancer screening efficiency, and the contextual factors	identified by Purvis Cooper et al. A group of 17 indicators were found in the literature	medicine physicians

					related to the harms and benefits discussion						
Are Providers Prepared to Engage Younger Women in Shared Decision-Making for Mammography?[34]	Martinez K., Deshpande A., Ruff A., Bolen S., Teng K. & Rothberg M.	2018	Journal of women´s health	USA	To assess readiness to engage younger women in SDM for mammography	Quant	Surveys	Health professionals (220) = nurse practitioners (11), internal medicine (100) and family medicine (54) physicians	Breast cancer	Strong support in favor of SDM	0,65
Health Care Providers' Perspectives on Barriers and Facilitators to Cervical	Nguyen-Truong C., Hassouneh D., Lee-Lin F., Hsiao	2018	Journal of Transcultural Nursing	USA	To explore health care providers' perception of barriers	Qual	Deeply, semi-structured interviews	Health professionals (10) = nurses' practitioners (4), internal medicine (3),	Cervical cancer	Lack of support for SDM	0,95

Cancer Screening in Vietnamese American Women[35]	C., Vy Le T., Tang J., Vu M. & Truong A.	and facilitators for cervical cancer screening in American Vietnamese women	internal/family medicine (1), obstetrics / gynecology/preventive medicine/ public health (1), family practice (1)

Table 1.1. *Original title "Früherkennung von Prostatakrebs mittels PSA test: Ergebnisse aus einer qualitativen Studie zu arztseitigen Barrieren bei der Umsetzung der informierten Entscheidungsfindung in Österreich". "not reported": Some of the studies do not mention the tools used in the survey, so one of the researchers (MJH) contacted the corresponding author to clarify this information. However, no response was obtained. SDM: Shared Decision-making. Qual: Qualitative. Quant: Quiantitative.

2.2.6 DATA ANALYSIS AND SYNTHESIS

The selected articles presented heterogeneous methodologies. For this reason, we chose to analyze individual study results. They were not considered representative of the sum of their statistical measures, that is, only thematic synthesis was conducted (Table 1.1).

Thematic synthesis[38] employed an inductive process. Three researchers (MJH, MC, MJP) independently read the articles and structured the analysis using the steps proposed by Strauss and Corbin[36]. First, in the citations included in the retrieved articles, they identified sections where healthcare professionals mentioned their perceptions of the difficulty or ease of SDM implementation. Second, the citations were grouped into codes (units that revolve around the same idea) and finally into categories (higher-grade units). Third, the categories were identified as barriers and facilitators. Barriers and facilitators were classified according to three factors based on their origin (who or what influenced the perception or attitude of the healthcare professional): the professional him/herself, patients, or healthcare system performance[38].

Once the researchers (MJH, MC, MJP) independently structured the categories into barriers and facilitators, the results were compared, and discrepancies were discussed until an agreement was reached.

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Subsequently, the articles selected for this SR were classified according to the percentage of adherence to SDM[29,30,33-35]. Thus, according to Pollard, Bansback, and Bryan's classification, four categories were identified[39]: Strong support for SDM (>80% adherence to SDM), Mild support for SDM (60%–80% adherence to SDM), Indifference towards SDM (40%–60% adherence to SDM), and Lack of support for SDM (<40% adherence to SDM). The articles that did not present a percentage or degree of adherence were not categorised[31].

2.3 RESULTS

2.3.1 DESCRIPTION OF INCLUDED STUDIES

The first database search yielded 977 studies: 30 in PubMed, 265 in PsycInfo, 393 in the Cumulative Index to Nursing and Allied Health Literature, and 289 in the Cochrane Library. After applying the inclusion and exclusion criteria in the different phases, eight articles[28-35] were selected (Figure 1.2). Seven of these were in English[28-30,32,34,35] and one was in German[31]. The articles were published between 2007 and 2018. Six studies were performed in the USA[28,29,32-35], one in Austria[31], and one in Canada[30]. Four studies focused on screening for prostate cancer[28,29,31,33,] and one for breast cancer[34], cervical cancer[35], colon cancer[31], and Down syndrome[30]. Five used quantitative methodologies[30,31,33-35], while the remaining three were qualitative studies[28,31,35]. The eight analysed articles included 988 healthcare professionals, of which 76.7% were physicians. The quality of the articles was valued between 0.53 and 0.95 (range: 0 to 1) with an average of 0.74 (standard deviation 0.12) points on the QualSyst[37] (Table 1.2).

Barrier codes (n=45) were more than the facilitator codes (n=30). Overall, most of the barrier codes were related to the health system (n=14), while the facilitator codes generally corresponded to the patients' attributes (n=14) (Table 2.2). All the selected studies reported at least one facilitator[28-35]. However, one study did not mention any barriers[30].

Figure 1.2. Selected articles flowchart

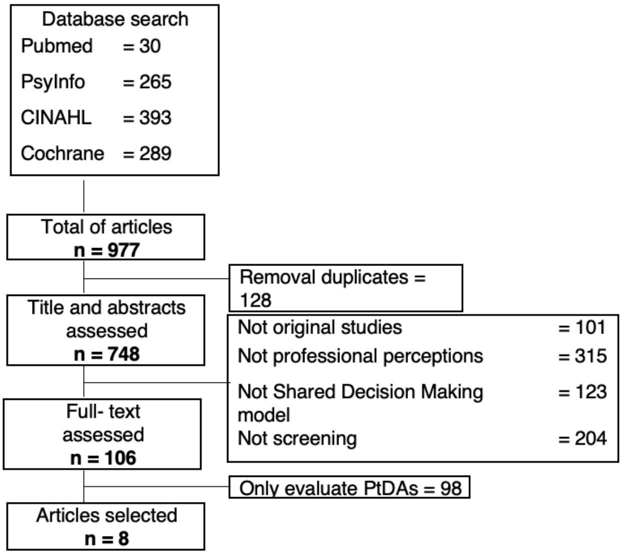

Figure 1.2. PtDAs: Patient Decision Aids.

2.3.2 BARRIERS TO SDM APPLICATION IN SCREENING PROGRAMMES

Healthcare professionals' attitudes and beliefs served as obstacles when they did not consider themselves to be experts in SDM[31] or when they were reluctant to accept some aspect of the screening process. In such scenarios, they potentially forgot to recommend screening during clinical meetings[28], held negative perceptions of diagnostic tests[28,31], argued that clinical experience was more useful than scientific evidence with regards to managing screening[33], or maintained their own beliefs regarding the effectiveness of screening[31].

The lack of knowledge about screening and communicative competence was a significant professional barrier[31]. Reportedly, 31.3% of healthcare professionals were unaware of the risks and benefits of screening[29] and did not have enough information about critical values related to diagnosis[33]. Concerning breast cancer, 21% and 16% overestimated and underestimated the risks of screening, respectively[34]. Additionally, 48% of the healthcare professionals reported inadequate communicative competence to involve patients in their health-related decisions, and only 8% of those who believed that they possessed these competencies felt sufficiently qualified to implement them[34]. On the contrary, the benefits were over-evaluated in prostate cancer as compared to the risks; thus, early detection substantially reduced mortality[33].

Healthcare professionals' aversion to incorporating SDM into screening could be due to certain characteristics of their patients. According to healthcare professionals, some patients preferred a paternalistic model and disease-centered care[29,30,32,33,35] or had a passive attitude toward their care. This passivity could be explained by a lack of motivation to get involved in the decisions[31].

Additionally, healthcare professionals identified the health state of the patient as a factor in SDM implementation. About 91% of the healthcare professionals initiated the discussions when their patients were in a good health condition, which decreased to 44% otherwise[31]. Multi-morbidity is also a barrier[29,33], especially in people with mental health pathologies[28].

Finally, healthcare professionals mentioned patients' socio-demographic characteristics as a barrier. Poor health literacy or patients' lack of knowledge regarding screening or SDM posed major barriers to SDM implementation[28,33,35]. Specifically, healthcare professionals considered that patients did not have adequate knowledge about SDM[28] or the benefits and harms of screening programmes[33,35]. Then, healthcare professionals also doubted the patients' ability to understand concepts such as false positives[31], false negatives[30], specific

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symptoms, risk factors, and risk estimation[31,35]. They also mentioned that older age, male gender[28], and idiomatic differences with the interlocutor[35] made SDM more complicated.

From the perspective of healthcare professionals, some elements of the structure and organization of health management could become barriers. The lack of time to apply SDM was the most frequently mentioned barrier[28,30,32,34], accounting for 80.5%[29]. For example, more than 77% of healthcare professionals spent less than five minutes of the clinical meeting discussing possible therapeutic options with patients[34]; this is the main limitation to increasing patients' participation in their healthcare[31]. Legal elements were also seen to impact care styles. In two studies performed in the US, the legislative system was mentioned as a threat[28,29]. In one study, this was because 49.6% of the participants felt responsible and neglectful if a patient refused to undergo screening, resulting in late diagnosis[29]. Consequently, healthcare professionals requested exams without considering patients' opinions. Additionally, 38.2% of clinicians, 11% of interns/residents, and 18.8% of academicians[29] considered the lack of remuneration for SDM activities as another barrier[29,31].

The barriers related to public policies included guidelines related to the healthcare system and scientific community. About 95.5% of healthcare professionals believed that the current healthcare system is focused on treatment[29] instead of prevention. This was reflected in screening requests being considered as indicative of care quality, regardless of the patient's opinion[33] to meet coverage goals. Nevertheless, another study identified the general lack of consensus on specific recommendations in clinical guidelines as a barrier[28], for example in colon cancer screening[32].

Table 1.2. Barriers and facilitators for the SDM practice in screening programmes

Factors	Barriers	Articles	Facilitators	Articles
Healthcare professionals’ perceptions	**1. Attitude and beliefs**			
	Negative attitude towards screening	28,31	Positive attitude towards screening	28,30
	Poor competence in SDM	31,34	The professional opinion does not influence adherence to screening	28,34
	Not contemplate the application of screening	31,34	Subsequent regret when the patients are not involved in the decision	33
	Discussion discourages adherence of patients	29	The uncertainty treatment allows evaluating the best alternative	33
	2. Skills and competences			
	Lack of knowledge in screening	28,30,32,33	Long working experience	29,34
	Lack skills in SDM	30,33	Family-medicine training	34
	Lack of knowledge in SDM	33	Same nationality or language Trustful relationship	35 35
The patient’s attributes	**3. Prescribed attitude**		**3. Open attitude**	
	Passive patients	28,31	Interest patients in involved in the decision	28,29,30,31
	Comorbidity patients removes the focus of preventive care	28,32	Patients with longer life expectancy evaluate the future profits and losses	28,32
	Assuming a priori the patients' s decision on screening	28,33	Personal history of risk sensitizes discussion	28
	No decision-making is required when there is a reduced life expectancy patient	28	Family history of risk sensitizes discussion	28
	Disease-centered care	28		
	4. Sociodemographic			
	Limited literacy in patients makes difficult to understand risk and benefits factors	25,28,30,32	High literacy patients make easy to understand risk and benefits factors	28,29,33,35

	Impaired physical and cognitive function in elderly age	25,32	High socioeconomic status increased discussion tools	28
	Different language makes communication difficult	26,32	Risky age sensitizes discussion	28
	Male sex patients are less participatory	32		
	5. Structural-organizational			
Healthcare system performance	Lack of assistence time	28,29,31,34,35	Assistance time increase	28
	Lack of remuneration to new decision-making activities	29,31	Referral to specialized staff o competent professionals	28
	Complaints and legal conflict	28,29	Reminders system about participation in screening.	28
	Including more activities given the high workload	28		
	Complexity of screening	29		
	6. Public politics			
	Rigid clinical guides in the application criteria screening	28	Focus on a preventive care	28
	Lack of scientific consensus for the customization of complex screening programmes	28	Solid Scientific evidence for the purpose of offer alternatives to screening	33
	Standardized screening adherence in at-risk population	33		

Table 1.2. Qualitative methodology uses an inductive process to agglutinate the main units in complex conceptual[36]. In this case, the "*codes*" are the phrases that are in each box associated with the articles that have been mentioned. The "*categories*" grouped the codes were represent in the title to each box. The categories, according to the healthcare professional perceptions are organized in barriers or facilitators around three factors: patients attributes, healthcare system performance or own healthcare professional perceptions. Articles 28,30,31,33 were categorized in barriers or facilitators in their original researcher.

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2.3.3 FACILITATORS OF SDM APPLICATION IN SCREENING PROGRAMMES

According to the healthcare professionals, if they exhibited favourable attitudes and beliefs towards screening, patients felt encouraged to engage in a discussion about whether to undergo screening[28,31]. Therefore, healthcare professionals had to be aware of all the possible unfavourable outcomes[33]. They also stated that the decision to implement SDM should be independent of their personal beliefs[29], even though 21.8% believed that a discussion could decrease programme adherence[29]. Additionally, failing to adequately facilitate discussions of the decision regarding screening generated feelings of remorse in some of them[33].

It was observed that healthcare professionals' communicative skills and competencies concerning the promotion of SDM had the capacity to lay the foundation of a relationship based on trust, closeness, and sensitivity to cultural beliefs, establishing an optimal space for patients to expose their fears and allowing joint decisions[35]. Thus, being a specialist in family medicine[34], belonging to the same nationality as the patient[35], and having work experience[29,34] of at least five years[35] were factors that facilitated SDM. One study reported that academics and community medicine specialists showed a greater degree of acceptance of SDM than residents or internal medicine physicians[34]. Nevertheless, 96% of the latter believed that PtDAs are beneficial during clinical encounters[29], compared to their more experienced colleagues (73.5%)[29].

The open attitude facilitator corresponded to codes in which the professionals considered the patient's attempts to engage in a detailed discussion about the decision as indicative of a proactive attitude. For example, 69.9%[29] of the professionals considered patient's interest as one of the pillars of improving participation, leading to a shared decision[28,29-31]. Those with a family medical report of the disease[28], risky behaviour (e.g., smoking)[28], and a medium/long life expectancy[28] of more than two years[32] showed a greater demand for SDM. Healthcare professionals also identified some socio-demographic elements that influenced patients' participation in health decisions.

High literacy was observed to be a significant facilitator[28]; 51.9% of the healthcare professionals believed that knowledge is a key factor[29]. Access and exposure to information make patients more aware of the implications of screening, thereby facilitating discussions[35]. According to healthcare professionals, patients who recognized that screening could lead to the early detection of diseases were more open to SDM[33]. Additionally, healthcare professionals stated that patients considered to be at high risk[28] and who had a high socio-economic level[28] also favoured the implementation of SDM.

Elements related to political and scientific guidelines that encourage participation in the healthcare system have been classified into public policies. Concerning prostate cancer, scientific evidence and clinical guidelines support routine screening regardless of the patient's opinion[33]. Nevertheless, another study reported the opposite: scheduled preventive visits enabled periodic meetings that facilitated discussion and access to more specialized health resources[28].

Screening reminders in the clinical file for high-risk patients, consulting more experienced healthcare professionals and having extra time, were facilitating factors under the organizational structure category[28].

2.4 DISCUSSION

This is the first SR to explore the elements that influence healthcare professionals' decisions to implement SDM in screening programmes. Eight original research articles were analysed[28-35], with most of the results pertaining to cancer screening[28,29,31-35]. Based on the number of articles assigned to each of the codes, time constraints[28,29,31,34,35] and healthcare professionals' lack of knowledge about the benefits and harms of screening[29,31,33,34] were identified as the principal barriers. Regarding the facilitators of SDM, high patient literacy[28-33,35] and interest in participation or having a proactive attitude[28-31] were the most notable ones[16,40]. Unlike other aspects of clinical care, in which patients are unhealthy, on the contrary, they are healthy people who take preventive measures to maintain their healthy condition. Therefore, the application of SDM differs in clinical and screening contexts. To identify these differences, we analysed these three factors together with both barriers and facilitators.

2.4.1 PERCEPTION OF HEALTHCARE PROFESSIONALS' FACTOR

Health professionals consider aspects of attitude for SDM[28-31,33,34] such as the belief that discussion can discourage adherence[29], while others do not see any relationship[28,33]. On the other hand, some studies find that CDT tends to increase adherence to screening[41]. In any case, the focus of SDM is not adherence to screening, but making the decision jointly by the actors. The health professional has the role of informing in a balanced way about risks and benefits, and in this way promoting the patients` autonomy[42]. Even if there are different opinions between the health professional and the patient, the patient`s autonomy should always be respected and the integrity of the professional preserved[43].

A SR, 2019, described that patients with cancer decided on an oncologic treatment. The most significant barriers to the implementation of SDM are related to clinical professionals' specialties and miscommunications[44]. Thus, patients should establish horizontal communicative relationships with healthcare professionals, and healthcare professionals should consider patients' preferences[45]. These results are consistent with our findings[28-32].

2.4.2 PATIENTS' ATTRIBUTES FACTOR

In our SR, healthcare professionals' beliefs about their patients' behaviour influenced SDM[28-33] our results confirm the findings of the previous study[44]. In screening studies there should be a higher concern about adverse effects, since their uncertainty, as well as adverse effects in treatments, which have been studied more rigorously[46].

In the SR mentioned above[44], the concerns of the patients about the adverse effects of cancer treatment were analogous to our results. However, despite the fact that the adverse effects of screening are known by the scientific community, it has been really difficult to transmit balanced information to the population, since it tends to give greater relevance to the benefits (overestimation of benefits) than to the risks (underestimation), which is known as an optimistic bias[47]. In cancer medical treatments both professionals and patients are more aware of the risks.

Previous studies support our results regarding patients' attributes that facilitate SDM, for example: young age[48–50], high educational level[49,50], higher socioeconomic level[50], and existing risk factors (smoking)[51]. Regarding gender, males seemed less participative; this result aligns with the findings of another study[52], in which females had a more active role[49]. However, another study found no such association[51]. Another element found in our study was that active participation indicated the patient's interest in being the protagonist in the clinical encounter[28,29,30,31]. Therefore, previous studies recommended that the patient's desired role should be explicitly explored at the beginning of the relationship because it can vary from passive to active or vice versa during an interview[50,53]. Additionally, if healthcare professionals are aware of the patients' preferences at the outset, it could be easier for them to adapt to their needs, resulting in greater satisfaction and reducing anxiety and confusion[54].

2.4.3 HEALTHCARE SYSTEM PERFORMANCE FACTOR

The healthcare system exerts its influence not only through its structure and organization but also through the health policy. In our case, lack of time was shown to be a major obstacle to the implementation of SDM[28,30,31,34,35]. While there is no consensus regarding whether SDM involves a greater time investment[18], previous studies have reported that it requires an extra 2.6 minutes[12] beyond 10-15 minutes reserved for the usual

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care[55,56]. Thus, 18-20 minutes would be optimal for an outpatient care meeting[55]. The literature mentions the need to extend the time devoted to clinical meetings, especially in 18 countries, where every patient receives a maximum of five minutes of the healthcare professional's time[57]. Such short durations, apart from being insufficient to correctly assess a patient's condition and establish a doctor-patient relationship, increase the risk of not detecting symptoms or pathological conditions. Additionally, existing evidence supports the inclusion of PtDAs in clinical encounters to improve the quality of care.

An outstanding element in our work revealed that healthcare professionals' fear of malpractice accusations[28,26] leads to defensive medicine. Therefore, healthcare professionals employ more screening, without considering the adverse effects[58]. The literature has established that if patients are involved in the decision and consider it their own, they do not take legal actions[59].

Regarding economic incentives, the studies included in our SR did not specify why they were considered as barriers[29,31]. To date, the payment system has focused on improvements in the remuneration of professionals who incorporate new strategies or achieve better biometric results, which could sometimes be a perverse incentive for professionals (to report better health indicators than the real ones or use invasive procedures to obtain good results) or, on the contrary, be beneficial as it would encourage professionals to create more effective methodologies to keep patients healthy[60]. Another point is that the payment system in the health sector has been changing; in the National Health Service in Britain, indicators incorporating the effect of interventions on well-being and life expectancy are used[61]. However, in the screening context, SDM is focused on facilitating participatory decisions rather than on adherence, or the lack of it, to screening programmes[62]. Therefore, remuneration related to the objective of implementing SDM should be adjusted by evaluating patient participation in decision-making rather than health outcomes. However, for professionals to consider this function as a part of their work, it should be introduced as an ethical and legal professional role[18] right from university training.

While clinical health guidelines based on the effectiveness of screening tests are a framework shared by healthcare professionals, they sometimes do not reflect their effectiveness. Therefore, evidence-based practice (EBP) should not only result into an improvement of biometric or population parameters (such as low mortality in screening) but also focus on the patient's preferences because it is, first and foremost, patients who are responsible for their care and who must evaluate the gains and losses they are willing to bear in each specific case[62]. Thus, the best option is discussing guideline recommendations with patients and making a shared decision using EBP and PtDAs[63,64].

2.4.4 EXPERIENCE OF OTHER COUNTRIES IN SDM FOR SCREENING PROGRAMMES

Countries that have developed SDM in screening programmes emphasize the development of public policies to overcome system (legal) and professional (professional training) barriers besides taking advantage of professional facilitators (PtDAs).

We highlight Switzerland, whose success is also due to the training of professionals in SDM in undergraduate and graduate studies of general internal medicine[26]. Additionally, a study raised the possibility of incorporating practice assistants (PAs) who are healthcare professionals and have administrative and clinical functions to overcome some of the barriers described in the system category[26]. The United States government has also promoted the implementation of a more participatory model, especially since the enactment of the Law of 2010 (The Patient Protection and Affordable Care Act). In this law, the use of PtDAs is recognized statewide for the first time and legally protects physicians from negligence lawsuits when they choose to use certified PtDAs, a concern that was referred to in our results as a system barrier[65]. The PtDAs have been developed for breast, colon, lung, melanoma, prenatal, and prostate cancer screening, among others[23,66]. Finally, research recognizes the need to make professionals aware of the controversies and benefits of screening and to increase SDM strategies for screening, especially for a more participatory model[66], which coincides with our results. Finally, Canada has a growing interest in considering SDM in the Canadian healthcare system. CanMEDS calls on physicians to not only inform patients but also actively facilitate their learning for a better physician-patient relationship. Physicians have a legal obligation to allow patient participation, which has prompted the creation of PtDAs[67], for breast cancer screening and cardiovascular diseases. However, this has not guaranteed its full implementation; therefore, different organizations have been willing to promote it[68], including universities that train undergraduate students or postgraduate programs[67], responding to the barriers of the professionals` factor.

Other countries have also started programmes in this direction. Ottawa Hospital[23] describes and evaluates many of them. (Annex 2.9.1).

2.5 PRACTICE IMPLICATIONS

Based on the results of this study, together with those reported previously, some proposals can be introduced to overcome the barriers in applying SDM. First, training in SDM should be introduced at the undergraduate level[15,29,69,70]. Consideration should also be given to providing training in communicative skills[65,71], empathy[71], strategies to respond to emotional signals[72], active listening[18,58,70], nonverbal language[59,71], and supportive care[70]. Early training would make it possible to generate a paradigm shift in the healthcare model, strengthening patients' position as active entities who are invested in their health and are aware of the benefits and adverse effects of preventive measures such as breast cancer screening.

Second, by incorporating PtDAs[15,64,73], professionals can effectively involve patients in their health-related decisions[9,53], which would allow the optimization of the limited time available during clinical meetings. PtDAs have been developed in different formats[12,64]: brochures, booklets, videos, DVDs, web pages, and interactive programmes for online or in-person use[12,73,74]. More recently, the hypothetical goal board model, wherein the objectives are established to guide and strengthen decision-making are aligned with the patient's priorities and values through a practical and realistic approach, has been introduced[56]. The evaluation of PtDAs has been effective in empowering patients, reducing their decision-making conflict[73-78], achieving effective patient-clinician communication[16], improving patients' knowledge related to their health condition[75,78], and resulting in greater satisfaction related to healthcare assistance[12].

Third, EBP must incorporate SDM as a joint strategy for clinical practice. Clinical guidelines, which are usually rigid in their recommendations, become more flexible when professionals consider the reality of each patient, making a joint decision that makes sense for both parties—healthcare professionals and patients. Recently, efforts have been made to determine the individual effect of the Grading of Recommendations Assessment, Development and Evaluation (GRADE)[79] or the participation of patients in the development of clinical guidelines in the United Kingdom by the National Institute for Health and Clinical Excellence[80].

However, to overcome the barriers to SDM implementation, it is necessary to consider the limitations stemming from the system, which are difficult for professionals to change. Limitations such as technological problems[76], time allocated for clinical meetings, and lack of tools for SDM. Changes in the healthcare system structure and health policy objectives, which make it possible to incorporate SDM into normal practice, will become a reality if there are more research and transfer of knowledge between researchers and politicians.

2.6 LIMITATIONS

The scarcity of relevant literature, which indicates a lack of specific research from the perspective of healthcare professionals while applying SDM in screening, constitutes one of the main limitations of this study. Another limitation is that in four studies[28,31,33,35], while the concept was spoken of in different terminology in the main text, the concept of SDM mentioned in the results was similar to that discussed by Elwyn[8]. Finally, most studies were conducted in the USA, which has a private healthcare system; thus, the results may not be representative of countries with public healthcare systems.

2.7 CONCLUSIONS

From the perspective of healthcare professionals, there is a greater perception of barriers than facilitators of SDM. These barriers included lack of time and knowledge about SDM and screening, while the most reported facilitators concerned patients’ interest and health literacy. New elements were revealed through the application of SDM to healthy people (screening) instead of patients (treatment); these included fears related to legal action (defensive medicine), rigidity in clinical guidelines, and a lack of remuneration for implementing new activities associated with SDM. Advances in SDM implementation require resources to create exclusive material for professionals, the use of PtDAs, training professionals in communicative competencies, and shifting the focus of clinical interventions from only biometric or population results to the incorporation of patient values as a new variable in the quality of care. This is a new challenge in the structuring and objectives of the healthcare system. Patients have more facilitators of SDM implementation than professionals and the healthcare system. Therefore, healthcare professionals should use this characteristic to promote active patient participation. Further, patients’ opinions should be considered when formulating clinical guidelines.

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2.9 ANNEXES

2.9.1 SUMMARY OF PTDAS REPORTED AT THE OTTAWA HOSPITAL

The table only shows the results of the PtDAs reported and evaluated by The Ottawa Hospital. Therefore, countries and PtDAs may be omitted, this does not mean that any of them are not in development[23].

Country	Screening	PtDAs	Year
Argentina	Breast Cancer	Detección precoz del cáncer de mama. Herramienta para la toma de decisiones compartidas. / Early detection of breast cancer screening. A tool for shared decisión-making.	2020
Australia	Breast Cancer	Should I Continue Having Mammograms to Screen for Breast Cancer? A decision aid for women aged 70 and older at their next screening mammogram	2005
	Cervical Cancer Screening	Making Choices: A decision aid for women with a mildly abnormal pap smear.	2006
	Colorectal Cancer	Making decisions: Should I have a screening test for bowel cancer?	2006
	Prostate cancer	Prostate cancer screening: Decisions for men with a family history of prostate cancer.	2014
Brazil	Prostate Cancer	Apoio à decisão no rastreamento do câncer de próstata. [Decision aid for prostate cancer screening.]	2019
Canada	Prenatal Testing	What are my options regarding prenatal screening tests?; Quelles sont mes options concernant le test de dépistage prénatal?	2017
	Prostate cancer	Le dépistage du cancer de la prostate : une décision qui VOUS appartient! [Prostate cancer screening: It's YOUR decision!]	2013
		Prostate Cancer Screening, Choosing Whether or Not to Screen; Dépistage du cancer de la prostate, choisir de	2019

		faire ou de ne pas faire le test de dépistage.	
Germany	Breast Cancer	Entscheidungshilfe Mammographie-Screening [Decision Aid for Mammography Screening]	2015
United Kingdom	Melanoma	Melanoma: follow-up with regular CT scans - yes or no?	2015
United States	Aortic Aneurysm	Abdominal Aortic Aneurysm: Should I Get a Screening Test?	2015
	Breast Cancer	Breast Cancer Screening and Dense Breasts: What Are My Options?	2015
		Breast Cancer Screening Decision Support Tool.	2017
		Breast Screening Decisions	2016
		Breast Cancer Screening: When Should I Start Having Mammograms?	2016
	Colorectal Cancer	Colon cancer: Which screening test should I have?	2015
	Health Screening	Health Screenings: Should I Buy Commercial Tests?	2016
	Lung Cancer	Is Lung Cancer Screening Right for Me? A Decision Aid for People Considering Lung Cancer Screening With Low-Dose Computed Tomography	2016
		Lung Cancer Screening Decision Support Tool.	2017
		Lung Cancer: Should I Have Screening?	2019
	Melanoma	Melanoma: follow-up with regular CT scans - yes or no?	2015
	Prenatal Testing	Pregnancy: Should I Have Screening Tests for Birth Defects?	2015
	Prostate Cancer	Prostate Cancer Screening with PSA Testing	2012
		Prostate Cancer Screening: Making the Best Choice	2014
		Prostate Cancer Screening: Should I Have a PSA Test? (Healthwise)	2016
		Prostate cancer screening: Should you get a PSA test? (Mayo Clinic)	2015

CHAPTER 3

DEVELOPMENT OF SUPPORT MATERIAL FOR HEALTH PROFESSIONALS WHO ARE IMPLEMENTING SHARED DECISION-MAKING IN BREAST CANCER SCREENING: VALIDATION USING DELPHI TECHNIQUE[2]

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[2] This chapter have been published at *BMJ Open Journal*

3.1 BACKGROUND

Shared Decision-making (SDM) is recommended in an uncertainty context -among others- in which it is necessary to argue on risks and benefits in health topics[1]. SDM is a relationship doctor-patient model, and both collaborate to deliberate over the best choice based not only on scientific evidence but also on women's preferences and values[2,3.] Thus, SDM invites you to change the paternalistic health model for a more participatory one, seeking patients' greater involvement in their health, instead of aiming at a greater adherence to treatments, procedures or medicines, even though it has also been associated as a result of its application[4].

In Spain, Law 21/2000 Health Information Rights, Patient Autonomy and Clinical Documentation[5] protects the right to decide freely. However, SDM is not explicitly recommended for screening programmes. And the scientific community is making efforts to create patient decisions aids (PtDAs)[6,7] to be integrated in the Early Detection Programmes of Autonomous Communities, but, at the moment, its use is not widespread."

The breast cancer screening programme currently falls under the Oncology Master Plan (Plan Director de Oncología) in Catalonia[8]. However, while there are strategies for incorporating women's values and preferences into the decision on whether having the examination or not, there is no associated framework on how to put them into practice[9]. The current situation in Catalonia is the this: the Breast Cancer Detection Programme (Programa de Detección del Cáncer de Mama) sends -every two years- women between 50 and 69 years old a letter informing them of the time and date when they should attend their local health centre to have a mammogram[10]. The programme achieves a high level of coverage, but it fails to incorporate an opportunity for women and professionals to exchange information and have a dialogue on her decision. To promote women's participation, several research teams have developed projects that involve women in making their decision on screening. In 2017, Toledo-Chavari and their colleagues created a PtDAs[5] (Annex 3.9.1), consisting of a trifold leaflet that provided balanced information on either the benefits or adverse effects, for both professionals and women to use it during the clinical appointment. However, based on the barriers and enabling factors cited in the literature[11-13], the researchers decided not to use the PtDAs alone, for it was not enough, and concluded that SDM training material aimed at health professionals was also needed. The manual is training material, since they are a useful tool to transmit knowledge and provide quick and simple information on how to operationalize new practices, introducing beginners into the theme on how to use it the same way advanced users do[14]. Considering that SDM is not a common practice, a manual could, to some extent, fill knowledge gaps on this model.

Our research team has therefore developed a handbook-manual and guide[15] aimed at health professionals who have a direct relationship with women. These documents should be used as reference material by health professionals when facing the decision with women on whether to perform -or not- to a mammography, taking into consideration key elements and providing the patient with: information and education, and interpersonal communication between doctor and patient for a final decision[16]. To facilitate the implementation of SDM, the model used as a reference was The Three-talk model. The model was created so that three key steps (1-Team Talk, 2-Option Talk, 3-Decision Talk) would be quickly grasped and to explain in an easy way how to apply SDM in generic health context for healthcare professionals[17]. In this chapter we are adapting the three steps of Model to specific health context in BC screening to: 1) Team talk; 2) Option talk and exploring preferences; 3) Decision talk. A self-assessment of the SDM was included in the manual, which should be applied at the end of the appointment so that professionals can identify strengths and weaknesses in the implementation of the SDM. Finally, the guide provides a summary of the handbook to be used in the same appointment as a reminder of the three steps.

The objective of this study is using a Delphi method to reach an agreement among experts on the contents and design of a manual and guide, designed by the research team and to be used by health professionals in the application of SDM in breast cancer screening.

3.2 METHODS

3.2.1 Delphi technique

The Delphi technique main objective is reaching consensus among experts on specific topics. For this reason, it was decided to use it since the moment you want developing training competencies, tools to support clinical practice or a response to a professional issue. Thus, seeking the opinion of experts is a common approach[18] and in this case experts are required for the development of a manual and guide because there are few documents focused on health professionals explaining the application of SDM, specifically for breast cancer screening. Another feature of the Delphi Technique is that participants undergo a series of online surveys question rounds, which are formulated with elements not agreed upon in the previous round[19-20]. This process is repeated continuously until one of the completion criteria is met[21]. A further requirement for the formulation of the Delphi is that the responses of all experts must be shared in each round, allowing experts to reassess their responses in the light of other experts' views. Finally, all the rounds must be carried out anonymously and therefore ensure that they do not influence on others just because of one expert's considerable knowledge on the topic. One of the limitation the

Delphi technique has is that it provides experts' opinion; however, other complementary techniques could also be considered to determine a final position on the subject of the study[18-20]. The experts participating in a virtual way can overcome barriers related to economic circumstances and geographical or time-related constraints[19,20]. Experts, according to literature, can be grouped into two broad categories: Subjects (Su) – people who would use the instrument in their profession-; and Specialists (Sp) –people who have knowledge about the subject due to their academic and/or professional experience[19,20]-.

3.2.2 PARTICIPANTS

The handbook and clinical practice guide, entitled 'The participation of health professionals in Shared Decision-Making in breast cancer screening' ´La participación de los profesionales de la salud en la Toma de Decisiones Compartida en el cribado de cáncer de mama´ (Annex 3.9.2 and Annex 3.9.3)[15], were developed by the research team. The first version was produced with the participation of three researchers with experience in SDM and BC screening, who acted as external reviewers, and two health professionals, who designed the plan for piloting the questionnaire online (Google form).

The included criteria for participants were as follows:

- **Subjects:** a) health professionals, preferably from primary care services, who provide direct care to women through breast cancer prevention activities, and b) health professionals, who have at least five years' experience[21] in the Spanish Health System.
- **Specialists:** a) international-level researchers whose research career has focused on the Shared Decision-Making model, and b) those who are proficient in Spanish (given that the handbook has been produced in Spanish). Preference was given to individuals who had developed educational support material for professionals[21].

To determine the size of the sample, literature was consulted. It is mentioning that large numbers (over 50 people) could imply an impediment for so many people reaching an agreement in a limited time. Moreover, it depends on the heterogeneity of the experts. If they are from different countries or various specializations, they enrich the opinions formulated[20]. Therefore, a limit between 7 and 30 was decided, most commonly being a total of 15 to 20 experts[20].

3.2.3 PROCEDURE AND DATA COLLECTION

The researcher's two sampling strategies were used to recruit participants: convenience sampling for specialists and snowball sampling for health professionals. For specialists, the researchers were looking for published articles about SDM and contacted the authors via e-mail (MJH, MC, MJP). For health professionals, researchers sent an e-mail with an invitation to (NC, AC), and they could be resent to other colleagues. Finally, the researchers (NC-AC) sent invitations via e-mail to 43 potential experts to participate in a Delphi, 30 of whom accepted. The aim was to determine the usefulness of the topics, the relevance of the content and the designed document of the material for the SDM on BC screening. The Delphi was being done on Google form between July and October 2020.

For round 1, open and close questions were considered with relevant topics to the research objective "The sections of the handbook are effective for understanding the application of SDM to breast cancer screening " or "Do you think that a guide concisely summarizing the SDM steps is necessary?". Participants should mark the degree of agreement to the questions using a Likert scale of 1 to 6, in which 1 was ‘completely disagree’ and 6 was ‘completely agree’. Later, when all experts finished the survey research (MJH-MC-MJP) and were already sent, experts received a report with the answers so that the participants could consider the other participants’ views (anonymous), especially in those questions, in which no agreement was reached, group (Cc=75). Disagreement questions were raised again in the following rounds (r) until the necessary agreement was reached in most transversal aspects. This was finally achieved in round 3.

3.2.4 DATA ANALYSIS

The researchers (MJH-MC-MJP-NC-AC) analysed participants' responses at the end of each round, considering the responses whose score on the Likert scale was 4 or above to be positive. Agreement was determined to be reached when the Coefficient of concordance (Cc) was higher than 75[22]. The Cc >75 was used. For calculation consider the next formula:

$$\boxed{Cc = \left(1 - \frac{Vn}{Vt}\right) x100}$$

Vn = Number of negative votes (score of less than 4); Vt = Total number of votes (n=6)[22]

For R3, the criteria established by Martínez (2003) were considered to bring the Delphi close[23].

3.2.5 ETHICAL DIMENSION

This research was approved by the Medicinal Ethics Committee Product Research Ethics Committee (CEIm) of the Institut d'Investigació Sanitària Pere Virgili (Pere Virgili Health Research Institute). Informed consent, which stated that participants accepted the conditions of participation upon agreeing to respond to the questionnaire which was secure. These conditions specified that responses were confidential and would only be used for the purpose of this research.

3.3 RESULTS

Out of the 30 professionals who initially agreed to participate, 20 (66.6%) went on to respond in the first round (R1), 16 (53.3%) in the second one (R2) and 17 (56.6%) in the third one (R3) (Figure 2.1). In R1, the mean age of the experts was 46.6 years (SD 10.25), 75% were female, 65% were doctors, 70% worked in the public sector and they were on average of 19 years' (SD 9.69) experience (Table 2.1).

Figure 2.1. Flow diagram of participation in each round

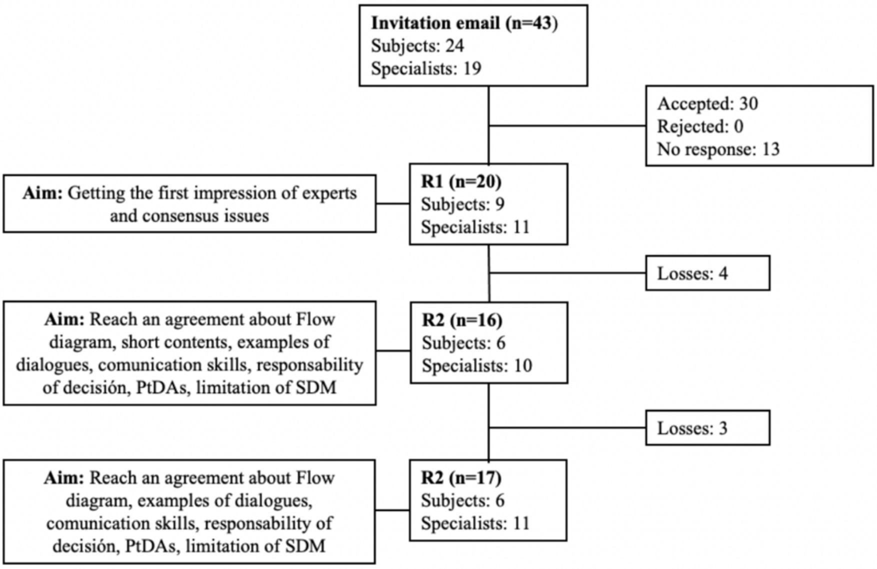


Table 2.1. Characteristics of the participants

Variable		Round 1		Round 2		Round 3	
		N	%	N	%	N	%
Sex	Female	15	75	12	75	13	76.47
	Male	5	25	4	25	4	23.52
	Total	20	100	16	100	17	100
Age range (years)	31-40	7	35	7	43.75	7	41.17
	41-50	6	30	4	25	5	29.41
	51-60	5	25	4	25	4	23.52
	61-70	2	10	1	6.25	1	5.88
	Total	20	100	16	100	17	100
Ownership of the affiliated institute, health centre or research site	Public sector	14	70	11	68.75	11	64.7
	Private sector	6	30	5	31.25	6	35.29
	Total	20	100	16	100	17	100
Profession	Nursing	4	20	2	12.5	3	17.64
	Medicine	13	65	11	68.75	11	64.7
	Psychology	1	5	1	6.25	1	5.88
	Other	2	10	2	12.5	2	11.76
	Total	20	100	16	100	17	100
Specialty	Family and community medicine or nursing	14	70	11	68.75	12	70.58
	Public health	1	5	1	6.25	1	5.88
	Gynaecology	1	5	1	6.25	1	5.88
	Endocrinology	1	5	1	6.25	1	5.88
	Research in health services	1	5	1	6.25	1	5.88
	Content development for Decision Support Systems for Healthcare	1	5	1	6.25	1	5.88
	None	1	5	0	0	0	0
	Total	20	100	16	100	17	100
Experience (years)	6-10	6	30	6	37.5	6	35.29
	11-20	6	30	5	31.25	6	35.29
	21-30	6	30	5	31.25	5	29.41
	31-40	2	10	0	0	0	0
	Total	20	100	16	100	17	100

Among the outcomes of the Delphi an agreement on the content and design of the documents could be reached. Among the three rounds carried out, four significant changes were made regarding the contents: 1) including examples of practical dialogues for each phase, 2) annexed additional information on communicative skills, 3) incorporation of information on how to manage professionals' responsibility in SDM 4) additional information about limitation of SDM model 5) elimination of the flow of the screening programme in Catalonia.

It was impossible to determine why professionals changed their decisions in the rounds, since they only had options to change their vote once the previous rounds results were known and their peers' arguments were read. Below there are the results for each round.

3.3.1 ROUND 1

R1 was designed to achieve two objectives: determinate its utility and clarify the content and the design of the supporting material. For this purpose, participants were asked 33 Likert-scale questions, 1 multiple-choice question and 6 open questions on the handbook and they were also given 2 Likert-scale questions and 4 open questions on the clinical practical guide (Table 2.2).

Table 2.2. Round 1 responses

Section	Questions using a Likert scale of 1 (Completely disagree) to 6 (Completely agree)	1	2	3	4	5	6	Cc
Evaluation of the Handbook on Shared Decision-Making in Breast Cancer Screening	1. The sections of the handbook are effective for understanding the application of SDM to breast cancer screening	0	5	5	10	55	25	90
	4. The 'Contents' section is suitable for this handbook	0	5	5	5	35	50	90
	5. The 'Objective of the material' section is suitable for this handbook	0	5	0	5	30	60	95
	6. The 'Who is it aimed at?' section is suitable for this handbook	0	5	0	10	35	50	95
	7. The 'Introduction' section is suitable for this handbook	5	10	0	10	45	30	85
	8. The 'Shared Decision-Making: What is it?' section is suitable for this handbook	0	5	5	10	40	40	90
	9. The 'Shared Decision-Making: Why is it important?' section is suitable for this handbook	0	5	0	5	45	45	95
	10. The 'Shared Decision-Making: 'What skills or competencies do health professionals need?' section is suitable for this handbook	0	5	5	35	35	20	90
	11. The 'Shared Decision-Making: What do patients think?' section is suitable for this handbook	0	10	0	10	35	45	90
	12. The 'Shared Decision-Making in breast cancer screening: The screening programme' section is suitable for this handbook	0	10	10	5	30	45	80

13. The 'Shared Decision-Making in breast cancer screening: Implementation of SDM in breast cancer screening' section is suitable for this handbook	0	5	0	5	45	45	95
14. The 'Shared Decision-Making in breast cancer screening: Self-assessment of the SDM process' section is suitable for this handbook	0	10	10	10	35	35	80
15. The handbook provides the minimum content on SDM in breast cancer screening that health professionals should be familiar with	0	5	0	20	50	25	95
16. The content of the handbook is sufficiently detailed	0	5	5	5	35	50	90
19.a. Figure 1: Models of healthcare (page 14) is useful	0	0	10	15	30	45	90
19.b. Figure 1: Models of healthcare (page 14) is clear	0	0	15	10	20	55	85
20.a. Figure 2: Role of the participants in the clinical encounter (page 15) is useful	0	5	5	10	35	45	90
20.b. Figure 2: Role of the participants in the clinical encounter (page 15) is clear	0	5	5	15	30	45	90
21.a. Figure 3: Elements of Shared Decision-Making (page 16) is useful	0	0	10	20	25	45	90
21.b. Figure 3: Elements of Shared Decision-Making (page 16) is clear	0	0	5	20	25	50	95
22.a. Figure 4: Communication skills (page 21) is useful	5	0	10	30	15	40	85
22.b. Figure 4: Communication skills (page 21) is clear	0	0	10	20	25	45	90
23.a. Figure 5: Flow diagram of the Early Detection of Breast Cancer programme (page 27) is useful	5	5	20	15	20	35	70
23.b. Figure 5: Flow diagram of the Early Detection of Breast Cancer programme (page 27) is clear	10	10	20	15	15	30	60
24.a. Figure 6: Team talk (page 34) is useful	10	5	0	30	25	30	85

24.b. Figure 6: Team talk (page 34) is clear	10	0	15	20	25	30	75
26.a. Figure 7: Option talk (page 36) is useful	5	5	0	30	40	20	90
26.b. Figure 7: Option talk (page 36) is clear	5	0	10	45	15	25	85
28.a. Figure 8: Decision talk (page 38) is useful	0	5	10	5	35	45	80
28.b. Figure 8: Decision talk (page 38) is clear	0	0	5	15	30	50	95
30.a. Figure 9: Shared Decision-Making steps (page 39) is useful	0	0	5	20	25	50	95
30.b. Figure 9: Shared Decision-Making steps (page 39) is clear	0	0	10	35	10	45	90
31. Does its design (colours, images) make the handbook easier to read for an SDM professional?	0	0	5	20	35	40	95

Closed questions	Options	Percentage (%)
2. Which section of the handbook do you think should be changed?	a) Front cover	0
	b) Objective of the material	0
	c) Who is it aimed at?	0
	d) Introduction	10
	e) Shared Decision-Making: What is it?	0
	f) Shared Decision-Making: Why is it important?	0
	g) Shared Decision-Making: What skills or competencies do health professionals need?	25
	h) Shared Decision-Making: What do patients think?	0
	i) Shared Decision-Making in breast cancer screening: The screening programme	15
	j) Shared Decision-Making in breast cancer screening: Implementation of SDM in breast cancer screening	0
	k) Shared Decision-Making in breast cancer screening: Self-assessment of the SDM process	0

	l) None					50		
	Total					100		
Evaluation of the Clinical Practice Guide: Implementation of SDM for Health Professionals	Questions using a Likert scale of 1 (Completely disagree) to 6 (Completely agree)	1	2	3	4	5	6	Cc
	1. Do you think that a clinical practice guide concisely summarizing the SDM steps is necessary?	0	15	10	5	5	65	75
	6. Is it useful to incorporate the Self-assessment section in the clinical practice guide?	0	5	10	25	25	35	85

Table 2.2. Cc: Coefficient of Concordance

A Cc higher than 75 was recorded for 32 of the Likert-scale questions and the minimum Cc was not reached by only 3 of them; in other words, no agreement was reached. These questions concluded that 'Flow diagram of the Early Detection of Breast Cancer programme', was clear (Cc=60) and useful (Cc=70) (Figure 2.2). The same applied to the question that determined Team talk (page 34) – to be clear (Cc=75). These questions were incorporated into R2.

Figure 2.2. Flow diagram of the early detection of breast cancer programme

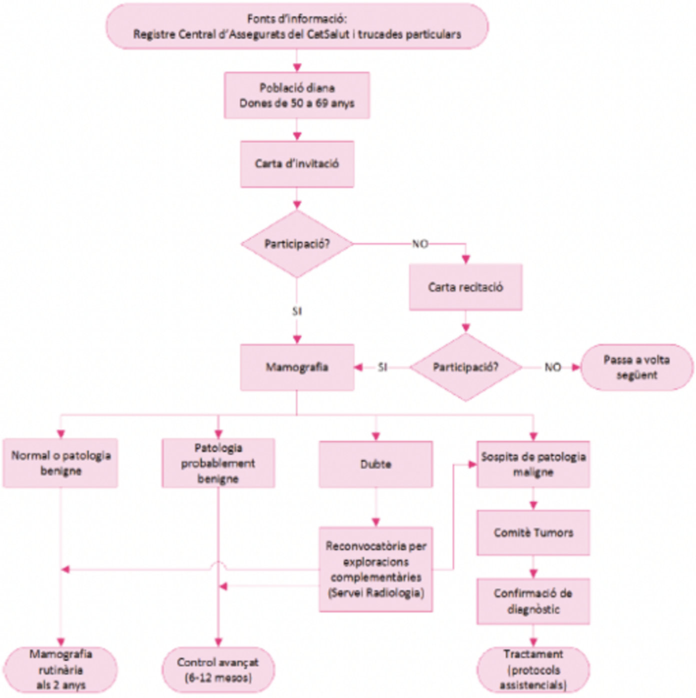
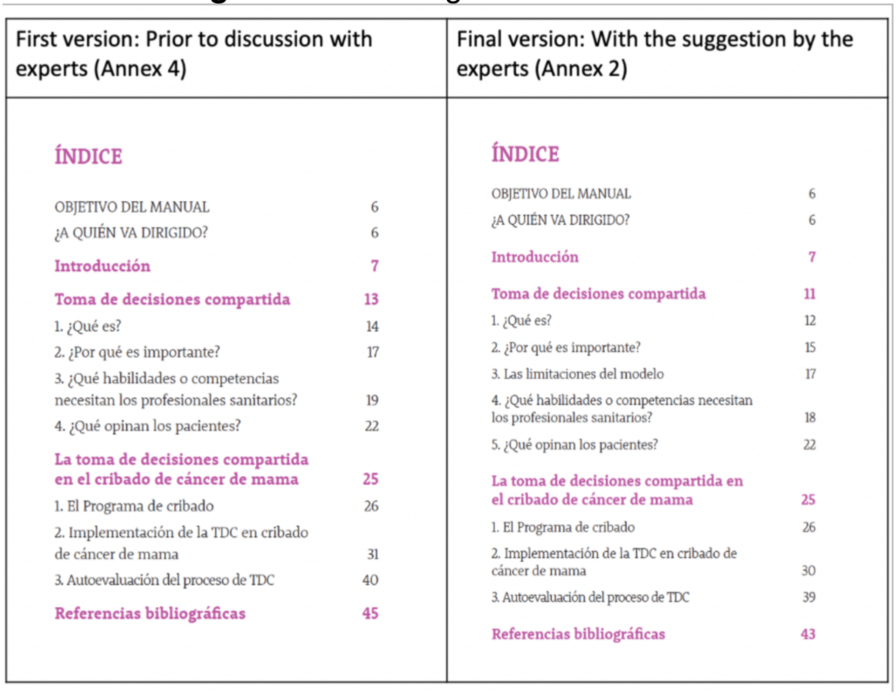


Figure 2.2. The clarity and usefulness of this figure was not agreed; therefore, it will be eliminated according to the results of R3.

In the multiple-choice question, participants were asked which section of the handbook should be edited: 10 responded ‘none’; 5 chose the section entitled ‘Which skills or competencies do health professionals need?’; 3 chose the ‘Screening programme’ section, and 2 chose the ‘Introduction’ (Figure 2.3).

Figure 2.3. Changes made to the index



First version: Prior to discussion with experts (Annex 4)	Final version: With the suggestion by the experts (Annex 2)
ÍNDICE OBJETIVO DEL MANUAL 6 ¿A QUIÉN VA DIRIGIDO? 6 Introducción 7 Toma de decisiones compartida 13 1. ¿Qué es? 14 2. ¿Por qué es importante? 17 3. ¿Qué habilidades o competencias necesitan los profesionales sanitarios? 19 4. ¿Qué opinan los pacientes? 22 La toma de decisiones compartida en el cribado de cáncer de mama 25 1. El Programa de cribado 26 2. Implementación de la TDC en cribado de cáncer de mama 31 3. Autoevaluación del proceso de TDC 40 Referencias bibliográficas 45	ÍNDICE OBJETIVO DEL MANUAL 6 ¿A QUIÉN VA DIRIGIDO? 6 Introducción 7 Toma de decisiones compartida 11 1. ¿Qué es? 12 2. ¿Por qué es importante? 15 3. Las limitaciones del modelo 17 4. ¿Qué habilidades o competencias necesitan los profesionales sanitarios? 18 5. ¿Qué opinan los pacientes? 22 La toma de decisiones compartida en el cribado de cáncer de mama 25 1. El Programa de cribado 26 2. Implementación de la TDC en cribado de cáncer de mama 30 3. Autoevaluación del proceso de TDC 39 Referencias bibliográficas 43

Figure 2.3. The final version included the limitation of SDM model in the index.

In their open responses, most participants considered the initiative to be positive and thought it would enable health professionals to access information on SDM using the Three-talk model in BC screening (Box 1). However, one of the participants suggested using the Agency for Healthcare Research and Quality model.

Box 1. Response to the question: Are the steps based on "Three-talk" suitable for the application of SDM in breast cancer screening? Please explain briefly

P3 : Yes, it shows how the health professional can implement SDM in a three-step process in a brief, practical and easy-to-read way. It describes the characteristics that differentiate each step, and specific examples of implementation in breast cancer screening.

The participants also provided some suggestions to modify the handbook. The most frequently cited were concerned about the length of the handbook and recommended simplifying the content (Box 2) and incorporating example dialogues, communication skills (Box 3) and instructions for using the PtDAs. The comments were incorporated in the questions in R2.

Box 2. Response to the question: How would you improve the elements selected in the previous question?

P7: I think that the handbook is very long, which may reduce motivation to read it.
P6: Very long and it doesn't show how to use the tool.

Box 3. Response to the question: What other content would you include in the clinical practice guide?

P3: Provide more information or example dialogues on how to use communication skills. This last [point] if the health professionals don't have a grounding or training in active listening, motivational interviewing, empathy, reflection, etc.
P10: I'd go into greater depth on relationship-building skills and give a few links to where they can find exercises to train themselves [in this].

Finally, in response to the question of whether the dialogues in each step represent their objective, most participants agreed (‘Team talk’ step, n=10; ‘option talk’ step, n=7; ‘Decision talk’ step, n=12) and made suggestions on the wording of the dialogues. Suggestions were also made to adapt the name of the original the Three-talk steps to a more representative one in the screening context. All the suggestions were incorporated into R2 to be approved or rejected by the other participants.

Only one of the questions evaluating the clinical practice guide did not reach the minimum Cc established: ‘Do you consider a guide that concisely summarises the SDM steps to be necessary?’ (Cc=75). This question was incorporated into R2. In the open questions, participants suggested changing the wording of the step 1 dialogues (n=3) and incorporating a review of communicative skills (Box 4); the same was applied to step 2, but participants added a comment about using relative risks instead of absolute ones (n=1) (Box 5).

Box 4 Response to the question: What elements would you change in step 1: ‘Team talk’?

P3: I’d include a few reviews, such as [on] active listening and deliberation. Perhaps using a phrase like ‘Remember to pay close attention and give assertive responses (active listening), and to think the options through carefully for the decision (deliberation)’.

Box 5. Response to the question: What elements would you change in step 2: ‘Option talk?

P15: Change relative risks to absolute risks.

They also proposed: eliminating the definition of SDM for step 3 in the guide (n=4), incorporating a brief clarification noting that women may also consult other people for support in making their decision (n=3) and mentioning the possibility of reversing the decision (n=4) (Box 6). Between 6 and 8 people stated that they would not make any change to steps 1, 2 or 3.

Box 6. Response to the question: What elements would you change in step 3: 'Decision talk'?

P11: I'd add the possibility of reversing the decision; I'd take out the explanation about SDM.

Finally, in the last question – 'What other content would you include in the clinical practice guide?' – participants reiterated the need to include a review of communication skills (n=3) and one of them proposed changing the self-assessment to use either the ASQ3 or the CollaboRATE instrument.

3.3.2 ROUND 2

R2 was structured around on open-question responses and included the elements about which agreement had not been reached in the previous round. Thirteen Likert-scale questions, 5 multiple-choice question and 6 open questions were produced in the handbook. For the clinical practice guide, 2 Likert-scale questions and 5 open questions were included (Table 2.3).

Table 2.3. Round 2 responses

Section	Questions using a likert scale of 1 (completely disagree) to 6 (completely agree)	1	2	3	4	5	6	CC
Evaluation of the Handbook on Shared Decision-Making in Breast Cancer Screening	1. Eliminate Figure 5: Flow diagram of the Early Detection of Breast Cancer Programme (page 27)	6.3	18.8	18.8	6.3	43.8	6.3	56.4
	2. Shorten content: the handbook format is very long	0	12.5	6.3	18.8	25	37.5	81.3
	4. Incorporate more examples of dialogues between the professional and the woman into each phase	18.8	6.3	6.3	31.3	31.3	6.3	68.9
	5. Add information on communication skills and competencies resources	0	12.5	25	12.5	43.8	6.3	62.6
	6. Add information on joint responsibility for the shared decision-making agreement	6.3	31.3	12.5	0	37.5	12.5	50
	7. Add information about resources on using the Patients Decision Aids (PtDAs). Note that this tool is intended to be used with the women	0	18.8	12.5	18.8	18.8	31.3	68.9
	8. Add information on the limitations of the SDM model	6.3	18.8	25	12.5	25	12.5	50
	9. Provide example dialogues on exploring the women's values, beliefs and preferences	0	18.8	12.5	18.8	31.3	18.8	68.9

Closed questions	Options	Percentage (%)
3. Which element of the	a) Objective of the material	0
	b) Who is it aimed at?	0
	c) Introduction	50

handbook would you shorten?	d) Shared Decision-Making: What is it?	0
	e) Shared Decision-Making: Why is it important?	0
	f) Shared Decision-Making: What skills or competencies do health professionals need?	0
	g) Shared Decision-Making: What do patients think?	6.3
	h) Shared Decision-Making in breast cancer screening: The screening programme	6.3
	i) Shared Decision-Making in breast cancer screening: Implementation of SDM in breast cancer screening	6.3
	j) Shared Decision-Making in breast cancer screening: Self-assessment of the SDM process	0
	k) None	31.3
	Total	100
10. Change the name of phase 2	a) Option talk (current name)	18.8
	b) Option talk and exploring preferences (proposal)	81.3
	c) Other	0
	Total	100
12. Phase 1 dialogue: Team Talk (page 34):	a) Now that we know that you can decide what to do about screening, we're going to talk about the characteristics of screening, so that you know what your options are (current dialogue).	12.5
	a) You have the option of deciding whether or not to have early-detection tests for breast cancer. If you're happy to, we can explore together what risks and benefits the test involves for you (proposal).	81.3
	c) Other	6.2
	Total	100

	14. Phase 2 dialogue: Option Talk (page 36)	a) I appreciate you sharing your views with me and I'm here to help you come to a good decision. Let's do a recap of your preferences and check whether you have any more questions (current dialogue).	18.8
		B) I'm here to help you make a decision. Let's look at what your preferences are and the various options available, and we'll check whether you have any questions about them (proposal).	75
		c) Other	6.2
		Total	100
	16. Phase 3 dialogue: Decision Talk (page 38):	a) Do you think that you're ready to make the decision or do you need more time? (current dialogue).	12.5
		b) Now that we've gone over the advantages and disadvantages of early detection, do you think that you can make the decision? Bear in mind that this can be delayed if you need more time or to talk about it with someone of your choice (proposal).	81.3
		c) Other	6.2
		Total	100

	Questions using a likert scale of 1 (completely disagree) to 6 (completely agree)	**1**	**2**	**3**	**4**	**5**	**6**	**CC**
Evaluation of the Clinical Practice Guide: Implementation of SDM for Health Professionals	1. A clinical practice guide is necessary for this handbook	6.3	0	12.5	25	31.3	25	81.3
	2. Improve the design of the clinical practice guide to improve understanding (colour, structure, etc.)	6.3	0	18.8	37.5	25	12.5	75
	3. Eliminate additional information (definitions of Risk factors, Mammography, Shared Decision-Making)	6.3	18.8	18.8	6.3	18.8	31.3	56.4

	4. Mention the possibility of reversing the decision in the follow-up plan	6.3	0	6.3	18.8	25	43.8	87.6
	5. Mention relationship-building competencies: active listening, showing empathy, clarification, etc.	12.5	6.3	12.5	6.3	43.8	18.8	68.9

Table 2.3. Cc: Coefficient of Concordance.

Of the 13 Likert-scale questions, only 3 reached a score of Cc>75. These underlined the need to: reduce the length of the handbook (Cc=81.3), create a clinical practice guide to accompany the handbook (Cc=81.3), and mention the possibility of reversing the decision in the follow-up plan (Cc=87.6).

The close ended questions included the following –'Which elements of the handbook would you shorten?'– to which the two most significant answers were 'the Introduction' (50%) and 'None' (31.3%). Following the comments made in the previous round, alternative formulations of the sample phrases for the dialogues in each of the Three-talk steps were given, as well as a change of name for step 2: 'Option talk and exploring preferences' (Plantear opciones y explorar preferencias), on which consensus was reached (81.3%).

In their responses to the open questions, those who considered the proposed dialogues unrepresentative of the steps had the opportunity to suggest a rewording. Finally, participants were able to include their final comments in both the handbook and the guide (Figure 2.4).

Figure 2.4. Changes made to the guide

First version: Prior to discussion with experts (Annex 5)	Final version: With the suggestion by the experts (Annex 3)
	

Figure 2.4. The final version simplification the information about breast cancer screening and only mention the aims and some characteristics in each steep. Also included the transversal skills communications.

Most had no further suggestions for each document, but some participants included comments about shortening the handbook (Box 7) and including this material in clinical practice guides, in order to improve implementation (Box 8).

Box 7. Response to 'Provide your final comments on the handbook'

> P10: None, the idea of including appendices on communication skills for the health professional, and on the screening tests for the women, seems like an excellent idea to me, to avoid making the handbook longer but offer additional tools for those health workers and women who would like more information.

Box 8. Response to 'Provide your final comments on the guide'

> P10: Clinical practice guidelines on the preventive approach to breast cancer that includes these points on shared decision-making would be very useful to support implementation. In any case, I don't think that it is a prerequisite to be able to produce the handbook that you are working on. This handbook could be incorporated into future Clinical Practice Guidelines (CPG).

3.3.3 ROUND 3

R3 was structured according to the 10 elements on which no agreement was reached in R2. Six questions with close ended, dichotomous answers were posed in the section evaluating the handbook, and 1 in the section evaluating the clinical practice guide; in addition to an open question. Of these, only those proposing an improvement to the organisation of the clinical practice guide, a change of colours and a review of cross-cutting communication skills in SDM reached a Cc of over 75% (Table 2.4).

Table 2.4. Round 3 responses

Section	Closed questions	Options	Percentage (%)
Evaluation of the Handbook on Shared Decision-Making in Breast Cancer Screening	1. Given that no consensus has been reached (56.4 %) on whether or not to eliminate Figure 5: Flow diagram of the Early Detection of Breast Cancer programme (page 27), please select one of the following options:	a) Eliminate. It does not add relevant information to this handbook	47.1
		b) Keep. Translate to Spanish and improve the image resolution	52.9
		Total	100
	2. Given that there is no consensus (68.9 %) about whether to add more examples of dialogues between the professional and the women for each phase, please select one of the following options:	a) One example per phase (current format)	35.3
		b) Three examples per phase (proposed new format) The image will be adapted to a more readable size for the handbook	64.7
		Total	100
	3. Given that there is no consensus (62.6 %) about whether to add information on communication skills and competencies resources to the handbook, please select one of the following options:	a) Yes, it is necessary to incorporate bibliographic references into the handbook for those who would like to find out more about this topic.	58.8
		b) No, the handbook is already too long to add more information.	64.7
		Total	100
	4. Given that there is no consensus (50 %) about whether to include information on joint responsibility for the SDM	a) Yes, it should be included because the information is not clear	41.2
		b) It is not necessary, it is already clear that the responsibility is shared	58.8

	agreement, please select one of the following options:	Total	100
	5. Given that there is no consensus (68.9 %) about whether bibliographic references should be added on the PtDAs– note that the PtDAs is an appendix to the handbook, to be used by the woman and health professional – please select one of the following options:	a) Yes, they should be added	52.9
		b) No, this is not necessary	47.1
		Total	100
	6. Given that there is no consensus (50 %) about whether to add information on the limitations of the model, please select one of the following options:	a) Yes, this is necessary because not doing so would mean producing one-sided material	58.8
		b) No, it is not necessary because the objective of the handbook is to show the advantages of implementing it	41.2
		Total	100
Evaluation of the Clinical Practice Guide: Implementation of SDM for Health Professionals	1. Given that there is no consensus about the design and content of the guide, please select one of the following options. The infographic will be adapted to a more readable size for the guide.	a) Current format	23.5
		b) Proposed new format	76.5
		Total	100

Since that agreement was not reached on the flow diagram for the Early Detection of Breast Cancer Programme, this figure was removed from the handbook, in light of the fact that it only applies to the region of Catalonia. The other elements in which no agreement was reached were the need for incorporating more samples of professional dialogues (64.7%); incorporating information about joint responsibility for the decision (41.2%); adding information on the limitations of the SDM model (58.8%), as well as adding supplementary resources on the way to use the SDM (52.9%) and on communication skills and competencies (58.8%). The researchers believed that the additional content would not entail substantial changes to the handbook but would provide more information for professionals who are not familiar with the model, and that is why all these elements were incorporated into the handbook.

The texts included were developed according to the proposals submitted by the participants in previous rounds. For example, the following elements were highlighted in the professional dialogues: the possibility of reversing the decision, needing more time, and accessing to support from a third person to make the decision (Figure 2.5).

Figure 2.5. Example of dialogues for the professionals to “team talk” step

Figure 2.5. a) “*You have the option of deciding wheter or not to participate in the breast cancer screening programe*”. b) “*Together we`ll look at information on the breast cancer screening programme, so that we can decide whether to participate or not”.* c) *“When you feel ready, we can make a decision jointly about your participation in the breast cancer screening programme.”*

The Delphi was brought to close in R3, taking into account the criteria cited by Martínez, regarding the elements about which agreement was not reached (23): a) the limited number of items for which Cc>75 was not achieved (6 of the 61 Likert-scale and closed questions); b) limited resources and time; c) the

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possibility that participants would abandon the study in a subsequent round, which would affect the external validity of the study. The last two criteria were applied in the context of the COVID-19 pandemic, given that half of the participants were health professionals who work in health centres.

3.4 DISCUSSION

The literature mentions certain barriers when applying SDM in BC screening, including limited time in clinical appointments and health professionals' lack of training in providing more participatory care[21]. This was the motivation for producing the first handbook and clinical practice guide on this subject, aimed at supporting health professionals by providing them with the essential elements for implementing SDM among women in a BC screening context.

The most relevant results included the validation of usefulness and relevance of support materials when using Delphi technique, considering the experts' opinion to reach agreements on editing the design and content, as well as their recommendation to incorporate these materials into the clinical practice guide. Delphi may be adapted to a generic model -The Three-talk- to one specifically designed for the BC screening context.

Of the 43 participants who were invited to respond the Delphi questionnaires, more than a half-showed interest in the topic of the research and collaborated in it. However, only 20 of them went on participating in the study. This may be related to the timetabling of the questionnaires, which coincided with the end of the first wave of the COVID-19 pandemic and the resurgence of cases at the beginning of the second wave.

Despite this, the professionals who decided to participate at the beginning of the process fulfilled their commitment, illustrated by the fact that the number of participants simply decreased by three between rounds, these having been lost from the Subjects category (n=3).

3.4.1 DISCUSSION BETWEEN THE PARTICIPANTS

It was easy to reach an agreement on the main content elements in the first round. Regarding the structure and development of SDM using the Three-talk model[17], which was considered suitable for BC screening, one of the participants initially suggested using the model created by the Agency for Healthcare Research and Quality[24]. However, this alternative model contains five steps, and the model proposed by the authors, with fewer steps, met all the requirements of SDM. Regarding the set of nine figures in the handbook, only one was eliminated, and the wording of three was edited.

The participants easily agreed that the initial version of the handbook was very long, 56 pages. Its length was due to the fact that it would be published in a pocket edition, which corresponds to 23 pages in a larger textbook edition. The researchers decided to maintain the smaller format because it is more transportable, whereas they eliminated the content elements agreed by the participants.

It was impossible to reach an agreement on six items. While agreement should be ideally reached for all items, yet, when a new round does not provide more information or it is unlikely to achieve a better result, the rounds of questions may come to an end despite there being a small number of disagreements remaining[21]. The formulation changes of the responses between R2 (Likert scale) and R3 (dichotomous) meant that participants had to opt for one of the options rather than rating their level of agreement on the statements, which undoubtedly made it more difficult to reach an agreement.

Certain responses to the open questions were analysed in depth by the researchers. One of the participants in R1 suggested that the professional self-assessment method could be changed from SDM-Q-doc[25] to Ask 3Q[26] or CollaboRATE[27]. However, Ask 3Q is a methodology for applying SDM, making it equivalent to the Three-talk model. Given that the Three-talk model received positive evaluation from the participants, the change was not made. The other tool, CollaboRATE, is designed for the patient's evaluation of the professional, which was not the purpose of this questionnaire[28]. Our objective was to enable the professional to evaluate the way he or she performs SDM, resulting in a self-guided learning of this methodology. The researchers, therefore, kept the original version, SDM-Q-doc, and adapted it for screening.

The decision on the flow diagram was affected by whether participants came from the region of Catalonia (of those living in Catalonia, 5/6 wanted to keep it, albeit improving its resolution; in contrast, the specialists from outside Spain (7/11) opted to remove it). Given that the objective of the handbook is to be used in other territories, the research group decided to eliminate the flow diagram.

The example dialogues suggesting how professionals should conduct SDM at each point in the process were widely accepted as a fundamental part of the handbook, even though no consensus was reached on whether to include more example dialogues for each step (Su=4/6; Sp=7/11). While Cc>75 was not reached, a larger proportion of both groups advocated for providing more examples. This may be directly related to the fact that both groups believed that SDM training for health professionals is still incomplete. Some of these participants therefore called for the handbook to provide more support, giving professionals greater confidence in implementation using the dialogues. The same conclusion can be reached regarding the decision to include more bibliographic references on communication skills and relationship-building competencies (Su=3/6; Sp=7/11) and including information about PtDAs (Su=5/6; Sp=4/11). In the latter case, the results differed from the two groups: most of the Subject participants wanted to add information to these tools, perhaps highlighting their lack of knowledge about them or lack of training in their use, while Specialists did not consider their inclusion so relevant, due to their familiarity with the tools.

3.4.2 HOW TO IMPROVE THE APPLICATION OF SDM TO SCREENING

While 83% of health professionals were strongly interested in promoting Shared Decision-making during the clinical encounter[28], they admitted their lack of training in the SDM model as one of the most significant barriers to its implementation in the screening context[13].

A review of the training health professionals had received confirmed our belief that there is a lack of strategies to familiarise health professionals with this model. In Spain, the topic has been introduced into medicine and health-related degree programmes[29-32]. However, it is not framed accurately within a SDM model, however, it is closer to communication or clinical communication skills, which have been used interchangeably as equivalents to the model. The level of accuracy and strategies used in this training are also unknown. Most training in SDM is acquired in postgraduate-level studies aimed for doctors and nurses[33], whereas particular attention should also be paid to health workers in primary care centres (including support and technical staff, as well as clinicians), who provide person-centred healthcare in a holistic manner[34].

Experts in SDM have argued it is necessary to prioritise adapting curricula to consolidate this training, by emphasising an education in communication skills and the accreditation of these competencies[35], within the framework of a horizontal care model. In addition, experts highlight the need to create partnerships between universities and interdisciplinary research groups to develop this material[35].

Experts also recommend a training methodology based on practical activities such as role plays, as well as teamwork, in teams of six people for instance, in a day-long training, and providing constructive feedback on students' capacity to express empathy, giving assertive responses, engaging them in active listening, and other skills[36]. This handbook and clinical practice guide, therefore, include dialogues and specific examples of how to apply them. And it will serve as reference material supporting an initial grounding in SDM for professionals who have not received any formal training in this subject, but also as supplementary material for those who have; enabling them to apply the skills and competencies acquired in the specific context of BC screening.

The final structure of our document responds to the need described in the preceding paragraph and highlighted by the participants in the study.

Given the change of paradigm that SDM entails, all measures that help familiarise professionals with SDM are important. For example, adding a section into Clinical Practice Guidelines (CPG) on how to include the patient in decision-making; thereby, coordinating evidence-based practice with SDM[37] may be useful. Patients may even participate, to some extent, in its development, as it is a current practice in such organisations such as the National Institute for Health and Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network[38]. In this sense, our proposed handbook and clinical practice guide, as well as the PtDAs, whose quality has already been evaluated and certified by international organisations such as The Ottawa Hospital[39], may be considered as complementary materials.

3.5 LIMITATIONS

The main limitation of the study was participants recruitment, which is a typical constraint. It was a particular problem in this case, since the empirical work coincided with the successive waves of the COVID-19 pandemic, which hindered the active participation of some professionals who had initially agreed to participate in the study. Despite this, there were fewer withdrawals from R2 onwards that might have been expected in those circumstances.

The change in the formulation of the R2 (Likert scale) and R3 (dichotomous) responses may have made it more difficult to reach the established minimum Cc for agreement. Nevertheless, with reference to Martínez (2003)[21], the research team determined that one more round would not have provided any added value to the results, as shown in the reasons described in the preceding sections. Nevertheless, the decision made regarding those elements about which no agreement had been reached did not significantly affect the participants' opinions regarding the basic concepts on which the initial questionnaire was based.

Finally, it should be noted that a systematic literature review (2018) showed that further research is still needed to determine the real impact that training interventions have on health professionals regarding SDM, since the level of certainty of the studies was low or very low. In this research, professionals who had received standard training were compared with those who had been trained in SDM; from the 15 studies, it was concluded that the results for patients' satisfaction, knowledge, decision-related conflict, regret, level of health and quality of life differed little or not at all from one to another[33]. Despite this, the demand for information and training expressed by this study's participants makes us believe that this first handbook aimed at health professionals for implementation in a BC screening context will help clarify the healthcare model focused on patients' needs and preferences. However, we have also noted the need to expand the training in SDM and develop empirical strategies to facilitate its implementation.

3.6 CONCLUSION

A horizontal relationship between patients and health professionals enables person-centred care to be delivered, in which that patient is considered a protagonist in the decisions made on his or her health. This has been recognised by several governmental organisations and incorporated into discourse and strategies. However, the practical application of this model is an area in which progress is still to be made. The handbook and clinical practice guide therefore aim to familiarise professionals with the model, helping them to engage women in the decision of either having BC screening or not. The results obtained enable us to conclude that, to apply it as a public policy, first there must be a pilot study with health professionals, which should be supplemented by formal training in SDM.

3.7 ACKNOWLEDGEMENTS

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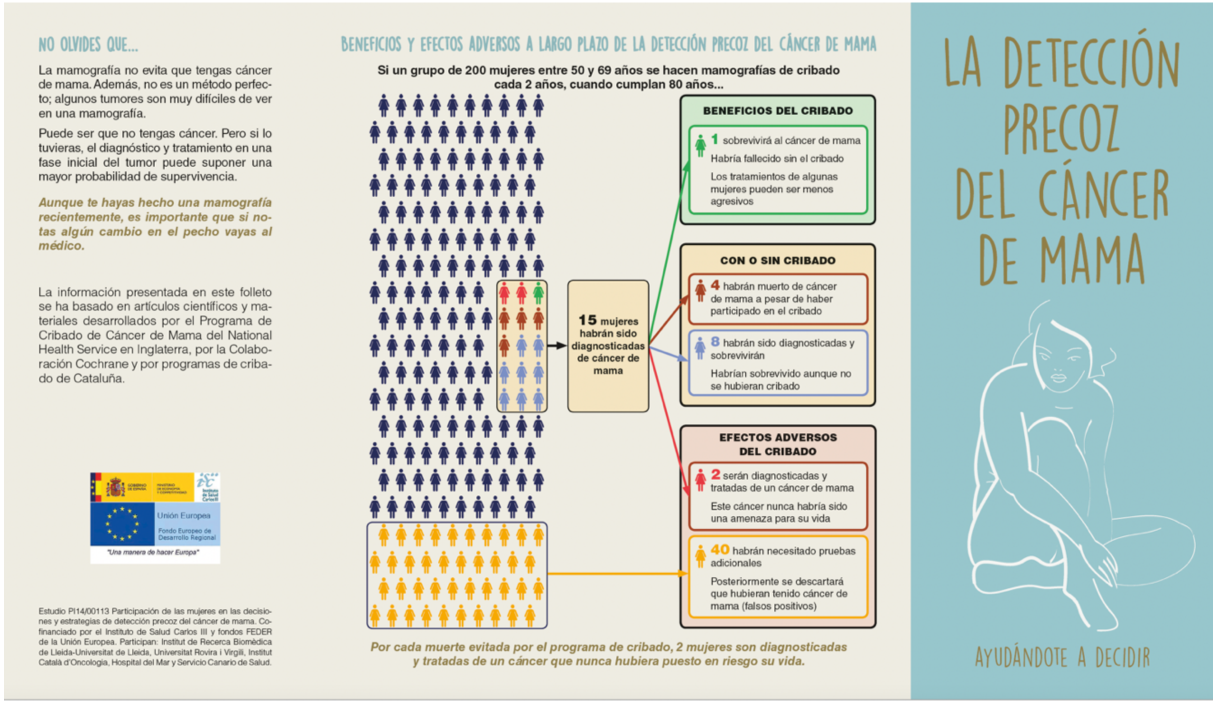
3.9 ANNEXES

3.9.1 PTDAS BREAST CANCER SCREENING



NO OLVIDES QUE...

La mamografía no evita que tengas cáncer de mama. Además, no es un método perfecto; algunos tumores son muy difíciles de ver en una mamografía.

Puede ser que no tengas cáncer. Pero si lo tuvieras, el diagnóstico y tratamiento en una fase inicial del tumor puede suponer una mayor probabilidad de supervivencia.

Aunque te hayas hecho una mamografía recientemente, es importante que si notas algún cambio en el pecho vayas al médico.

La información presentada en este folleto se ha basado en artículos científicos y materiales desarrollados por el Programa de Cribado de Cáncer de Mama del National Health Service en Inglaterra, por la Colaboración Cochrane y por programas de cribado de Cataluña.

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Estudio PI14/00113 Participación de las mujeres en las decisiones y estrategias de detección precoz del cáncer de mama. Cofinanciado por el Instituto de Salud Carlos III y fondos FEDER de la Unión Europea. Participan: Institut de Recerca Biomèdica de Lleida-Universitat de Lleida, Universitat Rovira i Virgili, Institut Català d'Oncologia, Hospital del Mar y Servicio Canario de Salud.

BENEFICIOS Y EFECTOS ADVERSOS A LARGO PLAZO DE LA DETECCIÓN PRECOZ DEL CÁNCER DE MAMA

Si un grupo de 200 mujeres entre 50 y 69 años se hacen mamografías de cribado cada 2 años, cuando cumplan 80 años...

15 mujeres habrán sido diagnosticadas de cáncer de mama

BENEFICIOS DEL CRIBADO

1 sobrevivirá al cáncer de mama

Habría fallecido sin el cribado

Los tratamientos de algunas mujeres pueden ser menos agresivos

CON O SIN CRIBADO

4 habrán muerto de cáncer de mama a pesar de haber participado en el cribado

8 habrán sido diagnosticadas y sobrevivirán

Habrían sobrevivido aunque no se hubieran cribado

EFECTOS ADVERSOS DEL CRIBADO

2 serán diagnosticadas y tratadas de un cáncer de mama

Este cáncer nunca habría sido una amenaza para su vida

40 habrán necesitado pruebas adicionales

Posteriormente se descartará que hubieran tenido cáncer de mama (falsos positivos)

Por cada muerte evitada por el programa de cribado, 2 mujeres son diagnosticadas y tratadas de un cáncer que nunca hubiera puesto en riesgo su vida.

LA DETECCIÓN PRECOZ DEL CÁNCER DE MAMA

AYUDÁNDOTE A DECIDIR

Annex 3.9.1. Page 1/2.

PARTICIPAR O NO PARTICIPAR EN EL CRIBADO DEL CÁNCER DE MAMA: ESTA ES LA CUESTIÓN

Estudios científicos recientes han identificado efectos adversos, antes desconocidos, de la detección precoz de cáncer de mama mediante mamografía. Por esta razón, este folleto tiene como objetivo informar sobre los beneficios y efectos adversos de participar en la detección precoz de cáncer de mama.

Este material informativo pretende ayudarte a sopesar pros y contras para que puedas tomar una decisión personal sobre si deseas participar o no en la detección precoz del cáncer de mama, en función de tus valores y preferencias.

¿QUÉ ES EL CÁNCER DE MAMA?

El cáncer de mama se desarrolla cuando algunas células empiezan a crecer de forma descontrolada, formando un tumor. A medida que el tumor crece las células malignas se pueden desplazar a otras partes del cuerpo y poner en peligro la vida de la persona afectada.

En Cataluña se diagnostican unos 4.000 casos nuevos de cáncer de mama al año. Las estadísticas nos dicen que 1 de cada 9 mujeres padecerá cáncer de mama a lo largo de su vida y que el 83% de las mujeres afectadas sobrevivirán a esta enfermedad.

¿QUÉ ES LA DETECCIÓN PRECOZ DEL CÁNCER DE MAMA?

La detección precoz del cáncer de mama, también denominada cribado, tiene por objetivo detectar un cáncer de mama en una etapa muy inicial, antes de que aparezcan síntomas. En su etapa inicial, el cáncer es más fácil de tratar y las oportunidades de sobrevivir son superiores.

El sistema sanitario público ofrece la posibilidad de participar en la detección precoz del cáncer de mama con el objetivo de reducir la mortalidad causada por este tumor. El programa de cribado se dirige a las mujeres entre 50 y 69 años y consiste en realizar una mamografía cada dos años.

La mamografía es una radiografía de la mama. Es la prueba más eficaz para detectar el cáncer de mama en mujeres que no presentan síntomas. El riesgo de algún daño por la exposición a esta radiación es muy pequeño.

BENEFICIOS DEL CRIBADO

El cribado reduce el riesgo de morir por cáncer de mama

La detección precoz puede salvar la vida a algunas mujeres porque se diagnostican y tratan antes de lo que se habría hecho sin cribado.

De cada 200 mujeres que se realizan mamografías de cribado cada dos años, entre los 50 y los 69 años, 1 mujer se salva gracias a la detección precoz del tumor.

El cribado detecta el cáncer en estadios más iniciales

Un cáncer detectado en estadios iniciales no necesita tratamientos tan agresivos como cuando está más avanzado; estos tratamientos tienen menos efectos secundarios y la probabilidad de recuperación es más alta.

EFECTOS ADVERSOS DEL CRIBADO

Errores en el diagnóstico: falsos positivos y falsos negativos

Los falsos positivos se producen cuando los resultados de la mamografía hacen sospechar de un posible cáncer de mama que en realidad no existe. Esto conlleva exploraciones adicionales que no serían necesarias.

De cada 200 mujeres que se realizan mamografías de cribado cada dos años entre los 50 y los 69 años, 40 tendrán un resultado falso positivo.

La situación contraria, el falso negativo, es mucho menos frecuente y se puede producir cuando la mamografía no muestra ninguna señal de cáncer de mama, aunque la mujer lo padezca.

El cribado puede detectar tumores inofensivos

Algunos tipos de cáncer que se detectan mediante la mamografía de cribado crecen tan lentamente que nunca hubieran llegado a ser un problema de salud. Algunos, incluso, habrían desaparecido de forma espontánea, sin tratamiento.

Actualmente no se puede saber qué lesiones progresarían y cuáles no, y por tanto, se ofrece tratamiento a todas las mujeres diagnosticadas. Algunas mujeres pueden recibir tratamientos que tienen efectos secundarios importantes, sin necesitarlos. Esto se conoce como **sobrediagnóstico** y **sobretratamiento**.

De cada 200 mujeres que se realizan mamografías de cribado cada dos años, entre los 50 y los 69 años, 2 serán tratadas de cáncer sin necesidad.

Annex 3.9.1. Page 2/2.

3.9.2 MANUAL “THE PARTICIPATION OF HEALTH PROFESSIONAL IN SHARED DECISION-MAKING ON BREAST CANCER SCREENING

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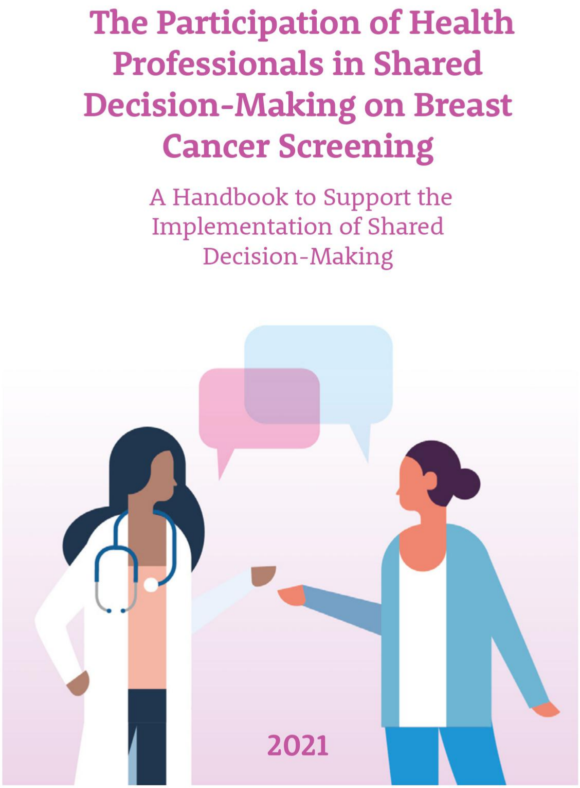
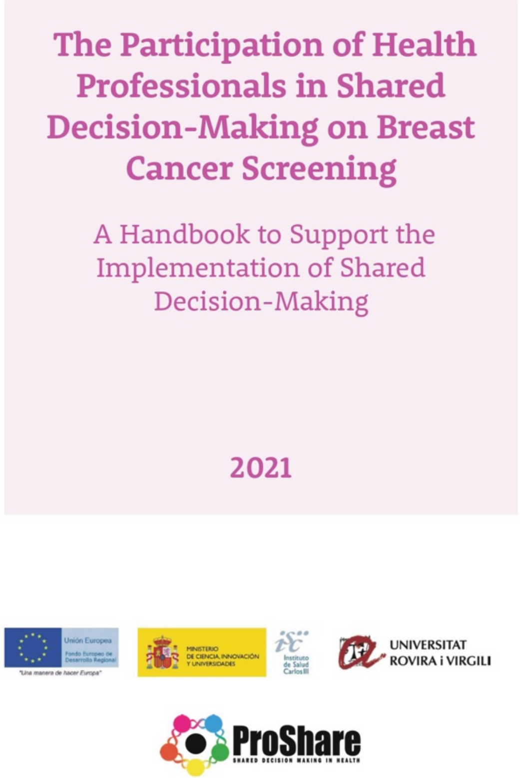


The Participation of Health Professionals in Shared Decision-Making on Breast Cancer Screening

A Handbook to Support the Implementation of Shared Decision-Making

2021



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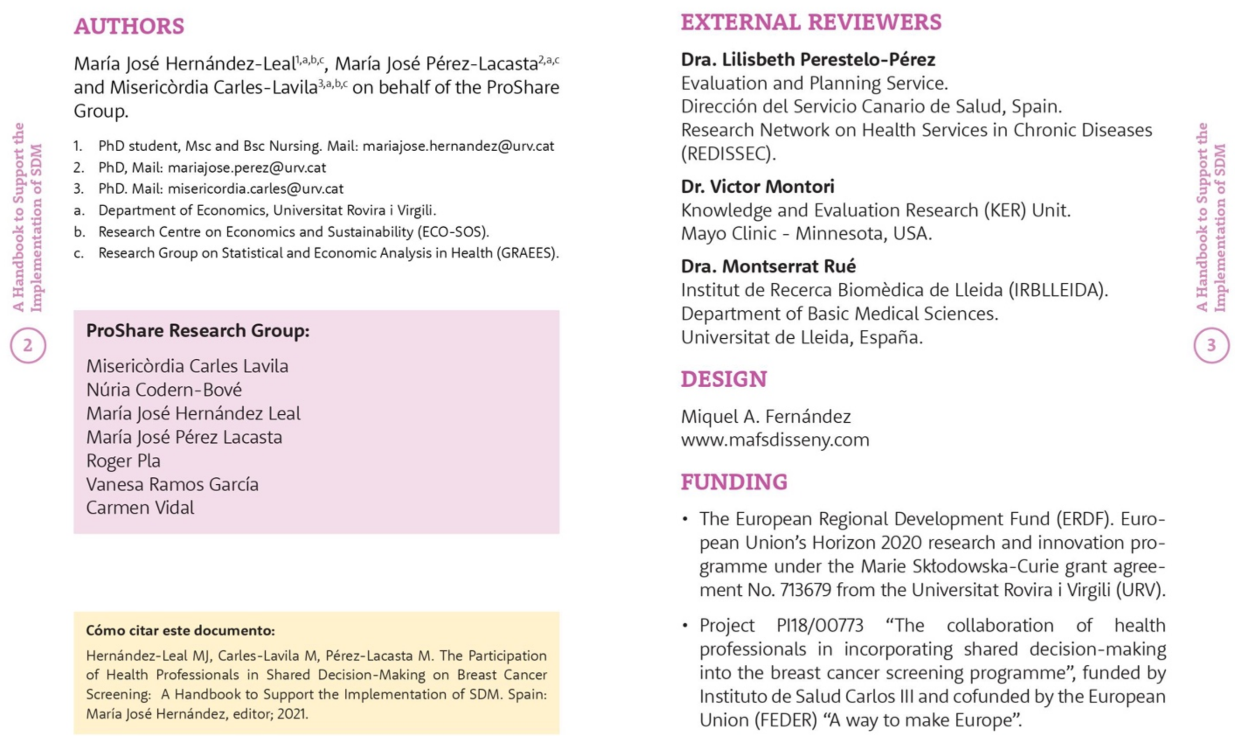
SHARED DECISION MAKING IN HEALTH



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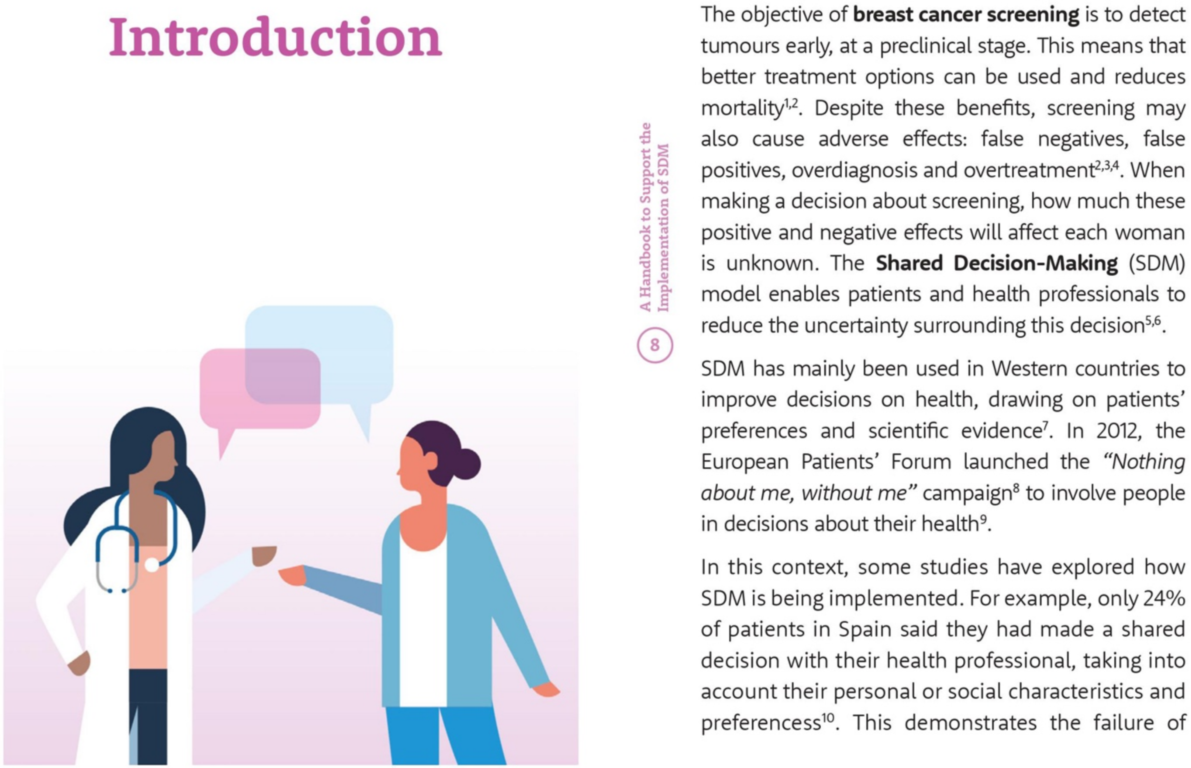
CONTENTS

THE OBJECTIVE OF THIS HANDBOOK

The aim of this handbook is to act as a guide on how to develop and implement **Shared Decision-Making (SDM)** in breast cancer screening.

WHO IS IT FOR?

Health professionals who are involved in breast cancer screening and have direct contact with women that are advised to participate in the programme.



Introduction

The objective of **breast cancer screening** is to detect tumours early, at a preclinical stage. This means that better treatment options can be used and reduces mortality[1,2]. Despite these benefits, screening may also cause adverse effects: false negatives, false positives, overdiagnosis and overtreatment[2,3,4]. When making a decision about screening, how much these positive and negative effects will affect each woman is unknown. The **Shared Decision-Making** (SDM) model enables patients and health professionals to reduce the uncertainty surrounding this decision[5,6].

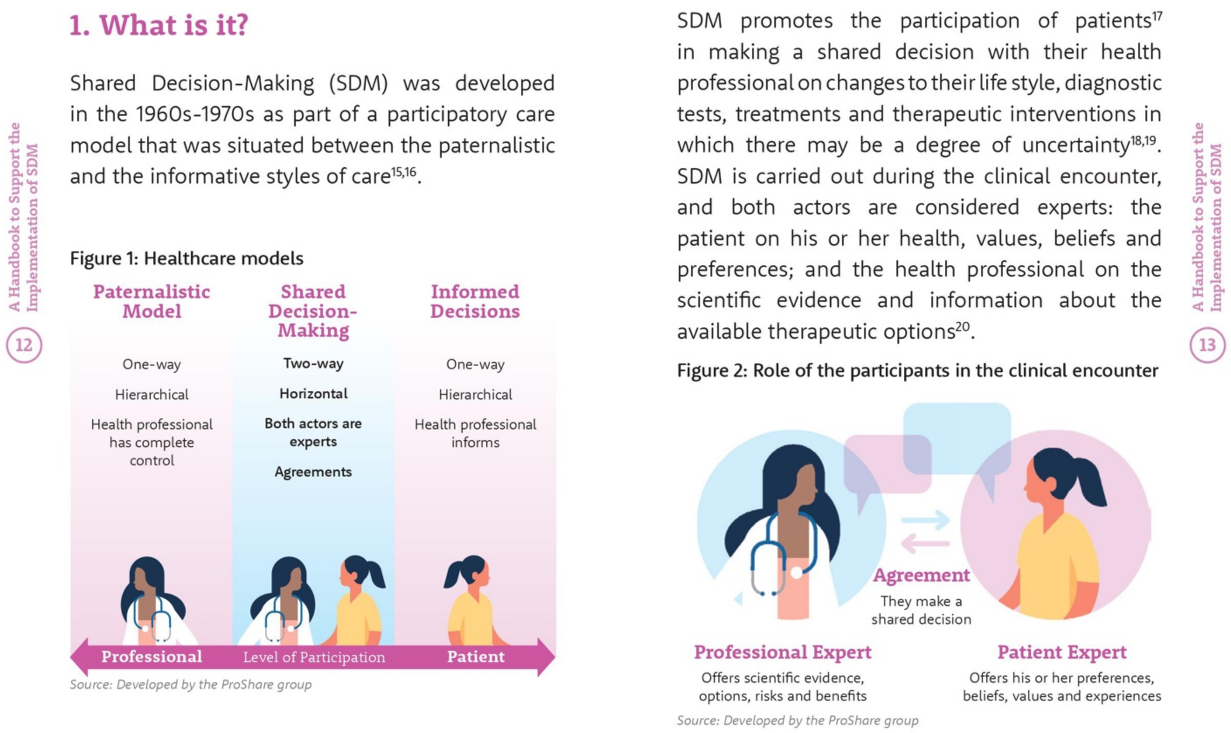
SDM has mainly been used in Western countries to improve decisions on health, drawing on patients' preferences and scientific evidence[7]. In 2012, the European Patients' Forum launched the *"Nothing about me, without me"* campaign[8] to involve people in decisions about their health[9].

In this context, some studies have explored how SDM is being implemented. For example, only 24% of patients in Spain said they had made a shared decision with their health professional, taking into account their personal or social characteristics and preferencess[10]. This demonstrates the failure of strategies aimed at involving people in their health, due to potential shortcomings in communication skills and the lack of channels for productive dialogue between the various actors in the clinical encounter[11].

To improve these strategies, the **Health Quality and Assessment Agency of Catalonia** describes Patient decision aids (PtDAs) as a key element in SDM, although it does not currently provide one for breast cancer screening[12]. However, a recent study developed a PtDAs for this purpose[13].

While there has recently been an increase in the amount of materials developed for patients[14], there are few resources to help professionals incorporate people's preferences and values into decision-making about health. This document offers health professionals scientific evidence on SDM, so that it can be applied to the breast cancer screening process.

Shared Decision-Making



1. What is it?

Shared Decision-Making (SDM) was developed in the 1960s-1970s as part of a participatory care model that was situated between the paternalistic and the informative styles of care[15,16].

Figure 1: Healthcare models

Paternalistic Model	Shared Decision-Making	Informed Decisions
One-way	**Two-way**	One-way
Hierarchical	**Horizontal**	Hierarchical
Health professional has complete control	**Both actors are experts**	Health professional informs
	Agreements	

Source: Developed by the ProShare group

SDM promotes the participation of patients[17] in making a shared decision with their health professional on changes to their life style, diagnostic tests, treatments and therapeutic interventions in which there may be a degree of uncertainty[18,19]. SDM is carried out during the clinical encounter, and both actors are considered experts: the patient on his or her health, values, beliefs and preferences; and the health professional on the scientific evidence and information about the available therapeutic options[20].

Figure 2: Role of the participants in the clinical encounter

Agreement
They make a shared decision

Professional Expert
Offers scientific evidence, options, risks and benefits

Patient Expert
Offers his or her preferences, beliefs, values and experiences

Source: Developed by the ProShare group

Therefore, the main objective of SDM is to guarantee that people are sufficiently informed when they make decisions about their health[21]. Achieving this goal requires continuous negotiation between the two experts, with the dialogue focusing on the values, preferences and circumstances of the patient, and the benefits, harms, risks and therapeutic options put forward by the health professional. As a result, this discussion creates more autonomous people with a greater sense of commitment and responsibility towards their health[20,22–24].

Figure 3: Components of Shared Decision-Making

A) Exchange of information between the patient and health professional	B) Deliberation about the different options	**C) A shared decision is made**

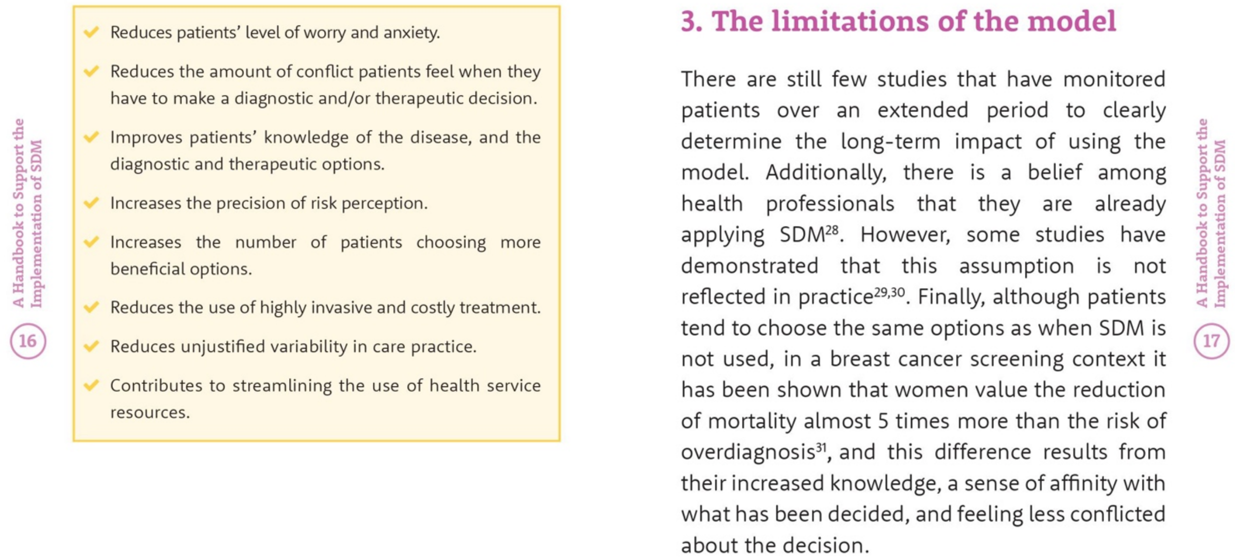
Source: Adaptation of Elwyn et al. 2012[20]

2. Why is it important?

SDM is based upon the principle of patient autonomy. Spanish Law 21/2000 on Rights to Information about Health, Patient Autonomy and Clinical Documentation protects patients' right to decide freely between the available clinical options after having received appropriate information on them[25]. Health professionals are therefore legally bound to comply with this principle, and may not be guided solely by the professional's intentions.

Additionally, implementing SDM has been proven to create a number of benefits for patients, professionals and health services[10, 24, 26, 27]:

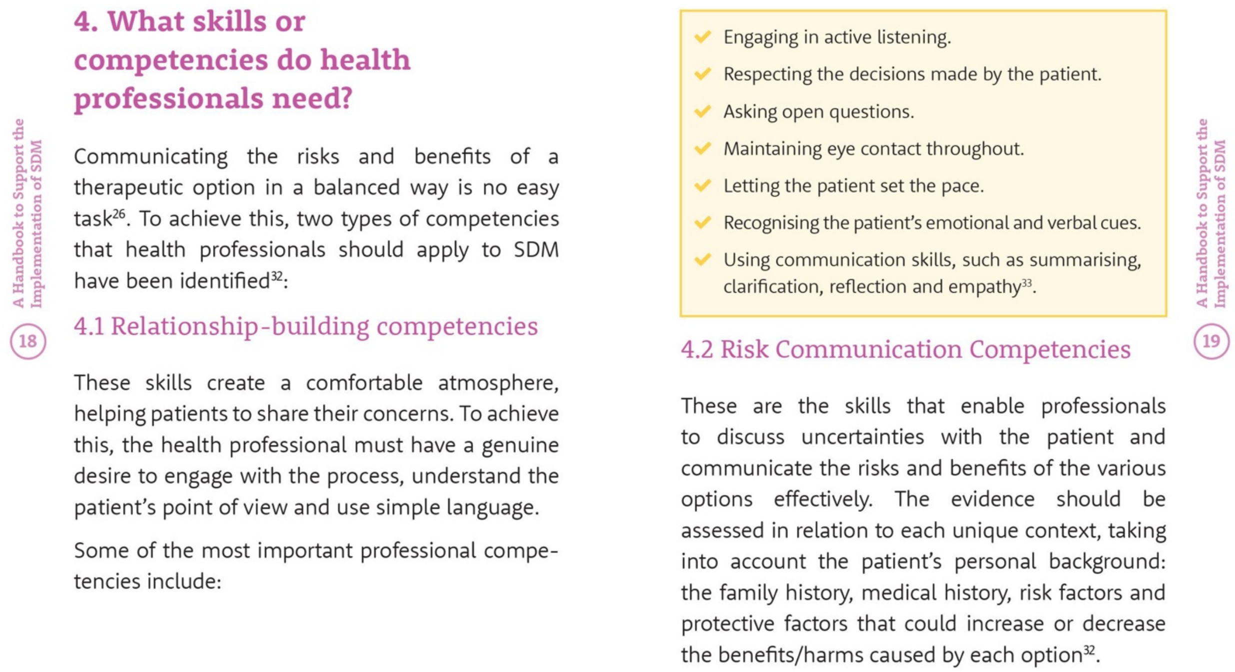
- ✓ Increases patient participation.
- ✓ Improves communication between the patient and health professional.
- ✓ Improves adherence to treatment.
- ✓ Improves biometric health results.
- ✓ Increases patient satisfaction with healthcare.



- ✓ Reduces patients' level of worry and anxiety.
- ✓ Reduces the amount of conflict patients feel when they have to make a diagnostic and/or therapeutic decision.
- ✓ Improves patients' knowledge of the disease, and the diagnostic and therapeutic options.
- ✓ Increases the precision of risk perception.
- ✓ Increases the number of patients choosing more beneficial options.
- ✓ Reduces the use of highly invasive and costly treatment.
- ✓ Reduces unjustified variability in care practice.
- ✓ Contributes to streamlining the use of health service resources.

3. The limitations of the model

There are still few studies that have monitored patients over an extended period to clearly determine the long-term impact of using the model. Additionally, there is a belief among health professionals that they are already applying SDM[28]. However, some studies have demonstrated that this assumption is not reflected in practice[29,30]. Finally, although patients tend to choose the same options as when SDM is not used, in a breast cancer screening context it has been shown that women value the reduction of mortality almost 5 times more than the risk of overdiagnosis[31], and this difference results from their increased knowledge, a sense of affinity with what has been decided, and feeling less conflicted about the decision.



4. What skills or competencies do health professionals need?

Communicating the risks and benefits of a therapeutic option in a balanced way is no easy task[26]. To achieve this, two types of competencies that health professionals should apply to SDM have been identified[32]:

4.1 Relationship-building competencies

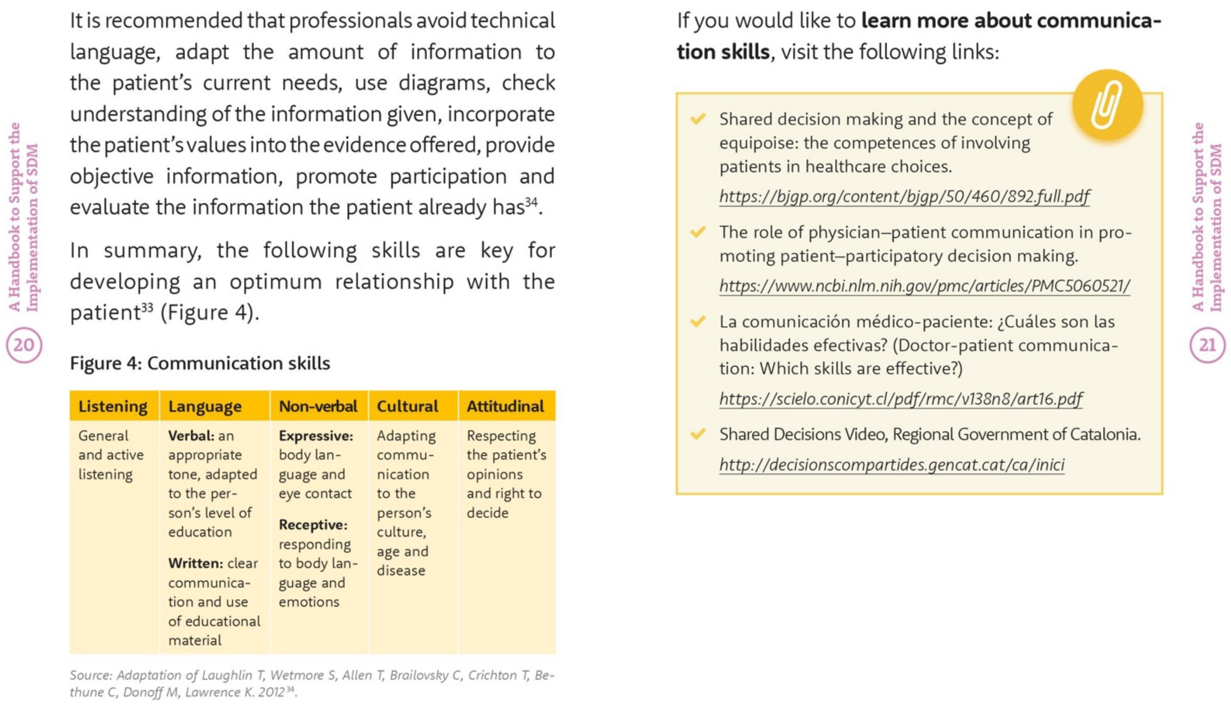
These skills create a comfortable atmosphere, helping patients to share their concerns. To achieve this, the health professional must have a genuine desire to engage with the process, understand the patient's point of view and use simple language.

Some of the most important professional competencies include:

- ✓ Engaging in active listening.
- ✓ Respecting the decisions made by the patient.
- ✓ Asking open questions.
- ✓ Maintaining eye contact throughout.
- ✓ Letting the patient set the pace.
- ✓ Recognising the patient's emotional and verbal cues.
- ✓ Using communication skills, such as summarising, clarification, reflection and empathy[33].

4.2 Risk Communication Competencies

These are the skills that enable professionals to discuss uncertainties with the patient and communicate the risks and benefits of the various options effectively. The evidence should be assessed in relation to each unique context, taking into account the patient's personal background: the family history, medical history, risk factors and protective factors that could increase or decrease the benefits/harms caused by each option[32].



It is recommended that professionals avoid technical language, adapt the amount of information to the patient's current needs, use diagrams, check understanding of the information given, incorporate the patient's values into the evidence offered, provide objective information, promote participation and evaluate the information the patient already has[34].

In summary, the following skills are key for developing an optimum relationship with the patient[33] (Figure 4).

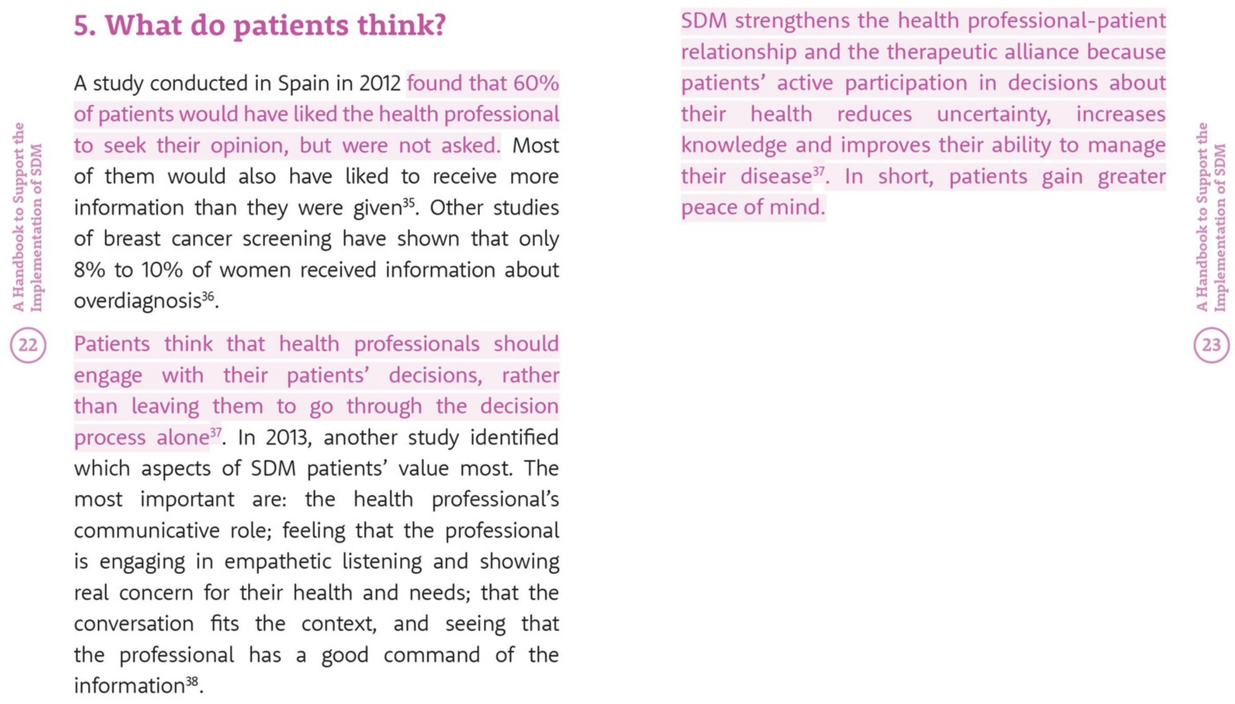
Figure 4: Communication skills

Listening	Language	Non-verbal	Cultural	Attitudinal
General and active listening	**Verbal:** an appropriate tone, adapted to the person's level of education **Written:** clear communication and use of educational material	**Expressive:** body language and eye contact **Receptive:** responding to body language and emotions	Adapting communication to the person's culture, age and disease	Respecting the patient's opinions and right to decide

Source: Adaptation of Laughlin T, Wetmore S, Allen T, Brailovsky C, Crichton T, Bethune C, Donoff M, Lawrence K. 2012[34].

If you would like to **learn more about communication skills**, visit the following links:

- ✓ Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices.
  https://bjgp.org/content/bjgp/50/460/892.full.pdf
- ✓ The role of physician–patient communication in promoting patient–participatory decision making.
  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060521/
- ✓ La comunicación médico-paciente: ¿Cuáles son las habilidades efectivas? (Doctor-patient communication: Which skills are effective?)
  https://scielo.conicyt.cl/pdf/rmc/v138n8/art16.pdf
- ✓ Shared Decisions Video, Regional Government of Catalonia.
  http://decisionscompartides.gencat.cat/ca/inici

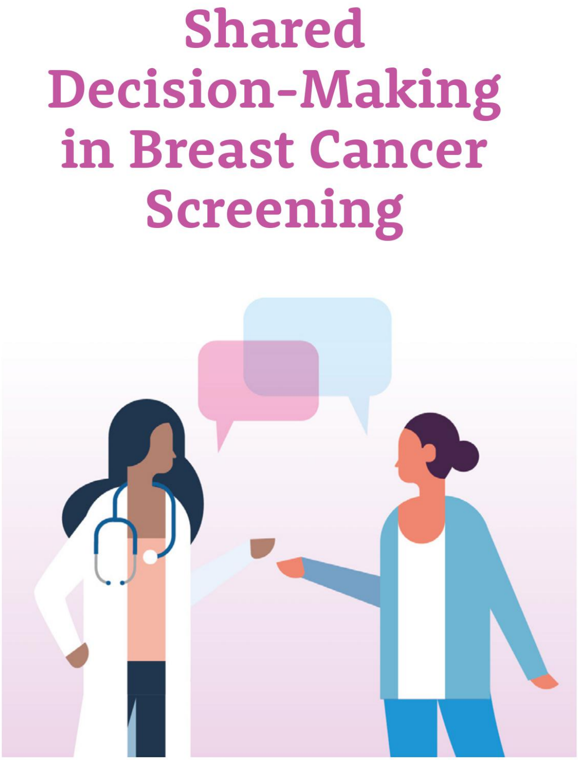


5. What do patients think?

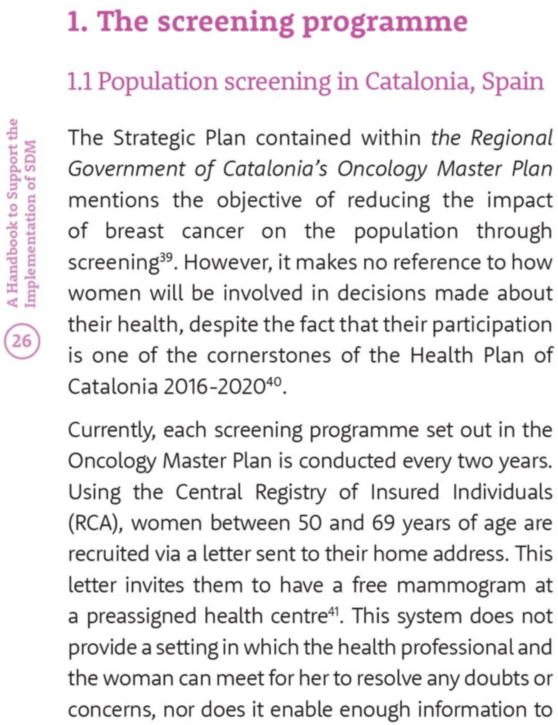
A study conducted in Spain in 2012 found that 60% of patients would have liked the health professional to seek their opinion, but were not asked. Most of them would also have liked to receive more information than they were given[35]. Other studies of breast cancer screening have shown that only 8% to 10% of women received information about overdiagnosis[36].

Patients think that health professionals should engage with their patients' decisions, rather than leaving them to go through the decision process alone[37]. In 2013, another study identified which aspects of SDM patients' value most. The most important are: the health professional's communicative role; feeling that the professional is engaging in empathetic listening and showing real concern for their health and needs; that the conversation fits the context, and seeing that the professional has a good command of the information[38].

SDM strengthens the health professional-patient relationship and the therapeutic alliance because patients' active participation in decisions about their health reduces uncertainty, increases knowledge and improves their ability to manage their disease[37]. In short, patients gain greater peace of mind.



Shared Decision-Making in Breast Cancer Screening

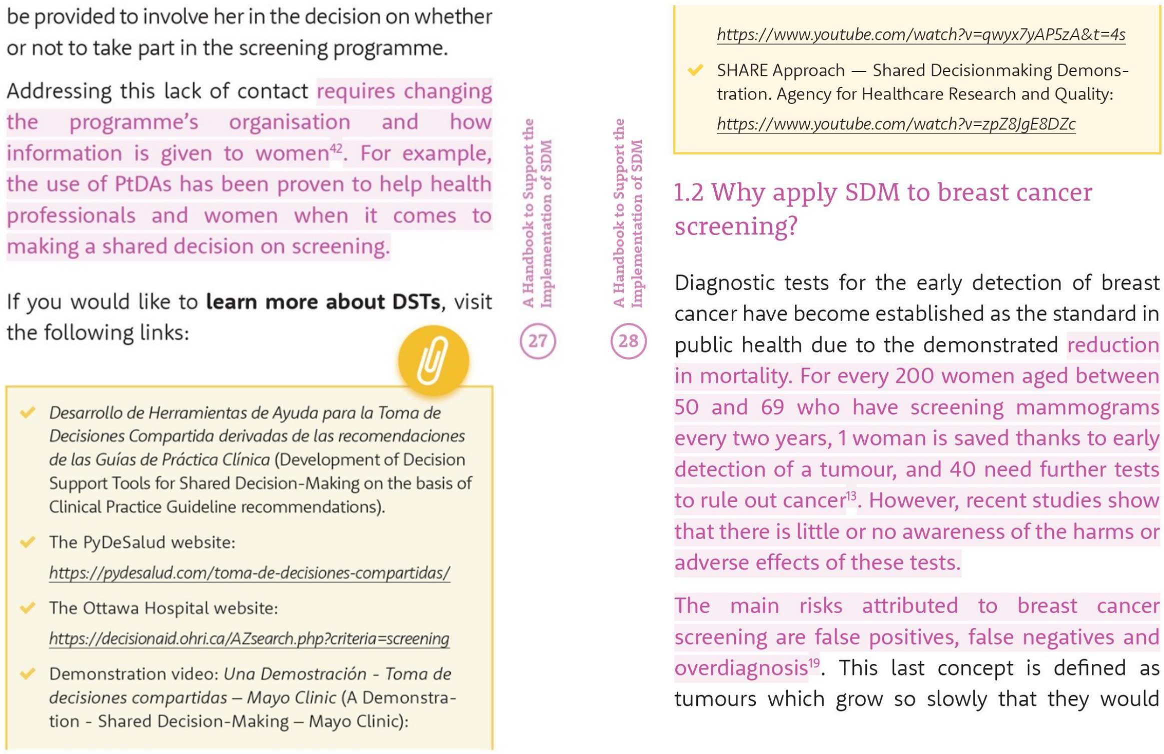


1. The screening programme

1.1 Population screening in Catalonia, Spain

The Strategic Plan contained within *the Regional Government of Catalonia's Oncology Master Plan* mentions the objective of reducing the impact of breast cancer on the population through screening[39]. However, it makes no reference to how women will be involved in decisions made about their health, despite the fact that their participation is one of the cornerstones of the Health Plan of Catalonia 2016-2020[40].

Currently, each screening programme set out in the Oncology Master Plan is conducted every two years. Using the Central Registry of Insured Individuals (RCA), women between 50 and 69 years of age are recruited via a letter sent to their home address. This letter invites them to have a free mammogram at a preassigned health centre[41]. This system does not provide a setting in which the health professional and the woman can meet for her to resolve any doubts or concerns, nor does it enable enough information to



be provided to involve her in the decision on whether or not to take part in the screening programme.

Addressing this lack of contact requires changing the programme's organisation and how information is given to women[42]. For example, the use of PtDAs has been proven to help health professionals and women when it comes to making a shared decision on screening.

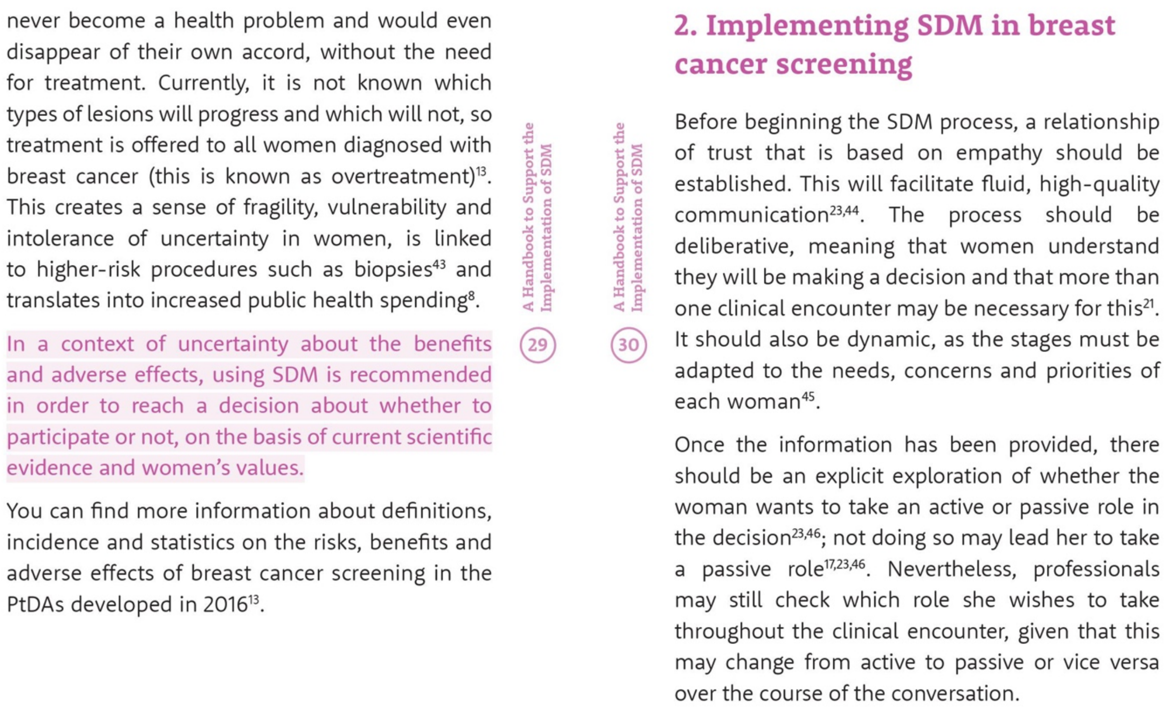
If you would like to **learn more about DSTs**, visit the following links:

- ✓ *Desarrollo de Herramientas de Ayuda para la Toma de Decisiones Compartida derivadas de las recomendaciones de las Guías de Práctica Clínica* (Development of Decision Support Tools for Shared Decision-Making on the basis of Clinical Practice Guideline recommendations).
- ✓ The PyDeSalud website:
  https://pydesalud.com/toma-de-decisiones-compartidas/
- ✓ The Ottawa Hospital website:
  https://decisionaid.ohri.ca/AZsearch.php?criteria=screening
- ✓ Demonstration video: *Una Demostración - Toma de decisiones compartidas – Mayo Clinic* (A Demonstration - Shared Decision-Making – Mayo Clinic):
  https://www.youtube.com/watch?v=qwyx7yAP5zA&t=4s
- ✓ SHARE Approach — Shared Decisionmaking Demonstration. Agency for Healthcare Research and Quality:
  https://www.youtube.com/watch?v=zpZ8JgE8DZc

1.2 Why apply SDM to breast cancer screening?

Diagnostic tests for the early detection of breast cancer have become established as the standard in public health due to the demonstrated reduction in mortality. For every 200 women aged between 50 and 69 who have screening mammograms every two years, 1 woman is saved thanks to early detection of a tumour, and 40 need further tests to rule out cancer[13]. However, recent studies show that there is little or no awareness of the harms or adverse effects of these tests.

The main risks attributed to breast cancer screening are false positives, false negatives and overdiagnosis[19]. This last concept is defined as tumours which grow so slowly that they would



never become a health problem and would even disappear of their own accord, without the need for treatment. Currently, it is not known which types of lesions will progress and which will not, so treatment is offered to all women diagnosed with breast cancer (this is known as overtreatment)[13]. This creates a sense of fragility, vulnerability and intolerance of uncertainty in women, is linked to higher-risk procedures such as biopsies[43] and translates into increased public health spending[8].

In a context of uncertainty about the benefits and adverse effects, using SDM is recommended in order to reach a decision about whether to participate or not, on the basis of current scientific evidence and women's values.

You can find more information about definitions, incidence and statistics on the risks, benefits and adverse effects of breast cancer screening in the PtDAs developed in 2016[13].

2. Implementing SDM in breast cancer screening

Before beginning the SDM process, a relationship of trust that is based on empathy should be established. This will facilitate fluid, high-quality communication[23,44]. The process should be deliberative, meaning that women understand they will be making a decision and that more than one clinical encounter may be necessary for this[21]. It should also be dynamic, as the stages must be adapted to the needs, concerns and priorities of each woman[45].

Once the information has been provided, there should be an explicit exploration of whether the woman wants to take an active or passive role in the decision[23,46]; not doing so may lead her to take a passive role[17,23,46]. Nevertheless, professionals may still check which role she wishes to take throughout the clinical encounter, given that this may change from active to passive or vice versa over the course of the conversation.

Factors that promote participation of the professional and the woman include: health professionals' motivation to involve the woman in her decision; the perception that SDM will have a positive impact on the clinical process; the woman having a high level of literacy, or her own desire to take an active part in decisions that affect her health[26,47]. In contrast, the following factors can impede SDM: time limitations in the clinical encounter; the woman being of an advanced age, having difficulty communicating in the language of the professional, being from an underprivileged socioeconomic background, or having a low level of literacy[23,26,46,47]; and the existence of mental health conditions[23,43].

2.1 The "Three-talk" model and steps

The three steps involved in this model are[48]:

STEP 1
Team talk

The main objective of this step is to communicate the need to make a decision as a team, whose members are the health professional and the woman. This involves communicating the objectives of the decision, why it needs to be made (existence of personal risk factors) and the options available on the basis of the evidence. Professionals should (a) stress that the woman may decide not to make a decision at that time and request the support of other actors, such as relatives or other specialists, and (b) be receptive to the reactions the woman may have upon facing this decision. They should therefore underline that they will support the woman through the process until she feels confident enough to make the decision.

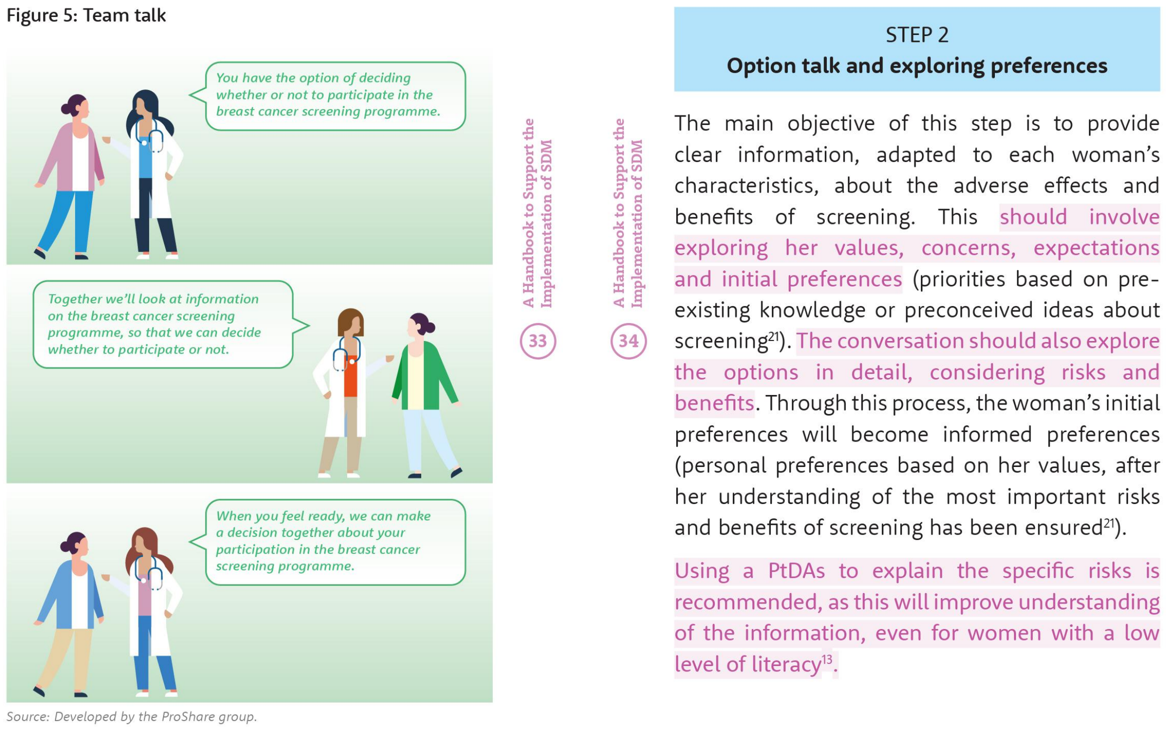


Figure 5: Team talk

You have the option of deciding whether or not to participate in the breast cancer screening programme.

Together we'll look at information on the breast cancer screening programme, so that we can decide whether to participate or not.

When you feel ready, we can make a decision together about your participation in the breast cancer screening programme.

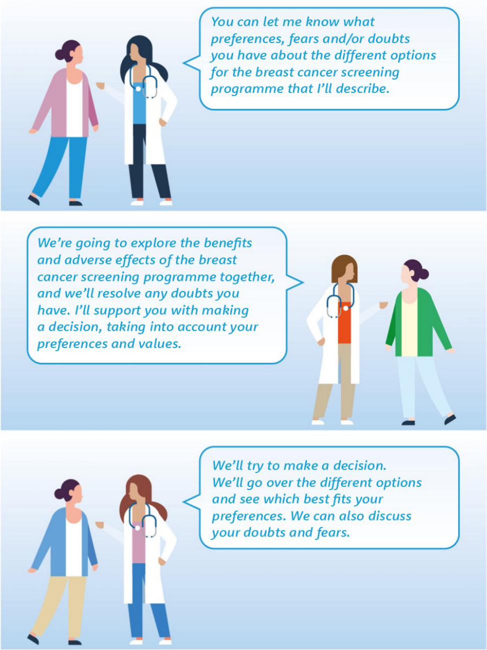
Source: Developed by the ProShare group.

STEP 2
Option talk and exploring preferences

The main objective of this step is to provide clear information, adapted to each woman's characteristics, about the adverse effects and benefits of screening. This should involve exploring her values, concerns, expectations and initial preferences (priorities based on pre-existing knowledge or preconceived ideas about screening[21]). The conversation should also explore the options in detail, considering risks and benefits. Through this process, the woman's initial preferences will become informed preferences (personal preferences based on her values, after her understanding of the most important risks and benefits of screening has been ensured[21]).

Using a PtDAs to explain the specific risks is recommended, as this will improve understanding of the information, even for women with a low level of literacy[13].

Figure 6: Option talk and exploring preferences



Source: Developed by the ProShare group.

STEP 3
Decision talk

At this step, the participants discuss the various options and make a decision on participation in breast cancer screening[48]. Professionals should underline the fact that they will support the woman in making the decision. They should also provide enough time for her to reflect on her priorities, even bringing up the option of delaying the decision to a later date or delegating it to the professional. In the latter case, it is recommended that participants identify the factors that are stopping her from making the decision by herself. Finally, they should confirm the decision, then agree on an action and follow-up plan[23,46] that enables the professional and woman to exchange ongoing feedback[45,46].

Figure 7: Decision talk

Source: Developed by the ProShare group.

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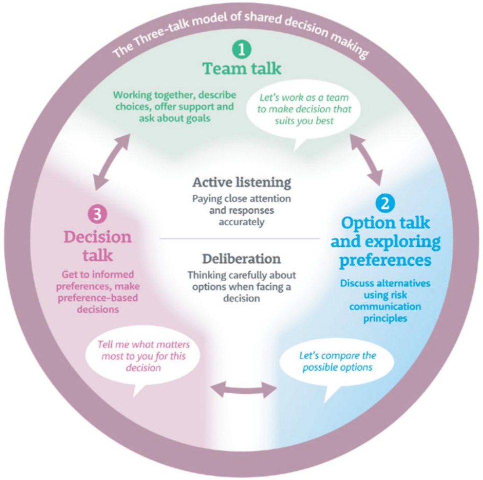
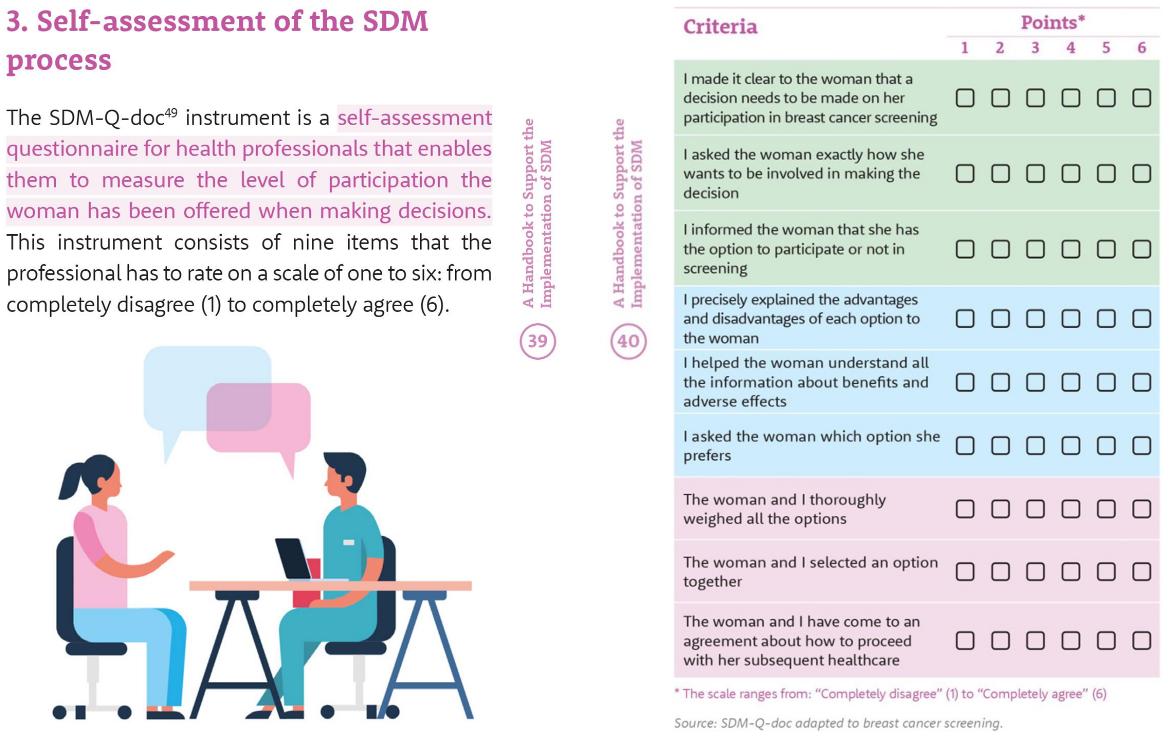
Figure 8: The steps of Shared Decision-Making



Source: Adaptation of A three-talk model for shared decision making. Elwyn G, et al 2017. Use authorised by the author[48].



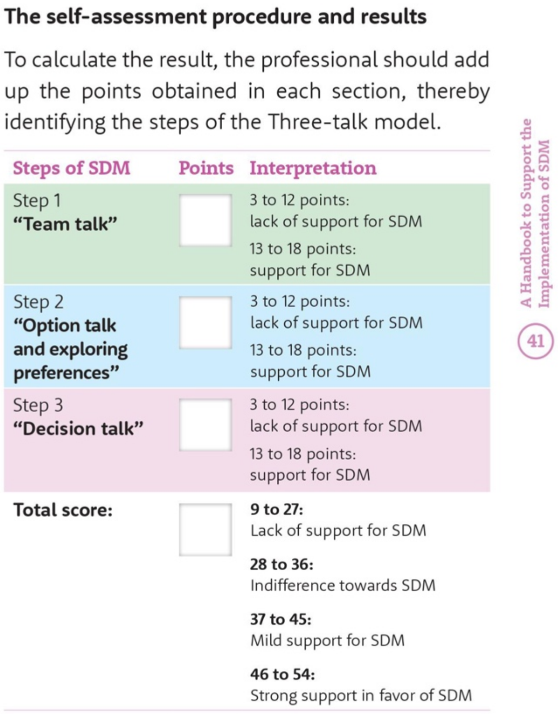
3. Self-assessment of the SDM process

The SDM-Q-doc[49] instrument is a self-assessment questionnaire for health professionals that enables them to measure the level of participation the woman has been offered when making decisions. This instrument consists of nine items that the professional has to rate on a scale of one to six: from completely disagree (1) to completely agree (6).

Criteria	Points* 1	2	3	4	5	6
I made it clear to the woman that a decision needs to be made on her participation in breast cancer screening	☐	☐	☐	☐	☐	☐
I asked the woman exactly how she wants to be involved in making the decision	☐	☐	☐	☐	☐	☐
I informed the woman that she has the option to participate or not in screening	☐	☐	☐	☐	☐	☐
I precisely explained the advantages and disadvantages of each option to the woman	☐	☐	☐	☐	☐	☐
I helped the woman understand all the information about benefits and adverse effects	☐	☐	☐	☐	☐	☐
I asked the woman which option she prefers	☐	☐	☐	☐	☐	☐
The woman and I thoroughly weighed all the options	☐	☐	☐	☐	☐	☐
The woman and I selected an option together	☐	☐	☐	☐	☐	☐
The woman and I have come to an agreement about how to proceed with her subsequent healthcare	☐	☐	☐	☐	☐	☐

* The scale ranges from: "Completely disagree" (1) to "Completely agree" (6)

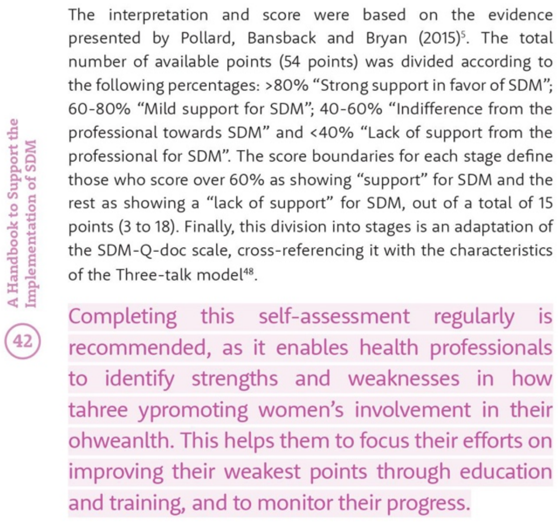
Source: SDM-Q-doc adapted to breast cancer screening.



The self-assessment procedure and results

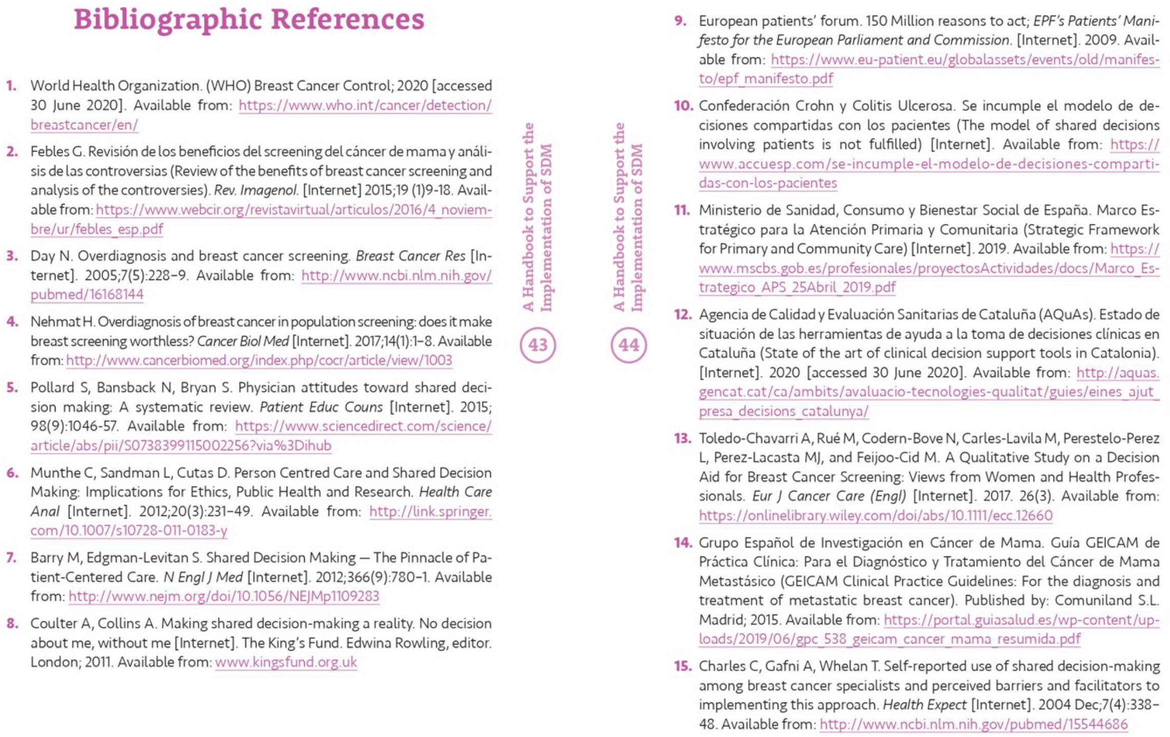
To calculate the result, the professional should add up the points obtained in each section, thereby identifying the steps of the Three-talk model.

Steps of SDM	Points	Interpretation
Step 1 **"Team talk"**	☐	3 to 12 points: lack of support for SDM 13 to 18 points: support for SDM
Step 2 **"Option talk and exploring preferences"**	☐	3 to 12 points: lack of support for SDM 13 to 18 points: support for SDM
Step 3 **"Decision talk"**	☐	3 to 12 points: lack of support for SDM 13 to 18 points: support for SDM
Total score:	☐	**9 to 27:** Lack of support for SDM **28 to 36:** Indifference towards SDM **37 to 45:** Mild support for SDM **46 to 54:** Strong support in favor of SDM



The interpretation and score were based on the evidence presented by Pollard, Bansback and Bryan (2015)[5]. The total number of available points (54 points) was divided according to the following percentages: >80% "Strong support in favor of SDM"; 60-80% "Mild support for SDM"; 40-60% "Indifference from the professional towards SDM" and <40% "Lack of support from the professional for SDM". The score boundaries for each stage define those who score over 60% as showing "support" for SDM and the rest as showing a "lack of support" for SDM, out of a total of 15 points (3 to 18). Finally, this division into stages is an adaptation of the SDM-Q-doc scale, cross-referencing it with the characteristics of the Three-talk model[48].

Completing this self-assessment regularly is recommended, as it enables health professionals to identify strengths and weaknesses in how tahree ypromoting women's involvement in their ohweanlth. This helps them to focus their efforts on improving their weakest points through education and training, and to monitor their progress.



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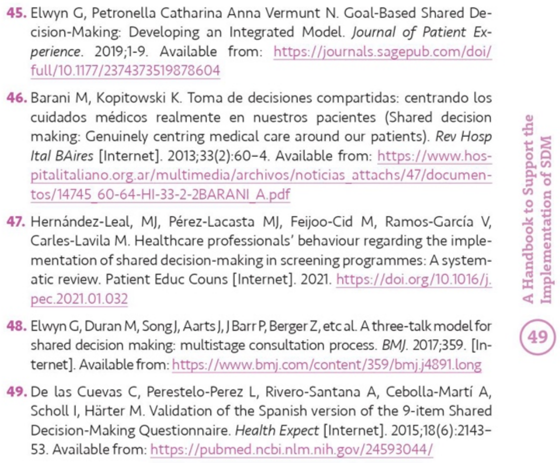

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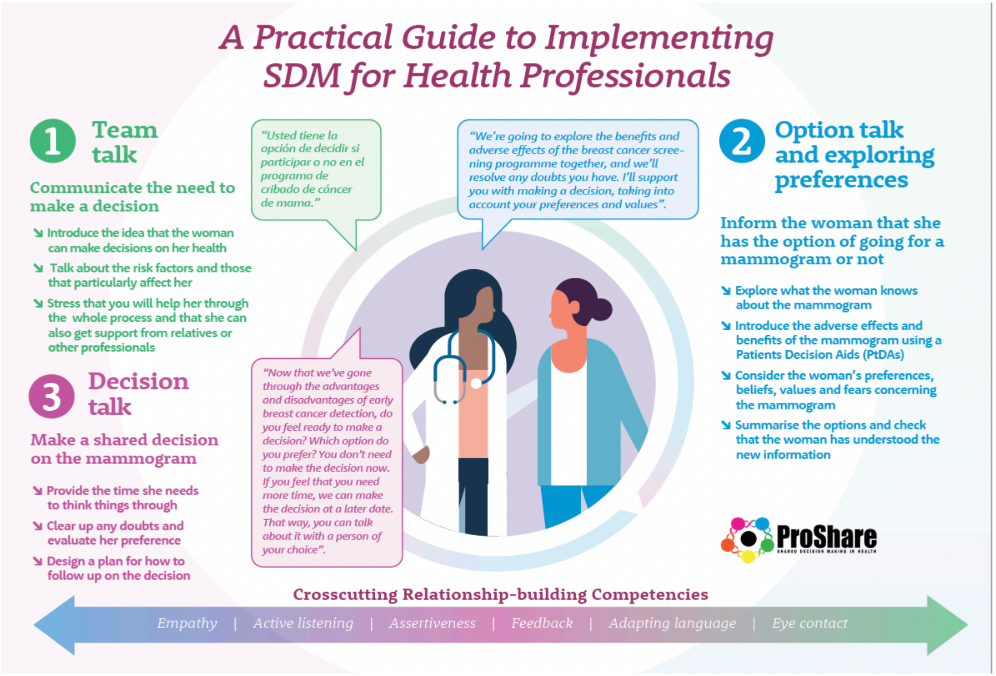
The Participation of Health Professionals in Shared Decision-Making on Breast Cancer Screening

A Handbook to Support the Implementation of Shared Decision-Making

2021

3.9.3 A PRACTICAL GUIDE TO IMPLEMENTING SDM FOR HEALTH PROFESSIONAL



A Practical Guide to Implementing SDM for Health Professionals

1 Team talk

Communicate the need to make a decision

- Introduce the idea that the woman can make decisions on her health
- Talk about the risk factors and those that particularly affect her
- Stress that you will help her through the whole process and that she can also get support from relatives or other professionals

"Usted tiene la opción de decidir si participar o no en el programa de cribado de cáncer de mama."

"We're going to explore the benefits and adverse effects of the breast cancer screening programme together, and we'll resolve any doubts you have. I'll support you with making a decision, taking into account your preferences and values".

2 Option talk and exploring preferences

Inform the woman that she has the option of going for a mammogram or not

- Explore what the woman knows about the mammogram
- Introduce the adverse effects and benefits of the mammogram using a Patients Decision Aids (PtDAs)
- Consider the woman's preferences, beliefs, values and fears concerning the mammogram
- Summarise the options and check that the woman has understood the new information

3 Decision talk

Make a shared decision on the mammogram

- Provide the time she needs to think things through
- Clear up any doubts and evaluate her preference
- Design a plan for how to follow up on the decision

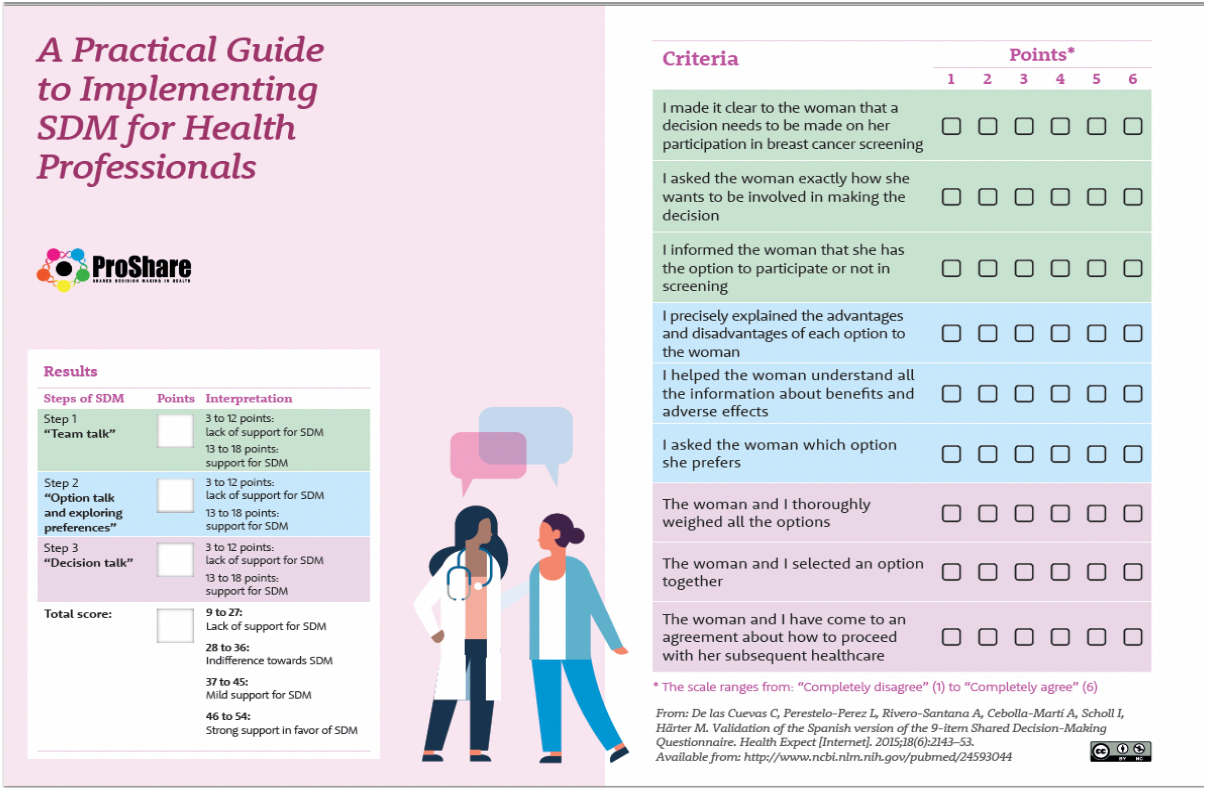
"Now that we've gone through the advantages and disadvantages of early breast cancer detection, do you feel ready to make a decision? Which option do you prefer? You don't need to make the decision now. If you feel that you need more time, we can make the decision at a later date. That way, you can talk about it with a person of your choice".

ProShare
SHARED DECISION MAKING IN HEALTH

Crosscutting Relationship-building Competencies

Empathy | Active listening | Assertiveness | Feedback | Adapting language | Eye contact

Annex 3.9.3 This document is available in spanish and english. Page 1/2



A Practical Guide to Implementing SDM for Health Professionals

ProShare

Results

Steps of SDM	Points	Interpretation
Step 1 **“Team talk”**	☐	3 to 12 points: lack of support for SDM 13 to 18 points: support for SDM
Step 2 **“Option talk and exploring preferences”**	☐	3 to 12 points: lack of support for SDM 13 to 18 points: support for SDM
Step 3 **“Decision talk”**	☐	3 to 12 points: lack of support for SDM 13 to 18 points: support for SDM
Total score:	☐	**9 to 27:** Lack of support for SDM **28 to 36:** Indifference towards SDM **37 to 45:** Mild support for SDM **46 to 54:** Strong support in favor of SDM

Criteria	Points*					
	1	2	3	4	5	6
I made it clear to the woman that a decision needs to be made on her participation in breast cancer screening	☐	☐	☐	☐	☐	☐
I asked the woman exactly how she wants to be involved in making the decision	☐	☐	☐	☐	☐	☐
I informed the woman that she has the option to participate or not in screening	☐	☐	☐	☐	☐	☐
I precisely explained the advantages and disadvantages of each option to the woman	☐	☐	☐	☐	☐	☐
I helped the woman understand all the information about benefits and adverse effects	☐	☐	☐	☐	☐	☐
I asked the woman which option she prefers	☐	☐	☐	☐	☐	☐
The woman and I thoroughly weighed all the options	☐	☐	☐	☐	☐	☐
The woman and I selected an option together	☐	☐	☐	☐	☐	☐
The woman and I have come to an agreement about how to proceed with her subsequent healthcare	☐	☐	☐	☐	☐	☐

* The scale ranges from: “Completely disagree” (1) to “Completely agree” (6)

From: De las Cuevas C, Perestelo-Perez L, Rivero-Santana A, Cebolla-Martí A, Scholl I, Härter M. Validation of the Spanish version of the 9-item Shared Decision-Making Questionnaire. Health Expect [Internet]. 2015;18(6):2143–53. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24593044

Annex 3.9.3 Page 2/2

CHAPTER 4

WOMEN'S PREFERENCE TO APPLY SHARED DECISION-MAKING IN BREAST CANCER SCREENING: A DISCRETE CHOICE EXPERIMENT[3]

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[3] This chapter have been sent at *Patient Education and Counseling Journal*

UNIVERSITAT ROVIRA I VIRGILI
SHARED DECISION-MAKING IN BREAST CANCER SCREENING PROGRAMMES: CONTRIBUTIONS
TO ITS IMPLEMENTATIONS
María José Hernández Leal

4.1 BACKGROUND

Breast cancer (BC) screening programmes have been widely adopted in developed countries because of their ability to detect malignant lesions early, thereby reducing mortality and improving survival[1,2]. In Spain, an incidence of 34,000 cases and 6,600 deaths due to BC were estimated in 2020[3]. The screening programme in the Spanish region of Catalonia is organised by the public health system. This screening programme entails sending a postal letter to women between 50 and 69 years of age every 2 years to undergo mammography in one health centre for free pay[4]. Several research and communication campaigns have focused on increasing women's adherence to screening to raise awareness of its importance. This is to the effect that the Spanish coverage reached 81.5% in 2017 in the target population (and has dropped to 73.7%, 3 years later, in a pandemic situation)[5]. The most cited reason for attending is the invitation letter issued by the organisations of the screening programme[6].

However, research also recognises the adverse effects of BC screening, which are usually not explained in a balanced way to women[7]. Adverse effects include false positives, false negatives, overdiagnosis, and therefore over-treatment[8]. Overdiagnosis refers to screen detected malignancy that would not have progressed to clinical or symptomatic disease and would never have caused a health problem during the lifetime of the women[9]. Currently, it is not possible to identify which lesions may progress. Therefore, all lesions are usually treated.

In cases of uncertainty, the literature recommends Shared Decision-making (SDM)[10]. It is based on more participatory care, so that women, based on their own beliefs and values, reach an agreement with the health professional[11] to undergo mammography, considering scientific evidence and available options. SDM has shown multiple benefits[12]; however, examining its costs, quality, and efficiency[12] to determine its applicability in different contexts is necessary. Some studies indicate that the application of SDM can mean a reduction in health costs[13], while other studies mention that such savings are unclear[14,15]. Thus, from health economics perspective, an approach to cost-benefit analysis can be generated through Discrete Choice Experiments (DCE)[16].

The DCE allows the determination of the utility of more participatory health care in the screening of BC through the preferences declared by women, as well as monetising those intangible values that improve the satisfaction of patients[17,18].

There is a dearth of studies focusing on knowing patients' preferences in an SDM[19], and none on women's preferences for the BC screening programme and their willingness to pay (WTP) for it. Therefore, this study aimed to analyse the declared preferences of women on the attributes of more participatory care (SDM) in contrast to the usual care with characteristics of a paternalist model for BC screening, establishing the relative importance of each through a DCE. In addition, the study participants were asked about their WTP for this type of health care.

4.2 METHODS

Our DCE design includes eight hypothetical profiles -choice sets- each with three characteristics -attributes- that can present different values -levels-. For the conjugation of these attributes and levels, a factorial design is considered, and it is assumed that they are independent of each other. Finally, each *choice set* contrasts with another, forming a choice task[20] that is presented to women to choose from as per their preference.

4.2.1 Definition of attributes and levels

Each choice set comprised three attributes justified in the SDM model[21–23].

- How the **information** is obtained**:** Women can be informed about the risks and benefits of breast cancer screening through a leaflet **or** by a health professional.
- **Dialogue** for mammography scheduled: Women communicate and discuss their preferences, fears, beliefs about breast cancer screening with a healthcare

professional, **or** the health system's schedule for mammography.

- Who makes the **decision**: Who among the actors decides to participate in breast cancer screening: the healthcare professional, the woman, **or** both.

The current functioning of the screening programme in a Spanish region, Catalonia, was used to determine the levels for each attribute: the health system schedules a mammography appointment by invitation letter every 2 years to women between 50 and 69 years of age; an information leaflet is attached to the invitation letter and the women decide whether to attend or not. Conversely, in relation to SDM, women inform themselves through a health professional, meet with him/her to discuss their beliefs about screening, and decide whether or not a woman should undergo mammography.

As a result, two levels were established for 'information' and 'dialogue' attributes representing the functioning of the SDM; the usual model and 3 levels were contemplated for the last attribute 'who makes the decision' (Table 3.1).

Table 3.1. Attributes and levels for options of Shared Decision-making in breast cancer screening

Attribute	Levels
1. How the **information** is obtained	1. Leaflet
	2. Healthcare professional
2. **Dialogue** for mammography scheduled	1. No, health system schedules mammography
	2. Yes, women share and discuss with a healthcare professional their beliefs and values about mammography.
3. Who makes the **decision**	1. The healthcare professional makes the decision
	2. Shared Decision-making by the healthcare professional and the woman
	3. The woman makes the decision

4.2.2 Experimental design

In this phase, attributes and levels are combined to create different choice sets that will be evaluated by women. The number of choice sets depends on the number of attributes and their levels. Following Reed Johnson et al.'s suggestions[24], four-choice sets were removed because they were implausible combinations and not consistent with the theory, leaving a total of eight choice sets. Those were eliminated if, without prior discussion, the professional or jointly, professional and women, decided for attending –or not- the screening, independent if they received the information with a leaflet or by a health professional.

The eight choice sets combined in pairs resulted in a maximum of 28 tasks (the action of choosing between two alternatives). Many of these could be eliminated, such as in the 16 cases in which one alternative dominated or was dominated by the other. Since SDM is considered a better option to resolve the uncertainty of this context[25], it was considered as a dominant choice set. The remaining 12 choice tasks were incorporated into the DCE survey, as this number is below the maximum number of tasks that can be included without causing participants to saturate[26].

4.2.3 Pre-test and refinement of the questionnaire

In March 2021, snowball sampling was carried out, and 11 women answered the questionnaire to identify the level of difficulty and understand the questions. Based on their comments, it was determined that the previous formulation of the questions had a conventional structured form to a descriptive form that included all the three attributes in one sentence (Figure 3.1). Subsequently, a randomised pilot study was conducted on 10 women to evaluate the recruitment process and the application of the survey, which was of a mixed form: online system (self-applied) and telephone system (guided)[27].

Figure 3.1. Choice task example of Shared Decision-making in breast cancer screening

Option A	Option B
I receive **information about the benefits and risks in a leaflet**, and I also **talk with a healthcare professional** about my fears or beliefs about mammography. Finally, **I make the decision** to attend -or not- to mammography.	I am **informed by a health professional** about the benefits and risks; my **mammography is programed by the health system**, so I do not manifest my fears, beliefs or preferences about the screening to a health professional. Finally, **I make the decision** to attend -or not- to mammography.

The survey was conducted between June and November of the same year in Spanish and Catalan. On the 12 choice task corresponding to the DCE, seven questions on sociodemographic (age, nationality, marital status, education, employment status, history of family breast cancer, and participation in screening) and a single, multiple-choice question on WTP for breast cancer screening care with SDM characteristics were incorporated (Annex 4.9.1).

4.2.4 Participants

The study was conducted in Catalonia, Spain, using a random sample of women aged 50–60 years who participated in three breast cancer screening programmes: Hospital del Mar in Barcelona, Cancer Prevention and Control Programme of the Catalan Institute of Oncology, and the Health Region of Lleida. This population had already been invited at least once by the national programme to undergo mammography. Therefore, it was assumed that the topic was more sensitive to their interests.

Women who had been diagnosed with breast cancer were excluded from the study.

The minimum required sample size was estimated to be 63 participants, calculated based on the empirical rule recommended by Johnson and Orme[28].

$$N>(500*c)/(t*a).$$

N=number of respondents, t=number of choice tasks, a=number of alternatives, and c= maximum number of levels

4.2.5 Data analysis

A mixed-effects conditional logit model was used to estimate women's preferences for different levels of SDM attributes in breast cancer screening. This is based on Daniel McFadden's theory of discrete choice, which seeks to describe the behaviour of decision-makers in the face of a decision problem, assuming that the declared preferences of those elections are based on obtaining the maximum possible utility[29]. The mixed-effects logistic regression model allows for the heterogeneity of preferences in the sample by treating the coefficients as random. It also allows multiple observations from each respondent, appropriate for our study, where each woman was presented with 12 choice tasks. All models included main effects without interaction terms. A model for each subgroup was fitted to allow for comparisons according to the WTP.

All the attribute variables were coded as dummy variables, with reference levels identified in tables with the results; further, they were specified as having a random component, assuming a normal distribution for all model coefficients. The coefficients indicate a change in preference from the reference level for each attribute[30].

When interpreting the model results, the statistical significance of the coefficients indicates whether attribute levels influence the choice set, whereas the coefficient size indicates the relative importance of one attribute level to another. We did not include an alternative-specific constant variable because our choice sets were unlabelled. Therefore, they had no utility beyond the attributes assigned to them in the experiment.

For all analyses, statistical significance was set at 0.05. All statistical analyses were performed using R statistical software.

4.2.6 Ethical dimension

This research was approved by the medicinal product research ethics committee (ceim) of the institut d'investigació sanitària pere virgili (pere virgili health research institute). informed consent was obtained, which stated that the participants accepted the conditions of participation upon agreeing to respond to the questionnaire. these conditions specified that the responses were confidential and would be used only for this research.

4.3 RESULTS

Of the 292 women invited to participate, 134 refused, 92 accepted but did not reply, and 66 submitted the survey (reflecting a 22.6% response rate), with one of them excluded due to a history of BC. Therefore, a total sample of 65 women was obtained, of which 2 responses were obtained by telephone and 63 via online forms (Figure 3.2). The participants' characteristics are presented in Table 3.2.

Figure 3.2 Flowchart of participants

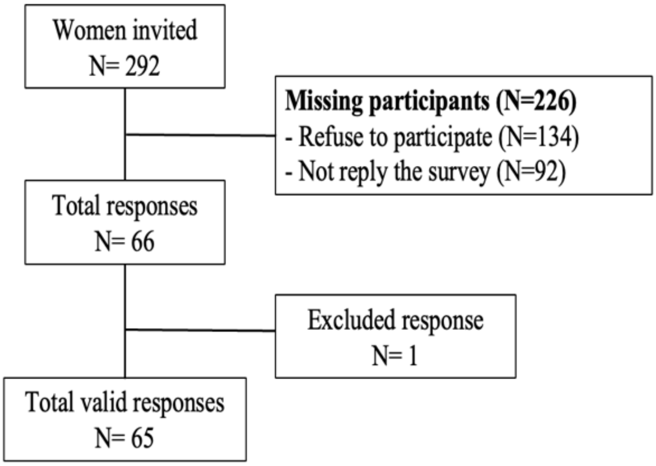

Table 3.2. Characteristics of participants

Characteristic		
Age (years)	56.9	(1.34)
Birthplace		
Spain	57	(87.7%)
Other country	8	(12.3%)
Civil status		
Single	17	(26.2%)
With a partner	48	(73.8%)
Education level		
Primary	18	(27.7%)
Secondary	26	(40.0%)
University	21	(32.3%)
Main occupation		
Unemployed	6	(9.23%)
Paid work	48	(73.8%)
Household chores	11	(16.9%)
Paid work		
No	17	(26.2%)
Yes	48	(73.8%)
Family history of breast cancer		
No	50	(76.9%)
Yes	14	(21.5%)
Unknown	1	(1.54%)
Do you have your mammogram regularly?		
No	11	(16.9%)
Yes	54	(83.1%)

Table 3.2. Categorical variables summarized with frequency and percentage. Age is summarized with the mean and the standard deviation.

4.3.1 Discrete choice experiment results and trade – off

According to the mixed-effects conditional logit model, the weighting for each attribute was estimated using the responses of the 12 tasks. There were no missing values in the answers.

The results show that the attribute '*who makes the decision*' was the only one important to women when considering SDM in breast cancer screening. Women preferred to make decisions alone (coefficient=2.879; 95%CI=2.297, 3.461) or shared decision-making with healthcare professionals (coefficient=2.375; 95%CI=1.573, 3.177), instead of the healthcare professional making it for them (Table 3). The marginal rate of substitution (MRS) between the two levels of who made the decision was 1.21. This meant that women perceive 20% more utility when making decisions by themselves than when they do with a healthcare professional.

The attributes of 'information' and 'dialogue' have no significant results. Therefore, women would be indifferent between receiving information on the benefits and risks of mammography through a leaflet or being informed by a healthcare professional (coefficient=-0.168; 95%CI=-0.665 , 0.329) and having a meeting with a healthcare professional to discuss about their preferences and beliefs for scheduling the next mammography instead of standard screening schedule (coefficient=0.145; 95%CI=-0.373 , 0.663).

Table 3.3. Results from the mixed-effects conditional logit model

Attribute	Levels	Coefficient/SD	SE	p-value
1. How the **information** is obtained	Leaflet	Reference category	-	-
	Healthcare professional, mean	-0.168	0.2536	0.509
	Healthcare professional, SD	1.473	0.3206	<0.001
2. **Dialogue** for mammography scheduled	No, health system schedules mammography	Reference category	-	-
	Yes, women share and discuss with a healthcare professional their beliefs and values about mammography, mean	0.145	0.2645	0.583
	Yes, women share and discuss with a healthcare professional their beliefs and values about mammography, SD	1.371	0.3212	<0.001
3. Who makes the **decision**	The healthcare professional makes the decision	Reference category	-	-
	Shared decision-making by the healthcare professional and the woman, mean	2.375	0.4093	<0.001

Shared decision-making by the healthcare professional and the woman, SD	1.415	0.5208	0.007
The woman makes the decision, mean	2.879	0.2967	<0.001
The woman makes the decision, SD	1.988	0.2626	<0.001

Table 3.3. SD, standard deviation (of the random effects); SE, standard error.

4.3.2 WILLINGNESS TO PAY FOR SDM

More than half of the participants (52.3%) were willing to pay for the SDM process in BC screening; most (38.5%) would be willing to pay between 10€ and 30€, and the rest (13.8%) would be willing to pay 40€ (Table 3.4).

Table 3.4. Willingness-to-pay woman for a SDM in breast cancer screening

Co-payment (euros)	n	%
0	31	(47.7%)
10	6	(9.23%)
20	6	(9.23%)
30	13	(20.0%)
40	2	(3.08%)
60 or more	7	(10.8%)

Two regression models were fitted to the sample of women according to their WTP: those who showed WTP and those who did not (Table 3.5). The results for both subgroups were similar to those obtained for the entire sample. Thus, the attribute ‘who makes the decision’ was the only one important to women regardless of their WTP.

Furthermore, the results for the subgroups show the same trends in women’s preferences about ‘information´ and ‘dialogue’ as in the regression model for the entire sample.

Table 3.5. Results from the mixed-effects conditional logit model stratified by willingness-to-pay

		No willing-to-pay			Willing-to-pay		
Attribute	**Levels**	**Coef./SD**	**SE**	**p-value**	**Coef./SD**	**SE**	**p-value**
1. How the **information** is obtained	Leaflet	Ref.	-	-	Ref.	-	-
	Healthcare professional, mean	-0.323	0.3706	0.383	-0.074	0.3768	0.845
	Healthcare professional, SD	1.537	0.4233	<0.001	1.434	0.4684	0.002
2. **Dialogue** for mammography scheduled	No, health system schedules mammography	Ref.	-	-	Ref.	-	-
	Yes, women share and discuss with a healthcare professional their beliefs and values about mammography, mean	0.187	0.3944	0.636	0.136	0.3825	0.721
	Yes, women share and discuss with a healthcare professional their beliefs and values about mammography, SD	1.599	0.4653	<0.001	1.479	0.4756	0.002
3. Who makes the **decision**	The healthcare professional makes the decision	Ref.	-	-	Ref.	-	-

Shared decision-making by the healthcare professional and the woman, mean	2.220	0.5852	<0.001	2.826	0.6392	<0.001
Shared decision-making by the healthcare professional and the woman, SD	1.449	0.5600	0.010	1.649	0.8826	0.062
The woman makes the decision, mean	2.784	0.4220	<0.001	3.006	0.4328	<0.001
The woman makes the decision, SD	1.803	0.3734	<0.001	2.548	0.4410	<0.001

Table 3.5. Coef., coefficient; SD, standard deviation (of the random effects); SE, standard error; Ref., reference category

4.4 DISCUSSION

4.4.1 Main findings

This study analysed women's preferences for the attributes -information, dialogue, and who makes the decision- of Shared Decision-making in a breast cancer screening programme through a DCE. The main result is that women prefer to make decisions themselves or together with the healthcare professional, but they exclude that the healthcare professional makes it for them. Women perceive 20 percent more efficacy in deciding than in making it jointly with the health professional. More than half of the women were willing to pay for screening with SDM characteristics. There was no difference in the responses obtained between women with a positive WTP and those who did not.

4.4.2 Attributes implications

For the first attribute, ***information***, the women in our study did not show a clear preference for an information leaflet where they were explained in a simple and balanced way the benefits and risks of screening or that this was done by a health professional. The lack of difference between the two alternatives could be related to the fact that women do not perceive a difference in the information received. This fact would be supported by studies such as the one by Longo et al.[19], who performed a DCE to know the SDM preferences of patients in the context of chronic diseases when the doctor was receiving, or not, some training for the use of risk communication tools. They reported that the second most important attribute for patients was that information was easy to understand. Therefore, using a patient decision aid (PtDA) could be adequate according to the preferences of women.

PtDAs deliver balanced information on the risks and benefits of BC screening, which increases informed decision-making (IDM)[31]. In a recent study in Spain[32], 23% of women who received information through this route made informed decisions about their participation in screening, compared to 0.5% in the control group, who only received information attached to the invitation letter by the screening programme. PtDAs would also have the advantage of being repeatedly consulted by women to review information, as opposed to a clinical visit. However, both strategies could be complementary, and PtDAs could prepare appointments for the latter to resolve doubts and review the information contained in PtDAs[33].

Some institutions, such as the NHS Cancer Screening Programmes, have already incorporated the invitation letter for screening a leaflet with information on the explicit need to make a decision: overdiagnosis, the balance of benefits and risk, and scientific uncertainties[34]. Documentation is scarce in our country, and until recently, various programmes have not provided balanced information on the benefits and adverse effects of early detection testing[35].

Conversely, a PtDA could be a good alternative for participants with a higher educational level, which is associated with greater literacy in health. Therefore, a greater ability to understand complex data such as prevalence and absolute risks[33]. It should be considered that the literature also points out that the higher the educational level the higher the interest of an SDM[19] since these have better access to information to be contrasted with the professional[36,37]. This difference may also be due to the type of decisions and contexts. In our particular case, we targeted preventive programmes, and the other studies mentioned were associated with disease processes.

Regarding the second attribute, ***dialogue***, the women in our study were indifferent between attending a presential appointment with a health professional to discuss their beliefs and concerns about participation in the screening or the standard way in which the healthcare system schedules the screening data. These results may be due to the wide acceptance of screening among women, due to the recognised benefits in addition to the minimisation of risks, which have been disseminated by persuasive public health preventive campaigns of different governments. This has led women to unquestionably participate in screening and not necessarily hesitantly discuss the benefits or risks, as well as their beliefs and fears about screening[38].

However, in a study by Longo et al. (2006)[19], the most relevant attribute for patients was their need to feel heard by their physicians, particularly because patients currently report not feeling heard[39]. Thus, communication remains an element to be considered by healthcare professionals when they interact with their patients. Having a receptive attitude, acceptance, not judging, and empathy are the first steps to generate a trusting relationship and thus advance to a more participatory model of health[40]. Without this, it is impossible to know the beliefs of patients and, therefore, encourage them to participate in the process of shared decision-making. This requires training in communication and transversal skills[37].

Conversely, there is a high probability that women already have beliefs or fears about BC, and they want to discuss them with a health professional. In particular, if we consider that having breast cancer and surviving it is not unusual[6], it makes women usually know other women already diagnosed or treated for BC. In our study, one in five women had a first-degree relative with a history of BC. This would increase if it were extended to other affective bonds such as friendships and other familiar or known people. This is an interesting point when you consider personalisation of screening, where women must be assisted by a healthcare professional to determine whether their risk is high, medium, or low, and thus, make recommendations for the frequency of screening in an SDM process[41].

In the third attribute, ***who makes the decision***, women reject a paternalistic health model, in which the healthcare professional or the system makes health decisions on their own. This result is consistent with the current trend of empowering patients and giving them more autonomy in any clinical decision[31,34]. However, this degree of autonomy may be unrealistic because of the lack of knowledge about adverse effects[42]. For example, a recent study indicated that Spanish women have low awareness of overdiagnosis[43,44]. Only 8.1% knew the meaning of overdiagnosis, although it increased to 54.2% in women who received decision aid[44].

In the study by Longo et al.[19], patients preferred to make decisions for themselves or with the health care professional and rejected the decision being made by a professional on their own, which coincides with our results. However, Longo’s study this attribute was one of the least important.

The characteristics of the clinical process are different when it comes to deciding on treatment than when working in an early detection context, where the target population is healthy. An option that has been well evaluated by women in previous studies[45] is to recommend the development of a targeted SDM to specific groups of women, such as women who need more information on the benefits and risks, those who have their first experience in screening, women who have lower educational levels, and those who have a high risk of being diagnosed with breast cancer. All these strongly require face-to-face appointments with healthcare professionals[33,46]. However, the implementation of Informed Decision-making (IDM) for women with a higher level of education and a low risk of being diagnosed with BC would be sufficient, and an appointment with a healthcare professional would not be essential[47]. This second group can be given PtDAs with simple and clear information on screening to make the decision autonomously[31,48,49], which implies a lack of decisión follow-up by the healthcare professional. A study is currently being conducted at the Mayo Clinic to determine whether women's discussion groups for decision-making could be a new line to support and prepare women for deciding on breast cancer screening[50]. This is based on the strategy mentioned above: the PtDAs could be delivered before the clinical meeting, and a conversation with other women about the information provided there would subsequently take place. As such, the appointment between the healthcare professional and the woman would aim only at the resolution of doubts or concerns born from the PtDAs[33].

In conclusion, the results of the DCE allow us to analyse SDM barriers and the difficulties in its applicability[37,51,52]. As such, the main approaches have been developed in contexts where decision-making is particularly difficult[52]. Therefore, there are still few examples of application in primary care, where decisions that could be considered less difficult but not less important for their impact on people's quality of life[48].

4.4.3 Willing-to-pay

The subgroups separating those who were or were not willing to pay showed a preference for making decisions jointly or alone. No studies were found on the WTP for SDM in the context of BC screening. Only one article was found for patients with BC diagnosis, but the results were focused on the WTP according to the type of treatment and not on the SDM characteristics[53]. Another study reported a prostate cancer study in which WTP participants preferred an active versus passive participation model[54].

Regarding the monetary value of an SDM. This can be compared with the results of Wilson et al.54 for patients with prostate cancer in the United States. It was determined that the men had WTP between \$25 and \$50 for the implementation of an SDM[54]. WTP was associated with marital status (single people valued more SDM), stage of SDM (those who were initiating the process of decision making preferred to pay versus those who were close to deciding), and the participation model (more active patients prefer to pay versus passive patients)[54].

In addition, Brito et al. (2020)[55] evaluated patient-reported experiences in the adult population in outpatient care through a DCE, in which SDM characteristics were included. In this case, respondents would pay, on average, €16 for a doctor who provides easy-to-understand explanations in relation to one who does not provide understandable explanations. They would also pay, on average, €20 for physicians who can ask questions or raise concerns, versus physicians who focus on providing information. Finally, they would pay, on average, €22 to physicians who involve the patient in making decisions in contrast to those who make decisions in a one-way manner [55].

Finally, it should be considered that in Spain, screening is fully covered by the National Health System (NHS) for women aged 50–69 years. However, the implementation of SDM could incur additional costs[13], which could be paid by the NHS or by women. In the latter case, the cost of pocket to perform screening is one of the determining elements for adherence to screening[56.]

4.5 PRACTICE IMPLICATION

The change from a paternalistic model to a participatory model of person-centred medicine would require restructuring of the BC screening programme so that women could make informed decisions for themselves or SDM together with the health professional

4.6 LIMITATIONS

The main limitation of the study, which forced us to change the design of the questions, was the difficulty for women to compare hypothetical profiles; we detected difficulties in understanding the differences between the profiles proposed in each choice task. In addition, their ability to detect differences between the 12 questions in the DCE survey was limited. There may be a tendency to choose models that have already been experienced in contrast to other unknown ones, such as the case of SDM.

Finally, it is difficult to precisely determine the availability to pay, since in Spain the screening of BC belongs to the NHS. Therefore, the services are free at the time of receiving them, and the population assumes that this is a consolidated health benefit and does not consider it should pay, more so when screening for other types of cancer (colorectal, for example) is currently being introduced, in which the NHS is strongly promoting.

4.7 CONCLUSION

This is the first study to determine women's stated preferences for BC screening when SDM is applied. Women reject a paternalistic health model and favour one with SDM or a variation of it (IDM). In contrast, more than half of the participants were willing to pay for active involvement in their health decisions.

Future research could include randomised clinical trials, in which women would experience health care with all the attributes that SDM elicits and then analyse their preferences, perceived satisfaction, and profit in contrast to regular attendance, and to identify the costs that the implementation of SDM would entail in the screening of BC for the NHS.

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SHARED DECISION-MAKING IN BREAST CANCER SCREENING PROGRAMMES: CONTRIBUTIONS
TO ITS IMPLEMENTATIONS
María José Hernández Leal

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4.9 ANNEXES

4.9.1 FULL SURVEY WOMEN'S PREFERENCES FOR BREAST CANCER SCREENING

We appreciate your collaboration in the ProShare research project "*The collaboration of healthcare professionals to include Shared Decision Making in the breast cancer screening programme*" (P18/00773), led by Dr. Misericòrdia Carles. This project is supported and funded by the Carlos III Institute of Health and co-financed by the European Regional Development Fund (ERDF) "A way of making Europe" y "European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement" No. 713679 and from the Universitat Rovira i Virgili (URV).

The objective of your participation is to identify women's preferences and determine the cost-benefit of a new care model for the breast cancer screening programme. So, we present you, in two hypothetical options and you must choose only one of them according to your preferences. Consider that there are no good or bad answers.

Your answers will be confidential and will only be used for research purposes. Answer the following questions truthfully, considering that your identity will never be exposed.

Shared Decision-making in Health

1. Socio-demographic characteristics

Name: ____

Age (years):_____________

Bithplace (mark with an X)

	Spain
	Other country

Civil status (mark with an X)

	Single
	With partner

5. Education level (mark with an X)

	Primary
	Secondary
	University

Main occupation (mark with an X)

	Paid work
	Household chores
	Unemployed

Family history of breast cancer (mark with an X)

	Yes
	No
	Unknow

Do you have your mammogram regularly? (mark with an X)

	Yes
	No

2. Experimental design

The next 12 questions will be asked in consultation on three characteristics of the breast cancer screening programme:

1. **How do I receive the information?** You will find two possibilities; in one of them you are informed about the benefits and risks of mammography through a **leaflet** or by **health professional**.

2. Dialogue about my preferences? You'll find two possibilities; in one, you **meet with a healthcare professional** to discuss your preferences, fears, or concerns about mammography. And on the other hand, **the health system** simply programmes its mammography according to its age.

3. Who makes the decision? You will find three options about who makes the decision for attended -or no- to mammography: the **health professional**, **the woman** or **jointly**. Independent if later this is concrete the mammography

In each question you must choose the option you prefer. Each option includes the three features above.

For example:
Question 0: Mark with an "X" the option you prefer

Opción A	Opción B
I am informed by a **healthcare professional** about the benefits and risks, **I also express my fears**, beliefs, or preferences of mammography. Finally, **I myself made the decision** attend -or not- mammography.	I am informed by a **healthcare professional** about the benefits and risks, **I also express my fears**, beliefs or preferences of mammography. Finally, **we jointly made the decision**

	attend -or not- to mammography.

We are aware that in some questions the options may be very similar to you, yet there is always some different characteristics There are no correct or incorrect answers, you should select only based on your personal appreciation.

SURVEY

1: Mark with an "X" the option you prefer

Opción A	Opción B
The healthcare professionals inform me about the benefits and risks; **I also tell them about my fears**, beliefs, or preferences for mammography. Finally, **the healthcare professional makes the decision** attend -or not- to the mammography.	**The healthcare professionals inform me** about the benefits and risks; **I also tell them about my fears**, beliefs, or preferences for mammography. Finally, **I myself made the decision** attend -or not- to the mammography.

2.Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks through a **leaflet**; **I also share with a healthcare professional my fears** or beliefs about mammography. Finally, **we jointly made the decision** attend -or not- to the mammography.	**I am informed by a healthcare professional** about the benefits and risks; **I also express my fears, beliefs,** or preferences of mammography. Finally, **I myself made the decision** attend -or not- to the mammography.

3. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks through **a leaflet**; **I also tell a healthcare professional my fears** or beliefs about mammography. Finally, **the professional makes the decision** attend -or not- to the mammography.	**The healthcare professionals inform** me about the benefits and risks; **I also tell them about my fears**, beliefs, or preferences for mammography. Finally, **I myself made the decision** attend -or not- to the mammography.

4. Mark with an "X" the option you prefer

Opción A	Opción B
I am informed by a healthcare professional about the benefits and risks, but **without the possibility of expressing my fears** or beliefs about mammography as it is defined by the health programme. Finally, **I myself made the decision** attend -or not- to the mammography.	**The healthcare professional informs me** about the benefits and risks**; I also tell them about my fears**, beliefs, or preferences for mammography. Finally, **the healthcare professional makes the decision** attend -or not- to the mammography.

5. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks through **a leaflet**; I also **tell a healthcare professional my fears** or beliefs about mammography. Finally, **we jointly made the decision** attend -or not- to the mammography.	**The healthcare professional informs me** about the benefits and risks; **I also tell them about my fears**, beliefs, or preferences for mammography. Finally, the **healthcare professional makes the decision** attend -or not- to the mammography.

6. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks through **a leaflet**; **I also tell a healthcare professional my fears** or beliefs about mammography. Finally, **I myself made the decision** attend -or not- to the mammography.	**The healthcare professional informs me** about the benefits and risks; **I also tell them about my fears**, beliefs, or preferences for mammography. Finally, **the healthcare professional makes the decision** attend -or not- to the mammography.

7. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks through **a leaflet**; **my mammography is programmed by the health system**, so I do not manifest my fears, beliefs, or preferences about mammography to a health professional. Finally, **I myself made the decision** attend -or not- to the mammography.	**The healthcare professional informs me** about the benefits and risks; **I also tell them about my fears**, beliefs, or preferences for mammography. Finally, the **healthcare professional makes the decision** attend -or not- to the mammography.

8. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks through **a leaflet**; **I also tell a healthcare professional my fears** or beliefs about mammography. Finally, **we jointly made the decision** attend -or not- to the mammography.	**I am informed by a health professional** about the benefits and risks; **my mammography is programmed by the health system**, so I do not manifest my fears, beliefs, or preferences about mammography to a health professional. Finally, **I myself**

	made the decision attend -or not- to the mammography.

9. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks in a **leaflet; I also share my fears** or beliefs about mammography with a health professional. Finally, **I myself made the decision** attend -or not- to the mammography.	**I am informed by a health professional** about the benefits and risks; **my mammography is programmed by the health system**, so I do not manifest my fears, beliefs or preferences about mammography with a health professional. Finally, **I myself made the decision** attend -or not- to the mammography.

10. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks in a **leaflet**; **I also share my fears** or beliefs about mammography with a health professional. Finally, **the professional makes the decision** attend -or not- to the mammography.	**I am informed by a health professional** about the benefits and risks; however I do not manifest my fears, beliefs or preferences about mammography as **it programmed by the health system**. Finally, **I myself made the decision** attend -or not- to the mammography

11. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks in a **leaflet**; **I also share my fears** or beliefs about mammography with a health professional. Finally, **the professional makes the decision** attend -or not- to the mammography	I receive information about the benefits and risks in a **leaflet**; **I also share my fear**s or beliefs about mammography with a health professional. Finally, **I myself made the decision** attend -or not- to the mammography

12. Mark with an "X" the option you prefer

Opción A	Opción B
I receive information about the benefits and risks a **leaflet**; **my mammography is programmed by the health system**, so I do not manifest my fears, beliefs or preferences about mammography with a health professional. Finally, , **I myself made the decision** attend -or not- to the mammography	I receive information about the benefits and risks in a **leaflet**; **I also share my fears** or beliefs about mammography with a health professional. Finally**, the professional makes the decision** attend -or not- to the mammography

3. Cost of health

The breast cancer screening is currently not paid to women, as it is covered by the public health service. Regardless of the current cost, if you had the option of attending a appointment with a healthcare professional to inform you about the benefits and risks of mammography, discuss with him/her your preferences and concerns and jointly make the decision to attend -or not to mammography **How much money would you be willing to pay?**

	0 euros
	10 euros
	20 euros
	30 euros
	40 euros
	60 euros o más

Thank you so much for the time you took to answer this survey to improve women's care in breast cancer screening.

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CHAPTER 5

GENERAL CONCLUSION

The thesis seeks to answer the question: *How to apply a Shared Decision-making in breast cancer screening programme in a context of National Health System be implemented?* The general objective is to determinate the acceptability by health professionals and women of Shared Decision-making and evaluate the possibilities of implementation in breast cancer screening programmes. Based on that, some research was carried out to know the barriers and facilitators of the SDM model in the context of screening programmes[1] to create supporting documentation for the implementation of SDM in breast cancer screening for healthcare professionals[2] and, eventually, to know women's declared preferences for this kind of participative care[3].

5.1 SUMMARY OF MAIN RESULTS

Shared Decision-making has become a framework for encouraging patients' participation in health care[4] and therefore, a practical way to implement a person-centered health system[5]. Even so, evidence is still required where SDM is implemented in various health contexts, being one of them in preventive programmes such as screening for different types of cancer.

There are barriers to the implementation of the SDM in the different international screening programmes, and lack of time continues to be one of the main ones, which has its origin in the health system organisation[1]. However, there is still no consensus on the time required for its implementation.

Therefore, this element is still interesting for research in specific health contexts such as screening, in which patients are healthy, but must make their decision either to have -or not- the preventive screening.

Barriers include lack of skills and tools for healthcare professionals to involve patients in decisions[1]. One possible cause is the clinical guidelines inflexibility, which serves as a benchmark for performance, but they lack components of the patient's participation[1]. However, there is international research on how PtDAs should be incorporated into clinical guidelines[7], specifically the United King's National Health Service has already included PtDAs for breast cancer screening when inviting women to have it[8].

In addition, there are barriers that appear to be more relevant for preventive examinations than for generic health care. The first one is health professionals' fear to receive legal charges for a late diagnosis[6]. This may be because of the increasing judicialization of medical actions, which has led health professionals to take "defensive" care attitudes as a response[9].

Another consequence of judicialization is that, in a preventive way, professionals perform unnecessary examinations, images or tests, generating a greater demand for these services to avoid legal accusations[9]. In contrast, some evidence shows that patients, by feeling committed to the decision in a shared decision-making, tend to reduce this type of legal actions[10].

Otherwise, facilitators strongly fall on patients[1]. They, seeking greater satisfaction from health services, demand better care. Patients are not only interested in a technical and decisive decision regarding their needs, but also, and profusely, in the treatment they receive during the appointment. Considering this, the SDM satisfies technical and treatment elements, and consequently there is a greater predisposition to become involved in decisions about their own health[1]. For this reason, patients should have an active attitude with the professional in their health care and strengthen an active role among elderly people, males, and people with either a lower educational level or a poor socioeconomic one, since these groups are less likely to participate[11].

Moreover, it is important to note that SDM in its application in screening contexts does not aim to increase adherence to screening, but force the decisions made to be consistent between the patient’s preferences and the available options[12]. However, it does not aim to increase adherence to screening, though evidence shows that the implementation of SDM: increases the adherence of screening[13]; provides greater satisfaction with the decision, increases knowledge and decreases the decisional conflict[14].

On the other hand, the analyzed medical history reports that professionals lack tools to incorporate patients in screening decisions[1]. For this reason, and thanks to experts' collaboration, two documents came out for health professionals to facilitate the application of the SDM in breast cancer screening, adapting The Three-Talk model[2]. The first document consisted of a Manual which includes the following sections 1) Introducing concepts of a SDM from its definition, origin, and patients' opinion; 2) Implementing SDM in BC screening using examples of professional-patient dialogues for each stage of the Three-talk model[15], emphasizing the communicative skills to be employed; 3) Self-assessment on how the SDM process has been implemented by health professionals themselves, using the SDM-Q-doc scale. 4) A PtDAs as a complement to the manual, even though, this had been developed in a previous study by the same research team [16]. The second document corresponds to a Guide illustrating on a single page the Manual contents summary, so that professionals can quickly remember the issues to be addressed during the clinical appointment with women[2].

In addition, from women's perspective, in a context of screening `who makes the decision to attend -or not- screening´

is the only significant element from their preferences point of view, which would make them more likely to make the decision, -what would resemble an Informed Decision-making, with a Shared Decision-making healthcare professional; the first option being 20% more useful than the second one[3]. In any case, they rule out the possibility that the healthcare professionals make themselves the decision of screening -current paternalistic health model-. On the other hand, referring to other elements of a SDM, women found irrelevant they are being informed either by an information leaflet or by a health professional. Or whether the mammography was programmed by the health system, or they discussed their beliefs regarding screening with a health professional.

These results show that women are highly aware of taking the preventive examination because of its benefits but, lack a sense of wondering about its adverse effects[17] due to their limited knowledge about them[16]. This, in turn, leads them to think that the decisions about screening are always made by themselves -since they are the ones to attend the health center to be screened-without considering that the first decision was made by screening programmes, when scheduling the appointment without asking them. We can conclude that SDM may be more needed in vulnerable groups or those at high risk for breast cancer, whereas a low-risk population would only need to be provided a leaflet with balanced information between benefits and adverse effects of screening (PtDAs)[18], later implementing an Informed Decision-making[19].

Finally, a 52.3% of women were willing to pay for more personalized care. Being a 38.5% between 10€ and 30€, figures close to those indicated in other studies[20,21].

5.2 POLICY IMPLICATIONS

The results of this thesis show that population screening programmes, such as the breast cancer one, still require greater efforts to make this process more participatory for women, through a Shared Decision-making, included a clinical appointment with a healthcare professional, or initially through Informed Decision-making, in which women are simply given information[19]. For example, it is proposed that healthcare professionals' curricular contents be intensified in the study of practices involving the patient in the clinical decision, and that effective communication methodologies be addressed, transversal skills and ways to integrate the values of the participants[22].

In this regard, the documents produced in the thesis of the Manual and Guide would be complementary material to be used in the training for health professionals. In addition, those documents could be used to improve the training for health professionals in this area. For this reason, the documents will be presented to local health authorities and will be available for those interested in learning about the SDM.

On the other hand, in a parallel way to the development of evidence in the implementation of SDM in breast cancer screening, it should not be forgotten that women have the right to be informed in a balanced way about the risks and benefits of screening, and so make their decision[23].

Screening programmes should therefore include simple information attached to the invitation letters, with PtDAs as an alternative, for they have proved to improve women’s knowledge of screening without being harmful for the current adherence to the programme[14].

In line with the above referred to, there should be an organizational restructuring of the breast cancer screening programme which included a SDM and in this way, focus health care on patients[18]. To do so, a face-to-face clinical appointment between women and a healthcare professional to make the decision jointly would be requested[19]. However, trained personnel, physical space, and availability of time for women to attend these appointments should also be requested[24].

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5.3 LIMITATIONS

These studies have presented different limitations related to the theme or methodology used, which have already been described in each of the chapters. However, we want to highlight some of them as they have special implication for the understanding of the results.

In chapter 2 of the Systematic Review[1] there were very few previous studies on the barriers and facilitators of the implementation of SDM in breast cancer screening and, therefore, the search was extended to the different screening programmes. In this way, we also found a very limited number of studies (only 8 studies). Of these, most had been carried out in early detection programmes for cancer and only one on breast cancer. In addition, six of the eight studies were conducted in the USA and none of them in Spain. These countries have different health systems, since in the USA a private health system predominates whereas in Spain it is mostly public. Therefore, the results found here are not completely transferable as local experiences, but they do allow an approach to understanding the phenomenon from a global dimension.

To write the Manual and Guide[2] the main difficulty was related to access to health professionals, since the rounds of the Delphi were carried out during the pandemic peak, and therefore, these were focused on their roles in clinical care, which caused a delay in getting the results. In addition, this was one of the main reasons, along with the fact that one more round would not provide new information, to close the Delphi survey on the round 3, despite not having reached the predetermined minimum concordance index among participants (Cc>75) in some of the questions. Also, another limitation focuses on the organizational difficulties for the transfer of these results to clinical practice and thus materialize the use of documents in clinical meetings between healthcare professionals and women.

In the last chapter, corresponding to the DCE[3], the survey given to women was redesigned, moving from a conventional script -where each attribute is separated in a structured way with its level- to a more descriptive one -to create a hypothetical case that includes all levels in a single sentence-. This was done after a pilot experience which had revealed the complexity for women to repeatedly compare two situations in which some attributes were repeated, and they found it hard to differentiate the two options from which they had to choose one.

There appeared to be two reasons for this difficulty. The first one is that women are not accustomed to the possibility of a SDM care model since they only know the standard model -appointment programmed by the system according to age-, and therefore, they had difficulty in relating the attributes of a SDM to breast cancer screening. The second one is that women have little knowledge of the breast cancer screening risks while a high awareness of attending screening for its benefits. In this way, women understand that when being sent the invitation for the screening, it is always them who decide to attend it, but never the professional. However, they do not believe that this decision is initially taken paternalistically by the screening programme by telling them when and where to attend the examination without being given any information or their beliefs being incorporated into the process.

5.4. FUTURE RESEARCH

Following the referred limitations, new research perspectives are proposed to improve the participation of women in breast cancer screening.

The first one has to do with studying, in the local context, those elements that incur barriers and facilitators to apply SDM in screening programmes and especially in breast cancer. In this sense, the investigations of the project Personalization of Breast Cancer Screening: Assessing Its Feasibility and Acceptability in the National Health System (DECIDO project), which the Ph.D. candidate has collaborated with, have revealed some of those from the perspective of the health professionals and the health system management, but always related to risk-based screening. Another qualitative research could be carried out exclusively on SDM.

On the other hand, a pilot study with a SDM applied in breast cancer screening is required. It would let evaluate the applicability of the Manual and Guide by healthcare professionals during the clinical appointment, and its impact to involve women in decision-making. For the latter, different tools can be used to measure participation, such as the same SDM-q-doc[25] scale incorporated in the manual or through a non-participant observer with the OPTION-scale[26]. In addition, the pilot project would show the preferences of those women who have already experienced the standard care model in their first mammogram, and who would then take part in a SDM in their second or third mammography; and, in this way, enable to compare the two situations, no longer in hypothetical scenarios (such as the DCE), but based on women's real experiences.

Also related to public policies, and from an economic perspective, the expenses for the Health System when applying the SDM in breast cancer screening are unknown. To this end, work is currently underway on a fourth article exploring these results.

Finally, this thesis has provided scientific evidence that supports the use of more participatory health models in the context of breast cancer screening in Catalonia, which can other way be transferable to similar care models, and thus advance in patient-centered care through practical models.

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CHAPTER 6

OTHER RESEARCH ACTIVITIES

6.1 ACADEMIC BACKGROUND OF THE Ph.D. CANDIDATE

María José Hernández holds a degree in nursing (2016) from the Pontifical Catholic University of Chile (PUC). Prior to her studies in the Doctoral programme at the Department of Economic, University of Rovira i Virgili (2019) she had started research related to Participation in Health.

Thus, in 2016 she began her master's thesis in Nursing at the PUC with the research of *Perception of barriers and facilitators of health professionals* to promote participation through Shared Decision-making at the Family Health Center. As a result, the article *Percepción de los profesionales de salud para la Toma de Decisiones Compartidas en Atención Primaria: barreras y facilitadores* was published in the journal Revista Medicina Familiar (2021)[1].

Between 2016-2017 she coordinated the project FONDECYT 11150227: Developing a comprehensive model of the relationships among expected patient participation in medical decision-making, experienced participation and satisfaction with healthcare for the Chilean population by Dra. Paulina Bravo. As a result, the article *Decisional Conflict in People with Diabetes Mellitus and Arterial Hypertension Users of the Primary Health Care Level of Chile* (2018) was published in the journal Revista Médica de Chile[2].

She also participated as a co-researcher in the FIENF project for the validation of a scale of informed decisions in mammography, which led to the article: *Validation of the Informed Choice instrument to measure the informed decision of mammography in Chilean women users of Primary Care*, published in the Journal Atención Primaria (2021)[3].

Finally, in her role as a research assistant of FONIS SA15i20213: Patient-Healthcare provider in the Chronic Care Model: understanding the load of Treatment and Trust in the relation to enhance self-management the article *Trust in the professional relationship of health and patient* (2020) was published in the journal Revista Cubana de Salud Pública[4].

Once she started the doctoral study programme with the COFUND scholarship, she became a member of the Research Group on Statistics, Economic Evaluation and Health (GRAEES) team, with whom she developed the research of her doctoral thesis. In addition, she became member of the Centre for Research in Economics and Sustainability (ECO-SOS), of the Department of Economics of the University of URV.

6.2 COLLABORATIONS WITH OTHER RESEARCH TEAMS

During her doctoral studying period she has also participated in other research projects.

In the DECIDO project, led by Dra. Montserrat Rué Monné from the University of Lleida and it belonging to our research group (GRAEES), that developed the FIS project P17/00834: Personalization of Breast Cancer Screening: Assessing Its Feasibility and Acceptability in the National Health System. The Ph.D. candidate has participated in discussion groups with health professionals to learn about health professionals and managers' perception on the implementation of a risk-based breast cancer screening, which also included a section incorporating the SDM in this process. As a result of the analysis, a survey was conducted to determine which professional, health system, screening programme and patient's factors influence on the application of risk-based screening.

Given her contribution to the development of both research projects, two articles in which she was co-author have been published: *Views of health professionals on risk-based breast cancer screening and its implementation in the Spanish National Health System: A qualitative discussion group study* (2022)[5] and *Barriers and Facilitators to the Implementation of a Personalized Breast Cancer Screening Program: Views of Spanish Health Professionals* (2022)[6]. Moreover, with this same group, a proposal for the structure of the screening programme and the budget that would involve incorporating a personalized screening with a Shared Decision-making that is directly related to the fourth article being currently drafted at the URV.

In addition, together with the principal investigator of the DECIDO project, she participated in the writing of the article *Advancing Personalized Breast Cancer Screening: The Role of Primary Care*[7] which has been accepted by the Journal Atención Primaria. The article presents clinical trials which evaluate personalized screening effectiveness and studies the effect of informing women of both benefits and adverse effects.

In 2021 she was accepted for a four-month research fellowship at Mayo Clinic. There she is also collaborating in different investigations, which are in progress, and therefore none of them has been published. Among them one scoping reviews *The role of time in the participation of patients in cancer treatment decision-making: A scoping review*, and *The systematic review: Time in the encounter and quality of care*.

On the other hand, she has collaborated in the analysis of data and the drafting of the article for the project *Clinician's Ability to Recognize Financial Toxicity in the Clinical Encounter.* Finally, she is participating in the elaboration of a proposal as co-researcher with Dr. Victor Montori in *Discussion groups for decision-making on breast cancer screening,* to know if the discussion groups among women about to have a mammography would be a decisive support in the Decision-making for breast cancer screening.

Finally, in order to create public policies from a perspective of the user's freedom of choice, she co-wrote the chapter on *Healthcare* in the book Ruta Republicana, elaborated by the Chilean Think Tank Ideas Republicanas (2021)[8].

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