

Decision aid for mammographic screening for women aged 40 to 49

Ferramenta de apoio à decisão no rastreamento mamográfico para mulheres de 40 a 49 anos

Herramienta de apoyo a la decisión de cribado mamográfico para mujeres de 40 a 49 años

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Abstract

Introduction: Breast cancer screening in Brazil is recommended for women aged 50 to 69 years, according to national guidelines for early detection of breast cancer of the National Cancer Institute/Ministry of Health. Although it is traditionally disseminated only as a beneficial practice, scientific evidence points to its complexity and the need to communicate the balance between risks and benefits, especially in younger women. **Objective:** To describe the participatory process of developing a decision aid for breast cancer screening when sought by women aged between 40 and 49 years in Brazil. **Methods:** Qualitative-participatory study that involved nine physicians and 104 women in the development process, following the recommendations of the International Patient Decision Aid Standards, which include four stages: conversation circles, evidence synthesis, and decision aid review and evaluation by physicians and women. **Results:** The decision aid developed is unprecedented in Brazil and all the physicians who used it considered it useful to help the conversation about the risks and benefits of breast cancer screening; 88.9% assessed that the information facilitated understanding — a view shared by 80% of the women — and 77.8% considered that it reduced or did not interfere with the consultation time. The decision aid was later improved with the suggestions. **Conclusions:** The study showed that the decision aid achieved its objective to provide shared decision support and good acceptance between doctors and women.

Keywords: Mammography; Health communication; Breast cancer; Mass screening; Use of scientific information for health decision making.

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Resumo

Introdução: O rastreamento do câncer de mama no Brasil é recomendado para as mulheres de 50 a 69 anos, conforme diretrizes nacionais para a detecção precoce do câncer de mama do Instituto Nacional de Câncer/Ministério da Saúde. Embora ele seja tradicionalmente difundido como prática apenas benéfica, as evidências científicas apontam sua complexidade e a necessidade de comunicar o balanço entre os riscos e os benefícios, sobretudo em mulheres mais jovens. **Objetivo:** Descrever o processo participativo de elaboração de uma ferramenta de apoio à decisão para o rastreamento do câncer de mama quando buscado por mulheres com idade entre 40 e 49 anos no Brasil. **Métodos:** Estudo qualitativo-participativo que envolveu nove médicos de diferentes estados do Brasil e 104 mulheres na etapa de elaboração e 40 na de avaliação da ferramenta, seguindo as recomendações do *International Patient Decision Aid Standards*, em quatro etapas: rodas de conversa, síntese de evidências, revisão de ferramentas e avaliação da ferramenta por médicos e mulheres. **Resultados:** A ferramenta elaborada é inédita no Brasil e todos os médicos que a utilizaram a consideraram útil na conversa sobre os riscos e benefícios do rastreamento; 88,9% avaliaram que as informações facilitaram o entendimento — visão compartilhada por 80% das mulheres — e 77,8% consideraram que reduziu ou não interferiu no tempo de consulta. A ferramenta foi posteriormente aprimorada conforme as críticas e sugestões. **Conclusões:** O estudo mostrou o alcance do objetivo da ferramenta em oferecer suporte à decisão compartilhada e boa aceitação entre médicos e mulheres.

Palavras-chaves: Mamografia; Comunicação em saúde; Neoplasias da mama; Programas de rastreamento; Uso da informação científica na tomada de decisões em saúde.

Resumen

Introducción: El tamizaje de cáncer de mama en Brasil se recomienda para mujeres de 50 a 69 años, de acuerdo con las directrices nacionales para la detección temprana de cáncer de mama del Instituto Nacional del Cáncer/Ministerio de Salud. Aunque tradicionalmente se difunde como una práctica puramente beneficiosa, la evidencia científica apunta a su complejidad y la necesidad de comunicar el equilibrio entre riesgos y beneficios, especialmente en mujeres más jóvenes. **Objetivo:** Describir el proceso participativo de desarrollo de una herramienta de apoyo a la decisión para el tamizaje de cáncer de mama cuando lo buscan mujeres de 40 a 49 años en Brasil. **Método:** Estudio cualitativo-participativo que involucró a médicos y mujeres en el desarrollo de la herramienta, siguiendo recomendaciones el *International Patient Decision Aid Standards*, que recomienda cuatro etapas: círculos de conversación, síntesis de evidencia, revisión de la herramienta y evaluación de la herramienta por parte de médicos y mujeres. **Resultados:** la herramienta desarrollada es inédita en Brasil y todos los médicos que la utilizaron la consideraron útil en la conversación sobre los riesgos y beneficios del tamizaje; el 88,9% evaluó que la información facilitaba la comprensión — visión compartida por el 80% de las mujeres — y el 77,8% consideró que reducía o no interfería en el tiempo de consulta. La herramienta fue posteriormente mejorada con sugerencias. **Conclusiones:** El estudio mostró el alcance del objetivo de la herramienta al dar apoyo a la decisión compartida y buena aceptación entre médicos y mujeres.

Palabras claves: Mamografía; Comunicación en salud; Neoplasias de la mama; Tamizaje masivo; Uso de la información científica en la toma de decisiones en salud.

INTRODUCTION

Breast cancer screening is characterized by performing mammography in asymptomatic women with the purpose of identifying cancer at an early stage to reduce mortality from this cancer.¹ Although mammographic screening is traditionally disseminated as a merely beneficial practice, scientific evidence points out its complexity and the need to communicate the balance between risks and benefits of interventions.^{2,3}

The risks of screening are the frequent false-positive results, which can cause psychological and emotional effects due to the fear of a cancer diagnosis, in addition to further imaging tests and biopsies that will result negative.⁴ There is also the diagnosis of cancers that would not need to be identified, as they are slow growing and do not threaten the woman's life (overdiagnosis), whose treatment may incur harms caused by the therapies used (overtreatment).^{1,5} Another issue is the high number of women to be screened so that death from breast cancer is potentially avoided, especially in younger women, which makes the harms caused by this practice more extensive.^{4,6}

In Brazil, the national guidelines for early detection of breast cancer from the National Cancer Institute/Ministry of Health (INCA/MS) recommend mammographic screening in women aged 50 to 69

years, every two years, due to the more favorable balance between risks and benefits.⁷ However, in 2020, 30% of screening mammograms performed on women in the Unified Health System (SUS) were on women under 50 years of age, 91.3% of them in the age group of 40 to 49 years.⁸

It is believed that the performance of screening mammograms outside the age group is due to the encouragement of medical societies that recommend annual screening for women aged 40 to 49,⁹ as well as civil society organizations and media campaigns, which disseminates the benefits of this practice, without presenting harms to women's health.¹⁰ This disregards the currently valued ethical premise that women must know in advance the implications of screening so that they can make informed choices about undergoing the examination.¹¹

Studies that evaluate the effectiveness of mammographic screening in the age group of 40 to 49 years indicate an increased risk, without conclusive evidence on benefits,¹² further reinforcing the need to involve women in the decision about screening, considering their preferences.¹³ National programs of mammographic screening of different countries offer objective information about the possible risks and benefits of screening so that women can make decisions, highlighting the lack of screening recommendations for women outside the target age group.¹⁴⁻¹⁶

Decision aids are instruments based on scientific evidence that seek to facilitate clinical communication about the risks and benefits of interventions to help people make informed choices about their health.¹¹ They not only provide information, but facilitate the cognitive processes that people use to make a decision.¹⁷ They improve the perception of risk in the face of the intervention, reduce uncertainty and increase the feeling of women's satisfaction by providing greater involvement in decisions about their own health.¹⁸

The shared decision, facilitated by support tools, is characterized by being a collaborative process between the health professional and the individual, who share technical information and individual preferences, to reach the most appropriate clinical decision.¹⁹

It is important to recognize the need for women to know the implications of mammographic screening, especially when requested before the age of 50, a common practice in Brazil. In view of the absence of specific instruments for this purpose in the country, the objective of this study was to describe the participatory process of developing a decision aid for breast cancer screening when sought by women aged 40 to 49 in Brazil.

METHODS

This was a project developed by researchers from a federal public institution specializing in cancer, which sought to develop and assess a tool to assist in the clinical communication of primary health care (PHC) doctors with women who request mammographic screening.

The study was characterized as qualitative-participatory²⁰ and involved doctors and women in the development of the tool, following the recommendations of the International Patient Decision Aid Standards.²¹ The research steps were as follows:

Preparation of the first version of the decision aid

The first version of the tool was based on surveying women's doubts about breast cancer screening and on the synthesis of evidence on the topic:

1. Survey of women's doubts: four rounds of conversations, lasting an average of one and a half hours, were conducted by two authors of this study in 2019, in public and private companies that previously requested educational lectures on breast cancer from the institution promoting the research and authorized it to be done. The women were invited to voluntarily participate in a meeting at the company itself, during the work day. The researchers initially administered a questionnaire with closed and open questions about undergoing breast cancer screening examinations and whether or not they had doubts about the topic, in addition to profile data. After filling it out, the debate began to share doubts, with audio recording, followed by an educational activity. There was the participation of 104 women, approximately 30 of them in each of three companies and 16 in another. The doubts raised in the questionnaire and in the recorded and transcribed debate were systematized and analyzed into three thematic axes: recommended routine, examinations and screening risks.
2. Synthesis of evidence on the risks and benefits of breast cancer screening in women aged 40 to 49 years: it was carried out in line with the systematic review that supported the guidelines for early detection of breast cancer in Brazil and its update, detailed in previous publications.^{7,22} The synthesis followed the same strategy as previous reviews, complementing the period from April 2017 to April 2020. Articles from references and institutions that carry out evidence synthesis on this topic were also analyzed.

The studies that supported the guidelines were evaluated, which covered the age range of 40 to 49 years, and four more systematic reviews, in addition to four articles on radiation in breast cancer screening found in the new search. The analysis addressed the following outcomes: reduction in general and specific mortality due to breast cancer, false-positives, false-negatives, excess tests, overdiagnosis, overtreatment and radiation risks.

To numerically illustrate the risks of screening, the systematic review of the Canadian Task Force was used,²³ as it is the most recent and considered of good quality by the Amstar assessment – A Measurement Tool to Assess Systematic Reviews,²⁴ applied by the two researchers independently.

3. Review of decision support tools for breast cancer screening: a search for these tools was carried out in international institutions and in the Ottawa Hospital's repository of decision support tools — Decision Aid Library Inventory, to evaluate the models and formats. Studies on its effectiveness and development process were also identified.

Assessment of the tool by doctors and women

The tool was evaluated by SUS PHC doctors, during clinical care for women aged 40 to 49 who requested screening mammography.

The doctors were invited by email through the contact network of a distance education course on early cancer detection, developed by the institution promoting the research, whose prerequisite was working in PHC. The invitation presented the research and asked about the interest in using the tool in clinical practice, as well as requesting the recommendation of other doctors.

Invitations were sent to 136 doctors and 31 agreed to receive the tool by email, along with the electronic evaluation form, to be filled out after use in clinical practice. Two contacts two weeks apart were made with participants to monitor use and encourage completion of the questionnaire. No doctor reported

withdrawing from participating in the study, but 22 did not respond to the messages. In the end, nine doctors from five Brazilian states participated in the study.

The tool's assessment form by doctors contained open and closed questions about the quality of the content, format, arrangement of information, clinical applicability and interference in consultation time.

The tool was also evaluated by women aged 40 to 49 via an electronic form. Initially, the assessment would be carried out by a focus group at partner companies; however, due to the limitations imposed by the COVID-19 pandemic, the form was sent to the women via a messaging application mediated by the companies' management. Given the small response, the form was also sent to the researchers' contact network via messaging application, requesting disclosure to women of the age group in question. For this analysis, only women aged 40 to 49 were considered.

The electronic form sent contained the decision aid and open and closed questions about the clarity of information, language, formatting and graphic elements.

Data collection took place from October 2019 to January 2022. For numerical variables, normality was assessed visually using histograms and formally using the Shapiro-Wilk test, using a value of $p < 0.05$ as the cutoff point for statistical significance. For variables with non-normal distribution, the median was calculated as a measure of central tendency and the interquartile range as a measure of dispersion. These analyses were carried out using the R software, version 4.2.2.

For open responses, systematization and identification of thematic axes and suggested modifications to the tool were carried out; all were considered and those that appeared contradictory were defined by consensus after debate among the researchers.

Regarding the participation of the subjects, the design and conduct of the study were carried out by the researchers and the participation of women and doctors took place in the development and evaluation of the decision aid.

The research was approved by the Ethics Committee, under Approval No. 19316719.3.0000.5274, and met all required ethical precepts, including the anonymous disclosure of results. The data collected for this research were used exclusively for these analyses and would not be shared.

RESULTS

The results are presented in the order of the research steps, divided into:

1. preparation of the first version of the tool; and
2. assessment of the tool by doctors and women.

First version of the tool

The majority of women who participated in the conversation circles were under 50 years old (68%), with a median of 39 years old and an interquartile range of 19.5 years old. Around 80% had higher education and health insurance (Table 1).

Among the participants, 85 (81.7%) reported having already undergone a routine examination to identify breast cancer, and 50 of these women were under 50 years old. The most frequently cited tests were ultrasound and mammography, either alone or combined. Chart 1 illustrates the doubts by thematic axes.

Table 1. Profile of women participating in conversation circles on breast cancer, October 2019.

Sociodemographic variables	n	%
Age (years)		
<40	52	50.0
40 to 49	19	18.3
≥50	31	29.8
No information	2	1.9
Education		
Elementary school	1	1.0
High school	22	21.2
Undergraduate	43	41.3
Post-graduate	37	35.6
No information	1	1.0
Health insurance		
Yes	87	83.7
No	17	16.3
Had breast cancer screening tests?		
Yes	85	81.7
No	19	18.3
Total	104	100

Chart 1. Questions from women in conversation circles on breast cancer, October 2019.

Axes	Doubts
Recommended routine for screening	At what age should a woman have a mammogram?
	How often does a woman have to have an examination?
	At what age is it recommended to have a breast ultrasound?
	How many times does a woman have to do a self-examination?
Examinations	What test effectively diagnoses cancer?
	Is there any test that is more accurate than a mammogram?
	Does breast ultrasound replace mammography?
Risks of screening	I heard that mammography has risks. What are they?
	Does the device used for mammograms emit any radiation that is harmful to women's health?
	What is the level of radiation given by the mammography examination?

The synthesis of evidence on mammographic screening in women aged 40 to 49 years, carried out as an update to previous published syntheses, confirmed that there is no satisfactory scientific support for its recommendation, as the risks outweigh the possible and controversial benefits. Screening for this age group remains “not recommended” in most guidelines, with decision support being indicated for women who seek this intervention.

The review of international models of decision aids for mammographic screening compared content and graphic resources used, supporting the formatting of the first version of the tool, submitted for evaluation by doctors and women (Figure 1).

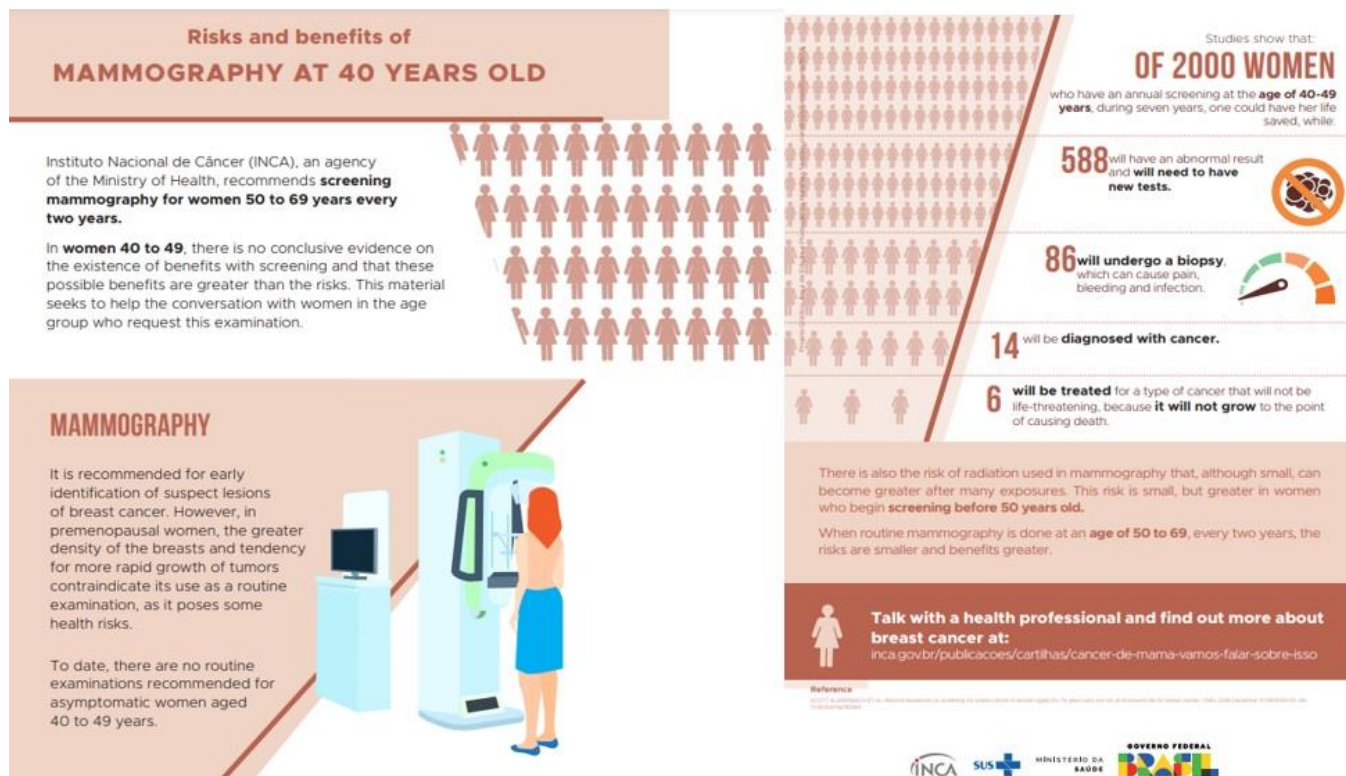


Figure 1. First version of the decision aid for breast cancer screening, front and back, Rio de Janeiro (RJ), 2022.

Assessment of tool by doctors and women

The tool was used by nine doctors, working predominantly in urban areas and with an average time of 10 years working in PHC (Table 2).

The doctors used the tool an average of six times, with a median of 5.5 and an interquartile range of 6.75. The format was rated as excellent and the text size as adequate by the majority (77.8%). The illustrations were considered adequate to communicate the content by 88.9%, as per the comment below

The illustrations are interesting, making the material attractive, but they have little influence on the transmission of the content.

All doctors considered the tool useful in helping to talk about the risks and benefits of screening in women aged 40 to 49 years, and 88.9% said that the information facilitated their understanding of the topic.

Great. I believe it is very valuable to health care professionals who provide direct care to patients.

The tool was used in different formats, with print predominating. Regarding consultation time, the majority said it did not influence it (55.6%), and the others disagreed regarding the increase in time using the tool.

Regarding the risks addressed, the majority considered the material complete, but there were two contrary and contradictory observations:~

Table 2. Profile of doctors and assessment of the form, content and use of the decision aid in breast cancer screening, 2022.

Sociodemographic variables and assessment topics	n	%
Age (years)		
29 to 39	4	44.4
40 to 49	3	33.4
50 to 59	1	11.1
60 and over	1	11.1
Sex		
Female	7	22.2
Male	2	77.8
In which state do you work?		
Rio Grande do Sul	1	11.1
Rio de Janeiro	2	22.2
Paraíba	1	11.1
Bahia	2	22.2
São Paulo	3	33.4
How long have you worked in primary health care? (years)		
Less than 5	3	33.4
5 to 9	0	0
10 to 19	3	33.4
20 or more	2	22.2
No information	1	11.1
Do you work mainly in an urban or rural area?		
Urban	7	77.8
Rural	1	11.1
Both	1	11.1
Do you have a specialization?		
Yes	7	77.8
No	0	0
No information	2	22.2
Area of specialization		
No information	2	22.2
Collective health	1	11.1
Family and community medicine	1	11.1
Gynecology and Obstetrics	5	55.6
On how many women have you used the tool?		
1 to 4	3	33.4
5 to 9	2	22.2
10 or more	3	33.4
No information	1	11.1
What format did you use?		
Printed	5	55.6
Computer screen	2	22.2
Both	2	22.2

Continue...

Table 2. Continuation.

Sociodemographic variables and assessment topics	n	%
Does the information make it easier for women to understand?		
Yes	8	88.9
Partially	1	11.1
No	0	0
How did you evaluate the text?		
Adequate	7	77.8
Insufficient	0	0
Excessive	2	22.2
What did you think of the format of the material?		
Great	7	77.8
Good	1	11.1
Satisfactory	1	11.1
Bad	0	0
What did you think of the illustrations in the material?		
Adequate for communicating content	8	88.9
Indifferent for communicating content	1	11.1
Bad for communicating content	0	0
Does the tool help doctors talk about the risks and benefits of breast cancer screening at ages 40 to 49?		
Yes	9	100
No	0	0
Did the use of the tool influence the consultation time regarding the screening approach?		
Yes, the consultation took longer	2	22.2
Yes, the consultation went faster	2	22.2
No change in time was noticed	5	55.6
Total	9	100

There was a lack of more visual emphasis on the “risks” issue.

The risks are not expressed in a neutral way, leading the patient to not want to have the examination.

There is no mention of the quantitative risk of radiation that they often ask about.

Regarding benefits, 77.8% considered that they were adequately addressed. There was criticism and considerations regarding the inclusion of topics:

Practically no benefit was addressed. The part that mentions the benefit is followed by contraindication in women before menopause.

Disclosure of the number of women who undergo screening, compared to the group who do not do so — these numbers have the “power” to stimulate appropriate decisions and engagement.

There is a popular culture, sometimes reinforced by some “doctors”, that breast ultrasound replaces mammography — I think it is convenient that the material specifically addresses the indication for each examination.

Among the potentialities of using the material, doctors highlighted a greater feeling of security, strengthening of the doctor-patient relationship, greater understanding of the risks for women, scientific support and greater ease in communication:

The patient feels safer with the care planning, because for them everything is a mammogram. Strengthening the doctor-patient relationship with scientific support from a renowned institution and speeding up consultation.

Regarding weaknesses, consideration was given to the extent of the material, partiality, increased consultation time and lack of quantification of the risk of radiation.

Only the consultation time increases a lot. When it comes to care in primary care, on the days of use, my schedule was overloaded with time.

The doctors' suggestions for the material were: reducing the amount of text, adjusting it for viewing on one page, visually highlighting the risks, quantifying the risk of radiation, more neutrality in the presentation of risks and benefits and greater emphasis on benefits.

Assessment by women

The tool's assessment form was answered by 40 women aged 40 to 49 years, with a median of 45 years and an interquartile range of 4.5 years. The majority were residents of the state of Rio de Janeiro, from different professions, with higher education and health insurance (Table 3).

Table 3. Profile of women who assessed the form and content of the decision aid for breast cancer screening, November 2021.

Sociodemographic variables and assessment topics	n	%
Education		
Elementary school	3	7.5
High school	5	12.5
Higher education	32	80.0
Health insurance		
Yes	34	85.0
No	6	15.0
State		
Rio de Janeiro	32	80.0
São Paulo	6	15.0
Goiás	1	2.5
Pernambuco	1	2.5
Did the material help you understand the risks and benefits of screening in the 40 to 49 age group?		
Yes	32	80.0
Partially	6	15.0
No	2	5.0
Did you have doubts about the topic covered		
Yes	13	32.5
No	18	45.0
No answer	9	22.5

Table 3. Continuation.

Sociodemographic variables and assessment topics	n	%
The amount of text was:		
Good	34	85.0
Little text	2	5.0
Lots of text	4	10.0
Were there any words that were difficult to understand?		
Yes	4	10.0
No	36	90.0
Format of material was:		
Good	33	82.5
Indifferent	5	12.5
Bad	2	5.0
Figures/illustrations:		
Adequate and help understand the text	32	80.0
Do not help or hinder	7	17.5
No information	1	2.5
Total	40	100.0

The majority (80%) found that the tool helped them understand the risks and benefits of screening in the 40 to 49 age group, while 15% said they partially understood and 5% said it did not help understanding. Women, even those who positively evaluated the informational support, reported doubts or felt a lack of other information, such as: what is recommended for this age group; the risk of radiation; the possible benefits; family history of cancer; the risks and benefits compared between age groups; and more details about overdiagnosis, as highlighted below.

For those who are not yet 50 years old, what is recommended?

How much radiation comes from a mammogram compared to an X-ray?

I thought there was a lack of more information, especially about women who would be treated for a cancer that would not pose a risk. How so? And if it evolves?

For 85% of women, the amount of text was good, while 10% thought there was too much text and that the words difficult to understand were “screening” and “false positive”.

The format of the material was evaluated as good (82.5%), indifferent (12.5%) and bad (5%) due to excessive text. The majority (80%) considered that the illustrations were adequate and helped to understand the text. Suggestions for improvements regarding the format included the instrument having only one sheet, using more attractive colors, having a greater number of illustrations and using photographs instead of drawings.

Some women found the content of the tool strange, as they had never accessed information about the risks of mammographic screening, at the same time as they observed frequent medical requests for routine examinations outside the target age group. The statements also showed a certain impotence in the face of this practice:

(...) *the information differs from what I knew until now.*

Why do doctors, to this day, prescribe such examinations even though they know their harm?

When your doctor prescribes it, even without you having any symptoms. What should I do?

Most of the suggestions highlighted in the study (Table 4) were incorporated into the final version of the decision aid (Figure 2). Contradictory suggestions were arbitrated by the researchers and those that were unfeasible, within the limits of the material, were not accepted.

Table 4. Summary of modifications to the tool based on analysis of suggestions from doctors and women.

Suggestions	Changes in final version of the tool
Tell us more about the benefits	The role of mammography detection in favoring treatment was introduced.
Quantify radiation risks	Inserted a comparison of risk between the target age groups and women aged 40 to 49 years.
Make it clearer what is recommended for those who are not yet 50 years old	Emphasis was placed on early diagnosis.
Clarify the words screening and false-positive	The word screening was replaced by routine examination. The word false-positive was kept, as it is explained in the text.
Talk about family history of cancer	The caveat is inserted that the material is for women without high risk for breast cancer and also the high-risk criteria.
Reduce text and format it more attractively	Text reduced and laid out on a single page, with brighter colors.

RISKS AND BENEFITS MAMMOGRAPHY AT 40 YEARS OLD

Instituto Nacional de Câncer (INCA), an institute of the Ministry of Health, recommends **screening mammography for women 50 to 69 years every two years**.

In **women 40 to 49**, there is no conclusive evidence on the existence of benefits with screening and that these possible benefits are greater than the risks. Therefore, INCA recommends not to offer screening to these women.

This material **seeks to help the conversation with women** in the age group who request this examination.

* Information at: www.inca.gov.br/tipos-de-cancer/cancer-de-mama/profissional-de-saude

Mammography
It is recommended for early identification of suspect lesions of breast cancer. However, in premenopausal women, the greater density of the breasts and tendency for more rapid growth of tumors contraindicate its use as a routine examination.

Studies show that:
OF 2.000 WOMEN who have an annual screening at the age of 40-49 years, during seven years, **one could have her life saved**, while:

- 588** will have an abnormal result and will need to have new tests **that do not confirm cancer** (false-positive results).
- 86** will undergo a **biopsy**, which can cause pain, bleeding and infection.
- 14** will be diagnosed with cancer.
- 6** will be treated for a **type of cancer that will not be life-threatening**, because it will not grow to the point of causing death.

There is also the risk of radiation used in mammography which - even small - can cause breast cancer after a long time. It is estimated that the risk of mammography causing cancer over time is five times greater in women who have a routine annual mammogram starting at 40 years old, compared to women who have the examination every two years starting at 50.

When routine mammography is done **at an age of 50 to 69**, every two years, the risks are smaller and benefits greater.

Talk with a health professional. To find out more about breast cancer, access:
www.inca.gov.br/publicacoes/cartilhas/cancer-de-mama-vamos-falar-sobre-isso

© KLARNSBACH, S. et al. Recommendations on screening for breast cancer in women aged 40-74 years who are not at increased risk for breast cancer. *CMAJ*, v. 190, n. 49, Dec. 2018. DOI:10.1503/cmaj.180463.
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INCA SUS GOVERNO FEDERAL

Figure 2. Decision aid for breast cancer screening, Rio de Janeiro (RJ), 2022.

DISCUSSION

The initial survey showed many doubts among women about breast cancer screening, which can be explained by controversies in recommendations and practices in Brazil, as demonstrated in the analysis of media messages in the Pink October campaign¹⁰.

When evaluating the tool, most doctors considered the format to be excellent and found that the information facilitated understanding of the topic, and all considered it useful for clinical communication. As for consultation time, most said it had no influence. Most women were unaware of the risks of screening and 80% rated it as informative.

The doctors' mostly favorable opinion about the tool was due to them feeling backed and supported to communicate in more depth a technical-scientific recommendation that is often mistakenly interpreted as a denial of access and the right to preventive examinations. Some authors stated that defensive medicine is one of the determinants of the high prevalence of screening in young women in Brazil and that it has even been explicitly used as a way to increase screening prescriptions in the country.²⁵

In a preliminary evaluation in the American context, DuBenske et al.²⁶ also observed a positive perception among PHC doctors with the use of a decision aid and all reported a change in the way they communicate about breast cancer screening, which is now considered more open, personalized, evidence-based and structured. On the other hand, a doctor's opinion that the benefits should be more highlighted in the tool probably reflects the influence of guidelines from medical societies, which promote the benefits of screening before the age of 50,⁹ without considering its risks, among other factors.

Different perceptions regarding the impact on consultation time must be evaluated on a larger scale, but it is urgent to reaffirm the need for adequate consultation time in PHC, considering its educational role. The variation in time spent and the concern about adding time were also observed in the study by DuBenske et al.²⁶ but were not correlated with decisional conflict. According to the authors, time depends on other variables and greater familiarity with the instrument may make its use faster.

For women, a favorable view also prevailed that the tool contributed to understanding the information. The doubts and strangeness regarding the content revealed a scenario of continued lack of knowledge about the risks of carrying out routine examinations to detect breast cancer, which also reflects the national scenario of absence of this debate and the lack of dialogic stance of professionals in this regard,¹² as highlighted by Shimizu Filho et al.²⁷ The widespread lack of knowledge on this topic was also highlighted by Colombo et al.²⁸ in the evaluation of a decision aid in Italy.

Decision support tools for breast cancer screening have been the subject of research in several countries²⁹⁻³¹. Systematic reviews seek to assess the quality of tools based on international quality standards³², to evaluate characteristics and outcomes,³³ impact on young women's intention to participate in screening⁴ and effectiveness in promoting informed decision and satisfaction with the decision.^{17,34} Knowledge, values, attitudes and intention to screen are dimensions explored in several studies. In general, these tools increase knowledge and informed decision-making, and the results regarding women's inclinations to screen are heterogeneous.^{20,33} The complexity of the topic is also highlighted, especially the concept of overdiagnosis, which is considered difficult to communicate, but is central to understanding the risks.¹³ Added to this is the existence of divergences in the way overdiagnosis is calculated and its underestimation in modeling studies and clinical trials.^{5,35}

The discrepancy between the stage of international production and the Brazilian experience emphasizes the need to move forward from the process of developing the tool, presented here, to the implementation phases. Using the tool will make it possible to dialogue about the risks and possible benefits of screening in light of the growing international literature. Due to the balance between risks and possible benefits of this practice,²³ it is expected that the majority of young women will not opt for screening when well informed, but prior information, degree of understanding of the material and individual values and preferences of the woman and the doctor must play an important role in the final decision, in addition to scientific evidence.²⁵

Involving the target audience in the development of decision aids is one of the internationally recommended quality criteria²¹ and is close to the perspective of shared production in health educational practices in Brazil.³⁶ The use of these tools is still innovative in Brazil, with little previous experience,³⁷ such as a tool for shared decision-making in prostate cancer screening.²⁰

The limitations of the present study were related to the evaluation of the tool, with the replacement of conversation circles with an electronic form in the COVID-19 pandemic, as well as the small participation of women with low education and lower socioeconomic status. The credibility of the proposing institution can also have induced possible positive inclination of doctors towards the tool. However, this influence is inherent to the process.

The strength of the work is its pioneering spirit, which covers a gap in breast cancer screening in Brazil, and its participatory methodological process with listening to those involved, providing improvements to the tool.

Implications for professional practice

The contribution to clinical practice is to provide a decision aid for use in PHC that helps communicate the implications of breast cancer screening in women under 50.

It is hoped that the study presented will stimulate frank debate on mammographic screening, increasingly assumed as an ethical precept of health practices in a scenario of uncertainty. Decision aids can help women exercise their right to autonomy in decisions that affect their bodies and health.

Once implemented, the perspective is to evaluate the applicability of the tool in a more comprehensive way and to understand the perception of women with different levels of health literacy about the impact of its use on the decision about breast cancer screening. The tool is available at: www.inca.gov.br/mama.

CONFLICT OF INTERESTS

Nothing to declare.

AUTHORS' CONTRIBUTIONS

ROMS: Project administration, Formal analysis, Conceptualization, Data curation, Writing – original draft, Writing – review and editing, Investigation, Methodology. MA: Formal analysis, Conceptualization, Data curation, Writing – original draft, Writing – review and editing, Investigation, Methodology, Supervision. AM: Formal analysis, Writing – review and editing, Methodology, Supervision,

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