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# BMJ Open What do women and healthcare professionals expect of decision aids for breast cancer screening? A qualitative study in France

Aïm-Eusébi Amélie <sup>1</sup>, Yannick Ruelle <sup>2,3,4</sup>, Bernard Frèche,<sup>5</sup>  
Mélodie Houlemare,<sup>2</sup> Aurélie Bonillo,<sup>5</sup> Laurie Bouaziz,<sup>1</sup> Cédric Rat,<sup>4,6,7</sup>  
Xavier Gocko,<sup>4,8,9,10</sup> Catherine Cerisey,<sup>3</sup> Isabelle Aubin-Auger,<sup>1</sup> Emilie Ferrat<sup>4,11</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr Aïm-Eusébi Amélie;  
[amelie.aim-eusebi@u-paris.fr](mailto:amelie.aim-eusebi@u-paris.fr)

## ABSTRACT

**Objective** Breast cancer screening decision aids (DAs) are designed to help women decide whether or not to participate in mammography-based programmes. We aimed to explore women's and healthcare professionals' expectations of a breast cancer screening DA, as part of the French DEDICACES study.

**Methods** This French qualitative study was based on semistructured, individual interviews with women from the general population, general practitioners (GPs), midwives, gynaecologists, radiologists and screening centre managers. Sampling was purposive and used diversification criteria. The inductive analysis was based on grounded theory.

**Results** Between April 2018 and May 2019, we interviewed 40 people: 13 women, 14 GPs, 4 gynaecologists, 3 midwives, 3 radiologists and 3 screening centre managers. The women and the healthcare professionals considered that a DA could help to improve levels of knowledge, harmonise medical practice and provide reliable, comprehensive information. Overall, the interviewees wanted an easy-to-use, intuitive, graphic-rich, interactive, computer-based, patient-centred DA. Use of the DA might be limited by a lack of familiarity with shared decision-making (SDM), the risk of misuse and a preference for asymmetric positive information.

**Conclusion** The present results are likely to facilitate the development of the first validated tool for SDM support in French breast cancer screening programmes.

## BACKGROUND

Breast cancer is the most common cancer worldwide and constitutes the leading cause of cancer death among women.<sup>1</sup> Most European countries organise mammogram-based breast cancer screening programmes.<sup>2</sup> The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis indicate that a significant decrease in breast cancer mortality requires a participation rate of at least 70%.<sup>2</sup> In France, free organised screening every 2 years has been available (for women between the ages of 50 and 74)

## Strengths and limitations of this study

- Qualitative study, inspired by grounded theory, that complied with the Consolidated Criteria for Reporting Qualitative Research throughout the study.
- The interview guides explored perceptions, attitudes and expectations related to breast cancer, diagnosis, prevention, screening and the decision aids.
- The data were provided by individual interviews in a diverse sample of both women and healthcare professionals.
- The degree of literacy of interviewed women was insufficiently assessed.
- Several experienced researchers triangulated the data.

since 2004. A prescription from a general practitioner (GP) or another physician is not required for screening; women can be screened by a radiologist on presentation of an invitation sent by the local screening coordination centre. However, the participation rate in France's organised screening programme was only 50% in 2018.<sup>3</sup> Even though the results of large, randomised, controlled trials have highlighted a significantly lower breast cancer mortality rate among women undergoing regular mammogram screening,<sup>4-6</sup> the risk-benefit balance is subject to debate.<sup>7,8</sup> It has been suggested that shared decision-making (SDM) can help women to weigh up the known benefits and risks of breast cancer screening.<sup>9-12</sup>

By providing information on options and outcomes, decision aids (DAs) can help women to decide whether or not to participate in breast cancer screening. A recent review reported that people exposed to DAs feel more knowledgeable, better informed and clearer about their values and they probably have a more active role in decision-making

and more accurate risk perceptions.<sup>13</sup> DAs therefore support the SDM. France currently lacks a breast cancer screening DA that women can use when consulting a visit with their health provider. The French ‘*Décision Partagée dans le Cadre du Dépistage du Cancer du Sein*’ (DEDICACES) study aims at building an online DA for SDM in breast cancer screening that can be used by both women and healthcare professionals preferentially during a consultation, in compliance with the International Patient Decision Aid Standards.<sup>14</sup>

## OBJECTIVE

The objective of our study was to explore women’s and healthcare professionals’ expectations of a breast cancer screening DA.

## METHODS

### Study design

This qualitative study, inspired by grounded theory, was based on semistructured, individual interviews of women, GPs, midwives, gynaecologists, radiologists and local screening programme managers in three areas of France (the *Oise*, *Val d’Oise* and *Alpes de Haute-Provence* counties). We perform individual interviews because cancer is a delicate subject for some people. Interviews were conducted in French—the mother tongue of all participants. The team of investigators was composed of eight researchers, females and males, trained to

lead interviews and perform qualitative analysis (A-AE, EF, BF, AB, MH, LB, IA-A and YR). All semistructured interviews were led by an investigator. MH and AB led women’s interviews; AB and MH led GP’s interviews and LB led healthcare professionals’ interviews.

### Participant sampling

The interviewed GPs were recruited from a list provided by the French national public health insurance system (CNAM). The women were recruited by snowball sampling or through their GPs (but not those interviewed for the study). Other healthcare professionals were recruited using snowball sampling. Sampling was purposive for all types of participants. Nobody refused to participate. Diversification criteria were applied in order to obtain a broad range of participants and points of view. Diversification criteria were discussed with the research team for all participants and were completed during data collection (table 1). Each interviewee gave her/his verbal and written informed consent prior to inclusion.

### Data collection

Audiotaped, semi-structured interviews were held face-to-face at the healthcare professional’s office or at home. One of the midwives and one of the screening programme managers underwent a phone interview.

The interview guides, developed by the investigators, were similar between the groups interviewed but each had some specificities. They explored perceptions,

**Table 1** Characteristics of the study participants

Participants	All participants (n=40)	Women (n=13)	GPs (n=14)	Other healthcare professionals* (n=13)
Age mean (range)	53.9 (29–75)	62.9 (42–75)	49.6 (34–68)	49.1 (29–70)
Gender				
Female, n (%)	29 (72.5)	13 (100)	8 (57.1)	8 (61.5)
Practices (n=27)				
Group	18	–	8	10
Solo	9	–	6	3
Educational level				
Primary school	2	2	0	0
Secondary school	7	7	0	0
Higher education	31	4	14	13
Area				
Rural	8	3	5	0
Semirural	10	6	4	0
Urban	22	4	5	13
Previous mammography (Y/N)	–	8/5	–	–
History of breast cancer (Y/N)	–	2/11	–	–
Interview mean duration in minutes (range)	55 (7–120)	69 (27–120)	69 (41–118)	27 (7–57)

\*Gynaecologists, midwives, radiologists screening and programme manager. GPs, general practitioners.

attitudes and expectations related to breast cancer, diagnosis, prevention, screening and the DA. In the second part of the interview, published DAs were shown as examples.<sup>15–21</sup> This enabled participants to state their opinions and expectations with regard to these tools and to describe the tools' strengths and limitations. Field notes were made during and after the interviews. A woman with history of breast cancer helped to build the interview guide of women's and GPs' groups and pilot tested it. The interview guide evolved during the study (online supplemental tables S1–S4).

### Data analysis

All interviews were transcribed verbatim and subjected to an inductive analysis based on grounded theory to analyse social interactions.<sup>22</sup> Next, the interview data were coded jointly by two pairs of investigators (MH+AB, A-AE+LB) and, in order to enhance inter-coder reliability, individually by four other investigators (BF, EF, YR and IA). We used MAXQDA software (V.12, VERBI Software, Consult-Sozialforschung GmbH, Berlin, Germany) for the analysis. Similarities and differences in the codes from the interviews were assessed and discussed by all the investigators until a consensus was formed. Data collection was achieved for each kind of participants after two interviews without new codes.

### Patient involvement

A patient was involved in the design of the study. She was a woman with history of breast cancer and helped to build the interview guide of women's group. She also participated in the evolution of the guide throughout the study. She had access to the results of the study.

## RESULTS

Between April 2018 and May 2019, we interviewed 40 people: 13 women, 14 GPs, 4 gynaecologists ('G' in the verbatim below), 3 midwives (M), 3 radiologists (R) and 3 screening programme managers (table 1). The mean duration of the interviews was 55 min and 27 s. We used the term 'healthcare professionals' to describe the GPs, gynaecologists, midwives, radiologists, and screening programme managers.

### Purpose of the tool

Women saw the tool as an aid to understand breast cancer screening.

It would be great to have information about breast cancer: things would be clearer for us. (Women 3)

Healthcare professionals expected the DA to improve their own level of knowledge about breast cancer and breast cancer screening.

I need objective data that I can rely on when discussing screening with women. (GP 6)

Healthcare professionals were interested in a tool that could help them to harmonise their practice with regard to breast cancer screening.

It would be great to have that sort of tool. It would help to harmonise things. (Midwife 3)

The interviewees stated that the decision support tool had to encourage women to visit their doctor and discuss breast cancer screening or to go to a local screening programme centre.

An information poster might prompt women to consult their doctor. (Woman 1)

[An information leaflet] would be useful if women have questions about mammography and breast cancer screening; they could discuss things with their GP. (GP 5)

### What kind of DA do people want?

#### The DA's characteristics

The women and the healthcare professionals wanted the DA to be quick to access and easy to use and understand DA.

It has to be easy, visual, and simple [...] – I'd rather have that sort of tool. (GP 10)

The information has to be concise because otherwise we'll throw it away [...]. It would be better to stick to something short and well targeted, with eye-catching stuff... (Woman 4)

The interviewees expected to have an intuitive tool with diagrams and graphics—something that was almost 'fun' to read. The healthcare professionals wanted the statistical information to be of value for the women.

It's good because there are different sorts of information - numbers but also diagrams; Visual things like that are more meaningful (Woman 6)

The women and the healthcare professionals also wanted a tool that was designed for all women, regardless of the latter's level of literacy.

Screening programs are intended to reduce social inequality, rather than increase it. (Manager 3)

The tool's characteristics will depend on who it's targeting. It depends on each woman. (Woman 4)

#### The medium used for the DA

The women and healthcare professionals suggested that the DA was best presented on a computer or a smartphone or, failing, that on paper (ie, a leaflet or poster). A video format might be of value for a DA on a computer or a smartphone.

The GPs suggested using the DA as a video or poster to disseminate the information in the medical waiting room. They also suggested that the tool could be directly integrated in their medical software.

It has to be something visual, something integrated into software. [...] It needs to be easy to access. (GP 4)

### Dissemination of the DA

The healthcare professionals suggested that the DA could be shared over the internet.

These days, having an instructive website would be more relevant than handing out leaflets. (Midwife 1)

The interviewees stated that word of mouth was also the best means of hearing about the tool. They also reported it would be interesting to use the media and social networks to present the tool.

It's important that someone talks to me about the tool. (Woman 2)

### Use of the tool

The women and the healthcare professionals agreed that the DA could be a useful lever for discussion during normal consultations or dedicated meetings.

It might also help me to answer questions. (GP 6)

Maybe it would help. It might have an influence and prompt the patient to ask questions that she wouldn't otherwise. (Woman 7)

If it's during a meeting, we can put the figures on the screen. But then you have to have a discussion; if the woman has questions, you can explain why the information is presented this way. (Manager 1)

For health professionals, their help in commenting and discussing the tool with women is indispensable.

The women were interested in receiving this type of information, along with explanations from their GP. However, they wanted to have the choice to use it or not with their doctor (table 2).

We have an informal discussion, we can... pass on messages... And then make a decision, saying I'm going or I'm not going. I weigh the pros and cons, that's it." (Woman 3)

### Disagreements about the tool: balanced or biased information?

#### Opinions on breast cancer screening

The participants pointed out the suboptimal effectiveness of breast cancer screening because of the harms associated with overdiagnosis and overtreatment.

What surprised me was the ability to diagnose something that wasn't there and treat someone who didn't need it. (Woman 12, before the presentation of the tools)

I am devastated by the results of the mammogram. Despite the double reading which I was inclined to give credit to... (GP 3, before the presentation of the tools)

**Table 2** Consensus representations

Women	Healthcare professionals
<b>Purpose of the tool</b>	
To understand screening	To complete their knowledge
	To harmonise screening/professional practice
To prompt women to visit their GP	To refer women to their doctor
<b>Characteristics of the tool</b>	
With concrete numbers	Give statistical information to women
Easy to understand	Easy to use
Adaptable to different women's profiles	Design for every women
Presence of diagrams	Digital tool
<b>Use of the tool</b>	
A lever for discussion if desired by the woman	A lever for discussion
Have the choice to use it or not with their doctor	The health professional is essential to use the tool

GP, general practitioner.

On the other hand, overtreatment could be seen as acceptable either because it applies to small tumours treatment or because it could save lives.

They are cared for anyway, it's not useless... (Woman 9, after the presentation of the tools)

I don't play the game of overdiagnosis. [...] Honestly, I don't believe in overdiagnosis. (Radiologist 3, before the presentation of the tools)

Sometimes it is even difficult for professionals to distance themselves from their personal experience.

If it's someone in my family or even me personally, I'd rather know about something and do a biopsy for nothing. (Gynaecologist 4, before the presentation of the tools),

Some participants considered the benefit–risk balance favourable, while others found it questionable. In this second case, the attitudes towards the tool differed according to the participants.

### Shared decision-making

Many of the interviewees were not familiar with the concept of SDM in medicine.

I didn't really have time to understand everything about this idea of shared decision-making... (Woman 5)

Support for shared decision-making? What's that? (GP 5)

Some midwives and GPs were in favour of sharing comprehensive, balanced information about screening with women. Hence, DAs could be of value to these healthcare professionals in their daily practice. The healthcare professionals considered themselves to be 'screening guides'; they wanted to provide women with reliable scientific data and enabling them to make an informed choice. Indeed, the healthcare professionals wanted to set out the facts and then accept the woman's decision. Furthermore, some of the women actively asked to receive comprehensive information from the healthcare professional so that they could decide for themselves whether or not to be screened.

I explain things but will never force anyone to be screened - if they don't want to, it's their choice. [...] It really is a shared decision and a mutual agreement with the patient. (Midwife 2)

It also depends on the cultural level, we will not work in the same way with a teacher, a nurse, or a woman who lives in the depths of her countryside. (GP 4)

The doctor needs to explain (the screening) properly. I want to be able to weigh up the positive and negative aspects. (Woman 6)

#### Asymmetric information/paternalistic model

Some women wanted their physician to help them to understanding information about screening at every step in the process. Some women asked for selective information but considered that it was not up to them to decide whether or not to go for screening. Other women were afraid of receiving screening results; this is why they did not want to know everything about screening and the risks of cancer in particular.

You can't let us choose because we don't understand anything about being screened or not (Woman 2, after the presentation of the tools)

Some GPs, gynaecologists and radiologists had the same view about asymmetric information provision, with a focus on the benefits of screening. They considered that giving selected, positive information to women was essential for avoiding fear of screening.

We have to explain things quickly and only go into detail if they ask for more information. [...] I don't know whether giving lots of impartial information is part of being a physician and above all part of making a diagnosis. (Radiologist 3, after the presentation of the tools)

If I tell them to get screened, they'll go without any hesitation. (Gynaecologist 1, before the presentation of the tools)

#### Convincing women to participate in screening

Some women thought the tool had to help healthcare professionals to convince everyone to participate in the screening. Similarly, some healthcare professionals stated

**Table 3** Dissenting representations

Women	Healthcare professionals
<b>Balanced or biased information?</b>	
Shared decision-making: free decision to participate in screening or not after receiving appropriate information	Shared decision-making: state the facts in a neutral manner and let the patient decide whether or not she wants to participate in screening
Paternalistic model: the doctor has the knowledge and must tell the women what to do	Asymmetric information: convince the patient to participate in organised screening because of the responsibility of knowing as a health professional
Lack of interest for such a tool in view of the sufficient data already available	No need for such a tool

that convincing women to enter a screening programme was the most important objective. They wanted to reassure women so that they would want to be screened (table 3).

Providing women with information is essential for motivating them to get screened. (GP 4, before the presentation of the tools)

Perhaps some women think of having a mammography without being prompted but not me - I wouldn't think of it. But if my doctor suggests it, I'll go! (Woman 2, before the presentation of the tools)

## DISCUSSION

### Summary of the main findings

Both the women and the healthcare professionals stated that a DA could help to improve knowledge, harmonise medical practice and provide reliable, comprehensive information. They expected the DA's to catalyse discussion between the patient and the physician during a consultation. Women and healthcare professionals wanted an easy-to-use, intuitive interactive computer-based DA, with diagrams and graphics. Some of the healthcare professionals and some of the women wanted a DA that leads to SDM. Our study highlighted several limitations to the tool, such as a lack of familiarity with SDM, the risk of misuse (ie, convincing women to participate in a screening programme without engaging an SDM process) and a preference for asymmetric, positive information.

### Study strengths and limitations

The study had a number of strengths. First, the investigators complied with the Consolidated Criteria for Reporting Qualitative Research throughout the study.<sup>23</sup> Second, the data were provided by a diverse sample of both women (including socioeconomic level) and healthcare professionals; given that the risk-benefit balance for breast cancer screening is currently unclear, SDM appears

to be the most ethical approach.<sup>11</sup> Third, the data were triangulated by several experienced researchers. Fourth, the samples of women and healthcare professionals were particularly diverse. Fifth, nobody refused to participate to the study; we think that snowball sampling was a good way to engage participants.

However, we insufficiently assessed the degree of literacy of interviewed women. Only one woman answered 'no' to the question designed to explore the level of literacy 'Do you need someone to help you understand prescriptions or medical information documents given by your doctor or pharmacist?' In the future, this may be important for adapting the DA for use with women of different literacy levels.

### Comparison with the literature data

As mentioned above, the women interviewed in the present study here knew little or nothing about SDM. When the concept was explained, however, some women thought that it was of value. Similarly, a qualitative study of a DA for breast cancer screening in Spain found that women valued the receipt of information on the benefits and risks of screening.<sup>24</sup> This seems to be true for all women, even though SDM interventions tend to benefit disadvantaged women (eg, those with a lower level of literacy) more than those with higher literacy or educational/socioeconomic status.<sup>25</sup> Becoming better informed might mean women are less likely to choose screening.

There is a growing body of evidence to show that DAs can improve value-congruent choices. In our study, the perception of screening seems to be modified by the presentation of the tools. Indeed, participants tend to cite the harms of screening more often after the tools have been presented to them. On the contrary, the presentation of the tools may have strengthened some participants in their conviction that screening was essential and its value indisputable. The latter found it questionable to tell women about the adverse effects of screening as this could reduce their motivation to undergo screening. These data are consistent with the literature. When compared with standard care in a broad variety of decision contexts, women exposed to DAs feel more knowledgeable, better informed, and clearer about their values; as such, they probably have a more active role in decision-making and a more accurate perception of risks.<sup>13</sup> Breast cancer screening DAs are known to improve levels of knowledge and promote informed decisions.<sup>10</sup> For this reason, DAs do not necessarily increase screening participation rates.<sup>26</sup> For example, the large-scale DECIDEO study of breast cancer screening demonstrated that exposure to the DA reduced the participation rate by almost 2% because the women felt better informed.<sup>17</sup> The above-mentioned Spanish qualitative study found that the provision of information on overdiagnosis is controversial among healthcare professionals.<sup>24</sup> An Australian study about overdetection in breast cancer screening recommended a staged approach to development and

piloting of DAs to further improve understanding of overdetection and support informed decision-making about screening.<sup>27</sup> The creation and deployment of a DA tool must therefore be accompanied by training for healthcare professionals on SDM.

Several studies have evaluated quality criteria for DAs and the pitfalls to be avoided when designing this type of tool. A review on risk communication developed decision box prototypes, presented them to focus groups of GPs and patients, and explored the participants' perceptions.<sup>28</sup> The model explored seven facets of the user experience: the DA had to be useful, usable (with effectiveness, efficiency and satisfaction), desirable, findable, accessible, credible and valuable (ie, more frequent SDM). Accordingly, the present study explored all of these aspects. We found that the study participants wanted an easy-to-use, intuitive, interactive, computer-based DA with diagrams and graphics. In a recent systematic review of the quality of DAs developed for women eligible for mammogram screening, the three best-rated dimensions of standard DAs were disclosure (transparency and conflicts of interest), information (the provision of sufficient detail) and outcome probabilities.<sup>29</sup> The women and the healthcare professionals interviewed in our study also stated that those three dimensions were important to them. We considered that a future DA must focus on all six dimensions, so that women and healthcare professionals engage with the tool.

### Implications for clinical practice

The present study explored expectations of a DA for SDM in breast cancer screening before its creation, from the future users themselves. Our work is the first step in the construction of this tool and will thus make it possible to avoid the pitfalls brought to light during the interviews. The future tool will allow adapting the information according to the age group of the patient. It's important to take time to acculturate healthcare professionals to the use of the DA to avoid its misuse. Our results should help to create an appropriate, added-value tool for use in this field and adapted to French context.

### CONCLUSION

Stakeholders in organised breast cancer screening programmes (women, GPs, gynaecologists, midwives, radiologists and screening programme managers) have a broad range of expectations of a DA. The interviews showed that a DA could help to improve levels of knowledge, harmonise medical practice and provide reliable, comprehensive information. Overall, the interviewees wanted an easy-to-use, intuitive, graphic-rich, interactive, computer-based and patient-centred DA. The idea of a DA was well received by the interviewees despite the fact the latter were unfamiliar with the concept of SDM. Along with the implementation of this type

of tool, it would be useful to raise awareness of SDM among healthcare professionals and breast screening candidates. The present work was the first step in the DEDICACES study and will be followed by the creation and then validation of the first DA for SDM support in France's breast cancer screening programmes.

#### Author affiliations

- <sup>1</sup>Université Paris Cité, Département de Médecine Générale, F-75006, Paris, France  
<sup>2</sup>Université Sorbonne Paris Nord, Département Universitaire de Médecine Générale, DUMG, F-93430, Villetaneuse, France  
<sup>3</sup>Université Sorbonne Paris Nord, Laboratoire Educations et Pratiques de Santé (LEPS), UR 3412, F-93430, Villetaneuse, France  
<sup>4</sup>Conseil scientifique du Collège National des Généralistes Enseignants (CNGE), Paris, France  
<sup>5</sup>Département de Médecine Générale, Faculté de Médecine et Pharmacie, Université de Poitiers, F-86000, Poitiers, France  
<sup>6</sup>Université de Nantes, Département de Médecine Générale, F-44007, Nantes, France  
<sup>7</sup>INSERM U1232, Centre de Recherche en Cancérologie et Immunologie, F-49000, Nantes, France  
<sup>8</sup>Département de Médecine Générale, Faculté de Médecine Jacques-Lisfranc, Université Jean-Monnet Saint-Étienne, F-42023, Saint-Étienne, France  
<sup>9</sup>Laboratoire SNA-EPIS EA4607, Université Jean-Monnet, F-42023, Saint-Étienne, France  
<sup>10</sup>HESPER, Health Services and Performance Research, EA7425, Université Claude Bernard Lyon 1, F-69100, Villeurbanne, France  
<sup>11</sup>Université Paris-Est Creteil, INSERM, IMRB, Equipe CEPIA, F-94010, Creteil, France

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**Data availability statement** Data are available upon reasonable request. The deidentified transcripts of the interviews are available from the corresponding author (amelie.aim-eusebi@u-paris.fr). Their reuse is possible for a purpose similar to that of our study, otherwise a new consent from the interviewees will be necessary.

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#### ORCID iDs

Aim-Eusébi Amélie <http://orcid.org/0000-0002-3605-9771>  
 Yannick Ruelle <http://orcid.org/0000-0002-4599-0613>

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