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Thèse

Pour le

DOCTORAT EN MÉDECINE (DES de MÉDECINE GÉNÉRALE)

Diplôme d'État
Par

Maïna THABAUD

Née le 04/07/1986 à Belfort (90)

Decision aids for women eligible to mammography breast cancer screening :
a systematic review update and an evaluation according to
the international standards

Présentée et soutenue publiquement le **8 novembre 2018** devant un jury composé de :

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Titre

Les outils d'aide à la décision pour les femmes éligibles au dépistage du cancer du sein par mammographie : une actualisation d'une revue systématique de la littérature et une évaluation selon les critères internationaux standards.

Résumé

Introduction : Le cancer du sein est le cancer le plus fréquent et également la première cause de mortalité chez les femmes dans le monde. Le développement des thérapeutiques et la détection précoce sont à l'origine d'une diminution de la mortalité spécifique. Cependant, le risque de faux positifs est élevé et entraîne des sur-diagnostic. Le bénéfice à l'échelle individuelle est différent du bénéfice à l'échelle globale. L'information des femmes pour une décision médicale partagée, tenant compte de leurs valeurs, peut être réalisée au moyen d'outils d'aide à la décision. Les objectifs de ce travail sont de compléter le répertoire des outils existants et d'en évaluer la qualité dans le cadre du dépistage du cancer du sein par mammographie.

Méthode : Nous avons actualisé et complété une revue de la littérature déjà existante issue de Pubmed. Les titres, puis les résumés, puis les textes entiers ont été examinés indépendamment par deux lecteurs. La qualité des outils d'aide a été évaluée selon les critères IPDAS (International Patient Decision Aid Standards instrument), en double aveugle également.

Résultats : Nous avons étudié quatre outils d'aide à la décision. Ils ont une évaluation au-dessus de 75/100 et sont donc intéressants. Les seules dimensions qui nécessitaient une amélioration étaient l'apport de précision sur le développement du processus d'élaboration de l'outil et d'évaluation de celui-ci.

Conclusion : L'actualisation de cette revue met en évidence l'existence d'outils de qualité à destination des femmes à risque moyen pour permettre un choix éclairé et partagé dans la réalisation du dépistage par mammographie.

Mots clés

Cancer du sein, Dépistage, Mammographie, Outils d'aide, Décision partagée, Dépistage précoce du cancer, Communication en santé, Soins primaires.

Title

Decision aids for women eligible to mammography breast cancer screening: a systematic review update and an evaluation according to the international standards

Abstract

Introduction: Breast cancer is the most common cancer and also the leading cause of death among women worldwide. The development of therapeutics and the early detection are the origin of a decrease of the specific mortality. However, the risk of false positives is high and leads to overdiagnosis. The benefits at the individual level are different from the profit at the global level. Decision support tools can be used to women's information for a shared medical decision, based on their values. The objectives of this work are to complete the inventory of existing tools and to evaluate their quality in mammography breast cancer screening.

Method: We updated and completed a review of the existing literature from Pubmed. Titles, then abstracts, then full texts were examined independently by two readers. The quality of the support tools was evaluated according to the International Patient Decision Aid Standards Instrument (IPDAS) criteria in double-blind.

Result: We studied four decision support tools. They obtain a score above 75/100 and are therefore interesting. The only dimensions that require improvement are precision regarding development and evaluation process.

Conclusion: The update of this review highlights the existence of quality tools for medium-risk women to enable informed and shared choice in mammography screening.

Keywords

Breast cancer, Screening, Mammography, Decision aid, Shared Decision Making, Cancer early detection, Decision Tool, Healthcare communication, Primary care.

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INTRODUCTION

1. Epidemiology of breast cancer

With an estimated 1.67 million new cancer cases diagnosed in 2012 (25% of all cancers), breast cancer is the second most common cancer in the world and by far the most frequent cancer among women. Incidence rates vary nearly fourfold across the world regions with rates ranging from 27 per 100 000 in Middle Africa and Eastern Asia to 96 per 100 000 in Western Europe. Breast cancer incidence in developed countries is higher, while relative mortality is greatest in less developed countries. Education of women is suggested in all countries for early detection and treatment.

Breast cancer is the first cause of women's mortality. Near 522 000 women died of breast cancer every year in the world (1), including 12 000 in France. Early detected, nine out of ten breast cancers would be treated successfully (2). Specific mortality related to breast cancer has decreased by 1.5% per year from 2005 to 2012 in the world (3). Therapeutic progress has contributed to this diminution. Another reason might be the development of early diagnosis and screening.

2. Mammography screening program

Gøtzsche and colleagues published a systematic Cochrane review of 2011 reporting that breast cancer screening based on mammography would lead to a reduction of specific mortality of 15% (4). In another systematic review of 2015, Myers and al. estimated this reduction of breast cancer mortality around 20% (5).

On one hand, there is no doubt that mammography screening decreases specific mortality (6). In accordance, many countries have implemented organized screening programs that vary regarding both age range and screening interval.

On the other hand, recent guidelines from USA, Europe, and Canada set out large variations between interpretations of the evidence around advantages and

disadvantages of mammography screening and adopt a cautious approach of breast cancer screening (7).

The most important harms associated with early detection of breast cancer by mammographic screening are false positive results with short-term negative psychological consequences for some women, overdiagnosis and overtreatment and possibly radiation-induced cancer. Estimation of cumulative risk of false positive for organized programs are around 20% for a woman who had 10 screens between the ages of 50 and 70 years (8). The Euroscreen Working Group calculated a summary estimate of overdiagnosis of 6.5% (8) versus 30% for Cochrane review (4). The estimated cumulative risk of death from breast cancer due to radiation from mammographic screening is 1 to 10 per 100 000 women, depending on age, frequency and duration of screening (8).

In 2016 Caverly and colleagues reported that 69% of the US cancer prevention and screening guidelines did not quantify benefits and harms or presented them in an asymmetric manner (9). The American Cancer Society has highlighted the confusion created by screening guidelines and proposes providing the public with clear guidance about the benefits, limitations and harms associated with taking a screening test (10).

3. Informed decision and shared decision making

“Informed decision-making” and “shared decision making” describe a process that enables a patient to participate in decisions about their health preferences (12).

Shared decision-making relates specifically to patient-clinician consultations where both parties collaborate by expressing preference and participating to decision (11).

Charles and al. conceptualized shared decision-making between a paternalistic and an informed decision-making model. This conceptualization highlights the importance of three components to the decision-making process: information exchange, deliberation, negotiation about and agreement to implement a treatment or screening decision (12, 13). But many health decisions are made outside of a clinical context and without any dialogue with a practitioner. It is the case for breast cancer: women

could accept or not a screening offer. Informed decision is the most appropriate term (11).

Stacey and al. explained that decision aids are tools designed to support people's decisions about tests and treatments when there is more than one reasonable option, and/or when people value benefits and harms differently. They reported that compared to usual care, people exposed to decision aids feel more knowledgeable, better informed, clearer about their values and they probably have a more active role in decision making and more accurate risk perceptions (14).

Reder and colleagues expressed that a decision aid can be widely used to support women in decision making. Decision aid also significantly increased women's knowledge about screening and decreased decisional conflict (15).

A remaining challenge is to determine the content of a decision aid and to assess the quality of such a document.

4. Creation of a decision aid

In France, there is no official decision aid for women about mammography screening. In 2017, the "Ministère de la Santé" presented an action plan to respond to the "Plan Cancer". It planned to invite all women aged from 50 years and older to a medical consultation with their general practitioner or gynaecologist. A leaflet would be attached to an invitation letter, in order to prepare this consultation and inform women about breast cancer screening. A web resource for personalized information would also be available to allow shared decision-making (2).

In order to create these tools, INCA (Institut National du CANcer) launched a call for projects in April 2017 (2). Nantes General Department of Medicine has responded to this call for projects and take part in it.

5. Objectives

Marion Johonet and Anna Valenza conducted a Pubmed review of decisions aids and evaluated their quality (16). Pubmed is one of the main medicine database, but not the only one source of information for an extended international review.

The aim of our study is to complete a review of decision aids according to the “International Patient Decision Aid Standards instrument v3” (IPDASI). IPDASI is an internationally recognized scoring system of decision aid quality, developed in 2009 (17). We actualised, completed and validated the review with other databases, following the same methods.

METHODS

1. Studies identification and selection

1.1 Pubmed actualisation

We conducted a systematic research to complete the first study made by Marion Johonet and Anna Valenza. Their Pubmed review went from January 1st, 1997 to April 20, 2017. We made an actualization up to June 20, 2018. The total period goes from January 1st, 1997 to June 20, 2018.

1.2 Other database analysis

We used international databases to incorporate studies about breast cancer and decision aids. Selected databases are Embase, Psychinfo, Cochrane, and “Banque de Données en Santé Publique” (BDSP).

References of identified articles were searched for additional relevant articles.

1. Analysis methodology

1.1 Algorithms

PUBMED

The algorithm used for Pubmed was similar to the algorithm previously made by Marion Johonet and Anna Valenza.

decision support techniques OR decision making OR decision aid OR decision tool OR computer assisted decision making OR risk assessment OR health communication OR patient participation OR decisions trees OR health knowledge, attitudes, practice OR choice behavior	AND	breast neoplasm OR breast cancer	AND	mass screening OR cancer early detection OR cancer screening
---	-----	---	-----	--

EMBASE

We adapted algorithm for Embase in order to keep similar analysis.

'decision making' OR 'decision aid' OR 'decision support system' OR 'risk assessment' OR 'medical information' OR 'patient participation' OR 'decision tree' OR 'attitude to health' OR 'decision tool'	AND	'breast tumor' OR 'breast cancer'	AND	'mass screening' OR 'early cancer diagnosis' OR 'cancer screening'
---	-----	---	-----	--

PSYCHINFO

We also adapted algorithm for Psychinfo in order to keep similar analysis.

Decision making OR Decision support System	AND	Breast neoplasm	AND	Cancer screening
--	-----	-----------------	-----	------------------

COCHRANE

We adapted algorithm for Cochrane in order to keep similar analysis.

Decision making OR Decision aid	AND	Breast cancer OR Breast neoplasm	AND	Mass screening OR Cancer screening
---------------------------------------	-----	--	-----	--

BANQUE DE DONNÉES EN SANTÉ PUBLIQUE (BDSP)

We searched in BDSP all occurrences with these keywords:

Cancer du sein	ET	Dépistage	ET	Aide à décision
----------------	----	-----------	----	-----------------

BDSP is a french database. Used keywords are equivalent to:

Breast cancer	AND	Screening	AND	Decision Aid
---------------	-----	-----------	-----	--------------

1.2 Process analysis

For process analysis, we used same methods as Marion Johonet and Anna Valenza.

Searching results were exported in ABSTRACTR®, a data processing software.

The successive steps for analysis were:

- Analysis based on title,
- Analysis based on abstract,
- Full text analysis.

The work was made by two reviewers, Maïna Thabaud (General practitioner substitute) and Flore Laforest (General practitioner and honorary research associate at Cardiff university), who made selection independently.

Conflicts between reviewers were resolved by consensus. If the disagreement persisted, the third reviewer (Sandrine Hild, PhD supervisor and Clinic leader at the Department of General Medicine of Nantes) resolved it.

Thanks to algorithms, we included any type of study that contained a decision aid for mammography breast cancer screening in average risk women.

The 17 criteria of exclusion were as follows:

- 1) The paper was published before 1997;
- 2) The paper is centred on breast cancer screening in high risk or symptomatic patients;
- 3) The paper is about breast cancer treatment;
- 4) The paper reports guidelines;
- 5) The paper discuss the efficiency, the implementation, the cost related to mass screening or the screening participation rate;
- 6) The paper deals with breast cancer prevention without mentioning mammography screening;
- 7) The paper mentioned an educational intervention for which there is no material information available (oral information, video, interview, ...);
- 8) The paper mentions an educational intervention aiming to promote breast cancer screening but does not provide a complete information regarding the harms of it ;
- 9) The information provided by the paper is only addressed to health professionals about the screening controversy;
- 10)The paper gathers insights, practices, knowledge or training of health professionals on the matter of communication on breast cancer screening;

- 11)The paper emphasizes on the importance of shared decision making, decision aids and health communication without implementing or using a decision aid;
- 12)The paper either mention or evaluate a risk score, factors leading to breast cancer and their potential impact on screening participation rates;
- 13)The paper evaluates women's knowledge or means of information used by women regarding breast cancer screening ;
- 14)The paper reports the informational need of women and their willingness to share decision making ;
- 15)Observational and descriptive studies reviewing psychological characters' of patients and other factors associated with screening ;
- 16)The paper mention decision aids or information about breast cancer that have not been evaluated or justified in a study or a paper;
- 17)The paper contained a decision aid already studied by Marion Johanet and Anna Valenza in their Pubmed review.

2. Data extraction and synthesis

2.1 Rating score

After reading full articles, decision aids were extracted from the paper if available. Authors were contacted to obtain decision aids which were not reported in selected articles.

Decision aids were evaluated by Maïna Thabaud and Flore Laforest, using the International Patient Decision Aids Standards instrument (IPDASI) (17). It was particularly adapted for screening test with 47 items in 10 dimensions (Appendix 1).

Each item was scored on a 4-point rating scale with possible responses as follows:

- strongly agree=score 4 (the issue is addressed clearly and comprehensively);
- agree=score 3 (the issue is addressed but with room for improvement);
- disagree=score 2 (the decision aid fails to clearly address the issue);
- strongly disagree=score 1 (the decision aid totally fails to address the issue).

Dimensions included more or less items (between 1 and 8 items), so the weighting of each item is different in total rating. The overall score was express on 100 (from 0/100: worst rating, to 100/100: best rating).

Concerning “Plain language” dimension, we calculated the Fry readability score (18) used in the original IPDAS checklist (19). This criteria is perfectly adapted to evaluate if texts are understandable by everyone:

- score=4: Fry readability score under 8 is considered “comprehensive and clear to understand”.
- score=3: Fry readability score up to 8 is related to a language “difficult to be understand by a majority of people”.

2.2 Statistics analysis

IPDAS is a score used to evaluate the quality decision aid and not to the quality of the article. We used Excel® to calculate means and deviations standards for each dimension and overall score.

Our results can be combined to Marion Johonet and Anna Valenza results.

RESULTS

1. Study Selection

1.1 Flow chart

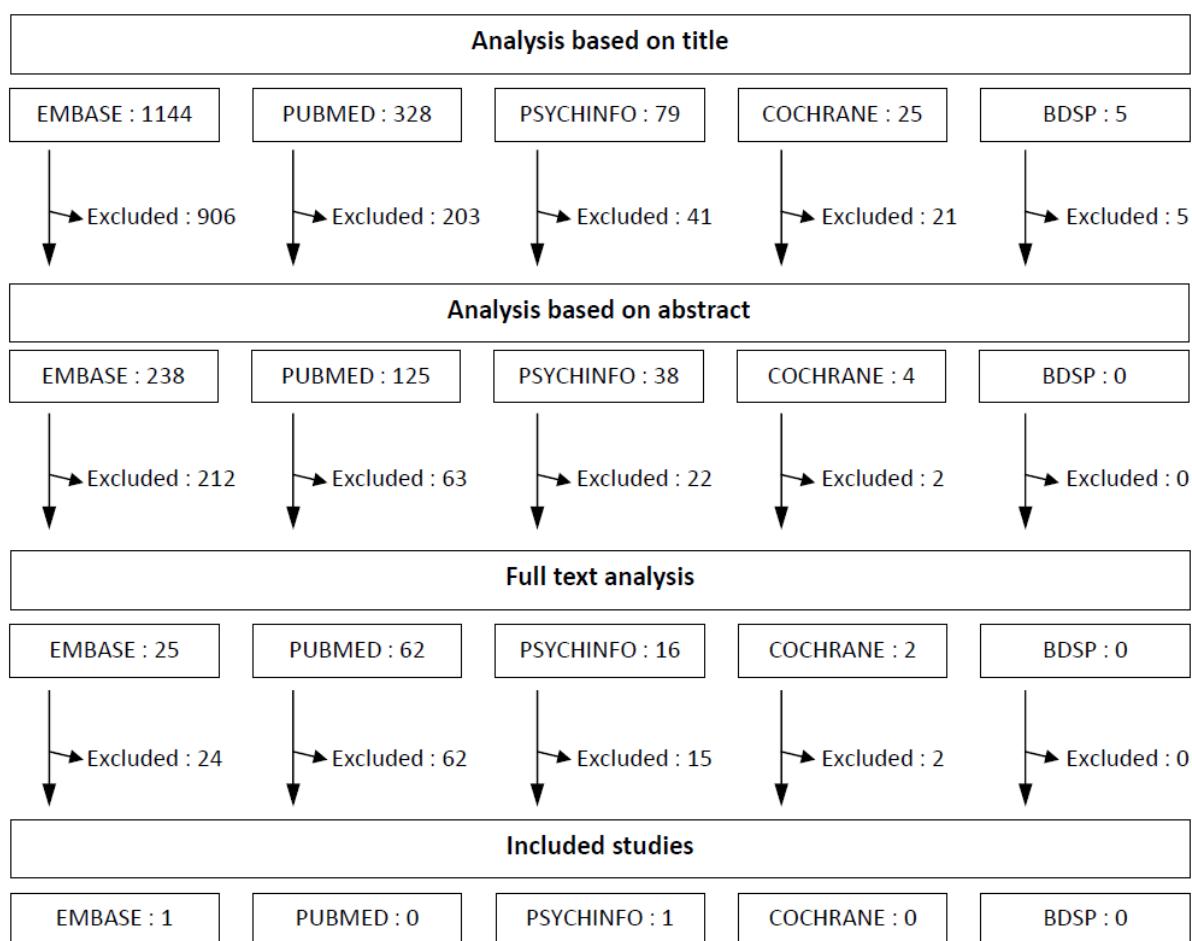
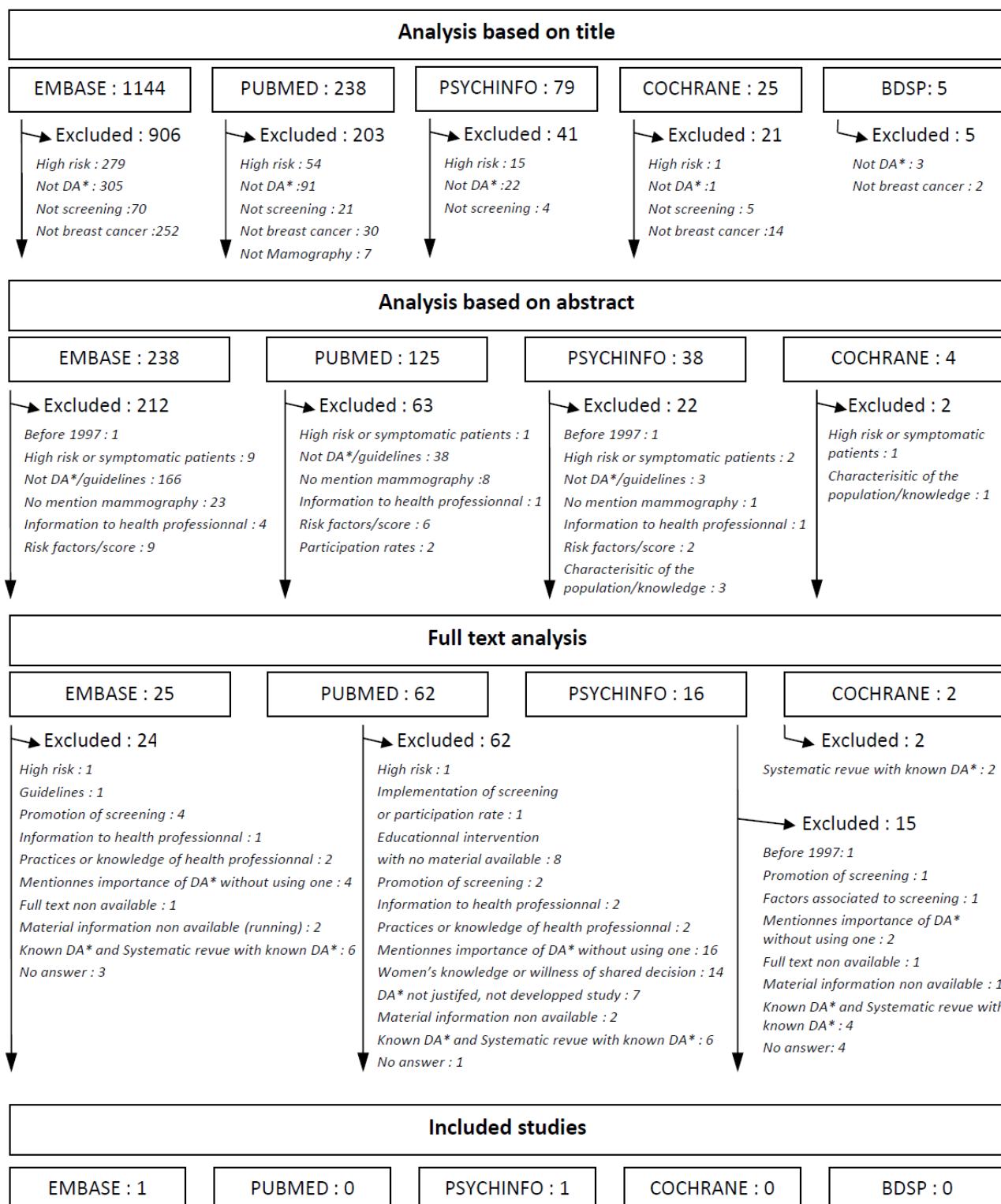


Figure 1: Global Flow-chart



DA* : Decision Aid

Figure 2: Detailed Flow-chart

581 titles, 405 abstracts, 105 full text-papers have been screened for eligibility using exclusion criteria. Finally, the review included only two papers (20; 21) corresponding to four decision aids (Appendix 2).

1.2 Precision about some exclusions

We precise some reasons of exclusion:

- Two studies were not available in their entirety (only abstract). Even the library of the university of Nantes couldn't obtain them. (22; 23),
- Seven articles were excluded after exchange with corresponding authors:
 - o One study because the principal author was dead and their colleagues couldn't access to the decision aid (24),
 - o Three studies were excluded because the studies were still running and no communication was allowed (25; 26; 27):
 - o C.Gunn specified that his article was a descriptive study without intervention (28).
 - o A.Krist did not use a decision aid: he gave information from the USPSTF (United States Preventive Services Task Force) (29).
 - o T.Onega did not use a decision aid. She used "existing evidence "(30).
- Seven studies were excluded because the material was not available and the main authors did not respond (31; 32; 33; 34; 35; 36; 37; 38).
- We excluded articles using decision aids already rated by Marion Johanet and Anna Valenza. (39; 40; 41; 42; 43)

2. Synthesis of results

2.1 Overall score

Four decision aid tools were found and they get an overall score higher than 75/100.

The overall mean is 89.10/100 with a standard deviation at 8.27 (low deviation).

Dimension very high rated (>75/100)	Dimension high rated (between 50/100 and 75/100)	Dimension low rated (between 25/100 and 50/100)	Dimension very low rated
Test : 99.31 Information : 99.23 ; Decision Guidance : 96.88 ; Probabilities : 94.53 ; Evidence : 93.75 ; 	Values : 73.44 ; Development 71.88 ; DST evaluation : 62.50	-	-

Table 1: Score classification for each dimension

2.2 Score for each dimension

Information (Appendix 3)

The providing information about the option give sufficient details to make a specific decision.

The mean was 99.23/100 (very high) with a standard deviation at 1.55 (strong homogeneity). Only Paul's decision aid was rated $\frac{3}{4}$ because it was less understandable about the natural course of the health condition, if no action was taken.

Keevil's decision aid was particularly well argued (Figure.3).

Understanding the Benefits and Harms of Mammography Screening



What are some of the benefits of mammography screening for breast cancer?

The primary benefit of screening is to find breast cancer early when it is most treatable. Mammograms can find changes in the breast up to two years before a patient or provider can feel them on physical exam. Finding breast cancer early can increase survival and also improve the chance of sparing a breast from surgery. Finding breast cancer early has been shown to reduce the number of breast cancer deaths in women by 25%-30%.

What are the risks (harms) of mammography screening for breast cancer?

Normal breast tissue can hide a breast cancer so that it doesn't show up on the mammogram. This is called a **false negative**.

Mammography can also identify an abnormality that looks like it is a breast cancer, but it is not. This is called a **false positive**. In addition to worrying about being diagnosed with breast cancer, a false positive means more tests and follow-up visits, which can be stressful, have more risks and be expensive.

Another harm of screening is finding extra cancers that would not have become dangerous. This is called **overdiagnosis** or **overtreatment**. Because doctors cannot tell which cancers will become dangerous, they are all treated the same. This is different than a false positive.

How accurate are my risk estimates?

The tool provides an estimate of your risk of developing breast cancer based on certain health factors. By looking at these risk factors we can assess whether you are at average risk for your age, high risk, or lower than average. The exact number may be an estimate.



Figure 3: illustration of information dimension by J. Keevil

Probabilities (Appendix 4)

The presentation of outcome probabilities is understandable.

The mean was 94.53/100 (very high) with a standard deviation at 4.70 (small heterogeneity).

The Healthwise decision aid was rated 2/4 because of the item: "The decision support technology allows the user to compare outcome probabilities across options using the same denominator and time period".

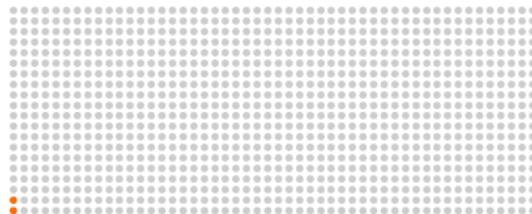
CeMPED (Centre for Medical Psychology & Evidence-based Decision-making, University of Sidney) decision aid was rated 2/4 because event or outcome probabilities were not well balanced.

Paul and Keevil were chosen to illustrate probabilities with points and figurines respectively (Figure 4 and Figure 5).

What happens to women aged 40 who screen or don't screen.

Below is a comparison of what happens to 1000 women who **start having** screening mammograms every 2 years for 10 years with 1000 women who **don't have** screening mammograms.³

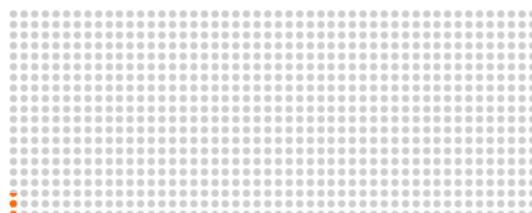
How many women aged 40 who start having screening mammograms every 2 years will die from breast cancer in the next 10 years?



Out of 1000 women aged 40 who *start having* screening mammograms every 2 years for the next ten years:

- 2 women will die of breast cancer

How many women aged 40 who do not have screening mammograms will die from breast cancer in the next 10 years?



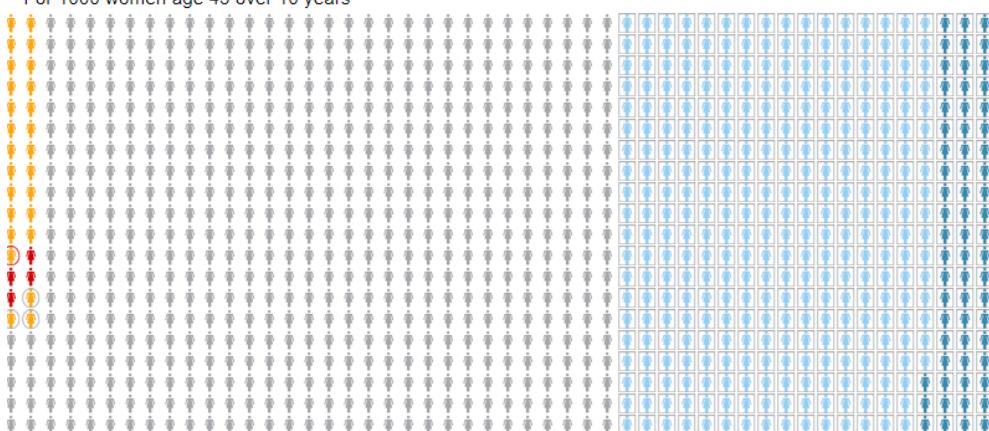
Out of 1000 women aged 40 who *do not have* screening mammograms every 2 years for the next ten years:

- 2.5 women will die of breast cancer

Figure 4: illustration of probabilities dimension by C.Paul

Decision: Get mammograms & how often? No Biennial Annual

For 1000 women age 45 over 10 years



Population		
100	1,000	10,000
Icon		
People	Blocks	
years		
1	10	

30 are diagnosed with breast cancer.

- > 22 survive breast cancer with or without screening.
- > 1 saved from a breast cancer death.
- > 4 die from breast cancer.
- > 3 extra are over-diagnosed by screening.

970 are not diagnosed with breast cancer.

- > 590 no breast cancer, recalls or biopsies.
- > 380 recalled for one or more false alarms.
- > 63 undergo a biopsy that is normal.

Continue

Figure 5: illustration of probabilities dimension by J.Keevil

Values (Appendix 5)

The patient can imagine positive or negative features, and choose considering his values.

The mean was 73.44/100 (high) with a standard deviation at 19.35 (significant deviation). This result presented a large heterogeneity.

Two were rated under 75/100 : CeMPED and Paul.

Two items had bad scores: options to imagine physical effects and social effects. Those were less comprehensive than psychological effects.

Keevil's decision aid was chosen to illustrate this dimension because it answered well to women's worries (Figure 6).

What Happens During Mammography Screening? ✖

A specially trained technician will perform your mammogram. To get a high-quality picture, your breast must be flattened. The technologist will place your breast on the machine's plate. The plastic upper plate is lowered to compress your breast for a few seconds while the technologist takes a picture. The whole procedure takes about 20 minutes. The actual breast compression only lasts a few seconds. You might feel some discomfort when your breasts are compressed, and for some women it can be painful. Make sure to tell the technologist if it hurts. A top to bottom and a side view of each breast are taken for a screening mammogram. Some women, such as those with large or dense breasts, or those who have breast implants, may need more pictures.

When will my results be available?

Every clinic has its own procedures for giving results. In most cases you will have to wait some time for the results of your mammogram. Generally speaking when a woman's mammogram is normal, a letter is sent sometime in the following 30 days telling her the results were normal. If something suspicious is found on your mammogram you will receive a call between 3-5 days after your original screening mammogram.

What happens if my mammogram is abnormal?

If your mammogram is abnormal you will receive a call back from the clinic between 3-5 days (sometimes earlier). You will be asked to schedule more images (sometimes called extra views) or other tests to help the doctors diagnose any potential problems. Some women will be required to have a breast ultrasound or MRI. Remember: Just because there is an abnormality it does not mean you have breast cancer. There are many reasons the doctor is asking for more information. According to the American Cancer Society, less than 10% of women called back for more tests are found to have breast cancer.

[Close Preview](#)

[Add to Summary](#)

Figure 6: illustration of values dimension by J.Keevil

Decision Guidance (Appendix 6)

This dimension must give a structured guidance to prepare a dedicated consultation.

The mean was 96.88 with a standard deviation at 6.25 (little heterogeneity). Only the Keevil's decision aid did not have a dedicated tool for patient to ask question to practitioners.

CeMPED decision aid, the only one paper tool, gave a large place to scribe the pros and cons of mammography screening (Figure 7).

These points make me feel like I want to continue having screening mammograms	These points are not important to my decision	These points make me feel that I want to stop having screening mammograms
[Handwriting lines]	[Handwriting lines]	[Handwriting lines]

Step 2: For each point above put *** next to the issues that are most important for your decision, ** next to fairly important issues, and * next to the least important issues.

Step 3: Weigh up the points from above and how important they are to your decision. Now tick the box that best shows what you have decided.

- | | | | | |
|---|--|--------------------------|---|----------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Continue having a mammogram every 2 years for the next 10 years | Have my next mammogram and after that decide about future ones | Undecided | Not have my next mammogram but I may reconsider later | Not have another mammogram |

Before you make your final decision, you may want to discuss your decision with your doctor.

Figure 7: illustration of the dimension guidance CeMPED

Development (Appendix 7)

Development Dimension demonstrates if the authors used a systematic development process.

The mean was 71.50/100 and the standard deviation showed a big scatter (32.87).

We did not find the original article for three decisions aids: J. Keevil, CePMED and Healthwise :

- For Keevil, we found a poster (44), and more information about the development process on the website.
- For the CeMPED, we rated with the lowest global score 25/100 because we had no information about development process.
- For the Healthwise, we gave ¼ for the two items about the justification of the content of the information.

Evidence (Appendix 8)

It emphasizes integrity and quality of evidence.

The mean was 93.75/100 with a standard deviation at 12.50. CeMPED's decision aid is rated ¼ because the description how research evidence was selected was not written.

Disclosure (Appendix 9)

It discloses transparency of the decision aid project.

Regarding this dimension, the mean was 87.50/100. The standard deviation at 25.00 showed a relative important heterogeneity due to the CeMPED's decision aid.

There were no information about the authors, and no provided information about the funding used for development.

For example by C. Paul, we could easily open the window describing references, acknowledgments, and useful links (Figure 8).

The screenshot shows a web page layout. On the left, a white box contains a 'Thankyou' section with text about helpful information and contact email. On the right, a vertical 'Navigation' sidebar lists links like Home, Introduction, About this site, etc. A green callout box labeled 'References' provides a detailed explanation of what references are and includes a link to 'View the references'.

Thankyou

Thankyou for reading the decision aid, we hope you found the information helpful.

If you have any comments regarding this decision aid, please email alexb@health.usyd.edu.au.

References

The references will tell you where our data came from and what assumptions and calculations we used. These are the best estimates based on available data and will need to be reviewed as new information becomes available. You do not have to read this to make your decision. » [View the references](#)

Navigation

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- The Decision Aid
- References
- Useful links
- Acknowledgements
- How to contact us

Figure 8: illustrate the dimensions evidence and disclosure by C.Paul

Plain language (Appendix 10)

It translates the level of readability.

The mean was 87.50/100 with a standard deviation at 14.43. The Paul's and the Keevil's decision aid had a Fry readability score upper than 8 but their decision tool was pedagogical so we rated ¾.

DST (Decision Support Technology) evaluation (Appendix 11)

The media helps patient to make a decision.

The means was 62.50/100 with the greatest scatter: standard deviation at 43.30.

Healthwise and CeMPED did respond at neither item:

- “There is evidence that the decision support technology helps patients improve the match between the features that matter most to the informed patient and the option that is chosen,”

- “The evidence that the patient support technology helps patients to improve their knowledge about options features”.

Test (Appendix 12)

As regards to the dimension Test, the aim of the screening is to be clearly understandable.

The mean was 99.31/100 with a good homogeneity (standard deviation at 1.39).

Only one decision aid about 2 items was rated equal or under 2/4. It was Paul’s DA about the description of “the next steps typically taken, if the test detects the condition or problem” and “the next steps if the condition or problem is not detected”.

J;Keevil and Healthwise broached overdiagnosis and false positive (figure 9 and figure 10).

Understanding Overdiagnosis

What is Overdiagnosis?

- Overdiagnosis is when a tumor is found by a screening mammogram that would not have caused clinical symptoms or death.
- Overdiagnosis is also called overdetection or overtreatment.
- Screening mammograms can find small cancers that would not affect a woman's life.

Mammograms and Overdiagnosis

- Mammograms are an important screening test for breast cancer.
- Screening tests can find cases of cancer early.
- When tumors are detected early, treatment is often easier and works better.
- Mammograms can be so sensitive that they find small tumors that would not affect a woman's life.

Can you tell which tumors are not going to spread?

- It is difficult to tell on a mammogram which tumors are dangerous and which ones are not, so all are treated the same.
- Some tumors will not grow or spread fast enough to affect a woman's life.
- Studies show that 10-30% of tumors found on a screening mammogram fit into this category.
- In this way, overdiagnosis can lead to unnecessary treatment, which is a potential harm of getting a screening mammogram.

What does this mean for me?

- Talk to your medical provider about the benefits and harms of having a mammogram.
- Overdiagnosis is a potential harm of having a mammogram.

Figure 9: illustration of dimension Test by J.Keevil (overdiagnosis)

Risks

False-positive test results and unnecessary biopsies with annual mammograms over 10 years*¹

	Number of women who will have at least one false-positive that results in more testing (but turns out not to be cancer)	Number of women who will have a biopsy they don't need
Ages 40–49	About 613 out of 1,000 women	About 70 out of 1,000 women
Ages 50–59	About 613 out of 1,000 women	About 94 out of 1,000 women
Ages 60–69	About 497 out of 1,000 women	About 98 out of 1,000 women

*Based on the best available evidence (evidence quality: moderate to high)

Mammograms may show an abnormal result when it turns out there wasn't any cancer (called a false-positive). This means you may need more tests—such as another mammogram, a breast ultrasound, or a biopsy—to make sure you don't have cancer. These tests can be harmful and cause a lot of worry.

Figure 10: illustration of dimension Test by Healthwise (false positive)

Overall results (Appendix 13)

The table resumed results for each dimension.

The overall mean was 89.10 /100 and the overall standard deviation at 8.27. All these decisions aids were well rated (upper than 75/100).

Systematic review (Appendix 14)

The table pointed out how our decision aids were situated among the review made by Marion Johonet and Anna Valenza.

DISCUSSION

1. Main results

In addition to the twenty-three decision aids of the precedent review, we extracted four decision aids from two articles.

We founded decision aids with high IPDAS evaluation. Three of the top five decision aids were found by our review (Appendix 14).

As regards of little results, overall results needed to put things into perspective.

1.1 IPDAS Dimensions

This study revealed that some dimensions were systematically well rated with good homogeneity: Information, Probabilities, Guidance, Evidence, Language, Disclosure and Test.

Others dimensions (Values, Development, DST evaluation) were often incomplete and heterogeneous. For dimension Values, options helping patients to imagine what is like to experience the physical and social effects, were less complete than the psychological effects. Moreover, for dimension Development, the content of information was not guided by needs of patients and health professionals. There was no proof that media helped patients to improve their knowledge and to make a decision.

1.2 Decision aids

On the four studies, CeMPED's decision aid made out because of wrong results.

First of all, we did not have associate documentation, in order to evaluate Development and to explain Decision Support Technology (DST).

Secondly, target population was women older than 70 years. Expectations could be different for younger and more active women than for older, but there is no justification about scientific content and information transmitted. They used a booklet, so personalization and need of information were not permitted.

Keevil's decision aid had the highest score. Only the systematisation of the development should be reviewed.

2. Comparison with first review

A comparison between the work of Marion Johanet and Anna Valenza (23 occurrences) and ours (4 occurrences) is not appropriate.

In their review, Marion Johanet and Anna Valenza found that only three dimensions were well rated: Information, Probabilities and Test. However, there was a large heterogeneity in Probabilities (standard deviation at 19.40). Others dimensions were often incomplete and heterogenous.

Three of the top five decision aids were found by our review. These high scores demonstrate the utility of our systematic review. These decision aids were not available in Pubmed so they were not accessible by health practitioner easily. Moreover, three decision aids were only cited in Sepucha's article, without dedicated articles.

3. Interpretation in light of literature

3.1 Dimensions Information and Probabilities.

Completed and equilibrated information on benefits and harms are actually considered as necessary for an enlightened choice. Informed choice may be assessed by combining measures of a person's knowledge, attitudes, and actual choice (11).

Dimensions Information and Probabilities were well rated because all of those decision aids included pictographs and more than one way of viewing probabilities. This presentation allowed to compare positives and negatives features of available options and showed them with equal details. According to the literature, risks presented with pictographs are easier to understand than natural frequencies (45). But in his study, Timmermans suggested that the affective evaluation of risks is higher when risks are presented as population figures, than percentage (46). Moreover, verbal translation with numeric risk may help people with a better comprehension in risks messages (47). Different view of probabilities assured more comprehensible and less influenced information (48).

3.2 Dimensions Values and Guidance

Dimensions Values and Guidance represent shared decision making. They integrate the patient in process decisions, in contrast with evidence based medicine which gives factual information. Decisions are influenced by emotions, feelings, fear, personal history and how people perceive the risk of cancer (49). In our decision aids, description of Values was respected.

It is easier with an internet based decision aid and a tool to print patient's question list and a resume of personalised information (50).

Patient involvement regarding the decision to have a mammogram requires a discussion about the pros and cons of mammography. So, the patient is able to participate as an active informed partner in this decision making process.

A space to express incertitude and questions is essential for decision aid to be a vector of balanced information (28).

3.3 Dimension Langage

About dimension Language, we had 2 Fry readability score which were higher than 8, related to a language "difficult to be understand by a majority of people".

Although we had a better score than Marion Johanet and Anna Valenza (73.90 for them; 87.50 for this study), those decision aids were not adapted for low literacy, numeracy skills or socially disadvantaged patients, while they are associated with greater cancer risk (51). Even for highly educated population, communication strategies with numerical risk might be complicated (47). Ethnic minority patients' numeracy, affect their ability to be involved in shared decision making, even if cancer risk information is discussed using both numerical formats and visual aids (52). We excluded also the studies which treat of dementia patients or minority specific class. A systematic review about those specific decision aids for multiple social disadvantages already exists. (51).

3.4 Dimension Test

The Feldman's systematic review argues that decision aid producers tend to rely more heavily on medical experts than on patients guidance. Content evaluations present that screening decision aids frequently focus on false positives but not on false negatives. The difficulty brought by incomplete information on probabilities or the accuracy of test results provides a lack of understanding for patients and therefore information distortion (53).

3.5 Dimension Development and DST evaluation

The dimension Development is the major lack in this evaluation. Similar results were obtained by Marion Johanet and Anna Valenza (68.30 for them; 71.88 for this study). It highlights that women needs are not well explored.

The practitioners are considered like a credible source of information and their advice could influence patient's decision (54). In literature, women's expectation is to spend time discussing with their doctor (55). However, whereas women trust their doctor's expertise in assessing these risk factors and applying associated guidelines, practitioners report using only minimal risk factors (most likely first degree relative history of breast cancer) to determine screening recommendations (56).

Professionals need to support patients making choices by turning raw data into information that is more helpful to the discussions than the data (48).

They need to tell explicitly to women that they have choice whether to get a mammography or not. Shared Decision Making process helps to spell out each step (57).

Even if internet is an excellent media to transmit information and to prepare a consultation dedicated to prevention, it could be improved. Developers of Web-based decision support tools should analyse what type of data want women, and then what they do with that information if they choose to receive it. Tools could be developed to allow women to choose and see their own individualized prognostic data or, alternatively, to receive valid but global information. The style of data presentation is an important consideration. (50)

3.6 Decision aid and Shared Decision making

Striking a balance between saying the importance of the screening and reducing the impact of fears is essential to implement mammogram decisions. (56) Many practitioners do not explain sufficiently the harms and benefits of breast cancer screening (58).

Despite good information, Elkin and colleagues underscore that women overestimate the benefits of mammography (59). Women are guided by their one experience and uncertainty.

Andersen and colleagues connect worries about the risk of breast cancer and explain that less information or too much information decrease the use of mammography. This association between information and mammography realization correspond with a bell-shaped curve. (60).

Edwards and colleagues emphasize the importance of information given and the worries reaction of the information received. Therefore, it is important to discuss about them during the consultation (48).

Women and clinicians recognize that screening pros and cons can be a complicated discussion which can (and from a patient's perspective, should) require a significant amount of time during the clinical visit (56).

4. Strengths and limitations

4.1 Strengths

At this time there is no systematic review about decision aid for mammography screening, which rated the quality of the decision aids with the IPDASi v3. A recent systematic review proposed a description of the shared decision key elements like specific content, type of communication and framework (57).

We conducted a systematic review of literature. We founded new decision aids in the different databases. The use of a PRISMA methodology gave us reliable results. We used the same exclusions/inclusions criteria as Marion Johanet and Anna Valenza to complete their review.

We didn't find many decision aids, as expected, which reinforce the strength of the work of Marion Johanet and Anna Valenza. Our decision aids were as diverse in term of population and medias, as theirs.

We used the IPDASi which is internationally recognized, to rate independently the decision aid. The work in trinomial reduces the subjective point of view.

4.2 Limitations

We couldn't use the same algorithm in the different databases. So we modified it for all the databases, adjusting to their criteria.

Many interesting articles were not available because the decision aid was still running (25; 26; 27) or because we didn't obtain an answer.

We did not have many results. Most of the articles were in Pubmed, Marion Johanet and Anna Valenza had already noted them. We found 16 articles which used decision aids already rated (figure.1).

Some decision aids could be actualized since Marion Johanet and Anna Valenza's analysis (april 2017 and june 2018). One example is the decision aid used by Reder and al (15), which was actualised between the article found by Marion Johanet and Anna Valenza (61)

Even if IPDAS is an international validated score, it remains an irreducible part of subjectivity. We reduced it by rating in double-blinded. However, our consensus was probably different from some decisions made by Marion Johanet and Anna Valenza.

Like Marion Johanet and Anna Valenza we didn't assessed risk of bias because the studies were not similar. Decision aids quality is independent of articles quality.

CONCLUSION

This update of literature confirms the existence of various decision aids. Through the IPDASi v3, our study highlighted the strengths and weakness of the existing decision aids concerning breast cancer screening by mammography for average risk women. The high quality of some of them is undeniable. The development and the evaluation of the decision support need to be clarified to understand better and respond to the women's expectations.

Multiplying information support and way of communication (pictograph, text, and video) improve comprehension and affect a wider part of the population. Tools are a good support but do not substitute to the discussion with a practitioner.

These results might be taken in consideration for the elaboration of further decision aid.

APPENDIX 1 : IPDASi

Dimension	Item
Information	<ol style="list-style-type: none"> 1. The decision support technology describes the health condition or problem (intervention, procedure or investigation) for which the index decision is required 2. The decision support technology describes the decision that needs to be considered (the index decision) 3. The decision support technology describes the options available for the index decision 4. The decision support technology describes the natural course of the health condition or problem, if no action is taken. 5. The decision support technology describes the positive features (benefits or advantages) of each option 6. The decision aid describes negative features (harms, side effects or disadvantages) of each option. 7. The decision support technology makes it possible to compare the positive and negative features of the available options. 8. The decision support technology shows the negative and positive features of options with equal detail (for example using similar fonts, order, and display of statistical information).
Probabilities	<ol style="list-style-type: none"> 1. The decision support technology provides information about outcome probabilities associated with the options (i.e. the likely consequences of decisions) 2. The decision support technology specifies the defined group (reference class) of patients for which the outcome probabilities apply. 3. The decision support technology specifies the event rates for the outcome probabilities (in natural frequencies). 4. The decision support technology specifies the time period over which the outcome probabilities apply. 5. The decision support technology allows the user to compare outcome probabilities across options using the same denominator and time period. 6. The decision support technology provides information about the levels of uncertainty around event or outcome probabilities (e.g. by giving a range or by using phrases such as "our best estimate is...") 7. The decision support technology provides more than one way of viewing the probabilities (e.g. words, numbers, and diagrams). 8. The decision support technology provides balanced information about event or outcome probabilities to limit framing biases.
Values	<ol style="list-style-type: none"> 1. The decision support technology describes the features of options to help patients imagine what it is like to experience the physical effects. 2. The decision support technology describes the features of options to help patients imagine what it is like to experience the psychological effects. 3. The decision support technology describes the features of options to help patients imagine what it is like to experience the social effects. 4. The decision support technology asks patients to think about which positive and negative features of the options matter most to them.
Decision Guidance	<ol style="list-style-type: none"> 1. The decision support technology provides a step-by-step way to make a decision. 2. The decision support technology includes tools like worksheets or lists of questions to use when discussing options with a practitioner.
Development	<ol style="list-style-type: none"> 1. The development process included finding out what clients or patients need to prepare them to discuss a specific decision 2. The development process included finding out what health professionals need to prepare them to discuss a specific decision with patients 3. The development process included expert review by clients/patients not involved in producing the decision support technology 4. The development process included expert review by health professionals not involved in producing the decision aid. 5. The decision support technology was field tested with patients who were facing the decision. 6. The decision support technology was field tested with practitioners who counsel patients who face the decision.
Evidence	<ol style="list-style-type: none"> 1. The decision support technology (or associated documentation) provides citations to the studies selected. 2. The decision support technology (or associated documentation) describes how research evidence was selected or synthesized. 3. The decision support technology (or associated documentation) provides a production or publication date. 4. The decision support technology (or associated documentation) provides information about the proposed update policy. 5. The decision support technology (or associated documentation) describes the quality of the research evidence used.
Disclosure	<ol style="list-style-type: none"> 1. The decision support technology (or associated technical documentation) provides information about the funding used for development. 2. The decision support technology includes author/developer credentials or qualifications.
Plain Language	<ol style="list-style-type: none"> 1. The decision support technology (or associated documentation) reports readability levels (using one or more of the available scales).
Using plain language	
DST Evaluation	<ol style="list-style-type: none"> 1. There is evidence that the decision support technology improves the match between the features that matter most to the informed patient and the option that is chosen 2. There is evidence that the patient decision support technology helps patients improve their knowledge about options' features
Test (for DSTs that are directed at investigations or screening tests)	<ol style="list-style-type: none"> 1. The decision support technology describes what the test is designed to measure. 2. The decision support technology includes information about the chances of having a true positive test result. 3. The decision support technology includes information about the chances of having a true negative test result. 4. The decision support technology includes information about the chances of having a false positive test result. 5. The decision support technology includes information about the chances of having a false negative test result. 6. If the test detects the condition or problem, the decision support technology describes the next steps typically taken. 7. The decision support technology describes the next steps if the condition or problem is not detected. 8. The decision support technology describes the chances that the disease is detected with and without the use of the test. 9. The decision support technology has information about the consequences of detecting the condition or disease that would never have caused problems if screening had not been done (lead time bias).

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APPENDIX 2 – Characteristics of Identified Studies on Decision Aids

Research motor	Author/year	Target population	Design	Primary outcome	Presentation Decision Aid
EMBASE	Keevil, 2017	Women 35-74 years old	RCT: group wih tool and group control, logistic regression	Satisfaction	Internet (online Decision Aid)
EMBASE	Healthwise, 2016	Women with average risk for breast cancer. Start mammograms at age 40-50	Not applicable	Not applicable	Internet (online Decision Aid)
EMBASE	CeMPED, 2005	Women aged 70 years or older	Not applicable	Not applicable	Paper
PSYCHINFO	Paul 2007	Maori women, 40-49 years	One time uncontrolled intervention with pre/post test	Screening participation	Internet (online Decision Aid)

APPENDIX 3 – Dimension Information

IPDASI-Dimension Information										
<i>Providing information about option in sufficient detail for making a specific decision</i>										
Mean by item	4,00	4,00	4,00	3,75	4,00	4,00	4,00	4,00	31,75	99,23
Standard deviation	0,00	0,00	0,00	0,50	0,00	0,00	0,00	0,00	0,50	1,55
Decision aids	item 1	item 2	item 3	item 4	item 5	item 6	item 7	item 8	score /32	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	32	100,00
Healthwise, 2016 (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	32	100,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	32	100,00
Paul 2007, PSYCHINFO	4	4	4	3	4	4	4	4	31	96,90

APPENDIX 4 – Dimension Probabilities

IPDASI-Dimension Probabilities										
<i>Presenting outcome probabilities</i>										
Mean by item	4,00	4,00	4,00	4,00	3,50	3,50	3,75	3,50	30,25	94,53
Standard deviation	0,00	0,00	0,00	0,00	1,00	0,58	0,50	1,00	1,50	4,70
Decision aids	item 1	item 2	item 3	item 4	item 5	item 6	item 7	item 8	score /32	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	32	100,00
Healthwise 2016 (Sepucha, EMBASE)	4	4	4	4	2	4	3	4	29	90,62
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	4	4	4	4	4	3	4	2	29	90,60
Paul 2007, PSYCHINFO	4	4	4	4	4	3	4	4	31	96,90

APPENDIX 5 – Dimension Values

IPDASi-Dimension Values						
<i>Clarifying and expressing values</i>						
Mean by item	2,25	3,00	2,50	4,00	11,75	73,44
Standard deviation	1,26	0,82	1,29	0,00	3,10	19,35
Decision aids	item 1	item 2	item 3	item 4	score /16	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	4	4	16	100,00
Healthwise 2016 (Sepucha, EMBASE)	2	3	3	4	12	75,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	2	2	2	4	10	62,50
Paul 2007, PSYCHINFO	1	3	1	4	9	56,25

APPENDIX 6 – Dimension Guidance

IPDASi-Dimension Decision Guidance				
<i>Structured guidance in deliberation and communication</i>				
Mean by item	4,00	3,75	7,75	96,88
Standard deviation	0,00	0,50	0,50	6,25
Decision aids	item 1	item 2	score /8	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	3	7	87,50
Healthwise 2016 (Sepucha, EMBASE)	4	4	8	100,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	4	4	8	100,00
Paul 2007, PSYCHINFO	4	4	8	100,00

APPENDIX 7 – Dimension Development

IPDASI-Dimension Development								
<i>Using a systematic developpement process</i>								
Mean by item	2,25	2,50	3,00	3,00	3,25	3,25	17,25	71,88
Standard deviation	1,50	1,73	1,41	1,41	1,50	1,50	7,89	32,87
Decision aids	item 1	item 2	item 3	item 4	item 5	item 6	score /24	Mean/100
Keevil 2017 (Sepucha, EMBASE)	3	4	3	3	4	4	21	87,50
Healthwise 2016 (Sepucha, EMBASE)	1	1	4	4	4	4	18	75,00
CeMPED 2005, sup70 years (Sepucha, EMBASE)	1	1	1	1	1	1	6	25,00
Paul 2007, PSYCHINFO	4	4	4	4	4	4	24	100,00

APPENDIX 8 – Dimension Evidence

IPDASI-Dimension Evidence							
<i>Using evidence</i>							
Mean by item	4,00	3,25	3,75	3,75	4,00	18,75	93,75
Standard deviation	0,00	1,50	0,50	0,50	0,00	2,50	12,50
Decision aids	item 1	item 2	item 3	item 4	item 5	score /20	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	4	4	4	20	100,00
Healthwise 2016 (Sepucha, EMBASE)	4	4	4	4	4	20	100,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	4	1	3	3	4	15	75,00
Paul 2007, EMBASE	4	4	4	4	4	20	100,00

APPENDIX 9 – Dimension Disclosure

IPDASI-Dimension Disclosure				
<i>Disclosure and transparency</i>				
Mean by item	3,50	3,50	7,00	87,50
Standard deviation	1,00	1,00	2,00	25,00
Decision aids	item 1	item 2	score /8	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	8	100,00
Healthwise 2016 (Sepucha, EMBASE)	4	4	8	100,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	2	2	4	50,00
Paul 2007, PSYCHINFO	4	4	8	100,00

APPENDIX 10 – Dimension Plain Langage

IPDASI-Dimension Plain Langage				
<i>Using plain langage</i>				
Mean by item		3,50	3,50	87,50
Standard deviation		0,58	0,58	14,43
Decision aids	FRY	item 1	score /4	Mean/100
Keevil 2017 (Sepucha, EMBASE)	9	3	3	75,00
Healthwise 2016 (Sepucha, EMBASE)	7	4	4	100,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	6	4	4	100,00
Paul 2007	13	3	3	75,00

APPENDIX 11 – Dimension Decision Support Technology (DST)

IPDASI-Dimension DST evaluation				
Mean by item	2,50	2,50	5,00	62,50
Standard deviation	1,73	1,73	3,46	43,30
Decision aids	item 1	item 2	score /8	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	8	100,00
Healthwise 2016 (Sepucha, EMBASE)	1	1	2	25,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	1	1	2	25,00
Paul 2007, PSYCHINFO	4	4	8	100,00

APPENDIX 12 – Dimension Test

IPDASI-Dimension Test											
Mean by item	4,00	4,00	4,00	4,00	4,00	3,50	3,25	3,75	4,00	34,50	99,31
Standard deviation	0,00	0,00	0,00	0,00	0,00	1,00	1,50	0,50	0,00	3,00	1,39
Decision aids	item 1	item 2	item 3	item 4	item 5	item 6	item 7	item 8	item 9	score /36	Mean/100
Keevil 2017 (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	4	36	100,00
Healthwise 2016 (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	4	36	100,00
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	4	4	4	4	4	4	4	4	4	36	100,00
Paul 2007, PSYCHINFO	4	4	4	4	4	2	1	3	4	30	97,22

APPENDIX 13 – IPDASi Overall Results

IPDASi-Total												
Mean by item	31,75	30,25	11,75	7,75	17,25	18,75	7,00	3,50	5,00	34,50	167,50	89,10
Standard deviation	0,50	1,50	3,10	0,50	7,89	2,50	2,00	0,58	3,46	3,00	15,55	8,27
Decision aids	Information /32	Probabilities /32	Values /16	Guidance /8	Development /24	Evidence /20	Disclosure /8	Langage /4	DST /8	Test /36	Score /188	Mean /100
Keevil 2017 (Sepucha, EMBASE)	32	32	16	7	21	20	8	3	8	36	183	97,34
Healthwise 2016 (Sepucha, EMBASE)	32	29	12	8	18	20	8	4	2	36	169	89,89
CeMPED 2005, sup 70 years (Sepucha, EMBASE)	32	29	10	8	6	15	4	4	2	36	146	77,66
Paul 2007, PSYCHINFO	31	31	9	8	24	20	8	3	8	30	172	91,49

APPENDIX 14 – Quality of Decision Aid. Evaluation based on IPDASI

Mean by item		27,1	25,7	10,5	5,6	16,5	13,4	4,7	3,0	5,6	30,2	142,3	75,7
Standard deviation		4,2	6,2	3,2	2,2	4,8	5,3	2,3	0,6	2,6	5,4	28,4	15,1
Decision Aids		Information /32	Probabilities /32	Values /16	Decision Guidance /8	Develop ment /24	Evidence /20	Disclosure /8	Plain language /4	DST Evaluation /8	Test /36	Score /188	Mean /100
Keevil 2017	<i>Maïna/Flore</i>	32	32	16	7	21	20	8	3	8	36	183	97,3
Schonberg 2014	<i>Anna /Marion</i>	31	32	13	8	21	20	4	4	8	35	176	93,6
Reder 2015	<i>Anna /Marion</i>	30	32	14	8	21	18	6	3	6	36	174	92,6
Paul 2007,	<i>Maïna/Flore</i>	31	31	9	8	24	20	8	3	8	30	172	91,5
Scariati 2015	<i>Anna /Marion</i>	32	31	14	8	21	11	6	3	7	36	169	89,9
Healthwise 2016	<i>Maïna/Flore</i>	32	29	12	8	18	20	8	4	2	36	169	89,9
Hersch 2015	<i>Anna /Marion</i>	29	32	10	6	21	15	4	3	8	34	162	86,2
Elkin2017	<i>Anna /Marion</i>	26	23	14	8	20	18	8	4	8	32	161	85,6
Mathieu 2007	<i>Anna /Marion</i>	30	31	11	8	20	15	4	3	8	31	161	85,6
Mathieu 2010	<i>Anna /Marion</i>	30	31	11	8	20	15	4	3	8	31	161	85,6
Eden 2015	<i>Anna /Marion</i>	23	22	14	8	20	18	8	4	8	30	155	82,4
Bourmaud 2016	<i>Anna /Marion</i>	29	30	15	8	18	11	4	3	4	32	154	81,9
Webster 2007	<i>Anna /Marion</i>	30	27	11	4	19	14	5	4	7	32	153	81,4
Baena-Canada 2015	<i>Anna /Marion</i>	28	29	6	3	18	20	8	2	6	31	151	80,3
Wong 2015	<i>Anna /Marion</i>	30	20	12	4	18	20	4	3	8	32	151	80,3
CeMPED 2005	<i>Maïna/Flore</i>	32	29	10	8	6	15	4	4	2	36	146	77,7
Toledo- Chavarri 2017	<i>Anna /Marion</i>	30	25	10	4	19	8	4	3	4	31	138	73,4
Gummersback 2015	<i>Anna /Marion</i>	26	17	10	4	13	12	4	2	8	34	130	69,1
Nekhlyudov 2009	<i>Anna /Marion</i>	25	24	11	5	13	14	2	3	2	30	129	68,6
Petrova 2015	<i>Anna /Marion</i>	24	29	10	4	13	5	2	3	8	31	129	68,6
Pasternack 2011	<i>Anna /Marion</i>	23	17	11	3	19	10	4	3	6	29	125	66,5
Rimer 2002	<i>Anna /Marion</i>	20	15	10	4	13	12	8	3	6	25	116	61,7
Pace 2014	<i>Anna /Marion</i>	25	20	8	2	10	6	2	3	2	28	106	56,4
Barrat 2005	<i>Anna /Marion</i>	22	29	4	3	10	5	2	2	2	23	102	54,3
Fuller 2015	<i>Anna /Marion</i>	23	9	9	4	10	10	2	2	2	22	93	49,5
Marschall 2003	<i>Anna /Marion</i>	19	24	4	3	10	5	2	3	2	17	89	47,3
Marschall 2005	<i>Anna /Marion</i>	19	23	4	3	10	5	2	2	2	16	86	45,7

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LIST OF ABBREVIATIONS

BDSP : Banque de Données en Santé Publique

CeMPED : Centre for Medical Psychology & Evidence-based Decision-making

DST: Decision Support Technology

INCA : Institut National du CAncer

IPDAS: International Patient Decision Aid Standards

IPDASI : International Patient Decision Aid Standards instrument

Serment d'Hippocrate

En présence des Maîtres de cette Faculté, de mes chers condisciples et selon la tradition d'Hippocrate, je promets et je jure d'être fidèle aux lois de l'honneur et de la probité dans l'exercice de la Médecine.

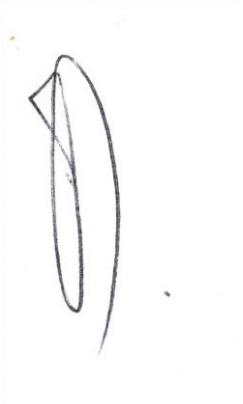
Je donnerai mes soins gratuits à l'indigent, et n'exigerai jamais un salaire au-dessus de mon travail.

Admis dans l'intérieur des maisons, mes yeux ne verront pas ce qui s'y passe, ma langue taira les secrets qui me seront confiés et mon état ne servira pas à corrompre les mœurs ni à favoriser le crime.

Respectueux et reconnaissant envers mes Maîtres, je rendrai à leurs enfants l'instruction que j'ai reçue de leurs pères.

Que les hommes m'accordent leur estime si je suis fidèle à mes promesses. Que je sois couvert d'opprobre et méprisé de mes confrères si j'y manque.

Vu, le Directeur de Thèse



Vu, le Doyen

De la Faculté de Médecine de
Tours

Tours, le

Thabaud Maïna

Nombre de pages : 72 – Tableaux : 14 – Figures : 10

Résumé :

Introduction: Le cancer du sein est le cancer le plus fréquent et également la première cause de mortalité chez les femmes dans le monde. Le développement des thérapeutiques et la détection précoce sont à l'origine d'une diminution de la mortalité spécifique. Cependant, le risque de faux positifs est élevé et entraîne des surdiagnostics. Le bénéfice à l'échelle individuelle est différent du bénéfice à l'échelle globale. L'information des femmes pour une décision médicale partagée, tenant compte de leurs valeurs, peut être réalisée au moyen d'outils d'aide à la décision. Les objectifs de ce travail sont de compléter le répertoire des outils existants et d'en évaluer la qualité dans le cadre du dépistage du cancer du sein par mammographie.

Méthode: Nous avons actualisé et complété une revue de la littérature déjà existante issue de Pubmed. Les titres, puis les résumés, puis les textes entiers ont été examinés indépendamment par deux lecteurs. La qualité des outils d'aide a été évaluée selon les critères IPDAS (International Patient Decision Aid Standards instrument), en double aveugle également.

Résultat: Nous avons étudié quatre outils d'aide à la décision. Ils ont une note au-dessus de 75/100 et sont donc intéressants. Les seules dimensions qui nécessitaient une amélioration étaient l'apport de précision sur le développement du processus d'élaboration de l'outil et d'évaluation de celui-ci.

Conclusion: L'actualisation de cette revue met en évidence l'existence d'outils de qualité à destination des femmes à risque moyen pour permettre un choix éclairé et partagé dans la réalisation du dépistage par mammographie.

Mots clés :

Cancer du sein, Dépistage, Mammographie, Outils d'aide, Décision partagée, Dépistage précoce du cancer, Communication en santé, Soins primaires.

Jury :

Président du Jury : Professeur Gilles BODY

Directeur de thèse : Docteur Sandrine HILD

Membres du Jury : Professeur Vincent CAMUS

Professeur Claude LINASSIER

Docteur Cédric RAT

Date de soutenance : le 8 novembre 2018

ERRATA

Analysis based on title

EMBASE : 1144

PUBMED : 328

PSYCHINFO : 79

COCHRANE : 25

BDSP : 5

Excluded : 906

Excluded : 203

Excluded : 41

Excluded : 21

Excluded : 5

Analysis based on abstract

EMBASE : 238

PUBMED : 125

PSYCHINFO : 38

COCHRANE : 4

BDSP : 0

Excluded : 212

Excluded : 63

Excluded : 22

Excluded : 2

Excluded : 0

Full text analysis

EMBASE : 26

PUBMED : 62

PSYCHINFO : 16

COCHRANE : 2

BDSP : 0

Excluded : 25

Excluded : 62

Excluded : 15

Excluded : 2

Excluded : 0

Included studies

EMBASE : 1

PUBMED : 0

PSYCHINFO : 1

COCHRANE : 0

BDSP : 0

Analysis based on title

EMBASE : 1144

PUBMED : 328

PSYCHINFO : 79

COCHRANE : 25

BDSP : 5

→ Excluded : 906

High risk : 279

*Not DA** : 305

Not screening : 70

Not breast cancer : 252

→ Excluded : 203

High risk : 54

*Not DA** : 91

Not screening : 21

Not breast cancer : 30

Not Mammography : 7

→ Excluded : 41

High risk : 15

*Not DA** : 22

Not screening : 4

→ Excluded : 21

High risk : 1

*Not DA** : 1

Not screening : 5

Not breast cancer : 14

→ Excluded : 5

*Not DA** : 3

Not breast cancer : 2

Analysis based on abstract

EMBASE : 238

PUBMED : 125

PSYCHINFO : 38

COCHRANE : 4

→ Excluded : 212

Before 1997 : 1

High risk or symptomatic patients : 9

Not DA/guidelines* : 166

No mention mammography : 23

Information to health professional : 4

Risk factors/score : 9

→ Excluded : 63

High risk or symptomatic patients : 1

Not DA/guidelines* : 45

No mention mammography : 8

Information to health professional : 1

Risk factors/score : 6

Participation rates : 2

→ Excluded : 22

Before 1997 : 1

High risk or symptomatic patients : 2

Not DA/guidelines* : 11

No mention mammography : 1

Information to health professional : 1

Risk factors/score : 2

Characterisitic of the population/knowledge : 4

→ Excluded : 2

High risk or symptomatic patients : 1

Characterisitic of the population/knowledge : 1

Full text analysis

EMBASE : 26

PUBMED : 62

PSYCHINFO : 16

COCHRANE : 2

→ Excluded : 25

High risk : 1

Guidelines : 1

Promotion of screening : 4

Information to health professional : 1

Practices or knowledge of health professional : 2

Mentionnes importance of DA without using one* : 4

Full text non available : 1

Material information non available (running) : 2

Known DA and Systematic revue with known DA** : 6

No answer : 3

→ Excluded : 62

High risk : 1

Implementation of screening

or participation rate : 1

Educationnal intervention

with no material available : 8

Promotion of screening : 2

Information to health professional : 2

Practices or knowledge of health professional : 2

Mentionnes importance of DA without using one* : 16

Women's knowledge or willness of shared decision : 14

DA not justified, not developed study* : 7

Material information non available : 2

Known DA and Systematic revue with known DA** : 6

No answer : 1

→ Excluded : 2

*Systematic revue with known DA** : 2

→ Excluded : 15

Before 1997 : 1

Promotion of screening : 1

Factors associated to screening : 1

Mentionnes importance of DA without using one* : 2

Full text non available : 1

Material information non available : 1

Known DA and Systematic revue with known DA** : 4

No answer : 4

Included studies

EMBASE : 1

PUBMED : 0

PSYCHINFO : 1

COCHRANE : 0

BDSP : 0