

Supplementary files

Table S1: Interview guide (women)

Hello, my name is [first name, family name]. I'm a researcher from the University of Paris 13 [or the University of Poitiers]. Thank you for finding the time for this interview. I am doing a research project about breast cancer screening and, in particular, the information about screening given to women. Our interview will be audio-recorded so that we can collect all the necessary data. Your personal information will be anonymized and then deleted at the end of the study.

1) [BREAST CANCER] **What do you know about breast cancer?**

(Prompt) What can you do to avoid breast cancer or to minimize the likelihood of developing it? To what extent do you feel concerned by breast cancer in your everyday life?

2) [BREAST CANCER SCREENING] **What do you know about breast cancer screening in France?**

(Prompt) What does screening mean for you? Do you feel concerned by breast cancer screening?

(Prompt) What do you think are the differences between organized screening programmes and individual screening?

(Prompt) What do you know about the effectiveness of screening?

3) [PARTICIPATION IN SCREENING] **Have you ever been screened for breast cancer? What did you think about that experience?**

(Prompt) How did you decide whether to get screened or not?

(Prompt) What information did you receive? Who gave you the information? How did you receive it?

(Prompt) How did you feel during the [first] screening?

4) [INFORMATION] **What information about breast cancer screening do you think you should have?**

(Prompt) What information would you have liked to have received but didn't?

(Prompt) How would you like to receive information about breast cancer screening? Who would you like to receive it from?

(Prompt) What format should this information have, in your opinion? Do you think that a healthcare professional should help you to decide?

(Prompt) You told me that you go for regular check-ups with a gynaecologist/general practitioner. Do you discuss breast cancer screening with him/her?

(Prompt) How would you raise the subject with him/her?

(Prompt) What do you expect from him/her?

- 5) [GENERAL IMPRESSION OF THE DECISION AIDS PRESENTED] **What do you think of these documents?** [*Show the interviewee the documents and let her look at them for 10 minutes or so*]

(Prompt) What do you think about these documents?

(Prompt) What did you get from the documents?

(Prompt) What have you understood from them? Are they easy to understand?

(Prompt) Were you already aware of this information about the advantages and risks [of screening]? If so, how did you receive the information?

- 6) [CONTENT AND FORMAT] **What do you think about the documents' content?**

(Prompt) And what about the format?

(Prompt) What would you change in these documents? (Prompt) What would you add to or remove from the documents? (Prompt) Which one do you prefer? Why? (Prompt) Which one is least meaningful for you? Why?

- 7) [SUMMARY OF THE SAMPLES SHOWN] **What do you think about these diagrams/figures /drawings?**

(Prompt) How did they enhance your knowledge about breast cancer screening? (Prompt) What do you think about the figures?

(Prompt) Do they help you to understand not only the advantages but also the risks associated with screening?

(Prompt) What other ways of presenting this information would you suggest?

- 8) [END PURPOSE OF THE INFORMATION] **How does this information influence your opinion about screening? Are there other things that you'd like to know before being able to make a decision?**

(Prompt) What additional information would you need?

Table S2: Interview guide for GPs

1) [BREAST CANCER SCREENING] **What do you think about breast cancer screening?**

2) [PROFESSIONAL ROLE] **What is your role in breast cancer screening?**

3) [REAL-LIFE EXAMPLE] **Can you tell me about a recent consultation during which you raised this subject with one of your [female] patients?**

(Prompt) How did the consultation go?

(Prompt) What information were you able to give to the patient?

(Prompt) What information were you unable to give to the patient?

(Prompt) In your opinion, what extra information would your patient liked to have received?

How was the decision made?

(Prompt) What was your role and what was the patient's role in the decision?

(Prompt) Did you form a consensus decision with the patient? How do you know that you did?

4) [THE TOOLS] **What do you think about using information tools and/or decision aids for shared decision-making during a consultation?**

And what about [the use of these tools and decision aids in] breast cancer screening?

(Prompt) What do you know about decision aids for shared decision-making? Have you already used any? If so, which ones? And why did you use them?

(Prompt) What do you understand by the term "decision aid"?

(Prompt) What format should this type of tool have?

(Prompt) What medium should the tool use, in your opinion?

How could [a decision aid] be integrated into shared decision-making with the patient?

5) [Practical example] **What do you think about these documents?** (*Show the interviewee the documents and let him/her look at them for 10 minutes or so*)

(Prompt) What do you think about the documents' content? And about their form?

(Prompt) What did you learn from them?

(Prompt) Which do you prefer? Why?

(Prompt) Which one is least meaningful for you? Why?

(Prompt) What would you change in these documents?

(Prompt) What would you add to or remove from these documents?

(Prompt) What did you learn [from the documents] about breast cancer screening? Do they help you to better understand not only the advantages but also the risks associated with screening?

(Prompt) How could these documents be used in practice?

(Prompt) Do you think that they are useful for your practice?

Table S3: Interview guides for other healthcare professionals

Hello, my name is [first name, family name]. I'm a house officer in general medicine at the Paris 7 Faculty of Medicine. Thank you for finding the time for this interview. I am doing a research project about breast cancer screening. Our interview will be audio-recorded so that we can collect all the necessary data. Please be aware that there are no right or wrong answers and that your personal information will be anonymized and then deleted at the end of the study.

Background information on the interviewee: age, type of practice, time since qualification, etc.

INTERVIEW GUIDE – GYNAECOLOGISTS and MIDWIVES

- 1) [BREAST CANCER SCREENING] **How do you address breast cancer screening with your [female] patients?**
- 2) [REAL-LIFE EXAMPLE] **Can you tell me about a recent consultation during which you raised this subject with one of your patients?**
[For midwives, if they do not address this subject]: Why don't you raise the subject of breast cancer screening with your patients?
- 3) [FEELING] **In your opinion, what do patients feel about this screening?**

(Prompt) What type of information do they ask for?

- 4) [PROFESSIONAL ROLE] **What information do you give them? What type of document or medium do you use?**
- 5) [TOOLS] **What do you think about information tools and/or decision aids for shared decision-making with regard to breast cancer screening?**
- 6) [PRACTICAL EXAMPLE] **What do you think about these documents?** *(Show the interviewee the documents and let him/her look at him/her for 10 minutes or so)*

(Prompt) What type of tools would you like to have at your disposal for advising women about breast cancer screening?

INTERVIEW GUIDE – RADIOLOGISTS

- 1) [REAL-LIFE EXAMPLE] **What happens when a woman attends your clinic for a mammogram?**

(Prompt) What happens for individual screening and for organized screening?

(Prompt) Do you perform a clinical examination and have a pre-screening interview?

(Prompt) Does this screening create any problems for you (organisational aspects, interpretation, giving the results to the patient, etc.)?

2) [PROFESSIONAL ROLE] **What type of dialogue do you have with the patients?**

(Prompt) Is this before or after you have analyzed the mammogram?

(Prompt) Do you wait for the second analysis?

3) [FEELING] **In your opinion, how do patients feel about this screening?**

(Prompt) If patients ask for more information, what type of tools do you use or would like to use?

4) [PRACTICAL EXAMPLE] **What do you think about these documents?** (*Show the interviewee the documents and let him/her look at them for 10 minutes or so*)

INTERVIEW GUIDE – SCREENING PROGRAMME MANAGER

1) [REAL-LIFE EXAMPLE] **How do you get involved in organized breast cancer screening?**

2) [PROFESSIONAL ROLE] **What sort of information should breast cancer screening candidates be given?**

(Prompt) What do you think about the official document used throughout France?

(Prompt) Have you developed other ways of informing patients?

3) [FEELING] **In your opinion, how do patients feel about this screening?**

4) [BREAST CANCER SCREENING] **What do you think about shared decision-making in breast cancer screening?**

5) [PRACTICAL EXAMPLE] **What do you think about these documents?**

(Show the interviewee the documents and let him/her look at them for 10 minutes or so)

Table S4: Examples of information tools and decision aids**Tool 1**

What is screening?

Screening means examining a group of people in order to detect disease or to find people at increased risk of disease.

In many countries, women between 50 and 69 years of age are offered an X-ray examination of the breasts – screening with mammography - every second or third year. The purpose of the screening examination is to find women who have breast cancer in order to offer them earlier treatment.

Screening with mammography has both benefits and harms. The aim of this leaflet is to help each woman weigh up the pros and cons in the light of her own values and preferences, in order that she can make a personal decision whether she wishes to attend.

If nothing abnormal is found by screening, it makes the woman feel reassured that she is healthy. But almost all women feel healthy before they are invited to screening. Furthermore, the invitation itself may cause insecurity. Therefore, screening creates both security and insecurity.

Benefits

Reduced risk of dying from breast cancer - Regular screening with mammography cannot prevent breast cancer, but it can perhaps reduce the risk of dying from breast cancer. A systematic review of the randomised trials of mammography screening found that:

If 2000 women are screened regularly for 10 years, one will benefit from screening, as she will avoid dying from breast cancer because the screening detected the cancer earlier.

Since these trials were undertaken, treatment of breast cancer has improved considerably. Women today also seek medical advice much earlier than previously, if they have noted anything unusual in their breasts. In addition, diagnosis and treatment have been centralised in many countries and are now provided by teams of breast cancer experts.

Because of these improvements, screening is less effective today and newer studies suggest that mammography screening is no longer effective in reducing the risk of dying from breast cancer (see *Documentation for the facts and figures* below).

Screening does not reduce the overall risk of dying, or the overall risk of dying from cancer (including breast cancer).

Harms

Overdiagnosis and overtreatment - Some of the cancers and some of the early cell changes (carcinoma in situ) that are found by screening grow so slowly that they would never have developed into a real cancer. Many of these screen-detected "pseudo-cancers" would even have disappeared spontaneously, if they had been left alone, without treatment.

Since it is not possible to tell the difference between the dangerous and the harmless cell changes and cancers, all of them are treated. Therefore, screening results in treatment of many women for a cancer disease they do not have, and that they will not get. Based on the randomised trials, it appears that:

If 2000 women are screened regularly for 10 years, 10 healthy women will be turned into cancer patients and will be treated unnecessarily. These women will have either a part of their breast or the whole breast removed, and they will often receive radiotherapy, and sometimes chemotherapy. Treatment of these healthy women increases their risk of dying, e.g. from heart disease and cancer.

Unfortunately, some of the early cell changes (carcinoma in situ) are often found in several places in the breast. Therefore, the whole breast is removed in one out of four of these cases, although only a minority of the cell changes would have developed into cancer.

More extensive surgery and aftertreatment - For women diagnosed at screening with a small "true" cancer, the operation and aftertreatment may be less extensive than if the cancer had been detected at a later time. However, as screening also leads to overdiagnosis and subsequent overtreatment of healthy women,

more women in total will have a breast removed when there is screening than if there had not been screening. Also, more women will receive radiotherapy unnecessarily.

False alarm - If the X-ray shows something that might be cancer, the woman is recalled for additional investigations. In some cases it turns out that what was seen on the X-ray was benign, and that it was therefore a false alarm.

If 2000 women are screened regularly for 10 years, about 200 healthy women will experience a false alarm. The psychological strain until it is known whether or not there is a cancer can be severe. Many women experience anxiety, worry, despondency, sleeping problems, changes in the relationships with family, friends and acquaintances, and a change in sex drive. This can go on for months, and in the long term some women will feel more vulnerable about disease and will see a doctor more often.

Pain at the examination - The breast is squeezed flat between two plates while an X-ray is taken. It only takes a moment, but about half of the women find it painful.

False reassurance - Mammography screening cannot detect all cancers. It is important, therefore, that the woman sees a doctor if she finds a lump in her breast, even if she has had a mammogram recently.

Gøtzsche PC, Hartling OJ, Nielsen M, et al. Mammography screening leaflet. Copenhagen: Nordic Cochrane Centre 2012. <https://www.cochrane.dk/mammography-screening-leaflet> (accessed Janv 2022)

Tool 2

Should I be screened with mammography for breast cancer?

For women between 40 and 49 years of age:

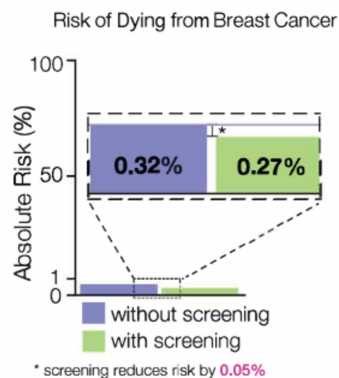
Among women who do not screen, the risk of dying from breast cancer is: **1 in 313**
 With regular screening your risk of dying of breast cancer is: **1 in 370**

However, with regular screening:
 ... your risk of having a false positive mammogram requiring further screening is: **1 in 3**
 ... your risk of having a biopsy is: **1 in 28**
 ... your risk of having part or all of a breast removed unnecessarily is: **1 in 200**

Be informed!

You may hear the risks or benefits of breast cancer screening described as either **absolute** or **relative**. But what does all this mean and how does it apply to you?

The main difference is that absolute risk takes into consideration the fact that whether or not you get screened or treated, you still have a baseline risk of dying of breast cancer: **1 in 313** or **0.32%**. With regular screening that risk changes to: **1 in 370** or about **0.27%**. Relative risk does not consider baseline risk in the same way and may lead to confusion about how regular screening reduces risk.



The absolute risk is simply the difference in risk between regular screening (0.27%) and no screening (0.32%).

$$0.32\% - 0.27\% = 0.05\%$$

Therefore screening in women aged 40-49 reduces your **absolute risk** of dying of breast cancer by 0.05%. So the **absolute benefit** of screening is 0.05%.

Relative risk only looks at the reduction in risk as a proportion of the total risk (so it doesn't consider that you are already at risk of cancer, this can lead to larger values than absolute risk).

$$0.05\% / 0.32\% = 15\%$$

Thus, screening in women aged 40-49 reduces your **relative risk** of dying of breast cancer by 15%. So the **relative benefit** of screening is 15%.

So how does this translate into actual numbers? Among 100 000 women aged 40 to 49 who are:

Screened **EVERY** 2 years for 11 years:

- 270 would die of breast cancer
- 32 700 would experience a false alarm
- 3600 would have a biopsy
- 500 would have part or all of a breast removed without having cancer
- 50 would escape a breast cancer death

NOT screened for 11 years:

- 320 would die of breast cancer
- 99 680 would not

For more info visit:

<http://www.canadiantaskforce.ca>

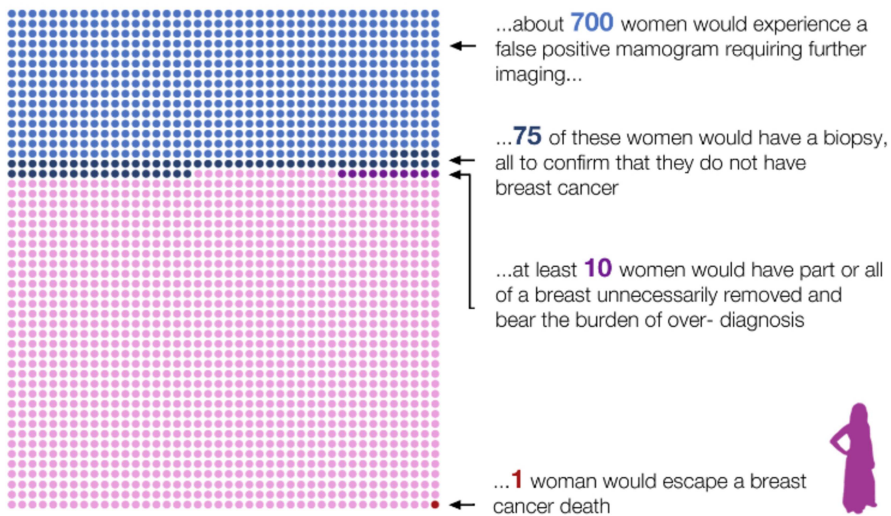
Should I be screened with mammography for breast cancer?

Absolute Benefit of Screening with Mammography

If we wanted to describe the previous information in regards to the effect on an individual woman then we can look at what would occur in a base of 2100 women instead of 100 000.

In the graphic below, each dot represents 1 woman (● = 1 woman)

If we screened **2100** women, aged 40-49 years, at average risk of breast cancer every two years for 11 years...



For more information visit: <http://www.canadiantaskforce.ca>

Should I be screened with mammography for breast cancer?

For women between 50 and 69 years of age:

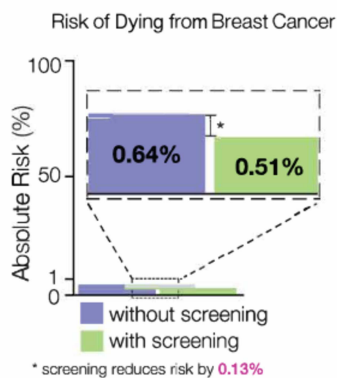
Among women who do not screen, the risk of dying from breast cancer is: **1 in 155**
 With regular screening your risk of dying of breast cancer is: **1 in 196**

However, with regular screening:
 ... your risk of having a false positive mammogram requiring further screening is: **1 in 4**
 ... your risk of having a biopsy is: **1 in 28**
 ... your risk of having part or all of a breast removed unnecessarily is: **1 in 200**

Be informed!

You may hear the risks or benefits of breast cancer screening described as either **absolute** or **relative**. But what does all this mean and how does it apply to you?

The main difference is that absolute risk takes into consideration the fact that whether or not you get screened or treated, you still have a baseline risk of dying of breast cancer: **1 in 155** or **0.64%**. With regular screening that risk changes to: **1 in 196** or about **0.51%**. Relative risk does not consider baseline risk in the same way and may lead to confusion about how regular screening reduces risk.



The absolute risk is simply the difference in risk between regular screening (0.47%) and no screening (0.64%).

$$0.64\% - 0.51\% = 0.13\%$$

Therefore screening in women aged 50-69 reduces your **absolute risk** of dying of breast cancer by 0.13%. So the **absolute benefit** of screening is 0.13%.

Relative risk only looks at the reduction in risk as a proportion of the total risk (so it doesn't consider that you are already at risk of cancer, this can lead to larger values than absolute risk).

$$0.13\% / 0.64\% = 21\%$$

Thus, screening in women aged 50-69 reduces your **relative risk** of dying of breast cancer by 21%. So the **relative benefit** of screening is 21%.

So how does this translate into actual numbers? Among 100 000 women aged 50 to 69 who are:

Screened **EVERY** 2 years for 11 years:

- 510 would die of breast cancer
- 28 200 would experience a false alarm
- 3700 would have a biopsy
- 500 would have part or all of a breast removed without having cancer
- 138 would escape a breast cancer death

NOT screened for 11 years:

- 640 would die of breast cancer
- 99 360 would not

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<http://www.canadiantaskforce.ca>

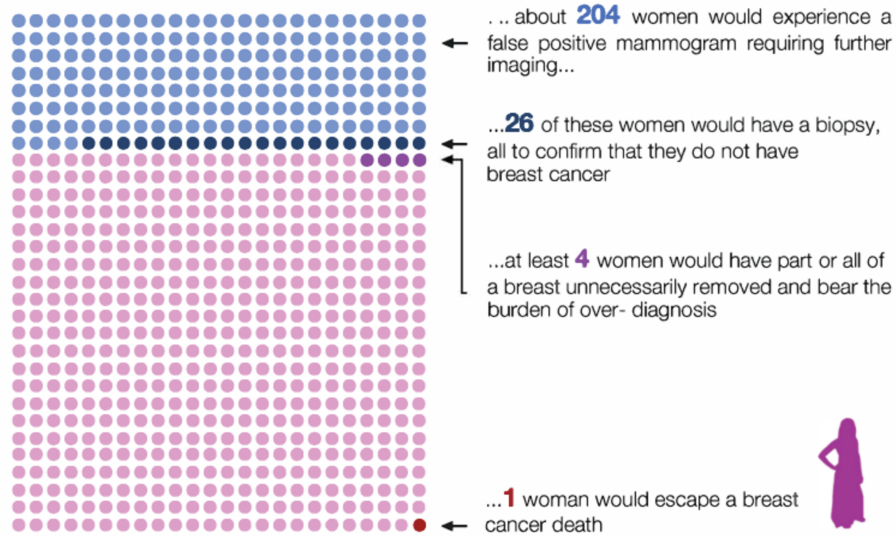
Should I be screened with mammography for breast cancer?

Absolute Benefit of Screening with Mammography

If we wanted to describe the previous information in regards to the effect on an individual woman then we can look at what would occur in a base of 720 women instead of 100 000.

In the graphic below, each dot represents 1 woman (● = 1 woman)

If we screened **720** women, aged 50-69 years, at average risk of breast cancer every two years for 11 years...



For more information visit: <http://www.canadiantaskforce.ca>

Should I be screened with mammography for breast cancer?

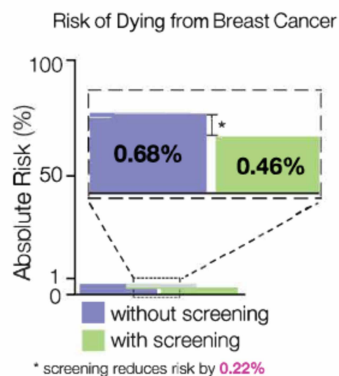
For women between 70 and 74 years of age:

Among women who do not screen, the risk of dying from breast cancer is:	1 in 146
With regular screening your risk of dying of breast cancer is:	1 in 217
However, with regular screening:	
... your risk of having a false positive mammogram requiring further screening is:	1 in 5
... your risk of having a biopsy is:	1 in 38
... your risk of having part or all of a breast unnecessarily removed is:	1 in 200

Be informed!

You may hear the risks or benefits of breast cancer screening described as either **absolute** or **relative**. But what does all this mean and how does it apply to you?

The main difference is that absolute risk takes into consideration the fact that whether or not you get screened or treated, you still have a baseline risk of dying of breast cancer: **1 in 146** or **0.68%**. With regular screening that risk changes to: **1 in 217** or **0.46%**. Relative risk does not consider baseline risk in the same way and may lead to confusion about how regular screening reduces risk.



The absolute risk is simply the difference in risk between regular screening (0.46%) and no screening (0.68%).

$$0.68\% - 0.46\% = 0.22\%$$

Therefore screening in women aged 70-74 reduces your **absolute risk** of dying of breast cancer by 0.22%. So the **absolute benefit** of screening is 0.22%.

Relative risk only looks at the reduction in risk as a proportion of the total risk (so it doesn't consider that you are already at risk of cancer, this can lead to larger values than absolute risk).

$$0.22\% / 0.68\% = 32\%$$

Thus, screening in women aged 70-74 reduces your **relative risk** of dying of breast cancer by 32%. So the **relative benefit** of screening is 32%.

So how does this translate into actual numbers? Among 100 000 women aged 70 to 74 who are:

Screened **EVERY** 2 years for 11 years:

- 460 would die of breast cancer
- 21 200 would experience a false alarm
- 2600 would have a biopsy
- 500 would have part or all of a breast removed without having cancer
- 222 would escape a breast cancer death

NOT screened for 11 years:

- 680 would die of breast cancer
- 99 320 would not

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<http://www.canadiantaskforce.ca>

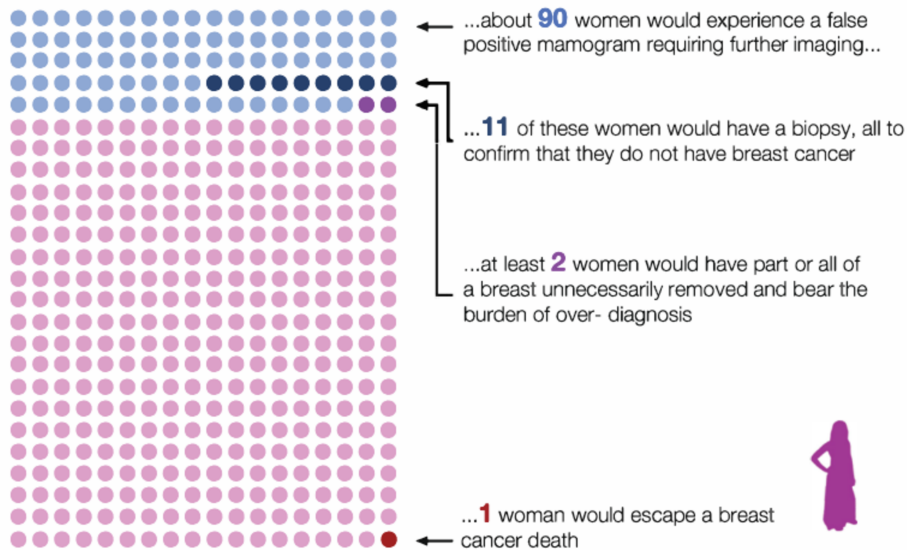
Should I be screened with mammography for breast cancer?

Absolute Benefit of Screening with Mammography

If we wanted to describe the previous information in regards to the effect on an individual woman then we can look at what would occur in a base of 450 women instead of 100 000.

In the graphic below, each dot represents 1 woman (● = 1 woman)

If we screened **450** women, aged 70-74 years, at average risk of breast cancer every two years for 11 years...



For more information visit: <http://www.canadiantaskforce.ca>

Canadian Task Force on Preventive Health Care. Breast Cancer (2011). Montreal: CTFPHC 2011. <https://canadiantaskforce.ca/tools-resources/breast-cancer-2/> (accesses Janv 2022)

Tool 3

Rappel

Dépistage individuel :
le médecin prescrit une mammographie sans passer par l'Adémas-69.

Dépistage organisé :
l'Adémas-69 envoie, tous les 2 ans, à toutes les femmes de 50 à 74 ans une lettre d'invitation à pratiquer une mammographie.

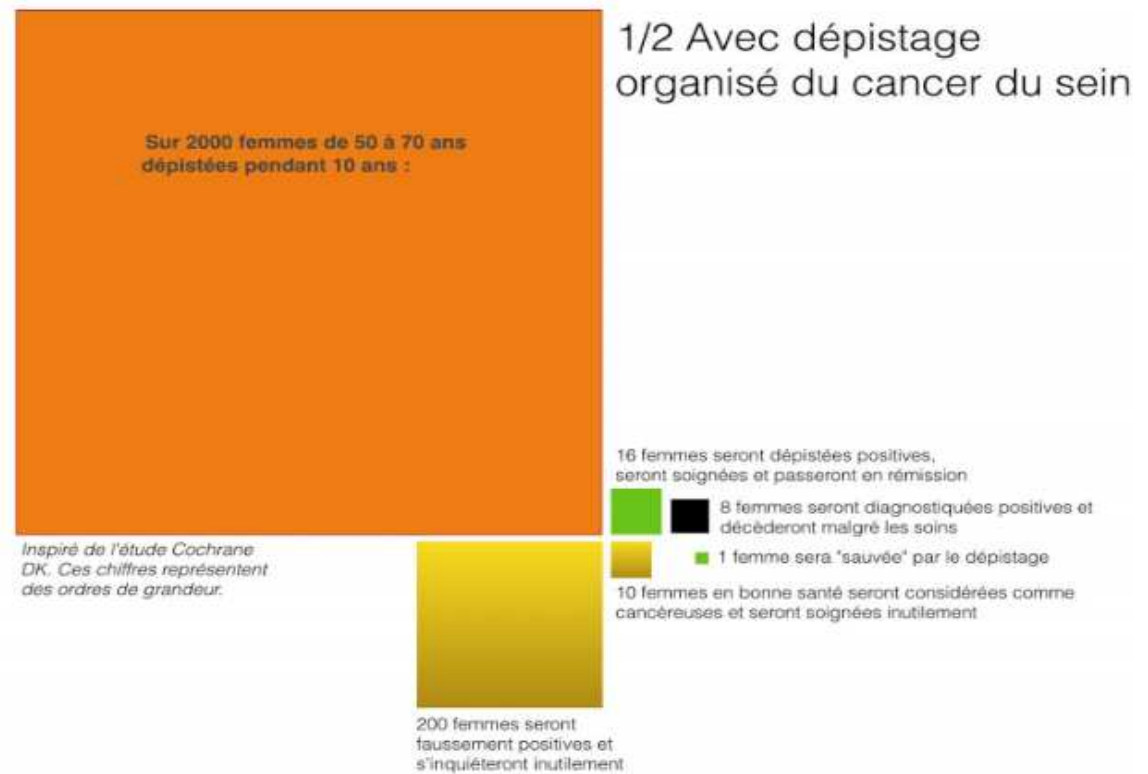
Dépistage organisé (Adémas-69)	Dépistage individuel
Rappel régulier et automatique de la date de l'examen	Rappel par le médecin lors d'une visite
Contrôle de la qualité technique des clichés	
Double lecture systématique à l'Adémas-69 des mammographies qui ne sont pas suspectes (cf. verso)	Pas de double lecture systématique
6 cancers sur 100 découverts par la seconde lecture	Pas de données chiffrées
Résultat immédiat et double lecture des clichés remis 15 jours plus tard	Résultat immédiat et pas de double lecture
Relecture possible de la mammographie par le médecin traitant ou le gynécologue	
Pas d'avance des frais pour la mammographie : gratuite	Avance des frais de la mammographie
Avance des frais des examens complémentaires	

Second niveau de décision :
faire le dépistage individuel ou participer au dépistage organisé.



Questions à poser à mon médecin

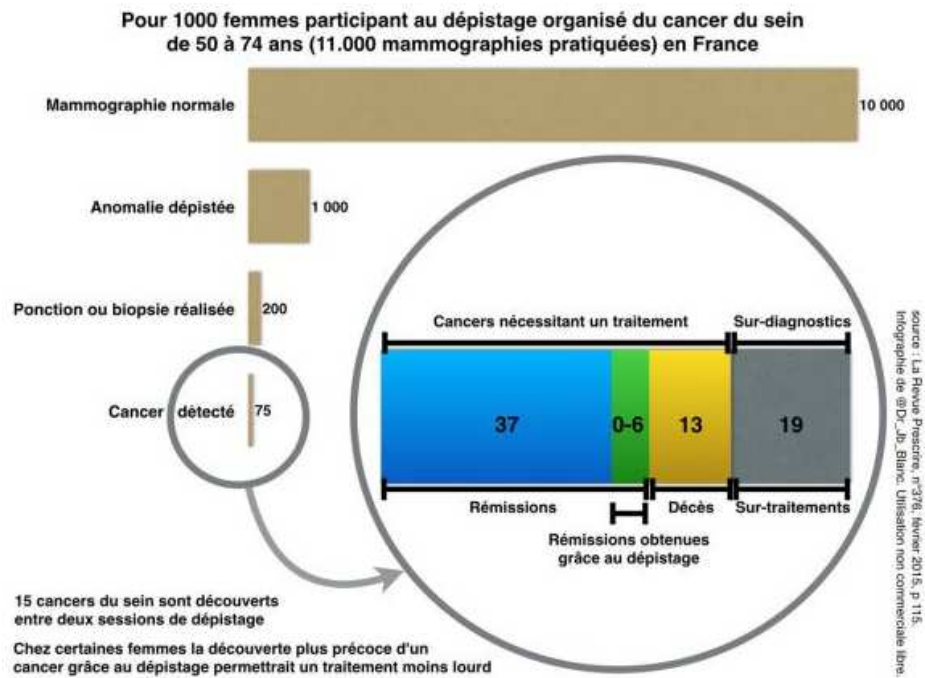
Bourmaud A, Soler-Michel P, Oriol M, et al. Decision aid on breast cancer screening reduces attendance rate: results of a large-scale, randomized, controlled study by the DECIDEO group. *Oncotarget* 2016;15(7):12885-92.

Tool 4

Blanc JB. Comment pratiquer la prise de décision partagée en médecine générale? [Mémoire en vue du diplôme inter universitaire de requalification à la pratique de la médecine générale]. Université de Rennes1 2015.

<https://sites.google.com/site/ladecisionpartagee/home> (accesses Janv 2022)

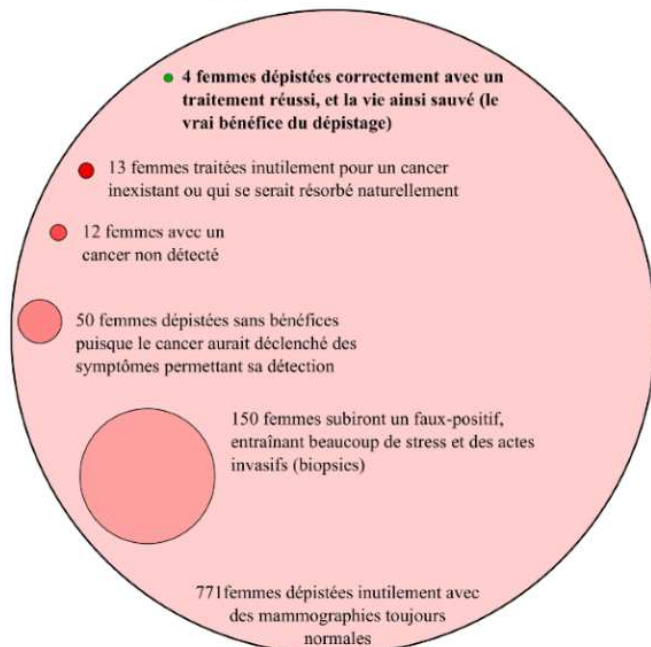
Tool 5



Prescrire. Partager avec les femmes les informations utiles pour décider de participer ou non au dépistage des cancers du sein. Rev Prescrire 2015;35(376):115.

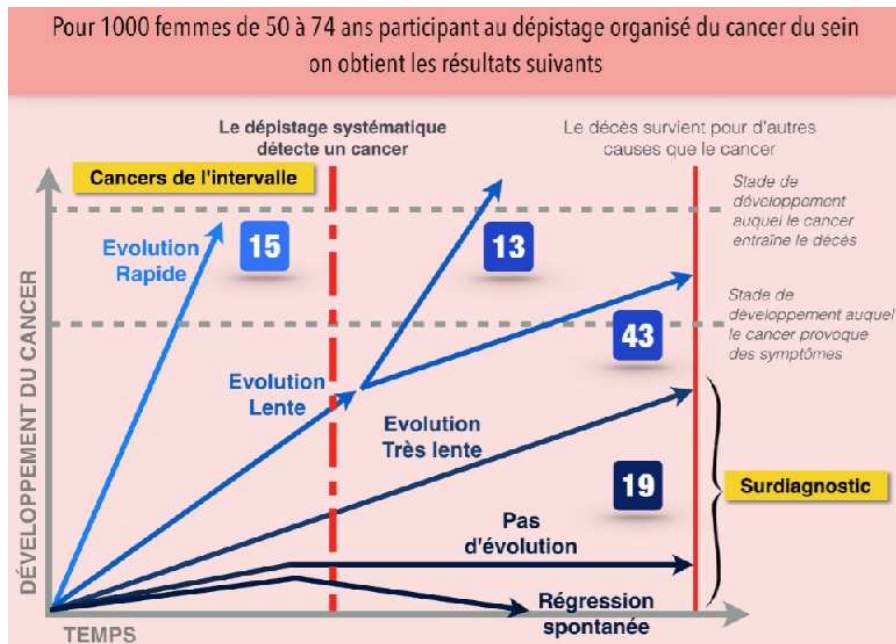
Tool 6

Sur 1000 femmes dépistées pendant 20 ans à raison d'une mammographie tous les deux ans:



Dur à avaler. La mammographie de dépistage pour le cancer du sein : inutile et dangereuse ? Noumea: Dur à avaler 2016. <https://www.dur-a-avaler.com/la-mammographie-de-dépistage-pour-le-cancer-du-sein-inutile-et-dangereuse/> (accessed Janv 2022)

Tool 7



PDQ® Screening and Prevention Editorial Board. PDQ Breast Cancer Screening. Bethesda, MD: National Cancer Institute 2021. <https://www.cancer.gov/types/breast/patient/breast-screening-pdq> (accessed Janv 2022)