Appendix

Appendix A: Materials for Chapter 2

Appendix B: Materials for Chapter 3

Appendix C: Materials for Chapter 5

Appendix A: Materials for Chapter 2

All Materials are translated into English and scaled down.

A.1 The Bayesian inference problem used in the pre-test

Example 1: Trisomy 21
Children with Down's syndrome have three copies of the chromosome 21; this is why it is also called Trisomy 21 (former name: mongolism). By measuring the nuchal translucency via ultrasound information can be obtained, whether a fetus has an increased risk of carrying the Down's syndrome.

- The probability that a pregnant woman gives birth to a child who has Down's syndrome is 0.15%
- If a woman is pregnant with a child who has Down's syndrome, the probability that the ultrasound test on nuchal translucency shows positive is 80%.
- If a woman is pregnant with a child who does not have Down's syndrome, the probability that the ultrasound test on nuchal translucency still shows positive is 8%.

A pregnant woman receives a positive test result. What is the probability that her child has Down's syndrome? ____% (Please describe briefly, how you arrived at your solution, if necessary use reverse side)

A.2 The three remaining Bayesian inference problems used during the tutorial

Example 2: Breast cancer
Breast cancer (Mamma carcinoma) is the most frequent type of cancer in females in Europe and also North America. It is long known that women with a family history, that means breast cancer in first- and second-degree relatives, have an increased breast cancer risk. By now two genes (BRCA1 and BRCA2) have been identified which, if they show mutations, can forward the development of a Mamma carcinoma.

- The lifelong risk for a woman in Germany to develop breast cancer is 8%.
- 5% of all women who have breast cancer show a mutation in one of the genes BRCA1 or BRCA2.
- In 0.29% of all women who do not develop breast cancer one also finds a mutation of one of the genes BRCA1 or BRCA2.

What is the risk of a woman who has a mutation of one of the genes BRCA1 or BRCA2 (= test positive) to develop breast cancer in the course of her life? ____%

Example 3: Colorectal cancer
To diagnose colorectal cancer, the hemoccult test – among others – is conducted to detect occult (not visible, hidden) blood in the stool. This test is not only performed from a certain age onwards, but also in a routine screening for early detection of colorectal cancer.
Imagine conducting a screening using the hemoccult test in a certain region. For symptom-free persons over 50 years of age who participate in screening using the hemoccult test, the following information is available for this region:

- The probability that one of these persons has colorectal cancer is 0.3%.
- If one of these persons has colorectal cancer, the probability is 50% that he or she will have a positive result in the haemoccult test.
- If one of these persons does not have colorectal cancer, the probability is 3% that he or she will still have a positive result in the haemoccult test.

A person (aged over 50, no symptoms) receives a positive test result in your screening. What is the probability that this person has colorectal cancer? ____%

Example 4: HIV
In order to diagnose an infection with the HIV-Virus (AIDS), a test that examines whether there are HIV-antibodies in the blood is performed. Imagine that you work in a public health department and perform HIV tests there. For heterosexual males from this region between 20 and 30 without any known risk factors, the following information is available:

- The probability that one of these persons is infected with HIV is 0.01%.
- If one of these persons is infected with HIV, then the probability for a positive result in the HIV-test is 99.8%.
- If one of these persons is not infected with HIV, then the probability for a positive result in the HIV test is still 0.01%.

A man of the mentioned group (heterosexual, between 20 and 30, no known risk factors) receives a positive test result. What is the probability, that he is infected with HIV? ____%

A.3 The two Bayesian inference problems used in the post-test

Diabetes
The insulin-dependent diabetes is one type of "sugar sickness" (Diabetes mellitus or shortly called Diabetes). After the outbreak of this type of diabetes, patients are dependent on insulin injections all their life. For this type of diabetes, there exists a certain gene position (two alleles among many others) that is associated with an increased risk of the occurrence of diabetes. The two alleles are called DR3 and DR4.

- The probability for insulin-dependent diabetes is 0.40%.
- If a person has insulin-dependent diabetes, then the probability that she/he has at least one of the two alleles DR3 or DR4 is 95%.
- If a person does not have insulin-dependent diabetes, then the probability that she/he has at least one of the two alleles DR3 or DR4 is 49.82%.

What is the probability that a person has insulin-dependent diabetes, if she/he has at least one of the two alleles DR3 or DR4? _____%

Mammography
Breast cancer (Mamma carcinoma) is the most frequent type of cancer in females in Europe and also North America. Mammography screening is a diagnostic method that is used as a routine examination in order to early detect breast cancer. For forty- to fifty-year old symptom free women who participate in such a routine examination, the following numbers are known:

- The probability that such a woman has breast cancer is 1%.
- If such a woman has breast cancer, then the probability that she receives a positive mammogram is 80%.
- If such a woman does not have breast cancer, then the probability that she receives a positive mammogram is 9.6%.

What is the probability that such a woman has breast cancer, if she has received a positive mammogram in the routine examination? _____%

A.4 Materials presented during the tutorial

(a) Slides to introduce technical terms

The tutorials started with two slides (slides were the same in both conditions) that were shown right after the pre-test was collected.

Slide 1

Here is again Example 1 that you just saw in the pre-test: *(see A.1)*

	Probability for...	%	p	Label
p(D)	Down's syndrome	0.15%	0.0015	Base rate
p(¬ D)	No Down's syndrome	99.85%	0.9985	1 - base rate
p(T|D)	Test positive, given Down's syndrome	80%	0.80	Sensitivity
p(T-|¬ D)	Test negative, given no Down's syndrome	92%	0.92	Specificity
p(T|¬ D)	Test positive, given no Down's syndrome	8%	0.08	1- specificity (= false-positive rate)

Slide 2

Test efficiency: Sensitivity, specificity, positive predictive value

	Disease present (D)	No disease (¬ D)
Test positive (T)	correct positive	false positive
Test negative (T-)	false negative	correct negative

$$\text{Sensitivity} = \frac{\text{correct positives}}{D}$$

$$\text{Specificity} = \frac{\text{correct negatives}}{\neg D}$$

$$\text{Positive predictive value} = \frac{\text{correct positives}}{T}$$

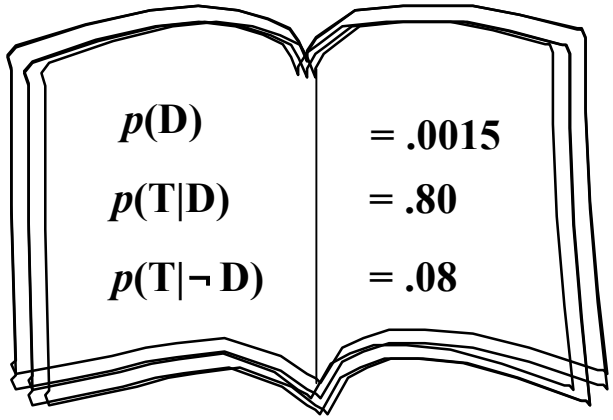
Example 1

	Down's syndrome (D)	No Down's syndrome (¬ D)
Test positive (T)	80%	8%
Test negative (T-)	20%	92%
	100%	100%

(b) Training slides in the rule-learning tutorial

After the technical terms had been explained, participants in the rule-learning tutorial were shown how to solve Example 1 with the help of Bayes' theorem (Slide 1). After that, three further problems were presented (see A.2) and the solution process was again demonstrated on Slides 2 – 4. Slides 2 – 4 were almost the same as Slide 1, the only difference being that the probabilities were not already printed on the right page of "the book".

Slide 1



$$p(D \mid T) = \frac{p(D \,\&\, T)}{p(T)} = \frac{p(D)p(T \mid D)}{p(D)p(T \mid D) + p(\neg D)p(T \mid \neg D)}$$

$$p(D|T) = \frac{\square \times \square}{\square \times \square + \square \times \square}$$

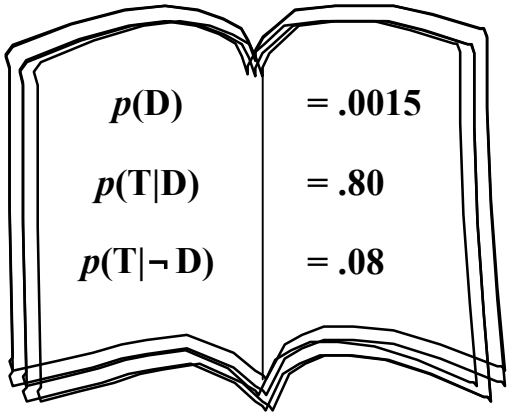
$$= \frac{\qquad\qquad}{\qquad\qquad} = \frac{\qquad\qquad}{\qquad\qquad} =$$

(c) Training slides in the representation-learning tutorial

After the technical terms had been explained, participants in the representation-learning tutorial were shown how to solve Example 1 by translating the probabilities into natural frequencies with the help of a natural frequency tree (Slide 1). After that, three further problems were presented (see A.2) and the solution process was again demonstrated on Slides 2 – 4. Slides 2 – 4 were almost the same as Slide 1, the only differences being that the probabilities were not already printed on the slides, and that the labels at the frequency tree were "Disease present" and "No disease" instead of "Down" and "No Down".

Slide 1

Probabilities

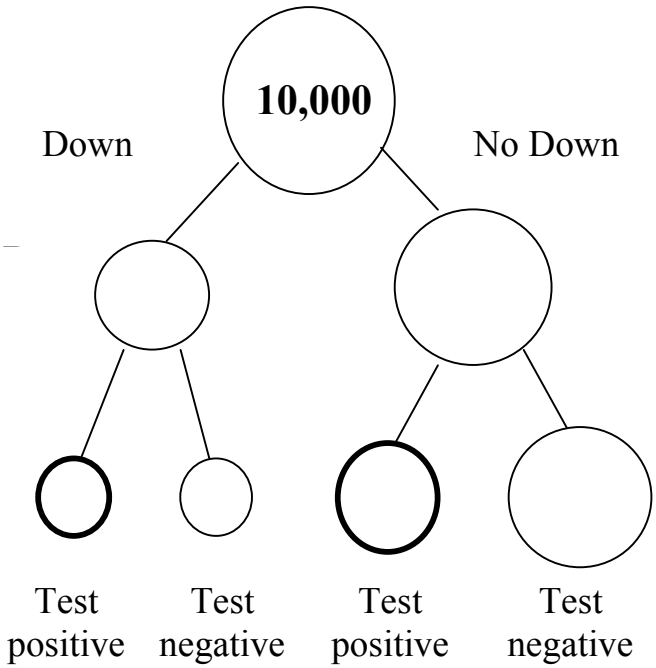


Bayes' theorem

$$p(D \mid T) = \frac{p(D \& T)}{p(T)} = \frac{p(D)p(T \mid D)}{p(D)p(T \mid D) + p(\neg D)p(T \mid \neg D)}$$

$$= \frac{(.0015)(.80)}{(.0015)(.80) + (.9985)(.08)}$$

Natural frequencies



$$p(D \mid T) = \frac{D \& T}{T} = \frac{D \& T}{D \& T + \neg D \& T}$$

$$= \text{\_\_\_\_\_} = \text{\_\_\_\_}$$

Appendix B: Materials for Chapter 3

All Materials are translated into English and scaled down.

B.1 The introductory text of the mammography problem used in Experiment 1 and 2

All six versions of the mammography problem used in Experiment 1 are displayed in Chapter 3 in Table 3.4. However, the table does not show the short introductory text that preceded the problem. Here it is:

"With the goal to reduce breast cancer mortality, women of certain age groups can obtain mammograms (x-ray pictures of the breast) even when they do not show any symptoms of breast cancer. Many women want to know what it exactly means when they receive a positive result in this routine screening (positive result = indicates disease). For women in the age group of forty to fifty years who do not show any symptoms of breast cancer and who participate in routine screening, the following information is available:"

B.2 Three of the four Bayesian inference problems used in Experiment 1

Four different Bayesian inference problems were used in Experiment 1. One of the four, the mammography problem, is displayed in all six versions in Table 3.4. The remaining three problems are listed below. For each problem, two of the six versions are presented (the short frequency task in the GH and in the FI menu), from which the numerical information for the other four versions can be derived.

Colorectal cancer

Short frequency task, GH menu
To diagnose colorectal cancer, the hemoccult test – among others – is conducted to detect occult blood in the stool. This test is not only performed from a certain age onwards, but also in a routine screening for early detection of colorectal cancer. Many participants in such a routine screening want to know what it exactly means when they receive a positive result (positive result = indicates disease). For symptom-free persons over 50 years old who participate in screening using the hemoccult test, the following information is available:
- 315 out of every 10,000 persons receive a positive result in the hemoccult test.
- 15 out of every 10,000 persons have colorectal cancer and receive a positive result in the hemoccult test.

Imagine a new representative sample of persons (without symptoms, same age group) who all receive a positive result in the hemoccult test in a routine screening. How many of these persons actually have colorectal cancer? _____ out of _____

Short frequency task, FI menu
(Same introductory text as above)
- 15 out of every 10,000 persons have colorectal cancer and receive a positive result in the hemoccult test.
- 15 out of every 10,000 persons have colorectal cancer and receive a negative result in the hemoccult test.
- 300 out of every 10,000 persons do not have colorectal cancer and receive a negative result in the hemoccult test.
- 300 out of every 10,000 persons do not have colorectal cancer and receive a positive result in the hemoccult test.

(Same question as above)

Lung damage

Short frequency task, GH menu
Pregnant women use the cosmetic product "Dermofit" to avoid stretch marks. Recently, Dermofit was suspected to cause prenatal lung damage. Therefore, many pregnant women wanted to know what it exactly means for their unborn child when they use Dermofit. Several studies examined mothers and their newborns to check whether the use of Dermofit during pregnancy does or does not cause lung damage. The following data are now available:
- In 5704 out of every 8,500 examined newborns, the mother had used Dermofit during pregnancy.
- 131 out of every 8,500 examined newborns had lung damage and the mother had used Dermofit during pregnancy.

Imagine a new representative sample of newborns whose mothers had used Dermofit during pregnancy. How many of these newborns do have lung damage? _____ out of _____

Short frequency task, FI menu
(Same introductory text as above)
- 131 out of every 8,500 examined newborns had lung damage and the mother had used Dermofit during pregnancy.
- 38 out of every 8,500 examined newborns had lung damage and the mother had not used Dermofit during pregnancy.
- 2,758 out of every 8,500 examined newborns did not have lung damage and the mother had not used Dermofit during pregnancy.
- 5,573 out of every 8,500 examined newborns did not have lung damage and the mother had used Dermofit during pregnancy.

(Same question as above)

Down's syndrome

Short frequency task, GH menu
Children with Down's syndrome have three copies of the chromosome 21; this is why it is also called Trisomy 21. Formerly, the only possibility to detect Trisomy 21 reliably during pregnancy was an incriminating examination of the amniotic fluid. Now a new ultrasound test was developed that is completely without risks. It is very important that pregnant women who undergo the new test understand exactly what a positive test result means (positive result = indicates disease). So far, the following data are available:
- 811 out of every 10,000 pregnant women who had the new ultrasound test received a positive result.
- 12 out of every 10,000 pregnant women who had the new ultrasound test were pregnant with a child that had Trisomy 21 and received a positive result.

Imagine a sample of pregnant women who received a positive result in the new ultrasound test. How many of these women are pregnant with a child that has Trisomy 21? ____ out of _____

Short frequency task, FI menu
(Same introductory text as above)
- 12 out of every 10,000 pregnant women who had the new ultrasound test were pregnant with a child that had Trisomy 21 and received a positive result.
- 3 out of every 10,000 pregnant women who had the new ultrasound test were pregnant with a child that had Trisomy 21 and received a negative result.
- 9,186 out of every 10,000 pregnant women who had the new ultrasound test were pregnant with a child that did not have Trisomy 21 and received a negative result.
- 799 out of every 10,000 pregnant women who had the new ultrasound test were pregnant with a child that did not have Trisomy 21 and received a positive result.

(Same question as above)

Appendix C: Materials for Chapter 5

All Materials are translated into English and scaled down.

Appendix C includes:

C.1 The two model pamphlets

Before reading the pamphlet, women in both groups received the following instruction:

The goal of this study is to develop, with your support, a pamphlet about mammography screening that is both comprehensive and useful. On the basis of currently available mammography pamphlets, we developed several drafts of such a pamphlet that are supposed to be evaluated in this study. You will find one of these drafts on the following pages. Please read the pamphlet draft first and then work through the two questionnaires. If you do not like the draft, please do not hesitate to say so. And if you cannot answer some of the questions about the contents of the pamphlet, please do not hesitate to make this clear – we will certainly not draw any negative conclusions about you, but we will get valuable information about what has to be improved in the draft. But please let us also know what you like about the draft.

Pamphlet with natural frequencies

INFORMATION ABOUT MAMMOGRAPHY SCREENING

This pamphlet addresses women who want to inform themselves about mammography screening. The information in this pamphlet should help you to decide whether the participation in the mammography screening makes sense for you or not.

BREAST CANCER

In Germany, 48 000 women are diagnosed with breast cancer every year. The frequency of breast cancer increases continuously with age. A diagnosis of breast cancer receive (per year):

- 4 of 1000 women between 30 and 39 years
- 12 of 1000 women between 40 and 49 years
- 25 of 1000 women between 50 and 59 years
- 23 of 1000 women between 60 and 69 years
- 25 of 1000 women between 70 and 79 years
- 26 of 1000 women between 80 years and older

Every year, 18 000 women die of breast cancer in Germany. Also the risk of dying from breast cancer increases with age. The following number of women die of breast cancer (per year):

- 1 of 1000 women between 30 and 39 years
- 4 of 1000 women between 40 and 49 years
- 8 of 1000 women between 50 and 59 years
- 8 of 1000 women between 60 and 69 years
- 13 of 1000 women between 70 and 79 years
- 25 of 1000 women between 80 years and older

Only little is known about the causes of breast cancer. But certain factors that can increase the risk of developing breast cancer can be deduced from scientific studies. This does not mean, however, that every woman who has one or even more risk factors will inevitably develop breast cancer. An increased risk can be assumed for women

- whose mother or sister had breast cancer;
- who have previously developed breast cancer;
- who are older than 50 (general age risk);
- who never had a child or who had their first child after the age of 30;
- who had the menarche (first menstrual period) in an early age at and at the same time entered menopause in late age.

WHAT IS MAMMOPGRAPHY SCREENING?

A *screening mammography* is performed to detect breast cancer in its early stages. Healthy women who do not have any symptoms or complaints receive an x-ray examination of the breast (mammogram) in certain intervals. The goal of mammography screening is to detect breast cancer as early as possible and by this to decrease breast cancer mortality. But mammography screening cannot prevent the development of breast cancer. Please note also that a mammography that is performed to follow up any symptoms or complaints is not called a screening mammography, but a *clinical mammography*.

WHO CAN PARTICIPATE?

The benefit of clinical mammography as a diagnostic test to follow up symptoms is indisputable. For the screening mammography, however, there have been doubts concerning the procedure and the benefits of screening healthy women, which is why mammography screening is not part of the statutory early cancer detection program in Germany. At the moment, several test mammography screening programs try to clarify whether mammography screening is beneficial and what quality standards should be applied.

These screening programs address women between 50 and 69 years of age and recommend that these women should have a screening mammography every other year. For this age group, the ratio between the advantages and disadvantages of screening participation seems most favorable. For women younger than 50 and older than 70 years, the benefit of mammography screening is not assured.

WHAT IS THE BENEFIT OF MAMMOGRAPHY SCREENING?

The goal of mammography screening is the reduction of breast cancer mortality. International studies showed that regular mammography screening could reduce breast cancer mortality by 25% to 30% for women between 50 and 69 years. What exactly does this information mean?

- Without mammography screening, 4 of 1000 women in this age group will die of breast cancer over a period of ten years;

– With mammography screening, 3 of 1000 women in this age group will die of breast cancer over a period of ten years.

That is, mammography screening saves 1 of 1000 participating women, that is 0.1%. Expressed differently, mammography screening reduces the number of breast cancer deaths from 4 to 3, that is, by 25%.

DISADVANTAGES OR LIMITS OF THE SCREENING

Risk of radiation

As an x-ray examination, mammography is associated with exposure to x-rays that can damage cells. A mammogram usually contains of two images per breast. In sum, 5 so-called milliSievert, a unit used for this kind of radiation, should not be exceeded. In apparatus with a raster scan, which are standard today, the radiation exposure is even lower than that, given that the apparatus is used optimally. In comparison, the amount of similar natural radiation, stemming from space or the earth and that everybody is exposed to, amounts to about 2 milliSievert per year. The radiation exposure associated with a mammography is therefore comparatively low. Nevertheless, according to estimations by different experts, this radiation exposure causes between 1.5 to 4.5 additional cases of breast cancer and 1 to 2 additional cases of death from breast cancer for every 10,000 women (for women who have annual screening mammograms from age 40 on, respectively).

Strains caused by false-positive results

If the mammography shows an abnormal result, although there actually is no breast cancer, this is called a "false-positive" result. Of every 1000 women who do not have breast cancer and who participate in a screening mammography for the first time, 90 receive a false-positive result. These numbers refer to a single examination – the probability of a false-positive result is larger when a woman participates in several examinations. Of every 1000 women who receive five screening mammograms over a time period of ten years, 250 receive at least one false-positive result. What are the *consequences* of false-positive results? If a mammography examination results in an abnormal finding (i.e., the test result is positive), further tests are required to ensure the breast cancer diagnosis or to rule it out. These tests may cause physical and psychological strains. Almost all women with a false-positive result receive an additional mammography examination or an ultrasound examination. About 1 of every 5 women with a false-positive result receives a biopsy to examine the breast tissue for cancer cells (histological examination).

Unwanted detection of precancerous lesions

In some cases very small tumors are detected by screening mammography that grow so slowly that they possibly would have never caused a problem for the affected woman.

Early detection does not equal longer life-expectancy

In some women the course of the disease cannot be stopped although it was detected in a screening. In this case they receive the cancer diagnosis earlier and the affected women have to live longer with the knowledge of having the disease.

Breast cancer that develops between screening examinations

Breast cancer can also develop between screening examinations. You should therefore keep paying attention to suspicious changes in your breast (see below). If you observe such changes, you should consult your physician as soon as you can.

HOW GOOD IS THE SCREENING MAMMOGRAPHY AS AN EXAMINATION METHOD?

In order to determine the effectiveness of an examination method, it is important to know how often false results occur. Ideally, the mammography should show a positive (abnormal) result, whenever there actually is breast cancer, and it should always show a negative (normal) result when there is no breast cancer. In fact, the following results can be expected:

- In 900 of 1000 women who have breast cancer, the mammography is able to detect the disease. That means that in 100 of 1000 women who have breast cancer, the disease is not detected (false-negative result).
- In 910 of 1000 women who do not have breast cancer, the mammography does actually not show any signs of the disease. That means that in 90 of 1000 women without breast cancer, the disease is incorrectly indicated (false-positive result, see above).

Now consider the following: It is known that despite of a hit rate of 90%, only 1 of 10 women who receive a positive result in mammography screening actually has breast cancer. How does this information fit together? The low predictive value of a positive mammogram is explained by the fact that naturally a lot more women without breast cancer participate in a screening than women with breast cancer. But when the number of women without breast cancer is large, also the mentioned false-positive rate of 9% results in a larger number.

A numerical example can illustrate this relationship:
- Imagine a group of 1000 women between 50 and 70 years who show no symptoms of breast cancer, who participate for the first time in mammography screening. Of these 1000 women, 11 have breast cancer.
- Of these 11 women with breast cancer, 10 receive a (correct) positive and 1 a (false) negative mammogram.
- Of the remaining 989 women without breast cancer, 899 receive a (correct) negative and 90 receive a (false) positive mammogram.
- Thus altogether, 100 out of the 1000 screening participants receive a positive mammogram. But of these 100 women with a positive mammogram, only 10 actually have breast cancer. Put differently, in 90 of 100 women with a positive mammogram, the suspected cancer is proved false by further diagnostic testing.
- Also the meaning of a negative mammogram can be drawn from this numerical example: Of the 1000 screening participants, 900 receive a negative mammogram. Of these 900 women with a negative mammogram, 899 actually do not have breast cancer. Put differently, in 1 of 900 women with a negative result the present disease is overlooked.

WHAT DO YOU HAVE TO EXPECT IN A SCREENING MAMMOGRAPHY?

The examination only lasts a few minutes. Both breasts are first placed between two paddles of Plexiglas and compressed for a short period of time. This can be uncomfortable and sometimes even painful. The compression is necessary to produce optimal images with the lowest possible dose of radiation. Two images are taken of each breast.

THE RESULT – AND WHAT HAPPENS NEXT?

The mammogram is negative (normal)
Women with a negative mammogram are recommended to have another screening mammography two years later. During this two-year interval, they should pay attention to suspicious changes in the breasts (because as mentioned above, mammography screening cannot prevent breast cancer), for example:
- externally visible deformation of the breast
- palpable nodes
- dents or hardening of the skin
- a new dimpling of the nipple
- skin change of the nipple
- clear discharge or bleeding from one nipple

The mammogram is positive (abnormal)
In this case, further examinations should be performed to clarify the diagnosis. In an ultrasound scan, the breast tissue is displayed with the help of sound waves. The ultrasound scan is used to re-evaluate the changes discovered by the mammogram. For some women, additional mammograms are done to display the abnormal area of the tissue more precisely. Magnetic resonance imaging of the breast can be considered in special situations. However, no imaging procedure can detect whether a node is benign or malign. In order to do this, the cells from the suspicious area have to be examined directly. *(The options of the tissue extraction, e.g., fine needle biopsy or vacuum biopsy are not included in this draft, but would be explained here in the final version of the pamphlet)*

MAMMOGRAPHY SHOULD BE QUALITY CONTROLLED

The screening mammography should differentiate as accurately as possible between healthy women and women who are suspected of having breast cancer. Only then would a recommendation for invasive tests or surgery be justified. Quality assurance according to European guidelines supports the goal of mammography screening to lower the number of breast cancer deaths. At the same time, it assures that the risks and strains for healthy women can be reduced as much as possible.
Numerous scientific studies show that a sufficiently good quality of mammography examinations can only be ensured when the examination is exclusively performed and evaluated by persons who at least perform 5000 examinations a year. Additionally, these persons have to participate in quality control circles, that is, they should allow other experts to regularly re-evaluate randomly picked mammograms. Moreover, the mammography apparatus and their operation have to meet the current quality standards.

CONTACT ADDRESSES
(not included in this draft)

Pamphlet with percentages

INFORMATION ABOUT MAMMOGRAPHY SCREENING

This pamphlet addresses women who want to inform themselves about mammography screening. The information in this pamphlet should help you to decide whether the participation in the mammography screening makes sense for you or not.

BREAST CANCER

In Germany, 48 000 women are diagnosed with breast cancer every year. The frequency of breast cancer increases continuously with age. A diagnosis of breast cancer receive (per year):

- 0.4% of the women between 30 and 39 years
- 1.2% of the women between 40 and 49 years
- 2.5% of the women between 50 and 59 years
- 2.3% of the women between 60 and 69 years
- 2.5% of the women between 70 and 79 years
- 2.6% of the women between 80 years and older

Every year, 18 000 women die of breast cancer in Germany. Also the risk of dying from breast cancer increases with age. The following number of women die of breast cancer (per year):

- 0.1% of the women between 30 and 39 years
- 0.4% of the women between 40 and 49 years
- 0.8% of the women between 50 and 59 years
- 0.8% of the women between 60 and 69 years
- 1.3% of the women between 70 and 79 years
- 2.5% of the women between 80 years and older

Only little is known about the causes of breast cancer. But certain factors that can increase the risk of developing breast cancer can be deduced from scientific studies. This does not mean, however, that every woman who has one or even more risk factors will inevitably develop breast cancer. An increased risk can be assumed for women

- whose mother or sister had breast cancer;
- who have previously developed breast cancer;
- who are older than 50 (general age risk);
- who never had a child or who had their first child after the age of 30;
- who had the menarche (first menstrual period) in an early age at and at the same time entered menopause in late age.

WHAT IS MAMMOPGRAPHY SCREENING?
[same as in frequency pamphlet]

WHO CAN PARTICIPATE?
[same as in frequency pamphlet]

WHAT IS THE BENEFIT OF MAMMOGRAPHY SCREENING?

The goal of mammography screening is the reduction of breast cancer mortality. International studies showed that regular mammography screening could reduce breast cancer mortality by 25% to 30% for women between 50 and 69 years. What exactly does this information mean?

- Without mammography screening, 0.4% of the women in this age group will die of breast cancer over a period of ten years;
- With mammography screening, 0.3% women in this age group will die of breast cancer over a period of ten years.

That is, mammography screening saves 0.1% of the participating women. Expressed differently, mammography screening reduces the number of breast cancer deaths from 0.4% to 0.3%, that is by 25%.

DISADVANTAGES OR LIMITS OF THE SCREENING

Risk of radiation
As a x-ray examination, mammography is associated with exposure to x-rays that can damage cells. A mammogram usually contains of two images per breast. In sum, 5 so-called milliSievert, a unit used for this kind of radiation, should not be exceeded. In apparatus with a raster scan, which are standard today, the radiation exposure is even lower than that, given that the apparatus is used optimally. In comparison, the amount of similar natural radiation, stemming from space or the earth and that everybody is exposed to, amounts to about 2 milliSievert per year. The radiation exposure associated with a mammography is therefore comparatively low. Nevertheless, according to estimations by different experts, between 0.015% to 0.045% of women participating in screening develop breast cancer and between 0.01% to 0.02% die from breast cancer because of the radiation exposure (for women who have annual screening mammograms from age 40 on, respectively).

Strains caused by false-positive results

If the mammography shows an abnormal result, although there actually is no breast cancer, this is called a "false-positive" result. Of the women who do not have breast cancer and who participate in a screening mammography for the first time, 9% receive a false-positive result. This number refers to a single examination – the probability of a false-positive result is larger when a woman participates in several examinations. About 25% of the women who receive five screening mammograms over a time period of ten years receive at least one false-positive result. What are the *consequences* of false-positive results? If a mammography examination results in an abnormal finding (i.e., the test result is positive), further tests are required to ensure the breast cancer diagnosis or to rule it out. These tests may cause physical and psychological strains. Almost all women with a false-positive result receive an additional mammography examination or an ultrasound examination. About 20% of the women with a false-positive result receive a biopsy to examine the breast tissue for cancer cells (histological examination).

Unwanted detection of precancerous lesions
In some cases very small tumors are detected by screening mammography that grow so slowly that they possibly would have never caused a problem for the affected woman.

Early detection does not equal longer life-expectancy
In some women the course of the disease cannot be stopped although it was detected in a screening. In this case they receive the cancer diagnosis earlier and the affected women have to live longer with the knowledge of having the disease.

Breast cancer that develops between screening examinations
Breast cancer can also develop between screening examinations. You should therefore keep paying attention to suspicious changes in your breast (see below). If you observe such changes, you should consult your physician as soon as you can.

HOW GOOD IS THE SCREENING MAMMOGRAPHY AS AN EXAMINATION METHOD?

In order to determine the effectiveness of an examination method, it is important to know how often false results occur. Ideally, the mammography should show a positive (abnormal) result, whenever there actually is breast cancer, and it should always show a negative (normal) result when there is no breast cancer. In fact, the following results can be expected:

- In 90% of the women who have breast cancer, the mammography is able to detect the disease. That means that in 10% of the women who have breast cancer, the disease is not detected (false-negative result).
- In 91% of the women who do not have breast cancer, the mammography does actually not show any signs of the disease. That means that in 9% of the women without breast cancer, the disease is incorrectly indicated (false-positive result, see above).

Now consider the following: It is known that despite of a hit rate of 90%, only 10% of the women who receive a positive result in mammography screening actually have breast cancer. How does this information fit together? The low predictive value of a positive mammogram is explained by the fact that naturally a lot more women without breast cancer participate in a screening than women with breast cancer. But when the number of women without breast cancer is large, also the mentioned false-positive rate of 9% results in a larger number.

A numerical example can illustrate this relationship:

- Imagine a group of women between 50 and 70 years who show no symptoms of breast cancer, who participate for the first time in mammography screening. Of these women, 1% have breast cancer.
- Out of this 1% of women with breast cancer, 90% receive a (correct) positive and 10% a (false) negative mammogram.
- Of the remaining 99% of women without breast cancer, 91% receive a (correct) negative and 9% receive a (false) positive mammogram.

- Thus altogether, 10% of the screening participants receive a positive mammogram, but of these women with a positive mammogram, only 10% actually have breast cancer. Put differently, in 90% of the women with a positive mammogram, the suspected cancer is proved false by further diagnostic testing.
- Also the meaning of a negative mammogram can be drawn from this numerical example: 90% of the screening participants receive a negative mammogram, and of these women with a negative mammogram, 99.9% actually do not have breast cancer. Put differently, in 0.1% of the women with a negative result, the present disease is overlooked.

WHAT DO YOU HAVE TO EXPECT IN A SCREENING MAMMOGRAPHY?
[same as in frequency pamphlet]

THE RESULT – AND WHAT HAPPENS NEXT?
[same as in frequency pamphlet]

MAMMOGRAPHY SHOULD BE QUALITY CONTROLLED
[same as in frequency pamphlet]

CONTACT ADDRESSES
[same as in frequency pamphlet]

C.2 Questionnaire 4

Questionnaire 4 listed 35 topics that the women could choose from for their subjectively "ideal" mammography pamphlet. Table A.1 gives an overview over the topics and the order in which they were presented in the questionnaire.

Table A.1 Topics in Questionnaire 4

Position	Topic
1.	Cumulative lifetime risk of breast cancer *
2.	Breast cancer incidence per year
3.	Relationship between breast cancer risk and age *
4.	Increasing breast cancer incidence in younger women
5.	Frequency of genetically determined breast cancer
6.	Cumulative lifetime risk of breast cancer death *
7.	Breast cancer mortality per year
8.	Relationship between breast cancer mortality and age *
9.	Mortality reduction through screening *
10.	Early detection of breast cancer does not equal longer life-expectancy
11.	Unwanted detection of precancerous lesions
12.	Breast cancer between screening tests
13.	Positive predictive value *
14.	Relationship positive predictive value with error rates and breast cancer prevalence *
15.	Diagnostic tests after positive mammogram
16.	Negative predictive value *
17.	False-positive rate *
18.	False-negative rate *
19	Risk of physiological and/or psychological strain due to false-positive results *
20.	Screening interval *
21.	Description of mammography procedure *
22.	Amount of radiation per mammogram
23.	Risk of radiation-induced breast cancer *
24.	Comparison of radiation risk with benefit of screening
25.	Debate about utility of mammography screening
26.	Relevance of quality control for mammography screening
27.	Clinical breast examination as other early detection method
28.	Breast self-examination as other early detection method
29.	Frequency of benign lesions in breast
30.	Symptoms of breast cancer
31.	Risk factors for breast cancer
32.	Survival rate of breast cancer
33.	Breast cancer therapy
34.	Frequency of breast-saving operations
35.	Contact addresses for more information

Note. * For these topics, women could choose between different formulations.

Please imagine the following:

A German cancer society asks you to put together a pamphlet. The goal of this pamphlet is to give women your age all the information they need to make a decision for or against participating in a mammography screening.

When answering the question about what information should be part of your pamphlet, you can concentrate on what information you personally evaluate as important, because the pamphlet is meant to be for women like you. But please remember: A pamphlet should contain the most important information and only be as extensive as necessary for reaching the goal of the pamphlet.

In the following you will find a list of possible pieces of information for your pamphlet. Because the same information can often be presented in different ways/formats, in some cases you will be able to choose among several formulation examples; we took most of these from other pamphlets on the subject of early breast cancer detection.

Please go through the list and decide for each piece of information:

- In your opinion, is this information important for your decision on whether to participate in a mammography screening and therefore should be included in an information pamphlet about the screening mammogram – or not?
- In case you pick the information for your pamphlet: Please additionally check from the given formulation examples („FE“) the one that you consider most comprehensive, if you think that the FE are similarly comprehensive, choose the formulation that explains the facts best. *(This step of course can be dropped when only one formulation example is given!)*

1. Cumulative lifetime risk of breast cancer	
FE 1: "In Germany, 1 out of every 10 women develop breast cancer at some point in her life (calculated till the 80th year of life)."	**FE 2:** "In Germany, 10% of all women develop breast cancer at some point in their life (calculated till the 80th year of life)."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

2. Breast cancer incidence per year
FE 1: "In Germany, 48.000 women develop breast cancer every year."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

3. Relationship between breast cancer risk and age	
FE 1: "From the fourth decade on, the risk of developing breast cancer increases with age."	**FE 2:** "From the fourth decade on, the risk of developing breast cancer increases with age. In particular, risk increases for women over 50 years of age."
FE 3: "From the fourth decade on, the risk of developing breast cancer increases with age. A diagnosis of breast cancer receive (per year): – 4 of 1000 women between 30 and 39 years – 12 of 1000 women between 40 and 49 years – 25 of 1000 women between 50 and 59 years – 23 of 1000 women between 60 and 69 years – 25 of 1000 women between 70 and 79 years – 26 of 1000 women between 80 years and older"	
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3	

4. Increasing breast cancer incidence in younger women
FE 1: "It is noticeable that during the last years, an increasing number of women younger than 50 years old are affected by breast cancer."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

5. Frequency of genetically determined breast cancer
FE 1: "About 5% of all breast cancer cases are genetically determined."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

6. Cumulative lifetime risk of breast cancer death	
FE 1: "Out of every 10 women who reach the age of 80, 3 women die of breast cancer."	**FE 2:** "Out of all women who reach the age of 80, 3% die of breast cancer."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

7. Breast cancer mortality per year
FE 1: „In Germany, 18.000 women die of breast cancer every year."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

8. Relationship between breast cancer mortality and age	
FE 1: "The risk of dying from breast cancer increases with age."	**FE 2:** "The risk of dying from breast cancer increases with age. This risk increases especially for women over 50 years of age."
FE 3: "The risk of dying of breast cancer increases with age. The following number of women die of breast cancer (per year): – 1 of 1000 women between 30 and 39 years – 4 of 1000 women between 40 and 49 years – 8 of 1000 women between 50 and 59 years – 8 of 1000 women between 60 and 69 years – 13 of 1000 women between 70 and 79 years – 25 of 1000 women between 80 years and older"	
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3	

9. Mortality reduction through screening	
FE 1: "International studies showed that regular mammography screening could reduce breast cancer mortality by 25% to 30% for women between 50 and 69 years."	**FE 2:** "For the group of women participating in the screening, the probability of dying of breast cancer decreases."
FE 3: "What benefits do the women participating in the screening have? The chance that 1 out of 3 early deaths of breast cancer can be prevented. And the chance that with a regular participation in the screening (ten mammography examinations), 1 of 1000 participating women does not have to die of breast cancer."	**FE 4:** "What benefit does mammography screening have? Without mammography screening, 4 of 1000 women in this age group will die of breast cancer over a period of ten years. With mammography screening, 3 of 1000 women in this age group will die of breast cancer over a period of ten years. That is, mammography screening saves 1 of 1000 participating women, that is 0.1%. Expressed differently, mammography screening reduces the number of breast cancer deaths from 4 to 3, that is, by 25%."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3 ❑ FE4	

10. Early detection of breast cancer does not equal longer life-expectancy
FE 1: "In some women the course of the disease cannot be stopped although it was detected in a screening. In this case they receive the cancer diagnosis earlier and the affected women have to live longer with the knowledge of having the disease."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

11. Unwanted detection of precancerous lesions
FE 1: "In some cases very small tumors are detected by screening mammography that grow so slowly that they possibly would have never caused a problem for the affected woman."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

12. Breast cancer that develops between screening examinations
FE 1: "Breast cancer can also develop between screening examinations. You should therefore keep paying attention to suspicious changes in your breast (see below). If you observe such changes, you should consult your physician as soon as you can."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

13. Predictive value of a positive (= abnormal) mammography result	
FE 1: "In 9 out of 10 women who receive a positive mammogram, further diagnostic testing shows that they do not have breast cancer."	**FE 2:** "In 90% of the women who receive a positive mammogram, further diagnostic testing shows that they do not have breast cancer."
FE 3: "Only 1 out of 10 women who receive a positive mammogram actually has breast cancer. Put differently, in 9 out of 10 women who received a positive mammogram, the suspected cancer is proved false by further diagnostic testing."	**FE 4:** "Only 10% of the women who received a positive mammogram actually have breast cancer. Put differently, in 90% of the women who receive a positive mammogram, the suspected cancer is proved false by further diagnostic testing."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3 ❑ FE4	

14. Relationship positive predictive value with error rates and breast cancer prevalence	
FE 1: "It is known that despite of a hit rate of 90%, only 1 of 10 women, who receive a positive result in mammography screening actually has breast cancer. How does this information fit? The low predictive value of a positive mammogram is explained by the fact that naturally a lot more women without breast cancer participate in a screening than women with breast cancer. But when the number of women without breast cancer is large, also the mentioned false-positive rate of 9% results in a larger number."	**FE 2:** "It is known that despite of a hit rate of 90%, only 1 of 10 women, who receive a positive result in mammography screening actually has breast cancer. How does this information fit? The low predictive value of a positive mammogram is explained by the fact that naturally a lot more women without breast cancer participate in a screening than women with breast cancer. But when the number of women without breast cancer is large, also the mentioned false-positive rate of 9% results in a larger number. A numerical example can illustrate this: – Imagine a group of 1000 women between 50 and 70 years who show no symptoms of breast cancer, who participate for the first time in mammography screening. Of these 1000 women, 11 have breast cancer. – Of these 11 women with breast cancer, 10 receive a (correct) positive and 1 a (false) negative mammogram. – Of the remaining 989 women without breast cancer, 899 receive a (correct) negative and 90 receive a (false) positive mammogram. – Thus altogether, 100 out of the 1000 screening participants receive a positive mammogram. But of these 100 women with a positive mammogram, only 10 actually have breast cancer. Put differently, in 90 of 100 women with a positive mammogram, the suspected cancer is proved false by further diagnostic testing."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

15. Diagnostic tests after positive mammogram
FE 1: "When the screening mammogram is positive, further examinations should be performed to clarify the diagnosis. In an ultrasound scan, the breast tissue is displayed with the help of sound waves. The ultrasound scan is used to re-evaluate the changes discovered by the mammogram. For some women, additional mammograms are done to display the abnormal area of the tissue more precisely. Magnetic resonance imaging of the breast can be considered in special situations. However no imaging procedure can detect whether a node is benign or malign. For this, the cells from the suspicious area have to be examined directly." *(The options of the tissue extraction, e.g., fine needle biopsy, vacuum biopsy are not included here, but will be explained in the final pamphlet version)*
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

16. Predictive value of a negative (= normal) mammography result	
FE 1: "For 10 of 10,000 women who receive a negative mammogram, it turns out later that they actually have breast cancer."	**FE 2:** "For 0.1% of the women who received a negative mammogram, it turns out later that they actually had breast cancer."
FE 3: "Out of 10,000 women who received a negative mammogram, 9,990 do not have breast cancer. Put differently, in 10 of 10,000 women who receive a negative mammogram, it turns out later that they actually have breast cancer."	**FE 4:** "99.9% of the women who received a negative mammogram do not have breast cancer. Put differently, 0.1% of the women who receive a negative mammogram, it turns out later that they actually have breast cancer."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3 ❑ FE4	

17. False-negative mammography results	
FE 1: "Mammography screening can detect most, but not all breast cancers."	**FE 2:** "In 10 out of 100 women with breast cancer, the screening mammography fails to detect the disease."
FE 3: "In 90% of the women who have breast cancer, mammography screening correctly detects the disease. Put differently, in 10% of the women with breast cancer, the screening mammography fails to detect the disease."	**FE 4:** "In 90 out of 100 women who have breast cancer, mammography screening correctly detects the disease. Put differently, in 10 out of 100 women with breast cancer, the screening mammography fails to detect the disease."
FE 5: "Up to 10% of all breast cancer cases cannot be detected by mammography screening."	
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3 ❑ FE4 ❑ FE5	

18. False-positive mammography results	
FE 1: "The mammogram may show abnormal results, although there is no breast cancer."	**FE 2:** "9% of the women who do not have breast cancer receive a false-positive screening mammogram."
FE 3: "In 91 out of 100 women who do not have breast cancer, mammography screening correctly does not indicate the disease. Put differently, in 9 out of 100 women without breast cancer, the screening mammography incorrectly indicates breast cancer."	**FE 4:** "In 91% of the women who do not have breast cancer, mammography screening correctly does not indicate the disease. Put differently, 9% of the women without breast cancer, the screening mammography incorrectly indicates breast cancer."
FE 5: "6 of 100 women who do not have breast cancer receive a false-positive mammogram."	
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2 ❑ FE3 ❑ FE4 ❑ FE5	

19. Risk of physiological and/or psychological strain due to false-positive results	
FE 1: "If a mammography examination results in an abnormal finding (i.e., the test result is positive), further diagnostic tests are required to ensure the breast cancer diagnosis or to rule it out. These tests may cause physical and psychological strains."	**FE 2:** "If a mammography examination results in an abnormal finding (i.e., the test result is positive), further diagnostic tests are required to ensure the breast cancer diagnosis or to rule it out. These tests may cause physical and psychological strains. Almost all women with a false-positive result receive an additional mammography examination or an ultrasound examination. About 1 of every 5 women with a false-positive result receives a biopsy to examine the breast tissue for cancer cells (histological examination)."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

20. Screening interval	
FE 1: "Women between 50 and 69 years who are not at high risk for breast cancer should receive a screening mammogram every other year."	**FE 2:** "Recommendations concerning the interval of mammography screening differ. Some experts recommend that women should only have a mammogram when their physician recommends it. Other experts recommend that Women between 50 and 69 years who are not at high risk for breast cancer should receive a screening mammogram every other year."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

21. Description of mammography procedure	
FE 1: "The examination only lasts a few minutes. Both breasts are first placed between two paddles of Plexiglas and compressed for a short period of time. This can be uncomfortable and sometimes even painful. The compression is necessary to produce optimal images with the lowest possible dose of radiation. Two pictures are taken of each breast."	**FE 2:** "The examination only lasts a few minutes. Both breasts are first placed between two paddles of Plexiglas and compressed for a short period of time. The compression is necessary to produce optimal images with the lowest possible dose of radiation. Two pictures are taken of each breast."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

22. Amount of radiation per mammogram
FE 1: "A mammogram usually contains of two pictures per breast. In sum, 5 so-called milliSievert, a unit used for this kind of radiation should not be exceeded. In apparatus with a raster scan, which are standard today, the radiation exposure is even lower than that, given that the apparatus is used optimally. In comparison, the amount of similar natural radiation, stemming from space or the earth and that everybody is exposed to, amounts to about 2 milliSievert per year. The radiation exposure associated with a mammography is therefore comparatively low."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

23. Risk of radiation-induced breast cancer	
FE 1: "Coming to us from the U.S., there is the fear that the x-rays of associated with mammography could cause breast cancer. Thanks to the use of modern equipment with very low radiation doses, this fear is almost of no relevance anymore today."	**FE 2:** According to estimations by different experts, the additional risk for developing breast cancer caused by the exposure to radiation during mammography screening is 0.015% to 0.045%. That is, for every 10,000 women who receive annual screening mammograms from age 40 on, radiation exposure causes between 1.5 to 4.5 additional cases of breast cancer and 1 to 2 additional cases of death from breast cancer."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**, namely ❑ FE1 ❑ FE2	

24. Comparison of radiation risk with benefit of screening
FE 1: "The radiation exposure caused by the mammography screening is very low. The benefits of mammography screening are much bigger than the risk of radiation-induced breast cancer."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

25. Debate about utility of mammography screening
FE 1: "The benefit of clinical mammography as a diagnostic test to follow up symptoms is indisputable. For the screening mammography, however, there have been doubts concerning the procedure and the benefits of screening healthy women, which is why mammography screening is not part of the statutory early cancer detection program in Germany. At the moment, several test mammography screening programs try to clarify whether mammography screening is beneficial and what quality standards should be applied."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

26. Relevance of quality control for mammography screening
FE 1: "Numerous scientific studies show that a sufficiently good quality of mammography examinations can only be ensured when the examination is exclusively performed and evaluated by persons who at least perform 5000 examinations a year. Additionally, these persons have to participate in quality control circles, that is, they should allow other experts to regularly re-evaluate randomly picked mammograms. Moreover, the mammography apparatus and their operation have to meet the current quality standards."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

27. Clinical breast examination as other early detection method
FE 1: "The medical services of the statutory health insurance companies provide an annual early detection examination for breast cancer for women from age 30 on. The physician palpates the breasts and the armpits thoroughly."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

28. Breast self-examination as other early detection method
FE 1: "The regular self-examination of the breast is, besides the clinical breast examination by your physician, a good method to detect changes in the breast. The best time for the self-examination is about one week after menstruation, because the breast is not tender or swollen anymore and changes can be detected easier. You can self-examine your breast following the described method: ..." *(the instruction for breast self-examination that would follow is not listed here due to lack of space)*.
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

29. Frequency of benign lesions in breast
FE 1: "In case you find anything unusual when palpating your breast, remember that in 80% of all cases these changes are benign."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

30. Symptoms of breast cancer
FE 1: "When you notice any of the symptoms listed below, you should consult a physician, although these alarm signals can often be attributed to harmless causes: – Unusual lumps and nodes in the breast or armpit – An unusual increase in the size of one breast – Change in the colour of the breast skin (redness) – One breast is unusually lower than the other – Dent or dimple on the breast – A new dimpling or skin change of the nipple – Clear discharge or bleeding from one nipple – An unusual swelling of the upper arm."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

31. Risk factors for breast cancer
FE 1: "Only little is known about the causes of breast cancer. But certain factors that can increase the risk of developing breast cancer can be deduced from surveys. This does not mean, however, that every woman who has one or even more risk factors will inevitably develop breast cancer. An increased risk can be assumed for women – whose mother or sister had breast cancer; – who have previously developed breast cancer; – who are older than 50 (general age risk); – who never had a child or who had their first child after the age of 30; – who had the menarche (first menstrual period) in an early age at and at the same time entered menopause in late age."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

32. Survival rate of breast cancer
FE 1: "When detected in an early stadium, breast cancer can be cured in over 90 % of the cases."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

33. Breast cancer therapy
FE 1: *(This information, e.g. about operation methods, radiation- and chemotherapy, cannot be listed here due to lack of space.)*
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

34. Frequency of breast-saving operations
FE 1: "In over 80% of the cases, a breast conserving operation is possible and the cosmetic result is good in most of these cases."
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

35. Contact addresses of further information providers (e.g. cancer societies)
FE 1: *(not listed due to lack of space)*
➲ Should this information be included in your pamphlet? ❑ **No** ❑ **Yes**

In case there is another piece of information, that you consider as very important and want to include in your pamphlet, but was not included in the list, you can note it here:

_____
_____
_____
_____
_____
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_____
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_____

Did you keep in mind to choose only as much information for your pamphlet as is necessary to reach the goal of the pamphlet (= to give women your age all the information they need for their decision for or against a participation in a mammography screening)?
Should you now have the feeling that some of the information you chose might be not as relevant as you initially thought, please go back and mark the topic with an „X" (this means that this topic is not part of your choices anymore). In case you do not want to make any changes in your choices, please go to the last questionnaire now.

C.3 Additional data tables

Table A.2
Knowledge *prior* to reading the model pamphlets – Means, medians and standard deviations for nine quantitative estimates concerning mammography screening in the two experimental groups

		FP			PP		
		Mean	*Md*	*SD*	*Mean*	*Md*	*SD*
Breast cancer incidence in 10 years WITHOUT screening	1.2%-2.5% [a]	9%	5%	10%	12%	10%	12%
Breast cancer incidence in 10 years WITH screening	1.2%-2.5% [a]	5%	1%	7%	7%	5%	9%
Breast cancer deaths in 10 years WITHOUT screening	0.4%-0.8% [a]	11%	5%	17%	12%	5%	13%
Breast cancer deaths in 10 years WITH screening	0.4%-0.8% [a]	7%	2%	13%	6%	2%	7%
False-positive rate	9%	11%	10%	21%	8%	5%	17%
False-negative rate	10%	10%	1%	25%	4%	2%	5%
Positive predictive value	10%	50%	50%	35%	30%	20%	31%
Negative predictive value	99.9%	61%	80%	41%	71%	89%	35%
At least one false-positive in 10 years of screening	25%	5%	1%	17%	2%	2%	2%

Note. [a] Values differed for specific age-groups.

Table A.3
Knowledge *after* reading the model pamphlets – Means, medians and standard deviations for nine quantitative estimates concerning mammography screening in the two experimental groups

		FP			PP		
		Mean	*Md*	*SD*	*Mean*	*Md*	*SD*
Breast cancer incidence in 10 years WITHOUT screening	1.2%-2.5% [a]	7%	3%	11%	14%	10%	13%
Breast cancer incidence in 10 years WITH screening	1.2%-2.5% [a]	4%	2%	4%	8%	4%	11%
Breast cancer deaths in 10 years WITHOUT screening	0.4%-0.8% [a]	7%	5%	8%	17%	10%	15%
Breast cancer deaths in 10 years WITH screening	0.4%-0.8% [a]	3%	1%	3%	6%	4%	6%
False-positive rate	9%	5%	1%	7%	9%	9%	7%
False-negative rate	10%	4%	1%	5%	9%	9%	7%
Positive predictive value	10%	41%	10%	44%	40%	10%	43%
Negative predictive value	99.9%	57%	90%	44%	49%	75%	45%
At least one false-positive in 10 years of screening	25%	6%	1%	12%	10%	5%	12%

Note. [a] Values differed for specific age-groups.

Table A.5
Comparison of knowledge before and after reading the model pamphlet: Values of *t* and *p* for paired sample *t*-tests

	FP			PP		
Topic	*t*	*df*	*p*	*t*	*df*	*p*
Breast cancer incidence in 10 years WITHOUT screening	1.12	19	.28	-0.04	13	.97
Breast cancer incidence in 10 years WITH screening	1.89	19	.07	0.54	12	.60
Breast cancer deaths in 10 years WITHOUT screening	1.52	20	.14	-1.23	13	0.24
Breast cancer deaths in 10 years WITH screening	1.93	19	.07	-0.75	13	0.47
False-positive rate	1.20	19	.24	0.20	16	.85
False-negative rate	1.03	20	.31	-1.66	15	.12
Positive predictive value	1.08	21	.29	-0.87	15	.40
Negative predictive value	-0.06	21	.95	1.82	16	.09
At least one false-positive in 10 years of screening	0.36	20	.73	-1.89	11	.09