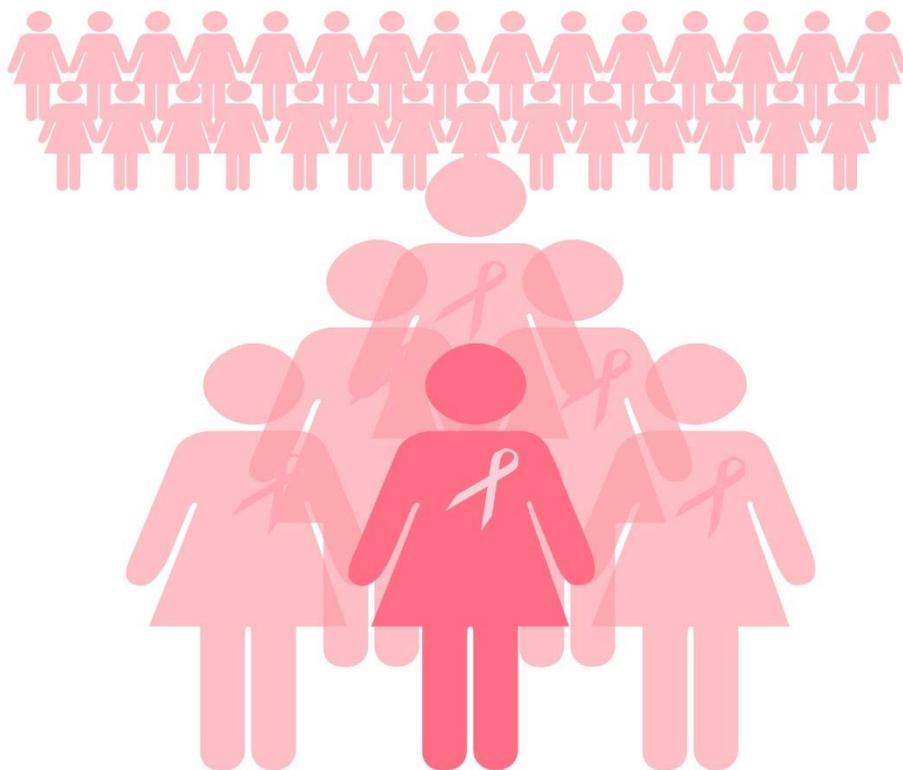


INFORMED CHOICE ON BREAST CANCER SCREENING: MESSAGES TO SUPPORT INFORMED DECISION



INFORMED CHOICE ON BREAST CANCER SCREENING: MESSAGES TO SUPPORT INFORMED DECISION

LAURENCE KOHN, FRANÇOISE MAMBOURG, JO ROBAYS, MICHEL ALBERTIJN, SABINE JANSSENS, KATHLEEN HOEFNAGELS, MAGALI RONSMANS, PASCALE JONCKHEER



Title:	Informed choice on breast cancer screening: messages to support informed decision
Authors:	Laurence Kohn (KCE), Françoise Mambourg (KCE), Jo Robays (KCE), Michel Albertijn (Tempera), Sabine Janssens (BSM-Management), Kathleen Hoefnagels (Tempera), Magali Ronsmans (BSM-Management), Pascale Jonckheer (KCE)
External experts and stakeholders:	Pierre Baldewyns (UNMS), Audrey Benard (WIV-ISP), Patrick Berteloot (VVOG), Anne Boucquiau (Fondation contre le cancer), Jean-Benoit Burrion (Brumammo), Frederic Buxant (GGOLFB), Serge Carabin (Fédération Wallonie Bruxelles), Annemie Coëme (Onafhankelijke Ziekenfondsen), Claudio Colantoni (Cellule stratégique Ministre Onkelinx), Christian De Bock (Education Santé), Erwin De Clercq (Vlaamse Liga tegen Kanker), Mariane De Vriendt (Ugent), Ellen De Wandeler (Kankercentrum), Sabine Debled (Administration de la fédération Wallonie Bruxelles), Murielle Deguerry (Observatoire de la Santé et du Social de Bruxelles-Capitale), Marie Dosquet (Kankercentrum), Hilde Engels (RIZIV – INAMI), Micky Fierens (LUSS), Chantal Goossens (Europa Donna Belgium), Liesbeth Lenaerts (WIV – ISP), Anne Liesse (Fédération Wallonie Bruxelles), Patrick Martens (Centrum voor Kankeropsporing), Veronica Mendez (Seno.be), Margarete Mortier (Royal Belgian Society of Radiology), Salvatore Murgo (Royal Belgian Society of Radiology), Patrick Neven (VVOG), Myriam Provost (SSMG), Vinciane Quidbach (Cellule stratégique Ministre Onkelinx), Ward Rommel (Vlaamse Liga tegen Kanker), Karin Rondia (Fondation contre le cancer), Griet Rummens (CM), Hannelore Storms (Vlaams Patiëntenplatform), Bernadette Taeymans (Question Santé), Ingrid Umbach (Mutualités Libres), Saskia Van Den Bogaert (FOD Volksgezondheid – SPF Santé publique), Didier Van der Steichel (Fondation contre le cancer), Reinhilde Van Eeckhoudt (Vlaams Agentschap Zorg en Gezondheid), Erik Van Limbergen (Centrum voor Kankeropsporing), Anne Vandenbroucke (Centre Communautaire de Référence pour le dépistage des cancers Wallonie-Bruxelles), Pieter Vandenbulcke (Vlaams Agentschap Zorg en Gezondheid)
External validators:	Emilie Lanoy (Institut Gustave-Roussy Villejuif, France), Peep Stalmeier (UMC St Radboud Nijmegen, Nederland), Koen Traen (OLV Ziekenhuis Aalst)
Acknowledgements:	Valérie Fabri (Mutualités socialistes), Agnès Leclercq (Mutualités libres), Michel Boutsen (Mutualités socialistes) for their collaboration in the reflection and exploratory analysis of the Belgian data. Nathalie Da Costa Maya (Centre de Diffusion de la Culture Sanitaire – CDCS) for the visual layout. Women who participated to the focus groups and testing messages. Physicians who participated to the focus groups
Other reported interests:	Membership of a stakeholder group on which the results of this report could have an impact.: Pierre Baldewyns (UNMS – NVSM), Jean-Benoit Burrion (Brumammo), Serge Carabin (Fédération Wallonie Bruxelles), Anne Vandenbroucke (Centre Communautaire de Référence pour le dépistage des cancers Wallonie-Bruxelles), Erik Van Limbergen (Centrum voor Kankeropsporing) Fees or other compensation for writing a publication or participating in its development: Jean-Benoit Burrion



(Brumammo)

Participation in scientific or experimental research as an initiator, principal investigator or researcher: Patrick Neven (VVOG)

Grants, fees or funds for a member of staff or another form of compensation for the execution of research: Patrick Neven (VVOG)

Consultancy or employment for a company, an association or an organisation that may gain or lose financially due to the results of this report: Jean-Benoit Burrion (Brumammo), Patrick Martens (Centrum voor Kankeropsporing)

Presidency or accountable function within an institution, association, department or other entity on which the results of this report could have an impact: Jean-Benoit Burrion (Brumammo), Patrick Martens (Centrum voor Kankeropsporing), Anne Vandenbroucke (Centre Communautaire de Référence pour le dépistage des cancers Wallonie-Bruxelles), Pieter Vandenbulcke (Vlaams Agentschap Zorg en Gezondheid), Reinhilde Van Eeckhoudt (Vlaams Agentschap Zorg en Gezondheid), Erik Van Limbergen (Centrum voor Kankeropsporing)

Layout:

Ine Verhulst

Disclaimer:

- **The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.**
- **Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.**
- **Finally, this report has been approved by common assent by the Executive Board.**
- **Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.**

Publication date:

8 januari 2014

Domain:

Good Clinical Practice (GCP)

MeSH:

Breast Neoplasms, Health Communication, Decision Making, Decision Support Techniques, Mass Screening

NLM Classification:

WP 870

Language:

English

Format:

Adobe® PDF™ (A4)

Legal depot:

D/2014/10.273/04



Copyright:

KCE reports are published under a “by/nc/nd” Creative Commons Licence
<http://kce.fgov.be/content/about-copyrights-for-kce-reports>.



How to refer to this document?

Kohn L, Mambourg F, Robays J, Albertijn M, Janssens J, Hoefnagels K, Ronsmans M, Jonckheer P. Informed choice on breast cancer screening: messages to support informed decision. Good Clinical Practice (GCP) Brussels: Belgian Health Care Knowledge Centre (KCE). 2014. KCE Reports 216. D/2014/10.273/04.

This document is available on the website of the Belgian Health Care Knowledge Centre.



■ TABLE OF CONTENTS

LIST OF FIGURES	4
LIST OF TABLES.....	4
LIST OF ABBREVIATIONS	5
■ SCIENTIFIC REPORT	6
1 INTRODUCTION	6
1.1 CONTEXT	6
1.2 BREAST CANCER SCREENING IN BELGIUM	7
1.3 SHARED AND INFORMED DECISION MAKING, INFORMED CHOICE, AND DECISION AIDS.....	7
1.4 EFFECTIVENESS OF COMMUNICATING THE RISK.....	8
1.4.1 Impact on cognitive outcomes	9
1.4.2 Impact on affective outcomes	9
1.4.3 Impact on Behavioural outcome	10
1.4.4 Conclusion	10
2 OBJECTIVE	11
3 METHODOLOGY	11
3.1 GENERAL SCIENTIFIC APPROACH	11
3.2 RESEARCH QUESTIONS	14
3.3 SPECIFIC METHODOLOGIES	14
4 ELABORATION OF THE MESSAGES: HOW TO COMMUNICATE RISK	14
4.1 METHODOLOGY	14
4.1.1 Databases	14
4.1.2 Inclusion / exclusion criteria	14
4.1.3 Quality appraisal	15
4.2 MATERIAL.....	15
4.2.1 Systematic reviews	15
4.2.2 Additional primary studies.....	15
4.2.3 Others	15
4.3 RESULTS	15



4.3.1	Communicate risk messages.....	15
4.3.2	Outcomes according to the way to communicate the risk	16
5	ELABORATION OF THE MESSAGES: THE CONTENT	19
5.1	TYPE OF INFORMATION TO BE INCLUDED IN A DECISION AID	19
5.1.1	IPDAS content criteria.....	19
5.1.2	Women's perspective.....	20
5.1.3	Practitioners' perspective.....	37
5.2	CLINICAL EVIDENCE AND BELGIAN DATA.....	43
5.2.1	Methodology.....	43
5.2.2	Belgian data	44
5.2.3	Results	44
5.2.4	Discussion of the current polemics	48
6	ELABORATION OF THE FINAL MESSAGES.....	50
6.1	REDACTION OF THE MESSAGES.....	50
6.2	CONTENT OF THE MESSAGES.....	50
6.3	PRESENTATION OF THE INFORMATION: FROM A MINIMALISTIC PAGE LAY-OUT TO A DESIGNED LEAFLET	51
6.4	TESTS OF THE MESSAGES	52
6.4.1	Technical readability statistics	52
6.4.2	Measuring the comprehensibility of a text	52
6.4.3	Result of the first test	55
6.4.4	Result of the second test	57
7	FINAL MESSAGES	58
7.1	COMMON MESSAGES TO ALL WOMEN.....	59
7.2	SPECIFIC MESSAGES BY AGE GROUPS	60
7.2.1	The risk of dying.....	61
7.2.2	10 years consequences of breast cancer screening	65
7.2.3	Consequences of breast cancer screening in the next months.....	69
■	APPENDICES	73
APPENDIX 1.	IPDAS CHECKLIST¹⁷	73



APPENDIX 2. SEARCH STRATEGIES.....	75
APPENDIX 2.1. SYSTEMATIC REVIEWS ON THE COMMUNICATION OF THE RISK IN GENERAL	75
APPENDIX 2.2. STUDIES ABOUT COMMUNICATION ON BREAST CANCER SCREENING	76
APPENDIX 2.3. STUDIES ABOUT WOMEN PERSPECTIVES ON COMMUNICATION AROUND BREAST CANCER SCREENING	77
APPENDIX 3. FORMAT OF COMMUNICATING RISK	79
APPENDIX 3.1. QUALITY APPRAISAL OF THE SYSTEMATIC REVIEWS	79
APPENDIX 3.2. DESCRIPTION OF THE SYSTEMATIC REVIEWS	80
APPENDIX 4. WOMEN PERSPECTIVES	89
APPENDIX 4.1. QUALITY APPRAISAL OF THE STUDIES	89
APPENDIX 4.2. DESCRIPTION OF THE STUDIES	90
APPENDIX 4.3. INTERVIEW GUIDELINES USED IN FOCUS GROUPS WITH WOMEN	93
APPENDIX 4.4. EXAMPLES OF VISUALS USED IN THE FOCUS GROUPS (WOMEN AND GPS)	100
APPENDIX 4.5. EXERCISE OF VALUE CLARIFICATION USED IN THE FOCUS GROUPS (WOMEN).....	104
APPENDIX 4.6. QUESTIONS THAT WOMEN HAVE ABOUT BREAST CANCER SCREENING	106
APPENDIX 5. PRACTITIONERS' PERSPECTIVE	108
APPENDIX 5.1. INTERVIEWGIDS FOCUSGROEP ARTSEN	108
APPENDIX 5.2. GUIDE D'ENTRETIEN FOCUS GROUP MÉDECINS	110
APPENDIX 6. CINICAL EVIDENCE - REVIEW OF RCTS STUDIES.....	112
APPENDIX 6.1. PICO	112
APPENDIX 6.2. SYSTEMATIC REVIEWS (SR) AND META ANALYSES (MA).....	112
APPENDIX 6.3. RANDOMISED CONTROL TRIALS	114
APPENDIX 6.4. FLOW DIAGRAM FOR SYSTEMATIC REVIEWS (SR) AND META ANALYSES (MA).....	115
APPENDIX 6.5. FLOW DIAGRAM FOR RANDOMISED CONTROL TRIALS	116
APPENDIX 6.6. QUALITY APPRAISAL	117
APPENDIX 6.7. DATA EXTRACTION TABLE	118
APPENDIX 7. CINICAL EVIDENCE - REVIEW OF OBSERVATIONAL STUDIES	126
APPENDIX 7.1. QUALITY APPRAISAL	126
APPENDIX 7.2. DATA EXTRACTION TABLE	128
APPENDIX 8. TEST OF THE MESSAGES	130



APPENDIX 8.1. FIRST TEST QUESTIONNAIRE130

APPENDIX 8.2. SECOND TEST QUESTIONNAIRE137

■ REFERENCES145

LIST OF FIGURES

Figure 1 – General design of the study12

Figure 2 – Elaboration of the messages13

LIST OF TABLES

Table 1 – Description of the focus groups25

Table 2 – Focus group participants characteristics25

Table 3 – Main questions of the participants before breast cancer screening by theme27

Table 4 – Mortality of women in Belgium for 1000 women over 10 years.....45

Table 5 – Burden of the disease in Belgium: incidence of breast cancer for 1 000 women over 10 years (number of cases).....46

Table 6 – Number of deaths caused by breast cancer with and without screening for 1000 women after 10 years participation (modeling).....46

Table 7 – Screening estimated harms for 10 years of screening for 1000 women47

Table 8 – Harms per screening round (one screening round for 1 000 women).....48

Table 9 – Overview of the readability results of the first test (threshold for success: 81%).....56

Table 10 – Overview of the readability results of the second test (threshold for success: 81%)57

Table 11 – Quality assessment of the systematic reviews on the way to communicate risk according to AMSTAR criteria79

Table 12 – Description of the systematic reviews on the way to communicate risk - partim design.....80

Table 13 – Description of the systematic reviews on the way to communicate risk - partim results and author's conclusions82

Table 14 – Critical appraisal of additional primary studies on risk communication86

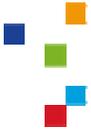
Table 15 – Description of the additional primary studies on risk communication.....87

Table 16 – Description of the studies on women perspectives in breast cancer screening.....90



LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ARR	Absolute Risk Reduction
BC	Breast Cancer
CDA	Computerized Decision Aid
CI	Confidence Interval
CPG	Clinical Practice Guideline
DA	Decision Aid
DMG	Dossier Médical Global
GMD	Globaal Medisch Dossier
IBM	Incidence Based Mortality
IDM	Informed Decision Making
IPDAS	International Patient Decision Aid Standards
M-A	Meta-analysis
MD	Mean Deviation
NNT	Number Needed to Treat
OR	Odd Ratio
RCT	Randomized Control Trial
RRR	Relative Risk Reduction
RR	Relative Risk
SDM	Shared Decision Making
SES	Socio Economic Status
SMD	Standardized Mean Difference
SR	Systematic Review



■ SCIENTIFIC REPORT

1 INTRODUCTION

1.1 Context

This report follows 4 previously published KCE clinical practice guidelines (CPG):

1. on breast cancer screening in general (KCE report 11¹) (2005)
2. on breast cancer screening with mammography for women in the age group 40-49 years (KCE report 129²) (2010).
3. on the identification of women at risk for breast cancer and on technical methods for breast cancer screening (KCE report 172³) (2012)
4. on breast cancer screening with mammography for women in the age group over 70 years (KCE report 176⁴) (2012)

These last three were initiated after a consultation of stakeholders, who were invited to prioritize clinical questions that they would like to be analysed in further KCE reports. These stakeholders were the RBSR (Royal Belgian Radiological Society), SSMG (Société Scientifique de Médecine Générale), GGOLF (Groupement des Gynécologues Obstétriciens de Langue Française de Belgique), LUSS (Ligue des Usagers de Soins de Santé), OBC (Oeuvre Belge du Cancer), Domus, VVOG (Vlaamse Vereniging voor Obstetrie en Gynaecologie), VLK (Vlaamse Liga Tegen Kanker), BKO (borstkankeropsporing), FW-B (Fédération Wallonie-Bruxelles) and Brumammo.

On the top of these CPG, they were asking for better information of the women, in the perspective of informed decision making to be screened.

This is in line with general trends to shift from the promotion of preventive Behaviours to informed decision making.

Indeed, while society encourage more and more informed decision making in health and emphasis the importance of informed consent and informed choice, it is clear that very little information is given to women on the potential consequences or adverse events of breast cancer screening in Belgium.



However, the right to information is clearly stated in the law on patients' rights. That is to promote screening or not, women have the right to have neutral information to help them make their decision knowingly.

The present report aims to answer this last issue and offers a partial update of the first report on the data available for 50-69 year-old women.

1.2 Breast cancer screening in Belgium

Generally speaking, screening "allows the detection of unrecognized diseases, defects or risk factors by simple tests, examinations or other procedures rapidly applied on a large scale. Screening test sorts out apparently well persons, who probably have the targeted disease or risk factor. Screening is not intended to be diagnostic. Persons with positive or suspicious findings must be referred to health care for diagnosis and treatment".^a

Today (2013), in Belgium, women have several possibilities to have their breast examined by a mammography:

- The **organized breast cancer screening programme** offers to women aged between 50 and 69 year free screening. Each women in the target age group is invited every two years to go to a recognized centre to get a 'Mammotest'/'screeningmammografie'. This consists of a mammography made by mammograph for which the quality is controlled as the quality of the pictures is. Pictures will be read by two independent radiologists. In case of doubt, a third one will decide. If there is suspicion of a cancer, women will be invited for further assessment. Women do not need any prescription for this examination. The programme is financed by the State, organized by each Region (Wallonie, Flanders and Brussels) and follows the European recommendations on breast cancer screening.
- Some **provinces** (administrative regional entities of Belgium) offers a free screening to their female inhabitants from 40 year-old. Because of the target age group, they do not follow the European recommendations on breast cancer screening

- The **opportunistic screening** is defined as a "screening restricted to persons who consult a health service for a reason other than the disease or health problem for which screening is being carried"^b. In Belgium, some physicians, generally gynaecologists, proposed it to women from 38-40 year-old without any symptoms to their breasts. He/she will generally prescribe them a mammography often directly followed by an echography. This examination is partly reimbursed by the health insurance, using nomenclature code for breast cancer diagnosis.

According to European recommendations, 50-69 year-old women are encouraged to get screened every two years.

Only data for the organized breast cancer screening program are available; we have no data on the opportunistic screening.

^a <http://asp.bdsp.ehesp.fr/Glossaire/>

^b <http://asp.bdsp.ehesp.fr/Glossaire/>

1.3 Shared and informed decision making, informed choice, and decision aids

This project aims to improve **informed decision making** (IDM) of the women. This could be defined as “any intervention in communities or healthcare systems intended to promote individuals’ informed decisions” (Briss 2004⁵, p.69), or “as the process a patient that through to make a decision about engaging in a medical or health-related procedure or activity considering benefits, harms, risks, health improvements, the match between these properties and personal values and preferences, and understanding the uncertainty and limitations of the procedures.” (Mullen 2006⁶, p. 189).

IDM interventions provide “evidence-based, balanced, understandable appropriate, and succinct information on disease and the potential intervention including any applicable risks and benefits of prevention or treatment options encourage individuals to participate in values clarification and decision making consistent with their preferences” (Briss 2004⁵ p.70).

Patients then often undergo a process of **shared decision making** (SDM) with a provider to make a final decision: the patient and people engaged in the decision exchange relevant information and express their preferences in the context of clinical setting⁵.

IDM with or without SDM should conduce to **informed choices** of the patient, i.e. that are “based on relevant knowledge while decision-maker’s attitude is consistent with his/her actual behaviour” (van Agt 2012⁷, p. 353).

A potential support to convey the information is to use **decision aids** (DA). According to the IPDAS (International Patient Decision Aid Standards), DA are “evidence-based tools designed to prepare clients to participate in making specific and deliberated choices among healthcare options. Patient decision aids supplement (rather than replace) clinicians’ counselling about options. The specific aims of decision aids and the type of decision support they provide may vary slightly, but in general they:

1. provide evidence-based information about a health condition, the options, associated benefits, harms, probabilities, and scientific uncertainties;

2. help patients to recognize the values-sensitive nature of the decision and to clarify, either implicitly or explicitly, the value they place on the benefits, harms, and scientific uncertainties (to accomplish this, strategies that may be included in the decision aid are: describing the options in enough detail that clients can imagine what it is like to experience the physical, emotional, and social effects; and guiding clients to consider which benefits and harms are most important to them);
3. provide structured guidance in the steps of decision making and communication of their informed values with others involved in the decision (e.g. clinician, family, friends).” (Stacey 2011, p.3)

1.4 Effectiveness of communicating the risk

The effectiveness of communicating risk with IDM or SDM interventions (using decision aids or not) to people facing treatment or screening decision is more and more assessed in the literature. Several reviews are available on this subject, from which some recent ones (Cochrane review of O’Connor et al.⁸, updated by Stacey et al. in 2011⁹ and Sheenan et al.¹⁰).

Depending on the studies, intervention groups received personalized risk information before screening, at the time of screening, or at the time of counseling or promotion of screening. This risk information could have different form including (non exhaustive list) individualized risk score, individual actual risk information (absolute or relative risk information) or (Computerized) Decision Aid ((C)DA).

Interventions related to the communication of the risk aimed to:

- promote of understanding of cancer screening;
- facilitate participation in decision making about cancer screening at a level that is comfortable for individuals;
- encourage individuals to make cancer-screening decisions that are consistent with their preferences and values.



To evaluate interventions' effectiveness, several measures are used in the studies. Mullen et al.⁶ reviewed the measures used in the context of first line screening for prostate, colorectal and breast cancer. They found that improvement in knowledge, participation in screening or screening intention and patient preference in decision making were often assessed while the consistency between personal value and screening decision are less measured.

IPDAS criteria are more and more often used to evaluate DA in particular⁸. These quality criteria were defined by more than 100 researchers, practitioners, patients and policy makers from 14 countries^{8, 11}. Together they identified "the things that you would need to observe in order to say that after using a patient decision aid, the way the decision was made was good and the choice that was made was good." IPDAS considers that the following criteria are important in a decision aid⁸:

- Decision quality: The DA improves the match between the chosen option and the features that matter most to the informed patient.
- Decision processes leading to decision quality: the DA helps patients to recognize that a decision needs to be made, know options and their features, understand that values affect the decision, be clear about the option features that matter most, discuss values with their practitioner, and become involved in preferred ways.

The detailed list of the IPDAS criteria is presented in Appendix 1.

In addition, from our general lecture of the literature, we are able to point out several impact of the communication of the risk to people.

1.4.1 Impact on cognitive outcomes

1.4.1.1 Improvement in knowledge

Decision aids performed better than usual care intervention improving individual knowledge. This was already showed by O'Connor et al.⁸ and confirmed later by Stacey et al.⁹, the mean difference reaches 13.77 out of 100; with a 95%confidence interval (CI) from 11.40 to 16.15 (n = 26). They also concluded that, when more detailed decision aids were compared to simpler decision aids, the relative improvement in knowledge was significant (MD 4.97 out of 100; 95%CI 3.22 to 6.72; n = 15). This knowledge was increased in 17 on 22 studies included by O'Brien et al.¹².

In Briss et al.,⁵ the improvement in knowledge included knowledge about the disease, the pros and cons of the screening and about the treatment options. The same is stated when studying personalized risk communication¹³ or with computerized decision aid¹⁰.

1.4.1.2 Accurate risk perception

O'Connor et al.¹⁴ reported that people who are exposed to DA with descriptions of outcomes and expressed probabilities were more likely to have accurate risk perception (RR 1.6 (95%CI 1.4 to 1.9), and this is more stronger when probabilities were expressed in numbers (RR 1.8 95%CI 1.4 to 2.3). than in words (RR 1.3 95%CI 1.1 to 1.5). This trend was already stated by Briss et al.⁵ and by Edwards et al.¹³ and confirmed in the Cochrane review of Stacey et al.⁹ (accurate risk perception: RR 1.74; 95%CI 1.46-2.08; n=14; description in numbers: RR 1.93 95%CI 1.58 to 2.37; description in words: RR 1.3 95%CI 1.09 to 1.48).

1.4.2 Impact on affective outcomes

1.4.2.1 Anxiety

O'Brien et al.¹² found no significant differences between DA group and usual care group in 5 out of 7 studies and a small significant decrease in anxiety when exposed to DA in the other two studies. Pooled results showed that the intervention group had less anxiety than the control group (weighted average standardized effect size -0.30 95%CI -0.53 to -0.08). Computerized DAs were shown not increasing anxiety compared to standard consultation or education¹⁰.

1.4.2.2 Satisfaction with decisions and/decision process

In the review of Stacey et al.⁹, people are more satisfied or there was no differences with the decision and/or the decision making process using a decision aid than for comparison interventions. Here also, Computerized DAs facilitated greater satisfaction with the decision making process than standard education¹⁰.



1.4.2.3 *Decisional conflict*

O'Brien et al.¹² reported that in 6 of 9 studies, people facing to DAs have significantly less decisional conflict compared with usual care. But pooled data showed no more significant effect. Nevertheless in the more recent Cochrane review, the comparison showed lower decisional conflict related to feeling uninformed (MD -6.43 of 100, 95%CI -9.16 to -3.70 n= 17) and lower decisional conflict related to feeling unclear about personal values (MD -4.81, 95%CI -7.23 to -2.40, n=14)⁹. Computerized DAs performed better than standard consultation or education in terms of lower decisional conflict¹⁰.

1.4.3 *Impact on Behavioural outcome*

1.4.3.1 *Uptake of screening test*

Edwards et al.^{13, 15} reported weak evidence that personalized risk communication increases uptake of screening tests (OR 1.5, 95%CI 1.11 to 2.03 and OR 1.31; 95%CI 0.98 to 1.77) with a smaller effect for mammography. Whether numerical calculations of risk are used and presented, the OR for test uptake was 0.82 (95% CI 0.65 to 1.03). For risk estimates or calculations which were categorized into high, medium or low strata of risk, the OR was 1.42 (95% CI 1.07 to 1.89). For risk communication that simply listed personal risk factors the OR was 1.42 (95% CI 0.95 to 2.12).

1.4.3.2 *Informed decision choice*

There is little evidence that personalized risk communication promoted or achieved informed decision making^{13, 15}.

O'Connor et al. reported value congruence with the chosen option for 2 on 3 studies⁸.

1.4.3.3 *Passivity in the decision making process / Patient-practitioner communication*

Stacey et al. reported that DA reduce proportions of people who were passive in decision making (RR 0.61, 95% CI 0.49 to 0.77, n=11) and that DA utilization appear to have positive effect on patient-practitioner communication (n=4)⁹.

1.4.4 *Conclusion*

IDM interventions improve knowledge about the disease, the advantages and disadvantages of screening and treatment option. Giving the outcomes and express probabilities in numbers improves the accuracy of risk perception. Affective outcomes are also improved with IDM: anxiety related to the decision is slight diminished and satisfaction with the decision (process) is sometimes better. Indeed, IDM impact the decisional conflict because of feeling uninformed or unclear about personal values. Finally, it reduces passivity of people in decision making and improves patient-practitioner communication. The effect on the communication of the risk on the uptake of the screening test, and particularly mammography is unclear.

These arguments plead for the use of IDM in breast cancer screening in women in Belgium, as well as in other healthcare fields.



2 OBJECTIVE

In the perspective of an informed decision making, **the present report aims**, on the basis of instructions from the scientific literature, the Belgian data and perceptions of patients and practitioners, to produce messages and information on breast cancer screening in a neutral way.

Women targeted are 40 to 49 year-old, 50-69 year-old, and 70-75 year old women without increased risk of breast cancer.

These messages have to be understandable by the majority of the women, including low educated women.

- These messages can be picked up by people who wish to communicate in a neutral way with women on the breast cancer screening, e.g. in the elaboration of decision aids.

The present report:

Does not attempt to understand the reasons why a woman will or will not be screened.

Does not intend to increase participation in the organized breast cancer screening programmes.

Does not intend to compete the organized screening program and opportunistic screening.

Does not attempt to assess the impact of a decision aid on knowledge attitude and Behaviour with regard to screening.

3 METHODOLOGY

3.1 General scientific approach

We decided to follow the ‘content development’ part of the methodology used by the Informed Medical Decision Foundation to develop decision aids: i.e. review clinical and patient-perspective literature, conduct patient focus groups, and collaborate with clinical advisors. These steps are preliminary to the production and evaluation of the decision aid¹⁶.

IPDAS has also defined criteria related to the development process of decision aids¹⁷.

- Users (people who previously faced the decision) were asked what they need to prepare them to discuss a specific decision.
- The decision aid was reviewed by people who previously faced the decision and were not involved in its development and field testing.
- People who were facing the decision field tested the decision aid.
- Field testing showed that the decision aid was acceptable to users (the general public & practitioners).
- Field testing showed that people who were undecided felt that the information was presented in a balanced way.
- The decision aid provides references to scientific evidence used.
- The decision aid reports the date when it was last updated.
- The decision aid reports whether authors of the decision aid or their affiliations stand to gain or lose by choices people make after using the decision aid.
- The decision aid (or available technical document) reports readability levels.

Based on these elements, we opt for the following process to develop neutral messages^c (see Figure 2). Each step will be detailed later in the text.

^c As a reminder, we do not aim at developing complete decision aid but only messages that can be used in such a tool.



Figure 1 – General design of the study

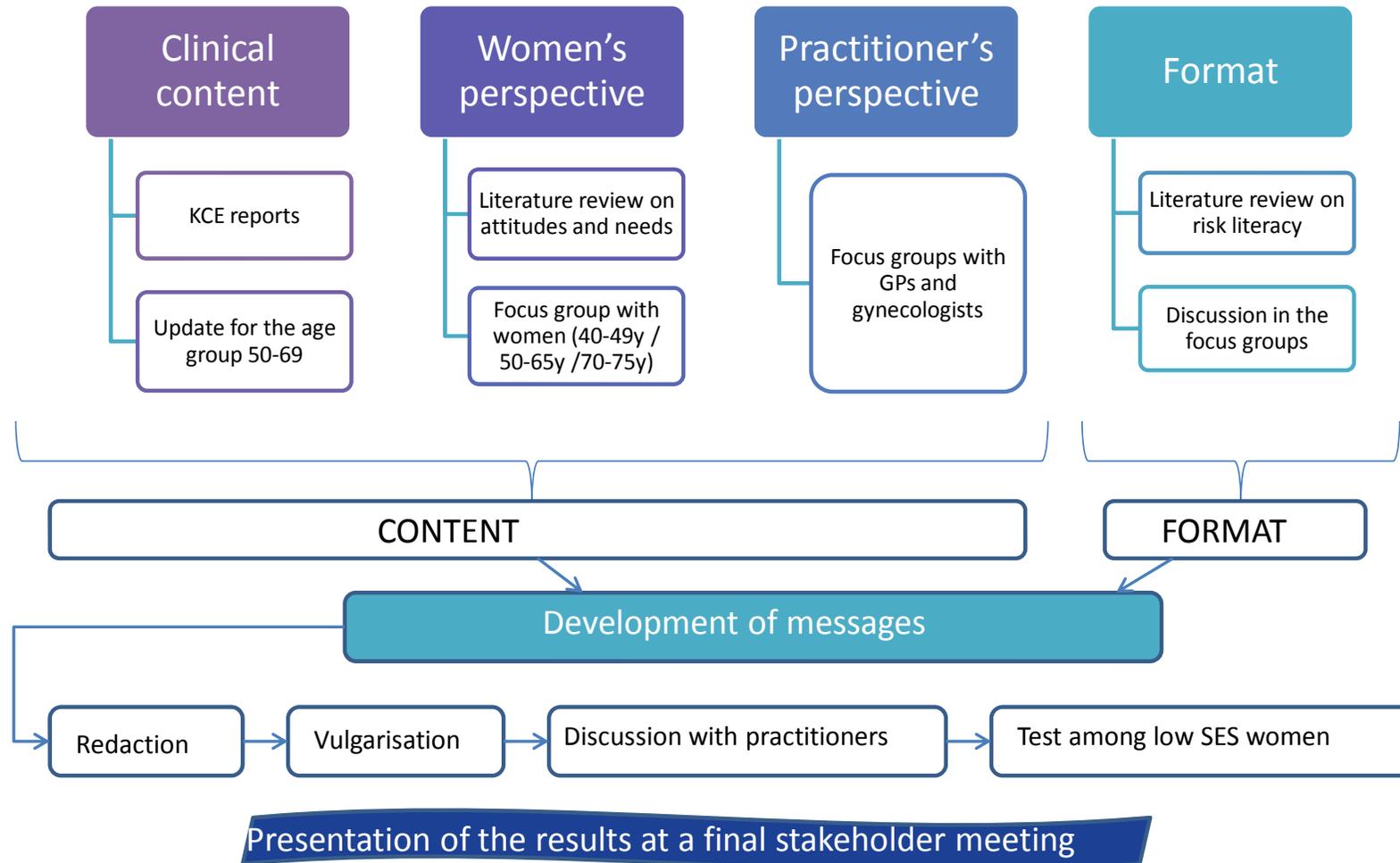
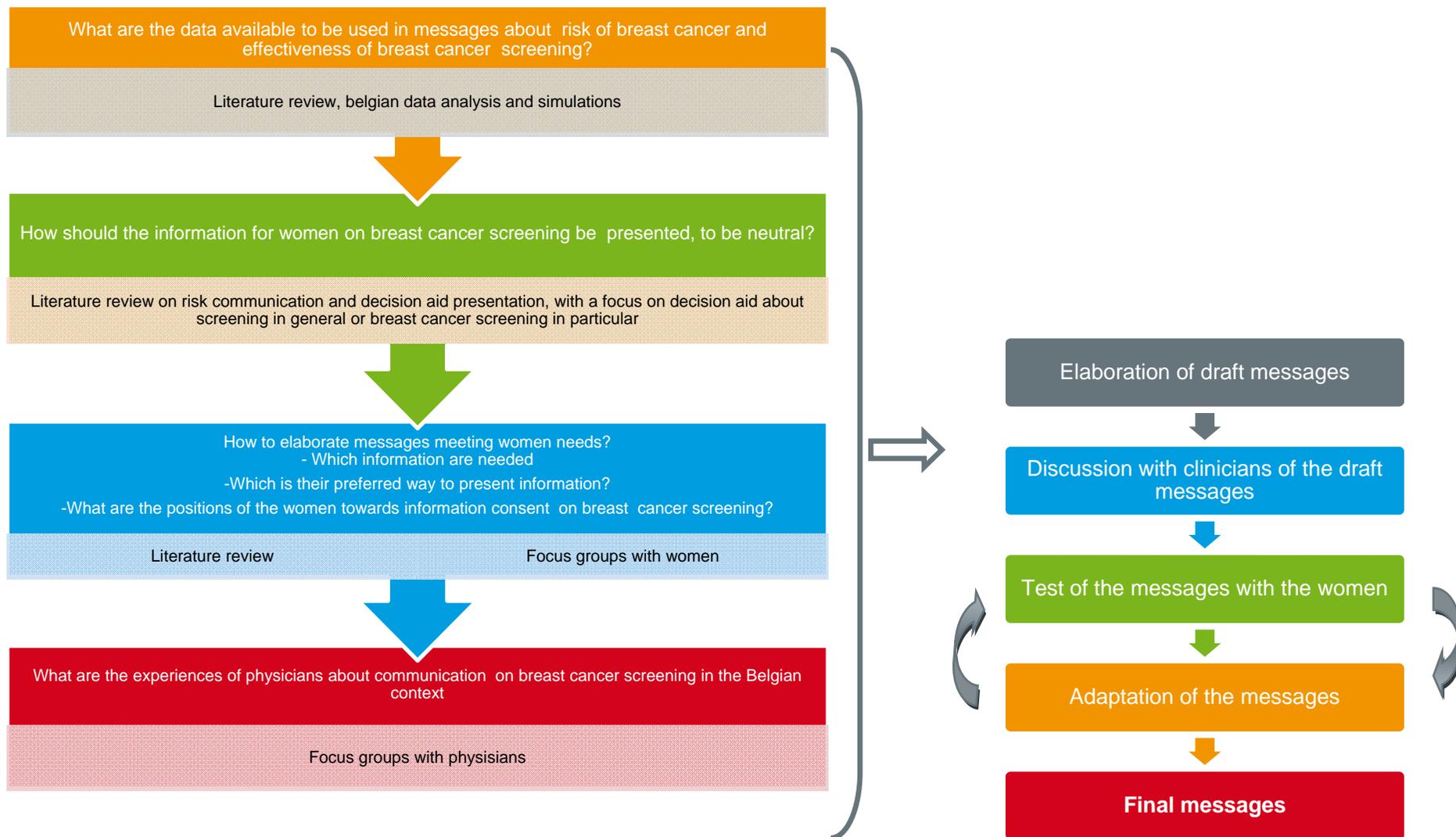




Figure 2 – Elaboration of the messages





3.2 Research questions

We translate our objective in several research questions:

- What form should information for women on breast cancer screening have to be neutral?
- How to elaborate messages meeting women needs?
 - Which information are needed?
 - Which is their preferred way to present information?
 - What are the position of the women towards informed consent on breast cancer screening?
- What are the experiences of physicians about communication on breast cancer screening in the Belgian context?
- What are the data available to be used in messages about risk of breast cancer and effectiveness of breast cancer screening?

More precisely, according to the age:

- What is the probability of dying because of a breast cancer compared to other causes of death?
- What are the consequences at 10 years of having her breasts screened or not?
- What are the consequences in the following months of having her breast screened?

3.3 Specific methodologies

Methodologies specific to each step of the study are presented in the beginning of each corresponding section.

4 ELABORATION OF THE MESSAGES: HOW TO COMMUNICATE RISK

We have searched, with a systematic approach, for information on the best way to communicate about risk in the scientific. This could give us insight on how to present messages. In our goal, we have to achieve understandable messages and neutral, i.e. non persuasive. We are not seeking for change in the adoption of the behaviour. We do not aim to produce a full decision aid.

4.1 Methodology

We first search for systematic review on the communication of the risk in general and completed our research with primary studies directly aimed at measuring communicating risk in the particular context of breast cancer screening.

4.1.1 Databases

We search in the following databases: MEDLINE, PreMEDLINE, Embase, Psychinfo, Sociological abstract and Eric.

Detailed search strategies are presented in Appendix 2.1 and Appendix 2.2.

4.1.2 Inclusion / exclusion criteria

We include only studies published in English, French or Dutch from 2002 until end of 2012.

For systematic review, we keep for further full text review only systematic review on the communication of the risk, with search in at least two databases and year of search documented and with a critical appraisal of the studies included.

For primary studies, we only included studies on healthy women with 'normal' risk of breast cancer. No type of studies were excluded except letters to the editors.



4.1.3 Quality appraisal

Quality appraisal of systematic reviews was realized using AMSTAR criteria.

Primary studies quality was assessed using the Cochrane Collaboration's risk of bias tool for RCTs, the critical review form of Law et al.¹⁸ for quantitative studies and the Côté and Turgeon's grid for the critical appraisal of qualitative research articles in medicine and medical education¹⁹.

4.2 Material

4.2.1 Systematic reviews

We have selected 6 systematic reviews related to the way to communicate risk or health effects in general. There is no systematic review dedicated to communicating on breast cancer screening.

Two Cochrane reviews from Aki et al.^{20,21} published in 2011 present a low risk of bias. Three are from moderate risk of bias (Winterbottom 2008²², Gallagher 2012²³ and Hildon 2012²⁴). And one presents a high risk of bias (Anker 2006²⁵).

Population concerned by the experiments are health professionals, policy makers, and/or consumers. Designs included are RCTs, quasi RCTs, and cross over studies using quantitative, qualitative or mixed-methods.

These systematic reviews are described in details in Appendix 3.

They covered the following issues in communicating risk:

- the **expression of numbers and probabilities** (Aki 2011a²¹)
- the **framing effect**: Aki et al. considered as well attribute framing as goal framing²⁰, when Gallagher²³ focused only on the effect of attribute framing.
- the **way to visually communicate about quantitative health risk**. Anker et al. in 2006²⁵ and Hildon et al. in 2012²⁴ They both included quantitative, qualitative or mixed methods studies.
- the use of **narrative information**: Winterbottom et al.²².

4.2.2 Additional primary studies

We completed our findings with the results of 4 additional primary studies on communicating risk, specifically for breast cancer screening: Ghosh et al.²⁶, Fagerlin et al.²⁷, Vahabi et al.²⁸, Wong et al.²⁹. Only the first one was an RCT with high risk of bias while the others are cross-sectional surveys of moderate to low quality.

4.2.3 Others

We also used IPDAS quality criteria¹⁷ and the reflexion of some books related to the presentation of the risks^{30,31}

4.3 Results

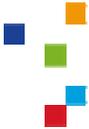
We identified several ways to communicate health messages and communicating risk in particular, from our literature review: statistics, visual representation and narrative information.

We have also identified several outcomes related to this type of communication. These are: the understanding of the risk by target people, their perception of the risk, the persuasiveness of the information and the impact of their behaviour. After a description on the way to communicate, we will present the results of these interventions according to their outcome.

4.3.1 Communicate risk messages

Communicating risk consist of giving information and probabilities to people. The aim of this is to allow them to estimate if they are at risk or not to live an event (such as disease, incident, death, etc.). Several ways to achieved it are or could be used:

- Expression of probabilities or statistics in general could be expressed: in terms of figures or verbally.
 - **Natural frequencies**: the chance of an event occurring in a population³², i.e, 4 women out of 100 will die from breast cancer.
 - **Percentages**: expression of the probability of the occurrence of an event, i.e. 4% of the women will die from breast cancer.



- **Absolute Risk Reduction (ARR):** the difference in risk between two groups²¹ i.e. for a risk of 10% in the control group, and a risk of 5 % in the intervention group, ARR would be 5%.
- **Relative Risk Ratio/Reduction (RRR):** the degree to which the risk of a bad outcome in the intervention group compares to the risk in the control group³². For example, for a risk of 10% in the control group and a risk of 5% in the intervention group, the RRR would be 50%.
- **Number needed to treat (NNT):** the number of patients who need to be treated in order to prevent one additional bad outcome²¹.
- Positively or negatively expression of the same information. The same information could be expressed positively or negatively (i.e. 96 out of 100 women will not die from breast cancer VS 4 out of 100 women will die from breast cancer). This is called the framing effect i.e. the perspective in which information is presented³¹. This could occur at two levels:
 - the effects of attribute framing, i.e. the positive versus negative formulation of information (for example: 'people who have sex with condom are more responsible and less selfish than people who have sex without condoms' vs 'people who have sex without condom are less responsible and more selfish than people who have sex with condoms),
 - the effects of goal framing, i.e. gain versus loss or messages emphasizing the positive outcomes of engaging in a health behaviour versus emphasizing on the negative outcomes of failing to engage in it ('breast cancer screening will save your life' vs 'not attending to breast cancer screening can cost you your life').
- Visual representation: tables, scales, bar, graphs, wall of people (icons arrays which total represent denominator, within different color/style icons representing numerator). For breast cancer screening, they are sometimes presented as 'wall of women'.
- Narrative information, i.e. stories, testimonials or even simple sentences describing causes, consequences of an illness or a treatment: Narratives could use the first or the third person²².
 - In order to help people to evaluate their own risk, giving comparative risk, i.e. the risk for other people with other characteristics, could be used. It highlights differences in risk related to the individual characteristics of the target patient vs relevant population³³

4.3.2 Outcomes according to the way to communicate the risk

4.3.2.1 Understanding the risk

Impact of the way to express probabilities

The systematic review of Aki et al.²¹ indicated that people (health professionals and consumers) performed better in estimating or interpreting a risk when statistics are expressed in natural frequencies than in percentages (Standardized Mean Difference (SMD) 0.69, 95%CI 0.45 to 0.93)²¹.

Relative Risk Reduction (RRR), compared with Absolute Risk Reduction (ARR), showed little or no difference in understanding (SMD 0.02 ;95% CI -0.39 to 0.43).

RRR or ARR are better understood than number needed to treat (NNT), (respectively SMD 0.73, 95% CI 0.43 to 1.04 and SMD 0.42, 95% CI 0.12 to 0.71)²¹. If the RRR is used, the baseline risk or the absolute change in risk should also be presented.

In the cross sectional survey of Vahabi²⁸, it appears that nearly two thirds of the participants prefer receiving information on breast health on a numeric format. Nevertheless, they also highlight that comprehension was significantly higher among women who received it in verbal format. Authors showed that women's comprehension was strongly associated with the interaction between received format and their format preference as well as their education level and their perceived benefit of breast cancer screening.

Uncertainty is difficult to understand and the presentation of confidence intervals did not increase this understanding²⁴



Finally, three IPDAS quality criteria¹⁷ concern the best understandability of the probabilities:

- Presentation of probabilities using event rates in a defined group of people for a specified time.
- Comparison of probabilities (e.g. chance of a disease, benefit, harm, or side effect) of options using the same denominator.
- Comparison of probabilities of options over the same period of time.

Impact of the framing

Participants in one study understood the message better when it was framed negatively than when it was framed positively (low quality evidence; 1 study; negative vs positive: SMD -0.58, 95%CI -0.94 to -0.22)²⁰.

Impact of visual representations

Even if bar charts are preferred by participants in the studies, tables and pictographs are better understood²⁴. Tables are accessible to all²⁴.

Illustrating proportion by part-to-whole sequential icons arrays permit to people to recognize proportions fairly successfully but only if they have not been randomly arranged²⁵. Indeed, the random presentation prevent a good estimation of the number of icons concerned in the whole set.

However, with their cross-sectional survey on evaluating the use of icons arrays Wong et al.³⁴ showed socio-cultural differences in the comprehension of the presentation of the information as a 'wall of women' in disfavour of African American and Latina women compared to 'white' women, and in favour of high education and higher numeracy skills.

The magnifying glass scale (a magnifying glass emphasis part of a scale) appears to be badly understood in general³⁴.

4.3.2.2 Perception of the (modified) risk

Impact of the way to express probabilities

RRR compared with ARR are perceived to be larger (SMD 0.41, 95% CI 0.03 to 0.79), while RRR and ARR are both perceived to be larger than NNT (respectively SMD 1.15, 95% CI 0.80 to 1.50 and SMD 0.79 (95% CI 0.43 to 1.15)²¹.

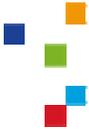
Impact of the framing

In general, positively framed messages lead to more positive perception of effectiveness of an intervention compared to negatively framed messages (low quality evidence; 2 studies; SMD 0.36, 95%CI -0.13 to 0.85)²⁰. In the particular case of screening messages, the loss messages led to a more positive perception of effectiveness compared to gain messages (moderate quality evidence; 5 studies; SMD -0.30 (95% CI -0.49 to -0.10)²⁰.

Impact of visual representations

No systematic reviews examined the effect of visual representation on the perception related to the risk. Nevertheless, in the RCT of Gosh et al., it appears that for women with inaccurate perception of risk of breast cancer, using a bar plus a frequency format diagram can improve the short term accuracy of risk perception²⁶.

One IPDAS criteria concern the visual representation to increase accurate perception of the risk, i.e. use of the same scales in diagrams comparing options.



4.3.2.3 Persuasiveness of the information

Impact of the way to express probabilities

RRR compared with ARR or NNT is more likely to be persuasive (respectively, SMD 0.66, 95% CI 0.51 to 0.81; SMD 0.65, 95% CI 0.51 to 0.80)²¹.

Impact of the framing

Compared to negatively framed messages, positively framed messages showed little or no difference in persuasiveness (low quality evidence; 11 studies; SMD 0.07, 95% CI -0.23 to 0.37)²⁰

Compared to gain messages, loss messages may have been more persuasive, but this was observed for treatment messages (very low quality evidence; 3 studies; SMD -0.50, 95%CI -1.04 to 0.04) and not for screening messages²⁰. Moreover, Gallagher et al. found no effect when persuasion was assessed by attitude/intentions or among studies encouraging detection in general. Nevertheless, they reported that for breast cancer detection, there was a trend towards a significant difference in the persuasive effect of the gain- versus the loss-framed message (k=10; r=-0.052, p=0.077). This reinforces Aki et al. statement in their conclusion: "The unexplained heterogeneity between studies suggests the possibility of a framing effect under specific conditions." (Aki 2001²⁰, p.2). Aki et al. concluded therefore that, to avoid persuasiveness, it is preferable to present balanced information.

Impact of visual representations

In order to achieve good quantitative judgement, and not in order to promote a behaviour, the size of a graphic element should be proportional to the number it portray because if they diverge, people will be more influenced by size than by numbers²⁵.

Impact of the narratives

In a third of the 17 studies included in the systematic review of Winterbottom²², narrative information influenced decision making more than the provision of no additional information and /or statistically based information. This persuasive effect is particularly stronger when studies employed first person narratives (twice as likely). Nevertheless, the

authors mentioned that "there was little consistency in the methods employed and the narratives' content to provide evidence on why narratives affect the decision process and outcome, whether narratives facilitate or bias decision making, and/ or whether narratives affect the quality of the decision being made". (Winterbottom, 2008²², p.2079)

4.3.2.4 Impact on the adoption of a behaviour

Impact of the way to express probabilities

No systematic review studied the impact of the way probabilities are expressed on the adoption of a behaviour, such as attending screening.

Impact of the framing

Compared to negatively framed messages, positively framed messages showed little or no difference in behaviour (moderate quality evidence; 1 study; SMD 0.09 (95% CI - 0.14 to 0.31). Same, compared to gain messages, loss messages showed little or no difference in behaviour (low quality evidence; 16 studies; SMD -0.06, 95%CI -0.15 to 0.03)²⁰.

Impact of visual representations

Graphs emphasizing the numerator of a risk ratio are more likely to promote risk behaviour changes²⁵.

Although accessible to less numerate and older populations, pictographs tended to lead to more risk avoidance²⁴.

Giving comparative risk

The fact that people feel themselves that their risk is above average, make them more likely to act upon the risk more than the ratio risk/benefit. A contrary, if they consider their risk as being below average, they could be reluctant to adopt behaviour they may otherwise have chosen. This was documented in the observational study of Fagerlin²⁷. Given comparative risk could therefore influence health decision.



Key messages

In order to write understandable messages, it is preferable to express numbers in natural frequencies instead of percentages, or ARR, presented in tables and not randomly arranged icons array. NNT are less understood.

To remain neutral, target accurate risk perception and avoid persuasiveness in communicating risks, it is preferable:

- To use ARR and not to use RRR – or if use it, give also baseline risk or absolute change risk
- To present balanced information, i.e gain and loss framed messages
- Not to give comparative risk
- When using graphs, the size of a graphic element should be proportional to the number it portrays.

Using narratives is uncertain in terms of facilitating or bias decision making.

IPDAS criteria regarding the format have to be respected:

- Presentation of probabilities using event rates in a defined group of people for a specified time.
- Comparison of probabilities (e.g. chance of a disease, benefit, harm, or side effect) of options using the same denominator.
- Comparison of probabilities of options over the same period of time.

5 ELABORATION OF THE MESSAGES: THE CONTENT

In order to elaborate the content of messages aiming to feed decision aids in breast cancer screening for women, this chapter describes the type of information needed according the women and the physician perspective. Last but not least, we identify data that have to be used in the messages. A short discussion on the current polemic about screening benefit feeds the last section of the chapter.

5.1 Type of information to be included in a decision aid

5.1.1 IPDAS content criteria

Some IPDAS criteria refer to the type of information that needs to be included in an effective decision aid¹⁷.

These are:

- Description of the condition (health or other) related to the decision.
- Description of the decision that needs to be considered (the index decision).
- Listing of the options (health care or other).
- Description of what happens in the natural course of the condition (health or other) if no action is taken.
- Information about the procedures involved (e.g. what is done before, during, and after the health care option).
- Information about the positive features of the options (e.g. benefits, advantages).
- Information about negative features of the options (e.g. harms, side effects, disadvantages).
- Information about outcomes of options (positive and negative) includes the chances they may happen.
- Information about what the test is designed to measure.
- Description of possible next steps based on the test results.



- Information about the chances of disease being found with and without screening.
- Information about detection and treatment of disease that would never have caused problems if screening had not been done.
- Asking people to think about which positive and negative features of the options matter most to them.
- Offering of possibilities to compare the positive and negative features of the available options.
- Showing the negative and positive features of the options with equal detail.

5.1.2 *Women's perspective*

In order to include the women's perspective in the development of our neutral messages, we reviewed the international literature and national studies. We complete this section with the findings from our 6 focus groups aiming at exploring the information needs and experiences in communication around breast cancer screening of women in the Belgian context.

5.1.2.1 *Methodology*

We used a qualitative method to approach these specific research questions. Focus groups are particularly suited to gathering substantial and comparable individual information and preferences while stimulating interaction, discussion and exchange of ideas between participants.

Literature review on women perspectives

Databases

We search in the following databases: MEDLINE, PreMEDLINE, Embase, Psychinfo, Sociological abstract and Eric

Search strategies

Detailed search strategies are presented in Appendix 2.3. They were completed with handsearching.

Inclusion / exclusion criteria

We include only studies published in English, French or Dutch until and including 2012.

All the type of design were included, except editorial or letter to the editors. We have excluded studies on non occidental population and high breast cancer risk women.

Quality appraisal

Quality appraisal of systematic reviews was realized using AMSTAR criteria³⁵.

Primary studies quality was assessed using the Cochrane Collaboration's risk of bias tool for RCTs, the critical review form of Law et al.¹⁸ for quantitative studies the Côté and Turgeon's grid for the critical appraisal of qualitative research articles in medicine and medical education¹⁹.

Focus groups with women

In order to identify the information that could help women of different language and age groups to make informed decisions concerning breast cancer screening, we carried out focus groups exploring the following topics:

- How do these women perceive breast cancer screening?
- What information - on breast cancer screening - do they expect (type, content, informant...)?
- Why do they make the decision to participate (or not) in breast cancer screening?

Six focus groups (3 for each language group of French and Dutch), scheduled to last two hours, took place between March 21st and April 18th 2013. Two groups contained women aged 40 to 49, two groups contained women aged 50 to 69 and two groups contained women aged 70 to 75. The focus groups were planned to allow a reflection time to adjust the 'interview guide' (see appendix) after the first group.



The recruitment of participants differed according to region. All the Dutch-speaking participants were recruited with the help of the Femma^d section of Brasschaat, whose representative recruited interviewees by phone (essentially Femma members). The French-speaking participants were recruited with the help of three associations. The women in the 40 to 49 group were recruited mainly by mail through the Mompreneur Network^e. The 'Vie Féminine' section of Namur helped with the recruitment of the participants aged 50 to 69 (mostly members of the association contacted by phone). The 70-75 group was recruited with the help of several 'FPS'^f sections active in the Province of Liège, who called for volunteers during their members' meetings/activities.

Ten to twelve women were asked to participate in each focus group in order to reach the ideal focus group size of six to eight participants (although we had decided in advance not to refuse anyone, should there be more than ten participants). The selection of the participants was not randomized as the women volunteering to participate had to be 'healthy', that is, without a personal history of breast cancer. Because of the delicacy of the subject, all were informed in advance about the topic of the interviews. The budget allocated to give each participant a small gift was divided between the organizations.

All Dutch focus groups took place in Brasschaat in a pleasant and easily accessible meeting room of the local Femma section. The French focus groups took place in the usual meeting places of the hosting organizations (in Montegnée, Namur and Alsemberg).

One moderator was in charge of the Dutch-speaking groups, and another took charge of the French-speaking groups. A reporter-analyst was present to observe and take notes during the interviews. The groups were recorded, with the consent of the interviewees.

^d Femma is a Dutch women's organization with 75 000 members in Flanders and Brussels

^e The Mompreneur Network is a network of women who are mothers and freelancers

^f FPS is a women's association active in Wallonia and Brussels

The focus groups were structured as follows (see 'interview guide' in appendix):

1. Introduction and presentation of participants (reasons for participation/experience with breast cancer screening/experience with breast cancer)
2. Individually: participants fill out a short questionnaire about their questions regarding breast cancer screening (see appendix)
3. Collective discussion
4. Individually: participants consult documents (individual worksheet and four different information factsheets) (see appendix)
5. Collective discussion
6. Individually: participants fill out a short final questionnaire about their health care decision-making process (see appendix)

Immediately after each focus group, the moderator and reporter debriefed the discussion and discussed the main topics considered by the interviewees. Afterwards, all interviews were summarized by the reporter, but no integral transcriptions were made.

In a first step, each focus group discussion was analysed. Following this, a transversal analysis was performed (without using software) based on the questions developed during the interviews. The analysis aimed to answer the research questions and point out general similarities and differences between age and/or language groups. The results can be found in section 5.1.2.2 Insight from the focus groups.

5.1.2.2 *Insight from the literature*

Regarding information needs of women to decide if they will or will not attend breast cancer screening, literature is scarce. It focuses more on the motivation, drivers and barriers to get screened. These last topics are out of scope of the present report. Anyway, we identified several studies published in peer review journals that give nevertheless insight on the way to communicate with women in women's perspectives. We have selected 14 papers, i.e. 1 RCT, 7 quantitative studies, 1 narrative review and 5 qualitative. All were of moderate to low quality.



In order to explore deeper this perspective in the Belgian context, we used also some findings from Belgian studies^{36, 37} as well as results from the quantitative evaluation of the breast screening media campaign in French-speaking Belgium³⁸. However, input from them is limited because these studies were also carried out with the objective to improve participation in breast cancer screening program and not in the perspective to explore information needs.

The meaning given to the screening

Hersch et al.³⁹ report that women consider breast screening as an opportunity for early detection, and consequently a way of minimizing potential regrets. Breast cancer screening is a source of anxiety: anxiety about attending, awaiting results and having follow up tests that false positive results entail. Nevertheless they are confident in the sensitivity of the mammography and are seeking with it for reassurance. According to the authors³⁹, this anxiety and the perception on the mammography results from persuasive impact of decades of screening promotion where benefits are overestimated and harms neglected.

Findings from open-ended questions in the RCT of Vahabi²⁸ indicated that some women want to detect early cancer whether other do not want to because of fear of radiation exposure or prioritizing other daily responsibilities. Beliefs on faith /destiny and body image and sexuality were the two common reasons for not attending breast cancer screening in this study. As breasts are symbolized in our society as a sign of womanhood, any action which could lead to their loss can be viewed as a risk taking behaviour. You can save your life but not necessarily your breasts. This reasoning could lead to not attempt the screening

In Belgian women, screening is perceived as the health behaviour associated to not develop breast cancer³⁶.

Information needs

In order to elaborate a decision aid, a distinction could be made between essential information, additional information and unnecessary information⁷.

As personal perceived risk for cancer increased, patients were more likely to seek information about screening on their own and in interaction with their physician⁴⁰. In their review Hersch et al. mentioned that 89% of 2305 surveyed women wanted information on limits of mammography screening and 82% wanted to know reasons why some people oppose screening³⁹.

Source of information

A survey in Germany, among 2 108 women, indicated that 78.8% of the women said that they are informed about breast cancer. These results are associated with higher educational level and age. Information was given by their gynaecologist in the majority of the cases (59.9%), while 5.8% reported having been informed by other physician⁴¹.

In the US, women are interested in online health information, including their own personalized risk, with the support of a real person to assist them. This could be useful to prepare them before to talk with their physician⁴²

Several studies, including Belgian ones, point to the important role of the physician in improving patient's knowledge on screening³⁷.

Desire to discuss with physician

The results of a telephone survey in 375 patients aged from 40 to 85 year-old in the USA showed that 80% of women were interested in discussing cancer risk, and in particular mammograms, with their primary care physicians, and several time, overall if they perceived themselves as average or higher risk to develop breast cancer⁴³.

As we already mentioned it, when perceived risk for cancer increased, patients were more likely to seek information about screening on their own and in interaction with their physician⁴⁰.



Opinion on shared decision

Chewning et al.⁴⁴ performed a systematic literature review on patient preferences for shared decision in different context. Some studies they included divided patients in three types according to their attitude to decision-making: those who wanted to delegate decision to the physician, those who wanted to share the decision and those who wanted to make the decision themselves. Population could therefore be divided on patients who wished to delegate and patients who wished to participate in decision, autonomous or by sharing it with the physician⁴⁴. They reported that the majority of the respondents belong to the last group (63%, 75 studies), 21% preferred to delegate decisions (25 studies). In the 16% remain, results are mixed. In studies focusing on cancer (27 studies published after 2000), 85% of the patients preferred also to participate in the decision.

In the qualitative study on how to increase screening participation in French-speaking Belgium, physician appears as the one who will decide on the utility of an examination, including screening. This attitude is occasionally perceived as paternalistic: some patients report feeling treated like children³⁶.

Knowledge and the estimation of the risk of breast cancer

Women reported in a qualitative study that they estimate their own risk of breast cancer based on guess, family history, according to age and information sheet⁴⁵. Data from the survey of Pöhlh et al. indicated that in Germany there are a large percentage of over- and underestimation of cancer risk⁴¹. Facione et al. in the US stated also this bad estimation of the risk⁴⁶.

It appears that an overestimation of the risk might cause anxiety and therefore overuse of screening. Another effect is that women to avoid anxiety do not attend to the screening and would therefore not benefit from the treatment in case of need⁴⁷.

In French-speaking Belgium, 9% of the surveyed women think that they will never suffer from breast cancer because they have no family background³⁸.

Knowledge of the women about breast cancer and breast cancer screening

According to an Australian study, women have sufficient knowledge about breast cancer in general but only 6% of 479 surveyed women knew that some breast cancer grows so slowly that they never affect health (Schwartz et al. 2000 mentioned by Hersch 2011³⁹).

Regarding breast cancer screening in particular, accordingly to a study in The Netherlands⁷, women seem to have sufficient knowledge about benefits and harms of screening, but less knowledge about false negative mammograms or overdiagnosis. Similarly, overdiagnosis awareness is minimal in Australian women, but authors found that women are able to understand it⁴⁸. Hersch et al. also stated that, according to the estimation over overdiagnosis they receive, women will be more or less careful in their personal decision making to be screened. Higher the estimates, higher cautious⁴⁸.

In French-speaking Belgium, women think that breast cancer screening is costly, painful and that, during the examination, the medical professionals are not respectful of the body and miss empathic communication. Breast cancer screening is scarce perceived as harmful: only risk radiation and pressure on the breast are evoked³⁶. In a survey among 600 French-speaking women, screening and cancer treatment are reported as ineffective for respectively 11% and 8% of the respondents³⁸.

Reason to attend or not breast cancer screening: the role of informed choice

We did not search for reason to attend or not screening because it is out of the scope of this project. We know from the section on the effectiveness of the decision aid in (breast)cancer screening that informed choice has few impact on screening behaviour. Nevertheless, the fact that information on what is needed to make an informed choice⁹ could be invoked as a motivation to be screened or not. We therefore emphasis here findings

⁹ An informed choice is defined as a choice based on relevant knowledge while the decision-maker's attitude is consistent with her actual screen behaviour⁴⁹.



from the qualitative literature related to the place of information in women participation to screening.

A systematic review was done by Ackerson et al. on the decision theory perspective on why women do or do not decide to have their breasts screened⁵⁰. This review highlighted that adherence of women to the screening is related to, among others, the fact that they have or have sought knowledge about risk and their understanding of it.

In a Norwegian qualitative study aiming to explore the decision making process of the women invited to a mammography screening program⁵¹, it appears that balanced information availability are not necessary used in their decision making process. Women do not weigh pro and con arguments, risk and benefits. In their case, the fact that they were invited by a trusting part (government) with a prescheduled appointment is enough to decide to participate, at least for women who decided to participate effectively.

There are a lot of reasons to (not) attend breast cancer screening that we are not going to develop here: attitude towards risk, beliefs regarding who control health (myself or others), cultural variation in attitude towards health and disease, own or other's previous experience with screening, etc⁵². However, in terms of information, the risk of overdiagnosis resulting from screening do not impact the decision of Australian women to be screened but whether the decision on the treatment of the tumor in case of positive result of the mammogram⁴⁸.

To our knowledge, the role of information, other than awareness of the breast cancer screening program, as not yet been explored in women perspective in Belgium. This is the aim of our qualitative approach described in the next section.

Key messages

The women perspective is mainly studied in the context of improving participation in breast cancer screening programmes.

Breast cancer screening could be perceived as an opportunity but also as a risk to discover a disease while women were healthy before to attend it. It could be a source of anxiety.

Women are seeking for information, mainly with their doctors and discuss with them about the opportunity to be screened in a shared decision making perspective.

While women report to be informed on this subject, generally they do not accurately estimate their risk of breast cancer and have no precise knowledge on breast cancer and risk related to breast cancer screening, such as overdiagnosis.

They do not necessarily seek information or use balanced information to decide to attend screening or not if they trust the part who advice to do so (physician, government).

A distinction could be made between essential information, additional information and unnecessary information.

5.1.2.3 *Insight from the focus groups*

Operation of the focus groups: people and atmosphere

- Focus group characteristics:

Six focus groups took place between March 21st and April 18th 2013, gathering a total of fifty-one Belgian women without a personal history of breast cancer. The focus groups lasted between 1 hour and 35 minutes and 2 hours and 10 minutes. The groups were made up of between six and eleven women, who each knew at least two other participants in the group. The women were aged between forty and seventy-five. All participants in the Dutch-speaking groups originated from the Province of Antwerp. The French-speaking participants came from the provinces of Liège, Namur and Brabant Wallon.

**Table 1 – Description of the focus groups**

	Focus group 1	Focus group 2	Focus group 3	Focus group 4	Focus group 5	Focus group 6
Language	Dutch	Dutch	French	French	Dutch	French
Age group	40-49	70-75	70-75	50-69	50-69	40-49
Date	21/03/13	29/3/13	2/4/13	15/4/13	16/4/13	19/4/13
Timing	4 PM - 6 PM	4 PM - 6 PM	10 AM-12 AM	2 PM – 4 PM	4 PM - 6 PM	7.30 PM – 9.30 PM
Place	Brasschaat	Brasschaat	Montegnée	Namur	Brasschaat	Alsemberg
Number of participants	6	11	9	7	11	7

Focus group participant characteristics

Except for the 40-49 groups, the Dutch-speaking participants seemed to have a higher social level than the French-speaking participants.

Participants could not have a personal history with breast cancer. However, we asked them if they knew women who had suffered from breast cancer and twelve participants (among whom eight women were above seventy) knew no one in their close environment with a history of breast cancer.

Forty-three women, among whom nine women were under 50, had already undergone one or more breast cancer screening. Three women took the initiative themselves to participate in a breast cancer screening (after a close friend died of breast cancer, or other personal reasons) whereas for the others, the screening was suggested to them by a health care specialist. The 40-49 and 50-69 age groups usually cite their gynaecologist as their reference concerning breast cancer matters. Younger Dutch participants clearly expressed the view that they considered the gynaecologist to be a trustworthy specialist whose opinion on the subject they value (which is not the case regarding their general practitioner). On the other hand, women from the 70-75 age groups tend to seek out their general practitioner, who plays an important role.

Table 2 – Focus group participants characteristics

	40-49 Dutch	40-49 French	50-69 Dutch	50-69 French	70-75 Dutch	70-75 French
Participants	6	7	11	7	11	9
No contact with cancer	1	1	-	2	3	5
Experience with breast cancer screening	3	6	11	6	11	6
Own initiative	1					2
Follow-up by gynaecologist	2	2	6	5	3	3
Follow-up by general practitioner			3	1	8	5



General atmosphere

Breast cancer screening is a delicate and sensitive subject. Nevertheless, the focus groups all went very well and took place in a very pleasant and respectful atmosphere, allowing each participant to express themselves without difficulty. The fact that the moderators and reporters (except during the first focus group) were women probably made the discussion over such personal matters less complicated. The presence of an observer during the first focus group did not seem to interfere with the group's dynamic.

What would women like to know before undergoing a breast cancer screening?

The participants were asked to list the two most important questions they ask(ed) themselves before a breast cancer screening. Twenty-eight different questions were collected. Each topic was discussed and the participants had the opportunity to add supplementary questions. All questions can be found in the next box.

The analysis of the questions asked more than once during the focus groups shows that all age groups share three concerns about breast cancer screening: is it harmful, what happens during the examination and is it painful?

Each group formulated age-related questions. In the age groups 70-75, the screening age limit of sixty-nine raised several questions. Women expressed how difficult it is for them to understand and accept the screening age-limit. The age groups 50-69 were more concerned by and critical of the usefulness of breast cancer screening. Participants questioned the screening frequency and the examination offered in the context of the 'free' mammogram. Probably because of the presence of four women who had never had a breast cancer screening, the Dutch-speaking age group 40-49 had more practical questions about breast cancer screening (who should be screened, what will happen, why should one be screened, why not, when, and where).

The participants' questions can be divided between four themes (see Table 3):

- Questions about breast cancer screening;
- Questions about the benefits and consequences of participating;
- Questions about breast cancer in general;
- Questions about practical organisation.



Table 3 – Main questions of the participants before breast cancer screening by theme

Breast cancer screening	Risks & benefits of breast cancer screening	Practical organization	Breast cancer
What happens during breast screening?	Is breast cancer screening harmful?	When do I get the results? (how long does it take?)	Why no more screening after age 70?
Does it hurt?	Is breast cancer screening really useful?	Where are the results sent?	When should one be screened for breast cancer because of risk of cancer? (family antecedents, pain...)
How often should one be screened? (is every two years sufficient)	Is breast cancer screening reliable?	Where do I go for breast cancer screening? (are some places better?)	What is the risk of getting breast cancer?
What is breast cancer screening?	Does breast cancer screening find every cancer?	How long does the screening take?	What can one do to prevent breast cancer?
Is a mammogram sufficient?	Are there statistics about screening results?	How should I prepare myself?	What happens if breast cancer is found?
Are there other ways to screen?	Does early detection have an impact on curing the cancer?	How long does it take to get an appointment?	
Who is offered breast cancer screening?		How much does it cost?	
What is a mammogram?		Can you ask to screen or do you have to wait to be invited?	
What are the possible outcomes?			

The participants of age groups 50-69, who have the longest and most wide-ranging experience of breast cancer screening, formulated the most questions. They were mainly searching for practical organizational-related information, but also expressed their need for a clear overview of the benefits and risks of breast cancer screening. This was also the case for the other groups.

During the focus group discussion, participants exchanged their points of view about the list of questions. Below, we support all statements with complementary and/or contradictory citations. Differences between language and age groups are also highlighted.

Breast cancer screening

- What is breast cancer screening according to participants?

During the focus group discussions, it quickly became obvious that breast cancer screening had different meanings. Some of the younger women who had never been screened did not know precisely what breast cancer screening involved nor to which specific technology it refers:

“Hoe gebeurt het onderzoek precies? Wat is het precies? Is dat zoals een radiografie?” (40-49)

“Waar mag ik mij precies aan verwachten?” (40-49)

Older -unscreened- women shared the same concerns:

“Ik wist niet wat een mammografie was, wat ze er gingen doen.” (70-75)

“Wat is het verschil? Ik weet dat niet?” (70-75)

French-speaking participants aged 40-49 spontaneously questioned themselves about the terminology and wondered whether a mammogram is considered to be a breast cancer screening technique:

“Je me suis demandée si la mammographie était considérée comme un dépistage.” (40-49)

“Le dépistage, c’est juste une mammographie.” (40-49)

“Il y a la mammographie et l’échographie.” (40-49)

“... il y a un manque de clarté par rapport à ce qu’il faut faire et à quel moment: mammographie ou échographie ? Je ne comprends pas ce qu’ils perçoivent avec l’un ou l’autre ni à quoi cela sert...” (40-49)

All the French-speaking women aged 50-69 except one made a distinction between mammogram and ‘mammothest’, whereas the younger ones are not familiar with the word:

“J’ai déjà entendu le terme mammothest dans une publicité, mais ce n’est pas clair.” (40-49)

“Le ‘mammothest’, c’est uniquement la radiographie des seins et c’est gratuit mais incomplet.” (50-69)

Breast cancer screening was associated with a combination of a mammogram and an ultrasound scan:

“La mammographie, c’est la radiographie, suivie d’une palpation et d’une échographie, elle est faite par un médecin et c’est payant.” (50-69)

According to them, the mammothest is not a full screening, but rather something for people who cannot afford the ‘real’ trustworthy screening. Their perception had sometimes been directly influenced by health care providers:

“Le mammothest est un outil pour les gens qui ne vont pas au dépistage, c’est une manière de les approcher. Si on va au dépistage, il n’y a pas d’intérêt à y aller.” (50-69)

“Il vaut mieux choisir l’examen complet.” (50-69)

“Une infirmière m’a dit que le mammothest est insuffisant.” (50-69)

“Si c’est juste pour le mammothest, je n’irai pas. Le médecin a dit que cela ne servait à rien. J’irai uniquement à un dépistage complet.” (50-69)

In the correspondent Dutch-speaking age group, some women also expressed a view concerning the perceived incompleteness of a ‘simple’ mammogram:

“Ik geloof niet in een mammografie alleen, enkel in een mammografie en een echografie.” (50-69)



They do not understand why all women are not automatically offered both tests and wonder why it is not done automatically:

“Waarom doet men niet automatisch een echografie?” (50-69)

“Is er dan wel een mammografie nodig? Met een echo kunnen ze veel beter iets opsporen. Als ze iets zien bij de mammografie, moet je toch een echo laten doen.” (70-75)

Contrary to their French-speaking counterparts, Dutch women do not distrust the free screening. After listening to the story of a cancer detected by an ultrasound scan but invisible at the mammogram, questions about the efficiency of mammogram were asked:

“Spijtig dat er bij gratis borstkanker screening geen echo bij is. Gebeurt dat alleen bij de radioloog of bij specialisten? Wat is de reden daarvoor?” (70-75)

- Are there other screening techniques beside mammography?

Several participants asked questions about possible alternatives:

“Waarom op deze manier screenen? Zijn er nog andere manieren om op borstkanker te testen ?”(40-49)

“Zijn er alternatieven? Nu wordt die keuze voor ons gemaakt”. (40-49)

“Is het het meest uitsluitende onderzoek? Want het is niet aangenaam.” (40-49)

How is the screening performed and by whom? Does it hurt? Some women considered information about the procedure to be important, and the question about pain was asked in all the groups:

“Zijn daar andere vrouwen aanwezig?” (40-49)

“Est-ce que cela fait mal à chaque fois ? ” (70-75)

- Who is offered breast cancer screening?

Questions about access to breast cancer screening were asked, directed at physical characteristics and the age of the targeted women:

“Met een A-cup of een grote boezem, is dat anders?” (40-49)

“Une femme qui allaite ou une femme enceinte est-elle hors de danger ? Doit-elle se faire dépister ?” (40-49)

“Les dames qui ont des seins en silicone: peuvent-elles se faire dépister comme les autres ?” (70-75)

The age limits concerning the first and the last screening were questioned, especially by those under or above these ages. These questions can also be seen as questioning who is at risk of developing breast cancer. Women above seventy expressed their desire to pursue screening after this age:

“ Pourquoi à 50 ans ?” (50-69)

“Waarom stopt dat ? Op 75 ? nee 70.” (50-69)

“Borstkanker screening stopt op 70. Zijn wij daarna misschien kankervrij?”

- How often should it be performed?

The frequency of screening and the risk that cancer might occur between two screenings was questioned. It was indicated that doctors formulate different recommendations regarding this matter:

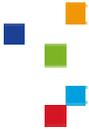
“Met welke frequentie screent men? Elk jaar of om de vijf jaar?” (40-49)

“Hoeveel keer per jaar mag je dat laten doen?” (40-49)

“Pourquoi est ce que certains gynécologues le proposent tôt et d’autres pas ? Certains tous les deux ans, d’autres tous les ans. Pourquoi y a-t-il deux “types de discours ?” (40-49)

“Welk nut als het maar om de 2 jaar is? En wat nadien, als de screening leeftijd is afgelopen?” (50-69)

“Ze zeggen wel dat alles in orde is maar wat gebeurt er in die periode van twee jaar?” (50-69)



- What are the possible outcomes of a mammogram?
In all age groups, precise information about the timing and presentation/content of the results is expected:

“Wat is de volgende stap. Dit moet meteen bij de uitnodiging staan. Ik wil alles weten... what if...” (40-49)

“Wat wordt er met die resultaten gedaan? Analyseert men ze statistisch? Of enkel een individuele test, waarvan men de resultaten weggooit na beoordeling.” (40-49)

“Comment se fera la mise à disposition des résultats.” (60-65)

“Wordt de informatie naar de huisarts doorgestuurd?” (60-65)

“Hoe lang duurt het voor je de uitslag krijgt, je zit al met de angst!” (70-75)

Risks and benefits of breast cancer screening

- The usefulness of participating in screening was questioned. Women wondered about the benefits of screening and expressed their fear of side effects. Discussions brought up the question about the use and efficiency of the breast cancer screening:

“Er is veel medische overconsumptie.” (40-49)

“Het is gratis. Is het dan wel afdoend? Misschien doen ze dat voor de goedkoop op die manier... Ik wil daar wel iets voor betalen als ik zeker weet dat het betrouwbaar is...” (40-49)

“Zijn er cijfers bekend? Wat wordt door de screening ontdekt, wat door iets anders?” (50-69)

“Quelles sont les conséquences du dépistage précoce sur la guérison?” (50-69)

“Zouden ze wel zeker ontdekken wanneer er kanker was?” (70-75)

- The question of whether screening is safe (not harmful) and free of side effects concerned all age groups but the 40-49 group had many questions on the topic during the discussions. Radiation risks and pressure on the breast during screening were their principal concerns:

“Hoe lang duurt dat? Die blootstelling?” (40-49)

“Ik wil daar wel meer over weten. Vergelijk dat nu eens voor mij met bijvoorbeeld een GSM. Of is dat vergelijkbaar met een radiografie van een pijnlijke duim? Ik wil dat weten.” (40-49)

“De vraag “is dat wel gezond” is alleen maar blijven groeien!” (50-69)

“Kan het aandrukken (platdrukken) van de borst geen negatieve gevolgen hebben?” (70-75)

“Zijn de X-stralen niet gevaarlijk (zijn dat wel X-stralen?), dat is toch ook niet 100% aangeraden” (70-75)

Participants aged 50 to 69 asked for statistics on these questions, and one of them asked a challenging question about the possible link between screening and cancer:

“Zijn er cijfers bekend?” (50-69)

“Er zijn heel veel borstkankers, komt dat niet door de screenings?” (50-69)

Practical organization

Participants formulated several concrete questions about practical matters related to breast cancer screening.

- Does one need to be invited? How long is the invitation valid?
These questions expressed a need for ‘patient empowerment’: being allowed and given the means to decide themselves when it is useful to be screened:

“Peut-on le faire d’initiative ou faut-il une prescription du médecin?” (40-49)

“Peut-on prendre l’initiative si on est plus jeune ou doit-on attendre d’être invitée?” (50-69)

“Hoelang kan je de uitnodiging laten liggen voordat je reageert?” (50-69)

“Quel est le délai avant d’avoir un rendez-vous?” (50-69)

In the 70-75 group, the topic was used to discuss women's wish to continue to be part of the screening programme:

"Vanaf 70 zouden ze ons bijvoorbeeld om de vijf jaar nog eens moeten uitnodigen." (70-79)

- Where can one go for breast cancer screening ?

Here, beside the need for practical information, participants also questioned the quality of the breast cancer screening providers, namely the mobile screening units:

"Doet men borstkanker screening overal (in ziekenhuizen en zo) of enkel in gespecialiseerde centra? Waar?" (40-49)

"Où le faire ? Certains lieux sont-ils plus fiables ?" (40-49)

"Est-ce moins performant de le faire par le bus de dépistage ?" (70-74)

The necessity of going to the same screening centre each time was discussed. This guarantees a more patient-friendly experience and above all a better knowledge of individual peculiarities:

"Il vaut mieux aller à chaque fois dans le même centre de dépistage, on est mieux surveillé, on nous connaît ils ont des infos sur les examens précédents et il y a un meilleur suivi, plus personnalisé." (50-69)

- How much does it cost?

"Est-ce que les assurances hospitalisation interviennent?" (40-49)

"Combien cela coûte-t'il ?" (50-69)

"Je ne sais pas ce qui est remboursé par la mutuelle ?" (70-74)

- How and when do you receive the screening results?

Waiting for the results can be a very stressful moment:

"Het is vooral belangrijk om zicht te hebben op wanneer je de uitslag ontvangt. Je maakt je toch zorgen." (40-49)

"Hoe lang duurt het voor je de uitslag krijgt, je zit al met de angst!" (70-75)

In the age group 50 to 69, the desire for more empowerment was again expressed, in terms of obtaining the screening results:

"Resultaten moet je ook naar huis gestuurd krijgen, ik heb dat nog nooit gekregen." (50-69)

And one woman was concerned about the use made of all the screening results:

"Wat wordt er met die resultaten gedaan? Worden ze door wetenschappers geanalyseerd? Of is het enkel een individuele test, waarvan men de resultaten weggooit na beoordeling?" (40-49)

Breast cancer

Some questions formulated by the participants are indirectly related to breast cancer, even if the illness had not been explicitly addressed in the focus groups. Given the objective of the focus groups, we will not go into the details of questions about causes, symptoms and cures.

Questions about groups at risk are directly linked to questions concerning the age limits for starting and/or stopping screening. There is also the question of whether all women should be invited to be screened, or only those at risk.

"Loopt elke vrouw evenveel risico of zijn er sommige vrouwen met meer of minder risico?" (40-49)

"Waarom stelt men iedereen een screening voor? Is dat niet overbodig?" (40-49)

"Borstkanker komt toch ook voor onder 50 jaar, waarom screent men dan pas op 50 jaar?" (50-69)

"Zijn wij na 70 jaar kankervrij?" (70-75)

How do women take the decision to participate in breast cancer screening?

- Women decide by and for themselves!

Participants explained that screening is a decision they make themselves. They considered that they are free to take whatever decision they want:

“Beslissen over borstkanker screening doe je zelf ! Familie, echtgenoot of huisarts hebben daar weinig inspraak in.” (40-49)

“On peut décider de ne pas y aller. ” (50-59)

“ J’y vais car j’ai envie. ” (70-75)

For some women, the decision, dictated by their conscience, is obvious:

“Je moet dat gewoon doen.” (40-49)

“Niet screenen ? Ik denk daar ook wel een keer aan , maar mijn gezond verstand zegt me van, ga maar!” (50-69)

“C’est ma décision d’y aller, je ne me pose pas la question, j’y vais de toute façon, c’est une habitude.” (70-75)

- Women sometimes take advice.
- As said before, gynaecologists and general practitioners play an important counselling role. Women also appreciated the opportunity to talk the subject over with other women (friend, daughter, ...):

“Les témoignages donnent de la crédibilité à l’information.” (50-69)

“Ce qui peut influencer, c’est l’entourage et les témoignages des proches.” (50-69)

“Cela se passe souvent de mère en filles, j’y vais avec ma fille, elle me le rappelle.” (70-75)

- How do women react to an invitation to participate in breast cancer screening ?
- Women can be invited in different ways
 - By mail

The invitation can come in the form of a letter sent by a health authority. However, this letter can be the cause of great stress, as some women testify:

“Toen ik de eerste brief kreeg, dacht ik dat ik kanker had. Dat was alles. Ik was ongerust. Ik had daar geen ervaring mee.” (70-75)

“Zo’n uitnodiging maakt mij onrustig.” (70-75)

That kind of writing can be found invasive and threatening. The invitation can be resented, being viewed as an obligation:

“Lorsque je reçois l’invitation, je la déchire tout de suite, je n’aime pas qu’on me force à me faire dépister régulièrement. ” (50-69)

«Zo’n brief knaagt aan je geweten, je moet wel gaan. »(50-69)

Other women consider that an invitation is a good reminder, especially for people who not often visit their doctor:

“Een uitnodiging per brief? Ok, ja, dan ga ik.” (70-75)

“Het is zoals een jaarlijkse oproep bij de tandarts, zonder dat doe je het niet want je voelt geen pijn.” (70-75)

“Jongere mensen gaan jaarlijks op bezoek bij hun gynaecoloog, voor de menopauze ga je naar je gynaecoloog voor controle, daarna ben je blij dat die uitnodiging komt!” (50-69)

- By health care representatives

When women are invited by a trusted health care provider, they feel that they cannot refuse the screening:

“Zo’n uitnodiging is nochtans confronterend. Ik voelde druk. Zeker als je gynaecoloog er persoonlijk op aandringt.”(40-49)

For others, it is considered normal to be invited by their doctor, because he knows them and their health history. This is particularly the case for the 70-75 group:

“Cela doit passer par le médecin traitant ou le gynécologue, il nous connaît et connaît nos antécédents.” (40-49)

“Om de twee jaar ga ik naar de gynaecoloog. Dan laat ik me screenen Een echo en een mammografie, want dat moet van de gynaecoloog. Ik doe dat heel graag, enfin, heel graag (gelach!) want dan voel ik me gerust.” (50-69)

“Ik wordt liever uitgenodigd via een arts dan met een brief. Je komt regelmatig bij huisarts, die kent je beter” Maar sommige mensen gaan nooit naar huisarts.” (70-75)

- o Publicity using mass media

Participants had different opinions about the impact of publicity. Some liked it and believed it to be a useful means of bringing screen to people's attention:

“ La publicité aussi a son importance, mais quelque chose d'esthétique, d'émotionnel, comme par exemple la publicité avec Miss Belgique qui évoque le lien mère-fille.” (40-49)

“La pub TV permet d'interpeller l'un et l'autre, de faire la remarque à ses proches.” (50-69)

“ De larges canaux de communication, c'est important, aussi pour annoncer qu'un courrier va être envoyé, pour qu'ils s'y attendent.” (40-49)

Other disliked it because they considered the subject too important to be displayed among commercial advertisements:

“La publicité les seins qui parlent: ça rend le sujet trop léger, alors que c'est sérieux et médical. Ce type d'info n'a pas sa place dans les médias. Il est préférable de se limiter à des affiches dans un espace pour les femmes, en milieu associatif ou autre.” (50-69)

“ Il y a trop de publicité pour nous inciter à nous faire dépister. C'est le médecin ou le gynécologue qui est le premier à devoir sensibiliser ses patients, pas la pub !” (50-69)

Are personal worksheets and information factsheets useful decision aids?

During the focus groups, all women (except the Dutch 40-49 group) were asked to look at a personal worksheet and four information factsheets about breast cancer screening outcomes (see appendix).

Personal worksheet

The personal worksheet did not trigger many reactions. None of the women suggested inserting such a questionnaire with the invitation to participate in screening. Nevertheless, comments were mostly positive.

The personal worksheet has been found interesting even if the style could be improved:

“L'idée est bonne, mais les questions sont trop cadrées.” (40-49)

“ Le style est important, c'est très formel, cela manque d'émotionnel.” (40-49)

“ C'est l'occasion d'en discuter avec son médecin, d'évoquer le sujet.” (40-49)

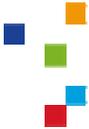
“ C'est intéressant, on prend conscience de ce qu'il faut éviter, ce sont les questions qui interpellent.” (40-49)

In the age group 50-69 this questionnaire was found unnecessary, and one woman even found it inadequate for less educated women, but admitting that it could be useful in the context of a group discussion with women about breast cancer screening:

“Een brochure zegt veel meer dan dat blad. Ik vind een brochure beter; dat blad geeft geen extra informatie.” (50-69)

“De eerste vraag is voldoende, als je ongerust bent dan moet je je laten onderzoeken.” (50-69)

“ C'est moins adapté pour une femme défavorisée. Plus adapté si c'est pour le partager dans un groupe de femmes. ” (50-69)



Information factsheets

Women were asked to go through four different documents. They were asked about the impact of the information and also about the best way to present it.

- Surprising statistics!

Women were surprised and found the results quite distant from their reality:

“Ze laten duidelijk zien dat dat niet veel verschil maakt.” (40-49)

“Ik schrik van grafiek 3. Uiteindelijk is dat maar één vrouw verschil.” (40-49)

- It can have a positive impact on the decision...

“Maar ja, zelfs een paar vrouwen helpen is heel belangrijk. Zelf als het maar één vrouw is.” (40-49)

“Ik laat me toch altijd screenen hoor. Zelfs met een klein effect.” (40-49)

- ...but also a negative impact.

- Considering the results, the usefulness of breast cancer screening was questioned and women aged 40 to 69 declared that these statistics could encourage them not to be screened any more/in the future.

One woman said that these statistics aimed to obliging women to be screened:

“Dit wil echt overhalen om een screening te doen. Ik heb er weinig aan. Die opeenvolgende stappen in figuurtjes is wel leuk. Maar je beslist zelf. En dit zegt doen doen doen.” (40-49)

- Other stated that the numbers were too distant from what is usually heard (“one woman out of nine will be in contact with cancer”) and believed:

“Dit lijkt erop dat screening eigenlijk nauwelijks nut heeft. ‘te verwaarlozen’ terwijl elk screening & geredde persoon gewonnen is zo’n informatie gaat ontraden...” (40-49)

“On se dit que le dépistage, c’est du luxe, c’est plutôt pour se rassurer.” (40-49)

“Tout ça pour ça !” (40-49)

“Dépisté ou pas, ça ne vaut pas la peine quand je vois les chiffres de décès. Et finalement, il y a très peu de femmes ‘sauvées.’” (50-69)

“Schrok van de resultaten: de verhalen zijn eigenlijk erger. Is de screening wel nuttig? De resultaten zijn verbazend.” (50-69)

- Statistics are ‘cold’

Except for the 70-75 age group, who found these factsheets rather interesting, the presentation of the facts was considered to be inappropriate in terms of just presenting just raw data:

“La manière dont cela est présenté manque de sensibilité, c’est statistique et froid.” (40-49)

“En parlant du cancer du sein, je ne pense pas à la mort mais à la perte d’un sein, au fait de toucher à la féminité. C’est le graphique qui me rappelle que c’est lié à la mort.” (40-49)

“Ce type de document ne mets pas en confiance, ça manque de sensibilité par rapport à tout ce qu’on peut ressentir, car on évoque que la mort.” (40-49)

Others stated that statistics are not so easy to interpret:

“On parle de décès attribuable au cancer du sein – est-ce réellement le cas ? Ou lié à d’autres cancers ? Ou à autre chose ?” (50-69)

“Ik snap dat niet.” (50-69)

“En général: je ne crois pas aux statistiques, cela ne me parle pas” (40-49)

“Ik en cijfertjes... Nee. Je moet dat gewoon doen. Zonder naar de cijfers te kijken. Die mogen weg. Ik doe dat gewoon. “ik denk dan ‘waar sta ik op die grafiek?’” “Ik moet eigenlijk geen informatie of folder hebben. Ik doe dat gewoon” (40-49)

- How should one present those facts?

- Factsheets number one and two were preferred. Number four was the one that was least liked:

“De drie opeenvolgende stappen zijn het interessantste. Die cijfers zijn niet belangrijk, wel het bestaan en de opdeling in drie stappen.” (40-49)

“n°1 is zeer interessant want je weet het vervolg van de screening, en krijgt ook voldoende informatie, dat is ook zo met die bolletjes, uiteindelijk, als de screening; je laat het best doen, 3 personen is niet zoveel, maar toch al goed.” (70-75)

Participants also formulated some recommendations based upon their past screening experiences and after reading all the documents. They stressed the importance of a honest, human and sensitive communication that helps women to control their anxiety and reassures them:

“ Important de désangoisser les femmes par rapport à l'examen.” (40-49)

“ C'est important de communiquer de manière plus émotionnelle.” (50-69)

“ Il faut pouvoir informer les gens sur ce que l'on peut éviter en faisant le test, les conséquences d'un cancer du sein qui n'est pas traité suffisamment tôt.” (40-49)

“Ik wil graag rustig zijn... Er met een gerust hart naartoe gaan. Je doet dat nooit met plezier. Daarom helpt eerlijke communicatie zoveel.” (40-49)

Discussion and conclusion

Strengths and weaknesses of the qualitative approach

The six focus groups (three in each language group and 2 in each age category) were sufficient to gather a range of information on women's perceptions of breast cancer screening and expectations of information about the subject. In every group, each woman knew at least two other people, sometimes more when they were members of the same association. This had a rather positive impact, making discussions very relaxed, while allowing the expression of different points of view. Geographical spread was not pursued. Because of the chosen way of recruitment, the Dutch-speaking participants all came from the province of Antwerp. The French-speaking participants came from three different

provinces. Unfortunately, no migrant women took part in the focus groups – they would certainly have had interesting points of view. Fifty-one women shared their point of view during the focus groups. Only eight of them had never participated in a breast cancer screening: four of these were under fifty, one was aged fifty and three were older than seventy.

Principal findings

All women, regardless their age or language group, agree on one fact: **the decision to undergo breast cancer screening** is theirs and theirs only! Even if the point of view and/or perception of husbands, daughters, female friends... are sometimes taken into account and testimonies are listened to, women say that they are at liberty to decide. This means that they could refuse breast cancer screening if they wanted to! (It is interesting to note that only one woman, under fifty, did not follow her gynaecologist's suggestion to be screened). However, having the possibility to be screened is seen by some women as an opportunity, an invitation that you cannot refuse issued by a trusted physician, or something your conscience just orders you to do!

Women do not all have the same **understanding of 'breast cancer screening'**. The different interpretations are age- but also language-related. For women without a personal history of breast cancer who are younger than fifty or older than seventy, 'breast cancer screening' equals a mammogram followed by an ultrasound scan (and maybe a breast palpation). This 'breast cancer screening' is not free of charge and is prescribed by a doctor (gynaecologist most of the time) who takes the initiative, or satisfies their patient's demand. For women aged between fifty and sixty-nine, 'breast cancer screening' can have the same meaning as described above. This is for example the case for the French-speaking women. They distrust the 'free screening', and prefer the *“combined screening”* which is what they call a mammogram. This misunderstanding can partly be explained by the attitude of some health care providers (general practitioners, nurses) who advise against 'free screening'. The Dutch-speaking women associate correctly the 'free breast cancer screening' with a mammogram, several of them said that they had abandoned the paid-for *“combined screening”* once they started receiving invitations to attend the free screening. Unscreened women also try to understand what screening is all about. This lack of clarity causes all



women to question the use of a mammogram rather than or combined with an ultrasound scan.

Breast cancer screening can be offered to women by different means, through an invitation from a health authority received by mail, an advertisement on television or a recommendation formulated by a health care provider. In the 40-49 and 50-69 age the gynaecologist is designated as the **reference concerning breast cancer matters**. On the one hand, younger participants clearly expressed considering him or her as a trustworthy specialist. On the other hand, the 70-75 age groups tended to seek out their general practitioner, who plays an important role. Except the younger participants, all participants appreciated receiving an invitation by mail. It was seen as a useful reminder, especially as not everyone sees their doctor on a regular basis.

Information on breast cancer screening and its techniques, the pros and cons, breast cancer and its treatments but also very practical tips about screening is welcomed by all women! They realise that, even if information is available, some aspects are not that clear. Whether screening is harmful, painful and what happens at this peculiar examination are the main concerns. These uncertainties nevertheless, did not prevent the participants from deciding to undertake breast cancer screening. The fact of being invited can be reason enough to decide to participate! If all groups agreed on the fact that the message should highlight the positive effects of screening, each group nevertheless expressed specific needs concerning the media favoured to communicate this information.

- The 40-49 age group:
A website, a folder referring to the website, sent out with the invitation to be screened, pictures of the screening device... but with humanity and emotion. This age groups expressed its need to render screening more human by using information and communication technologies.
- The 50-69 age group:
This group disliked mass media communication about breast screening, considering that such an intimate subject should be treated with more respect. Posters in women's associations are considered far more effective. Testimonials of women about their experience in this area were also appreciated, and could take place during meetings with other women. This group is more interested in communication

centered on the human aspect of the matter, rather than the medical or technical questions.

- The 70-75 age group:
This group underlined the fact that communication about cancer and its consequences before a screening can be a source of great anxiety. On one hand, some focus group participants said that they would like to be informed in advance about the possible screening outcomes and treatments, but on the other hand, they do not want to be unnecessarily scared by such information.
- First time screeners essentially have questions about:
 - Breast cancer screening – in order to understand the techniques used and appreciate their usefulness and reliability;
 - The target group (women at risk) - in order to determine whether they are part of it;
 - The frequency of screening;
 - Practical matters – so as to be correctly prepared for the screening.

Several participants underlined the need for a special **information tool** for first time-screeners (a folder sent out with the invitation for example). This certainly needs to be taken into account.

Statistics about the effects of screening can discourage women to come forward for screening. Information factsheets with statistics are considered interesting, but the models shown were felt to have lacked humanity and sensitivity. The numbers are too distant from what is usually heard (that one woman out of nine will be in contact with cancer) and clarification would be welcomed. Only the 70-75 age group was less critic about the numbers. This was an opinion that breast cancer screening messages should be about life, not death.

Several women shared, during the focus groups, their experiences of false alarms and worrying extra tests. These issues were also approached in the submitted factsheets but were not further discussed.



Key messages

Women acknowledge that there is plenty of information available (both on breast cancer and breast cancer screening) but they still do not feel sufficiently informed on the matter. However, this has not prevented them from deciding to be screened.

The concept of breast cancer screening in the context of health officials' recommendations needs to be clarified:

- Choice of mammogram vs ultrasound scan (most women of all age groups have usually chosen screening combining both);
- Choice of target group (50-69) (women start screening earlier, and most want to carry on after 70).

There is a difference in perception between the Dutch- and French-speaking groups:

- Most French-speaking women distrust the 'mammothest', considered to be an unworthy screening method. They are willing to pay to undergo what they believe to be the ideal screening, a combination of a mammogram and an ultrasound scan;
- Most Dutch-speaking women trust the mammogram when it is advised. They question nevertheless the fact that ultrasound scans are not systematically advised, as they seem more efficient and less painful.

The decision to participate in breast cancer screening does not depend on the information received and is mostly taken by the women themselves. However, they acknowledge the advice received from their gynaecologist (40 to 69) or their general practitioner (70-75).

Information such as statistics on screening outcomes and chances of dying from breast cancer can influence the perception of the usefulness of screening and encourage women not to be screened any more/in the future.

There is a difference in information expectations:

- Some women favour honest information received in advance (about pain, efficiency, possible outcomes);

- Others prefer to avoid too much information, which is for them source of anxiety and stress;
- Specific decision aids for each age group will be valued.

The breast screening decision aid should present information in a sensitive manner and could include testimonials. It should

Essential

- Define breast cancer screening;
- Highlight the benefits and risks of breast cancer screening;
- Describe the possible outcomes of screening in a positive and human way.

Additional

- Possibly give some information about breast cancer (risk factors, population at risk, prevention);
- Provide practical/organisation information of the screening.

5.1.3 Practitioners' perspective

5.1.3.1 Methodology

In order to explore their experiences and needs around communication on breast cancer screening with 'normal risk' women who have no symptoms or complaint regarding their breast, we carried out 2 focus groups with physicians (1 for each language group of French and Dutch). They were scheduled to last two hours in March and April 2013.

General Practitioners and gynaecologists were recruited using public listing of physicians. We chose to interview physicians working with patients with low socioeconomic status as well with high economic status according to their place of practice.

We invited 6 GPs and 6 gynaecologists in each language group, i.e. 12 physicians. They have received a little financial compensation for their participation.

French-speaking focus group took place in Brussels and Flemish-speaking group in Antwerpen.



One moderator was in charge of the Dutch-speaking group, and another took charge of the French-speaking group. A reporter-analyst was present to take notes during the interviews as well as an observer. The groups were recorded, with the consent of the interviewees.

The focus groups were structured as follows

- Introduction and presentation of participants
- Collective discussion
- Topics discussed were (see 'interview guide' in appendix):
 - Context of a discussion with a patient about breast cancer screening
 - Questions from the patients
 - Information available to the physicians and quality of it
 - Difficulties in communication around breast cancer screening
 - Information needs and improvements in communication needed
 - Opinion on type of visual communication tools

Immediately after each focus group, the moderator and reporter debriefed the discussion and discussed the main topics considered by the interviewees. Afterwards, all interviews were summarized by the reporter, but no integral transcriptions were made

We performed a descriptive analysis of the discussions.

The analysis aimed to answer the research questions.

Six French-speaking (3 GPs, 3 gynaecologists) and 6 Flemish-speaking physicians (3 GPs and 3 gynaecologists) have participated in two separated discussions.

5.1.3.2 *Physicians' attitudes to breast cancer screening.*

Physicians who participated in focus groups are all convinced that women have to be screened and that their role is to encourage women to take this action good for their health. Just one of them had recently discussed this topic in a "dodecagroup"^h and is a little less dubitative of the effectiveness of the screening.

Their opinions on the women age to begin screening vary: some advice to begin before 40 year-old, when other from 40 year-old or from 50 year-old. The rhythm to be screened varies also in their mind (once a year or every two years).

Some of them do not know when screening has to be stopped and how to explain to their patients that at a certain age, it is not necessary anymore to have their breast screened.

5.1.3.3 *Breast cancer screening subject and the medical consultation*

Opportunities to discuss breast cancer screening

Breast cancer screening is part of preventive action offered to patients, depending on their age or gender. This could or have to be discussed during the medical consultation. It is a routine topic in consultation, as well for GPs than for gynaecologists.

GP cited as opportunities to discuss this subject

- invitation letters that are send to women (by the Communities for women from 50 year-old or by other organisation from 40 year-old women)
- the DMG+/GMD+ⁱ that warns the GP that the patient comes into consideration for the screening

^h The "dodecagroupes" are small, closed groups of a dozen GPs. They meet about ten times a year to discuss a topic based on their practice groups. Groups were organized by the SSMG (Scientific Society of General Medicine) to provide continuing medical education in French-speaking Community of Belgium.

ⁱ DMG /GMD Dossier médical global +: Global Medical File. It contains all medical data of a patient (such as, chronic disease, current treatments ...). It



- 'reminder cards' furnished by scientific associations (SSMG or Domus) can be used to check with the patient if every preventive action has been taken or will be

“Jongere artsen gebruiken vaak de tool van Domus Medica. Die is zeer visueel, met kleurtjes en zo. Dat werkt gemakkelijk. Ik doe dat samen met de patiënten. Ik zeg dan: ‘Kijk, we schrijven elk familielid op en dan vullen we dit in.’ Dan zijn patiënten meestal wel overtuigd om al dan niet een onderzoek te doen.”

As the GPs will see patients several times in a year, breast cancer screening could be addressed easily but patients come rarely only to discuss this topic. It is something that comes on the discussion at the end of the consultation.

Gynaecologists however see their patients once a year. They also have many think to discuss, not only breast cancer. Nevertheless, some women come to their appointment with questions about breast cancer, sometimes because they know someone who has breast cancer, or just because they are worried about it. The menopause is also a moment when women have questions about breast cancer in general, because of the availability of hormonal therapy.

Talking about breast cancer screening in a consultation

Participants in the focus groups are all confronted to different types of women: those who are anxious and are demanding for screening whatever their age, sometimes even from very young women (in their thirties) in the richest parts of Belgium. They must sometimes be restrained and denied prescription review. This decision is not simple for the physician who fears that this patient could be one of the scarce cases of breast cancer in their age group.

“Jonge vrouwen vragen soms ook om een screening. Dan moeten wij zeggen dat zoiets niet nodig is. Maar stel dat zo'n vrouw drie maanden later een gezwell in haar borst vindt. Wat zal haar reactie tegenover jou zijn? Jij hebt haar als arts gezegd dat een screening niet nodig was...”

allows a better coaching and better cooperation between physicians.'+ encompasses preventive activities.

“Moi je ne vais jamais dire à une personne qui demande de faire un dépistage du cancer du sein, mais ne le faites pas parce que vous n'êtes pas à risque, ça je ne le dirai jamais ! Parce qu'on ne sait jamais...”

Other women, mainly in less-privileged areas, do not want to be screened because they have enough to do or think. They are not ill and do not want to become ill. They have a more short-term view.

Participants to the focus groups do not complain on specific difficulties to talk about breast cancer (screening). As we have already mentioned, it is more a question of time available to discuss this topic than the topic in itself. Indeed, the breast cancer topic seems to be no taboo anymore, except in population with Maghreb origin.

The questions of the patients

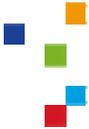
According to the physicians, questions from patients concern the necessity to be screened: Is a blood test not sufficient? Is (self-)breast palpation not enough? They raise also mainly practical aspects of the screening: where could I get screened, when, how long last the examination, does it hurt, etc. The pain seems to be their main preoccupation.

Some women question the necessity of the screening, the age to begin, the age to stop, and the rhythm to be screened. But in general, physicians have the feeling that they have not many questions. Once the examination is presented as useful for them by their practitioner, women will attend it (or not) but without many interrogations.

Some women, who have already been screened, are reluctant to do it again because of pain. Therefore they insist on questioning the necessity of the mammography and seek for alternative (such as MRI).

Few of the patients' physicians/respondents ask for mortality risk of breast cancer. Some question the link between breast cancer and hormonal therapy. They are demanding of figures to decide if they will begin/continue such treatment.

Risks related to the screening, such as overdiagnosis, overtreatment, or interval cancers are hardly ever discussed. Some physicians do not provide this kind of information that do not come spontaneously from the patient because it is difficult to explain and they have the feeling that they will give arguments to women not to participate in the screening.



“Dat is moeilijk uit te leggen aan patiëntes. Je geeft hen dan veel redenen om niet te gaan. Dat leidt tot omgekeerde effect.”

The only aspect that is sometimes raised by patients is the radiation risk. This one is perceived as minimal and out of scope by the physicians we met. One of them compares the risk to a flight from Belgium to New York and ask his patients if they will renounce to such a travel because of the rays exposure.

“Ik zeg hen: ‘Als je één keer naar New York vliegt, dan heb je evenveel straling binnen als na een mammografie. Zou u dat weerhouden om naar New York te gaan? En die straling is dan ook nog eens over heel je lichaam verspreid en niet alleen op je borsten.’ ‘Ah, is dat niet meer dan dat?’, zeggen ze dan. En dan doen ze het wel.”

To answer their patient's responses, physicians cited as source of information the scientific medical literature, the dodecagroups, and seminars.

5.1.3.4 *Information and tools needs of the physicians to communicate around breast cancer and screening*

GPs asked for clear information on identifying candidates to screening (age, rhythm).

In order to present risks to their patients, physicians reported needing simple, direct messages, possibly summarized in a written support that they can give to their patient, allowing them to read it at ease, to reflect on it at home and to come to a next consultation to discuss it. Indeed, patients are perceived by respondents as stressed during a medical consultation, therefore physician need to go direct to the point, because patients will not retain the message once out of the doctor's office.

The use of (visual) tools to facilitate communication aroused not really from the discussion. It is not obviously necessary to give patients statistics to help them to understand the necessity of an intervention. They feel that patients are not prepared to understand risks and not in state to discuss it. For example, when talking about breast cancer screening, women do not ask for their risk of mortality due to breast cancer. In fact, physician reported that because cancer is associated to death, it is not easy to

discuss about it: in many case, when you speak of death, patient stop to listen.

It is difficult to talk about risk and statistics with patients, it is too complex.

“Quand on commence à parler de risques, de chiffres, j’ai l’impression que les gens ont plus de difficultés à comprendre à suivre, parce qu’on parle de statistiques et ça reste très abstrait (...) je ne sais pas s’il n’y a pas moyen de leur expliquer de manière très simple, dans leur langage quotidien. »

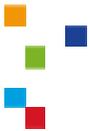
In general and, according to the examples we proposed as base for thinking (see Appendix 4.4), the use of visuals during the consultation in order to discuss risk and/or effectiveness of breast cancer screening do not interest all the physicians we met.

Cons arguments are that visuals:

- Could potentially scare women
- Are complicated to understand
- Ask for deep understanding of the practioner on the way to use it
- Gynaecologists have already experimented such tools in the context of the use of hormonal therapies but have abandoned the use of it because of the above reasons.
- They insist on the fact that visuals require guided lecture: this kind of messages have to be discussed with the physician, you could not just give it to women. Physicians have to be trained how to use it and to be clear on their objective, the messages they want to illustrate using the visuals.

“(…) c’est utile si on le maîtrise bien, parce que si on le prend comme ça, hop, je vais vite vous montrer un truc... et qu’on commence à lire devant la patiente, ça ne va pas... »

In addition, while patients need clear and simple messages, physicians would need more complete information: Who is concerned? Who is not? In other words with whom may I use the visual? What are the scientific bases? What are their limits? Etc. Such tool needs an explanative booklet.



Pro arguments concern:

- Visual aspect
- Easy to understand
- Colorful

Some of the tools (presented in appendix) appear to be 'pro screening' when others are perceived as 'against screening'.

- **'The wall of women'** with emphasis on each step' figure is appreciated because its simplicity of understanding and because of the sequential steps and the few messages it conveys. However it is perceived as 'pro screening'. There is too many women who have problems, it is better to positive the message: more women have no problems than problems. Showing only the first block of 1 000 women could be sufficient.
- The **'colour explained bullets'** figure is appreciated because every information is available but is also perceived as too heavy. This aspect give it for some a more neutral feature, very clear, when for others, it is perceived as 'against screening' and as too complicated to be understand by the patients. Bullets are less appreciated than 'pops'. An advantage is that it presents data about false positives.
- The **'text with bars'** figure, comparing death due to breast cancer to death from all causes, is not appreciated by the participants in both groups. It is perceived as unclear, complex, with too many figures. If it is appreciated by some participants, it is identified as usable for more intellectual people.
- The last example present the same information that the color bullets but in a **table** format. It is perceived as 'too dry', not enough visual but could also be perceived as clearer and to the point.

These types of visuals could be available in websites. But physicians would like to get up-to-date figures on the number of participants to the screening, how many breast cancers were found in general and at an early stage of development in particular, in order to motivate women to participate.

As we have already mentioned it, physicians we met are practically convinced on the necessity of a breast cancer screening, with different opinion on the best moment and way to do it. They are especially keen to

attract more women and ask questions when the brakes screening participation. The low participation of women with Maghreb origins or low socio-economic backgrounds is a theme that came up often in the discussions.

In this context, the idea of medical shared decision is not always followed by participants in the focus groups. In general, visual tools or messages appear to be more acceptable if they encourage screening, not shared-decision making between the practitioner and his/her patient. Nevertheless, some physicians seemed to be more and more open to discuss in a neutral way with candidate breast cancer screening. But it is very difficult to achieve a completely neutral communication, even if only because of the information you choose to give or not.

Physicians must have all the information and, graphics could help to understand specific aspects. The danger to give visuals to the patients is to insist on the aspects that are visually represented and not the others.

5.1.3.5 Discussion

Limitations

These findings have to be read with caution due to the following limitations of the data collection:

We have only carried out 2 focus groups due to lack of resources. To catch opinions of both GP and gynaecologist, we were obliged to discuss with them together in a single language group. Nevertheless, rapidly it appeared that their experiences vary because of the type of consultation they have: GPs see more regularly their patients than gynaecologists. More, GPs tend to consider gynaecologist as the specialists in the topic. This has not facilitated an 'equal' discussion. More GPs followed the guideline of the breast cancer screening program, while gynaecologists have their own schema of screening.

Besides, we sometimes met difficulties in the French-speaking group to get out of the debate "Mammotest" (i.e. mammography with double-blinded lecture) vs "bilan sénologique" (mammography directly read by the radiologist and directly followed by an echography) and to get out of the discussion on how to improve participation in breast cancer screening in the Flemish-speaking groups.



For practical reasons and availability of the physicians, participants were generally coming from the same area. Some of them knew each other and this has probably lead to more 'social desirability' than in groups where nobody know the other participants. In the case of Antwerpen, physicians see also the same type of patients that are probably not representative of the women in Belgium.

We have discussed with a majority of rather 'experienced' physicians. We guess that discussion with younger generation could have lead to other responses, probably more opened to prevention, share-decision making and evidence-based medicine since these concepts are more and more included in the training of the physicians.

Finally, the physicians we met were convinced by the utility of the screening but we have to keep in mind that they were volunteers to participate in the discussion, which may reflect their particular interest in this topic.

Highlight from other studies

In 2010, 101 GPs were surveyed by telephone in Brussels and in Wallonia to assess the efficacy of the communication campaign on the breast screening program³⁸. Some question could illustrate our findings. Firstly, 96% of the physicians reported that they found breast cancer screening for women from 50 to 69 year-old rather or very important. Secondly, they were asked to detail the questions that women use to ask them about breast cancer screening. As we stated during the focus group, pain during the examination was cited by 32% of them, followed by practical aspects (31%) and efficiency of the Mammotest (27%) Age suited for screening was found in 16% of the surveyed physicians and questions about irradiation in 10%. This is in line with our findings.

The qualitative study in French-speaking part of Belgium, aiming to improve colon and breast cancer screening confirm also some of our findings: they report that there is 3 types of patients: the decision maker patient, the active patient and the free patient. Some of them expect that their GP will direct them and decide for them, other want to be reassured while some are qualified as 'uncultivated', because they do not understand why they have to take preventive activities³⁶. They also highlight diversity of breast cancer screening practices among GPs (age to be screened and rhythm).

Key messages

During the focus groups with GPs and gynaecologists we can keep in mind that:

- **Physicians are convinced that women have to be screened but they do not agree or doubt on the best way to do the screening: at which age, which rhythm, when to stop.**
- **Physicians show more paternalistic attitude to their patients, they seem not totally ready to share decision with them. They will decide if the patient has to be screened or not.**
- **Physicians in Belgium seem to be rather concerned by increasing participation in breast cancer screening, particularly in low socioeconomic or foreign women than to give neutral messages to every patient.**
- **Physicians do not feel a lot of questions from the women to decide to get screened.**
- **They do not easily use statistics to communicate risk because they do not feel the need to do so and presenting statistics to patients is difficult.**
- **Visuals are not really attractive for them in the framework of the consultation.**
- **They will need more scientific information to be able to use a decision aid in their consultation**



5.2 Clinical evidence and Belgian data

5.2.1 Methodology

5.2.1.1 Literature review on clinical evidence

In order to present data in the messages, we based our estimate of the benefits of breast screening on randomized control trials (RCTs) and meta-analyses of breast screening. Indeed, RCTs provide the most reliable information on the effects of breast screening. High-quality randomized controlled trials are prone to fewer distorting effects, or biases, than are observational studies.

Databases

We performed a broad search of the electronic databases OVID MEDLINE, Embase, and the Cochrane Database of Systematic Reviews (CDSR) for systematic reviews (SR) and meta-analysis (M-A). Thereafter, we performed a separate search for randomized control trial (RCT) published after the search made for selected SR.

Search strategies

For MEDLINE database, the following MeSH terms were used in combination with usual language: Breast neoplasms (MeSH) and mass screening (or early detection) (MeSH) and mammography (MeSH). For EMBASE, the following Emtree terms were used: 'cancer screening', 'breast cancer' and 'mammography'. Those MESH and Emtree terms were first combined with a standard search strategy to identify systematic reviews (SR) or meta-analysis (M-A). In a second time, those MeSH and Emtree terms were combined with a standard search strategy to identify RCTs.

Detailed search strategies are in Appendix 6.

Inclusion / exclusion criteria

This report is an update of previous KCE report 11⁵³ (search made in 2004), thus we used a date restriction (2004-February 2013) and a language restriction (English, Dutch, French).

Inclusion criteria used for selection based on title, abstract or full text were: population (women without breast cancer and without particular breast

cancer risk), intervention (mammography), outcome (mortality, morbidity, additional diagnosis tests, over diagnosis and over treatment), design (SR or meta-analysis or RCT), key question (screening), age of population (>50 and <69 years), and original publication. Relevant publications were selected independently by 2 reviewers (FM, JR).

Identified systematic reviews

In the systematic search for literature reviews, 80 citations on the topic were identified in database searches. The majority of citations were excluded on the basis of title and abstract; 8 citations were retrieved in full and reviewed in more detail. On the basis of the full text, 5 reviews were included. The systematic reviews on RCTs, written by Götzsche and Nelson^{54, 55}, are mainly focused on mammography outcomes. Two reviews are focused on overdiagnosis^{56, 57} and one on ductal carcinoma in situ (DCIS)⁵⁸.

Identified RCT

The literature search for relevant RCTs was carried out in February 2013 and identified 169 citations. The majority of citations were excluded on the basis of title and abstract; one paper was retrieved in full and reviewed in more detail. On the basis of the full text, this study was excluded because of the study design (not an RCT). Figure in Appendix 6.5 shows the flow of randomized controlled trials from selection to in-or exclusion.

Additional search

We performed furthermore a short review of the papers describing the evaluation of outcomes of service screening in Europe (EUROSCREEN Working Group)⁵⁹. Those papers will be discussed in point 5.2.2.

Quality appraisal

- Systematic reviews:

The quality of the retrieved SR and meta-analyses was assessed using the checklists of the Dutch Cochrane Centre (www.cochrane.nl). All critical appraisals were done by a single KCE expert (see Appendix 6.6.1 for an overview of the scores).

- Randomized controlled trials

We found no RCT published after the search date of the Cochrane (November 2008)⁵⁴.

Data extraction and summary

For each systematic review, the search date, publication year, included studies and main results were extracted. Data extraction tables are provided in Appendix 6.7.

5.2.2 Belgian data

Belgian data were used to document the burden of the breast cancer in terms of mortality, the long term effect of the screening and the direct consequences of it.

5.2.2.1 Belgian Cancer Registry (BCR)

The Belgian Cancer Registry Foundation is a public institution which collects data concerning new cancer cases in Belgium and makes up statistics from these data (<http://www.kankerregister.org/>).

5.2.2.2 Belgian organized screening

As recommended by European Commission, Belgium started a national organized screening programme. The target age groups as defined by the program are women aged 50 to 69 years. Belgian breast cancer screening programmes are organized by: Brumammo (Bruxelles, <http://www.brumammo.be/>), le Centre Communautaire de Référence pour le dépistage des cancers (CCRef: <http://www.ccref.org/>) (Communauté Française) and BorstKankerOpsporing (BKO) (Vlaamse Gemeenschap: <http://www.zorg-en-gezondheid.be/>).

5.2.2.3 Intermutualistic Agency (IMA)

The Intermutualistic Agency (IMA) centralises data coming from all Belgian sickness funds. IMA compiled and published several reports on the national screening program containing data on the target age groups as defined by the program (50-69 years). IMA complemented this with information on persons outside the target age-group, with a particular focus on the tests used, delays between screening tests and possible confirmation and treatments following testing (<http://www.nic-ima.be/>).

5.2.3 Results

As the SRs and RCTs retrieved in 2013 are the same than those found in 2011, this report is based on the same basic evidence than the KCE report 176⁶⁰.

In order to feed our decision aid for women aged >40 and <75 year-old, we searched specific data for three age-range: 40-49, 50-69 and >70 year-old.

- For women between 40-49 years of age, we used as basic information, data issued from KCE report 129⁶¹;
- For women aged 50-69 years, we performed a rapid update of literature found for KCE report 11⁵³. This update is described in point 2.2.3. We found in 2013, the same SR than in 2011. Consequently, we calculated data concerning women between 50-69, on the same basic trials than used for women aged 70-74 years in the KCE report 176⁶⁰.
- For women aged >70 years, we used as basic information, data issued from KCE report 176⁶⁰.

Our aim was to inform the Belgian population on:

- The burden of the disease
- The screening estimated benefits (in general and according to the type of screening)
- The screening estimated harms (in general and according to the type of screening)

5.2.3.1 Observed burden of the disease

Breast cancer is a frequent cause of death in Belgium. In order to give comparison points for women of the burden of this disease, we present the overall death rate over 10 years per age group and 3 other specific causes of death.

We decided to present results in 10 year age-groups, other choices are possible but we did this for following reasons: the first age group, 40-49 is a specific group with very different incidence, mortality and effect of screening, as demonstrated with the largest UK AGE trial. We decided then to use age groups of the same size for the other ages, this is more consistent, and avoids the need to extrapolate too far. The organized screening in Belgium goes from 50 to 69, but this is a very long period to



extrapolate given the rapidly evolving secular trends in mortality figures. due to developments in treatment and diagnosis.

Table 4 shows breast cancer specific mortality based on data from the Belgian cancer registry from 2008. All results are presented for 1000 women over 10 years. We used the Belgian life table (2010) to adjust for competing mortality.

Other causes of death were taken from Statbel causes of mortality (2008), applied to the Belgian life table to adjust for competing mortality.

Table 4 – Mortality of women in Belgium for 1000 women over 10 years

	40-49 year-old		50-59 year-old		60-69 year-old		70-79 year-old		Source
Mortality from all cause	n=15.0		n=36.8		n=75.5		n=199.5		Statbel life table (2010)
Mortality from specific causes	n	Percentage of total death							
Death from breast cancer	2.2	14%	5.0	13%	8.0	10%	11.0	5%	Belgian Cancer Registry (2008) applied to life table (2010)
Death from cardiovascular disease	2.2	14%	6.0	16%	15.0	20%	53.7	27%	Statbel cause of mortality (2008) applied to life table (2010)
Death from other cancers	6.5	43%	18.4	50%	37.3	49%	76.8	38%	Statbel cause of mortality (2008) applied to life table (2010)
Death from violent causes	2.7	18%	3.5	1%	4.1	<1%	7.8	4%	Statbel cause of mortality (2008) applied to life table (2010)



Table 5 shows incidence of breast cancer

Table 5 – Burden of the disease in Belgium: incidence of breast cancer for 1 000 women over 10 years (number of cases)

	40-49 year-old	50-59 year-old	60-69 year-old	70-79 year-old
Breast cancer incidence	21.5	35.3	40.7	31.0

Source: Belgian Cancer register (2008) applied to life table

5.2.3.2 Estimated benefits of screening.

Table 6 simulates benefits obtained by 1000 women participating at organized screening after ten years.

Incidence of breast cancer and breast cancer specific mortality is based on data from the Belgian cancer registry from 2008. All results are presented for 1000 women over 10 years. We used the Belgian life table (2010) to adjust for competing mortality.

We adjusted the mortality in the unscreened group in three ways:

- We applied a time lag for the mortality and mortality reduction of 5 years^j.
- Taking into account the participation rate 60% (IMA data 2006-2007) and the reduction caused by the screening in the population 50-69 and assuming 20% screening in the age groups 40-49 and 70-79.
- The results of the meta-analysis of Gøtzsche et al.⁵⁴, 2011 showed us that screening mammography reduced the risk of death from breast cancer by about 25% reduction in breast cancer mortality in the age-group 50-69 and by 15% in the age group 40-49, amongst those offered screening. It's important to note that those results are based on an intention to-treat-analysis, regardless of the degree of compliance.

^j This explains the differences with the mortality reported in table 1. So, for example, number of deaths caused by breast cancer found in age range 40-49 years takes into account deaths occurring between 45 and 55y.

Those results are valid for population based screening but not for individual women who decide to participate in a screening schedule. Consequently, we follow Barat et al.³² and applied a 23% reduction in the age-group 40-49 and a 37% reduction in breast cancer mortality in the age-group 50-69, which is a reduction after adjustment for participation following the methodology developed by Glasziou⁶².

Table 6 – Number of deaths caused by breast cancer with and without screening for 1000 women after 10 years participation (modeling)

	Cancers diagnosed in 40-49 year-old	Cancers diagnosed in 50-59 year-old	Cancers diagnosed in 60-69 year-old	Cancers diagnosed in 70-79 year-old
Number of deaths caused by breast cancer without screening	3.8	8.4	11.5	6.4
Number of deaths caused by breast cancer with screening	2.9	5.3	7.3	4.0

5.2.3.3 Screening estimated harms

The screening related harms are interval cancers, overdiagnosis, false positive results and unnecessary tests (for example, punctures or biopsy not followed by surgery).

As there is considerable uncertainty surrounding overdiagnosis, we took the same estimation than those used for the base case in KCE report 176.⁶⁰ In this the rate of overdiagnosis was estimated at ten percent for invasive cancer.

The risk of cancers induced by X-rays was calculated only for younger (<50 years of age) women because this risk appears to be very low after 55 years of age.



The numbers of false positive results are issued from data currently published by organized screening programmes in Flanders & French Community . For the decision aid in Dutch, we used a recall rate of 3.5% and subtracted the proportion (0.5%) undergoing surgery in the IMA data, giving 3% false positives. For the decision aid in French, we used a recall rate of 10% and subtracted the proportion (0.4%) undergoing surgery in the IMA data, giving 9.6% false positives

The numbers of false negative results are issued from data published by organized screening programmes in Flanders & French Community. Among the screened women, 75% of the found cancers are screen-detected and 25% is interval cancer. In those 25% of cancers not detected by screening, it's impossible to distinguish between false negative results and interval cancers. Nevertheless, the message to women remains the same: each breast symptom or suspicion of change in breast must be investigated although mammography was appraised as normal.

Table 7 simulated harms occurring for 1000 women participating at organized screening after ten years.

Number of cases in Brussels is too small to use to get a valuable estimation.

Table 7 – Screening estimated harms for 10 years of screening for 1000 women

	40-49 year-old	50-59 year-old	60-69 year-old	70-79 year-old	Sources
Overdiagnosis	2.2	3.5	4.1	3.1	KCE report 176, 10% overdiagnosis assumed
Cancers induced by x-rays	0.5	Not available	Not available	Not available	KCE report 129

For the numbers of unnecessary recalls (false positive) we used the data from the Flanders and French-speaking community. As no Belgian data were available outside the organized screening program (thus before the age of 50 and after the age of 69), we search for international data. Nevertheless the range is too large (e.g., for 40-49 years: 0.9% - 6.5%² to propose to use it in messages for women.) In absence of valuable we assumed that the performance of the regional program could be the best guess for these age group.

For the numbers of unnecessary punctures or biopsy in the Dutch community, we used the biopsy rate in the organized screening (0.8%) and subtracted the proportion undergoing surgery in the IMA data (0.5%), giving a proportion of 0.3%. For the numbers of unnecessary punctures or biopsy in French Community, we used the biopsy rate in the organized screening (1.9%) and subtracted the proportion undergoing surgery in the IMA data (0.4%), giving a proportion of 1.5%. We used the incidence data on Breast cancer as a proxy for the proportion of women undergoing a surgical intervention performed for all age groups as we did not have better data on the subject.

False reassurance is in principle possible but it is not proven that it leads to delayed health seeking when a woman becomes symptomatic; few studies evaluate the impact of negative mammogram results. Women stated that they would not delay evaluation of a new abnormal physical finding despite a prior negative mammogram in one survey⁵⁵.

Table 8 – Harms per screening round (one screening round for 1 000 women)

	40-49 year-old (extrapolation)*	50-59 year-old	60-69 year-old	70-79 year-old (extrapolation)*	Sources
False positive (unnecessary recalls)	30 in Flanders 96 in French-speaking Community	Recall rates in Flanders & French-speaking Community with number of surgery abstracted			
Unnecessary punctures or biopsies	3 in Flanders 15 in French-speaking Community	IMA Data proportion punctures / Biopsie minus proportion surgery			

* Unknown but assumed to be the same than for 50-69 year-old women.

5.2.4 Discussion of the current polemics

5.2.4.1 The sources of the polemics

The publication in 2001 of the first meta-analysis done at Nordic Cochrane Center⁶³ has stimulated a debate about the potential benefits and harms of breast cancer screening. The debate has focused on the reduction in mortality and the number of women over diagnosed and consequently over treated.

A working group of the International Agency for Research on Cancer (IARC) re-examined in 2002, the available evidence and confirmed the benefit of mammographic screening in women from 50 to 69 years of age⁶⁴. Population-based service screening programmes have continued to be implemented thereafter without substantial changes in screening

policy⁶⁵. Nevertheless, there is still discussion over breast cancer screening effectiveness.

5.2.4.2 The KCE point of view

We tried here to give a summary of the actual state of this debate and choose therefore to restrict our discussion on the evaluation of the current service screening programs in Europe. We used therefore publications of the EUROSCREEN Working Group published in October 2012 in the Journal of Medical Screening.⁵⁹

The EUROSCREEN Working Group is a cooperative group that includes experts involved in planning and evaluating most of the population-based screening programs in Europe. Based on studies published in peer reviewed scientific journals, the experts sought to review the accumulated evidence and develop the best current estimate of the impact of population-based service screening in Europe. Those publications discussed mainly the breast cancer mortality reduction and the over-diagnosis due to the screening.⁵⁹ They are based on observational studies and not on RCTs as in the meta-analysis of Gøtzsche et al.⁵⁴ Nevertheless, we know that high quality studies focused on breast cancer screening such the RCTs performed in the 20th century are unlikely to happen in the coming years.

Breast cancer mortality reduction

Broeders⁶⁶ conducted a systematic literature review to assess the impact of mammographic screening programmes in Europe. This SR appraised as of low quality reviewed the European trend studies, the incidence based mortality (IBM) studies and the case-control (CC) studies. Broeders analysed estimates of the reduction in breast cancer mortality for women invited versus not invited and/or for women screened versus not screened. The results of IBM studies and the results of CC studies were each pooled using a random effects meta-analysis. Those IBM studies were conducted in Denmark, Finland, Italy, Norway, Spain and Sweden. The pooled mortality reduction was 25% (relative risk (RR) 0.75, 95% confidence interval (CI) 0.69–0.81) among invited women and 38% (RR 0.62, 95%CI 0.56–0.69) among those actually screened. Although there is a consensus among breast cancer screening experts that case-control studies are not reliable about the effect of screening.⁶⁴, we retrieved one other SR focused



on the IBM studies alone.⁶⁷ This SR appraised as of low quality, summarized also the studies conducted in Denmark, Finland, Italy, Norway, Spain and Sweden. Njor⁶⁷ analysed carefully the papers reporting those trials results in order to avoid the duplicate use of some data as to avoid overlap in study populations. Then, she classified studies in three groups defined in function of the estimation of expected breast mortality in absence of screening. Group 1 contained studies where the expected breast cancer mortality was estimated from women not yet invited, group 2 studies where the expected breast cancer mortality was estimated from regional and historical comparison and group 3 studies where the expected breast cancer mortality was estimated from a historical comparison group subsequently combined with data for nonparticipants. To avoid selection bias, author chooses to use invitation to screening instead of participation in screening as the primary exposure. The results of IBM studies were pooled in three separated groups using a fixed effects weighted average of the RRs on a logarithmic scale. The RRs were 0.76–0.81 in group 1; 0.75–0.90 in group 2 and 0.52 to 0.89 in group 3. Although not based on a formal quality appraisal checklist, author stated that the studies with the most unbiased comparisons are those able to control for changes over time without introducing a healthy user bias and where the accrual period is similar to the follow-up time for breast cancer deaths. She concluded that her best estimate of the breast cancer mortality reduction among women invited to screening, was a combined RR estimate of 0.74 (95%CI 0.64–0.87) after 6–11 years of follow-up for women offered screening at age 50–69. Those mortality benefit (25-26%) estimated by Broeders as by Njor^{66, 67} are the same than those (25%) achieved in systematic review of randomized control trials.⁵⁴

Overdiagnosis

Overdiagnosis is defined as diagnosis of a breast cancer through screening that would not have been diagnosed in the woman's lifetime without screening. As methodological approaches to estimate overdiagnosis vary widely, Paci et al referred to the six estimates of overdiagnosis calculated by members of the EUROSCREEN Working Group. Those estimates were adequately adjusted for underlying risk and lead time. They were issued from screening programmes in Florence (Puliti), Copenhagen (Olsen), Italy (Paci), England and Wales (Waller, Duffy) and The Netherlands (de Gelder). The most plausible estimate of

overdiagnosis ranges from 1 to 10%, where overdiagnosis is expressed as a percentage of the expected incidence in the absence of screening. This is a measure for overdiagnosis in women screened between 50 and 79 years, including carcinoma in situ.⁵⁹ For Denmark, a study by Njor et al. 2013 estimated overdiagnosis in a population based cohort study following 57 763 women from Copenhagen municipality (from 1991) and Funen County (from 1993), targeted by organized screening, aged 56-69 when the screening programmes started, and followed up to 2009. This study estimated that overdiagnosis most likely amounted to 2.3% (95% confidence interval –3% to 8%) in targeted women. Among participants, it was most likely 1-5%. Author underlined that at least eight years after the end of screening were needed to compensate for the excess incidence during screening.

If we refer to the SR of RCTs, rates of overdiagnosis varying from less than 1% to 30% with most from 1% to 10% were cited in the SR done for the USPTSF.⁵⁵ Gøtzsche reported that the level of overdiagnosis was about 30% in the RCTs that did not introduce early screening in the control group, and somewhat larger in the sub optimally randomized trials before screening of the control group.⁵⁴

If we refer to the SR of RCTs, we can use estimations done by Biesheuvel. Biesheuvel analysed publications issued from the first RCTs and he selected the least biased overdiagnosis estimates. Excluding DCIS cases, over-detection ranged from 7% to 21% for women aged 60–69 years.⁵⁶ For the current analysis, we assumed 10% overdiagnosis as used in the KCE report 176.

Key messages

- **Service screening in Europe can achieve a mortality benefit comparable to the benefit observed in RCTs.**
- **Although difficult to quantify, overdiagnosis is a fact that we have to mention in the information for women.**



6 ELABORATION OF THE FINAL MESSAGES

6.1 Redaction of the messages

Messages were written according to the results of the literature study and the focus groups with women and physicians.

Therefore, the text adheres where possible to the International Patient Decision Aid Standards (IPDAS) criteria (see chapter 5). IPDAS is an internationally-recognised scheme to improve the quality and effectiveness of patient decision aids. This organisation develops criteria to which effective decision aids should adhere.

As the messages developed in this project are only one part of a decision aid - focussing on sound statistical information on the outcomes of breast cancer screening - several IPDAS recommendations are not applicable to our work. Nevertheless, keeping the IPDAS guidelines in mind helped in developing the messages. This can be seen in for example the choice to outline different options next to each other in an equivalent way and to refrain from showing a preference between options.

IPDAS stresses the neutrality of information: a decision aid should inform and empower its reader. As such, a decision aid should help a user to decide, instead of deciding for the user. Such an aim is a worthy cause. Much effort in this decision aid on breast cancer screening went into ensuring neutral information for women on the advantages and disadvantages of breast cancer screening. However, it should be noted that this aim remains a goal, as fully equivalent neutral information is an aim that cannot be reached. For example, the impact of the 'recency effect' - i.e. the order in which text is presented influences the perception of a reader - is inescapable. Whatever the editing choice, one argument has to be presented last and therefore receives more attention from the reader.

6.2 Content of the messages

The material for the decision aid consists of two main parts:

1. an introduction on breast cancer screening;
2. age-specific information on the advantages and disadvantages of participating in breast cancer screening.

The introduction sets out the group that the text is targeting, offers a number of general remarks on breast cancer, details the risk of a woman being diagnosed during her life with breast cancer and outlines basic information on the medical techniques used during screening.

The scope of this introductory text is limited. No attempt was made to write an extensive guide on breast cancer screening. The text offers hardly any information on screening procedures. This minimalistic approach was adopted because its messages are to be included in more expansive texts (from other organisations), that pay considerable attention to the medical process and procedures during a breast cancer screening.

The focus of this project is to provide specific and statistically-sound material on breast cancer screening. This is the second and largest part of the messages. As the text aims to inform women in a neutral way of the advantages and disadvantages of participating in breast cancer screening, it focuses on numerical and statistical information about the results of breast cancer screening. That is crucial information for helping women to make a balanced yet personal decision whether or not to participate in breast cancer screening, especially as such information is sometimes presented in an inaccessible format, is often rather complexly formulated or is based on questionable data.

As the advantages and disadvantages of participating in breast cancer screening vary considerably depending on age, medically correct information for women on breast cancer screening must contain age-specific data regarding the outcomes of breast cancer screening. Thus, the major part of the text consists of four chapters with a similar structure and content, but each targeting a different age group. Chapters were written for women in the following age brackets: 40-49 years, 50-59 years, 60-69 years, 70-79 years.



This editing decision is radical yet necessary. Not only does the frequency of breast cancer occurrence differ considerably according to age, but also the scientific advice offered to women about whether they should undergo screening differ according to age group.

Each 'age chapter' has an identical structure. It starts with details about the chances of dying over the next ten years of breast cancer versus other causes of death, and continues with an outline of the quantitative impact of screening (or not screening) on the chance of dying of breast cancer, and how physicians proceed, i.e. the number of women needing follow-up examinations.

These age-specific messages consist of a side by side comparison of the situation of women who participate in breast cancer screening versus women who do not participate in any screening programme. This parallel approach ensures that each woman, whatever her imminent decision on the screening, receives similar information on both options and can easily compare the outcome of both choices.

Each age chapter includes a summary of the official governmental advice for the age group about whether or not to participate in screening and some factual information on official screening.

As noted elsewhere, extensive statistical evidence was used from the screening programmes organised by the French-speaking (Mammotest) and Dutch-speaking (*Vlaams Bevolkingsonderzoek naar Borstkanker*) communities. These organised screening programmes collected a large and reliable dataset on the outcome of screening programmes. Note, however, that the results of both screenings differ, notably on the number of referrals to follow-up examinations after the initial mammography screening. This difference led to messages with different odds in the Dutch and French versions of the decision aid, meaning that the figures could be fine-tuned to regional differences. The aim of the text is to remain as relevant as possible to the situation and surroundings of the reader.

6.3 Presentation of the information: From a minimalistic page lay-out to a designed leaflet

The design choices of the decision aid relied considerably on advice of existing scientific analysis regarding adequate decision aids (see section 4 Elaboration of the messages: How to communicate risk). Consequently, much of the effort in the production of the decision aid went into facilitating the readability of the text, both in terms of applying the scientific advice regarding the approach of the content of patient decisions aids, but also in applying a number of technical writing practices that facilitate the readability of the text. Examples of these practices include short sentences, the use of active verb conjugation and short paragraphs.

As the messages were originally meant to be inserted into other documents, a minimal layout - e.g. no subheads, few text formatting - was preferable. Reducing the lay out requirements eases the inclusion process into other texts and formats.

Moreover, a choice for a minimalistic page lay-out often strengthens the readability of the text. A clear outline of the text in chapters and paragraphs helps the reader to navigate through the messages.

However, this aim was hindered by the strong numeric and graphical character of the messages. A considerable part of the text consists of pictogrammes, graphically representing the outcomes of screening versus no screening. The choice to use pictogrammes - as such a readability device - thus hinders another readability choice.

Seen the remarks of a first readability test and additional comments of specialists, the project opted to submit a designed leaflet. Once made by a graphist specialized in health communication. to a second testing. Obviously, the design followed the guiding principles for our decision aid.

6.4 Tests of the messages

These messages aim to help women to make an important life decision – whether or not to participate in breast cancer screening. As this is a sensitive topic, an extensive supervision of the medical content is advisable and was exhaustively assured through two focus groups with general practitioners and gynaecologists, a revision of the text by cancer and screening experts, i.e. representatives of Belgian scientific associations of GPs and gynaecologists and representatives of the breast cancer screening programmes from the three Belgian regions, i.e. Flanders, Wallonia and Brussels. All in all, the text went through eleven separate revision rounds.

A further supervision of the text is also worthwhile. This second ‘screening’ is not concerned with how medically correct the information is, but how ‘readable’ the text is for the target group. Indeed, medically sound information can be incomprehensible to a large part of the population due to use of jargon, complex formulations and superfluous details.

Therefore, the messages were extensively tested on their readability: the accessibility of the text and its messages to the target group of women aged 40 to 79. Two different tests were applied:

1. the ‘technical’ readability of the text, measured by standardised tools on the complexity of a text;
2. the ‘real world’ readability of the text, measured by a test to see whether women tracked and understood the information in the document.

6.4.1 Technical readability statistics

A number of statistics exist that assess the readability of a text. These tools are based on mathematical formulas and use variables such as, for example, the average length of sentences or the number of words with four or more syllables. The statistical results are then translated into a score that indicates how easy or difficult a text is to read. Often, the score translates into a reading (schooling) level that is expected to be needed to easily understand the text.

As these statistics consist of technical calculations, the tools offer a limited approach to readability. A text may consist of utter nonsense, but can qualify as an extremely readable document. Nevertheless, these kinds of

readability statistics do help on-going editing choices. Their focus on short sentences and easy words help to produce messages that are better digested by a majority of readers, especially when combined with lists of difficult words.

The French and Dutch messages were submitted to different tests, as the underlying calculations of readability test vary with the peculiarities of each language. The French text was analysed with the Kandel & Moles test; the Dutch text with the Douma test. Each text received a reading level indication between ‘fairly easy’ and ‘fairly difficult’. These results are deemed acceptable, given the obligatory and frequent use of a number of rather complex medical terms, such as breast cancer examination (‘borstkankeronderzoek’) and mammography (‘mammographie’).

6.4.2 Measuring the comprehensibility of a text

However interesting the outcome of technical readability tools, the ‘real world’ comprehensibility of a text is a more important test of readability, as it aims to measure whether women understand the text’s messages. Such a readability test explores whether respondents understand the content of a text, instead of measuring the readability of words and sentences. Successful readability or comprehensibility is reached when the target group finds and understands the information in the text.

6.4.2.1 Developing a readability test

A readability test measures whether a respondent can find and understand the correct information in a text when needed. Central to the concept of readability — and subsequently its testing — is to find out whether a person can find the correct information and interprets the information correctly. One can compare the situation with reading a railway schedule. Memorising the precise departures is superfluous, but the respondent should, however, be able to find, for example, the correct departure time, platform and any other information useful for her trip.

A readability test mimics a day-to-day reading situation, wherein someone reads a document at their leisure. An ideal test environment consists of someone in a familiar environment, reading a text in a leisurely manner, posing herself some questions on the topic of the text and looking up the answers to those questions in the text.



Similarly, a readability test should not limit the amount of time needed to find the information — once again mimicking the day-to-day-situation that poses no deadline on finding information in a leaflet. During the test, the interviewer nevertheless kept track of the time needed to find an answer, as a comparably long time hints at a readability issue.

To measure this more encompassing concept of readability annex comprehensibility, a test was developed that operationalized readability in terms of:

- *Being able to find* specific information in a text;
- *Being able to understand* the content of that information.

Twenty five open-ended questions were developed that asked respondents specific questions on subjects in the text. An example of such a question would be:

Suppose that you do not participate in the breast cancer screening. What is the largest cause of death for women of your age?

Care was taken that each readability question should:

- *ask for a factual answer*, like a precise number or a term. This allows for a clear demarcation between wrong and right answers;
- *avoid any obvious correct answer*, forcing a respondent to prove that she has understood the information;
- *have one unambiguous success criterion*, interpretable in only one manner, i.e.:
 1. one right page on which the information can be found;
 2. one keyword or figure that was the trigger to answering the question correctly.

The threshold for success of a readability test should be high. A readable text is a text that allows the vast majority of its readers to find and understand the information they need. For the purposes of this test, the success of the readability test was defined as:

- 90 percent of the respondents having found the correct location of the information;
- and 90 percent of the respondents being able to produce the correct answer to the question.

Thus, the test had to reach an overall success rate of 81 per cent of correct answers, being $0.90 * 0.90$. It should be noted that this threshold for success is arbitrarily constructed. Similar or slightly lower figures are used in other readability tests, but no standard to measure readability is widely accepted. Apart from the fact that a high threshold follows from the concept of readability, no convincing justification for one threshold or another exists.

6.4.2.2 *Pre-testing the questionnaire*

A pre-test was carried out with a provisional list of 25 questions. This pre-test focused on the quality of the questions, aiming to test and weed out questions that were ambiguous or could be answered with slightly different answers.

The pre-test was carried out with five women (three Dutch-speaking and two French-speaking), each answering the 25 questions. After answering the pre-test, considerable attention was given to a discussion with each respondent how she had interpreted the questions and had formed her search strategy towards the answer.

Of course, neither the precise answers nor the difficulty or ease with which the women answered was of importance during this pre-test. A pre-test is a technical test of the quality of the instrument.

Based on the experiences of the pre-test, the project team decided on the final list of fifteen questions. Several questions from the original list of 25 questions were deleted as they showed deficiencies. For instance, some questions asked respondents to suppose that they belonged to another age group. These questions were deemed too complex and hardly relevant for a respondent. A woman reading a text on breast cancer screening needs to find information relevant to her own situation. Information on women of other age groups is of secondary importance and of an almost academic interest.

Other questions were well suited yet dropped in order to ensure a balanced questionnaire that pays more or less equal attention to all parts of the text. The final list of fifteen questions measured more or less equally the readability of each chapter. Questionnaire is available in Appendix 8.1.



6.4.2.3 *A first readability test with thirty women*

The readability test took place with thirty respondents, divided equally between the Dutch-speaking (15 women) and French-speaking (15 women) language groups.

The test took place in a face-to-face-setting and was carried out by the researchers on this project. Most interviews were concluded within a time span of twenty minutes, including a first reading of the text and the full questioning session.

The respondents were recruited with a view to ensuring a good representation of women with a low or medium schooling level, i.e. schooling up to secondary school. This translates into a school leaving age of 18 years or younger. Thus, twenty out of thirty women possessed a secondary school-level education or lower.

This focus on respondents with a lower schooling level is due to the fact that a readability test proves itself mostly by its comprehensibility to respondents without advanced schooling.

Within each language group, attention was also paid to representation of the four age groups concerned by the messages. Overall, participation was made up of 8 women of 40-49, 8 women of 50-59, 8 women of 60-69 and 6 women of 70-79.

The test presented women with the text and asked them to read the document carefully. No time limit was imposed, as there is usually no time limit when anyone reads a text at their own leisure – for example, there would never be a time limit imposed on a woman reading in her own house.

When the respondent finished her reading, the fifteen open ended questions were posed one by one. (Appendix 8.1). The text of each question was also presented in written form, so that the respondent could make no mistake about the precise content of the question. Once again, this approach mimics the day-to-day-situation, in which a woman would ask her own questions about the text.

Each question was answered by the respondent, while using the text to look up her answer. One can compare the test to an open-book exam. It is important to stress that the concept of 'readability' has nothing to do with the ability to memorise or to reproduce information. As the information in,

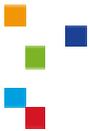
for example, a leaflet is at any time readily available to the respondent, there is no point in measuring whether anyone can reproduce information by heart. In 'the real world', a respondent has access to, for example, a brochure and can seek the information she needs at any time. Consequently, there is no point in measuring the amount of information retained by memory.

6.4.2.4 *A second readability test with thirty women*

The first readability test succeeded in reaching the threshold value (see results), but the test also pointed to a difficulty for women in interpreting the quantitative data. Therefore, a second version of the decision aid was developed. This tool reduced the amount of information somewhat, but for mostly presented the data in a professional and more accessible page design.

A second readability test was executed, following the contours of the first test: thirty respondents (different from the first group), divided equally between the Dutch-speaking (15 women) and French-speaking (15 women) language groups, assuring a large representation of women with a low or medium schooling level and a distribution over the four age groups concerned by the messages.

To be noted is that the second test used an adapted version of the test instrument, replacing two questions that delivered a near optimal response during the first test (indicating a very readable part) for additional questions on the statistical information. This second version of the test thus placed the mark higher, by replacing easy questions with difficult questions. Questionnaire is available in Appendix 8.2.



6.4.3 *Result of the first test*

The readability test scored 81.7 percent of correct answers, which passed the threshold of 81.0 percent. The text succeeded and can be described as comprehensible for the vast majority of women.^k

However, the test results varied following different subgroups within the population. Most noteworthy was a reduced readability within the group of 70-79 years (reaching 74%) and, somewhat surprisingly, the failure of the group of women possessing a university degree (72%). Both results were heavily influenced by a shared group of two older women with a university degree and scoring considerably below average.

Women of a low schooling level (lower secondary schooling or lower) scored 80%, narrowly missing the threshold of success. This may be seen as a surprisingly good result, hinting at a very comprehensible text.

The main difficulty women experienced turned out to be the correct interpretation of statistical information. As long as the document consisted of plain text, no significant difficulties were experienced. Statistics and especially relative odds (i.e. “the odds of 1 000 women living for 10 years”) were more difficult to comprehend. The five questions specifically asking for quantitative information scored a success rate of 72 per cent, below the threshold of 81 per cent. Consequently, the final editing (albeit moderate, given the overall success of the readability test) focused on a more accessible presentation of quantitative information.

^k The answers of two respondents were removed from the analysis, as during the test they did not look up their answers in the text. Instead they answered the questions from memory or from their beliefs and/or knowledge on cancer in general and breast cancer specifically. This attitude not only led to very low and atypical scores (not surprisingly, seeing that the questions were conceived in order not to be intuitive) but goes against the concept of a readability test that aims to measure whether women can look up and find the answers to questions in a text. This decision to remove both respondents from the analysis led to a dataset of answers from 28 respondents.



Table 9 – Overview of the readability results of the first test (threshold for success: 81%)

Characteristic of participant	Category	Number of participants	Percentage of correct answers
Age group	40-49 years	8	88%
	50-59 years	8	80%
	60-69 years	7	82%
	70-79 years	5	74%
Educational level	Higher education, university	4	72%
	Higher education, non-university	6	82%
	Upper secondary	11	86%
	Lower secondary (or lower)	7	80%
Focus of the questions	Statistical information	28	72%
	Textual information	28	87%
Chapter of the text	Page 1. Who this text is aimed at	28	83%
	Page 2. General information	28	83%
	Page 3. The screening	28	87%
	Page 4. Risk of dying	28	73%
	Page 5. Effects of...	28	79%
	Page 6. Recommendation	28	91%
Total		28	82%



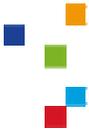
6.4.4 Result of the second test

The second readability test scored 83.3 percent of correct answers, which passed the threshold of 81.0 percent and is better than the result of the first test. The decision aid succeeded and can be described as comprehensible for the vast majority of women.

Contrary to the first test, the second test was successful for each part of the decision aid and within almost each subgroup in the population. The notable exception is women of low schooling and the age group of 70-79 years. As this age group consisted solely of women of primary schooling, both subgroups considerably overlap.

Table 10 – Overview of the readability results of the second test (threshold for success: 81%)

Characteristic of participant	Category	Number of participants	Percentage of correct answers
Age group	40-49 years	9	84%
	50-59 years	8	88%
	60-69 years	10	81%
	70-79 years	3	79%
Educational level	Higher education, university	1	100%
	Higher education, non-university	9	82%
	Upper secondary	9	92%
	Lower secondary (or lower)	11	76%
Focus of the questions	Statistical information	30	85%
	Textual information	30	84%
Chapter of the text	Page 1. Who this text is aimed at	30	84%
	Page 2. Risk of dying	30	81%
	Page 3. Long term effects	30	90%
	Page 4. Short term effects	30	82%
Total		30	83%



7 FINAL MESSAGES

Here are the final messages. They are presented by age groups. They are downloadable by age group from the KCE website.

In French:

http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_4_0-49.pdf

http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_5_0-59.pdf

http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_6_0-69.pdf

http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_7_0-79.pdf

In Dutch:

http://kce.fgov.be/sites/default/files/page_documents/KCE_Borstkanker_40-49_0.pdf

http://kce.fgov.be/sites/default/files/page_documents/KCE_Borstkanker_50-59_0.pdf

http://kce.fgov.be/sites/default/files/page_documents/KCE_Borstkanker_60-69_0.pdf

http://kce.fgov.be/sites/default/files/page_documents/KCE_Borstkanker_70-79_0.pdf

Éléments d'information
à intégrer dans les outils
de communication sur le
dépistage du cancer du sein
pour les femmes de 40 à 49 ans



Informatie op te nemen in
communicatie-instrumenten
over borstkankeropsporing
bij vrouwen van 40 tot 49 jaar





7.1 Common messages to all women

This is the introductory text for every concerned age group. The last sentence on the second page is always adapted to the targeted age group in the downloadable version.

Informations générales sur le dépistage du cancer du sein

Qu'est-ce que le dépistage du cancer du sein ?

Le dépistage du cancer du sein a pour objectif de faire baisser le nombre de morts causées par le cancer du sein. **Le dépistage n'empêche pas d'avoir un cancer du sein mais trouve parfois le cancer plus tôt.**

Le cancer du sein peut se développer entre deux dépistages. Parfois le dépistage ne trouve pas le cancer. Consultez un médecin à chaque signe inquiétant, même si tout allait bien lors de votre dernier dépistage.

1 femme sur 9 aura un jour un cancer du sein. C'est le risque cumulé sur toute une vie. **Mais ce risque varie par catégorie d'âge.**

Sur une période de dix ans :

- parmi les femmes entre **40 et 49 ans**, **1 femme sur 50** aura un cancer du sein.
- parmi les femmes entre **50 et 59 ans**, **1 femme sur 28** aura un cancer du sein.
- parmi les femmes entre **60 et 69 ans**, **1 femme sur 25** aura un cancer du sein.
- parmi les femmes entre **70 et 79 ans**, **1 femme sur 32** aura un cancer du sein.

La majorité des femmes ne meurent pas du cancer du sein.

Kolm L et al. Dépistage du cancer du sein: messages et support d'un choix éclairé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013.

Comment se passe le dépistage du cancer du sein ?

Une mammographie. Le premier examen d'un dépistage du cancer du sein est toujours une 'mammographie'. Une mammographie est une radiographie des seins. La dose de rayons est faible. Elle est peu dangereuse après 50 ans.

Une échographie. Parfois le résultat de la mammographie n'est pas clair. On passe alors un deuxième examen. C'est une 'échographie'. L'échographie utilise des ultrasons qui sont sans danger.

Une mammographie et une échographie ensemble ? Certains médecins proposent aux femmes de faire une mammographie suivie directement d'une échographie. L'utilité de faire ces deux examens (ensemble) à toutes les femmes n'est pas prouvée. Ces médecins ne suivent pas les normes de qualité des autorités européennes et belges.

Algemene informatie over borstkankeropsporing

Wat is borstkankeropsporing?

Borstkankeropsporing probeert de sterfte door borstkanker te verminderen. **Het onderzoek voorkomt geen borstkanker, maar het ontdekt een kanker soms vroeger.**

Borstkanker kan zich ontwikkelen tussen twee borstsonderzoeken. Soms spoort een onderzoek een kanker niet op. Raadpleeg een arts bij elk verdacht teken. Zelfs als bij een borstsonderzoek enkele maanden vroeger alles OK was.

1 vrouw op 9 krijgt ooit borstkanker. Dit is de kans opgeteld over een heel leven. **Maar per leeftijdscategorie verschilt het risico.**

Over een periode van tien jaar:

- krijgt van de vrouwen van **40 tot 49 jaar** **1 vrouw op 50** borstkanker
- krijgt van de vrouwen van **50 tot 59 jaar** **1 vrouw op 28** borstkanker
- krijgt van de vrouwen van **60 tot 69 jaar** **1 vrouw op 25** borstkanker
- krijgt van de vrouwen van **70 tot 79 jaar** **1 vrouw op 32** borstkanker

De meerderheid van de vrouwen overleeft borstkanker.

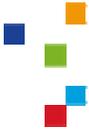
Kolm L et al. Borstkankeropsporing: boodschappen ter ondersteuning van een geklartemede keuze. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216Aa. | Laatste update : december 2013.

Hoe gebeurt het onderzoek bij borstkankeropsporing?

Een 'mammografie' is steeds het eerste onderzoek bij borstkankeropsporing. Een mammografie is een röntgenfoto van de borst. De hoeveelheid röntgenstraling is klein. Ze is weinig gevaarlijk na 50 jaar.

Een 'echografie'. Soms is het resultaat van een mammografie onduidelijk. Dan gebeurt een tweede onderzoek. Dat is een echografie. Een echografie gebruikt geluidsgolven die niet gevaarlijk zijn.

Een mammografie en een echografie samen? Sommige artsen stellen aan de vrouw voor om een mammografie en een echografie meteen samen uit te voeren. Het nut om die twee onderzoeken steeds samen te doen is niet bewezen. Deze artsen volgen niet de kwaliteitsnormen van de Europese en Belgische overheden.

**Informations générales sur le dépistage du cancer du sein**

Pour qui sont ces informations ?

Pour les femmes avec un risque 'normal' de cancer du sein. Ce texte est écrit pour les femmes qui ont un risque 'normal' de cancer du sein. Il s'agit de la majorité des femmes.

Sur **1000 femmes**, **935** ont un risque normal d'avoir le cancer du sein.

Vous avez peut-être un risque 'plus élevé'. S'il y a des cas de cancers du sein dans votre famille ou si vous avez déjà eu un cancer du sein, vous avez peut-être un risque 'plus élevé'.

Parlez-en avec votre médecin si :

- deux membres ou plus de votre famille proche ont eu le cancer du sein;
- un membre de votre famille proche a eu un cancer du sein avant 40 ans.

La 'famille proche', ce sont vos enfants, parents, grands-parents, frères, sœurs, oncles et tantes. Les autres membres de la famille ne sont pas votre 'famille proche'.

Pas en cas de problèmes. Le dépistage du cancer du sein est pour les femmes qui n'ont pas de problèmes aux seins. En cas de problèmes aux seins, consultez votre médecin.

À quoi servent ces informations ?

Participer, ou non, à un dépistage du cancer du sein a des avantages et inconvénients. Ce texte informe des avantages et inconvénients immédiats et dans les 10 ans qui suivent le dépistage.

Les chiffres utilisés concernent le dépistage du cancer du sein organisé par les autorités belges, appelé aussi «Mammotest». Ils ont été complétés par les connaissances les plus fiables de la recherche scientifique nationale et internationale.

Les chiffres dépendent de l'âge de la femme. Ce texte s'adresse aux femmes de 40 à 49 ans.

Algemene informatie over borstkankeropsporing

Voor wie is deze tekst?

Voor vrouwen met een 'normaal' risico op borstkanker. Deze tekst is voor vrouwen met een 'normaal' risico op borstkanker. Dat is de grote meerderheid van de vrouwen.

Op **1000 vrouwen** hebben **935** een normaal risico op borstkanker.

U hebt misschien een 'verhoogd' risico. Dit kan onder meer als er in uw familie borstkanker voorkomt of als u zelf al borstkanker had. Spreek erover met uw arts als:

- twee of meer van uw directe familieleden borstkanker hadden;
- één direct familieled jonger was dan 40 jaar toen ze borstkanker ontdekte.

'Directe familieleden' zijn uw kinderen, ouders, grootouders, broers, zussen, cooms en tantes. Andere familieleden tellen niet mee.

Niet bij duidelijke problemen. Borstkankeropsporing is er voor vrouwen zonder duidelijke problemen aan hun borsten. Raadpleeg uw arts bij elk probleem aan uw borsten.

Waarvoor dient deze tekst?

Deelnemen of niet deelnemen aan een borstkankeropsporing heeft voordelen en nadelen. Deze tekst informeert over de onmiddellijke voordelen en nadelen, maar ook over die in de volgende 10 jaar.

De gebruikte cijfers hebben betrekking op de door de overheid georganiseerde borstkankeropsporing (Vlaams bevolkingsonderzoek naar borstkanker). Ze werden aangevuld met inzichten uit het meest betrouwbare nationale en internationale wetenschappelijk onderzoek.

De cijfers zijn anders voor elke leeftijd. Deze tekst gaat over vrouwen van 40 tot 49 jaar.

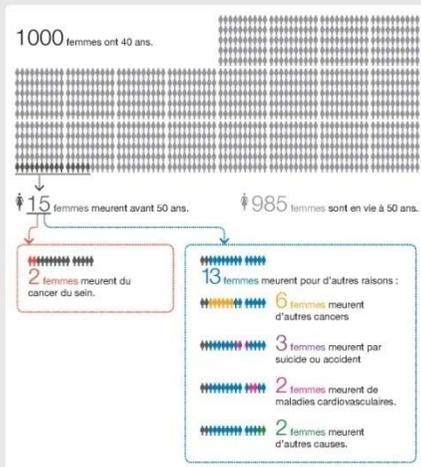
7.2 Specific messages by age groups

7.2.1 The risk of dying

7.2.1.1 40-49 year old

40-49 ans > Le risque de mourir

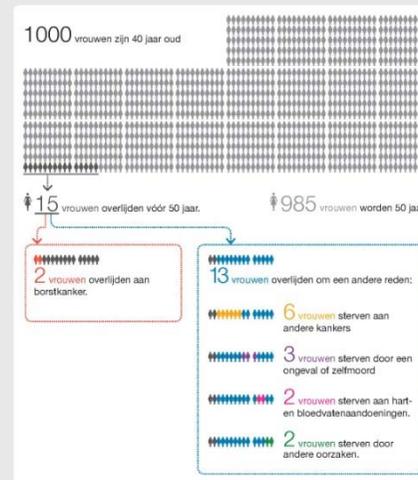
Le dépistage du cancer du sein veut faire baisser le nombre de morts causées par le cancer du sein. Ce tableau montre le nombre de femmes qui meurent entre 40 et 49 ans et les causes de ces morts.



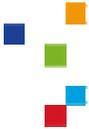
Kohn L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216Ba. | Dernière mise à jour : décembre 2013

40-49 jaar > Het risico om te sterven

Borstkankeropsporing probeert de sterfte door borstkanker te verminderen. Deze tabel toont het aantal vrouwen die tussen 40 en 49 jaar overlijden en hun doodsoorzaken.



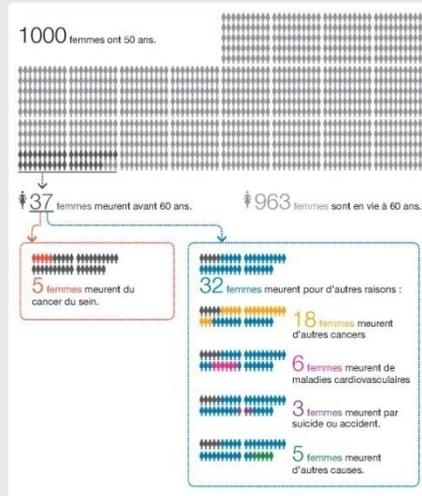
Kohn L et al. Borstkankeropsporing: boodschappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216Ba. | Laatste update : december 2013



7.2.1.2 50-59 year old

50-59 ans > Le risque de mourir

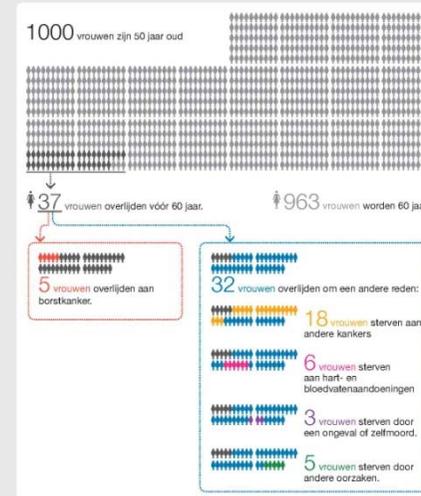
Le dépistage du cancer du sein veut faire baisser le nombre de morts causées par le cancer du sein. Ce tableau montre le nombre de femmes qui meurent entre 50 et 59 ans et les causes de ces morts.



Klein L et al. Dépistage du cancer du sein: messages en support d'un check-inform. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013

50-59 jaar > Het risico om te sterven

Borstkankeropsporing probeert de sterfte door borstkanker te verminderen. Deze tabel toont het aantal vrouwen die tussen 50 en 59 jaar overlijden en hun doodsoorzaken.



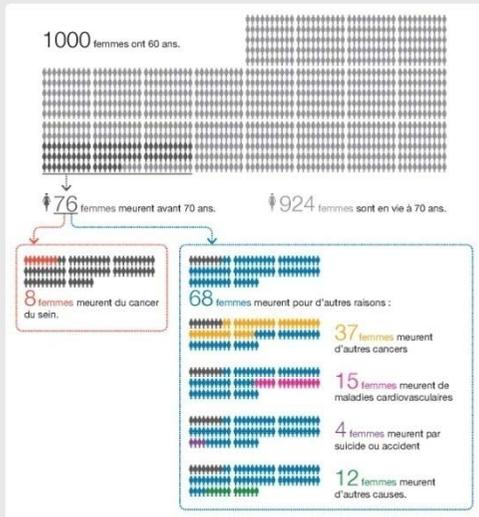
Klein L et al. Borstkankeropsporing - locochappen ter ondersteuning van een gelijknamende leus. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216A. | Laatste update : december 2013



7.2.1.3 60-69 year old

60-69 ans > Le risque de mourir

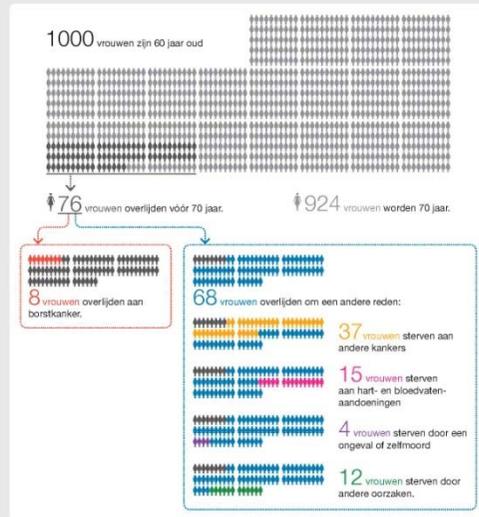
Le dépistage du cancer du sein veut faire baisser le nombre de morts causées par le cancer du sein. Ce tableau montre le nombre de femmes qui meurent entre 60 et 69 ans et les causes de ces morts.



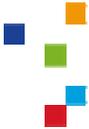
Kohn L et al. Dépistage du cancer du sein: messages et support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013

60-69 jaar > Het risico om te sterven

Borstkankeropsporing probeert de sterfte door borstkanker te verminderen. Deze tabel toont het aantal vrouwen die tussen 60 en 69 jaar overlijden en hun doodsoorzaken.



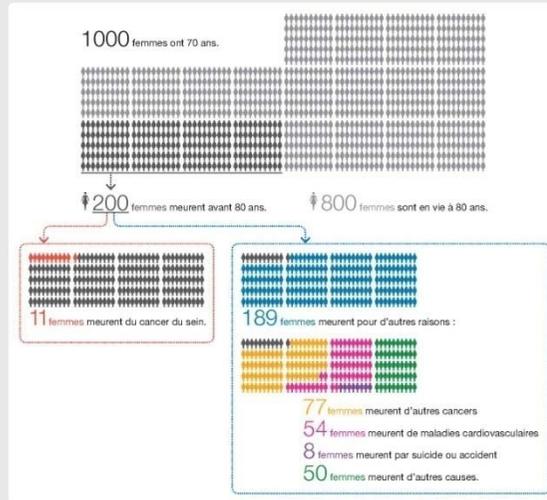
Kohn L et al. Borstkankeropsporing: locochappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216Aa. | Laatste update : december 2013



7.2.1.4 70-79 year old

70-79 ans > Le risque de mourir

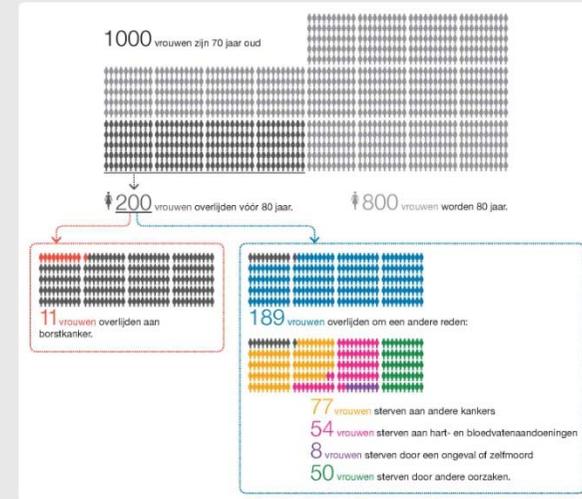
Le dépistage du cancer du sein veut faire baisser le nombre de morts causées par le cancer du sein. Ce tableau montre le nombre de femmes qui meurent entre 70 et 79 ans et les causes de ces morts.



Kahn L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013

70-79 jaar > Het risico om te sterven

Borstkankeropsporing probeert de sterfte door borstkanker te verminderen. Deze tabel toont het aantal vrouwen die tussen 70 en 79 jaar overlijden en hun doodsoorzaken.



Kahn L et al. Borstkankeropsporing - locochapagen ter ondersteuning van een geïnformeerd keuze. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216A. | Laatste update : december 2013



7.2.2 10 years consequences of breast cancer screening

7.2.2.1 40-49 year old

40-49 ans > Les conséquences du dépistage du cancer du sein dans les 10 ans qui suivent

Ne pas se faire dépister

1000 femmes n'ont pas de dépistage du cancer du sein

Chez 20 femmes on trouve un cancer du sein et elles sont traitées. Chez 980 femmes on ne trouve pas de cancer du sein.

4 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer.

16 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer.

Se faire dépister

1000 femmes ont un dépistage du cancer du sein chaque année

Chez 22 femmes on trouve un cancer du sein et elles sont traitées. Chez 978 femmes on ne trouve pas de cancer du sein.

3 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer. Ces 3 femmes meurent du cancer du sein même si le dépistage a découvert leur cancer plus tôt.

16 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer. Le dépistage du cancer du sein découvre le cancer plus tôt. Cela rend le traitement plus efficace.

1 femme a un cancer du sein au cours de sa vie. Elle en mourra peut-être un jour. Ce cancer est causé par l'exposition aux rayons X des mammographies faites avant la ménopause.

Les autorités européennes et belges déconseillent le dépistage du cancer du sein aux femmes de 40 à 49 ans. Pourquoi ? Les rayons X des mammographies peuvent provoquer un cancer du sein chez les femmes avant la ménopause. Cela n'arrive pas souvent, mais ce risque est inacceptable pour les autorités. De plus, le cancer du sein est plus rare entre 40 et 49 ans. Pour ces femmes, les avantages sont trop faibles, comparés aux désavantages.

Kohn L et al. Dépistage du cancer du sein: messages en support d'un choix éclairé. Bruxelles: Centre Fédéral d'Expérimentation des Soins de Santé (KCE), 2013. KCE, Reports 216bis. [Dernière mise à jour: décembre 2013]

40-49 jaar > De gevolgen van borstkankeronderzoek gedurende de volgende 10 jaar

Niet meedoen aan borstkankeronderzoek

1000 vrouwen doen geen borstkankeronderzoek

Bij 20 vrouwen vindt men borstkanker en zij worden behandeld. Bij 980 vrouwen vindt men geen borstkanker.

4 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker.

16 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog.

Wel meedoen aan borstkankeronderzoek

1000 vrouwen doen elk jaar een borstkankeronderzoek

Bij 22 vrouwen vindt men borstkanker en zij worden behandeld. Bij 978 vrouwen vindt men geen borstkanker.

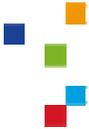
3 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker. Deze 3 vrouwen overlijden aan borstkanker ondanks het vroeger opsporen door het borstkankeronderzoek.

16 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog. 1 vrouw leeft dankzij het borstkankeronderzoek nog minstens 10 jaar na de ontdekking van de kanker. Het borstkankeronderzoek ontdekt de kanker vroeger en daardoor werkt de behandeling beter. 2 vrouwen worden teveel behandeld. Ze hebben een 'slapende' borstkanker die zich niet ontwikkelt. Zonder het borstkankeronderzoek hadden ze er nooit iets van gemerkt. Artsen kunnen niet voorspellen of slapende kankers ooit wakker worden. Daarom behandelen ze ook de slapende kankers. Men spreekt van 'overbehandeling'.

1 vrouw krijgt gedurende haar leven borstkanker. Misschien stoft ze er ooit aan. Deze borstkanker is veroorzaakt door de röntgenstralen van mammografieën die vóór de menopauze gebeuren.

De Europese en Belgische overheden raden borstkankeropsporing af tussen 40-49 jaar. Waarom? De röntgenstralen van een mammografie kunnen borstkanker veroorzaken bij vrouwen vóór de menopauze. Dit gebeurt zeer zelden, maar toch vindt de overheid dit risico onaanvaardbaar. Bovendien komt borstkanker minder voor tussen 40-49 jaar. Voor deze vrouwen wegen de voordelen van borstkankeropsporing niet op tegen de nadelen.

Kohn L et al. Borstkankeropsporing: boodschappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Koördinerend Bureau voor de Gezondheidszorg (KCE), 2013. KCE, Reports 216Aa. [Laatste update: december 2013]



7.2.2.2 50-59 year old

50-59 ans > Les conséquences du dépistage du cancer du sein dans les 10 ans qui suivent / 50-59 jaar > De gevolgen van borstkankeronderzoek gedurende de volgende 10 jaar

Ne pas se faire dépister

1000 femmes n'ont pas de dépistage du cancer du sein

Chez 35 femmes on trouve un cancer du sein et elles sont traitées. Chez 965 femmes on ne trouve pas de cancer du sein.

8 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer. 27 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer.

Se faire dépister

1000 femmes ont un dépistage du cancer du sein (Mammotest) tous les 2 ans

Chez 38 femmes on trouve un cancer du sein et elles sont traitées. Chez 962 femmes on ne trouve pas de cancer du sein.

5 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer. Ces 5 femmes meurent du cancer du sein même si le dépistage a découvert leur cancer plus tôt. 27 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer. 3 femmes restent en vie encore au moins 10 ans après la découverte du cancer grâce au dépistage du cancer du sein. Le dépistage du cancer du sein découvre le cancer plus tôt. Cela rend le traitement plus efficace. 3 femmes sont traitées en trop. Elles ont un cancer du sein 'dormant' qui ne se développe pas. Sans dépistage, elles ne l'auraient jamais remarqué. Les médecins ne savent pas si un cancer dormant risque de se réveiller un jour. Ils traitent donc aussi les cancers dormants. On parle de 'surtraitement'.

Les autorités européennes et belges conseillent aux femmes de 50 à 69 ans un dépistage organisé (Mammotest). Le Mammotest est une mammographie analysée par deux spécialistes différents. Le Mammotest suit les normes de qualité recommandées par les autorités européennes. La recherche scientifique prouve l'utilité de ce dépistage pour les femmes de 50 à 69 ans.

Kohn L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216(A) | Dernière mise à jour : décembre 2013

Niet meedoen aan borstkankeronderzoek

1000 vrouwen doen geen borstkankeronderzoek

Bij 35 vrouwen vindt men borstkanker en zij worden behandeld. Bij 965 vrouwen vindt men geen borstkanker.

8 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker. 27 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog.

Wel meedoen aan borstkankeronderzoek

1000 vrouwen doen elke 2 jaar een borstkankeronderzoek

Bij 38 vrouwen vindt men borstkanker en zij worden behandeld. Bij 962 vrouwen vindt men geen borstkanker.

5 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker. Deze 5 vrouwen overlijden aan borstkanker ondanks het vroeger opsporen door het borstkankeronderzoek. 27 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog. 3 vrouwen leven dankzij het borstkankeronderzoek nog minstens 10 jaar na de ontdekking van de kanker. Het borstkankeronderzoek ontdekt de kanker vroeger en daardoor werkt de behandeling beter. 3 vrouwen worden teveel behandeld. Ze hebben een 'slapende' borstkanker die zich niet ontwikkelt. Zonder het borstkankeronderzoek hadden ze er nooit iets van gemerkt. Artsen kunnen niet voorstellen of slapende kankers ooit wakker worden. Daarom behandelen ze ook de slapende kankers. Men spreekt van 'overbehandeling'.

De Europese en Belgische overheden raden vrouwen van 50-69 jaar aan om elke twee jaar een borstkankeronderzoek te doen, in het kader van de georganiseerde opsporing (Vlaams bevolkingsonderzoek naar borstkanker). Het Vlaams bevolkingsonderzoek naar borstkanker doet een mammografie, waarna twee verschillende specialisten het resultaat analyseren. Het Vlaams bevolkingsonderzoek naar borstkanker volgt de kwaliteitsnormen van de Europese overheid. Wetenschappelijk onderzoek bewijst het nut van borstkankeropsporing voor vrouwen van 50-69 jaar.

Kohn L et al. Borstkankeropsporing - Boodschappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kankercentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216(A) | Laatste update : december 2013



7.2.2.3 60-69 year old

60-69 ans > Les conséquences du dépistage du cancer du sein dans les 10 ans qui suivent **60-69 jaar** > De gevolgen van borstkankeronderzoek gedurende de volgende 10 jaar

Ne pas se faire dépister

1000 femmes n'ont pas de dépistage du cancer du sein

Chez 40 femmes on trouve un cancer du sein et elles sont traitées. Chez 960 femmes on ne trouve pas de cancer du sein.

11 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer.

29 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer.

Se faire dépister

1000 femmes ont un dépistage du cancer du sein (Mammotest) tous les 2 ans

Chez 44 femmes on trouve un cancer du sein et elles sont traitées. Chez 956 femmes on ne trouve pas de cancer du sein.

7 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer. Ces 7 femmes meurent du cancer du sein même si le dépistage a découvert leur cancer plus tôt.

29 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer. 4 femmes restent en vie encore au moins 10 ans après la découverte du cancer grâce au dépistage du cancer du sein. Le dépistage du cancer du sein découvre le cancer plus tôt. Cela rend le traitement plus efficace. 4 femmes sont traitées en trop. Elles ont un cancer du sein 'dormant' qui ne se développe pas. Sans dépistage, elles ne l'auraient jamais remarqué. Les médecins ne savent pas si un cancer dormant risque de se réveiller un jour. Ils traitent donc aussi les cancers dormants. On parle de 'surtraitement'.

Les autorités européennes et belges conseillent aux femmes de 50 à 69 ans un dépistage du cancer du sein tous les deux ans dans le cadre du dépistage organisé (Mammotest). Le Mammotest est une mammographie analysée par deux spécialistes différents. Le Mammotest suit les normes de qualité recommandées par les autorités européennes. La recherche scientifique prouve l'utilité de ce dépistage pour les femmes de 50 à 69 ans.

Kuhn L et al. Dépistage du cancer du sein: messages et support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013

Niet meedoen aan borstkankeronderzoek

1000 vrouwen doen geen borstkankeronderzoek

Bij 40 vrouwen vindt men borstkanker en zij worden behandeld. Bij 960 vrouwen vindt men geen borstkanker.

11 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker.

29 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog.

Wel meedoen aan borstkankeronderzoek

1000 vrouwen doen elke 2 jaar een borstkankeronderzoek

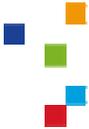
Bij 44 vrouwen vindt men borstkanker en zij worden behandeld. Bij 956 vrouwen vindt men geen borstkanker.

7 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker. Deze 7 vrouwen overlijden aan borstkanker ondanks het vroeger opsporen door het borstkankeronderzoek.

29 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog. 4 vrouwen leven dankzij het borstkankeronderzoek nog minstens 10 jaar na de ontdekking van de kanker. Het borstkankeronderzoek ontdekt de kanker vroeger en daardoor werkt de behandeling beter. 4 vrouwen worden teveel behandeld. Ze hebben een 'slapende' borstkanker die zich niet ontwikkelt. Zonder het borstkankeronderzoek hadden ze er nooit iets van gemerkt. Artsen kunnen niet voorspellen of slapende kankers ooit wakker worden. Daarom behandelen ze ook de slapende kankers. Men spreekt van 'overbehandeling'.

De Europese en Belgische overheden raden vrouwen van 50-69 jaar aan om elke twee jaar een borstkankeronderzoek te doen, in het kader van de georganiseerde opsporing (Vlaams bevolkingsonderzoek naar borstkanker). Het Vlaams bevolkingsonderzoek naar borstkanker doet een mammografie, waarna twee verschillende specialisten het resultaat analyseren. Het Vlaams bevolkingsonderzoek naar borstkanker volgt de kwaliteitsnormen van de Europese overheid. Wetenschappelijk onderzoek bewijst het nut van borstkankersporing voor vrouwen van 50-69 jaar.

Kuhn L et al. Borstkankersporing - Levenshappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kankercentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216Aa. | Laatste update : december 2013



7.2.2.4 70-79 year old

70-79 ans > Les conséquences du dépistage du cancer du sein dans les 10 ans qui suivent / 70-79 jaar > De gevolgen van borstkankeronderzoek gedurende de volgende 10 jaar

Ne pas se faire dépister

1000 femmes n'ont pas de dépistage du cancer du sein

Chez 31 femmes on trouve un cancer du sein et elles sont traitées. Chez 969 femmes on ne trouve pas de cancer du sein.

6 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer. 25 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer.

Se faire dépister

1000 femmes ont un dépistage du cancer du sein tous les 2 ans

Chez 34 femmes on trouve un cancer du sein et elles sont traitées. Chez 966 femmes on ne trouve pas de cancer du sein.

4 femmes meurent du cancer du sein dans les 10 ans après la découverte du cancer. Ces 4 femmes meurent du cancer du sein même si le dépistage a découvert leur cancer plus tôt. 25 femmes ont un cancer du sein mais sont encore en vie 10 ans après la découverte du cancer. Le dépistage du cancer du sein découvre le cancer plus tôt. Cela rend le traitement plus efficace. 2 femmes restent en vie encore au moins 10 ans après la découverte du cancer grâce au dépistage du cancer du sein. 3 femmes sont traitées en trop. Elles ont un cancer du sein 'dormant' qui ne se développe pas. Sans dépistage, elles ne l'auraient jamais remarqué. Les médecins ne savent pas si un cancer dormant risque de se réveiller un jour. Ils traitent donc aussi les cancers dormants. On parle de 'surtraitement'.

Les autorités européennes et belges déconseillent le dépistage du cancer du sein aux femmes après 70 ans. À cet âge, peu de femmes meurent d'un cancer du sein comparé aux autres causes de décès. Après 70 ans, le dépistage du cancer du sein a plus de désavantages que d'avantages.

Les femmes de 70 à 79 ans peuvent encore se faire dépister. Elles en parlent d'abord avec leur médecin. Il connaît leur état de santé. Il peut leur expliquer les avantages et les désavantages d'un dépistage.

Kohn L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216As | Dernière mise à jour : décembre 2013

Niet meedoen aan borstkankeronderzoek

1000 vrouwen doen geen borstkankeronderzoek

Bij 31 vrouwen vindt men borstkanker en zij worden behandeld. Bij 969 vrouwen vindt men geen borstkanker.

6 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker. 25 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog.

Wel meedoen aan borstkankeronderzoek

1000 vrouwen doen elke 2 jaar een borstkankeronderzoek

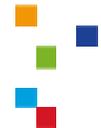
Bij 34 vrouwen vindt men borstkanker en zij worden behandeld. Bij 966 vrouwen vindt men geen borstkanker.

4 vrouwen overlijden aan borstkanker in de 10 jaar na de ontdekking van de kanker. Deze 4 vrouwen overlijden aan borstkanker ondanks het vroeger opsporen door het borstkankeronderzoek. 25 vrouwen lijden aan borstkanker maar leven 10 jaar na de ontdekking van de kanker nog. 2 vrouwen leven dankzij het borstkankeronderzoek nog minstens 10 jaar na de ontdekking van de kanker. Het borstkankeronderzoek ontdekt de kanker vroeger en daardoor werkt de behandeling beter. 3 vrouwen worden teveel behandeld. Ze hebben een 'slapende' borstkanker die zich niet ontwikkelt. Zonder het borstkankeronderzoek hadden ze er nooit iets van gemerkt. Artsen kunnen niet voorspellen of slapende kankers ooit wakker worden. Daarom behandelen ze ook de slapende kankers. Men spreekt van 'overbehandeling'.

De Europese en Belgische overheden raden borstkankeropsporing af vanaf 70 jaar. Op die leeftijd sterven weinig vrouwen aan borstkanker in vergelijking met andere doodsoorzaken. Vanaf 70 jaar zorgt borstkankeropsporing voor meer nadelen dan voordelen.

Een vrouw van 70 tot 79 jaar kan nog steeds een borstkankeronderzoek ondergaan. Ze overlegt daarover best eerst met haar arts. Die kent haar gezondheid en legt haar de nadelen en voordelen van een borstkankeropsporing uit.

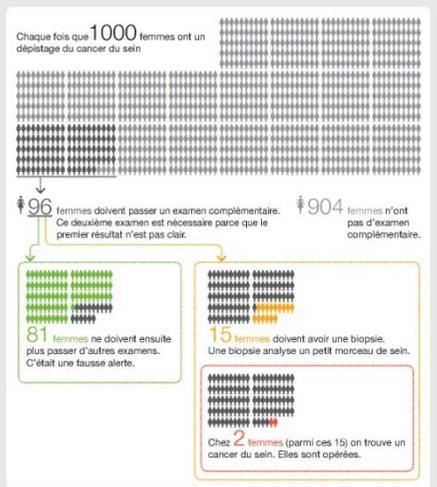
Kohn L et al. Borstkankeropsporing - Loochthappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kankercentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216As | Laatste update : december 2013



7.2.3 Consequences of breast cancer screening in the next months

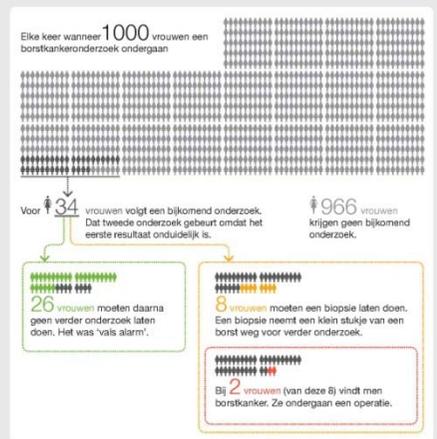
7.2.3.1 40-49 year old

40-49 ans > Les conséquences du dépistage du cancer du sein dans les mois qui suivent

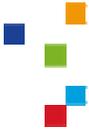


Kohn L et al. Dépistage du cancer du sein: messages et support d'un choix éclairé. Bruxelles: Centre Fédéral d'Équilibre des Soins de Santé (KCE), 2013. KCE Reports 216bis. Dernière mise à jour : décembre 2013.

40-49 jaar > De gevolgen van borstkankeronderzoek in de volgende maanden

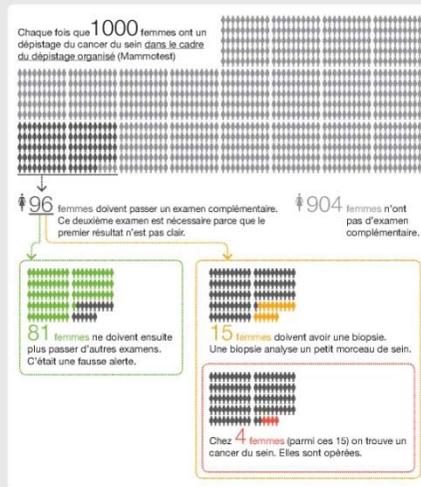


Kohn L et al. Borstkankeropsporing - boodschappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216bis. Laatste update : december 2013.



7.2.3.2 50-59 year old

50-59 ans > Les conséquences du dépistage du cancer du sein dans les mois qui suivent



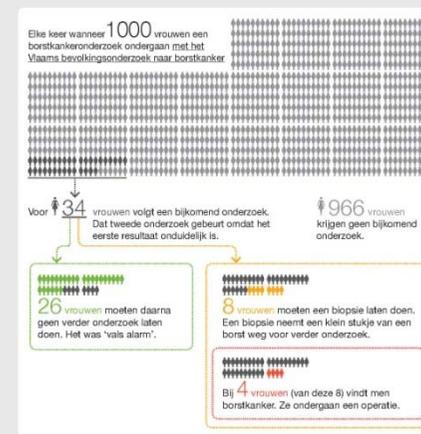
Les chiffres présentés ici se basent sur le dépistage organisé (Mammotest).

Certains médecins proposent aux femmes de faire une mammographie suivie directement d'une échographie. Cette combinaison d'examens ne suit pas les recommandations européennes.

Il n'y a pas de données fiables sur les conséquences de ce type de dépistage. Ceci ne permet pas de savoir si cette manière de se faire dépister est recommandable.

Klein L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013

50-59 jaar > De gevolgen van borstkankeronderzoek in de volgende maanden



Deze cijfers zijn gebaseerd op de resultaten van het Vlaams bevolkingsonderzoek naar borstkanker.

Sommige artsen stellen aan de vrouw voor om samen met een mammografie meteen ook een echografie uit te voeren. Deze combinatie van onderzoeken is niet in overeenstemming met de Europese aanbevelingen.

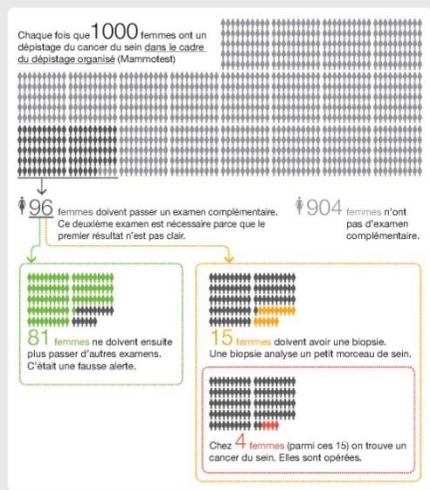
Er zijn geen betrouwbare gegevens over de resultaten van deze vorm van borstkankeropsporing. Het is onduidelijk of ze aan te raden is.

Klein L et al. Borstkankeropsporing: locustudie naar de ondersteuning van een geïnformeerd keuzen. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216Aa. | Laatste update : december 2013



7.2.3.3 60-69 year old

60-69 ans > Les conséquences du dépistage du cancer du sein dans les mois qui suivent



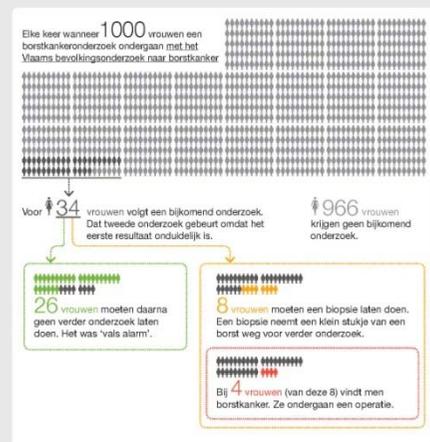
Les chiffres présentés ici se basent sur le dépistage organisé (Mammotest).

Certains médecins proposent aux femmes de faire une mammographie suivie directement d'une échographie. Cette combinaison d'examens ne suit pas les recommandations européennes.

Il n'y a pas de données fiables sur les conséquences de ce type de dépistage. Ceci ne permet pas de savoir si cette manière de se faire dépister est recommandable.

Klein L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216A. | Dernière mise à jour : décembre 2013

60-69 jaar > De gevolgen van borstkankeronderzoek in de volgende maanden

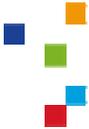


Deze cijfers zijn gebaseerd op de resultaten van het Vlaams bevolkingsonderzoek naar borstkanker.

Sommige artsen stellen aan de vrouw voor om samen met een mammografie meteen ook een echografie uit te voeren. Deze combinatie van onderzoeken is niet in overeenstemming met de Europese aanbevelingen.

Er zijn geen betrouwbare gegevens over de resultaten van deze vorm van borstkankeropsporing. Het is onduidelijk of ze aan te raden is.

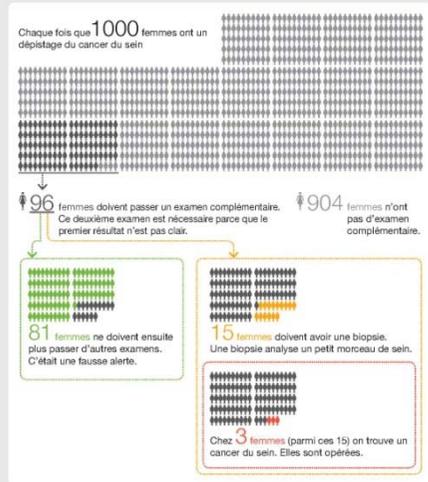
Klein L et al. Borstkankeropsporing - Loochthappen ter ondersteuning van een geïnformeerd keuzes. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216Aa. | Laatste update : december 2013



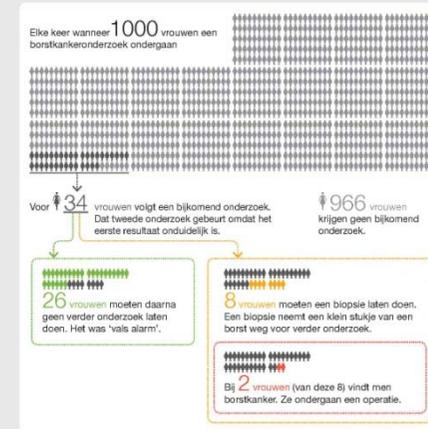
7.2.3.4 70-79 year old

70-79 ans > Les conséquences du dépistage du cancer du sein dans les mois qui suivent

70-79 jaar > De gevolgen van borstkankeronderzoek in de volgende maanden



Kahn L et al. Dépistage du cancer du sein: messages en support d'un choix informé. Bruxelles: Centre Fédéral d'Expertise des Soins de Santé (KCE), 2013. KCE Reports 216As. | Dernière mise à jour : décembre 2013



Kahn L et al. Borstkankeropsporing - Loochthappen ter ondersteuning van een geïnformeerde keuze. Brussel: Federaal Kenniscentrum voor de Gezondheidszorg (KCE), 2013. KCE Reports 216As. | Laatste update : december 2013



■ APPENDICES

APPENDIX 1. IPDAS CHECKLIST¹⁷

1.	The decision aid describes the condition (health or other) related to the decision.	Yes/No
2.	The decision aid describes the decision that needs to be considered (the index decision).	Yes/No
3.	The decision aid lists the options (health care or other).	Yes/No
4.	The decision aid describes what happens in the natural course of the condition (health or other) if no action is taken.	Yes/No
5.	The decision aid has information about the procedures involved (e.g. what is done before, during, and after the health care option).	Yes/No
6.	The decision aid has information about the positive features of the options (e.g. benefits, advantages).	Yes/No
7.	The decision aid has information about negative features of the options (e.g. harms, side effects, disadvantages).	Yes/No
8.	The information about outcomes of options (positive and negative) includes the chances they may happen.	Yes/No
9.	The decision aid has information about what the test is designed to measure.	Yes/No
10.	The decision aid describes possible next steps based on the test results.	Yes/No
11.	The decision aid has information about the chances of disease being found with and without screening.	Yes/No
12.	The decision aid has information about detection and treatment of disease that would never have caused problems if screening had not been done.	Yes/No
13.	The decision aid presents probabilities using event rates in a defined group of people for a specified time.	Yes/No
14.	The decision aid compares probabilities (e.g. chance of a disease, benefit, harm, or side effect) of options using the same denominator.	Yes/No
15.	The decision aid compares probabilities of options over the same period of time.	Yes/No
16.	The decision aid uses the same scales in diagrams comparing options.	Yes/No
17.	The decision aid asks people to think about which positive and negative features of the options matter most to them.	Yes/No
18.	The decision aid makes it possible to compare the positive and negative features of the available options.	Yes/No
19.	The decision aid shows the negative and positive features of the options with equal detail.	Yes/No



Development Process		Answer
20.	Users (people who previously faced the decision) were asked what they need to prepare them to discuss a specific decision.	Yes/No
21.	The decision aid was reviewed by people who previously faced the decision who were not involved in its development and field testing.	Yes/No
22.	People who were facing the decision field tested the decision aid.	Yes/No
23.	Field testing showed that the decision aid was acceptable to users (the general public & practitioners).	Yes/No
24.	Field testing showed that people who were undecided felt that the information was presented in a balanced way.	Yes/No
25.	The decision aid provides references to scientific evidence used.	Yes/No
26.	The decision aid reports the date when it was last updated.	Yes/No
27.	The decision aid reports whether authors of the decision aid or their affiliations stand to gain or lose by choices people make after using the decision aid.	Yes/No
28.	The decision aid (or available technical document) reports readability levels.	Yes/No
Effectiveness		Answer
29.	There is evidence that the decision aid (or one based on the same template) helps people know about the available options and their features.	Unknown
30.	There is evidence that the decision aid (or one based on the same template) improves the match between the features that matter most to the informed person and the option that is chosen.	Unknown



APPENDIX 2. SEARCH STRATEGIES

Appendix 2.1. Systematic reviews on the communication of the risk in general

Appendix 2.1.1. MEDLINE via OVID

1. Health Communication/es, mt [Ethics, Methods]
2. risk information.mp.
3. risk perception.mp.
4. *Decision Making/es [Ethics]
5. risk communication.mp.
6. *Communication/mt [Methods]
7. *Decision Support Techniques/
8. *Data Interpretation, Statistical/mt [Methods]
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. limit 9 to ("review articles" and last 10 years)
11. limit 10 to (dutch or english or flemish or french)

Appendix 2.1.2. PreMEDLINE via OVID

1. risk information.mp.
2. risk perception.mp.
3. risk communication.mp.
4. 'decision making'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
5. 'decision support'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

6. communication.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
7. 'data interpretation'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
8. meta-analysis.mp,pt. or review.pt. or search:.tw.
9. limit 8 to (dutch or english or flemish or french)
10. 1 or 2 or 3 or 4 or 5 or 6 or 7
11. 8 and 9 and 10
12. limit 11 to yr="2002 -Current"

Appendix 2.1.3. Psychinfo via OVID

1. risk information.mp.
2. risk perception.mp.
3. risk communication.mp.
4. 'data interpretation'.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
5. scientific communication/ or information dissemination/
6. *decision making/ or *decision support systems/ or *framing effects/
7. 1 or 2 or 3 or 4 or 5 or 6
8. limit 7 to (("0830 systematic review" or 1200 meta analysis) and (dutch or english or french) and last 10 years)

Appendix 2.1.4. EMBASE

- #9 8 AND ([meta analysis]/lim OR [systematic review]/lim) AND ([dutch]/lim OR [english]/lim OR [french]/lim) AND [Embase]/lim AND [2002-2013]/py
- #8 #2 OR #3 OR #4 OR #5 OR #6 OR #7
- #7 'medical information'/mj
- #6 'decision support system'/mj
- #5 'risk communication'



- #4 'risk perception'
- #3 'risk information'
- #2'patient decision making'/mj

Appendix 2.2. Studies about communication on breast cancer screening

Appendix 2.2.1. MEDLINE via OVID

1. Health Communication/es, mt [Ethics, Methods]
2. risk information.mp.
3. risk perception.mp.
4. *Decision Making/es [Ethics]
5. risk communication.mp.
6. *Communication/mt [Methods]
7. *Decision Support Techniques/
8. *Data Interpretation, Statistical/mt [Methods]
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. *Breast Neoplasms/pc [Prevention & Control]
11. 9 and 10
12. *Breast Neoplasms/
13. *Mass Screening/
14. 12 and 13
15. 9 and 14
16. 11 or 15

Appendix 2.2.2. PreMEDLINE via OVID

1. risk information.mp.
2. risk perception.mp.
3. risk communication.mp.
4. 'decision making'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

5. 'decision support'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

6. communication.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

7. 'data interpretation'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

8. 'breast cancer'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

9. screening.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

10. 1 or 2 or 3 or 4 or 5 or 6 or 7

11. 8 and 9 and 10

Appendix 2.2.3. Psycinfo via OVID

1. risk information.mp.

2. risk perception.mp.

3. risk communication.mp.

4. 'data interpretation'.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

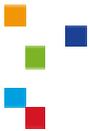
5. scientific communication/ or information dissemination/

6. *decision making/ or *decision support systems/ or *framing effects/

7. 1 or 2 or 3 or 4 or 5 or 6

8. *Breast Neoplasms/

9. *Cancer Screening/



10. 8 and 9
11. 7 and 10

Appendix 2.2.4. Embase

#8 AND #12 AND ([dutch]/lim OR [english]/lim OR [french]/lim) AND [Embase]/lim AND [2002-2013]/py
#8 AND #12
#10 AND #11
'cancer screening'/mj
'breast cancer'/mj
#9 #8 AND ([meta analysis]/lim OR [systematic review]/lim) AND ([dutch]/lim OR [english]/lim OR [french]/lim) AND [Embase]/lim AND [2002-2013]/py
#8 #2 OR #3 OR #4 OR #5 OR #6 OR #7
#7 'medical information'/mj
#6 'decision support system'/mj
#5 'risk communication'
#4 'risk perception'
#3'risk information'
#2 'patient decision making'/mj

Appendix 2.2.5. Eric and Sociological abstract

S1 subject("Screening Tests")
S2 all("Screening Tests") AND all(literacy numeracy)
S3 all("Screening Tests") AND all(numeracy)
S4 (decision aid) AND all(numeracy)
S5 subject("Visual Aids")
S6 subject("Visual Aids") AND ("risk assessment")
S7 subject("Visual Aids") AND ("Risk Assessment")
S8 ("Risk Assessment") AND (breast cancer)
S9 ("Risk Assessment") AND (breast cancer) AND "Communication"

Appendix 2.3. Studies about women perspectives on communication around breast cancer screening

Appendix 2.3.1. MEDLINE via OVID

breast cancer screening.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
informed consent.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
choice Behaviour.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
2 or 3
1 and 4
(qualitative or interview or focus group).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
1 and 6
5 or 7

Appendix 2.3.2. PreMEDLINE via OVID

breast cancer screening.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
informed consent.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]



choice Behaviour.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

2 or 3

1 and 4

(qualitative or interview or focus group).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

1 and 6

5 or 7

Appendix 2.3.3. Psychinfo via OVID

Decision Making/

*Breast Neoplasms/

Informed Consent/

information need*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

*cancer screening/

1 or 3 or 4

2 and 5 and 6

Appendix 2.3.4. EMBASE

#1.7 #1.1 AND #1.4 AND #1.6 AND [Embase]/lim

#1.6 #1.2 OR #1.3 OR #1.5

#1.5 'decision making'/exp

#1.4 'qualitative research'/exp

#1.3 'informed consent'/exp

#1.2 'information'/exp OR information

#1.1 'breast cancer screening'



APPENDIX 3. FORMAT OF COMMUNICATING RISK

Appendix 3.1. Quality appraisal of the systematic reviews

Table 11 – Quality assessment of the systematic reviews on the way to communicate risk according to AMSTAR criteria

Systematic review	1	2	3	4	5	6	7	8	9	10	11
Aki et al. 2011 ²¹	Y	Y	Y	N	Y	Y	Y	Y	Y	Cannot answer	Cannot answer
Aki 2011 et al. ²⁰	Y	Y	Y	N	Y	Y	Y	Y	Y	Cannot answer	Cannot answer
Anker et al. 2006 ²⁵	Cannot answer	Cannot answer	Y	Y	N	N	N	Cannot answer	Cannot answer	Cannot answer	Cannot answer
Gallagher et al. 2012 ²³	Cannot answer	Cannot answer	Y	N	N	N	?	Y	Y	Y	Cannot answer
Hildon et al. 2012 ²⁴	Cannot answer	Y	Y	Y	N	N	Y	N	Y	Cannot answer	Cannot answer
Winterbottom et al. 2008	Cannot answer	Cannot answer	Y	Y	N	Y	Y	N	Not applicable	Cannot answer	Cannot answer



Appendix 3.2. Description of the systematic reviews

Table 12 – Description of the systematic reviews on the way to communicate risk - partim design

Author, year	Objective	Number of studies included	Type of studies included	Patients - Population	Intervention	Comparison	Outcomes
Aki et al., 2011	To evaluate the effects of using alternative statistical presentations of the same risks and risk reductions on understanding, perception, persuasiveness and Behaviour of health professionals, policy makers, and consumers.	35	randomized and non-randomized controlled parallel and cross-over studies	health professionals and consumers	natural frequencies	percentages	<ul style="list-style-type: none"> • Understanding (measured as correct estimate or interpretation of a risk) • Perception • Persuasiveness
Aki et al., 2011	To evaluate the effects of attribute (positive versus negative) framing and of goal (gain versus loss) framing of the same health information, on understanding, perception of effectiveness, persuasiveness, and Behaviour of health professionals, policy makers, and consumers.	35	randomized controlled trials, quasi-randomized controlled trials, and cross-over studies		negatively-framed health messages	positively-framed health messages	<ul style="list-style-type: none"> • Understanding • Perception (measured as rating on a scale of perceived effectiveness) • Persuasiveness (measured as a hypothetical decision or intention or willingness to adopt an intervention) • Behaviour



Author, year	Objective	Number of studies included	Type of studies included	Patients - Population	Intervention	Comparison	Outcomes
Ancker et al., 2006	describes recent experimental and focus group research on graphics as a method of communication about quantitative health risks.	24	evaluation studies		graphs describing probabilities, frequencies, or chances of health events that had not been covered in Lipkus and Hollands' review.		<ul style="list-style-type: none"> accuracy or consistency of quantitative reasoning or perceptions effect on Behaviours or intentions. users' likes and dislikes
Gallagher et al., 2012	This meta-analysis distinguished the outcomes used to assess the persuasive impact of framed messages (attitudes, intentions, or Behaviour).	94	published, peer-reviewed papers		gain-framed messages (emphasizing the positive outcomes of engaging in a health Behaviour)	loss-framed messages (emphasizing the negative outcomes of failing to engage in a health Behaviour)	health Behaviour attitude towards the Behaviour, Behavioural intention, or actual Behaviour.
Hildon et al., 2012	To review the literature on the impact of compositional format and content of quantitative data displays on people's comprehension, choice and preference.	30	quantitative qualitative mixed methods	public students patients clinicians commissioners	bar charts , pictographs and (numerical and non-numerical) tables ; Consistent line graphs; pie charts and scatter plots		people's 'comprehension' (or interpretation) of the data; the way displays affect's their 'choice' (either hypothetically or their Behaviour in practice) people's 'preference' (or liking) for one display over another.



Author, year	Objective	Number of studies included	Type of studies included	Patients - Population	Intervention	Comparison	Outcomes
Winterbottom et al., 2008	This systematic review synthesizes the evidence about the persuasiveness of narrative information on individuals' decision making.	17					

Table 13 – Description of the systematic reviews on the way to communicate risk - partim results and author's conclusions

Author, year	Results of the review	Author's conclusions
Akl et al., 2011	<p>Participants (health professionals and consumers) understood natural frequencies better than percentages (SMD 0.69 (95% confidence interval (CI) 0.45 to 0.93)).</p> <p>Risk reductions of interventions, and compared with ARR, RRR had little or no difference in understanding (SMD 0.02 (95% CI -0.39 to 0.43)) but was perceived to be larger (SMD 0.41 (95% CI 0.03 to 0.79)) and more persuasive (SMD 0.66 (95% CI 0.51 to 0.81)).</p> <p>Compared with NNT, RRR was better understood (SMD 0.73 (95% CI 0.43 to 1.04)), was perceived to be larger (SMD 1.15 (95% CI 0.80 to 1.50)) and was more persuasive (SMD 0.65 (95% CI 0.51 to 0.80)). Compared with NNT, ARR was better understood (SMD 0.42 (95% CI 0.12 to 0.71)), was perceived to be larger (SMD 0.79 (95% CI 0.43 to 1.15)). There was little or no difference for persuasiveness (SMD 0.05 (95% CI -0.04 to 0.15)).</p>	<p>Natural frequencies are probably better understood than percentages in the context of diagnostic or screening tests. For communicating risk reductions, relative risk reduction (RRR), compared with absolute risk reduction (ARR) and number needed to treat (NNT), may be perceived to be larger and is more likely to be persuasive. However, it is uncertain whether presenting RRR is likely to help people make decisions most consistent with their own values and, in fact, it could lead to misinterpretation.</p>



Author, year	Results of the review	Author's conclusions
Aki et al., 2011	<p>In the context of attribute framing, participants in one included study understood the message better when it was framed negatively than when it was framed positively (1 study; SMD -0.58 (95% confidence interval (CI) -0.94 to -0.22); moderate effect size; low quality evidence). Although positively-framed messages may have led to more positive perception of effectiveness than negatively framed messages (2 studies; SMD 0.36 (95% CI -0.13 to 0.85); small effect size; low quality evidence), there was little or no difference in persuasiveness (11 studies; SMD 0.07 (95% CI -0.23 to 0.37); low quality evidence) and Behaviour (1 study; SMD 0.09 (95% CI -0.14 to 0.31); moderate quality evidence).</p> <p>In the context of goal framing, loss messages led to a more positive perception of effectiveness compared to gain messages for screening messages (5 studies; SMD -0.30 (95% CI -0.49 to -0.10); small effect size; moderate quality evidence) and may have been more persuasive for treatment messages (3 studies; SMD -0.50 (95% CI -1.04 to 0.04); moderate effect size; very low quality evidence).</p> <p>There was little or no difference in Behaviour (16 studies; SMD -0.06 (95% CI -0.15 to 0.03); low quality evidence). No study assessed the effect on understanding.</p>	<p>Contrary to commonly held beliefs, the available low to moderate quality evidence suggests that both attribute and goal framing may have little if any consistent effect on health consumers' Behaviour. The unexplained heterogeneity between studies suggests the possibility of a framing effect under specific conditions.</p> <p>In the absence of evidence for the superiority of one frame over the other, a balanced presentation when producing patient information or decision aids is likely to be the safest approach.</p>



Author, year	Results of the review	Author's conclusions
Ancker et al., 2006	<p>The best design for a graphic depends upon the purpose of the risk communication. Some communications are intended to enhance quantitative understanding or promote good arithmetic judgments, whereas others are intended to promote Behaviour change.</p> <p>For good quantitative judgments, the size of a graphic element should be proportional to the number it portrays. When the size diverges from the number, people are more influenced by the size than by the number.</p> <p>Patients can recognize proportions fairly successfully with part-to-whole sequential icon arrays.</p> <p>Proportions are difficult to assess in randomly arranged icon arrays and possibly also when the icons are jittered. This could account for the dislike of random-arrangement arrays found in qualitative studies. Icon arrays may be better than random ones in any situation that requires the viewer to estimate a proportion or compare two proportions.</p> <p>Graphs emphasizing the numerator of a risk ratio are more likely to promote risk Behaviour changes.</p> <p>Bar charts, arranged icons, risk ladders, scales and sequentially have been used successfully to help viewers place individual risks in context of other risks or make specific comparisons between risks. Perceptions are strongly influenced by the design of graphics. Magnifying the low end of a risk scale to call attention to very small probabilities reduces the perceived size of low risks, risks as well as higher. If the scale of a ladder is altered so that a particular risk is closer to the high end of the ladder, this inflates viewers' perception of that risk.</p>	<p>Graphical features that improve the accuracy of quantitative reasoning appear to differ from the features most likely to alter Behaviour or intentions. For example, graphs that make part-to-whole relationships available visually may help people attend to the relationship between the numerator (the number of people affected by a hazard) and the denominator (the entire population at risk), whereas graphs that show only the numerator appear to inflate the perceived risk and may induce risk-averse Behaviour. Viewers often preferred design features such as visual simplicity and familiarity that were not associated with accurate quantitative judgments. Communicators should not assume that all graphics are more intuitive than text; many of the studies found that patients' interpretations of the graphics were dependent upon expertise or instruction. Potentially useful directions for continuing research include interactions with educational level and numeracy and successful ways to communicate uncertainty about risk.</p>



Author, year	Results of the review	Author's conclusions
Gallagher et al., 2012	<p>Gain-framed messages were more likely than loss-framed messages to encourage prevention Behaviours ($r=0.083$, $p=0.002$), particularly for skin cancer prevention, smoking cessation, and physical activity. No effect of framing was found when persuasion was assessed by attitudes/intentions or among studies encouraging detection.</p> <p>Breaking down the detection category by Behaviour domain revealed one notable domain, breast cancer detection, in which there was a trend towards a significant difference in the persuasive effect of the gain- versus the loss-framed message ($k=10$; $r=-0.052$, $p=0.077$).</p>	<p>Gain-framed messages appear to be more effective than loss-framed messages in promoting prevention Behaviours.</p>
Hildon et al., 2012	<p>As regards format, tables and pictographs appeared better understood than bar charts despite the latter being preferred. Although accessible to less numerate and older populations, pictographs tended to lead to more risk avoidance. Tables appeared accessible to all. Aspects of content enhancing the impact of data displays included giving visual explanatory cues and contextual information while still attempting simplicity ('less is more'); ordering data; consistency. Icons rather than numbers were more user-friendly but could lead to over-estimation of risk. Uncertainty was not widely understood, nor well represented.</p> <p>Representation of uncertainty: Confidence intervals did not increase understanding of uncertainty</p>	<p>As regards compositional format, tables and pictographs were judged to be more accurate decision aids than bar charts. It was also noted that over-estimation and avoidance of risk can occur with the use of icons. This data display method may be more appropriate for older and less numerate populations. Tables appeared accessible to all though for complex data, bar charts may be more appropriate. Studies of decision-support software have indicated that numerical tables are more effective than graphs unless the task demand is high.</p> <p>When the decision is a simple binary or categorical choice, formats other than bar charts may be the most appropriate.</p> <p>With bar charts, choice may be driven by rank ordering rather than whether options are within or outside of normal variation.</p>



Author, year	Results of the review	Author's conclusions
Winterbottom et al., 2008	Narrative information influenced decision making more than the provision of no additional information and/or statistically based information in approximately a third of the studies (5/17); studies employing first person narratives were twice as likely to find an effect. There was some evidence that narrative information encouraged the use of heuristic rather than systematic processing. However, there was little consistency in the methods employed and the narratives' content to provide evidence on why narratives affect the decision process and outcome, whether narratives facilitate or bias decision making, and/ or whether narratives affect the quality of the decision being made.	The use of narratives in interventions to facilitate medical decision making should be treated cautiously.

Table 14 – Critical appraisal of additional primary studies on risk communication

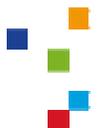
Quantitative studies (Law et al.)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Fagerlin et al., 2007	Y	N	Y	+/-	N	NA	NA	Y	NA	NA	Y	Y	NA	N	Y
Vahabi et al., 2010	Y	Y	Y	Y	NA	NA	NA	Y	NA	NA	Y	Y	NA	Y	Y
Wong et al. 2012	Y	Y	Y	Y	U	NA	Y	Y	NA	NA	Y	Y	Na	N	Y

RCT (Risk of bias tool)	1u	2	3	4	5	6	7
Ghosh et al., 2008	OK	NA	NO	NO	Unclear	Unclear	NO



Table 15 – Description of the additional primary studies on risk communication

Author; date	Design	Main results / authors conclusions
Fagerlin et al., 2007	Convenience sample of 249 women visitors to a hospital cafeteria approached by research assistants Half of participants were given comparative risk information that indicated that their risk was below average (i.e. average woman's risk was 12%), while half were given comparative risk information that revealed that their risk was above average (i.e. average woman's risk was 3%).	“This study demonstrate that people are more likely to act upon a risk when they feel that their risk is above average. Thus, patients' preferences for a treatment might be more influenced by whether they perceive themselves as lower or higher risk than the average person, rather than on the risk/benefit trade-off of the treatment. Thus, clinicians and health educators should carefully consider whether or not to include comparative risk. The current results suggest that incorporating comparative risk information into a tailored decision aid can have unintended results. When patients' risks are below average, receiving the comparative information may discourage them from undergoing beneficial treatments that they might otherwise have chosen. By the same token, patients whose risks are above average may be inclined to undergo risky treatments that they otherwise might not have chosen.”
Ghosh et al., 2008	RCT 150 women at increased risk for breast cancer. aged 40 years or older presenting to the Breast Diagnostic Clinic Intervention: education with a bar graph (BG group) Comparison: bar graph plus a frequency format diagram (BG+FF group),	“Breast cancer risk communication using a bar graph plus a frequency format diagram can improve the short-term accuracy of risk perception among women perceiving inaccurately high risk. Combining visual displays with numerical and written information can be effective in communicating risk information.”
Vahabi et al., 2010	Cross sectional survey 180 women from community settings with no history of breast cancer received an information brochure with probabilities presented in verbal format or an information brochure with probabilities presented in numerical format	“Comprehension of information depends on readiness to receive information, education and numeracy skills.”



Author; date	Design	Main results / authors conclusions
Wong et al., 2012	<p>Cross sectional survey 420 English, Spanish or Chinese, to women aged 50-80 recruited from primary care practices. They had at least one clinic visit in the previous 2 years. The part of the survey on breast cancer: was only addressed to women aged 50-65 years.</p> <p>Intervention: visuals: wall of 100 women” (for those filling out breast or colon) or the icon array, “wall of 10,000 women” and magnifying glass graphic (for those filling out cervical).</p>	<p>“Race/ethnic differences were associated with women’s ability to take a quantitative cancer risk statistic verbally provided to them and report it in a visual format.”</p>



Katapodi et al. 2009	Y	Y	Y	Y	N	NA	NA	NA	NA	NA	Y	Y	NA	N	Y
Pohls et al. 2004	Y	Y	Y	Y	NA	NA	NA	NA	NA	NA	Y	Y	NA	N	Y
van Agt et al. 2012	Y	Y	Y	Y	N	Y	NA	NA	NA	NA	Y	Y	NA	Y	Y
Narrative review (AMSTAR)															
Hersch et al. 2011	N	N	N	U	N	N	N	N	N	N	N	Y			

Appendix 4.2. Description of the studies

Table 16 – Description of the studies on women perspectives in breast cancer screening

Author; date	Design	Main results
Østerlie et al. 2008	8 focus groups 50-69 y-o women Prospective design 3 meetings: 1st 2 weeks between invitation and participation in screening, 1 week after examination, 6 months after examination)	Mammography = threshold mile They are grateful for having being invited to the c-screening with a pre-scheduled appointment. Decision to be screened is here not been made according the informed choice: prescheduled appointment made by a system in which they have trust.
Buchanan et al. 2005	Telephone survey to discuss cancer risk and risk management among a general population of primary care patients	Interest of discussing cancer risk was generally high. If participants have already discuss breast cancer risk with their physician, they are more likely to discuss it again in the future. Those with poor perceived health were more likely to discuss breast cancer risk. If the risk of BC is self-attributed, women are more likely to discuss it
Dillard et al. 2010	Survey in 1729 adults aged 40 y and older to examine relationship between perceived risk of cancer and Behaviours during decision making	As perceived risk for cancer increased, patients were more likely to seek information about screening on their own and interaction with their physician



Author; date	Design	Main results
Facione 2002	770 women survey in US	Own risk is perceived lower. Optimism. Cancer knowledge and education decrease unwarranted optimism
Geller et al. 2007	Survey in 17/23 countries on type of tools used to communicate with women and content	Pamphlets are the most used + invitations (with pre-appointment)
Hersch et al. 2013	Qualitative studies with focus groups over overdiagnosis	Over-diagnosis awareness is minimal but women are able to understand it. According to the estimation over overdiagnosis, women will more or less be careful in their personal decision making. Higher the estimates, higher cautious. Overdiagnoses impact not the decision to be screen but whether to treated in case of positive result of the mammogram.
Hersch et al. 2011	Discussion of qualitative and quantitative studies of women attitudes to BC screening and informed choice	89% of 2305 women wanted info on limits of mammo screening and 82% wanted to know reasons why some people oppose screening. Intervention increase knowledge and reduce the proportion of women who remained undecided. DA increased informed choice (adequation between attitude and decision based on knowledge). Some women may not wish to individually evaluate detailed mammo info → different level of info. Difference in preference amongst fully informed women X community consensus in favor of screening
Humpel et al. 2004	Interviews self estimation of risk	Reasons to estimate they own risk of BC were guess, family history, according to age and information sheet. Women tend to overestimate their risk
Katapodi et al. 2009	Cross sectional survey	If the perceived risk of BC is underestimated, it might cause anxiety and therefore overuse of screening. Or it could induce the risk not to be to the screening and benefit from the treatment.
Pohls et al. 2004	Survey among 2108 healthy women	There is a large percentage of over and under estimation of BC risk. Risk factors associated are not well known. Knowledge is better in advanced education level
Unruh et al. 2004	8 focus groups in US about online breast cancer risk information (18-65 year-old)	Participants were interested in online health information with the support of a real person to assist them.



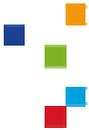
Author; date	Design	Main results
Vahabi et al. 2003	RCT pamphlet providing risk/benefit of BC screening using verbal (quail) expression of probabilities and the other using numeric 25-45 y-o with no history of BC - Canada	Findings from open-ended questions: some women want to detect early cancer other not because of fear of radiation exposure or prioritizing other daily responsibilities. Beliefs on faith /destiny and body image and sexuality were the two common reasons. As breast are symbolized in our society as a sign of feminity, any action which could lead to their loss can be viewed as a risk taking behaviour. You can save your life but not necessarily your breasts. Trust in expert opinion by lay people. Searching for BC could be a source of distress and a way to render pathological otherwise healthy lives.
van Agt et al. 2012	Expert consensus + survey in invited women	Women seem to have sufficient knowledge about benefits and harms of screening, but less knowledge about false negative mammograms or overdiagnosis
Vernon 1999	Review on risk perception and risk communication related to screening behaviour	Changing risk perception is possible but do not necessarily imply modification in cancer screening



Appendix 4.3. Interview guidelines used in focus groups with women

Appendix 4.3.1. French-speaking guideline

	Questions	Timing
<p>1. Qui nous sommes et objectif de la rencontre</p>	<ul style="list-style-type: none"> • ‘Qui sommes nous’: Sabine et Magali • Entretien sur le dépistage du cancer du sein. Chaque femme recevra un jour / a déjà reçu une/plusieurs invitations pour un dépistage. • Nous développons un outil d’aide à la décision, c’est-à-dire des explications qui aident les femmes à prendre leur décision. <p>La loi sur les droits des patients prévoit que tout le monde doit pouvoir disposer d’information supplémentaire quand il s’agit de prendre des décisions en rapport avec sa santé.</p> <p>Dans ce cas, il s’agit de la décision de participer, ou non, au dépistage du cancer du sein préventif (alors qu’on n’est pas malade, qu’on ne se plaint de rien) quand on y est invité par un médecin qui vous le propose, ou à l’initiative des autorités (au moyen d’une invitation écrite – lettre) ...</p> <p>Parce qu’une femme peut décider elle même de faire ou non, ce type de dépistage. C’est pourquoi il est important pour nous de savoir ce que vous souhaitez savoir sur le dépistage du cancer du sein avant de vous faire dépister. Nous voulons avoir l’avis de différentes femmes. C’est pour cela que l’avis de chacune est important, qu’on ait déjà été invitées à pratiquer/ pratiqué un dépistage du cancer du sein ou non.</p> <p>Au cours de cette discussion, nous voulons découvrir quelles informations les femmes recherchent, comment elles prennent leur décision.</p> <ul style="list-style-type: none"> • Il s’agit d’une initiative des autorités. Une mission du Centre fédéral d’expertise des soins de santé. Il ne s’agit pas d’une initiative commerciale. • Avant de débiter notre discussion, quelques précisions : <ul style="list-style-type: none"> ○ anonyme ○ enregistrement mais seulement à usage interne ○ questions ? 	



2. Qui êtes-vous: tour de table	<ul style="list-style-type: none">• Prénom suffit• Pourquoi participez-vous ?• Avez-vous déjà été confrontée au cancer du sein dans votre entourage?• Avez-vous déjà pratiqué un dépistage du cancer du sein ?	→10'
3. Préparation individuelle	<ul style="list-style-type: none">• souligner:<ul style="list-style-type: none">○ il s'agit du dépistage du cancer du sein et non du cancer○ on peut aborder ce qui concerne l'examen de dépistage, mais aussi les avantages et inconvénients○ notez ce qui vous semble important, ce que vous souhaitez savoir avant	→5' 15
4. Tour de table: vos 2 questions les plus	<ul style="list-style-type: none">• Noter les 2 questions les plus importantes pour chacune	→15' 30
5. Tour de table	<ul style="list-style-type: none">• Y a-t-il des sujets qui n'ont pas été abordés ?	
6. Ramasser feuilles		
7. Discussion	<ul style="list-style-type: none">• Approfondir les thèmes les plus cités (7) : quoi et comment• Approfondir 3 thèmes spécifiques <p>Relances possible :</p> <p>Risque d'être malade, risques liés à la maladie, risque de mourir, délais, etc</p> <p>risques liés à l'examen, questions pratiques liées à l'examen (comment ça se passe, combien ça coûte, différence entre mammoth et autre (pour les 50-69 ans)</p> <p>infos sur la maladie, sur les traitements, sur la prévention de la maladie, etc.</p>	→60' 1h30
8. L'outil de décision	<p>Invitation</p> <ul style="list-style-type: none">• De quelle manière souhaitez-vous être invité ? (par la poste, médecin généraliste, gynécologue, affichage...?)• Quelle information aimeriez vous recevoir à l'occasion de cette (contenu, quantité, type d'info...)? <p>Première réaction et première concertation</p> <ul style="list-style-type: none">• Comment avez-vous réagi à l'invitation• Avec qui en avez-vous parlé/auriez vous aimé en parler ? (Rôle du généraliste/gynécologue) <p>Information complémentaire ?</p> <ul style="list-style-type: none">• Quelle information attendiez vous afin de décider de participer ou non à ce type de dépistage ?• Comment souhaitez-vous recevoir ce type d'info (rechercher vous-même, dans un dépliant, sur un site web, via	→30'



généraliste, gynécologue...) ?

- Combien d'info souhaitez-vous? Quand pensez-vous être (in)suffisamment informés
- Regardez la feuille de travail.
- Vous ne devez pas la remplir !
- Est-ce que cela aurait pu vous aider à décider à participer à un dépistage préventif ?
- oui, non , pourquoi ?

Information visuelle: distribuer

- Quelle information vous semble la plus utile ?
- Quel est le visuel le plus efficace ? 1-2-3-4
- Préférez vous le texte/les graphiques/les visuels
- Points forts et faibles des exemples ?

2h

Décision

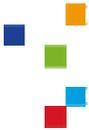
- Souhaitez-vous décider vous-même
- Avec qui en parlez-vous ?
- Quels arguments vous influencent ?
- Si jamais dépistage ?
- Pourquoi n'en avez-vous jamais pratiqué

Au participantes ayant déjà pratiqué un (ou plusieurs dépistages)

- Expérience, questionnements ? Quid après le dépistage ? Questions complémentaires ...

9. 2^{ème} questionnaire

- Remercier (cadeau)
 - Que deviennent les résultats ?
 - Si vous êtes intéressés, laissez adresse mail
-



Appendix 4.3.2. Dutch-speaking guideline

Verduidelijkende noot

Vooraf - bij het vastleggen van de afspraken - wordt met de contactpersoon ter plaatse doorgenomen:

- deelnemende vrouwen behoren tot de aangegeven leeftijdscategorie
- deelnemende vrouwen hebben/hadden geen borstkanker of niemand met borstkanker in de onmiddellijke omgeving (moeder, dochter, zus...)

1. Intro & doel van de avond toelichten

- 'Wie zijn wij?': Kathleen en Sabine
- gesprek over borstkankerscreening. Elke vrouw zal daar ooit een uitnodiging voor ontvangen/al eens of meermaals voor uitgenodigd zijn.
- Wij maken een beslissingshulp, dat is een uitleg die vrouwen helpt bij hun beslissing. De wet op de patiëntenrechten voorziet dat iedereen over extra informatie moet kunnen beschikken wanneer er beslissingen i.v.m. de gezondheid moeten genomen worden. Hier: i.v.m. beslissing om al dan niet deel te nemen aan preventieve borstkankerscreening (op een moment dat je niet ziek bent, geen klachten hebt), en daarvoor uitgenodigd wordt door je arts die dit voorstelt, op initiatief van de overheid (via een brief)... Want een vrouw kan zelf beslissen of ze deelneemt. Daarom is het voor ons belangrijk om te weten te komen wat u graag vooraf wil weten over borstkankerscreening. We willen daarover de mening horen van verschillende vrouwen. Daarom is de mening van diegenen hier aan tafel die nog nooit een uitnodiging kregen/nog nooit deelnamen aan een screening even belangrijk als die van vrouwen die deze ervaring wel hebben.
- Met dit gesprek willen we horen welke informatie vrouwen vooral zoeken, hoe ze beslissen.
- Dit is een initiatief van de overheid. Een opdracht van het Federaal Kenniscentrum Gezondheidszorg. Het is geen commercieel product. Femma hielp ons.
- We beginnen zometeen met het gesprek. Voor de duidelijkheid:

- anoniem
- tapen, maar enkel om naderhand opnieuw te beluisteren

- vragen?

2. Wie bent u? Ronde van de tafel

- Voornaam volstaat
- waarom neemt u deel?
- bent u al geconfronteerd met borstkanker in uw omgeving of uzelf?
- hebt u zelf al een borstkankerscreening meegemaakt?

De notulist noteert grondig de mate van vertrouwdheid van elke deelnemster met borstkanker en borstkankerscreening. Dit is een nuancering bij de latere analyse

Verduidelijkende noot

De vragen naar waarom mensen deelnemen en of ze al geconfronteerd werden met borstkanker, zijn hier op zijn plaats om de uiteindelijke respons correct te interpreteren. Misschien zit er — ondanks de voorafgaande screening bij de groepssamenstelling — toch een deelnemster aan tafel die wel ervaring heeft met borstkanker bij zichzelf of in haar omgeving. Op dat ogenblik is het te laat om de deelname van de vrouw aan het gesprek te weigeren.

- Voor de moderator is het belangrijk om dit vooraf te weten, zodat kan vermeden worden dat de ervaringen van deze vrouw het denken van de andere deelnemsters beïnvloedt.
- Bij de resultatenverwerking kan desgewenst de feedback van de deelnemster in kwestie buiten beschouwing gelaten worden.

Ervaring met andere groepsgesprekken leert dat dergelijke vragen erg nuttige informatie leveren voor de verwerking van de input. Vaak tekent zich een onderscheid af tussen de visies van respondenten met een 'gemotiveerde deelname' (bv.: 'ik neem deel omdat borstkankerpreventie me erg bezighoudt') en 'sociale deelname' (bv. 'ik ben meegekomen met een vriendin').

⇒ TOT HIER: 10 MIN



3. korte schriftelijke voorbereiding

doelstelling:

- op neutraal moment (voor elk gesprek) peilen naar eigen kennis en beleving van borstkankerscreening door de deelnemster
- reflectief moment dwingend inbouwen bij elke deelnemster

uitvoering:

individuele vragenlijst invullen
vragenlijst: zie laatste bladzijde

Verduidelijkende noot

Om de bijkomend gesuggereerde vragen te kunnen integreren, worden er twee aparte vragenlijstjes verspreid:

3. bij het begin, ter voorbereiding van gespreksonderdeel 4
 4. afrondend
- benadrukken: het gaat hier over de screening, niet over borstkanker zelf
 - benadrukken dat er zowel zaken aan bod kunnen komen die te maken hebben met het onderzoek als zaken die te maken hebben met voor- en nadelen van een screening
 - benadrukken: noteer wat u **voor uzelf** belangrijk vindt, wat u graag vooraf wil weten

Geen verkeerde antwoorden, ook kleinere zaken, ...

⇒ TOT HIER: +5 MIN = 15 MIN

4. Tafelrondje: uw twee meest belangrijkste vragen over borstkankerscreening

doelstelling:

- persoonlijke aandachtspunten ophalen

uitvoering:

- alle leden van de groep afgaan
- geen discussie
- moderator stelt verduidelijkende vragen
- moderator noteert op groot bord en prioriteert (welke thema's worden eerst genoemd + welke thema's worden het vaakst genoemd).

Verduidelijkende noot

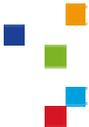
Hier inventariseert de moderator enkel de thema's die de gespreksdeelnemers zelf aanbrengen. Vragen als 'Ik hoorde niemand die vragen had over ...' komen in deze fase nog niet aan bod (zie gespreksonderdeel 7)

⇒ TOT HIER: +15 MIN = 30 MIN

5. Tafelrondje: zijn er andere aandachtspunten die u tot nog toe niet hoorde?

6. Vragenlijstjes ophalen

⇒ TOT HIER: +10 MIN = 40 MIN



7. Groepsgesprekken: de vragen uitdiepen

doelstelling:

meestgehoorde vragen uitdiepen. “waarom” en “hoe”

streefcijfer: 7 stellingen

enkele ‘aparte’ ideeën toetsen & uitdiepen.

streefcijfer: 3 stellingen

Verduidelijkende noot

‘Streefcijfer’: binnen het afgebakende tijdsbestek van het gesprek kan niet elk thema dat de deelnemers aanhaalden verdiepend behandeld worden. Daarom de beperking tot 10 thema’s.

Uitvoering:

- U noemde ‘xxxxxxxxx’: waarom? Waarom vindt u dat? ...
- discussies van 5 à 10 minuten per keer
- voldoende stilstaan bij onderscheid tussen info over het onderzoek en info over de resultaten van het onderzoek

enkele opvallende niet genoemde thema’s aanhalen. Mogelijk hierbij:

- over hoe de screening in zijn werk gaat
- over eventuele kosten –
- over de risico’s verbonden aan de screening, de ziekte, ...
- over borstkanker en borstkankerbehandeling,
- ...

⇒ TOT HIER: +60 MIN = 1U40 MIN

8. Het kader rondom en formaat voor een beslissing over borstkankerscreening

Doelstelling:

overstap naar concreter en opbouwend niveau: aanbevelingen vanuit de groep

Uitvoering:

groepsdiscussies, uitgelokt door deelnemers aan te spreken

De vragen worden afgeleid uit de voorbije gespreksonderdelen en variëren per focusgroep.

Mogelijke thema’s en vragen:

9. uitnodiging

Op welke manier wilt u graag uitgenodigd worden voor een screening (per bost, via de huisarts, gynaecoloog, ...)?

Welke informatie wilt u bij zo’n uitnodiging graag meteen krijgen (inhoud, hoeveelheid info...)?

- Eerste stappen en initieel overleg

Hoe reageerde u/denkt u te reageren op zo’n uitnodiging?

Met wie sprak u erover / wilt u erover spreken?

Rol van de huisarts, gynaecoloog...

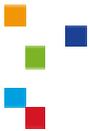
- Bijkomende informatie

Welke informatie verwacht(te) u alvorens u beslist(te) om al dan niet deel te nemen aan een dergelijke screening?

Hoe wilt u die info krijgen (zelf opzoeken, in een folder, op een website, via huisdokter, gynaecoloog, ...)?

Hoeveel informatie wilt u? Wanneer vindt u dat u te weinig geïnformeerd bent of — net omgekeerd — hebt u het gevoel dat u te veel informatie ontvangt?

Kijkt u a.u.b. rustig naar dit werkblad. U hoeft dit **NIET** in te vullen. Enkel doornemen en beoordelen: zou het u helpen om te beslissen over deelname aan een preventieve screening wanneer u vooraf een dergelijke oefening maakt? Waarom wel/niet?



- Visuele informatie

Vindt u dit soort visuele informatie waardevol (voorbeelden tonen)?

Welke informatie vindt u waardevol?

Aan welke opmaak geeft u de voorkeur?

- visueel
- tekst/f

Sterktes en zwaktes van elk van de voorbeelden?

- Beslissen

Wilt u zelf beslissen of liever niet?

Met wie overlegt u alvorens een beslissing te nemen?

Welke argumenten leiden uw beslissing? Welke spelen geen rol?

Verduidelijkende noot

Bij een gespreksverloop waar de deelnemers zich weinig open tonen en aangeven dat sommige thema's gevoelig liggen, kunnen bovenstaande vragen overgeslagen worden.

Aan **niet-deelneemsters**

Waarom nam u niet deel?

Aan **deelneemsters**

tijdens borstkankerscreening? Ervaringen, onduidelijkheden, ...

Wat na de borstkankerscreening? Bijkomende vragen, ervaringen, onduidelijkheden, ...

⇒ TOT HIER: + 30 MIN = 2U10

9. Afrondend

Tweede vragenlijstje

Bedanken (incl. cadeautje)

Wat gebeurt er met de resultaten?

Interesse in eindresultaat: laat e-mail achter aub

⇒ TOT HIER: +5 MIN = 2U15

Enkele voorafgaande vragen

Uw voornaam:

Uw leeftijd vandaag: jaar Uw woonplaats (postcode):

Als men u uitnodigt voor een borstkankerscreening, welke informatie wilt u daarover dan vooraf krijgen?

(begin aub met het belangrijkste)

Wat wil u nog weten over borstkankerscreening?

Enkele afrondende vragen

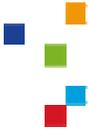
Uw voornaam:

Kreeg u ooit al een uitnodiging voor een borstkankerscreening?

- ja, op de leeftijd van jaar kreeg ik de eerste uitnodiging
- nee

Nam u al ooit deel aan een borstkankerscreening?

- ja, voor het eerst op de leeftijd van jaar
- nee



Indien u **al aan een borstkankerscreening deelnam**, onderging u toen een mammografie?

- ja
- nee

Indien u **al meerdere keren** aan een borstkankerscreening deelnam, hoeveel keer gebeurde dat al?

..... keer

Wordt u **met betrekking tot borstkanker** opgevolgd door een huisarts?

- ja, ik ga ong. om de maanden/jaren op consultatie
- nee

Wordt u **met betrekking tot borstkanker** opgevolgd door een gynaecoloog?

- ja, ik ga ong. om de maanden/jaren op consultatie
- nee

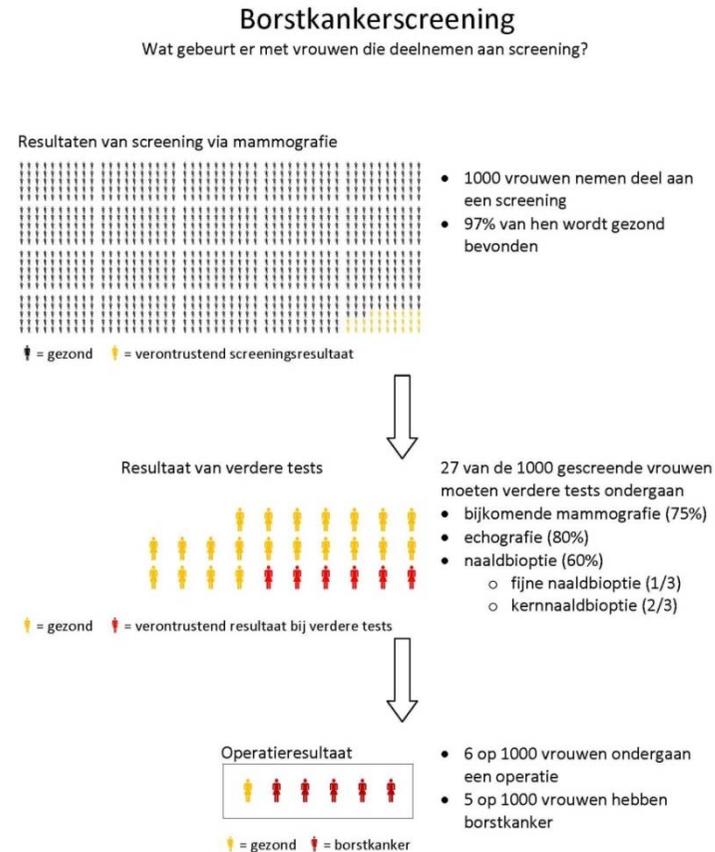
Wanneer er een beslissing over uw gezondheid genomen moet worden (algemeen, niet specifiek in verband met borstkanker), wie neemt die beslissing dan? Meerdere antwoorden zijn mogelijk.

- ik
- mijn huisarts
- de specialist
- anderen:

.....

Appendix 4.4. Examples of visuals used in the focus groups (women and GPs)

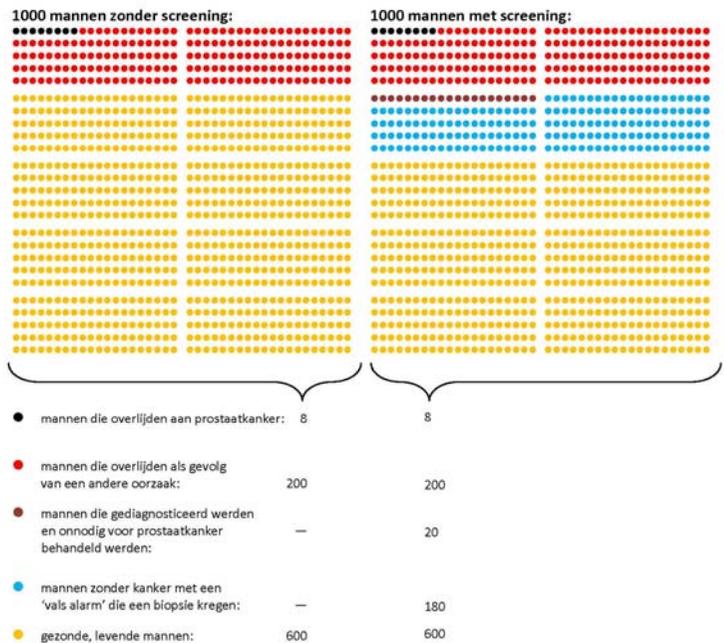
Appendix 4.4.1. Dutch-speaking



Source: Adapted from Pasternack I, Saalasti-Koskinen U, Makela M. Decision aid for women considering breast cancer screening. *Int J Technol Assess Health Care*. 2011;27(4):357-62

Vroege detectie van prostaatkanker

Aantallen voor mannen van 50 jaar of ouder; mannen die deelnamen aan screening versus mannen die niet deelnamen aan screening



Source: Adapted from Djulbegovic M, Beyth RJ, Neuberger MM, Stoffs TL, Vieweg J, Djulbegovic B, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials *BMJ* 2010 Sep 14;341:c4543

Vrouwen tussen 70 en 79 jaar

Wat zijn de mogelijke resultaten wanneer u besluit om deel te nemen aan een preventieve mammografische screening?

Neem 1 000 vrouwen van 70 jaar die zich gedurende 10 jaar jaarlijks laten screenen. Wat gebeurt er met hen? Gemiddeld levert dit volgende resultaten:

- ◆ 961 vrouwen hebben geen kanker
- 751 vrouwen krijgen een normaal resultaat
- 244 vrouwen krijgen één keer in die 10 jaar een abnormaal resultaat
 - bij 213 van deze abnormale resultaten gaat het om een vals alarm, wat zal blijken na bijkomende onderzoeken
- ◆ bij 31 vrouwen wordt er dankzij de screening borstkanker ontdekt

- ◆ 8 vrouwen krijgen borstkanker in de periode tussen twee screeningsonderzoeken

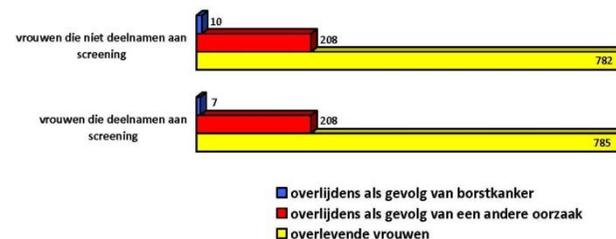
De screening wil het aantal overlijdens ten gevolge van borstkanker terugdringen. We kunnen ongeveer het aantal vrouwen berekenen dat moet deelnemen aan een screening om dit overlijden uit te sluiten.

Als we 100 vrouwen van 40 tot 49 jaar gedurende 10 jaar één keer per jaar onderzoeken:

- zullen 3 overlijden als gevolg van borstkanker vermeden worden
- zullen er 208 vrouwen overlijden aan een andere oorzaak dan borstkanker
- zullen 7 vrouwen, ondanks de screening, overlijden aan borstkanker

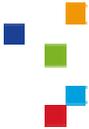
Hoe groot is de kans om te overlijden aan borstkanker?

Vergelijking van het aantal overlijdens bij 1000 vrouwen tussen de 70 en 79 jaar die zich wel en niet lieten screenen



De grafiek geeft aan dat overlijdens als gevolg van kanker zeldzaam zijn. Screening voorkomt dat er jaarlijks 1 vrouw op 1000 minder sterft aan borstkanker.

Source: Agence de la santé publique du Canada. Renseignements sur la mammographie à l'intention des femmes de 40 ans et plus: Un outil d'aide à la prise de décision pour le dépistage du cancer du sein au Canada. 2009.



Vroege detectie van prostaatkanker

Aantallen voor mannen van 50 jaar of ouder; mannen die deelnamen aan screening versus mannen die niet deelnamen aan screening

	1000 mannen zonder screening	1000 mannen met screening
Voordelen		
Hoeveel mannen stierven aan prostaatkanker?	8	8*
Hoeveel mannen stierven aan een andere oorzaak?	200	200
Nadelen		
Hoeveel mannen kregen een positieve diagnose en werden onnodig voor prostaatkanker behandeld?***	-	20
Hoeveel mannen zonder kanker kregen een 'vals alarm' en een biopsie?	-	180

* Dit betekent dat 8 op 1000 mannen (ouder dan 50 jaar) zonder screening binnen de 10 jaar stierven aan prostaatkanker.

** Bv. verwijdering van de prostaat of bestraling, wat kan leiden tot incontinentie of impotentie.

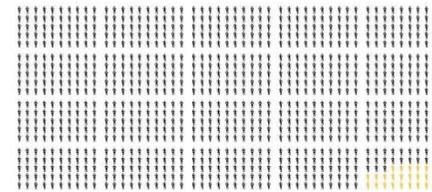
Source: Adapted from Djulbegovic M, Beyth RJ, Neuberger MM, Stoffs TL, Vieweg J, Djulbegovic B, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials *BMJ* 2010 Sep 14;341:c4543

Appendix 4.4.2. French-speaking

Dépistage du cancer du sein

Qu'arrive-t-il aux femmes qui subissent un dépistage ?

Résultats du dépistage par mammographie



♂ = en bonne santé ♀ = résultat de dépistage inquiétant

- 1000 femmes participent au dépistage
- Pour 97% des femmes aucun cancer du sein n'est constaté

Résultats des autres examens



- 27 des 1000 femmes dépistées doivent subir d'autres examens
- Mammographie complémentaire (75%)
- échographie (80%)
- biopsie (60%)

♂ = en bonne santé ♀ = résultats des examens complémentaires inquiétants

Résultat de l'opération



- 6 femmes sur 1000 subissent une opération
- 5 femmes sur 1000 ont un cancer du sein

♂ = en bonne santé ♀ = cancer du sein

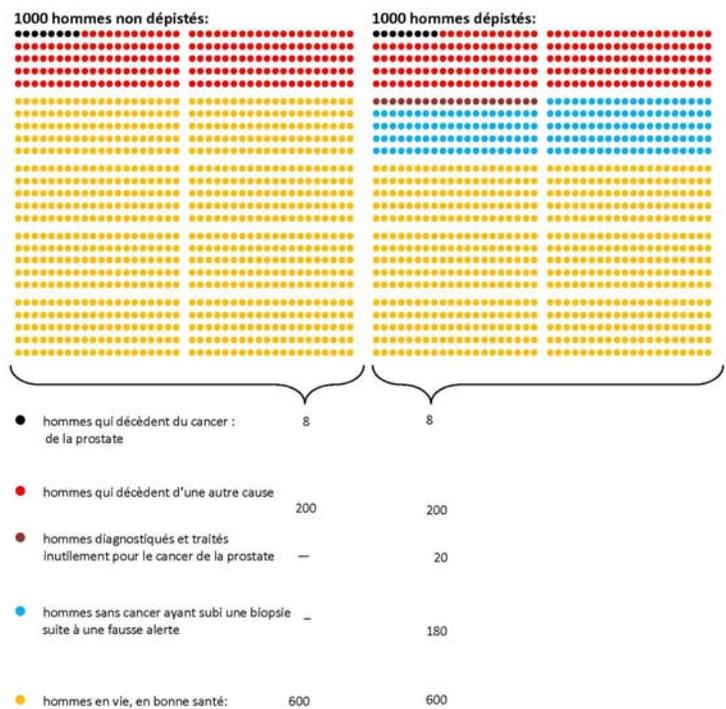
Source: Adapted from Pasternack I, Saalasti-Koskinen U, Makela M. Decision aid for women considering breast cancer screening. *Int J Technol Assess Health Care*. 2011;27(4):357-62

2

Détection précoce du cancer de la prostate

Chiffres pour les hommes à partir de 50 ans.

Hommes ayant participé à un dépistage et hommes n'ayant pas participé à un dépistage



Source: Adapted from Djulbegovic M, Beyth RJ, Neuburger MM, Stoffs TL, Vieweg J, Djulbegovic B, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials *BMJ* 2010 Sep 14;341:c4543

Femmes âgées de 40 à 49 ans

Si vous décidez de subir des mammographies de dépistage, quelle est la probabilité que les résultats du dépistage se réalisent ?

3 femmes développeront le cancer du sein entre les visites de dépistage

Soit 1 000 femmes de 40 ans qui commencent à participer à un programme de dépistage et qui s'y soumettent chaque année pendant 10 ans. Qu'arriverait-il? Nous avons constaté qu'elles obtiendront généralement les résultats suivants :

Puisque le dépistage a pour but de réduire le risque de mourir du cancer du sein, nous pouvons examiner le nombre estimatif de femmes qui doivent participer à un programme de dépistage pour éviter un décès.

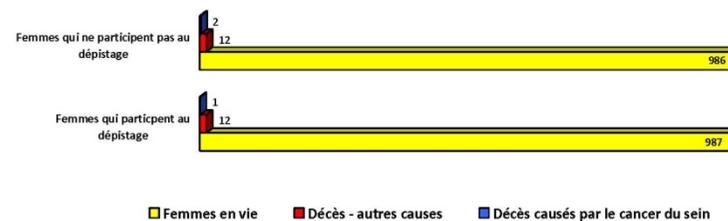
- 981 femmes n'auront pas le cancer du sein
 - 451 femmes obtiendront des résultats normaux
 - 549 femmes obtiendront des résultats anormaux à un certain moment au cours des 10 ans
- 533 des résultats anormaux seront de fausses alertes qui se révéleront normaux après un autre examen
- 16 femmes auront un cancer du sein détecté au dépistage

Si nous examinons une fois l'an 1 000 femmes âgées de 40 à 49 ans pendant une période de 10 ans:

- Un décès attribuable au cancer du sein sera évité
- 12 femmes mourront d'une cause autre que le cancer du sein
- 2 femmes mourront du cancer du sein malgré le dépistage

Quelle sera alors la probabilité de mourir du cancer du sein?

Comparaison des décès chez 1 000 femmes âgées de 40 à 49 ans qui participent et qui ne participent pas au dépistage



Les barres indiquent que le décès attribuable au cancer du sein est rare. Le dépistage permet d'éviter un décès causé par le cancer du sein parmi 1000 femmes âgées de 40 à 49 ans qui participent au dépistage chaque année.

Source: Agence de la santé publique du Canada. Renseignements sur la mammographie à l'intention des femmes de 40 ans et plus: Un outil d'aide à la prise de décision pour le dépistage du cancer du sein au Canada. 2009.

Détection précoce du cancer de la prostate

Chiffres pour les hommes à partir de 50 ans.

Hommes ayant participé à un dépistage et hommes n'ayant pas participé à un dépistage

	1000 hommes non dépistés	1000 hommes dépistés
Avantages		
Combien d'hommes décédèrent du cancer de la prostate ?	8*	8
Combien d'hommes décédèrent d'une autre cause ?	200	200
Désavantages		
Combien d'hommes eurent un diagnostic positif et furent traités inutilement pour le cancer de la prostate ?**	-	20
Combien d'hommes sans cancer eurent une fausse alerte et une biopsie ?	-	180

* Ceci signifie que 8 hommes sur 1000 (âgés de plus de 50 ans) non dépistés décédèrent du cancer de la prostate dans les 10 ans.

** Par exemple ablation de la prostate ou rayons, ce qui peut mener à l'incontinence ou l'impuissance.

Source: Adapted from Djulbegovic M, Beyth RJ, Neuberger MM, Stoffs TL, Vieweg J, Djulbegovic B, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials *BMJ* 2010 Sep 14;341:c4543

Appendix 4.5. Exercise of value clarification used in the focus groups (women)

Appendix 4.5.1. Dutch-speaking

Persoonlijk werkblad

Dit werkblad helpt u om enkele belangrijke overwegingen te maken alvorens u beslist om deel te nemen aan een preventieve mammografie. Deze oefening zegt u niet welke beslissing u moet nemen. Ze wil u enkel helpen om er vooraf grondig over na te denken. Vul dit blad in en richt u zich tot uw arts indien u er graag verder met iemand over praat. Dit werkblad helpt u om uw gedachten te ordenen

Stap 1 – Hoe hoog schat u uw persoonlijk risico in op borstkanker en op gezondheidsproblemen in het algemeen?

Hoe bezorgd bent u over de kans om zelf borstkanker te krijgen?

- zeer bezorgd
 een beetje bezorgd
 onbezorgd

Hoe beoordeelt u uw eigen gezondheid?

- ik ben in goede gezondheid
 mijn gezondheid is middelmatig
 ik ben ongezond

Stap 2 – Wat doet u om de gezondheid van uw borsten te bewaken?

Laat u uw borsten regelmatig onderzoeken door een specialist?

- ja
 nee

Onderging u tijdens de voorbije twee jaar een mammografie?

- ja
 nee

Beperkt u uw alcoholgebruik tot één glas per dag?

- ja
 nee

Heeft u een gezond lichaamsgewicht?

- ja
 nee

Doet u minstens vier keer per week aan lichaamsbeweging (snelwandelen, zwemmen, ... gedurende dertig tot zestig minuten)?

- ja
 nee



Stap 3 — De voor- en nadelen van een mammografie

Overloop de verschillende voordelen en ongemakken van een mammografie. Voeg eventuele andere voordelen en ongemakken toe. Vink de belangrijkste voordelen en ongemakken aan (☑).

mogelijke voordelen	mogelijke ongemakken
gemoedsrust	mogelijkheid dat de kanker toch niet opgespoord wordt
opsporing van kanker in een vroeg stadium waardoor makkelijker te behandelen	bijkomende onderzoeken en ongerustheid bij een 'vals alarm'
minder risico om te sterven aan kanker	geen enkele invloed op levensduur, levenskwaliteit en onnodige diagnose
andere voordelen	andere ongemakken

Stap 4 — Wat denkt u van een preventieve mammografie?

Kies de stelling die het best aansluit bij uw mening:

- ik wil in de toekomst (nog) graag dergelijke screenings voor mezelf
- ik twijfel of ik in de toekomst (nog) graag dergelijke screenings voor mezelf wil
- ik wil in de toekomst geen dergelijke screenings (meer) voor mezelf

Stap 5 — Wie moet er beslissen of u al dan niet een preventieve mammografie moet ondergaan?

- ikzelf, nadat ik daarover nagedacht heb of er met mijn arts over gesproken heb
- ik wil dit samen met mijn arts beslissen
- ik wil dat mijn arts daarover beslist
- ik weet het niet

Stap 6 — Welke bijkomende vragen over borstkankerscreening heeft u? Schrijf ze hier neer:

Stap 7 — U kunt dit werkblad voorleggen aan uw arts

Appendix 4.5.2. French-speaking

Feuille de travail personnelle

Cette feuille de travail a pour but de vous aider à examiner les éléments importants lorsque vous prenez une décision concernant les mammographies de dépistage. Elle n'a pas pour objet de vous dire quoi faire exactement. Il s'agit simplement de vous aider à bien réfléchir à la question.

Veillez remplir la feuille de travail et, si vous estimez devoir en discuter davantage, alors adressez-vous à votre professionnel de la santé.

La feuille de travail vous aidera à organiser vos idées en passant en revue ce qui suit :

ÉTAPE 1 : À combien établissez-vous votre risque à l'égard du cancer du sein et de votre santé en général?

Comment vous sentez-vous à l'égard de votre risque de cancer du sein?

- Très inquiète
- Un peu inquiète
- Pas inquiète

Comment évaluez-vous votre santé en général?

- Je suis en bonne santé
- Ma santé est correcte
- Je suis en mauvaise santé

ÉTAPE 2 : Que faites-vous pour la santé de vos seins?

Vous faites-vous examiner les seins par un professionnel de la santé dans le cadre de votre examen médical périodique?

- Oui
- Non

Avez-vous subi une mammographie de dépistage au cours des deux dernières années?

- Oui
- Non

Limitez-vous votre consommation d'alcool à une consommation ou moins par jour?

- Oui
- Non

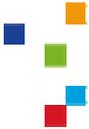
Avez-vous un poids santé?

- Oui
- Non

Faites-vous de l'exercice modérément au moins quatre fois par semaine (par exemple la marche rapide ou la natation pendant 30 à 60 minutes, quatre fois par semaine)?

- Oui
- Non

Source: Agence de la santé publique du Canada. Renseignements sur la mammographie à l'intention des femmes de 40 ans et plus: Un outil d'aide à la prise de décision pour le dépistage du cancer du sein au Canada. 2009.



ÉTAPE 3 : Les avantages et les inconvénients potentiels de subir des mammographies

Examinez chacun des avantages et des inconvénients. Ajoutez d'autres avantages et inconvénients importants pour vous. Déterminez l'importance de chacun en les cochant (✓).

Avantages potentiels	Inconvénients potentiels
Tranquillité d'esprit	Possibilité que le cancer ne soit pas détecté
Dépistage du cancer à un stade précoce et traitement plus simple	D'autres examens et l'inquiétude suscitée par les fausses alertes
Moins de risque de mourir du cancer du sein	Aucune amélioration de la longévité ou de la qualité de vie et diagnostic inutile
Autres avantages	Autres inconvénients

ÉTAPE 4 : Que pensez-vous des mammographies de dépistage?

Choisissez l'énoncé qui correspond à ce que vous pensez:

- Je veux commencer ou continuer de subir des mammographies
- Je ne suis pas certaine
- Je ne veux pas commencer ou continuer de subir des mammographies

ÉTAPE 5 : Qui devrait décider si vous devez commencer ou continuer de subir des mammographies?

- Moi, après avoir réfléchi au conseil que j'ai reçu de mon professionnel de la santé
- Je veux partager la prise de décision avec mon professionnel de la santé
- Je veux que mon professionnel de la santé décide
- Je ne suis pas certaine

ÉTAPE 6 : Quelles questions vous posez-vous concernant le fait de commencer ou de continuer de subir des mammographies? Inscrivez-les ici

ÉTAPE 7 : Vous pourriez souhaiter montrer cette feuille de travail à votre professionnel de la santé.

Source: Agence de la santé publique du Canada. Renseignements sur la mammographie à l'intention des femmes de 40 ans et plus: Un outil d'aide à la prise de décision pour le dépistage du cancer du sein au Canada. 2009.

Appendix 4.6. Questions that women have about breast cancer screening

Principal questions of the participants regarding breast cancer screening

- Is breast cancer screening harmful? (pressure on breast? x-rays?)
- What happens during breast cancer screening?
- Does it hurt? (each time)
- How often should one be screened? (is every 2 years sufficient?)
- Is breast cancer screening really useful (benefits)?
- What is breast cancer screening?
- Is a mammogram sufficient (why only mammogram)?
- What happens once you're too old (70+)? (Why no screening after 70?)
- When should one undergo breast cancer screening because of risk of cancer (family antecedents, pain...)?
- Is breast cancer screening reliable?
- Results: When do I get them ? (how long does it take?)
- What is the risk of getting breast cancer? (after 70?)
- Does breast cancer screening find every cancer?
- Are there statistics about screening results?
- Are there different (other) ways of screening?
- Practical: How long does it take?
- Practical: Where do I go for breast cancer screening? (are some places better than others?)
- Results: who are they sent to?
- Who is offered breast cancer screening? (why me?)
- What can one do to prevent cancer?
- Has early detection of breast cancer an impact on beating it?
- What is a mammogram?
- Practical: How should one prepare oneself?
- Practical: How long before getting an appointment?

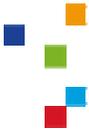


- Practical: How much does it cost?
- Results: What are the possible results?
- Result: What happens if breast cancer is found?
- Can you ask to be screened or do you have to wait to be invited?

17 – Principal questions of the participants regarding breast cancer screening, per age group

	Age 40-49	Age 50-69	Age 70-75	Non screened
1	Is breast cancer screening harmful?	How often should one be screened?	Is breast cancer screening harmful?	Is breast cancer screening harmful?
2	What happens during breast cancer screening?	Is breast cancer screening harmful?	Does it hurt?	What is the risk of getting breast cancer? (after 70)
3	Does it hurt?	What happens during breast cancer screening?	What happens once you're too old?	What happens once you're too old?
4	What is breast cancer screening?	Does it hurt?	What happens during breast cancer screening?	Is breast cancer screening really useful?
5	Does breast cancer screening find every cancer?	Is breast cancer screening really useful?	When should one be screened because of risk	Does breast cancer screening find every

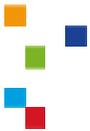
			of cancer?	cancer?
6	How often should one be screened?	Is a mammogram sufficient?	Is breast cancer screening reliable?	What happens during breast cancer screening?
7	Is breast cancer screening really useful?	When should one be screened because risk of cancer?	Is breast cancer screening really useful?	Who is offered breast cancer screening?
8	Is a mammogram sufficient?	Are there statistics about screening results?	Is a mammogram sufficient?	How long does a breast cancer screening take ?
9	Is breast cancer screening reliable?	Where do I go for breast cancer screening? Are some places better?	When does one get the results?	Does it hurt?
10	When does one get the results?	What is breast cancer screening?	What is the risk of getting breast cancer? (after 70)	How should one prepare oneself?



APPENDIX 5. PRACTITIONERS' PERSPECTIVE

Appendix 5.1. Interviewgids focusgroep artsen

Q	Formulering / Hoofdonderwerp	Herstel
	Inleiding	
1	Om te beginnen wil ik u vragen om u, in het kort, voor te stellen:	<ul style="list-style-type: none">• Wie bent u ?• Bent u huisarts of gynaecoloog ?• Waar werkt u (plaats+ type praktijk)• Sinds hoelang oefent u uw beroep uit ?
2	Wanneer wij u gecontacteerd hebben om deel te nemen aan deze studie, wat was uw reactie?	<ul style="list-style-type: none">• Thema• Processus
3	In het algemeen, hoe komt u ertoe te spreken over borstkankerscreening met een patiënte?	<ul style="list-style-type: none">• Type van patiënte, leeftijd• Verband met het screeningprogramma• Gebeurtenis in de omgeving• Mediacampagne• Vrijwillig voorstel van uwentwege (zo ja, aan wie stelt u dit voor ?)• ...
4	Welke zijn de vragen die deze patiënten stellen betreffende borstkankerscreening?	<ul style="list-style-type: none">• Mortaliteitsrisico's met betrekking tot borstkanker en in vergelijking met andere risico's• Risico's van behandeling en de gevolgen (mastectomie, behandeling door geneesmiddelen, stralingen)• Betrouwbaarheid van de test• Praktische aspecten• Risico's met betrekking tot de screening (bestraling ? Risico van vergissing: vals + en vals -?)• ...
5	Over welke informatie beschikt u om hen te antwoorden?	<ul style="list-style-type: none">• Wetenschappelijke artikels• Statistische gegevens



		<ul style="list-style-type: none">• (door ...)• Folder• Rapporten/ guidelines• Informaties van het georganiseerd programma• Andere
6	Hoe evalueert u deze informatie?	<ul style="list-style-type: none">• Kwaliteit• Gebruiksvriendelijkheid• Kwantiteit• Duidelijkheid• Eenvoud
7	Welke informatie ontbreekt u eventueel?	<ul style="list-style-type: none">• Inhoud• Format (grafieken, visueel, foto's, schema's, enz.)
8	In het algemeen, hoe voelt u zich met betrekking tot hun vragen? (voorbeelden)	<ul style="list-style-type: none">• Eenvoudig/moeilijk aan te snijden onderwerp• Op uw gemak met de statistische gegevens en de uitleg erover• Helder beeld van wat hen te doen staat
9	Globaal gezien, welke zijn de punten met betrekking tot de communicatie rond borstkankerscreening die u zou willen verbeterd zien?	<ul style="list-style-type: none">• inhoud• format
10	Welke suggesties zou u willen formuleren om de communicatie naar de vrouwen toe te verbeteren?	<ul style="list-style-type: none">• inhoud• format
11	Indien wij u neutrale berichten geven betreffende borstkankerscreening, met inbegrip van de voor- en nadelen voor vrouwen van 40 tot 75 jaar. Hoe denkt u deze berichten te gebruiken (of niet)?	Voorbeeld van een Canadees DA
12	Suggesties? Andere punten die moeten worden behandeld?	

Dankbetuigingen en slot



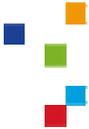
Appendix 5.2. Guide d'entretien focus group médecins

Q	Libellé / sujet principal	Relance
Introduction		
1	Pour commencer j'aimerais que vous vous présentiez brièvement:	<ul style="list-style-type: none">• qui êtes-vous• vous êtes MG ou gynéco• Où travaillez-vous (lieu + type de pratique)• Depuis combien de temps exercez-vous ?
2	Quand nous vous avons contacté pour participer à cette étude, quelle a été votre réaction ?	<ul style="list-style-type: none">• Thème• Processus
3	De manière générale, comment en venez-vous à discuter du dépistage du cancer du sein avec une patiente ?	<ul style="list-style-type: none">• Type de patiente, âge• Lien avec le programme de dépistage• Événement dans l'entourage• Campagne médiatique• Proposition spontanée de votre part (si oui à qui proposez-vous ?)• ...
4	Quelles sont les questions que vous posez alors ces patientes sur le dépistage du cancer du sein ?	<ul style="list-style-type: none">• Risques de mortalité liée au cancer du sein et par rapport aux autres risques• Risques de traitement et conséquences (mastectomie, traitement médicamenteux, rayons)• Fiabilité du test• Aspects pratiques• Risques liés au dépistage (irradiation? Risque d'erreur: faux + et faux - ?)• ...
5	De quelles informations disposez-vous pour leur répondre ?	<ul style="list-style-type: none">• Articles scientifiques• Données statistiques (produites par ...)• Folder• Rapports / guidelines



	<ul style="list-style-type: none">• Infos du programme organisé• Autre
6	Comment évaluez-vous ces informations ? <ul style="list-style-type: none">• Qualité• Facilité d'utilisation• quantité• clareté• simplicité
7	Quelles informations vous manquent éventuellement ? <ul style="list-style-type: none">• Contenu• Format (graphiques, visuels, photos, schémas, etc.)•
8	De manière générale, comment vous sentez-vous par rapport à leurs questions ? (exemples) <ul style="list-style-type: none">• Sujet facile / difficile à aborder• A l'aise avec les données statistiques et leur explicationIdée claire de ce qu'elles doivent faire
9	Globalement quels sont les points liés à la communication autour du dépistage du cancer du sein que vous souhaiteriez voir améliorer ? <ul style="list-style-type: none">• contenu• format
10	Quelles suggestions pourriez-vous formuler pour améliorer la communication envers les femmes ? <ul style="list-style-type: none">• contenu• format
11	si nous vous donnons des messages neutres sur le dépistage du cancer du sein, en ce compris les bénéfices et les inconvénients pour les femmes de 40 à 75 ans. Comment pensez-vous utiliser (ou pas) ces messages ? Exemple du DA canadien
12	Suggestions ? Autres points à aborder ?

Remerciement et clôture



APPENDIX 6. CINICAL EVIDENCE - REVIEW OF RCTS STUDIES

Appendix 6.1. PICO

Benefit

- *Patient*: women between 50 and 69 years without breast cancer symptom and without high risk of breast cancer
- *Intervention*: organized screening
- *Comparison*: usual care
- *Outcomes*: mortality (all causes and specific), morbidity (mastectomy partial or complete)

Harms

- *Patient*: women between 50 and 69 years without breast cancer symptom and without high risk of breast cancer
- *Intervention*: organized screening
- *Comparison*: usual care
- *Outcomes*: diagnosis or therapeutics radiation side effects, additional diagnosis tests, true positive, true negative, over diagnosis and over treatment.

Appendix 6.2. Systematic reviews (SR) and meta analyses (MA)

A broad search of electronic databases (MEDLINE, EMBASE, CDSR) was conducted in february 2013.

Appendix 6.2.1. Search for SR and MA

Search questions	Benefit and harms of mammography screening (70-74 y)	
Note	Specific search for systematic reviews and meta-analysis Update of KCE report 11 (search date 2004).	
Date	2013/02/07 on OVID Ovid MEDLINE(R)	
Keywords	Breast neoplasms (MESH) and mass screening (or early detection) (MESH) and mammography (MESH)	
MEDLINE (OVID):	1. meta-analysis.pt,ti,ab,sh. (45518)	21
Filter	2. 1 or (meta anal\$ or metaanal\$).ti,ab,sh. (56845)	
SR or M-A	3. (methodol\$ or systematic\$ or quantitativ\$).ti,ab,sh. (499224)	
	4. ((methodol\$ or systematic\$ or quantitativ\$) adj (review\$ or overview\$ or survey\$)).ti,ab,sh. (39228)	
	5. (MEDLINE or Embase or index medicus).ti,ab. (44094)	
	6. ((pool\$ or combined or combining) adj (data or trials or studies or results)).ti,ab. (8792)	
	7. 6 or 4 or 3 or 5 (530702)	
	8. 7 and review.pt,sh. (104506)	
	9. 8 or 2 (143689)	
	10. Case report.tw. (104528)	
	11. Letter.pt. (454859)	
	12. Historical article.pt. (119600)	
	13. Review of reported cases.pt. (0)	
	14. Review,multicase.pt. (0)	
	15. or/10-14 (671198)	

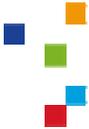


- 16. 9 not 15 (140150)
- 17. Breast/ or Breast Diseases/ (15776)
- 18. Neoplasms/ (133631)
- 19. 17 and 18 (120)
- 20. exp Breast Neoplasms/ (127431)
- 21. (breast\$ adj5 neoplas\$).tw. (1510)
- 22. (breast\$ adj5 cancer\$).tw. (116701)
- 23. (breast\$ adj5 carcin\$).tw. (20936)
- 24. (breast\$ adj5 tumo\$).tw. (20027)
- 25. (breast\$ adj5 metasta\$).tw. (13740)
- 26. (breast\$ adj5 malig\$).tw. (5506)
- 27. exp Carcinoma, Ductal, Breast/ (9496)
- 28. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 (157471)
- 29. mammography.mp. (16782)
- 30. Mammography/ (14054)
- 31. 29 or 30 (16782)
- 32. mass screening.mp. or Mass Screening/ (50868)
- 33. early detection of cancer.mp. or "Early Detection of Cancer"/ (5130)
- 34. 32 or 33 (54862)
- 35. 16 and 28 and 31 and 34 (171)
- 36. limit 35 to (female and humans and yr="2004 -Current" and "all adult (19 plus years)" and (dutch or english or french)) (41)
- 37. from 36 keep 1-41 (41)

('mammography'/exp/mj OR 'mammography'/exp) AND ([meta analysis]/lim OR [systematic review]/lim) AND ([dutch]/lim OR [english]/lim OR [french]/lim) AND [female]/lim AND [Embase]/lim AND [2004-2013]/py

CDSR Breast neoplasms) and (early detection or mass screening) and mammography, from 2004 to 2013 in Cochrane Reviews 3
07/02/2013

Embase 'cancer screening'/exp/mj OR 'cancer screening'/exp AND ('breast cancer'/exp/mj OR 'breast cancer'/exp) AND 43
07/02/2013



Appendix 6.3. Randomised control trials

A rapid search of MEDLINE and EMBASE was conducted in February 2013.

Appendix 6.3.1. Search for RCTs

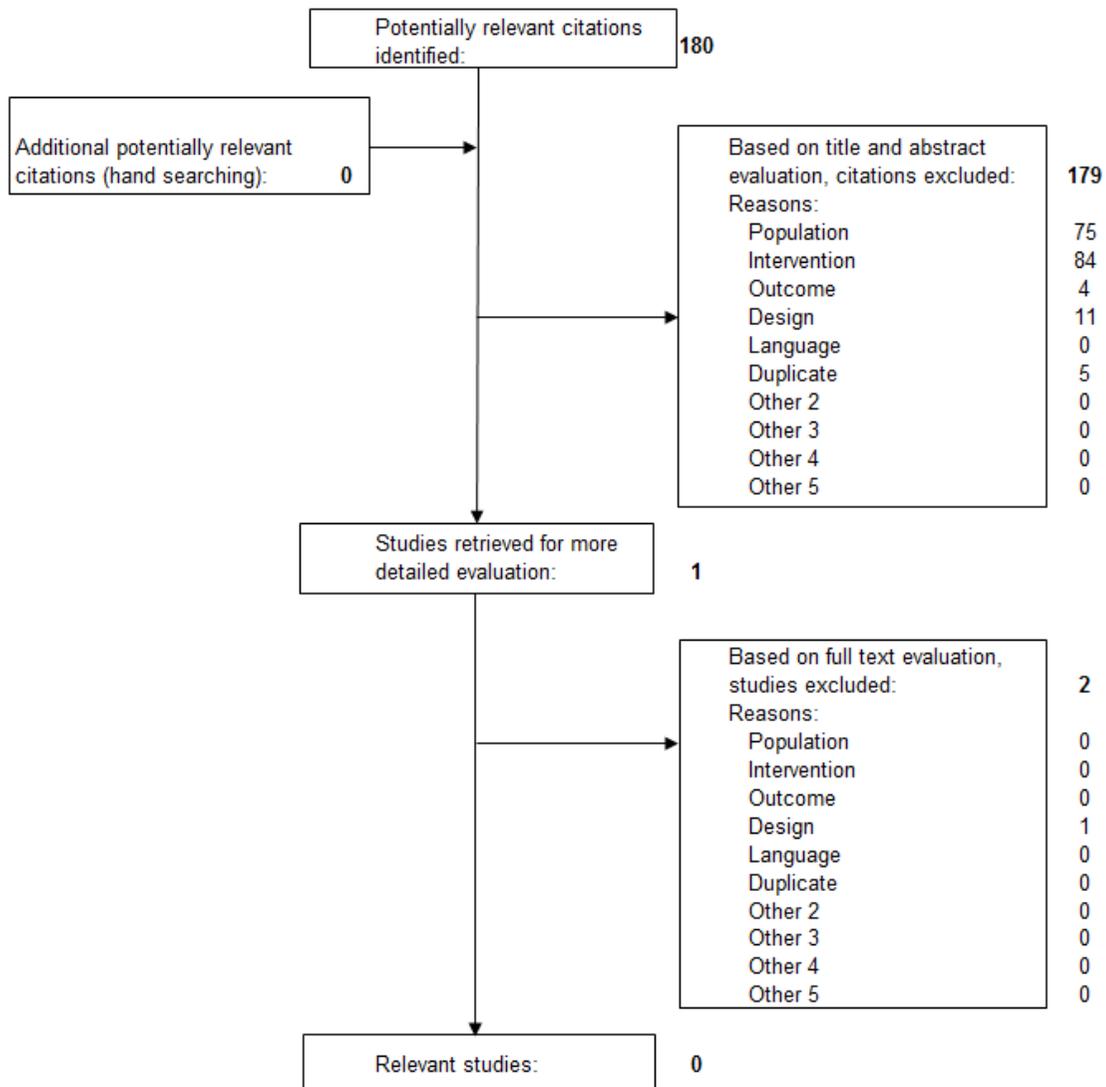
Search questions	Benefit and harms of mammography screening
Note	Specific search for randomised control trials Update of Cochrane SR ⁶⁸ (search date Nov 2008)
Date	2013/04/27 on Ovid MEDLINE(R) <2007 to February 2013>
Keywords	Breast neoplasms (MESH) and mass screening (or early detection) (MESH) and mammography (MESH)
MEDLINE (OVID):	<ol style="list-style-type: none"> 1. Mass screening.m_titl./ 2. *Mass Screening/ 3. 1 or2/ 4. mammography.m_titl./ 5. *Mammography/ 6. 4 or 5 7. 6 or 3 8. breast neoplasm.m_titl/ 9. *Breast Neoplasms/ 10. 8 or 9 11. 7 and 10 11. Randomized controlled trials/ 12. Randomized controlled trial.pt. 13. Random allocation/ 14. Double blind method/ 15. Single blind method/ 16. Clinical trial.pt. 17. exp clinical trial/

18. or/11-17
19. (clinic\$ adj trial\$.tw.
20. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3)).tw.
21. Placebos/
22. Placebo\$.tw.
23. Randomly allocated.tw.
24. (allocated adj2 random).tw.
25. or/19-24
23. 18 or 25
26. Case report.tw.
27. Letter.pt.
28. Historical article.pt.
29. Review of reported cases.pt.
30. Review,multicase.pt.
31. or/26-30
32. 25 not 31
31. 11 and 32
32. limit 31 to (yr="2007 -Current" and (dutch or english or french))

Embase 27/02/2013	'cancer screening'/exp/mj OR 'cancer screening'/exp AND ('breast cancer'/exp/mj OR 'breast cancer'/exp) AND ('mammography'/exp/mj OR 'mammography'/exp) AND ([controlled clinical trial]/lim OR [randomized controlled trial]/lim) AND ([dutch]/lim OR [english]/lim OR [french]/lim) AND [female]/lim AND [Embase]/lim AND [2007-2013]/py	64
--------------------------	--	----

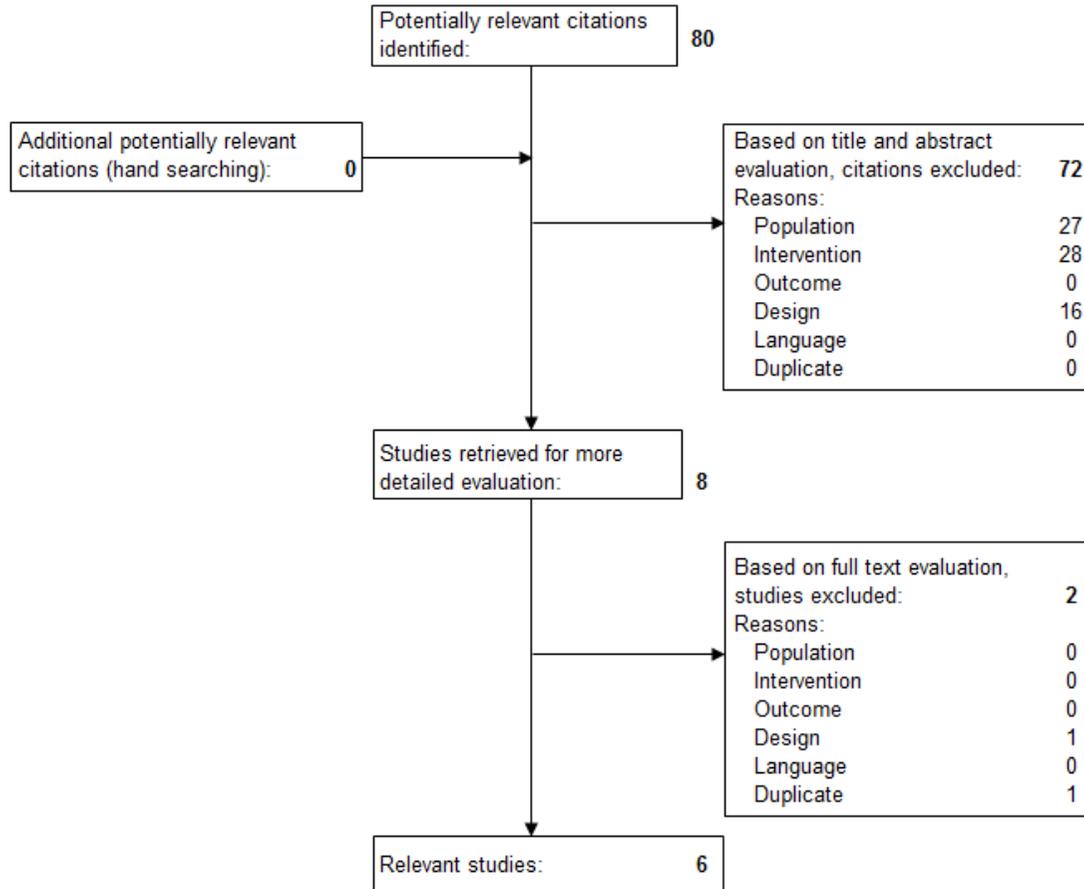


Appendix 6.4. Flow diagram for systematic reviews (SR) and meta analyses (M-A)





Appendix 6.5. Flow diagram for randomised control trials





Appendix 6.6. Quality Appraisal

Appendix 6.6.1. Systematic reviews and meta-analyses

Items	Bisheuvel	Götzsche	Jorgensen	Nelson	Virnig
Search date	Dec 2006	Nov 2008	April 2007	Dec 2008	Jan 2009
Intervention	Incidence in screened population	Breast cancer screening	Incidence in screened population	Breast cancer screening	DCIS in screened population
Controle	Incidence in unscreened population	No breast cancer screening	Incidence in unscreened population	No breast cancer screening	DCIS in unscreened population
1	Yes	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes	Yes	Yes
3	Yes	Yes	Yes	Yes	Yes
4	+/-	Yes	Yes	+/-	Yes
5	Yes	Yes	Yes	Yes	Yes
6	Yes	Yes	Yes	Yes	Yes
7	-	Yes	Yes	Yes	Yes
8	-	Yes	Yes	Yes	Yes
9	Yes	Yes	Yes	Yes	Yes
Comment	Good quality	High quality	High quality	High quality	High quality

Legend of items 1 to 9 of the quality appraisal:

1. Is de vraagstelling adequaat geformuleerd?
2. Is de zoekactie adequaat uitgevoerd?
3. Is de selectieprocedure van artikelen adequaat uitgevoerd?
4. Is de kwaliteitsbeoordeling adequaat uitgevoerd?
5. Is adequaat beschreven hoe data-extractie heeft plaatsgevonden?
6. Zijn de belangrijkste kenmerken van de oorspronkelijke onderzoeken beschreven?
7. Is adequaat omgegaan met klinische en statistische heterogeniteit van de onderzoeken?
8. Is statistische pooling op een correcte manier uitgevoerd?
9. Zijn de resultaten van de systematische review valide en toepasbaar?



Appendix 6.6.2. Systematic reviews from EUROSCREEN

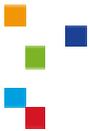
Author	1 a prior design	2. two independent data extractors	3 comprehensive literature search	4 publication status	5 list included excluded studies	6 characteristics included studies	7 quality assessment	8 scientific quality in formulating conclusions	9 methods to combine studies	10 publication bias	11 conflict of interest	Included	
Broede rs, 2012	Yes	Yes	Cannot answer	No	Yes	Yes	Yes	No	No	Yes	No	Yes	Yes
Njor, 2012	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	Yes	No	Cannot answer	Yes

Appendix 6.7. Data extraction table

Appendix 6.7.1. Specific mortality reduction

Systematic review

Reference	Methodology	Patient characteristics	Intervention(s)	Results primary outcome	Critical appraisal of review quality
Götzsche⁶⁸	<ul style="list-style-type: none"> SR Funding: Danish Institute for HTA Search date: Nov 2008 Databases: Pubmed + search on author names in the author field Study designs: RCT 	<ul style="list-style-type: none"> Eligibility criteria: Women without previously diagnosed breast cancer. Patient characteristics: <ul style="list-style-type: none"> - Women aged 39 to 74 years 	Screening (annually or biennially) vs Routine care	<ul style="list-style-type: none"> Specific mortality reduction Follow up 13 y: Adequately randomised: RR: 0.90 (0.79, 1.02) Suboptimally randomised: RR: 0.75 (0.67, 0.83) All:	Level of evidence: <ul style="list-style-type: none"> High Distinction between adequately randomised and suboptimally randomised trials



- N included studies: 9
(New York/HIP, Malmö I and II, Two County, Canada a and b, Stockholm, Göteborg, UK Age trial)
 - Intervention group: N = 298 552
 - Control group:
 - N = 309 538
- RR: 0.81(0.74, 0.87)

Götzsche (subgroup patients > 50y)⁶⁸

- | | | | | |
|--|---|---|--|--|
| <ul style="list-style-type: none"> • SR • Funding: Danish Institute for HTA • Search date: Nov 2008 • Databases: Pubmed + search on author names in the author field • Study designs: RCT • N included studies: 8
<i>(New York/HIP, Malmö I and II, Two County, Canada a and b, Stockholm, Göteborg)</i> • Intervention group: N = 146 284 • Control group: • N = 122 590 | <ul style="list-style-type: none"> • Eligibility criteria: Women without previously diagnosed breast cancer. • Patient characteristics:
- Women aged 50 to 74 years | <p>Screening (annually or biennially)</p> <p>vs</p> <p>Routine care</p> | <ul style="list-style-type: none"> • Specific mortality reduction <p>Follow up 13 y:</p> <p>Adequately randomised: RR: 0.94 (0.77, 1.15)</p> <p>Suboptimally randomised: RR: 0.70 (0.62, 0.80)</p> <p>All: RR: 0.77(0.69, 0.86)</p> | <p>Level of evidence:</p> <ul style="list-style-type: none"> • High <p>Distinction between adequately randomised and suboptimally randomised trials</p> |
|--|---|---|--|--|



Appendix 6.7.2. All- cause mortality reduction

Systematic review

Reference	Methodology	Patient characteristics	Intervention(s)	Results primary outcome	Critical appraisal of review quality
Götsche⁶⁹	<ul style="list-style-type: none"> SR Funding: Danish Institute for HTA Search date: Nov 2008 Databases: Pubmed + search on author names in the author field Study designs: RCT N included studies: 4 <i>(Malmö / Canada, Kopparberg, Stertgland)</i> Intervention group: N = 94 387 Control group: N = 77 508 	<ul style="list-style-type: none"> Eligibility criteria: Women without previously diagnosed breast cancer. Patient characteristics: - Aged 40-74 	<p>Screening (annually or biennially)</p> <p>vs</p> <p>Routine care</p>	<ul style="list-style-type: none"> All-cause mortality reduction <p>Follow up 13 y:</p> <p>Adequately randomised (N = 73 654): RR: 1.00 (0.95, 1.04)</p> <p>Suboptimally randomised(N=98 261): RR: 0.99 (0.97, 1.02)</p>	<p>Level of evidence: High</p> <ul style="list-style-type: none"> Underpowered to detect an all-cause mortality reduction

*Appendix 6.8.1. False positive and false negative mammography results***Systematic review**

Reference	Methodology	Findings	Critical appraisal of review quality
Nelson⁷⁰	<ul style="list-style-type: none">• Data analysis• Sources: Breast Cancer Surveillance Consortium (USA-BCSC)• Years: 2000 to 2005	<ul style="list-style-type: none">• Women aged 70-79:<ul style="list-style-type: none">○ False positive results: 68.8 per 1000 women per screening round○ False negative results: 1.5 per 1000 women per screening round○ Additional imaging: 64.03 per 1000 women per screening round○ Biopsy rates: 12.2 per 1000 women per screening round○ Screen-detected invasive cancer: 6.5 per 1000 women per screening round○ Screen-detected DCIS: 1.4 per 1000 women per screening round	



Appendix 6.9.1. Over-diagnosis

Reference	Study	Type of study	Findings Women aged 40-79:	Range
Nelson⁷¹	<ul style="list-style-type: none"> Paci, 2006 Olsen, 2006 Duffy, 2005 	Modelled estimations	Rates of overdiagnosis	Less than 1%
	<ul style="list-style-type: none"> Zahl, 2004 	Modelled estimations	Rates of overdiagnosis	30%
	<ul style="list-style-type: none"> De Koning, 2006 	Modelled estimations	Rates of overdiagnosis	Between 1 and 10%
Götzsche⁷²	<ul style="list-style-type: none"> Shapiro, 1977, Shapiro, 1982, Shapiro, 1989 	Review	Level of overdiagnosis in the trials that did not introduce early screening	30%
	<ul style="list-style-type: none"> Baratt 2005; Douek, 2003; Fletcher, 2003; Götzsche, 2004; Jonsson, 2005; Ries, 2002; WHO, 2002; Zahl, 2004 	Observational studies	Incidence increases of reported for Australia, Finland, Norway, Sweden, UK and USA	40% to 60%
	<ul style="list-style-type: none"> Paci, 2004 	?	Proportion of overdiagnosed cases	5%
	<ul style="list-style-type: none"> Olsen, 2003 	?	No overdiagnosis	



Biesheuvel

Type of study	Study	Estimations of overdetetection as reported by primary author (CI)	Recalculated by reviewer as %	Remarks
Estimates of overdetetection in included studies using the cumulative-incidence method (definition in chap 4)				
RCT	Two County (Moss)	ARD: - 0.13 (-0.29 to 0.04) per 1000 women years (women aged 40-74)	5.1	ARD: absolute risk difference
Population based programme	Paci (Italy)	RR: 109.7% (105-115) (women aged 70-74)	9.7	RR: relative risk Period: 1990-1999
Estimates of overdetetection in included studies using the incidence rate method (definition in chap 4)				
Population based programme	Zahl (Sweden)	RR: 1.01 (0.96-1.05) (women aged 70-74)	1	
Population based programme	Zahl (Norway)	RR: 0.89 (0.70-1.12) (women aged 70-74)	-11	
Population based programme	Jonsson (Sweden) Initial phase	RR: 1.84 (1.50-2.24) (women aged 70-74)	84	Considered by reviewer as least biased estimation
Population based programme	Jonsson (Sweden) Stabilized phase	RR: 1.03 (0.82-1.30) (women aged 70-74)	3	

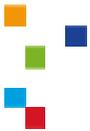


Jorgensen

Reference	Type of study	Publicly organised screening programmes	Modelled risk ratios	Remarks
Jörgensen⁷³	SR of observational studies, meta-analysis + modelling	England and Wales	1.57 (1.53 to 1.61)	<ul style="list-style-type: none"> • DCIS were included or estimated at 10% of diagnosis • Most common age range: 50-69 y.
		Manitoba, Canada	1.44 (1.25 to 1.65)	
		New South Wales, Australia	1.53 (1.44 to 1.63)	
		Sweden	1.46 (1.40 to 1.52)	
		Norway	1.52 (1.36 to 1.70)	
		Overall (pooled analysis)	1.52 (1.46 to 1.58)	

Appendix 6.9.2. DCIS

Reference	Methodology	Findings	Critical appraisal of review quality
Virnig⁷⁴	<ul style="list-style-type: none"> • SR • Funding: AHRQ (Agency for Healthcare Research and Quality, USA) • Search date: Jan 2009 • Databases: MEDLINE, and others • Study designs: observational • N included studies: 63 	All breast cancer patient: DCIS incidence rose there from 1.87 per 100 000 in 1973–1975 to 32.5 in 2004.	Level of evidence: High



Appendix 6.10.1. Overtreatment

Systematic review

Reference	Methodology	Patient characteristics	Intervention(s)	Results primary outcome	Critical appraisal of review quality
Götzsche	<ul style="list-style-type: none"> SR Funding: Danish Institute for HTA Search date: Nov 2008 Databases: Pubmed + search on author names in the author field Study designs: RCT N included studies: 8 <i>(New York/HIP, Malmö I and II, Two County, Canada a and b, Stockholm, Göteborg)</i> Intervention group: N = 145 536 Control group: N = 104 943 	<ul style="list-style-type: none"> Eligibility criteria: Women without previously diagnosed breast cancer. Patient characteristics: - Median age: 39-74 	Screening (annually or biennially) vs. Routine care	<ul style="list-style-type: none"> Number of mastectomies and lumpectomies Adequately randomised: RR: 1.31 (1.22, 1.42) Suboptimally randomised: RR: 1.42 (1.26, 1.61) All: RR: 1.35 (1.26, 1.44)	Level of evidence: <ul style="list-style-type: none"> High Distinction between adequately randomised and suboptimally randomised trials



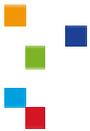
APPENDIX 7. CINICAL EVIDENCE - REVIEW OF OBSERVATIONAL STUDIES

Trying to value the current population based screening in Europe, we choose to restrict our analysis on publications of the EUROSCREEN Working Group. Two SR were published in October 2012 in the Journal of Medical Screening^{66 67}.

Appendix 7.1. Quality Appraisal

SR done by Broeders⁶⁶

Item	Score	Justification
1. Was an 'a priori' design provided?	Yes	
2. Was there duplicate study selection and data extraction?	Cannot answer	“we “ is not defined
3. Was a comprehensive literature search performed?	No	Pubmed is only cited
4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?	Yes	
5. Was a list of studies (included and excluded) provided?	No	No list of excluded publications
6. Were the characteristics of the included studies provided?	Yes	See table 2
7. Was the scientific quality of the included studies assessed and documented?	No	
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	No	
9. Were the methods used to combine the findings of studies appropriate?	Yes	
10. Was the likelihood of publication bias assessed?	No	
11. Was the conflict of interest included?	Yes for SR No for each study	

**SR done by Njor⁶⁷.**

Item	Score	Justification
1. Was an 'a priori' design provided?	Yes	
2. Was there duplicate study selection and data extraction?	Yes	
3. Was a comprehensive literature search performed?	No	Only Pubmed is cited
4. Was the status of publication (i.e. grey literature) used as an inclusion criterion?	Yes	
5. Was a list of studies (included and excluded) provided?	No	No list of excluded studies
6. Were the characteristics of the included studies provided?	Yes	
7. Was the scientific quality of the included studies assessed and documented?	No	
8. Was the scientific quality of the included studies used appropriately in formulating conclusions?	No	
9. Were the methods used to combine the findings of studies appropriate?	Yes	
10. Was the likelihood of publication bias assessed?	No	
11. Was the conflict of interest included?	Yes for SR No for included studies	



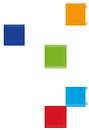
Appendix 7.2. Data extraction table

Reference	Methodology	Patient characteristics	Intervention(s)	Results primary outcome	Critical appraisal of review quality
Broeders⁶⁶	SR of observational studies Funding: Euroscreen Search date: Feb 2011 Databases: Pubmed + publications fulfilling the inclusion criteria were added by the working group Study designs: Trend studies (n 17), IBM* studies (n 20) and CC● studies (n 8)	Eligibility criteria: Women without previously diagnosed breast cancer. Patient characteristics: at least some of the age groups between 50 and 69	Population-based screening programme in Europe	Breast cancer mortality reduction	Level of evidence:
Trend studies	5 descriptions of the trend over time in BCM† in relation to the timing of the introduction of PBS‡, or 12 which included a more detailed analysis quantifying the impact of screening on mortality			Due to varied methodology and comparisons in the studies, no attempt was made to produce a pooled estimate of the effect of screening	
IBM studies	20 IBM studies – one each from Denmark, Norway and Spain, two from Italy, seven from Finland and eight from Sweden	Population is classified by effective screening or by invitation to screening		For invitation to screening:(RR) 0.75 (95% [CI] 0.69–0.81), heterogeneity (P=0.23). For attendance to screening:(RR)0.62 (95% CI 0.56–0.69), (P =0.40).	
Case-control studies	8 CC studies one from Iceland, one from Italy, four from the Netherlands and two from the UK Designs were very similar	Population is classified in women ever screened versus women never screened		For invitation to screening:(OR) 0.69 (95% [CI] 0.57–0.83), heterogeneity (P=0.005). For attendance to screening after adjusting for self-selection:(OR)0.52 (95% CI 0.42–0.65), (P =0.17).	

*IBM: incidence-based mortality, ●CC: case-control, †BCM: breast cancer mortality, ‡PBS: population-based screening



Reference	Methodology	Patient characteristics	Intervention(s)	Results primary outcome	Critical appraisal of review quality
Njor ⁶⁷	SR of incidence-based mortality studies Funding: Euroscreen Search date: March 2011 Databases: Pubmed + publications fulfilling the inclusion criteria were added by the working group 20 IBM* studies: one from Denmark, seven from Finland, two from Italy, one from Norway, one from Spain and eight from Sweden (same studies as Broeders).	Eligibility criteria: Women without previously diagnosed breast cancer. Patient characteristics: at least some of the age groups between 50 and 69	Population-based screening programme in Europe	Breast cancer mortality with follow-up duration: 6–11 years:(RR) 0.74 (95% CI 0.64–0.87). Based on the most methodological sound studies.	Level of evidence:
		Comparison group: women not yet invited		RRs ranging from 0.76 to 0.81, each at borderline statistical significance	
		Comparison group: historical data from the same region or historical data supplemented by current data		RRs ranging from 0.75 to 0.90	
		Comparison group: historical comparison group combined with data for non-participants		RRs ranging from 0.52 to 0.89	



APPENDIX 8. TEST OF THE MESSAGES

Appendix 8.1. First test questionnaire

Appendix 8.1.1. French-speaking questionnaire

Instructions test de lisibilité

Déroulement du test:

1. Utiliser uniquement les pages relatives à l'âge de la répondante
2. La femme âgée de 40 à 74 ans lit le texte à son propre rythme (pas de pression de temps)
3. La femme conserve le texte
4. Les questions sont posées l'une après l'autre à la femme. La femme peut voir la question (à l'aide des feuillets en fin de document)
5. La femme utilise le texte pour répondre aux questions. Elle dispose de tout le temps nécessaire.

Ceci imite la lecture d'un dépliant à la maison. Il ne s'agit pas d'un exercice de mémorisation de l'information, mais un exercice qui vérifie si l'information peut être retrouvée.

Evaluation du test:

- La page correcte = emplacement correct
- La réponse correcte = contenu correct

Évaluation du temps nécessaire pour trouver l'information: à noter uniquement pour les questions pour lesquelles le temps de réponse dépasse le temps moyen de réponse



Nom de la femme:.....

Age:

Dernier diplôme obtenu:

Question	La réponse attendue	Page correcte ?	Réponse correcte ?	Situation de la réponse dans le texte
1. Vous ne vous faites <u>pas dépister</u> . Quelle est la principale cause de décès des femmes de votre âge ?	40-49: autres cancers 50-59: autres cancers 60-69: autres cancers 70-79: autres cancers	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	4. Le risque de mourir
2. Que vous conseillent les autorités belges concernant le dépistage du cancer du sein ?	40-49: déconseille 50-59: conseille 60-69: conseille 70-79: déconseille	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	6. recommandation
3. Vous ne vous faites <u>pas dépister</u> . Quel est votre risque d'avoir le cancer du sein ?	40-49: 20 femmes sur 1000 50-59: 35 femmes sur 1000 60-69: 40 femmes sur 1000 70-79: 31 femmes sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	5. Les suites de
4. Toutes les femmes peuvent avoir le cancer du sein. Mais combien de femmes sur 1000 femmes ont un <u>risque normal</u> d'avoir le cancer du sein ?	935 sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Pour qui est ce texte
5. Votre médecin vous propose de passer en même temps une mammographie et une échographie. Est-ce toujours mieux ?	non	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	3. Comment se passe
6. Vous vous faites dépister. Combien de femmes sur 1000 seront toujours en vie dix ans plus tard ?	40-49: 986 sur 1000 50-59: 966 sur 1000 60-69: 928 sur 1000 70-79: 802 sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	4. Le risque de mourir
7. Est-ce que le dépistage du cancer du sein empêche d'avoir le cancer du sein ?	Non	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	2. Information générale



8. <u>Vous vous faites dépister</u> . Combien de femmes de votre âge sont traitées pour un cancer dormant ?	40-49: 2 femmes sur 1000 50-59: 3 femmes sur 1000 60-69: 4 femmes sur 1000 70-79: 3 femmes sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	5. Les suites de
9. Imaginez que vous ayez fait un dépistage il y a six mois. Pouvez-vous avoir le cancer du sein maintenant ?	oui	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	2. Information générale
10. Vous vous faites dépister. Combien de femmes de votre âge restent en vie grâce au dépistage du cancer du sein ?	40-49: 1 vrouw 50-59: 3 vrouwen 60-69: 4 vrouwen 70-79: 2 vrouwen	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	5. Les suites de
11. Qu'est ce qu'une mammographie?	Une radiographie des seins	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	3. Le dépistage du cancer
12. Pourquoi les médecins traitent-ils également les cancers dormants ?	Ils ne savent pas faire la différence entre les cancers	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	5. Les suites de
13. Imaginez que vous ayez le cancer du sein. Quel est le risque le plus élevé: mourir ou survivre ?	survivre	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	2. Information générale
14. Imaginez que vous avez un risque plus élevé d'avoir le cancer du sein. Que devez-vous faire si envisagez de faire un dépistage du cancer du sein ?	En parler avec son médecin	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Pour qui est ce texte
15. Deux membres de votre famille proche ont eu le cancer du sein. Avez-vous un risque 'plus élevé' d'avoir le cancer du sein ?	oui	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Pour qui est ce texte



Appendix 8.1.2. Dutch-speaking questionnaire

Instructies bij de test

Verloop van de test:

1. De vrouw van tussen 40 en 74 jaar leest de tekst door op eigen ritme (geen tijdsdruk)
2. De vrouw houdt de tekst bij
3. De vragen worden één voor één voorgelegd aan de vrouw. De vrouw mag de vraag zien (met behulp van de bladjes achteraan dit document)
4. De vrouw gebruikt de tekst om de vraag te beantwoorden. Ze mag er zo lang als ze wil over doen

Dit imiteert het lezen van een folder thuis. Het is geen oefening in het memoriseren van informatie, maar een oefening die nakijkt of informatie gevonden wordt

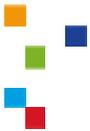
Bedoeling van de test:

- de duidelijkheid van de vragen te meten. *Niet die van de antwoorden...*
- bij elke vraag daarom:
 - inschatten hoelang het duurt om de informatie op te zoeken
 - met de vrouw kort overleggen of ze de vraag moeilijk of makkelijk vond, hoe ze de vraag interpreteerde, ...
 - Kan de vrouw de gebruikte statistiek vatten, genre 'wat is de kans' = X op 1000
- Naderhand: met de vrouw doorheen de hele tekst even gaan en elke alinea bespreken: wat is moeilijk, hoe leest men dat, ...
- Eindbedoeling: uit 25 vragen er 15 duidelijke vragen selecteren

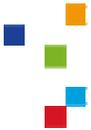


Leeftijd van de vrouw: Hoogste diploma:

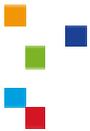
vraag	Het juiste antwoord	Correct of niet & opmerkingen	Antwoordlocatie in de tekst
1. U neemt <u>geen</u> deel aan het borstkankeronderzoek. Wat is de grootste overlidjensoorzaak bij vrouwen van uw leeftijd?	40-49: andere kankers 50-59: andere kankers 60-69: andere kankers 70-79: andere kankers		5. De kans om te sterven
2. Wat raadt de Belgische overheid u aan over borstkankeronderzoek?	40-49: afraden 50-59: aanraden 60-69: aanraden 70-79: afraden		7. aanbeveling
3. Mag iemand van 33 jaar op basis van deze tekst beslissen om een borstkankeronderzoek te doen?	Nee		1. Voor wie is deze tekst
4. U ondergaat een borstkankeronderzoek. Wat weet u over het onderzoek dat als eerste uitgevoerd wordt?	'röntgen' vernoemen		3. Het onderzoek tijdens
5. U neemt <u>geen</u> deel aan het borstkankeronderzoek. Wat is uw kans dat u borstkanker krijgt?	40-49: 20 vrouwen op 1000 50-59: 35 vrouwen op 1000 60-69: 40 vrouwen op 1000 70-79: 31 vrouwen op 1000		6. De gevolgen van
6. Hoeveel vrouwen op 1000 lopen een 'normaal risico' op borstkanker?	935 op 1000		1. Voor wie is deze tekst
7. Welke techniek gebruikt een echografie?	Geluidsgolven		3. Het onderzoek tijdens
8. Is de moeder van uw echtgenoot een direct familielid van u?	Nee		1. Voor wie is deze tekst
9. Uw arts stelt u voor om een mammografie en een echografie tegelijk uit te voeren. Is dit altijd beter?	nee		3. Het onderzoek tijdens
10. Als 1000 vrouwen een borstkankeronderzoek	34 vrouwen		4. Vals alarm



ondergaan, hoeveel vrouwen moeten daarvan een bijkomend onderzoek doen?			
11. Noem een voordeel voor een vrouw om niet aan borstkankeronderzoek deel te nemen.	Niet ongerust maken Of Geen overbehandeling		4. Vals alarm 6. De gevolgen van
12. Voortkomt een borstkankeronderzoek dat u borstkanker krijgt?	Nee		2. Algemene informatie
13. U neemt <u>wel</u> deel aan het borstkankeronderzoek. Wat is uw kans om de volgende tien jaar te overlijden aan borstkanker?	40-49: 3 op 1000 50-59: 5 op 1000 60-69: 7 op 1000 70-79: 4 op 1000		5. De kans om te sterven
14. Wat doet een vrouw van 77 jaar best wanneer ze een borstkankeronderzoek wil ondergaan?	Eerst overleg met arts		7. aanbeveling
15. U neemt <u>wel</u> deel aan het borstkankeronderzoek. Wat is uw kans dat u overbodig behandeld zal worden?	40-49: 2 vrouwen op 1000 50-59: 3 vrouwen op 1000 60-69: 4 vrouwen op 1000 70-79: 3 vrouwen op 1000		6. De gevolgen van
16. Stel dat u zes maanden geleden een borstkankeronderzoek onderging. Kan u nu borstkanker krijgen?	Ja		2. Algemene informatie
17. Heeft <u>wel</u> meedoen aan borstkankeronderzoek een nadeel?	Ja, overbodige behandeling		6. De gevolgen van
18. Als 1000 vrouwen een borstkankeronderzoek ondergaan, bij hoeveel vrouwen wordt borstkanker vastgesteld?	4 vrouwen		4. Vals alarm
19. Heeft <u>niet</u> meedoen aan borstkankeronderzoek een voordeel?	Geen overbodige behandeling Of Geen nodeloze ongerustheid		6. De gevolgen van



20. Stel dat u 77 jaar bent. Mag u een borstkankeronderzoek ondergaan?	Ja		7. aanbeveling
21. Wat is de kans dat u ooit in uw leven borstkanker krijgt?	1 op 10		2. Algemene informatie
22. Waarom behandelen artsen ook slapende borstkankers?	Ze kunnen geen onderscheid maken tussen kankers		6. De gevolgen van
23. Stel dat u borstkanker hebt. Waarop hebt u het meeste kans: overlijden of overleven?	overleven		2. Algemene informatie
24. Stel dat u een verhoogd risico op borstkanker loopt. Wat moet u doen wanneer u een borstkankeronderzoek overweegt?	Overleg met uw arts		1. Voor wie is deze tekst
25. Stel dat u 43 jaar bent. Waarom is een mammografie ongezond?	Röntgenstralen + jongere vrouwen		7. aanbeveling

**Appendix 8.2. Second test questionnaire***Appendix 8.2.1. French-speaking questionnaire***Instructions test de lisibilité**

Déroutement du test:

1. Utiliser uniquement les pages relatives à l'âge de la répondante
2. La femme âgée de 40 à 74 ans lit le texte à son propre rythme (pas de pression de temps)
3. La femme conserve le texte
4. Les questions sont posées l'une après l'autre à la femme. La femme peut voir la question (à l'aide des feuillets en fin de document)
5. La femme utilise le texte pour répondre aux questions. Elle dispose de tout le temps nécessaire.

Ceci imite la lecture d'un dépliant à la maison. Il ne s'agit pas d'un exercice de mémorisation de l'information, mais un exercice qui vérifie si l'information peut être retrouvée.

Nom de la femme:.....

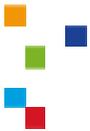
Age:

Dernier diplôme obtenu:

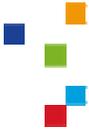
Question	La réponse attendue	Page correcte ?	Réponse correcte ?	Situation de la réponse dans le texte
1. Quelle est la principale cause de décès des femmes de votre âge ?	40-49: autres cancers 50-59: autres cancers 60-69: autres cancers 70-79: autres cancers	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	2.Le risque de mourir
2. Que fait une biopsie	40-49: analyse un morceau de sein 50-59: analyse un morceau de sein 60-69: analyse un morceau de sein 70-79: analyse un morceau de sein	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	4. Conséquences dans les mois à venir
3. Vous ne vous faites <u>pas</u> dépister. Quel est votre risque d'avoir le cancer du sein ?	40-49: 20 femmes sur 1000 50-59: 35 femmes sur 1000 60-69: 40 femmes sur 1000 70-79: 31 femmes sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	3. Conséquences dans les 10 ans



4. Toutes les femmes peuvent avoir le cancer du sein. Mais combien de femmes sur 1000 femmes ont un <u>risque normal</u> d'avoir le cancer du sein ?	935 sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Informations générales (Pour qui sont ces informations)
5. Votre médecin vous propose de passer en même temps une mammographie et une échographie. Est-ce toujours mieux ?	non	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Informations générales (Comment se passe le dépistage) +XX
6. Combien de femmes sur 1000 de votre catégorie d'âge seront toujours en vie à 50/60/70/80 ans	40-49: 985 sur 1000 50-59: 963 sur 1000 60-69: 924 sur 1000 70-79: 800 sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	2. Le risque de mourir
7. Est-ce que le dépistage du cancer du sein empêche d'avoir le cancer du sein ?	Non	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Information générale (qu'est ce que le dépistage)
8. <u>Vous vous faites dépister</u> . Combien de femmes de votre âge sont traitées pour un cancer dormant ?	40-49: 2 femmes sur 1000 50-59: 3 femmes sur 1000 60-69: 4 femmes sur 1000 70-79: 3 femmes sur 1000	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	3. Conséquences dans les 10 ans
9. Imaginez que vous ayez fait un dépistage il y a six mois. Pouvez-vous avoir le cancer du sein maintenant ?	oui	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Information générale (Qu'est ce que le dépistage)
10. <u>Vous vous faites dépister</u> . Combien de femmes de votre âge restent en vie encore au moins 10 ans grâce au dépistage du cancer du sein ?	40-49: 1 femme 50-59: 3 femmes 60-69: 4 femmes 70-79: 2 femmes	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	3. Conséquences dans les 10 ans
50-59 et 60-69 11. Vous participez à un <u>dépistage en dehors du dépistage organisé</u> . Chez combien de femmes sur 1000 ce premier dépistage ne trouve pas de signe	40-49: 966 50-59: 900 60-69: 900 70-79: 980	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	4. Conséquences dans les mois à venir



de cancer ? 40-49 en 70-79 11. <u>Vous vous faites dépister</u> . Chez combien de femmes sur 1000 ce premier dépistage ne trouve pas de signe de cancer ?				
12. Pourquoi les médecins traitent-ils également les cancers dormants ?	Ils ne savent pas si le cancer risque de se réveiller un jour	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	3. Conséquences dans les 10 ans
50-59 et 60-69 13. Vous participez à un dépistage organisé (Mammotest). Combien de femmes sur 1000 doivent <u> finalement </u> être opérées ? 40-49 en 70-79 13. Vous vous faites dépister. Combien de femmes sur 1000 doivent <u> finalement </u> être opérées ?	40-49: 4 50-59: 4 60-69: 4 70-79: 4	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	4. Conséquences dans les mois à venir
14. Imaginez que vous avez un risque plus élevé d'avoir le cancer du sein. Que devez-vous faire si envisagez de faire un dépistage du cancer du sein ?	En parler avec son médecin	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	1. Pour qui est ce texte
50-59 et 60-69 15. Vous participez à un dépistage organisé (Mammotest). Combien de femmes sur 1000 doivent <u> passer </u> un deuxième examen ? 40-49 et 70-79 15. <u> Vous vous faites dépister </u> . Combien de femmes sur 1000 doivent <u> passer </u> un deuxième examen ?	40-49: 34 50-59: 96 60-69: 96 70-79: 96	<input type="checkbox"/> oui <input type="checkbox"/> non	<input type="checkbox"/> oui <input type="checkbox"/> non	4. Conséquences dans les mois à venir



Ce texte vous incite:

- à participer au dépistage du cancer du sein
- à ne pas participer au dépistage du cancer du sein
- ni l'un ni l'autre

Pourquoi?

- référence à un fait, un chiffre le quel:
- pas de référence spécifique (= contenu général du document),
pourquoi.....

Autres remarques

Appendix 8.2.2. Dutch-speaking questionnaire

Instructies bij de test

Verloop van de test:

1. Uitsselectie van enkel de leeftijdsspecifieke bladzijden voor de vrouw
2. De vrouw van tussen 40 en 74 jaar leest de tekst door op eigen ritme (geen tijdsdruk)
3. De vrouw houdt de tekst bij
4. De vragen worden één voor één voorgelegd aan de vrouw. De vrouw mag de vraag zien (met behulp van de bladjes achteraan dit document)
5. De vrouw gebruikt de tekst om de vraag te beantwoorden. Ze mag er zo lang als ze wil over doen

Dit imiteert het lezen van een folder thuis. Het is geen oefening in het memoriseren van informatie, maar een oefening die nakijkt of informatie gevonden wordt



Naam van de vrouw: Leeftijd: Hoogste diploma:

vraag	Het juiste antwoord	Juiste bladzijde?	Juiste antwoord?	Antwoordlocatie in de tekst
1. Wat is de grootste overlijdensoorzaak bij vrouwen van uw leeftijd?	40-49: andere kankers 50-59: andere kankers 60-69: andere kankers 70-79: andere kankers	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	2. Le risque de mourir
2. Wat doet een biopsie?	40-49: onderzoekt borstweefsel 50-59: onderzoekt borstweefsel 60-69: onderzoekt borstweefsel 70-79: onderzoekt borstweefsel	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	4. Conséquences immédiates
3. U neemt <u>geen</u> deel aan het borstkankeronderzoek. Wat is uw kans dat u borstkanker krijgt?	40-49: 20 vrouwen op 1000 50-59: 35 vrouwen op 1000 60-69: 40 vrouwen op 1000 70-79: 31 vrouwen op 1000	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	3. Screening dans les 10 ans
4. Borstkanker kan alle vrouwen treffen. Maar hoeveel vrouwen op 1000 lopen een ' <u>normaal risico</u> ' op borstkanker?	935 op 1000	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	1. Le cancer du sein
5. Uw arts stelt u voor om een mammografie en een echografie tegelijk uit te voeren. Is dit altijd beter?	nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	1. Le cancer du sein 50-69: ook imediat
6. Hoeveel vrouwen op 1000 uit uw leeftijdscategorie worden XX jaar?	40-49: 985 op 1000 50-59: 963 op 1000 60-69: 924 op 1000 70-79: 800 op 1000	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	2. Le risque de mourir



7. Voortkomt een borstkankeronderzoek dat u borstkanker krijgt?	Nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	1. Le cancer du sein
8. U neemt <u>wel</u> deel aan het borstkankeronderzoek. Bij hoeveel vrouwen van uw leeftijd wordt een slapende borstkanker behandeld?	40-49: 2 vrouwen 50-59: 3 vrouwen 60-69: 4 vrouwen 70-79: 3 vrouwen	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	3. Screening dans les 10 ans
9. Stel dat u zes maanden geleden een borstkankeronderzoek onderging. Kan u nu borstkanker krijgen?	Ja	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	1. Le cancer du sein
10. U neemt <u>wel</u> deel aan het borstkankeronderzoek. Hoeveel vrouwen van uw leeftijd leven nog minstens tien jaar dankzij het borstkankeronderzoek?	40-49: 1 vrouw 50-59: 3 vrouwen 60-69: 4 vrouwen 70-79: 2 vrouwen	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	3. Screening dans les 10 ans
50-59 en 60-69 11. U kiest voor <u>niet-georganiseerde opsporing</u> van borstkanker. Bij hoeveel vrouwen op 1000 vindt het eerste onderzoek niets? 40-49 en 70-79 11. U laat een borstkankeronderzoek doen. Bij hoeveel vrouwen op 1000 vindt het eerste onderzoek niets?	40-49: 966 50-59: 900 60-69: 900 70-79: 980	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	4. Conséquences immédiates
12. Waarom behandelen artsen ook slapende borstkankers?	Ze weten niet of de kanker ooit kan ontwaken	<input type="checkbox"/> ja <input type="checkbox"/> nee	<input type="checkbox"/> ja <input type="checkbox"/> nee	3. Screening dans les 10 ans



<p>50-59 en 60-69 13. U neemt deel aan de <u>wel georganiseerde opsporing</u> van borstkanker. Hoeveel vrouwen op 1000 moeten <u>uiteindelijk</u> geopereerd worden?</p> <p>40-49 en 70-79 13. U laat een borstkankeronderzoek doen. Hoeveel vrouwen op 1000 moeten <u>uiteindelijk</u> geopereerd worden?</p>	<p>40-49: 4 50-59: 4 60-69: 4 70-79: 4</p>	<p><input type="checkbox"/> ja <input type="checkbox"/> nee</p>	<p><input type="checkbox"/> ja <input type="checkbox"/> nee</p>	<p>4. Conséquences immédiates</p>
<p>14. Wat raadt de Belgische overheid u aan over borstkankeronderzoek?</p>	<p>40-49: afraden 50-59: aanraden 60-69: aanraden 70-79: afraden</p>	<p><input type="checkbox"/> ja <input type="checkbox"/> nee</p>	<p><input type="checkbox"/> ja <input type="checkbox"/> nee</p>	<p>3. Screening dans les 10 ans</p>
<p>50-59 en 60-69 15. neemt deel aan de <u>wel georganiseerde opsporing</u> van borstkanker. Hoeveel vrouwen op 1000 moeten een tweede onderzoek laten doen?</p> <p>40-49 en 70-79 15. . U laat een borstkankeronderzoek doen. Hoeveel vrouwen op 1000 moeten een tweede onderzoek laten doen?</p>	<p>40-49: 34 50-59: 96 60-69: 96 70-79: 96</p>	<p><input type="checkbox"/> ja <input type="checkbox"/> nee</p>	<p><input type="checkbox"/> ja <input type="checkbox"/> nee</p>	<p>4. Conséquences immédiates</p>



Uitleiding

Zet de tekst u aan om:

- deel te nemen aan borstkankeronderzoek
- geen boodschap
- niet deel te nemen aan borstkankeronderzoek

Waarom?

- verwijzing naar feit of cijfer, welk:
 - geen verwijzing (= algemene teneur van de tekst), waarom:
-
-
-

Andere opmerkingen

.....

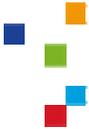
.....

.....



■ REFERENCES

1. Paulus D, Bonneux L, Mambourg F. Dépistage du cancer du sein. 11B ed. Brussels: KCE = Federaal Kenniscentrum voor de Gezondheidszorg = Centre fédéral d'expertise des soins de santé = Belgian Health Care Knowledge Centre; 2005.
2. Mambourg F, Robays J, Camberlin C, Vlayen J, Gailly J. Dépistage du cancer du sein entre 40 et 49 ans. 129 B ed. Brussels: KCE = Federaal Kenniscentrum voor de Gezondheidszorg = Centre fédéral d'expertise des soins de santé = Belgian Health Care Knowledge Centre; 2010.
3. Verleye L, Desomer A, Gailly J, Robays J. Dépistage du cancer du sein : comment identifier les femmes exposées à un risque accru - Quelles techniques d'imagerie utiliser ? Brussels: Centre fédéral d'expertise des soins de santé (KCE); 2012. KCE report (D/2011/10.273/91) Available from: https://kce.fgov.be/sites/default/files/page_documents/KCE_172B_depistage_du_cancer.pdf
4. Mambourg F, Robays J, Gerkens S. Dépistage du cancer du sein entre 70 et 74 ans. 176B ed. Brussels: KCE = Federaal Kenniscentrum voor de Gezondheidszorg = Centre fédéral d'expertise des soins de santé = Belgian Health Care Knowledge Centre; 2012.
5. Briss P, Rimer B, Reilley B, Coates RC, Lee NC, Mullen P, et al. Promoting Informed Decisions About Cancer Screening in Communities and Healthcare Systems. *Am J Prev Med.* 2004;26(1):67-80.
6. Mullen PD, Allen JD, Glanz K, Fernandez ME, Bowen DJ, Pruitt SL, et al. Measures Used in Studies of Informed Decision Making About Cancer Screening: A Systematic Review. *Annals of Behavioral Medicine.* 2006;32(3):188-201.
7. van Agt H, Fracheboud J, van der Steen A, de Koning H. Do women make an informed choice about participating in breast cancer screening? A survey among women invited for a first mammography screening examination. *Patient Educ. Couns.* 2012;89(2):353-9.



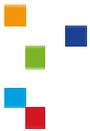
8. O'Connor AM, Bennett C, Stacey D, Barry MJ, Col NF, Eden KB, et al. Do patient decision aids meet effectiveness criteria of the international patient decision aid standards collaboration? A systematic review and meta-analysis. *Med Decis Making*. 2007;27(5):554-74.
9. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2011(10):CD001431.
10. Sheehan J, Sherman KA. Computerised decision aids: a systematic review of their effectiveness in facilitating high-quality decision-making in various health-related contexts. *Patient Educ Couns*. 2012;88(1):69-86.
11. 2012 Update of the International Patient Decision Aids Standards (IPDAS) Collaboration's Background Document. Volk R, Llewellyn TH, editor.; 2012.
12. O'Brien MA, Whelan TJ, Villasis-Keever M, Gafni A, Charles C, Roberts R, et al. Are cancer-related decision aids effective? A systematic review and meta-analysis. *J Clin Oncol*. 2009;27(6):974-85.
13. Edwards AGK, Evans R, Dundon J, Haigh S, Hood K, Elwyn GJ. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database Syst Rev*. 2006(4):CD001865.
14. The benefits and harms of breast cancer screening: an independent review. *Lancet*. 2012;380(9855):1778-86.
15. Edwards A, Unigwe S, Elwyn G, Hood K. Effects of communicating individual risks in screening programmes: Cochrane systematic review. *BMJ*. 2003;327(7417):703-9.
16. Informed Medical Decisions Foundation. How the Foundation Develops Decision Aids [Web page].2012. Available from: http://informedmedicaldecisions.org/wp-content/uploads/2013/05/DA_Development_Brief.pdf
17. International Patient Decision Aid Standards (IPDAS) Collaboration. IPDAS 2005: Criteria for Judging the Quality of Patient Decision Aids [Web page].2005. Available from: http://ipdas.ohri.ca/IPDAS_checklist.pdf
18. Law M, Stewart D, Pollock N, Letts L, Bosch J, M W. Critical Review Form – Quantitative Studies [Web page]. McMaster University. Available from: www.canchild.ca/en/
19. Cote L, Turgeon J. Appraising qualitative research articles in medicine and medical education. *Med Teach*. 2005;27(1):71-5.
20. Akl EA, Oxman AD, Herrin J, Vist GE, Terrenato I, Sperati F, et al. Framing of health information messages. *Cochrane Database Syst Rev*. 2011(12):CD006777.
21. Akl EA, Oxman AD, Herrin J, Vist GE, Terrenato I, Sperati F, et al. Using alternative statistical formats for presenting risks and risk reductions. *Cochrane Database of Systematic Reviews*. 2011(3).
22. Winterbottom A, Bekker HL, Conner M, Mooney A. Does narrative information bias individual's decision making? A systematic review. *Social Science & Medicine*. 2008;67(12):2079-88.
23. Gallagher KM, Updegraff JA. Health message framing effects on attitudes, intentions, and behavior: A meta-analytic review. *Annals of Behavioral Medicine*. 2012;43(1):101-16.
24. Hildon Z, Allwood D, Black N. Impact of format and content of visual display of data on comprehension, choice and preference: a systematic review. *International Journal for Quality in Health Care*. 2012;24(1):55-64.
25. Ancker JS, Senathirajah Y, Kukafka R, Starren JB. Design features of graphs in health risk communication: a systematic review. *J Am Med Inform Assoc*. 2006;13(6):608-18.
26. Ghosh K, Crawford BJ, Pruthi S, Williams CI, Neal L, Sandhu NP, et al. Frequency format diagram and probability chart for breast cancer risk communication: a prospective, randomized trial. *BMC Women's Health*. 2008;8:18.
27. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. "If I'm better than average, then I'm ok?": Comparative information influences beliefs about risk and benefits. *Patient Education & Counseling*. 2007;69(1-3):140-4.



28. Vahabi M, Gastaldo D. Rational choice(s)? Rethinking decision-making on breast cancer risk and screening mammography. *Nursing Inquiry*. 2003;10(4):245-56.
29. Wong ST, Perez-Stable EJ, Kim SE, Gregorich SE, Sawaya GF, Walsh JM, et al. Using visual displays to communicate risk of cancer to women from diverse race/ethnic backgrounds. *Patient Educ Couns*. 2012;87(3):327-35.
30. Gigerenzer G. *Calculated Risk*. New York: Simon & Schuster; 2002.
31. Woloshin S, Schwartz L, Welch G. *Know your chances: understanding health statistics*. Berkeley: University of California Press; 2008.
32. Barratt A, Howard K, Irwig L, Salkeld G, Houssami N. Model of outcomes of screening mammography: information to support informed choices. *BMJ*. 2005;330(7497):936.
33. Fagerlin A, Dillard AJ, Smith DM, Zikmund-Fisher BJ, Pitsch R, McClure JB, et al. Women's interest in taking tamoxifen and raloxifene for breast cancer prevention: response to a tailored decision aid. *Breast Cancer Research & Treatment*. 2011;127(3):681-8.
34. Wong N, King T. The cultural construction of risk understandings through illness narratives. *Journal of Consumer Research*. 2008;34(5):579-94.
35. Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC Med Res Methodol*. 2007;7:10.
36. Roussel S, Deccache A. Améliorer la participation aux programmes organisés de dépistage du cancer du sein et du cancer colorectal mis en place en Communauté française de Belgique - Partie 1: Population. Bruxelles: UCL-RESO; 2011.
37. Doumont D, Hoyois C. Identification des freins et des leviers dans le cadre d'un dépistage du cancer du sein. Bruxelles: UCL-RESO; 2011. Dossiers techniques 11-63
38. Dedicated Research. *Le Mammotest: Post-test de campagne*. Brussels: 2010.
39. Hersch J, Jansen J, Irwig L, Barratt A, Thornton H, Howard K, et al. How do we achieve informed choice for women considering breast screening? *Prev Med*. 2011;53(3):144-6.
40. Dillard AJAJ, Couper MPMP, Zikmund-Fisher BJJ. Perceived risk of cancer and patient reports of participation in decisions about screening: the DECISIONS study. *Medical decision making : an international journal of the Society for Medical Decision Making*. 2010;30(5 Suppl):96S-105S.
41. Pohls UG, Renner SP, Fasching PA, Lux MP, Kreis H, Ackermann S, et al. Awareness of breast cancer incidence and risk factors among healthy women. *European Journal of Cancer Prevention*. 2004;13(4):249-56.
42. Unruh HK, Bowen DJ, Meischke H, Bush N, Wooldridge JA. Women's approaches to the use of new technology for cancer risk information. *Women & Health*. 2004;40(1):59-78.
43. Buchanan AHAH, Skinner CSCS, Rawl SMSM, Moser BKBK, Champion VLVL, Scott LLLL, et al. Patients' interest in discussing cancer risk and risk management with primary care physicians. *Patient education and counseling*. 2005;57(1):77-87.
44. Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. *Patient Educ Couns*. 2012;86(1):9-18.
45. Humpel NN, Jones SCSC. "I don't really know, so it's a guess": women's reasons for breast cancer risk estimation. *Asian Pacific journal of cancer prevention : APJCP*. 2004;5(4):428-32.
46. Facione NC. Perceived risk of breast cancer. Influence of heuristic thinking. *Cancer Practice*. 2002;10(5):256-62.
47. Katapodi MC, Dodd MJ, Lee KA, Facione NC. Underestimation of breast cancer risk: Influence on screening behavior. *Oncology Nursing Forum*. 2009;36(3):306-14.



48. Hersch J, Jansen J, Barratt A, Irwig L, Houssami N, Howard K, et al. Women's views on overdiagnosis in breast cancer screening: a qualitative study. *BMJ*. 2013;346:f158.
49. Marteau TM, Dormandy E, Michie S. A measure of informed choice. *Health Expect*. 2001;4(2):99-108.
50. Ackerson K, Preston SD. A decision theory perspective on why women do or do not decide to have cancer screening: systematic review. *J Adv Nurs*. 2009;65(6):1130-40.
51. Osterlie W, Solbjør M, Skolbekken JA, Hofvind S, Saetnan AR, Forsmo S. Challenges of informed choice in organised screening. *Journal of Medical Ethics*. 2008;34(9):e5.
52. Sadigh G, Kelly AM, Fagerlin A, Carlos RC. Patient preferences in breast cancer screening: lessons to be learned from the US Preventive Services Task Force. *Acad Radiol*. 2011;18(11):1333-6.
53. Paulus D, Mambourg F, Bonneux L. Breast cancer screening. Good Clinical Practice (GCP). Brussels: Belgian Health Care Knowledge Centre (KCE); 2005 02/05/2005. KCE Reports 11 Available from: <https://kce.fgov.be/publication/report/breast-cancer-screening>
54. Gotzsche PC, Nielsen M. Screening for breast cancer with mammography. *Cochrane Database of Systematic Reviews*. 2011(1):CD001877.
55. Nelson HD, Tyne K, Naik A, Bougatsos C, Chan BK, Humphrey L, et al. Screening for breast cancer: an update for the U.S. Preventive Services Task Force. *Annals of Internal Medicine*. 2009;151(10):727-37.
56. Biesheuvel C, Barratt A, Howard K, Houssami N, Irwig L. Effects of study methods and biases on estimates of invasive breast cancer overdiagnosis with mammography screening: a systematic review. *Lancet Oncology*. 2007;8(12):1129-38.
57. Jorgensen KJ, Gotzsche PC. Overdiagnosis in publicly organised mammography screening programmes: systematic review of incidence trends. *BMJ*. 2009;339:b2587.
58. Virnig BA, Tuttle TM, Shamliyan T, Kane RL. Ductal carcinoma in Situ of the breast: A systematic review of incidence, treatment, and outcomes. *J. Natl. Cancer Inst*. 2010;102(3):170-8.
59. Paci E. Summary of the evidence of breast cancer service screening outcomes in Europe and first estimate of the benefit and harm balance sheet. *J Med Screen*. 2012;19 Suppl 1:5-13.
60. Mambourg F, Robays J, Gerkens S. Breast cancer screening amongst women aged 70-74 years of age. Good Clinical Practice (GCP). Brussels: Belgian Health Care Knowledge Centre (KCE); 2012. KCE Reports 176 (D/2012/10.273/20) Available from: <https://kce.fgov.be/publication/report/breast-cancer-screening-amongst-women-aged-70-74-years-of-age>
61. Mambourg F, Robays j, Camberlin C, Vlayen J, Gailly J. Breast cancer screening with mammography for women in the agegroup of 40-49 years. Good Clinical Practice (GCP). Brussels: Belgian Health Care Knowledge Centre (KCE); 2010 07/07/2010. KCE Reports 129 Available from: <https://kce.fgov.be/publication/report/breast-cancer-screening-with-mammography-for-women-in-the-agegroup-of-40-49-years>
62. Glasziou PP. Meta-analysis adjusting for compliance: the example of screening for breast cancer. *J Clin Epidemiol*. 1992;45(11):1251-6.
63. Olsen O, Gotzsche PC. Screening for breast cancer with mammography. *Cochrane Database Syst Rev*. 2001(4):CD001877.
64. Vainio, editor. Breast Cancer Screening. Lyon: IARC Press; 2002.
65. Union CotE. Council Recommendation of 2 December 2003 on cancer screening. *Official Journal of the European Union*. 2003;L327:34-8.
66. Broeders M, Moss S, Nystrom L, Njor S, Jonsson H, Paap E, et al. The impact of mammographic screening on breast cancer mortality in Europe: a review of observational studies. *J Med Screen*. 2012;19 Suppl 1:14-25.
67. Njor S, Nystrom L, Moss S, Paci E, Broeders M, Segnan N, et al. Breast cancer mortality in mammographic screening in Europe: a



- review of incidence-based mortality studies. *J Med Screen*. 2012;19 Suppl 1:33-41.
68. Boyce C, Neale P. *Conducting in-depth interviews: a guide for designing and conducting in-depth interviews for evaluation input*. Watertown, USA: Pathfinder International; 2006.
69. Mack N, Woodsong C, MacQueen KM, Guest G, Namey E. *Qualitative research methods: a data collector's field guide*. North Carolina, USA: Family Health International; 2005.
70. Bloor M, Wood F. *Keywords in qualitative methods. A vocabulary of research concepts*. Thousand Oaks: Sage; 2006.
71. Eyssen M, Kohn L, Lambert M-L, Van den Steen D. *HTA Polysomnographie et monitoring à domicile des nourrissons en prévention de la mort subite*. Brussels: Centre fédéral d'expertise des soins de santé (KCE); 2006. (D/2006/10.273/60) Available from: https://kce.fgov.be/sites/default/files/page_documents/d20061027360-2.pdf
72. Lorant V, Geerts C, D'Hoore W, Sauwens D, Remmen R, Peremans L, et al. *Médecine générale : comment promouvoir l'attraction et la rétention dans la profession?* Brussels: Centre fédéral d'expertise des soins de santé (KCE); 2008. (D/2008/10.273/64) Available from: https://kce.fgov.be/sites/default/files/page_documents/d20081027364.pdf
73. De Gendt T, Desomer A, Goossens M, Hanquet G, Léonard C, Melard F, et al. *Etat des lieux de l'ostéopathie et de la chiropraxie en Belgique*. Brussels: Centre fédéral d'expertise des soins de santé (KCE); 2010. (D/2010/10.273/92) Available from: https://kce.fgov.be/sites/default/files/page_documents/kce_148b_ost%C3%A9opathie_et_chiropraxie_en_belgique.pdf
74. De Gendt T, Desomer A, Goossens M, Hanquet G, Léonard C, Roberfroid D, et al. *Acupuncture: State of affairs in Belgium*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2011. (D/2011/10.273/06) Available from: [https://kce.fgov.be/sites/default/files/page_documents/kce_153c_acupuncture_in_belgium\(2\)_0.pdf](https://kce.fgov.be/sites/default/files/page_documents/kce_153c_acupuncture_in_belgium(2)_0.pdf)

