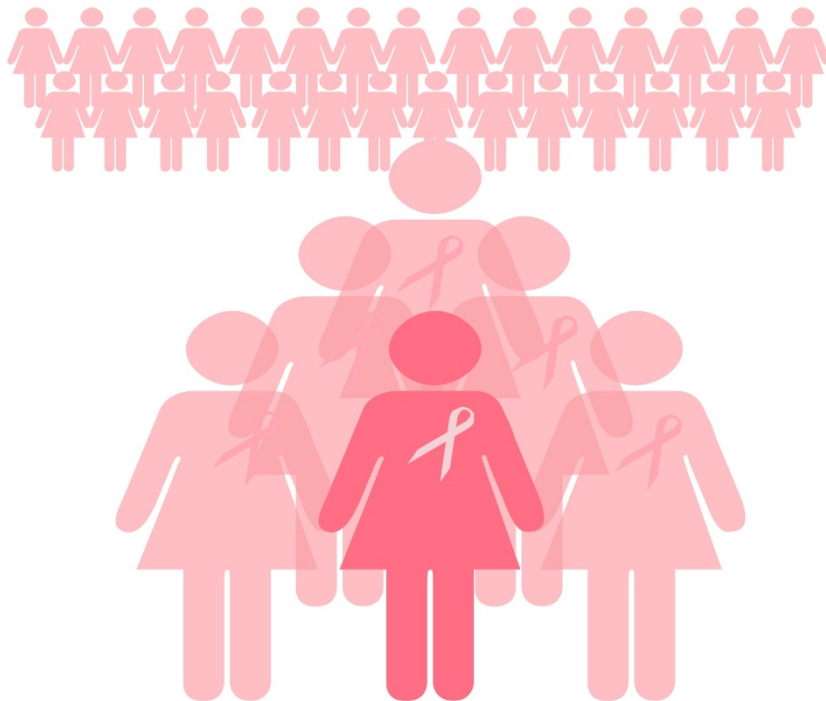


SYNTHESIS

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





Belgian Health Care Knowledge Centre

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

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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:

07 April 2014 (2nd print, 1st print: 08 January 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/2014/10.273/03

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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 – Synthesis. Good Clinical Practice (GCP) Brussels: Belgian Health Care Knowledge Centre (KCE). 2014. KCE Reports 216Cs. D/2014/10.273/03.

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



■ FOREWORD

It may be hard going but sometimes it is well worth driving home the message. We have lost track by now of the number of KCE reports in which we have advocated involving the patient in their healthcare choices! This participation implies furnishing clear and balanced information, a challenge we have taken up by developing a series of messages and a body of information to guide women faced with the choice of undergoing screening for breast cancer. These messages are not a full-blown decision-making tool but they can be usefully used in conjunction with the tools produced by other actors.

When you set off on this kind of adventure, you quickly realise how far removed the medical/technical language of our manuals and guides to good practice is from the plain talking you need to ensure that a message is understood and taken on board by lay persons. The adventure becomes particularly arduous when it comes to getting the message across in an area such as screening for breast cancer, an area populated by "believers", "non-believers" and an array of "dissidents". It was therefore necessary to simplify the (far from perfect) results of the scientific studies and present them in as objective and neutral a way as possible.

Mission Impossible? Of course not! Others have ventured there before us. We were therefore able to call on experts not only in the field of screening or gynaecology, but also in the field of health promotion and communication. We would like to take this opportunity to thank them wholeheartedly for this very informative cooperation!

We hope that this instrument will be effectively used in practice and, ultimately, help women make full use of the healthcare possibilities open to them on the basis of an informed choice."

Christian LÉONARD
Deputy general director

Raf MERTENS
General director



■ ABSTRACT

CONTEXT

This report follows on from the publication of a series of clinical guidelines devoted to screening for breast cancer in women. After considering screening in general, screening via mammography in women between the ages of 40 and 49 and those over the age of 70 and the identification of high-risk women, the KCE has set out on a quest to inform women about breast cancer screening.

This type of information has indeed been considered a priority in the field by a group of stakeholders comprised of representatives of the RBSR (Royal Belgian Radiological Society), the SGAM (Scientific Society of General Medicine), the GGOLF (Grouping of Belgium's French-language Gynaecologist-Obstetricians), the LUSS (League of Health Care Users), CBO (Belgian Cancer Society), Domus, the VVOG (Flemish Association for Obstetrics and Gynaecology), the VLK (Flemish League Against Cancer), the BKO (Breast Cancer Screening), the CFWB (French Community Wallonia-Brussels) and Brumammo.

There is a growing trend in today's society toward informed decision-making by patients, emphasising the importance of informed consent and informed choice. Advising women in Belgium about the potential consequences, even the side-effects, of breast cancer screening is an integral part of the right to information stipulated in the law on the rights of the patient. Setting out the bare bones of the matter can help women take an informed decision with all the facts at hand, whether alone or in consultation with a health care professional.

AIM

The aim of this report is to generate neutral messages and information for use in communication tools related to breast cancer screening. This information and these messages are earmarked at women aged 40 to 79 with no increased risk of breast cancer. These messages are not a full-blown decision-making tool but they can be usefully used in conjunction with the tools produced by other actors.

This report also updates the evidence that was already published for women between the ages of 50 and 69.



METHODS

The messages have been developed in using data from the scientific literature, epidemiological data and the perceptions of Belgian women and practitioners.

We based ourselves partially on the 'content development' stage of the methodology used by the Informed Medical Decision Foundation¹⁶ and the IPDAS criteria (International Patient Decision Aid Standards) relevant for the development of neutral messages. In practical terms, we conducted a review of the international literature dealing with the effectiveness of breast cancer screening in women aged 50-69, a review of the literature on the perspectives of patients and clinicians, 6 focus groups with women, two focus groups with general practitioners and gynaecologists and expert consultation.

The questions related to research and the general scientific approach were put to a group of stakeholders in the field of breast cancer screening: representatives of the Belgian government (regional and federal), of the administrative authorities, the National Institute for Health and Disability Insurance (INAMI/RIZIV), scientific associations representing general practitioners, gynaecologists and radiologists as well as representatives of existing breast cancer screening programmes, health insurance funds, patient organisations and medical journalists.

The messages were tested for their readability and comprehensibility among an initial sample of 30 women. The adjusted messages were then dressed up in a more comfortable and attractive presentation and re-tested among a new sample of 30 women.

RESULTS

We have developed messages about breast cancer, breast cancer screening and about screening outcomes for women in the four age groups concerned: 40-49 years, 50-59 years, 60-69 years and 70-79 years. These messages can be used in their entirety by those who wish to communicate in a neutral way with women on screening for breast cancer, for example within the framework of the development of decision-making tools.

They are not sufficient in themselves to ensure comprehensive communication on screening for breast cancer and are not designed to be delivered as such to women. For example, these messages do not contain any practical information or information about what breast cancer actually is.

These messages also contain some useful concepts that shed light on what screening involves. They also provide information on the importance of breast cancer as a cause of mortality and the short- and long-term consequences of breast cancer screening. Finally, women can also use them as a basis for discussion with their doctor when consulting them about their decision.

The messages have the following characteristics: they are expressed in absolute numbers, are presented using the same denominator (1000 women), furnish information on gains and losses, they show with the same level of detail the positive and negative aspects of the options. The time frame is specified and is identical for the different options. Each visual is on the same scale. In addition, we have avoided the narrative style.

These messages can be downloaded in French and Dutch from the KCE^a website. They have all passed the readability test.

^a 40-49 years: full version and separate figures available at the address:
in French:
http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_40-49.pdf

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

50-59 years: full version and separate figures available at the address:



in French:

http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_50-59.pdf

In Dutch:

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

60-69 years: full version and separate figures available at the address: *i*

n French:

http://kce.fgov.be/sites/default/files/page_documents/KCE_Cancer_sein_60-69.pdf

In Dutch:

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