

Rijksinstituut voor Volksgezondhei en Milieu Ministerie van Volksgezondheid, Welzijn en Sport





# **Graduation Report**

Decision-Making By Women On Participating Or Not Participating In The Organized Breast Cancer Screening



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Decision–Making By Women On Participating Or Not Participating In The Organized Breast Cancer Screening

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## Abstract

## Context

Breast cancer is the most common type of cancer among women in the Netherlands. Since 1989, every two years, Het Rijksinstituut van Volksgezondheid en Milieu (RIVM) organizes a breast cancer screening for women between 50 and 75 years old. The Dutch government organizes the screening because the advantages at the general population level are considered higher than the potential disadvantages. Over the last years, the policy of RIVM considering the screening was mostly focused on the interests of the public as a whole. On a citizen level the advantages do not necessarily outweigh the disadvantages (e.g., over-diagnosis, false positives, false negatives) (RIVM, 2012). Recently, RIVM introduced a more responsible role towards the public in its policy (see figure 1). RIVM is adopting a more individually centred approach, taking into account more personal and citizen-level factors, and supporting women with informed decisionmaking. However, research made RIVM aware of the fact that (1) not all women do make well-informed choices yet and (2) women have a very positive attitude towards the screening (Douma et al., 2016). It seems that the new goals ask for another communication strategy.



Figure 1 shows the changing role of RIVM

This project addressed the challenge: "how can women be supported in making a well-informed decision whether they want to participate or not in the organized breast cancer screening?"

## Research

A user-centred design research is carried out, in which a diverse group of women was included regarding ethnicity and literacy. Besides that, a broad, specified context study is conducted to explore solution space.

## Decision-making

In the current communication strategy, only risk numbers are communicated. This strategy is based on the rational decision-maker's perspective, who has the capabilities and motivation to understand and to interpret the risk information (Timmermans, 2013). However, it is often experienced as 'jargon' and 'difficult to understand'.

Literature research showes that, besides 'accurate information' also the elements 'freedom of choice' and 'awareness of personal values' are essential for a well-informed decision (Timmermans, 2013). The user-centred research of this project showes that women do not make a well-informed decision and, perhaps more importantly, are not supported to do so. A noteworthy thing is that women receive a regular envelope when entering the program at the age of 50. The envelope includes the information and invitation at the same time. Besides this, women do not only base their decision on the rational models. Beliefs also seem to influence women's decision-making process (Timmermans, 2013). The inspirational research of this project showes that women are also aware of different meanings that are associated with the screening, such as: menopause, aging, uncertainty of life and bodily changes. These meanings play a role in the decisionmaking process. The current communication material does not give attention to all essential elements for well-informed choices, and moreover to the other meanings. Inspirational research showes that another communication focus might be just as effective: emotions as a source of information (Roeser, 2006). If RIVM showes more empathy to women's perspectives and communicates in a common language

instead of 'jargon' (quantitative information about risks), emotion could be used as an effective source for informing and for emphasizing the other essential elements (see figure 2).



Figure 2 shows strategy proposal.

### Design concept

A periodic intervention of 3 magazines between the age of 49 and 50 is designed, which should activate and guide the decision-making process (see figure 3). The magazines offer women's stories which represents (1) living scenario's, (2) different choice options and (3) different motivations for decisions. The women's stories create:

A. the possibility to emphasize the 3 essential elements for a well-informed choice

B. space to show empathy to women's interests and concerns, regarding menopause, aging and uncertainty in an inspiring and sensitive way (see figure 4).

After the third magazine, the woman will receive the first invitation. Whether the design concept realizes a well-informed decision-making on the long-term needs to be further tested as is recommended RIVM. Although, the concept test revealed that the magazine gives the possibility to emphasize 'communicating on an emotional level'.



Figure 3 shows the effect of the implementation of design intervention in service.



Figure 4 shows the two types of content that the women's stories emphasize.

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# Chapter 1. foundation

This chapter provides a short explanation on where this project started from. In this chapter will be discussed: the starting point, the project goal, the used design method Vision In Design (Hekkert and Van Dijk, 2011) and the personal goals (of the graduation student).

## 1.1 Introduction

## Context

Breast cancer is the most common type of cancer among women in the Netherlands. Approximately 1 out of 8 women in the Netherlands gets diagnosed with this disease. Since 1989, every two years, the Dutch government organizes a breast cancer screening for women between 50 and 75 years old. Through the organized screening, breast cancer can be detected and treated at an early stage. Besides that, research showes that partly due to the organized screening, 850 female lives are saved every year. However, the organized screening also has negative consequences on the individual and group level, which will be discussed below. When organized breast cancer screening was introduced, the overall advantages were higher than the overall disadvantages, seen at target group level. However, depending on someone's personal situation the balance between the advantages and disadvantages of participation differs. This is why participating in the organized screening is a personal decision and not compulsory (RIVM, 2012).

## What happens in this context?

Public health policy aims to reduce health risk factors at a population and individual level, partly by communicating information about risks. It is considered to be important to communicate this information to people in order to help them to make informed choices about their health and safety. Rijksinstituut voor Volksgezondheid en Milieu (RIVM), the Dutch public research institute regarding public health and environment, is taking action to realize the aim of this policy, communicating risk information to the public. Despite that, little impact has been found of risk information on decision making and behaviour.

One reason for this might be that the presentation of the risk information is too abstract, and often too complicated to understand

for many people (Peters et al., 2007). Another reason for this might be that psychological models of risks that determine how people think and feel about risks, and the impact that risks have on people's decisions and behaviour, differ from the experts' perspectives on risks (Morgan et al., 2002). Additionally, apart from the information RIVM is presenting to the public, nowadays, the current population can collect information through many different channels.

Recently, RIVM is taking a more active and responsible role, assisting people to consider health risks in their decision making and behaviour. The research project (Visioning Risk) is set up by the RIC Risk communication group at the RIVM and the RISC Risk communication team of the VU medical centre, who's aim is to:

Design novel visualizations of quantitative risk information, which are easier to understand while taking into account people's beliefs about specific health risks.

This graduation project will be part of the research project 'Visioning Risk'. The focus in particular will be on the organized breast cancer screening.

This graduation project started with the impression that the public has a very positive attitude towards cancer screening, based on a study of Douma et al. (2016). Cancer screening may lead to early detection and timely treatment. However, the screening may also lead to negative consequences, like: over-diagnosis, false positive diagnosis, false negative diagnosis, and health risks of the radiation used in the procedure. It seems that people overestimate the benefits and underestimate the possible harms. This might be explained by the fact that the risk information presented to the public is abstract and complicated. Besides that, it could be explained by the fact that the screening policies have been striving for increasing participation which transpired through their communication strategy (Gigerenzer, 2015).

## Who is involved?

Women between the age of 50 and 75 years old are invited to participate in the organized screening every two years. These women are invited by the executive organisation: Het Bevolkingsonderzoek Borstkanker. Het Bevolkingsonderzoek Borstkanker is divided over 5 local sub-organisations, which are active in their disgnated districts.

Het Bevolkingsonderzoek Borstkanker offers the organized screening in collaboration with RIVM. RIVM is the leading organization of the organized screening. It is a research institute which conducts research into public health and environment, and it is an independent institute which advises the government based on research findings. Nowadays, it is also taking a responsible and advising role towards the public.

The general practitioner (G.P.) and hospital are involved in the transition from the organized screening to the follow-up test.



## What are the challenges?

In the current situation, there seems to be an imbalance between social interests and personal interests. The Dutch government has organized the biennial screenings because the advantages at the general population level were considered higher than the costs and the potential disadvantages. Over the last year, the policy of RIVM and the screening was mostly focused on the interests of the public as a whole. On a citizen level the advantages do not have to outweigh the disadvantages. At the moment, based on the new policy, RIVM is taking a more responsible role towards the public. RIVM is adopting a more individually centered approach, taking into account more personal and citizen-level factors. RIVM wants to support the public in making well-informed choices, and focuses more on personal interests. However, research made RIVM aware of the fact that not all women do make well-informed choices yet, and that women have a very positive attitude towards the screening (Douma et al., 2016). The question is how the communication material has influence on this. It seems that these new goals need another communication strategy.

Risk experts and communication advisors of RIVM already work on renewing the communication strategy. RIVM wants to inform the government and public with its research findings as good as possible. In searching for new manners how to communicate their research findings (i.e. risks), using too much jargon is a common pitfall. The challenge of this project was to approach the problem solving from an additional perspective: user centered design. This project searched for a communication manner, by focusing specifically on the user group.

### **Project goals**

There are two project goals of this graduation project. The main goal of this project is to address the challenge: "how can women be supported in making an well-informed decision whether they want to participate or not participate in the organized breast cancer screening?". This proposal lays out a possible approach aimed to tackle this problem, emphasizing the perspective of the user (the potential participant). Furthermore I argue for its desirability and feasibility and

hope to inspire RIVM to apply this design in their communication. The other goal of this project is to inspire RIVM with this usercentered approach. The project will be approached with the method 'Vision In Design' (Hekkert and Van Dijk, 2011) (explained in the next paragraph) and user centred design techniques, which are used in the 'Design For Interaction' field. User centred techniques will be used along the project to enhance the understanding of why the user group interacts with the Bevolkingsonderzoek Borstkanker service in that way it does, and to develop an interaction and intervention that suits the user group.





## 1.2 Vision In Design

## Value of method

The method that is used in the process of this graduation project, is the method 'Vision In Design' (Hekkert and Van Dijk, 2011). This method gave me as a design student guidance through the research and design process towards a meaningful design concept. The method helped me to question why the context is constructed the way it is constructed. The method helped me to first determine the impact carefully, and after that to transform the impact into a design intervention.

In this research & design project, the context was studied and deconstructed by analysing the context from different perspectives: a psychological, societal, public health care, statistical and servicedesign perspective. These perspectives helped to understand why the context is constructed the way it is constructed. They are studied through different types of studies, which will be explained in the next chapter.

## **Relevance method for this project**

RIVM and VU medical center already study how women can be supported in their decision-making process. The 'Visioning Risk' group conducts research into: people's beliefs about specific health risks, the attitude towards risks and the impact risk perception has on behaviour. Besides that, the 'Visioning Risk' group studies the impact and application of risk visualizations.

However, the relevance of this additional research & design project in comparison with research of the 'Visioning Risk' group, is the different approach. This project is not set-up according to a social scientif approach, but according to a user centred design approach. The approach of this project is supported by the method 'Vision In Design' (Hekkert and Van Dijk, 2011). The method helped to understand the personal interests of the user group, and to search for solution space by analysing a broad, but also specified, context from different perspectives. The contribution of using a design approach is that, next to identifying risk perceptions and behaviour qualitatively, it can develop possible solutions to the problem and put forward policy advice.

Furthermore, by using a qualitative approach, I was able to incorporate an ethnically diverse set of participant in this study, including women with low literacy skills and women that have difficulty understanding Dutch. Thereby, the outcomes and suggestions apply better to all women in Dutch society.

## Short explanation of how the method is applied

#### Research stage

The 'Vision In Design' method (Hekkert and Van Dijk, 2011) guides the designer through a process of deconstructing the current product or service, interactions and context. The deconstruction will take place in a framed context: the domain. The method supports the designer to explore an enriched or future oriented context. The designer collects context factors out of the broad context analysis. These factors can be seen as research findings, and exists of different forms: principles, states, trends and developments. These factors are analysed and bundled into clusters that resulted in certain insights. The clusters with its insights give an overview of the current situation and context. The clusters are bundled in one overview, the conclusion, which is the endpoint of the research stage.

#### Design stage

### Design statement

After that, the designer formulates a design statement. This is a statement that concludes the analysis, and defines a goal and a

direction to further guide the design process. In this project the goal lays out the desired effect that the design concept aims to evoke. The direction lays out the desired interaction that the design concept aims for.

### Interaction qualities

The interaction vision explains the design direction on an interaction level. The designer describes the interaction by using interaction qualities. The type of interaction that should be designed to realize the desired interaction, is described by an interaction vision and its qualities.

#### **Design parameters**

In this project design parameters are defined to describe which functions and qualities are needed for a design intervention. They furthermore provide information on which functions are required to realize the desired effect. Besides that, they provide information on which qualities are required to realize the desired interaction. The parameters guide the designer in the development of the design concept.

### Process

The process of 'Vision in Design', which is applied in this project, can be visualized by a loop (see Figure 6), and the following steps:

- 1. analysing the current service
- 2. analysing the experienced interaction and the impact the service has on the experience
- 3. studying a broad context to explore solution space for a design intervention
- 4. defining design goal and direction (design statement)
- 5. defining desired interaction (interaction vision)
- 6. summarizing functions and qualities into design parameters
- 7. designing an intervention in the service

The method is visualized with a loop shape (see Figure 6). This loop visualizes the stages of the process of the 'Vision In Design' method.

The visual will be presented a several times. The visual will indicate which stage of the process will be discussed in that specific paragraph.

Figure 12 (page 20) shows the different steps of the research process in more detail. Figure 27 (page 60) shows the different steps of design process in more detail.



*Figure 6* showing the process of this design project, based on the method Vision In Design, which can be visualized as a loop.

## 1.3 Personal goals

I decided to participate in this project because of the (thematically) challenging focus of the project and because of my personal interest. It is a challenge to bridge the different perspectives of the stakeholders: RIVM, the health risk experts and the user group. It seems challenging to me to approach this project within an environment that is not familiar with the design field.

Moreover, that I appreciate the social focus of this project. During the bachelor and master, all the different design methods and techniques that I came across, mostly focussed on technology and business cases. At some moments, I missed the link to, and focus on, socially relevant topics. This graduation assignment seems like a perfect project to me, in where this social relevance is included. By literature and user studies, I will link this project to the minor Psychology I did during my Bachelor. The project will be inspired by psychological theories, but also social and communication theories.

Design approaches from the Design Aesthetics Area support me as a designer to include social, psychological and cultural factors. Therefore I choose for the design method Vision in Product Design, and a mentor from this design area. Getting inspired by the Vision In Product design method will hopefully help me to focus and include the different social, psychological and cultural factors. Besides that, cocreation will be used in this graduation project. I believe that bringing different perspectives together will help us to understand each other, and it will help to create common ideas. Therefore I choose for a Chair who has expertise in that field.

A personal goal in this project is to give a self-confident final presentation, to finish my bachelor and master with a presentation (of a design) which has relevance and which I can appreciate.



Figure 7 shows the challenge for Hanna

# **Research Part**

# Chapter 2. introduction to research

This chapter introduces the research part, and discusses the research approach of this project.

## 2.0 Intro

## Social relevance

The current society focusses on personal freedom, wealth and happiness. This enhances the individualistic perspective and personal responsibility, which is also reflected in the health domain. Citizens are involved in improving their own health and actively participating in health care, according to Meij (2007) and Elwyn et al. (2016). Themes such as shared decision-making and autonomy have become important in the field of healthcare, according to Godolphin (2009) and Stirrat et al. (2005). Focussing on the organized screening, experts working in the field of the organized breast cancer screening put an emphasis on realizing well-informed decisions of the user group whether to participate or not to participate in the organized screening.

The question is whether the user group realizes a well-informed choice regarding screening participation. Do all women of the subject group take the accurate information, their freedom of choice and their personal values into account when making their decision?

## **Current situation**

According to Timmermans (2013) not all citizens are capable to process information or are motivated enough to make choices, according to the required elements for a well-informed decision (see chapter 4.2). Besides that, according to a comparable study on population-based colorectal cancer (CRC) conducted by Douma et al (2016), people seem to unquestionably support the organized screening which is promoted by the government, instead of experiencing the freedom of choice. Furthermore, people do not base the decision on sufficient knowledge about risks which the screening entails.

There is little evidence that the current communication strategy has made a major impact on people's decisions and behaviour. The information flyer and webpage presents quantitative risk numbers. The presentation of quantitative risk information is abstract, often too complicated, insufficient and not in line with information needs of users.

## **Desired situation**

In the desired communication strategy, RIVM supports women to make a well-informed decision on whether they want to participate or not in the organized breast cancer screening. In this project, a wellinformed decision is interpreted as a decision based on the following aspects:

- 1. accurate, relevant and balanced information
- 2. freedom of choice
- 3. mindful choice: being aware of personal values and preferences.

This interpretation is based on theories of Timmermans (2013). Currently, RIVM is already searching for manners to support citizens to make a well-informed decision. The project focused on developing a communication strategy that puts the woman and her needs for information at the heart of defining a proper manner for providing information. The context and user's desires are therefore studied carefully.

## **Research** areas

The design question for this project was to find out how women currently make their decision, and how women can be supported in making a well-informed decision on whether to participate or not to participate in the organized breast cancer screening in the future.

Different research methods are used to study the service, interactions and context. The research methods that are used, are:

- user centered design research
- literature study
- inspirational research

The research methods will be shortly explained in the following section, and are shown in the following visual (see Figure 8).

## 2.1 Research methods



Figure 8 shows the different research areas and methods this project focussed on.

## User centered design research

#### Interviewing user group

The interviews with the user group were set up to study:

- women's experiences with the current service
- women's perspective on the organized breast cancer screening
- women's decision-making process

The detailed research plan of the interview sessions with the user group can be found in appendix 1.

Since it is a qualitative study, the study of eight participants was expected to obtain sufficient insights and information. This is based on previous similar studies in Social Medicine and TU Delft. An intervention was used in this study to prepare the participant for the interview itself. The usage of the intervention (see Figure 9) was inspired on the Context Mapping technique (Sleeswijk Visser et al, 2005). Before the interview, participants received a booklet with questions at home. Participants were asked to recall memories, and reflect on their experiences, ideas, and perspective on the organized breast cancer screening. For example, women were asked about their associations with the organized screening, their memory of the first invitation letter and the decision. This intervention offered touchpoints to elaborate on during the interview session. Eventually, this approach should give the opportunity to obtain more information out of the interview session itself.

The interview results were mostly in line with research results from previous conducted research. However, the interview session resulted in a rich impression of what women experience, which was valuable inspiration for the research & design project.

### Interviewing experts

Semi-structured interviews with experts were conducted to generate a richer understanding of certain topics. Experts could give support in making the academic research conclusions less abstract by offering



examples of every day practice.

Prof. Dr. D.R.M. (Daniëlle) Timmermans was interviewed on decision-making processes among patients. She is Professor of Risk Communication and Patient Decision-making at the Department of Social Medicine and the EMGO Institute of the VU Medical Center.

Henk de Vries, professor of general practitioners medicine was interviewed on how the medical field supports women in the decisionmaking process and the process of the organized breast cancer screening.

Petra Westdorp (manager Midden-West) and Mariet Kimminga (communication advisor) of the organization Het Bevolkingsonderzoek Borstkanker were interviewed to generate an understanding of the projects and activities applied by the executive organization.

An interview with a social worker at Mammarosa, Ina Speelman, was conducted to study the role of the non-profit organization Mammarosa and to gather knowledge about issues concerning the Arabic and nonwestern groups in the Netherlands.

## Literature study

A literature study is conducted to find out which factors play a role within the domain. These factors are used to answer the simple research questions and generate an understanding on why the context, the interactions or the service are the way they are. These factors are selected from academic articles out of the collection of RISC risk communication research group at RIVM & VU Amsterdam. Additional academic articles and news articles are used to broaden the perspectives of the exploration. The literature study enhanced the understanding on the 5 research themes. The literature study is supported by additional interview sessions.

Figure 9 the intervention which was used in the interview study to prepare the participants for the session

### Inspirational research

### Stretched context analysis

The stretched context analysis was set up as inspiration research. This research was especially valuable for the certain stage of the 'Vision In Design' process in which this research was conducted. This research was set up to explore the solution space of this research & design project. This analysis served to inspire, and therefore was not academic. It started from associations of the user group and design team, and studied the associations and meanings that the user group ascribe to the organized screening. Collage-making activities supported this research. The research results are documented in a logbook (see Figure 10). Pages of this logbook can be found in appendix 4.

## Creative session

An input session was set-up with women from different ethnical backgrounds, and women who have low literacy capabilities. The session had an creative approach, to generate insights and ideas together with the subject group about the design direction. Women with differences in ethnicity and literacy were involved in this stage of the project, to also take their beliefs and perceptions into account, and to take their capabilities into consideration.

In the facilitated session women talked about: turning 50, bodily changes and health choices. A few exercises were applied to stimulate the creativity within this conversation. The goal was to find out how women want to deal with these changes and health choices around the age of 50, and to develop ideas as input for the ideation phase. The decision for the organized breast cancer screening was also discussed, but in a later stage of the creative session. Design parameters could be abstracted from the research results (read chapter 7).



Figure 10 inspirational research results were documented in a logbook

# Chapter 3. domain & research themes

This chapter discusses the framed or specified context, which is defined in the beginning of this project. This domain is studied in the further research & design project. Furthermore, this chapter gives an impression of the research themes and questions, which are used to study the domain.

## 3.1 Domain

The following factors are included in the frame of the analysis.

## **Organized screening**

Since the start of the organized screening in 1989, the treatment of breast cancer has significantly improved. The mortality rates from breast cancer has decreased since 1989. Half of this has been realized through the introduction of the organized screening, and half of this has been realized through better treatment. It is known that women who regularly participate in the screening program are 50% less likely to die because of breast cancer, than women who do not participate. (RIVM, 2012)

The organized screening was set up in 1989, because there were more benefits on the target group level (women in the Netherlands between 50 and 75 years old) than the disadvantages. However, the balance of benefits versus disadvantages differs on an individual level. This is why the screening program has been organized in such a way that it still remains a personal decision whether a person wants to participate or not. (RIVM, 2012)

This research & design project will study the service and communication material which is offered by the RIVM (leading organization) and Het Bevolkingsonderzoek Borstkanker (executive organization) (see Figure 11).

## Decision-making & differences in motivation and capabilities

Citizens show different motivations and capabilities in making an analytical (deliberate) choice. People make use of simplified decisionmaking techniques to make their choice. Institutions that set up the organized screening feel their responsibility to support women in their decision. (Timmermans, 2013).

Differences in motivations and capabilities will be taken into account in this research & design project (see Figure 11).

## Age group

A study of Landelijk Evaluatie Team Bevolkingsonderzoek Borstkanker (LETB) in 2016 showed that the participation loyalty (which is calculated over the last 2 screening rounds) is 91,1%. This analysis assumes that the first decision influences further decisions. For that reason, there is an interest in how women make their first decision to participate or not participate.

*The research and design project will focus further on the first decision makers: the age range between 48 and 56 years old (see Figure 11).* 

## Associations

The solution space of this research & design project will be enriched with explorative research into themes that are indirectly involved within this domain (see Figure 11). These associations are themes which are experienced by the focus group: aging, the transition to a new life phase (menopause), femininity and uncertainty of life. Furthermore, other context factors are explored which could inspire the project goal (supporting women in well-informed decision-making), such as future technologies and the usage of emotion as communication source and as strength in moral judgement.



Figure 11 is showing the domain and topics that are studied within this research & design project.

## 3.2 Research themes

The domain is analyzed on 3 levels: service level, interaction level and context level. These levels are based on the 'Vision In Design' method (Hekkert and Van Dijk, 2011). Furthermore, each level is explored via different perspectives: a service-design, a psychological, a statistical, a societal and a public health (care) perspective. This resulted in studying 5 themes, which analyzed the levels and explored the levels via different perspectives. Simple research questions are used to study each theme (see Figure 12).

## Theme 1: Organized screening and its service

service interaction context

On a service & interaction level: exploring and deconstructing the current service offered by RIVM.

- What does the service offered by the organized screening express and how do women interact with the service?

On a context level: understanding why the context is, the way it is.

How do women think and feel about breast cancer screening?
And to what extend are women aware of the negative consequences of participation to organized screening?

### Theme 2 : Decision-making process

context

On a context level: generating an understanding of decision-making processes and how decisions are made by women.

- How do people make a well-informed decision?
- How do women decide to participate or not participate in the organized screening?
- What are women's motivations to participate or not participate?

#### Theme 3 : Risk-factors

service interaction context

On a service and interaction level: generating a perspective on the risk communication strategy of the RIVM.

How does RIVM communicate the risk information about the breast cancer? And why?

On a context level: generating an understanding of the risk numbers of the breast cancer and the organized screening.

What are the risk numbers of the disease and the risk numbers of participation or not participate?

## Theme 4 : organized breast cancer screening and its associations context

On a context level: generating an overview of context factors that play directly or indirectly a role.

- Which stakeholders are involved within the domain?
- Which factors are associated with the organized screening and (in)directly influence women's way of thinking?

## Theme 5 : solution space

future context

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On a future context level: exploring solution space for a design intervention, and to broaden the perspective on how to communicate risk information.

How do people perceive information effectively in such a way that the information influences people their way of thinking or behaviour?



## Overview of study of domain: decision-making among women (48-56 years old) about participation in the organized breast cancer screening

Figure 12 is presenting a overview of the research themes and methods that are used to study the domain. This visual also shows the process of the research phase.

# Chapter 4. analysis results



This visual indicates the stages of the research & design process, which will be described in the chapter 4. In this chapter, the findings of the analysis of domain will be presented for each theme. Each theme presents the insights which answer the research questions, and which are based on the findings of the literature study and interview sessions. These findings are the important factors which play a role in the domain and are clustered into insights. The findings are focussing on the 3 levels: service level (the envelop), interaction level (interaction between women and envelop) and context level (factors around women & envelop). The envelop contains the information flyer and invitation. The levels can be recognized by the labels through the report.

# 4.1 The organized screening & its service *theme 1.*

This theme explored the set-up of the current service, and the attitude of women towards the organized breast cancer screening, by studying the following questions:

- What does the service offered by the organized screening express and how do women interact with the service?
- How do women think and feel about breast cancer screening? And to what extend are women aware of the negative consequences of participation to organized screening?

## The service of the organized screening and its interactions service interaction

# Insight 1. A specific informing step does not exist within the user journey of the service.

The service offered by RIVM and Het Bevolkingsonderzoek borstkanker is shown in the visual on the next page. The participation or nonparticipation journey is visualized (see Figure 13).

The service offered by RIVM and Het Bevolkingsonderzoek borstkanker consists out of four steps:

- 1. Invitation
- 2. Mammography
- 3. Examination x-ray by two specialists
- 4. Result

This envelope consists of an invitation letter for the periodic check-up. There is a proposed date in the envelop, which can be changed. This envelope also consist of a flyer with information about:

- the procedure of the organized screening

- the risks: potential benefits and consequences of the organized screening

If a woman decides to participate to the organized screening, a mammography will be applied (2nd stage of the service). After that (3th stage of the service), the mammography photos will be studied by two specialists. Finally (4th stage of the service), women receive the result. Women receive the result at home if the result is negative (no abnormalities found). If the result is positive (abnormalities found or unclear results), women are called by their G.P. and will officially receive the result at home afterwards.

The further process, depends on the outcome of the test. If the test results are positive (abnormalities found or unclear results) women step into a further procedure and do further testing. This procedure is not part of the service, and will be applied by the medical center.

A noteworthy thing about the service is that women receive just one envelope, and the envelope includes on the hand the information, and on the other hand the invitation. These findings resulted in insight 1.

## Insight 2. The first invitation is the same as all other invitations.

When women turn 50, they enter the regular organized screening program. During the next organized screening, these women receive the regular envelope with an invitation and an information flyer at home (see Figure 13). There is no separate letter for those who receive the letter for the first time and have to make a decision for the first time.

# Insight 3. Women already make their decision before the first invitation letter.

One of the findings of the interviews sessions was that most women already made their decision before they received the invitation letter. Their personal beliefs seem to influence their decision. Besides that, the organized screening seems to be a topic women talk about at the age of 50. Stories and opinions of others seem to effect the decision making of some women.

## User journey of service

goals	decision on participation to organized screenning		participation to organized screenning	waiting for test results	perceiving test results	undergoing follow-up test and perceiving follow-up test		
phase in journey		naking process				abnormalities detected	not enough information different way of diagnose	
insight 2: 1st ever invitation = like all the others					T/10 found cancer diagnosed	T/10 found cancer diagnosed		
	→	participating not participating	→ <b> </b> ]	+/- 10 days	→	x abnormalities detected	is needed x not enough information	
0. almost 50 years old	1. invitation		2. the mammography	3. examination x-ray by 2 radiologists	4. the result	5. further research	6. second result 7. diagnose & treatment	
	afte	r 2 years						
						<i>e</i>	diagnosed with cancer without organized screening	
experiences & <sup>insig</sup> emotions	it 1. envelope consis	ts of info + invitation						
stakeholders involvement								
G.P.'s								
Friends								
Bevolkingsonderzoe	ek 👘							
RIVM								
Medical centre			2					

Figure 13 is showing the user journey of the service offered by Het Bevolkingsonderzoek Borstkanker & RIVM and highlighting two important insights.

# 4.1 The organized screening & its service *theme 1.*

## Additional insight. Women complain about the methodology

During the interview sessions, it was found that most of women dislike the methodology that is used in the organized screening. Women complain about the old-fashioned and painful method: mammography.

## Context analysis

The 'Vision In Design' (Hekkert and Van Dijk, 2011) method supported the design student to explore an enriched and future oriented context. The designer collected context factors out of the broad context analysis. These factors can be seen as research findings, and exists of different forms: principles, states, trends and developments. The following descriptions give a short explanation of the different forms, according to the 'Vision In Design' method (Hekkert and Van Dijk, 2011):

- *Principle:* a stable pattern in life, and often a fundamental human concern or pattern of behaviour.
- *State:* a phenomenon that appears as fixed, and does not need to exist in the long run.
- *Trend:* a reflection of a development in human behaviour, which exist in combination with a development.
- *Development:* a changing or unstable pattern in the environment or in the concerns of people.

The factors that were generated out of the context analysis, were analysed and bundled into clusters. These clusters resulted in certain insights. The clusters and its insights gave an overview of the current situation and context. The clusters are bundled in one overview, the conclusion, which was the endpoint of the research stage.

## Women's attitude towards the organized screening



Insight 4. There is *awareness* among women about the disease since breast cancer exists in their environment.

Factors represent the research findings and are presented as principles, states, trends or developments (according to 'Vision In Design' method (Hekkert and Van Dijk, 2011)). The factors on which this insight is based, are discussed below.

- State: women are aware of the disease, and it's seriousness, because of stories of people around them (insight out of interview with user group, theme: 3. bevolkingsonderzoek borstkanker – see appendix 1).
- Principle: women who fear developing cancer have a higher risk perception, in which fear is defined as an emotional reflection to the threat of cancer, studied by Yavan et al. (2010). This study showed a correlation between the high perception of breast cancer risk and the fear of developing cancer.
- Principle: worries about cancer and the rate of self-tests performance were higher among women with a family history of cancer, and it was shown that women with a family history of breast cancer had better breast cancer knowledge and awareness about the screening (Yavan et al., 2010).

"Someone from my choir has been operated for breast cancer this week. Now it comes close. And when I look around, there are several women that I know who have had breast cancer or other forms of cancer. Then you can not act like it does not exist ..."

Participant TDo1 (interview with user group)

- Trend: the overrepresentation of low-risk patients with better health conditions who participate in preventive research suggests that many decisions are not informed decisions. Participants who agree on preventive medical research, might base their decision on an overestimation of their own risk. Citizens who choose not to participate in preventive medical research might base their decision on insufficient knowledge (Timmermans, 2013).
- State: women participate because they know women in their environment who suffer of suffered from breast cancer (insight out of interview Henk de Vries, G.P. VUmc Amsterdam – see appendix 2).



Insight 5. Women's image of breast cancer is guided by experiences & stories from their environment.

*This insight is based on the following factors and research findings of the interview sessions (see appendix 1).* 

- Principle: Negative and positive feelings are labelled on in-mind representations of objects or events. These labels support humans in decision-making. Stimulus from an object or event evokes an emotional evaluation. This often happens without being aware of it. Evaluating emotionally is a natural approach to criticize things, and the emotional evaluation is used as heuristic for making complex decisions, according to a theory of Slovic et al. (2007). This theory suggests that these labels linked to events or objects (which are used for the emotional evaluation), are a result of life experiences. People are motivated to avoid negative feelings, such as disappointment or regret. For example, women decide to participate in the organized breast cancer screening, even though the risk of getting cancer is low, because they fear that they will regret it afterwards.
- Principle: People's mood influences the decision approach: analytical or holistic. A positive mood leads to a more holistic way of thinking. A negative mood (such as fear or sadness) leads to a more analytical way

And, Marrianne that close friend.that was the motivation to do it." Participant WD02 (interview with user group)

"Well, I thought: I do see a lot of women around me with breast cancer.

of thinking.

- Principle: Stories of other people are a common information source for women's decision-making process, about whether to participate or not in organized breast cancer screening. This resulted out of the interview session with the user group (insight out of interview, theme: 5. information sources – see appendix 1).
- State: Women are aware of the seriousness and frequency of the disease. When opening the envelope with the test result, women experience fear of suffering from the disease. However, this mostly happens after women experienced that a second test was needed once. Experiences of women they know, or stories that women hear from others in their surroundings, affect affect the images that women have on breast cancer. This resulted out of the interview sessions with the user group (insight out of interview, theme 3 and theme 4 see appendix 1).

# 4.2 **Decision-making process** *theme 2.*

*This theme explored the decision-making process, and how this decisions is made by women, by studying the following questions:* 

- How do people make a well-informed decision?
- How do women decide to participate or not participate in the organized screening?
- What are women's motivations to participate or not participate?

## *The definition of a well-informed decision*

RIVM and Het Bevolkingsonderzoek Borstkanker are striving for women making a well-informed decision. The following three elements are essential for a well-informed decision.

## Necessary for making an informed decision is:

1. Accurate, balanced, unbiased and relevant information that women can understand, about:

- the purpose and benefits of organized screening;
- the harms and risks of the organized screening;
- Information about medical, social and financial implications;
- Information and instructions about the entire procedure;

Necessary for making a personal (or autonomous) decision is:

- 2. Personal decision, freedom of choice, by:
- experiencing freedom to choose;
- possible advisory role of GP, or another medical expert

*Necessary for making a decision in accordance with personal values/ attitude/preferences:* 

3. Insight into personal values and preferences, by:

- Personal weighing of all information in relation to personal values and preferences.

This essential element for a well-informed decision is also described as 'a mindful choice'. *Mindful* can be defined by being conscious or aware of something. In this project, *mindful* is interpreted as 'being conscious of personal values and preferences'.

(Baron 2007, WRR 2009, Timmermans 2013, Marteau et al 2001, Rimer et al 2004, Irwig et al 2006 Denters et al 2013).

Insight 6. A decision can be defined as well-informed, if the decision fulfils the following criteria: 1) accurate, relevant and balanced information, 2) freedom of choice is experienced, and 3) a mindful choice.



## Decision strategy user group & motivations

Factors represent the research findings and are presented as principles, states, trends or developments (according to 'Vision In Design' method (Hekkert and Van Dijk, 2011)). The insights are based on the factors and research findings of the interview sessions (see appendix 1).

# Insight 7. Most of the women do not make their decision controlled, but automatically, without in-forming themselves.

The results of interview with users showed that women make their decision automatically (not controlled), and base their decision on certain simple considerations, such as:

#### "breast cancer is really serious, so I participate." or "It is a some service from the government, which is good, right? I just

*participate."* Out of the interview sessions resulted that the decision is already made before the envelope with information arrives (insight out of interview – see appendix 1). Women do not make use of the information flyer to make their decision. In this way, some women are not informed about the negative consequences (risk factors) of the organized screening. Information in media and stories from other women is used to shape an opinion, without using the (risk) information offered by RIVM.

This insight is in line with a study, of Douma (2016). An important factor that was generated out of this study, is the following one.
*State*: the Dutch public is more aware of the benefits than possible harms. The overall positive image of the Dutch public towards breast

cancer screening program might be explained by the fact that people

have more knowledge about the benefits of the screening, than about its possible harms and risks (Douma et al., 2016).

# Insight 8. Women do not experience the freedom of choice for the decision whether to participate or not to the organized screening.

The interview sessions showed women do not experience freedom of choice in the current procedure. Women seem to be supportive towards the organized screening, because women experience the screening as an offer from the government (insight out of interview – see appendix 2). Women mention considerations, as:

## 'This research is part of it anyway, right?'

# Insight 9. Not all women are aware of their personal values, or do not weigh their values in relation with all information.

Out of the interviews resulted that not all women do make their decision mindful, being aware of their variety of personal values and preferences. It seems like women base their decision mostly on one value they have, health (insight out of interview – see appendix 1).

## Insight 10. The decisions of women are driven by beliefs and dogma's.

The considerations of women are driven by certain beliefs, or dogma's. The dogma's are used to simplify the decision. For example: one women defined the value health as really important. She defined her belief '*better safe than sorry*' in an earlier stage of life, which simplified her further decisions in life. She automatically participates in the organized breast cancer screening because of her belief. An remarkable thing about these beliefs or dogma's is that, these beliefs or dogma's can be misconceptions. The misconceptions influence the decision.

Another important factor, that plays a role within the domain of decision-making is the following factor.

Principle: Heuristics make the decision-making process easier. A common heuristic for women within the decision-making process about the screening is: "organized screening, that just what people do". Such a heuristic is used as a criteria. An expert also makes use of heuristics in a decision-making processes. These heuristics are rules of thumbs, which can be used to simplify the de-cision problem, and solve this analytically. A person who uses these heuristics, makes a decision in a more intuitive way (insight out of interview D.Timmermans, see appendix 2).

Based on the previous insights (insight 7 till 10), is assumed that most of the decision are not made well-informed yet. Because of a lack of focus one of the 3 aspects of a well-informed decision:

- 1. Using accurate, relevant and balanced information
- 2. Feeling freedom of choice
- 3. Making a mindful choice: aware of personal values and preferences

## Insight 11. Within our society not every individual is as motivated and capable to make a decision regarding her (or his) health.

*Principle*: not all citizens are capable or motivated to make wellinformed decisions . However the society can support these citizens in their decision-making, for example by nudging. According to Timmermans (2013) making informed decisions is limited by the capacities of people to process information and the variation in skills and motivation for making choices. However, it is possible to make choices easier for less motivated citizens, by for example making the healthier decision easier or more attractive. This is called *nudging*.



"It is not an issue at all for me! It's just painful and annoying, but it never happened that I thought: 'Maybe I should not participate.' It like an 'APK keuring' (periodic technical car inspection) for me!" Participant WD04 (interview with user group)

"In fact, I have already made the choice to participate before. The screening gives me the opportunity to be ahead of something, and I believe that is more important than all those other things." Participant WD05 (interview with user group)

## Interview results

The interview results are documented in the appendix 1. The interview data was analysed on every specific theme of the interview. Insights were generated out this. The insights are supported by quotes of participants.

## Representation of the decision strategy of user group

An overview of the interviewed personas is made (see Figure 15), to keep the richness of all the interviews data. An impression of the participant group is given, with their personal values in life, and the way they make decisions. It is presented in the decision strategy model of Timmermans (2013).

## Information sources usage of women

An overview is created that shows the information sources usage of the participants (see Figure 16). The overview represents what kind of sources women use to find an answer on their question, or to ask their questions to. Besides that, this visuals show that women talk about their choices with people close to them: friends, family members and colleagues. Women come across media items, which influence women's choices sometimes.

## Definitions of terms used in decision-making theories

The theme decision-making is explored via a psychological perspective. This section uses more jargon than other sections. A short explanation of certain terms is explained in the section below.

**Heuristic:** automatic and analytical decisions, procedures to simplify systematically and processing and using information selectively, for example: the route to work, the doctor's way of making a diagnosis.

**Habits:** automatic and intuitive decisions, for example: drinking a coffee in the morning.

**Controlled intuitive decisions:** the information is not analysed and advantages and disadvantages are not compared, for example: buying a new jacket.

**Controlled well-informed decisions:** the information is analysed and advantages and disadvantages are compared, for example: buying a new car.

Based on definitions used in decision-making theorie of Timmermans (2013).



habits

Holistic

controlled intuitive choices

## Information sources which women use in their decision-making



Figure 16 information sources which women use to inform themselves (based on results of interview session)

# 4.3 **Risk factors** *theme 3*.

This theme explored risk communication strategy of RIVM, and generating an understanding of the risk numbers of breast cancer and the organized screening.

- How does RIVM communicate the risk information about breast cancer? And why?
- What are the risk numbers of the disease and the risk numbers of participation or non-participation?

## *Risk communication by RIVM*

service interaction

Insight 12. Risk information is presented in jargon, in terms that non-experts have difficulties to understand or to relate to.

This insight is based on the factors that are discussed below.

- State: risk information is communicated by numbers. However it is difficult to relate to these numbers for people. There is a need for a more useful affective way, and a manner that people understand, studied by Explore Ferro (2017).
- State: according to a study of Gigerenzer et al. (2008) many doctors, patients, journalists and politicians do not understand what health statistics mean, or draw wrong conclusions on statistics without even noticing.
- Principle: according to the study of Gigerenzer at al. (2008) there is need for transparent communication, that the human mind can easily digest, by focusing on visual and numerical representations.

-> *State*: Risk number seems to have a little impact on women their

decision-making process. This resulted out of the interview session with the user group (insight out of interview, theme: 4. decision-making, see appendix 1).

Insight 13. Lack of knowledge among women about about potential negative consequences of participating

*This insight is based on the following factor and research finding of the interview sessions (see appendix 1).* 

- State: Dutch public has more knowledge and awareness about benefits than possible harms. The overall positive view of the Dutch public towards breast cancer screening program might be explained by the fact that people are more aware of and have more knowledge about the benefits of the screening, than about its possible harms and risks, according to a study of Douma et al. (2016)
  - Trend: Not all women are aware of the negative consequences of participating in het bevolkingsonderzoek borstkanker. This resulted out of the interview session with the user group (insight out of interview, theme: 3. Bevolkingsonderzoek borstkanker, see appendix 1).

Two remarkable quotes of the participants were:

"Does mammography contains of risks? I did not know anything about risks." (participant WD01)

"Those personal risk figures... I might go living towards them, and that will make me scared or something. That's a waste of my time, that's a waste of quality of life. No, really. I do not want to know, take life as it comes now, and go with it. That's nice, isn't it?" (participant TD02)

# *Risk of ever incurring the disease in life*

The participation or non-participation includes risks. This is partly caused by the risks of getting the disease during life. Another part is caused by the test risks of the research itself.

# Insight 14. Risk of incurring the disease consists of 3 types: heredity, hormones and life style.

The life risk contains out of 3 types:

### 1. Heredity

People can have a predisposition, but having specific genes do not guarantee the development of breast cancer.

## 2. Hormones

Breast are dependant on hormones to keep functioning. However, constant exposure to hormones is harmful as well. Long-term exposure can be caused by different factors. These factors are the risk factors for long-term exposure to these hormones:

- early menstruation
- late menopause
- never had children
- giving birth later in life (>35 years old)
- no or for a short time breast feeding
- taking birth control pills
- taking hormone preparation pills for longer than 2 or 3 years.

## *3. Life style*

Besides that an unhealthy life style enhances the risk of suffering from breast cancer. There a different life style factors that are risk factors, like:

- drinking alcohol (everyday more than one glass over a longer period of time)

- little psychical activities
- overweight during and after menopause

An overview of the type of risks and the risks numbers are visualized on the next page (see Figure 17). This model is based on an intern workdocument of department L&G, RIVM – "lekenperspectief bevolkingsonderzoek borstkanker", which will not be published and is only available for internal usage. A variation of this risk model is presented on the next page. This model is summarizes findings of different studies into risk factors regarding to breast cancer and the organized screening of RIVM and Integraal Kankercentrum Nederland, (Integraal Kankercentrum Nederland, 2018), (Integraal Kankercentrum Nederland, June 2018), (RIVM, 2017), (RIVM, November 2011).



Figure 17 showing risk factors independent and dependent of organized breast cancer screening.
## *Risks – participation to organized breast cancer screening*

The participation or non-participation risks, are also caused by the test risks of the research method. The test used in the organized screening should distinguish participants who have the disease from those who do not have the disease. A test must be able to distinguish between two groups: "possibly sick" versus "not sick".

The quality of a test to distinguish between two groups, is closely related to the test properties: specificity and sensitivity. The test properties have a lot of impact on the success of the organized screening (RIVM, 2012).

#### Sensitivity

The sensitivity of a test is the probability that the test gives a "positive" or "abnormality" result to people who have the disease. In other words: the sensitivity of a test is the percentage of right positive results among the sick participants. The higher the sensitivity is, the better the test detects sick women. A low sensitivity causes a high rate of false-negative results (RIVM, 2012).

#### Specificity

The specificity of a test is the probability that the test gives a "negative" result to people who do not have the disease. In other words, the specificity of a test is the percentage of correct negative test results among healthy participants. The higher the specificity, the better the test indicates healthy women as healthy. A test with a low specificity causes a high rate of false-positive results. The best tests quality is a test with a sensitivity of 100% (everyone who has the disease is detected and referred to further research) and a specificity of 100% (nobody who is healthy is referred to further testing). However, these tests do not exist much. This indicates why the false-negative and false-positive test results happen (RIVM, 2012).



Figure 18 shows the test risks of the organized breast cancer screening on sensitivity and specificity scale.

### Sensitivity vs. Specificity

The analysis of het LETB (2016) showed a program sensitivity of 84% against a program specificity of 98,9% of het Bevolkingsonderzoek Borstkanker, during 2004 - 2009. The program specificity is very high compared to other countries. The test risks of the organized breast cancer screening are shown in the figure above (see Figure 18).

Insight 15. Mammography the method which is used for the organized screening, does not have the ideal test quality yet (sensitivity of 100% and specificity of 100%), which means that the test produces some false-negatives and false-positives.

### Rational decision-maker

The Dutch government has organized the biennial screenings because the advantages at the general population level were considered higher than the costs and the potential disadvantages. On a citizen level the advantages do not have to outweigh the disadvantages. This is why the screenings program has been organized in such a way that it still remains a personal decision whether a person wants to participate or not (RIVM, 2012).

The future contains of probabilities. It is not sure which pre-defined risks will come true. In the following visual (Figure 19) is shown that each decision consist of certain risks. It is important to mention that the risk numbers differ per risk factor.

A noteworthy thing to mention is that it seems difficult for people to make a personal decision only based on these risks, since it is difficult to understand and to imagine the probabilities in relation with the person its potential future.



Insight 16. Not all citizens have the motivation or capabilities to make a rational decision in each situation, which is taken as standard in the Well-Informed Model of the health-care system.



Figure 19 shows the difficulties when basing a decision only on risk numbers

## Chapter 5. stretching the context



This visual indicates the stages of the research & design process, that will be described in chapter 5. In this chapter, the findings of the stretched context analysis will be presented. The findings are mostly inspirational factors for this project. The findings will be presented per theme: theme 4) organized screening & its associations and theme 5) solution space. Each theme presents the insights which answer the research questions of that theme, and which are based on the inspirational research which was conducted.

# 5.1 Organized screening & its associations *theme 4.*

In the next pages the findings of the broad context exploration can be found. The stakeholders and their relations are analysed. Furthermore the inspirational research was conducted to explore the context by a more creative approach. This exploration relies on making collages. The insights in this chapter are based on the findings (selected context factors) out of these activities.

The research questions of this theme, were:

- Which stakeholders are involved within the domain?

- Which factors are associated with the organized screening and (in) directly influence women their way of thinking?

### stakeholders

#### context

Different stakeholders are involved within the domain of the organized breast cancer screening. The stakeholders and relations can be seen in the visual on the next page (see Figure 20). The most important stakeholders for this project are:

- RIVM
- Het Bevolkingsonderzoek borstkanker
- Women between 50 and 75 years old (target group for organized screening)

### RIVM

RIVM is het leading organization, which conducts research about public health and environment, and communicates research findings. Researcher from the epidemiological field work for the organization. The research department conducts research, and communicates finding to the government and academic field. The communication department focusses on communicating the risk information (based on research findings) to society.

### Het Bevolkingsonderzoek borstkanker

Het Bevolkingsonderzoek borstkanker, is the executive screening organization. The screening organization organized the screening. Laboratory technicians conduct the testing, and send the photos to x-ray specialists who analyze the photos. The screening organization works together with the medical field. If another test is needed, women visit the hospital.

### Women between 50 and 75 years old

Most women are in contact with family and friends and support each other, during the decision-making, the screening and if further testing is needed. However, also other organizations deliver support. Women organizations give support to women from different ethnical background, by informing women on breast cancer, self-checking and the screening (interview Mammarosa, see appendix 2) Patient organizations give care to women who suffer from the disease.



Figure 20 overview of stakeholders that are direct or indirect connected with the user group, RIVM and Het Bevolkingsonderzoek Borstkanker.

# 5.2 **Inspirational research** *thema 4.*

Other factors that are not directly linked to the topic 'decision-making for the organized screening', were also studied within this project. These areas were studied by the inspirational research. This research was especially relevant for that stage within the Vision In Design process (Hekkert and Van Dijk, 2011). This inspirational research explored the meanings and associations of the organized screening. Several topics resulted out of the interview sessions with the user group. Furthermore, these topics were based on own associations with the organized breast cancer screening. The topics were explored by online searching activities, and analysed by analysed by making collages.

*The following topics were explored:* 

- Femininity
- Menopause
- Aging
- Uncertainty of life
- Emotions as source of information

The important results of the inspirational research are shown here, the other results can be found in the appendix 4.

Insight 17. In many cultures, the female breast is associated with gender and sexuality. Within society the symbolism of the breast is used in communication and body language, which leads for some women to difficulties in accepting their body.

This insight is based on the following factors. The factors resulted out of a visit to the exhibition The Female Touch (2018), at Gemeente Museum Den Haag, and the collage-making activity to explore the symbolisms and usage of the female body (see Figure 21).

- -> *State*: Female breasts are in many cultures related to gender and sexuality. The female breast is a symbol for femininity and fertility.
- *Principle*: Women use their personal femininity to express themselves. The female body language contains many symbolisations, such as fertility, tenderness and sex.
- *State*: Women struggle with accepting their body, and the acceptation of body differences.

### Femininity

Figure 21 exploration of the symbolism and usage of the female body (language).



#### Menopause

stretched context

## Insight 18. For most women, the menopause also starts during the age of 50 (when women receive their first invitation).

This insight is based on the following factors, which resulted out of the collage-making study to explore what the menopause entails and how women experience the menopause (see Figure 22).

- State: The menopause is a realisation moment. During the menopause women experience the realisation that time is passing by.
- -> *State*: the menopause itself is a body transition in which women lose their fertility. Women describe the menopause, as: "not sexy"
  - State: the menopause seems to be a taboo. Women (and also men) laugh or do not talk about it. However, women experience the menopause as complicated.

### Menopause

Figure 22 exploration of the what the menopause entails and how women experience the menopause.



#### Aging stretched context

## Insight 19. Women fear aging. This could be explained the negative image of aging in the Dutch society.

This insight is based on the following factors, which resulted out of the collage-making study to explore what the aging entails and how women experience aging and its meanings (see Figure 23).

- *State*: Aging has impact on women their body image, and influences their behaviour (Chrisler & Ghiz, 1993).
- State: On the other hand, other cultures have a more positive image of aging. For example, aging is more associated with wisdom (Birren, 1990, pp. 320–322).

### Aging

Figure 23 exploration of what aging entails and how women experience aging and its meanings.



### Uncertainty of life

stretched context

## Insight 20. During certain moments of life, people become aware of the uncertainty of life, which brings up fears for some people.

This insight is based on the following factors, which resulted out of the collage-making study to explore what the uncertainty of life entails and how people experience and deal with uncertainty (see Figure 24).

- State: people believe in something bigger than themselves and their knowledge to deal with the uncertainty. This results out of a study of Dein (2016).
- Principle: things or occasions let people realise what they value in life. Sometimes the uncertainty comes very close which makes people aware the finiteness of life. However, other people also find these life lessons in stories or experiences from others around them. This resulted out of the interview sessions with user group (interview results – theme 2: personal values, see appendix 1).

### Uncertainty of life

Figure 24 exploration of what uncertainty of life entails and how women experience and deal with uncertainty



## Associations in relation to service

*This following insights are based on research findings of the interview session with the user group, and literature research.* 

## Insight 21. The organized screening triggers tension and feelings, such as fear and shame.

Research has shown that women experience barriers, and emotions during the procedure of the Bevolkingsonderzoek Borstkanker. (received from internal source RIVM – risk overview) Also out of the interview sessions resulted that the organized screening triggers feelings and tension. Women fear for the disease, or feel shame and/or pain during the testing. RIVM & Bevolkingsonderzoek Borstkanker do not give much attention to the emotional part in their current communication strategy, but mostly focus on the rational part. Namely, RIVM & Bevolkingsonderzoek Borstkanker focus on prevention and risk numbers in their current communication strategy.

The emotional impact seems to exist during different stages of the procedure of the organized screening. During the invitation stage women are triggered to think about the topic breast cancer, but also all its different associations, such as: bodily and health changes, aging and the uncertainty of life. During the test phase, women are aware of the disease breast cancer, and are aware of the consequences of the disease. All these factors seem to have a meaning for women in this stage of life, and seem to effect women their way of thinking and their emotions.

## Insight 22. The invitation for the organized screening is experienced as a confirmation of aging.

The first invitation letter arrives during the age of 50. At that age, women go through the menopause, a certain transition which is influenced by female hormones and goes along with mental struggles. It seems that women become aware of the fact that they are becoming older, which includes associations and emotions. It is a moment of realization, and creates a feeling of: time is passing by. The topic menopause, appears to be a taboo in the current society. A remarkable insight is that, when women receive the first invitation, women experience the envelope as a confirmation or trigger. The interviews sessions with the user group (see appendix 1) shows that the first invitation is a moment of realization, or triggers a negative feeling, like: *'alright, so now I also join this group of old people.'* 

# 5.3 **Solution space** *theme 5.*

This following insights are based on research findings (factors) out of a broad literature and news articles study. Factors represent the research findings and are presented as principles, states, trends or developments (according to Vision In Design method (Hekkert and Van Dijk, 2011)). These findings resulted out of the inspirational research to search for solution space.

## Communication on an emotional level

Insight 23. Emotions are a natural source of information. A personal story which people can relate to seems to have more impact than many forms of statistics.

*Principle:* According to psychological theories of neuroscientist Tali Sharot, emotion is mentioned as a really effective source of information (Psychologie Magazine 8, 2018). This source of information is contradicting to the source information used by RIVM. RIVM does its communication mostly via rational information sources. Emotion as a source of information, has been an inspiring element for – this project.

## Insight 24. Emotions are useful for decision-making processes, in order to make moral judgements.

*Principle:* The usage of emotion in decision-making has been supported by Prof.dr. S. Roeser of the TU Delft, who did research on moral emotions and risk politics. According to Roeser (2006) emotions have often been not taken seriously in political debates about risky technologies, and emotions has been associated with laypeople. The rational decision-making is based on the understanding of quantitative information about risks. However, emotions are necessary in order to make moral judgements on the ethical aspects of risks, such as justice, fairness and autonomy.

Insights 25. A mechanism why human beings can collaborate in large numbers, is: imagination. People have the ability to invent stories which help people to imagine the future world, another world or things in the world we don't know.

*Principle*: According to the historian, philosopher, futurologist, Yuval Noah Harari (2015), humans cooperate effectively with each other because we believe in similar things, like gods, nations, money and human rights. None of these things exists outside the stories that people invent and tell one another, except in the common imagination of human beings. The power of human beings: to visualize the world or future, by stories that people invent and communicate to each other which triggers imagination, has been an inspiring principle for this project too (Harari, 2017).

## Chapter 6. conclusion



This visual indicates the stages of the research & design process, that will be discussed in chapter 6. In the research findings of this project will be conclude. The most important insights will be discussed, which direct to the design direction.

This chapter ends with a summary of the analysis (see Figure 25). The summary describes the five main topics of the domain. After that, a final conclusion is formulated driven by the perspective of the design student.



Figure 25 shows the process of the final stage of the analysis

1. Women are aware of breast cancer and hope that the organized screening offers a solution for the disease.



Breast cancer is a common disease. Women know other women who have or have had breast cancer. Stories from women around them, like friends, colleagues, family members or neighbors, seem to have a big impact on women risk perception. It seems like women take these stories seriously. Within our society there is much hope and belief in het Bevolkingsonderzoek Borstkanker, as a solution for the high frequent and seriousness of this disease. 2. Women do not make a well-informed decision on whether or not to participate in the organized breast cancer screening and, perhaps more importantly, are not supported to do so.



RIVM is communicating risk information about breast cancer and the screening. It should be mentioned, that RIVM also communicates that women can decided themselves whether they want to participate or not. However, out of the interviews resulted that most of the women: do not process the risk information in their decision and are not aware of their personal values when making the decision. Besides that, some women do not experience the freedom of choice, but experience this as a service offered by the government which everyone should follow.

3. Beliefs influence decisions of women regarding their health.



4. Effective risk communication should focus on stories people can relate to emotionally.



W Women simplify their health decision by making their decision automatically, and by using heuristics. Heuristics seem to be based on their personal beliefs or dogmas, which are already defined earlier in life. Women do not seem to be aware of these heuristics and are not aware of the validity of their beliefs in this context. These beliefs may lead to misconceptions. People experience difficulties in the interpretation and understanding of risk numbers. From the epidemical field, there seems to be an demand for transparent communication that the human mind can easily digest by focusing on visual representations of risk numbers. RIVM is also struggling with how to present risk numbers of breast cancer and the screening. However, another focus might be just as effective: emotions as a source of information, which is a natural manner of communication. A personal story which people can relate to, seems to have more impact than all forms of statistics.

5. The invitation letter is experienced as a confirmation of aging.



Aging has a negative image in the Dutch society. Aging has impact on women's body image, which also influences behaviour. During the menopause women experiences all the complications of aging. The menopause triggers the awareness and realisation of life that is passing by. Often during this phase, women get their first invitation for the screening. Women experience this letter as a confirmation of aging, and experience different emotions.

### 6.2 Conclusion

### **Rational decision-maker**

On the one hand, the breast cancer screening has a functional meaning for women: preventing the disease or detecting the disease in an early stage. Currently, this functional meaning is promoted by RIVM & Het Bevolkingsonderzoek Borstkanker. In the current communication strategy, the risk numbers are communicated which explain the risks of the research and disease. The risk information should support women to reach an informed decision. However, this strategy is based on the rational decision-maker's perspective, who has the capabilities and motivation to understand and to interpret the risk information (Timmermans, 2013). The risk information is often experienced as 'jargon' and 'difficult to understand' for people outside epidemiological field.

#### Women's decisions

User-centered research of this project showes that women do not only base their decision on rational models. A lot of women can not identify with the rational decision-maker, who criticizes the relevant health information on advantages and disadvantages. Beliefs seem to influence women's decision-making process, such as the one: 'better safe than sorry'. Furthermore, the positive attitude towards the screenings seems to distract women from making a well-informed decision. Women do not weigh the disadvantages, nor the advantages, in relation to their personal values (Timmermans, 2013). The inspirational research of this project showes that women also experience concerns which are associated with the organized screening and women are aware of different meanings that women ascribe to the screening, such as: aging and bodily changes. The impact of these meanings play a role in the decision-making process of their health choices.

### 3 essential elements & meanings women ascribe to screening

The question is whether promoting the preventive function of the

organized screening, and whether only communicating the risk information, will supports female citizens in making well-informed decisions. Besides accurate information, also the essential elements 'freedom of choice' and 'awareness of personal values', seem to be useful for a well-informed decision. The current communication material does not give much attention to these elements. Furthermore, the context analysis reveals that other factors have meaning for women and have impact on women's decision-making. The current communication strategy does not pay attention to other meanings that women ascribe to the screening, such as aging, bodily changes and the uncertainty of life.

If the organized screening focusses also on the other essential elements which are valuable for a well-informed decision and the different meanings that women ascribe to the screening, the communication material could:

- A. also connect to women who are not tend to make a rational decision in this context,
- B. support women in being aware of personal values and freedom of choice. RIVM might enable women to define their well-informed decisions by basing the decision on the three essential elements.

#### Furthermore:

C. if the RIVM showed more empathy to the concerns of women and communicate this in a common language instead of 'jargon' (quantitative information about risks), emotion could be used as a source of information.

The meaningful associations could be used as inspiration to think about the future and for making a well-informed decision. "How do I want to deal with bodily changes in the future? And does participating in the organized screening fit into this future image?".



Figure 26 shows the current situation and a vision on the desired situation

## Design Part

## Chapter 7. design statement & interaction vision



*How to create a more meaningful interaction?* 

This visual indicates the stages of the research & design process, that will be discussed in chapter 7. This chapter shows how the research findings are transformed into a design direction, and describes the translation of the experienced interaction qualities into desired interaction qualities. Furthermore, the following chapters outline the design parameters which serve as a foundation for the design phase.

### 7.0 Intro

The following figure (Figure 27) visualizes and explains the process of the transformation from research into design. A design statement is formulated which guides the design process. The design statement consists of a goal and a direction. This statement was based on the conclusion of the research. The type of interaction that should be designed to realize the design statement, was explored by applying design techniques (iterating on an interaction vision) and a creative session with the user group.

#### Interaction vision

An interaction vision defines a sample of a situation in which desired interaction qualities come forward. Different interaction visions are explored to search for inspirational situations and desired qualities. Finally, one interaction vision (metaphorical situation) was chosen that showed similarities regarding to making a choice during a transition between life phases, and that showed inspirational and desired interaction qualities.

### **Creative session**

The creative session was set-up to elaborate with the user group on the design statement. The session focused on mapping experiences and associations with aging, health choices and the organized screening. Interaction qualities and functions were selected, which are necessary to reach the goal and which describe the desired interaction to reach the goal through a specified direction (communicating on an emotional level).

### Design parameters

The design parameters guided the design process towards the final design intervention which realized the design statement. The design parameters are based on the interaction qualities and functions. The parameters are used to develop a mechanism that evokes the desired effect, and to develop a design form that evokes the desired interaction.

CONCLUSION ANALYSIS	6. DESIGN STATEMENT	7. INTERACTION VISION	8. SELECTING Q & F	9. DESIGN PARAMETERS	10. DESIGN CONCEPT
Bringing together insights to formulate conclusion	Defining design direction	Exploring type of interaction	Selecting qualities & functions	Defining desired effect and interaction.	Designing final concept
Bringing together the insights and inspiration, creating an final vision on the domain.	Based on conclusion of research phase, formulating a design statement, which guides the design process. Design statement describes the goal and direction.	Exploring which experience of the interaction is needed, to realize the goal and direction. Exploring by applying design techniques (interaction vision(s)) and a creative session. Using insights from the research	Selecting qualities (Q) and functions (F), which are necessary to reach the goal, and which describe the design direction.	Definining the design parameters (based on the selected qualities and funtions), which are needed to realize the goal and direction of the design statement. The design parameters are used as guide-lines through the design process to develop the desired effect (based on goal) and desired interaction (based on design direction).	<ol> <li>Designing a mechanism to reach the desired effect.</li> <li>Designing a design form to bring mechanism into existence, and to realize the desired interaction.</li> </ol>
Insight Insight	Design Statement Goal Direction	Interaction vision(s) searching for inspirational methaporical situations, to finally choose one.	F1 $Q1$ $F2$ $Q2$ $F3$ $Q3$ $F4$ $Q4$	Desired effect Goal F1 F2 F3 Desired interaction Direction	Design concept Desired effect mechanism 1. Construction Desired interaction design form 2.
Insight		mapping experiences and associations with <b>aging</b> , <b>health choices</b> and the <b>organized screening</b> .		F4 Q1 Q3 Q2 Q4 F5* *function has been inspirational in detailing	Ö

Figure 27 shows how the research phase transformed into the design phase, and shows which steps are taken to realize the design statement.

### 7.1 Design statement

The following design statement has been formulated to direct the further design process. This design statement is based on two important outcomes, and led to the design statement:

1. If the communication material of RIVM & the organized screening focused more on all 3 elements necessary for a well-informed decision, the communication material could help to achieve the policy of informed health choices.

2. If the communication material of RIVM & the organized screening focused also on other aspects than only risk information and showed empathy to women their concerns, emotions could be used as a source of information.

I want to inspire women below the age of 50 in how they want to deal with bodily changes and health choices while aging as input for the decision whether to participate or not in the organized screening *(goal)*, by communicating on an emotional level about essential elements for a wellinformed decision *(direction)*.



### 7.2 Interaction vision

The current interaction with the service is experienced by women as: 'following the APK (Periodic Technical Inspection) inspection'. The service is experienced as 'impersonal', 'automatic' and 'hindmost'. The context analysis explored options for designing another experience. The following interaction vision, has been formulated to inspire the further design process on interaction level. This vision is based on the conclusion of the research phase. I wanted to design a more meaningful interaction in addition to the functional interaction.

# Making a final study choice in the last months of high-school, when ending the puberty and approaching maturity.



## 7.3 Interaction functions

From the interaction vision and creative session, it was possible to abstract interaction functions which describe more concretely how the design intervention should function. This is used as inspiration for the ideation phase. This is used as inspiration for the ideation phase (see Figure 27).

### Inspirational situation

#### Interaction vision

Within the metaphorical situation (end of high-school) many activities are organized to support high-school students in searching for a suitable education. In the meanwhile, this situation describes a life phase in which teenagers are growing-up and are experiencing aspects of a new lifestyle. The following desired functions were abstracted from this inspirational situation.

Four examples out of the metaphorical situation inspired the desired interaction functions:

- *Informative element*: receiving information about the end of the high-school phase, and the possibilities for the next phase
- *Explorative element*: searching for and trying out new possible futures, like joining try-out days at different universities or meeting up with older students.
- *Creating awareness element:* experiencing awareness of personal interests, because of organized activities
- *Activating element:* offering material in class to activate the decision-making process, such as a study choice application.

### Creative session

Another desired function resulted out of the creative session (see Figure 28) in which mainly women from different ethnical backgrounds presented their personal experiences. A main insight of the creative session was that 'self-care' becomes important during the age of 50 years old. - Self-care and the awareness to choose healthily, appear to come naturally along with bodily transitions. Women experience a feeling of 'my body starts calling for more attention'. The functionality 'selfcare' is another function which might be valuable to transpire through the design concept. This function has been inspirational and convincing for the design statement, but is not taken into account in the design parameters.

### **Desired interaction functions**

The inspirational situations of the interaction vision and women's desires of the creative session were abstracted to describe on a more concrete level how the design intervention should function, by:

- F1. Informing F2. Exploring F3. Creating awareness F4. Activating
- F5. Self-care.

The selected functions are influenced by the research outcomes of the research stage. The first three functions (F1, F2 and F3) refer to the three essential elements for a well-informed decision. The numbers reference to the visual (see Figure 27).



Figure 28 showing an impression of the creative session with some of the participants.

## 7.4 Interaction qualities

From the interaction vision, it was possible to abstract interaction qualities which describe more concretely how the interaction with the design intervention should be experienced. This is used as inspiration for the ideation phase (see Figure 27).

### Inspirational situation

Four examples out of the metaphorical situation inspired the desired interaction qualities (see Figure 29).

- *Inspiring*: inspired by grown-ups, adults or other student, for example because of their job or lifestyle.
- *Pure*: identifying with the story of the other person.
- *Connectedness*: feeling connected to the other, because you appreciate the way in which you are approached.
- Sensitive: experiencing space for emotions which come across during the decision-making process.

### **Desired interaction qualities**

The inspirational situations are abstracted to describe on a more concrete level how the design intervention should be experienced, as:

Q1.Inspiring Q2.Pure Q3.Connectedness Q4. Sensitive



The numbers reference to the visual (see Figure 27).

## 7.5 Design parameters

The aim of this design stage was to create a design intervention and to realize the design statement. Interaction functions were selected which are necessary to reach the desired effect (based on goal): the well-informed decision consisting of the three essential elements. Interaction qualities and functions are selected which might lead to the desired interaction (based on direction): communicating on an emotional level. The selected interaction qualities and functions are called: the design parameters.

The design parameters guided the design process towards a final design intervention. The parameters are used to develop a mechanism that evokes 'the well-informed decision consisting of the three essential elements', and to develop a design form that reaches 'communicating on an emotional level'. The process in shown in the beginning of this chapter (see Figure 27), and is showed in more detail on this page (see Figure 30).

### Which parameters guide to the desired effect?

The following design parameters were used as guide-lines to design a mechanism which should realize the desired effect: a well-informed decision. These parameters are based on the 3 essential elements for a well-informed decision.

- *F1. Informing*: information about the advantages and disadvantages which people can relate to.
- *F2. Exploring*: to explore the possible choice options
- *F3. Creating awareness*: to create awareness on personal values

### Which parameters guide to the desired interaction?

Furthermore, several different design parameters were defined to further develop the mechanism into a design form and to make the mechanism unfold. These parameters were based on the desired interaction functions and qualities.

- *Q1. Inspiring*: inspiring by other their stories
- Q2. Pure: identifying with offered material
- Q3. Connectedness: feeling listened to
- *Q4. Sensitive:* experiencing space for emotions which come across during the informing phase and decision-making process.

After all, these parameters are used in the concept test. The final concept is tested on the defined parameters, to study whether the design realizes the effect and aspects of the desired interaction. Other design criteria used in the design process can be found in the appendix (see appendix 5).



Figure 30 shows how the design parameters are used to guide the development of the design intervention.



This visual indicates the stages of the research & design process that will be discussed in chapter 8. This chapter shows which creative techniques are used to transpire the defined design parameters into concept ideas. This chapter presents also the designed mechanism and design forms.

### 8.0 Intro

The ideation and concepting process was like a recycling process: bringing in ideas, iterating on ideas, reflecting on previous ideas, combining idea elements, iterating on new ideas, and bringing in ideas again. The interaction functions and qualities inspired the ideation process. The design parameters guided the ideation towards the final concepts (see Figure 31).

Creative techniques were applied to generate ideas on, (1) desired effect level and (2) desired interaction level. The design statement, and the interaction functions and qualities are used as input for the creative techniques. The following paragraphs give an impression of the results.

Eventually, a mechanism was developed that is expected to evoke the desired effect. The mechanism was conceptualized by two different design forms to evoke the desired interaction. Finally, two different design interventions/design concepts were proposed to RIVM. One final concept is further developed for RIVM.

Other concept ideas can be found in appendix 6. The visual (see Figure 30) illustrates how the interaction qualities and functions inspired the ideation of the design intervention.



Figure 31 shows how the design parameters are used to guide the development of the design intervention.

## 8.1 Creative techniques

### Exploring functionalities

### Technique

The determined interaction functions, as described in the previous chapter, are used as input for an ideation session. 'How could you' - questions were formulated, to (1) elaborate further on the interaction functions, (2) quickly explore the functionalities of the service and (3) generate ideas and options for a potential design intervention (Boeijen, 2013).

The results are visible in the logbook and copies of the logbook in the appendix (see appendix 4). A few quick views are shown as examples (see Figure 27), with highlighted ideas that are further developed.

### Ideas

These activities resulted in ideas how to conceptualize the functions: exploring and activating. The following ideas were gathered, and developed further in the design process.

- *F2. Exploring*: conceptualized by giving support to visualize options, to browse online, to browse through magazines, or to follow a role model.
- *F4. Activating:* conceptualized by broadcasting interviews, or sending content via (social) media channels.



*Figure 32* impression of the creative technique which was applied to explore: freedom of choice & activate.

## 8.1 Creative techniques

### Exploring the design statement

### Technique

An creative technique was used to explore the associations with the goal and direction, to generate ideas that were linked to the design statement (see Figure 33). The statement was deconstructed into elements. These element were exchanged with comparable elements from different contexts. Ideas were generated out of the exchanged elements. This activity was inspired by the *Analogies & Metaphors* technique of the Delft Design Guide (Boeijen, 2013).

### Goal

"I want to inspire women below the age of 50 in how they want to

deal with bodily changes and health choices while aging, as input for

the decision whether to participate or not to the organized screening,"

### Direction

"by communicating on an emotional level about the 3 essential elements for

a well-informed decision."

### Ideas

These activities resulted in ideas how to approach women differently. - The approach how to deal with mind struggles or changes, inspired how to deal with bodily struggles or changes. This approach shows more empathy, and focusing on talking, experience and reflecting.

- The approach how to deal with fun facts, inspired how to deal with risk numbers about serious things. This approach shows more lightness and easiness in its communication.



## 8.1 Creative techniques

### **Exploring** qualities

### Technique

During the second stage of the ideation, the interaction qualities were used as input to explore the design properties in detail and developing ideas into concepts. The creative techniques that were used, could be described as a combination of techniques: collage making and random stimulus activities (Tassoul, 2009). Pictures were selected from magazines and were used as stimulus to brainstorm further on.

The results are visible in the logbook and copies of the logbook in the appendix (see appendix 4). A few quick views are shown as examples (see Figure 34, Figure 35 and Figure 36).

Figure 34 impression of the creative technique which was applied to explore: sensitive





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Figure 35 impression of the creative technique which was applied to explore: pure

### Ideas

These activities resulted in ideas how to conceptualize the qualities: inspiring, pure and sensitive. The following ideas were gathered, and developed further in the design process.

- *Q1. Inspiring*: might be conceptualized by different type of role models.
- *Q2. Pure*: might be conceptualized by applications or cards with questions that trigger own thoughts and emotions.
  - Q3. Connectedness (visible in appendix): might be shown through the existing channels (envelope or webpage), or through channels or location that women already associate with topic as: body and health
  - *Q4. Sensitive*: might be realized by creating a feminine experience focussing on 'listening to your feelings'.



Figure 36 impression of the creative technique which was applied to explore: inspiring
## 8.2 Mechanism

#### Selected mechanism

During the brainstorm activities (see chapter 8.1) and while defining the interaction vision (see chapter 7.2), the desired mechanism was explored. A mechanism was needed that realizes the desired effect: a well-informed decision. The defined design parameters (F1, F2 and F3) represented the essential elements for a well informed decision.

The mechanism, that was selected for further development, was: *"Visualizing the future by presenting role models."* 

#### Argumentation

The mechanism can emphasize the 3 essential elements needed for a well-informed decisions. Chapter 7.5 explains why this mechanism was chosen, based on three selection criteria (design paremeters):

- **F1**. *Informing*: informing women about the risks by showing different life scenarios and experiences of women.

- *F2. Exploring*: offering space to explore choice options by presenting different women who made contrasting choice options.

- **F3**. Creating awareness: creating awareness by showing empathy to women beliefs and concerns and emphasizing personal values.

## visualizing the future by presenting role models



Figure 37 mechanism inspired by the situation of the interaction vision: role models inspire prospective students.



Figure 38 shows an impression of the ideation: role models inspired by personas

## 8.3 Final concept

During the brainstorm activities (see chapter 8.1) and while defining the interaction vision (see chapter 7.2), the desired design form was explored. A design form was needed that was expected to unfold the mechanism. Besides that, the interaction with the design concept aimed to be experienced in a certain way: according to the desired interaction.

The defined design parameters (F4, Q1, Q2, Q3 and Q4) represented the requirements for the desired interaction and guided the design process. Afterwards, different concept ideas were criticized on the defined parameters.

The design concept that was chosen to develop further, was:

#### CARE magazine

Women stories represented in a magazine, in which role models are used as a mechanism to evoke the desired effect: making a well-informed decision before the age of 50.

#### What is it?

A magazine which introduces role models, who represent (F1) scenario's, (F2) choice options and (F3) different motivations for decisions. The intervention will be periodic during the age between 49 and 50.

#### Why stories?

The magazine offers women guidance towards a well-informed decision, and reports material to show empathy to women their interest and concerns.

Different topics can come across through these stories, namely:

1) essential elements of a well-informed choice

2) ways of dealing with themes such as: aging, menopause, bodily changes and uncertainty are presented to the women.

#### Argumentation

The design concept is criticized on the design parameters.

-*F4. Activation:* an attractive magazine to read will be sent by mail. The combination of magazines should guide the user through the decision-process.

- *Q1. Inspiring*: the magazine is supposed to offer inspiring women stories.

- Q2. *Pure:* the magazine is supposed to offer women stories which are still pure, and easy to relate to.

-Q3. Connectedness: the magazine offers space for a common language, in which RIVM is supposed to show empathy to women's concerns and the meanings that women ascribe to the screening (aging, femininity and uncertainty), instead of only using jargon (quantitative information about risks).

-Q4. Sensitivity: the magazine offers material which makes use of emotions as source of information that might evoke a reaction by women, and that might trigger women's decision-making process.



#### In consultation with RIVM

*Two concept ideas that both were expected to unfold the mechanism (visualizing the future by presenting role models), were:* 

- a TV series
- a magazine

*The development of the concepts and the concept ideas, can be found in appendix 6.* 

The same mechanism was unfolded through two different desig or communication forms. The concepts were presented to the department CvB (communication department RIVM), and the desirability and feasibility was discussed. The opinion of RIVM was taken into account in the decision-making process for the final concept.

#### **RIVM's motivations**

The motivations that were mentioned by RIVM to choose for the concept CARE Magazine were the following:

- The magazine offers the opportunity to bring in an intervention before the age of 50, which will give women the time and space to make a decision before entering the regular screenings program.

- The magazine offers the opportunity to approach women differently, in a sensitive way by showing empathy to women's concerns, beliefs and the meaning the organized screening might entail.

- RIVM seemed to believe more in the feasibility of the magazine above the TV series, because of its communication channel. The magazine makes use of the current communication channel (see Figure 39).



Figure 39 implementation of design intervention into current service.



This chapter shows how the desired interaction qualities and functions were used to further develop the

design concept.

## 9.0 Intro

The final concept was further developed and detailed by using the interaction qualities and functions. These were summarized by the design parameters to realize the desired interaction (see chapter 7.3).

#### Designing the desirability

The interaction qualities and functions guided the design process towards the desired interaction: *inspiring, pure, connectedness and sensitive*. These qualities and functions were expected to reach the defined design direction: *communicating on an emotional level about the essential elements for a well-informed decision*. The direction was based on the research findings of this analysis and the direction seemed an effective approach fitting to the desires of the user group.

Usage scenarios were set up based on these qualities and functions. This is an creative technique inspired by User Stories within the Scrum method (Agile Scrum Group, 2018). These scenarios give support in thinking about and designing all the different interactions and the usage elements of the design concept. The user stories can be found in appendix 6.

According to the guidelines of the graduation manual (Delft University of Technology - Faculty of Industrial Design Engineering, 2018), the student is supposed to deliver a relevant project result by an argument for desirability. The interaction qualities and functions were guidelines to address the desirability of the design concept. Whether the design concept is suitable for its stated purpose, 'communicating on an emotional level', will be discussed in paragraph 9.2, by highlighting the following design parameters:

- Q1. Inspiring
- *Q2. Pure*
- Q3. Connectedness
- Q4. Sensitive

#### Designing feasibility and viability

This research & design project was conducted in collaboration with RIVM and TU Delft.

First, one of the project goals (see chapter 1) was to deliver a relevant result to RIVM by proposing a design concept which could be supported by a convincing motivation regarding to suitability and feasibility. The implementation of the design concept should be feasible for RIVM.

This project also needed to address the learning objectives of a graduation project. According to the guidelines of the graduation manual, the student had to deliver a relevant project result by an argument for desirability, but also for: viability and feasibility (Delft University of Technology - Faculty of Industrial Design Engineering, 2018).

Taking into account these requirements, the detailing phase also focused on the aspects: feasibility and viability. The design proposal focused on feasibility and viability can be found in paragraph 9.3. This paragraph will discuss the implementation of the concept, by highlighting:

- Selection of women
- How will this magazine be spread out?
- How will the magazine be produced?
- Implementation roadmap

## 9.1 Content of women's stories

#### **Design intervention**

A periodic intervention by CARE magazine between the age of 49 till 50 years old. A magazine which includes: rich content and reports of local 50-years old women who are admired by others.

#### Periodic intervention by editions

The periodic intervention of the magazine should guide women through the decision-making process. The content of a magazine depends on the edition. Each magazine focusses on another aspect of the well-informed decision. After the third magazine the user is exposed to all three essential elements of a well-informed decision and will be prepared for the invitation.

This project proposes the following build-up of the three editions. This build-up proposal is based on the principle of Contextmapping (Sleeswijk Visser et al, 2005), a technique used for designing with users. This method is used to understand people's experiences and desires. During a Contextmapping process, the user is guided from thinking about current experiences to recalling past experiences to finally thinking about future possibilities. The periodic interventions could be inspired by this process.

A proposal would be:

- 1. Edition 1. *Proud Of Who I Am* personal values Focusing on now: who is she and what does she values?
- 2. Edition 2. *Exploring Space* experiences & lifecycle Reflecting on the past: which experiences does she have with other health and life decisions?
- 3. Edition 3. *Dream* future & choice Thinking about the future: which are the possibilities and what are the risk scenario's?

Creating a plan: what does she wants to choose and how does she want to deal with aging in the future?

#### The stories

A several women stories will present women who serve as role models. The role model represent (F1) different future scenario's, (F2) different choice options and (F3) different personal motivations for a decision. Different topics can come across through these stories, namely: (1) essential elements of a well-informed choice (2) ways of dealing with themes such as: aging, menopause, bodily changes and uncertainty are presented to the women. The proposal is that the women's stories will be aligned with the edition of the magazine.

An sample story is illustrated in Figure 41. This story is based on an interview with Malika and used for the concept test.



Figure 40 proposal for periodic intervention: 3 editions working towards final decision

## Zorgzame Malika

uit Amsterdam vertelt ons hoe zij heeft gezorgd voor haar kinderen, nu meer tijd heeft om voor zichzelf te zorgen, en hoe zij zorgt voor een warme en veilige ontmoetingsplek voor wijkbewoners.

## Kun je omschrijven wie je bent en waaraan je werkt bij ZINA?

Ik ben Malika, ik ben 53 jaar. Wij komen hier altijd samen op maandag, en werken aan 'ik ontmoet mij', een lichaamsgericthe training voor migrantenvrouwen. In de week help ik mee aan de administratie en lunch ophalen. Iedere zaterdag hebben we een informatie middag. De informatie komt dan hier heen. Ook een keertje kwam er informatie over borstkanker. Twee vrouwen zijn er toen achter gekomen dat ze borstkanker hadden. Ze durfden niet. Ze waren bang voor roddelen of iets. Ik weet het niet precies.

Dat heb ik op die dag ontdekt, dat ik voorlichting echt belangrijk vind. Soms komt er iemand aan een groep van 15 vrouwen voorlichting geven, en informatie brengen. Ik heb ontdekt dat ik dat echt belangrijk vind. Ik word ook ouder, en ik hoor vrouwen om mij heen ook verhalen vertellen. Door de voorlichting krijgen vrouwen door hoe belangrijk het is.

En waarom zijn juist voorlichtingen zo belangrijk?

De voorlichtingen maken duidelijk wat je kan voelen. Als je iets voelt, of het de ziekte is of niet. Dan blijf je niet piekeren. Soms heb ik gewoon pijn, en dan weet ik nu hoe ik moet voelen, en dan weet ik nu dat ik niet bang hoef te zijn. Meer kennis.

## Heb je al eens mee gedaan aan het bevolkingsonderzoek?

Ik heb al een paar keer mee gedaan. Gewoon zelf via de huisarts, had ik gevraagd of ik mee kon doen. Een keer had ik iets in mijn borst. Toen ben ik langs de huisarts geweest, en was het iets anders. Soms dan vraag ik mij af: 'is het iets ergs of niet?' Dan ga ik altijd even langs de huisarts, om het te laten controleren.

## En kwam dat op een bepaalde leeftijd dat je er meer mee bezig was?

Nee, nee, het is niet altijd zo geweest. Ik denk sinds 6 jaar geleden. Toen begon het bij mij. Ik had gewoon veel klachten, borstpijn enzo. Ik voelde het gewoon, iets klopte er niet. Dat was het lichaam dat iets aangaf.

#### En nu ben je over de 50, denk je tegenwoordig vaker na over je gezondheid?

Zeker, baarmoederhals kanker en borstkanker is nu dichterbij gekomen. Kom je bij de 50, met de overgang, dan komt alles dichterbij. Dat heb ik ook gemerkt, niet alleen bij mij, maar ook bij meer vrouwen. Met de overgang beginnen de hormonen te veranderen, dan moet je gewoon altijd uitkijken.

### Dat voelt zo dat je meer moet gaan uitkijken rond de 50?

Ja, voor mijn mening. Je lichaam geeft meer klachten. Ik heb soms zoveel klachten, dan die, dan die, dan die. Dan zie je, de hormonen



"Bij 50 worden geeft je lichaam meer klachten. Dan zie je, de hormonen beginnen te wisselen. Soms denk je: 'misschien heb ik dit, misschien heb ik dat? Je blijft gewoon piekeren."



Figure 42 layered content: A. well-informed decisions topics, B. womens topics.

#### Layered content

The content of each magazine will be based on two layers (see Figure 42):

- A layer of content which should support women in their wellinformed decision:

relevant information, and attention to exploring choice options and the importance of personal values.

A layer of content which should enhance the feeling of connectedness:

attention to topics the subject group can relate to and identify with, such as: aging, menopause, bodily changes and uncertainty of life.

The women's stories will contain content of both layers, which is

illustrated in the figure above.

#### Extra content

The magazine should mostly focus on the women's stories. However, the experience of browsing through a magazine would also be preferable. The proposal is to further develop and test different concepts, to search for a balance between women's stories and further content of the magazine.

#### Magazine content

The current proposal is based on a quick women's magazine study. The magazines: *Opzij, VK magazine, Psychologie Magazine, Happinez, Flow* and *AH magazine*, were compared with each other (see Figure 44)

Out of this study followed some essential aspects for a magazine feeling (see Figure 44). The proposal is to include this aspects. Essential aspects for a magazine, are:

- Attractive eye-catchers, like visuals and photos.
- Content page
- Introduction column
- What's next page

#### Self-insight pages

From this study furthermore resulted the insight that women magazines offer rich content to its readers (see Figure 44). Magazines such as, *Psychologie magazine, Flow* and *Happinez*, aim to support people in gaining insight into themselves and life. Knowledge and activity pages are offered to readers to support them in these selfinsight gaining processes.

This rich content shows options for how to include additional content in a magazine. Besides the women's stories, pages could be used to highlight relevant information and personal reflections needed for a well-informed decision. Additional pages could be included within CARE magazine, to support women even more with their wellinformed decision. However, the amount of additional pages should be tested, to find out which is the right balance between women's stories and additional content.

The current proposal is to included pages of:

- Asking the expert: "Is it true...?"
- Activities

#### A page of: Is it true...?

Content which focusses on explaining relevant information needed for a well-informed decision: rejecting misconceptions and explaining pro's and con's of the organized screening.

This content could dive into an information topic that is aligned with the theme of its edition. The information should elaborate on the existing information flyer. The communication manner should be informal and easy to understand.

It might set up in a "we asked the expert"- manner. The expert could be a researcher at RIVM or another institute. This researcher would be asked to explain:

- Misconceptions (based on dogma's)
- Personal risk factors
- Participation or non-participation risk factors
- Pro's vs. con's.

An example is shown in Figure 43.

#### A page of: a self-insight gaining activity

Content that focusses on guiding the reader through a thinking process. This activity could be linked to the theme of the magazine its edition.

An example is shown is Figure 45.

*"Het wordt ons aangeboden door de overheid, dus het is goed om mee te doen, toch?"* 

#### waarheid:

Examine she brother prudent add day ham. Far stairs now coming bed oppose hunted become his. You zealously departure had procuring suspicion. Books whose front would purse if be do decay. Quitting you way formerly disposed perceive ladyship are. Common turned boy direct and yet.

#### als je er zo naar kijkt:

Examine she brother prudent add day ham. Far stairs now coming bed oppose hunted become his. You zealously departure had procuring suspicion. Books whose front would purse if be do decay. Quitting you way formerly disposed perceive ladyship are. Common turned boy direct and yet.



adviesvanbroers.nl



Milena haar uitleg is ook in een video te zien: care/

10

klopt het ...? | een vraag aan de onderzoeker

## Klopt het ...?

Milena Broers van het RIVM helpt ons.



Figure 44 shows an impression of essential elements for a magazine.

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## vraag 3. wat zegt dit over jou?

Sta even stil bij hoe jij naar je waarden leeft.

## 1. Volg jij nu dat wat je belangrijk vind?

Examine she brother prudent add day ham. Far stairs now coming bed oppose hunted become his. You zealously departure had procuring suspicion. Books whose front would purse if be do decay. Quitting you

#### 2. Hoe kan je dat blijven volgen wat je belangrijk vind?

Examine she brother prudent add day ham. Far stairs now coming bed oppose hunted become his. You zealously departure had procuring suspicion. Books whose front would purse if be do decay. Quitting you way formerly disposed perceive ladyship

Danielle haar hulp is ook te beluisteren: **care/hulpvantimmerboog.nl** 



#### Impression of three magazines

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An impression of each edition is given on the following pages. This proposal offers a suggestion of how 'content needed for a well-informed decision', could be spread out over three editions. The proposal describes which topics could be discussed in each magazine.

Besides that, the proposal gives an impression of what kind of content the self-insight pages could contain.

## **Care Magazine**



## **Care Magazine**

Exploring space

### **Care Magazine**



an, Layla, Adelheid Ho kuity vertellen hun eru haal over mogelijke ver komst scenarios, too ondheidsrisico's en vir zaan met onzekerheid. pas Klopt het dat geloven: welk factoren bors veroorzaken? spreken met o Milena

# **Care Magazine**

edition 1/2018

## **Proud of who you are** leven naar je persoonlijke waarden



Lisan, Layla, Adelheid & Guity vertellen hun verhaal over 50 worden, levensfases, persoonlijke waarden en keuzes. Wat zijn jouw persoonlijke waarden? Vind jouw persoonlijke waarden in de psychologie test. Klopt het dat wij geloven: wat de overheid aanbiedt altijd goed is om te doen? We spreken met onderzoeker Milena. Edition 1. Proud Of Who You Are

#### How to life according to your personal values

The first magazine will focus on: the consciousness of turning 50, and entering a new life phase. This magazine will introduce women to the topics:

- Turning 50
- Life phases
- Personal values
- Decisions in life

The theme of this magazine will be: 'being proud of who you are'. The cover is shown in Figure 46. A role model will be asked to introduce the theme and the topics within an introduction column in the beginning of the magazine.

#### Interview part

Four women will be interviewed on the topic: personal values, life phases and turning 50. Other decisions in life will be discussed.

#### Activity part

The activity might be a test, focussing on finding personal values, and to become aware of the fact till what extend the person lives towards these values, or how to improve this. The activity will be written by an researcher out of the psychology field.

#### Expert part

The 'Is it true that?' page will focus on giving another perspective on a certain misconception. An example could be, discussing the fact that women participate to screenings, since they want to act right.

Figure 46 sample cover of edition 1.

# **Care Magazine**



Lisan, Layla, Adelheid & Guity vertellen hun verhaal over levensfases en overgangen, keuzes en veranderingen. Wat zijn voor jouw belangrijke veranderingen geweest? Vind lessen uit die eerdere keuzes.

Klopt het dat wij geloven: we eigenlijk geen keuze hoeven te maken voor de screening? We spreken met onderzoeker Milena. Edition 2. Exploring Space

#### How to deal with changes and choices

The second magazine will focus on reflecting and envisioning changes, choices and going from one phase to another. This magazine will introduce women to topics, such as:

- Choices
- Changes

\_

- Life phases
  - Transitions

The theme of this magazine will be: 'exploring space'. The cover is shown in Figure 47. A role model will be asked to introduce the theme and the topics within an introduction column in the beginning of the magazine.

#### Interview part

Four women will be interviewed on the topics: choices, changes and life phases. Other life transitions will be discussed.

#### Activity part

The activity will support women by guiding them through a reflection. This reflection will focus on pervious life transitions and previous important choices.

#### Expert part

The 'Is it true that?' page will focus on giving another perspective on a certain misconception. An example could be, discussing the fact that women don't experience deciding whether to participate or not to the organized screening as a choice.

# **Care Magazine**

edition 2 / 2018

# hoe maak je eenvoørstelling van de toekomst?



Lisan, Layla, Adelheid & Guity vertellen hun verhaal over mogelijke toekomst scenarios, gezondheidsrisico's en omgaan met onzekerheid. Hoe kan je toekomst eruit zien? Visualiseer verschillende toekomsten om te vinden welke bij je past.

Klopt het dat wij geloven: *welke factoren borstkanker veroorzaken?* We spreken met onderzoeker Milena. Edition 3. Dream

#### How to imagine your future

The third magazine will focus on envisioning the future. This magazine will introduce women to the topics:

- Different future scenarios
- Life style and risk factors
- Pros and cons of participation
- How to deal with uncertainties

The theme of this magazine will be: 'dream'. The cover is shown in Figure 48. A role model will be asked to introduce the theme and the topics within an introduction column in the beginning of the magazine.

#### Interview part

Four women will be interviewed on the topics: different future scenarios, life style and risk factors, pros and cons of participation and how to deal with uncertainty.

#### Acitivity part

The activity will support women in envisioning future scenarios. This activity will guide women in imagining the consequences of certain decisions.

#### Expert part

The 'Is it true that?' page will focus on giving another perspective on a certain misconception. An example could be, discussing lifestyle risk factors. The expert could talk about the proven risk factors, and give example of manners how to care for yourself concerning food, physical movement and relaxation.

## 9.2 The interactions with women's stories

The interaction between the user and the women's stories was defined by using the design parameters to realize the desired interaction (see chapter 7.3). The designed interaction will be explained, referring to these parameters.

#### - Q1. Inspiring

Every women and her story should have something special that inspires another woman. This special aspect might be about: her personality or her actions during her life(cycle), depending on the edition of the magazine.

A quick WhatsApp interview study was done to find out what 50+ women admire about other women of the same age. The results of this study can be found in the appendix (see appendix 6).

This studied showed that women mostly appreciated other women's characteristics and actions. The descriptions which participants gave can be summarized in the following way:

- Following own path being willful
- Continue with courage and positivity
- Powerful & steady being yourself regardless of any environment
- Caring for others

Besides that, women associate these characteristic and actions with certain roles in a certain context, namely:

- Family
- Work
- Being yourself specifically everywhere (related to being powerful)

#### - **Q2**. Pure

However, the stories should keep the feeling of reality, in such a way that other women can identify with these stories. Findings of the quick WhatsApp study showed that women already admire characteristics and actions of regular women. Participants mentioned examples of real stories they know from women around them.

The proposal is for the implementation for this design concept is, to begin with interviewing local admired women. The design concept could be further developed from there on (see paragraph 9.3). These women might be well-known by other women in the region. However, it is important that this fame should not harm the feeling of connectedness which is experienced by other women. It is necessary that other women can keep identifying with this person.

#### - Q3. Connectedness

The topics of the women stories showing empathy to women's concerns and associations (aging, femininity and uncertainty) with the organized screening. The stories will not make use of jargon (quantitative information about risks).

#### - Q4. Sensitivity

The stories might evoke certain emotions while reading, since the stories will focuss on the sensitive part of women's stories. The role models might give advice on sensitive topics, and might create awareness on the importance of the sensitive part.

## 9.3 Implementation of design concept

#### Selection of the women

Women's stories should represents stories of diverse group of women. This group should be representative for a differences in background, talents and motivations. Women will be selected on differences in:

- Ethnicity
- Education
- Final decision on whether to participate or not to the organized screening.

#### How will the magazine be spread out?

#### Cross-media usage

The current information flyer is spread via post. The intention is to elaborate further on this channel. However, this concept proposal includes also some further development recommendations, to crossmedia usage in the communication strategy.

The proposal is to offer the magazine:

- Hard-copy and offline, via post
- Online copy via the webpage (see Figure 50 and Figure 49),
- Online video reports of the women's stories (see Figure 51).

The usage of the offline and online channel has different reasons. The magazine could be spread out via the same communication channel, as its flyer and invitation letter. This is an existing channel which is well-known among the user group. The magazine will be send to women between 49 and 50 years old. This magazines should also be available for different age group women, though. This would be one reason to also offer the magazines online.





Figure 50 an example of CARE magazine online: the main page shows all types of content of the magazine

Figure 49 an example of a women story online - story of Malika

#### Future plans RIVM

Furthermore, the online version would be in line with the development plans of CvB (department of RIVM), to switch from offline to online. This switch is planned, because of sustainability reasons. Cross-media usage could be a first step towards this goal and let women get used to the online possibilities. The integration of online and offline is showed by other magazines and newspapers already.

#### Language differences

Besides that, the online channel have an important role for the usability of the concept. One of the design requirements was, that the concept should be usable for people from different ethical backgrounds and with low-literacy. The videos should include subtitles, and be available to support different groups of women in understanding the women's stories.



Figure 51 shows how women's stories could also be presented as an online video with subtitles.





#### How will the magazine be produced?

#### Current communication department

The communication department of RIVM, CvB, focusses on informing citizens about the organized screenings (see Figure 52). The communication team wants to create acceptance and awareness on the existence of the organized screening and enhance the understanding of the purpose of the organized screening, by using:

- The webpage
- Flyer
- Public media (like newspaper, radio, tv)

The communication material mostly focusses on delivering accurate information.

#### The future department

An editor's team works on the adjustments of a publication, and/or editors literally write the content. A quick analysis is done on editor's team of other magazines, such as *VK magazine, Hapinnez & Psychology Magazine,* to get an understanding of these kind of teams.

An editor's team of magazines exists out of:

- A chief editor
- Content manager
- Editor's manager online
- Editor's manager print
- Visual designer
- And different editors (who write content) or freelancers

The chief and managers are comparable to the members who are already included in a communication team. However, an editor's team distinguishes themselves by additional members: the editors and the visual designers. The visual designer has an important role in creating a corporate identity. The editors (which could also be freelancers) have an important role in writing the relevant and desirable content, based on their expertise or based on research or interviews. The communication team of RIVM – CvB can be inspired by these additional members (see Figure 53). These members should have an important role in enriching the content of the publications.

Figure 53 the future communication department

#### Roadmap

Literature discusses the need for community involvement to identify parameters to guide an innovation process towards sustainable development. A research of Fraser et al. (2006) studied the impact of involving the community. This research concluded that involving the community delivers a collection parameters to guide the further concept development process. Engaging the user group is done in this research & design project. It would be interesting to continue doing this in the further development of the concept idea.

The bottom-up approach is recommended for managing the implementation of the design intervention into the current service. This approach enhances the success of the implementation, by offering the users the opportunity to give their feedback and to help improving the concept idea fitting to their desires. Out of every sessions with the community or users, parameters for further development of the concept and the implementation could be defined, and will help to guide the development further.

An suggestion for the implementation is sketched in a roadmap towards the future and is visible in the additional visual (see Figure 54). The roadmap assumes that the concept will be tested during 3 moments of community involvement:

- 1. Local (on a neighborhood scale) Geuzenveld
- 2. Local (on a province scale) area Middle-East
- 3. National included the 5 areas

The amount of participants (women between 49-50) will scale-up, but also the selection role women will scale-up while applying the tests from local to national.



## chapter 10. evaluation & recommendations

This chapter contains the evaluation of the final design concept. The prototype, concept test and research findings are presented in this chapter. Finally, the conclusion & recommendations are presented.

## 10.1 Prototyping

#### Sample magazine

To test whether the concept idea will deliver the desired effect (a wellinformed decision based on the 3 essential elements), a concept test was set up. The concept idea was translated into a prototype that represented different aspects of the idea. Other magazines inspired the prototype. Two interviews were set up locally to create two representative women's stories. The development of the prototype was an iterative and creative process, in which making quick small prototypes were used to design the final prototype. A few impressions are given on these pages (Figure 55 and Figure 55).





Figure 55 quick prototyping to develop final prototype

#### *Final prototype*



#### 1. receiving envelope with magazine (including an eye-catching image on cover)



2. exploring content of magazine

#### **Eerlijke** Lisan

Lisan van de Fruittuin van Wes vertelt over haar persoonlijke waarden, haar levensfase en hoe zij denkt over keuzes. Hoe kwam zij ooit tot de beslissing van Flevoland naar Amsterdan te gaan.

en van de gasten van de fruittuin van West lep voorbij, en groette nog: 'Ik zie dat het e goed gaat!'. "Ja, tot ziens he," zei Lisan achend, "in oktober en dan nog in zo'n

isan yan de Fruittuin yan W azomer dag in oktober. Lis bezig in het bedrijf van ha



#### 3. scanning stories with catchy images and quotes



4. exploring diverse women's stories

5. understanding relevant information

6. gaining self-insight

#### Impression of cross-media usage

The cross-media link between offline and online is made visible in the prototype of the magazine (offline version). A conceptual prototype has been developed to gather insights into the online possibilities, such as language options. This prototype with the online functions is not used in the concept test, and the online interaction experience is not tested. The following figures give an impression of the online functionality. The prototype is available in the following link (can be copied to webbrowser):

https://invis.io/JAP0LRL8PVG#/330241037\_Online\_Design\_ Hphttps://invis.io/JAP0LRL8PVG#/330241037\_Online\_ Design\_Hp





4. online translations stories

5. online videos with subtitles



## 10.2 Concept test

A short summary of the concept test will be described in this paragraph. The complete research plan and research findings can be found in the appendix (appendix 7).

#### **Research goal**

The aim of the concept test was to study whether the final concept achieved the project goal: supporting women in making a wellinformed decision about whether to participate or not in the organized screening (desired effect). Furthermore, this test investigates which interaction aspect (focusing on the desired interaction) could be improved in the current design concept .

#### Summary of the set-up

#### Participants

Women with diverse backgrounds and with low-literacy were included in the sample of this study since their experiences and opinions might be different than those of the members of the project team. Another important reason for including them was the wish to let their experience transpire into the development of the design. Women were recruited in the area Geuzenveld, Amsterdam-West.

#### Sample women's stories

Two women from Amsterdam-West were interviewed. Those interviews were used as content for the women stories pages of the magazine. These women lived in the same area as those women who participated in the experiment.

#### Survey

The survey included questions to evaluate the concept on the design parameters. The questionnaire consisted of closed-ended questions.

Besides the closed questionnaire, the facilitator asked three additional

questions focusing on the evaluation of the interaction with the concept and the usability. These open-questions enhanced the understanding of the participant's motivations.

#### Findings

Due to circumstances of the experiment, the desired effect could not be fully tested. Not all women were able to read the magazine. Eventually, a smaller group participated. Participants only tested the designed material. The data of the of the close-ended questionnaire did not lend itself to a full analysis because of the small sample size. However, it was possible to gather valuable and novel insights from both the questionnaire and, above all, from the additional questions which the facilitator asked. These questions focussed on the interaction and functionality. The insights will be discussed in the following section.

#### Insights about experienced interaction

#### Language women stories

Low-Dutch-speaking women had difficulties to read the content of the designed magazine. These women could not read the women's stories. Besides that, these little-Dutch speaking women did not recognize the cross-media links. They were not aware of the fact that they could watch the videos online. Women experienced a need for translations offline and online.

#### Inspiring women stories

However all participants, including these women and other participants, were enthusiastic about the appearance of the magazine. Women experienced the tone of the magazine as light and optimistic. Women appreciated the included photos and to see other women out of a similar context. Furthermore, women made positive remarks on the two interviews. Some recognized themselves in aspects of Malika (story 1), and others recognized themselves in aspects of Lisan (story 2). The stories are experienced as eye-opening or inspiring.

#### Additional insight

#### Taboos

The research reveals that women that women with a Moroccan background experience difficulties with the acceptance of the disease within their cultural group. Women experience a desire to talk about the disease, check-ups and taboos within a group.

#### **Conclusion experienced interaction**

The research findings gave an impression of the experienced interaction. The findings are based on the data of the three additional questions.

It seemed that women experienced the following interaction qualities:

- Q1. Inspiring: being inspired by other's stories
- Q2. Pure: identifying with offered material
- Q3. Connectedness: feeling listened to

Women appreciated the topics of the stories. These were experienced as 'topics about them instead of the research' (Q3). Some of them could recognize themselves in these stories (Q2) and mentioned quotes out of the women's stories that they valued. Besides that, some women valued the stories as 'eye-opening' or 'inspiring, because of the effort of another person' (Q1).

It could be argued whether the other two interaction qualities were experience:

- F1. Activation: for decision-making
- Q4. Sensitive: experiencing space for emotions which come across during the decision-making process.

The fact that women wanted to keep the magazine and take it home, even though this was not possible, could be a sign for the activation (F1) of the design concept. Furthermore, the fact that women felt comfortable to talk about their own experiences could be a sign for the sensitivity (Q4) of the design concept. Women felt that the topic is approached in a sensitive way, which made them feel comfortable to speak about their own experiences. However, in the additional three questions women did not specifically mention experiences that directly linked to 'activation' and 'sensitivity'.

## 10.3 Conclusion

#### Project goal 1. supporting women in making a well-informed decision

The main goal of this project was to conclude with a proposal which addresses the challenge: "how can women be supported in making a well-informed decision whether they want to participate or not in the organized breast cancer screening?"

In the current society, well-informed decisions are valued as important and it is seen as a quality criteria. Although, 'supporting the public in well-informed decision-making' is a complicated issue that experts have different opinions about. The purpose of a well-informed decision is already argued. On the one hand, well-informed decisions are defined as decisions that are based on (1) relevant information. On the other hand well-informed decision are defined a decision that are based on (1) relevant information, (2) experiencing freedom of choice and in line with (3) personal values. The last one refers to a deliberate choice.

This project started with the expectation that women mainly have knowledge about the advantages and that women participate automatically. The challenge is to communicate the advantages, but moreover the disadvantages effectively, and to trigger women to make a decision.

The current communication strategy of Het Bevolkingsonderzoek Borstkanker focusses on the essential element (1) informing, in order to help women in making a well-informed decision. This strategy focusses on the rational decision-maker with unlimited possibilities. This rational decision-maker is expected to process all information, to make choices in accordance with the scientific knowledge which indicates what is healthy, and to oversee the consequences of a decision. However, the designed communication strategy focusses not only on the rational decision-maker, but also on women who are not motivated or talented enough to make a rational decision in each situation. This strategy is based on the findings of the user centered research and inspirational research of this project. This research showes the variety of women that participates in the screening, who vary in ethnical background, age, health, talents and motivations. Furthermore, it reveals the emotional aspects that have impact on women's decision-making process, such as: beliefs, associations and meanings that women ascribe to the screening. Finally, this project focussed on the other interpretation and purpose of a wellinformed decision, namely: next to (1) accurate, relevant and balanced information, also taking into account (2) experiencing freedom of choice and (3) being aware of personal values. This analysis resulted in a direction that focusses on an additional source of information: emotion.

A design concept is proposed which addresses the challenge: supporting women in making a well-informed decision which fulfils the 3 essential elements. The latter offers a mechanism (role models to visualize the possible futures) and design form (a magazine with women's stories) to support women before the age of 50 in wellinformed decision-making.

#### Argumentation

The research phase resulted in 3 elements which are essential (informing, experiencing freedom of choice and being aware of personal values), and specified the goal (a well-informed decision) in more detail. Besides that, out of the research phase resulted an effective design direction: *communicating by focusing on an emotional level*.

The goal and direction were summarized in one design statement. The design parameters explained the desired effect (a decision based on the 3 essential elements) and interaction (activating, inspiring, pure, connectedness and sensitivity) in more detail. The design statement and design parameters guided the design process.

The process focussed on two steps:

- designing a mechanism that could evoke the desired effect
- and designing an design form that could evoke the desired interaction.

#### Mechanism

To reach the desired effect the mechanism, "visualizing the future by presenting role models", is proposed. This mechanism gives the possibility to emphasize the 3 essential elements needed for a wellinformed decisions:

- F1. Informing
- F2. Exploring
- **F3**. Creating awareness

The desired interaction is conceptualized by the design form: CARE magazine. This magazine also unfolds the mechanism (role models to visualize possible futures). This magazine will introduce role models, who represent (F1) living scenario's, (F2) different choice options and (F3) different motivations for decisions. These role models are presented through women's stories.

#### Design form

The design form gives the possibility to emphasize the desired interaction by focussing on the parameters:

- F4. Activation
- Q1. Inspiring
- Q2. Pure
- Q3. Connectedness
- Q4. Sensitivity

#### Evaluated interaction

A mechanism to reach the desired effect is proposed for now, and should be validated in another concept test. The final concept is tested on the desired interaction, and showed some of the desired interaction qualities. Women experience the interaction with the concept as:

- **Q1**. Inspiring
- Q2. Pure
- Q3. Connectedness

It could be argued whether the other two interaction qualities were experienced:

- F1. Activation
- Q4. Sensitivity

Women appreciated the topics of the stories, and some of them could recognize themselves in these stories and mentioned the stories as eye-opening. The fact that women felt comfortable to talk about their own experiences and that women wanted to take the magazine home, could be a sign for the sensitivity and the activation of the design concept. However, women did not specifically mention the sensitivity and the activation in the additional three questions.

#### Project goal 2. user centred design approach

The other goal of this graduation project was to inspire RIVM with an user centred design approach. This project showes the project members of the RIVM an impression of another approach how to address the communication challenge.

#### Argumentation

#### Inspiration research

The most valuable aspect of this research & design project is the inspirational research that was conducted. This inspirational research focussed on broadening the solution space by involving a diverse user group regarding age (also below 50), ethnicity and literacy, and by studying the meanings that women ascribe to the organized screening. Through this research the way of communication, 'communication on an emotional level', was deduced and implemented. This inspirational research also resulted in a collection of topics that are associated with

the organized screening, namely 1) the concerns women experience and 2) the meanings women ascribe to the organized breast cancer screening, such as: aging, bodily changes and uncertainty of life. These findings inspired the project to look differently at the decision-making question and to use these topics as input for the decisions-making process.

#### Involvement user group

Furthermore, the involvement of the user group has been a valuable element of this research & design project. Women's desires and needs transpire through the process. In all stages of this project, women are involved to study and understand women's experiences, and to use their input in the development of the final concept. Including differences in ethnicity and literacy has been characteristic for this project. Involvement of diversity in ethnicity and literacy, was based on different reasons:

- a. since previous research suggested that women from other ethnical backgrounds and with low-literacy do participate less in the organized screening.
- b. since their experiences and opinions might be different than those of the members of the project team.
- c. Another important reason was the wish to let their experience transpire into the development of the design.

The user centred approach is used in the interview sessions with the user group, the creative session and the concept test. This approach differs from the academic approach which has been used in the project team 'Visioning Risk', and showes how to look at and address the project challenge differently.

## 10.4 Recommendations

#### Studying the effect on the long-term

This research & design project delivered a proposal for a design intervention, supported by one sample of an edition of CARE magazine. This sample gave an impression of the designed interaction. Due to time limits, not every edition is developed and tested. If we want to discuss whether this design concept reaches the well-informed decision-making, it will be necessary to develop the concept and investigate the effect of intervening between the age of 49 and 50. For now, the design concept is only proposed, and proposal suggest that the design concept might reach the desired effect (well-informed decision-making by focusing on 3 essential elements).

Additionally, it would be valuable to investigate the willingness of women to make the decision when intervening, since research suggests (Timmermans, 2013) that women do not make and do not want to make a well-informed decision about their participation at the moment. The question is whether the other communication material or another type of intervention would have another effect on the decision-making. This can be tested with the currently designed concept and intervention.

Besides that, it would be interesting to investigate whether this design intervention supports women in understanding the advantages and disadvantages of the organized screening. Research suggests that women are mainly aware of advantages (Timmermans, 2013) and not much about the disadvantages. However, taking into account balanced information (essential element 1) is necessary for a well-informed decision. The question is whether another type of communication would help women to see and understand risks. The impact of women's stories and perhaps the impact of the additional magazine pages ('is it true that...?') could be tested on the risk perception of users.

#### **Role models**

Furthermore, which interaction qualities to emphasize or what type of role model to use could be further explored. The sample magazine (prototype) focused mostly on the quality 'inspiring'. Admired women were interviewed. It would be interesting to explore the influence of other qualities, for instance 'purity' and base stories and role models on this quality. The question is whether stories should mainly be inspiring, pure, or connecting, and how to balance these qualities to enable women to make the most well-informed decisions.

#### The envelope and letter

Due to time limits, the proposed design concept stayed on a conceptual level. The detailing phase of the concept needs more attention. The project mainly explored the type of women's stories and the set-up of a magazine. Additional concept details were not explored further. It would be interesting to focus on the other aspect of the design intervention, such as:

- Which type of envelope suites the magazine? To what extent should the sender be visible?
- What type of letter is included? What story does this letter tell and what is the tone of the included letter?

#### **Research set-up final concept test**

A final concept test was conducted to study whether the final concept would reach the desired effect (well-informed decision). The concept test could not accurately test 'the well informed decision-making' given the circumstances of the experiment. Due to a language deficiency, several participants could not participate in the test. Therefore, a small group of eight participated in the test. Participants who participated in the test condition were excluded from the research data. The effect of the design concept could not be analysed, since the experienced functionalities could not be compared among the magazine condition and current material condition. Nevertheless, this experiment delivered several interesting insights regarding the experienced interaction with the women's stories and the willingness to read this magazine. Unfortunately, the desired effect and desired interaction could not be studied properly in the conducted experiment, therefore selecting the sample group more carefully is recommended for a next study. This could avoid difficulties during the experiment itself. This concept test included mostly low-literacy and mostly non-Dutch speakers. A sample group with diversity in ethnicity and literacy was consciously chosen to test the willingness of these women to use the design concept, since research suggest that women with different ethnical backgrounds and with low-literacy participate less in the organized screening. Including these women in the sample group has been a strength of this research. This gave novel insights about which aspect of the design concept should be further improved, such as: the crossmedia link and the online videos of the women's stories.

However, in a next concept test including high-literacy and native speakers is recommended. It would be valuable to study the experiences from high-educated people with the women's stories and, for example, to investigate whether the stories are helpful for them to become aware of and to understand the disadvantages of the organized breast cancer screening.

Besides this, a research team with at least two members who conduct the experiment, is recommended for a next concept test. The results of the concept test might have been influenced by the researcher (who was also the project leader and designer of this design concept). The way of asking questions in the additional part of the experiment, might have influenced women's input. Besides that, the analysis of the research data (women's input) has been performed by only one person. By conducting the study and interpreting the data with two member independently of each other, would make the perspective of the researcher (and project leader and designer) not leading and influencing.

#### Additional research&design project

This project focused on a diverse group of women who all have to

decide whether they want to participate or not to the organized screening. Whether this broad focus was useful, can be discussed. Along the project, I understood that some groups of women from different ethnical backgrounds are dealing with other difficulties. After the interview with Mammarosa, I realized that certain groups of women face different problems and misunderstandings regarding the breast cancer screening. These women are still struggling with understanding breast cancer and overcoming taboos. I believe there is a need for another approach to these women. A well-informed decision is one step to far, since they first have to understand and accept the disease.

I recommend further research into how to approach women with a different ethnical background by focusing on the following questions:

- How should the communication strategy deal with women groups who do not recognize the disease yet?
- How do different cultural backgrounds perceive the design intervention? What type of topics, content and women's stories do they need or desire?

#### **Different design forms**

The project focused on development of a magazine as the design form. The design choice based on the parameters and in consultation with RIVM. The women's stories and the desired interaction was tested in the concept test in which a prototype was used. The creation of the prototype gave insights on the following two aspects:

- The production: a lot of small booklets (magazines) together consume a lot of material.
- The usability: non-Dutch speakers would be unable to use the magazine at all.

This research & design project focused a little on designing the crossmedia (online magazine and online videos) usage. I recommend to further develop, but moreover test the alternative design forms: online video and online magazine. The alternatives offer advantages regarding sustainability and costs. Besides that, the language possibilities of these design forms are valuable.

#### cross-media usage of women's stories



Figure 57 design form: online videos (with subtitles)



Figure 58 design form: online magazine



Figure 59 design form: magazine (offline)

## 10.5 A message to RIVM

#### Two scenario's: inspiring or presenting reality

The qualities 'inspiring' and 'pure' mainly influenced the development of the women's stories. Such stories support women in visualizing their future by offering sample stories that 50 year old women can identify with or feel inspired by.

#### Interviews for prototype magazine

The development of the women's stories within this research&design project focussed mainly on the interaction quality 'inspiring' and less on the quality 'pure'. Locally admired women were selected within the neighbourhood where the concept test took place. These women were selected for the interview for prototype magazine, on remarkable characteristics that resulted out of the WhatsApp study. The remarkable characteristics (personality and actions) came forward in the interviews with these women. Besides that, both selected women had an active role in the community which also came forward in the stories. Locally 'admired' women were selected to make the women's stories attractive to read and to make women dream about their future. Their locality was important for the feeling of connection to these women's stories.

More focus on the other quality 'pure' will give another experience to these stories. Ordinary women could also be selected to make the women's stories pure and honest, and to trigger women to think about their own future. The focus determines which role models will be selected and what users will experience while interacting with the design intervention. I propose two options or a combination of the two options to RIVM, depending on the message RIVM wants to send.

#### If RIVM's message is 'inspiring for the future'

If the goal of the communication team (CvB) is 'to inspire', the user of

the magazine should experience an eye-opening and enriched feeling. In the first place, three essential elements for a well-informed decision (1) informing, (2) experiencing freedom of choice and (3) weighing information in relation to personal values, should be promoted through this magazine. The elements for a well-informed decision that will be stimulated mostly, are:

(2) experiencing freedom of choice and exploring choice options(3) feeling surprised by the personal values of other women and how these are used in women's decision

Besides that, this goal will help RIVM to communicate a broader story by focusing on the advantages and disadvantages (risk information) of the organized breast cancer screening, but moreover focusing on 'health decisions for the future' in general. If the goal of CvB is 'to inspire', the communication material could focus on the design direction of this project. RIVM could inspire women how they want to deal with bodily changes and health choice while aging, as input for the decision whether to participate or not in the organized screening.

#### Role models

Role models will be selected on their personality and actions. The personalities will represent differences in personal values, the actions will show possible health choices and examples of how to live towards personal values. The personalities will also represent differences in participation and non-participation in the organized breast cancer screening. The effect this diversity has on women's (user's) feeling of trust towards the organized screening and RIVM should be further tested.

#### Magazine and stories

The magazine will be mostly additional to the current information flyer, which offers the accurate information (needed for a wellinformed decision). This magazine will support women in the other two aspects of a well- informed decision: (2) experiencing freedom of choice and (3) being aware of personal values.

#### If RIVM's message is 'pure and representing reality'

If the goal of the communication team (CvB) is 'pure and representing reality', the user of the magazine should experience 'feeling assured of her knowledge'. In the first place, three essential elements for a well-informed decision (1) informing, (2) experiencing freedom of choice and (3) weighing information in relation to personal values should be promoted through this magazine. The elements for a well-informed decision that will be stimulated most, are:

(1) understanding the possible scenarios (risk information) by other women's stories

(2) experiencing freedom of choice and exploring choice options

This goal will help RIVM to explain the advantages and disadvantages (risk information), by communicating on an different level. The stories will represent the different possible scenarios (risks), and communicate on an emotional level. The decision-making might be triggered by the effectiveness of the emotional communication source.

#### Role models

Role models will be selected on their actions and experiences. The actions will represent the possible choice options regarding the organized breast cancer screening, and the experiences represent the risk scenarios of the participation or non-participation of that screening. The choice of role models should also represent the decision of non-participation.

#### Magazine and stories

The magazine will be mostly additional to the current information flyer, and will focus mostly on the (1) accurate informing element of a well-informed decision, by explaining the risk scenarios through other's experiences. The magazine will mostly support women in the following two aspects of a well-informed decision: (1) understanding the risk information and (2) experiencing freedom of choice.

#### Usage of stories in other context

The concept of periodic intervention of the magazine focusses on well-informed decision making using content that pays attention to the well-informed decision, and to themes which the user group can relate to. This concept is currently designed for the case for Het Bevolkingsonderzoek Borstkanker.

However, this concept and its communication strategy might also be applied in different contexts. From a conceptual perspective, the content of the designed magazine consists of two layers:

1. well-informed decision topics

2. user group topics

These layers might be filled in with content fitting to another context. (see Figure 60).

The organized breast cancer screening is one part of the 9 offered screenings programs by Het Bevolkingsonderzoek and RIVM. The screenings program consists out the following 9 tests.

During pregnancy:

- Bloedonderzoek zwangeren
- Down-, edwards en patauscreening
- Structureel Echoscopisch Onderzoek

After birth:

- Neonatale hielprikscreening
- Neonatale gehoorscreening

Cancer:

- Bevolkingsonderzoek baarmoederhalskanker
- Bevolkingsonderzoek borstkanker
- Bevolkingsonderzoek darmkanker

Further concept development should explore whether this concept of a periodic intervention of a magazine with content using an understandable language, is also desired by other user groups. These could be user groups of other screenings programs, such as future parents, 30-year old women, or 50+ men.

#### Weaving programs together

Besides that, further concept development could explore how the tests of the screenings program could be linked to each other. Women are confronted with multiple decisions from the screenings program. The questions is whether women have the willingness to make a well-informed decision every time. It would be interesting to analyse how these different tests and decisions could weave together.



*Figure 60* conceptual reconstruction of the underlying idea behind the magazine which might be applied on other screening programs too.

#### Other design forms

To conclude with, I recommend further developing and testing the alternative design forms: online video and online magazine. The alternatives offer advantages regarding sustainability and costs. Besides that, the language possibilities of these design forms are valuable.

The possibilities online appear to be already in development, based on a conversation with the communication department for the organized screening. The webpage already offers short videos. Usability research (of communication department RIVM) showed that the findability of the videos has been rated insufficient and that the amount of offered information is experienced as 'too much'. The current videos focus on the decision and motivations (only well-informed decision topics and no women topics). Nevertheless, the implementation of the women's stories online could build further on the insights gathered out of the previous evaluation of the webpage and videos, concerning:

- the findability of the videos
- the amount of offered content in videos and on webpage.

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# appendix o.

# project proposal

The following appendix presents the original project proposal.

### Ao Proposal

### project proposal

Breast cancer is the most common type of cancer among women in the Netherland. Approximately 1 out of 8 women in the Netherlands get diagnosed with this disease. Since 1989 the government organizes every two years a breast cancer screening for women between 50 and 75 years old in the Netherlands. Due to the organized screening, breast cancer can be detected and treated at an early stage. Besides that. research showed that due to the organized screening, 850 women lives are saved every year. However, the organized screening also includes negative consequences. When organized screening was introduced, the overall advantages were higher than the overall disadvantages. seen at a target group level. However, depending on someone's personal situation the balance differs between the advantages and disadvantages to participate. This is why participating in the organized screening is a personal decision and not compulsory. This is also why the RIVM, opened a project proposal to help them with the question: "how could women be supported in making an well-informed decision whether they want to participate or not to the organized breast cancer screening?"

The research project (Visioning Risk) is set up by RIC Risk communication group at the RIVM and the RISC Risk communication team of the VU medical centre, who aim to:

Design novel visualizations of quantitative risk information, which are easier to understand while taking into account people's beliefs about specific health risks.

Public health policy aims to reduce health risk factors at a population and individual level, also partly by communicating information about risks. It is considered to be important to communicate this information to people in order to help them to make informed choices about their health and safety. However, little impact has been found of such information on decision making and behaviour.

One reason for this might be that [1] the presentation of the risk information is too abstract, often too complicated to understand for many people (Peters et al., 2007). Another reason for this might be that [2] psychological models of risks that determine how people think and feel about risks, and the impact risks have on people's decisions and behaviour, differ from the experts' perspectives on risks (Morgan et al., 2002). Additionally, apart from the information RIVM is presenting to the public, nowadays, the current population can collect information through many different channels. Recently, RIVM is taking a more active and responsible role, to assist people in considering health risks in their decision making and behaviour.

This graduation project will be part of the research project Visioning Risk. The focus of this graduation project in particular will be on this one: organized breast cancer screening. The public has a very positive attitude towards cancer screening (Douma et al., 2016). Cancer screening may lead to early detection and timely treatment. However, the question is whether people are aware of the negative consequences: e.g., over-diagnosis, false positives, false negatives and health risks of the radiation used in the procedure. The information presented to the public is rather abstract and complicated. For example, it is not always clear to the public that the risk of getting cancer is related to age. Furthermore, it seems that people overestimate the benefits and underestimate the possible harms. This might be explained by the fact that screening policies have been striving for increasing participation which transpired through their communication strategy, according to Gigerenzer (2015).

#### Approach

The challenge for this graduation project is to inspire RIVM with this research and design project. The project will be approached with a certain method and user focused design techniques, which are used in the Design For Interaction field. User centred techniques will be used along the project in total. First, to enhance the understanding why women interact with the Bevolkingsonderzoek Borstkanker service the way they are.

The approach of this project in total, is inspired by the approach: Vision In Product Design (Hekkert and Van Dijk, 2011). This approach will give me, as a design student, guidance through a research and design process towards an meaningful design concept. The approach will help me, to questioning why the context is constructed the way it is constructed. Besides, this approach will help me first, to carefully determine and design the impact, and after that the approach will help me transform the impact into a final design proposal. In this research & design project, the context will be deconstructed by analysing the context from different perspectives: a psychological, societal, public health care, statistical and service-design perspective. These perspectives will be studied through literature research and interviews. These perspectives will help to understand why the context is constructed the way it is constructed.

In a later stage, user centred design techniques will used to involve user their desires into the concept creation. "Co-Creation" design techniques will be applied to bring the users together to support them in the exploration and creation of a design intervention. Finally, users will involved to evaluate the design proposal.

#### Phases

The aim of this project is to support women in making informed decisions, based on pros and cons, about whether participating to organized breast cancer screening. This design research consists of 5 phases (which are also shown in the planning):

- Phase I: Defining domain and researching context
- Phase II: Design direction
- Phase III: Concept designing
- Phase IV: Testing & redesigning
- Phase V: Presenting concept design

In phase I and II, research will be conducted to get a better understanding about:

[a] how breast cancer risk information is communicated by RIVM, and how the information is presently perceived by women

[b] through which channels women gather information to decide for yes/no participating

[c] people's experience with, and perspective towards , breast cancer screening, and how this impacts their decisions.

[d] the attitude towards the breast cancer screening in society, in a more general perspective

In the end of the analysis (research part: phase I and II), a conclusion will be created on the current communication strategy of the organized screening, and how this influences women in their decisionmaking. Finally, a design statement will be formulated to point out the design focus and goal for the further design part of this project. Important functionalities will be determined for a design intervention. These functionalities will be design parameters for the ideation part of this project.

Phase III will focus on creating a design intervention that supports women in making a well-informed decision. This design phase will be explorative, and women of the user group and other stakeholders will be included in the creation of concept ideas. A creative session will be set-up to achieve this. Important qualities will be determined for a design intervention. These qualities will be the design parameters for the concept development part of this project.

Phase IV will focus on evaluating the final design concept. An experimental concept test will be conducted to evaluate the final design proposal. An prototype will be designed, which should represent the mechanism of the design intervention and it should express the important interaction functions and qualities. This prototype will be used, to test the proposed design intervention.

#### personal goals

I decided for participating in this project, because of the challenge and my personal interest. It seems challenging and valuable to bridge between the different perspectives of the stakeholders: RIVM, the health risk experts, the user group, and within a context that is not familiar with the design field (see Figure 7).

Besides that I appreciate the social focus of this project. During the bachelor and master, all the different design methods and techniques that came across, mostly focussed on technology and business cases. At some moments, I have been missing the link to, and focus on, social relevant topics. This graduation assignment seems like a perfect project, in which this social relevance is included. By literature and user studies, I will link this project to the minor Psychology I did. The project will be inspired by psychological theories, but also social and communication theories.

Design approaches from the Design Aesthetics Area support me as a designer to include social, psychological and cultural factors. Therefore I choose for the design method Vision in Product Design, and a mentor from this design area. Getting inspired by the Vision In Product design method, will hopefully help me focusing and including the different social, psychological and cultural factors. Besides that, co-creation will be used in this graduation project. I believe that bringing different perspectives together will help to understand each other, and it will help to create common ideas. Therefore I choose for a Chair who has expertise in that field.

A personal goal in this project, is to give a self-confident final presentation, to finish my bachelor and master with a presentation (of a design) which has relevance and which I can appreciate.



Figure 61 shows the position of Hanna between the stakeholders.

appendix 1.

# **Interview User Group**

### A1.1 Research plan

Interviewing user group

### Interviewing User group

Semi-structured interviews with the user group were set-up (see Figure 12 ).

### Goal

The aim of the interview study with the user group was, to enrich the understanding of:

- the experiences with the service
- their perspective on the organized breast cancer screening
- and their decision-making process.

The interview results were mostly in line with other previous research results. However, the interview session resulted in a rich impression of what women experience, an input and inspiration for the design part.

#### Sub-goals

The sub-goals of this study were:

-Mapping women's perspectives (ideas, beliefs, and expectations) regarding breast cancer screening.

- Mapping women's experiences with the service: information letter and invitation, choice process to participate or not participate, and the screening itself.

- Mapping decision strategies of women.

#### Study design

The interviews are mainly retrospective, but also focusing on the future, by asking how women have made or will make their choice regarding breast cancer screening. A booklet with a number of questions was offered to the user group in advance, in order to recall their memories and thoughts about the topic (see intervention). The themes of the booklet (see intervention) were used as guideline for the interview. The booklet and interview was divided into different themes:

1. The first theme focused on women their personal values, in order to get an impression of the person who was interviewed, and to explore the influence of personal values in their current decision strategy.

2. The second theme focused on women their perspective on health, breast cancer and the organized screening, and it's associations.

3. The third theme focused on women their experiences with the decision making process. The participants were asked about their decision-making process, and which considerations they took into account.

4. The fourth theme focused on women their usage of information manners. Participants were asked about which information sources they used, and whether they took risk numbers into account.

5. The last theme focused on doing a small assignment together with the participant. This assignment was conducted, to figure out women their desires regarding to the decision process and breast cancer screening.

#### Sample

Since it is a qualitative study, eight participants were expected to obtain sufficient insights and information. This is based on previous similar studies in Social Medicine and TU Delft.

#### Recruitment

A request for recruiting participants, is distributed via the social network. People who showed interest received a patient information letter, an informed consent form, and a booklet (see intervention) in order to prepare the participants for the interview session. The patient information letter informed the participant on the fact that audio recordings are made, if the participant would give permission.

The diversity of literacy and ethnical background within the sample group, has been a point for discussion. An additional creative session

has been conducted, to also involve women with low literacy and different ethical backgrounds into this research & design project (see chapter 7 - Creative Session).

#### Intervention

An intervention is used within this study, to prepare participant for the interview itself. The usage of the intervention is inspired on the Context Mapping technique (Sleeswijk Visser et al, 2005). Before the interview, participants received a booklet with questions at home. Participants were asked to recall memories, and reflect on their experiences, ideas, and perspective on the organized breast cancer screening. For example, women were asked about their associations with the organized screening, their memory of the first invitation letter, and their decision. This intervention offered touchpoints to elaborate on during the interview session. Eventually, this approach should give the opportunity to obtain more information out of the interview session itself.

#### Organization

Participants were categorized into three groups: participants who always participate in the breast cancer screening (WD), participants who sometimes participate in the breast cancer screening (TD) and participant who do not participate in the breast cancer screening (GD). Participants are numbered in the order in which the interviews were conducted. The data is connected to this number (WD01, TD01, GD01, WD02 etc.) and in this way it will be possible to identify the participant.

#### Duration and place

Filling in the booklet took the participants approximately 30 minutes. The interview sessions were done at home. The interviewer visited each participant. The interview took approximately 45 minutes.

### A1.2 Interview set-up

*The interview questions are documented in Dutch, since the interview sessions were conducted in Dutch.* 

#### Onderzoek fase 1:

Dit interview wordt uitgevoerd aan de hand van een boekje wat de deelnemers vooraf hebben ingevuld. Precieze vragen kunnen dus per deelnemer verschillen.

Tijd	Onderdeel	Vragen
5 minuten	Introductie	Smalltalk om het gesprek aan de gang te krijgen. Hoe gaat het met je? Waar ben je op dit moment zoal mee bezig?
		Bedank de deelnemer voor deelname aan het onderzoek. Leg het onderzoek en de context van het onderzoek uit. (zoals ook beschreven in brief en protocol).
		Benoem dat alle antwoorden anoniem worden gehouden en niet zullen worden gedeeld, ook niet met <b>bijv. Ebelien.</b>
		Hoe ging het invullen van het boekje? Heb je daar nog vragen over?
10 minuten	persoonlijke waarden en normen (Thema 1)	Welke vijf waarden heb jij ingevuld? Waarom zijn deze waarden belangrijk voor je? Kun je dat kort toelichten? Ben je je op bepaalde momenten bewust van je persoonlijke waarden? Zo ja welke momenten?
5 minuten	Algemene associaties (Thema 2)	Beeld eigen gezondheid: Wat komt zijn de eerste dingen die in je opkomen bij het begrip gezondheid?
		Ben jij je bewust van je gezondheid?
		Wat vind jij belangrijk als het gaat je eigen gezondheid? Hoe zorg jij voor je eigen gezondheid?
		<b>Beeld borstkanker:</b> Hoe kijk jij naar de ziekte borstkanker? Komt het voor in je omgeving? Ben je wel eens bang dat het je zelf overkomt?
	(Thema 3)	Beeld bevolkingsonderzoek: Wat komt zijn de eerste dingen die in je opkomen als je denkt aan het bevolkingsonderzoek borstkanker?
		Door wie verwacht jij dat het bevolkingsonderzoek wordt opgezet? Wie/of welke instanties voelden betrokken bij het onderzoek?

Ervaringen met screening proces (thema 4)	Een thema vraag ging over de eerste uitnodiging. Kun je jouw herinnering van de eerste uitnodiging beschrijven? Had u daarvoor al eerder van het bevolkingsonderzoek gehoord? Heb je mee gedaan ja/nee? - Hoe heb je de dag van het bevolkingsonderzoek
	ervaren? - Hoe heb je de uitslag ervaren?
	Hoe heb je de <b>begeleiding</b> in het proces ervaren? Wie hebben je begeleidt in dit proces (personen/instanties)? Kun jij je de envelop nog herinneren? Zo ja, wat?
	Wat herinnert jij je van de informatiefolder? Wat vond je van de folder?
	Wat herinnert jij je van de uitnodiging? Wat vond je van de uitnodiging? Wat voelde je bij de uitnodiging?
	Hoe voelt dat, dat de datum van je onderzoek al vast staat voor je een keuze hebt gemaakt?
	Het laatste thema ging over het maken van de keuze. Wat kun jij je nog van het maken van je keuze herinneren?
	Kunt u vertellen of je gekozen met uw verstand of gevoel?
Automatisch of gecontroleerd (thema 5)	Hoe ervaarde je het maken van je keuze? Hoeveel was je met je keuze bezig van een schaal van 1 op 10? → 5-10
	Heb je getwijfeld over wat je zou doen? Waar gingen je twijfels over?
	→ 1-5 Kun je vertellen of je het wel of niet meedoen aan het bevolkingsonderzoek als een keuze ziet? Of is het bijvoorbeeld iets "dat je gewoon hoort te doen"? Waarom?
	screening proces (thema 4)

### A1.2 Interview set-up

	Analytisch of holistisch (heuristieken) (thema 5)	Kun je vertellen wat je <b>overwegingen</b> zijn geweest? Wat waren uw verwachtingen van het bevolkingsonderzoek voordat u de uitnodiging thuis kreeg? 
		Ben jij je bewust geweest van je persoonlijke waarden in je keuze?
		Welke persoonlijke waarde speelde een belangrijke rol in jouw keuze?
	Tevredenheid keuze	Kun je vertellen wat je gevoel was over je keuze (goed of fout)? Waarom voelde dat zo?
10 minuten	Informatiebronnen (thema 5)	Welke bronnen heb je gebruikt in het vormen van je beslissing?
		Wat heeft je geholpen om een besluit te vormen? En waarom? Waar heb je dat gevonden? (bijv. informatie weergeven door instanties) En wat heeft juist <i>niet</i> geholpen?
		Heeft iemand je geholpen met een besluit vormen? Zo ja wie? En wat hielp aan het contact met die persoon?
		En wie heeft u juist <i>niet</i> kunnen helpen?
		Wie of wat heeft voornamelijk jouw vertrouwen gewonnen in deze keuze?
		Heb je wel eens gehoord van het RIVM?
10 minuten	Reflectie op keuze	Hoe kijkt u terug op uw beslissing om wel/niet mee te doen? Was het een goede of foute keuze? En waarom?
		Wat wist u voor niet, dat u graag had geweten?
10 minuten	Toekomst situatie	Achterhaal hoe de deelnemer in de toekomst ondersteund zou willen worden in haar keuze:

	Reflectie	Zou je op een schaal van 1 op 10 kunnen aangeven in hoeverre je het belangrijk vindt om zelf een weloverwogen keuze te maken? Zou u op een schaal van 1 op 10 kunnen aangeven in hoeverre je het belangrijk vindt dat je een passende advies
	toekomst	bij jou krijgt? In een toekomst situatie, over 2 jaar wanneer er opnieuw een bevolkingsonderzoek plaats vindt, waarbij je opnieuw mee kan doen aan het bevolkingsonderzoek, hoe zou je willen dat de procedure voorafgaand aan het onderzoek
		verloopt? Belangrijk: u mag vrij denken, alle ideeën mogen er zijn, en er is geen goed of fout! <i>Aanvullende vragen, zoals:</i> Wat zou u voor de volgende keer kunnen helpen, via welk
C minuton	A fall sitilar	kanaal, op welk moment? Wie zou je vertrouwen?
5 minuten	Afsluiting	Heb je nog vragen? Bedankt voor de deelname aan het onderzoek! Je antwoorden waren zeer waardevol en zullen gebruikt worden in de verbetering van de risicocommunicatie over het bevolkingsonderzoek borstkanker van het RIVM.

### A1.3 Interview intervention

The booklet prepared participants for interview session. The booklet is written in Dutch, since the interview sessions were conducted in Dutch.



### A1.3 Interview intervention



### A1.4 Interview results

This paragraph shows the insights which are generated out the analysis of the interview session. The insights are presented per theme, and are supported by quotes out of the interview sessions.

"We are all there for our breasts, so you look at each other: 'well, there we go. We're all here, for our breasts,' in that way." In the waiting room for the mammography// Participant WD05

#### Interview theme 1. Personal values

#### Insight 1. Women become aware of their personal values when something happens that relates to a certain value.

"No, if you sometimes do not feel safe, at such a moment you realize how important it is to feel safe again." Participant WD05

"Wait a minute, I think health is the most important thing! Only if you are healthy, you don't feel that. And the moment you are not healthy, I think that health is the only thing that matters, because you want to become healthy again." Participant TD01

## Insight 2. Women take their values into account when they make a decision with or without awareness.

"Maybe ... when making choices. At such moments when you think: 'would I do this, or would I that...' Then you'll come back to your own values or something." Participant TD01

"That is why I also think that you should not get too attached to all those values. But that you occasionally think about it again, of: 'what drives me?' or 'why am I doing this?" Participant WD03

"But I also want to do it for my environment, that you do not ...

because you do not want to do stupid things, in such a way that you become ill. My family, that would be very difficult for them too." Participant WD03

"In fact, I have already made the choice before, when I receiving an invitation, this gives me the opportunity to be at something earlier, and I believe that is more important than all those other things." Participant WD05

## Insight 3. Personal beliefs seem to influence women their attitude to life, and it that way their decision making.

"I think: 'I do it, than it would not have been my fault of being too late.' Participant WD02

"The earlier you are, the better. I really believe in that." Participant WD06

"Of course I will be afraid, then, but I can not worry about it now. Because then you I can not life the way I like it. Yes, we see that by then, I'm too down-to-earth for that, I think." Participant WD06

"So, the positive approach, not going to worry in advance, I think that is a waste of time. And a waste of quality of life too." Participant TD02

#### **Interview theme 2.** Health

*The purpose of this theme was to warm-up the thoughts of the participants, and the conversation. This theme is not further analysed.* 

### A1.4 Interview results

### Interview theme 3. Bevolkingsonderzoek Borstkanker

### A. The disease

Insight 4. Women are aware of the disease, and it's seriousness, because of stories of people around them.

"Well, I thought: I do see a lot of women around me with breast cancer. And, Marrianne that close friend. Yes, that was the motivation to do it." Participant WD02

"Someone from my choir, has been operated for breast cancer this week. Then it comes close in my surrounding. And when I look around, there are several women that I know who have had breast cancer or other forms of cancer. And then you can not do, as if it does not exist ..." Participant TD01

"I was there when the bandage was removed ... well it's a mutilation from here to Tokyo." Participant TD02

## Insight 5. Women have the image of breast cancer, that good opportunities to treat the disease are existing.

"My image of the disease ... I do not think directly: 'oh you got breast cancer, you will die'. I do realize it, but I do not think in that way." Participant WD04

#### B. The organized screening

## Insight 6. Not all women are aware of the negative consequences of participating in het bevolkingsonderzoek borstkanker.

"Are there risks in mammography? I did not know about risks that were involved in a mammography" Participant WD01 "I thought, well no, it's like the dentist every six months, no problem at all. Sometimes you have a something, well I just did this for safety reasons." Participant WD01

"Once happened that I had to go to an extra mammography check, and then they saw something that was not good. I did not think about it, that 'oh that could happen ...'. On the other hand, I jumped into it totally blind. This occasion changed the experiences of the other researches, and made it more loaded." Participant WD04

# Insight 7a. A lot of women have a positive attitude to the test result. Their first thought is: 'Oh, probably I won't have anything'.

"No no I was never afraid of, or thought about the disease. It was of course close to me, because I am a daughter of my mother, but that is not something that you really think of ... You can also get an accident in the city, or whatever." Participant WD01

"So apparently it can be not good either. Because my first reaction is just simply: 'I would not have it." Participant WD04

"Of course I will be afraid, then, but I can not worry about it now. Because then you I can not life the way I like it. Yes, we see that by then, I'm too down-to-earth for that, I think." Participant WD06

#### Insight 7b. A negative experience with a test result can influence their positive attitude towards the test results into a more tensed attitude.

"Yes, I'm nervous, no but it's okay, all those other times I always had to sweat a lot, I started sweating so terribly and it was so exciting, that's what I always call 'anxious sweat'" participant WD01

### A1.4 Interview results

"When I got another call, I thought: "Yes, I really can not do this besides everything else at the moment!" But, what can I not handle? I can not handle the tension of the result!" Participant WD04

#### Interview theme 4. Decision-Making

## Insight 8. Some women do make the decision to participate intuitively, and not controlled.

"It is not an issue at all for me! It's just painful and annoying, but it never happened that I thought: 'Maybe I should not participate.' It like an APK check for me!", participant WD04

"Nobody asks me: 'do you want to participate in this research?' The letter just arrives! If you really wanted to give someone a choice, you actually should get a letter: "Do you want to join..." Participant WD04

## Insight 9. The decision to participate or not participate, happens mostly before the information & invitation letter arrives.

" No, I already knew that if I would get a letter at the age of 50, I would join. I knew that right away. That letter was not a moment for me to think about whether I would participate in that research. That was already clear for me." Participant WD04

## Insight 10. Women talk to each other about het bevolkingsonderzoek borstkanker and their decision.

## Insight 11. The moment that the information & invitation letter arrives, is a moment of realization the she became 50.

"Then I thought ... I am getting old. I really thought: 'oh my god, now I also belong to the old club, and I have to go to the tietenpletter too.'

#### Participant WD06

#### Insight 12. Risk number seems to have a little impact on women.

"Those personal risk figures, then I might go living towards them, and then I'm going to be scared or something, that's a waste of my time, that's a waste of quality of life. No, really. I do not want to know, take life now as it comes, and then you go with it, and that's nice?" Participant TD02

### **Interview theme 5.** Information Sources

## Insight 13. Stories of other people are a most common manner of information source.

"Well, I always find it interesting to talk about it with others. There you get arguments again, you formulate yourself your own statement again. So I think that's good. Thinking about it together, makes you think." Participant WD03

Insight 2. Women are tend to search quickly on internet for answers on their questions, but for most questions they reach out to an expert, like a G.P.

"No, I did not search for information, why and why not. Nowadays with internet, you have these extreme people who are very much against ... I only become uncertain about that." Participant WD02

## Insight 14. Women are tend to talk with someone in their environment, they trust about certain doubts.

"Well, then I talked to Max (her son) about it. We talked about whether I would go or not. Because it also gives radiation, and so we weighed the positive things against negative things. Max really thinks that I should do it. Of course you get radiation, but if you are in an airplane you also get radiation." Participant WD02 "Therefore I have asked my brother who is familiar in the field of health as well. I have the feeling that I can trust him, the opinion he gives, or his judgment or his knowledge that he shares." Participant WD03

"At first I did not discuss it at all, and later I talked about it with my daughter again, and she also said: 'yes, breast cancer has often good treatment possibilities. There are many women who can be cured. " And when I say: 'If I die anyway, I prefer to hear it as late as possible.' This is not such a good argument anymore. Because maybe that is a difference between dying and not dying." Participant TD01

#### Insight 15. Women do have the image of a good balance of pro's and con's in the information provided by het bevolkingsonderzoek borstkanker.

"Because if you search for organized screening at the institute who offers it, there are other things than when you look for the negative sides." Participant TD01

#### Interview theme 6. The Future

#### Insight 16. A well-informed decision feels important for women, but a personal advise doesn't feel good for women.

"You do not know that result in advance. But you have to take into account all those results which can come out. And I think it is good in itself, to think about it beforehand." Participant TD01

# Insight 17. Women experience the research methodology as painful, human unfriendly and not in line with the current technology.

Insight 18. Women mention psychical discomfort of the research day, as something they do not like about het bevolkingsonderzoek borstkanker.

"If the method was designed by women, it would have been very different! For sure." Participant WD04

"But if it would be important to me, then the pain would be ok. The pain is doable. But with all those doubts that I already have, and the pain involved, I think: 'leave it', but if the method would be more human-friendly, then perhaps I would participate." Participant TD02 appendix 2.

## **Interview Insights Experts**

### A2.1 Insights Interview

### Prof. dr. Dr. D.R.M. Timmermans

*Prof. dr. Dr. D.R.M. (Daniëlle) Timmermans was interviewed on decisionmaking processes among patients. She is Professor of Risk Communication and Patient Decision-making at the Department of Social Medicine and the EMGO Institute of the VU Medical Center.* 

## Insight 1. Nobody processes risk information completely in an analytical way.

People tend to process risk information using heuristics to simplify the complex decision area.

#### Insight 2a: Heuristics make the decision-making process easier.

An expert makes use of heuristic in a decision-making process. These heuristics are rules of thumbs, which can be used to solve a decision problem analytically. However, the person uses these heuristics in a more intuitive way. A common heuristic for women within the decision-making process about the screening is: "organized screening, that just what people do". Such a heuristic is used as a criteria.

## **Insight 2b. It seems like people make use of heuristics in every** decision-making process.

## Insight 3. Information with high affective impact has a larger impact on a decision.

Information with a high affective impact guides judgement. Such information seems like a heuristic which plays an important role in the decision-making. This information has a high impact on the decision. For example, people do not let in more information, when they are so focused and concerned about one thing.

## Insight 4: Doubts can arise in every analytical decision making stage which can lead to re-thinking.

In an analytical decision making process, doubts can arise. Every time these doubts arise because of on another question, such as: "do I have enough information to base a decision on?" or "do I need to weight the decision criteria differently?"

## Insight 5: The target group of the organized breast cancer screening seem to not doubting about their decisions.

It seems like women between 50 and 75 years old do not doubt about their decision. In this way, women are not triggered to start re-thinking their decision and its criteria's and not triggered to start looking for new information.

## Insight 6: Het bevolkingsonderzoek Nederland keeps themselves outside the policital game.

The organization: het bevolkingsonderzoek Nederland, do not participate in the political field and keep themselves outside media and discussions.

Prof. dr. Dr. D.R.M. (Daniëlle) Timmermans was interviewed on decision-making processes among patients. She is Professor of Risk Communication and Patient Decision-making at the Department of Social Medicine and the EMGO Institute of the VU Medical Center.

Henk de Vries, professor of general practitioners medicine was interviewed on the topic: how G.P.'s support patients in decisionmaking processes and the case organized breast cancer screening

### based on interview Prof. dr. Dr. D.R.M. Timmermans

*This visual presents a several insights that were gathered out of the interview sessions schematically.* 



### A2.2 Insights Interview

### Prof. of G.P.'s Medicine Henk de Vries

Henk de Vries, professor of general practitioners medicine was interviewed on the topic: how the medical field supports women in the decision-making processes and further process of the organized screening and the case organized breast cancer screening. This paragraph shows the interview

*"Bij het bevolkingsonderzoek borstkanker is meer vraag dan goed voor ze is."* 

#### State: Burgers in Nederland zouden willen dat dit al de oplossing was voor de ernst van en de hoge kans op de ziekte borstkanker.

"Er is veel wishfull thinking, en er is maar weinig geloof in het bevolkingsonderzoek borstkanker," noemt Henk de Vries.

State: Het bevolkingsonderzoek borstkanker probeert in ieder geval iets te doen, en helpt mee aan het oplossen van het probleem borstkanker, ook al is het nog niet de perfecte oplossing voor de ernst en het hoge risico.

"Het onderzoek is niet de hele wereld, maar we laten vrouwen toch gaan. Voordelen op populatie niveau wegen maar net op tegen de nadelen op populatie niveau."

"Het is een onderzoek die groots is opgezet, een draaiende machine."

"De ernst en de kans maken dat we het bevolkingsonderzoek zo serieus nemen, en het onderzoek blijven doen."

State: de huisarts probeert te snappen waar een mogelijk patiënt mee zit en misvatting te corrigeren, maar de uiteindelijke verantwoordelijkheid blijft bij de patiënt. Stappen procedure preventie vragen

Stap 1. De vraag om advies door een arts begint met een intake. Dit een explorerend gesprek, waarbij de arts een beeld probeert te vormen, gekeken naar emoties, cognitie en gedrag.

Stap 2. De arts probeert misvattingen te corrigeren.

Stap 3. Er wordt geen advies gegeven. De keuze blijft bij de patiënt.

"Ik adviseer bij angst om deel te nemen, want dan heb je zekerheid."

#### State: Bij preventie zaken blijft de keuze bij de burger. Bij andere medische zaken gaat het om de patiënt over de drempel helpen, of geruststellen.

"Bij veel zaken van twijfel gaat het om de patiënt over de drempel helpen. Bij een patiënt die last heeft van depressieve klachten, helpen wij de patiënt over de drempel om een keer met een psycholoog te gaan praten. Bij preventie en leefstijl ligt dat anders. Dit blijft de keuze van de burger zelf. Ook al verandert dit leefstijl de laatste jaren ook steeds meer, zoals bij bijvoorbeeld roken."

## State: Vrouwen doen mee omdat ze vrouwen in hun omgeving hebben met borstkanker.

Hoge deelname wordt beïnvloedt door hoge percentage vrouwen dat leidt aan borstkanker.

"Vrouwen doen mee met het onderzoek, omdat borstkanker zo veel in de omgeving voorkomt."

"De letterlijke risico cijfers worden niet gebruikt. Het gaat voornamelijk om de grote ernst van de ziekte en de hoge kans die mensen lopen op de ziekte."

### A2.2 Insights Interview

### Prof. of G.P.'s Medicine Henk de Vries

State: Preventief onderzoek is op dit moment toch de beste methode die wetenschappelijk is bewezen.

Zelfscan blijft wetenschappelijk onderzocht, niet effectief te zijn. Er worden of andere dingen gevoeld of een bobbeltje wordt niet gevoeld.

State: Bij het bevolkingsonderzoek borstkanker is sprake van overconsumptie

Expats uit het Oost-blok komen langs de huisarts voor halfjaarlijkse onderzoeken. Huisartsen met de vrouwen van de onderzoek weerhouden. Wetenschappelijk onderzoek heeft aangetoond dat jong screenen niet effectief is, en de te veel straling schadelijk is.

### A2.3 Insights Interview

### Bevolkingsonderzoek Borstkanker

An interview with Petra Westdorp (manager Midden-West) and Mariet Kimminga (communication advisor) was conducted to generate an understanding of the projects and activities applied by the executive organisation: Het Bevolkingsonderzoek Borstkanker.

Insight: the organisation is working on the same themes as RIVM, but the difference is that they work by doing & trying and not according to academic procedures.

Currently, Het Bevolkingsonderzoek Borstkanker works on:

- information events for non-Dutch speaking women

- better communication matter to prepare women for the painful and uncomfortable factors of the research.



### A2.4 Insights Interview

### Mammarosa

An interview with Ina Speelman (social worker for Mammarosa) explained about the fund. Insights are shared.

In the interview with Ina Speelman, we discussed the purpose of fund Mammorosa. Mammarosa informs women from different cultural backgrounds about breast cancer and its prevention. Mammarosa believes that the lack of knowledge in certain cultural groups, mostly influences women (and men) their attitude towards breast cancer. This is the reason why Mammarosa is working on enhancing the knowledge, to prevent the misconceptions and beliefs. I would like to share the activities that Mammarosa organizes to enhance the knowledge about breast cancer and the prevention.

#### Insight: the usage of key-women

Mammarosa work with key-women. These women can be seen as the keys between a specific cultural group and the organization Mammarosa. These key-women present and facilitate workshops about raising awareness on breast cancer, and talk-sessions for women who suffer from breast cancer. The workshops and sessions focus on connectedness and recognition.

#### Insight: focus on life style

Mammarosa organizes workshops to create awareness on the importance of lifestyle. Experts on nutrition, physical movement and relaxation facilitate workshops to inspire women on how work on a healthy lifestyle.

This insights out of the interview session, was an argumentation for focusing on different cultural backgrounds in the concept development. *The final concept test partly focussed on this: how do women from different cultural backgrounds perceive the envelope?* 

## appendix 3.

## **Context Factors From Literature Study**

The following appendix shows the context factors (research findings) which were generated out of the literature study. These factors are presented per research theme and separated over different topics.

### A3.1 Context Factors - theme 1

Attitude Towards Organized Screening & Breast Cancer

*This paragraphs shows the collected factors (states, principles, trends and developments), described as insights, which studied that specific theme.* 

#### Knowledge

The following insights are based on a study of Kosgeroglu et al. (2011).

- The overall breast cancer knowledge of women is reasonable. Almost 50% of women know the risk of breast cancer during life. Almost all women know the symptoms of breast cancer.

- Education level plays a role in the process of integration of prevention actions, diagnosis and treatment of breast cancer. Besides that, level of education creates awareness (Altunkan, 2008).

- Education level has a role in awareness and practice breast self-examination.

- Most of women know that family history influences the risk of breast cancer.

- Other risk factors are less known (like alcohol consumption, getting or not getting children at a late age, or obesities). Besides that women believe, that certain factors are risk factors for breast cancer, but this is not proven (as stress, physical environment or anticonception).

A study of Douma et al. (2016) showed that people heard more often of the breast cancer screening topic, when they were female, older and higher educated. **People mostly used traditional information sources** (newspaper/radio). Older people used websites and social media less often. (Douma et al., 2016)

A study of Nadalin et al. (2016) conducted in Canada, showed the need for promotion activities in Ontario that are widely available in a simple format, which lets women know about the possibility and take away the barriers of screening. **Systems of other countries show that promotion of organized screening is needed to take away the barriers of women to participate.** 

#### Attitude

The study of Douma (2016) showed that people support the breast cancer screening program, but this may not be based on sufficient knowledge or a full comprehension of what screening entails.

- People have a positive attitude towards screening, without knowing what the screening entails.

- The overall positive view of the Dutch public towards breast cancer screening program might be explained by the fact that people are more aware of and have more knowledge about the benefits of the screening, than about its possible harms and risks.

#### **Beliefs**

The following insights are based on a study of Harvey et al. (2015).

- Most recalls result in 'false negatives'. False positives have been shown to increase patient anxiety and reduce quality of life. This fear has impact on the breast cancer screening behaviour. **Women want better accuracy from their screening mammogram and fewer additional checks**. A motivating reason for women to attend the screening, is recommendation from a healthcare provider.

#### **Responsibility GP's and trust in GP's**

The following insights are based on a study of Ferrat et al. (2013).

- General practitioners (GP's) and gynaecologists are in the special position to provide individually preventative messages to increase or decrease the participation in organized breastcancerscreening.

According to Gigerenzer (2015), focussing on informing citizens risks loweres participation rates, because well informed women may realise that for most cancers it is unclear whether the benefits of screening transcend the harms. Historically, screening policies aimed for increasing participation, which influenced people in such a way that nowadays people overestimate the benefits and underestimate the harms. This is changed, at least in Germany.

### A3.2 Context Factors - theme 2

**Decision-Making Processes** 

#### **Decision Strategy**

Insight: Informed decision-making consists out of 3 components: making an informed decision, making a personal decision and making a decision in accordance with personal values, attitudes and preferences.

Different studies showed in a similar way that informed decisionmaking consists out the components:

- 1. Making an informed decision
- 2. Making a personal decision

3. Making a decision in accordance with personal values/attitudes/ preferences

Based on studies of Baron (2007), Timmermans (2013), Marteau et al (2001), Rimer et al (2004), Irwig et al (2006), Denters et al (2013).

Researchers from different studies mention the following aspects as "being important":

1. Required for making an informed decision:

Accurate, relevant, unbiased and balanced information (about purpose, benefits, harms and risks, entire procedure, test results)

2. Required for making a personal decision:

Freedom of choice and free from constraint

3. Required for making a decision in accordance with personal values/attitudes/preferences:

Mindful choice, and aware of personal values and preferences

Insight: The analytical way of decision making consists out of 5 steps: identifying decision to make, identifying the options and gathering information, structuring and analyzing the situation, assessing and evaluating the choice-options, and making a decision.

The rational decision-making model which is the underlying concept of analytical informed decision-making, consists out of the steps:

1. Identifying/recognising decision to make

A discrepancy must be observed between the current situation and the desired situation. A decision problem can be given to the voter, such as the choice to participate in the organized screening, or the voter might construct a decision problem himself, for example if he thinks he is too unhealthy and needs to work on this.

2. Identifying the options and gathering information An analytical approach means that the decision problem is divided into components, such as specifying the goals of the choice selection process, naming the choice options and determining possible consequences of all choice options.

For example: when making the choice whether participate or not participate in the organized screening for breast cancer, there are the options: participate, not participate, and another options could not participate this time but next the time. Advantages and disadvantages that have to be determined. If the voter makes use of an heuristic approach to the decision problem, the voter will not obtain the same amount of information about all options. For example, if not participating is not an option for her because breast cancer is existing in her family, she will only consider information for the options participate each time or participate the next time

#### 3. Structuring and analysing the situation

Values will be assigned to the different components of the choice problem based on opportunities, treats, strengths and weaknesses. The different choice criteria will weigh the decision options. A potential participant of the organized screening should have the assess to all possible consequences of each option, to determine how important she find the advantages and disadvantages in reaching the ultimate goal. A voter using an heuristic approach will not make use of the risk, but analyzing the choices in a different way. For example, the participating in the population screening can be valued positively because it allows controlling the fear of cancer.

4. Assessing and evaluating the choice-options Information can be gathered in every phase: objective or subjective information.

This information is gathered to shape and test their own preference.

5. Make decision

According to an analytical, normative approach, scores can be integrated to choose the option with the highest weighted score. However, a heuristic rule can be used as well, if not all information is analyzed.

6. Act on made decision

(Timmermans 2013).

#### Insight: not all citizens are capable or motivated to make wellinformed decisions . However the society can support these citizens in their decision making by for example nudging.

According to Timmermans (2013) making informed decisions is limited by the capacities of people to process information, the variation in skills and motivation for making choices. This evokes the question what we should understand to stimulate well-informed and well-considered decisions. However, it is possible to make choices easier for less motivated citizens. Based on the principle 'nudging': offering a choice in which the best option is the easiest option, influences a person if the person allows himself to choose for this option. An example is to stimulate the purchase of healthy products by making them recognizable and available in shops.

## Insight: citizens do not make their own decision but trust on the decision of another person

Another reason for why citizens do not make an well-informed decision, is because they trust another person, such as the general practitioner or the government. The citizen believes that the GP made a well-considered decision, and the person goes along with this choice.

**Insight: the intuitive affective way has impact on the judgement of risk, and therefore this might have a lager impact on the decision.** Psychological theories suggest that people process risks in two different ways: in an intuitive affective way and in an analytical way. The theories of Denes-Raj et al. (1994) and Slovic et al. (2004) suggest that the risks with a high affective act, guide the judgement of the risk, and might have a larger impact on decision than risks with a low affective impact.

#### **Influencing Factors**

Insight: According to Timmermans (2013) the decision strategy is based on three areas: knowledge of the voter (motivation and capabilities), context (physical and social) and decision problem

#### (complexity, context, information)

#### Automatically vs. Intuitively Decision-Making

Insight: people choose automatically when a choice is based on habits, well-learned tasks or traditions. When people can not rely on their experiences and the situation is new, people have to weigh the possible options in a controlled manner.

According to several psychological theories, different models exist that assume that there are two different cognitive systems that underlie reasoning, for example the theory proposed by Shiffrin and Schneider (1997). The automatic processing of information is activation of a series of memory nodes, which will be activated by the influence of certain cues or stimuli in the environment or within the person himself. These nodes are activated automatically, without any need of control or awareness. This occurs when a task is performed frequently. In a controlled process of information processing, conscious attention is required from the person. The short-term memory is used. Controlled information processing is therefore limited by information processing capabilities of the short-term memory. This distinction also applies to choices. People automatically choose when choices are based on habits, well-learned tasks or traditions. If situations are new and people can not rely on their experiences, they have to weigh the possible options consciously.

#### analytical vs. Holistic

# Insight: the targetgroup makes use of analytical decision making processes and heuristic decision processes to analyse the best health option

In an analytical approach, the problem is divided into the different parts (like goals, criteria, and preferences) and each part is evaluated separately. Finally, all the information is integrated into overall overview and judgement. In a holistic approach, the choice problem is not divided into parts. Someone makes a choice because he or she feels intuitively that a certain choice is the right one, for example used in situation as a new sport or car.

Analytical decision-making takes more effort and is more transparent. Holistic or intuitive decision-making is faster and easier, but less transparent and often less reliable. Heuristic decisions process is a simplified form of analytical decision making process. In such a process not all options are included. The voter makes decisions based on heuristics or rules of tumb. Less steps are needed to solve a problem, it costs less effort and less information is needed compared to the analytical decision making process. This is information is based on research of Timmermans (2013).

#### **Emotions**

#### Insight: negative and positive feelings connected to labels on representations of events and objects, help people to make decisions.

All information evokes a emotional evaluation, often without being aware of this. The affective evaluation is a natural manner to critize things, and can be used as heuristic for making complex decisison. A theory of Slovic et al. (2014) suggests in mind representations of objects and events, are combined with emotional labels. These representations with an emotional label result out of experiences in life. The negative and positive feelings connected to these labels, help people to make decisions.

## Insight: the mood influences the decision approach: analytical or heuristic.

A positive mood leads to a more heuristic way of thinking. A negative mood leads to a more analytical way of thinking. Besides the fear of negative feelings is a criteria in a decision making process. Mood circumstances influence people their decision making approach. People are motivated to avoid negative feelings as disappointment or regret. People take a negative feeling as a criteria into account in their decision making process. For example, women decide to participate in the organized breast cancer screening, however the risk of getting cancer is low, because of the fear that they will regret it afterwards. This information is based on research of Timmermans (2013).

### A3.3 Context Factors - theme 3

Communication Of Risk Information

#### **Risk Communication**

Insight: Risk information is communicated by numbers. However it is difficult to relate to these numbers for people. There is a need for a more useful affective way, and a manner that people understand.

There is a need for a good explanation of the three types of outcomes of the organized breast cancer screening research. Women do not experience the feeling of 'being forced' by the appointed proposed in the invitation letter. The tone of voice used in the information flyer attached to the invitation letter is serious but does not evoke worries. This resulted out of a study conducted by Explore Ferro (2017).

According to a study of Gigerenzer et al. (2007) many doctors, patients, journalists and politicians do not understand what health statistics mean or draw wrong conclusions from it without even noticing. The classic doctor-patient relationship exists out of paternalism, trust in authority, determinism (physicians who seeks causes instead of chances) and the illusion of certainty (patients who seek certainty when there is none). Information flyers and website distributed to doctors by the pharmaceutical industry, often report evidence in nontransparent manners that present mostly benefits of the interventions.

#### According to Gigerenzer hopes and anxieties are easily influenced and manipulated by information from the outside.

The public is sensitive for manipulation of their anxieties and hopes, in such a way that it undermines the goals of well-informed consents and decisions. Gigerenzer et al. (2007) recommends the statistical literacy education, and to shape an emotional climate in a society in where hopes and anxieties are no longer easily manipulated from the outside. To create an environment better-informed and more relaxed attitude towards their health. in where hopes and anxieties are no longer easily manipulated from the outside, and in where citizens can develop a better-informed and more relaxed attitude towards their health.

Insight: A study of Gigerenzer et al. (2007) discusses confusing against transparent representations. The study recommends the usage of frequency statements above single-event probabilities; absolute risks above relative risks; mortality rates above survival rates; natural frequencies above conditional probabilities.

Insight: According to the study of Gigerenzer at al (2008) there is need for transparent communication, that the human mind can easily digest, by focusing on visual and numerical representation of risk information.

Insight: population figures user for risk interpretation showed the biggest affective impact, however it is unclear whether the figures are the most effective in terms of understanding.

A study of Timmermans et al (2008) showed that population figures have the biggest affective impact. Furthermore, risks presented as population figures were also interpreted as significantly greater than the risks presented in other formats. This study of Timmermans et al (2008) suggests that the risk format plays a role in the decisionmaking process, although it remains unclear whether the population figures are the most effective in terms of understanding. The impact of population figures might be because these visual representation is more concrete and easier to imagine.

#### **Risk Communication RIVM**

Insight: women do perceive an information booklet in where the breast cancer screening risks are presented. The risks are mostly textual represented by frequency statements. The possible outcomes of the screening are represented by singleevent probabilities. This is a confusing representation according Gigerenzer at al (2007). RIVM offers a webpage online where people can search for information. The risks are mostly textual represented by frequency statements.

#### U beslist zelf of u meedoet

Net als ieder medisch onderzoek heeft het bevolkingsonderzoek niet alleer voordelen maar ook nadelen. U beslist zelf of u meedoet. Het is belangrijk dat u in elk geval rekening houdt met het volgende:

#### U kunt zich ongerust maker

Het kan gebeuren dat u wordt doorverwezen naar het ziekenhuis. Bijvoorbeeld omdat er een afwijking gevonden is op een van de rontgenfoto's. Of omdat de foto's niet genoeg informatie geven. Dat hoeft nog niet te betekenen dat u borstkanker heeft. Maar het kan u wel ongerust maken.

#### U loopt de kans onnodig behandeld te worden

Bij sommige vrouwen groeit borstkanker zo langzaam dat zij er tijdens hun leven geen last van hebben. Maar borstkanker wordt bijna altijd behandeld. Wordt er in het ziekenhuis borstkanker bij u gevonden? Dan kan het zijn dat u wordt behandeld voor kanker waarvan u geen last zou krijgen.

Het bevolkingsonderzoek biedt geen volledige zekerheid Borstkanker wordt in zeven van de tien gevallen ontdekt. Als er op de röntgenfoto's niets te zien is, bestaat er toch een kleine kans dat u borstkanker heeft.

U kunt borstkanker krijgen tussen twee onderzoeken in U krijgti elke twee jaar een uitnodiging voor het bevolkingsonderzoek. Het is mogelijk dat u borstkanker krijgt tussen twee onderzoeken in. Daarom is het belangrijk om naar uw huisarts te gaan als u klachten aan uw borsten krijgt.

*i* Kijk voor meer informatie over het bevolkingsonderzoek op www.bevolkingsonderzoekborstkanker.nl.

#### Doet u niet mee aan het bevolkingsonderzoek?

Vul dan het afmeldformulier in op de achterkant van de brief bij deze folder

#### Voor vrouwen van 50 tot en met 75 jaar

#### U kunt meedoen vanaf uw 50° jaar

Er zijn twee redenen waarom u kunt meedoen vanaf uw soe: Borstkanker komt vaker voor bij vrouwen die ouder zijn dan so jaar. Acht op de tien vrouwen die borstkanker knijgen, zijn ouder dan so. Borsten van jongere vrouwen hebben vaak meer klier- en bindwefsel. Daardoor kunnen we borstkanker minder makkelijk vinden met röntgenfoto's. Ook is dit weefsel gevoeliger voor straling.

#### U krijgt elke twee jaar een uitnodiging

U kunt elke twee jaar meedoen aan het bevolkingsonderzoek. Vaker röntgenfoto's laten maken, heeft voor de meeste vrouwen meer nadelen dan voordelen.

#### Het bevolkingsonderzoek stopt na uw 75e jaar

Bij vrouwen boven der 55 jaar groeit borstkanker meestal langzaam. Op deze leefvijd is de kans klein dat we borstkanker ontdekken waaaaan vrouwen overlijden. Meedoen aan het bevolkingsonderzoek zou ervoor kunnen zorgen dat deze vrouwen onnodig worden behandeld tegen kanker. U ontvangt een uitnodiging vanaf 50 jaar tot het jaar waarin ur 76 wordt.

De Gezondheidsraad geeft advies De overheid bepaalt voor wie het bevolkingsonderzoek is. Dat gebeurt na advies van de Gezondheidsraad, die alle voordelen en nadelen op een rij zet. De Gezondheidsraad adviseert om de leeftijden voor het bevolkingsonderzoek voorlopig niet te veranderen.

RIVM represent the risk information textual, in a transparent way. The risks are represented by frequency statements, absolute risks and mortality rates. However, the information is present in a textual communication manner. According to Gigerenzer at al (2008) there is need for transparent communication manners, which that the human mind can easily digest, by focusing on visual and numerical representation of risk information.

Insight: Risk can be defined as the probability of effects resulting from exposure to environmental factors. In this metric risk is dependent on available knowledge, inherently uncertain in terms of outcomes, and expressed as a probabilistic value.

### A3.4 Context Factors - theme 4

### **Organized Screening & Associations**

## Trend: Overrepresentation of low-risk patients vs. underrepresentation of high-risk patients

The overrepresentation of low-risk patients with better health conditions, who participate in preventive research suggests that many decisions are not informed decisions. Participants who agree on preventive medical research, may base their decision on an overestimation of their own risk. Citizens who choose not to participate in preventive medical research may base their decision on insufficient knowledge. People give reasons to themselves why they do not have to participate in preventive health research, like privacy, disinterest, practical matters such as no time, but also, they do not want to know possible risks, and they feel healthy and want to keep this. The lower participation rate of people with a lower socio-economic status also seem to be due to different opinions and expectations about preventive medical research. According to these people, there are more disadvantages and fewer advantages to preventive research. This information is based on research of Timmermans (2013).

#### State: citizens are expected to make conscious healthy decisions, however the questions is whether all citizens are capable to make good, healthy decisions.

The concept that an individual can choose a caregiver or treatment themselves, making a personal choice for prenatal screening or preventive medical research has become increasingly important during the last years. This fits in a general social trends more autonomy and personal responsibility. Besides that, nowadays the government emphasizes that citizens must take more health responsibility themselves, and prescribes what is and is not allowed. Citizens are expected to make conscious decisions concerning their health. The question is whether everyone is capable to make good, healthy choices. This information is based on research of Timmermans (2013).

#### State: Borstkankervereninging Nederland offers the most effective detection method, and the method that avoid unnecessary anxiety the most.

RIVM propose that they offer only the best breast cancer screening program to screen breast cancer. According to RIMV, this is important because the screening program is offered to a target group of 'healthy' women. They want to avoid unnecessary anxiety as much as possible. Until now, mammography is the best way to investigate a large group of women for breast cancer (RIVM, 2011)

Healtcare State: 'Totalbodyscans' provide false security and therefore it should be prohibited, according to doctors. Patients feel reassured if no abnormalities result out of the test, however in six months they still can be very ill (Trouw, 2015).

Economical State: the preventive screenings are raising the costs in the care area, stated by professor of Ethics Theo Boer (Trouw, 2015).

Ethical State: Preventive screenings provide unnecessary fears among patients, stated by professor of Ethics Theo Boer (Trouw, 2015).

#### Economical state: patients and ex-patients do complain about the difficulties they experience to make an agreement with insurance organizations.

Cancer patients or ex-patients do not get a life insurance after a cancer diagnosis despite or their recovery. Insurance organizations do not dare to make an agreement on a life insureance. Currently, researchers at Integraal Kankercentrum (IKNL) have developed a calculation model that enables insurers to assess the mortality risks based on current and improved prognoses for breast cancer patients. The Dutch Association of Insurers embraces this model (Trouw, 2018).

Principle: there is a limit to the amount of information that can be proposed to women and that can be processed by women, according to Nynke de Jong. RIVM is taking into consideration to give support in the decision making process for women (De Volkskrant, 2014).

#### Principle: women act on their emotions.

According to professor of clinical epidemiology Yolanda van der Graaf, women mainly participate to hear that they have nothing, out of fear to feel guilty afterwards. Women act on their emotions. What if you do not go and a lump will be discovered after a month? She judges differently as a woman than as a scientist (De Volkskrant, 2014).

#### Mythe/principle: discover earlier is better = not always true.

According to oncologist Sabine Linn at Antoni van Leeuwenhoek, the mythe 'discovering earlier is always better', is not true. According to Linn, this often means that women only know longer that they have cancer. It is the nature of the tumor that determines whether the tumor will cure. The influence of timing and being earlier, is only sometimes true. In case of a very aggressive tumors, slow-growing tumors and innocent tumors, early detection has no added value. At the moment you discover it yourself, you are either in time or you are too late, the same for a mammogram (De Volkskrant, 2014).

**State: computermodels did show that half of the 34% of the decrease of breast cancer mortality, is caused by mammography.** According to Harry de Koning, professor of evaluation of screening at the Erasmus MC. In the Netherlands, breast cancer mortality amount has decreased by 34 percent in the last 25 years and half of this is due to mammograms. To make this distinction computer models are required (De Volkskrant, 2014).

#### State: Not all academic researchers are completely independent.

These researchers do have business interests, which they keep secret. An example of this is, Chris Meijer. Meijer is a clinical pathologist at the VU University Medical Center, who is conducting research into cervical cancer. He does and did business and worked together with commercial companies, and publishes and advises about his work field. His different interests are not transparent to the outside world, but are kept concealed (NRC, 2015).

Trend: The focus for the future is on supporting citizens to choose better and encourage healthcare professionals to take more responsibility to coach their less skilled voters (next to the current policy: protection, providing information and quality assurance)

The society should protect citizens against the consequences of wrong decisions if the condition of making an own choice is available. In the future, the government should have the task to promote free, autonomous choices by their citizens, by:

1. Stimulating the development of good information for citizens

2. Monitoring and securing the quality of information needed for informed choices

3. Promoting citizens their skills to make free choices

4. Encouraging healthcare professionals to take responsibility for coaching the less skilled voter

5. Providing support that enable citizens to choose better

6. Nudging by making healthy choices the easy choices

7. Taking a certain responsibility for possible harmful consequences of free choices

8. Protecting citizens from the adverse consequences of choices made by other citizens.

Nowadays, in the current policy, protection, providing information and quality assurance are basic principles. The focus for the future is on supporting citizens to choose better and encourage healthcare professionals to take more responsibility to coach their less skilled voters. This information is based on research of Timmermans (2013).

#### Development: Religion is rapidly becoming less important, where faith has affected everything from rulers to borders to architecture.

There have long been predictions that religion would fade from relevancy as the world modernizes, but all the recent surveys are finding that this is happening fast. France will have a majority secular population soon. So will the Netherlands and New Zealand. The United Kingdom and Australia will soon lose Christian majorities. Religion is rapidly becoming less important than this has ever been, even to people who live in countries where faith has affected everything from rulers to borders to architecture (National Geographic, n.d.).

#### Development: The majority in the Netherlands disbelief in God.

According to a study set up in 2014, the Netherlands has more disblievers than believers. Slightly more than 25 percent of the population is atheist, while 17 percent believe in the existence of God. The others (about 60 percent) locate themselves between religious belief and disbelief. Somethysts says that: 'there must be something like a higher power of strength'. Agnosts say that they do not to know whether there is a God or something like a higher power (Trouw, 16 Januari 2015).

In this time, human put themselves in the center, according to professor of theology and religious studies Joke van Saane. Technological developments support this. For example Facebook, a profile determines who the person is, instead of his village, his family or his church (Trouw, 16 Januari 2015).

#### Development: People do not believe in common norms and rules anymore, like dogma expressed by the Church.

Since 'being yourself and being unique', is the norm, dogmas and rules that apply to everyone are no longer needed. According to Van Saane, this is why the amount of churches is changing, because these are based on dogmas and common rules. In this way God and his institutions lost their power of expression (Trouw, 16 Januari 2015). Trend: People are living in an information society, in where people have easy access to any kinds of information (Trouw, 8 juni 2015).

Trend: people tend to do more and more health and body checks: there is a wish for 'totalbodyscans' (Trouw, 8 juni 2015).
## A3.5 Clustering Factors

analysing and structuring the factors

This image shows the overview of factors and clusters. All the collected factors were analysed and reorganised, to generate an overall understanding of context and the relations between the factors.



## appendix 4.

## Analysis Results - Inspirational Research

The following appendix shows the context factors generated out of the stretched context analysis, focussing on the future and associations with the organized screening. These factors are presented per research theme and presented as copies from the collage-making activities out of the logbook.

### A4.1 Stretching the context



#### Stretching the context

Additional context analysis is done, to generate context factors that implicit or explicit have effect on the domain, to explore the design space and inspire the designer.

*The following directions are used to explore a broader context:* 

#### *Exploring the future 2030*

What does the context of 2030 look like, what different technologies or trends play a role? What does the target group of 2030 look like, what kind of generation acts in this context? What are the other methodology possibilities?

#### Exploring women & their femininity

How do women look at their female body? How does shame plays a role? What usage has the female body? What about women & their emotions?

Exploring women & their age

What kind of factors play a role in women their life during the age of 50?



#### Logbook

Magazine and newspaper articles, a museum visit, an interview with two members of the organisation Het Bevolkingsonderzoek Borstkanker, research articles and internet post are used as material for the generation of context factors. All the material is documented in a logbook. This book supports the designer to look back and work further on the generated material. In the following pages main insights of this exploration will be shown.



## A4.3 Future (2030)

development in technology will create possibilities to make systems personalized, also for health care.

Development: aging - more people will become older

Trend: usage of artificial intelligence – the technology is used in different fields. AI tracks persons and can make the environment adapt to the person.

Trend: usage of robots in medical centres – robots are used to perform operations. The social and creative skills of a doctor will become more important.

Trend: the effect of increasing usage of social media on shame – shame for intimate body parts seems to become less visible by social media.





## A4.3 Future (2030)

A generation which is used to new technologies: usage of robots, social media and personalized systems.

**Development: internationalization -** Women will have an international focus.

**Development: technology innovation** - women grew up in a world with new technologies.

(effect of) Trend: healthy focus - women passed through a healthy life style trend.

Trend: building families later in life - people delay their marriage and get less children.





State: accepting yourself - women struggle with accepting their body and accepting the differences between women.

Principle: showing yourself vs. shame - till what extend women show their body parts differs per culture and personality. Principle: body language - women use their personal femininity to express themselves, and with contains symbolisations.



Other Tests



### Hormones



### Menopause



Hormones

### A4.5 Women & Age Menopause

The relation of hormones, emotions and breasts:

State: Hormones influences on behaviour- Women experience difference moods during the her cylcus.

Principle: exposure to hormones in relation to breast cancer breast are depended on hormones to keep functioning. However, a constant exposure to hormones can cause breast cancer. The menopause start around the age of 50 too.

State: The menopause as a taboo - The menopause is complicated. People laugh or do not talk about it, though.

State: The menopause is a realisation moment - during the menopause women experience the realisation that time is passing by.

Bodily changes



with how creativity

Activities



Uncertainty Of Life



Uncertainty Of Life



### A4.5 **Women & Age** *Uncertainty Of Life*

Negative image of aging in our society:

State: aging has impact on body image - and influences behaviour

State: association with wisdom -in other cultures aging is associated with wisdom.

Trend: **spirituality and aging** - among some women spirituality is becoming more important.

People tend to strive against uncertainty and believe or act to fight against it.

State: people believe in something bigger than themselves and their knowledge - to deal with the uncertainty. Trend: avoiding risks- because of science and technology risk can be determined and avoid, and people start to believe in this.

Sometimes people feel themselves what is valuable for them in life.

Principle: things or occasions let people realise what they value in life - sometimes uncertainty comes very close and make people aware of the uncertainty, but people also find the their life lessons in objects, persons or experiences around them.

## A4.6 Meanings

the meanings and associations that women ascribe to the organized screening





## appendix 5.

## **Design Directions & Design Criteria**

The following appendix shows different design directions that were considered. Furthermore, the design criteria and design wishes that resulted out of the research part, are document in appendix 5.

direction o



I want to enable women to make a personal decision on whether to participate or not participate to the organized screening, by creating a moment of self-reflection and by communicating the image of possible futures senarios.

direction 1

## Het Bevolkginsonderzoek Borstkanker

## to add to scientific research



It's not only about prevention on an individual level, but also working on prevention on a global level.

According to the principle that people tend to strive against the uncertainty of life, and nowadays use science and technology to determine and avoid the risk. People seem to believe in science.

direction 2

## Het bevolkingsonderzoek borstkanker

## support women to follow their well-informed intuition



Health is just one of the personal values. Insipring women to listen to their personal values, while being well-informed.

direction 3

Het bevolkingsonderzoek borstkanker -

## how do I survive bodily changes?



Enabling women to deal with the age confrontation, by crossing the taboo of the menopause.

Instead of confronting women with their age and body changes, and letting women suffering from the negative image on aging, inspire women to think about suiting possibilities for the future.

### A5.2 Design criteria

Design Criteria

### **Decision criteria**

1. Requirement for an informed decision about participation to the organized breast cancer screening, is accurate, relevant, unbiased and balanced information (about purpose, benefits, harms and risks, entire procedure, test results).

2. Required for making a personal decision about participation to the organized breast cancer screening, is freedom of choice and free from constraint.

3. Required for making a decision in accordance with personal values/attitudes/preferences about participation to the organized breast cancer screening, is mindful choice, and aware of personal values and preferences. Breast cancer risk criteria

4. Design intervention should not harm high-risk women with:a) breast cancer family history,b) the age group > 50 years old.

5. Design intervention should not harm risk women who: a) had (breast) cancer before,

- b) did not do breastfeeding,
- c) got their first child after the age of 30,
- b) did not get a child
- e) had an early menstruation
- f) had a late menopause

6. Design intervention should not distract women from possible symptoms, as:

- a) lump in breast
- b) breast (skin) thicker than normal
- c) blood from nipple
- d) change of nipple

### Breast cancer screening risk criteria

7. Design intervention should not harm

a) the participants who do get the result no abnormalities but who have breast cancer (2 out of 1000)

b) the participants who do get the result not enough information and who have breast cancer. (12% of the 12 out of 1000)

c) the participants who do get the result abnormalities detected and who have breast cancer. (50% of the 11 out of 1000)

### Organized breast cancer screening

8. The design intervention should not harm the running machine of the organized breast cancer screening.

### A5.2 Design Criteria

Design Wishes

#### **Decision criteria**

1. Design intervention should reach the target group of first time decision makers, before turning 50 years old.

- 2. Design intervention supports the user in its context (physical and social), which influences the decision:
- The incubation time of their decision idea
- Experiencing the freedom of choice
- 3. Design intervention supports the user and his knowledge (motivation and capabilities), which influences the decision:
- The awareness of personal values
- Awareness about topics as, aging, menopause, femininity and uncertainty of life

4. Design intervention supports the user with the decision problem (complexity and information), which influences the decision:

- Understanding the risk information on an emotional level

### Breast cancer risk criteria

5. Design intervention stimulates high-risk women to participate in organized screening.

6. Design intervention supports high-risk women to participate in organized screening.

#### Breast cancer screening risk criteria

7. Design intervention should decrease the harm of the physical state of women who participate to screening, and receive the result abnormalities detected or not enough information, but who are not diagnosed with breast cancer.

8. Design intervention should inform women on the potential negative experience of the screening, as a risk of their participation.

#### Attitude towards breast cancer criteria

1. Design intervention should not distract women from the awareness about the seriousness and high frequency of the disease.

2. Design intervention should not scare women about the possibility of getting breast cancer.

3. Design intervention might increase the motivation to improve the solution (organized screening by mammography) for the serious and frequent disease breast cancer.

#### Organized breast cancer screening

1. Design intervention should not overwhelm women with the subject breast cancer.

2. Design intervention and its associations, aging, uncertainty of life, menopause and body changes, should stimulate a positive effect on women.

3. Depending on the stage phase within the service, the interaction with the design intervention should be experienced as activating, connecting, realizing, self-caring and explorative.

4. Along the service, the interaction with the design intervention should be experienced as meaningful, because of the qualities: supportive, sensitive, inspiring, pure and connectedness.

## appendix 6.

## Idea Generation & Concept Development

The following appendix presents the activities that were conducted to generate ideas and concepts. The creative session with a multicultural user group will be discussed. Appendix 6 shows copies out of the logbook. The copies show collage-making and brainstorm activities used to generate ideas. This appendix also shows an impression of the rapid prototypes that were developed.

### A6.1 Creative session

*The following paragraph describes the creative session, and concludes with an additional insight to the context analysis.* 

### Approach & Session

stretched context interaction

An input session was set-up with women from different ethnical backgrounds, and women who have low literacy capabilities. The session had an creative approach, to generate insights and ideas together with the subject group about the design direction. Women with differences in ethnicity and literacy were involved in this stage of the project, to also take their beliefs and perceptions into account, and to take their capabilities into consideration.

In the facilitated session women talked about: turning 50, body changes and health choices. A few exercises were applied to stimulate the creativity within this conversation. The goal was to find out how women want to deal with these changes and health choices around the age of 50, and ideas as input for the ideation phase. The decision for the organized breast cancer screening was also a topic, but in a later stage of the creative session.

#### Approach

#### Participants

Women around the age of 45 till 60 years old were recruited in a community center in Geuzenveld (multi-cultural neighborhood in Amsterdam, the Netherlands). Participants were mostly selected on their ethnicity. Women were shortly introduced to the graduation project and the concept of the creative session. They were asked whether they were interested in participating to the session.

Four to six women were expected to participate. Besides that, two experts working at RIVM would participate as buddies of the facilitator. Both women are experts on the topics of this graduation project: decision-making, risk communication and the organized breast cancer screening. Sharell Bas is working as a junior-researcher at the RIVM, and Linda Douma is working as a PhD student at the VU and RIVM. Both of them were asked to keep on low profile, and only listening or asking questions.

#### Methods

The methods were not mentioned to the participant, to avoid explaining women the complexity of the methodology. Only a simple overview of the planning was shown to the participants. Short instructions guided the participants through the procedure.

The session started with an *collage-making activity* to stimulate the feeling of comfort within the team and the intuitive creativity, according to creative facilitation techniques (Tassoul, 2009). The activity was about: turning 50 and health choices. The collage were discussed afterwards. In the discussion I was searching for important functions and qualities of the phase around 50 and making health choices. Together with the two buddies, I asked, as a facilitator, open questions to stimulate women elaborate on their stories and examples.



Figure 63 before the session started: the location of and material used during the session.

The intention of the session was to focus mainly, on this part. An ideation part was set-up as well, if time would be available. The intention of the ideation part was, to create a final vision with the team and a design wish. Women would do a creative exercise together: *the dynamic brainwriting technique and using How Could You -questions* (Tassoul, 2009). However, because of the size of the session team and the limited time, it was not possible to complete the last part of the session.

#### Procedure

The set-up of the procedure is shown in the appendix (see appendix 6).

### Material

The facilitator brought newspapers and magazines, which could be used in the collage making exercise. Besides that the facilitator prepared A3-papers to guide the participants and the facilitator within the session.

#### The session

It was an very energetic session. In the end the team spent 1,5 hours discussing, and 10 women participated. Women younger than 50 were not presented, only women older than 50 presented. The session took place in community center Eigenwijks – Geuzenveld, in room Jakarta. A very ethnical mixed group with women from Egypt, Morocco, Iran, Turkey, Indonesia and The Netherlands joined the session. The fact that so many women showed up, was a surprise. As a facilitator, I appreciated it a lot that Sharell and Linda, were supporting the facilitation of the session. Both of them gave support in listening and asking questions. All the participants gave a lot of input. Those women really liked talking, which was great for the richness of examples and explanations. Sometimes, it was hard to let just one person talking at a time.

Since there were many more participants than expected, we focussed mainly on the beginning of the set-up: understanding the important functions and qualities during the phase of turning 50 and decisionmaking for health choices.



Figure 64 after the session: the after talk with some of the women that joined the session.

### Conclusions

stretched context interaction

## Insight 25. Self-care becomes important around the age of 50, because of the body that starts calling for more attention.

An interesting insight that resulted out of the creative session in Geuzenveld, is that self-care becomes an important focus around the age of 50. During this age women start to experience their bodily changes, and women start to feel that their body is asking for more self-care. Women in Geuzenveld gave the impression that health decisions go along with this bodily changes naturally. Women appear to give care to their body for the future, because they become more aware of the health changes and the uncertainty of the future. Elements such as: doing sport activities, maintaining social contacts, diets and hospital visits, become part of everyday life. For some women it seems natural that the organized screening is part of these self-care activities, for other women other activities are more preferred.

### A6.2 Session set-up

Creative Session with women (ethnical and literate differences from interview group)

tijd	wat	Specifiek wat
12:00 – 12:15 <b>15 min</b>	Intro - Collage Intuïtieve creativiteit	<ul> <li>Aanvullen templates met knip/plak: <ul> <li>Wat denk jij bij de fase: 50</li> <li>worden?</li> </ul> </li> <li>Welke gezondheidskeuzes herinner jij je (misschien wel rond de 50)?</li> </ul>
12:15 – 12:25 10 min	Summary – Functies & kwaliteiten van veranderingen en keuzes rondom levensfase van 50	<ul> <li>Bespreken van collages en in gesprek</li> <li>Noteren belangrijke punten</li> <li>levensfase rond 50</li> <li>Kun je die fase omschrijven met gevoelens?</li> <li>En dingen die belangrijk zijn, die dan spelen?</li> <li>Gezondheidskeuzes</li> <li>Kun jij je gezondheidskeuzes herinneringen rond die leeftijd?</li> <li>Hoe ervaar jij gezondheidskeuzes (gevoelens, waarden)? En bevolkingsonderzoek?</li> <li>Anders willen/gemis?</li> </ul>
12:25 – 12:30	Intermezzo –	
12:30 – 12:40 <b>10 min</b>	Design visie – Gemeenschappelijke wens en gewenste kwaliteiten uitspreken	Bespreken gewenste ervaring en gewenste kwaliteiten (contrast op zoeken) - Wij zouden willen dat de levensfase met keuze voor bevolkingsonderzoek
		borstkanker en veranderingen, verloopt als - En aanvoelt als Uiteindelijk 2 kwaliteiten selecteren.

12:40-	Ideation –	Ideeën generen geassocieerd met de
12:55		gewenste kwaliteiten.
	dynanamic brainwriting	
	technique	- "Dan laten we nu het verhaal
		van 50 worden even los, en
		bevolkingsonderzoek"
20 min		- "Jullie mogen je gedachten even
		de vrije loop laten"
		- Hoe kan iets meer <kwaliteit 1="" of<="" td=""></kwaliteit>
		2 > aanvoelen? Aan welke
		dingen denk jij bij?
		Stel het zou niet, maar ?
12:55 -	Concept -	Waardevolle ideeën voor onze casus
13:10	iii-vragen om ideeën te	selecteren
	selecteren en plaatsen	
	over assen: kwaliteit 1	- Welk ideeën vinden jullie
	tegen kwaliteit 2 (evt.	opvallen, zijn nieuw, speciaal?
15 min	meer kwaliteiten)	- Is dat idee veel/ weinig van
		kwaliteit 1 of kwaliteit 2?
		- Welke combinaties van hoog in
		kwaliteit 1 en hoog in kwaliteit 2
12.10	Et al.	kunnen we maken?
13:10-	Final –	Voorkeur uitspreken
13:15	Uitspreken voorkeur of	
	combinaties	- Welk idee past het meest bij jou
		wens: "ik willen dat de
		levensfase met keuzes en
		veranderingen, aan voelt/
		ervaren wordt als "

*The creative session set-up is documented in Dutch, since the session was conducted in Dutch.* 

## A6.3 Results creative session

### Theme 1. How do women experience turning 50?

### What we thought of:

The following quotes resulted out of the collage-making activity.

"Decreased health condition, wrinkles, menopause, getting more weight, physical complaints, less patient" – Sylvia

"I was still working when I was 50 years old. When I stopped working, when I turned 60 things changed."

### "I went to Mecca"

"It is important to just keep doing the regular things, and keeping the social contacts. Age is not important. Mentality and personality is very important. Health is related to lifestyle not age. Life keeps going. I just do what I can do, and want to do. Listening to myself."

"I didn't feel like 50. I still felt like a fit person, like I was 20. I was a sportive women. I did sports. Nowadays I walk." – Fami

"More attention to what you are eating, more contact with people, more psychical movement, caring for grandchildren, looking for a senior apartment."- Eptisam

"Doing sports, menopause, eating more healthy, making cookies." – Khadija

"Starting with menopause, diabetes and cholesterol, surprise from children"

What we agree on:

The following quotes resulted out of common discussion.

### 1. "less is possible, and feeling tired more often."

"I was a swimmer. When I turned 48, 50. The 500 meters became more difficult."

"Beforehand I could go to work without sleeping, after partying. But nowadays that's not possible anymore."

"You just feel it."

### 2. "Looking back on the age 50, you felt fit."

"I felt like a fit mother, caring for children and working."

"This generation is different. We don't act like we are old. We don't sit inside in front of the television. You know your 60, but you don't feel like 60. You keep going, going to the gym, caring for grand children etc."

"If I compare myself to women in Morocco I know, from the same age, they say: 'I am old.' That's painful, because I think: 'you are not old'"

## 3. "Keep feeling young because of clothes, making 'you' beautiful, caring for yourself."

"You feel of age depends on your surrounding, and mentality."

"Turning 50 gave me a simulation to continue. If you keep thinking: 'today I choose this color.' It gives energy.

"You are 50, but you feel like 20. It's about keeping with the time."

4. "It's about continuing: reading, physical exercise, and keep connected with others like we are used to."

"Keeping in contact with younger people, supports you to keep feeling young."

"Our generation is about real contact and activities, no computer and social media."

### 5. "The usage of technology is sometimes hard for us."

"There should be also another manner. Not only the app, but also acceptgiro when you want to transfer money."

"Within our family we say, now we don't use our telephone for half an hour."

"That's in your family, my son doesn't have time."

## Theme 2. What are other health decisions do women come across?

### What we thought of:

The following quotes resulted out of the collage-making activity.

"You have to pay more attention to what you eat. More movement."

"Cycling, walking, less salt, sugar, fat, fish and meat."

"Walking, stopping with smoking within house, less meat."

"The course I did for health ambassador. That I still can do sports or dance for 1 hour. Not eating to much and give attention to the groceries."

"More physical movement, going outside, cycling, going to G.P. more often, high cholesterol because of stress and personal circumstances. Eating more healthy because of advice of G.P."

### What we agree on:

The following quotes resulted out of common discussion.

### 1. "Via – via we spread knowledge about health"

"I became a health ambassador after doing a course. I would like to learn about it, and tell it to others."

"We tell each other about it."

**2. "Via – via we start focusing or choosing on health"** "The G.P. can tell you about it."

"I heard about it via Gina, in this community center."

"We tell each other."

### 3. "Understanding is important"

"It is important to listen to the person who is going to make change. Why is she doing it in this way? What makes it difficult? For example, I really like salt... blab la bla..."

### 4. "We do it for the future"

"For diabetes, cholesterol. Later in life you will get everything otherwise."

"People will become older. You hope that you can still move when you will be 80."

"It is just to prevent disease."

"Your body asks for other things. Less fat, less food. Every age has another demand. We talk about normally. Every age your body asks for other things."

"Disease doesn't have to do anything with age."

### 5. "For our generation it is important to keep moving"

"It is about keep moving. In this generation people don't move, we sit in front of the television or computer, but we still eat the same food: potatoes, vegetables and meat."

Theme 3. How do women experience the support of Het Bevolkingsonderzoek in health changes while aging?

The following quotes resulted out of common discussion. About we the organized screening we have different opinions:

### 1. "It makes you feel scared"

"I participated for 3 times, but because of fear I stopped. During the days of this research, I felt so scared, because of the result ant the pain."

"I participated, but I am 66 years old now, and I stopped."

"When I became 60, I start becoming more scared, for the result. You hear stories around you, and you starting thinking... maybe I will also become sick, and maybe I also won't have so much time anymore."

### 2. "It gives you a feeling of control."

"It is not a pleasure, but it is important."

"It gives a safe feeling, that you are still healthy."

"You will never know when you will become sick."

### 3. "We agree on that the government offers you this as a service for free, which is an important reason the participate."

"It is in for free here, in Morocco it is not for free."

"That is nice, isn't it?" "They give it to you."

### 4. "We talk about it within our community."

"When the bus is in our surrounding again, we talk about it."

The different organized screenings don't feel similar "They are all different. With baarmoederhals kanker you have to do it by yourself, at home .... "

"For Darmkanker I am more scared, also because it is existing in our family."

### 5. "The result phase gives us some tension."

"I am happy that I had to do further testing. However, I didn't like it that they already treated me like a cancer patient. Then I think, let me and my husband first go to the doctor to see whether I have cancer, before ..."

"The laboratory technician sometimes say stupid things."

## 6. "We don't think really think about the risks of the organized screenings"

"It is always good to do it."

"It is was directly found, after detection."

"I don't understand why there are not other screenings, for more organs."

"There are already so many different screenings, diabetes, cholesterol. For me it is ok."

## **7. "We are no doctors. We have to trust in them."** "They know more than we do."

**8. "We think we know what will happen."** "Do you have it, or not."

"Yes I know, that when it is negative, they would call me."

"Otherwise you will get a letter." "When I got that call, I was still thinking, let's see."

### 9. "For us it feels like, the government cares for you."

"In Egypt it is totally different. Be happy with what you get."

"You don't get it for all diseases."

# 10. "Other manners to support us while aging: we don't only focus on the medical aspect, also the social aspect is very important for us."

"This community center for example helps us to keep moving, we can do sport for 1euro. But also the keep in contact with others!"

"It about caring for yourself, this is offered to you, they care for you. We experience it that way."

## A6.4 Exploring functionalities

The following section show the functionalities that resulted out of the creative session and interaction vision, and how these were further explored. Question were set-up to generate ideas how to realize these functions.










### A6.5 Exploring qualities

The following section show the qualities that resulted out of the interaction vision, and how these were further explored. Question were set-up to generate ideas how to realize these qualities. Furthermore, collage-making activities were applied to generate ideas.









### A6.6 Ideation overview

selecting and combining idea elements



### A6.6 Ideation overview

selecting and combining idea elements



bringing idea elements together into concepts





Zorgsalon



Magazine



**TV** series



### A6.8 Concepts based on mechanisms

The ideation process was like a recycling process: bringing in ideas, iterating on ideas, reflecting on previous ideas, combining idea elements, iterating on new ideas, and bringing in ideas again. The interaction functions and qualities inspired the ideation process. The design parameters guided the ideation towards the final concepts. Finally, five different concepts were generated. The concepts were based on 3 different mechanism.

#### 1. Visualizing the future by presenting role models

#### Inspiration

This mechanism was inspired by the interaction vision: "turning 18 and prepare yourself for a new life in another university city".

#### A story that inspired this idea:

"The moment that I had to choose for an university and program, I experienced difficulties to discover out myself what I wanted to study. I were surrounded by friends who were all going to do medicine in Amsterdam. Actually I wanted to join them, on the other hand I knew that this choice was also about my future. I tried Psychology in Amsterdam, but I was aware of the fact that I didn't like this program. I quitted, but then again: I was struggling what to choose for. I remember that day that I eventually visited Delft: I experienced one of the courses and a bit of the student lifestyle with older students. It was a good example of what I would choose for. Then I really felt that I wanted to this, and I decided sign in for Industrial Design."

#### Principle

The principle of this mechanism would be: inspiring women by helping them to visualize different futures with the usage of role models and their stories.

#### **Concept ideas**

This mechanism is implemented in 2 concepts ideas:

\* Television series: inspiring by showing life stories of women to admire (see Figure 66).

\* Magazine: inspiring by sharing magazines including interviews with women to admire (see Figure 65).

### **CARE** magazine

**content: bevolkingsonderzoek borstkanker & more:** menopause, ouder worden, lichaamsveranderingen, onzekerheid van het leven, keuzes.



Figure 65 concept: magazine



Rijksinstituut voor Volksgezondheid en Milieu Ministerie van Volksgezondheid, Welzijn en Sport

#### serie: Help, hoe ga ik om met 50 worden?!

documentaine: NL'se mouwen in beeld.



**Personages:** Kritische Katrien, Avontuurlijke Anna, Brave Bea, Voorzichtige Vera en Jolige Jolien. en **een BNN'er als presentratrice**.



Figure 66 concept: tv - series

### A6.8 Concepts based on mechanisms

Other mechanisms and design forms to reach the design statement

2. Playing a role in habitual behavior by triggering in certain life moments of a girl or women.

#### Inspiration

On the one hand, this mechanism was inspired by the name of the department for which I am practicing this project: Lifecycle & Health. The organized breast cancer screening is one part of the preventive measures during life cycle offered by public health care.

On the other hand, this mechanism is inspired by cultural and religious traditions. For example, in the Jewish culture awareness and gratefulness to life is created during some phases of the life-cycle when going from one phase to another, like the tradition: Bar Mitswa. The specialty of these traditions, are these meaningful moments in which people become aware of aging & time that is passing by.

#### Principle

The principle of this mechanism would be: using the awareness during these life moments to elaborate on the question during that phase of life related to health and bodily changes.

#### **Concept ideas**

This mechanism was implemented in one concept idea:

\* RIVM & HEMA lingerie department: intervening during certain life moments of girls and women, when they experience bodily changes (see Figure 68).



Figure 67 ideation: female life cycle and small traditions

Rijksinstituut voor Volksgezondheid en Milieu Ministerie van Volksgezondheid, Welzijn en Sport

HEMA

# **HEMA die** aandacht maakt voor vrouwen van verschillende leeftijden

Door middel van leeftijdsgebonden lingerie lijnen, een poging tot gewoonte gedrag om in verschillende levensfases, over je lichaam van de toekomst na te denken.



Figure 68 concept: HEMA & RIVM campagne

### A6.8 Concepts based on mechanisms

Other mechanisms and design forms to reach the design statement

#### 3. Offering activities that create awareness

#### Inspiration

This mechanism is inspired by the material that is offered to people by different brands, with goal such as: making people aware of their emotions, thoughts or personal values. For example, this u mindfulness applications or calendars with life lessons.

#### Principle

The principle of this mechanism would be: creating moments of realization and guiding women in their decision-making process by activities. Within the creative phase was searched for, a manner to support women in seeing different perspectives and reconstructing elements they value into a plan for the future (see Figure 69).

#### **Concept ideas**

This mechanism was implemented in 2 concept ideas:

\* Game - different perspectives (multiple glasses): activating by offering a game to switch perspectives (see Figure 71).

\* Horizons card set - follow your horizon: activating by offering a game to find a personal route on the map to the future (see Figure 70).





Figure 70 concept: horizons card set - follow your horizon

*Figure 71* concept: game - different perspectives

### A6.9 Prototyping

*Two concept ideas that both conceptualized the mechanism: 'visualizing the future by presenting role models', were visualized by prototypes. These were:* 

- a TV series

- a magazine

The same mechanism was unfolded by two different design/ communication forms. The concepts were presented to the department CvB (communication department RIVM), and the desirability and feasibility was discussed. The opinion of RIVM was taken into account in the decision-making process for the final concept. *The motivations that were mentioned by RIVM, to choose for the concept Magazine, were the following:* 

- The magazine offers the opportunity to bring in an intervention before the age of 50, which will give women the space to make a decision before entering the regular screenings program.

- The magazine offers the opportunity to approach women differently, in a sensitive way by showing empathy to women's concerns, beliefs and the meaning the organized screening might entail.

- *RIVM* seems to believe more in the feasibility of a magazine, above the *TV* series, published by this governmental institute .

*The following pages show impressions of the prototypes, which represented the two concept ideas, and which were presented to RIVM.* 

### A6.9 Prototyping

**Mechanism:** visualizing the future by presenting role models **Design form:** TV series



202

# Francine over:

eranderingen

Ik kende de gang van zaken in de Kamer...

N.a.ron:verdriffde

### A6.9 Prototyping

**Mechanism:** visualizing the future by presenting role models **Design form:** magazine





#### Antwoord op lezersvragen over gezondheid, voeding, leefstijl en psyche, Deze week: Worden de borsten van Nederlandse vrouwen groter?

borstgrootte, want veel vrouwen loper Is we de mode-industrie moeten geloven worden borsten groter en groter. Zo liet de Nederlandse rond met de verkeerde maat, tekende Volkskrant-columnist Ionica Smeets al lingeriefabrikant Hunkemöller in eens op in deze krant. Marktonderzoeken 2010 een marktonderzoek naar behama-ten uitvoeren: die bleek gemiddeld 80C, zijn dus onbetrouwbaar om conclusies te kunnen trekken over werkelijke borstterwijl dat in de jaren negentig nog 75B was. In 2013 meldde lingerieketen Inti-macy dat de gemiddelde behamaat van grootte. Maar ze maken wel nieuwsgierig: zit er een kern van waarheid in de claim?

Jaarlijks worden er in Nederland twinrikaanse vrouw in twintig jaar tijd 8 naar 34DD is gegaan. tig- tot dertigduizend borstimplantaten geplaatst. Al die vrouwen hebben na de ek: het getal staat voor de htrek onder de borsten. De letter, is gedefinieerd als de operatie natuurlijk een grotere bh nodig, maar toch is deze groep te klein om de toename te verklaren die Hunkemöller omtrek en de om ogte van de te verkondigde. e maten zijn

schrift Maturitas. Volgens Petra Peeters, hoogleraar aan het UMC Utrecht en co-auteur van het onderzoek, gaf 20 procent van de vrouwen die meedeed aan een bevolkingsonder-zoek voor borstkanker toentertijd aan grotere borsten te hebben gekregen na de menopauze. Maar: 'Dit waren meestal vrouwen die ook een gewichtstoename hadden opgemerkt.' Als borsten gemiddeld inderdaad gro-

ter zouden worden, is dat waarschijnlijk te verklaren door het toenemende aantal mensen met overgewicht, denken Peeters en Klipping. In 2017 had meer dan 15 procent van de Nederlandse vrouwen volgens het CBS overgewicht, een percentage dat al jaren toeneemt. En als je aankomt, wor-

SIR EDMUND . 8 SEE van Dinox, een centrum dat onderzoek doet naar de veiligheid van hormonale anticonceptie. Op internet circuleren soms wilde ver-

halen dat hormonen in het drinkwater effect zouden hebben op borstgrootte,

maar daar is geen enkel wetenschappelijk bewijs voor. Sowieso is er bijna geen sprake van gedegen studies naar borst-

sprake van geuegenstudies naar Dorst-grootte, stellen de Britse antropologen Nicola Brown en Joanna Scurr in een stu-die uit 2016. Ze sloegen er de wetenschap-pelijke literatuur op na en vonden slechts 31 artikelen waarin op een betrouwbare

manier verslag werd gedaan van borst-

Alleen van de Verenigde Staten en het Verenigd Koninkrijk bleek data beschik-baar te zijn over meerdere jaren. In die

name in lichaamsomtrek over de borsten gevonden vergeleken met de jaren vijftig:

in het Verenigd Koninkrijk 6,3 centimeter en in de Verenigd Koninkrijk 6,3 centimeter en in de Verenigde Staten 6,4 centimeter. Misschien is dat te wijten aan vergrij-zing in die landen, want veel vrouwen die

ouder worden krijgen grotere borsten. Vooral na de menopauze merken vrou-

wen vaak een toename van hun cupmaat, schreven Nederlandse wetenschappers in 2004 in het wetenschappelijk tijd-

landen werd inderdaad een kleine toe

groottes

den ook je borsten groter.

ja

1 184 15

verkondigde. Een andere mogelijkheid is het gebruik van hormonialeanticoneptie: dat kan een verp kanarde effect stiftdelijke van der vers panarde effect stiftde

Onze vrouwen aan het woord:





#### Wat doe je nu?

Examine she brother prudent add day ham. Far stairs now coming bed oppose hunted become his. You zealously departure had procuring suspicion. Books whose front would purse if be do decay. Quitting you way former-ly disposed perceive ladyship are. Common turned boy direct and yet.

Over fact all son tell this any his. No insisted confined of weddings to returned to debating rendered. Keeps order fully so do party means young. Table nay him jokes quick. In felicity up to graceful mistaken horrible consider. Abode never think to at. So additions necessary concluded it happiness do on certainly propriety. On in green taken do offer witty of.

#### Leef je nu meer met je waarden?

Written enquire painful ye to offices forming it. Then so does over sent dull on. Likewise offended humoured mrs fat trifling answered. On ye position greatest so desirous. So wound stood guest weeks no terms up ought. By so

> Written end it. Then so offended h On ye posit stood gues these am s mean time

Hoe heb

aangepa

Far sta

procur

purse if

ly dispose turned be

Over fact a confined of rendered. R

up to grace Abode neve sary conclu

propriety.

Hoe kii

Wat is o jou gev Her old co So at parti new horse collected l



way now I

### A6.10 WhatsApp study

This sections shows the data of the WhatsApp study and the insights that were generated out of this. The research question was: "What do women admire in another women?"

#### in familie/gezin

#### Bewondering voor: heftige gebeurtenis en toch doorgaan.

Geen se	rvice 奈	14:56	
<b>&lt;</b> 5			
All		Vandaaq	10

Ik denk aan mijn vriendin die ondanks alles gewoon weer naar school gaat en haar werk weer oppakt.. haar dochter heeft botkanker en na 3 zware chemokuren een operatie gehad waarvan de tumor is verwijderd en een botprothese is geplaatst a.s. vrijdag begint ze met haar 1e chemobehandeling die ze daarna nog 2 keer moet ondergaan en dan gaat ze in revalidatie.. heel heftig allemaal!



Hai Hanna, hier mijn bewonderenswaardige persoon: Het betreft een moeder van 3 kinderen, middelbare school, gescheiden. Diagnose borstkanker. Ze is ervan overtuigd dat je daarvan niet hoeft te overlijden. Maakt zich meer zorgen om haar kinderen die zich zorgen maken over haar dan zij over zichzelf. Is nog in behandeling maar wil zo snel mogelijk weer terug naar haar werk. Hoe vermoeid ze ook is van de behandelingen, ze straalt positiviteit uit. Gelukkig kan ze ook huilen als ze zich ontspant.

#### in familie/gezin

Bewondering voor: lijden aan ziekte en toch positief in het leven blijven staan.

#### werk of welke rol dan ook

Bewondering voor: standvastigheid, bij jezelf blijven, onafhankelijk van welke omgeving dan ook.



< 6

14:28

je je broer of valt bet mee? Vandaag

Bepaalde vrouwen intrigeren me, ik vind ze boeiend. Bijv. Angela Merkel. Hoe zij weet stand te houden in een mannen-grijze pakken-wereld en volgens mij trouw blijft aan haar waarden. Ik bewonder haar standvastigheid, vastberadenheid, moed en waarden (inzake vluchtelingencrisis; Duitsland heeft de meeste

14:55

migranten in Europa).

Een andere vrouw is Yvonne; m'n vriendin vanaf m'n 19e. Zij heeft zich ontwikkeld tot een onafhankelijke, sterke en humorvolle vrouw. Dát bewonder ik in haar, juist omdat wie ze was door haar ouderlijke omgeving, deze ontwikkeling feitelijk belemmerde. Ze heeft zich daaraan ontworsteld. 13:33

Ik bewonder moed, trouw aan mensen en waarden, vasthoudendheid als je ergens in gelooft en er vol voor gaan, liefdevol zijn en barmhartigheid, anders durven zijn dan het 'normale'.....

10:41

13:37

13:26

13:30

#### Geen service 🗢

#### 14:56

leeftijd be Vandaag ;? En wat r het, dat je haar/ze bewondert

> Btw, naam is niet nodig, en juist ook alleen een omsch zijn!

#### Hoi hanna, leuk onderzoek!

Wie me gelijk te binnen schiet is iemand een zangeres (die ik niet persoonlijk ken, alleen van haar muziek) die een heel krachtige vrouw is, eigenzinnig, kunstzinnig, haar eigen weg gaat

Bewondering voor: sterk, eigenzinnig en haar eigenweg gaan.

werk

#### 

- Welke vrouw(en) rond jouw leeftijd bewonder jij? En wat maakt het, dat je haar/ze bewondert? -

09:59 🗸

Btw, naam is niet nodig, en mag juist ook alleen een omschrijving zijn! 10:36 4/

Ik heb veel bewondering voor mijn zus. Wel iets jonger (17 jaar) Haar vriend (en zij dus ook) zat gedurende 3 jaar in de schuldhulpverlening. Toch hebben zij, door anders /zuiniger te gaan leven, creatief om te gaan met geld, en doordat Diana weer is gaan werken, gedurende de 3 jaren, alles kunnen doen, inclusief uitjes met de kinderen. De kinderen zijn hierbij niets te kort gekomen. Ik heb hier veel bewondering en respect voor! Zij is een hele sterke vrouw! 17:31

Bewondering voor: doorzetten, creativiteit gebruiken en sterk blijven.

in familie/gezin

💵 KPN NL 奈

4

09:50

juist ook alleen een omschrijving zijn! 10:36 🗸

#### Vandaag

Goedemorgen, Dit vind ik best lastig. Echt bewonderen heb ik niet.. Makkelijker om te vertellen wat ik niet bewonder. Zoals gekonkel en negativiteit, mening hebben over anderen. En geloof mij daar ken ik er wel een aantal van. Maar wat ik mooi vind is dat vrouwen krachtig zijn, in welke rol dan ook. Maar niet ten kosten van anderen. En voor zichzelf durven te kiezen. Deze vrouwen heb ik wel graag in mijn buurt,en dat lukt gelukkig aardig

Bewondering voor: krachtig, voor haarzelf durven kiezen

welke rol dan ook

Ha Hanna,

Ik bewonder vrouwen van mijn leeftijd die

. onafhankelijk zijn in doen en denken, vrouwen die een (maatschappelijk) doel voor ogen hebben en daarvoor gaan, vrouwen die creatief zijn en scheppen.

Hoop dat dit zo voldoende duidelijk is. Mocht je vragen hebben, let me know!

Hartelijke groet, Gera Bewondering voor: **voor een doel gaan, creatief zij en scheppen.** 



Hoi Hanna,

Ik weet zo niet een specifieke bekende vrouw van rond de 55 die ik bewonder.

In het algemeen bewonder ik vrouwen van mijn leeftijd die nog lachend naar het leven kijken. Die onafhankelijk, en constructief kritisch naar de wereld en naar zichzelf kijken. Die het leuk vinden om harmonieuze aandacht te blijven geven aan hun uiterlijk en gezondheid en aan hun omgeving, dus nog volop in het leven staan! Ik bewonder mensen die zich kwetsbaar op durven stellen en vooral positief en empathisch zijn.

Kan je hier iets mee Hanna? 18:09

Vandaag

Bedankt Jacolette voor je input

18:09

0

### A6.11 User stories

The defined interaction qualities were used to set-up usage scenarios, a technique inspired by User Stories within the Scrum method (Agile Scrum Group, 2018). These scenarios guided the concept development towards a detailed design intervention, concerning the desirability. These stories supported in addressing the user's values and needs. The different stories are written down below, and are used to guide the further development of the design concept.

#### Inspiring

I can imagine my future inspired by others comparable experiences.

I experience freedom of choice, and be inspired by different choice options while interacting with the design intervention. (1/3: condition for a well-informed decision)

#### Sensitive

I can make my decision mindful, and be aware of my personal values. (2/3: condition for a well-informed decision)

I experience -being aware of my emotions- while interacting with the design intervention.

#### Pure

I see another perspective on my (mis)conception while interacting with the design intervention. *(preventing dogma's)* 

I feel well-informed with relevant information after interaction with the design intervention.

#### Activation

I feel triggered to make a decision while interacting with the design intervention

#### Connected

I feel understood by Bevolkingsonderzoek Borstkanker & RIVM.

I can relate to the content and themes Bevolkingsonderzoek Borstkanker & RIVM are offering me.

I feel support by Bevolkingsonderzoek Borstkanker & RIVM, in how I want to care for my future self.

appendix 7.

# **Final Concept Test**

*The following appendix presents the set-up of the concept test and the research findings.* 

### A7.1 Concept test

#### **Research goal**

The goal of this study is to evaluate the designed concept on whether this design intervention support women in making a well- informed decision (design goal).

#### Sub-goals

Evaluating concept on different design parameters:

- Evaluating concept on function: *F4. activation* activation for decision-making process
- Evaluating concept on function: *F1. informing* relating to the advantages and disadvantages
- Evaluating concept on function: *F2.exploration* exploring possible choice options
- Evaluating mechanism on function: *F3. creating awareness* mindful of personal values

#### **Research question**

Does the design concept support women to think about the 3 essential elements of a well-informed decision? (desired effect)

#### Sub-questions

- Does the design intervention activate the decision-making process?
- Does the design intervention support women to relate to the advantages and disadvantages?
- Does the design intervention support women to explore the possible choice options?
- Does the design intervention create awareness on personal values?

### Approach

#### Study Design

This research considers a small size qualitative study.

Women stories represented in a magazine, is used as mechanism to evoke an effect: a process to make a well-informed decision before the age of 50 years old. This design concept will be evaluated with the subject group (focusing on first decision-making women between 48 and 56 years old). Whether this mechanism evokes this effect, or the desired interaction, is tested in an experimental study. This study would compared the desired effect among two conditions. One condition (control group) would make use of the original information flyer, the other condition (test group) would make use of the recently designed magazine. The magazine condition would be compared with the original information flyer condition.

This study would mostly focus on evaluating the mechanism, but would also explore the usage of the form and channel. The content, or information about advantages and disadvantages, do not include new information and is based on existing information offered by current material of the RIVM.

The desired effect is operationalized by measuring the experience among the following design parameters:

- Understanding
- Explorative
- Creating awareness

One aspect of the desired interaction, was also tested, and was operationalized by measuring the experience among the design parameter:

- Activation

Data would be collected with a questionnaire and a few additional questions. The data would be analyzed thematically. The results of the magazine condition (test group) would compared with the results of the original information flyer condition (control group).

#### Method

#### Sample & location

The participants between the age group 45 and 65 years old were recruited. Women with diverse backgrounds and with low-literacy were included in the sample of this study, since their experiences and opinions might be different than the project team, and to let their experience and opinion transpire into the development of the design . Women were recruited in the area Geuzenveld, Amsterdam-West.

Participants participated to the experiment on the 18th of October in the community center Eigenwijks in Geuzenveld and Huis van de Wijk De Anker in Osdorp. The participants were randomly assigned to one of the two conditions.

#### Sample size

Sixteen participants would be included in the sample group. The participants would be divided over the two conditions. This size should deliver enough insights for the evaluation of the mechanism, and to measure the experience on certain parameters. This size was based on the size of comparable qualitative studies. Participants of research phase 1 and 2,were excluded in research phase 3.

#### Recruitment

Participants were invited by the graduation student. VUmc, TU Delft and RIVM were mentioned as collaboration partners within the recruitment material.

Participants were recruited in the community centre. Furthermore, an announcement was spread out by the graduation student. People who were interested, received an informed consent form.

#### Stimuli

An sample envelope was offered to the participants.

The envelope of the *test group* consisted of:

- An introduction letter concerning in the organized screening, the decision and the magazine.
- A sample magazine, including:
- 1. two women stories with local interviewed women,
- 2. pages showing the well-informed choice aspects,
- 3. pages showing a magazine look-and-feel

The envelope of the *control group* consisted of:

- An invitation letter to the organized screening
- The current information flyer

#### Women stories

Two women from Amsterdam-West were interviewed, which was used as content for the women stories pages of the magazine. These women lived in the same area as women who participate in the experiment.

The envelope of the original information flyer condition consisted of:

- the current introduction letter
- the original information flyer

#### Procedure

The facilitator of the experiment shortly introduced the participant to the experiment. The facilitator explained that the participant would have time to use and explore the envelope and its content, and that afterwards the participant would have time to fill in a survey. The facilitator offered the participants randomly an envelope. The content was self-explanatory. After 10 minutes, the participants were asked to fill in a questionnaire. The facilitator asked some additional questions after the participant completed the questionnaire.

The concept test will take +/- 10 minutes, and the additional survey will take +/- 15 minutes more.

#### Data collection

The survey included questions to evaluate the concept on the five design parameters. The questionnaire consisted of closed-ended questions and the participants had to give answers on continues scales. The relationship of the experience level of the five interaction qualities were measured on a 0-to-5- scale. Participants had to evaluate the experience level of activating, relating, explorative and creating awareness parameter.

Besides this survey questions, the facilitator asked three additional questions focusing on evaluating the functionality, and enhancing the understanding of the participants argumentation.

The questionnaire and additional question can be found in appendix 7.

#### The Experiment

#### Process

During the experiment some unexpected difficulties came across. This is why, the set-up of the experiment has been changed a little from the research plan.

First, language barriers have been a problem during the experiment. Some women could not read the questionnaire independent. As a facilitator, I guided these women through the questionnaire. This was mostly the case for three out of the eight participants.

Second, fewer women could participate to the experiment. This was caused by language barriers. During the experiment, the facilitator took the decision to let the women that were able to participate, mostly participate in the test group to reach an sufficient amount of participants within that test group. Eventually, eight women participated in the test group and three women participated in the control group.

#### Reflection on process

Interesting insights about the design form were gathered out of the experiment.

Eventually, the comparison between the current material (control group) and designed material (test group) could not be made. This was the reason why the material could not be fully tested on the desired effect (well-informed decision). Due to the circumstances, it was not possible to collect enough data for the control group. This was on the one hand caused by the design form, and on the other hand caused by the sample group.

It might have been interesting to conduct another measurement. This second measurement could have focused better on the sample group, to balance out the diversity in ethnical background and literacy of the participants. However, due to time limits of this graduation project, it was not possible to conduct another measurement.

#### Results

The results can be found in the appendix 7.2

#### Conclusions

*Testing on the desired effect – making an well-informed decision* Does the design concept supports women to think about the 3 essential elements of a well-informed decision? (desired interaction)

The desired interaction, the well-informed decision, could not be fully tested within the conducted experiment. The difference in experience rate could not be compared between the current material and designed material. This is why, the main research question could not be answered completely. However this experiment, gathered insights on the experienced interaction.

*Testing on the desired interaction – communication on an emotional level* The experience was measured on a activation, exploration, mindfulness and inspiration level. Besides that, this qualitative research explored the underlying arguments of the participants, concerning the tone of the material, the magazine and the stories, and their information needs.

#### Answering the sub-questions

*A.* Does the design intervention activate women their decision-making process?

It seems that women experience curiosity and feel surprised, when opening the envelop with its magazine. Women do not feel fear for the disease, while quickly reading through the magazine. Women are aware of the frequency of the disease, and the importance of breasts checking, while reading it. The women stories are experiences as activating, and eye-opening.

*B.* Does the design concept support women to get an impression of the advantages and disadvantages?

#### Could not be tested.

*C.* Does the mechanism of the design support women to explore the possible choice options?

#### Could not be tested.

*D. Does the mechanism of the design create awareness on personal values?* 

Could not be tested

#### **Insights - additional questions**

#### Ethnical differences

Out of the research resulted, that women with a Moroccan background experience difficulties with the acceptance of the disease within the ethnical group. Women experience a desire to talk about the disease, check-ups and taboos within a group.

#### Usability of the design concept

#### Language women stories

Low-Dutch-speaking women had difficulties to read the content of the designed magazine. These women could not read the women stories. Besides that, these low-Dutch-speaking women did not recognize the cross-media links. They were not aware of the fact that they could watch the videos online. Women experienced a need for translations offline and online.

#### Inspiring women stories

These women and the other participants, were enthusiastic about the appearance of the magazine. Women experienced the tone of the magazine as light and optimistic. Women appreciated the included photos, and to see other women out of a similar context. Furthermore, women made positive remarks on the two interviews. Some recognized themselves in aspects of Malika (story 1), and others recognized themselves in aspects of Lisan (story 2). The stories are experienced as eye-opening or inspiring.

#### Reflection

The insight that the magazine, creates awareness on the importance of the breast check-ups should be further tested. This unbalanced impression that women experience might be explained by the bias of the experiment. Women seem to be driven by their beliefs and are very aware of the importance of breast check-ups before they start the experiment. Besides that the experience level of the freedom of choice and the experience on getting an impression of the importance of personal values, should be further tested. These aspects could not be tested due to the circumstances of the experiment. Another concept test is needed to test the desired effect (well-informed decision based on 3 essential elements).

### A7.2 Results concept test

The qualitative data of the test group (eight participants) was analyzed thematically. The results of the control group were not taken further into account. The sample size of the control group was too small to draw any conclusions on.

The data is analyzed on the themes of the questionnaire and additional (open-)questiones. However, the sample group was eight participants was too small to draw any conclusions on the results. The results of the questionnaire are not taken into account in the conclusion (chapter 10). However, it was possible to gather valuable and novel insights from both the questionnaire and, above all, from the additional questions which the facilitator asked. These questions were focusing on the interaction and functionality. The insights will be discussed in the chapter 10.

#### First impression - activation

#### Rated experience level

Women experienced the envelop and its including material as surprising, rated on a scale of 5, with an average of 4. Women experienced curiosity, rated on a scale of 5, also with an average of 4. These averages are based on the input of all eight participants.

#### Input participants

The following insights are based on input participants gave, in the open-question area of the survey.

# Insight 1. The material raises awareness on the importance of checking your breasts.

Women experience checking as important, and checking as in a selfchecking or an organized checking (based on the results of D1 - NL). However, some women experience the organized screening as very important. Some women, is very aware of the frequency of the disease, and experience the organized screening as very important manner to deal with the disease. (based on D3 – Morocco).

#### Insight 2. The material does not scare off.

The booklet its tone is not experienced as heavy or intense, and does not scare off women (based on the results of D7 – Morocco).

# Insight 3. The stories are experienced as eye-opening or inspiring.

Women mentioned that, they experienced the stories as inspiring or eye-opining, and in this way activating to make their own health-decision. The commitment of another (Malika in the prototype magazine), who is working on raising awareness on breast cancer and self-care in a certain group, triggered to think about the topic (based on D2 – NL). Besides that, one participant mentioned that: 'stories can be eye-opening, to think about yourself, for example: health' (based on D8 – NL).

# The information material focusing on 3 aspect for well-informed decision

#### **Tone of material**

Rated experience level – tone of material

Women experienced the feeling of being addressed, rated on a scale of 5, with an average of 4. This average is based on the input of all eight participants. Women experienced the themes of the information material as interesting, rated on a scale of 5, with an average of 4. This average is based on the input of four participants. Not every participant was able to read the content, due to language barriers.

#### *Input participants – tone of material*

The following insights are based on input participants gave, in the open-question area of the survey concerning the tone of the information material.

## Insight 4. The tone of the material comes across as convenient and clear.

Women experience the booklet as easy to read (based on D1 - NL). Besides that, one of the participant mentioned that she recognized herself, in one of the stories (based on D2 - NL)

#### Informing by focusing on 3 aspect of a well-informed decision

*Rated experience level – information focusing on 3 aspects* Women experienced the freedom of choice, rated on a scale of 5, with an average of 5. This average is based on the input of four participants. Not every participant was able to read the content, due to language barriers.

Women got an impression of the importance of personal values, rated on a scale of 5, with an average of 4. This average is based on the input of three participants. Not every participant was able to read the content, due to language barriers.

#### *Input participants – information needs*

The following insights are based on input participants gave, in the open-question area of the survey concerning the further information needs of participants.

#### Insight 5. Wish for information about breast research.

One participant experienced a need for further information about the research itself (based on D8 – NL).

#### Insight 6. Wish for additional information event.

One participant experienced a need to talk together with connections about the topic breast cancer and check-ups, to work on crossing taboos. (based on D7 – Morocco).

#### Women stories

#### Rated experience level – women stories

Women experienced the feeling of recognition, rated on a scale of 5, with an average of 4. This average is based on the input of four participants. Not every participant was able to read the content, due to language barriers. Furthermore, women experienced the feeling of being inspired, rated on a scale of 5, with an average of 4. This average is again based on the input of four participants.

# Insight 7. The stories and pictures of other women in a similar situation are appreciated.

Women like the appearance of the booklet and the pictures of other women (based on D3 – Morocco, D5 – Turkey, D6 – Iran). These arguments were mostly mentioned by women, who had difficulties with the Dutch language. Besides that, women liked to see and read about real people or women, who are in a similar situation, in this magazine (based on D7 – Morocco, D4 – China, D6 – Iran). One participant even mentioned that she appreciated the focus on women, instead of researchers (based on D4 – China).

# Insight 8. Many women experienced the need for language options.

Women from another ethnical background than Dutch, experienced the booklet as hard to read. These women mentioned, that they desired a translated magazine in their own language, or online videos with subtitles (D3 – Morocco, D4 – China, D5 – Turkey, D6 – Iran).

#### Insight 9. Wish for more short stories.

One participant experienced the women stories as long stories. This participant desired more short version of the stories (based on D1 – NL).

*Remark: only the additional questions are taken into account in the conclusion.*