PREFACE

Writing this thesis has been an educational and demanding process. Several people have helped me along the way, and I want to start off by saying thank you to my supervisor Terje Andreas Eikemo for all the advice and input he has given me. I would also like to thank Mirza Balaj for her ideas and supportive words, especially around the time when I realized that I had to make some drastic changes to my project.

Next, I would like to thank the women who participated in my group interviews. They all took the task I gave them very seriously, and their enthusiasm made writing this thesis more fun. A big thank you, also, to the very helpful employees at BreastScreen Norway, who helped me find the texts used in this thesis, and who were willing to talk to me about their work. Their positive attitude towards all new knowledge about the program made me even more motivated to finish this project.

I would also like to thank the members of the two study groups that I have been lucky enough to be a part of. To have someone to share breakthroughs and frustrations with has been crucial in the writing process, and it is always nice to have an excuse to eat biscuits and chocolate. Lastly, I want to thank my friends Monique and Ingvild, and my family for their support, as well as my very patient and helpful boyfriend Endre. An extra thank you to my father, who has read and given excellent feedback on pretty much every thesis and assignment I have ever written.

Johanna Gjefsen
Trondheim, 28.05.2018.

SUMMARY

Key findings from the Norwegian Institute of Public Health's public report from 2018 show that there are still significant social inequalities in health in Norway. The national strategy to reduce such inequalities includes a plan to reduce differences in health-related behaviour, and knowledge is thought to be a social determinant that affects this. BreastScreen Norway, which is responsible for the mammography program, considers distribution of information to be one of their main responsibilities. Their goal is to increase the knowledge about screening among the women in their target group, facilitating an informed decision about attendance.

The main objective of this thesis has been to see whether what the authors at BreastScreen Norway hope to achieve by distributing information about the mammography program, is in accordance with how women perceive the information. To this end, eight women were given two examples of invitations distributed by BreastScreen Norway, and they were interviewed in groups and asked to express their opinions on the texts. Two representatives from BreastScreen Norway were also interviewed so that the program's intentions could be accurately rendered. A text analysis was conducted to achieve a more objective presentation of the two invitations.

The results show that the informants perceived the texts as understandable, but that most of them felt they got more information than they needed. The representatives from BreastScreen Norway were aware that women want shorter texts, but are not able to give them this due to legal, professional, and financial constraints. They also find it likely that the majority of women do not use the distributed information when making their decision, but rather other sources.

The conclusion is that the informant's ages and preferences when it came to the choice of words and layout in the invitations, did not seem to affect their understanding of them. BreastScreen Norway must adhere to restrictions that potentially affect individuals' ability to gain new knowledge, as the constraints affect the content and length of the information. Women's use of other sources when deciding whether to attend screening might render BreastScreen Norway's information distribution redundant.

SAMMENDRAG

Nøkkelfunn fra Folkehelseinstituttets folkehelserapport fra 2018 viser at det fortsatt er betydelige sosiale ulikheter i helse i Norge. Den nasjonale strategien for å redusere slike ulikheter inkluderer en plan for å redusere forskjeller i helserelatert oppførsel, og kunnskap er en determinant som kan påvirke dette. Det norske mammografiprogrammet anser distribusjon av informasjon som en av sine hovedoppgaver. Deres mål er å øke kunnskap om screening blant kvinnene i målgruppen, slik at disse kan foreta et informert valg om deltakelse i programmet.

Hovedmålet med denne masteroppgaven har vært å se på om det er samsvar mellom hva mammografiprogrammet ønsker å oppnå med informasjonen de sender ut, og hvordan kvinnene som mottar den oppfatter informasjonen. I et forsøk på å finne ut av dette har åtte kvinner fått to versjoner av invitasjoner som mammografiprogrammet har distribuert, og de ble intervjuet i grupper for å gi uttrykk for sine meninger om tekstene. To representanter fra mammografiprogrammet har også blitt intervjuet for å få en mest mulig presis gjengivelse av hva mammografiprogrammet ønsker å oppnå med invitasjonene. I tillegg har det blitt foretatt en tekstanalyse for å gi en mer objektiv presentasjon av de to tekstene.

Resultatene viser at informantene oppfatter tekstene som forståelige, men at de fleste av dem følte de fikk mer informasjon enn de hadde behov for. Representantene fra mammografiprogrammet var klare over at kvinnene ønsker kortere tekster, men kan ikke gi dem dette på grunn av lovregulerte, profesjonelle og økonomiske begrensninger. De fant det også sannsynlig at majoriteten av kvinnene ikke bruker informasjonen når de tar sin avgjørelse, men heller bruker andre kilder.

Konklusjonen er at informantenes alder og preferanser når det kommer til ord og layout i invitasjonene, ikke virker å påvirke deres forståelse av dem. Mammografiprogrammet må følge visse restriksjoner som påvirker lengden og innholdet i informasjonen de sender ut, og dette kan potensielt påvirke personers muligheter til å tilegne seg ny kunnskap. Kvinners bruk av andre kilder når de skal avgjøre om de ønsker å delta i programmet, kan føre til at mammografiprogrammets informasjonsdistribusjon blir overflødig.

TABLE OF CONTENTS

Chapter 1

1 INTRODUCTION

According to Mackenbach (2012:761) it is a known paradox that socioeconomic inequalities in health have persisted in Western Europe despite the fact that most countries have established themselves as welfare states. Comparative studies have found that inequalities in mortality are not smaller in countries with relatively universal welfare policies, such as Norway, than they are in countries with more liberal or family-based welfare arrangements (Mackenbach, 2012:762). In fact, key findings from the Norwegian Institute of Public Health's public report (2018) show that in some measures, the inequalities have widened, especially among women, and can result in a five- to six-year difference in life expectancy at birth. The inequalities in health are bigger in Norway today than in several other European countries, and can affect health-related behaviour and prevalence of diseases in all age groups (Strand, Steingrimsdottir, and Grøholt, 2018). Over the last two decades, this persistence of health inequalities has given rise to an extensive number of empirically grounded theories and conceptual schemes (Mackenbach, 2012:762). One example is the theory of fundamental causes, which is perhaps the most prominent theorization of the social determinant perspective. I will give a more detailed description of this theory in chapter 3.

The original plan for my thesis was to write a critique of the term the social gradient in health, which is actively used in the theory of fundamental causes to illustrate social inequalities. The term is used to describe a pattern where an individual's health status improves in accordance with the individual's socioeconomic status (SES). In other words, if you have a high SES, you are likely to be in good health, while if your SES is low, you are more likely to be in bad health. When I first read about this term, it struck me as simplistic, but during my search for relevant literature, I realized that it was more complex than I first thought, and not deserving of the critique I had in mind. I only realized this after reading about the subject for an extended amount of time. The term is used in a variety of texts that are meant to be educational to the public. The fact that a person would potentially need to read a lot of information to understand such a term fully, made me more aware of the fact that since words and terms can be perceived differently by different people, the educational value might also differ. I was curious of what consequences this might have for inequality in health. According to Rimal (2000:221) there are several indications that knowledge can affect people's actions. If the person who has acquired knowledge also has a strong belief in his or her own abilities, this increases the likelihood that the new knowledge will be used to change behaviour. The belief in one's own abilities is called self-efficacy and is often seen in context with the term empowerment (Rimal, 2000:221). Empowerment describes the process where individuals, groups or societies mobilize resources to handle their own challenges. A prerequisite for this, is that the person or group experience a feeling of adequate control over the factors that might lead to a positive result (Sørensen *et al.*, 2002). In other words, dissemination of knowledge will have a larger effect if the reader feels that he or she understands the information and has an influence on their own life situation. How the information is phrased and understood, can therefore be crucial when it comes to whether knowledge influences health related behaviour or not (Rimal, 2000:221).

1.1 TOPIC AND RESEARCH QUESTIONS

In this thesis, I will consider the effect that the choice of words and phrasing can have on the reader's understanding of an informative text. The overall objective is to see whether variations in the understanding of terms and concepts can affect the transmission of health-related knowledge. Research has shown that written information gives an advantage to people with high SES, as it is considered more likely that they utilize new knowledge when making decisions. An example is a study from New South Wales, where the target group for the mammography program is the same as in Norway. They found strong positive associations between knowledge about and belief in the benefits of screening, indicators of health status and service utilization, and whether women previously had a mammogram within the recommended period (Achat, Close, and Taylor, 2005:312). People with high SES are also more likely to stay healthy, and less likely to die from disease (Phelan, Link and Tehranifar, 2010:28). In other words, knowledge, even though it is often distributed free of charge, might possibly strengthen the tendencies of social inequality in health.

To consider the effect of informative texts, I will analyse two invitations with attached information that have been distributed by BreastScreen Norway. There are in total four versions of the invitation to attend screening, and I have chosen the oldest and the newest version. My main objective is to see whether what the authors at the institutional level hope to achieve by distributing these invitations, is in accordance with how the women actually perceive them at an individual level. With this objective in mind, I have three research questions that I wish to investigate:

1. What does BreastScreen Norway wish to obtain by the information that they distribute?
2. How is the written information about breast cancer perceived by women?
3. What can explain the lack of compliance between opinions about the content and function of such informational texts?

My hypothesis is that how BreastScreen Norway hopes that the texts will be used and understood, is not be in full compliance with how the women use and understand them. This hypothesis is the basis for my assumption in research question three for there to be differences in opinions between the relevant agents. I base my hypothesis on research done by Marit Solbjør (2012), who has investigated how Norwegian women position themselves in accordance with the discourse linked to the necessity of information about screening participation. She describes how there is an ongoing discussion about what can be considered adequate and relevant information when it comes to invitations to screening. At the same time, the women in her focus groups are largely satisfied with the information they receive, and so it seems that the women who read the information, and the professionals in charge of distributing accurate information, are not in complete agreement (Solbjør, 2012).

To answer the first research question, I have interviewed representatives from BreastScreen Norway. In addition to understanding what they intend to achieve with the texts they distribute, I hope to get an impression of whether they actively work to equalize inequalities in health. In an effort to answer the second research question, I have conducted three group interviews with women who have had the opportunity to read the selected texts in advance, and were asked to talk about their impressions and opinions on them. I have also attempted to give the reader of this thesis a more objective introduction to the invitations through a text analysis. In an attempt to answer the third research question, I have introduced and seen my results in the light of the fundamental cause theory and institutional theory.

1.2 THE NORWEGIAN MAMMOGRAPHY PROGRAM

A mammographic screening is done through x-ray technology, and this form of screening is established in most European countries (Solbjør, 2012:194). The word “screen” refers in this context to an older version of the word, that means netting used to sift flour. In metaphorical terms, screening is a sort of sieve, where we want to sift through the symptom free individuals, and hopefully catch the ones that have a hidden disease (Sætnan, 2012). The goal is to be able to start treatment at an early stage. Screening is considered relevant for breast cancer, as it is a disease where early treatment might affect mortality rates. It is also the most frequently occurring form of cancer among Norwegian women (Solbjør, 2012:194). The Cancer Registry of Norway is the country’s national screening centre, and the mammography section is called BreastScreen Norway. The program’s steering committee was established by the Norwegian Directorate of Health in 2015, and the advisory committee is appointed by the Registry (Cancer Registry of Norway, 2018a). The mammography program offers a publicly financed examination to all women in the age group 50–69 years and has been a nationwide program since 2004 (Solbjør, 2012:194). One of BreastScreen Norway’s responsibilities is to distribute information about the program to the target group, and it is this responsibility that this thesis will focus on. Women who are in this group, receive an invitation every other year with a pre-set appointment and a fact sheet. The fact sheet includes information about breast cancer, mammographic screening, and the appointment (see appendix B). BreastScreen Norway’s other responsibilities cover the planning and execution of the program, including the distribution of information to staff at screening clinics (Cancer Registry of Norway, 2018b).

Numbers from 2015 showed that the target group for the Norwegian mammography program was approximately 600 000 women. Overall the participation rates have been high, in the period 2006–2013 it was 75 percent independent of screening round, and 84 percent of all invited women have participated at least once since the program started in 1996 (Hofvind *et al.*, 2015). These numbers are above what the guidelines from the European Union considers to be the desirable level of participation (Perry *et al.*, 2008:43). A hypothesis on why so many women choose to attend, is because the invitation is sent out with a pre-set appointment. But mammography programs have also received criticism that the high attendance rate might be a result of skewed information, phrased in a way which emphasises the positive sides of having a mammographic scan (Solbjør, 2012:195). In the Norwegian program, the information sent out with the invitation has in the later years included more detailed information about the potential negative sides than before. For example, on the fact sheet from 2017, the risk of overdiagnosis is explained in detail (see appendix B). Some critics also claim that mortality rates have not decreased significantly since the start-up of the program (Mæhlen and Zahl, 2007:6). An evaluation completed by the Research Council of Norway in 2015 indicates, however, that the Norwegian mammography program achieves a mortality reduction of between 20 and 30 percent among invited women, which is in accordance with the goal that was set for the program at the start-up (The Research Council of Norway, 2015:149).

1.3 DEFINITIONS

In this thesis, health will be defined by the ability and capacity a person has to fill a certain role in a social system. Included here is both the more objective health status, and the person's perceived health. Sickness will be used in cases where the way health is perceived by the individual or surrounding society, is central, while disease will be used to describe the more objective, medical assessment of a person's health status. I will go more into detail about these definitions in chapter 2.1.

BreastScreen Norway will be called the program for short, while the Cancer Registry of Norway will be called the Registry. I will use the word invitation when referencing the letter that includes the date for the pre-set appointment for screening, but it is worth mentioning that the program does not use this word about their most recent letter. The informants were asked to read two invitations, one information brochure, and one fact sheet (see appendix A and B). Sometimes, there will be a reference to text 1 and text 2. Text 1 is the oldest invitation and the brochure, while text 2 is the newest invitation and the fact sheet. These are sent out together, and therefore occasionally need to be seen in context.

1.4 THESIS STRUCTURE

Previously in this chapter, I have given a brief introduction to how distribution of knowledge possibly strengthens social inequalities in health, and to how BreastScreen Norway contributes to health-related knowledge distribution. In chapter 2, I will look at why health is considered important both in our society, and in the field of sociology. I will also explain why social inequalities are considered to be a problem. I will go on to introduce the theory of fundamental causes and institutional theory in chapter 3. The theory of fundamental causes is meant to explain why there is a lasting association between socioeconomic status and mortality over time, and may help explain why distribution and utilization of knowledge can affect health (Phelan, Link and Tehranifar, 2010:28). Institutional theory focuses on how organizations develop in coexistence with its surroundings, and may help detect what hinders and helps BreastScreen Norway in their work (Lewin and Volberda, 2003, as cited in Håland 2008:16). In chapter 4, I will introduce the texts that my informants have read through a text analysis. I will also present the method used in this thesis. The results of my interviews will be described in chapter 5, and later discussed in the light of the theories in chapter 6. Below the reader can find an overview of the research topic and thesis structure.

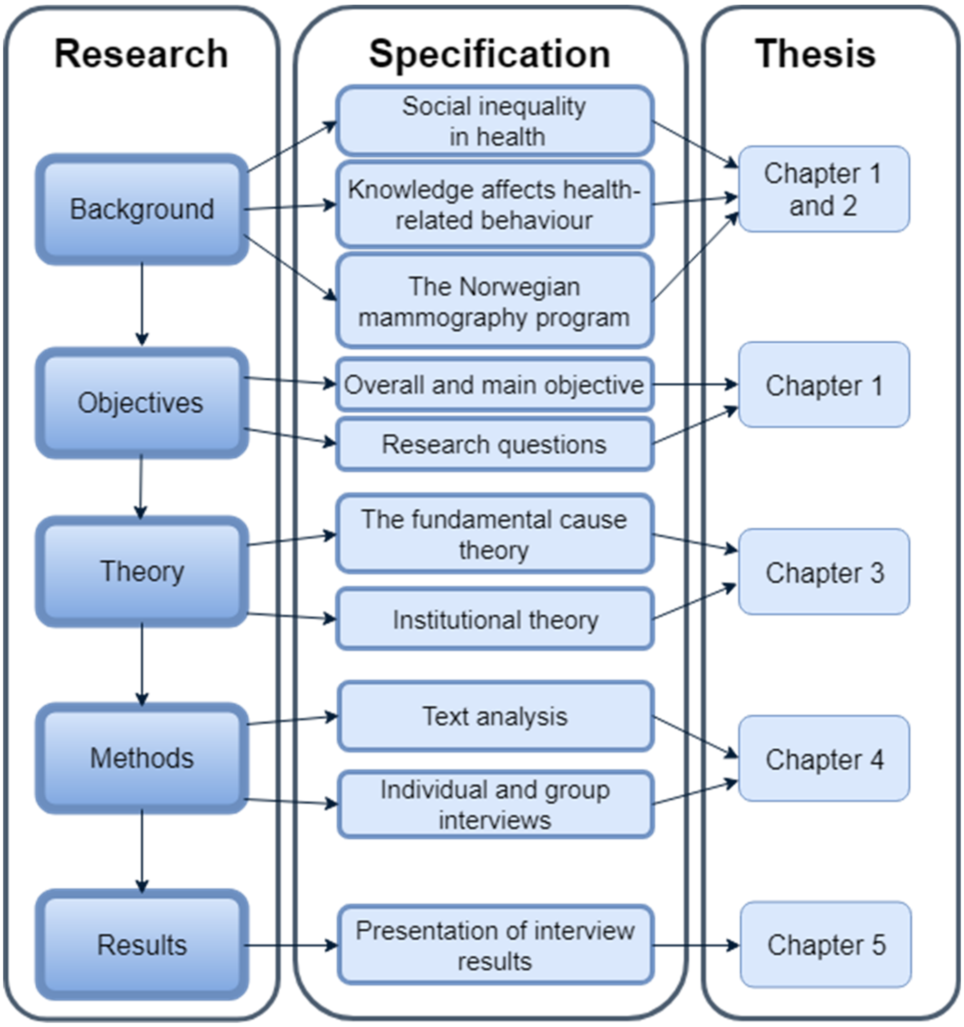

Figure 1. Overview of research topic and thesis structure.

Chapter 2

2 SOCIETAL AND SOCIOLOGICAL RELEVANCE

In this chapter, I will argue why health and social inequality in health both have societal and sociological relevance. First, I will describe national and global strategies to reduce inequalities in health, and why these inequalities are considered problematic. Thereafter I will explain how health is embodied in our social world, before I suggest that the increasing medicalization is gradually making health more relevant to our everyday lives. At the end of this chapter, I will describe how the Norwegian mammography program can be viewed as a form of paternalism.

2.1 INEQUALITY AS A SOCIAL PHENOMENON

In Norway, as in most other countries, we see a social inequality when it comes to health. Regardless of whether you measure it by education, occupation or income, the social differences seem to show a gradient where we can assume that the higher socioeconomic status (SES) a person has, the better his or her health is likely to be (Sosial- og helsedirektoratet, 2005:7–8). There is no clear answer why there is a connection between SES and health. According to Elstad (2008:27) one suggestion is that a person's occupational class might represent variations in health conditions in the workplace, while income influences consumption and the standard of a person's material living conditions. Education is related to cultural practises and health related behaviour, for example different lifestyles or habits when it comes to the utilization of health services. An example of such habits can be how often a person gets a medical check-up, and this might be influenced by a person's income and consumption as there is often a co-payment fee for medical examinations (Elstad, 2008:27).

So why is social inequality in health considered to be a problem? The Norwegian Ministry of Health and Care Services' group of experts on the field of social inequality have named five reasons; Firstly, it is thought to be unfair, as people with lower SES are deprived of life chances and freedom. Equality when it comes to health is considered to be an inherent dignity, as health both has value in and of itself, and is a condition for someone to live the life they wish to. Secondly, inequality is considered to be an issue for a person's living conditions, as failing health is thought to be an important factor that leads to social exclusion. This is because it stands in the way of both participation and productivity. Thirdly, there is the issue of public health, as the population's health-potential is not fully utilized. The fourth reason is that it constitutes a problem for the social economics, as bad health limits a person's ability for employment and contribution to the creation of wealth. The fifth and last reason, is that social inequality in health presents a problem for the welfare and quality of life of the people (Sosial- og helsedirektoratets ekspertgruppe - sosial ulikhet i helse, 2005:4).

The tendency for there to be a link between SES and health, has been clear over time, and in Norway the Health Department works actively to reduce what they call "gradientutfordringen", or the gradient challenge (Sosial- og helsedirektoratet, 2005:7–8). In Stortingsmelding number 20 (Helse- og omsorgsdepartmentet, 2007), there was an outline for a national strategy to reduce social inequalities in health. The goal is to achieve this without at the same time reducing the health of specific groups, and it was underlined that it should be expected that the work will be time-consuming and will demand long-term efforts. Four areas of action were drawn; to reduce social differences that contribute to differences in health, to reduce social differences in health-related behaviour and utilization of health services, to make a targeted effort to include everyone socially, and to develop further knowledge and tools across sectors (Helse- og omsorgsdepartmentet, 2007). The Norwegian strategy to reduce social inequality is based on the principle of universalism. According to Dahl, Bergsli, and van der Wel (2014) universalism is a term with several meanings, but at the core it is a welfare arrangement that covers everyone. This implies an equality of status for all when dealing with the welfare state. Still, universal arrangements are limited. They are linked to defined categories of need, such as old age, sickness, and unemployment. Strictly speaking, very few welfare programs are fully universal, for example the public mammography program only covers women aged 50–69 (Dahl, Bergsli, and van der Wel, 2014:25–26).

The reduction of social inequalities in health has also been on the agenda of the World Health Organization (WHO) for some time. In 1998, a goal was set to reduce the inequalities in health between socioeconomic groups within each member country by at least one fourth by the year 2020 (Sosial- og helsedirektoratet, 2005:7–8). Some researchers have used a river as a metaphor to distinguish between upstream and downstream factors. Downstream factors can be understood as individual behaviours, health policy, and medical care, while upstream factors, are linked to the general socioeconomic structure of society. These upstream factors are largely outside of the individual’s control. Just as what happens upstream can affect the river further downstream, structure impacts health directly and indirectly by creating mechanisms that act as social determinants of health. These are distributed in a way that reflects general socioeconomic stratification (Øversveen *et al.*, 2017:103–104). WHO wishes to reduce social inequality by improving such social determinants of health. They focus on, among others, place of birth, age, place of residence, and occupation, as well as political system and social norms in the residential country (World Health Organization, no date).

As I have mentioned, the theory of fundamental causes is a prominent theorization of the social determinant perspective. Another example is the socio-ecological model. Though I will not present this model further in this thesis, it does frequently utilize a useful illustration of social determinants of health, often referred to as the Meikirch model (Bircher and Hahn, 2017). A detailed version of this model can be seen below. The determinants are believed to influence health-related behaviour, as I will explain more detailed in chapter 3.1., and all levels of influence are considered important (Sallis, Owen, and Fisher, 2014:43). At the individual level, we find knowledge and self-efficacy, at the community level we find access to information, and at the social and structural level we find resources and services, policies and regulations, which I find to be relevant determinants when we look at the effect of the distribution of information about mammographic screening.

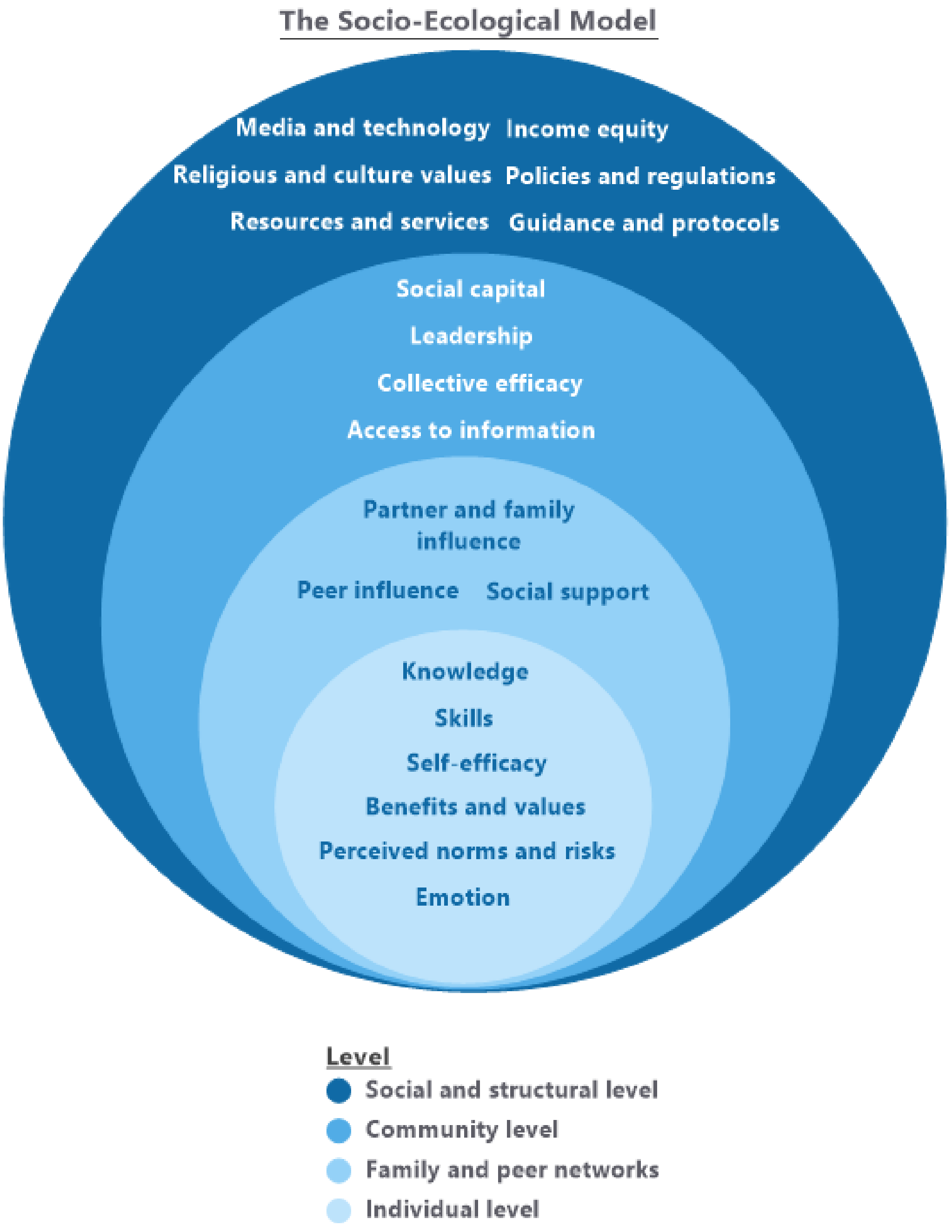

Figure 2. Meikirch model (Bircker and Hahn, 2017), with added information derived from Sallis, Owen, and Fisher (2014).

2.2 HOW IS HEALTH LINKED TO SOCIETAL AND STRUCTURAL CONDITIONS?

Health is a term that is defined in multiple ways, and therefore cannot be called an absolute and objective phenomenon (Underlid, 2010). According to Dahl, van der Wel, and Harsløf (2010:10–11), the term is viewed differently in English depending on whether it is looked upon in a biomedical (disease), psychological (illness) or sociological (sickness) dimension. In this thesis, I will mainly use the sociological definition, although I will use disease about more objective medical diagnoses, such as malignant tumours, and when describing the fundamental cause theory, as this is the term Link and Phelan (2005) use. From a sociological viewpoint, the definition of health tends to entail the ability and capacity a person has to fill a certain role in a social system. Here, it is possible to look at the person's role in a society which might make the person exposed to sickness, how the person copes in the role as a sick individual, and to what extent the person is able to fill his or her other roles in the society while he or she is sick. In the last ten years there has been what can be called a theoretical shift in a more social direction. Health used to be viewed as the absence of disease, then it was looked at more as the presence of wellbeing, whilst now, it has become increasingly about the ability to participate socially (Dahl, van der Wel, and Harsløf, 2010:10–11). Health is therefore not purely a materialistic phenomenon with clearly defined causal laws, but also subjectively idealistic. It is not just about the patient's objective state, but also about how a person defines his or her personal health, and what consequences their definition has for their actions (Underlid, 2010). With this, sickness becomes something that is not just physical, but also something that is embodied and social. It has become something that occurs in the relation between the individual and the society. For example, the question of someone's employability is up to, not only the person, but also the labour market and the society surrounding him or her (Dahl, van der Wel, and Harsløf, 2010:10–11).

As we can see, health is deeply embedded in the social world if we look at it from the perspective of a person's social roles. However, health is not only a part of this world when it is seen from the patient's perspective. Social scientists have shown how medical knowledge is itself social and reflects the culture and politics of its time (Hardey, 1998:1). Medical knowledge is often viewed as objective, as it is a result of research with strict and clearly defined guidelines that strive for medical neutrality. But, as history shows, what is considered the correct guidelines can change with both political and social changes (Hardey, 1998:9). Take, for example, the reaction Ignaz Semmelweis was met with from his peers when he in 1847 tried to suggest that doctors should wash their hands between performing an autopsy in the morgue, and delivering babies in the maternity ward. At the time, he was ridiculed, while today it is seen as an obvious necessity as we know about the existence of bacteria, and Semmelweis is now called the “saviour of mothers” (Lund, 2006).

The social aspect of medical knowledge does not only affect guidelines and routines, but also the definitions of the medical terms used. As we have seen, even the definition of health has changed over time (Dahl, van der Wel, and Harsløf, 2010:10–11). According to Tøssebro (2010:57) health, together with other health related terms such as physical impairment, is what can be called a sensitising concept, meaning a concept that we can all recognize, but might find it difficult to define within clear boundaries. In a way, it gives more of an indication than a clear definition. Because of this, it is not surprising that associations connected to the term can vary across time, places, and languages (Tøssebro, 2010:57). The right to define what can be considered sickness, illness or disease is often called medicalization, and is an extensive process that leads to a widespread use of medical expertise and terminology. Medicalization can play out differently, as it can mean to view a problem in medical terms, to use medical terminology to describe or understand a problem, or to initiate medical action to deal with a problem. The medicalization in today's society can result in an increased use of a language with a medical framework that concerns our everyday lives (Lian, 2012:49).

According to Lian (2012:44) an interesting sociological question is why some things are medicalized, while others stay outside of medicine's responsibility. There is no clear answer to this question, as medicalization is a complex interaction between several agents and factors that all work in the same general direction, although with different motives (Lian, 2012:53). One example is the health professionals such as doctors, that play an important role in this process, as they have the power to make the medical definitions (Lian, 2012:49). In a way, they have the power to define what can be considered normal in their society, and they have an interest in doing so (Lian, 2012:55). The interest can have both altruistic and more selfish motives, as they help create the need for their field of expertise, but at the same time are increasingly able to help other people through their professional competence (Lian, 2012:49). Other examples are the pharmaceutical industry and the media, who make money off of increased medicalization, and patients, who need to legitimize their conditions (Lian, 2012:53).

Some claim that medicalization is closely linked to technology. According to Hofmann (2017:1) technology has been key in many of the recent years' medical advances, but it also has its downsides. One such downside, which is often discussed in debates about modern medicine, is overdiagnosis. Overdiagnosis can be defined as the diagnosis of a biomedical condition that would not have resulted in symptoms, disease or death if left undetected. This is, for example, the case with some slow-growing malignant tumours. Overdiagnosis can in some cases be seen as a kind of medicalization; while medicalization is a process where previously non-medical aspects of our lives become medicalized, overdiagnosis results in a diagnosis of people who previously would have been defined as healthy (Hofmann, 2017:1). Operating on these patients, despite the risk of overdiagnosis, receives extensive critique from some professionals, but as with medicalization, overdiagnosis can be made with altruistic motives. It is still not possible with our technology to distinguish between, for example, slow- and fast-growing tumours. All tumours are then removed, to ensure that the fast-growing ones are always dealt with at the earliest possible stage (Hofmann, 2017:6).

Altogether, the cooperative causes for the patterns of social inequality in health are very complex, and can be seen at both a micro, meso, and macro level. At the micro level, unfavourable health behaviour might cause bigger risks for sickness, while social integration and participation can be viewed as protective mechanisms. Feelings of empowerment and self-efficacy can influence this. At a meso level, we can, among other things, look at the qualities of work environments, or at families. Material and psychosocial aspects at a person’s place of work could affect the individual’s health, while family relationships and social support can serve as a protector against health risks. Lastly, at the macro level, an example might be the welfare state, where a country’s politics and values affect the implementation of social health services, which in turn affect the health of the nation’s inhabitants (Dahl, van der Wel, and Harsløf, 2010:12–13).

Since screening for cancer, a health service offered by the welfare state, is done mainly on healthy people, it is considered important that the potential users of any such program has the opportunity to make an informed choice about whether or not they wish to participate. This means that women who are eligible for an official mammographic screening program are both considered recipients of the advice of health authorities, and responsible individuals with the right to choose not to take this advice (Solbjør, 2012:194). The principle of informed choice can be said to be a form of paternalism. Paternalism can be defined as the relationship between the controlling and the controlled, for example the employer and the employee. It involves an almost father-like care from the controlling agent, and paternalism comes in several forms (Gundersen, 2018). According to Dahl, Bergsli, and van der Wel (2014:34–35) it can be negative, which means that it prevents damage, or positive, which means that it promotes something good. In the case of mammographic screening, the screening itself can be described as negative, as it prevents the potential damage of advanced cancer, while the program that offers screening is promoting a preventive healthcare service that is by many considered as something good. Paternalism can also be passive or active, meaning it refrains from or chooses to act. BreastScreen Norway plays an active role when distributing information, but holds a more passive role when it comes to influencing participation. Lastly, paternalism can be hard or soft. What differs hard and soft paternalism, is what is the motive for action. The motive for hard paternalism is to do good, while it for soft paternalism is to make sure that a decision is made by someone who is competent and fully informed. For example, if the patients are considered accountable for their own actions, soft paternalism will not intervene in their health-related decisions, as is the case with the choice to participate in a screening program. The motive for soft paternalism is simply to improve the decision-making process (Dahl, Bergsli, and van der Wel, 2014:34–35). It is easier to justify negative and passive paternalism, for example to remove risk factors, than it is to justify positive and active paternalism, where for example protective factors are introduced. Dahl, Bergsli, and van der Wel (2014:35) state that this can be explained by the fact that there is often a larger consensus about what bad living conditions are, than about what is needed to live a good life.

Chapter 3

3 THEORETICAL BACKGROUND

In this chapter, I will introduce the theoretical background for my thesis. First, I will present the fundamental cause theory, which is, as I have previously mentioned, a theorization of the social determinant perspective. This theory provides several terms and concepts that can be useful when describing social inequalities in health, but most importantly it provides a potential explanation for why knowledge attainment and utilization can affect health-related behaviour. This can in turn influence social inequalities, though it is the correlation between knowledge and behaviour that will be the main focus in this thesis. I will also introduce institutional theory. Although the processes implied by the fundamental cause theory operate at both individual and contextual levels, I find that the theory does not cover potential contextual factors that shape and limit BreastScreen Norway as an organization. My hypothesis is that the relevant agents in this thesis are not in full agreement about the contents of the relevant texts. Organizations are often shaped and limited by their surroundings, as I will come back to in chapter 3.2., and BreastScreen Norway's opinions and work are potentially shaped by this. Therefore, I find it necessary to include a theory that can help describe the factors that can influence an organization.

3.1 FUNDAMENTAL CAUSE THEORY

The theory of fundamental causes has been developed primarily by Jo C. Phelan and Bruce G. Link. As mentioned, its purpose is to explain why there is a lasting association between socioeconomic status and mortality over time, a pattern that can be illustrated using the social gradient in health (Phelan, Link and Tehranifar, 2010:28). The theory turns towards upstream factors and requires a closer examination of the societal forces that generate social inequality (Øversveen *et al.*, 2017:105). Link and Phelan suggest that the theory is necessary because it is important to look at what «puts people at risk of risks» (Link and Phelan, 1995:80). Here, contextualizing risk factors, meaning exposure to individually-based risk factors such as poor diet and lack of exercise, are considered to be important. Another important factor is that access to resources help people avoid the risk and negative consequences of sickness. It is the social conditions that give access to such resources (illustrated in figure 2) that is considered fundamental causes (Link and Phelan, 1995:81). These resources are not distributed evenly across the population, and there is a tendency for health to be reproduce over time. Not even in the cases where what is called intervening mechanisms, such as vaccines, have improved the health status in a population, can we see absolute equality in health (Phelan, Link and Tehranifar, 2010:29). This is for example the case for mammographic screening, which can be defined as an intervening mechanism. Despite widespread population programs that have resulted in a decrease in mortality, the social gradient for breast cancer patients, that previously was inverted so that women with high SES were more at risk, seems to be turning. This means that the women with low SES now are at the same or higher mortality risk than women with high SES (Gadeyne *et al.*, 2017).

The strong mortality gradients based on SES are not new. For SES, the first association was observed in France in the early 19th century (Phelan and Link, 2005). Phelan and Link (2005) argue that the theory of fundamental causes can explain how there simultaneously can be vast improvements in population health, and a creation of large socioeconomic and racial disparities in mortality for specific causes of death. They claim that it is the expanded capacity to control disease and death, in combination with existing social and economic inequalities, that create such health disparities. This is because the benefits of the expanded capacity are unevenly distributed according to key resources such as knowledge, money, power, prestige, and beneficial social connections. There are several theories, in addition to the theory of fundamental causes, that have attempted to explain the mortality gradients, for example the social selection explanation, in which genes affect health, which in turn affects SES. There is also a second social selection explanation, in which genes influence factors like intelligence, which influences both health and SES. Alternatively, we find the social causation explanations, which find the answer in the stress and hardship that is associated with lower SES or minority racial status (Phelan and Link, 2005). Phelan and Link (2005) can agree that these theories explain, at least in part, the creation of disparities in mortality, but feel that they struggle to also explain the vast improvements in population health. This is where the authors feel that their theory is necessary, as the improvements can be explained by the previously mentioned expanded capacity to control disease and death (Phelan and Link, 2005).

According to Phelan and Link (2005) disease does not flow directly from the fundamental causes, although they play a necessary role. It was, for instance, not enough to introduce better housing, hygiene, and vaccines to the poor in the USA in the 19th century. The poor were more at risk for death of diseases such as cholera, but when the conditions changed, and the disease became rare, the health disparities did not disappear. The authors explain this by pointing out that as new discoveries that can control disease are made, new items will be added to the list of health-enhancing circumstances, and those who have more resources will, on average, be better able to access and benefit from the new knowledge we gain. Also, cholera might not be a problem any longer, but new risk factors have appeared in the meantime, such as pollution, or risk enhancing behaviour such as over-eating (Phelan and Link, 2005). Today, SES-inequalities in mortality reflect the new major causes of death, such as cancers and cardiovascular disease (Phelan, Link and Tehranifar, 2010:29).

Due to the factors that hinder the disappearing of health disparities, Phelan and Link (2005) state the association between SES and disease seems to be reproduced through a set of intervening mechanisms that change over time and vary from place to place. According to the theory of fundamental causes, this dynamic reproduction occurs because the flexible nature of key resources allows the association to be reproduced in various circumstances. The authors feel that such flexible resources are important in at least two ways. Firstly, whether individuals are aware of, have access to, and are supported in their efforts to engage in health-enhancing behaviour is influenced by their resources. Secondly, resources shape the access to what the authors describe as broad contexts, such as social networks and occupations, and these have varying risk and protective factors (Phelan and Link, 2005). For example, perceived social isolation and loneliness are associated with increased risk of early mortality (Holt-Lunstad *et al.*, 2015). With this, the processes implied by the fundamental cause theory operate at both individual and contextual levels. Link and Phelan (2005) argue that SES disparities in mortality arise because people with a higher SES use their flexible resources, such as knowledge, to avoid risks and assume protective strategies. It follows that the link between SES and mortality should become less apparent if people cannot use their resources in this way (Phelan and Link, 2005). To better understand how flexible resources might facilitate the creation of new mechanisms linking SES and health, we can again consider an example concerning screening for cancers. Screening has, as previously mentioned, made it possible to detect cancer earlier, and this increases the chances of survival. Since the screening procedures represent relatively recent technological advances, we can imagine a time before the procedures existed, and there was no mechanism linking SES to screening access to health. But after the screening procedures were developed, resourceful people in countries where screening was not offered through population programs, could use their resources to gain access to the potentially life-saving screens. And so, a new mechanism took shape (Phelan, Link and, Tehranifar, 2010:30).

Phelan, Link, and Tehranifar (2010:35–36) address a noteworthy limitation to the fundamental cause theory; The resources that increase health might not be used by the individual with their health in mind, but rather to attain other life goals. For example, a person might keep fit in an effort to achieve beauty, rather than good health. Such competing goals are referred to by Lutfey and Freese (2005) as countervailing mechanisms. These might not necessarily threaten the truth-value of the theory, as the fundamental relationships only require that “the effects of the [countervailing] mechanisms are cumulatively smaller than the effects of mechanisms producing the fundamental relationship” (Lutfey and Freese, 2005:1365). But as the countervailing mechanisms can be used to explain results that do not support the theory, they also pose a challenge to the falsifiability of it (Phelan, Link, and Tehranifar, 2010:35–36). For this reason, as well as for the fuller understanding of health inequalities, Phelan, Link, and Tehranifar (2010:35–36) consider it to be desirable to attend to countervailing mechanisms. In the effort to do so, they suggest that the power of health attainment to shape behaviour is largely due to social forces. With this, successful countervailing mechanisms are also likely to be embedded in strong social norms and support, especially for high SES individuals. The authors suggest that status attainment is a possible countervailing mechanism (Phelan, Link, and Tehranifar, 2010:35–36). For example, Courtenay (2000:1389) proposes that what can be considered characteristics of masculinity, such as the denial of weakness and engagement in risky behaviour, often undermine men’s health. With this, the pursuit of masculine status may help explain why women live longer than men despite having generally fewer resources, a fact that would not be predicted by fundamental cause theory (Phelan, Link, and Tehranifar, 2010:35–36). Despite this, Phelan, Link, and Tehranifar (2010:36) expect the goal of good health in most cases to be compatible with goals of power, self-esteem, and so on. They would therefore expect there to be an inequality in how individuals use their resources to achieve more of what they desire, and, as usual, high SES individuals would achieve more (Phelan, Link, and Tehranifar, 2010:36).

The theory of fundamental causes has only rarely been tested empirically. One such test was done by Mackenbach *et al.* (2015), and their results provided some support for the theory. However, there were some exceptions that indicated the need of further analysis. The theory has also received critique. Firstly, the fundamental cause theory has an inconsistent definition of the terms health and socioeconomic status, but gives little reflection on how the use of different measures may affect findings (Øversveen *et al.*, 2017:108). Secondly, Freese and Lutfey (2011:71–72) have noted that the concept of resources is sometimes stretched and put to use wherever it fits best. Not all empirical phenomena will fit easily into the categories SES, resources, mechanisms, and health outcomes, although the fundamental cause theory depends on being able to distinguish them if it is to claim that SES acts as a basic cause (Freese and Lutfey, 2011:72; Øversveen *et al.*, 2017:106). A third critique of the theory of fundamental causes, is that the theory interprets the relationship between SES and health as essentially linear and unidirectional. SES determines access to resources, which further impacts the individual's ability to avoid risk and sickness. Consequently, SES is practically moved outside of the analysis, having a one-way impact that does not need to be explained (Øversveen *et al.*, 2017:106). Øversveen *et al.* (2017:106) argue that this implies an a priori assumption that SES is not receptive to either the resources currently available, or to health outcomes. They refer to Mackenbach (2012) when pointing out that the fundamental cause theory explains health inequalities in terms of other inequalities. This may be interpreted as nothing more than a repetition of the relationship between SES and health, "reformulating the problem without coming any closer to specifying the pathways and mechanisms that can explain the health gradient" (Øversveen *et al.*, 2017:106).

3.2 INSTITUTIONAL THEORY

Institutional theory rose to importance in the field of organizational theory in the 1970's (Scott, 2001:xix). As previously mentioned, the theory focuses on how organizations develop in coexistence with its surroundings (Lewin and Volberda, 2003, as cited in Håland 2008:16). Scott (2001:49) defines institutions as "multifaceted, durable, social structures, made up of symbolic elements, social activities, and material resources". The definition of institutions can, as Scott's version is an example of, be perceived as quite abstract, but the key is that institutions have norms and practices that regulate the way the agents handle important tasks. This is thought to be necessary due to the belief that some challenges should be handled within certain boundaries if the society is to be maintained over time (Skirbekk, 2015). Scott (2001:xx) shows that institutional theory originates from the mindset of the 1960's open systems theory in organizations. This mindset focuses on the way organizations are limited, shaped, and renewed by their context and surroundings. Examples of older sources of inspiration for institutional theory within the field of sociology are Marx, Durkheim, Weber, Parsons, Mead, and Berger and Luckmann (Håland, 2008:16).

Organizations can be defined as collectives that are built up to promote one or more purposes, and they often have formalised rules and a division of labour (Berg, 2014). In this thesis, I define BreastScreen Norway as an organization. Many programs that are implemented to promote health take place in organizational settings, and theories that provide insight into organizations can also give insight into how to an organization may encourage or discourage positive health behaviours. Although organizational theories used in health promotion often focus on promotion within the organization itself, for example by using the socio-ecological model, it is possible to look at health promotion at the organizational and societal level, by looking at how the organization's behaviour is affected by the way it interacts with its surroundings (Butterfoss, Kegler and Francisco, 2014:336–337). An example is when two or more organizations with similar purposes might decide to collaborate as the increasing complexity of health, social issues, economics, and politics make it more likely that the organizations will be successful if they work together (Butterfoss, Kegler and Francisco, 2014:346). This was, for example, the case in 1991, when the Norwegian Cancer Society provided 5 million Norwegian kroner to the Directorate of Health for the planning and initiation of publicly available mammographic screening (Hofvind *et al.*, 2017:15).

Within institutionalism we often distinguish between the old and new, and according to Powell and DiMaggio (as cited in Håland 2008:17) the two have the following aspects in common: The focus on the relationship between organizations and their surroundings, a sceptical attitude towards the rational agent model, and a desire to highlight how certain aspects of the reality in organizations are not necessarily consistent with their formal descriptions. Institutionalism is also seen as a state-dependent process. In this process, organizations have limited options to choose from, and consequently become less instrumentally rational (Powell and DiMaggio, 1991, as cited in Håland 2008:17).

In this thesis, I will mainly refer to new institutionalism. Within the sociological tradition, new institutionalism has its roots in cognitive theory, phenomenology, culture studies, and ethnomethodology (Scott, 2001:39). One of the important ways in which new institutionalism differs from old institutionalism is that it not only defines the surroundings of organizations as local communities, but also non-local surroundings, such as an industry, a profession or a nation. As I will come back to, professional influence seems to affect the work of BreastScreen Norway. In addition to this, new institutionalism emphasizes the relationship between legitimacy and stability, rather than interests, conflicts, and strategies, as is done in old institutionalism (Powell and DiMaggio, 1991, as cited in Håland 2008:17–18). I consider this relationship to be relevant for the work of the mammography program.

One leading article is often cited when describing new institutionalism; Meyer and Rowan's ”Institutionalized Organizations: Formal Structure as Myth and Ceremony” (1977). The authors claim that organizations must incorporate procedures defined by institutionalized and widespread rational concepts of organizational work, and by doing this they increase legitimacy and chances of survival (Meyer and Rowan 1977:41). Meyer and Rowan derive their definition of institutional rules from Berger and Luckmann (1967), and define these as ”classifications built into society as reciprocated typifications or interpretations” (Meyer and Rowan, 1977:42). These rules can be taken for granted, be supported by public opinion, or be legally required (Starbuck, 1976 in Meyer and Rowan, 1977). Meyer and Rowan (1977:42) emphasize the enormous significance institutional rules have for organizations. In addition to spreading fast in the modern society, the rules define new organizational situations, redefine existing situations, and specify the means to handle these in a rational manner (Meyer and Rowan, 1977:42; Håland 2008:19–20). Further, Meyer and Rowan (1977:45) highlight how technological systems become taken-for-granted means to achieve organizational goals, showing that technologies are institutionalized myths that are binding for organizations. Independently of whether this institutional technology is actually effective, it establishes the organization as rational and modern (Meyer and Rowan, 1977:45; Håland 2008:20). Meyer and Rowan (1977:49) introduced the term isomorphism, which means to have similar structure or appearance with something else. Isomorphism with institutions in the surrounding is central for organizations, as it promotes their success and survival. This is relevant for a main point given by the authors; An organization's success is dependent on other factors than efficient coordination and control over production activities. Organizations will attain legitimacy and resources that are necessary for survival, unrelated to their production efficiency, when they live in highly developed institutionalized surroundings and succeed in achieving isomorphism with these surroundings (Meyer and Rowan, 1977:49; Håland 2008:20).

Another leading article describing new institutionalism is DiMaggio and Powell's ”The Iron Cage Revisited: Institutional Isomorphism and Collective Rationality in Organizational Fields” (1983). The authors have further developed the term isomorphism, basing it on Hawley's (1968) definition of it as: "[…] a constraining process that forces one unit in a population to resemble other units that face the same set of environmental conditions" (DiMaggio and Powell, 1983:149). Organizations may change their goals or develop new practices, but overall, organizational agents construct an environment around themselves that is constraining their ability to change further in later years (DiMaggio and Powell, 1983:148; Håland 2008:21). The authors claim that isomorphism is the term that best captures the process of homogenization, and further distinguish between isomorphism based on competition and isomorphism based on institutionalism. When based on competition, isomorphism is acquired when organizations become similar in an attempt to adapt in the same way to a common market. In an institutionalized perspective, which is the perspective that is relevant to this thesis, the organizations compete for legitimacy and political power (DiMaggio and Powell 1983:152; Håland 2008:21). DiMaggio and Powell (1983:152) identify three types of mechanisms that contribute to this form of isomorphism Firstly, we find coercive isomorphism, which refers to both cultural expectations in the community it is a part of, and the formal and informal pressure from other organizations that the current organization is dependent on. An example of coercive isomorphism is how national laws regulate an organization's activity. Secondly, we find mimetic processes, in which other organizations are mimicked, and legitimacy can be attained if the organizations that are mimicked are successful. DiMaggio and Powell (1983:152) claim that mimetic processes most often occur in situations where there is uncertainty about technology, goals, or surroundings. The third kind of processes that contribute to isomorphism, is normative pressure. Normative pressure mainly comes from professionalization. This is defined as the fight for professional legitimacy among members of an occupational group, and it also implies that recruitment is done among organizations that are similar to each other (DiMaggio and Powell, 1983:152; Håland 2008:21).

New institutionalism has received critique from Zucker (as cited in Håland 2008:22), who claims that it is at risk of forgetting that naming a process or structure is different from explaining it. Another critique of institutional theory has been that it is almost inherently static, while the world it seeks to explain is almost inherently dynamic (Pescosolido *et al.*, 2011:7). DiMaggio and Powell (as cited in Håland 2008:22) have recognized that newer directions of new institutionalism are concerned with including changes and power, rather than solely concentrating on the legitimization process and social reproduction, and that a greater understanding of the fact that institutions are products of human action, and not just limitations for them, has been established. The authors admit that even if rules and routines create order and reduce insecurity, there are also conflicts, contradictions, and ambivalence within institutionalizing processes. Agents and their interests are seen as institutional constructs in a new institutionalism perspective, and cultural frameworks establish approved means and define what is considered desirable results (Powell and DiMaggio 1991, as cited in Håland 2008:22).

Chapter 4

4 METHOD

In this chapter I will introduce the texts that my informants have read through a text analysis. There will be a separate analysis for the invitations and for the informational texts included with the invitations. The analysis of the texts was used as a starting point when I made the interview guides both for the group interviews and the interview with BreastScreen Norway. I will also describe my recruitment process, and the methods I used while conducting my interviews.

4.1 TEXT ANALYSIS

As I wished to consider whether variations in the understanding of terms and concepts can affect the transmission of health-related knowledge, I decided to pick two health-related texts and put them to the test. The texts I chose were the invitation letters sent out to women who are in the target group of the Norwegian mammography program, as these are texts that are meant to reach a wide variation of women. Breast cancer is also interesting when it comes to the gradient in health, as this for a long time has been a disease with an inverted gradient, meaning that women with high SES were more at risk, but where the gradient now seems to be turning (Gadeyne *et al.*, 2017). I chose the first invitation ever to be sent out, which was the one sent out during the pilot project, which started up in 1995 (see appendix A). The reason why is twofold; since it is the oldest invitation, I expected it to be the one that was most different from the others when it came to choice of layout and phrasing. In addition to this, the invitation was sent out before the implementation of a national strategy to reduce social inequality in health, which came into place for the first time in 2007 (Dahl, Bergsli, and van der Wel, 2014:13). The second invitation I chose is the most recent one, from 2017 (see appendix B). This is the first invitation to also be sent electronically, while the previous ones were sent exclusively by post. Because of this, I expected the invitation to have a different layout, and also a phrasing that might be perceived as more common by today's readers. These invitations were both sent with additional information, the invitation from 1996–1997 had a brochure included, and the invitation from 2017 had a two-page fact sheet (see appendix A and B). Although these were separate texts, I decided to include them as a part of the invitation, as they are both meant to help the women make their decision about participating in the program. The first invitation also had a questionnaire included, but this is excluded in my analysis for two reasons; firstly, it was meant to give the program information about the patient, and not the other way around. Secondly, I wanted to compare similar texts, and as there was no questionnaire in the most recent invitation, I left it out. I removed the date and the co-payment cost, as these would reveal to the informants that one text was older than the other, and I thought this might affect their opinions about them. They were, however, told how the texts were distributed.

I wanted to have my participants read these texts to get examples of how women may subjectively perceive them. But I also needed a more objective view. To this end, I did a text analysis, as seen below. The initial inspiration for the different categories, were standard text analysis categories such as logos, pathos, and ethos, visible agent, and the differentiation between expressive, informative, appellative, and poetic language functions (Jørgensen and Onsberg, 2008:79; Svennevig and Hagemann, 2018). Most of these were difficult to apply to the texts in an objective manner and were later removed. I still based the category "Informativity" on the informative language function. With this language function, the focus is one the subject on hand, and the information should be factual and objective. The sender is often visible, but not prominent (Svennevig and Hagemann, 2018). The categories "Amount and type of information" and "Information less related to the subject" are meant to help underline whether the information fills the requirements for informative language functions. "Visible agent" was also included, to see how apparent the sender is. The remaining categories were included both to help illustrate the differences between the texts, and to highlight elements that might influence the reader's experience, such as pictures and layout. Where it was possible, I rated the degree of each category on the scale from 1 to 3, where 1 is to a small or no extent, and 3 is to a large extent. The texts are seen relative to each other, and I did one analysis for the invitation letters, and one for the added information. The categories were used as inspiration for the interview guide for both the group interviews and the interviews with BreastScreen Norway (see appendix E and F). For the group interviews, I focused on informativity and visible agent, while in the interview with the representatives from the program, I also asked about the background for the stable and changing elements.

Table 1. Text analysis of letters of invitation, see appendix A and B.

Invitation	**1996–1997**	**2017**
Informativity	3. The focus is on the subject on hand, and the information is to the point and objective.	3. The focus is on the subject on hand, and the information is to the point and objective.
Amount and type of information	2. Limited information about cancer and screening, some information about appointment. Cancer: • Is something you might die from. Screening: • Target group. The appointment: • Time and place. • Contact information if you need to change appointment times, have had cancer earlier, or are disabled in need of extra facilitation. • Co-payment, and how to pay. • Privacy Policy. • Information about how to fill out the included questionnaire.	3. Limited information about cancer and screening, mainly information about appointment. Cancer: • Is something you might die from if it is not discovered early. Screening: • Target group. • How often women within the target group will receive an invitation. • The program is voluntary. • You may request not to receive invitations to screening. The appointment: • Time and place. • Contact information if you need to change appointment times, have had cancer earlier, or need disabled in need of extra facilitation. • Co-payment, what it covers, and how to pay.

Amount and type of information		- Privacy Policy and reservation rights. - How to prepare for the appointment. - How and when you can expect to receive the results.
Information less related to the subject	1. None.	2. Some. - Encouragement to follow the Cancer Registry of Norway on Facebook. - Information about how it is now possible to receive digital letters from the Registry.
Visible agent	3. Apparent sender. - The sender refers to themselves as "we". - BreastScreen Norway's logo is on the invitation.	3. Apparent sender. - The sender refers to themselves as "we". - Several links to the Registry's webpages.
Length	One page, 186 words.	Two pages, 416 words.
Pictures and illustrations	One BreastScreen Norway logo.	Seven small illustrations, one Facebook logo.
Stable elements across time	- Information about co-payment, and how it can be payed. - Information about Privacy Policy. - The purpose of the program is to prevent death. - Definition of the target group. - Time and place for the appointment, and the encouragement to contact them if you do not plan to attend.	

	• Encouragement to contact them if you have had cancer earlier or have special needs.	
New elements	-	• Reservation right. • The right to request not to receive invitations in the future. • Facebook and digital letters. • Information about what the co-payment covers. • How to prepare for the appointment. • Information about where you can find the invitation in English.
Degree of repetition	1. None.	1. None.

Table 2. Text analysis of additional information sent out with invitations, se appendix A and B.

Added information	**1995**	**2017**
Informativity	3. The focus is on the subject on hand, and the information is to the point and objective.	3. The focus is on the subject on hand, and the information is to the point and objective.
Amount and type of information	2. Limited information about cancer, mainly about screening and appointment. Cancer: • Who are at risk, and why it is important to discover it early. Screening: • Explains how screening is thought to decrease mortality. • Description of the program and how the results are read. • Mentions the possible need for a follow-up. • Encourages self-examination. Appointment: • How to get an appointment, and how you will receive the results. • Information about what to do if you have had	3. Some information about cancer and appointment, mainly about screening. Cancer: • Why some tumours might never become cancer. • Early discovery increases the chances of keeping the breast. • The form of cancer that affects most women in Norway. • Contact information for if you suspect hereditary cancer in the family. Screening: • Overdiagnosis. • Possible need for a follow up. • Mammography uses x-rays and might not uncover all cancers. • Target group. • The program's goal. Appointment: • Length, how the screening is performed. • When you can expect the results.

Amount and type of information	breast cancer earlier, or need help with the questionnaire.	• Information about what a possible follow-up entails.
Information less related to the subject	1. None.	1. None.
Visible agent	3. Apparent senders. • Two logos for BreastScreen Norway. • List of collaborators on the back of the brochure.	3. Apparent sender. • The sender refers to themselves as “we”. • One logo for the BreastScreen Norway. • Links to the Cancer Registry of Norway’s webpage.
Length	444 words. 8-page brochure.	855 words. 2-page fact sheet.
Pictures and illustrations	Four pictures of a woman, two identical logos for BreastScreen Norway.	One illustration that describes how many women out of a 1000 that cleared for cancer, asked to go to a follow up, and diagnosed with cancer. One logo for BreastScreen Norway. One British flag.
Stable elements across time	• Explanation why certain women are in the target group. • Information about the possibility of a follow-up, but that this does not necessarily mean that the patient has cancer. • Information for those who have had breast cancer previously. • Why it is important to discover cancer early. • Women should self-exam, even though they participate in the program, and contact their GP if they discover anything abnormal.	

	• Information about how the x-rays causes little health risk. • Statistics of breast cancer, though more detailed in the fact sheet.	
New elements	-	• Information about possible overdiagnosis. • Link to where you can find information in English. • Recommends talking to your GP if you have questions about screening.
Degree of repetition	• Argues that mammography can save lives three times, although phrased differently.	• That you can find more information on the Registry's webpage is mentioned three times. • That the program wishes to prevent death is mentioned three times. • Information about possible overdiagnosis and why it is difficult to distinguish between this and a correct diagnosis, is mentioned twice.

A development that is similar between the invitations and the brochures, is that the ones sent out in 2017 are significantly longer than the first to ever be sent out. Even though the fact sheet is only two pages long, it still has almost twice as many words as the brochure from 1995. The invitation has more than twice the amount of words. Consequently, the newer text contains more detailed information, has a larger degree of repetition, and is the only one that deviates slightly from the subject on hand. The newer text also has no pictures, only small logos and illustrations. The illustrations help separate the texts into parts sorted by theme, for example a phone next to the information about when you should contact them, or a hand holding a bank card next to information about co-payment. The older texts have no such illustrations. Instead the brochure has four pictures of the same woman. In one of the pictures, she is getting a mammography scan. Since all of the pictures fill a whole brochure page, and the logo of the program is on the back page, only three of the pages actually have a significant amount of text on them.

4.2 GROUP INTERVIEWS

I wanted to see how the texts are perceived by the readers, and if there is a difference in the understanding of women within the target group, and outside of the target group. To do this, I decided to conduct focus group interviews with women of varying ages and background where they would have the opportunity to express their subjective opinions. In focus group interviews you collect several informants to discuss one or more topics. Such interviews can be useful as they generate data efficiently because one interviews multiple people at the same time, and due to time constraints, I felt this was beneficial. It can also be helpful for the informants to discuss their ideas and opinions with each other, as this can contribute to more spontaneous answers (Tjora, 2012:122–123). Ideally, a focus group should have between six and twelve informants, and last between one and two hours. If the topic is especially focused, and does not cover sensitive or difficult subjects, one might consider smaller groups and shorter interviews, as trust can be established relatively fast (Tjora, 2012:124 and 126). I considered this to be the case in my planned interviews, as the subject would only be the two invitations with their attached information brochure and fact sheet. The questions I wanted to ask were worded in such a way that it would be easy to answer them without telling personal stories, unless the informant wanted to. Therefore, I organized three interviews with small focus groups.

4.2.1 Recruitment

As mentioned, I wanted to recruit women of different ages and background to see whether this might affect their level of understanding. Having informants of different ages would mean that some of the women I interviewed would not be in the target group for the program at the time of the project, but they could be in the future, or have been in the past. At first, I tried recruiting through social media and by approaching people at shopping centres. The hope was that the information about the project would in this way reach a more varied group of women than it would have if I were to contact women in my own network. Unfortunately, this approach turned out to be inefficient. Especially talking to people in shopping centres lead nowhere, as people seemed to avoid a conversation with me purely because I was holding flyers (see appendix C). I realized that I had to change tactics and decided to give out gift cards to participants. Shortly after this, I managed to recruit three people through mutual acquaintances. This experience made me realize that people are more likely to say yes if they are asked by someone they know, and so I started to contact some local groups and organizations to have representatives there present the project to their members on my behalf. This turned out to be effective, as seven informants volunteered from the same organization, where information about my project had been sent out in their newsletter. Out of the total of ten volunteers, eight were interviewed. One person had to withdraw from the project as it became very difficult for her to fit an interview into her schedule, the other person had to withdraw because of sickness on the day of the group interview. All the women who participated in the group interviews have been made anonymous in this thesis.

The initial difficulty with recruitment affected the size and number of groups that I interviewed, as the limited budget for gift cards decided at what point I stopped trying to recruit more informants. Also, some of the informants that were recruited from the local organization expressed that it would be nice to be in the same group as some of their fellow members. As it often can be beneficial with homogenous groups when conducting focus group interviews, I tried to make this possible. Homogeneity inside a group helps access people’s personal experiences or opinions, while heterogeneity between groups can provide a wider knowledge about the topic (Solbjør, 2012:199). When the women from the organization were placed together, that automatically meant that there would be one group of three consisting of the first people recruited. These three happened to be a quite homogenous group as well, since they were the youngest informants, and either students or newly educated. To make the groups even, I decided to have three groups of three, one consisting of the youngest informants, and two consisting of women from the organization. The informant who was ill on the day of the group interview, would have been in group 1. The remaining two members of group 1 knew each other from before, while the informants in the other groups had never met. The fact that they are grouped by age was coincidental. And so, my final selection of informants were:

Table 3. Selection of informants, group interviews.

Name	**Bjørg**	**Kari**	**Mari**	**Jeanette**	**Stine**	**Lene**	**Ina**	**Marianne**
Age	80	72	66	50	40	25	25	20
Group	1	1	2	2	2	3	3	3

As the groups then ended up being on the smaller side, I decided not to bring a co-moderator, as I had first considered. Often, a co-moderator can be beneficial, as the extra person can be responsible for tasks such as making sure that the recording equipment works, and that the informants are feeling at ease (Tjora, 2012:124–125). The reason I still decided to conduct the interviews alone, was because I did not want the interview to feel dissuasive to the informants in any way, and I was worried that the number of moderators being almost the same as the number of informants, would have that effect. Also, it would most likely be easy to keep track of all informants in such a small group. In addition to this, I hoped and anticipated that a smaller group would help the interview take the shape of a conversation, rather than an interview with clearly defined questions and answers.

4.2.2 Individual interviews

I also met with the informants before the group interviews, to give them the texts and to get an understanding of their prerequisite knowledge about the subject. They were aware that the subject was cancer prior to the individual meetings, but I did not tell them that it was specifically breast cancer and invitation to mammographic screening. The reason was that I wanted to know their opinions based on their current level of knowledge and feared they would prepare for the meeting if they had all the information before we met. Since all the informants expressed worry about whether they knew enough to participate, despite the fact that the invitation to the interview explicitly said that no prerequisite knowledge was necessary (see appendix C), I consider withholding some of the information until we met as needed, as it gave a more correct picture of how the informational texts are perceived by average women.

4.2.3 Transcription

The questions and answers in the individual interviews were short enough for me to able to write them down (see appendix D). All three group interviews were, however, recorded and transcribed. The recordings were deleted when the transcriptions were complete. I transcribed them in bokmål to remove dialect characteristics that might have given pointers to the identity of the informants (Tjora, 2012:144), and all quotes cited here will have been translated into English by me. Everything related to the subject was transcribed in full, but I did not include some of the personal stories as they contained sensitive information about the informants' friends and family. I also did not transcribe words that indicated that the informant was thinking, or prompting other informants to keep talking, such as "Eh" and "Mhm". I did however include "Mhm" and "Mm" if these words indicated that the person agreed with the others. The reason I did not include words that suggested that the informants were hesitating or temporarily stopped talking, was because the subject was not sensitive, and I felt it was unlikely that these pauses had any underlying meaning.

The recordings of the interviews were mostly good, and in interview 1 and 2 I could easily hear everything that was being said. Transcribing interview 3, however, turned out to be more problematic, as the informants and myself were all the same age and had very similar voices. This meant that if two or more people spoke at the same time, it was virtually impossible for me to hear who was speaking. This was especially the case if one informant stated something and the others expressed agreement by saying "Yes", "No", and "Mm" or "Mhm". Because of this, I am in some instances unsure whether there was an agreement between some or all of the informants, and might have misjudged the level of consensus within the group.

4.3 INTERVIEW WITH BREASTSCREEN NORWAY

I wanted to see if there was a correlation between what BreastScreen Norway wishes to obtain by the information they distribute, and how women perceive the information. Therefore, I decided to talk to someone at BreastScreen Norway about the process of writing and designing the layout for invitations and written information. I also wanted to see if they were aware of the potential difficulty of writing a text that would have to reach such a varied group of people, and how they work to make the information equally accessible for all.

My initial contact with BreastScreen Norway was with the purpose of accessing older versions of the invitation to screening. In this connection, I was also able to arrange an interview with the leader of the program and the adviser that has the daily responsibility for the information materials. Originally, they were to be interviewed separately, and so the interview guides were made partly with their specific positions in mind. However, at arrival the representatives wished to be interviewed together, and so I decided to mainly ask the more general questions about BreastScreen Norway's work. As the thesis focuses on the work of the organization, the individual questions were of lesser importance, and the last-minute changes most likely did not affect the results discussed here significantly. If anything, interviewing the representatives together was beneficial, as they were able to give input on each other's statements, which gave me extended information about the subjects (Tjora, 2012:123). Had the subject been of a more sensitive nature, interviewing the representatives together might have led to one or both holding some information back, but as they were talking on behalf of their place of work, I find this unlikely. The interview was transcribed in full, but I left out names and conversations with third parties. The recording was deleted when the transcription was complete. The representatives have not been made anonymous, as they speak on behalf of their named place of work. They are aware of this and have given their consent. Still, they have not been named, as they have not given their personal opinions on the subject. The representatives have read through the results from the interview to assure that I have portrayed the program in a manner that is accurate. Some alterations have been made to the results, due to some misunderstandings on my part during the interview, mainly about the composition of the group responsible for the most resent invitation revision. Any thoughts or conclusions that are stated here beyond those listed in the results, are made by me, and BreastScreen Norway cannot be held accountable.

4.4 LIMITATIONS

As the focus groups that I conducted were small, there is a limitation to how representative these groups are of the Norwegian female population. I also based the group interviews solely on subjective opinions, and since these can vary greatly, it is not possible to generalize my informant's viewpoint about the texts to such an extent that I can say something about the national attitude towards them. I will however refer to my informants' opinions as the opinions of the majority of Norwegian women in my discussion. This is due to them being in accordance with results from focus groups conducted by BreastScreen Norway, as I will get back to when presenting the results from the interview with their representatives. BreastScreen Norway's focus groups were larger, and therefore more representative. Another limitation with my group interviews, was that I had decided not to ask sensitive questions, mainly because I thought it would make recruitment easier. As I have mentioned, I wanted to interview women of varying background, but in an effort not to ask them questions they could perceive as too personal, I did not ask background-questions. Because of this, I do not know the informants' SES, but since my main objective is not directly linked to their status, I still consider the results from the group interviews useful.

It seemed clear to me during the group interviews that most of the informants had an above average interest in women's health, and that they were all very positive towards a public mammography program. This was also the case for the informants in BreastScreen Norway's focus groups and it might have coloured the women's opinions of the texts. It is also possible that my own positive feelings towards a public program affected the way I asked questions both in the groups interviews, and the interview with the representatives from BreastScreen Norway.

During the transcription of the group interviews, I noticed a pattern in how often the informants in the two groups of three spoke. The person who sat right across the table from me spoke far more than the other informants, while the person sitting next to me said far less. I am unsure whether this was coincidental. If not, a possible explanation could be that I unconsciously tended to direct my questions to the person sitting right in front of me, rather than to the person I had to turn to look at. If this was the case, the results from these interviews could be missing some of the thoughts of the informants who sat next to me, rather than across from me. Also, the way I conducted the interview with the first group was slightly different from the other two. In group 1, they went back and forth between the texts when talking about them, and I noticed that this was inefficient, and that it was difficult for the informants to keep track of what we had talked about and not. Therefore, in the following group interviews, I made sure to talk about one text at a time. The informants in interview 2 and 3 went more into detail, and this might be because the structure of the interview allowed it to a larger extent than the structure of the first group interview did.

Chapter 5

5 RESULTS

In this chapter, I will present the results from my interviews. As the group interviews were conducted before the interview with the representatives from BreastScreen Norway, these will be presented first. The results are sorted by theme based on the text analysis, rather than by groups, and so the results from the different group interviews will be referred together. Details and statements from the group interviews were later used in the conversation with BreastScreen Norway's representatives. As a reminder to the reader, text 1 is the oldest invitation with an added information brochure (appendix A). Text 2 is the invitation that is currently distributed, with an added fact sheet (appendix B).

5.1 GROUP INTERVIEWS

5.1.1 Prerequisite knowledge of breast cancer

As mentioned, I asked to meet the informants individually one to three days prior to the group interview. During the individual interviews, I asked the informants about their knowledge about the program and breast cancer in general. The aim was to get an impression about the level of knowledge each of them had, and whether this would affect their impressions of the texts that they were given. Not surprisingly, all informants had heard about the program, and the women who were within the target group or older knew more details than the women who were younger. What did surprise me, however, was the how difficult the women found listing what they thought were the potential risk factors for breast cancer. The two oldest informants quite easily listed general risk factors for cancer and bad health, such as inactivity, poor diet, smoking, and substance abuse. At first, the remaining informants struggled to list any factors at all. Jeanette and Stine mentioned poor diet, while Marianne suggested radiation and excessive sunbathing. Lene mentioned environmental factors, while Ina and Stine said genetics. Mari felt it was purely coincidental, and said it was more a matter of who had pulled the shortest straw.

Although all participants listed some risk factors when asked, it seemed to me during the groups interviews that especially the informants in group 2 perceived breast cancer to be somewhat of an unstoppable force. For example, this group suspected that the number of women diagnosed with breast cancer were higher than 2 out of 1000 and thought a possible explanation could be that the remaining women diagnosed probably found the cancer through self-examination, and therefore were not included in the statistics listed in the fact sheet. Group 2 also, unlike group 1, saw no reason to mention risk factors. While group 1 thought that the risk factors still relevant for the target group should be listed in the information, group 2 thought a list of risk factors would change very little. In fact, they worried that listing them might stop women from going to the appointment. Their reasoning was that women might avoid going if they felt they had not lived a healthy life and worried about being judged or told to change their lifestyle by the health personnel.

5.1.2 Informativity and language

All informants agreed that both texts seemed to the point and focused on the subject at hand, and that they largely were provided with the information they needed. Group 2 and 3 did, however, show quite a bit of concern for the groups of women who for various reasons are not as strong readers as the informants felt themselves to be. Lene based her worries on statistics she had heard of that indicated that one in four adult Norwegian struggles to attain information through text. The groups especially thought that the fact sheet sent out with the most recent invitation would be troublesome for people who are not used to reading extensive and formal texts, and feared that these women might miss out on important pieces of information because of the length and choice of words. They underlined the importance of hiring outside writers to help prepare a text that is easily accessible to all groups.

Some of the informants also felt that the language in the texts was a strange mixture between too formal and not formal enough. Lene said that she perceived the most recent invitation as so informal, that if she were to receive it she would have double checked if this was a serious program. She would much rather that it was made clear early that the national health system supports the program. Group 2 was not happy about the use of the expression “ha glede av” (enjoy or appreciate) in the second invitation. The sentence was something akin to “We would like you to let us know if you will not attend, as others might appreciate your appointment.” Stine pointed out that women will hardly enjoy a scan, and the group agreed that they would rather use a word meaning benefit or utilize. Jeanette and Lene also wanted to replace the word "invitasjon" with "innkalling", as the word invitation gave them the association of being invited to something nice. They felt that the word "innkalling" (notice of attendance) would make it more likely that women would attend the pre-set appointment, and their groups agreed.

Although some words and phrases felt too informal, the invitations also gave group 2 a feeling of a top-down approach. They did not like the use of the word "bør" (should) in the oldest invitation, as it felt like they were being told what to do. They also did not appreciate how some of the information in the current invitation was made to sound like the women needed to adhere to the employee's needs. For example, the invitation urges the women to not wear perfume one the day of their appointment, as this can cause allergic reactions with the staff. The group felt that asking the women to not wear perfume was fair, but why did only the staff's allergies matter? It could just as easily be relevant for patients and other people in the hospital. All groups also agreed that although this kind of information needed to be formal to be taken seriously, the invitation and information could be directed more towards the women's feelings. The informants felt that is was more likely that the women invited would go if they felt that this was relevant to them and their futures, and that the people who work in the program genuinely care about their well-being.

Kari: *"[...] Give people a feeling of safety in this, to show up, that is the whole point. And then you need the sort of information that makes people feel at ease, right. [...] I have been noticed, in a way, and, and taken care of. That is important in this program, I think."*

5.1.3 Amount and type of information

The informants in group 2 and 3 made it clear that there is such a thing as too much information. They felt that the fact sheet sent out with the current invitation was so crammed with information that it was difficult to see the forest for the trees. Because of this, five out of eight informants preferred the information brochure to the fact sheet. A sixth preferred the fact sheet because it was digital, but said she would have liked it to be significantly shorter. Only the informants in group 1 thought the length of the fact sheet was fine as is, and would not have minded some extensive information, although Bjørg would have cut some excessive words here and there. Lene explained that one of the problems with long texts is that people tend to think that they will read it later, but then they never do.

Lene: *“[...] I notice it in myself, if I receive an email with a web page that I am supposed to go into, [...] I would have thought ‘Oh, great, there is a lot of information, but I don’t have time to read this right now’.”*

When asked what they would have cut to make the fact sheet shorter, both group 2 and 3 said they would significantly reduce the part about overdiagnosis. They did not understand why it needed to be repeated three times in a two pages long text. When I explained that I suspected that it was because the program had received critique when they only mentioned it briefly, Stine protested:

Stine: *“It is probably not a lot of critique, it’s probably about three physicians that are talking loudly, and then it’s called a big critique because a couple of magazines traded two articles, and then all of us have to suffer for it.”*

Group 2 would have cut the part about overdiagnosis altogether, while group 3 felt that it could have been possible to make an information page about it on the Registry’s website, and then link to it in the fact sheet, so that those who were interested could read more. Group 2 also mentioned this as an option, if cutting it out completely was not possible. When asked why they did not feel the need to include it, group 2 explained that they did not feel like it was their job to consider how difficult or easy it is to decide whether a tumour is benign or malignant. Part of the reason they would go to an appointment, would be for a professional to make that decision. Lene and Stine also pointed out that the risk of overdiagnosis or incorrect treatment is present in most areas of health care, particularly preventive programs, and they did not understand why it had to be emphasized more for mammography scans than other programs and procedures.

While group 1 would have liked more information about the possible feeling of anxiousness and restlessness, the two other groups would not mind if that was cut all together. They felt that writing about it would make women worried, rather than addressing it in a helpful way. If it were to be kept in the information, group 2 would have included contact information to someone the worried women could talk to, but they felt that just stating that the feelings could appear would do more harm than good. Lene, who was in her mid-twenties at the time of the interview, felt this might be more the case for the generation that is in the target group now, than it would be for her own generation.

Lene: *[... T]ake the difference between my me and my mother, for example, [...] she is in a way in the generation above me, and have maybe been the sort of generation [where these] kinds of programs and stuff aren't normal. While we are raised in a generation where we get these sort of things thrown at us, and we are more used to just carrying it out. [...] While for my mother, I think that she would, if it was shoved in her face that she might feel anxiousness and restlessness, then she would feel anxiousness and restlessness."*

There were also elements of text 2 that group 2 and 3 appreciated. For example, group 2 thought the part regarding biopsy was very informative. They also liked the first page of the invitation. Group 3 liked the part of the fact sheet where the fact that some women feel discomfort during the screening is addressed. They thought it would help the women to be mentally prepared, and to know that the pain is common and harmless.

5.1.4 Visible agent

When asked if they felt the sender of the invitation was apparent, five out of eight informants said yes straight away. Mari said she had not thought about who the sender was, and Jeanette and Marianne felt it might be beneficial if the sender was made clearer. Marianne suggested to do this by using more logos on the first page, as people often associate trust with for example the logo of the Norwegian Cancer Society, who were listed as a collaborator in the information brochure. She pointed out that a lot of people will not have seen the logo of BreastScreen Norway before. Even though it seemed that the informants felt they knew where the information came from, it did not seem like they were completely sure during the interviews. When referring to the sender, they mentioned the Cancer Society, the municipalities, the state, and the health care system, but no one referred to the Cancer Registry of Norway or BreastScreen Norway other than when I asked about the sender directly. A couple of the informants did mention that it might be helpful with some very short facts about the program to help establish it as a program that people can trust. These facts should include when and why the program started, and how many women have attended since the start. Marianne also mentioned that she felt it was unclear where the statistics and facts came from and would have liked to see some sources.

5.1.5 Layout, pictures, and illustrations

None of the informants liked the layout of the oldest invitation, as they felt it was compact and that it was difficult to skim if they were looking for specific information. They all, however, liked the information brochure included with the invitation. They felt it was timeless, and six out of eight were very vocal about how much they liked the pictures. The remaining two did not mind them, but would not have missed them too much if they were not included. The reason why the pictures were so well received, was partly because they made the text feel easier to read, partly because they showed a woman during a scan, which the informants felt was a good idea, and partly because they liked the pictures in and of themselves. They appreciated how the pictures showed a healthy woman with healthy breasts. If they were to change something, they might have included a variation of women, with different ages, breast shapes, and ethnicity, but they would still have been topless and smiling in the pictures.

The informants liked the first impression that text 2 gave. A couple mentioned the use of colours, and how some words and sentences were highlighted as positive elements. Group 2 and 3 also seemed positive towards the use of small illustrations that showed what the information was about, for example a credit card next to the information about payment. They did point out that it was sometimes difficult to understand in which order they were meant to read the text on the first page of the fact sheet. The informants were also split when it came to the illustration that showed how many out of 1000 women who would be asked to come back for further examination, and how many of them would need treatment. Three of the informants thought it would calm them down to see that very few have cancer, and that to be called back for further examination does not necessarily mean that you are sick. One informant felt the illustration was unclear. She and the remaining four informants also thought it could have the opposite effect of what the sender wanted. They thought that when women see that the scan rarely uncovers cancer, then they might not bother to go.

5.1.6 Potential for improvements

All the groups were asked what the invitation and additional information would look like if they were to make them. Group 1 were quite happy with the second text and would have used that with a few additions. Firstly, they would have included a picture of a woman at a mammography scan, and a woman demonstrating self-examination with an explanatory caption. Secondly, they would devote more space to talking about feelings of restlessness and anxiousness. Here, they differ from the two other groups. A possible explanation for the difference in opinions, is that Kari herself had experienced a lot of uneasiness after her first scan, so much so that she never attended another. She explained that it was largely caused by a fear of getting the results back and finding out she had cancer. She thought that more detailed information about how to handle such fears might help women like her to show up. Lastly, they would have included more information about how women can help prevent sickness, such as information about relevant risk factors.

When asked which text they preferred, group 2 said that if they had to choose one, they would pick text 1, but they would have the material in the brochure put into the covers of text 2. It seemed that they in general liked the design, and layout of the second text. What they disliked about it, was the amount of text and lack of pictures. If it were up to them, they would make sure to phrase the text differently, with the aim to be perceived as serious and straight to the point, but at the same time as a program that genuinely care about women's health and wellbeing. The group felt that a lot of the second text was more interesting for health personnel than it would be for the average woman, like the part about overdiagnosis, while it could do with more information about how to prepare for the appointment.

Stine: *"[...] They don't have to explain the underlying factors, I want to know when the bus will be leaving, not how it functions."*

The second group would have replaced the illustration of statistics concerning breast cancer with pictures of various healthy, topless women. This group would also exclude information about what happens after someone is diagnosed, as this is the next chapter, and should have its own fact sheet. The group would, however, include more about preventive self-examination. They suggested including a link to a video where it is demonstrated, and also to include an attachment that they had seen used before. This was a little sign that worked as a reminder to self-exam regularly, and it was waterproof so that women could place it in their showers. The group said that they would have made sure to use people who specialized in layout design and writing, as to get a text with the best possible quality. The group would also have made separate information for some of the largest immigration groups. They felt a direct translation into English would benefit some groups, but might not suffice for the immigrants with minimal education, and who come from countries that have health care systems that are largely different from our own. They expressed surprise when I told them no such adapted version exists.

Mari: *"[…] I took it for granted, that there would be information in Urdu […], Arabic, I mean, texts that are made specifically."*

In group 3, two of the informants answered that they preferred text 1, while the last one preferred text 2, as she likes to receive information online. When asked what their ideal texts would look like, it turned out that the two who preferred text 1, would not mind if the text had the layout of text 2 and was sent online, but that it's content should be more like text 1. By that they meant less text and more pictures. The sentences should be easy to read and to the point. The group also underlined the need to phrase information that might worry some women in such a way that is has a positive angle. A good example of this was "Women with small tumours that have not spread, have very good living prospects". Like group 2, group 3 also felt it was important to find the balance between a text that seems serious and professional, but at the same time personal. Group 3 would have liked to see the information in a more chronological order. To them, most of the information on the last page of the fact sheet should have come earlier. For example, information about why you are receiving an invitation, and how the appointment will take place should come before the part about overdiagnosis. Also, they thought information about where to find the English version should be at the top of the first page, as a person who does not speak Norwegian is unlikely to leaf through the whole text. They felt that a chronological order would give the text a better flow and make specific information easier to find. Lene and Marianne could have done without the illustration of cancer statistics, while Ina found it reassuring. They would all have liked to see some pictures, mainly from a mammography scan, so that women who are new to the program can see how it is performed. They would also have liked a link to a video about how to perform self-examination. The group would have kept the little illustrations of a telephone, bankcard, and so on next to the information. They would, however, exclude the part about anxiousness and restlessness, and either significantly reduce the part about overdiagnosis, or make an information page of its own that the women could choose to go to.

5.2 INTERVIEW WITH BREASTSCREEN NORWAY

5.2.1 Layout, pictures, and illustrations

The representatives from BreastScreen Norway were able to answer the questions asked by the informants in my interviews. They explained that they had themselves had five focus groups in 2015 and 2016, and that most of what my informants had commented on or suggested, had also come up in their groups. The women in the program's focus groups read drafts of the invitation used today, which was altered as a result of the feedback before it was distributed, although some elements could not be changed. The fact that the format of a brochure appealed to my informants, did not come as a surprise to the program's representatives. One of them explained that they would have liked to keep the format, including pictures, but it has been made difficult because of secure digital mail. The current invitation had to be adapted so that it could be sent in the format of digital mail, and this means that the size of the file cannot exceed 100 kilobytes, which greatly limits the use of pictures, and the text will not be in a brochure format. It is possible to send bigger files, but it costs more, and is not in BreastScreen Norway's budget. The changes that had to be made because of digital post, also affected who made the invitation that is used today. Usually, they hire outside graphic designers to help make the invitations, but since the need for a revision of the invitation came around the same time as the implementation of digital mail, they ended up doing it in-house. Although some of the employees involved in the revision had experience with graphic design, the program felt it was not entirely successful, and since there is an ongoing upgrade of the Cancer Registry's graphic profile, the plan is to change the invitation so that the graphic design is consistent throughout the Registry.

The representatives also explained that the reason they currently only distribute text-based information, even though they know videos, pictures, and drawings are recommended, is that they do not have the budget. They are hoping to make information videos in the future, and are planning to adapt some videos that one of the representatives has made for educational purposes, so that these can be published on their website.

5.2.2 Informativity and language

The revision of the current text was done by a project group at the Cancer Registry. They also invited six professionals with expertise in different important fields to give input on the drafts, as well as professionals from the breast clinics. None of the external people involved were writers by profession or had a background in communication of health information, as my informants thought would be useful, but when finalising the information, the project group involved a colleague at the Cancer Registry with a journalistic background. One of the representatives explained that they had tried to use a professional writer when making information material during the first years of the program's existence, but that the text ended up being so oversimplified that it was no longer accurate. Since the program's task is not to sell the idea of going to a screening, but rather to inform women that they have the opportunity, the simplified text could not be used. Nevertheless, the project group did benefit from the external experts, in addition to the focus groups, in the efforts to make the text as accessible as possible. One expert was, for example, specialized in communicating statistics to non-statisticians.

Representative 1: *"We have been very conscious of trying to unite subject and recipient. And one might disagree whether it has been successful or not, but we have consciously worked to achieve it."*

One of the representatives also explained that the reason why they have not made texts specially for non-Western immigration groups, is because they do not have the resources or adequate knowledge to adapt the invitation in the best way possible. They are aware that it would be beneficial, and as a step in the direction of making adapted invitations, they started a PhD project on the subject that will end in 2019. The project tries to uncover some of the health barriers that might be the cause of low participation among one of the immigration groups known to rarely attend.

The program consciously avoids using the words "innkalling" or "invitation", which were discussed by some of my informants. As with my informants, some of the women in the program's focus groups disliked the use of the word invitation because it gave the wrong associations. They would have preferred to receive a notice of attendance, but the program avoids this because it indicates that the woman must go to the pre-set appointment. The Swedish program tried to use the Swedish word for offer, but had to change it as the women had a more sale-related association with the word, which raised the question of whether the appointment came with the possibility of a bargain. The program therefore feels that asking women if they want to attend is a better solution than using any of the three suggested words.

My informants seemed to think that a text that played on the reader’s emotions would make her more likely to attend a screening. My impression was that the representatives agreed with this, but that they did not play on emotion because it gives the impression that the text is a sales pitch. They avoid this for the same reason they did not use the simplified version of the text; it is not their job to sell the program, but rather to give women all the necessary information that they need to make a conscious decision. Still, they sometimes felt there was a dilemma between the wish to advice women in accordance with European and Norwegian guidelines, which recommend screening, and at the same time provide the women with information that is presented in a neutral fashion. They felt that they could easily have written a more positive text, but both the program and their critics find that giving the women the opportunity to make an informed decision is the best way to go. The program’s critics are generally part of a small, but significant academic community that in Norway are mainly represented by a handful of researchers. Still, their opinions hold a lot of weight, partly because they actively use the media as an information channel, and therefore reach a large group of people. The program also experience critique from the professionals at the breast clinics if the facts in the texts are not phrased precise enough to be accurate from a medical point of view. One of the representatives explained that because of all the different perceptions of what can be considered correct information, it is virtually impossible to make texts that pleases all parties.

Representative 2: *“Who are the ones who claim the right to define what is the correct information in accordance with the role that we hold? No matter who is holding a role, [the role] will be affected by the ones holding it.”*

5.2.3 Visible agent

The representatives from the program did not seem surprised when I mentioned that my informants tended to get the sender of the invitation mixed up with other organisations or health care services. In their experience, this was quite common, and the sender was often assumed by the women to be the Norwegian Cancer Society. They explained that the reason that they had a list of co-operators in the brochure from 1995, but no mention of any in 2017, was because the start-up of the program was a cooperation. This has changed over the years, and since 2016 the Cancer Registry assumed full responsibility for the administration of it. They sometimes have collaborations with for example the Cancer Society, but mostly they work on their own.

When asked if their impression was that the information they send reaches the intended receivers, the representatives answered that they felt it did not reach as many as they would have liked. According to staff at the screening clinics, many women seem to not have read the information properly when they show up for their appointment. This has not only been the case with the current information, but also the previous versions. The program considers it a priority to make invitations and information in such a way that increases the likelihood that they will be read. As of now, they think that it is likely that most women, despite the wishes of BreastScreen Norway, base their decision on other sources than the information that the program distributes. These sources are most likely friends, family, and the media. Some might also attend their appointment because of what might be considered a strong trust in the official health system. This trust might, however, play out differently in different groups in the society. It is, for example, thought to be a possible explanation for why immigrant women attend more rarely. The suggestion is that if a woman comes from a country where the health system works very differently, they might not have the automatic trust in the health system's recommendation as someone raised in Norway would have.

Except from the effort to identify potential barriers that keep women from attending screening, sending invitations with prescheduled appointments, and sending out one reminder for non-attenders, the program does nothing extra to reach the women who do not attend. This is because they want to respect the women's choice to not participate. According to the representatives, approximately 85 percent of all women in the target group have attended a screening at least once, and around 5 percent have asked to not receive invitations. One of the representatives referred to research from Sweden that showed that a lot of the women who do not attend screening programs, are positive towards the existence of a program, but often do not show up because "life got in the way", and they never got around to it. The representatives seemed very understanding of this and felt that they had to look at the women's lives as a whole.

Representative 1: *"[...I]t is one of many topics that the women and people deal with in their lives in general [...]. It is not like breast cancer and prevention of it is the most important thing in life."*

5.2.4 Amount and type of information

As with most of the feedback from my informants, their thoughts on length and type of information were familiar to the representatives from the program. Women from their focus groups had also expressed that they felt they got too much information too soon and would have liked the part about overdiagnosis to be shorter. The length and amount of details in the text can, again, be explained by the expectations of professionals for the information to be precise and detailed.

Representative 2: *"[... W]e perceive that the women probably want something else than a lot of the social scientists, ethicists, and [...]carriers of opinions want us to inform them of."*

But it is also worth mentioning that a part of the reason why the brochure from 1995 could be as short as it was, was because it was written at a time where there was no requirement for the program to ensure that women could make an informed decision. This became a requirement when there was a change in how the women are defined while they attend screening. Today, they are considered patients, and are thereby covered by the law about patient and user rights (Pasient- og brukerrettighetsloven). Because of this, the program is required to inform the patients of the main pros and cons with screening. One of the representatives explained that the cons, such as overdiagnosis, quite easily become the dominant part of the information texts, as they are unknown terms for the average reader, and therefore need to be explained more thoroughly. The pros, on the other hand, are often easily explained. For example, there is no need to explain why increasing the chances of survival is positive, and so it can be mentioned in just one sentence. The program is also required to give information about the Privacy Policy, as details from the screening results are logged by the Registry unless the woman uses her reservation rights. The length of the texts is, in addition to this, also caused by a steady increase in knowledge about breast cancer and the effect of a population program.

In an effort to make the text as short as possible, but at the same time give women access to all the information available, the program tries to keep their webpage updated at all times. They inform the women about where they can find more information in the fact sheet. They also have a Facebook page, together with the Cervical Cancer Screening Program, where they give more current information, such as where the mobile clinic will be in the next weeks. Their experience is that the Facebook page is successful, since their posts often are shared and liked by the women following them. The program also tries to make the text more comprehensive by making sure that the information in the invitation is strictly facts about the appointment and the Privacy Policy, while the fact sheet includes the more academic information and information about practical aspects related to the screening examination. They also try to make it clear why this is something women need to read, for example through the headline that can translate into “Points to consider”. By this, they try to show that the women actually have to consider whether they want to attend or not.

When I mentioned that the only thing my informants agreed could be written about more extensively, was self-examination, the representatives explained that there is currently very little evidence that self-examination reduces mortality rates. According to the literature, self-examination can be quite stressful for women because they find it difficult to separate normal hormonal changes in the breasts from more alarming changes. Therefore, the program does not recommend regular self-examination, but instead urges women to contact their doctor if they discover changes unrelated to menstrual changes. In general, the program wanted to keep the women informed, but not worry them unnecessarily. When I explained that some of my informants thought it likely that mentioning anxiousness and restlessness might make women anxious and restless, it seemed to be a dilemma. On one hand they did not want to create unnecessary worry among 600 000 women every other year, but on the other hand some women, as a couple of the informants also mentioned, might become anxious either way, but feel relieved when they see that the uneasy feelings are common. Also, informing the women of potential risk factors is necessary when the goal is to help them make informed decisions.

5.2.5 Potential for improvements

The representatives for the program explained that they constantly try to improve. In addition to the focus groups, they have also given out questionnaires to women who have recently attended, and they conduct varied research projects. They did, however, describe problems in recruiting that were quite similar to the ones that I experienced myself. Most women they contacted never responded at all, and those who did want to attend tended to have above average positive interest in the program. One of the representatives gave an example where they had asked women who had just been screened whether they were happy with the information they received. She jokingly compared the results to the results of a corrupt election; almost all of the women said that they were satisfied. The representatives underlined that the research they did was not done to exclusively emphasis the pros of a screening program. If there are ever research results that might tip the scale in favour of ending the program, these results will be published, and the program's future will be considered by a neutral part. This was last done in 2015, and it was concluded that the program should continue.

As mentioned, most of the feedback regarding the current text were familiar to the representatives, but as I had asked my informants to compare the text from 1995 with the text from 2017, there were also some comments that were new. For example, the representatives did not know that the pictures from the oldest text were so well-liked and would consider putting similar pictures up on their webpage. They also seemed to think that Lene had a point when she said that it might be useful to make brochures that younger people would consider reading, because if women hear and read information about the program throughout their lives, they might be more likely to take an informed decision when they reach the right age.

Chapter 6

6 DISCUSSION

The overall objective of my thesis was to consider whether variations in the understanding of terms and concepts can affect the transmission of health-related knowledge. More specifically, I wanted to see whether what BreastScreen Norway hope to convey through the distribution of information, is in accordance with how the women actually perceive it. To answer two of my research questions, I conducted three group interviews with women of different ages where they were given the opportunity to talk about their thoughts on the texts, as well as an interview with representatives from BreastScreen Norway to see what their aim is when they distribute these texts. I expected to find that the program's wishes and the women's perception were not in full agreement. My suspicion was reinforced after the group interviews, as the women had been critical towards the texts, although positive towards the program. The women felt that the invitations gave them more information than they felt they had time to or interest in dealing with. Prior to the interview with the representatives from BreastScreen Norway, I therefore expected to meet an organization that does not fully understand the needs of the average women in their target group. Instead I met representatives who were very understanding of both the women's wishes and needs, and who recognized that mammographic screens are far from the most pressing thing on the average woman's to-do list. But despite their insight in the women's everyday lives, they were unable to adapt their information according to some of the women's suggestions. In the following discussion I will go into further detail of why this might be the case, and I will do so through the use of the theories introduced in this thesis.

I consider my findings to be the following: Firstly, the women seemed to associate different things with key words, such as the Norwegian words for invitation and notice of attendance. Secondly, they wanted short and easy-to-read texts with pictures, not only because the information would be more accessible, but also because they did not want to spend more time on the text than what was absolutely necessary. Thirdly, my text analysis indicated that the sender was apparent, but the women seemed to forget who the sender was, and BreastScreen

Norway considered this a common problem. A fourth finding was that the women considered the second text to be almost too informative and factual, and would rather have a text that mainly told them the appointment time and how to prepare, and that had a larger degree of acknowledgement of the more personal aspects of screening. And lastly, BreastScreen Norway seemed to be very aware of what the majority of women wish for in the information they distribute, but due to the law about patient rights, economic restrictions, and the consideration of the opinions of their colleagues and critics, they are not able to give the women what they want.

I would like to note that in the following discussion, institutional theory is mainly used to describe potential limitations to BreastScreen Norway's work, or rather how the organization is prevented from fulfilling all the wishes of the women in the target group. Institutional theory has a well-developed conceptualization of the pressures from the institutional environment that is working on organizations, which may help us to appreciate the mechanisms involved. It has, however, received critique for not showing enough of an understanding for the fact that institutions are products of human action, and not just limitations for them (Powell and DiMaggio, 1991, as cited in Håland, 2008:22). Had I included different theories in this thesis, the enabling surroundings of an organization such as BreastScreen Norway might have been more apparent.

The theory of fundamental causes is not without its flaws either. Although the theory provides several terms and concepts that I find useful when describing social inequalities in health, they do explain health inequalities in terms of other inequalities. As have been pointed out by critics, this can be a way of reformulating the problem without coming any closer to specifying pathways and mechanisms that explain the health gradient (Øversveen *et al.*, 2017:106). In the case of my thesis, the use of this theory has helped describe the correlation between health-related knowledge and behaviour, but it has not explained the underlying factors that might explain inequalities in breast cancer mortality. Had this been within the scope of my thesis, it would have been beneficial to consider a different theory, also because the theory of fundamental causes does not cover the potentially reversed causation of SES and health, where health issues can prevent a person from completing an education or keeping a job (Strand, Steingrimsdottir, and Grøholt, 2018). An alternative theory could be the previously mentioned socio-ecological model, which focuses on social determinants in health, and also on health promotion in organizations (Sallis, Owen and Fisher, 2014).

6.1 DO THE WOMEN PERCEIVE THE TEXTS AS ACCESSIBLE?

It seemed clear to me that choice of words mattered to my informants. All three groups spent a significant amount of time discussing word associations, redundant words, and words they would have liked to replace. Two of the groups seemed to find the introduction of term overdiagnosis particularly unnecessary. Although their goal of cutting or replacing words always was to make the text feel more clear and easy to read, it seemed to me that the informants felt the words they did not care for were annoyances, rather than something that would hinder their understanding of the texts. Also, their opinions sometimes varied significantly. In addition to this, I perceived the women to be strong readers, and some of them also described themselves as such. Their opinions might therefore not be representative to women with less experience in reading extensive texts. I therefore feel that the results submitted in this thesis do not give a clear indication of whether words and concepts affect the transmission of knowledge about mammographic screening in Norway.

The reason I decided to include women with ages outside of the mammography program's target group, was because I wanted to see whether the women who the texts were meant for would perceive them differently than the others. It seemed that among my informants, prerequisite knowledge about the program was age dependent. This was, however, the only thing that was clearly differed between age groups. The knowledge about breast cancer specific risk factors was low among all the informants. The general understanding of the texts seemed to be quite similar, though the two eldest informants did not find extensive information as problematic. This might be due to age or be affected by the fact that the first interview was conducted differently than the other group interviews, but could also be due to Kari's experience with anxiousness and restlessness. Another explanation might be that one of the main reasons the younger informants preferred the shorter versions, was because they did not feel like they had time to read the longer ones. Since the two eldest informants were above the age of retirement, they might feel like they have more time on their hands to read such texts. The younger informants' need for less time-consuming texts, could be considered in accordance with the research referred to by one of the representatives, where Swedish women had stated that they sometimes did not attend screening because “life got in the way”. This might also be the case with reading the information, something Lene also pointed out, as the women might plan to read it, but never get around to it.

The women wanted invitations and information that was to the point, visually pleasing, short, and easy to skim through to find the specific information they were looking for. My informants, in accordance with the informants from BreastScreen Norway’s focus groups, felt that they received the information they needed, but that they also got more information than necessary. They wanted the practical information, such as the date for their appointment and how to prepare. Despite this, a significant amount of the information they did receive would never concern them, as it was only relevant for women who were called in for a follow-up or who were diagnosed with cancer. The women felt that this information should be sent out to those it concerned, rather than to everyone. As mentioned, information about follow-up and diagnosis is included mainly due to the rights that women have as patients while they are attending screening (Pasient- og brukerrettighetsloven, 2018). This could be viewed as an example that people do not always appreciate the increased use of medical terminology in today’s society, as it is the result of defining the women as patients despite most of them being healthy (Lian, 2012:49). Some of my informants also felt the texts had a certain top-down approach, and did not seem to appreciate the feeling that someone higher up in the system were telling them what to do. Instead, several of my informants would have preferred if the texts gave them a feeling that the Norwegian health care system genuinely cares about their well-being. It might seem like they wish for an active, positive, soft paternalism when it comes to the informational texts, where the health care system gently encourages people to attend screening by promoting what is considered the elements that will do the women good. This is a contrast to what is often considered the form of paternalism that is, as previously mentioned, most easily justified; the negative and passive approach (Dahl, Bergsli, and van der Wel, 2014:34–35).

My informants seemed to feel that the texts were accessible to them, but were worried for those who were not as strong readers as they felt themselves to be. They thought it likely that the texts would be difficult to read for those who are not used to reading extensive texts, and for immigrants who do not read Norwegian well. A suggested solution was to adapt the information with immigrants in mind, which the representatives seemed to think would happen sometime in the future. Another suggested solution was to take advantage of the fact that the invitation can now be sent online, and link to separate sites with extensive information about subjects such as overdiagnosis, as such sites would help make the texts that the women receive shorter. This might, however, not reduce potential inequalities in knowledge utilization, as were the informants' goal. Firstly, the invitation is both distributed by post and digital mail, as some women in the current target group are not familiar with digital mail, and perhaps not particularly comfortable with the use of online services in general. Women in future target groups might be more susceptible to this solution than the current one is, as they are more adept in the use of such services. Secondly, increased knowledge could in theory help people who have less of the favourable determinants in health, such as an extensive social network, to access the same information as those with several positive determinants (Øversveen *et al.*, 2017:103–104). This would be beneficial, as both knowledge and beneficial social connections are in the fundamental cause theory considered to be flexible resources that directly shape individual health behaviours (Phelan and Link, 2005). But, as previously mentioned, there is also thought to be link between self-efficacy, empowerment, and knowledge utilization (Rimal, 2000:221). As empowerment refers to the ability to mobilize resources, and low SES people tend to have reduced feelings of empowerment, they might not consider seeking out the extended information available at all (Sørensen *et al.*, 2002). And since they also tend to have less flexible resources, the result could be that information distribution through a combination of invitations and online links, might largely benefit those with strong feelings of self-efficacy and empowerment, and who have several flexible resources.

6.2 BREASTSCREEN NORWAY'S MANDATE AND LIMITATIONS

As we have seen, reducing inequalities in health-related behaviour and utilization of health services is a part of Norway's national strategy, and as such public mammography programs are examples of how medicine reflects the culture and politics of its time. Mammographic screens are what Link and Phelan refer to as intervening mechanisms, and negative health-related behaviour such as over-eating is an example of contextualizing risk factors, which can put people at risk of risks (Link and Phelan, 1995:81; Phelan, Link and Tehranifar, 2010:29). As previously mentioned, BreastScreen Norway seems to have taken on a soft paternalism approach in their role as an information provider, although the representatives never defined it as such. It can still be viewed as a fitting description for their approach, since they do not try to reach non-attenders after sending them one invitation and one reminder, and this shows how they view the women as competent enough to make choices about their own lives. This approach does not, however, give the women free reins to pick and choose what information they want. My informants wanted more information about self-examination, and this seemed to be a wish that the representatives in BreastScreen Norway had heard before. But in this case, they would not give the women this information as there is currently very little evidence that self-examination reduces mortality rates. Including information about this would, in the representatives' opinion, not improve the information, as is the aim of soft paternalism (Dahl, Bergsli, and van der Wel, 2014:34–35). It would also make the information longer, and possibly more difficult to read.

It is also likely that they would not include information about self-examination to maintain their reputation as precise academics. As one of the representatives mentioned, they would always receive feedback both from critics and colleagues if they wrote something that was less than accurate. This can be seen as an example of normative processes, the form of isomorphism that mainly comes from professionalization, which is defined as the fight for professional legitimacy (DiMaggio and Powell, 1983:152; Håland, 2008:21). In some cases, the representatives perceived the feedback as fair, as they all strive for information that is as correct as possible, while in other cases the gap between the women's opinions and the opinions of the professionals could feel quite frustrating, as they differed so much that it was impossible to reach a mutual agreement.

Stine's quote about the critics of the mammography program turned out to be quite spot on (see chapter 5.1.3.). When I asked the representatives who these critics were, they told me about an academic community that is considered to be significant, but the Norwegians who represent this community were so few that the representatives easily named them all. The fact that their opinions still hold so much weight, could also be an example of professionalization (DiMaggio and Powell, 1983:152; Håland, 2008:21). It is possible that the combination of professionalization and the soft paternalism approach gives greater power to the critics at the women's expense. After all, the discussion between BreastScreen Norway and its critics is not whether women should be able to make informed decisions, they all feel that this is the way to go, the question is rather what can be considered the correct type and amount of information. In the process of trying to improve this information, and at the same time maintain professional legitimacy, BreastScreen Norway seems to be put in a situation where they move away from what the target group themselves consider to be what women need. Instead, the program moves towards what some consider to be over-information, where important aspects might be lost because it drowns in the excessive information. This might be at least part of the explanation for why women do not seem to have read the information prior to their appointment. In other words, over-information could stand in the way of women's opportunity to gain resources that could have shaped their individual health behaviours in a positive manner. Considering that BreastScreen Norway's impression is that the majority of the women have not read the information properly, it is likely that those who do not read it represent both high and low SES. The consequences of not reading the information can however be greater for those with low SES, as they have less flexible resources to begin with, and could have greatly benefited from increased knowledge (Phelan and Link, 2005).

Professionalization is not the only form of isomorphism that seems to affect BreastScreen Norway's work. As mentioned, coercive isomorphism refers to formal and informal pressure from other organizations that the current organization is dependent on, in addition to the cultural expectations in the community it is a part of (DiMaggio and Powell, 1983:152; Håland, 2008:21). National laws are examples of this, and as we have seen, the scope of the informative texts distributed by BreastScreen Norway is not only regulated by their academic peers, but also by the law about patient and user rights. This law requires that anyone who is defined as a patient has the right to be informed and participate in choices made about their own health (Pasient- og brukerrettighetsloven, 2018). Institutionalism can also be considered to affect BreastScreen Norway's decision about the technology they use for the distribution of information. As we have seen, Meyer and Rowan (1977:45) considered technologies to be institutionalized myths that are binding for organizations. Updated technological systems establishes an organization as rational and modern, even if the systems are ineffective. Although the Internet could not have been included in the definition of technologies at the time of publication, the authors' view seems to be accurate for digitalization in the case of BreastScreen Norway (Meyer and Rowan, 1977:45; Håland, 2008:20). The representatives seemed to feel that the adaptations that had to be made to text 2 due to the implementation of secure digital mail had reduced the visual quality of the text. Still, adapting to the new format was considered necessary to keep up with the times, and the better versions of the available formats were too expensive. The restricted budget did seem to be another significant limitation to BreastScreen

Norway's work, and appeared to hinder the distribution of more accessible knowledge through for example pictures and videos. The lack of such accessible information might be another example of a lost opportunity for people with low SES to gain resources, and can contribute to maintaining a social gradient in health (Phelan and Link, 2005).

As previously explained, overdiagnosis can be described as a form of medicalization (Hofmann, 2017:1). For the prevention of breast cancer, medicalization can appear to be somewhat of a double-edged sword; On one hand, mammography has become an intervening mechanism that with documented results reduces breast cancer related mortality (Phelan, Link and Tehranifar, 2010:29; The Research Council of Norway, 2015). On the other hand, mammography programs entail that presumably biomedically healthy women are temporarily defined as patients, and the information they have the right to access as patients, such as information about overdiagnosis, creates a disagreement between the readers of screening-related information and the professionals. This is a disagreement that limits the work of BreastScreen Norway, as we have seen from the representatives' statements. Medicalization also means that women have to deal with a medicalized language that they might find difficult to understand. Again, this could hinder low SES individuals in attaining resources (Phelan and Link, 2005).

6.3 IS THE DISTRIBUTION OF INFORMATION REDUNDANT?

The representatives from BreastScreen Norway thought it likely that very few women based their decision about attending mammography screens mainly on the information they received, if they based it on the information at all. It seemed more likely that the women's choice was made on the basis of the advice of friends, family, and the media. One might question whether information distribution then is worth the expense, especially considering that BreastScreen Norway seems to have a limited budget available. Seen from a fundamental cause perspective, the answer is to this question is yes. Extensive social networks are, as we have seen, favourable determinants in health that are unevenly distributed in the population (Øversveen *et al.*, 2017:103–104), and we can therefore not assume that all women in the target group of the mammography program have a network that will inform them of preventive healthcare programs. Both knowledge and social networks are flexible resources, and lacking one, it would be beneficial to increase the access to the other, as these resources shape health behaviours (Phelan and Link, 2005). But if an increase in knowledge is to make up for the lack of social networks, people with low SES need to be able to utilize it. If a text feels inaccessible to the reader, it will affect their feeling of self-efficacy and empowerment, and so if information about the mammography program is to have any effect at all, BreastScreen Norway needs to make sure it is understandable to all groups of women (Rimal, 2000:221; Sørensen *et al.*, 2002). As previously shown, they are aware of this, but have difficulty achieving it within their current limitations. And so, one might conclude that the text currently does not reach the target group in accordance with BreastScreen Norway's intentions.

The women do not only seem to overlook the information, they also forget who is responsible for the running of the program. This could be another sign that the text does not properly reach the intended readers, but it also raises the question; does it matter? The intention of the information is to give the women the opportunity to make an informed decision about attending, but it is also desirable that they decide to attend, as many of them do. They might not be up to speed on the mandate of BreastScreen Norway, but they know that the program is recommended by the national healthcare system, and in many cases by people in their social networks, and this seems to be enough. Granted, BreastScreen Norway has received critique that they exploit Norwegian women's blind trust in the healthcare system, but this general trust is hardly something BreastScreen Norway can change. Breast cancer mortality among Norwegian women has been reduced since the introduction of a national program, and some might say that the end justifies the means, which in this case is exploitation of blind trust. But this again raises the question of whether distribution of information is redundant. In this case, it is more difficult to give a clear answer, as BreastScreen Norway have no definite number of how many actually read and make use of their information in the decision-making process. At the same time, trust in the healthcare system might not be evenly distributed among social groups, which means that some women possibly find research about mammographic screening important if they are to make a decision.

As we have seen, Link and Phelan have pointed out that new discoveries can add to the list of health-enhancing circumstances that those with more resources have better access to. Low SES individuals often access them eventually, but by that time, new risk factors have appeared (Phelan and Link, 2005). Still, intervening mechanisms will improve the health status in a population (Phelan, Link and Tehranifar, 2010:29), and if we look at the Norwegian mammography program in particular it seems, based on the attendance rate, to have reached the point where the majority of the population has access to it. It could therefore be possible that to attend screening is gradually becoming the norm, and this could result in information distribution to play an even smaller role in the future than it does today. This possibility can be illustrated by Lene’s quote about the difference between her and her mother. While Lene considered her mother to be easily influenced by the information because she was not used to screening programs, Lene herself, who felt that her generation has to attend screenings, take vaccines, and have health check-ups quite regularly, would just consider it to be a point of her to-do list that she needed to get out of the way. I do, however, think it is a possibility that the women find it reassuring to know that the information and research exists and is available, even if they choose not to read it, and if this is the case, the information has a purpose even if the women do not utilize it actively.

Chapter 7

7 CONCLUSION

The results submitted in this thesis do not give a clear indication of whether terms and concepts affect the transmission of health-related knowledge specifically about mammographic screening. This is because my informants seemed to find some words to be annoyances if they gave the wrong association or were very technical, but they were not described as elements that hindered understanding. Also, the selection of informants was too small and appeared to homogenous for me to able to generalize their opinions. There were some variations in knowledge and opinions between the different age groups, but this did not appear to have a significant effect on the informants' level of understanding. The informants wanted shorter texts than those distributed today, and seemed to encourage a form of knowledge distribution that could be described as following the principles of active, positive, and soft paternalism (Dahl, Bergsli, and van der Wel, 2014:34–35). They suggested reducing the length of the current invitation and fact sheet by moving the more detailed parts of the information onto dedicated sites on the Cancer Registry's webpage, as this might benefit those who are less adept readers. The link between self-efficacy, empowerment, and knowledge utilization indicates, however, that this would not help those with low SES (Rimal, 2000:221). Also, this might be less than beneficial for the women who are not as used to online services.

BreastScreen Norway seems to have taken on the paternalism approaches that the informants appreciated, as they focus on helping women make informed decisions when promoting the program (Dahl, Bergsli, and van der Wel, 2014:34–35). The restrictions that they must adhere to, can be explained by coercive and normative isomorphism, as this entails legal constraints and professionalization (DiMaggio and Powell, 1983:152; Håland, 2008:21). These constraints can potentially affect low SES individual's opportunity to obtain flexible resources by gaining knowledge that could influence their health-related behaviour, as the constraints affect the content and length of the information. This can in turn hinder the reduction of social inequality in health, which might also be the consequence of BreastScreen Norway's limited budget, as this affects the way in which they distribute information. The distribution of health-related knowledge can be perceived as beneficial from the point of view of the fundamental cause theory, though today’s text is not fully utilized in the way that is BreastScreen Norway’s intention (Phelan and Link, 2005). It is possible that information distribution about mammography screening will play an even smaller role in the future if attending screening becomes what is considered the norm, though women might still consider the access to information reassuring.

This thesis has focused on the correlation between health-related knowledge and behaviour, and social inequality has been used as an example of what the potential consequences of uneven knowledge distribution may be. A proposal for further research could be a project that focuses on how SES and health-related behaviour affects inequality in mortality rates, for example a long-term study of a larger selection of women with known socioeconomic statuses within BreastScreen Norway’s target group. Use of theories that focus less on organization’s limitations, and less on a linear and unidirectional relationship between SES and health, might lead to different points of discussion than those presented in this thesis.

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APPENDICES

APPENDIX A

Invitation (1996–1997) with attached informational brochure (1995). These were distributed together until the revision of the texts in 2003.

MAMMOGRAFI

3. januar 1996

Kari Nordmann
Storgt. 1
0101 Oslo

Invitasjon til mammografiundersøkelse

Vi har den glede å invitere alle kvinner i Akershus, Hordaland, Oslo og Rogaland som er født i 1927–1946 til mammografiundersøkelse. Dette tilbudet bør du benytte deg av. Erfaringer fra andre land viser at slike undersøkelser kan redde liv.

Tid er reservert for deg: onsdag 16. januar kl. 11.30

Sted: Fridtjof Nansens vei 15, 3. etg.

Dersom den oppsatte timen ikke passer, kan du endre tidspunkt ved å ringe mammografisenteret på tlf. 22 45 13 10 mellom kl. 10 og kl. 13.

På baksiden av dette brevet er det et enkelt spørreskjema som vi ber deg fylle ut før du møter til undersøkelsen. Videre ber vi deg betale egenandelen på kr 91 over vedlagte postgiro innen en måned. Postgiroen kan også betales i bank.

Alle opplysninger du gir vil bli behandlet i henhold til personvernloven. De som behandler opplysningene har taushetsplikt.

Dersom du er bevegelseshemmet eller har operert inn silikoninnlegg i brystene, kan du ringe rett til mammografisenteret og få tatt røntgenbildene der. Hvis du er operert for brystkreft tidligere, vennligst se den vedlagte brosjyren.

Med vennlig hilsen

Steinar Ø. Thoresen
Lege og prosjektleder

Et samarbeidsprosjekt mellom
Den Norske Kreftforening,
Kreftregisteret,
Sosial- og helsedepartementet,
Statens helseundersøkelser
og fylkene.

[redacted]

En mammografi-
undersøkelse
kan redde liv.

Bakside

Forside

Tilbud om mammografiundersøkelse

Erfaringer fra andre land viser at dødeligheten av brystkreft kan reduseres med om lag en tredjedel ved systematiske helseundersøkelser med mammografi. Åtte av ti tilfeller av brystkreft finnes hos kvinner over 50 år. Derfor inviteres du nå til mammografiundersøkelse. Tilbudet omfatter undersøkelse hver annet år, og er en forebyggende helseundersøkelse.

Hva er mammografi?

Mammografi er en røntgenundersøkelse av brystene som gjør det mulig å oppdage brystkreft på et tidlig stadium. Undersøkelsen tar kort tid og innebærer lite ubehag for de fleste kvinner. Stråledosen er svært liten og medfører ingen helserisiko.

Hvordan får du time til undersøkelse?

Sammen med denne brosjyren følger et invitasjonsbrev der det står oppgitt hvor og når du skal møte for undersøkelse. Vedlagt ligger også et spørreskjema som vi ber deg fylle ut hjemme og levere ved undersøkelsen. Personalet der du skal fotograferes kan hjelpe deg dersom det er uklarheter ved skjemaet.

Hvordan får du vite resultatet?

Røntgenbildene blir fremkalt neste dag og undersøkt av to erfarne røntgenleger. Du vil deretter få skriftlig svar om resultatet innen 14 dager.
De aller fleste vil få brev om at det ikke er påvist kreftsykdom eller andre forandringer i brystene. Disse vil om to år få invitasjon til ny undersøkelse.

Etterundersøkelse

Erfaringer fra andre land viser at om lag 1 av 20 kvinner må til etterundersøkelse. Dette kan skyldes at røntgenbildene ikke er av god nok kvalitet, eller at bildene viser forandringer som må undersøkes nærmere. I de fleste tilfeller dreier det seg om godartede forandringer som er nokså vanlige i normale bryst. Blir du innkalt til etterundersøkelse, betyr det med andre ord ikke nødvendigvis at du har brystkreft, men at det er nødvendig med flere undersøkelser. Etterundersøkelsen består av nye røntgenbilder - og eventuelt ultralyd, og andre prøver.

Selvundersøkelse

Selv om du får utført mammografiundersøkelse hvert annet år, bør du undersøke brystene dine regelmessig selv. Merker du noe unormalt, er det viktig at du kontakter lege.

Det er viktig å oppdage brystkreft tidlig

Leveutsiktene etter påvist brystkreft bestemmes hovedsakelig av svulstens størrelse og av om den har spredd seg til andre organer enn brystet. Kvinner med små svulster uten spredning har meget gode leveutsikter. Det er derfor helt avgjørende å oppdage brystkreft tidlig.

Er du operert for brystkreft?

Har du fått fjernet ett bryst på grunn av brystkreft, bes du møte til mammografiundersøkelsen for å ta bilder av det andre brystet. Hvis du er operert for brystkreft med brystbevarende operasjon, bes du ta kontakt med mammografisenteret i ditt fylke.

Tenk på fremtiden din
- benytt deg av tilbudet om
mammografiundersøkelse!

APPENDIX B

Invitation with attached fact sheet (2017). Distributed together and available online.

Vil du delta i Mammografi programmet?

I Norge får alle kvinner i alderen **50 til 69 år** automatisk tilbud om røntgenundersøkelse av brystene, såkalt mammografi screening, **hvert annet år**. Hensikten er å oppdage brystkreft i et tidlig stadium, for at færre kvinner skal dø av sykdommen. Mammografi programmet er et **offentlig tilbud** som ledes av Kreftregisteret. **Det er frivillig å delta.**

Reservert tid:

Sted:

Dersom du **ikke vil benytte tilbudet** eller vil **endre timen**:

Vi setter stor pris på beskjed dersom du ikke kommer, da kan andre ha glede av din time.

Når du skal bestemme deg for om du vil **benytte dette tilbudet**, anbefaler vi å **lese vedlagte faktaark**.

Snu arket for å lese om **betaling, reisekostnader, forberedelser og praktiske forhold** ved undersøkelsen.

Se også www.kreftregisteret.no/mammografi

Med vennlig hilsen

Solveig Hofvind

Solveig Hofvind, leder for Mammografi programmet

Vi ber deg om å ringe oss dersom du:

- Har tatt mammografi i løpet av de siste seks månedene
- Går til behandling/kontroll etter brystkreftoperasjon, og ikke har avtale med legen din om at noen av kontrollene skal gjøres i Mammografi programmet
- Er rullestolbruker, har andre funksjonshemminger eller behov for tilrettelegging

Benytt telefonnummeret på første side for nærmere avtale!

Betaling og reisekostnader

- **Pris kr.**
- Dette dekker både screeningundersøkelsen og eventuelle tilleggsundersøkelser. Beløpet inngår ikke i frikortordningen.
- Vi ser helst at du betaler med bankkort, men bankgiro er også en mulighet.
- Du må selv dekke eventuelle reisekostnader. Screeningundersøkelsen inngår ikke i ordningen for pasientreiser.

Hvordan skal du forberede deg?

- Ikke bruk talkum eller kremer i brystregionen på undersøkelsesdagen, da dette kan gjøre det vanskelig å vurdere bildene.
- Vennligst unngå parfyme, da dette kan utløse allergiske reaksjoner hos dem som utfører undersøkelsen.

Hvordan får du resultatet?

- Alle får skriftlig beskjed om resultatet.
- Vanligvis tar dette 2 – 4 uker.

Reservasjonsrett

Kreftregisteret registrerer relevante opplysninger knyttet til screeningundersøkelsen din i henhold til kreftregisterforskriften. Opplysningene brukes i planlegging og til utsendelse av invitasjoner, og i kvalitetssikring, evaluering og forskning i Mammografi programmet.
Du har rett til å reservere deg mot at personopplysningene dine (navn, adresse og fødselsnummer) knyttet til screeningundersøkelser med normalt funn lagres permanent i Kreftregisteret.

Informasjon om rettigheter, og hvordan du kan reservere deg, finner du på våre nettsider www.kreftregisteret.no/mammografi

Ønsker du ikke invitasjoner?

Gi beskjed via våre nettsider, eller ved å kontakte Kreftregisteret på tlf. 22 45 13 00 eller e-post mammografi @kreftregisteret.no.

Unngå å sende fødselsnummer og helseopplysninger i e-post!

Du kan få digitale brev fra oss
Opprett digital postkasse på www.norge.no

Følg oss gjerne på Facebook
www.facebook.com/kreftsjekken

Hva kan mammografi screening innebære?

Når vi inviterer til mammografiscreening, er prinsippet at vi må undersøke mange friske personer for å finne brystkreft hos noen få, slik at noen av disse skal unngå å dø av sykdommen.

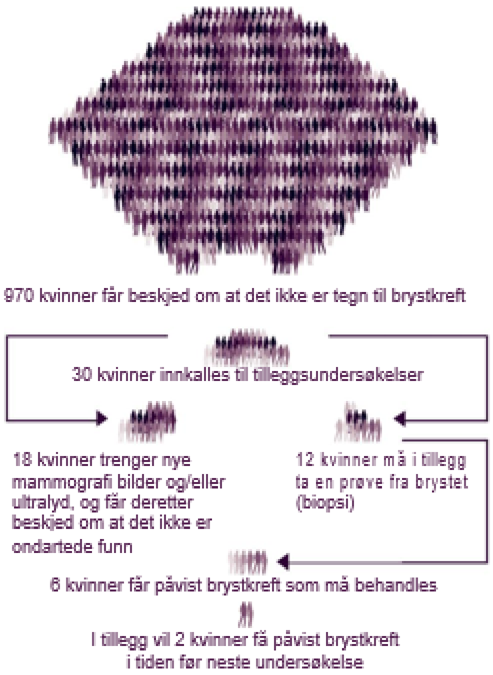
Samtidig vet vi at mammografi screening kan medføre ulemper, som risiko for overdiagnostikk*.

Det er opp til den enkelte å velge om man vil benytte tilbudet. På dette arket finner du informasjon som kan hjelpe deg å finne ut hva du ønsker.

Utdypende informasjon og statistikk, samt informasjon om diskusjonen rundt verdien av mammografiscreening, finner du på nettsidene våre
www.kreftregisteret.no/mammografi

Ønsker du å snakke med fagpersoner om mammografi screening, anbefaler vi at du snakker med fastlegen din.

Når 1000 kvinner undersøkes



970 kvinner får beskjed om at det ikke er tegn til brystkreft

30 kvinner innkalles til tilleggsundersøkelser

18 kvinner trenger nye mammografi bilder og/eller ultralyd, og får deretter beskjed om at det ikke er ondartede funn

12 kvinner må i tillegg ta en prøve fra brystet (biopsi)

6 kvinner får påvist brystkreft som må behandles

I tillegg vil 2 kvinner få påvist brystkreft i tiden før neste undersøkelse

Momenter å vurdere

Den viktigste nytten ved mammografi - screening er at det fører til **færre dødsfall av brystkreft** blant kvinner i målgruppen.

Når det oppdages brystkreft som er liten og ikke har spredd seg, øker også sjansene for å kunne **beholde brystet etter operasjon.**

Når mammografi bildene vurderes, kan det være **vanskelig å skille** mellom godartede og ondartede forandringer. **Innkalling til tilleggsundersøkelse** er da nødvendig. For de fleste viser det seg at forandringene er ufarlige. Dette omtales da som en falsk positiv mammografi undersøkelse.

Mammografi screening vil innebære en **risiko for overdiagnostikk*.** I dag er det ikke mulig å skille ut hvilke krefttilfeller som er overdiagnostiserte, og derfor får alle med påvist brystkreft tilbud om behandling.

I mammografi benyttes **røntgenstråler**, dette kan i teorien gi risiko for utvikling av brystkreft. **Risikoen er svært lav,** også ved regelmessig deltagelse i screeningprogrammet.

I forbindelse med mammografi undersøkelsen kan man oppleve **engstelse og uro**, både i tiden fram til svaret foreligger og ved innkalling til tilleggsundersøkelse.

Mammografi finner ikke alle tilfeller av bryst-kreft. Brystkreft kan også oppdages mellom to undersøkelser. **Oppsøk derfor alltid lege om du oppdager en kul eller forandringer i brystet,** selv om du nylig har vært til mammografi .

* Overdiagnostikk

Ved mammografi screening kan det oppdages saktevoksende kreftsvulster som aldri ville blitt store nok til å gi symptomer eller bli til fare for liv og helse.

For kvinnen betyr det at hun aldri ville ha merket sykdommen uten mammografi screening. Hun kan dermed få en kreftdiagnose og bli behandlet for brystkreft uten egentlig å trenge det. Dette kalles overdiagnostikk, og må ikke forveksles med feil diagnose.

Det er umulig å si hvem som blir overdiagnostisert, siden det ikke finnes metoder for å skille mellom de brystkrefttilfellene som trenger behandling og de såkalt snille brystkrefttilfellene som kanskje ikke trenger det.

Hvordan er mammografi screeningen lagt opp?

Her kan du lese om hvorfor du har fått invitasjon til Mammografiprogrammet, samt praktiske forhold rundt selve.

Hvorfor får du invitasjon?

Brystkreft er den kreftformen som rammer flest kvinner i Norge.

I løpet av livet kommer en av ni kvinner til å få påvist brystkreft eller forstadier til brystkreft.

Mammografi er en røntgenundersøkelse av brystene som kan oppdage brystkreft før sykdommen gir symptomer som følbar kul.

I Norge inviteres alle kvinner i alderen 50 til 69 år til mammografi screening hvert annet år.

Hensikten er at færre i målgruppen skal dø av brystkreft. Effekten er best dokumentert for denne aldersgruppen.

Hvordan foregår mammografi-undersøkelsen?

Hele besøket tar 10–20 minutter.

Først vil en radiograf stille deg noen spørsmål og se etter forandringer på brystene. Denne informasjonen brukes når røntgenlegene vurderer bildene.

Det legges press på brystene i noen sekunder når bildene tas. Noen kvinner synes det er ubehagelig, men dette gjøres for å få best mulig kvalitet på bildene.

Hva skjer etter undersøkelsen?

To røntgenleger vurderer bildene, uavhengig av hverandre.

Du får skriftlig beskjed, uansett hva resultatet er. Vanligvis tar dette 2–4 uker.

Det kan bli behov for tilleggsundersøkelse

Noen blir innkalt til tilleggsundersøkelse ved brystdiagnostisk senter. Dette er noe mer vanlig for kvinner som kommer for første gang, og for kvinner med brystprotese.

For de fleste innebærer tilleggsundersøkelsen tilleggsbilder og/eller ultralyd. I noen tilfeller er det også nødvendig å ta prøve fra brystet (biopsi).

Innkalling til tilleggsundersøkelse trenger ikke å bety at du har brystkreft.

Er du tidligere operert for brystkreft?

Dersom du fortsatt går til kontroller, skal du følge disse. Noen av kontrollene kan foregå i Mammografi programmet dersom dette er avtalt med legen din.

Når kontrolltiden er avsluttet (inntil ti år), kan vanlig opplegg i Mammografi programmet følges. Ring oss gjerne for å gi beskjed!

Har du mistanke om arvelig brystkreft i familien?

Du kan få veiledning ved medisinsk-genetisk avdeling for din helseregion. Rådfør deg med fastlegen din!

For information **in English**, please see
www.kreftregisteret.no/en/mammography

MAMMOGRAFI programmet

På nettsidene våre kan du finne mer informasjon om Mammografi programmet, samt om brystkreft, risikofaktorer og utvikling av sykdommen.

www.kreftregisteret.no/mammografi

Sist oppdatert desember 2017

APPENDIX C

Invitation to group interview. Given out in Norwegian.

Norwegian version:

Invitasjon til deltakelse i forskningsprosjekt (deltakere vil motta gavekort).

Hei! Mitt navn er Johanna Gjefsen, og jeg skriver for øyeblikket en masteroppgave i sosiologi ved NTNU. Oppgaven min handler om tekstbruk i forebyggende helsearbeid, og jeg bruker kreft som eksempel. Med tekstbruk i denne sammenhengen mener jeg artikler, brosjyrer og lignende som er ment å hjelpe leseren med å forebygge sykdom. I forbindelse med oppgaven er jeg på utkikk etter kvinnelige informanter som kunne tenke seg å bli med i et gruppeintervju der deltakerne vil snakke om to slike informasjonstekster som de har lest på forhånd. Det kreves ingen forhåndskunnskaper om temaet for å delta, men deltakerne må ha fylt 18 år. Alle som intervjues vil bli anonymisert i oppgaven, og spørsmålene kommer ikke til å være sensitive. Tidspunktet for intervjuet vil så godt det lar seg gjøre tilpasses deltakernes timeplan.

Alle informanter vil få et gavekort til Trondheim kino som takk for innsatsen. Dersom du ønsker å delta eller har spørsmål, så ta gjerne kontakt på telefon [telefonnummer] eller mail [mailadresse]. Påmeldingsfrist er 10. mars.

English translation:

Invitation to participation in research project (participants will receive gift cards).

Hi! My name is Johanna Gjefsen, and I am currently writing a master’s thesis in sociology at NTNU. My thesis is about the use of texts in preventive health care, and I am using cancer as an example. By the use of texts in this context, I am referring to articles, brochures and similar texts that are meant to help the reader prevent disease. In the connection with the writing of this thesis, I am searching for female informants who would like to attend a group interview where the participants are going to talk about two such informational texts that they have read in advance. There is no need for prerequisite knowledge about the subject to attend, but the informants must be 18 years of age or older. All informants will be made anonymous, and the questions will not be of a sensitive nature. The date of the interview will be adapted to the participants schedule if possible.

All informants will receive a gift card for Trondheim cinema as a thank you for their participation. If you wish to attend or have any questions, feel free to contact med at [phone number] or [email]. The deadline for entry is March 10th.

APPENDIX D

Interview guide individual interviews.

Norwegian version:

1. Hvor gammel er du?
2. Har du hørt om det nasjonale programmet for brystkreftundersøkelse?
3. Hvem tror du dette programmet ønsker å nå?
4. Hva tror du kan gi økt risiko for brystkreft?
5. Har du sett noen av disse tekstene før?

English translation:

1. How old are you?
2. Have you heard about the national mammography program before?
3. Who do you think is in the target group for this program?
4. What do you think can lead to an increased risk of breast cancer?
5. Have you seen any of these texts before?

APPENDIX E

Interview guide for group interviews.

Norwegian version:

1. Hva synes dere om teksten? Tekst 1 og 2.
2. Var det noe i teksten som overrasket dere, i så fall hva? Tekst 1 og 2.
3. Lærte dere noe nytt? Tekst 1 og 2.
4. Var det noe i teksten som var vanskelig å forstå? Tekst 1 og 2.
5. Om dere skulle brukt ett ord for å beskrive teksten, hvilket ord ville hver enkelt av dere valgt og hvorfor? Tekst 1 og 2.
6. Er det informasjon dere savner?
7. Hva synes dere om at det blir sendt med brosjyre/informasjonsark sammen med invitasjonen?
8. Hva synes dere er hovedforskjellene mellom de to tekstene?
9. Hvilken av tekstene likte dere best og hvorfor?
10. Hvis dere hadde fått i oppgave å forbedre teksten (dere likte best), hva ville dere endret på?

English translation:

1. What do you think about the text? Text 1 and 2.
2. Did you find anything in the text suprising, if so what? Text 1 and 2.
3. Did you learn anything new? Text 1 and 2.
4. Was there anything in the text that was difficult to understand? Text 1 and 2.
5. If you were to use one word to describe the text, which word would you use? Text 1 and 2.
6. Is there any information that you miss?
7. What do you think of there being an added brochure/fact sheet to the invitation?
8. What do you feel are the main differences between these texts?
9. Which text did you like best and why?
10. If you were to improve the text (you liked the best), what would you change?

APPENDIX F

Interview guide for interviews with representatives from BreastScreen Norway.

Norwegian version:

Person med daglig ansvarlig for informasjonsmateriell, hadde ansvar for det mest nylige revisjonsarbeidet.

Om mammografiprogrammet:

1. Hva er mammografiprogrammets største styrker og svakheter?
2. Hvorfor er formidling av informasjon viktig for denne typen program?

Om det daglige ansvaret:

1. Hvilke oppgaver har du i forbindelse med det daglige ansvaret for informasjonsmateriell?
2. Hvor stor av informasjonsmaterialet deres er tekstbasert?
3. Hvilke andre typer materiell bruker dere? (bilde/lyd)
4. Hvilke plattformer prøver dere å nå kvinnene på, og hva er erfaringsmessig mest effektivt? (sosiale medier, nyhetsmedier, brev osv)
5. Har du inntrykk av at informasjonen dere sender ut når mottaker?
6. Pleier dere å få tilbakemeldinger og spørsmål fra kvinner i forbindelse med invitasjonene, og hva går i så fall disse ut på?

Om revisjonsarbeidet:

1. Hva var grunnen til at dere så et behov for å revidere invitasjonen?
2. Hva har dere fokus på når dere utarbeider nytt materiell?
    a. Hvem bidrar i arbeidet med å utforme nytt materiell?
3. Hva er utfordringene rundt å utforme denne typen materiell?
4. Jeg har lagt merke til at invitasjonene og informasjonen som sendes ut har blitt lengre over tid, hva er grunnen til dette?
5. Layouten på dagens invitasjon og faktaark skiller seg fra tidligere invitasjoner, hva er grunnen til dette?
6. Hvilke språk er invitasjon og informasjon tilgjengelig på?

Øvrig:

1. Er det noe mer du ønsker å legge til?

Leder av programmet, overordnet ansvar, har jobbet som informasjonsmedarbeider i programmet tidligere.

Forebyggende helsearbeid:

1. Hva mener du er den største utfordringen for den norske folkehelsen?
2. Hva mener du er grunnen til den økende forekomsten av brystkreft i Norge?
3. Hvorfor er informasjonsformidling viktig i forebyggende helsearbeid?

Kreftregisteret:

1. Kan du fortelle litt om hvordan Kreftregisteret jobber med forebyggende helsearbeid?
2. Hvem er deres faste samarbeidspartnere?
3. Opplever du at den norske befolkningen er mottakelige for informasjonen dere sender ut?
4. Hvilke tilbakemeldinger får dere på arbeidet deres fra publikum?

Mammografiprogrammet:

1. Hva er mammografiprogrammets største styrker og svakheter?
2. Hvilke plattformer prøver dere å nå kvinnene på, og hva er erfaringsmessig mest effektivt?
3. Kan du si litt om hva som er formålet med å sende ut invitasjon til undersøkelse?
4. Hvor mange kvinner har bedt om invitasjonsstopp?
5. Hva gjør dere for å nå den andelen kvinner i målgruppen som ikke deltar i programmet, men som heller ikke har bedt om invitasjonsstopp?
6. Ser dere fellestrekk blant kvinner som ikke deltar?
7. Hva gjøres for å sørge for at informasjonen om programmet er tilgjengelig for innvandrerkvinner?
8. Lykkes dere med å sende alle kvinner i målgruppen invitasjon til riktig tid?
9. Jobber Kreftregisteret også med forebygging rettet mot kvinner utenfor programmets målgruppe?
    a. Ja: Hva går dette arbeidet ut på?
    b. Nei: Hvem har dette ansvaret?

Øvrig:

1. Er det noe mer du ønsker å legge til?

English translation:

Person with the daily responsibility for information materials and was in charge of the most resent revision of the invitation.

About the mammography program:

1. What are the programs biggest strengths and weaknesses?
2. Why is the distribution of information important to this type of program?

About the daily responsibility:

1. What tasks do you have in connection with your daily responsibility for the information materials?
2. What percentage of your information material is written information?
3. What other forms of material do you use? (Image/sound.)
4. What platforms do you use to reach the women, and which ones have proved to be the most effective? (Social media, the media, letters and so on.)
5. Are you of the impression that the information reaches the intended recipient?
6. Do you receive feedback on the invitations, and if you do, what does the feedback entail?

About the revision:

1. Why did you feel it was necessary to revise the invitations?
2. What do you focus on when making new materials?
    a. Who contributes to the work?
3. What are the challenges of making such materials?
4. I have noticed that both the invitations and the information that is distributed have become longer over time, what is the reason for this?
5. The layout of today’s invitation and fact sheet differs from older versions, what is the reason for this?
6. What languages are the invitation and information available in?

Other questions:

1. Is there anything you would like to add?

Leader of the program, has overall responsibility. Has previously worked as information adviser in the program.

Preventive health care:

1. What are the biggest challenges to the Norwegian public health?
2. What is the cause of the increased prevalence of breast cancer in Norway?
3. Why is information distribution important in preventive health care?

Cancer Registry of Norway:

1. Can you talk a little about how the Cancer Registry of Norway works for preventive health care?
2. Who are your regular collaborators?
3. Do you feel that the Norwegian population is susceptible for the information that you distribute?
4. What feedback have you received from the public?

The mammography program:

1. What are the programs biggest strengths and weaknesses?
2. What platforms do you use to reach the women, and which ones have proved to be the most effective?
3. Can you talk a little about the purpose of distributing invitation to screening?
4. How many women have asked not to receive invitations?
5. What do you do to reach the women in the target group that do not participate in the program, and that have not asked to not receive invitations?
6. Do you see any common features among the women who do not attend?
7. What is done to make the information for accessible to immigrated women?
8. Do you succeed in distribution the invitations to all women in the target group on time?
9. Does the Norwegian Cancer Registry do preventive work aimed at women outside of the program's target group?
    a. Yes: What does this work entail?
    b. No: Who has this responsibility?

Other questions:

1. Is there anything you would like to add?

APPENDIX G

Consent form signed by everyone who were interviewed. Given out in Norwegian. States "I have received information about this research project and I am willing to attend".

Samtykke til deltakelse i studiet

Jeg har mottatt informasjon om studien, og er villig til å delta.

(Signert av prosjektdeltaker, dato)

(Signert av masterstudent, dato)