Mammographic screening among immigrant women in Norway; disparities in attendance and selected screening outcomes

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Abbreviations

95% CI:	95% Confidence Interval
BMI:	Body Mass Index
BRCA:	BReast CAncer gene
CRN:	Cancer Registry of Norway
DCIS:	Ductal Carcinoma In Situ
EEA:	European Economic Area
ER:	oEstrogen Receptor
EU:	European Union
GP:	General Practitioner
HRT:	Hormone Replacement Therapy
HIC:	High-Income Countries
HIV:	Human Immunodeficiency Virus
IARC:	International Agency for Research on Cancer
IBC:	Interval Breast Cancer
IHC:	ImmunoHistoChemical
LCIS:	Lobular Carcinoma In Situ
LIC:	Low-Income Countries
MIC:	Middle-Income Countries
NGO:	Non-Governmental Organisation
OCP:	Oral Contraceptive Pill
OR:	Odds Ratio
PICO:	Population, Intervention, Comparison and Outcome
PIN:	Personal Identification Number
PR:	Progesterone Receptor
PRISMA:	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PPV:	Positive Predictive Value
RR:	Relative Risk
SDC:	Screen-Detected Cancer
TNM:	Tumour Node Metastasis
UK:	United Kingdom
US:	United States (of America)
WHO:	World Health Organisation

Definitions

BreastScreen Norway: The national breast cancer screening programme in Norway.

High-incidence countries: Countries with a high incidence of breast cancer (roughly covering Northern America, Australia, New Zealand and Europe excluding Eastern Europe and parts of Central Europe).

High-income countries: Countries defined as high-income countries by the United Nations based on 2014 gross national income per capita from the World Bank (1) .

Interval breast cancer: Breast cancer diagnosed after a negative or false positive screen, either before the next screening appointment or within two years among women who have reached the upper age-limit for BreastScreen Norway.

Low-incidence countries: Countries with a low incidence of breast cancer (roughly covering Latin America and the Caribbean, Africa, Asia, Eastern Europe, parts of Central Europe and Oceania excluding Australia and New Zealand).

Low-income countries: Countries defined as low-income countries by the United Nations based on 2014 gross national income per capita from the World Bank (1).

Middle-income countries: Countries defined as middle-income countries by the United Nations based on 2014 gross national income per capita from the World Bank (1).

Positive predictive value: The proportion of screen-detected cancers among recalls.

Prevalent screen: The first screening examination in BreastScreen Norway.

Recall: Examination where women are called back for further examinations due to abnormal mammographic findings on the screening mammogram.

Relative risk: The risk of one outcome divided by the risk of another outcome.

Screen-detected cancer: Breast cancer diagnosed after a recall within six months after the screening examination.

Subsequent screen: Screening examinations in BreastScreen Norway after the prevalent screen.

Summary

Breast cancer is the most common type of cancer affecting women worldwide, and in 2018, it was estimated that 2.1 million women would be diagnosed with the disease. Incidence and mortality rates vary geographically. Further, the risk of breast cancer has been shown to increase for immigrants from countries with a low incidence of breast cancer when they migrate to countries with a high incidence. European studies have shown that groups of immigrants are diagnosed with more advanced breast cancer, have lower survival from the disease and are younger at diagnosis than non-immigrants. Despite these observed differences, non-immigrants and immigrants receive the same recommendations for breast cancer screening.

In this thesis, I investigated aspects of breast cancer and mammographic screening among immigrants compared to non-immigrants in the national breast cancer screening programme in Norway, BreastScreen Norway. The aim was to generate knowledge about disparities in mammographic screening attendance and screening outcomes between immigrants and non-immigrants offered organised breast cancer screening in Norway. This was done through several studies in the period 2016-2019.

First, we performed a systematic review with a meta-analysis, and showed that immigrant and minority women living in Europe, Northern America, Australia and New Zealand have had lower breast cancer screening attendance rates than other women in the countries under study. These findings contextualised the findings in the next study, in which we found that from 1996 to 2015, immigrants from all countries had lower attendance rates than non-immigrants in Norway. Among immigrants, attendance rates were highest for immigrants from high-income countries, while attendance rates were lowest for immigrants from low-income countries. Differences in attendance rates between non-immigrants and immigrants from the Nordic countries, the British Isles and Oceania were no longer statistically significant after adjusting for sociodemographic factors. Differences in attendance rates between non-immigrants and immigrants from all other regions reduced, but persisted, after adjusting for sociodemographic factors. Among immigrants, attendance rates increased with years since migration.

In a third study, we found that important indicators to measure the performance of breast cancer screening (performance measures) were different between non-immigrants and immigrants who attended BreastScreen Norway from 1996 to 2015. For example, non-

immigrants more often had previous mammograms available for comparison at a screening examination than immigrants did. Further, immigrants had higher recall rates and lower positive predictive values than non-immigrants, which was only partly explained by screening history and age. Immigrants from low-incidence countries were younger than non-immigrants at the time of diagnosis. Among immigrants from low-incidence countries, tumours detected tended more often to be of histological grade 3, and interval breast cancers were more often triple-negative, compared with non-immigrants.

Finally, we conducted qualitative interviews to explore attendance in BreastScreen Norway for one specific immigrant group, that of women from Pakistan. We showed how many human and non-human actors act on Pakistani immigrant women when they consider attending mammographic screening, for instance by revealing possibilities, giving doubt and creating worries, encouraging, facilitating, discouraging or hindering attendance. The actors highlighted were trust in healthcare and mammographic screening, the written information from BreastScreen Norway, the gender of the radiographer, family life, daughters, general practitioners, non-governmental organisations and religious beliefs.

The results in this thesis contribute to a better understanding of mammographic screening attendance and screening outcomes for immigrants in Norway. Combining our results with results from other studies suggest that one should work to increase attendance rates among immigrant women. At the same time, the age group targeted and interval for screening might not be optimal for subgroups of immigrant women. Further knowledge is needed before one can recommend changes in mammographic screening recommendations based on ethnicity, including considerations of survival, cost versus benefit and the pros and cons of stratifying screening based on ethnicity compared to the pros and cons of stratifying screening based on breast density and other factors. The results in this thesis also suggests that the way in which mammographic screening is offered is not optimal for Pakistani immigrant women, a finding that could be valid also for other immigrant groups.

List of articles

Article I

Bhargava S, Moen K, Qureshi SA, Hofvind S. Mammographic screening attendance among immigrant and minority women: a systematic review and meta-analysis. Acta Radiol 2018;59:1285–1291.

Article II

Bhargava S, Tsuruda K, Moen K, Bukholm I, Hofvind S. Lower attendance rates in immigrant versus non-immigrant women in the Norwegian Breast Cancer Screening Programme. J Med Screen 2018;25:155–161.

Article III

Bhargava S, Akslen LA, Bukholm I, Hofvind S. Performance measures among non-immigrants and immigrants attending BreastScreen Norway – a population-based screening programme. Eur Radiol 2019; Feb 14. doi:10.1007/s00330-019-6009-2 (Epub ahead of print).

Article IV

Bhargava S, Hofvind S, Moen K. Gender, letters, relatives and God: Mediating actors in mammographic screening among Pakistani women in Norway (rejected by Acta Open, Feb 11, 2019, with a request to resubmit by July 11, 2019).

1. Introduction

1.1 Immigrants in Norway

1.1.1 History and trends of post-World War 2 immigration

The International Organisation for Migration define a migrant as "any person who is moving or has moved across an international border or within a State away from his/her habitual place of residence" (2). This movement includes refugees, labour migrants, family migrants, and people moving for other reasons. The number of migrants is increasing, and in 2017 it was estimated that over 250 million people lived outside their country of origin in 2010 (3).

Xenophobia against migrants is an important source of racism, and migrants may experience discrimination in health, social security, housing, education and work to a larger extent than non-immigrants (4). In this thesis, I explore a potential source of inequality and inequity in immigrants meeting with health services, by exploring disparities in mammographic screening attendance and screening outcomes between immigrants and non-immigrants through one systematic review of attendance rates in Europe, Northern America and Oceania, two registry-based cohort studies from Norway, and one qualitative study of Pakistani immigrant women in Norway.

In the 1950s and 1960s, net migration to Norway was negative or low, and in 1970, less than 1.5% of Norway's population were immigrants (5, 6). Since 1970, net migration has been positive, meaning that immigration to Norway has been greater than emigration from the country, and, as a consequence, that the number of immigrants in the Norwegian population has steadily increased.

Reasons for immigration to Norway differ, with the extent for different reasons varying from year to year (Figure 1) (7). In the early 1970s, immigrants from Pakistan, Turkey and Northern Africa arrived as so-called guest workers. Since the 1980s, there have been spikes in immigration related to civil unrest and war (Figure 1 and 2). As seen in Figure 2, immigration trends have reflected post-war emigration from Vietnam, ethnic conflict in Sri Lanka in the 1980s, unrest during the military dictatorship in Chile, the ongoing civil war in Somalia since the 1980s, the dissolution of Yugoslavia and the Kosovo War, the invasions of Afghanistan and Iraq, and, most recently, the civil war in Syria.
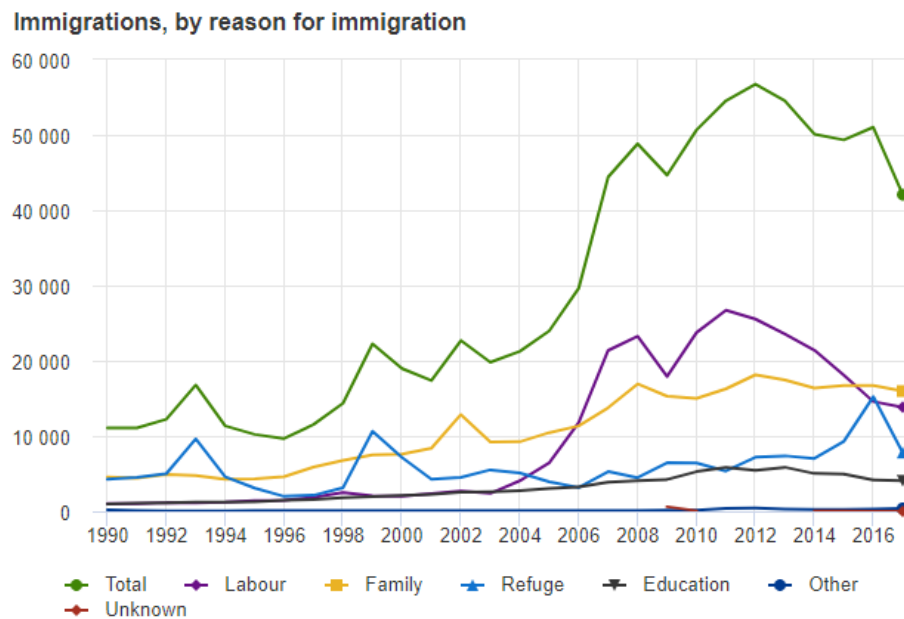
Figure 1: Reason for immigration to Norway over time. This figure does not include immigrants from Nordic countries (source Statistics Norway, https://www.ssb.no/en/befolkning/artikler-og-publikasjoner/many-immigrate-for-family-reasons, 2018).
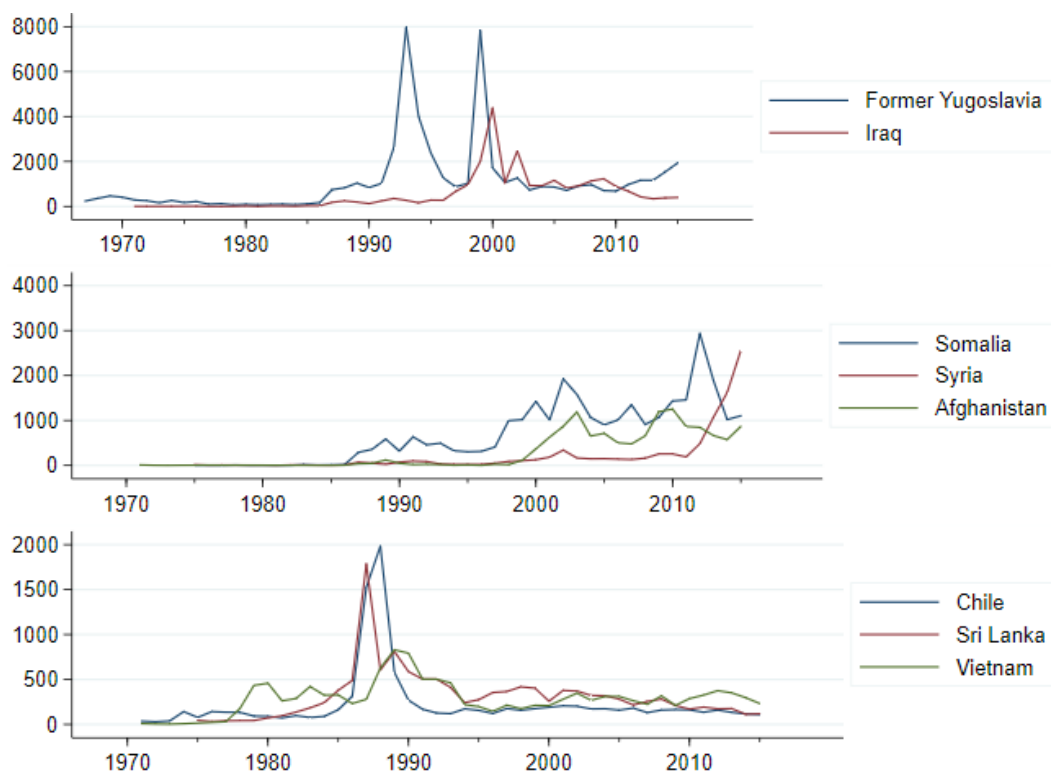
Figure 2: Immigration over time for immigrants from eight selected countries/regions. The graph was constructed using STATA with microdata from Statistics Norway (8). Please be aware of different values on the y-axis.
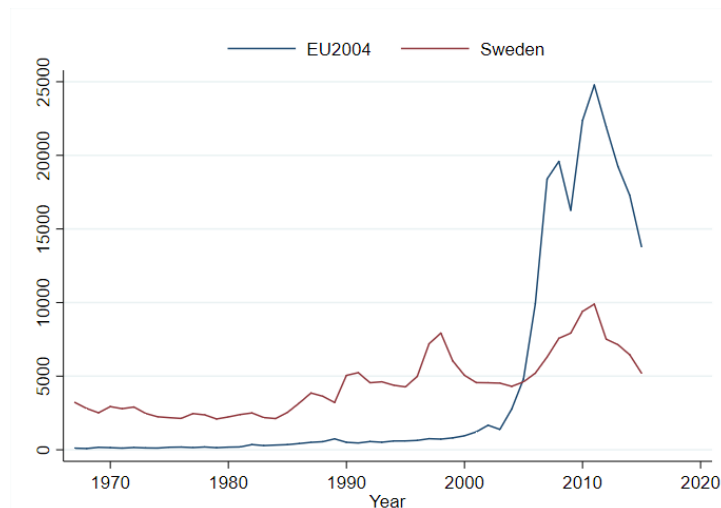
Figure 3: Changes in immigration over time for immigrants from the countries that joined the EU in 2004 (EU2004) with Sweden included as a reference group. The graph was constructed using STATA with microdata from Statistics Norway (8).

The expansion of European Union (EU) in 2004 entitled inhabitants in the new EU member states, mostly Central and Eastern European countries, to move freely within the union to live, work and study through the Citizens' Rights Directive (9). While Norway is not a member of the EU, the directive also included Norway as a member of the European Economic Area (EEA). Consequently, perhaps combined with the economic recession in Europe at the end of the decade (2000s), net immigration to Norway peaked during the period 2007–2014, to a high degree due to an increase in labour immigration (Figure 1 and 3).

There has been a slow and steady increase in family immigration (Figure 1). Between 1990 and 2016, 36% of immigrants from outside the Nordic countries were family immigrants (7); either migrating after marriage to a person living in Norway (family establishment) or where a spouse, parents, children or other family members immigrated after the reference person (family reunification). The most populous immigrant groups for family immigration in total were from Poland, Thailand and Somalia, while for family establishment specifically, the most populous groups were from Thailand, Pakistan and the Philippines.

Surveys by Statistics Norway have examined Norwegian people's perception of immigrants from 2002 to 2017 (10). In 2017, about 70% of the respondents thought that immigrants were positive for the Norwegian work force and cultural life. However, about 25% responded that immigrants misuse social welfare services and that immigrants were a source for insecurity in

the society, and about 50% responded that immigrants should strive to become as similar to Norwegians as possible.

1.1.2 The composition of the current immigrant population

In 2018, the Norwegian population consisted of 5.3 million people, of whom about 746,000 (14%) were immigrants and 170,000 (3%) were children of immigrants (11). Immigrants had arrived from all continents and had family backgrounds from 221 countries and autonomous regions, with almost 50% migrating from other European countries (Figure 4). In 2017, about 25% of immigrants and their decedents lived in Oslo, the capital city of Norway, but immigrants resided in all of the country's 426 municipalities (5).
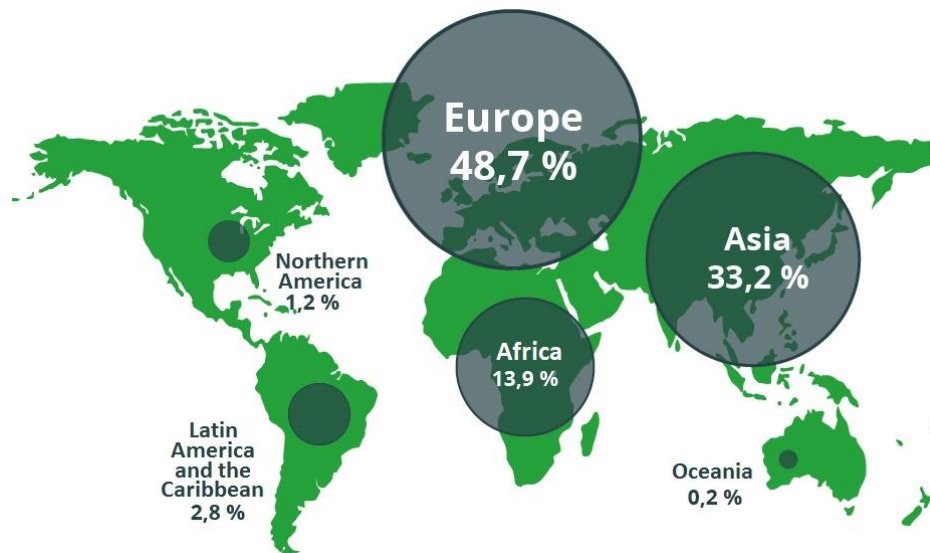
Figure 4: Continent of origin for immigrants living in Norway in 2018. The text has been translated from Norwegian to English with permission from Statistics Norway (source Statistics Norway, https://www.ssb.no/innvandring-og-innvandrere/faktaside/innvandring, 2018).

Nearly half of all immigrants in Norway are women (48%) (5). However, the proportion of women varies among immigrant groups. In 2018, more than 62% of immigrants from Poland, Great Britain, Afghanistan and Syria were men, to a large extent labour immigrants and refugees (5). Overall, 84% of immigrants from Thailand were women (calculated with microdata from Statistics Norway's Statistics Bank (8)). Furthermore, more than two thirds of immigrants from Russia, Ukraine, the Philippines and Brazil were women. About three quarters of family establishments and almost 60% of family reunifications were women immigrating to men who were already living in Norway, and women emigrating from

Thailand, the Philippines, Brazil, Russia and the United States (US) were the most populous groups of immigrant women establishing a family with men without an immigrant background (7). On the other hand, immigrant women from Afghanistan, Somalia and Pakistan usually married men with an immigrant background.
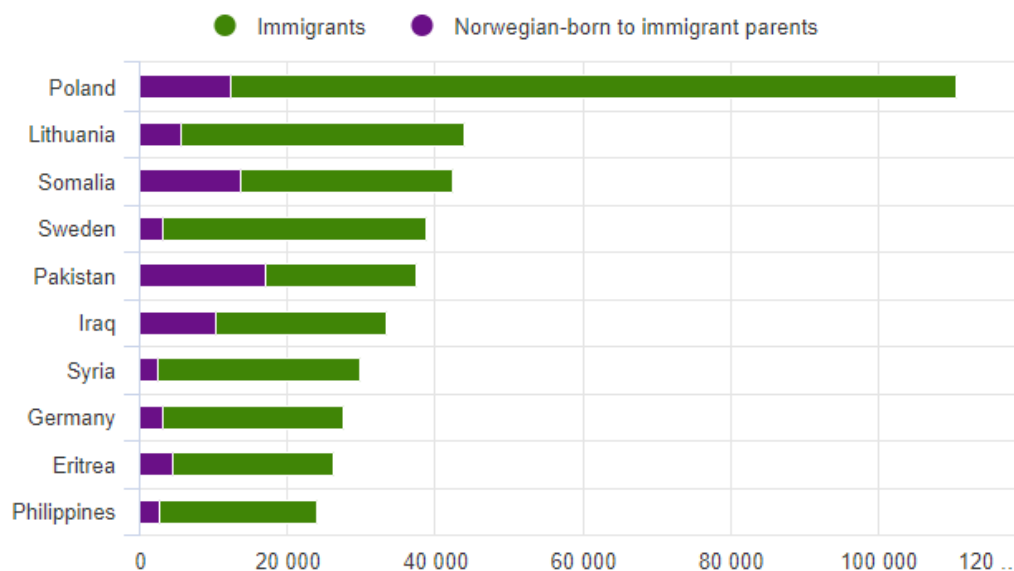
Figure 5: Number of immigrants and Norwegian-born to immigrant parents from the ten most populous groups by country of origin as of January 1st 2018 (source Statistics Norway, https://www.ssb.no/en/befolkning/artikler-og-publikasjoner/14-per-cent-of-population-are-immigrants, 2018).

After an increase in migration from the country following the expansion of EU in 2004, immigrants from Poland are now the most populous group of immigrants in Norway (Figure 5). The ten most populous groups with an immigrant background includes people from four European countries, four Asian countries and two African countries. In 2060 it is expected that 1,700,000 (24%) of the Norwegian population of 7 million people will be immigrants, and a further 9% will be children of immigrants, as both the absolute number of immigrants and the proportion of immigrants in the overall population are expected to continue to increase (6, 12).

1.1.3 Definition and categorisation of immigrants

Several terms can be used to describe a person with a family background from a foreign country. In this thesis, I have used Statistics Norway's definition of immigrants as people who are born abroad with two foreign-born parents and four foreign-born grandparents (13). With

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this definition, a person born in Norway to foreign-born parents is not defined as an immigrant. Further, I have used the term immigrant background when describing immigrants and their Norwegian-born children.

Studies differ in their way of categorising the countries of origin for immigrants. The terms western and non-western countries, developed, less developed, least developed and developing countries, high-income (HIC), middle-income (MIC) and low-income countries (LIC), and so on, are often used for partly overlapping populations (14).

In this thesis, I mainly used two categorisations of countries. I primarily divided countries according to the local incidence of breast cancer, into high-incidence countries and low-incidence countries (further described in the article based on study III). High-incidence countries roughly include Northern America, Australia, New Zealand and Europe excluding Eastern Europe and parts of Central Europe. In study II, we divided countries into HIC, MIC and LIC, as done by the United Nations, based on gross national income per capita from the World Bank (1). LIC roughly cover many countries in Sub-Saharan Africa, as well as some countries outside Africa, such as Afghanistan, Nepal and Haiti. MIC roughly cover most other countries in Africa and Asia, as well as many countries in Eastern Europe, Latin America and the Caribbean. HIC roughly cover most countries in Europe and Northern America, as well as many countries in Eastern Asia and the Middle East. When referring to sources using other non-geographical terms, I will use the terms in the reference with quotation marks.

1.1.4 Sociodemographic status among immigrants in Norway

On a group level, immigrants differ from the rest of the population in several respects. As it is challenging to define integration, comparison of distributions of sociodemographic factors (e.g. educational status and work participation) between non-immigrants and immigrants is often used as a proxy indicator for integration (13). In the following, some sociodemographic differences between immigrant groups and between immigrants and non-immigrants are described. The differences between immigrants described, exemplify the problem of categorising immigrants as one group with shared characteristics.

In Norway, immigrants in general have had lower income than non-immigrants, but there have been major differences among immigrant groups (15). While immigrants from the United Kingdom (UK) and Scandinavia have had higher income on average than the general population, income among immigrants from Eritrea and Afghanistan has been as low as about

half of that of the general population. In 2015, over 30% of the household income for immigrants from Somalia, Iraq, Afghanistan, Turkey and Pakistan came from various kinds of government benefits (15). Income disparities increased from 2010 to 2015 between non-immigrants and immigrants from Asia, Africa, Latin America, Oceania (except Australia and New Zealand) and Europe outside EU/EEA. Disparities in income among immigrants has varied according to reason for immigration and length of residency (15). Fewer immigrants than non-immigrants live in self-owned housing, but the rate has increased with increasing income and increasing number of years of residency in Norway (16).

In 2016, 16% of immigrants had tertiary (higher) education of four years or longer, which was twice as many as in the general population (17). However, the proportion of immigrants who did not have any tertiary education was also slightly higher than in the general population (30% versus 27%). For immigrants who arrived through family reunification, about 40% did not have any tertiary education (17). While refugees in general had low educational status, labour immigrants had higher educational status than the general population (17).

Fertility rates were higher among immigrants than among non-immigrants in 2016, and the highest fertility rates were observed among immigrant women from Africa, who gave birth to one child more than immigrants in general (2.82 versus 1.86) (5). While there was a trend that fewer non-immigrants married, there was an increasing number of marriages where at least one person had an immigrant background (5). Part of the explanation might be that co-habitation without being married is far more common among non-immigrants than among immigrants. Despite a long history in Norway, immigrants from Pakistan were overrepresented in households with multiple families with children, and only 9% of immigrants from Pakistan lived alone, compared to 20% of all immigrants and 17% of the rest of the population (18).

In the period 2002–2016, immigrants had lower employment rates than non-immigrants (19). This difference reduced from 2004, largely due to increased immigration from the countries that joined the EU in 2004. Refugees had lower employment rates than other immigrants. Immigrants from Africa, Asia, Latin America, Oceania (except Australia and New Zealand) and Europe outside EU/EEA less often had paid work compared to the rest of the population, and those who had paid work less often worked full time. People in the age group 55–66 years, women and recent immigrants from these countries had particularly low employment rates.

1.1.5 Immigrant health

While immigrants to HIC in general have unfavourable distribution of sociodemographic factors compared to non-immigrants, some studies, mainly from Northern America, have shown a health advantage in immigrants compared to non-immigrants, an epidemiological paradox often referred to as the healthy migrant effect (20, 21). Other studies argue that this effect diminishes with time since migration, and does not hold true for refugees, who suffer poor health due to their living conditions (21). A related term known as salmon bias describes that migrants with poor health might not show up in national statistics in the country they have immigrated to, as they travel to their birth countries when they get ill, thus being perceived as healthy in the country where they have resided, but ill in their birth country (20). Similarly, some immigrants might travel to their birth country for screening, and could thus be registered as unscreened in their country of residence (22).

Statistics Norway showed that immigrants from ten countries (Iraq, Turkey, Iran, Pakistan, Chile, Vietnam, Serbia-Montenegro, Bosnia-Hercegovina, Sri Lanka and Somalia) in 2005/2006 had worse self-reported health than non-immigrants reported in 2002, and that the self-reported health was worst among women aged 55–70 (23). In 2015, immigrants aged 45–66 from Africa, Asia, Latin America, Oceania (except Australia and New Zealand) and Europe outside EU/EEA more often received health benefits than the rest of the population (19). A survey of immigrants from twelve countries (Poland, Bosnia-Hercegovina, Kosovo, Turkey, Iran, Iraq, Afghanistan, Pakistan, Sri Lanka, Vietnam, Eritrea and Somalia) in 2016 showed that immigrants from these countries more often reported cramped housing, poor health, mental health problems, and physical and mental exhaustion after work than the rest of the population (24). Using a three-level scale for satisfaction with life (low, middle and high), the proportion of immigrants who reported low satisfaction was higher than for non-immigrants, but the proportion of immigrants who reported high satisfaction was also higher than for non-immigrants.

A recent study from Norway showed that cancer was less often diagnosed in immigrants than in non-immigrants (25). Certain conditions have been reported to be more common among immigrants than among non-immigrants, such as diabetes, Human Immunodeficiency Virus (HIV) infection, tuberculosis and adult mental health disorders, with mental health problems being more common in immigrant women than men (26). In addition, less physical activity, overweight and to a certain extent smoking, which are risk factors for a number of diseases

including cancer, have been shown to be more frequent among immigrants than among non-immigrants (26).

A review of migrants' utilisation of somatic healthcare services in Europe found that migrants more often went to a general practitioner (GP) than non-immigrants and had similar or higher use of specialist care and hospitalisations (27). Results for emergency room use were diverging. In Norway, it has been shown that a lower proportion of immigrants use their GP compared to non-immigrants, but that among people who visit their GP, immigrants visit their GP more frequently than non-immigrants (28). Among immigrants, older people have been found to use their GP less frequently than younger people (28). A Norwegian study of emergency primary health care use showed that immigrants as a whole had a lower contact rate than non-immigrants, and that women had higher contact rates than men regardless of geographical region of origin (29). The study further showed that immigrants from Poland and Germany (mainly labour immigrants) had lower contact rates than non-immigrants, while immigrants from Somalia and Iraq (mainly refugees) had higher contact rates.

There were no published articles about mammographic screening attendance among immigrant women in Norway prior to this PhD study. There have been many studies examining mammographic screening attendance rates among immigrant and minority women in other countries in Europe, Northern America and Oceania, showing that immigrant and minority women have lower attendance rates than other women (30-32). A systematic review explored factors associated with attendance, but only included studies from the US and did not focus on immigrants specifically, other than showing that being a recent immigrant negatively affected mammography use (33). As far as I am aware of, no other review has examined mammographic screening attendance rates among immigrant women.

1.2 Breast Cancer

1.2.1 Breast cancer incidence
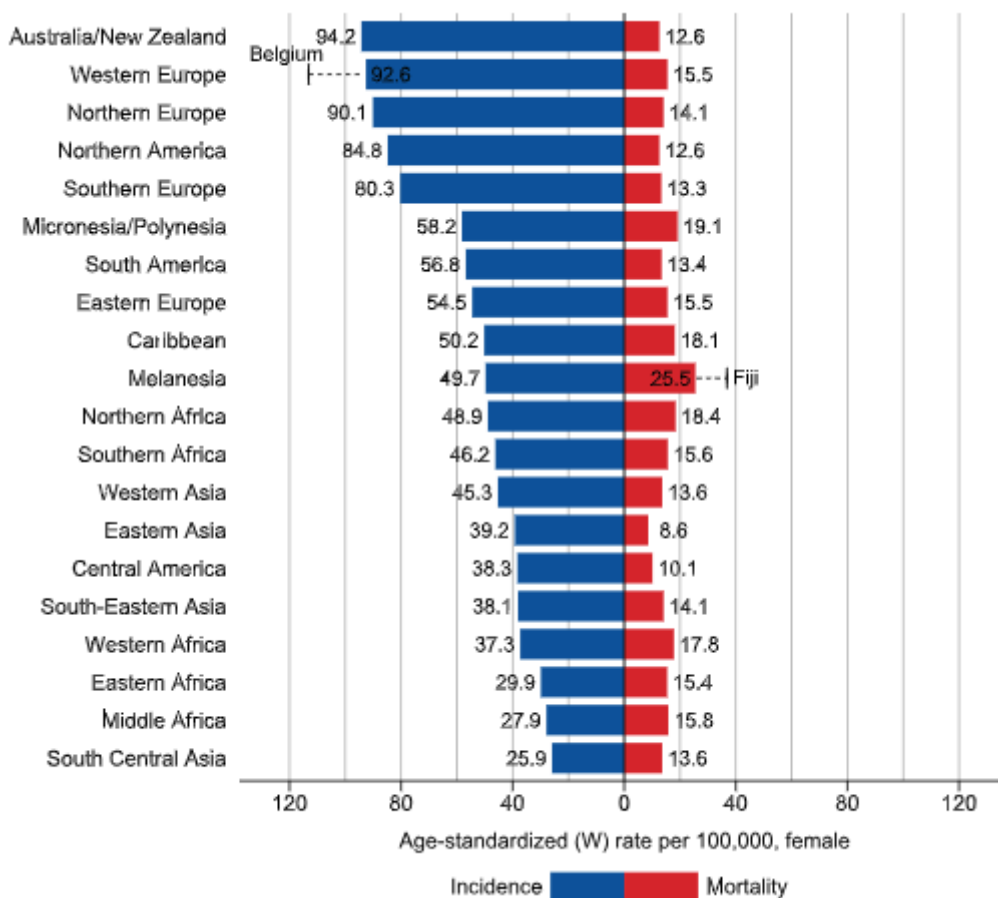
Figure 6: Incidence and mortality rates for breast cancer by geographical region. The quality of registration of incidence and mortality varies, with a lower proportion of high-quality registries in Africa, Asia and South America than in other regions (source GLOBOCAN 2018 (34)).

Breast cancer is the most common type of cancer affecting women worldwide, with an estimated 2.1 million new cases in 2018 (34). Estimates of age-standardised incidence rates vary geographically, ranging from 25–30/100,000 in Middle Africa, Eastern Africa and South-Central Asia, to over 80/100,000 in Northern America, Northern Europe, Western Europe, Southern Europe and Australia/New Zealand (Figure 6). While incidence rates have been highest in Northern America, parts of Europe and Australia/New Zealand, the absolute number of cancer cases diagnosed has been higher outside these regions.
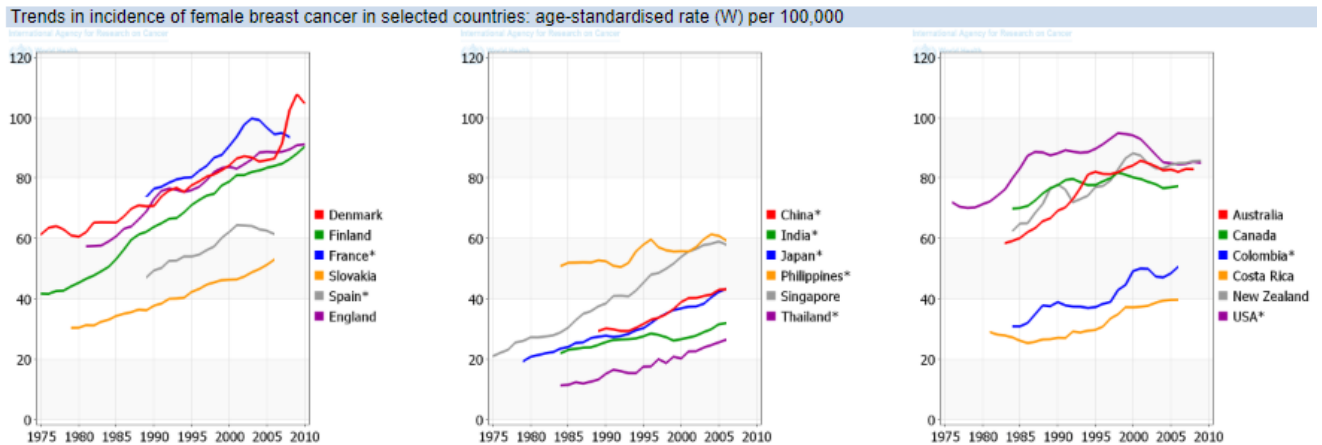
Figure 7: Trends in age-standardised incidence of breast cancer in selected countries. The International Agency for Research on Cancer (IARC) has given permission to use this figure even though it is no longer available online (source IARC, 2018).

Breast cancer incidence rates have increased over the last decades (Figure 7). For countries with organised breast cancer screening, the increase has been observed both before and after the implementation of screening, but often with a spike in incidence in the years following the introduction of screening. For some countries, such as the US, the incidence of breast cancer has reached a plateau or started decreasing, which may be associated to, among others, a decrease in the use of hormone replacement therapy (35).

In Norway, it is by law mandatory to report cancers to the Cancer Registry of Norway (CRN), and data for solid tumours are considered almost complete (36). Breast cancer is the most common type of cancer affecting women also in Norway, and the incidence has increased steadily since the start of registration in 1952 (37). Nine percent of women in Norway are expected to be diagnosed with breast cancer before they turn 75 years old (37). The annual incidence rate of breast cancer for women in Norway was estimated at 131.1/100,000, corresponding to 3589 new cases in 2017 (37).

1.2.2 Treatment of breast cancer according to tumour characteristics

The natural course of breast cancer is thought to develop from early-stage, small, node-negative tumours that grow in size and can spread to distant organs (38). While early-stage tumours, depending on histopathological tumour characteristics, may only require breast-conservation surgery and radiotherapy, diagnosis of more advanced tumours, if considered curable, usually require a combination of surgery, chemotherapy (single medications or

multiple medications used in succession or simultaneously), other cancer medications (for instance anti-hormonal treatment) and radiotherapy (39, 40). Breast cancer is considered incurable if it has metastasised to other organs, and is in such cases usually treated with chemotherapy, other medications and best supportive care (40, 41).

Surgery is the cornerstone of curative breast cancer treatment, as all treatment with curative intent depends on the tumour being surgically removed (39). Whether breast cancer is considered operable or not, depends on the tumour's TNM-status (42). T (tumour) describes the size and infiltration of the primary tumour, N (node) describes the number and position of affected lymph nodes, and M (metastasis) describes the absence or presence of distant metastases. Based on these three characteristics, breast cancer is staged I-IV, and the tumour is classified as operable, potentially operable after neoadjuvant treatment, or inoperable based on these stages and the TNM-status (40).

The possibility to use certain medications in the treatment of breast cancer depends on the histopathological characteristics of the tumour, as these medications directly target certain characteristics. Tumours that express oestrogen or progesterone receptors (ER or PR) may be targeted by endocrine treatment (anti-hormonal treatment) (39, 40). The choice of endocrine treatment depends on whether the woman has gone through menopause or not. Tumours with an overexpression of the Her2-gene may be targeted by treatment with the monoclonal antibody trastuzumab or other medications (39).

Apart from some (but not all) small, node-negative tumours, most potentially curable breast cancer patients are recommended treatment with post-operative chemotherapy. In Norway, the most commonly used chemotherapies in breast cancer treatment include epirubicin, cyclophosphamide and taxanes (40). In addition to the characteristics described above, the choice of chemotherapy regimen in curative intent is further guided by the tumour's histological grade, which is graded 1-3, and Ki67 protein status (including degree of tumour cell proliferation), which is graded 0-100% (39, 40). The higher grades are associated with more aggressive disease, and require treatment with more intensive regimens.

For choice of post-operative, medical treatment strategy in curative intent, tumours in women in Norway are categorised into eleven groups with different recommendations for treatment according to TNM-, Her2-, ER- and PR-status, histopathological grade and Ki67 proliferation status (40). The Norwegian categorisation is in keeping with the acknowledged St. Gallen

International Breast Cancer Conference Expert Panel categorisation of tumours according to predicted response to various treatments (43).

Radiation therapy may be used post-operatively after breast-conserving surgery, non-radical surgery, for large tumours and after lymph node positive disease as part of curative treatment, and for management of painful skeletal metastases in a palliative setting (39, 40).

Postmenopausal women may also receive treatment with bisphosphonates in order to prevent skeletal metastasis or to prevent morbidity from such metastases if present (39, 40).

All treatment modalities discussed are used both in curative and palliative intent. They are all associated with side-effects, including side-effects that may persist for many years, and it is important that the choice of recommended treatment takes patient's preferences and co-morbidities into consideration.

1.2.3 Breast cancer survival and mortality

Worldwide, about 630,000 women died from breast cancer in 2018 (34). Differences in mortality rates were smaller than differences in incidence rates, and some of the regions with the lowest incidence rates had the highest mortality rates (Figure 6). For instance, the mortality rates were higher in Africa and Oceania outside Australia and New Zealand than in other continents. These differences can be attributed to more favourable survival from breast cancer in regions with a high incidence of breast cancer (44). Survival from breast cancer is stage-dependent, and early-stage, node-negative, stage I tumours have far greater survival than late-stage, metastatic, stage IV tumours (45). Poor survival rates from breast cancer in LIC could be associated with inadequate access to early-stage diagnosis and optimal treatment.

In Norway, the 5-year relative survival from breast cancer in the period 2013-2017 was 100% for stage I tumours and 28% for stage IV tumours (37). The mortality rate was estimated at 21.7/100,000, corresponding to 623 deaths from breast cancer among women in 2016. The mortality rate has reduced in recent years, as the 5-year relative survival has increased to about 90% (all stages included) (37).

1.2.4 Breast cancer risk factors

While the cause of breast cancer is unknown on an individual level, several studies have identified risk factors that increase the risk of developing the disease on a group level (46-48). Women might develop breast cancer despite only having female gender as a risk factor, while other women might never develop breast cancer despite having multiple risk factors for the disease. In the following, I will discuss some of these risk factors (Table 1 and 2).
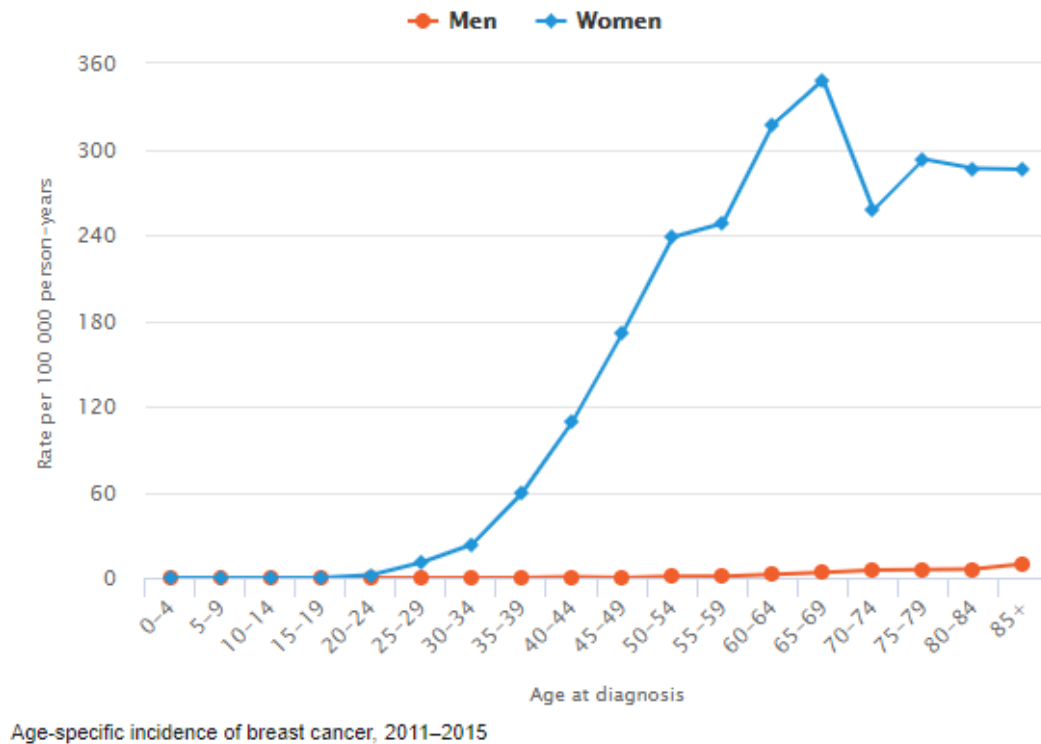
Figure 8: The two biggest risk factors for breast cancer are female gender and increasing age (source CRN (49)).

Table 1: Non-modifiable risk factors:

Risk factor	About the risk factor
Gender	Being a female is the strongest risk factor for breast cancer, as only 0.5% of breast cancers are diagnosed in men (Figure 8) (46).
Age	Age is the second strongest risk factor for breast cancer. Figure 8 shows the rate increase by age in Norwegian women, and also the incidence spike when women reach the target age for BreastScreen Norway (age 50–69) and the compensatory drop in the years after they leave the target age (49). Finally, the incidence rate reaches a plateau. The relative risk (RR) for breast cancer among women over 70 years old has been reported to be >10 compared to women younger than 50 (48).
Age at menopause and menarche	Both early age at menarche and late age at menopause is associated with a higher risk of breast cancer. Each yearly delay in menarche has been associated with a reduction of about 5% in breast cancer risk (48). The increase in incidence increases with age before menopause. The incidence rate of breast cancer is twice as high for women who undergo menopause at age 55 versus age 45 (48).
Personal history of breast cancer	Women previously diagnosed with breast cancer have a 3–5 times increased risk of breast cancer in the contralateral breast (47).
Family history of breast cancer	Less than 15% of women with breast cancer have a family member with the disease (47). Having one first-degree relative with breast cancer doubles the risk of breast cancer, and the risk increases with number of affected relatives (47, 48).
Hereditary factors	Up to 10% of breast cancers in "Western" countries are due to genetic predispositions (46). Several breast cancer susceptibility genes have been identified. Mutations in Breast Cancer Gene 1 or 2 (BRCA1 and BRCA2) account for 3–5% of all breast cancers and up to 50% of hereditary breast cancers (48). Mutations in the BRCA genes are associated with a ten times increased risk of breast cancer (47).
Country of birth	Geographical variation in the incidence of breast cancer was discussed in section 1.2.2. Women in "developed countries" have a five times higher risk of breast cancer (reference group not given) (46).
Mammographic breast density	Breast density can be correlated with other breast cancer risk factors (e.g. genetic predispositions), but is also considered an independent risk factor (48). RR for breast cancer has been reported to be 4 for women with very dense breasts (BI-RADS 4) compared to women with the least dense breasts (BI-RADS 1) (47).
Previous benign disease	Proliferative lesions, such as fibroadenomas and atypical hyperplasia, are associated with a 1.5–5 times increased risk of breast cancer (46, 48). Previous ductal or lobular carcinoma in situ (DCIS or LCIS) doubles the risk of invasive breast cancer (47).

Table 2: Modifiable risk factors:

Risk factor	About the risk factor
Parity	Nulliparous women have an up to twofold increased risk of breast cancer compared to parous women (48).
Age at first pregnancy	Late age of first childbirth is associated with an increased risk of breast cancer. Women aged ≥30 years when they give birth to their first child have an RR of 1.2–2.3 compared to women <20 years at first childbirth (48).
Breast feeding	For every 12 months of breastfeeding, the risk of breast cancer has been found to decrease by about 4% compared to women with equal number of full term pregnancies who have never breastfed (48).

Oral contraceptive pill (OCP)	Ten years use of the combined oestrogen-progestogen OCP has been associated with an increased risk of breast cancer (RR=1.24), but the risk decreases with time since discontinuation (47, 48). However, OCP is mainly used by young women with a low risk of breast cancer.
Hormone replacement therapy (HRT)	Long-term users (≥5 years) of combined oestrogen-progestogen HRT have been shown to have an increased risk of breast cancer (RR=1.63) (48). The increased risk can be seen as early as after two years use, but the risk decreases with time since discontinuation (47).
Body mass	The relationship between body fat/composition and breast cancer risk is complex. In premenopausal women, in whom most of the oestrogen is produced in the ovaries, high body fat appears to have a protective effect against breast cancer (RR=0.7 for Body Mass Index (BMI) >35, reference group not given) (46, 47). RR for postmenopausal women with BMI>35 has been reported to be 2 (46).
Radiation	According to a Norwegian study, if 100,000 women had biannual breast cancer screening over the course of 20 years from age 50–69, 0.1–3.1 women would die due to excess radiation compared to 350 lives saved (50). There also appears to be a small risk of developing a second cancer close to radiotherapy treatment fields (47).
Alcohol	Even at low levels, there appears to be an association between alcohol consumption and breast cancer, and the risk increases with amount of alcohol (48). Three or more drinks per day has been associated with a 40–50% increased risk of breast cancer compared to women who never drink alcohol.
Diet	High intake of saturated fat has been correlated with an increased risk of breast cancer (RR=1.5) (46, 47).
Physical activity	Studies have shown that increased physical activity has a protective effect on breast cancer both for pre- and postmenopausal women, but that the evidence seems to be stronger for postmenopausal women (48).

1.2.5 Breast cancer among immigrants

Women who migrate from low-incidence countries to high-incidence countries have been found to have a lower incidence of breast cancer than the population in the country to which they migrate (51, 52). However, studies have shown that incidence rates increase with time since migration, and that daughters of immigrants have comparable rates of breast cancer as other non-immigrants, indicating risk adaptation (51, 52). In Europe, groups of immigrants have been shown to have different clinical and histopathological breast cancer features than non-immigrants, such as more advanced disease, higher proportion of triple-negative breast cancers (ER-, PR- and Her2-negative) and younger at diagnosis than non-immigrants (53-57).

A recent Norwegian study from the CRN did not find differences in breast cancer incidence when comparing non-immigrants to all immigrants combined (25). The study did however find variations when stratifying immigrants by region of origin. Immigrants from the Nordic countries and other Western European countries had higher incidence of breast cancer than

non-immigrants, while the lowest rates were observed among women from East Asia, South Asia and Sub-Saharan Africa. Another recent Norwegian study showed that immigrants from "non-Western countries" had more advanced breast cancer than non-immigrants (56). The study also showed that 54% of breast cancers diagnosed in "non-Western immigrants" were detected in women younger than 50 years old, compared to 21% in non-immigrants.

The lower incidence of breast cancer among immigrants from Asia and Africa compared to non-immigrants could be due to lower prevalence of known risk factors for breast cancer in the countries from which they emigrate. Many immigrants from outside Europe and Northern America emigrate from countries where women have higher parity, longer period of breastfeeding, lower age at first pregnancy, later age at menarche, lower alcohol consumption and lower prevalence of obesity (48). The incidence of breast cancer is also increasing in these countries, and as Bray et al describe, this is often "considered the result of the "westernisation" of lifestyles, an ill-defined surrogate for changes in factors such as childbearing, dietary habits and exposure to exogenous oestrogen (…)" (p. 229) (58).

1.3 Screening for breast cancer

1.3.1 Organised breast cancer screening

The aim of breast cancer screening is to reduce disease-specific mortality by detecting breast cancer at an early stage, before it develops to advanced stage disease that is more difficult to treat (48). In most high-incidence countries, this entails screening asymptomatic women with an average risk of breast cancer with mammography at set intervals when they are in an age-range considered at increased risk for developing breast cancer (48). Screening does not diagnose breast cancer, but women with abnormal findings on the screening mammogram are referred for further assessment, including so-called triple assessment with a clinical examination, imaging and tissue sampling (48).

A report from 1968 commissioned by the World Health Organisation (WHO) described ten criteria that should be fulfilled when considering whether a condition is suitable for screening (59). These criteria included that the condition should be an important health problem, that there should be an accepted treatment, that there should be facilities for diagnosis and treatment and that the natural history of the condition should be adequately understood. With advances in diagnostics and treatment, numerous emerging or modified criteria have been proposed (60), and in Norway six additional criteria have been suggested (61). These new

criteria include a definition of the target population, equal access for the entire target population, informed consent, quality assurance to minimise potential risks of screening, ethical considerations and that overall benefits should outweigh the harms.

Screening can be described as organised or opportunistic. Organised screening programmes have a well-defined target population, national or regional units responsible for delivery of services to the entire target population, are subject to quality assurance and should enable informed decision making (48). Opportunistic screening refers to screening tests outside organised programmes, and rely on individuals requesting a test themselves, or on the initiative of individual healthcare providers (48).

Cancer prevention strategies may aim to prevent the development of cancer (primary prevention) or to detect cancer early enough to reduce mortality (secondary prevention) (48). Mammographic screening is a secondary preventive tool (48). It tests presumably healthy, asymptomatic women for breast cancer, aiming to detect and treat cancers at an early, curable stage (48). In order to potentially achieve the benefits of mortality reduction and reduce the incidence of advanced stage breast cancer, early detection must be followed by access to appropriate diagnosis and treatment.

1.3.2 Challenges in estimating the effectiveness of breast cancer screening

Breast cancer screening can, as most other medical tests, give false positive results. False positive screening results occur when women without breast cancer (unexposed) have abnormal screening mammograms (interpreted as exposed), and are recalled for further assessment (62). In BreastScreen Norway, the cumulative risk for false positive screening results after 20 years of biennial screening has been found to be 20% (63).

In breast cancer screening, some women will be diagnosed with breast cancer even though they would never have experienced any morbidity or mortality from the disease had it remained undetected. Consequently, these women undergo surgery and potentially also other treatment unnecessarily (overtreatment). The concept of diagnosing such tumours that would never have caused any problems if they remained undetected is referred to as overdiagnosis (48), which is not the same as wrong diagnosis. Overdiagnosis can't be avoided, as at the time of detection, one does not know whether the tumour detected would have grown fast without treatment or would have grown so slowly that it would never have caused the woman any harms without detection (48).

In the past decades, there have been numerous debates about the balance of potential benefits against potential harms of breast cancer screening. Many of the debates have centred around the related concepts of overdiagnosis and mortality reduction. Estimates of overdiagnosis and mortality reduction vary greatly, depending on whether studies use individual- or group-level data (64, 65), whether the follow-up time is long enough (64, 66), whether the study takes lead-time into consideration (66, 67) (Figure 9), whether the study focuses on women who are actually screened (per protocol) instead of including all women who are offered screening (intention to treat) (64, 66, 68), whether the study includes non-advanced cancers (65, 66), and other factors.
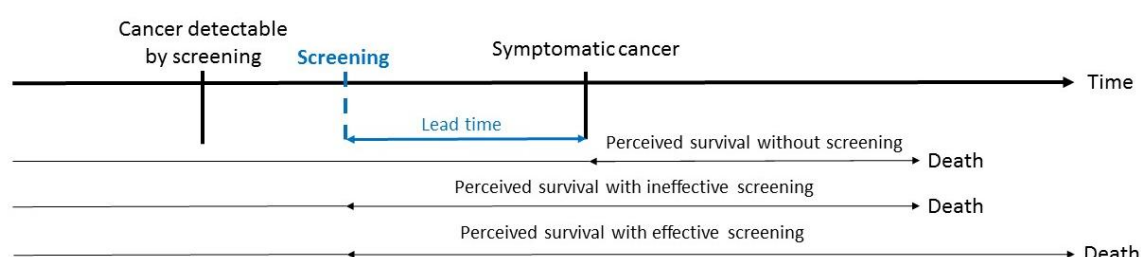
Figure 9: Lead-time is the time gained for treatment due to early detection compared to a situation where treatment would only be possible when the cancer became symptomatic.

A thorough discussion of methodological considerations and of the balance of benefits versus harms is outside the scope of this PhD study. The WHO body IARC and other national and international institutions have considered the benefits of mammographic screening to outweigh the harms, and mammographic screening is thus recommended as a secondary preventive measure to at-risk women in age groups targeted for screening in high-incidence countries (48).

1.3.3 Performance measures

Recommendations for breast cancer screening are themselves no guarantee that the desired mortality reduction will be achieved. The possibility to achieve a future mortality reduction from breast cancer screening also depends on how well the screening programme performs, which can be evaluated through performance measures (69). Performance measure include attendance rates, as well as screening outcomes, such as proportion of eligible women re-invited within the specified screening interval, rate of women recalled for further assessment, breast cancer detection rates and histopathological tumour characteristics. Set levels for

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performance measures are generally based on best practice rather than evidence, and the desired levels do not differentiate between immigrants and non-immigrants (69, 70).

1.3.4 Breast cancer screening in Norway

BreastScreen Norway started as a pilot project in four counties in 1996, and became nationwide in 2005 after a gradual expansion (71). Screening is performed at 26 stationary units and 4 mobile units that serve more rural areas. Women pay a user fee of 240 NOK (€26), which entitles them to the screening examination and diagnostic follow-up. The Cancer Registry Regulations (Kreftregisterforskriften) and the Personal Health Data Filing System Act (Helseregisterloven) regulate the programme, which is administered by the CRN (72, 73).

All women aged 50–69 are offered mammographic screening every two years, in total ten examinations over 20 years. Women receive the offer by a letter with a changeable, pre-scheduled time and date, and an accompanying information sheet. The letter and information sheet, in total four pages, are meant to provide women with "balanced, high-quality information about mammographic screening to enable them to make an informed choice about whether to participate" and to "ensure that women have the practical information they need to make use of their screening invitation" (p. S10) (71).

The letter offering screening and the information sheet are written in Norwegian, but two paragraphs about breast cancer screening and BreastScreen Norway are available in English, Urdu and Arabic after navigating through subpages in Norwegian on the CRN's website. Women who do not avail of the offer for mammographic screening receive a reminder four to eight weeks after their original appointment, informing them that they can call and re-schedule their appointment for screening.

The two-year period in which all women in the target age group are offered a screening examination is referred to as a screening round. The number of women offered screening in a screening round is currently about 600,000 and increasing. In each round, attendance is about 75%. Attendance varies between the counties, ranging from 62% in Oslo, the capital city of Norway, to 82% in the rural county Sogn og Fjordane (74). As described in chapter 1.1.1, net migration was negative or low until the 1970s, which is less than 50 years ago. Hence, few Norwegian-born children of immigrants have reached the target age for screening.

Mammograms taken at private institutions are not included in the national attendance rates. Women may obtain mammograms at private institutions before reaching the target age for screening and more often than the two-year interval in BreastScreen Norway. In 2008, an estimated 9% of women aged 45-49 had had a mammogram at a private institution over the course of one year (half a screening round), compared to 5% of women aged 50-69 and 7% of women aged 70-74 (75). The percentage of women who had had a mammogram at a private institution was in general greater in Oslo than in other parts of Norway.

Women offered to attend BreastScreen Norway from 1996 to 2015 have had similar distribution of income, but higher net worth compared to all women aged 25–67 (76). A quarter of the women offered screening had tertiary education, 22% received disability benefits, 10% had never been married and 12% lived in Oslo. Low attendance rates have been observed among women with low income, who were outside the workforce or unemployed, who were unmarried or divorced/separated and who lived in Oslo, among others.

The 72,207 immigrant women offered breast cancer screening from 1996 to 2015 accounted for 8% of all women offered screening (76). Immigrants had in general a lower distribution of income and net worth, higher proportion with tertiary education, married women and women living in Oslo, and fewer women receiving disability benefits than non-immigrants.

There was great variation in sociodemographic factors between immigrants from different regions invited for screening (76). Women from Northern Africa & Western Asia had the highest proportion of women with low income and <10 years education, but also the highest proportion with a Norwegian citizenship and the second highest proportion of married women. Women from Western Europe had the highest proportion of women with high income and net worth. Women from the Baltic countries had the highest proportion of women with employment and >17 years education. A lower proportion of immigrants from the Baltic countries lived in Oslo compared to non-immigrants, but for all other immigrant groups, a higher proportion of women lived in Oslo compared to non-immigrants.

1.4 Immigrants from Pakistan and their relevance for this thesis

1.4.1 The Norwegian-Pakistani community

In study IV, we explored Pakistani immigrant women's attendance in breast cancer screening in Norway. Pakistan is a country in South Asia, and despite linguistic, religious and other

sociocultural differences between and within the countries in South Asia, women from Pakistan are often grouped together with other women from South Asia for practical reasons and in order to increase statistical power in studies.

Pakistanis have a long history in Norway since the 1970's, and the majority of Pakistani immigrants living in Norway today immigrated more than 20 years ago (11, 77). While most of the early immigrants were labour migrants, those who immigrated after 1975 have primarily been family immigrants (78).

Immigrants from Pakistan make up the 9th largest group of immigrants in Norway and the 5th largest group if children of immigrants are included (5). Pakistani immigrants and their descendants (hereafter referred to as the Norwegian-Pakistani community) account for over 37,000 of the 5.3 million people living in Norway. Norwegian-Pakistanis are in many ways an integrated part of the Norwegian society, as they include members of parliament from three political parties, cultural personalities, high-profiled journalists and well-known medical doctors.

As a group, the Norwegian-Pakistani community differs from the overall population in Norway in several aspects. Sixty-seven percent of the Norwegian-Pakistani community reside in Oslo, compared to 12% of the total population (78). While three quarters of the Norwegian population are members of the Church of Norway, the vast majority in the Norwegian-Pakistani community are Muslims (79). In Norway, 69% of women aged 15–74 had paid work in 2008. Among Pakistani women who have immigrated to Norway through family immigration, only 31% had paid work, which is considered low even compared to other immigrant women (80). As part of the explanation for these differences, Statistics Norway suggest traditional division of work in the household, low educational status and that many Norwegian-Pakistani women report difficulties with the Norwegian language (80).

1.4.2 Factors of possible influence to mammographic screening attendance
Studies in Europe, Northern America and Oceania have shown that immigrants and minority women have had lower mammographic screening attendance rates than other women (30-32). We thus expected that we would find lower mammographic screening attendance rates among immigrant women than among non-immigrants.

There are many factors influencing whether women will attend mammographic screening after receiving an offer to do so, regardless of immigrant status. Studies in Europe and Northern America have identified the cost of the examination, lack of transportation, trouble navigating the healthcare system, language difficulties, lack of translation, lack of social support, cultural norms, modesty, lack of knowledge about mammography and competing priorities as barriers preventing women from attending (81-83). The studies referred to were conducted in countries that varied in terms of healthcare systems, screening guidelines, inclusion and composition of immigrant groups and other aspects, and the identified barriers varied between the studies.

Some studies investigating such barriers have included women from Pakistan. A Canadian study with South Asian women aged 50 and above identified language, transportation, lack of female health providers and lack of knowledge as potential barriers to mammographic screening (83). A Danish study that included Pakistani immigrant women revealed that major life stressors and competing priorities dominated immigrant women's daily lives, which left little room for prioritising mammographic screening despite knowledge of breast cancer and the breast cancer screening programme (82).

Pakistani women may also be subject to minority stress, which is the additional stress minorities may experience through stigma, prejudice and discrimination due to their minority position (84). This stress includes coping with exogenous stress from, among others, discrimination and unfavourable sociodemographic status minorities may experience, but also internalisation of negative social attitudes and fear of how others may judge them.

1.4.3 Selecting an immigrant group for the qualitative study

In the qualitative study (study IV), we wanted to explore attendance among one of the larger immigrant groups that also had low attendance rates in BreastScreen Norway. We chose to focus on Pakistani immigrant women for several reasons. Pakistani immigrants make up one of the largest immigrant groups in Norway and have a long history in the country. Health service disparities that systematically exclude people with a Pakistani background could thus affect a sizable group, who have been exposed to the Norwegian language and public services over a long period of time.

From 1996 to 2015, 2978 women born in Pakistan were offered to attend BreastScreen Norway. Background material for the article based on study II in this thesis showed that when

considering women from 72 countries, women from Pakistan ranked 52nd in terms of ever having attended (59% for Pakistani women versus 86% for non-immigrants). However, women receive 10 invitations over 20 years, and looking at attendance following all invitations, women from Pakistan ranked 70th (34% attendance for Pakistani women versus 78% for non-immigrants), indicating that many Pakistani women who have attended have not done so regularly.

South Asian immigrant women in Norway had lower incidence rates of breast cancer than non-immigrants between 1990 and 2012 (25). A Norwegian study showed that South Asian immigrant women have had more advanced disease and have been younger at diagnosis than non-immigrant women (56). Another Norwegian study showed that immigrant women from two South Asian countries (Pakistan and Sri Lanka) and Somalia combined have had more advanced breast cancer and lower survival from the disease than non-immigrants (54). Breast cancer may thus be an important health concern for women from Pakistan. When looking at all invitations, women from Pakistan had among the lowest attendance rates. When dividing attendance rates after all invitations over attendance rates for ever having attended (all/ever), the difference was only larger for women from Somalia than for women from Pakistan.

One may argue that some of these arguments are even more valid for women from Somalia. However, I am not familiar with the Somali language or the Somali community, but I am able to speak and understand Hindi, the most widely spoken native language in India, and which is mutually understandable with Urdu, the national language in Pakistan. I was thus not dependent on an interpreter when talking to Pakistani women. I am also familiar with aspects of the Pakistani community, as described in chapter 4 (Reflexivity).

As far as I know, there have been no studies exploring Pakistani women's mammographic screening attendance in Norway. However, a study investigated Pakistani and Somali women's attendance in the cervical cancer screening programme, and identified, among others, lack of trust towards the healthcare system, lack of access to female doctors, religious beliefs and language difficulties as barriers to screening attendance (85).

2. Aims

Prior to this project, only one study had examined immigrant or minority women's attendance in BreastScreen Norway, showing that women residing in municipalities considered to be Sami communities had higher attendance rates, lower recall rates and lower cancer detection rates than women residing in municipalities considered to be non-Sami communities (86). We did thus not know the extent of possible differences in attendance rates and screening outcomes between immigrants and non-immigrants offered organised breast cancer screening in Norway. Further, we lacked knowledge and understanding of immigrants' experience of the screening venture.

The overall aim of this thesis was to provide knowledge regarding attendance in organised breast cancer screening and screening outcomes for immigrants in Norway, and to compare these findings to those for non-immigrants.

I attempted to bridge knowledge gaps and addressed the overall aim through four studies. The studies had the following objectives:

Study I: To compare mammographic screening attendance among immigrant and minority women to that of other women by giving an overview of previous studies exploring attendance rates among immigrant and minority women – a systematic review

Study II: To investigate mammographic screening attendance rates among various immigrant groups compared to non-immigrants in Norway. Further, we wanted to investigate how attendance rates varied between immigrant groups throughout the study period and with years since immigration – a cohort study with a historic cohort

Study III: To explore mammographic screening performance measures among non-immigrants and immigrants attending BreastScreen Norway – a cohort study with a historic cohort

Study IV: To improve the understanding of Pakistani women's attendance in breast cancer screening by mapping out the actors involved in the screening venture, explore how these actors work and what they do as actors influencing attendance – a qualitative study

3. Materials and methods

The four studies in this thesis covered a variety of study designs: a systematic review that included a meta-analysis (study I), two registry-based cohort studies with historic cohorts (studies II and III) and a qualitative study (study IV). As different study designs require different considerations, I have grouped the discussion of materials and methods into study I, studies II–III and study IV. As I've had a team of supervisors, project group members and other colleagues without whom I could not have written this thesis, I will mostly use the pronoun "we" rather than "I".

3.1 Study I

3.1.1 Data sources (materials)

Systematic reviews aim to identify all relevant studies addressing a clearly formulated question, exclude studies according to specified criteria, critically appraise the selected studies and summarise the findings (87). We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline's checklist in order to ensure that relevant considerations were taken in all parts of the study (88). Following the PICO framework (Population, Intervention, Comparison and Outcome) (89), we attempted to find out whether immigrant and minority women (P) targeted for mammographic screening (I) had lower attendance rates (O) than other women (C). We carried out a systematic search of PubMed, Embase, Google Scholar and Cochrane using combinations of variations of the following words/phrases: breast cancer, ethnicity, immigrant, migrant, minority, race, screening, mammography, mammogram, participation, attendance, inclusion and selection. The search phase identified 1369 articles to be considered for inclusion in the study.

3.1.2 Data handling

Women born in other countries than where the study was conducted were defined as immigrants. Women born in the country where the study was conducted, who had an ethnicity that was different to that of the majority population in the country, were defined as minority women. In some studies, women were categorised according to self-reported ethnicity or name recognition, not by registered country of birth. These women could be immigrants, but could also be a mix of children of immigrants, other non-immigrant minorities, non-immigrants married to immigrants and other non-immigrants. As all immigrants are

minorities, but not all minorities are immigrants, these women were categorised as minority women.

My main supervisor and I read all 1369 abstracts, and excluded articles that were written in languages other than English, Norwegian, Swedish or Danish, or had objectives irrelevant for the review. We read the full text of the remaining articles, scanned the reference lists in review articles for relevant studies, and excluded studies according to the following criteria;

- where it was not possible to extract data from later than 1994
- where only post-intervention data was available after 1994
- with <1000 participants
- where women in the immigrant or minority group could not be separated from other women
- where women aged <40 could not be excluded
- with a selected group of women (e.g. only women with a prior mammogram)
- where it was not possible to calculate absolute counts from reported percentages
- where calculated numbers differed from numbers presented in the article
- with other obvious or likely errors.

After these exclusions, 33 studies were included in the review.
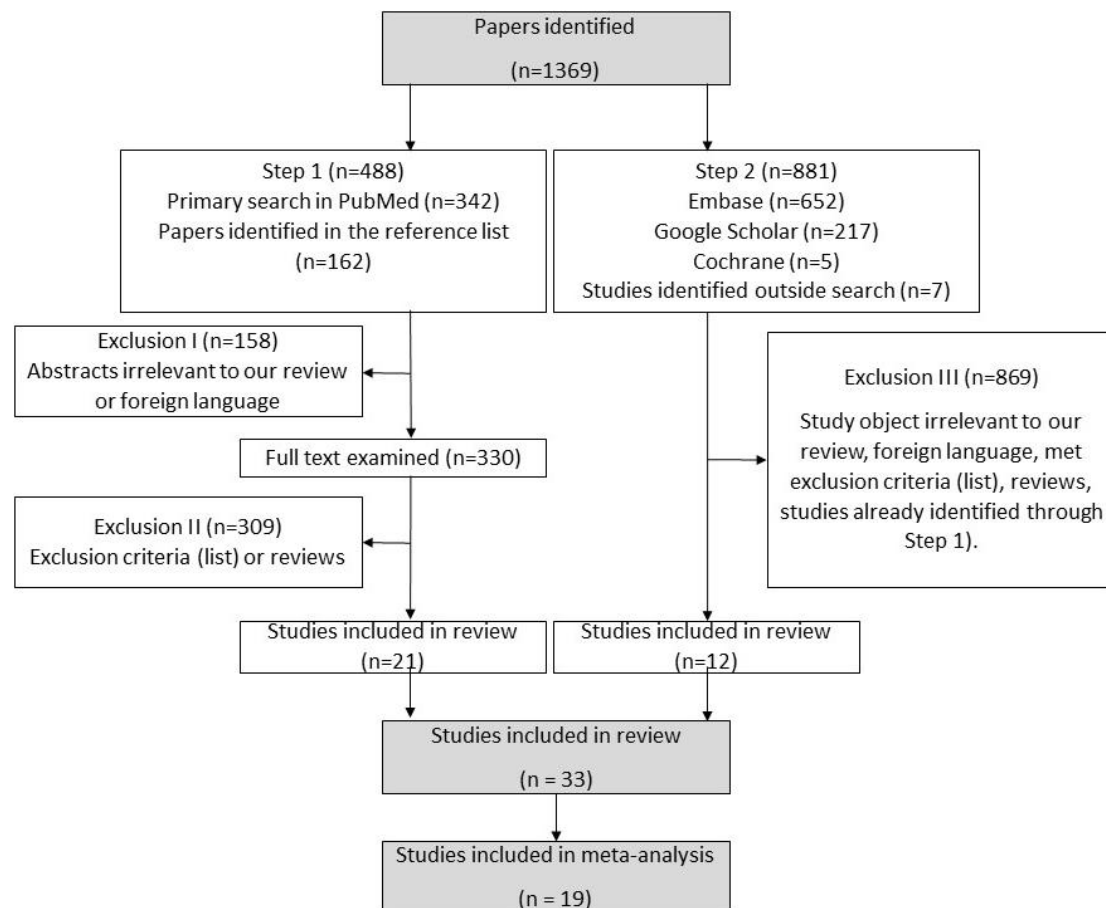
Figure 10: Flowchart of the study selection process. In the Cochrane reviews, articles that were included in the reviews were examined.

3.1.3 Data analyses

Data on screening attendance was extracted or calculated from the 33 studies that were included in the review. From these 33 studies, my main supervisor and I selected studies that compared attendance among immigrant or minority women to that of other women for a meta-analysis. Where studies reported both on recent attendance and whether the women had ever attended, we selected recent attendance. Where two studies had overlapping populations, the study with the highest number of participants or the longest study period was selected. For two articles that had populations partly overlapping with other studies, we were able to extract data not included in the other studies.

Nineteen studies with a comparison group were included in the meta-analysis. These studies answered similar, but not identical, questions. They included different groups of immigrant and minority women, and had different classifications of immigrant and minority women.

Some studies explored attendance among selected groups of immigrants or minorities where other immigrants and minorities were included in the control group (thus we used the term "other women" rather than non-immigrant or non-minority).

The studies were performed in settings that varied greatly in aspects such as organisation of breast cancer screening, access to individual-level data and attendance rates in the control group. We did not expect the true effect to be the same in all the studies, and used a random effects model for the meta-analysis (90). However, we performed sensitivity analyses with a fixed effects model, a model purely based on population size and a model excluding the three largest studies. We calculated odds ratios (OR) comparing screening attendance among immigrant and minority women (cases) to that of other women (controls). We used I^2 statistics to assess statistical heterogeneity among studies, and interpreted I^2 vales of 25%, 50% and 75% as low, medium and high heterogeneity, respectively (91).

3.1.4 Ethical considerations

Study I did not contain original individual-level data and did not require approval from an ethical committee or data protection authority. All data was collected from articles that had undergone a peer-review process before publication. Peer-reviewed, scientific journals are expected to take precautions in order to ensure that the articles they publish follow the most up to date ethical guidelines. However, the data might originally have been collected for other purposes than to compare mammographic screening attendance rates.

The decision to perform the study may itself be an ethical consideration. Many studies have compared mammographic screening attendance rates among immigrant and minority women to that of other women, but a systematic review was lacking. As individual studies may result in contradicting outcomes, it was important with a summarising systematic review for this topic that has been extensively researched.

3.2 Studies II–III

3.2.1 Data sources (materials)

Studies II–III were cohort studies with historic cohorts (87). These studies had two main sources for individual-level data; the CRN and Statistics Norway. All legal residents in Norway are assigned a unique eleven-digit personal identification number (PIN) based on

their date of birth and gender. The women's PIN was used to merge registry data from the CRN to data from Statistics Norway on an individual level. A project-specific serial number replaced the PIN for each woman before the data was released to me and other researchers.

Statistics Norway is an autonomous institution responsible for official statistics in Norway and is subject to guidelines and financial framework by the Norwegian government and parliament (92). The institution's statistics are produced based on raw data mainly from administrative registries and survey questionnaires. Data is obtained from approximately 80 administrative registries, among others the Populations Register, which is maintained by the Directorate of Taxes, and the Norwegian Labour and Welfare Administration's Register of Employers and Employees. Statistics Norway supplies individual-level data to researchers at approved institutions given compliance with data protection rules.

In study II, we merged data about breast cancer history and screening attendance from the CRN with data about date of birth and death and sociodemographic factors not available at the CRN (country of birth, immigration, emigration, county of residence, income, net worth, education level, disability benefit recipient status, marital status and citizenship) from Statistics Norway.

In study III, we merged data about performance measures and breast cancer from the CRN with data about date and country of birth from Statistics Norway. The performance measures under study were attendance rates, screening history (prevalent or subsequent screens) and the following screening outcomes: recall rates, positive predictive values (PPV), cancer detection rates and tumour characteristics (histopathological type, maximum tumour diameter, histological grade, lymph node-, ER-, PR- and Her2-status).

3.2.2 Data handling

The study population in study II consisted of 885,979 women in the target group for BreastScreen Norway with no history of breast cancer. These women received 4,053,691 invitations to the programme between January 1996 and December 2015, an average of 4.6 invitations per woman. The women were born in 195 different countries, which I categorised into 20 geographical regions. The regions were modified from the United Nations' Population Division (1) based on geographical proximity, and political, historical and cultural similarities.

The source files for sociodemographic data from Statistics Norway, which included women born 1901–2015, allowed us to categorise annual income and net worth into deciles for all women aged 25–67. We chose this age range even though study II included women aged 50–69 only in an attempt to compare women's income and net worth to that of working women. Women with a disability degree reported as ≥50 were classified as disability benefit recipients. In order to ensure that income, net worth and disability benefit recipient status referred to values leading up to the screening examinations, we used values from the year prior to each screening appointment.

Using a variable for county of residence, we were able to categorise women as living in Oslo or not at the time of the screening appointment. For educational status, Statistics Norway provided information about the highest level of education recorded. These levels were classified as primary and lower secondary (≤10 years), upper secondary (11–13 years), short tertiary (≤4 years of college/university) and long tertiary (>4 years of college/university). For marital status (not married, married/registered partner, unmarried or widowed) and citizenship, only the most recently updated data were available.

In study III, we examined attendance for 887,443 women with no history of breast cancer, offered screening between January 1996 and December 2015. As screening examinations were the unit of analysis, analyses other than attendance only included the 752,676 women who had attended at least once. We divided the women's birth countries into countries with high and low incidence of breast cancer, based on the results in study II, where we observed that groups of women with low attendance rates often were born in countries with a low incidence of breast cancer. Low-incidence countries are in general less affluent than high-incidence countries, and are also less likely to offer mammography through organised screening programmes. Geographical variations in incidence of and survival from breast cancer could be associated with differences in diet and reproductive and hormonal factors (93), as well as differences in mammographic screening uptake, and it is possible that these differences lead to variations in performance measures.

For screening history, we defined prevalent screens as the first screening examination in BreastScreen Norway. Subsequent screens was defined as all screening examination after the prevalent screen, regardless of the number of years since the previous examination. Recalls were defined as examinations where women were called back for further examinations due to abnormal mammographic findings on the screening mammogram. We defined PPV as the proportion of screen-detected cancers (SDC) among recalls. We included both carcinoma in

situ and invasive cancers in the definition of breast cancer. We referred to SDC as breast cancers that were diagnosed after a recall within six months after the screening examination. Breast cancers diagnosed after negative or false positive screens, either before the next scheduled examination or within two years among women who had reached the upper age-limit for BreastScreen Norway, were referred to as interval breast cancers (IBC).

Histopathological type was categorised as DCIS, invasive carcinoma of no special type, invasive lobular carcinoma and other. For all tumour characteristics other than histopathological type, we excluded DCIS. We examined whether the maximum tumour diameter was ≥2 cm, whether the tumours were ER-, PR- or Her2-positive, whether there were positive lymph nodes, and the histological grade. Using ER-, PR- and Her2-status, we classified tumours by immunohistochemical (IHC) subtypes based on a modified version of the St. Gallen surrogate IHC-classification of molecular subtypes of breast cancer (43). Her2-status was not available prior to 2005. We did not consider Ki67 proliferation status in the modified classification, as this was only available for 1.4% of tumours.

In studies II–III, we excluded screening episodes where the woman had been diagnosed with breast cancer, had emigrated or had died before the scheduled screening date.

3.2.3 Data analyses

In studies II–III, we used established statistical methods as described in epidemiological textbooks (87, 94-97). We performed descriptive statistics of attendance by country of birth, screening period and years since immigration. We used Fischer's exact test to compare attendance among immigrants to non-immigrants, and among immigrants from HIC, MIC and LIC over time. We used Poisson regression to compare attendance among immigrants, stratified by region of birth, to non-immigrants, and calculated crude and adjusted RR with 95% confidence intervals (95% CI) for attendance after the first invitation the women received (first invitation) as well as for whether they had ever attended (ever attendance).

We performed pairwise associations between candidate variables to avoid multicollinearity, using the coefficient of determination (R^2) with a cut-off value of 0.10, and ended up excluding age and employment status from our adjusted model. The adjusted regression model included income, net worth, education level, disability benefit recipient status, marital status, citizenship, place of residence and screening year. As values can change from one

examination to another, we used sociodemographic values from a random invitation for ever attendance, and also excluded screening year.

In study III, we calculated distributions of prevalent and subsequent screening examinations (screening history), recalls, SDC and IBC among all screening examinations. As IBC could be diagnosed up to two years after the screening examination, analyses of IBC did not include women screened after 2013. The distribution of histopathological type was presented for all malignancies, while the remaining tumour characteristics (tumour diameter, histological grade, lymph node status, molecular subtype, and ER- and PR-status) were presented for invasive cancers only.

Results for immigrants were stratified into high- and low-incidence countries. Using Fisher's exact test, we compared performance measures for each group of immigrants to non-immigrants. Student's t-test was used for comparisons of means (age at screening, age at diagnosis and tumour diameter). Using Poisson regression, we calculated RR with 95% CI unadjusted and adjusted for screening history and age (RR_{adj}), comparing performance measures among immigrants with those among non-immigrants.

In studies I–III, all tests were two-sided, and we considered p-values <0.05 as statistically significant. All statistical analyses were carried out using STATA/MP 14.1 or 15.0 for Windows.

3.2.4 Ethical considerations

The use of data in studies II–III had been approved by the Regional Committees for Medical and Health Research Ethics (reference 2013/795). Collection of data by the CRN and use of screening data for administrative, quality control and research purposes is regulated by the Cancer Registry Regulations (72). This includes the use of information about the screening examination in BreastScreen Norway. Registry data from the CRN and Statistics Norway were merged on an individual level for each woman, increasing the risk of identification. However, data was analysed using a project-specific serial number instead of the women's PIN, reducing the likelihood of identification, and we presented results on group level only.

I did not obtain consent from each woman individually. In fact, there was no direct interaction between researchers and the study participants, and almost all study participants are unaware that they have been part of these studies. While the CRN is exempt from

obtaining consent for use of individual screening and cancer data according to regulations, women have the option to opt out of registration of normal findings, but not if the examination leads to detection of malignant disease. We obtained data for all women who had not refused registration of normal findings for quality assurance and research, and all women who ultimately received diagnosis of breast cancer.

3.1 Study IV

3.3.1 Study participants

The interviews with the study participants were the main source of data in study IV. Field work was conducted in the greater Oslo area in 2017 and 2018, where organised screening has been offered since the start-up of BreastScreen Norway in 1996. I was provided with contact details for potential study participants from members of the project group for this PhD study (referred to as the project group), Norwegian classes for adult immigrants and a non-governmental organisation (NGO). While several potential interviewees were interested in the study, some did not have time to take part in interviews, some wanted group teaching sessions about mammographic screening and breast cancer rather than to participate in interviews, and others wanted to participate, but only by phone. Further, some project group members only agreed to recruit study participants if the interviews were conducted by phone. Consequently, we obtained permission to conduct interviews after getting oral rather than written consent, arguing that this would allow us to recruit women who wanted to be interviewed by phone and women who could not read or write. We ended up with a convenience sample of 16 women with a Pakistani family background who agreed to participate in dialogical, exploratory in-depth interviews.

Despite being a convenience sample, the interviewees showed variation in several aspects. Fourteen interviewees lived in the greater Oslo area, while two lived in other parts of the country. Thirteen women, all born in Pakistan, were in the target age group for breast cancer screening (age range 50–64) and three women with a Pakistani family background, two of whom had lived at least part of their childhood in Pakistan, were younger than the target age group (age range 24–39). Some had immigrated to Norway in the last few years, while others had lived in the country for decades. Ten of the women in the target age group for screening had attended regularly (always) or irregularly (at least once), while two had turned 50 but were still waiting for the date for their first appointment. One woman had never participated despite having received several invitations. Four of the women did not have any higher

education, of whom three could not read or write. Ten of the interviewees had paid work, and included both unskilled labourers and women in jobs that required higher education. Two of the women were medical doctors, but did not have work that involved diagnosing or treating breast cancer.

Nine key informants, of whom four had a Pakistani family background, were consulted for advice about breast cancer and mammographic screening among Pakistani women and about topics to cover prior to the interviews. Some of them were also consulted regarding temporary findings during and after the interview period. These key informants, who included health professionals, researchers and women working at NGOs, had experience working with immigrant health. Six of them had previously worked to increase screening attendance among immigrant women.

Other inputs included results from studies I–III, discussions with supervisors, conversations with project group members, presentations at scientific meetings, teaching sessions for health service personnel, presentations at Norwegian classes, media coverage and informal conversations. Inputs were discussed with co-authors, key informants and supervisors, and gave insights that helped to form the study.

3.3.2 Theoretical perspectives

Several models have been used in attempts to understand (non-)attendance in mammographic screening among women with an Asian family background. Some studies have tried to understand attendance through the Health Belief Model, which attempts to predict health-related behaviour with an emphasis on a person's beliefs (98, 99). Simplified, if a woman believes breast cancer is a serious illness, that she is susceptible to breast cancer, that mammographic screening is beneficial and barriers are overcome, she will go for screening. Other studies have used the Theory of Reasoned Action, in which individuals are considered to be rational, and will decide whether to engage in a certain behaviour if they deem it reasonable after considering the available information (98). Yet other theoretical perspectives that have been applied to try to understand or increase screening attendance among women with an Asian family background include the Social Cognitive Theory in attempts to understand attendance in relation to women's self-efficacy (98), the Cultural Explanatory Model trying to understand how the socio-cultural context influences knowledge, attitudes and behaviour relating to care (100), identifying barriers preventing attendance and

facilitators enabling attendance (101), and exploring the need for tailored information (102, 103),

We considered several of these theoretical perspectives, but sought a model that better encompassed both actions that are a consequence of careful reasoning as well as actions that are influenced by social interactions, daily routines, emotions and other considerations not purely explained by reasoning. Ultimately, we were inspired by French anthropologist Bruno Latour, who introduces a way of understanding the social world in which we live our lives (104). He suggests that the social domain consists of human and non-human actors. These actors interact by making each other do things. As described by Latour (p. 46) (104):

> *An actor is what is made to act by many others. An 'actor' (…) is not the source of an action but the moving target of a vast array of entities swarming toward it.*

This means that a woman's decision to attend screening or not is a result of the actions of numerous human and non-human actors with which she interacts. It is by following the actors in their own ways and by exploring the associations between them, to see how they are connected and how they change, that one can observe the different ways in which actors make other actors do things, such as lead to uncertainty, create possibilities, give worries and promote reflections, as well as "authorise, allow, afford, encourage, permit, suggest, influence, block, render possible, forbid, and so on" (p. 72) (104), actions for other actors.

The actors are interdependent and all benefit from being part of the network. When a woman attends screening, she gets to find out if she has breast cancer, the radiographer and radiologist get to do their jobs, and the feedback mechanisms and equipment perform the tasks for which they are made. The network will fall apart if an actor is not fully activated or is absent from the network. For instance, if the radiographer is absent (or present but unable to communicate with the woman), the woman can't go through with the examination and the machine does not get to perform the tasks it is made for.

Latour differentiates between intermediaries and mediators. Intermediary actors are more straightforward to understand, as they transport force or meaning without transformation; what you put in defines what you get out. For instance, when you press the elevator button, you expect the elevator to arrive at your level. We were more interested in exploring and understanding mediating actors, where the input is not necessarily a good predictor of the output. For instance, some women who receive an offer for screening attend, and some don't. The letter offering screening is thus a mediator, as the service provider does not know

whether women will attend or not when they send out the letter, and neither the infinite number of actions that occur from the letter is sent to the decision about screening attendance is made. In the wording of Latour (p. 39) (104):

> *Mediators transform, translate, distort or modify the meaning or the elements they are supposed to carry.*

In order to identify an actor, Latour wants us to ask: "Does it make a difference in the course of some other agent's action or not?" (p. 71) (104).

As the input from a mediating actor cannot fully predict the output, we cannot use them as a recipe for how they act. We rather consider the actor perspective as a sensitising concept, which we use to suggest in what directions to look (105).

We aimed to map out actors involved when Pakistani women attend breast cancer screening, and to explore what the actors do as actors, and thereby observe the variety of ways actors make other actors do things, such as create thoughts and emotions that encourage, permit, limit or prevent screening attendance.

3.3.3 Interviews

I conducted all interviews with study participants and conversations with key informants myself. I attempted to treat the interviews as processes where knowledge was created in the interaction between me, the interviewer, and the interviewee, keeping in mind that this knowledge was made possible by the interaction, as described by Holstein and Gubrium (106). This is opposed to treating the interviews as a process where the respondents sit on pre-existing, non-dynamic facts that we only have to ask the right questions to reveal.

As we discussed sensitive matters, I believed individual interviews were more appropriate than focus group discussions, as some women might be reluctant to discuss issues related to breasts with a group of people they did not know. I used interview guides in the interviews (Appendix). These guides were an aid guiding what topics to discuss and were also used to steer the conversation back to relevant topics when needed, not a checklist to be followed chronologically. The interview guides were semi-structured and consisted of bullet points rather than questions. The guide for the initial interviews also included a word map and vignettes. The vignettes were statements from key informants and project group members and imagined situations that the women were asked to comment on. The guide for the initial

interviews was influenced by various inputs, including conversations with peers, key informants, project group members and supervisors and by literature searches.

One interview was conducted at a University location with which I am affiliated, and also the interviewee had an affiliation with this institution. Most other women were interviewed at a neutral location, other than those who were interviewed by phone. While the interviews generally lasted for at least 40 minutes, the duration ranged from 26 to 74 minutes. The default language in the interviews was Norwegian. However, seven women were interviewed in Urdu, as some of them did not speak Norwegian, some had problems understanding my Norwegian dialect and some only agreed to participate if the interviews were conducted in Urdu. I wrote out all interviews sentence by sentence in Norwegian, regardless of the spoken language of the interview.

Four women agreed to participate in repeat interviews. We aimed for repeat interviews in order to strengthen the findings by giving the participants time for reflections and to take part in these reflections. Interview guides for the repeat interviews were based on findings in the initial interviews and the ongoing analyses.

3.3.4 Data analyses

In study IV, the analytical process was considered a continuous activity throughout the project. Observations and analyses were discussed with co-authors, project group members and key informants throughout the study period. I got an overall impression of the transcripts and field notes by reading through them repeatedly. I then went through the texts line by line, identifying phenomena of potential interest, which were labelled with descriptive codes. These codes consisted of keywords or phrases describing the text of interest. Related codes were grouped together in themes, and I wrote analytical notes for the themes. The analytical notes influenced the interview guide for repeat interviews.

We looked at the material from multiple perspectives, such as rationales for attendance and the work women needed to perform in order to attend breast cancer screening. However, based on the interviews and the analytical notes, inspired by Latour's description of actors, we decided to identify and explore human and non-human actors that play a role when Pakistani women attend mammographic screening. The coding process was repeated in order to map out actors and see how they act, and the transcripts were coded according to these actors. We

analysed and discussed individual actors (chapter 5.4) and overall findings (chapter 6.1.4.) in relation to previous research and relevant theoretical inputs other than the actor-perspective.

The initial coding process, where I generated new labels (codes) that I attached to text fragments of interest without being limited by the number of potential codes, can be described as open (107), while the latter part of the process mapped out core categories based on the theoretical input from the actor perspective.

The interviewees offered opinions about how other women than themselves reason and act, as well as advice about how to make more Pakistani women attend screening. As the women are not only passive actors that are being acted upon, but also act back on the other actors, we sought and included their advice in our analyses in order to get a more complete understanding of the actors in the network.

The format of presenting findings from study IV differs from the format of presenting results from the other studies. Qualitative studies typically focus on identifying, describing and explaining the findings rather than presenting numbers, and may, as in the presentation of findings in this thesis, involve use of quotations and presenting findings in theoretical contexts (108).

3.3.5 Ethical considerations

The study was approved by the Norwegian Data Protection Authority (case number 2017/2727). I obtained written or oral consent from the 16 women interviewed. In order to protect the women's identity, they were given pseudonyms, and their reported age was 0–2 years higher or lower than their real age. Some study participants asked repeatedly if I could confirm that their names would not be published anywhere, and these women were explained that their real names would not figure anywhere other than in the consent form. The interviews were recorded with an audio recorder, and the recordings were deleted after transcription. The transcripts were stored on an encrypted server, which was only accessible to authorised personnel. Directly person-identifying information, such as names, and indirectly person-identifying information, such as education, place of work and screening history, were removed before transcripts were transferred away from the encrypted server.

4. Reflexivity

4.1 An interpretation of reflexivity

Researchers have subjective impressions and values that can influence their findings. Dewalt, Dewalt and Wayland state that "We need to be aware of who we are, understand our biases as much as we can, and to understand and interpret our interactions with the people we study" (p. 290) (109). In qualitative research, these influences are considered an inevitable part of the research process (107). Hennink, Hutter and Bailey describe reflexivity as a process that involves conscious self-reflection on the part of the researchers to make explicit their potential influences on the research process (110). In short, reflexivity refers to the process where the researcher reflects over his position's influence on the knowledge that is generated in the interaction between the researcher and the study participant.

4.2 About the first author

I was the lead investigator in all studies described in this thesis. During the study period, I was 31–34 years old. I'm a medical doctor who graduated from Trinity College Dublin in 2009. As a medical student, I spent a summer as a volunteer worker at a hospital in Zambia, and worked as a student with a temporary licence to practice medicine at a nursing home in Norway. After graduation, I did my medical internship in Dublin and Limerick, before I worked as a doctor in the Norwegian Armed Forces for two years, both in Norway and in Afghanistan, a country in South Asia. After I left the armed forces, I started specialising in oncology, and worked at the university hospitals in Trondheim and Bergen for a total of 3.5 years. Through my education and work, I've been exposed to people living under a variety of circumstances in different cultural contexts, as well as healthcare services in several different settings. This could serve as a strength, as I believe it has put me in a better position to understand that immigrants have emigrated from countries that differ greatly in the way health services are offered.

I conducted this PhD study with BreastScreen Norway at the CRN and the Institute for Health and Society at the University of Oslo. For the first two years and four months, I worked fulltime on the PhD study. This gave me the opportunity to focus on the PhD study and time to gain in-depth knowledge about relevant and interesting topics. Since the end of July 2018, I have in addition worked part-time (40%) as an acting consultant oncologist at a local hospital in a suburb of Oslo.

My parents emigrated from India to Norway about 40 years ago. As my family background is Indian, I have experience of being a minority and have a family background from foreign country. I might also be considered a *Desi*, a term South Asian people use to describe the people, their diaspora, the culture and languages they share. I've grown up in a Hindu family, but consider myself an atheist. My first language is Norwegian, and I'm also fluent in English. As mentioned previously, I am also able to communicate with Pakistani women in Urdu, if they prefer so, as I also speak Hindi.

I'm born and raised in Bergen, a city on the west coast of Norway. Two-thirds of people with a Pakistani family background in Norway live in Oslo, and only a small proportion of people with a Pakistani family background live in my home city of Bergen (78). I have thus had little prior interaction with the Norwegian-Pakistani community. My Norwegian dialect from Bergen appeared to be hard to understand, even for some of the women who said they knew Norwegian well, which in some interviews was the reason why the language switched from Norwegian to Urdu during the interview.

4.3 Reflexivity in studies I–III

While the concept of reflexivity is often associated with qualitative research, I will in this section discuss reflexivity in terms of the quantitative studies in this thesis.

Co-authors, supervisors and other people involved in the PhD study had very different backgrounds. They varied greatly in their knowledge of, and experience with, mammographic screening, biomedicine, statistical analyses and research interviews, among others. Most had mainly been involved in quantitative research, while some had extensive experience with qualitative research. This served as a strength, as they emphasized different values, and their combined in-depth knowledge covered a broad range of aspects relevant to the PhD study. However, all contributors advised me strongly to include information they considered important influenced by their backgrounds, and focused on very different topics they urged me to highlight, especially in the introduction section of this thesis. Consequently, I was advised to include more information than what was feasible in the articles and in this thesis. For instance, the introduction and discussion in this thesis were far longer than they are now, and at one point, the article for the qualitative study (study IV) was over 16,000 words. Further, the contributors differed greatly in their feedback, often giving contradicting recommendations in terms of wordings, content, structure, analytical approaches and

interpretations. For instance, some wanted me to get straight to the point, while others focused on elaborating, spending time to let the knowledge mature and criticising the current status. Having analysed the data in all four studies myself, I arguably had the most comprehensive understanding of each individual study and how they relate to each other. I believe that I was well positioned to choose the most suitable of two or more contradicting options. However, as I seldom considered either advice as wrong, I ran the risk of choosing the easiest option rather than the most suitable option.

As a medical doctor specialising in oncology, my daily work in the years prior to this PhD study mainly involved treating patients who were already diagnosed with cancer with medication, radiotherapy or best supportive care. While I have some years experience dealing with cancer patients, I have little experience dealing with cancer-free people undergoing preventive or diagnostic cancer-investigation.

This PhD study focuses on screening and early detection of breast cancer. The studies required skills that were very different from those I had prior experience with or knowledge about, and my lack of skills and experience with screening and early detection of breast cancer could be a limitation in this PhD study. I had learnt very basic statistical theory in medical school, and I learnt more basic statistics through an online course with the Norwegian Medical Association, including how to use SPSS for simple statistical analyses. My statistical and epidemiological knowledge were nowhere close to being at the level required in this project, and I had no experience with complex statistical programmes such as STATA. Competent colleagues, intensive studying and a course in STATA helped me acquire the skills needed for studies I–III, and I subsequently conducted all the analyses myself.

My medical background clearly served as a strength in several aspects of the research work, as I was very familiar with concepts used in studies I-III, for instance negative and positive test results, cancer diagnoses, the expected natural course of untreated cancer, tumour characteristics and differences in prognosis for early- and late-stage disease. My medical background may however have made me focus more on biomedical aspects of medicine and cancer, and less on cultural and societal aspects.

I did not collect any data from the participants, and could thus not directly influence the raw data. I cleaned the raw data for errors, organising it in ways that were convenient for the analyses process, and tested data handling through preliminary analyses. In this process, I discussed the measures taken and results from preliminary analyses with my main supervisor

and other colleagues at the CRN who were experienced in handling registry data, and followed their recommendations.

The handling of raw data and analyses chosen influenced the results of the studies. This includes choice of search phrases, handling of studies without absolute counts and model of analysis for the meta-analysis in study I, choice of income variables and categorisation of income into deciles rather than quartiles or a continuous variable in study II, and handling of missing values and categorisation of countries in studies II–III.

4.4 Reflexivity in study IV

This PhD study consisted of both qualitative and quantitative studies. I did not have any experience with qualitative research methods before starting this PhD study. In fact, most of the research articles I've read since qualifying as a medical doctor have been quantitative. In addition to learning about qualitative research methods, I also had to get familiar with the related field of anthropology.

In the other studies, I analysed pre-collected data registered and collected by the CRN, Statistics Norway and the Population's Registry, among others. In study IV, data and knowledge was generated in the interaction between me, a researcher, and the study participants (111). As described below, I could in some ways be perceived as an outsider with preconceived assumptions, and in other ways an insider, being positioned to better understand the topics discussed from the women's own perspectives, both perspectives having the potential to influence the findings.

The women might have perceived me as an outsider with a connection to the service providers due to my position as a medical doctor and a researcher. This could explain why some women gave answers about cancer and screening before I had brought up these issues in the interviews. Further, all the participants were women, most of them belonging to a generation older than me. Friends, colleagues and key informants had raised the question whether it would be difficult for me to get in touch with Pakistani women, as they might be reluctant to talk to a man, which was an issue I brought up in most of the interviews. The women interviewed argued that as long as it was only a conversation and no examination, it was not a problem that I am a man. Some women did argue that women who seldom left their homes on their own would be reluctant to or prevented from talking to me because I am a man.

In some ways, my position as a *Desi* might have put me in an insider position with an understanding of the Pakistani community that could be unavailable to most non-*Desis*. The women could express themselves in their own language, and we had some cultural references in common. In fact, some women only agreed to participate if they could speak Urdu. Utilising my *Desi* background as well as allowing women with varied backgrounds, perspectives and experiences time to tell their stories was a way of promoting knowledge production. However, being a *Desi*, but a non-Muslim and non-Pakistani might have led me to make assumptions that are more true for Hindus and Indians, and less for Muslims and Pakistanis. My assumptions were challenged through conversations with the study participants and discussions with co-authors and key informants.

My knowledge of the Urdu language might have put me both in an insider and outsider position. The women might perceive me as an insider, as they could talk to me in their preferred language. However, I'm not fluent in Urdu, had to ask the women to clarify 2–3 times in most interviews, and had to look up some words in a dictionary afterwards. This made it clear that Urdu was not my preferred language, which might push me towards an outsider position for women who preferred to speak Urdu, as they might have needed to simplify their language.

After interviews, I offered women a symbolic gift, for instance a box of luxury chocolates or homemade crisp bread. The first interviews were conducted during Ramadan in 2017. As a non-Muslim, I do not fast during Ramadan. One woman had not told her family about the interview, as she thought they would disagree in her taking part. She did not accept my offer of homemade crisp bread after the interview, and I got the impression that she got uncomfortable by my offer. It was only later that I realised that there were several issues that I might have ignored. Firstly, offering dry crisp bread during Ramadan when Muslims fast might be considered inappropriate. Also, if she had hidden from her family that she was taking part in the interview, she might have problems explaining who had made the crisp bread and why she had received them.

5. Results

The studies in this thesis generated knowledge of different aspects of mammographic screening among immigrant women. Study II revealed differences in attendance rates between immigrant and non-immigrant women in Norway through a cohort study. These findings were in keeping with studies exploring differences in attendance rates between immigrant and minority women versus other women in Europe, North America and Oceania, as shown through a systematic review with a meta-analysis in study I. In study III, we explored differences in recall rates, histopathological tumour characteristics and other mammographic screening outcomes between immigrant and non-immigrant women among those who attended. Having observed differences in performance measures (attendance rates and screening outcomes), study IV explored attendance for one group at risk of non-attendance for breast cancer screening through a qualitative study. The idea behind such an approach was that in order to increase attendance rates for immigrant groups at risk of non-attendance, and thereby improve screening outcomes, we needed to get a better understanding of their attendance. In the following, I will present the results from each study individually.

5.1 Study I

The meta-analysis in this systematic review included results from 19 studies, and showed that immigrant and minority women had 36% lower odds for attendance in mammographic screening than the rest of the population. The OR was 0.61 (95% CI 0.43–0.88) in studies with data from European countries, 0.69 (95% CI 0.63–0.76) in studies with data from the US and 0.58 (95% CI 0.44–0.77) in studies with data from Oceania. Immigrants and minority women had lower mammographic screening attendance rates than other women in 18 of the 19 studies included in the meta-analysis. The only study deviating from this pattern was a study showing that Turkish minority women had higher attendance rates than other women in Germany.

The meta-analysis included studies comparing immigrants' attendance rates to that of other women in Australia, Canada, Denmark, the Netherlands, Sweden and Switzerland. These studies showed that immigrants had lower attendance rates than non-immigrants (64% versus 82%). Studies from Australia, England, Germany, New Zealand, Scotland and the US compared attendance among minority women with those among other women. These studies combined showed that minority women had lower attendance rates than other women (44% versus 53%).

Study	Country	Immigrant/Minority	Cases	Controls	OR (95% CI)
Europe					
von Euler-Chelpin et al. (2008)	Denmark	Immigrant	1125	38564	0.58 (0.51-0.66)
Kristiansen et al. (2012)	Denmark	Immigrant	11375	84489	0.62 (0.60-0.65)
Lagerlund et al. (2002)	Sweden	Immigrant	5242	40799	0.57 (0.53-0.62)
Vermeer et al. (2010)	the Netherlands	Immigrant	88342	2162320	0.36 (0.36-0.37)
Bulliard et al. (2004)	Switzerland	Immigrant	1517	8822	0.66 (0.59-0.74)
Jensen et al. (2012)	Denmark	Immigrant	5997	138219	0.43 (0.41-0.46)
Berens et al. (2014)	Germany	Minority	18658	404991	1.14 (1.10-1.17)
Szczepura et al. (2008)	the UK (England)	Minority	6829	142173	0.56 (0.53-0.59)
Bansal et al. (2012)	the UK (Scotland)	Minority	16348	123026	0.89 (0.86-0.92)
Subtotal (I-squared = 99.9%, p = 0.000)					
Oceania					
Weber et al. (2014)	Australia	Immigrant	24117	77225	0.78 (0.76-0.81)
BreastScreen Australia (2015)	Australia	Minority	486282	35359914	0.43 (0.42-0.43)
BreastScreen Aotearoa (2008-2015)	New Zealand	Minority	371875	2537158	0.59 (0.59-0.59)
Subtotal (I-squared = 100.0%, p = 0.000)					
Canada					
Sun et al. (2010)	Canada	Immigrant	3138	17397	0.73 (0.67-0.79)
Subtotal (I-squared = .%, p = .)					
the US					
Selvin et al. (2003)	the US	Minority	1514	3995	0.73 (0.64-0.82)
Edwards et al. (2009)	the US	Minority	60675	21047	0.73 (0.71-0.76)
Zhou et al. (2010)	the US	Minority	1155	5881	0.62 (0.55-0.71)
Meissner et al. (2007)	the US	Minority	2710	7253	0.75 (0.69-0.83)
Kandula et al. (2006)	the US	Minority	1574	15790	0.56 (0.50-0.62)
Aldridge et al. (2006)	the US	Minority	1737	64408	0.78 (0.68-0.91)
Subtotal (I-squared = 82.7%, p = 0.000)					
Overall (I-squared = 99.9%, p = 0.000)					

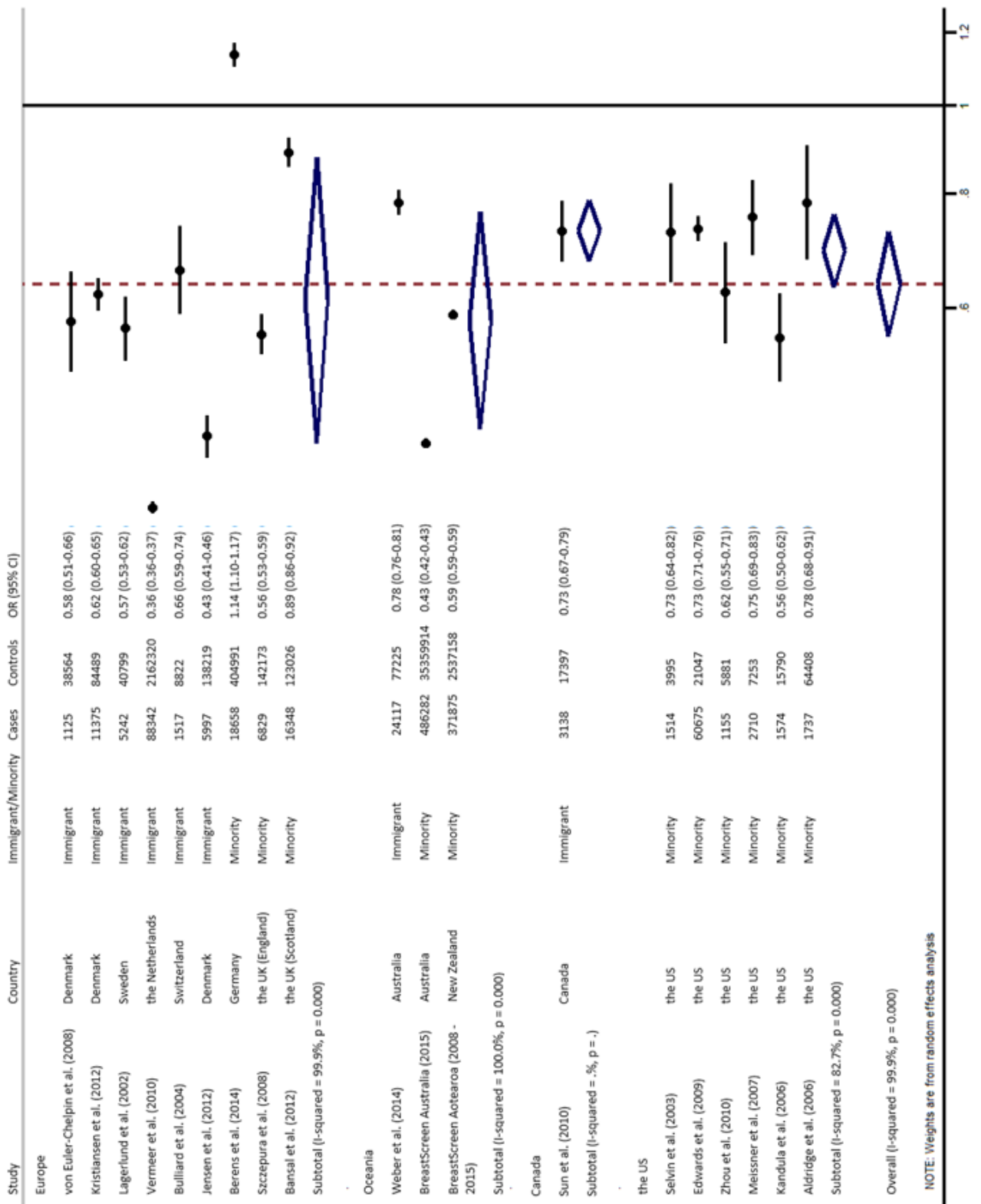NOTE: Weights are from random effects analysis

Figure 11: Meta-analysis of 19 studies comparing mammographic screening attendance rates among immigrant (I) or minority (M) women with that among the rest of the population.

5.2 Study II

Immigrants living in Norway from all countries (where at least 100 of the invited women were born) had lower mammographic screening attendance rates than non-immigrants after the first invitation they received, after all invitations they received during the study period, and for having attended at least once. Overall, 78% of all invitations sent to non-immigrants in the 20-year study period resulted in attendance, versus 56% of invitations sent to immigrants (p<0.001). Overall, 76% of non-immigrants had attended following their first invitation, versus 53% of immigrants (p<0.001). Overall, 86% of non-immigrants had ever attended, versus 67% of immigrants (p<0.001).

Non-immigrants had higher attendance rates than immigrants throughout the study period (Figure 12). However, attendance rates varied greatly between immigrant groups. Among immigrants, immigrants from HIC had the highest attendance rates throughout the study period, followed by immigrants from MIC. Differences in attendance rates between immigrant groups changed over time, and at the end of the study period, there was no longer any statistically significant difference in attendance after first invitation between immigrants from HIC and MIC (Figure 12).

Attendance rates increased with years since immigration for all immigrant groups. However, for women from LIC there was no increase in attendance with years since immigration for women who had immigrated less than 20 years ago.

Adjusting for sociodemographic factors attenuated the differences between immigrants and non-immigrants, but the differences remained pronounced for women from most regions. For women from the Nordic Countries, the British Isles and Oceania, differences in attendance rates between immigrants and non-immigrants were no longer statistically significant after adjusting for sociodemographic factors.

Table 3: The five highest and lowest attendance rates among immigrants by country of birth.

	All invitations		Attendance at least once	
	Highest	Lowest	Highest	Lowest
1	The Netherlands and	Somalia (14%)	The Faroe Islands and	Somalia (27%)
2	Denmark (74%)	Myanmar (30%)	Denmark (83%)	Slovakia (39%)
3	The Faroe Islands (73%)	Lithuania, Morocco and	The Netherlands (82%)	Lithuania (40%)
4	Switzerland (72%)	Pakistan (34%)	Sweden, Finland and	Palestine, Myanmar and
5	Sweden and Finland (71%)		Switzerland (80%)	Latvia (44%)
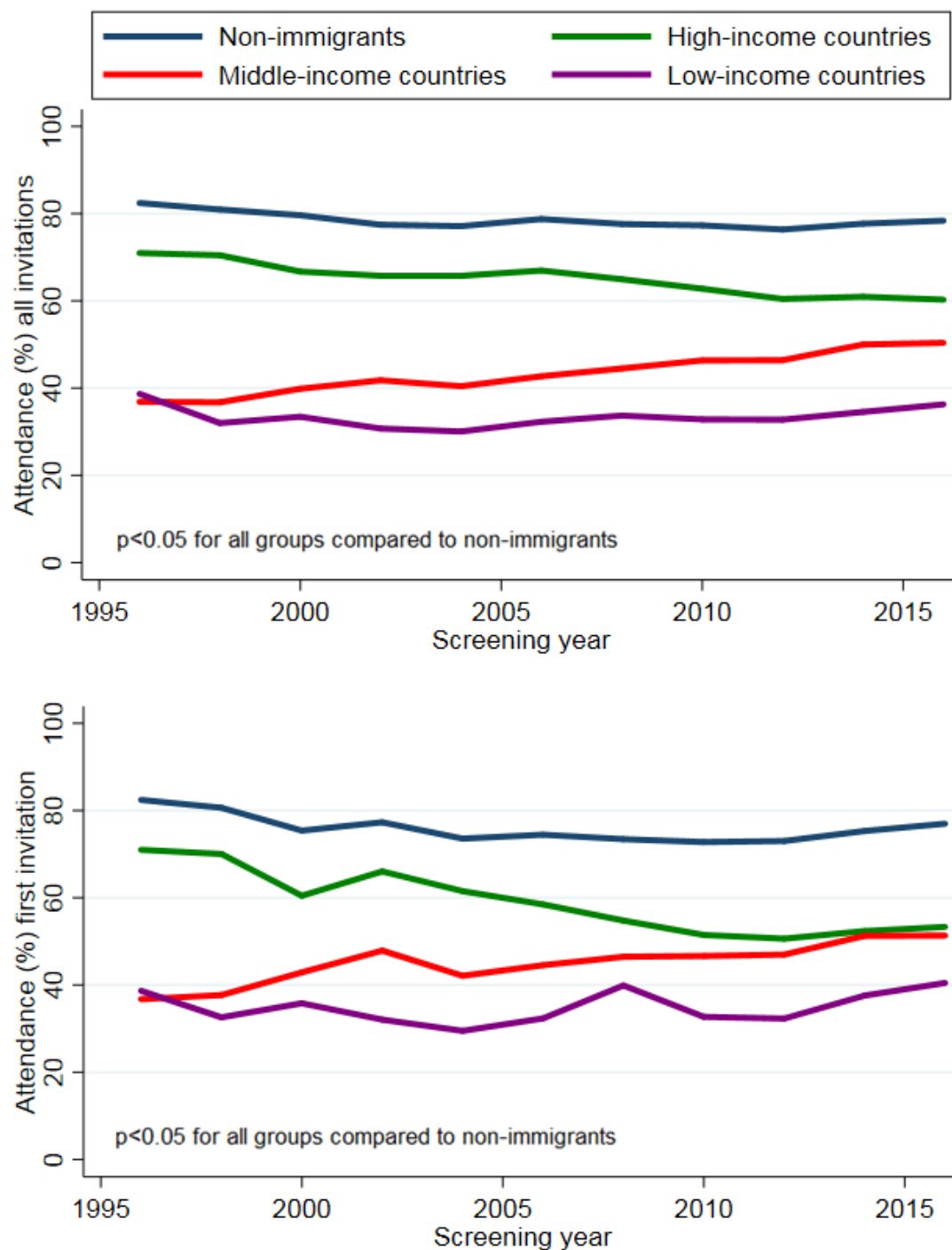
Figure 12: Attendance rates by scheduled screening year for all invitations from BreastScreen Norway (above) and following the women's first invitation (below).

5.3 Study III

Overall, 32% of all screening examinations performed among immigrants were prevalent screens, compared to 24% (p<0.001) among non-immigrants (Table 4). Immigrants had higher recall than non-immigrants (RR_{adj} 1.13, 95% CI 1.10–1.16) and lower PPV (RR_{adj} 0.93, 95% CI 0.87–0.99). RR_{adj} for SDC and IBC did not differ significantly between the two groups. RR_{adj} of SDC ≥2 cm among immigrants versus non-immigrants was 1.15 (95% CI 1.02–1.31). Regression analyses of the remaining tumour characteristics for SDC and IBC did not show statistically significant results when comparing immigrants to non-immigrants.

Overall, 27% of screening examinations among immigrants from high-incidence countries and 36% among immigrants from low-incidence countries were prevalent screens, compared to 24% among non-immigrants (p<0.001 for both immigrant groups compared to non-immigrants) (Table 4). Recall was higher for immigrants from high-incidence countries (RR_{adj} 1.10, 95% CI 1.06–1.15) and low-incidence countries (RR_{adj} 1.15, 95% CI 1.11–1.19) than for non-immigrants. Immigrants from high-incidence countries did not have statistically significantly different PPV than non-immigrants (RR_{adj} 0.98, 95% CI 0.90–1.06), while RR_{adj} for PPV for immigrants from low-incidence countries was 0.86 (95% CI 0.78–0.95). Immigrants from high-incidence countries had borderline higher RR_{adj} for SDC (1.09, 95% CI 1.00–1.19) and higher RR_{adj} for IBC (1.30, 95% CI 1.11–1.53) than non-immigrants, while immigrants from low-incidence countries had non-significant differences for SDC (RR_{adj} 0.98, 95% CI 0.89–1.09) and borderline significant differences for IBC (RR_{adj} 0.80, 95% CI 0.63–1.00) versus non-immigrants.

Compared to non-immigrants, SDC in immigrants from high-incidence countries were more often ER-positive (RR_{adj} 1.03, 95% CI 1.00–1.06), while differences in tumour characteristics for IBC were not statistically significant (Table 5). Compared to non-immigrants, SDC in immigrants from low-incidence countries were more often histological grade 3 (RR_{adj} 1.34, 95% CI 1.11–1.61), and IBC were more often triple-negative (RR_{adj} 1.81, 95% CI 1.11–2.94).

Table 4: Performance measures among immigrants and non-immigrants attending BreastScreen Norway. Relative risks are adjusted for age and screening history (prevalent or subsequent screen).

	Non-immigrants	Immigrants	Immigrants from	
			high-incidence countries	low-incidence countries
Invitations, no.	3,790,629	274,593	114,756	159,837
Screens, no.	2,951,375	153,026	78,756	74,270
Attendance, %	77.9	55.7***	68.6***	46.5***
Prevalent screens, no. (%)	704,309 (23.9)	48,367 (31.6***)	21,429 (27.2***)	26,938 (36.3***)
Age at diagnosis, mean (SD)	60.3 (5.8)	59.1*** (6.0)	60.6 (6.0)	56.9*** (5.1)
Attendance[a]	1.00 (ref)	0.72 (0.72 – 0.72)	0.88 (0.88 – 0.89)	0.60 (0.60 – 0.60)
Recall	1.00 (ref)	1.13 (1.10 – 1.16)	1.10 (1.06 – 1.15)	1.15 (1.11 – 1.19)
Positive Predictive Value (PPV)	1.00 (ref)	0.93 (0.87 – 0.99)	0.98 (0.90 – 1.06)	0.86 (0.78 – 0.95)
Screen-Detected Cancer (SDC) (1996–2015)	1.00 (ref)	1.04 (0.97 – 1.12)	1.09 (1.00 – 1.19)	0.98 (0.89 – 1.09)
Interval Breast Cancer (IBC) (1996–2013[b])	1.00 (ref)	1.07 (0.94 – 1.23)	1.30 (1.11 – 1.53)	0.80 (0.63 – 1.00)

* $p<0.05$, ** $p<0.01$, ***$p<0.005$. Non-immigrants as reference group.

[a] Adjusted for age only

[b] Screened 1996–2013, followed for IBC 1996–2015

Table 5: Relative risks for tumour characteristics among immigrants compared to non-immigrants attending BreastScreen Norway, adjusted for age and screening history (prevalent or subsequent screen).

	Screen-detected breast cancers				Interval breast cancers			
	Non-immigrants	All immigrants	High-incidence	Low-incidence	Non-immigrants	All immigrants	High-incidence	Low-incidence
Invasive (no.)	13,406	692	388	304	4099	216	143	73
Tumour diameter > 2cm	1.00 (ref)	1.15 (1.02–1.31)	1.16 (0.98–1.37)	1.14 (0.95–1.38)	1.00 (ref)	1.08 (0.95–1.23)	1.05 (0.89–1.24)	1.13 (0.92–1.39)
Histological grade 3	1.00 (ref)	1.14 (0.99–1.31)	0.98 (0.80–1.20)	1.34 (1.11–1.61)	1.00 (ref)	1.03 (0.87–1.22)	0.92 (0.74–1.15)	1.24 (0.98–1.58)
Positive lymph node status	1.00 (ref)	1.08 (0.95–1.24)	1.14 (0.96–1.36)	1.01 (0.83–1.23)	1.00 (ref)	1.03 (0.87–1.21)	1.08 (0.89–1.30)	0.93 (0.70–1.25)
ER-positive	1.00 (ref)	1.01 (0.98–1.04)	1.03 (1.00–1.06)	0.98 (0.94–1.03)	1.00 (ref)	0.99 (0.91–1.07)	1.02 (0.93–1.11)	0.93 (0.80–1.08)
PR-positive	1.00 (ref)	1.00 (0.95–1.05)	0.98 (0.92–1.05)	1.03 (0.96–1.10)	1.00 (ref)	0.96 (0.85–1.08)	1.01 (0.87–1.16)	0.86 (0.68–1.09)
Luminal A-like	1.00 (ref)	0.99 (0.93–1.06)	0.99 (0.91–1.09)	1.00 (0.91–1.10)	1.00 (ref)	0.89 (0.75–1.07)	0.87 (0.69–1.10)	0.93 (0.71–1.23)
Luminal B-like (Her2-negative)	1.00 (ref)	1.04 (0.83–1.30)	1.19 (0.90–1.56)	0.85 (0.59–1.23)	1.00 (ref)	1.23 (0.86–1.74)	1.31 (0.86–2.00)	1.08 (0.59–1.98)
Luminal B-like (Her2-positive)	1.00 (ref)	1.00 (0.76–1.32)	0.98 (0.66–1.44)	1.03 (0.70–1.51)	1.00 (ref)	0.92 (0.57–1.48)	1.26 (0.76–2.11)	0.42 (0.14–1.27)
Her2-positive (non-luminal)	1.00 (ref)	0.94 (0.56–1.56)	0.72 (0.32–1.59)	1.19 (0.62–2.28)	1.00 (ref)	0.85 (0.44–1.62)	0.79 (0.33–1.87)	0.94 (0.36–2.43)
Triple-negative	1.00 (ref)	1.00 (0.68–1.48)	0.80 (0.45–1.44)	1.24 (0.74–2.08)	1.00 (ref)	1.33 (0.91–1.94)	1.02 (0.58–1.78)	1.81 (1.11–2.94)

5.4 Study IV

We mapped out and explored actors in the networks surrounding Pakistani women when they attend screening. While it is impossible to discuss all actors that emerged in the 183 pages of interview transcripts, we aimed to focus on some actors that were important to the women when they considered attending BreastScreen Norway. In the following, these actors will be discussed, as well as opinions the interviewees offered about other actors, including other Pakistani women.

Trust in healthcare and mammographic screening:

The women interviewed had a high degree of trust in the Norwegian healthcare system in general and in mammographic screening specifically. They did not show any doubt in whether mammographic screening was appropriate and whether women should attend. Shabana was in the opinion that one should go for screening as the government offers the examination because they only want what is best for women. Asma thought that one should go in order to find out about ones health. Tahira argued:

> *[One should go for mammographic screening] instead of being worried that one has cancer. It is better to go for the examination and not have to worry*

In keeping with Grimen (112), one may consider a trusting person as one who is willing to leave something valuable in another person's custody. The women were confident that they should leave their bodies in the custody of the screening examination, and trust was thus an actor enabling screening. The interviewees trust in the importance of mammographic screening was so strong that they even enthusiastically offered reasons for why other women should attend. Their enthusiasm for screening is especially interesting considering that a recent Norwegian study identified lack of trust in healthcare as a barrier for attendance among Pakistani women in another national cancer screening programme – the cervical cancer screening programme (85).

The invitation letter and information sheet:

None of the women interviewed expressed that the written information from BreastScreen Norway had blocked their attendance. For women who did not know Norwegian or women who could not read or write, the letter had acted through putting people to work; the women contacted family members who could read Norwegian, and family members took time to

translate and convey the information. This can be understood as an example of the work clients have to do that is invisible to service providers (113).

Some women, including women who understood Norwegian, argued that translating information to Urdu would allow more people to attend, for instance as the information would be easier to understand and might be perceived as more interesting. According to one of the younger women, Begum, her mother was not interested in health-related information in Norwegian, but would attend health-related seminars in Urdu and tell her family enthusiastically what she had learnt when she came home.

Several of the women argued that the information from BreastScreen Norway was too comprehensive, which some of them said was a reason why they had not read the information (but still attended). Women advised that more women would attend if the information was short, basic, direct and in a wording that was easy to understand.

The radiographer's gender:

Before the screening examination, the women are interviewed by a radiographer, who inspects and sometimes touches the naked skin on their upper body. None of the women were comfortable with the idea of a male radiographer, and for some women, a male radiographer would have blocked them from attending. As expressed by Ifran:

> *It is a VERY big problem for many Muslim women, and even I would not have gone if it was a man. Absolutely not, because in Islam, it is like that, that one is not allowed to walk naked in front of men*

Also other women used their Muslim backgrounds as explanations for why they did not want to be examined by a male. Other explanations centred around culture and tradition, with interviewees explaining that Pakistani women are not used to interacting with men outside their close circles. A few of the interviewees were also concerned that husbands of some women would be reluctant to let their wives go for screening if they thought the examination was conducted by a man.

Some of the women had had male radiographers previously, and also these women were strongly opposed to male radiographers. One of the women had had a very upsetting experience with a male radiographer, which had resulted in her non-attendance in the following ten years. Also results from studies elsewhere have reported that the radiographer's gender can be a potential barrier to screening among South Asian women (83). In order to

overcome this barrier, interviewees suggested that the invitation letter should state that women may request a female radiographer.

Family life:

Women argued that family and home commitments could and should be prioritised before their own health, and could thus limit the possibility to attend their screening appointment. Some of the women explained how hectic periods in their children's lives due to exams and other major events had prevented them from attending.

The women's commitment to family influenced their possibility to attend screening, and may be perceived as an example of care ethics, where a moral problem is dealt with through intensifying relationships and enhancing empathetic involvement (114). Azra's elaboration regarding non-attendance echoed many interviewees' voices, and is an example of the concern and compassion the women had for their significant others:

> *The way we Pakistani women think is that we don't think so much about ourselves. We think more about our family, what are the benefits for them, we don't put ourselves first*

Other women argued that considerations to family life did not only permit, but also promoted attendance, as they would be less able to fulfil their commitments at home if they became ill.

Daughters:

In the Norwegian-Pakistani community in 2018, 46% of people were born in Norway (11). One can expect that Norwegian-born daughters of Pakistani immigrants and their mothers differ in their degree of acculturation, which has been described as the "phenomenon which results when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original cultural pattern of either or both groups" (p. 149) (115).

Some of the women suggested that informing women through their daughters would allow more women to attend the examination, and requested that this should be done. The women's daughters could facilitate screening by translating the written information, raising awareness about breast cancer screening and bringing their mothers to the examination. The younger women in this study had informed their mothers about the examination and some had accompanied their mothers to the examination as well.

Other women did not see the daughters as actors that enabled screening, and were opposed to informing women through their daughters. Begum, one of the younger interviewees, argued that it was unfair to expect that she should be responsible for her mother's screening appointment, and Nasreen, one of the older women, argued:

In the Pakistani community, children should not teach their parents what is wrong

The general practitioner (GP):

The nationwide GP programme in Norway provides all inhabitants with a GP, and the GP programme is among the public services with the highest user satisfaction, second only to the public libraries (116). The women seemed to expect the GP to be an important actor in the network, which is especially interesting considering that GPs are not directly involved in screening. BreastScreen Norway is a vertical programme with a centralised organisation (117). The GP does not receive any information about women with negative screening results, and might only be informed about a breast cancer diagnosis when the woman is discharged from the hospital after surgery for breast cancer.

The interviewees requested a more horizontal screening programme, bringing the service closer to their daily lives. They described the GP as an actor that should be deeply involved in the screening venture, and suggested that the GP provide information about screening. Further, interviewees recommended that there should be a collaboration between the GPs and the service providers, so that GPs could remind women with an upcoming appointment that they must attend, thus reducing the risk that an important appointment slipped out of their mind and was missed.

The GP was considered to be particularly well positioned to promote screening attendance given the high status GPs and other doctors have in the Norwegian-Pakistani community. Further, several women encouraged using Urdu- and Hindi-speaking children of Pakistani and Indian immigrants in the information process, as many children of immigrants from these countries are health professionals.

Non-governmental organisations (NGOs):

Some interviewees, including women who could not read, had gotten information about breast cancer and screening from lectures at NGOs. While the letter from the service provider offering screening is a one-way mode of communication relying on the women opening and reading the letter, lectures at NGOs allowed for situations where the women could listen and

discuss topics of interest with the presenter and other participants. Several of the women encouraged using NGOs, both to reach out to women with information, and to get more women to attend the examination. Ifran suggested:

> *So what one could do, is that one could have screening days at NGOs, put 20 women in a bus, accompanied by someone who speaks Urdu, and take them for a trip to the examination where they are met by a female radiographer, have a meeting with a doctor or someone else, where they get information about the examination and get to ask questions, and are then brought to the examination*

Religious beliefs:

de Cruz argues that the range and quality of scientific knowledge was far more advanced in the "Islamic world" than in Europe between the 9th and 15th century, but that today predominantly Muslim countries underperform in common scientific metrics and are hotbeds for pseudoscientific ideas (118). As one possible interpretation of this, she shows that some scholars argue that Arabic science has lost influence to more conservative theology (118). A study among American Muslims found that higher religiosity was associated with a lower rate of recent mammography, and studies among Muslim women have identified religious beliefs as a barrier to breast and cervical cancer screening (85, 119).

Interviewees argued that there was no conflict between religious practices and mammographic screening as long the radiographer was a woman, and suggested that regular teaching events in mosques would promote attendance. Some women argued that their religious beliefs not only authorised screening, but also encouraged women to go for the examination. In the words of Shabana:

> *I pray, and I believe my God has given me the right to have good health and to go for the examination, and I have to do what is best for my body in order to be a good human being*

The findings in this study regarding religious beliefs are particularly interesting given that a recent study in the same area (the Oslo region) with an overlapping age group (25–70) listed religious beliefs as a barrier against attendance among Pakistani and Somali women in the national cervical cancer screening programme (85).

The actors are explored in more detail in the article based on study IV. With respect to readability and the amount of results in this thesis, private service providers, monetary

expenses, transportation, worries and digital tools are described further in the article, but not here.

6. Discussion

6.1 Interpretation of main findings

Studies included in this PhD study found that immigrant women, regardless of country of origin, had lower attendance rates in BreastScreen Norway than non-immigrants. This was in keeping with findings from studies in other countries. Adjusting for sociodemographic factors reduced differences, but differences persisted for most immigrant groups compared to non-immigrants. We found less favourable screening outcomes, including histopathological tumour characteristics, among immigrants in total and groups of immigrants compared to non-immigrants. Lastly, we explored the actors involved when Pakistani women attend mammographic screening, and found that the way breast cancer screening is offered in Norway might be suboptimal for Pakistani women, thus possibly discouraging attendance.

6.1.1 Study I

The meta-analysis showed that immigrant and minority women in Europe, Northern America, Australia and New Zealand had lower mammographic screening attendance rates than other women. The consistency of this finding across study countries and immigrant groups was striking, almost as if there was something inherent with being an immigrant that prevented attendance. A Swedish study of rationales for postponing cervical cancer screening among immigrant women from Sweden's neighbouring countries Norway and Denmark revealed that competing needs related to immigration were overwhelming in the first years after immigration (120). This included the invitation for cervical cancer screening just being one of many offers to deal with, navigating a new health care system and considerable changes in life situation and routines. These considerations could also be true for immigrant women invited for mammographic screening, regardless of their country of origin.

Only one study showed higher attendance rates among minority women than the rest of the population; a study showing that Turkish minority women aged 50–64 had higher attendance rates than other women in Germany, while Turkish minority women aged 65–69 had lower attendance rates than other women (121). There was a substantial increase in migration from Turkey to West Germany after the West German government signed a labour recruitment deal with Turkey in 1961 (122). Even though women born in 1961 first turned 50 years old in the last year of the study period, it is possible that Turkish minority women in the study includes women born in Germany, as migration between Germany and Turkey dates back to the days

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of the Ottoman empire, and thus predates the labour recruitment deal (122). Studies in two of Germany's neighbouring countries, Denmark and the Netherlands, found that Turkish immigrants had lower attendance rates than non-immigrants (123, 124). It should be noted that screening attendance for the general population was far higher in the Danish (70%) and Dutch (83%) studies than in the German (49%) study.

Six of the nineteen studies included in the meta-analysis were conducted in the US, where the organisation of screening differed from the other study countries included. While screening in the other study countries mainly was organised and offered to all women in a target age group, health care insurance has been shown to be a strong predictor for screening attendance in the US (125). In the US, higher attendance rates have been observed among immigrants with health care insurance than among non-immigrants without (126). However, all studies in the meta-analysis from countries where women received offers for screening regardless of their insurance status showed that immigrants had lower attendance rates than non-immigrants. Some of these differences might be influenced by differences in sociodemographic factors, such as income and education (127).

There was a high degree of heterogeneity between the studies included in our review. The studies were conducted in countries that differed in many aspects in relation to the offer and uptake of breast cancer screening, including age groups targeted, screening intervals recommended, structure of screening as organised or opportunistic and screening uptake in the general population. Further, the studies differed in the way they evaluated attendance, definitions and categorisations of immigrants, and whether registration of attendance was self-reported or based on registry data. As we thus expected that the true effect differed between studies, we chose a random effects model accounting for both within and between study variations. Using this model, all studies were weighted similarly, meaning that an Australian study with over 30,000,000 observations was weighted 5.37%, while a study from the US with about 5500 observations got a similar weighting of 5.12%. However, the main finding of lower attendance rates among immigrant and minority women persisted in sensitivity analyses with other models that were more influenced by population size.

6.1.2 Study II

In study II, we found that immigrants offered screening in BreastScreen Norway from 1996 to 2015 had lower attendance rates than non-immigrants. This is in line with other studies from

Europe, Australia and Northern America, as shown in study I. For immigrants from the Nordic countries, the British Isles and Oceania, differences in attendance were non-significant or borderline significant after adjusting for sociodemographic factors. For immigrants in general and for immigrants from all other regions, differences were less pronounced, but still present, after adjusting for sociodemographic factors. The residual difference in attendance between immigrants and non-immigrants could possibly be further explained by sociodemographic factors not available in this study (such as religiosity and travelling distance to the screening unit (119, 128)), differences in understanding of health and body, biomedical knowledge of breast cancer and screening, pre-migratory factors or immigrant status. Also other studies have shown that adjusting for sociodemographic factors can attenuate or eliminate differences in attendance related to ethnicity (126, 129, 130).

Differences in attendance rates between immigrants from HIC and MIC decreased over the 20-year study period, and for attendance after first invitation, the difference was no longer statistically significant at the end of the study period. The expansion of EU in 2004 (described in chapter 1.1.1) could be part of the explanation for the decrease in attendance rates among women from HIC. This expansion dramatically changed the distribution of birth countries among women emigrating from HIC, as these new EU members states were categorised as HIC. Women born in most of these new EU member states were shown to have low attendance rates, which reduced the average attendance rates for immigrant women from HIC, while the attendance rates increased for immigrant women from MIC in the same period. It is possible that women from the new EU member states travel to their home countries for screening, as shown in a study of cervical cancer screening among Polish, Slovak and Romanian women in the UK (22), but it is also possible that they remained unscreened.

Women from Somalia had, by far, the lowest rates for attendance after the first offer for screening they received, for ever having attended and for attendance after all offers sent during the study period. Immigrants from Somalia have low income compared to other immigrant groups in Norway, and fewer Somalis own their own home, are employed or have an education that is approved in Norway (15-17, 19). Further, immigrants from Somalia receive much negative media attention (131), and a qualitative study identified distrust towards the healthcare system as a barrier against cervical cancer screening among Somali immigrant women in Norway (85). I theorise that one-sided public focus on negative aspects in the Somali community could result in distrust from Somalis towards official institutions, and, consequently, Somali women may not feel that the public offer for mammographic

screening speaks to them. However, these arguments are contradicted by surveys showing that immigrants from Somalia have higher life satisfaction than other immigrants, and that they have a higher degree of trust in the political system, the judicial system and the police than the general population (132).

6.1.3 Study III

The low screening attendance rates among immigrants matter if immigrants have worse outcome from breast cancer due to non-attendance. In study III, we observed that performance measures for organised screening in BreastScreen Norway differed between immigrants and non-immigrants in the period 1996–2015. Some, but not all, of the differences in recall rates and PPV between non-immigrants and immigrants was explained by differences in age and screening history, and lower attendance rates with potentially more irregular attendance among immigrants likely explains the differences further.

The results in this study contribute to the debate about stratified screening based on ethnicity. Women from low-incidence countries were younger at diagnosis than non-immigrants. This could be influenced by the younger age at screening due to shorter time in Norway. However, differences in performance measures remained after adjusting for age and screening history. Further, a recent study showed that over 50% of breast cancers diagnosed in "Non-Western" immigrants in Norway were detected before the age of 50, while the proportion was 21% in non-immigrants (56), a difference that could also be influenced by different age distributions.

It is possible that the lower age at diagnosis is a result of immigrants from low-incidence countries reaching the prevalence peak at a younger age than non-immigrants. This hypothesis is further strengthened by the findings of similar SDC rates between non-immigrants and immigrants from low-incidence countries after prevalent screens, but lower SDC rates among immigrants from low-incidence countries after subsequent screens, as shown in the article based on study III.

Immigrants from low-incidence countries had a higher rate of triple-negative IBC, and a tendency towards a higher proportion of histological grade 3 tumours and tumours >2 cm than non-immigrants, suggesting more advanced tumours among immigrants from low-incidence countries. A study comparing Moroccan Arab immigrant women to European women, showed differences in molecular subtypes between the groups, and a higher proportion of histological grade 3 tumours and tumours >2 cm among Moroccan Arab women (57). Studies

in the US have shown that African Americans, Hispanics and Asian Indians more often have triple-negative breast cancer than non-Hispanic Whites (133).

Many of the modifiable risk factors for breast cancer described in 1.2.4 have an unfavourable distribution in high-incidence countries. After migrating from low-incidence countries to high-incidence countries, women could face lifestyle changes with a more unfavourable exposure to modifiable risk factors, which may lead to a higher incidence of breast cancer (52). As the incidence of breast cancer has been shown to increase with time since migration, it is possible that adjusting for time since migration could further have reduced the differences observed in study III.

Combining the results from study III with results from other studies, including those referred to in this chapter, suggests that there could be biological differences in breast cancer between groups. The findings in study III suggest that immigrants from low-incidence countries might benefit from starting and stopping screening at a younger age than non-immigrants, and perhaps also at more frequent intervals. A recent study from the US recommended considering stratified screening based on ethnicity, suggesting lower screening-age for non-white groups (134). Perhaps one size does not fit all?

Challenges with universal guidelines also exist in other fields, for instance, a universal definition of BMI can be challenging. Body size, body composition and fat distribution may vary based on ethnicity, and a WHO expert consultation stated that "the proportion of Asian people with a high risk of type 2 diabetes and cardiovascular disease is substantial at BMIs lower than the existing WHO cut-off point for overweight" (p. 157) (135, 136).

6.1.4 Study IV

While study II and III revealed differences in attendance rates and other performance measures between immigrants and non-immigrants, study IV explored aspects that could give a better understanding of disparities in screening attendance. We showed that trust in healthcare and mammographic screening, the invitation letter and accompanying information sheet, the radiographer's gender, family life, daughters, GPs, NGOs and religious beliefs were important actors influencing Pakistani women's mammographic screening attendance. I have discussed some of the actors together with the findings in chapter 5.4, and the discussion here will be on a more general level.

Before the mid-1990s, there was very little research on migrants' health in Norway, and there are still many missing pieces in the understanding of the topic (26). According to Tuana, ignorance is not simply something that is missing, but something that is constructed and preserved (137). There have been campaigns aimed at increasing attendance rates in breast and cervical cancer screening among Pakistani women in Norway (138), and after these campaigns, strategies to deal with knowledge gaps, taboos and language difficulties suggested by people involved in the campaigns have centred around providing more information, for instance through educating the women or translating the information (139). Background data for study II shows that attendance rates among Pakistani women only increased from 32% to 36% for all invitations in the 5-year periods before and after the campaigns. The findings in study IV show that it is ignorant to believe that the low mammographic screening attendance rates among Pakistani women is simply due to lack of information.

In the words of the Danish philosopher Søren Kierkegaard, "if one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there" (140). Based on the findings in study IV, the vertical organisation of the screening programme and the communication using comprehensive, written letters in Norwegian, did not meet the Pakistani women where they were. This is particularly important if Pakistani women have low attendance rates and consequently lower survival from breast cancer because of the way the screening programme is organised and offered.

In Shakari's study of families in the Norwegian-Pakistani community, family life and religion were considered of great importance (141). Children were expected to respect and obey their parents, and loyalty to the family was described to sustain from immigrants to their Norwegian-born children. Female gender roles were described as traditionally being related to housework and childcare, and male gender roles with taking care of the family financially. Several of the findings in study IV echo Shakiri's findings, for instance how family life was so important that it could hinder screening, that family members could facilitate screening by translating information or bringing the women to the examination, and Nasreen's statement about how children are not supposed to teach their parents what is (right and) wrong.

The issue of Norwegian-Pakistani women's rights have reached mainstream media in Norway. For instance, in 2018, Norwegian-Pakistani men and women have debated women's rights in their community in one of the most published daily newspapers (142). Some of the findings in study IV can be interpreted as a contribution to feministic public health strategies for improved public health (143). The interviewees were very much in favour of screening

and considered themselves attenders even though they did not always attend. They pointed out that some women may not be allowed to attend by their husbands and that women's commitment to and compassion for their family might prevent them from attending. With this in mind, the interviewees offered suggestions for how to encourage more Pakistani women to attend, and how to make mammographic screening more accessible.

6.2 Methodological considerations

6.2.1 Data quality at the Cancer Registry of Norway

In this project, data on mammographic screening was obtained from the CRN. The CRN collects data about women who are invited to attend screening in BreastScreen Norway (72). However, women with a negative screening examination have the right to request that their data is deleted from the CRN, and about 1.9% of attending women have made use of this right (71). As we lacked information about these women, we did not know whether they as a group were a source of systematic error in studies II–III. For the remaining women, we had complete information about attendance and recall.

I received data about breast cancer from the CRN. By law, all cancers must be reported to the CRN, and the CRN collects data from clinicians, pathologists, discharge data, laboratory reports and death certificates (36, 73). Data is considered 99% complete for reporting of breast cancer (36). However, information about histopathological tumour characteristics is less complete.

Increasing knowledge about breast cancer has resulted in the need for information on new variables, and Her2-status was not collected and registered until 2005 (71). Her2-status is thus lacking for many tumours in our study. Registration of all tumour characteristics that were considered in study III, other than Her2-status, were more than 90% complete on subgroup level. Reasons for missing information about histopathological tumour characteristics included missing tumour diameter due to locally advanced disease or neoadjuvant therapy, and missing hormonal status due to changes in processes for data collection and registration (71).

An even newer variable described in chapter 1.2.2, Ki67 proliferation status, was not included in our studies. As this is a marker that has only been recorded recently, the data file only had information about Ki67 proliferation status for 1.4% of tumours. Ki67 proliferation status

may be useful in future studies, as this is now routinely analysed for newly diagnosed tumours.

6.2.2 Data quality at Statistics Norway

Information about sociodemographic factors in study II and III was almost complete for non-immigrants, as we had data for ≥99% of women for all sociodemographic factors (except employment status prior to 2001). For immigrants, the rate of missing data was 4% for income, 2% for net worth, 17% for education (no recorded education) and <1% for years since immigration.

For most factors, we had yearly information, making it possible to give levels of sociodemographic factors close to the time of the screening appointment. For education level, marital status and citizenship, we did not have yearly information, and the given level of these factors might not reflect the level at the time of the appointment.

Statistics Norway do not automatically receive information about immigrants' education (17). They receive some information through different registries and some information through surveys, but the proportion of immigrants with no recorded education is high and increasing as more immigrants arrive in Norway (further discussed below).

Statistics Norway provided three values for income for each year, and we chose the value which included all types of income without deducting tax. The interpretation of the variable "net worth" might be of limited value, as this variable was put together by deducting debt from holdings, meaning that for instance a business woman who had taken up a large loan to finance her business would be classified in the lowest decile.

We did not have information about employment status prior to 2001, but from 2001 we had information about employment status for 99.5% of non-immigrants and 96.6% of immigrants. Employment status was excluded from study II in order to avoid multicollinearity, but is included in the discussion here to show possible limitations of data from Statistics Norway used in these studies.

6.2.3 Selection bias

In epidemiological studies, some errors are random, and will reduce towards zero as the study size increases (94) (Figure 13). Systematic errors, also referred to as bias, remain despite

increasing study size, indicating that the source of the error lies in the structure of the study, rather than arising randomly by chance. The degree to which a study is free from such biases is referred to as the internal study validity (96). I will in the following consider some sources of systematic errors, namely selection bias, information bias and confounding, that could potentially have influenced the internal validity in studies I–III.
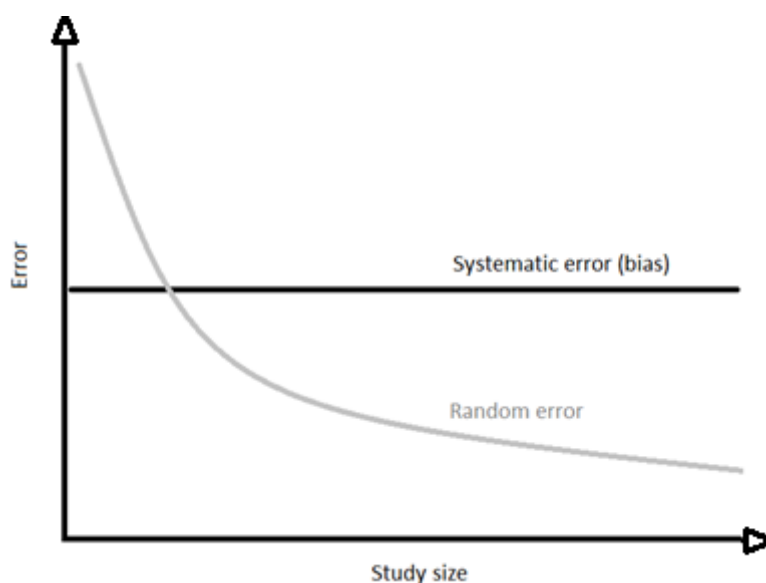
Figure 13: The relation between study size and the likelihood of random error (grey) and systematic error (black). Modified from Rothman (94).

Selection bias originates in the factors influencing participation/inclusion in the study, and occurs when there is differing association between exposure and outcome for those who are included and those who are not (94).

Only 19 of the 1369 (1.4%) articles identified in the literature search in study I were included in the meta-analysis, and the exclusion criteria were a source of selection bias. We excluded studies with <1000 cases or controls. This lead to the exclusion of several studies comparing immigrants to non-immigrants. However, these excluded studies rarely differed from the main finding in the meta-analysis, that immigrant and minority women had lower attendance rates than other women, and the exclusion of these studies are thus unlikely to have biased the overall outcome of the meta-analysis.

All the studies from the US included in study I showed lower attendance rates among minority women than among the control groups. However, other studies from the US have

found similar or higher attendance rates among minority women compared to the control group (125, 144-146), but were typically excluded due to lack of absolute counts or low number of study participants. The exclusion of these studies could have introduced a bias exaggerating the magnitude of the overall outcome of the meta-analysis.

In studies II and III, we excluded women with a prior diagnosis of breast cancer regardless of the age at which they received their diagnosis. These women received tailored follow-up with annual mammograms for at least 10 years after diagnosis (40). After 10 years, women in the target age range for screening received invitations from BreastScreen Norway according to the general recommendations for all women (biannual mammography). Women younger than 50 years at the end of the 10-year follow-up period typically received annual mammograms until they reached the target age range for BreastScreen Norway and continued with biannual mammography within the programme. We thus excluded women who underwent treatment and follow-up for breast cancer, but subsequently followed the general screening guidelines in BreastScreen Norway. If these women have a higher risk of breast cancer and are more concerned about cancer prevention than women with no history of the disease, it is possible that the attendance and cancer detection rates are underestimated in these studies.

Studies II and III covered the same time-period, and women who were diagnosed with breast cancer, had emigrated or had died before their scheduled screening date were excluded in both studies. However, data was extracted separately for both studies, and there were 1464 more women included in study III than in study II. We used morphology codes to exclude women based on breast cancer diagnosis. In study II, all women with a registered morphology code were excluded after diagnosis. However, the datasets also included morphology codes not only for women with breast cancer, but also for a small minority of women with benign breast conditions. These women are not misclassified, but the classification is not typically performed and is thus not complete. As women who are diagnosed with benign conditions continue to receive invitations from BreastScreen Norway, some women with benign breast conditions were excluded from study II, but not from study III. We do not know whether this represents a random or systematic error. It is, however, unlikely that it biased our results, as repeating analyses of attendance for women in study II with the study population from study III only gave minor deviations (0.0–0.2% difference in attendance on birth country-level).

In study II and III, 0.7% of screening examinations were performed on women <48 years old. Of these, 99.9% were screened in Oslo between 1999 and 2002 as part of the Oslo-project, in which women aged 45–49 years living in Oslo were offered mammographic screening (147).

These women had lower attendance rates and lower cancer detection rates than women aged 50-69 screened in the period before the Oslo-project (147). However, even though the proportion of immigrants is higher in Oslo than in any other county, I believe that the inclusion of the younger women in the Oslo-project is unlikely to have biased the results substantially, as they only accounted for a small proportion of women in the study.

6.2.4 Information bias

Information bias occurs when the information from or about the subject under study, such as information about exposure and disease, are misclassified (94).

In study I, some of the studies were based on self-reported data about attendance. The use of self-reported screening history has been shown to overestimate the true screening history, and there may be ethnic differences in such self-report bias in mammographic screening (148). However, the consistent findings of lower attendance rates among immigrant and minority women makes it unlikely that self-report biased the overall outcome in study I.

In study II and III, women were excluded from the date of emigration. Emigration data from Statistics Norway may be less reliable than other population statistics due to lack of reporting and delayed registration of emigration (149). People with no known whereabouts in Norway for two years are registered as emigrated. This means that women who have emigrated without reporting migration to the authorities, might not be registered as emigrated until two years after migration. These women will still receive offers for screening and be registered as non-attenders. While delayed registration of emigration likely affects immigrants more than non-immigrants, it is unlikely that it changes the finding of lower attendance rates among immigrants from all countries compared to non-immigrants.

In study II, the variable for educational level from Statistics Norway was a major potential source for information bias. Only 1% of non-immigrants lacked recorded education (76). Among immigrants, 17% did not have any recorded education, ranging from 8% among immigrants from Western Europe to 38% among immigrants from Eastern Africa (76). Information about immigrants' education was registered for people who had studied abroad with financing from the Norwegian State Education Loan Fund or people with jobs that required Norwegian authorisation in order to practice (150). Systems for obtaining information about education from other countries are lacking. For most immigrants with education from other countries and who had not been in contact with Norwegian educational

institutions, information about education was missing if they had not replied to surveys inquiring about educational level in 1991, 1999 or 2011 (150). Women with no recorded education thus included both women without formal education and women with education that was not recorded in Norwegian registries. This group is of particular interest as women with no recorded education had particularly low attendance rates (76). As the real distribution of educational status among women with no recorded education is unclear, I do not know whether this information bias influenced the results in the adjusted analyses, and, if so, in what direction.

6.2.5 Confounding

Confounding occurs when a variable independently influences both the exposure and outcome, thus influencing the association between exposure and outcome (94). Confounders should be adjusted for in order to get the true association between exposure and outcome.
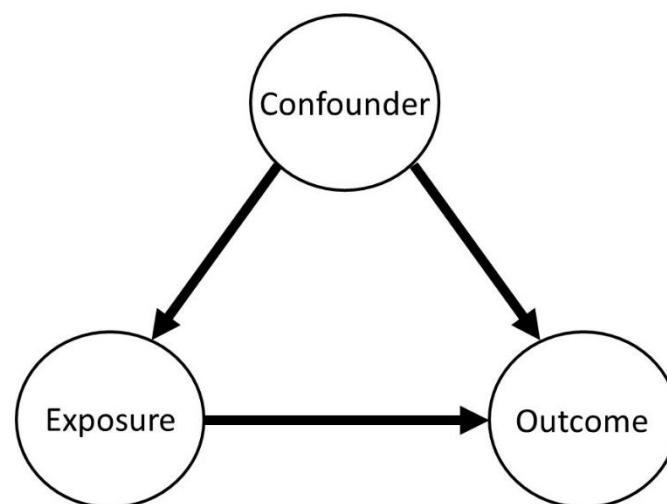
Figure 14: The confounding variable influences both the exposure and outcome. Any association between exposure and outcome will be influenced by the confounding variable. Modified from Webb et al (87).

The studies included in study I were performed in different settings, including settings varying in the organisation of breast cancer screening. In the US, insurance coverage differs between ethnic groups, as fewer Non-Hispanic Whites are uninsured compared to other ethnic groups (151). Further, mammographic screening attendance varies with insurance status, as women without health insurance have lower attendance rates than women with health

insurance (152). For the meta-analysis, we only included unadjusted numbers. The association between minority status and screening attendance may thus be influenced by differential distribution of insurance status between minority women and other women in the studies from the US. If a confounder explains the observed association between the exposure and outcome, the relationship between the confounder and the outcome has to be very strong (153). Adjusting for insurance status might have reduced differences in attendance between minority women and other women, but the overall OR would likely have remained significantly below baseline.

In study II, we adjusted for available sociodemographic factors we expected to influence screening attendance (income, net worth, education, disability benefit recipient status, marital status, citizenship, whether the women were living in Oslo or not and screening year). These variables have been shown to impact attendance rates both for non-immigrants and immigrants, and to be distributed differentially between the groups, as well as between groups of immigrants (76). Adjusting for these factors reduced differences between non-immigrants and immigrants. However, residual confounding due to unavailable or unknown factors may still exist.

In study III, we adjusted for age and screening history. There are additional factors that were differentially distributed between non-immigrants and immigrants that could potentially further reduce observed differences. Educational status was differentially distributed between the groups (76), and a Norwegian study has shown differences in breast cancer incidence between women with higher and lower educational status (154). A study based on a British screening cohort showed that Asian women were less likely to be nulliparous, more likely to have more than three children and had denser breasts than white British/Irish (155). Another British study showed that South Asian and Black women were less likely to use menopausal hormone therapy than White women (156). As described in the introduction, increasing parity is associated with decreased risk of breast cancer, and high breast density and HRT-use have been shown to be associated with increased risk of breast cancer. I do not know whether adjusting for these factors would have influenced performance measures. Further, combined oestrogen-progesterone therapies commonly used in the Nordic countries have been associated both with favourable and less favourable tumour characteristics (157).

6.2.6 Generalizability

Generalisability, or external validity, refers to the degree to which the results may be relevant to populations that did not participate in the study (96).

In study I, all but one study included in the meta-analysis showed that immigrant and minority women had lower attendance rates than other women. When discussing selection bias, I described how studies from the US where groups of minority women had similar or higher attendance rates compared to other women were excluded, often due to adjusted numbers. This might limit the generalisability of the studies performed on data from the US.

All studies that were included in the review in study I were performed in the United Nations Population Division's regions (1) of Northern Europe, Western Europe, Australia/New Zealand or Northern America. These are also the regions with the highest incidence of breast cancer (34). It is likely that the main findings in study I are more generalizable to other high-incidence countries and less generalizable to low-incidence countries. A study of Arab women in Qatar showed that Qatari women (26%) had lower mammographic screening attendance rates than Arab women from "the Levant" (34%) and North Africa (31%), and higher attendance rates than women from "other Gulf Cooperation Council and regional countries" (14%) (158). The study further showed that these differences were influenced by differential distribution of socioeconomic factors, as, for instance, women from "the Levant" and North Africa (and their husbands) were more likely to have higher education and jobs in management than other groups. As Qatari women had low attendance rates and I have described how sociodemographic factors may attenuate differences in attendance rates, it is not surprising that immigrant women to Qatar with favourable distribution of socioeconomic factors had higher attendance rates than the host population.

Study II and III were registry-based cohort studies with historic cohorts. The CRN has a high degree of completeness (36). Further, only 1.9% of attending women have requested that information about negative screening results are deleted (71). Lastly, the proportion of missing sociodemographic data was low for most factors (76). The women in study II may thus be representative for women in Norway in the target age range for mammographic screening in the study period. Hinders for this generalisation included the high proportion of immigrant women with no recorded education, lack of employment data prior to 2001 and the static variables (for instance marital status). The women in study III may be representative for women in Norway who have attended mammographic screening. A major hindrance for this generalisation is the unavailability of Her2-data prior to 2005, as this is a new marker that was

not utilised in the beginning of the study period, giving a high proportion of women with breast cancer that could not be categorised by molecular tumour subtype.

While I argue above that the findings in study II and III are highly generalizable to the population from which they were selected, I will now discuss some major issues in generalising these results to other populations.

We can expect that non-attenders have more advanced disease than attenders and that the proportion of ER-receptor positive breast cancer increases with age, meaning that tumour characteristics in study III might have limited generalisability to non-attenders and age groups not targeted for screening (48).

The Nordic model of healthcare traditionally considers equity in access as a central principle (159). With shared features allowing the description of a common model of healthcare, one could argue that our results from study II and III can be generalizable to other Nordic countries. However, the organisation of mammographic screening differed between the Nordic countries in the study period, as, for instance, Sweden offered screening to a different age group (40–74 years), at different intervals (1.5 year intervals to women aged 40–49, biannually to women aged 50–74) and with different organisation of screening facilities compared to Norway (160). Study II and the Swedish and Danish studies included in the systematic review (study I) did, however, all show that immigrants had markedly lower attendance rates than non-immigrants.

Age ranges covered, screening intervals, the use of independent double reading and organisation of screening facilities may also, in addition to other factors, reduce the generalisability of the results in this thesis to settings outside the Nordic countries. Screening programmes differ in their registration of tumour characteristics and other performance measures (160). In Norway, screening has been offered through an organised programme, where invitations are sent to a pre-defined target population, with systems for recall, further assessment, treatment and quality assurance (48). Organised programmes differ from opportunistic screening, where health providers offer screening or encourage women to participate outside the setting of organised programmes (48). The findings in this thesis may be more generalizable to other countries with organised screening, such as other European countries, than the US and other countries where screening has been mainly opportunistic.

Studies II–III were conducted with high-quality individual-level data covering a large number of women in Norway. The studies must, however, be interpreted in the setting in which they

were performed. While women targeted for screening, service providers, legislators, politicians and patient organisations in other countries can learn from our studies, they must keep in mind that our results may not be directly applicable to their countries, and consider which of our findings are relevant in their settings. In order to bridge knowledge gaps, studies on breast cancer and mammographic screening should be performed in countries where such studies are lacking, instead of taking for granted that findings from studies in other countries are valid universally.

6.2.7 Quality of the research in study IV

Moen and Middelthon describe four questions that should be addressed in all stages of qualitative studies; whether the study is transparent, whether the researcher is positioned to understand, whether the study is positioned to transcend perspectives, and whether the study is positioned to produce knowledge and insight that is portable (161).

1) Is the study transparent?

In February 2017, the Norwegian Data Protection Authority approved an application for this study. The application included a ten page long study protocol describing the planned study, the interview guide for the initial interviews and the consent form used in the study. These documents informed the 16 initial interviews and 4 repeat interviews. Several updated versions of the interview guides are available, as are field notes, plans for recruiting women, mind maps, analytical notes and transcripts from all interviews. These documents formed the basis for the article in study IV, and numerous drafts of the article are available, including drafts with critical revisions by the co-authors and drafts with changes based on feedback from reviewers. By exploring these and other documents, it is possible to follow the choices and changes made from the planning of the study to submission of the article. However, most researchers who come across this study will only do so through reading the article.

The analytical process was considered a continuous activity throughout the study, and we have attempted to describe the analytical process in the article (and in this thesis). With an enormous amount of choices and changes made in the study period and the journal's word count limitation, we had to choose to describe those we felt were most relevant and important, which is a limitation to the transparency of the study.

2) Is the researcher positioned to understand?

In chapter 4 (Reflexivity), I discussed how my position as the lead investigator may have influenced my interaction with the women and my understanding of the knowledge production. As described there, I had to balance several insider and outsider positions. My background as a *desi* provided me with some insight unavailable to most non-*desis*, but as a non-Pakistani and non-Muslims male, I ran the risk of ignoring aspects that were not familiar to me because of my background, but important to the women I interviewed. I also ran the risk of taking for granted that aspects that were familiar to me because of my Indian family background were also relevant for Pakistani women.

In the interviews, I attempted to leave time for the women's stories to unfold before asking questions to explore their reasonings. My understanding of Urdu allowed me to understand the women when they spoke in their preferred language. Discussions with key informants, literature searches and following the public discourse provided me with contextual information.

A major potential hindrance to my understanding of the matter was that I interviewed a relatively small number of women over a relatively short period of time, and few women participated in repeat interviews. I may thus have ignored important actors and ways in which the actors made the other actors act. On the other hand, the actors that were identified through the ongoing analyses were discussed with the interviewees, co-authors and key informants as they emerged in the analyses and as their actions were observed. In this way, my evaluation is that the field work was comprehensive enough to understand interactions and rationales for the identified actors. A hindrance to my understanding of the women's perspective was that I did not take part in a central insider activity, the meeting between Pakistani immigrant women and screening personnel, and I may be considered an outsider in this important activity.

The women represented a broad range of backgrounds with respect to literacy, education, age, work status, screening history and years lived in Norway. We tried unsuccessfully to recruit women with a history of breast cancer and more non-attenders, for instance by contacting four hospitals in an attempt to recruit women with breast cancer. I believe that more non-attenders and women with a history of breast cancer would have contributed with valuable understandings that was unavailable to me from my position.

3) Is the study positioned to transcend perspectives?

At the start of this PhD study, my perspectives were to a large degree influenced by my biomedical education and clinical experience as a doctor. Further, the screening provider,

BreastScreen Norway, initiated the project and was my main work place during the study period, which likely influenced my perspectives. Keeping this in mind, I took several steps in attempts to move on from, and develop, my perspectives.

Prior to the interviews, I consulted key informants who had experience working to understand and increase screening (non-)attendance among Pakistani women in Norway. The key informants had varied backgrounds, which could have differentially influenced their perspectives. The youngest key informant was in her early 40s, while the oldest was almost 70 years old. Some of the key informants had a Pakistani family background, others did not. Some of them were health professionals, others were not. The key informants contributed with their perspectives and experiences, and gave me feedback on my perspectives on the topic under study and my plans for the interviews.

During the interview period, I talked to and spent time with Pakistani women, and actively strove to understand the stories they told from their perspectives by listening and by asking questions when I did not understand. For instance, when the women used phrases or concepts that were unfamiliar to me, I asked them to explain or to elaborate. The interviewees had varied backgrounds, including in terms of sociodemographic factors and screening history, and contributed with perspectives that in many aspects differed from each other's perspectives and from mine.

I reflected on my own position, as described in chapter 4 (Reflexivity) and previously in this chapter. My supervisors contributed with their perspectives on the research topic, and gave critical comments to my interpretations. I also had additional discussions with insiders and outsiders about the analyses and drafts of the article, including member checking of selected findings with women with a Pakistani background, including interviewees, key informants and people not involved in the project.

Based on these considerations, I believe that the study was positioned to transcend perspectives.

4) Is the study positioned to produce knowledge and insight that is portable?

In study IV, the knowledge was produced through interviews with a group of Pakistani immigrant women of whom most had had a mammogram. We have addressed strengths and limitations of study IV in this thesis and in the article, and argue based on these discussions that the insight gained through this study is valid for the context in which it was produced.

The high proportion of Pakistani immigrant women in Norway invited for screening who have never attended (41%) is a major limitation to the portability of the insight produced to the Norwegian-Pakistani community in general. However, assuming that the interviewees perspectives are formed in a context where Pakistani family background, upbringing, values and experiences play a big role, the findings may still be of relevance to the Norwegian-Pakistani community in general and also to women with a Pakistani family background in other countries.

Assuming that some of the findings in this study are formed in a context where having an immigrant background is relevant, some of the knowledge produced could be of relevance to other immigrant women. However, having focused on Pakistani women, perspectives that are formed in contexts where other immigrant backgrounds play a role may remain silent. Some of the knowledge produced in a context where Pakistani family background specifically plays a major role might have limited relevance for understanding attendance for other immigrant groups at risk of non-attendance, such as Somali women, and some of the knowledge produced in a context where Somali family background plays a major role might have limited relevance for Pakistani women.

This study provides insight in how the way in which breast cancer screening is offered might not be suitable for all women. We focused on Pakistani immigrant women in Norway. A Norwegian study showed that in addition to immigrants, also older people, people with low educational status and people who are not working can be described as having low health literacy (162), as they had difficulties understanding written health information (163). Some of the identified actors could also be of relevance to these groups and other immigrant groups, and one could, for instance, explore whether involving the GP in the screening process and the mode of offering screening through written invitations is suitable for these groups.

The study introduces a variety of actors and shows how they might act in relation to screening. Based on the findings from our study, screening providers in other countries may ask whether the actors and actions identified in Norway are relevant for breast cancer screening in their countries. Written information, the gender of service providers, religious beliefs and the other actors identified are also involved in other health services, and the insight produced in this study should be of interest for people working with minority health in other settings in Norway, and people working with other minority health issues in other countries.

7. Conclusions and future perspectives

7.1 Conclusions

The main results of the studies included in this thesis are:

1) In a systematic review, immigrant and minority women in Europe, Northern America and Oceania were generally shown to attend mammographic screening less often than other women.

2) In a cohort study with a historic cohort, immigrant women, regardless of country of birth, had lower breast cancer screening attendance rates than non-immigrants. Differences in attendance rates between non-immigrants and immigrants reduced after adjusting for sociodemographic factors, but remained statistically significant for most immigrant groups. Attendance rates varied between immigrant groups, and increased with time since immigration.

3) In a cohort study with a historic cohort, results of performance measures of organised mammographic screening in Norway differed between non-immigrants and immigrants. Recall rates were higher for immigrants than non-immigrants, and the positive predictive values of recalls were lower. These differences were not fully explained by age and screening history. Immigrants from low-incidence countries were diagnosed with breast cancer at a younger age than non-immigrants. Interval breast cancers among immigrants from low-incidence countries were more often triple-negative, which is associated with worse outcome.

4) In a qualitative study of 16 Pakistani immigrant women in Norway, we identified and explored several actors that played a role for their attendance in breast cancer screening attendance. These actors included trust in healthcare and mammographic screening, the information material distributed to prospective screening participants, the gender of screening radiographers, women's family responsibilities, the women's daughters, general practitioners, non-governmental organisations and religious beliefs. These and other human and non-human actors work together in networks and act on the women, influencing attendance in organised mammographic screening, by, for instance, creating thoughts and emotions, enabling or preventing attendance in organised breast cancer screening in Norway.

7.2 Planned studies versus performed studies

Originally, this project intended to explore breast cancer and organised mammographic screening through studies resulting in the publication of four manuscripts:

A. Attendance among immigrant women in BreastScreen Norway
B. Incidence of breast cancer and tumour characteristics among immigrants and non-immigrants invited to attend BreastScreen Norway
C. Survival from breast cancer stratified by country of origin, tumour characteristics, detection method and socioeconomic factors
D. Immigrant women's attitude to, and awareness of, mammographic screening

Study I in this thesis was performed due to delays in data delivery from Statistics Norway. In addition to the studies in this thesis, I was also involved in a study which investigated attendance among non-immigrant and immigrant women stratified by sociodemographic factors, in which I was a co-supervisor and the last author of an article (76). I was additionally involved in four scientific publications outside of the PhD study. Two of these have been published (164, 165), while an article entitled "Waiting times and choice of treatment following cancer diagnosis: comparison between immigrants and Norwegian host population" and an article in Norwegian about standardised wait times in breast cancer screening are currently under review. With all the studies described, as well as teaching sessions and participation and presentations at national and international scientific meetings, the study concerning differences in survival will be performed outside this PhD study.

7.3 Implications and future perspectives

All the studies described in the previous paragraph, as well as teaching sessions and participation and presentations at national and international scientific meetings, have generated well-needed knowledge about breast cancer and mammographic screening among immigrant women in Norway. We do, however, still have an abundance of unpublished data that can be used for additional studies. I have already started work on the planned study C (survival), and hope that I'll be given the opportunity, as a postdoctoral researcher, also to explore county-wise variations, choice of treatment and time-trends for tumour characteristics of breast cancer between non-immigrants and immigrants. I also hope to be involved in qualitative studies exploring attendance for Somali women and other non-Pakistani immigrant groups, as well as other groups with increased risk of non-attendance.

The systematic review (study I) demonstrated that low mammographic screening attendance rates among immigrant and minority women is an issue in Europe, Northern America and Oceania. In order to meet acceptable levels for attendance rates and other performance measures (69), service providers should work to increase screening attendance among immigrant and minority women. While the organisation of breast cancer screening varies between countries and local factors might be of importance in understanding non-attendance, service providers can learn from each other in attempts to promote equality in access and improve attendance among immigrant women and other groups at increased risk of non-attendance.

The findings in study II showed that immigrant women in Norway have had lower mammographic screening attendance rates than other women regardless of country of origin. As shown in study I, these findings were consistent with findings from other countries, and as in other studies, we found major differences in attendance rates between immigrants from various countries (124), that attendance rates increase with time since immigration (166), and that differences in attendance rates attenuate or disappear after adjusting for sociodemographic factors (129). Ideally, screening providers should continuously collaborate with NGOs, mosques and other important actors in immigrant communities, for instance through screening days every six months, as suggested by some of the interviewees in study IV. This may, however, be limited by personnel and other resources screening providers are able to prioritise for such purposes.

Immigrants may differ from non-immigrants in their contact with somatic healthcare services also in other settings, for instance with lower cervical cancer screening attendance rates and more contacts per patient with GPs (27). Findings from studies showing differences in breast cancer screening attendance between immigrants and non-immigrants could thus be of interest also in other settings. Study II emphasizes the importance of access to individual-level screening and sociodemographic data in order to reveal differences in attendance between groups and the effect of sociodemographic factors on attendance. The study has, for instance through media attention (167, 168), contributed to a change in legislation, as the CRN now has access to country of birth in their registries (72).

In study III, we revealed differences in how results of performance measures for organised mammographic screening in Norway differed between non-immigrants, immigrants from high-incidence countries and immigrants from low-incidence countries. Also this study received media attention (169). Combining results from study III with results from other

studies, including the Norwegian study that showed that more than more than 50% of "Non-Western" immigrant women diagnosed with breast cancer were younger than 50 years old (56), one could ask whether groups of immigrant women should be offered mammographic screening at a younger age than non-immigrants. A recent study in the Journal of the American Medical Association (JAMA) suggested race-based screening guidelines with lower screening age for non-white groups in the US (134). However, further studies are needed before recommending stratifying guidelines based on ethnicity, including studies of survival, cost versus benefit, changes in screening outcomes with increasing years since migration, and potential benefits of stratifying screening for immigrant groups compared to stratification according to other factors, such as breast density, use of OCP or HRT and parity.

In particular, I hope that study IV will spur many other qualitative studies in order to improve understanding of non-attendance for other groups. The findings *unproduce* some of the ignorance about non-attendance in screening among immigrant women from Pakistan, and indicate that the way women are offered mammographic screening in Norway may not be optimal for these women. In order to increase attendance rates among immigrant women from Pakistan, thereby potentially reducing the proportion of subsequent screens and recalls, increasing the PPV, and, ideally, preventing late-stage disease and death from breast cancer, Pakistani women might require information in a different language or mode than non-immigrants. I believe that providing information in a language and mode that is better suited to Pakistani immigrant women's needs will contribute towards increasing their knowledge about breast cancer and mammographic screening, and will put them in a better position to make an informed choice about attendance. In addition to the aforementioned collaboration with mosques and NGOs, I recommend exploring collaboration between screening providers and GPs, as the interviewees trusted their GP, who they expected to be an important actor in health-related issues.

The gender of the screening radiographer was identified as an important actor that could prevent mammographic screening for Pakistani immigrant women. Several of the women suggested that more women would attend if the invitation letter stated that they could request a female radiographer. This is a specific recommendation from the women that BreastScreen Norway could consider whether is appropriate to include when offering mammographic screening.

Ideally, a randomised controlled trial should be performed to see whether attendance rates, cancer detection rates and other performance measures improve if immigrant women from

Pakistan receive invitation letters in Urdu. However, the possibility to conduct a randomised controlled trial is limited by the low number of Pakistani women and, more importantly, the low number of breast cancers among Pakistani women.

Our findings, for instance regarding trust and religious beliefs, differed from a study exploring cervical cancer screening among women from Pakistan and Somalia, even though the target populations overlap in terms of age (85). The findings among Pakistani women must be interpreted in the context they are found, and cannot uncritically be applied to other settings, including other immigrant groups. As women from Somalia had by far the lowest attendance rates in study II, and Somali women in Norway likely have more advanced disease and lower survival than non-immigrants (54), it is especially important to explore mammographic screening attendance among women from Somalia, for instance through collaborative projects with the Norwegian-Somali community and through qualitative studies. Further, while I encourage and welcome qualitative studies exploring low attendance rates among various immigrant groups, qualitative studies on attendance should also be performed among other groups at risk of non-attendance. For instance, non-attendance among women with low educational status should be explored, as Norwegian studies have shown that women with ≤10 years of formal education have benefitted less from improvements in breast cancer incidence and mortality and have lower mammographic screening attendance rates than higher educated women (76, 154).

Finally, breast cancer is the most common type of cancer affecting women worldwide, and the risk of breast cancer increases with migration from low-incidence countries to high-incidence countries (34, 52). With increasing global migration, the proportion of immigrants in the population also increases, both in Norway and other countries. In this thesis, I have demonstrated differences in breast cancer and mammographic screening between immigrants and non-immigrants, as well as between immigrant groups. This thesis emphasizes the importance of individual-level data about screening history, breast cancer, country of birth and other sociodemographic data in epidemiological studies, and the value of qualitative studies in order to get a better understanding of cooperation with at-risk groups. With its strengths and limitations, this thesis is an important contribution to the understanding of breast cancer and mammographic screening among immigrant women in Norway. I hope that the findings in this thesis will aid migrant health workers, BreastScreen Norway, legislators, politicians, and most importantly the women themselves, in optimising the offer for breast cancer screening.

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9. Appendix

9.1 Interview guide for primary interviews

This interview guide was translated to English at the request of a researcher in another country, who was interested in this study.

Introduction

This is an interview guide for interviews with informants in the project «Subproject 4. Immigrant women's participation in organized screening mammography in Norway". The interviews will primarily be based on the map on the last page, supplemented by the information in the rest of the guide. The interviews may make it necessary to ask other questions or discuss other topics, and the interviews may deviate from guide. It is an aim, but not an absolute demand, that as many topics as possible from this guide are covered. The interview guide may also be modified based on the interviews, which means that the interview guide may vary from one interview to the other. The interviews are estimated to last 1-1,5 hours.

Main goal: Generate knowledge about immigrant women's participation and non-participation in organized mammographic screening in Norway through exploring their experiences of the invitation for mammography.

This interview guide is valid for the primary interview. The interview guide is a dynamic tool, and may therefore be modified if new topics emerge. The topics in the subsequent interviews will depend on the primary interviews and the interviews with other informants.

The guide also includes vignettes. By vignettes I mean small stories, pictures, cases and more that I will ask the informants to talk about or comment.

Introduction (max 10 minutes)

Present myself
- Who am I/are we?
- What is my role / our roles in this interview?

About the project
- Superficial information about the project (the entire PhD project)
- Why is the project important?
- More detailed information about the this subproject
- Why do I wish to talk to this specific informant based on the description of the project?

Ethical considerations
- Thank the participant for agreeing to take part in the interview
- Go through the consent form, which the participant should have already read
- Advantages and disadvantages of participating in the interview
- Talk about anonymising data. Mention that no one should recognise the informant from these data or analysed data, but that the informant may recognise quotes and situations.
- Emphasize the right to withdraw from the project at any time

The informant will here get the opportunity to ask questions before we continue with the interview guide. I will here emphasize that the informant can ask questions at any point in the interview.

About the informant (max 5 minutes)

Emphasize that our goal is that the information the informant provides should help generate knowledge about immigrant women's relation to health in general and breast health specifically, and that we hope that this information can aid us in providing a better tailored health service / information.

Background questions:
- Name (emphasize that we will use an alias)
- Birth place
- Age
- Family (partner, children)
- Employment (yes/no)
- Education
- Breast cancer self or friends/family
- Mammographic screening history (yes/no/intervals. More details later)

Interview guide (ca 10-15 minutes per topic)

Topic 1: Insight into immigrant women's view on health, illness, treatment in general, including personal and public preventive measures

Key words:
- Disease/illness and health
- Treatment of health problems and disease
- Preventive disease (self, others, public)

Topic 2: Insight into situations where immigrant women do or do not see the need for treatment, use self-treatment, traditional medicine, alternative treatment, complementary treatment or Western medicine.

Key words:
- Seeking health services
- Treat self
- Seek public health services
- Seek other health services
- Does not need treatment
- Why not contact doctor

Topic 3a: Insight into immigrant women's view on breast cancer
Topic 3b Insight into immigrant women's view on preventive measures against breast cancer

Key words:
- A: What, why
- A: Consequences
- B: Avoid breast cancer (self, others)

Topic 4a: Knowledge about immigrant women's view on the invitation for mammographic screening
Topic 4b: Knowledge about how an invitation for mammographic screening fits into the everyday life of an immigrant woman

Key words:
- A: What is mammographic screening?
  - If the woman does not know what mammographic screening is, then this must be explained ("mammographic screening is an x-ray examination of the breasts which is used to detect breast cancer")
- A: Show invitation: Can you remember ever seeing this?
- B: Prioritisations
- B: Why / why not? Self, others
- B: Language

Vignettes

Vignette 1: "Immigrant women do not attend mammographic screening because their husbands don't allow them to."

Vignette 2: "Immigrant women might not want to be interviewed by a male."

Vignette 3: "Immigrant women don't attend mammographic screening because the examination might be conducted by a male"

Vignette 4: Show navigation on computer: how to access information about mammographic screening in Urdu or Arabic on the Cancer Registry's website. Do you think you would be able to access this information?

Closure

- Do you have any questions?
- Are there any topics you feel we should have discussed?
- What do you feel now / how do you feel after the interview?
- May I contact you for a follow-up interview?
- Information about how to contact me if needed (se consent form)
- Thank the informant for her help ☺

Interview guide as a circular map with topics on a superficial level close to the center and on a more detailed level in the outer part of the circle.

Health

Self treatment

Why treat or not?
(alternatively why go to the
doctor

Public health service

Food

Traditional medicine

Health
problems

Other treatment

Self-treatment

Self prevention

Does not need
treatmend

Disease/illness

Must be treated by
public health service

Public prevention

Can be treated by
others

Behandling

Sykdom og
helse

Other prevention

What, where information

Mammografi

Kul i brystet

Has your GP mentioned?

What

Expences

Invitation

Language (incl is
English better
than Norwegian?

Why

Should you go to the doctor? Would you
go to the doctor

Importance /
prioritizing

What do you want
to know

Consequences

Proression

Show an invitation
letter

Why

Prognosis

Why not

How to avoid

Navigation

Priorities

9.2 Interview guide for repeat interviews

Forord

Dette er en intervjuguide til andregangsintervjuer med deltakere i prosjektet «Subproject 4. Immigrant women's participation in organised screening mammography in Norway». 13 kvinner har gjennomført førstegangsintervjuer, og de fleste sa ja til å bli kontaktet på nytt. På bakgrunn av informasjonen fra førstegagnsintervjuene har vi laget analytiske notater og utarbeidet en modell som skal beskrive ulike typer arbeid kvinnene må gjøre, både fysisk og mentalt, for å gjennomføre en screeningundersøkelse (se vedlegg). Modellen og de analytiske notatene ble brukt som utgangspunkt for å lage intervjuguiden til andregangsintervjuene. Innholdet i guiden er dynamisk, og jeg vil vurdere fra intervju til intervju om det er nødvendig med flere punkter, færre punkter eller om noen av punktene skal endres.

Kvinnene har uten forventninger om å få noe tilbake takket ja til intervjuene. Jeg har oppfattet rekrutteringsprosessen som krevende, og uten at disse kvinnene hadde takket ja hadde det ikke vært mulig å gjennomføre studien. To av personene som skulle hjelpe til med rekruttering av kvinner har forklart at pakistanere har vært i Norge i mange år og at de har blitt forsket mye på. De mente at pakistanere er lei av at forskere kommer og snakker med dem, forteller at dette kommer til deres nytte, for så at de ikke hører noe fra forskerne igjen. Jeg ønsker derfor i andregangsintervjuene å tilby kvinnene at jeg senere ringer dem og informere om resultatene.

Hovedmålsetning: Generere kunnskap om hvilket arbeid pakistanske kvinner må gjøre for å møte til organisert mammografiscreening i Norge.

Innledning (5 minutter)

Introduksjon
- Takke for hjelpen så langt
- Rask oppsummering av hva vi snakket om sist og foreløpige funn
- Beskrive plan for dette intervjuet, gjerne starte med «det er mye du må gjøre før du kan/for å kunne gå til en mammografiundersøkelse…»

Informanten vil her få anledning til å stille spørsmål før vi fortsetter med intervjuet.

Aktuelle samtalepunkter (5-10 minutter per punkt) (se neste side)

Fra listen på neste side vil jeg i andregangsintervjuene diskutere/utdype punkter som vurderes relevante basert på førstegangsintervjuene. Ut ifra intervjuene kan det bli hensiktsmessig å diskutere emner som ikke er med i intervjuguiden eller modellen, alt ettersom hvordan samtalen utvikler seg. Dersom det blir tid til overs kan vi også diskutere punkter fra intervjuguiden som jeg vurderer som relevante. En hensikt med andregangsintervjuene er å forstå «hvorfor» og «hvordan» mer enn «hva», og jeg vil derfor under intervjuet forsøke å ha følgende i bakhodet:
- Hva gjorde du?
- Hvorfor er det viktig?
- Hvorfor gjorde du som du gjorde?

Avslutning
- Har du noen spørsmål?
- Er det noe du mener vi burde ha snakket om?
- Takk for hjelpen ☺

Tro på mammografi (MG)

- Dine meninger om MG
- Viktighet
  - Hvor viktig er MG
  - Hvorfor
- Mulige problemer med MG
  - Farer
  - Virker det?
- Alternativer til MG
- Hvorfor bør man (ikke) gå til MG

Tanker om å få brystkreft

- Erfaringer
  - Egne
  - Andres
- Hva ville det bety å få?

Fortell litt om hvordan det var (og hva du gjorde) forrige gang du gikk til MG

- Kom på det
- Invitasjonsbrev
  - Hva gjorde du med det
  - Invitasjon vs innkalling
  - Aktivt, informert valg
- Interaksjon med andre (hva de sa, mente, tenkte, gjorde)
  - Venner og familie
  - Helsepersonell
- Bestemte å gå
  - Hvem involvert
    - *Hvordan*
  - Gjorde hva for å bestemme
  - Hvorfor gikk du
    - *Hadde time?*
    - *Helseårsaker*
    - *Normer/sosiale forventninger/status*
  - Hva talte imot?
    - *Jeg er frisk/Bra sist*
    - *Tvil*
    - *Tid*
    - *Utfordringer/problemer*

- Finne tid
  - Utfordringer?
  - Hvordan løste
- Reiste dit
  - Transportmetode
  - Følge
    - *Hva gjorde du for å finne*
    - *Hva gjorde hun/han*
- Ankom der
  - Hvordan fant jeg ut hvor jeg skulle
  - Hva hendte
- Folk
  - De ansatte
  - Andre personer
- Undersøkelsen (US)
  - Klær/Deodorant
  - Forventet oppførsel
  - Kommunikasjon før og under undersøkelsen
  - Hvordan foregikk US
- Hva skjedde
  - Tanker og følelser
- Reise hjem
- Etter undersøkelsen
  - Gjorde/fortalte hva/hvem
  - Hvorfor (ikke) fortelle
  - Respons

Fortell hvordan det var forrige gang du IKKE gikk til MG

- Hva var annerledes?
- Tid vs ork/arbeid
- En gang vs regelmessig

Undersøkerens kjønn

- Betydning
  - for deg
  - for andre pakistanske kvinner
  - for pakistanske menn
  - for den du møter på US
- Hvorfor av betydning
  - Hva bryter det med
  - Hva kan gå galt
    - Hvordan
    - Hvorfor
- Grad av viktighet
  - Sammenliknet med andre ting

  - Forferdelig?
  - Dersom kun menn tilgjengelig
- Ting du gjorde
  - Gjorde på forhånd
    - Tenkte
    - Snakket med andre
    - Forsøkte å avverge
- Hva gjør du hvis mann tilstede?

Utgifter

- Tilgang til penger da du gikk
  - Måtte du velge bort noe?
- Hvem sine penger?
  - Dine
  - Andres
    - Hvordan spurte om?

Barnas, mannens og venners roller

- Hva mener de om MG
  - Hvor mye betyr det for dem
- Gjort noe for å involvere dem?
- Informasjon gjennom dem
  - Har du søkt/fått?
    - *Hvordan skjedde det*
  - Hvorfor (ikke)
  - Praktisk riktig
  - Etisk riktig å bruke barna
- Rolle da du gikk
  - Invitasjonsbrev
  - Diskusjoner om deltakelse
  - Gå sammen med
  - Snakke om hva som skjedde
- Dele erfaringer

Fastlegens rolle

- Informasjon om MG
  - Har du snakket med fastlegen
  - Kan du snakke med fastlegen
  - Hvorfor (ikke) snakke
- Behov for tilrettelagt info

Religionens rolle

- Hørt rel ledere snakke om?
- Kombinere religion og MG
  - Undersøkelsen

- o Forebygging
- o Ansvar og roller
- o Forutbestemt?
- Interaksjon med menn
  - o Forbud? Evt eget ønske
  - o Unntak

Invitasjonsbrev

- Hva gjorde jeg da jeg fikk det
  - o Leste selv
  - o Noen andre leste
  - o Så bare tid/sted
  - o Leste ikke
- Språk
  - o Forstod jeg norsken?
  - o Forstod jeg innholdet/budskapet?
  - o Mengde informasjon
- Hvorfor leste jeg (ikke) det?
  - o Hvorfor delta om ikke lest

Informasjon

- Søkt info?
- Hvordan fikk jeg info sist?
- Hvem ønsker jeg info fra?
  - o Fastlegen

- o NGO'er
- o Møter
- o Andre
- Ikke-skriftlige virkemidler
  - o Hvorfor?
  - o Videoer
  - o Figurer
  - o Talemeldinger

Undersøkelsen ifht annet

- Tilpasninger for å kunne delta
  - o Hvorfor tilpasse
  - o Hvorfor (ned)prioritere
- Tidsklemma
- Prioritering av kvinner
  - o Egentid
  - o Ansvar for hjem og familie
  - o Egen og andres vurdering av deres plass i hjemmet
- Hva om det ikke passer

Bekymringer

- …for undersøkelsen?
  - o Forstå hva jeg skal gjøre
  - o Eksponere meg

- o Helse til å gjennomføre/stå
- o Smerte/ubehag
- …for resultatet
  - o Kreft? Frisk hvis ikke kreft?
- Gjør hva ved bekymringer
- Var jeg bekymret da jeg ikke møtte? Hvorfor?
- Hvordan håndtere bekymringer

Samvittighet

- Møtt
  - o Andre oppgaver valgt bort/utsatt?
  - o Er andre negative?
  - o (Hvorfor) dårlig samvittighet
  - o Håndtere dårlig samvittighet
- Ikke-møtt
  - o Hvorfor ikke møtt?
    - ▪ *Andre oppgaver viktigere*
    - ▪ *Turte ikke møte*
  - o Egen vurdering av risiko for brystkreft ved å ikke møte?
- Hvordan håndterte du skyldfølelsen?

10. Articles I-IV with supplementary material

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