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

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Oslo, April 2019
### Abbreviations

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

Article II

Article III

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.
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.](https://www.ssb.no/innvandring-og-innvandrere/faktaside/innvandring)

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
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 cohabitation 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

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 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 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 comorbidities 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:

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>About the risk factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>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).</td>
</tr>
<tr>
<td>Age</td>
<td>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 &gt;10 compared to women younger than 50 (48).</td>
</tr>
<tr>
<td>Age at menopause and menarche</td>
<td>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).</td>
</tr>
<tr>
<td>Personal history of breast cancer</td>
<td>Women previously diagnosed with breast cancer have a 3–5 times increased risk of breast cancer in the contralateral breast (47).</td>
</tr>
<tr>
<td>Family history of breast cancer</td>
<td>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).</td>
</tr>
<tr>
<td>Hereditary factors</td>
<td>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).</td>
</tr>
<tr>
<td>Country of birth</td>
<td>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).</td>
</tr>
<tr>
<td>Mammographic breast density</td>
<td>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).</td>
</tr>
<tr>
<td>Previous benign disease</td>
<td>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).</td>
</tr>
</tbody>
</table>

Table 2: Modifiable risk factors:

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>About the risk factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parity</td>
<td>Nulliparous women have an up to twofold increased risk of breast cancer compared to parous women (48).</td>
</tr>
<tr>
<td>Age at first pregnancy</td>
<td>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 &lt;20 years at first childbirth (48).</td>
</tr>
<tr>
<td>Breast feeding</td>
<td>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).</td>
</tr>
</tbody>
</table>
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
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 (Kreftregisterforskrifteren) 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, prescheduled 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 reschedule 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.
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 I² statistics to assess statistical heterogeneity among studies, and interpreted I² values 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 a 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%).
Table 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.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Group</th>
<th>Cases</th>
<th>Controls</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>von Euer-Chelpin et al. (2008)</td>
<td>Denmark</td>
<td>Immigrant</td>
<td>1125</td>
<td>38564</td>
<td>0.58 (0.51-0.66)</td>
</tr>
<tr>
<td>Kristiansen et al. (2012)</td>
<td>Denmark</td>
<td>Immigrant</td>
<td>11575</td>
<td>84489</td>
<td>0.62 (0.60-0.65)</td>
</tr>
<tr>
<td>Lagerlund et al. (2002)</td>
<td>Sweden</td>
<td>Immigrant</td>
<td>5242</td>
<td>40799</td>
<td>0.57 (0.53-0.62)</td>
</tr>
<tr>
<td>Vermeer et al. (2010)</td>
<td>the Netherlands</td>
<td>Immigrant</td>
<td>89042</td>
<td>2162320</td>
<td>0.30 (0.26-0.35)</td>
</tr>
<tr>
<td>Bullard et al. (2004)</td>
<td>Switzerland</td>
<td>Immigrant</td>
<td>5157</td>
<td>8822</td>
<td>0.60 (0.59-0.74)</td>
</tr>
<tr>
<td>Jensen et al. (2012)</td>
<td>Denmark</td>
<td>Immigrant</td>
<td>5997</td>
<td>138219</td>
<td>0.42 (0.41-0.46)</td>
</tr>
<tr>
<td>Boren et al. (2014)</td>
<td>Germany</td>
<td>Minority</td>
<td>28658</td>
<td>404991</td>
<td>1.14 (1.10-1.17)</td>
</tr>
<tr>
<td>Szepura et al. (2008)</td>
<td>the UK (England)</td>
<td>Minority</td>
<td>8829</td>
<td>142173</td>
<td>0.50 (0.53-0.59)</td>
</tr>
<tr>
<td>Bansal et al. (2012)</td>
<td>the UK (Scotland)</td>
<td>Minority</td>
<td>36348</td>
<td>123026</td>
<td>0.89 (0.86-0.92)</td>
</tr>
</tbody>
</table>

Subtotal (I-squared = 95.9%, p = 0.000)

Canada

Sun et al. (2010) | Canada | Immigrant | 3138 | 17197 | 0.73 (0.67-0.79) |

Subtotal (I-squared = 5%, p = .)

Subtotal (I-squared = 95.9%, p = 0.000)

Overall (I-squared = 95.9%, p = 0.000)

*NOTE: Weights are from random effects analysis.*
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.

<table>
<thead>
<tr>
<th>All invitations</th>
<th>Attendance at least once</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Highest</td>
</tr>
<tr>
<td>1</td>
<td>The Netherlands and Denmark (74%)</td>
</tr>
<tr>
<td>2</td>
<td>Myanmar (30%)</td>
</tr>
<tr>
<td>3</td>
<td>The Faroe Islands (73%)</td>
</tr>
<tr>
<td>4</td>
<td>Switzerland (72%)</td>
</tr>
<tr>
<td>5</td>
<td>Sweden and Finland (71%)</td>
</tr>
</tbody>
</table>

Table 3: The five highest and lowest attendance rates among immigrants by country of birth.
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 (RRadj 1.13, 95% CI 1.10–1.16) and lower PPV (RRadj 0.93, 95% CI 0.87–0.99). RRadj for SDC and IBC did not differ significantly between the two groups. RRadj 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 (RRadj 1.10, 95% CI 1.06–1.15) and low-incidence countries (RRadj 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 (RRadj 0.98, 95% CI 0.90–1.06), while RRadj 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 RRadj for SDC (1.09, 95% CI 1.00–1.19) and higher RRadj 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 (RRadj 0.98, 95% CI 0.89–1.09) and borderline significant differences for IBC (RRadj 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 (RRadj 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 (RRadj 1.34, 95% CI 1.11–1.61), and IBC were more often triple-negative (RRadj 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).

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

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

<sup>a</sup> Adjusted for age only

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

![Graph showing the relation between study size and the likelihood of random error (grey) and systematic error (black). Modified from Rothman (94).](image)

**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).](image)

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 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.
8. References

64. Falk RS. Why are results of organised mammography screening so difficult to interpret? Tidsskr Nor Lægeforen. 2014;134:1124-1126.


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 (see 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.

Self treatment
Public health service
Traditional medicine
Other treatment
Self-treatment
Does not need treatment
Must be treated by public health service
Can be treated by others

What, where information
Has your GP mentioned?
Expenses
Invitation
Language (incl is English better than Norwegian?)
Importance / prioritizing
Why
do you want to know
Show an invitation letter
Why
Why not
Navigation
Priorities

Mammografi
Kul i brystet

Sykdom og helse

Health
Why treat or not? (alternatively why go to the doctor)
Health problems
Disease/illness
Food
Self prevention
Public prevention
Other prevention

What
Why
Should you go to the doctor? Would you go to the doctor
Consequences
Proression
Prognosis
How to avoid
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 førstegangsintervjuene 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 pakistancer har vært i Norge i mange år og at de har blitt forsket mye på. De mente at pakistancer 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 etter hvor lang og utviklet samtalen 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 forøke 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/problemef

Finne tid
- Utfordringer?
- Hvordan løste
- Reiste dit
- Transportmetode
- Følgø
  - Hvordan gjoede du for å finne
  - Hvordan gjoede 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 følelse
  - 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 du med
  - Hva kan gå galt

Fastlegens rolle
- Informasjon om MG
  - Hvor mye betyr det for dem
  - Gjort noe for å involvere dem?
  - Informasjon gjenom dem
    - Har du sakt/fått?
    - Hvordan skjød je 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

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

Barnas, mannens og venners roller
- Hva mener de om MG
  - Hvor mye betyr det for dem
  - Gjort noe for å involvere dem?
- Informasjon gjenom dem
  - Har du sakt/fått?
  - Hvordan skjød je 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

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

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Invitasjonsbrev

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

Informasjon

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

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

Undersøkelsen ifht annet

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

Bekymringer

- ...for undersøkelsen?
  - Forstå hva jeg skal gjøre
  - Eksponere meg

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

Samvittighet

- Møtt
  - Andre oppgaver valgt bort/utsatt?
  - Er andre negative?
  - (Hvorfor) dårlig samvittighet
  - Håndtere dårlig samvittighet
- Ikke-møtt
  - Hvorfor ikke møtt?
    - Andre oppgaver viktigere
    - Turte ikke møte
  - Egen vurdering av risiko for brystkreft ved å ikke møte?
- Hvordan håndterte du skyldfølelsen?
10. Articles I-IV with supplementary material
Article 1
Mammographic screening attendance among immigrant and minority women: a systematic review and meta-analysis

Sameer Bhargava1,2, Kåre Moen2, Samera Azeem Qureshi3 and Solveig Hofvind1,4

Abstract

Background: Groups of immigrant and minority women are more often diagnosed with advanced stage breast cancer than other women. Mammographic screening aims to reduce mortality from breast cancer through early detection in asymptomatic women.

Purpose: To compare mammographic screening attendance among immigrant and minority women to that of other women.

Material and Methods: A literature search of PubMed, Embase, Google Scholar, and Cochrane identified 1369 papers published between January 1995 and March 2016. In the review, we included 33 studies investigating mammographic screening attendance among immigrant and/or minority women. In a meta-analysis, we included 19 of the studies that compared attendance among immigrant and/or minority women with that among other women, using a random effects model.

Results: The review included studies from Europe, North America, and Oceania, with 42,666,093 observations of opportunities for mammographic screening. Attendance was generally lower among immigrant and minority women compared to other women (46.2% vs. 55.0%; odds ratio = 0.64, 95% confidence interval = 0.56–0.73; \( P < 0.05 \), \( I^2 = 99.9\% \)). Non-Western immigrants had lower attendance rates than other immigrants.

Conclusion: Immigrant and minority women had lower mammographic screening attendance than other women, which could potentially put them at increased risk for more advanced breast cancer. This review emphasizes the importance of continued efforts to engage with the preventative health needs of diverse populations in attempts to achieve equality in access to, and use of, care.

Keywords
Breast cancer, emigrants and immigrants, minority health, mammography, screening, attendance

Introduction

Breast cancer is the most common cancer among women worldwide (1). Incidence rates vary geographically, from 27 per 100,000 in Middle Africa to 96 per 100,000 in Western Europe (1), between ethno-racial groups within countries, and within ethno-racial groups over time (2,3). Women who migrate from countries with lower breast cancer incidence to countries with higher breast cancer incidence have been shown to increase their risk of developing breast cancer, whereas their daughters are reported to have...
incidence rates comparable to the rest of the population (4–6). Importantly, groups of immigrant and minority women are more often diagnosed with late stage breast cancer than other women, which is associated with a higher mortality rate from the disease (3,7–9).

While there is currently no strategy for primary prevention of breast cancer, mammographic screening represents secondary prevention (10,11). The observed improvements in breast cancer mortality are probably due to a combination of detection of early stage disease through screening and improved treatment (10).

Mammographic screening rates differ between and within countries (Suppl. Table 1) (12). Screening services can be organized or opportunistic. Organized screening programs have a national or regional team responsible for delivering services, enforcing quality requirements, and reporting performance metrics and other results. Most countries in the European Economic Area, along with Australia and New Zealand, offer organized mammographic screening (12,13). In North America, Canada offers organized screening, while breast cancer screening in the United States is mainly opportunistic. In opportunistic screening, mammography is performed for the early detection of cancer, but not within organized programs. In opportunistic screening, payment and reimbursement may depend on the women’s healthcare insurance.

Screening recommendations do not take into account differences in incidence and stage of disease between ethno-racial groups. As immigrants and minorities receive the same recommendations as other women, disparities in screening rates based on immigrant or minority status represent a potential for inequality in access. Our objective was to explore such a potential inequality by comparing mammographic screening attendance among immigrant and minority women to that of other women.

**Material and Methods**

We carried out a systematic review of published papers evaluating screening attendance among immigrant and minority women with data from studies carried out from January 1995 to March 2016, stratified by country and continent. We also conducted a meta-analysis evaluating attendance among immigrant and minority women vs. women in the rest of the population. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline’s checklist was used to ensure that relevant considerations were taken in all parts of the study (14).

In our review, we defined immigrants as women born in any other country than where the study was conducted, and minority women as women born in the country under study, with an ethnicity reported as different from that of the majority in that country. If it was not clear whether the women were immigrants or minorities due to missing information about country of birth, we placed them in the minority group.

In the studies included in this review, information about screening attendance was collected both from registries and through surveys. Most studies from North America were surveys that had asked women if or when they had had a mammogram, but not necessarily whether the procedure had been performed in a diagnostic or screening setting. We considered all mammograms included in this review screening mammograms since they were reported in papers considering mammography as a preventive procedure.

**Literature search**

Following the “PICO” (Population, Intervention, Comparison and Outcome) framework, the objective of our review was to determine whether immigrant and minority women (P) in age groups targeted for mammographic screening (I) had lower screening attendance rates (O) than the rest of the population (C). Fig. 1 summarizes the process we used to identify, assess and include studies. We started with a search of PubMed (step 1) using two different combinations of search terms. Each combination included several of the following words/phrases: breast cancer, ethnicity, immigrant, migrant, minority, race, screening, mammography, participation, inclusion, and selection (see Supplemental Material for detailed search strategy). We reviewed abstracts of all articles identified and the full text if the abstract indicated that the study had investigated screening attendance among immigrant and/or minority women.

The PubMed search identified 488 papers, either directly (n = 342) or indirectly through a careful review of referenced publications listed in those papers (n = 146). Review articles were not included in our study, but were read in order to identify relevant original articles. Two researchers (SB and SSHH) read the abstracts of the papers independently and excluded 158 papers based on the abstracts. Reasons for initial exclusion were that the study objectives were irrelevant for this review (n = 154), or the article had been written in a language other than English, Norwegian, Swedish, or Danish (n = 4). Any disagreement between SB and SSHH was resolved by examining the full text of the paper. A total of 330 papers were read in full, of which 21 were included in the review. The remaining papers were excluded because they met one or more of the exclusion criteria (Suppl. Table 2).

In step 2, we searched Embase (n = 652), Google Scholar (n = 217), and Cochrane (n = 5) for relevant
papers (see Supplemental Material for detailed search strategy). These searches led to the inclusion of 12 additional papers. Finally, we identified seven papers we came across through other sources and participation in international meetings, but due to our exclusion criteria, none of these were included in the review.

Altogether, we identified 1369 papers through steps 1 and 2, of which 33 were included in the review. From the included papers, data on screening attendance were extracted or calculated.

**Statistical analyses**

Some studies reported ever attendance and whether the attendance was within a defined period. From these studies, we selected attendance in the defined period for the meta-analysis. Other studies had overlapping populations. From these studies, we included the study with the highest number of observations and the longest period. For two of the papers reporting on studies of populations partly included in other publications, we extracted data not included in the other paper (15,16). Only studies with a control group were included in the meta-analysis, as we compared immigrant and minority women to non-immigrant and non-minority women.

The studies included were performed in settings that differed greatly with respect to organization of mammographic screening services and attendance rates in the control group. Also, the studies asked similar but not identical questions and included different immigrant and minority groups. For the meta-analysis, we chose a random effects model over a fixed effects model as we did not expect the true effect to be the same in all studies (17). Additionally, we performed sensitivity analyses using a fixed effects model, a model purely based on population size and models excluding the three largest studies. We calculated odds ratios (OR) for mammographic screening attendance among immigrant or minority women (cases), using non-immigrant or non-minority women as controls. Statistical heterogeneity among studies was assessed through $I^2$ statistics. For the interpretation of $I^2$, results of 25%, 50%, and 75% were interpreted as low, medium, and high heterogeneity, respectively (18). We considered $P$ values <0.05 statistically significant. All statistical analyses were carried out using STATA/MP 14.1 for Windows.

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*Fig. 1. Flowchart of selection of papers included in the meta-analysis. In the Cochrane reviews, we examined the papers examined in the reviews.*
Results

Overview

Our review covered 42,666,093 observations of opportunities for screening attendance in ten countries across three continents, of which 42,363,681 were included in our meta-analysis (Suppl. Fig. 1, Suppl. Tables 3 and 4). The number of opportunities for screening was in the range of 1089–35,846,196. Overall, immigrant and minority women had lower attendance rates than the rest of the population, with an OR of 0.64 (46.2% vs. 55.0%, 95% confidence interval [CI] = 0.56–0.73; P < 0.05, I² = 99.9%) (Suppl. Fig. 1). Among the 19 papers included in the meta-analysis, only one showed higher attendance rates among immigrant or minority women, showing that Turkish minority women had higher attendance rates than other women in Germany (19).

Sensitivity analyses using a fixed effects model and a model purely based on population size resulted in lower overall ORs in the range of 0.47–0.50. Analyses without the three largest studies resulted in overall ORs of 0.68–0.76 (range).

In Europe, the attendance rate was 64.1% among immigrant and minority women compared to 77.6% among other women, resulting in an OR of 0.61 (95% CI = 0.43–0.88; P < 0.05, I² = 99.9%) (Suppl. Fig. 1). In the United States, the corresponding rates were 48.9% and 78.3%, respectively, resulting in an OR of 0.69 (95% CI = 0.63–0.76; P < 0.05, I² = 83.8%). In Oceania, the attendance rates were 42.8% and 53.0%, respectively, giving an OR of 0.58 (95% CI = 0.44–0.77; P < 0.05, I² = 100%).

Immigrant women

Immigrants had lower attendance rates than other women in Australia, Canada, Denmark, the Netherlands, Sweden, Switzerland, and the U.S. (64.1% vs. 81.8%) (Suppl. Fig. 1, Suppl. Tables 3 and 4). While the papers included in our review had different definitions and categorizations of immigrants, most immigrants were from so-called Western countries, with the exception of the studies from Denmark, which had similar numbers of Western and non-Western immigrants. In general, non-Western immigrants appeared to have lower screening attendance than other immigrants.

Minority women

The papers included in our review reported lower attendance rates for minority women than non-minority women (43.6% vs. 53.3%). In England, South Asian women had lower attendance rates than other women; in Scotland, women with backgrounds from Pakistan, Africa, “other South Asian” countries, and India had the lowest attendance rates; and in the United States, several papers reported lower attendance among ethnic minority women than among non-Hispanic whites. Only one study, conducted in Germany, showed higher attendance rates among minority women than in the rest of the population. (Suppl. Fig. 1, Suppl. Tables 3 and 4).

All four papers that specifically compared indigenous minorities to a control group found lower attendance rates among indigenous women (Suppl. Fig. 1, Suppl. Tables 3 and 4).

Discussion

This review demonstrates that immigrant and minority women, however defined, attended mammographic screening less often than other women. With a single exception, the lower attendance rates were observed irrespective of country and continent of residence. Immigrant women from non-Western countries had lower attendance rates than other immigrant groups, putting them at disproportionate risk for diagnosis of advanced breast cancer and, correspondingly, higher rates of morbidity and mortality. Other work has indicated that this disparity forms part of wider inequalities in access to and utilization of health services between immigrants and non-immigrants (20). Our results emphasize the importance for health systems and health services to find ways of better engaging with immigrant and minority groups in efforts to address their health needs.

This includes addressing circumstances that may prevent immigrant and minority women from accessing preventive care. An issue of general importance would be to ensure that disease prevention is shaped and delivered in ways that renders it meaningful in the lived worlds of those to whom it pertains (21).

Insurance status has been shown to be a strong predictor of screening attendance in the United States (22), where screening is mainly opportunistic. The impact of insurance status was demonstrated in a study in which higher screening attendance was observed among insured immigrants than among uninsured natives (23). However, screening attendance was also significantly lower among immigrants in countries with organized screening programs although many such programs offer screening free of charge.

Income, education, and other sociodemographic factors may influence screening attendance (24). Income may also be relevant in the setting of organized screening, as women in some countries have to pay user fees. It is possible that part of the difference observed could be explained by sociodemographic disparities, as adjusting for sociodemographic factors can
attenuate or eliminate ethnic differences related to attendance (23,25,26).

Women from certain ethnic groups may be less likely to receive information and recommendations about mammographic screening from their physicians (27). If they receive such information and recommendations, it is possible that the language, wordings, and content of the information may not reflect different needs for information. To better understand how disparities in social, economic, and cultural circumstances as well as perceptions of health and disease may affect screening attendance, a host of structural, political, and societal factors must be considered (28–31). Importantly, many disparities are produced and reproduced in the course of daily medical practice.

Only one paper in our review demonstrated higher screening attendance among minority women than among other women. The group in question was Turkish-named women in Germany, identified through a name-based algorithm (19). This group might have included both Turkish immigrants and German-born women with a Turkish background, and a higher degree of acculturation may be expected among non-immigrant minority women than among immigrants. Additionally, the higher attendance rates were mainly observed in the younger part of the target group. Studies in neighboring Denmark and the Netherlands have found lower attendance among Turkish immigrant women than among non-immigrants (32,33).

The high degree of heterogeneity between reviewed studies, both in total and within geographical areas, as represented by the I²-values (Suppl. Fig. 1), represent a limitation of our study. We evaluated attendance rates in countries with different organization of screening and definitions of immigrant and minority women. Further, the studies varied in screening intervals and age groups of the study population. The control groups differed in terms of screening attendance, and several papers, particularly from the United States, were based on self-reported information with potential recall bias (34). However, the observed trend in the meta-analysis was convincing, and all but one study had ORs significantly below baseline.

The majority of the papers identified in the primary search were from the United States. Most of these papers were excluded, either due to small sample size or because they had been carried out before 1995. Nonetheless, our review included more papers from the United States than from any other country, potentially giving a geographical bias. Screening in the United States is mainly opportunistic, and the results might not be as valid for high-income countries offering organized screening.

The varying size of study populations from different countries may also have contributed to geographical skewness. Australian women accounted for 84.2% of the study population in the meta-analysis, and in total, women from Oceania accounted for more than 90%. However, the random effects model chosen for our meta-analysis reduced the impact of the size of the study population.

It should be noted that we excluded papers that presented rates or adjusted percentages of attendance if absolute counts were not provided. Furthermore, we excluded papers where we identified a discrepancy when adding counts provided for subgroups and comparing these to the total sample size. Papers with results that we were not able to recalculate were also excluded. These omissions could have led to the exclusion of relevant results.

All the papers from the United States reported lower attendance rates among minority women than their respective control groups. Other studies from the United States have found that African-American and/or Hispanic women may have similar or higher attendance rates than non-Hispanic whites (35). We excluded these papers, primarily because they did not present absolute counts.

The meta-analysis included accumulated data from studies with similar, but not identical designs that we attempted to generalize. Based on our methods and material we assumed that the random effects model accounting for both within and between study variations was appropriate. This resulted in very similar weights across studies (range = 5.05–5.37%) and a conservative estimate compared to other models. All models except the random effects model showed significantly larger differences in the observed attendance rates between immigrant and minority women in countries with organized screening programs compared to the United States where screening is mainly opportunistic.

In conclusion, our review identified that immigrant and minority women generally attended mammographic screening to a lesser degree than other women did. This could potentially put them at increased risk for being diagnosed with breast cancer in a more advanced stage. ORs varied between the studies, and attempts to achieve equality in access to screening should not only address features shared by services in different countries, but importantly also local factors that prevent individuals from gaining access to screening. This could include structural, political, and societal factors.

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Declaration of Conflicting Interests
The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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References


Article 1 - Supplementary material
Search strategy

We used the U.S. National Institute of Health’s National Library of Medicine’s PubMed search engine to identify papers on mammographic screening among immigrants and minorities (Step 1). We used the following combinations of search terms:

Search 1: (((((participation) OR participated) OR inclusion) OR selection)) AND (((((breast cancer[MeSH Terms]) OR "breast cancer") AND (((((ethnic group[MeSH Terms]) OR ethnicity[MeSH Terms]) OR immigrant[MeSH Terms]) OR immigration[MeSH Terms]) OR minority health[MeSH Terms]) OR migrant[MeSH Terms])) AND (((mass screening[MeSH Terms]) OR mammography[MeSH Terms]) OR screening) OR mammography))

Search 2: (((participation[Title/Abstract]) OR inclusion[Title/Abstract])) AND ((("breast cancer"[Title/Abstract]) OR "breast neoplasm"[Title/Abstract])) AND ((((((ethnicity[Title/Abstract]) OR ethnic[Title/Abstract]) OR immigrant[Title/Abstract]) OR immigration[Title/Abstract]) OR minority[Title/Abstract]) OR race[Title/Abstract]) OR
racial[Title/Abstract]) OR migrant[Title/Abstract]) OR migration[Title/Abstract]) AND
((screening[Title/Abstract]) OR mammography[Title/Abstract])

We searched other databases with the following search terms (Step 2):

Google Scholar: allintitle: mammography OR mammogram OR "breast screening" OR "breast cancer screening" immigrant OR minority OR migrant OR ethnicity OR ethnic OR immigration OR migration participation OR selection OR screening OR inclusion OR attendance

Cochrane (title, abstract, key words): (mammography OR mammogram OR "breast screening" OR "breast cancer screening") AND (immigrant OR minority OR migrant OR ethnicity OR ethnic OR immigration OR migration) AND (participation OR selection OR screening OR inclusion OR attendance)

Embase, keyword, limited to abstract, 1995 – current, article, English, Norwegian, Danish or Swedish: (mammography OR mammogram) AND (immigrant OR minority OR ethnic) AND (screening OR attendance)
Supplemental Table 1: Organization and overall attendance rate of mammographic screening in countries included in this review

<table>
<thead>
<tr>
<th>Country</th>
<th>Program type</th>
<th>Coverage/guidelines</th>
<th>Main method of recruitment</th>
<th>Attendance rate in the target group (2010)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>NS</td>
<td>Age 50-74; every 2 years</td>
<td>PI</td>
<td>54%</td>
</tr>
<tr>
<td>Canada</td>
<td>NS</td>
<td>Age 50-69; every 2 years</td>
<td>Area-dependent</td>
<td>47%</td>
</tr>
<tr>
<td>Denmark</td>
<td>S</td>
<td>Age 50-69; every 2 years</td>
<td>PI</td>
<td>73%</td>
</tr>
<tr>
<td>Germany</td>
<td>NS</td>
<td>Age 50-69; every 2 years</td>
<td>PI</td>
<td>56%</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>N</td>
<td>Age 50-74; every 2 years</td>
<td>PI</td>
<td>81%</td>
</tr>
<tr>
<td>New Zealand</td>
<td>N</td>
<td>Age 45-69; every 2 years</td>
<td>-</td>
<td>68%</td>
</tr>
<tr>
<td>Sweden</td>
<td>S</td>
<td>Age 40-49; every 18 months</td>
<td>PI</td>
<td>70%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>NS</td>
<td>Age 50-69; every 2 years</td>
<td>PI</td>
<td>48%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>N</td>
<td>Age 50-69; every 3 years</td>
<td>PI</td>
<td>73%</td>
</tr>
<tr>
<td>United States</td>
<td>O</td>
<td>Different guidelines</td>
<td>PR</td>
<td>67%</td>
</tr>
</tbody>
</table>

a) Data collected from references (2-4) unless otherwise specified.
b) Program types: N = National screening policy with national program implementation; NS = National screening policy with state/provincial/regional screening and program implementation; S = State/provincial/regional screening and program implementation; O = Other.

c) Method of recruitment: PI = Personal invitation; PR = Physician referral.

d) Australia: Women aged 50-74 receive an invitation, but all women aged 40 and above are eligible for a free mammogram every two years. Age group expanded from 50-69 in 2013. Attendance rate is for 2010-2011.

e) Canada: In some regions screening programs include women aged 40-49 (5).

f) German data from other references (6-8)

g) New Zealand: Age group expanded from 50-64 years in 2004 (9).

h) United States: No organized, population-wide program. The American Cancer Society and the U.S. Preventive Task Force differ in their mammography recommendations for different age groups (10, 11). Financing of screening depends on whether a woman has health insurance, and the extent of screening is affected by the proportion of women who have some reimbursement for mammography (12).
Supplemental Table 2: Criteria applied to exclude papers for the review

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Publications in languages other than English or a Scandinavian language</td>
</tr>
<tr>
<td>• Review articles</td>
</tr>
<tr>
<td>• Study period prior to 1995</td>
</tr>
<tr>
<td>• In studies including data prior to, and following 1995, we omitted data from before 1995 if possible</td>
</tr>
<tr>
<td>• Number of study participants (total number of minority women, total number of immigrant women or total number of controls) in subgroups &lt;1000</td>
</tr>
<tr>
<td>• Not possible to differentiate between women in the immigrant or minority group and in the control group</td>
</tr>
<tr>
<td>• Post-intervention data available from 1995 or later</td>
</tr>
<tr>
<td>• Not possible to exclude women aged &lt;40 years</td>
</tr>
<tr>
<td>• Studies among selected groups consisting solely of women who:</td>
</tr>
<tr>
<td>• had a history of breast cancer</td>
</tr>
<tr>
<td>• were non-adherent to screening guidelines</td>
</tr>
<tr>
<td>• had previously attended mammographic screening</td>
</tr>
<tr>
<td>• were classified as women with high risk of breast cancer</td>
</tr>
<tr>
<td>• were classified as elderly (not specified)</td>
</tr>
<tr>
<td>• required care</td>
</tr>
<tr>
<td>• were covered by public insurance due to poverty</td>
</tr>
<tr>
<td>• Not possible to calculate absolute counts from reported percentages</td>
</tr>
<tr>
<td>• Calculated numbers differ from numbers presented in paper</td>
</tr>
<tr>
<td>• Other obvious or likely errors</td>
</tr>
</tbody>
</table>
Supplemental Table 3: Main findings of immigrant and minority women’s attendance in mammographic screening in Europe, Oceania and Canada (non-U.S.)

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study area</th>
<th>Age groups and population studied (n)</th>
<th>Study period</th>
<th>Source of ethnicity and screening information. Selection of participants</th>
<th>Study design</th>
<th>Major findings</th>
<th>Included in the meta-analysis (Figure 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BreastScreen Australia Monitoring Report (2015) (1)</td>
<td>Australia</td>
<td>Age 50-69 486,282 minority women (Aborigines and Torres)</td>
<td>1996-2013 (17 rounds)</td>
<td>Ethnicity: self-reported Screening: registry Selection: Population-wide</td>
<td>Longitudinal study examining screening past 2 years</td>
<td>• Rates have increased in the indigenous population (25.0%-35.1%) and among non-indigenous women (39.7%-54.9%). • Indigenous women are screened at a lower rate than</td>
<td>Yes</td>
</tr>
<tr>
<td>Study</td>
<td>Weber et al. (2014) (13)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>New South Wales, Strait Islanders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sample size</td>
<td>35,359,914 controls</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey, response rate</td>
<td>Wales (Survey, 18%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selection</td>
<td>Immigrant women, New Zealand, Oceania, East Asia, Southeast Asia, Central and South Asia</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Ethnicity and screening</td>
<td>Self-reported</td>
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<tr>
<td>Study design</td>
<td>Cross-sectional study</td>
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<tr>
<td>Timeline</td>
<td>2006-2010</td>
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</tbody>
</table>

- Immigrants had lower attendance rates than non-immigrants in past 2 years (64.1% versus 69.5%).
- Lowest attendance rates among immigrants from East and Central Europe (55.5%), Central and South Asia (56.4%), Oceania excluding New Zealand (57.6%), and East Asia (58.5%).
- Among immigrants, the highest attendance rates were among those from the UK and Ireland (69.5%).

Immigrants had lower attendance rates than non-immigrants in past 2 years (64.1% versus 69.5%). The study was a cross-sectional examination of screening past 2 years in the non-indigenous population. The sample included immigrant women from New Zealand, Oceania, East Asia, Southeast Asia, Central and South Asia, the UK, and Ireland. The lowest attendance rates were among immigrants from East and Central Europe (55.5%), Central and South Asia (56.4%), Oceania excluding New Zealand (57.6%), and East Asia (58.5%). Among immigrants, the highest attendance rates were among those from the UK and Ireland (69.5%).
<p>| Western Europe, East and Central Europe, Middle East and North Africa, Sub-Saharan Africa, America North, Central and South) 77,225 controls | Canada | among women from Sub-Saharan Africa (69.7%), the Americas (69.6%) and New Zealand (68.5%). |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Age Group</th>
<th>Participants</th>
<th>Ethnicity and Screening</th>
<th>Study Design</th>
<th>Attendance Rates</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sun et al. (2010) (14)</td>
<td>Canada</td>
<td>Age 50-69</td>
<td>3138 immigrant women (Asian and others) 17,397 controls</td>
<td>Self-reported</td>
<td>Cross-sectional study examining past 2 years and ever</td>
<td>Immigrants had lower attendance rates than non-immigrants over past 2 years (56.5% versus 64.1%) and ever (83.2% versus 89.0%). The Asian subgroup had lower attendance rates (42.5% past 2 years and 71.1% ever).</td>
<td>Yes (Funen only)</td>
</tr>
<tr>
<td>Von Euler-Chelpin et al. (2008) (15)</td>
<td>Denmark</td>
<td>Age 50-69</td>
<td>3748 immigrant women 69,300 controls</td>
<td>Registry</td>
<td>Cross-sectional study examining in all 4 rounds and ever</td>
<td>Immigrants had lower attendance rates than non-immigrants in all 4 rounds (47.8% versus 66.8%) and ever (75.9% versus 85.1%).</td>
<td>Yes (Funen only)</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Age Group</td>
<td>Year</td>
<td>Immigration Details</td>
<td>Ethnicty and Screening</td>
<td>Study Details</td>
<td>Attendance</td>
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</tr>
<tr>
<td>Holk et al. (2002) (16)</td>
<td>Copenhagen</td>
<td>Age 50-69</td>
<td>1993-1997</td>
<td>11,597 immigrant women (Yugoslavia, Pakistan, Poland, Turkey and other)</td>
<td>Registry Selection: Population-wide</td>
<td>Cross-sectional study examining screening past 2 years</td>
<td>Immigrants had lower attendance rates than non-immigrants (62.6% versus 70.8%).</td>
</tr>
<tr>
<td>Jensen et al. (2012) (17)</td>
<td>Central Denmark region</td>
<td>Age 50-69</td>
<td>2008-2009</td>
<td>5997 immigrant women (Western and other)</td>
<td>Registry</td>
<td>Cross-sectional study examining</td>
<td>Immigrants had lower attendance rates than non-immigrants (62.9% versus 79.6%).</td>
</tr>
</tbody>
</table>

Immigrants from Pakistan (34.2%), Yugoslavia (41.5%) and Turkey (48.3%) had the lowest attendance rates.
<table>
<thead>
<tr>
<th>Kristiansen et al. (2012)</th>
<th>Copenhagen</th>
<th>non-Western) 138,219 controls</th>
<th>Selection: Population-wide</th>
<th>screening past 2 years</th>
<th>• Non-Western immigrants had lower attendance rates than Western immigrants (57.3% versus 68.8%).</th>
<th>Yes</th>
</tr>
</thead>
</table>
| Germany                 | Duisburg, Bielfeld, | Age 50-69 11,375 immigrant women (Western and non-Western) 84,489 controls | 1991-2008 (8 rounds) | Ethnicity and screening: Registry Selection: Population-wide | Cross-sectional study examining screening ever | • Immigrants had lower attendance rates than non-immigrants (63.9% versus 74.0%).
<p>|                         |            |                               |                           | Cross-sectional study | • Non-Western immigrants had lower attendance rates than Western immigrants (61% versus 67%) |     |
| Berens et al. (2014)    |            |                               |                           | Cross-sectional       | • Turkish minority women had higher attendance rate than | Yes |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>Sample Size</th>
<th>Study Details</th>
<th>Attendance Rates</th>
<th>Results</th>
</tr>
</thead>
</table>
| Paderborn, Hamburg and Berlin | 18,650 minority women (Turkish-named) 404,999 controls | Screening: Registry  Selection: Population-wide | study examining screening past 2 years | non-Turkish women (52.3% versus 49.1%), mostly due to higher screening among those aged 50-59.  
• Among those aged 65-69, Turkish women had lower attendance rates than non-Turkish women (40.2% versus 47.0%). |
<p>| The Netherlands | Age 50-75 88,342 immigrant women (Europe, 1997-1998 and 2007-2008 (2 rounds) | Ethnicity and screening: Registry | Longitudinal, examining screening past 2 years | • Immigrants had lower attendance rates between 1997-1998 (60.6% versus 81.0%) and between 2007-2008 (65.8% versus 84.3%). | Yes |</p>
<table>
<thead>
<tr>
<th>Country</th>
<th>Study Details</th>
<th>Selection: Population-wide</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Zealand</td>
<td>BreastScreen Aotearoa (2015) (9) New Zealand Age 45-69 (50-64 for 2004-2014) (5 rounds) Ethnicity: Self-reported 5 cross-sectional studies,</td>
<td></td>
<td>• Rates have increased for Maori (41.5%-63.9%), Pacific Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• In 1997-1998 women from Turkey, Morocco, Suriname and “other non-Western” countries had lower attendance rates than the average for immigrants.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• In 2007-2008 women from Turkey, Morocco and “other non-Western” countries had lower attendance rates than the average for immigrants.</td>
</tr>
</tbody>
</table>

Other Western, Turkey, Morocco, Suriname, Netherlands Antilles, other non-Western) 2,162,320 controls
<table>
<thead>
<tr>
<th>Country</th>
<th>Study</th>
<th>Age</th>
<th>Study Period</th>
<th>Ethnicity and Screening</th>
<th>Cross-sectional Study</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| Sweden  | Lagerlund et al. (2002) (21) | Age 40-74 | 1988-1997 (5 rounds) | Ethnicity and screening: Registry | Cross-sectional study examining if women have attended | • Immigrants had lower attendance rates than non-immigrants (84.3% versus 90.4%).  
• Among immigrants, Nordic women had the highest |

- 371,875 minority women (Maori and Pacific)  
- 2,537,158 controls  

Screening: Registry. Selection: Population-wide  

(47.6%-68.7%) and other women (62.4%-73.4%).  

- Maori and Pacific women are screened at a lower rate than the rest of the population.
<table>
<thead>
<tr>
<th>Country</th>
<th>Study Area</th>
<th>Age Range</th>
<th>Number of Participants</th>
<th>Ethnicity and Selection</th>
<th>Study Design</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Switzerland</td>
<td></td>
<td>Age 50-70</td>
<td>1517 immigrant women</td>
<td>Registry</td>
<td>Cross-sectional study examining screening past 2 years</td>
<td>- Foreign nationals had lower attendance rates than Swiss nationals (37.9% versus 48.0%)</td>
</tr>
<tr>
<td>North America, South America, Asia, Africa and Pacific</td>
<td></td>
<td>40,799 controls</td>
<td></td>
<td>Population-wide</td>
<td>screening once in the past 2 invitations</td>
<td>attendance rates (88.0%), while African (76.6%) and North American (73.6%) women had the lowest rates (Note: low number of African and North American women).</td>
</tr>
<tr>
<td>Switzerland</td>
<td></td>
<td>1993-1995 (1 round)</td>
<td></td>
<td></td>
<td>screening past 2 years</td>
<td></td>
</tr>
<tr>
<td>Switzerland</td>
<td></td>
<td>Aigle, Aubonne and Morges</td>
<td>8822 controls</td>
<td></td>
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<tr>
<td>Switzerland</td>
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</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Age</td>
<td>Ethnicity</td>
<td>Screening</td>
<td>Selection</td>
<td>Study Findings</td>
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</tbody>
</table>
| Bansal et al. (2012) (23) | United Kingdom | Age 50-69 | minority women, 16,348; controls, 123,026 | Cross-sectional, examining first routine screening invitation (3 year period) | Self-reported. | - Minority women had lower attendance rates than controls (74.8% versus 76.9%).
- Among minorities, Pakistani women had the lowest attendance rates (58.1%), while other Caucasian British (77.0%), Chinese (74.0%) and Caucasian Irish (73.9%) had the highest rates. | Yes |
| Price et al. (2010) (24) | Coventry and Warwickshire | 3539 minority women (South Asian) | 2000-2002 (1 round) | Ethnicity: Name recognition. Screening: Registry Selection: Population-wide (GP) | Cross-sectional study examining past 3 years | South Asian minority women had lower attendance rates than controls (70.3% versus 79.8%). | Yes |
Overview of the main findings (non-U.S.). Data was either extracted from the cited papers or calculated from data available in the cited papers unless otherwise specified.

a) Study round two included women aged 50-71 and round 8 included women aged 48-49.

b) Data for Pacific women only available for 2006-2012. Data for Maori women and other women available for all years.
Supplemental Table 4. Main findings of immigrant and minority women’s attendance in mammographic screening in the U.S.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Population a</th>
<th>Study area/ Survey</th>
<th>Study period</th>
<th>Study design</th>
<th>Major findings</th>
<th>Included in the meta-analysis (Figure 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aldridge et al. (2006) (26)</td>
<td>Age ≥ 40 1737 minority women (H) 64,408 controls</td>
<td>50 U.S. states and DC (BRFSS response rate 44.5%)</td>
<td>2002</td>
<td>Cross-sectional examining screening ever</td>
<td>Hispanic minority women had lower rates of screening than the Caucasian majority population (87.5% versus 89.9%).</td>
<td>Yes</td>
</tr>
<tr>
<td>Coughlin and Uhler (2000) (27)</td>
<td>Age ≥ 50 1597 minority</td>
<td>49 U.S. states (BRFSS)</td>
<td>1994-1997</td>
<td>Cross-sectional study examining screening past 2 years and ever</td>
<td>• AAPI had an attendance rate of 71.7%.&lt;br&gt;• Almost 82.0% of AAPI aged ≥ 40 had ever had a mammogram.</td>
<td>No</td>
</tr>
<tr>
<td>Study</td>
<td>Age Group</td>
<td>Sample Size</td>
<td>Year(s)</td>
<td>Study Design</td>
<td>Findings</td>
<td>Controls</td>
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</tr>
<tr>
<td>Coughlin and Uhler (2002) (28)</td>
<td>Age ≥ 40</td>
<td>7247</td>
<td>1998-1999</td>
<td>Cross-sectional</td>
<td>• Hispanic minority women had an attendance rate of 68.6% over past 2 years.</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Minority</td>
<td>women (H)</td>
<td></td>
<td>study examining</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No controls</td>
<td></td>
<td></td>
<td>screening past 2 years</td>
<td></td>
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</tr>
<tr>
<td>Dean et al. (2014) (29)</td>
<td>Age ≥ 40</td>
<td>2586</td>
<td>2004, 2006 and 2008</td>
<td>Cross-sectional study, pooled data from 3 years, examining screening past 1 years</td>
<td>• African American had an attendance rate of 68.5% over past 1 year</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>AA</td>
<td></td>
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<td>study</td>
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<tr>
<td></td>
<td>No controls</td>
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<tr>
<td>Study</td>
<td>Population</td>
<td>Study Design</td>
<td>Year</td>
<td>Attendance Rates</td>
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<tr>
<td>Edwards et al. (2009) (30)</td>
<td>Age 45-75 minority women (AA, H, NH and Japanese), 60,675</td>
<td>Cross-sectional study examining every 2 years from 1993-1998</td>
<td>1999-2002</td>
<td>• Minority women had lower attendance rates than the control group (46.4% versus 54.2%).&lt;br&gt;• Among minorities, Hispanic (43.4%), African American (43.9%) and native Hawaiian women (45.2%) had lower attendance rates than minority average.&lt;br&gt;• Japanese women (50.2%) had higher attendance rates than the average for minorities.</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Gomez et al. (2007) (31)</td>
<td>Age 50-80 minority women (China, Japan, the Philippines), 1521</td>
<td>Cross-sectional study examining screening past 2 years</td>
<td>2001</td>
<td>• Overall attendance rate was 64.5%.&lt;br&gt;• Foreign-born women had an attendance rate of 62.7%, increasing with length of stay (highest among US-born).&lt;br&gt;• Japanese women had the highest attendance rate (70.6%).</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Study (Reference)</td>
<td>Population</td>
<td>Age</td>
<td>Study Design</td>
<td>Year</td>
<td>Findings</td>
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</tbody>
</table>
| Hamon et al. (2014) | Korea, South Asia and Vietnam, of whom 1197 were immigrants. No controls. | | Cross-sectional study examining ever screened | 1999-2002 | • Korean women had the lowest attendance rate (52.1%).
| | | | | | • Immigrant and minority women had lower attendance rates than Caucasian control group (86.6% versus 89.6%).
| | | | | | • Among immigrant and minority women, Japanese minority women had the highest attendance rates (87.9%).
<p>| | | | | | • Native Hawaiians had the lowest attendance rates (84.3%). |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Age Criteria</th>
<th>Location</th>
<th>Year</th>
<th>Methodology</th>
<th>Key Findings</th>
<th>Note</th>
</tr>
</thead>
</table>
| Kandula et al. (2006)  | Cross-sectional | ≥ 40 years old                   | California (CHIS, overall response rate 37.7%) | 2001 | Examining screening past 2 years       | - Minority women had lower attendance rates than the Caucasian control group (66.3% versus 77.9%).  
  - Among minority women Vietnamese and “other Asians” had the highest attendance rates (72.7% and 72.6%).  
  - Korean women had the lowest attendance rates (53.1%).                                               | Yes  |
<p>| Lees et al. (2005)     | Cross-sectional | ≥ 40 years old                   | U.S. population (NHIS, 2000) | 2000 | Examining attendance rates             | - Minority women had lower attendance rates than Caucasian control group (58.4% versus 66.7%).           | No   |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Women (race/ethnicity, controls)</th>
<th>Overall response rate (72%)</th>
<th>Screening past 2 years</th>
<th>Findings</th>
<th>Study locations</th>
<th>Year</th>
<th>Study design</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lim (2010) (35)</td>
<td>African Americans and Hispanics (H)</td>
<td>7716 controls</td>
<td>72%</td>
<td>Screening past 2 years</td>
<td>African Americans had higher attendance rates than Hispanic women (59.6% versus 56.8%), but not if Spanish-speaking women were excluded.</td>
<td>California (CHIS)</td>
<td>2007</td>
<td>Cross-sectional study examining screening past 2 years</td>
</tr>
<tr>
<td>Mack et al. (2009) (36)</td>
<td>Minority (H and A)</td>
<td>No controls</td>
<td>Screening past 2 years</td>
<td>Hispanic women had an attendance rate of 68.7% over past 2 years and 82.0% ever.</td>
<td>California (CWHS, response rates 72%, 72%, 74% and 74% in the years 2002-2005)</td>
<td>2002-2005</td>
<td>Cross-sectional studies (pooled), examining screening past 2 years</td>
<td>No</td>
</tr>
<tr>
<td>Study</td>
<td>Age ≥ 40</td>
<td>Minority Women (AA and H)</td>
<td>Controls</td>
<td>Year</td>
<td>Study Design</td>
<td>Findings</td>
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</tbody>
</table>
| Meissner et al. (2007)                      | 2710     | 2753                      | U.S. population (NHIS) | 2000 | Cross-sectional study examining screening past 2 years | • Minority women had lower attendance rates than control group (64.7% versus 70.9%).  
• Hispanic women had lower attendance rates than African American women (60.7% versus 68.3%).  
• Foreign-born women had a lower attendance rate than US-born women (59.8% versus 70.1%). |
<p>| Nguyen et al. (2009)                        | 1089     | Vietnamese                | California | 2004-2007 | Cross-sectional study examining screening past 2 years | • Vietnamese women had an attendance rate of 69.4% over past 2 years and 86.9% ever (pre-intervention data). |</p>
<table>
<thead>
<tr>
<th>Study Reference</th>
<th>Age Group</th>
<th>Sample Size</th>
<th>Setting</th>
<th>Study Design</th>
<th>Finding</th>
<th>Controls</th>
<th>Race/Ethnicity</th>
<th>Attendance Rates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schumacher et al. (2008) (39)</td>
<td>Age ≥ 40</td>
<td>3293 minority women (AI and AN)</td>
<td>Alaska and Navajo Nation (EARTH study)</td>
<td>2004-2007</td>
<td>Cross-sectional study examining screening past 2 years and ever</td>
<td>American Indian women had lower attendance rates than Alaska native women, both over the past 2 years (47.2% versus 70.7%) and ever (69.9% versus 88.2%).</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Selvin and Brett (2003) (40)</td>
<td>Age 40-64</td>
<td>1514 minority women (AA and H)</td>
<td>U.S. population (NHIS, response rate 74%)</td>
<td>1998</td>
<td>Cross-sectional study examining screening past 2 years</td>
<td>Minority women had lower attendance rates than Caucasian control group (63.2% versus 70.3%). African Americans attended at a higher rate than Hispanic women (66.7% versus 59.5%).</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Suarez et al. (2000) (41)</td>
<td>Age ≥ 40</td>
<td>2239 minority women</td>
<td>New York, Florida, Unspecified</td>
<td>Cross-sectional study examining</td>
<td>Hispanic minority women had an attendance rate of 57.9% over past 2 years.</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Age</td>
<td>Sample Size</td>
<td>Area</td>
<td>Study Type</td>
<td>Screening Period</td>
<td>Attendance Rate comparison</td>
<td></td>
<td></td>
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<tr>
<td>Valdovinos et al. (2016) (42)</td>
<td>40-74</td>
<td>2260</td>
<td>Bronx, Chicago, Miami and San Diego (HCHS/SOL)</td>
<td>Cross-sectional study examining screening past 2 years</td>
<td>2008-2011</td>
<td>H had an attendance rate of 74.5% over the past 2 years.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zhou et al. (2010) (43)</td>
<td>40-79</td>
<td>2304</td>
<td>U.S. population (NHIS, response rates)</td>
<td>Longitudinal study examining screening past year</td>
<td>2000 and 2005</td>
<td>Hispanic women had lower attendance rates than the control group (41.7% versus 53.3%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Mexican American women had the lowest attendance rate (53.6%), while Central American and Cuban American women had the highest rates (70.5%).

No controls

Texas and California (response rate 83%)
Overview of the main findings (U.S.). Data is either extracted from the cited papers or calculated from data from the cited papers unless otherwise specified. The American studies included are based on surveys. Unless otherwise specified, ethnicity and screening are self-reported, and the selection is a sample of the total population. In the few cases where this was not specified, we assumed that the surveys included self-reported ethnicity and screening, and that the selection was a sample of the total population.

a) A = Asian, AA = African American, AAPI = Asian Americans and Pacific Islanders, AI = American Indian, AN = Alaska Native, H = Hispanic, NH = Native Hawaiian
Supplemental Figure 1: Meta-analysis of 19 studies comparing mammographic attendance among immigrant or minority women with the rest of the population.


<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Immigrant/Minority</th>
<th>Cases</th>
<th>Controls</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Europe</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>von Euler-Cheim et al. (2008)</td>
<td>Denmark</td>
<td>I</td>
<td>1125</td>
<td>38564</td>
<td>0.58 (0.51-0.66)</td>
</tr>
<tr>
<td>Krabbe et al. (2012)</td>
<td>Denmark</td>
<td>I</td>
<td>11375</td>
<td>84489</td>
<td>0.62 (0.60-0.65)</td>
</tr>
<tr>
<td>Lagerlund et al. (2002)</td>
<td>Sweden</td>
<td>I</td>
<td>5242</td>
<td>40799</td>
<td>0.57 (0.53-0.62)</td>
</tr>
<tr>
<td>Vermeir et al. (2010)</td>
<td>Netherlands</td>
<td>I</td>
<td>88342</td>
<td>2162320</td>
<td>0.36 (0.36-0.37)</td>
</tr>
<tr>
<td>Bullard et al. (2004)</td>
<td>Switzerland</td>
<td>I</td>
<td>1517</td>
<td>8822</td>
<td>0.66 (0.59-0.74)</td>
</tr>
<tr>
<td>Jensen et al. (2012)</td>
<td>Denmark</td>
<td>I</td>
<td>5997</td>
<td>138219</td>
<td>0.43 (0.41-0.46)</td>
</tr>
<tr>
<td>Berens et al. (2014)</td>
<td>Germany</td>
<td>M</td>
<td>18650</td>
<td>404999</td>
<td>1.14 (1.10-1.17)</td>
</tr>
<tr>
<td>Szczepura et al. (2008)</td>
<td>UK (England)</td>
<td>M</td>
<td>6829</td>
<td>142173</td>
<td>0.56 (0.53-0.59)</td>
</tr>
<tr>
<td>Bansai et al. (2012)</td>
<td>UK (Scotland)</td>
<td>M</td>
<td>16340</td>
<td>123026</td>
<td>0.69 (0.66-0.92)</td>
</tr>
<tr>
<td><strong>Subtotal (I-squared = 99.9%, p = 0.000)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oceania</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weber et al. (2014)</td>
<td>Australia</td>
<td>I</td>
<td>24117</td>
<td>77225</td>
<td>0.78 (0.76-0.81)</td>
</tr>
<tr>
<td>BreastScreen Australia (2015)</td>
<td>Australia</td>
<td>M</td>
<td>485282</td>
<td>35359914</td>
<td>0.43 (0.42-0.43)</td>
</tr>
<tr>
<td>BreastScreen Aotearoa (2005-2015)</td>
<td>New Zealand</td>
<td>M</td>
<td>371875</td>
<td>2537158</td>
<td>0.59 (0.59-0.59)</td>
</tr>
<tr>
<td><strong>Subtotal (I-squared = 100.0%, p = 0.000)</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Canada</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sun et al. (2016)</td>
<td>Canada</td>
<td>I</td>
<td>3136</td>
<td>17397</td>
<td>0.73 (0.67-0.79)</td>
</tr>
<tr>
<td><strong>Subtotal (I-squared = %, p = .)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Selvin et al. (2003)</td>
<td>USA</td>
<td>M</td>
<td>1514</td>
<td>3995</td>
<td>0.73 (0.64-0.82)</td>
</tr>
<tr>
<td>Edwards et al. (2009)</td>
<td>USA</td>
<td>M</td>
<td>60375</td>
<td>21047</td>
<td>0.73 (0.71-0.76)</td>
</tr>
<tr>
<td>Zhou et al. (2010)</td>
<td>USA</td>
<td>M</td>
<td>1155</td>
<td>5881</td>
<td>0.62 (0.55-0.71)</td>
</tr>
<tr>
<td>Messner et al. (2007)</td>
<td>USA</td>
<td>M</td>
<td>2710</td>
<td>7253</td>
<td>0.75 (0.69-0.83)</td>
</tr>
<tr>
<td>Kandula et al. (2006)</td>
<td>USA</td>
<td>M</td>
<td>1574</td>
<td>15790</td>
<td>0.56 (0.50-0.62)</td>
</tr>
<tr>
<td>Aitkne et al. (2006)</td>
<td>USA</td>
<td>M</td>
<td>1737</td>
<td>64408</td>
<td>0.78 (0.68-0.91)</td>
</tr>
<tr>
<td><strong>Subtotal (I-squared = 82.7%, p = 0.000)</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Overall (I-squared = 99.9%, p = 0.000)</strong></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**NOTE:** Weights are from random effects analysis.
Article 2
Lower attendance rates in immigrant versus non-immigrant women in the Norwegian Breast Cancer Screening Programme

Sameer Bhargava¹,², Kaitlyn Tsuruda¹, Kåre Moen², Ida Bukholm³,⁴ and Solveig Hofvind¹,⁵

Abstract

Objective: The Norwegian Breast Cancer Screening Programme invites women aged 50–69 to biennial mammographic screening. Although 84% of invited women have attended at least once, attendance rates vary across the country. We investigated attendance rates among various immigrant groups compared with non-immigrants in the programme.

Methods: There were 4,053,691 invitations sent to 885,979 women between 1996 and 2015. Using individual level population-based data from the Cancer Registry and Statistics Norway, we examined percent attendance and calculated incidence rate ratios, comparing immigrants with non-immigrants, using Poisson regression, following women’s first invitation to the programme and for ever having attended.

Results: Immigrant women had lower attendance rates than the rest of the population, both following the first invitation (53.1% versus 76.1%) and for ever having attended (66.9% versus 86.4%). Differences in attendance rates between non-immigrant and immigrant women were less pronounced, but still present, when adjusted for sociodemographic factors. We also identified differences in attendance between immigrant groups. Attendance increased with duration of residency in Norway. A subgroup analysis of migrants’ daughters showed that 70.0% attended following the first invitation, while 82.3% had ever attended.

Conclusions: Immigrant women had lower breast cancer screening attendance rates. The rationale for immigrant women’s non-attendance needs to be explored through further studies targeting women from various birth countries and regions.

Keywords
Mammography, screening, attendance, breast cancer, immigrant, inequality

Introduction

Breast cancer is the most common cancer among women worldwide and in Norway, with the highest incidence occurring in Europe, North America and Oceania.¹,² In these regions, immigrant women have lower breast cancer incidence, overall, than non-immigrants, but this effect is not observed among second generation immigrants.³,⁴ Immigrant and ethnic minority women are also diagnosed with more advanced disease than non-immigrants.⁵,⁶

As mammographic screening has both benefits and harms, recommendations underscore the importance of enabling women to make an informed choice about screening participation.⁷ In Norway, the European Union (EU), Australia, New Zealand and North America, most independent panels and policy makers recommend mammographic screening for women in higher-risk age-ranges.⁸ These recommendations are in keeping with those from the International Agency for Research on Cancer,¹⁴ but guidance is not stratified by women’s country of origin.

Studies suggest that sociodemographic factors influence attendance rates in high-income countries (HIC).¹⁵–¹⁷ Low income, low educational status and being married have been found to be associated with non-attendance. A recent Norwegian study suggested that improvements in breast cancer incidence and mortality after the turn of the century have primarily benefited higher educated women.¹⁸ Studies from other HIC have shown that
immigrant women have lower attendance rates than non-immigrants,\textsuperscript{19,20} however, some of these studies are limited by small sample sizes, short study periods or inaccuracies associated with self-reported attendance.

About 14% of Norway’s population are immigrants, and their children account for a further 3% of the population.\textsuperscript{26} Although 53% of immigrants come from Europe, the 10 countries from which most women have emigrated include Somalia, Iraq, Syria, the Philippines, Pakistan and Eritrea. Many Pakistani immigrants have lived in Norway since the 1970s, and their descendants almost equal the number of Pakistani immigrants. Most immigrants from the new EU member states have lived in Norway for less than five years. Since 1989, family reunification has been the most common reason for immigration, followed by work. Employment rates are lower for immigrants than non-immigrants, and less immigrant women are employed than immigrant men. A higher proportion of immigrants from the EU member states are employed than non-immigrants, while the proportion of employed immigrants from Africa and Asia is lower compared with the rest of the population.

The Norwegian Breast Cancer Screening Programme (NBCSP) started in four counties in 1996, and was nationwide in 2005 after a staggered implementation. The programme offers two-view mammographic screening to women aged 50–69 through 10 screening rounds over 20 years. Currently, approximately 600,000 women are invited to each screening round.\textsuperscript{27} Women are identified through the National Registry, and receive a personalised invitation letter with a time and place for examination. Screening is performed at 26 stationary and four mobile units. Women must pay their travel expenses to the screening location, and a user fee of 240 NOK (about €26) for screening and any subsequent recall and diagnostic work-up. The average attendance rate for a screening round is 75%, and 84% of invited women attended the programme at least once between 1996 and 2014.\textsuperscript{28} Attendance rates per screening round vary between regions, from 62% in Oslo to 82% in the rural county of Sogn og Fjordane. The programme is described in detail elsewhere.\textsuperscript{29}

In this study we aim to investigate mammographic screening attendance among various immigrant groups compared with non-immigrants, and to see how this has varied when adjusted for sociodemographic factors. We also wanted to investigate how attendance rates have varied among various immigrant groups since the start of the programme in 1996, and how attendance rates vary with years since immigration.

Methods

The Cancer Registry of Norway holds attendance information for approximately 900,000 women invited to the NBCSP since its inception in 1996. The Norwegian resident registry allocates all residents a unique personal identification number, which allows linkage of information from the screening programme to other registries. Statistics Norway gathers information from several population-based registries,\textsuperscript{30} which contain information about country of birth, date of immigration to Norway and sociodemographic factors. This provides a unique opportunity to merge data on an individual level from different population registries with the mammographic screening database, and to examine the attendance rates in the NBCSP among non-immigrant and immigrant women.

Data sources and modifications

Our study population of 885,979 women received 4,053,691 invitations between January 1996 and December 2015 (Table 1). We extracted data about invitations, attendance, age and region from the Cancer Registry database, and followed the women from month of first appointment until month of breast cancer diagnosis, emigration, death or end of study period. Women with a prior history of breast cancer were excluded. Statistics Norway provided information on country of birth, country of origin two generations previously, date of immigration and sociodemographic factors (income, net worth, education, employment status, disability benefit recipient status, marital status, citizenship and age at immigration). Data from the Cancer Registry of Norway was merged with that from Statistics Norway using the personal identification number. Immigrant women were defined as women born abroad with two foreign-born parents and four foreign-born grandparents.\textsuperscript{30} All other women were considered non-immigrants. In a sub-group analysis we investigated attendance rates for 1352 non-immigrant women who were daughters of immigrants (henceforth referred to as second generation immigrants).

We divided immigrant women, according to their country of birth, into geographical regions based on the United Nations’ Population Division,\textsuperscript{31} with some modifications (Cyprus and Kosovo were included in Southern Europe, and Greenland was included in Northern Europe). Based on political, historical and cultural circumstances, we further divided Northern Europe into Norway (non-immigrants), the (other) Nordic Countries (Sweden, Denmark, Finland, Iceland and Greenland), the Baltic Countries (Estonia, Latvia and Lithuania) and the British Isles (United Kingdom, Ireland, Channel Islands and Isle of Man). The four regions of Oceania were combined into one region as very few women originated from countries other than Australia or New Zealand. As it would be very difficult to present all 21 regions in figures, we used the United Nations’ Population Division’s categories of HIC, middle-income countries (MIC) and low-income countries (LIC) for graphical presentations (see online appendix for categorisation).

We chose sociodemographic variables based on findings from other studies and the data available.\textsuperscript{15-17,19,22,28,32} Data on yearly income and net worth were available for all years. We categorised these data into deciles derived from all women in Norway aged 25–67.
Table 1. Number of women, invitations, attendance rates and crude and adjusted incidence rate ratios for attendance after the first invitation and whether women have ever attended the Norwegian Breast Cancer Screening Programme, 1996–2015, by (a) non-immigrants versus immigrants, (b) geographical region of birth and (c) second generation immigrants versus other non-immigrants.

<table>
<thead>
<tr>
<th>Women (n)</th>
<th>Invitations (n)</th>
<th>Invitations/ women (x, SD)</th>
<th>Attendance (%)</th>
<th>IRR first invitation</th>
<th>IRR ever attended</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>First</td>
<td>Ever</td>
<td>Crude</td>
<td>Adjusted</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-immigrants</td>
<td>813,772</td>
<td>3,779,810</td>
<td>4.6 (2.5)</td>
<td>76.1</td>
<td>86.4</td>
</tr>
<tr>
<td>All immigrants</td>
<td>72,207</td>
<td>273,881</td>
<td>3.8 (2.5)</td>
<td>53.1</td>
<td>66.9</td>
</tr>
<tr>
<td>Total</td>
<td>885,979</td>
<td>4,053,691</td>
<td>4.6 (2.5)</td>
<td>74.2</td>
<td>84.8</td>
</tr>
</tbody>
</table>

(a) Overview of non-immigrants versus immigrants

(b) Immigrant women by geographical region

| The Nordic Countries | 15,059 | 62,201 | 4.1 (2.6) | 69.0 | 80.2 | 0.91 (0.90–0.92) | 0.98 (0.97–1.00) | 0.93 (0.92–0.94) | 1.00 (0.99–1.01) |
| The Baltic Countries | 1545   | 3382   | 2.2 (1.4) | 31.9 | 42.0 | 0.42 (0.39–0.45) | 0.57 (0.53–0.62) | 0.49 (0.46–0.52) | 0.62 (0.59–0.66) |
| The British Isles | 3018   | 13,401 | 4.4 (2.7) | 64.2 | 76.3 | 0.84 (0.82–0.87) | 0.95 (0.92–0.99) | 0.88 (0.87–0.90) | 0.99 (0.96–1.01) |
| Western Europe | 4642   | 25,508 | 4.0 (2.5) | 60.1 | 71.8 | 0.79 (0.77–0.81) | 0.88 (0.86–0.91) | 0.83 (0.82–0.84) | 0.92 (0.90–0.94) |
| Southern Europe | 5969   | 23,451 | 3.9 (2.5) | 46.3 | 61.8 | 0.61 (0.59–0.63) | 0.70 (0.68–0.72) | 0.72 (0.70–0.73) | 0.80 (0.79–0.82) |
| Eastern Europe | 8944   | 29,969 | 3.4 (2.3) | 47.4 | 60.8 | 0.62 (0.61–0.64) | 0.78 (0.76–0.80) | 0.70 (0.69–0.72) | 0.84 (0.83–0.86) |
| Northern Africa | 875   | 3370   | 3.9 (2.7) | 37.9 | 54.4 | 0.50 (0.46–0.54) | 0.68 (0.62–0.74) | 0.63 (0.59–0.67) | 0.78 (0.73–0.83) |
| Eastern Africa | 2252   | 6914   | 3.1 (2.2) | 33.6 | 46.0 | 0.44 (0.42–0.47) | 0.57 (0.54–0.61) | 0.53 (0.51–0.56) | 0.65 (0.62–0.67) |
| Middle Africa | 150   | 432   | 2.9 (2.1) | 50.0 | 60.0 | 0.66 (0.56–0.77) | 0.77 (0.65–0.91) | 0.69 (0.61–0.79) | 0.79 (0.69–0.90) |
| Southern Africa | 189   | 689   | 3.6 (2.4) | 52.9 | 68.3 | 0.70 (0.61–0.80) | 0.78 (0.69–0.89) | 0.79 (0.72–0.87) | 0.87 (0.80–0.95) |
| Western Africa | 472   | 1538   | 3.3 (2.5) | 54.0 | 65.7 | 0.71 (0.65–0.77) | 0.87 (0.80–0.94) | 0.76 (0.71–0.81) | 0.87 (0.82–0.93) |
| South-Eastern Asia | 7853   | 28,956 | 3.7 (2.4) | 50.2 | 65.2 | 0.66 (0.65–0.67) | 0.77 (0.75–0.78) | 0.76 (0.74–0.77) | 0.85 (0.84–0.86) |
| South-Central Asia | 8358   | 33,249 | 4.0 (2.7) | 44.2 | 62.0 | 0.58 (0.57–0.60) | 0.75 (0.74–0.77) | 0.72 (0.71–0.73) | 0.87 (0.86–0.89) |
| Western Asia | 3215   | 11,467 | 3.6 (2.4) | 41.7 | 59.3 | 0.55 (0.53–0.57) | 0.68 (0.66–0.71) | 0.69 (0.67–0.71) | 0.80 (0.78–0.83) |
| Eastern Asia | 1958   | 7147   | 3.7 (2.6) | 45.9 | 59.4 | 0.60 (0.58–0.63) | 0.74 (0.71–0.78) | 0.69 (0.66–0.71) | 0.82 (0.79–0.85) |
| Northern America | 2616   | 9545   | 3.6 (2.5) | 54.3 | 67.1 | 0.71 (0.69–0.74) | 0.87 (0.84–0.90) | 0.78 (0.76–0.80) | 0.92 (0.89–0.95) |
| Caribbean | 277   | 1036   | 3.7 (2.5) | 50.5 | 65.0 | 0.66 (0.59–0.75) | 0.80 (0.72–0.90) | 0.75 (0.69–0.82) | 0.86 (0.79–0.93) |
| Central America | 224   | 872   | 3.9 (2.5) | 52.7 | 68.3 | 0.69 (0.61–0.78) | 0.81 (0.72–0.91) | 0.79 (0.72–0.86) | 0.88 (0.81–0.96) |
| South America | 2554   | 9752   | 3.8 (2.5) | 56.2 | 72.3 | 0.74 (0.71–0.77) | 0.86 (0.83–0.89) | 0.84 (0.82–0.86) | 0.94 (0.92–0.96) |
| Oceania | 247   | 1002   | 4.1 (2.7) | 59.5 | 69.6 | 0.78 (0.71–0.87) | 0.92 (0.83–1.01) | 0.81 (0.74–0.88) | 0.93 (0.87–1.01) |

(c) Second generation immigrants versus other non-immigrants (excluding second generation immigrants)

<table>
<thead>
<tr>
<th>Women (n)</th>
<th>Invitations (n)</th>
<th>Invitations/ women (x, SD)</th>
<th>Attendance (%)</th>
<th>IRR first invitation</th>
<th>IRR ever attended</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-immigrants</td>
<td>1352</td>
<td>6125</td>
<td>4.5 (2.5)</td>
<td>70.0</td>
<td>82.3</td>
</tr>
</tbody>
</table>

Notes:

- Adjusted for income, net worth, education, disability benefits, marital status, citizenship, whether women were living in the capital city or not and screening year.
- Adjusted for income, net worth, education, disability benefits, marital status, citizenship and whether women were living in the capital city or not.
Disability benefit recipient status was dichotomised, and women were classified as recipients if their disability degree was ≥50%. As women may receive invitations early in the year, we used data on income, net worth, employment status and disability benefit recipient status from the year prior to each screening appointment. For each invitation, a variable indicated whether women were living in or outside of Oslo at the time of screening appointment. The highest level of education recorded, as provided by Statistics Norway, as none/unspecified, primary and lower secondary, upper secondary, short tertiary (≤4 years of college/university) or long tertiary (>4 years of college/university). Statistics Norway retrieved educational data from 1971 onwards from national registries (not self-reported), while educational data prior to 1971 was based on the 1970 national census (self-reported). Surveys performed in 1991 and 1999 have reduced the proportion of immigrants with unknown educational level. Only the most recently updated data were available for marital status, which was categorised as not married, married/registered partner, unmarried or widowed. Whether the women were Norwegian citizens or not also pertained to the most recently updated data. Lastly, we used age at time of screening appointment and age at immigration to calculate years since immigration.

**Statistical analyses**

We performed descriptive analyses of attendance rates by country of birth, screening period and years since immigration. Using Fischer's exact test, we compared each group to non-immigrants, and to women born in HIC, MIC and LIC over time. All tests were two-sided and considered significant if \( p < 0.05 \). Crude and adjusted incidence rate ratios (IRR) were calculated with 95% confidence intervals (95% CI) for attendance among immigrant compared with non-immigrant women, using Poisson regression with robust variance. We investigated first round attendance for each woman (first invitation), and whether women had ever attended the programme. Results were stratified by region of birth. Our adjusted regression model included income, net worth, education, disability benefit recipient status, marital status, citizenship, place of residence and screening year. To avoid multicollinearity, we performed pairwise associations between candidate variables using the coefficient of determination \( R^2 \) with a cut-off value of 0.10. Hence, age and employment status were excluded from our adjusted model. When analysing whether women had ever attended, we used sociodemographic values from a random invitation if a woman had received more than one invitation, and also excluded screening year. Statistical analyses were conducted using STATA/MP 14.1 for Windows.

**Results**

We analysed data pertaining to 813,772 non-immigrant women who had received 3,779,810 invitations to screening, and 72,207 immigrant women who had received 273,881 invitations (Table 1). Attendance rates following the first invitation were 76.1% for non-immigrant women, and 53.1% for all immigrant women; 86.4% and 66.9%, respectively, had ever attended.

Over the 20-year observation period, non-immigrant women had consistently higher attendance rates than immigrant women (Figure 1). Differences in attendance rates between immigrants from HIC, MIC and LIC decreased over time. At the end of the study period, women born in HIC and MIC attended at similar rates following the first invitation \( (p = 0.09) \). Looking at all invitations, attendance rates increased considerably with years since immigration. At 0–2 years after immigration, attendance rates were about 30% for women born in HIC, MIC and LIC. At 38–42 years after immigration, rates were 73.1% for women from HIC, 54.0% for women from MIC and 63.4% for women from LIC (Figure 2).

Women in our study were born in 195 countries. We present results for women by geographic region of birth (Table 1), and by country of birth for the 72 countries from which there were more than 100 women eligible for participation in the programme (online Appendix). Women born in Somalia had the lowest attendance rate following their first invitation to the programme (16.7%) (online Appendix). The rate was also <40% for women born in the Baltic countries (<40% for women born in each of the Baltic countries, and 31.9% combined), Eastern Africa (33.6%), Northern Africa (37.9%) (Table 1), Iraq (37.1%), Pakistan (37.4%), Morocco (37.5%) and Afghanistan (37.6%), amongst others (online Appendix).
In general, attendance rates and IRRs were lower after the first invitation than ever attendance. The lower attendance rates following first invitations were particularly prominent among women born in Somalia (16.7% versus 26.6%), Afghanistan (37.6% versus 57.7%), Iraq (37.1% versus 56.5%) and Pakistan (37.4% versus 58.6%). Immigrant women had lower attendance rates following their first invitation to screening than non-immigrants, with adjusted IRRs (95% CI) of 0.81 (0.81–0.82); adjusted IRRs (95% CI) for ever having attended screening was 0.89 (0.88–0.90) (Table 1).

Women from certain continents and regions had similar attendance rates to non-immigrants, as measured by adjusted IRR following their first invitation. This pertained to women from Oceania (0.92, 95% CI: 0.83–1.01), the (other) Nordic countries (0.98, 95% CI: 0.97–1.00), the British Isles (0.95, 95% CI: 0.92–0.99) and Australia/New Zealand (0.93, 95% CI: 0.84–1.03). The same groups also had attendance rates similar to non-immigrants for ever having attended.

Second generation immigrants had higher attendance rates than immigrants, but lower than other non-immigrants. When adjusted for sociodemographic factors, second generation immigrants had similar attendance to other non-immigrants, with IRR (95% CI) of 0.96 (0.93–1.00) after first invitation, and 0.99 (0.97–1.01) for attendance at least once (Table 1). Of second generation immigrants, 97.9% were descendants of immigrants from Europe or North America.

Discussion

This study showed lower attendance rates among immigrants than non-immigrants in the NBCSP between 1996 and 2015. Rates varied substantially between groups of immigrants depending on country of birth, and increased with duration of residency in Norway. Our findings are in keeping with studies from other HICs. Differences in attendance rates between non-immigrant and immigrant women were less pronounced, but still present, when adjusted for sociodemographic factors. Adjusted IRRs were higher for ever having attended screening than for attendance after the first invitation. Women born in Northern Africa, South-Central Asia and Western Asia in particular had low rates for attendance after first invitation compared with attendance at least once. Our findings might imply that immigrant women who attend screening do so irregularly, and that past attendance may have a larger effect on future attendance for non-immigrants than immigrants. This hypothesis is strengthened when considering attendance across all invitations (online Appendix).

The difference in attendance rates between immigrant women born in HIC and other immigrant women decreased over the 20-year observation period, largely because a smaller proportion of immigrant women born in HIC took part in the screening programme towards the end of the observation period. In 2004, Cyprus, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia and Slovenia (all HIC) joined the EU, ensuring free movement of people within the European Economic area, of which Norway is a member (despite not being an EU member). This expansion changed demographics among immigrants born in HIC, as the proportion born in the new EU member states increased substantially. Women born in most of these countries had lower attendance rates than women born in HIC overall.

Figure 2 shows that attendance rates increased with years since immigration. Immigrants arriving in Norway face many circumstances that are different from their home countries; linguistic, social and economic circumstances might prevent recent immigrants from gaining access to, or prioritising screening. For instance, recent immigrants might have difficulties understanding the invitation letter in Norwegian. With increasing length of stay, we expect that women become more familiar with the Norwegian language and the health care services. Our findings might indicate that prioritisation of and access to screening increases with time since immigration. Notably, immigrants from LIC who immigrated less than 20 years ago did not have increased attendance with years since immigration, while LIC immigrants who immigrated more than 30 years ago had higher attendance rates than corresponding MIC immigrants. Only 259 women from LIC in our population immigrated over 30 years ago, and numbers should therefore be interpreted with caution. Over 66% of women from LIC who had immigrated less than 20 years ago were born in Somalia or Afghanistan. Less than 2% of women from LIC who had immigrated over 30 years ago were born in these countries.

Data on immigrants from individual countries and regions are often combined into larger geographical units to obtain sufficient statistical power. In our study, immigrant women from Southern and Western Africa had higher attendance rates than women born in other parts of Africa, and also than women born in some parts of
Europe. Presenting results for all women from Africa as one group would fail to reveal these differences. The groups in our graphical presentations fail to reveal similar differences. For instance, women born in the (other) Nordic Countries, the British Isles, and Western Europe had the highest attendance rates, and were categorised as HIC. Women born in the Baltic countries had the lowest attendance rates, but were also categorised as HIC.

Regional differences in adjusted IRR showed that differences in attendance persisted despite adjusting for the sociodemographic factors available to us. It is possible that including other sociodemographic factors, such as religion, religiosity, family size, smoking, alcohol use or comorbidities, would have given different estimates. The observed differences in attendance could also represent different reactions to receiving the invitation letter. Some women might see the formal wording and logo and feel obliged to attend, while others might feel that this is not something relevant for them. Some women might read the invitation letter and the accompanying fact sheet, weigh the benefits against the harms, and decide not to attend. Fewer women from Southern and Western Africa had no recorded education or low income compared with women from other parts of Africa (results not shown). It is possible that the higher attendance among women from Southern and Western Africa is a result of more women making an informed decision to participate, as they were better able to understand the invitation letter, and that they were in a better position to prioritise money for screening.

Pre-migratory factors, such as health habits, preventive health services including mammographic screening and cancer risk in the women’s country of origin could also contribute to explaining the differences. The Baltic countries have lower breast cancer incidence rates than most other European countries. If we theorise that low incidence rates of a disease leads to lower awareness of that disease in the population, we can hypothesise that lower disease incidence rates of a disease leads to lower awareness of that disease. The Baltic countries had the highest attendance rates, and were categorised as HIC.

Women born in the Baltic countries had the lowest attendance rates, but were also categorised as HIC.

Invitation letters are issued in Norwegian only, which could work to exclude women who have difficulties understanding written Norwegian. Limited information about the programme is offered online in English, Arabic and Urdu, but to access this information women need to identify and navigate an unfamiliar website, in which foreign-language information is not readily available. In 2009–2010, both the Cancer Registry of Norway and the Oslo Breast Centre headed campaigns to increase non-Western immigrants’ screening attendance, in particular women from Pakistan. Educational DVDs in Urdu and Somali were uploaded to YouTube by the Norwegian Cancer Society shortly after these campaigns. A small increase in attendance from 32% to 36% among Pakistani-born women following the campaigns corresponds to an increase in attendance among other women born in MIC.

Language, cost of the examination, personal income and patient navigation are factors that might contribute to prevent access to preventive health care, such as mammographic screening. Other factors may include differences in perception of health and disease, and breast cancer awareness. However, regardless of these factors, in order for a service to be utilised, it must be considered meaningful for the people for whom it is intended.

This study aimed to identify groups that are not reached by the current strategies. Identifying groups of non-attenders may indicate that strategies to reach these groups have been unsuccessful. Equity in access to healthcare is traditionally considered a central principle of the Nordic model of healthcare. Access to health care must take into account formal availability, actual accessibility, relevance and acceptability. To ensure access equity, information and accessibility should ideally be tailored to the needs of the various immigrant groups.

The main strength of this study is the complete and detailed data about screening attendance, sociodemographic factors and country of birth on an individual level for a large population over a 20-year period. This study also has limitations: some data from Statistics Norway are inaccurate, for instance, women who emigrate without notifying the authorities are considered non-attenders in our study, until registered as emigrated. A larger proportion of immigrants than non-immigrants emigrate, which may result in artificially low attendance rates among immigrants, although it is unlikely that this is a major limitation as the registration as emigrated is delayed, rather than missing. Further, results are presented with birth country as the smallest geographic unit, not taking into account heterogeneity among women from the same birth country. In a British study, Hindu-Gujaris had
higher attendance rates than other Hindus and Muslims in the period 2001–2004.44 Our data do not allow us to identify such differences among Indian women in Norway. While we have data about the women’s sociodemographic factors after immigration to Norway, we have limited pre-migratory information.

Conclusion

Between 1996 and 2015, immigrant women from all continents, regions and countries had lower attendance rates in the NBCSP than non-immigrants. Based on our findings, we recommend qualitative research targeting women from various birth countries or regions, to explore the rationales for immigrant women’s attendance and non-attendance in organised mammographic screening.

Research ethics

This study has been approved by the regional committee for medical and health research ethics in South-eastern Norway, REC South East (2013/795).

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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References


30. Statistics Norway. This is Statistics Norway – statistics and analyses that benefit society


Article 2 - Supplementary material
Appendix

Categorisation of countries into high-, middle- and low-income countries:

- **High-income countries:** Denmark, Greenland, Finland, Faroe Islands, Iceland, Sweden, Belgium, Andorra, Estonia, France, Greece, Ireland, Croatia, Italy, Latvia, Malta, the Netherlands, Liechtenstein, Luxembourg, Monaco, Poland, Portugal, San Marino, Lithuania, Spain, United Kingdom, Russia, Switzerland, Germany, Slovenia, Hungary, Austria, Slovakia, Czech Republic, Seychelles, Brunei, United Arab Emirates, Hong Kong, Israel, Japan, South Korea, Kuwait, Cyprus, Macao, Saudi Arabia, Singapore, United States Virgin Islands, Barbados, Bahamas, Canada, Cayman Islands, Aruba, Curacao, Trinidad and Tobago, United States, Puerto Rico, Argentina, Chile, Uruguay, Venezuela, Australia, French Polynesia, New Zealand and New Caledonia.

- **Middle-income countries:** Albania, Bulgaria, Belarus, Romania, Moldova, Turkey, Ukraine, Bosnia-Herzegovina, Macedonia, Serbia, Montenegro, Kosovo, Algeria, Angola, Botswana, Ivory Coast, Egypt, Djibouti, Ghana, Cameroon, Cape Verde, Kenya, Congo-Brazzaville, Lesotho, Libya, Mauritius, Namibia, Morocco, Nigeria, Sao Tome and Principe, Senegal, Sudan, Swaziland, South Africa, Tunisia, Zambia, Armenia, Azerbaijan, Bangladesh, Bhutan, Myanmar, Sri Lanka, the Philippines, Georgia, India, Indonesia, Iraq, Iran, Jordan, Kazakhstan, China, Kyrgyzstan, Laos, Lebanon, Malaysia, the Maldives, Mongolia, Palestine, Pakistan, Timor-Leste, Tajikistan, Turkmenistan, Uzbekistan, Syria, Thailand, Vietnam, Yemen, Belize, Costa Rica, Cuba, Dominica, the Dominican Republic, Grenada, Guatemala, Honduras, Jamaica, Mexico, Nicaragua, Panama, El Salvador, Saint Lucia, Bolivia, Brazil, Guyana, Colombia, Ecuador, Paraguay, Peru, Suriname, Solomon Islands, Fiji, Tonga, Tuvalu, the Federates States of Micronesia, Samoa and Palau.

- **Low-income countries:** Burundi, Comoros, Benin, Eritrea, Ethiopia, the Gambia, Guinea, Guinea-Bissau, Congo, Liberia, Madagascar, Malawi, Mozambique, Zimbabwe, Rwanda,
Central African Republic, Sierra Leone, Somalia, South Sudan, Tanzania, Togo, Uganda, Burkina Faso, Afghanistan, Cambodia, North Korea, Nepal and Haiti.

Number of women, invitations and attendance rates to the Norwegian Breast Cancer Screening Programme, 1996-2015. We present attendance rates for first invitation, whether the women had attended at least once (ever) and all invitations (number of screening episodes/number of invitations) for birth countries where at least 100 women in our study population were born.

<table>
<thead>
<tr>
<th>Immigrants from Europe</th>
<th>Women (n)</th>
<th>Invitations (n)</th>
<th>Attendance (%)</th>
</tr>
</thead>
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<td>Immigrants from the Nordic Countries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td>5623</td>
<td>23,610</td>
<td>72.8% 82.6% 74.2%</td>
</tr>
<tr>
<td>Faroe Islands</td>
<td>196</td>
<td>856</td>
<td>71.4% 82.7% 73.4%</td>
</tr>
<tr>
<td>Finland</td>
<td>2271</td>
<td>9601</td>
<td>67.6% 79.5% 71.0%</td>
</tr>
<tr>
<td>Iceland</td>
<td>1077</td>
<td>3586</td>
<td>59.5% 71.4% 65.5%</td>
</tr>
<tr>
<td>Sweden</td>
<td>5853</td>
<td>24,438</td>
<td>67.5% 79.7% 71.3%</td>
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<tr>
<td>Immigrants from the Baltic Countries</td>
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<td></td>
</tr>
<tr>
<td>Estonia</td>
<td>238</td>
<td>631</td>
<td>39.1% 49.6%* 41.0%</td>
</tr>
<tr>
<td>Latvia</td>
<td>363</td>
<td>790</td>
<td>32.5%* 43.5%* 35.4%*</td>
</tr>
<tr>
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<td>1961</td>
<td>29.9%* 39.5%* 34.4%*</td>
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<td>United Kingdom</td>
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<td>12,666</td>
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</tr>
<tr>
<td>Immigrants from Western Europe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>Total Migrants</td>
<td>Naturalized</td>
<td>Naturalized Adults</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------------</td>
<td>-------------</td>
<td>--------------------</td>
</tr>
<tr>
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<td>1141</td>
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<td>Belgium</td>
<td>213</td>
<td>886</td>
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<td>France</td>
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</tr>
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<td>3922</td>
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</tr>
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<td>1221</td>
<td>5009</td>
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</tr>
<tr>
<td>Switzerland</td>
<td>292</td>
<td>1236</td>
<td>66.4%</td>
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**Immigrants from Southern Europe**

<table>
<thead>
<tr>
<th>Country</th>
<th>Total Migrants</th>
<th>Naturalized</th>
<th>Naturalized Adults</th>
<th>Naturalized Children</th>
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</thead>
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<td>2838</td>
<td>11,780</td>
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</tr>
<tr>
<td>Croatia</td>
<td>491</td>
<td>2066</td>
<td>53.0%</td>
<td>67.6%</td>
</tr>
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<td>Italy</td>
<td>235</td>
<td>833</td>
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<td>62.1%</td>
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<tr>
<td>Kosovo</td>
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<td>2971</td>
<td>43.9%</td>
<td>60.0%</td>
</tr>
<tr>
<td>Macedonia</td>
<td>317</td>
<td>1458</td>
<td>43.5%</td>
<td>63.4%</td>
</tr>
<tr>
<td>Portugal</td>
<td>180</td>
<td>615</td>
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<td>56.7%</td>
</tr>
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<td>Serbia</td>
<td>425</td>
<td>1673</td>
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<td>59.8%</td>
</tr>
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<td>Spain</td>
<td>327</td>
<td>1256</td>
<td>55.4%</td>
<td>65.7%</td>
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**Immigrants from Eastern Europe**

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<th>Country</th>
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<th>Naturalized Adults</th>
<th>Naturalized Children</th>
</tr>
</thead>
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<td>345</td>
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</tr>
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<td>333</td>
<td>959</td>
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<td>422</td>
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<td>2635</td>
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<tr>
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<td></td>
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<tr>
<td>Ghana</td>
<td>132</td>
<td>327</td>
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<td>67.4%</td>
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<tr>
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<td>57.3%</td>
<td>69.1%</td>
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<td>499</td>
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<td>43.9%*</td>
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<td>7034</td>
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<td>65.9%</td>
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<tr>
<td><strong>Immigrants from South-Central Asia</strong></td>
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</tr>
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<td>1180</td>
<td>4927</td>
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<td>Male %</td>
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<td>----------</td>
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<tr>
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<tr>
<td>Kazakhstan</td>
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<td>585</td>
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<td>37.4%</td>
<td>58.6%</td>
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<td>Sri Lanka</td>
<td>1443</td>
<td>4583</td>
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<td>54.7%</td>
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</table>

**Immigrants from Western Asia**

<table>
<thead>
<tr>
<th>Country</th>
<th>Total</th>
<th>Males</th>
<th>Female</th>
<th>Male %</th>
<th>Female %</th>
<th>Both %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iraq</td>
<td>1263</td>
<td>4328</td>
<td>37.1%*</td>
<td>56.5%</td>
<td>37.9%*</td>
<td></td>
</tr>
<tr>
<td>Lebanon</td>
<td>200</td>
<td>607</td>
<td>44.5%</td>
<td>59.0%</td>
<td>47.4%</td>
<td></td>
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<tr>
<td>Palestine</td>
<td>108</td>
<td>350</td>
<td>31.5%*</td>
<td>44.4%*</td>
<td>38.6%*</td>
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<td>219</td>
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<td>48.9%*</td>
<td>36.1%*</td>
<td></td>
</tr>
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<td>4814</td>
<td>47.5%</td>
<td>66.0%</td>
<td>40.0%</td>
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**Immigrants from Eastern Asia**

<table>
<thead>
<tr>
<th>Country</th>
<th>Total</th>
<th>Males</th>
<th>Female</th>
<th>Male %</th>
<th>Female %</th>
<th>Both %</th>
</tr>
</thead>
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<tr>
<td>China</td>
<td>1194</td>
<td>3913</td>
<td>43.0%</td>
<td>54.8%</td>
<td>45.0%</td>
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</tr>
<tr>
<td>Hong Kong</td>
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**Immigrants from Northern America**

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<th>Female</th>
<th>Male %</th>
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**Immigrants from Latin America and the Caribbean**

**Immigrants from Central America**

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**Immigrants from South America**

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* Attendance rates rank among the lowest 10 in each category.
Article 4
Gender, letters, relatives and God: Mediating actors in mammographic screening among Pakistani women in Norway

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Keywords: Breast cancer, emigrants and immigrants, minority health, mammography, screening.

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Funding: This project was supported by a grant from the Norwegian Breast Cancer Society, funded by the Norwegian ExtraFoundation for Health and Rehabilitation (2016/FO76429) (https://www.extrastiftelsen.no/logo/ English description towards the end). The funding source had no involvement in the conduction of the study, interpretation of the results or preparation of the manuscript.
Abstract:

Background: Pakistani immigrant women in Norway have lower attendance rates in the national breast cancer screening programme than non-immigrants and immigrants from most other countries.

Purpose: To identify and analyse human and non-human actors that play a role for Pakistani immigrant women’s attendance in the screening programme in Norway.

Material and Methods: Qualitative interviews with 16 Norwegian-Pakistani women in 2017 and 2018. Inspired by Latour, we explored how human and non-human actors act and interact when Pakistani immigrant women consider attendance in the screening programme.

Results: We found trust in healthcare and screening, the gender of screening radiographers, the screening programme’s information material, women’s daughters, women’s family responsibilities, general practitioners, non-governmental organisations and religious beliefs to be several of the actors playing a role for breast cancer screening attendance among Pakistani immigrant women in Norway.

Conclusion: Many human and non-human actors work to shape and influence Pakistani immigrant women’s screening attendance, for instance by creating thoughts, raising doubts, generating worries, and encouraging, enabling, facilitating, discouraging or preventing attendance in organised breast cancer screening.
Introduction

Based on qualitative interviews, this paper aims to identify human and non-human actors that play a role for attendance in the national breast cancer screening programme in Norway (BreastScreen Norway) among immigrant women from Pakistan living in the country. Who and what are these actors, and how do they act when women consider attending the programme and when they go for their examinations?

BreastScreen Norway invites all women in Norway between 50 and 69 years of age to biennial mammographic screening as a secondary preventive tool against breast cancer (1). Women who do not attend have a higher risk of being diagnosed with advanced stage disease than women who do, and improvements in breast cancer-specific survival are probably due to a combination of mammographic screening and improved treatment (2). From a public health perspective, mammographic screening attendance should be as high as possible to reduce disease-specific mortality (3).

Norwegian studies have shown that low screening attendance rates are associated with certain sociodemographic factors, such as earning a low income, residing in Oslo and being an immigrant (4). Among immigrants with particularly low attendance are those with a background from Pakistan. Only 59% of the 2978 Pakistani women who were invited to BreastScreen Norway between 1996 and 2015 had ever attended, compared to 86% of non-immigrants. When comparing mammographic screening attendance among immigrants from 71 different countries, women from Pakistan ranked 51st in terms of ever having attended (5). Moreover, women receive 10 invitations over 20 years, and only a third (34%) of all invitations sent to Pakistani women resulted in attendance. This proportion was more than twice as high (78%) among non-immigrants, and when comparing immigrant groups, Pakistani women ranked third lowest (no 69 out of 71).
As far as we know, no previous study has explored attendance in BreastScreen Norway among Pakistani women living in Norway. In Denmark, a study that included Pakistani immigrants revealed that major life stressors and competing priorities often left little room for breast cancer screening, and this was so even among women who had knowledge both about the disease and about the screening programme (6). In Canada, a study among women from Pakistan and other South Asian countries identified language difficulties, problems with transportation to the screening facility, reluctance to being touched by male health providers, and a lack of knowledge about breast cancer as barriers to screening (7).

Our aim of this study was to start the work of mapping actors that might contribute to shape screening (non)participation among Norwegian-Pakistani women. Put slightly differently, we were interested in exploring actors that contribute to bring about or hinder screening attendance in this specific group of women. Clearly, women themselves need to act if screening is to occur. Screening will take place only if women are actors that act in specific ways (ultimately by showing up at a screening centre). If they act in other particular ways, screening statistics will stumble. However, however women act, they are hardly ever acting alone. As Latour (8) reminds us, one should never consider an actor a “pure and unproblematic source of action” (p. 46). Rather, an actor is “what is made to act by many others” (p. 46). These others can be other humans, but they need not be. Indeed, in the wording of Latour, an actor is “any thing that does modify a state of affairs by making a difference” (p. 71). Thus, in order to identify an actor, the question Latour wants us to ask is simply: “Does it make a difference in the course of some other agent’s action or not?” (p. 71). Following him, what we are asking in this paper is who and what may make a difference in Pakistani women’s actions versus the national breast cancer screening programme, and in what ways these actors act.
The Norwegian-Pakistani community

There is a large Pakistani diaspora in Norway, and women born in Pakistan make up the 5th largest immigrant group invited to organised breast cancer screening in the country (5). A majority of the immigration from Pakistan occurred more than 20 years ago (9, 10), and consisted mostly of labour migrants, whereas those who have arrived after 1975 have come primarily through family immigration (11). Pakistani immigrants and their descendants (hereafter called the Norwegian-Pakistani community) account for over 37,000 of the 5.3 million people living in Norway.

In some ways, the Norwegian-Pakistani community shows signs of being an integrated part of Norwegian society, and includes members of parliament, local politicians, cultural personalities, high-profiled journalists and well-known medical doctors. The Norwegian-Pakistani community also differs from the overall population, for example in terms of residence pattern (67% of Norwegian-Pakistanis reside in Oslo, as compared to only 12% of the total population (11)) and with respect to religion (three quarters of the overall population are members of the Church of Norway, whereas the vast majority of Norwegian-Pakistanis are Muslims (12)). Moreover, while 69% of women aged 15-74 had paid work in 2008, this was the case for only 31% of Pakistani women who had come to Norway through family immigration (13). As factors possibly contributing to this, Statistics Norway suggests traditional division of work in Pakistani-Norwegian households and low educational status (13). They also point out that many Pakistani-Norwegian women have difficulties with the Norwegian language.
Material and Methods

Study setting

This paper draws on qualitative research carried out in and around Oslo in 2017 and 2018. The research was part of a larger study using several different research approaches to investigate breast cancer and breast cancer screening attendance among immigrant women. So far, the project has demonstrated that immigrant and minority women have lower attendance rates than other women across the world (14), and that this is the case also in Norway, both overall and for all levels of all sociodemographic factors studied (4, 5).

Qualitative interviews

Sixteen women with a Pakistani family background participated in qualitative interviews. Thirteen of them were in the target age group for BreastScreen Norway (between 50 and 64 years), whereas three were in their twenties and thirties. In the latter group, one was born in Pakistan, another grew up in Pakistan, and the third was born and raised in Norway.

The interviewees were recruited through the larger research project, through Norwegian classes for adult immigrants in a suburb of Oslo, and through a multicultural non-governmental organisation (NGO) promoting participation in the Norwegian society among immigrants in an area of Oslo with a high proportion of immigrants.

Our aim was to include women with different backgrounds with respect to age, education, work, time in Norway and screening participation. Six of the sixteen interviewees were not employed at the time of the interview, whereas ten had paid work. The latter group included both unskilled labourers and women who had jobs that required higher education. Two were medical doctors (they did not have work related to breast cancer). Four women did not have any higher education, of whom three could not read and write.
Among the interviewees who were in the target group for BreastScreen Norway, ten had attended screening at least once, two had not yet had their first appointment, and one had never participated despite being invited several times (she had however had an opportunistic examination before she reached the age group targeted by the programme). The women who had attended screening had been screened either regularly (i.e., they had always attended when receiving an invitation) or irregularly (i.e., they had attended at least once, but not always).

Interviews were semi-structured in the sense that the interviewer (the first author) had prepared a topic guide, but at the same time aimed to let the interviewees contribute to steer the discussion. The topic guide for initial interviews was developed on the basis of literature review and conversations with people involved in the larger research project and the group of key informants. It covered topics related to sickness and health, breast lumps, attendance in breast cancer screening, and breast cancer treatment, and consisted of a bullet list of keywords (rather than ready-formulated questions), as well as vignettes and a word map. All interviews were audio recorded.

Four women were interviewed twice. We aimed for repeat interviews when possible in order to allow opportunities for more in-depth exploration of salient topics.

The interview guides were dynamic in the sense that they were updated after each interview to reflect emerging insight and remind ourselves of themes that we still needed to understand better. The interview guide for follow-up interviews was prepared based on the initial interviews and our preliminary analyses of them.

Most interviews were conducted in Norwegian. However, seven women were interviewed in Urdu, either because they preferred this, because they had difficulties understanding the first
author’s Norwegian dialect, or because they only agreed to participate in the study if they could speak Urdu.

**Key informant interviews**

In preparation for the interviews proper, the first author consulted nine key informants, i.e. persons with experience and/or positions of relevance to the topic of the study. The key informants, all of whom were women, had prior experience from immigrant health work and included health professionals, researchers and persons working for NGOs. Six of them had been involved in projects aimed to increase cancer screening attendance among immigrants. Four had a Pakistani family background, while five did not. The key informants were asked about experiences and opinions regarding breast cancer and organised breast cancer screening among Pakistani women, and for advice on how to get in touch with potential study participants. They were also consulted during data analysis.

**Other inputs**

Several additional intakes provided the authors with experiences and impressions that contributed to shape the study. For example, the first author gave presentations about breast cancer and breast cancer screening during the study period, including in Norwegian classes for immigrants. These became occasions that generated insight into some of the things people wanted to know about these topics. The first author also followed the general public discourse for intakes of relevance to the study, and found relevant themes discussed in TV and radio debates, social commentaries, lectures, newspaper articles and books. Additional inputs came from numerous informal conversations about the project.

**The first author’s position**

The first author conducted the fieldwork for this study. He is a Norwegian-born male in his 30’s, which means he had a different gender and age than the interviewees. His professional
and academic background (a medical doctor specialising in oncology and a cancer-screening researcher) made him an insider with respect to biomedical perspectives on cancer, but clearly an outsider with respect to women’s perspectives on cancer screening.

With respect to the Pakistani-Norwegian cultural context, he was arguably both an insider and an outsider. His parents emigrated from India to Norway about 40 years ago, and he may thus be considered a desi (a loose term used by people from the Indian subcontinent to refer to its people, its diaspora, and the culture and languages they have in common). As a desi, he was familiar with aspects of the Norwegian-Pakistani community that is unavailable to most non-desis. However, as a non-Pakistani, he continually ran the risk of ignoring aspects that are more common among Pakistanis than among Indians, and taking for granted that aspects familiar to him because of his Indian background are also relevant for Pakistanis.

The first author is fluent in Norwegian and English, and speaks and understands Hindi/Urdu (spoken Hindi and Urdu are interchangeably understandable).

As always in research, the authors’ preconceived assumptions and knowledge undoubtedly played a role for their understanding of the participants’ perspectives. Striving to transcend his preconceptions, the first author allowed plenty of time for participants’ stories to unfold, and continuously attempted to identify information that could challenge or disconfirm what he took for granted. His assumptions and analyses were moreover continuously challenged in the ongoing dialogue with co-authors and key informants.

*Ethical considerations*

The study was approved by the Norwegian Data Protection Authority (case number 2017/2727). All interviewees provided informed consent to participate, in most cases in writing. However, some interviews were conducted by phone, and oral consent was obtained from women participating in these, as well as from women who could not read or write.
Transcripts did not include directly person-identifying information and were stored on an encrypted server at the Cancer Registry of Norway. The audio recorder and consent forms were stored in a locked cupboard in the same institution, and recordings were deleted after transcription. We have given study participants pseudonyms in this paper.

**Data management and analysis**

The analytical process was considered a continuous activity throughout the study. All interviews were written out in Norwegian by the first author regardless of the language spoken, and this was done within a day after they had been conducted. Transcripts and field notes were first read through several times to get an overall impression of the material, and the first author thereafter went through them sentence by sentence, intensely examining them and generating codes to categorise their contents. Terms that had been used in the conversations were often used as code labels. Numerous themes were identified based on these codes, and analytic notes were written for many of them. Inspired by Latour, for this article we identified and explored human and non-human actors that played a role in Pakistani women’s reflections about and interactions with the breast cancer screening programme. We attempted to find out how these actors acted, for instance how they authorised, encouraged or forbade screening attendance. While the initial coding process was open, the latter part of the process was more selective in nature, informed by theory and aiming to map out core categories given the actor perspective (15).

Since an important aim was to learn from women’s experiences and perspectives, we explicitly asked them for advice regarding the breast cancer screening programme, and we include their main recommendations in our findings.
Results

_Trust in healthcare and breast cancer screening_

The interviewees clearly had a high degree of trust in Norwegian public healthcare services. As an example of how strongly articulated their trust could be, consider Shabana’s response when she was asked to elaborate on why she thought women should participate in breast cancer screening. Without a flinch, she answered:

_The government and the doctors think about what is best for us. After all, it is our best they have in mind. If there is a problem, it will be investigated._

Other women used different terms, but the fundamental tone was rather similar across the group of interviewees. It goes without saying that the trust they expressed may not necessarily pertain to all Pakistani-Norwegian women. However, the finding of marked trust is still of interest given that a recent study identified exactly the opposite – a lack of trust in the healthcare system – as a barrier working to block cervical cancer screening among Pakistani women in Norway (16). Among the women we interviewed, the situation was clearly different. They were confident breast cancer screening was important, and they enthusiastically offered reasons for why one should attend such screening.

In addition, there was often a sense of urgency among them to contribute to get others to participate. One interviewee recommended that breast cancer screening attendance among immigrants be promoted through dedicated screening days at NGOs, during which women would attend lectures about breast cancer screening before being offered transport to a screening facility for the examination. Another recommendation was to stimulate attendance by removing user fees and possibly even by offering attending women a reward:

_It should be free. No, not only free, but maybe there should be some kind of voucher, if you attend. Maybe some kind of reward system._ (Tahira)
Finally, a few interviewees argued that screening was so important that women should be forced to attend. It was as if they wanted to remove screening from the list of things about which women needed to make active decisions by rendering attendance compulsory.

Grimen (17) likens a trusting person to someone who is willing to leave something of value in another person’s custody. He or she feels ensured that the entrusted person will not in any way harm his or her interests, but rather be protective of them. Understood in this way, trust would be a basic, but often immensely important, prerequisite for willingness to succumb to medical care. The considerable confidence women had in their healthcare providers thus clearly seemed to work to promote participation in BreastScreen Norway.

**Gender of the radiographer**

The second actor we will consider is *gender*, and more specifically the gender of the radiographers working at one of the 26 stationary or four mobile screening units. Women clearly found the gender of this category of healthcare personnel to be an important actor in breast cancer screening.

While some women were willing to attend screening even if the radiographer was a man, not one of them were comfortable with this scenario. Alone the possibility that one might encounter a male radiographer gave rise to negative emotions.

In some cases, this was linked to previous, self-experienced and upsetting incidents with male examiners. Rashida, for example, had experienced what she portrayed as highly inappropriate behaviour by a male radiographer, and this had led her to not attend breast cancer screening for over ten years. In most cases, however, the women had not had such experiences, but they were still uneasy with the idea of male radiographers. It created emotional distress and plans for or de facto non-attendance. Ifran may serve as an example. She had not thought of the possibility that the radiographer could be a man until she arrived at the screening centre for
her appointment, but it struck her as soon as she sat down in the waiting room. She decided that if it turned out that a man were to examine her, she would excuse herself, pay the user fee and leave. For her, a male radiographer would have blocked her from getting the screening examination.

Before describing the women’s rationales for why it was important that the radiographer be a woman, an outline of the radiographer’s interaction with screening attenders in Oslo may be in place. In typical cases, the woman is brought to an interview room, where the radiographer asks her about symptoms of breast cancer, informs her about the examination and gives her an opportunity to ask questions. The woman then removes the clothes from her upper body, and the radiographer inspects her naked breasts and armpits. If the woman has signs or symptoms that may be suspicious of cancer, the radiographer notes this for the radiologist’s attention and may also put a marker on her skin. The woman is then brought to the examination room, with the mammography machine, where the radiographer positions her for the examination. In the process of doing so, he or she often touches the skin on the woman’s upper body, including her breasts. After the examination is over, the woman returns to the dressing room and puts her clothes back on.

Several interviewees described how they were uncomfortable undressing in front of, or being touched by, men at the screening centre. Some added that they were not really used to interacting closely with men from outside of their most immediate social circles. Said Begum, one of the younger interviewees, with reference to women older than herself:

*It’s a bit like, women who never see men they don’t already know. And then seeing a man, especially of another race - that would be a crisis. It’s just a no-go (...) They don’t have any male friends, they are not used to interacting with other men [other than family and friends of the family]. They are somewhat separated from they are children, and a lot is left there.*
Interviewees also pointed out that some Pakistani husbands might act to block screening attendance for their wives if they were not confident that it was a woman who conducted the examination. Ifran (whose husband had not interfered with her own screening attendance) explained:

> *If the husband thinks that the examination is conducted by a man, of course he will not allow it, but if the husband is ensured that this examination is conducted by a female, I don’t think he will do any nonsense, because he will not be interested in losing his wife.*

Some interviewees made clear that their religious beliefs explicitly forbade them being examined by a male. They explained that in Islam, women are not allowed to be naked in front of a man. As Tahira remarked:

> *It is our religion, we are Muslims. A man should not look at a woman’s body.*

Notwithstanding this, women were adamant that male examiners was not a problematical issue only for Muslim women, but for lots of non-Muslims and non-immigrants as well. Having a Pakistani and/or Muslim background did not necessarily render them an ‘other’ (18) with respect to this, but rather united them with many women with various other backgrounds. In effect, they refused to be given the position of the problematic, ethnically different other in this question. Well-argued resistance against othering has also been a theme in other work among ethnic minorities in the “West” (e.g. (19)).

When asked for recommendations, several of the interviewees argued that the invitation letter from BreastScreen Norway would encourage more women to attend if it stated that they could request a female radiographer.
The written information received from BreastScreen Norway

The written information material sent from the screening programme to the women was another important actor in the screening venture. Women due for screening receive a letter (in Norwegian) offering them screening at a specific (but changeable) time and date. The letter is accompanied by an information sheet (also in Norwegian) about breast cancer and breast cancer screening. In total, the information package consists of four pages of text (see reference (20) for the invitation letter and information sheet).

Interestingly, none of the interviewees said that the exclusive use of Norwegian in the information material had blocked their own attendance. On the contrary, several women had attended screening despite not knowing Norwegian at all – and, in some cases, even if they did not know how to read. In these cases, however, the letter from BreastScreen Norway had acted by putting people properly to work. Some of the necessary labour was carried out by women themselves, and typically included the work of contacting and interacting with family members who were able to read Norwegian. Additional work was carried out by these family members as they engaged with the tasks of translating and explaining the information. Alina, who did not speak Norwegian, outlined how this could occur:

*If they get a letter, they get someone who knows Norwegian to read it for them. My sister knows some families where no one can read or write [Norwegian?] at all. There they call her and tell her on the phone that they have gotten a letter from the doctor or somewhere else, take a photo of the letter, send it to her, and she calls them back and explains.*

This is an example of the considerable labour that clients and their significant others may have to engage with in order to utilise health services, and which often remains invisible to service providers (21).
Some interviewees noted that women who did know Norwegian might find the information from the national screening programme more interesting and easier to engage with if it was in Urdu. Begum drew a parallel to her mother to make this point. She was not interested in health-related information in Norwegian, but who went to health-focused seminars in Urdu and later enthusiastically shared with the rest of the family what she had learnt.

When asked for advice, interviewees recommended that information about mammographic screening be made available in Urdu. They argued that this would allow women with limited or lacking Norwegian language skills to understand the contents of the letter better, and encourage more women to attend screening.

Apart from language challenges, the interviewees drew attention to another way in which the information material from the national breast cancer screening programme might work to hinder screening attendance. Several explained how they had been discouraged from reading the whole information package because they felt it was too complex and too comprehensive. At one point, Tahira exclaimed:

*You know, the content of the letter, it is not right. It is not good! There is SO much information in the letter, long and broad. Who has a head where something that long and broad fits?*

One reason why the text is as long as it is would seem to be that the information is intended to serve as a basis for invitees to make an informed decision about screening participation. In the words of BreastScreen Norway (1), the four-page information package is supposed 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). The interviewees hardly perceived it to work this way, and rather thought of it as an
unnecessarily convoluted and dense text that discouraged participation and needed to be shortened and made more to the point. Tahira again:

_The information should be direct. (...) It should only say what time you have an appointment, and that’s it!_

Women also argued that the information should be more persuading in tone and content. Nasreen suggested the following:

_‘That examination is good for your health, and will cost you less than if you get the disease and receive treatment’, something like that. A bit powerful, it has to be short, but powerful (...) Direct information in their own language._

_Family life_

A fourth actor of significance was women’s family lives. Interviewees described how looking after their family and home was utterly important for them, and in many cases could and should be prioritised before looking after their own health. This meant that family commitments at times interfered with the feasibility of attending mammographic screening. For instance, significant events in children’s lives (such as exams, births or driving tests) often led to busy periods for mothers and could work to prevent screening participation. Zaynab, for example, narrated:

_When I got the first invitation, that period was hectic. My husband was not that available, and some of my children had exams. It was busy around then, and I just did not have the time._

Some women felt that they would outrightly fail both themselves and their family members if they prioritised their own health before their responsibilities at home. Explained Azra:
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.

Interviewees argued that from they are young, many Pakistani women are not used to being prioritised, and thus would not rank their own cancer screening needs over their commitments towards others. When asked what Pakistani women would choose before their own health, Nasreen was in no doubt:

[They will prioritise] Being at home, cooking and cleaning!

Interviewees also pointed out that a sub-set of Pakistani women did not attend breast cancer screening because they were dependent on their husbands. Whenever this was the case, women would not only need to negotiate time for the examination versus their own schedules and responsibilities, but also versus those of the husband’s. Alina elaborated:

They only leave their house with their husbands; they don’t want to go alone. The husband might not have time; he has to work and might not be finished in time for the examination. They can’t go on their own, women who are uneducated.

While family life could thus supplant screening attendance for some women, the exact opposite was true for others – with the precise same rationale. Indeed, some interviewees argued that their family commitments not only allowed, but almost commanded that they get screened for breast cancer, because if they were to get ill, they would not be able to contribute at home. Umara, for example, asserted that if you do not go for screening and get breast cancer as a result, your husband will leave you for a woman who is not ill.

Shakari has documented the importance of family life in the Norwegian-Pakistani community (22). In this section, we have seen how utterly dedicated women were to their family commitments. Their well-developed care ethics (23), with considerable concern and
compassion for the people with whom they were closely connected, could at the same time work to limit their possibility to attend breast cancer screening, at least in periods. However, the importance of the maternal role could also in some cases act as a reason to take part in screening.

**Daughters**

While children are of course part of family life, women portrayed their daughters as such important actors for screening participation that we have chosen to discuss them separately. Several interviewees (but not all, as we will return to) advised that to channel information about breast cancer screening through young women would help improve screening attendance in their mothers’ generation. Children had a better grasp of the Norwegian language and better knowledge about how public systems can be navigated, and they could thus make information easier to understand and help with the practicalities of attending screening. Fatima, for example, recommended that children learn about breast cancer screening in school, so that they could inform their mothers about the need to attend.

Most interviewees did not problematize whether it was appropriate to inform women through their children, but rather took for granted that the daughters ought to play a role. As Azra pointed out:

*Why else do we have children? We look after them, so they also need to look after us when we get older!*

Daughters could aid by accompanying their mothers to the screening centre, which some of the younger interviewees had indeed done. One of them, Hadia, explained how much Pakistani women wanted to be accompanied by them:
They think it is super social and nice, when I follow my mother to the examinations where I drive, bring her, we have a cup of coffee on the way back, she thinks it’s great. She thinks ‘She [Hadia] takes part in everything, I get to spend time with my daughter’. What Pakistani woman would not want to be social like that?

However, there were both younger and older women who were opposed to relying on children to inform their mothers. Begum, for example, one of the younger women, pointed out:

*I have so many other responsibilities, and I have already contributed lots and reminded [my mother] about appointments, but I have my own life now and don’t live with them. It is like a never-ending upbringing, and I have already reminded her lots and know that she’s been a few times, but I have no idea how often one should go. It is unfair to expect that I should be responsible for this.*

Nasreen, one of the older interviewees, also rejected the idea that daughters should inform women in order to increase attendance. She argued that children were not supposed to teach their parents what is right and wrong; it should be the other way around.

Among those taking an intermediate position between these views was Shabana, who was reluctant to rely on information through children, but felt that if women did not understand health-related information, it was appropriate to use their daughters to inform them.

Forty-six percent of people in the Norwegian-Pakistani community in 2018 had been born in Norway (9), and one would anticipate a different degree of acculturation among them than among their Pakistani-born mothers. Acculturation is 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) (24). While immigrants’ daughters will often be in continuous first-hand contact with aspects of social life in both countries from they are born, immigrants themselves are only in first-hand
contact with Norwegian society from the time of immigration. Many daughters are thus in an intermediate position from which they can effectively mediate between their mothers’ first and second cultural contexts, and many interviewees highlighted this as a significant positive force contributing to screening participation.

*General practitioners*

A sixth actor was of significance mostly due to his or her marginalisation in the screening venture: the general practitioner (GP). Women had expected their primary care doctor to be involved in breast cancer screening and were surprised that this was not the case. Their analysis was that the exclusion of GPs from the breast cancer screening programme acted to hinder screening uptake.

BreastScreen Norway is a vertical programme with a centralised management and objectives (25). The programme offers screening, operates its own screening centres, and informs attendees about screening results. When examinations turn out positive, women are referred for assessment at breast diagnostic centres in regional public hospitals. If diagnosed with cancer, they are thereafter referred for surgery. It may be first when a woman is discharged from hospital after surgery for breast cancer that her GP receives any information about the diagnosis.

In effect, therefore, GPs are excluded from the breast cancer screening venture, and the study participants criticized this because they saw GPs as actors excellently positioned to provide information about and promote the examination. As Tahira remarked:

*The GP should have a connection to the mammography people, so when you have an appointment for mammography, the GP will know and can say ‘you have got an appointment for this, and this is something you must attend’.*
Tahira’s recommendation is perhaps particularly understandable given the central position of the GP scheme in the Norwegian healthcare system. Each citizen is allocated a specific primary care doctor as their initial point of contact for health-related issues. The GP goes by the name *fastlege* (literally: “permanent doctor”), and is intended to bring services close to patients, address a broad range of patient needs, and help maintain stability in the doctor-patient relationship. Interviewees pointed out that GPs also have a high status in the Norwegian-Pakistani community and that they are thus particularly well positioned to encourage and promote screening attendance. They also noted that there are now many Urdu- and Hindi-speaking GPs, and that this is an asset with regards to health promotion among Pakistani women, including the provision of information about breast cancer screening.

*Non-governmental organisations (NGOs)*

A seventh actor of importance were the range of NGOs women knew of and interacted with. Some interviewees specifically mentioned that they had gained knowledge about breast cancer and mammographic screening from such NGOs, and many saw NGOs as potentially important promoters of screening participation in the Pakistani-Norwegian community. Among recommendations brought forward was that NGOs should be utilised to teach about screening. Ifran, who had attended an NGO lecture about breast cancer and breast cancer screening, explained:

> What can be done, is that one can cooperate with NGOs and mosques, right, because that’s where people are. And that you get in touch with them [Pakistani women] in another way, right, so you have access through NGOs and Norwegian classes, but you’ll especially get in touch with many through NGOs.

The information package distributed by BreastScreen Norway represents a one-way mode of communication and provides no opportunity for interaction between sender and receiver (if
women do want additional information, the information sheet somewhat ironically recommends that they talk to their GP, who – as we have seen – is otherwise excluded from the screening venture). On the other hand, lectures at NGOs allowed for social, three-way learning situations where women could listen, ask questions and discuss emerging topics with each other and presenters, and also provided learning opportunities for women who could not read or write well.

**Religious beliefs**

Interviewees were adamant that their religion authorised and encouraged mammographic screening, even though it was Allah who decided the final outcome in cases of ill health. As long as the radiographer was a woman, none of the interviewees who addressed the topic had religious views that prevented them from attending screening. Shabana, for example, argued to the contrary that her God had given her the right to have good health and the opportunity to go for screening examinations, and Ifran explained how God and science could very well act together:

*I believe in prayer, right, you answer your calling, (...) but that is in addition to, not a replacement. There are things you have to do in parallel, but I’m a religious person, so I believe prayers are answered. So, I think, science has a great meaning in Islam too, and there is no conflict between science and religion, so one has to avail the offer [of breast cancer screening] and the possibility that exists, and at the same time have faith that your God will help you.*

As mentioned above, some interviewees recommended that the screening programme cooperate with mosques in order to reach Pakistani women. In 2009-2010, a collaborative project which included participation from the Oslo Breast Centre, the Norwegian Cancer Society and the Cancer Registry of Norway ran campaigns aiming to increase screening
attendance among immigrants, especially women from Pakistan (26). These campaigns featured Urdu-speaking doctors as “ambassadors” for screening, educational DVDs in Urdu, and one-off teaching events in Urdu at mosques in Oslo. While women praised such events as highly useful, they emphasised that they ought to be offered regularly. As Tahira explained:

*There should be courses or seminars about breast cancer screening, and the mosque is a good place for that. There are different courses in the mosques... and tell about reasons and that it is important... as soon as you attend mammography you don’t need to worry about whether you have a mass or not. And they [courses] have to be yearly or every six months.*

There was some disagreement among study participants as to whether courses like this would lead to higher attendance. Among those who were in doubt was Hadia, who argued that women are not all that interested in non-religious topics when going to the mosque. Nasreen, to the contrary, believed that women were very interested indeed in hearing about such topics in mosques.

*Other*

Monetary expenses had not blocked screening attendance for any of the interviewees themselves, but they pointed out that the user fee could potentially prevent attendance for women with meagre financial resources. Some recommended that the examination be free of cost so as to enable more women to attend. As Tahira opined:

*These things that will save lives should be free. I mean, if someone can pay for it, that’s fine, but what should someone who does not have much income do.*

Difficulties with transportation had also not prevented screening in the group of interviewees, but they emphasized that transportation could make attendance difficult for others. In sprawling Oslo, there is only a single BreastScreen Norway screening facility, and getting
there often involved driving to an unfamiliar destination and paying road toll and parking fees. Some women recommended more screening units in Oslo, so as to bring screening closer to where women live.

A few interviewees had worries related to the screening examination that are not mentioned above, and some of these brought forward thoughts about non-attendance. Some women were concerned about pain and discomfort during the examination, and Noor had experienced that radiographers were rough and disregarded how painful the examination could be. Rashida had concerns about potential side effects of radiation, and also about whether registered data could potentially be accessed by other actors than BreastScreen Norway.

Private breast cancer screening services had enabled some women to have a mammogram before they had reached the target age for the programme. When Noor was in her 40s, she had requested referral to mammography, but her GP had advised her to wait until she was old enough to receive an invitation from the programme. However, Noor was worried about cancer and adamant that she wanted a mammogram, and a private institution had rendered the examination possible:

_I wanted to have it because I had three friends who had gotten breast cancer._

It was however unclear for several interviewees that there are different providers of mammographic screening (private as well as public), and some did not discern the national screening programme from other providers of mammography.

Mass media and global online actors such as Google and YouTube, were important sources of information (and questions) about breast cancer and mammographic screening. Umara, for example, explained how she had actively searched for information about mammography on YouTube, whereas Rashida’s worries about radiation were influenced by a TV programme about the risk associated with too many radiological examinations.
In discussions about information from the screening programme, several women recommended that the programme utilise popular social media platforms to reach out to more women, and among the concrete recommendations were informative voice messages through WhatsApp.

**Discussion**

Tuana theorizes ignorance as something which is constructed and preserved as opposed to something that is simply missing (27). Migrant health is arguably under-researched in Norway (28), and the relative lack of willingness to prioritize this research field could act to produce ignorance about significant predictors of health and longevity among immigrants.

The aim of this study has been to help unproduce some of the ignorance about the low breast cancer screening attendance among Pakistani immigrant women in Norway. As long as there is deficient knowledge about who and what may enable and hinder this group of women from accessing and utilizing mammographic screening, providers of such screening will be imperfectly positioned to understand and respond to the experiences and needs that contribute to shape this situation. It is our hope that our findings might prove useful for politicians, legislators, the public health sector, BreastScreen Norway, and – not the least – for Norwegian-Pakistani women themselves.

According to Danish philosopher Kierkegaard, the secret in the art of helping is to realize that in order to lead a person to a specific place, “one must first and foremost take care to find him where he is and begin there” (29). To provide written information about the breast cancer screening programme in a language that many women in the target population have difficulties understanding, hardly lives up to Kierkegaard’s advice. Also the contents of the information package circulated by the screening programme did not seem to find women where they were at. It was deemed to be too comprehensive, too difficult to understand, and
lacking in information that was perceived as relevant. These findings would seem to speak to the importance of involving user representatives when information about preventative health is developed.

Women also pointed out what they perceived to be a confusing contradiction in the information they received. The screening programme invited them to an examination that aimed to prevent them from dying from the disease, while at the same time seemingly downplaying the importance of that examination. This was perceived to be so because the information package emphasized that it was up to women themselves whether they wanted to avail themselves of the screening opportunity or not. The interviewees reasoned that it was irrational, almost irresponsible, that the screening provider would leave women to draw their own conclusions in a question on which the provider was clearly the expert and where women’s survival was in the balance. They argued that the programme should send the clear message that mammographic screening is an important preventative health measure which every woman of a certain age should make sure they avail themselves of.

Strategies to increase attendance among immigrant women usually focus on improving delivery and uptake of information, for instance by educating women or translating the information to foreign languages (30). A systematic review of cancer screening interventions among Asian women argued that mailed translated education materials alone were not effective in increasing screening uptake among Asian minority women, and that combining multiple strategies is more likely to increase attendance than single interventions (31). In Norway, Pakistani women have had low mammographic screening attendance rates also compared to other immigrant groups, even though information campaigns with written and oral information in Urdu have targeted the Norwegian-Pakistani community in attempts to increase attendance (5, 26).
Whereas information is undoubtedly essential for successful screening programmes, and this information has to be perceived as relevant, timely and understandable among the persons the programme is targeting, this study demonstrates that it would nonetheless amount to near ignorance if one assumed that the low breast cancer screening rates among Pakistani immigrant women in Norway were simply or overwhelmingly due to lacks of knowledge and information.

As we have seen, several other actors were perceived to play very significant roles indeed in the screening venture.

Some of these actors were portrayed as – either de facto or potential – prominent allies of breast cancer screening. What daughters, GPs, NGOs and mosques had in common was that they could act as helpful mediators between the screening programme and Pakistani women. The interviewees pointed to concrete ways in which each of them could and should be more extensively involved in the screening venture if the aim was to propagate the health benefits of mammographic screening in the Pakistani-Norwegian community.

That GPs are in effect excluded from breast cancer screening in Norway was particularly hard to understand among the women we interviewed. The GP was exactly the actor women would expect to take centre stage in a programme of this kind. They argued that their “permanent doctors” were excellently positioned to provide information about screening, encourage screening participation, and to communicate and follow up screening results. This is a pointed critique of the vertical organisation of BreastScreen Norway. Women had a high degree of satisfaction with their GPs and reasoned that GPs could and should be entrusted to bring screening services closer to their daily lives and ordinary interactions with the health sector.

A striking finding in this study was the importance women attached to breast cancer screening. Even though not all were regular attenders, all were strongly in favour of
screening, and, at that, passionate about getting other women to attend. Their enthusiasm clearly sprang from preventative health concerns, but it could arguably also be read as a contribution to the ongoing debate about women’s position in the Norwegian-Pakistani community. In 2018, Norwegian-Pakistani men and women have engaged in media debates about the (unsatisfying) rights of women in their community (32). Among explanations for Pakistani women’s non-attendance in breast cancer screening pointed out by the interviewees, was that women are prevented from screening attendance due to their many responsibilities in the family and that some women are not allowed to attend by their husbands. Against this background, women’s enthusiasm for screening and their many ideas eagerly put forward about how to get more women to attend could be interpreted as reflective of subtle feminist engagement for the benefit of female and public health (33).

In conclusion, many human and non-human actors acted on Pakistani women and influenced their mammographic screening attendance, for instance by raising doubt, giving worries, stirring confusion, promoting opportunities, encouraging and putting others to work, thus enabling, facilitating, discouraging or blocking attendance. Among actors that were involved when Pakistani women attended BreastScreen Norway were the gender of radiographers, women’s trust in healthcare, the written material sent to women prior to screening, several aspects of Norwegian-Pakistani family life and religious beliefs. If one were to listen to the women who took part in this study, a key to improved breast cancer screening attendance among Pakistani-Norwegian women would be to strike partnerships with this last-mentioned group of actors.
References


