

# DO MAMMOGRAPHY SCREENING PROGRAMMES REACH IMMIGRANT WOMEN?

## A TELEPHONE SURVEY OF SEVEN EUROPEAN COUNTRIES

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### ABSTRACT

**Introduction:** Immigrant women residing in Norway have lower rates of breast cancer, but the tumours are diagnosed at a later stage, giving worse prognosis and higher mortality rates compared with Norwegian born women. The aim of this study is to shed light on breast screening programmes in Europe to see if women from all ethnic groups have access to and whether they participate in screening programmes.

**Methods:** A questionnaire was prepared regarding participation in breast cancer screening, including special considerations for immigrant women. Contact persons at European cancer screening programmes in UK, Austria, Norway, Finland, Sweden, Denmark and France were interviewed in semi-structured phone interviews followed up by a structured literature search.

**Results:** Population based breast cancer screening programmes were available free of charge in six countries, with a co-payment in Norway. Screening

invitations were written in the countries' main language. The participation rate in the UK, Austria, Norway, Finland, Sweden, Denmark and France varied between 72% and 87%, independent of the percentage of immigrants in the country. Compared to women born in the country immigrant women were thought to show a lower participation rate in all national screening programmes, though some countries work through immigrant organizations to reach more women from these groups.

**Conclusion:** To reach all eligible women, a combined approach, adapted to the target population to ensure that all women have the same chance for early diagnosis and life-saving treatment, is needed. Participation in organized programs for breast cancer should be free of charge.

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### INTRODUCTION

Though European countries have made good progress in reducing disease specific deaths in recent years, significant differences remain between countries, and many thousands of cancer deaths could be avoided each year if best practice in early detection were applied equally in all Member States (1).

Cancer is the second leading cause of death in the industrialized countries and breast cancer is by far the most frequent cancer death in women (2). Screening programmes are either publicly or privately funded (3).

As an example the situation in Norway is outlined. There were 2956 new cases of breast cancer in women with a mortality of 645 in in 2,5 mill women of Norway in 2012. (4).

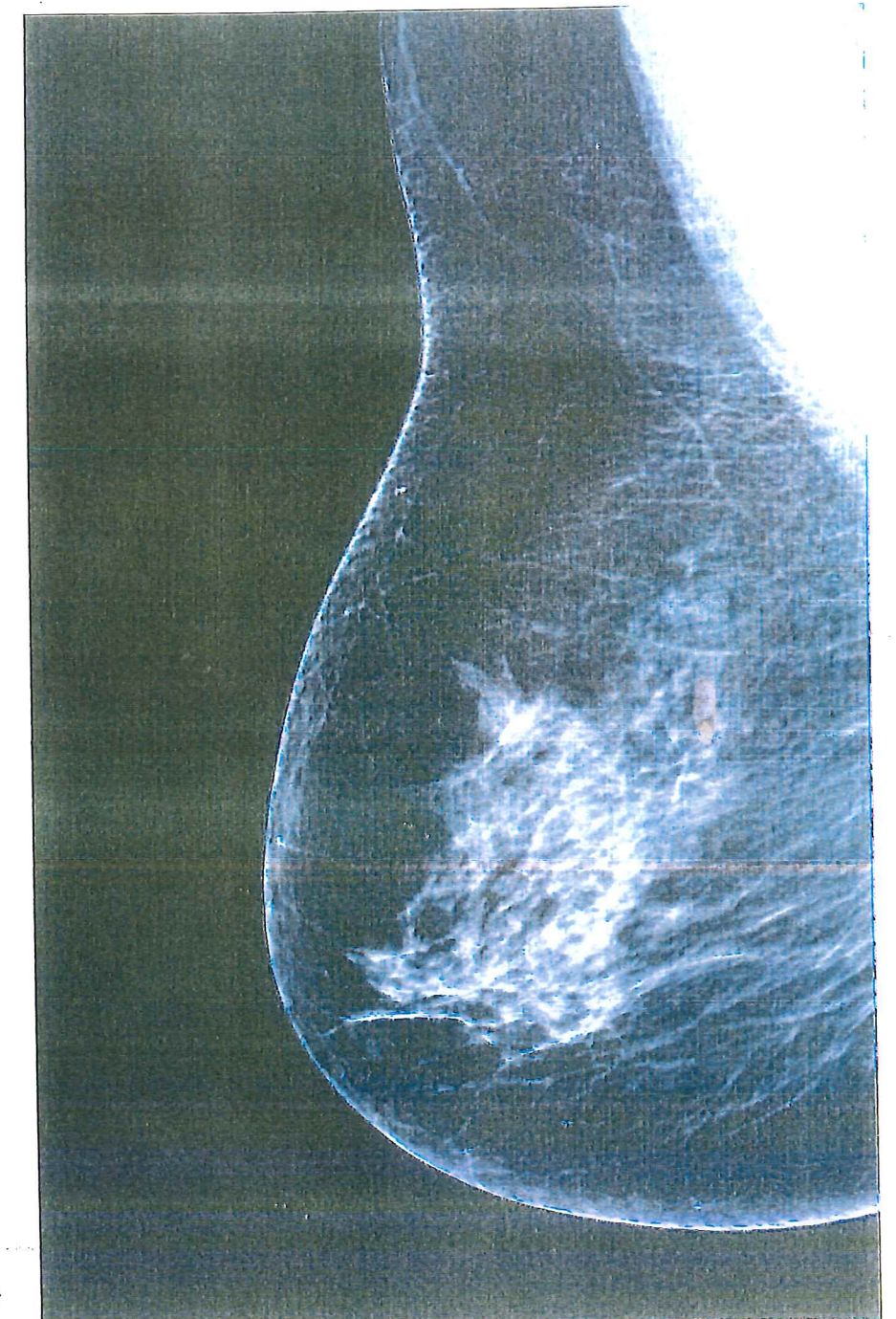
The highest incidence of cancer found in women in Norway is breast cancer, and one in 12 Norwegian women will develop this disease before the age of 75 (4) Screening programmes for cancer aim at reaching the whole population at risk as a relevant

method of secondary prevention. The Norwegian Breast Cancer Screening Programme, inviting women aged 50–69, was started at the end of 1995 as a pilot project in four Norwegian counties (4). Today the breast cancer screening programme is offered nationwide (ibid.) and shows a participation rate of over 75% (5,6).

Research shows that the incidence of breast cancer appears to be lower among immigrant women than among non-immigrant women; but the survival rate for immigrant women is lower. This low survival rate might be caused by the fact that cancer in these women is diagnosed in a late stage of the disease (2).

The number of immigrants in European countries varies, but they constitute a non-negligible proportion of between 4 and 38% of the total population, and the proportion is on the increase in many countries (7). By the 1st of January 2015 the immigrant population (immigrants and their descendants) comprised 14,9% of the Norwegian population. This immigrant population included immigrants from 221 different countries (8).

Exploration of variables such as social position or ethnic background in studies of equity in public screening programmes in Europe is of major importance (9). People emigrate for different reasons, and it would be incorrect to consider immigrants as a monolithic group. Nevertheless, immigrant women can be considered a vulnerable group, underserved by both the scientific and health care communities (10,11). Clarification of ethnic origin in public registers



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is difficult in many European countries, partly for historical reasons.

This study aims to investigate immigrant women's perceived access and participation in organized screening programmes for breast cancer in Norway and six other European countries.

#### METHODS

The study presented here is based on a telephone survey and designed to give a comprehensive picture of immigrants' participation in breast screening programmes. To investigate systematic differences between countries, we chose four Nordic countries, all with almost similar health care models, and three countries in different parts of Europe. Semi-structured telephone interviews with key informants from the UK, Austria, France, Norway, Finland, Sweden, and Denmark were conducted. Those key informants all hold central positions in the various cancer screening organisations holding valuable information on the topic (12). The key informants were identified by the Norwegian Cancer registry as recognized collaborators on a list delivered at an international meeting at the beginning of the study. All data were collected during 2013.

#### INTERVIEWING AND RECORDING

Seven telephone interviews were conducted. A recording device to improve accuracy and internal validity documented the interviews. Respondents were assured anonymity. Each telephone interview lasted between 20 and 45 minutes.



Two co-authors were present during each interview, taking notes on the semi-structured questionnaire developed for the purpose of the study. Inclusion was dependent on a verbal informed consent following a short description of the study. The interviews were transcribed and the data verified individually.

Additionally a structured literature search (12) was performed and 15 articles from the search were included in the analysis.

#### ANALYSIS

For the purpose of analysis and within the framework of grounded theory, data gained from our recordings were coded and grouped. Thereafter information from the different interviews was compared (12,13).

#### LIMITATIONS OF THE STUDY

Data obtained express the perceived access and participation of immigrant women in organized screening programmes. Additionally only one key informant was interviewed in each of the included countries. By having only qualitative data we cannot reach scientifically based generalizations, but the outcome consensus among our informants about immigrant women's participation in national breast cancer screening programmes is nevertheless clear. Recall bias must be accounted for, because informants relied solely on their memory. Ethics

The Regional Committee for Medical and Health Research Ethics of Norway (REK) approved this research project.

#### RESULTS & DISCUSSION

According to The Cancer Registry of Norway, the incidence rate of breast cancer in Norway rose until 2005. Since 2005, the incidence has shown a plateau, with a slight decrease for the last five-year period (14). The attendance rate in the screening programme in 2012 was 75 % (14). Based on our informants the participation rate for immigrant women in the UK, Austria, Norway, Finland, Sweden, Denmark and France were considered lower than participation of the non-immigrant population. Comparing results for population can be seen in Table 1. As data registries do not record ethnicity or country of origin, the exact attendance rate by ethnicity or country of origin remain uncertain.

Breast cancer screening by mammography in the investigated countries is restricted to certain age groups. Enrolment to the mammography screening program is made by mail, based on the population registry, except in the UK, where there is no population registry. Here it is based on the GPs' patient lists. Organized invitation letters are only sent in the official language of the country in question, except for Austria, where there are additional texts in Turkish and Bosnian (Serbo-Croatian). The enrolment letters in the UK are sent in English

with a reference to a website with information in various languages.

Our results showed that screening programmes are provided by the public health system free of charge except for Norway, where mammography screening requires a co-payment corresponding to about two hours' wage before taxes for an unskilled worker (15). All informants told us that their experience was that that minority groups are not reached, but at the same time none of the countries today had statistical evidence. No country included in the study has information indicating in which country the woman was born, due to data protection laws prohibiting the identification of birth country in public registers or due to lack of linkages between different registers. Data on birth country, ethnicity or mother tongue would be necessary for language adjustment of the enrolment letter. The attendance rate for immigrants is an estimation performed by our key informants.

All informants from the seven countries had the impression that immigrant

women had a much lower participation rates than native women. The representative for Sweden even expressed it as «a big difference – we have a high number of immigrants but low participation».

We found further that authorities in Austria, UK, France and Denmark had extensive collaboration with immigrant organizations to reach out to the immigrant population with a general nationwide approach. As immigrants often reside in clusters and designated areas, authorities in the UK, Norway, France and Denmark made additional efforts to target those areas with adapted information. Our informants estimated that access for immigrant women is lower than for native women, while focusing on the need to know the actual participation of minorities in the screening programme. Immigrants will continue to make up an increasing and significant part of the urban and rural population of Europe.

Previous European studies show that breast cancer stage and diagnosis can dependent on socio-economic status (16)

and lower health literacy levels (17). This leads to the assumption that immigrant women, due to reduced access rates, will continue to be at higher risk of late cancer detection, which may be a cause of the higher mortality rates seen in a Swedish study (18). Here research shows that the mortality rates of malignant breast tumors were highest in immigrants coming from outside the Nordic countries (18). This kind of data is not available for Norway. As the composition of the immigrant population changes over time so should the public health approach.

For Europe as a multicultural society, equity is a central value of multiculturalism. It is necessary to make an effort to maintain respect for differences while recognizing that some differences conspire against equity.

This study indicates that migrant women in various countries in Europe do not participate in screening programmes at the same rate as woman from the majority population. There-



TABLE 1

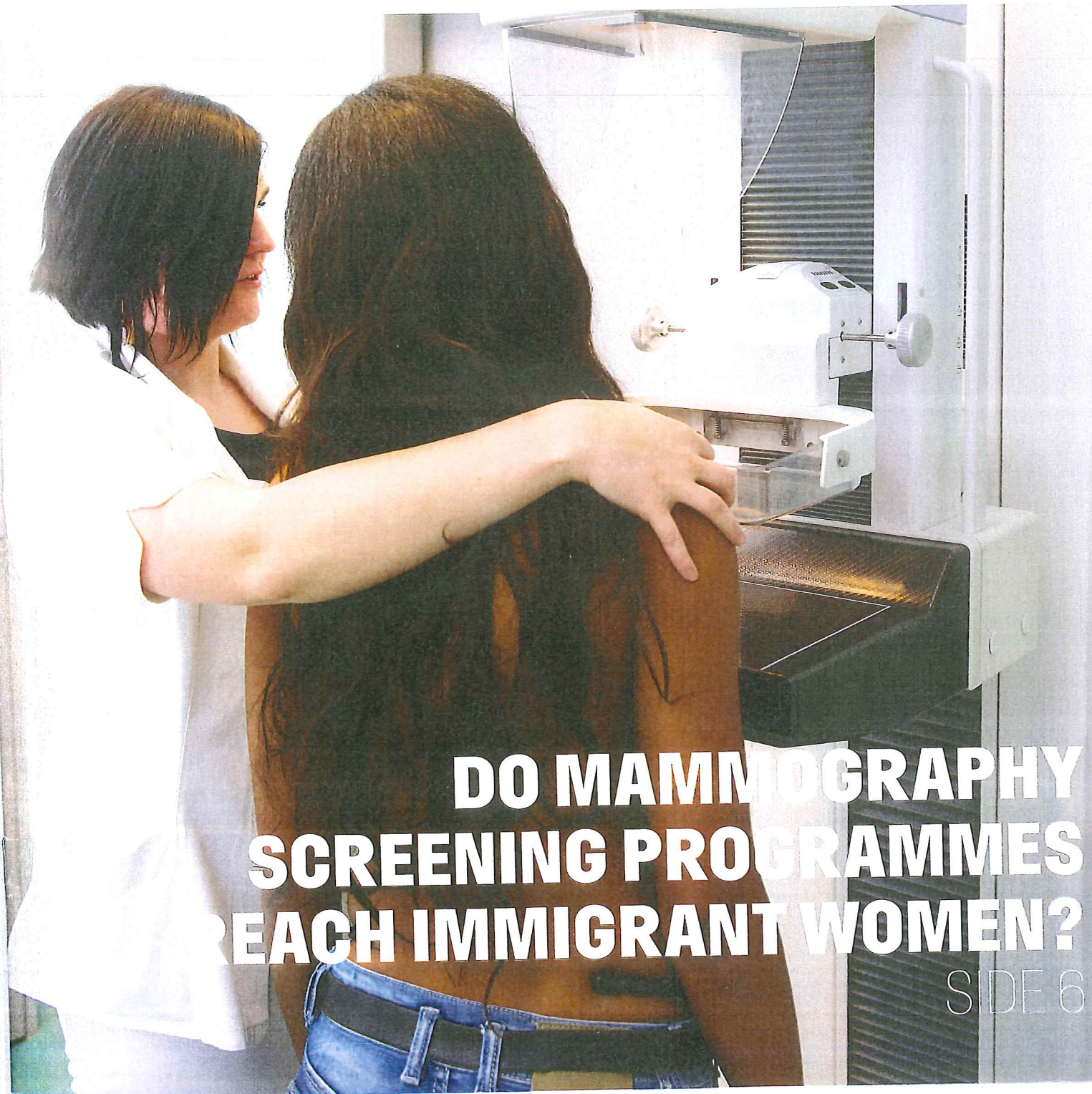
Comparison: Breast cancer screening in seven different countries in Europe

	Norway	Finland	Sweden	Denmark	Austria	France	UK
Perform screening	yes	yes	yes	Yes	yes*	yes	yes
Cost to participants	yes, a fee	no	no	no	no	no	no
Immigrants born outside country	10.9% (2012)	4.6% (2010)	14.3% (2010)	10.4 (2012)	15.2% (2010)	19.0% (2008)	8.3% (2006)
Participation-rate (year)	75% (2009)	87.4% (2009)	72.0% (2009)	73.7% (2009)	80.2% (2009)	75.4% (2009)	75.3% (2009)
Enrolment letter in:	Norwegian	Finnish	Swedish	Danish	German + Bosnian + Turkish	French	English
Knowledge of country of origin in programme	No	No	No	No	No	No	No
Collaboration with immigrant organization	No	No	No	Yes	Yes	Yes	Yes

\*] Country wide from autumn 2013

# RADIOGRAFEN

RADIOGRAF RÅDET 43. ÅRGANG - NR. 7 SEPTEMBER 2015



## DO MAMMOGRAPHY SCREENING PROGRAMMES REACH IMMIGRANT WOMEN?

SIDE 6

I DETTE NUMMER:

5 NORDISK MØDE I DANMARK

12 JO FLERE HØJTUDDANNEDE, DES MERE INNOVATION

14 NON-CONTRAST ENHANCED MAGNETIC RESONANCE ANGIOGRAPHY TECHNIQUES

fore health promotion and screening information need to include a multifaceted intervention focusing on awareness concerning the importance of preventive care (10,11), information about breast screening programmes and motivation to seek screening. We saw further that health promotion and screening information has to be offered in a multitude of linguistically and culturally appropriate educational materials conveying the desired message. Health promotion professionals, together with minority communities, need to encourage cultural competence among staff working in community health programmes (11,19). This indicates both inequalities in prevention measures and the fact that information did not reach them.

As we know from previous research, challenges immigrants face could be both practical and interpersonal (11). These challenges include a lack of language proficiency, limited reading comprehension, the complexity of terms and interpersonal problems with medical personnel or simply that the written invitation is sent to a previous and not actual address (11,17,19, 20). By focusing on personal experience and relationships to the salience of health information, and the desire for local cultural relevance in health

communication gaps can be closed (17). Restricted access to information on mother tongue or ethnicity in public registers is a challenge for equal access to health improving services.

Basic determinants of health, such as access to health care and screening programmes, could be improved by the involvement of immigrant groups (21,22). The present study indicates that the problem is two-fold: lack of information about ethnicity in national registers makes it very difficult to describe actual rates of breast cancer screening in immigrant women, while lack of information materials in the participants' own languages may present a barrier to inclusion in breast cancer screening. Participation is free in the included countries except for Norway, and we assume that the cost of participation for the individual participant may present a further barrier (23). As members of many immigrants groups would be financially less well off than the majority population, the cost of screening could deter some immigrants from participating.

### CONCLUSION

We conclude that monitoring of the health of migrants is essential for health

systems in order to quickly respond to their needs. The collection of data requires that we go beyond standard procedures and include an «outreaching» approach. At the same time researchers need to adapt their methods to include minority groups in their study population, so that attendance rates as a part of quality control are easy available to policy makers.

### THE AUTHORS' CONTRIBUTIONS

The study presented here was developed in collaboration between all three authors. USG was main author while HL contributed significantly in the article USG and JB defined the research theme and designed the methods. USG and HL conducted the interviews. USG and HL analysed and interpreted the data (analyst triangulation). All authors (USG, HL, JB) have contributed to, reviewed, and approved the manuscript.

### ACKNOWLEDGEMENTS

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### CONFLICT OF INTEREST

None.

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