

CRN – case number 1

Institution: Cancer Registry of Norway
Administrative unit: Cancer Registry of Norway
Title of case study: Cancer in immigrants
Period when the underpinning research was undertaken: 2014 and onwards
Period when staff involved in the underpinning research were employed by the submitting institution: PhDs and postdocs were employed in the period from 2014 to 2021. Several permanent employees have also been involved
Period when the impact occurred: 2017 and onwards

<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>Our studies have contributed to the knowledge on cancer among immigrants in Norway. Substantial efforts were invested in conducting research that led to an amendment to the CRN Regulation, enabling the incorporation of information on country of birth in the registry. This regulatory modification transpired in 2018 and enabled the inclusion of immigrant-specific incidence in our annual publication, and more easily available data on country of birth for researchers. The data have also been used to enhance the understanding of incidence trends. Our research elucidated lower attendance rates for screening among immigrants, efforts to mitigate this are now being investigated further.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>Key research and aims:</p> <p>The Cancer Registry of Norway undertook multiple research initiatives with the overarching aims of investigation cancer incidence (1), assessing the stage distribution and survival (2, 3), and examine cancer screening attendance (4, 5) among immigrants in Norway.</p> <p>Key findings:</p> <p>Cancer incidence in immigrants (1). This study encompassing 5,508,429 Norwegian-born and 850,008 immigrants residing in Norway from 1990 to 2012. The study, which included 498,336 cancer cases, revealed a lower overall cancer incidence among immigrants compared to the Norwegian-born population. Immigrants from high-income countries exhibited comparable incidence rates as the Norwegian-born. Noteworthy findings included higher incidence rates of lung cancer in men born in Eastern Europe, elevated rates of stomach cancer in Eastern European immigrants, and increased rates of liver cancer among immigrants from low-income countries.</p> <p>Stage at diagnosis and survival among immigrants (2, 3). These studies were performed on a population ranging from 213 320 to 500 255 cancer cases diagnosed between 1990 and 2014. The studies identified no substantial differences in stage at cancer diagnosis between immigrants and those who were Norwegian-born, except for breast cancer where non-Western immigrants presented with more advanced stages (2). Immigrants in Norway had better survival relative to those who were Norwegian-born. Substantially better survival was observed among non-Western-born lung cancer patients and sub-Saharan African breast cancer patients. Conversely, immigrants from Eastern Europe with melanoma and prostate cancer demonstrated somewhat worse survival compared to their Norwegian-born counterparts (3).</p> <p>Cancer screening attendance rates among immigrants (4, 5). The third strand of studies investigated cancer screening attendance rates among immigrants. In the study on breast cancer screening attendances in the Norwegian Breast Cancer Screening (4), involving 885 979 women aged 50–69 who had received an invitation to screening between 1996 and 2015, immigrants</p>

displayed lower attendance rates (53.1%) than Norwegian-born women (76.1%). Notably, women born in Somalia had the lowest attendance rates in the first round (16.7%). The cervical screening study included 208 626 immigrants and 1 157 223 Norwegian-born women found lower screening attendance among immigrants across all age groups (5). Immigrants from Lithuanian had the highest non-adherence rate at 78%. All of the abovementioned studies were carried out on registry-based data.

Names of the key researchers and what positions they held at the administrative unit at the time of the research (where researchers joined or left the administrative unit during this time, these dates must also be stated).

Giske Ursin, Director of CRN, led the research project Cancer incidence among immigrants. A postdoctoral candidate **Kirsti Vik Hjerkind** was employed in the project (2014–2021).

Inger Kristin Larsen, Researcher at Department of Registration at the CRN, led the research project Stage at diagnosis and survival among immigrants. A PhD-student, **Håvard Thøgersen**, was employed for three years (2016–2019).

Solveig Hofvind, Head of Screening Section, Section of Breast Cancer Screening, and **Mari Nygård**, Head of Department, Department of Research (since 2019), led the research projects on screening attendance. **Maarit K. Leinonen** Postdoctoral fellow, Department of Research (2015–2019), and **Sameer Bhargava**, PhD student, Section of Breast Cancer Screening (2016–2019) was employed in these projects.

Other permanent employees from the CRN were also involved. They have been employed throughout the period 2012–2022, unless otherwise stated:

Bjørn Møller, Head of Department of Registration

Elisabete Weiderpass, Head of Department, Department of Research until December 2018

Trude Eid Robsahm, Researcher, Department of Research

Ronnie Babigumira, Advisor (now PhD student), Department of Research (2013–)

Stein Aaserud, Advisor, Department of Registration (2014–2022)

Kaitlyn Tsuruda, Advisor, Section of Breast Cancer Screening (2016–)

Suzanne Campell, Advisor, Department of Research

Ameli Tropé, Head of Screening Section, Section of Cervical Cancer Screening (2015–)

Gunhild Mangerud, Advisor, Section of Breast Cancer Screening

3. References to the research (indicative maximum of six references)

1. Hjerkind KV, Qureshi SA, Møller B, Weiderpass E, Deapen D, Kumar B, Ursin G. Ethnic differences in the incidence of cancer in Norway. *Int J Cancer*. 2017;140(8):1770-80. DOI: [10.1002/ijc.30598](https://doi.org/10.1002/ijc.30598)
2. Thøgersen H, Møller B, Robsahm TE, Aaserud S, Babigumira R, Larsen IK. Comparison of cancer stage distribution in the immigrant and host populations of Norway, 1990-2014 *Int J Cancer*. 2017;141(1):52-61. DOI: [10.1002/ijc.30713](https://doi.org/10.1002/ijc.30713)
3. Thøgersen H, Møller B, Robsahm TE, Babigumira R, Aaserud S, Larsen IK. Differences in cancer survival between immigrants in Norway and the host population. *Int J Cancer*. 2018;143(12):3097-105. DOI: [10.1002/ijc.31729](https://doi.org/10.1002/ijc.31729)

4. Bhargava S, Tsuruda K, Moen K, Bukholm I, Hofvind S. Lower attendance rates in immigrant versus non-immigrant women in the Norwegian Breast Cancer Screening Programme. *J Med Screen*. 2018;25(3):155-61. DOI: [10.1177/0969141317733771](https://doi.org/10.1177/0969141317733771)
5. Leinonen MK, Campbell S, Ursin G, Tropé A, Nygård M. Barriers to cervical cancer screening faced by immigrants: a registry-based study of 1.4 million women in Norway. *Eur J Public Health*. 2017;27(5):873-9. DOI: [10.1093/eurpub/ckx093](https://doi.org/10.1093/eurpub/ckx093)

4. Details of the impact (indicative maximum 750 words)

In 2013, The Ministry of Health and Care Services in Norway published a national strategy for immigrant health. Among one of three main aim was to ensure that health and care services had access to the most recent knowledge about immigrants' health for use in the development of health services. At that time, the absence of comprehensive national data on immigrants' health was significant. Below we have outlined 6 areas that might have been influenced by our initial studies:

A foundation for knowledge on cancer in immigrants

The initial studies on immigrants and cancer in Norway included in this impact case have been collectively cited 134 times, and the findings have provided a solid knowledge foundation for our understanding of cancer in immigrants in Norway. This is evident, among other, in the national Public Health Report for 2022, where these studies, along with data from the Cancer Registry of Norway, constitute the majority of references summarizing the topic "Cancer among immigrants" (6).

Legislation changes

To meet the goals of the national strategy from 2013, it became clear that data on the country of birth must become more accessible. Substantial efforts were made to amend the Cancer Registry of Norway Regulation, in order to enable the inclusion of information about the country of birth in the registry. The regulatory modification took place in 2018.

The use of country of birth to enhance understanding of concerning incidence trends

Research revealed that immigrants in Norway had a lower cancer risk for most cancer sites compared to the host population (1). However, certain immigrant groups had a higher risk of primary liver cancer. The incidence of liver cancer had shown a worrisome increase in Norway, and the trend was suspected to be related to a growing proportion of immigrants from countries with higher risk of this specific cancer. Information on country of birth made it possible to assess the incidence trends among individuals born in Norway. The result of this analysis was somewhat surprising – there had been an increase in the incidence of primary liver cancer among the Norwegian-born population as well, and the earlier assumptions about causation were refuted (7).

The reason for low attendance in screening among immigrants needed further examinations, and new studies were conducted

Immigrant women from non-Western countries had a more advanced stage of breast cancer at diagnosis (this was not found for cervical cancer) (2). The breast cancer finding corresponded with the observed lower participation rate in immigrants to mammography screening (4). This was a worrisome discovery. Several research projects were funded by The Norwegian Cancer Society enabling us to continue working on projects to investigate barriers to participation in screening (NCS), and other closely related issues.

- **Qualitative studies** were conducted to identify and explore factors that may facilitate immigrants' access to screening (8), immigrants women's perspectives on breast cancer and screening (9).

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- **A randomised controlled trial** was performed to explore attendance at mammographic screening among immigrants who received the invitation and information in their language of origin (Arabic, English, Polish, Somali or Urdu) and Norwegian compared to Norwegian only. However, the study did not reveal any differences in attendance between the groups (10).
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- **Lower attendance among immigrants were also shown in a study on colorectal cancer screening (11)**, and the national colorectal cancer screening programme, implemented in 2023, has tried out new methods (e.g. by distributing screening information during Friday prayer at the mosque and they will conduct a randomized study to assess the impact of verbal information on participation).

Outreach activities and collaboration

The mammography screening programme has engaged in outreach activities and collaborated with immigrant groups (e.g. Bydelismødre “District mothers”, voluntary, primarily minority women trained in parenting, health and community related issues, to bridge gaps between immigrant women and community services, addressing local challenges) and has created informational videos in several languages that were made available online in response to requests from participants and other stakeholders.

International collaborations

For several decades, the Nordic cancer registries have maintained a strong and close collaboration. Nonetheless, collaboration has been lacking around immigrants and cancer. The reasons for this limitation are not clear, though the sensitivity of country of birth information may have contributed to the hesitancy some countries have in making the data available, and therefore reducing the ability of cross-country research collaboration. It was not until 2023 that population-based studies on the incidence and mortality of cancer were published from four out of five Nordic countries (12, 13). We believe that a foundation has been established for a close collaboration on this topic in the years to come.

5. Sources to corroborate the impact (indicative maximum of ten references)

We have listed the primary sources that corroborate the impact we believe this case has contributed on:

A foundation for knowledge on cancer in immigrants

6. Spilker RI, T; Hussaini, L; Labberton, AS; Ali WA; Syse, A; Olsen, AO; Qureshi, SA; Bærug, AB; Straiton, ML; Kumar, BN; Bruun T. Folkehelse rapporten. Helse blant personer med innvandrerbakgrunn. Folkehelseinstituttet: Folkehelseinstituttet; 2022 [updated 2022 Aug 26; cited 2023 Dec 08. Available from: [Health in the immigrant population - NIPH \(fhi.no\)](https://www.fhi.no)

Legislation changes

Place of birth was added in Forskrift om innsamling og behandling av helseopplysning i Kreftregisteret (Kreftregisterforskriften) §1-7 (Opplysninger om krefttilfeller i Kreftregisteret) pkt. 1.4. Available from: [Forskrift om innsamling og behandling av helseopplysninger i Kreftregisteret \(Kreftregisterforskriften\) - Kapittel 3. Behandling av helseopplysninger i Kreftregisteret - Lovdata](#)

The use of country of birth to enhance understanding of concerning incidence trends

7. Hjerkind, K. V., Larsen, I. K., Aaserud, S., Møller, B., & Ursin, G. (2020). Cancer incidence in non-immigrants and immigrants in Norway. *Acta oncologica (Stockholm, Sweden)*, 59(11), 1275–1283. DOI: [10.1080/0284186X.2020.1817549](https://doi.org/10.1080/0284186X.2020.1817549)

The reason for low attendance in screening among immigrants needed further examinations, and new studies were conducted

Qualitative studies

8. Bhargava, S., Czapka, E., Hofvind, S., Kristiansen, M., Diaz, E., & Berstad, P. (2022). Polish immigrants' access to colorectal cancer screening in Norway - a qualitative study. *BMC health services research*, 22(1), 1332. DOI: [10.1186/s12913-022-08719-3](https://doi.org/10.1186/s12913-022-08719-3)
9. Bhargava, S., Hofvind, S., & Moen, K. (2019). Gender, letters, relatives, and God: mediating actors in mammographic screening among Pakistani women in Norway. *Acta radiologica open*, 8(9), 2058460119875015 DOI: [10.1177/2058460119875015](https://doi.org/10.1177/2058460119875015)

Randomised controlled trial

10. Hofvind, S., Iqbal, N., Thy, J. E., Mangerud, G., Bhargava, S., Zackrisson, S., & Berstad, P. (2023). Effect of invitation letter in language of origin on screening attendance: randomised controlled trial in BreastScreen Norway. *BMJ (Clinical research ed.)*, 382, e075465 DOI: [10.1136/bmj-2023-075465](https://doi.org/10.1136/bmj-2023-075465)

Lower attendance among immigrants in colorectal cancer screening

11. Bhargava, S., Botteri, E., Berthelsen, M., Iqbal, N., Randel, K. R., Holme, Ø., & Berstad, P. (2023). Lower participation among immigrants in colorectal cancer screening in Norway. *Frontiers in public health*, 11, 1254905. DOI: [10.3389/fpubh.2023.1254905](https://doi.org/10.3389/fpubh.2023.1254905)

Outreach activities and collaboration

Translated information in the national mammography screening programme is available here: https://www.kreftregisteret.no/en/screening/BreastScreen_Norway/Translations/

International collaborations

12. Lamminmäki, M., Leivonen, A., Heinävaara, S., Nygård, M., Ursin, G., Campbell, S., Stefansdóttir, H., Hirvonen, E., Toikkanen, S., Vejborg, I. M. M., Njor, S. H., & Sarkeala, T. (2023). A population-based cohort study on changes in breast, lung and colorectal cancer incidence and mortality among non-Western immigrant women. *BMC cancer*, 23(1), 665. DOI: [10.1186/s12885-023-11140-6](https://doi.org/10.1186/s12885-023-11140-6)
13. Sarkeala, T., Lamminmäki, M., Nygård, M., Njor, S. H., Virtanen, A., Leivonen, A., Hirvonen, E., Toikkanen, S., Campbell, S., Stefansdóttir, H., Ursin, G., & Heinävaara, S. (2023). Cervical, liver and stomach cancer incidence and mortality in non-Western immigrant women: a retrospective cohort study from four Nordic countries. *Acta oncologica (Stockholm, Sweden)*, 62(9), 977–987. DOI: [10.1080/0284186X.2023.2245557](https://doi.org/10.1080/0284186X.2023.2245557)