

The Norwegian Breast Cancer Registry (NBCR): A clinical register that monitors surgical care with the intention to increase the quality of treatment given to breast cancer patients in Norway

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ABSTRACT

Increased focus on quality indicators and the use of clinical registries for breast cancer has shown higher compliance with recommended treatment in several studies. Norwegian Breast Cancer Registry (NBCR) has presented data on quality indicators since 2015. The registry is 95% complete for surgical treatment during 2015-2021. Over time, increased compliance to recommended surgical therapy has been observed. The completeness of data is, unfortunately, a problem, particularly for breast radiology outside the Norwegian mammography screening program, and for data on oncological treatment. Automation of data capture is a priority at the Cancer Registry of Norway (CRN), with the ongoing INSPIRE (INcreaSe Pharmaceutical REporting) and SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) projects. These projects may add important data and improve the completeness and quality of the NBCR, which is useful for improving the quality of care given to Norwegian breast cancer patients.

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INTRODUCTION

Breast cancer is the most common cancer in women in Norway. Women with breast cancer symptoms are referred to 17 different breast centers that also diagnose patients via the Norwegian mammography screening program, known as BreastScreen Norway. This screening program invites women aged 50-69 to two-view mammography biennially. BreastScreen Norway is administered by the Cancer Registry of Norway. Overall in 2021, 4011 women were diagnosed with breast cancer (1). The optimal management of patients with breast cancer is complex and requires the expertise of specialist from different disciplines. The main disciplines treating breast cancer are in pathology, radiology, surgery, and oncology. All these disciplines are represented in the Norwegian Breast Cancer Group (NBCG). This group is responsible for annual revisions of the national guidelines for diagnostics, treatment and follow-up of breast cancer patients in Norway (2). The CRN publishes annual clinical registry reports with detailed statistics for 11 different cancer sites, including breast cancer (1).

To increase the quality of the epidemiological data on diagnosis, treatment and follow-up of breast cancer, the Norwegian Breast Cancer Registry (NBCR) was developed in collaboration with NBCG. The NBCR was designed with nine clinical reporting modules that include diagnostics, surgical and oncological treatment, and follow-up. A separate notification is submitted for

every event during diagnosis, treatment, and follow-up. The modules are used for both primary breast cancer treatment, when local and regional relapses occur, and when the patients are diagnosed with metastases.

The NBCR gained national status in 2013. Data reporting is mandatory and regulated in Chapter 2 § 2-1 of the Cancer Registry Regulations. Norwegian clinical departments register in CRN's electronic reporting service (KREMT). Pathology data is automatically sent from the various pathology departments and is a copy of pathology reports sent to the clinicians. Clinical data from NBCR was first published in 2014. At the same time, a reference group was established with members from the various health trusts. The members of this reference group are professionals who investigate, treat, and follow up on breast cancer patients in all health regions in Norway, with representatives from breast cancer surgery, pathology, radiology, and oncology. In addition, the reference group includes epidemiologists and statisticians from CRN. Regular meetings are held where the purpose is to ensure access to up-to-date medical knowledge, support the clinical relevance of the quality register, and evaluate compliance and results of the recommended treatment. The registry is currently 99% complete for pathology data and 95% for surgical treatment data. Radiology data outside of BreastScreen Norway and oncology data are less complete (1). It has so far not been possible to conduct studies which includes information on hospital administered cancer medications.

QUALITY INDICATORS

Clinical registration of breast cancer treatment with a focus on quality indicators has been shown in several studies to provide higher compliance with recommended therapy and increased survival (3-5). In 2010, EUSOMA (European Society of Breast Cancer Specialists) proposed 14 mandatory quality indicators (QIs) for breast centre certification that cover diagnosis, management, and follow-up of breast cancer patients (6). In 2015, the NBCR reference group decided to apply a sample of EUSOMA quality indicators to the Norwegian data. Regular evaluation of the quality indicators has since been a priority in the annual reports. The intention has been to increase the quality of treatment given to breast cancer patients in Norway. In 2017, the number of QIs were increased from 14 to 17 by EUSOMA (7). Across countries, there is unfortunately no agreement on which QIs to use. There is a large heterogeneity of QIs in breast cancer care. In a systematic review of QIs for breast cancer care, not a single identical indicator was found in 22 of the documents analysed. There were only four comparable QIs that appeared more frequently in the analysed documents (8).

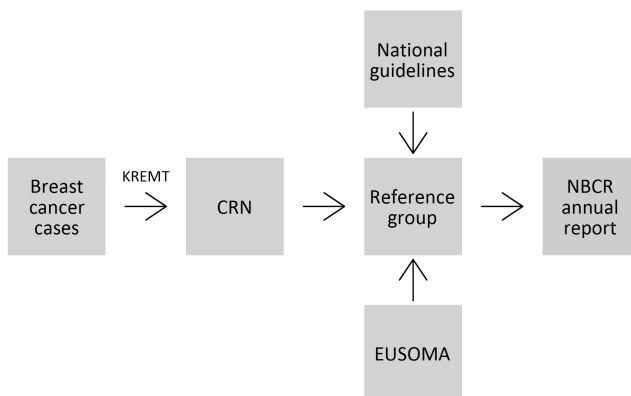


Figure 1. Process of the NBCR annual report.

SURGICAL QUALITY INDICATORS IN NBCR

Breast and endocrine surgery is a relatively new surgical sub-specialty in Norway, created in 2007. Since then, surgical techniques have evolved with the introduction of so-called oncoplastic breast surgery, where larger tumors can be removed from the breast with good cosmetic results (9). Previously, breast surgery was performed by general surgeons at 60 different hospitals. The number of hospitals providing breast cancer surgery was reduced with the introduction of BreastScreen Norway, which became nationwide in 2005 (10). During the expansion period, specialised multidisciplinary breast centres were established across Norway. The number of hospitals performing breast cancer surgery was reduced to about 20, ensuring women, regardless of where they lived in Norway, were offered the same diagnostics and treatment for breast cancer (11). NBCR has incomplete oncology data for all patients and in-

complete radiology data for patients diagnosed outside of BreastScreen Norway, so quality indicators in these fields are not reliable. However, pathology and surgery data are close to complete, and reporting on quality indicators in these fields has been possible.

Breast-conserving surgery

International studies with more than 20 years of follow-up have shown that breast-conserving surgery and mastectomy have equal results in terms of breast cancer-specific survival (12), provided that patients undergoing breast-conserving surgery receive radiotherapy after the surgical treatment. Studies have also shown that breast-conserving surgery results in higher patient satisfaction than mastectomy, even after breast reconstruction (13). The Norwegian national guidelines for Breast Cancer have widened the indication for breast-conserving surgery in line with international publications. This type of surgery is now offered to most patients where it is possible to achieve a cosmetically good result. The proportion of patients operated with breast-conserving surgery has been a quality indicator in the NBCR since 2015. Annually, data is reported on the proportion of breast-conserving surgery for tumors ≤ 3 cm at the Norwegian hospitals that offer breast cancer surgery. EUSOMA article 11c recommends that the minimum standard is 70% with a target of 85% (7).

Until 2005, about 60% of breast cancer patients in Norway had their entire breast removed. This proportion has decreased since 2005 with increased breast-conserving surgery (11). In 2014, there was a wide variation in breast-conserving surgery rates between hospitals, with some high-volume hospitals having a percentage as low as 60%. Part of the explanation might have been a difference in patient populations, but most likely, this was not the whole truth. Data on breast-conserving surgery have been thoroughly discussed at both the breast and endocrine surgeons' annual meetings and oncological meetings on several occasions. In addition, courses have been arranged for Norwegian breast and endocrine surgeons on oncoplastic breast surgery, teaching them new breast-conserving techniques. An increasing proportion of Norwegian breast cancer patients are operated with breast-conserving surgery (Figures 3 and 4). In 2021, 88% of Norwegian breast cancer patients with a tumor size ≤ 3 cm underwent breast-conserving surgery, and 15 out of 19 hospitals met the target of 85% (1).

Immediate breast reconstruction in Norway

For some patients, the best surgical treatment is to remove the entire breast (mastectomy). For example, patients with widespread breast disease, several tumors in different parts of the breast, BRCA1/2 gene mutations, or patients who prefer to remove the entire breast. Since the late 1990s, women who have had their breast removed have been offered reconstruction of the breast at the same time as the operation for cancer (immediate breast reconstruction) internationally. Up until 2010,

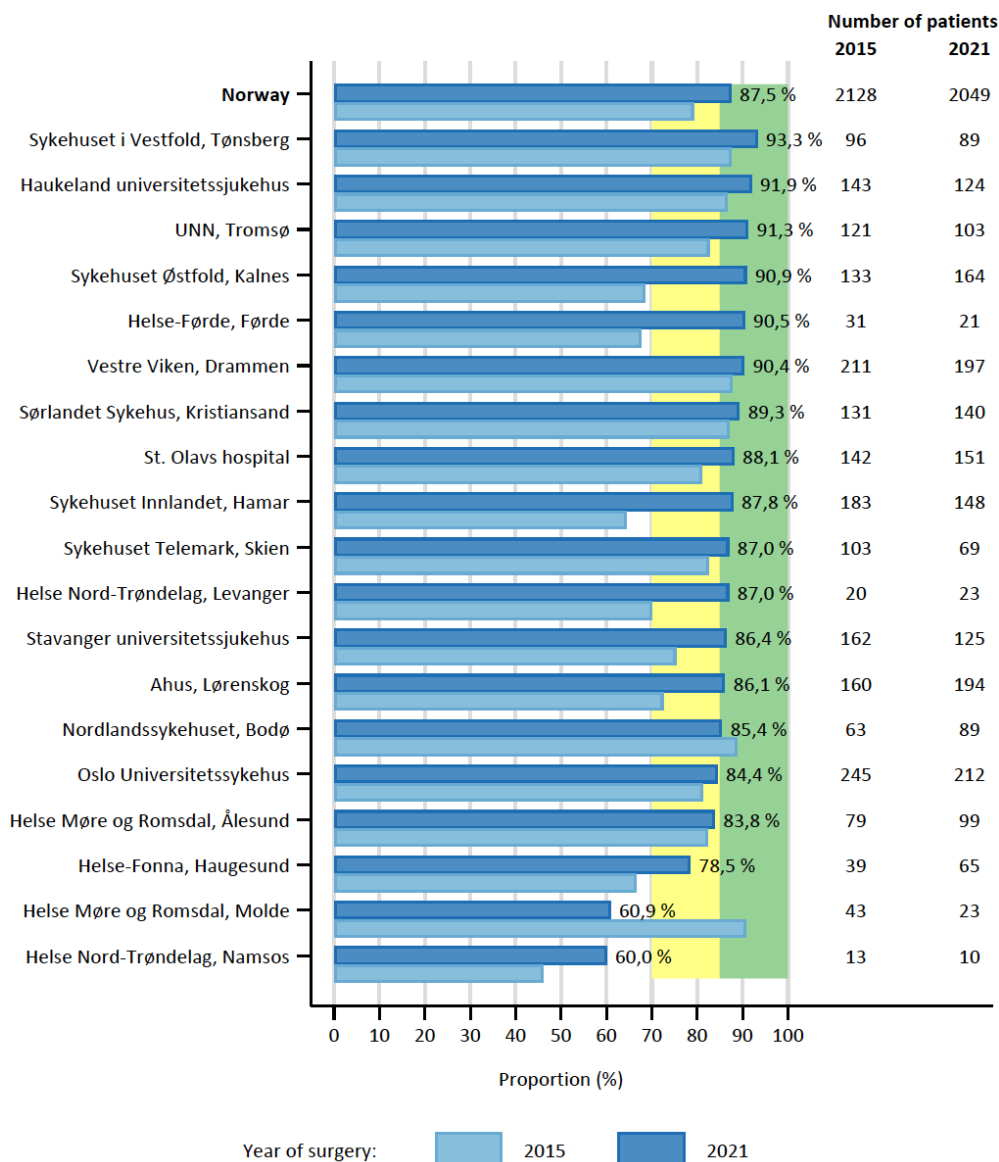


Figure 2. Proportion of women who received breast-conserving surgery among those with tumors ≤ 3 cm in Norway, 2015 and 2021.

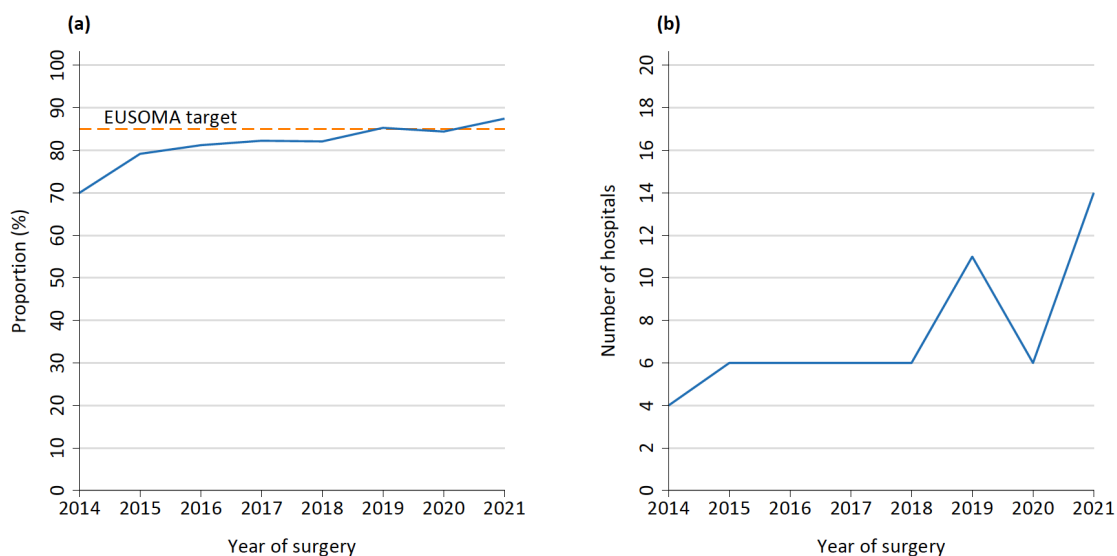


Figure 3. Breast-conserving surgery in Norway. 3a) Proportion of women with tumours ≤ 3 cm who received breast-conserving surgery, and 3b) number of hospitals who met the EUSOMA target of 85 % during 2014-2021.

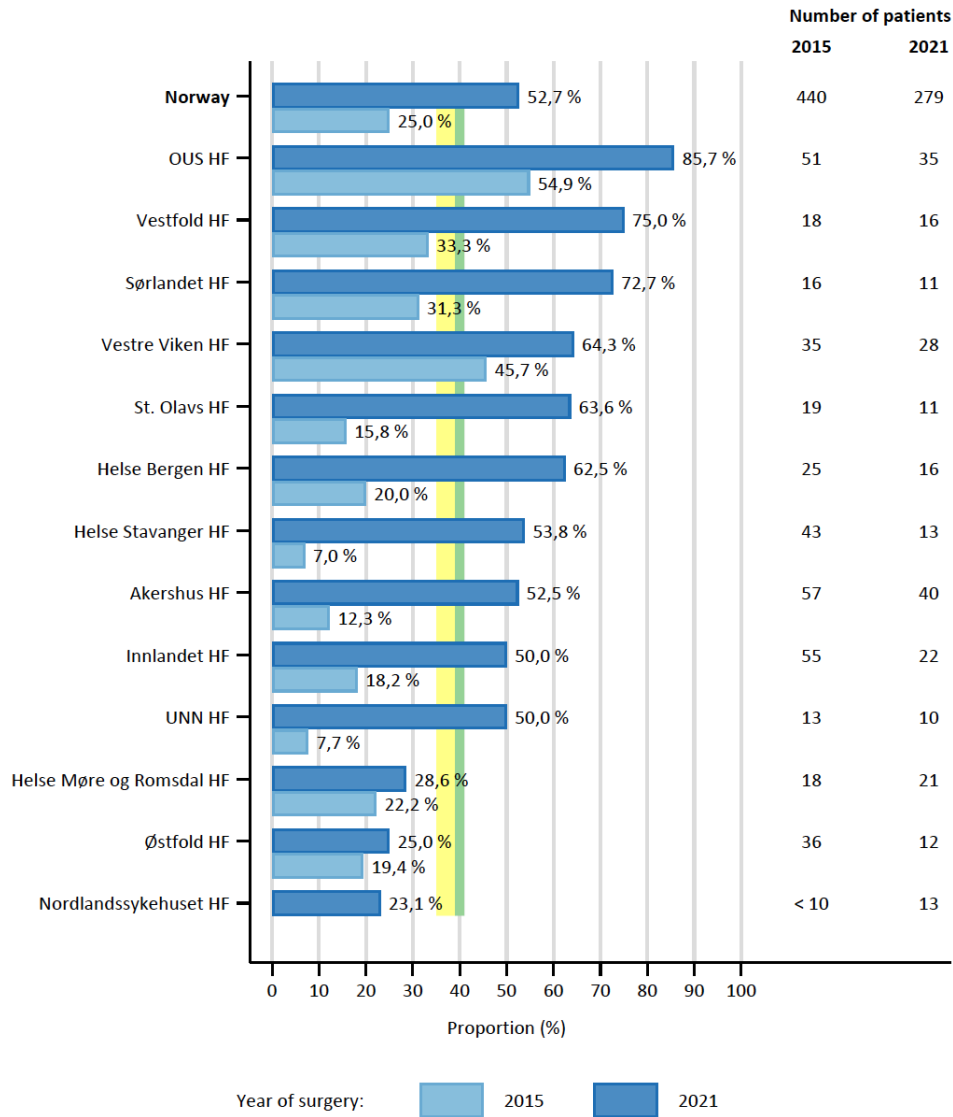


Figure 4. Proportion of women who received immediate breast reconstruction among those <70 years operated with mastectomy in 2015 and 2021.

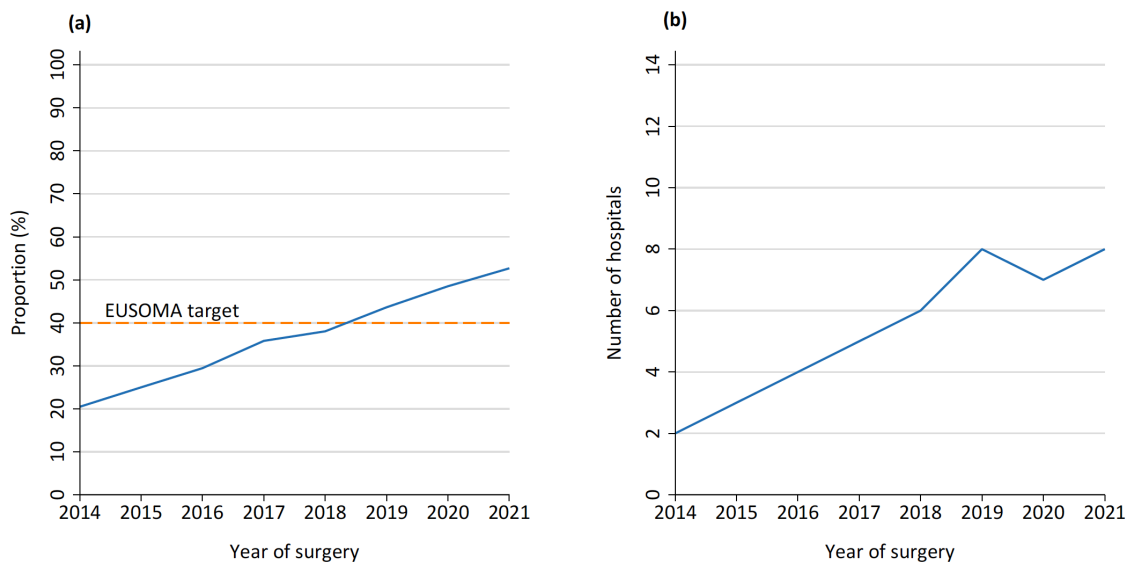


Figure 5. Mastectomy with immediate breast reconstruction in Norway. 5a) Proportion of women <70 years operated with mastectomy who received an immediate breast reconstruction and 5b) Number of hospitals who met the EUSOMA target of 40% immediate breast reconstruction in patients <70 years operated with mastectomy during 2014-2021.

this was only done occasionally in Norway. The low proportion of breast-conserving surgery led to long waiting times for breast reconstructions after breast cancer treatment (secondary reconstruction). In 2012, public funds were allocated to reduce the waiting time for secondary reconstruction. At the same time, the national guidelines recommended that patients with no contraindications should be offered primary reconstruction (2). EUSOMA's article 9c recommends a minimum standard of 40% primary reconstructions after mastectomy, with no upper target.

The proportion of primary reconstructions after mastectomy was first reported in the annual report in 2015 and has since been reported annually. In 2015, only 23% of breast cancer patients operated with mastectomy under 70 years of age in Norway had a primary reconstruction. Further, some hospitals did not offer this type of surgery at all, and there were considerable variations in the proportion of such operations between the hospitals. Large hospitals with plastic surgical expertise also had surprisingly few primary reconstructions. This became a topic of media reports and was discussed in different meetings with breast and plastic surgeons. Since 2015, breast and plastic surgical departments have been actively working to implement a uniform offer to breast cancer patients in Norway, with successful results. In 2021, 53% of breast cancer patients operated with mastectomy < 70 years of age in Norway were operated with primary reconstruction at 13 different hospitals.

FUTURE PERSPECTIVES

Reporting clinical data is time-consuming and not prioritized in a hectic clinical daily life. The reporting has been manual, time-consuming, and consequently incomplete. Few Norwegian clinical departments have had dedicated coders for this work, as recommended by EUSOMA (14). Efforts to improve manual reporting have not been successful. Automation of data capture has therefore been a priority in the CRN in recent years. Today, access to radiotherapy data is automated. The

most effective way to collect data on cancer medications is through the hospital systems for ordering/administering medical oncological treatment. The INSPIRE (INcreaSe Pharmaceutical REporting) project was initiated to collect data automatically and electronically on cancer medication from the hospital's systems to the CRN. The project is a unique collaboration between 12 pharmaceutical companies, the Association of Pharmaceutical Companies in Norway, the Norwegian Cancer Society, Inven2, the Cancer Registry of Norway, and the four Regional Health Trusts (15). There are data from drug cancer treatment given both in hospitals and by prescription. Lung cancer was the first cancer form to introduce an automated collection of drug cancer treatment. Automated collection of breast cancer drug treatment was presented for the first time in the 2021 annual clinical report. Additionally, there is an ongoing project to introduce SNOMED CT, a common standardized terminology designed for precise health information documentation. This terminology will support the clinician's work with automated reporting to health registries in the future, with increased quality of data and health services. It will also facilitate the use of artificial intelligence in the future.

CONCLUSION

Several studies have shown that increased focus on quality indicators reporting by clinical registries for breast cancer contributes to higher compliance with recommended treatment. Results presented from NBCR show increasing use of recommended treatment, based on surgical parameters recorded with high completeness.

The completeness of data capture is still a problem for some modules, particularly breast radiology outside of BreastScreen Norway and oncological treatment. Automation of data capture, and the ongoing INSPIRE and SNOMED CT projects is a priority in the Cancer Registry of Norway. These projects should improve the completeness and quality of data reported in the NBCR, which may benefit Norwegian breast cancer patients.

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