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Downgrading of referrals to breast cancer patient pathway

ORIGINAL ARTICLE

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BACKGROUND

The purpose of the study was to investigate whether the downgrading of external referrals to breast cancer patient pathways was clinically justifiable and led to a more correct prioritisation of patients who are referred to the specialist health service.

MATERIAL AND METHOD

The study included 214 external referrals to breast cancer patient pathways at the Breast Screening Centre, Oslo University Hospital, which were downgraded in 2020 since they did not meet the national criteria. The information obtained from electronic patient records included age, district of Oslo, name of referring doctor, outcome after investigation and treatment, as well as recommended timeframe for initiating the investigation. The quality of the referrals was also assessed.

RESULTS

A total of 3 % (7/214) of patients were diagnosed with breast cancer. Five were in the age group 40–50 years (9 %, 5/56), one was over the age of 50 years (1/31) and one was in the age group 35–40 years (1/38). None were below the age of 35 years. A total of 95 doctors had their referrals downgraded.

INTERPRETATION

The study indicated that the downgrading of referrals to breast cancer patient pathways led to a more correct prioritisation of patients who are referred to the specialist health service. The results indicated that the downgrading was

clinically justifiable for the age groups under 35 years and over 50 years, but that caution must be exercised when downgrading referrals in the age group 40–50 years.

Main findings

In 2020, 20 % (214/1057) of referrals to breast cancer patient pathways were downgraded since they did not meet the national criteria.

Of 214 patients whose referrals were downgraded, seven (3 %) were diagnosed with breast cancer, five of whom were in the age group 40–50-years.

None of the women in the age group under 35 years whose referral was downgraded were diagnosed with breast cancer.

Among 95 referring doctors, 88 had 1–2 referrals that were downgraded, while seven doctors had more than three.

In order to ensure a standardised process for the investigation and treatment of breast cancer, a patient pathway was introduced in 2015. The aim was to clarify the division of responsibilities between the primary care service and the specialist health service and specify time frames (1), whilst giving cancer patients security and predictability (2).

In 2021, SINTEF evaluated the cancer patient pathway in Norway (3). In the report, they concluded that the system had been a qualified success, where the prioritisation of patients in the pathway had increased the pressure on the specialist health service and led to shorter deadlines within the same resource framework (3, 4). Two factors in particular were highlighted as challenging: *interaction* between different levels of the health service, where communication problems between the primary care service and the specialist health service could lead to uncertainty about which patients should be included in the patient pathway, and *local bottlenecks* due to a shortage of personnel (especially within radiology and pathology services) and material resources such as operating theatres.

The breast cancer patient pathway starts as soon as a hospital receives a referral marked 'patient pathway'. Patients are referred for investigation in the patient pathway for one of two reasons: either they present with a symptom and are referred by a GP or other clinician, or malignancy is suspected in a mammogram taken in the public health service's breast cancer screening programme or at a private institute. The Norwegian Directorate of Health has guidelines for referral to the patient pathway, and in the case of breast cancer there must be a justified suspicion of cancer based on established national criteria (Box 1) (1).

Box 1 Criteria for referrals to the breast cancer patient pathway (1):

Patients must be referred for investigation in the patient pathway if one or more of the following symptoms or findings are present:

- Suspected tumour based on palpation
- New-onset nipple inversion or where the nipple does not come out on stimulation
- New-onset skin tethering
- Sores or eczema on the nipple or areola
- Clinical suspicion of cancer in lymph nodes in the armpit
- Suspected change found in mammogram from breast cancer screening, showing a category 4 or 5 result, and where the consensus meeting confirms the suspicion, or in an examination at a private diagnostic imaging institute

If axillary metastasis is found with unknown primary, the patient must be referred to a breast cancer patient pathway.

Where breast cancer has been diagnosed and the patient has not been referred to a breast cancer patient pathway, they must be referred to this pathway.

In our experience, many GPs are not aware of the Norwegian Directorate of Health's guidelines, and submit referrals to the patient pathway for new symptoms in the breast without a justified suspicion of breast cancer. Based on the requirement for justified suspicion, the radiologists at our breast screening unit have been 'downgrading' referrals that do not meet the national criteria since 2018 (1).

In the breast cancer patient pathway, the time from receipt of referral to the first appointment for investigation should be a maximum of seven calendar days (1). Downgrading a radiological referral means that the patient is not included in the patient pathway, but gets an appointment for investigation based on the clinical information in the referral. Most people then get an appointment within four weeks, which is the recommended deadline for starting an investigation in the prioritisation guide for patients with new lumps and masses with suspected malignancy (5). There is no separate prioritisation guide for new symptoms in the breasts. A standard letter is sent from the Department of Breast Diagnostics to the referring doctor, informing them that the referral has been downgraded, and a copy of the national criteria is attached. The breast diagnostics performed at our department is the same regardless of whether the patient is on the breast cancer patient pathway or not.

The purpose of this study was to gain more knowledge about whether the downgrading of the breast cancer patient pathway has been clinically justifiable. We also wanted to shed light on whether the system can lead to a more correct prioritisation of patients who are referred to the specialist health service.

Material and method

We conducted a retrospective quality assurance study, which was assessed by the data protection officer at Oslo University Hospital, and an exemption was granted for the requirement for consent pursuant to section 26 of the Health Personnel Act.

The study included referrals to the patient pathway that were downgraded in 2020. Radiologists with specialist expertise in breast diagnostics assessed the referrals and downgraded those that they believed did not satisfy the requirement of a justified suspicion of breast cancer. The radiologists also recommended a timeframe for initiating the investigation. All referrals marked 'patient pathway' were assessed quickly, usually on the same day they were registered as received. A letter to the referring doctor about downgrading and the investigation timeframe was sent within ten days. The secretaries who deal with our post registered the date of downgrading, the patient's personal identification number in the Norwegian Patient Registry (NPR ID number), and the name of the referring doctor and their medical practice. In a retrospective review, the following information was retrieved from the electronic patient record and registered: age, district of Oslo, referring doctor, results from imaging and pathology results after tests and surgery. Mammography and ultrasound results were routinely classified as normal/benign, likely to be benign, uncertain or likely to be malignant/malignant. Pathology results in the medical record were retrospectively assessed as unclear, normal/benign findings, premalignant changes or ductal carcinoma in situ (DCIS)/malignant findings.

We also registered the timeframe for initiating the investigation, as recommended by the radiologist performing the assessment of the referral: within 2–3 weeks, within 4 weeks or within 6–8 weeks.

We performed a retrospective quality assessment of the referrals based on two minimum requirements: a) Did the referral contain sufficient anamnestic information for the radiologist to carry out an appropriate assessment? b) Was a clinical examination of the breasts and axillae performed? The latter is listed by the Norwegian Directorate of Health as a filter function in referrals to the breast cancer patient pathway (1).

The database program Claris Filemaker Pro, version 19.4, was used to register and sort data, calculate the age distribution in five-year age groups and create histograms for selected data.

Results

In 2020, the Breast Screening Centre received 5200 external referrals, of which 1057 were marked 'breast cancer patient pathway'. A total of 224 (21 %) of the referrals to the patient pathway were registered as downgraded. Seven of these were not assessed for inclusion (six had an incorrectly registered NPR ID

number and one was mistakenly sent to breast diagnostics). Three patients who were not Oslo University Hospital patients and who chose to be examined by another institution were also excluded. The remaining 214 referrals were included in the study, as shown in Figure 1.

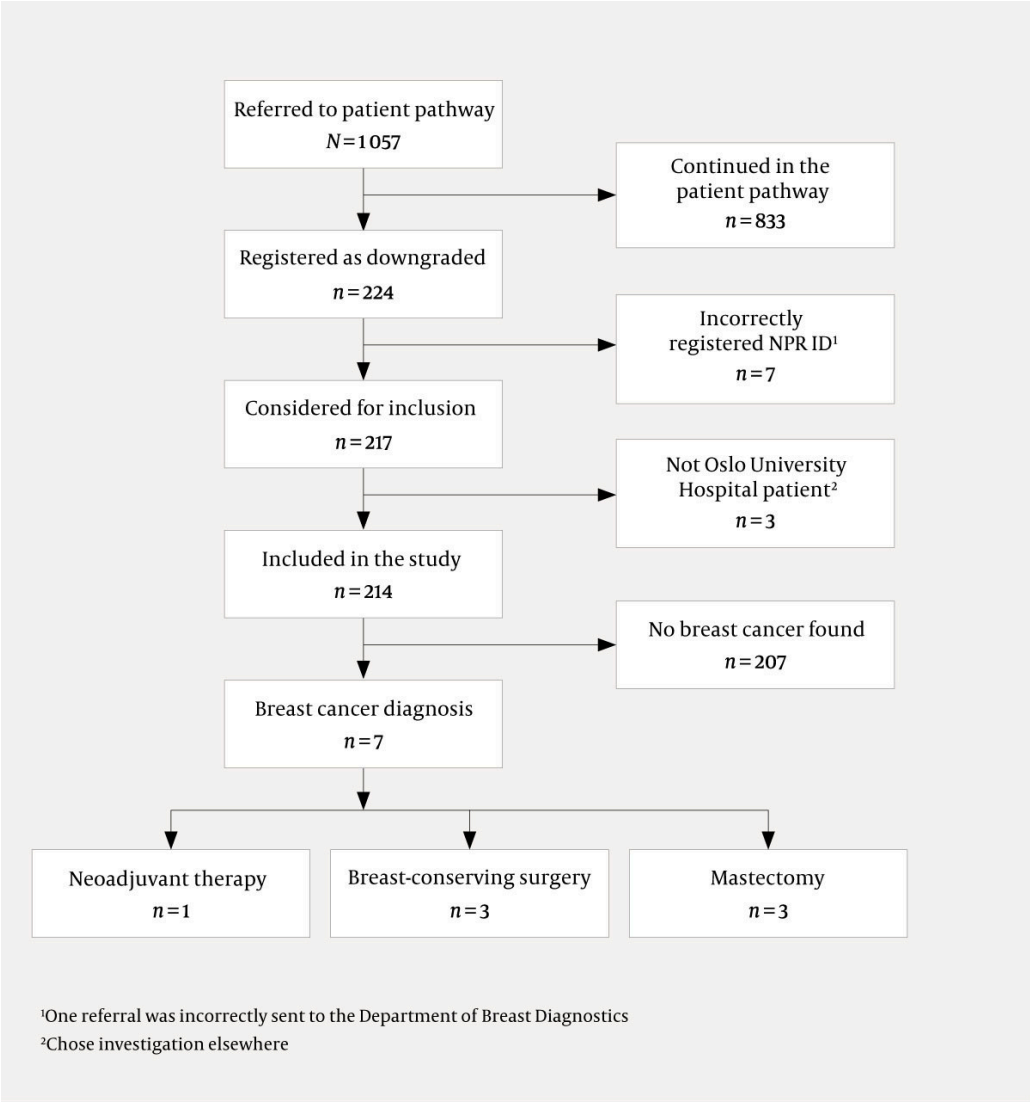

Figure 1 Flowchart for downgraded breast cancer patient pathway referrals to the Breast Screening Centre, Oslo University Hospital in 2020

The average age of study participants was 39 years (range 16–83 years). The distribution in five-year age groups is shown in Figure 2. The downgraded referrals were relatively evenly distributed between the Oslo districts in relation to population size, as shown in Table 1.

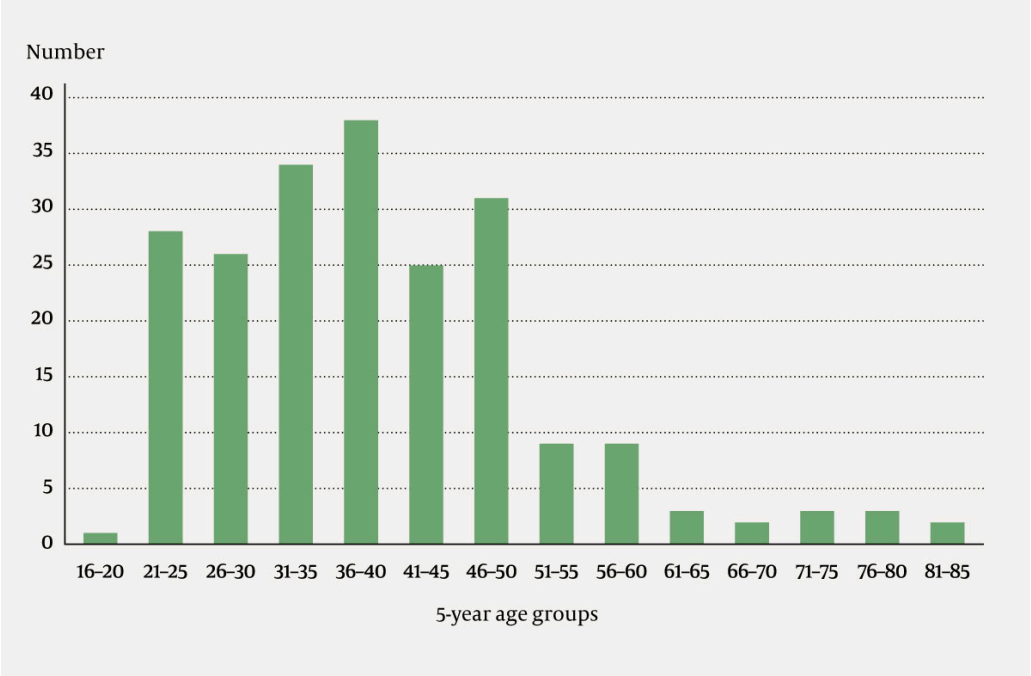

Figure 2 Downgraded breast cancer patient pathway referrals to the Breast Screening Centre, Oslo University Hospital in 2020, where the study participants are divided into five-year age groups.

Table 1

Downgraded referrals to the breast cancer patient pathway at Oslo University Hospital in 2020, distributed by district

Oslo district	Population (*n*)	No. of downgraded referrals (*n* (%))
Bjerke	33 422	16 (0.05)
Frogner	59 269	23 (0.04)
Gamle Oslo	58 671	17 (0.03)
Grünerløkka	62 423	25 (0.04)
Nordre Aker	52 327	18 (0.03)
Nordstrand	52 459	14 (0.03)
Sagene	45 089	10 (0.02)
St. Hanshaugen	38 945	12 (0.03)
Søndre Nordstrand	39 066	8 (0.02)
Ullern	34 569	16 (0.04)
Vestre Aker	50 157	13 (0.03)
Østensjø	50 806	19 (0.04)
Stovner1	27 542	2
Alna[1]	49 801	3
Outside Oslo		18

[1]Oslo districts in the catchment area for Akershus University Hospital

Seven patients were diagnosed with breast cancer (3 %). Five of these were aged 40–50, one was over the age of 50 years, while the youngest was aged 35–39. The reason for referral was palpatory findings in the breasts of three women, secretion from the mammilla in three, and CT findings in one. Two patients were diagnosed with DCIS, two with extensive DCIS and an infiltrating component, and three with infiltrating cancer. One patient received neoadjuvant chemotherapy, the other six received primary surgical treatment, of which three received breast-conserving treatment and three underwent mastectomy (Figure 1). The new priority and waiting times for the women diagnosed with breast cancer are summarised in Table 2.

Table 2

Priority and waiting times for investigation in the seven patients who were diagnosed with breast cancer after their referral to a breast cancer patient pathway was downgraded

Patient	New priority/recommended waiting time (days)	Timeframe for investigation (days)
1	14–21	2
2	14–21	4
3	28	16
4	28	6
5	28	22
6	42–56	22
7	42–56	35

Of the 207 patients who were not diagnosed with breast cancer, the radiologist assessing the referrals recommended that 47 % should be investigated within 2–3 weeks, 40 % within four weeks and 13 % within 6–8 weeks.

The assessment of the quality of downgraded referrals showed that 17 out of 214 lacked information on clinical examination, three lacked relevant anamnestic information and one lacked both. Both quality criteria were met for the seven women who were diagnosed with breast cancer, with the exception of one referral in which a clinical examination was missing due to suspected COVID-19.

A total of 95 doctors had their referrals downgraded, 88 of whom had 1–2 referrals each. The other seven had 3–12 referrals each, one of which resulted in a breast cancer diagnosis.

Discussion

This retrospective study is a review of external referrals to the breast cancer patient pathway that the radiologists at the Department of Breast Diagnostics, Oslo University Hospital in 2020 chose not to refer to this pathway since they did not meet the national criteria for referral. The study showed that most women were prioritised for investigation within four weeks. Seven women (3 %) were diagnosed with breast cancer. One of these underwent investigation five weeks after receiving a referral, while investigation was initiated for the other six in less than 23 days. This appears to suggest that the downgrading system was clinically justifiable and in line with the recommended deadline.

The literature search we conducted did not identify any previously published work on the downgrading of breast cancer patient pathway referrals.

External patients who are referred to our Department of Breast Diagnostics can be divided into three groups: those who are referred to the patient pathway and are registered in this pathway; those who are referred to the patient pathway but are deprioritised; and those who are referred for investigation outside the patient pathway. Referrals that are registered in the patient pathway also include referrals of suspected changes in a mammogram taken in the public health service's breast cancer screening programme, where a category 4 or 5 result is agreed by consensus, and which are therefore referred to the patient pathway according to the national criteria (Box 1).

Ninety-seven cases of cancer detected in the screening programme in Oslo in 2020 (DCIS and infiltrating cancer) are registered in the Norwegian Cancer Registry's report from 2022 (6). After a new review of the registry data by the first author together with the Mammography Section in the Cancer Registry, the number was adjusted up to 115, of which 40 (35 %) had a category 4 or 5 result (data not shown).

In the Norwegian Patient Registry, an organ-specific cancer diagnosis was registered in 2020 in 45 % (450/1,011) of patients who started the breast cancer patient pathway at Oslo University Hospital (7). Patients referred to the pathway from the breast cancer screening programme, or patients who started the pathway following breast diagnostics, will in most cases be diagnosed with cancer. This is in contrast to women who are referred on the basis of clinical findings. Based on a review of our own activity data, it can be assumed that the proportion of these is around 30–35%; however, new studies are needed to obtain a more reliable estimate of the proportion of breast cancer diagnoses in this group.

This study has nevertheless shown that the proportion of malignant findings in the patient pathway group that was downgraded is very low compared to the group that was not downgraded. This indicates that the downgrading has led to more correct prioritisation of patients who are referred to the specialist health service.

In the Norwegian Directorate of Health's document on the breast cancer patient pathway, a new lump in the breast in women over the age of 50 is to be regarded as suspected malignancy (1), and these referrals were not downgraded by our radiologists. This may explain why only one patient over the age of 50 was diagnosed with breast cancer in the study (3 %, 1/31). Of the other seven, five were aged 40–50 years (9 %, 5/56). This suggests that caution should be exercised when deprioritising this age group for referral to the patient pathway. In the patient group under the age of 35, no one had breast cancer.

Our findings indicate that downgrading women under the age of 35 with new symptoms in the breast without a justified suspicion of breast cancer was the right decision. We believe that it is also correct to downgrade women over 50, provided that the national criteria are met.

Referrals that did not meet the national criteria were not linked to specific districts or GPs. The vast majority of GPs had less than three downgraded referrals each, and 90 % of the referrals were of sufficient quality for the radiologists to perform an appropriate assessment.

The national criteria should make it easier for GPs to filter which patients should be referred to the breast cancer patient pathway and help ensure the correct prioritisation of patients for referral to the specialist health service. We found that many GPs are not familiar with the criteria, but also have the impression that the criteria can be difficult to understand.

SINTEF's final report notes that although GPs are generally satisfied with the patient pathway system, the guidelines for the cancer patient pathway are only one of a multitude of guidelines (3). It also points out that GPs' knowledge of patient pathways and referral criteria varies. We believe that our system of downgrading and providing written feedback to GPs about national criteria will help to improve the communication between the primary care service and the specialist health service. New studies are needed to clarify whether the system will, in the long term, improve referral practices and reduce unnecessary referrals to the breast cancer patient pathway. More research is also needed to understand why GPs' assessments of the patient pathway are sometimes at odds with the specialist health service's admission criteria. Information that could help to inform this work may include the number of patients who are upgraded to the patient pathway and the reason for referral among those who are downgraded and do not have breast cancer.

In order to ensure effective prioritisation of healthcare services, the Norwegian health service is organised according to the principle of the lowest effective care level (8, 9). Good referral practices are a prerequisite for setting the right priorities in the specialist health service. If the GP does not follow the referral criteria for the patient pathway, the doctor assessing the referral has to spend time and resources on reprioritising the referrals. The Office of the Auditor General of Norway has pointed out that poor-quality referrals to the specialist health service lead to unnecessary use of resources in hospitals (9). Closer follow-up of the GPs' referral practices is likely to reduce the number of downgraded referrals because it will ensure that the right decision will be made at the lowest care level.

The patient pathway sets stringent criteria for diagnostics deadlines and puts pressure on resource allocation and private services, as pointed out in the SINTEF report (3). Because the implementation of the patient pathway in Norway was introduced without financial incentives, it can pose a challenge for health trusts' priorities (3, 4). Several health trusts have had to resort to the private sector to circumvent the bottlenecks in the patient pathway, particularly within radiology. Previously calculated estimates of marginal costs linked to the use of private operators at the Department of Breast Diagnostics at Oslo University Hospital in 2015 showed that the unit price for investigation was 44–114 % higher compared to investigation at a hospital (10).

One of the objectives of the patient pathway is to lower the threshold for rapid access to health care. Wrong prioritisation of patients, may be counterproductive and lead to an unwanted increase in demand for healthcare services. If the threshold for rapid access to breast diagnostics is lowered, the signal this sends to the population may increase concerns about cancer. This concern does not correspond to the actual incidence of breast cancer, particularly in younger age groups. Health anxiety may have an adverse effect on the total consumption of health services, and in a Danish study, increased consumption of somatic health services was found in 41–78 % of patients with severe health anxiety (11).

The retrospective design and the fact that radiologists with varied experience and competence independently assessed the referrals were weaknesses of the study. Although the assessments are based on national criteria, we found that this variation can impact on the decision-making process. We observed that radiologists with knowledge of patient pathway indicators and an interest in patient pathways are most likely to adhere to the national guidelines. We also found that capacity has an effect on the number of referrals that are downgraded, and when capacity is low, the national criteria are enforced more strictly.

Conclusion

The system of downgrading referrals to the breast cancer patient pathway at the Department of Breast Diagnostics at Oslo University Hospital seems to have contributed to a more correct prioritisation of patients who are referred to the specialist health service. The results indicate that the downgrading has been clinically justifiable for the age groups under 35 years and over 50 years, while caution must be exercised in the downgrading of referrals to the patient pathway for the age group 40 - 50 years.

This article has been peer-reviewed.

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