

Swedish National
Breast Cancer Study

Karma

Breast cancer variables from the NKBC register in Karma (2019-)

Sweden has recorded breast cancer patients at a regional level for more than 30 years. In 2008, the regional registers were replaced with a national quality register for breast cancer (NKBC), and Karma holds breast cancer records for all Karma study participants who have been diagnosed with breast cancer as a primary diagnosis. The register documents the chain of hospitalized treatments from the first time of cancer diagnosis to cases with cancer relapses or decease. The register is restricted to information on the first breast diagnosed with cancer and is restricted to invasive cancer, in situ cancer and carcinosarcoma. Women with Phyllodes tumors, sarcoma, lymphoma or radiation-induced angiosarcoma are not included in the register. The register does not include information of deceased women where and an autopsy was performed.

The register includes initial contact and follow-up information of the women on diagnosis, pre-surgical diagnostics, occurrences of tumors, kind of surgery performed, and treatment/diagnostic latencies. It also includes information on short/long term complication and relapses in relation to treatments, patient satisfaction, and cosmetics.

For more details, see Variable Description under <https://cancercentrum.se/samverkan/cancerdiagnoser/brost/kvalitetsregister/dokument/>

Versions in NKBC:

Versions	From Date
1.0.0	2007-05-01
1.0.1	2008-02-19
1.0.2	2013-01-01
1.0.3	2014-07-03
1.0.4	2016-03-04
2.0.0	2017-10-01
2.1.0	2018-02-19
2.2.0	2018-06-26

Inclusion / exclusion

Inclusion criteria:

- Location: Primary breast cancer C50* (ICDO3).
- Side: One breast cancer per side, the earliest detected, whether it is invasive cancer or cancer in situ.
- Gender: Women and men.
- Age: All ages.
- Morphology: Invasive breast cancer and breast cancer in situ (C24: 094, 096, 146, 194, 196, 896, 996). Mb Paget (85403) is classified as invasive cancer, according to the ICDO classification. Carcinosarcoma (89803).
Some other morphologies should be registered if the patient is being treated for breast cancer. However, they will not be investigated. An example of such morphology is Neuroendocrine Tumor NET (82463).
- Diagnostic basis: All except autopsy detected cases.

Exclusion criteria:

- Morphology: Phyllodes tumor (C24: 051, 056), Lymphoma, Sarcoma (except Carcinosarcoma, see inclusion criteria above), Radiation-induced Angiosarcoma, Suspected cancer (C24: 993).
- Diagnostic basis: Autopsy detected breast cancer cases.
- Protected identity: Patient with a protected identity should not be registered.
- Declining participation: Patients who decline participation in the register should not be registered.
- Reservnummer: Patients with reservnummer should not be registered.

Karma holds the following NKBC breast cancer variables:

Recoded variables

Based on the original NKBC register variables, the following commonly used tumor characteristics were recoded for ease of use.

diagdat

Breast cancer diagnosis date

invasive

Tumor invasiveness.

1 = Invasive tumor with or without in-situ component

0 = in-situ only tumor

laterality

Tumor in right or left breast. One record per breast side.

1 = right breast

2 = left breast.

t

Tumor size in millimeters

t_cat

Categorized tumor size

0 = Not palpable tumor or tumor in situ

1 = tumor <20 mm

2 = tumor 21-50 mm

3 = tumor >50 mm

4 = Fixed at the chest wall, skin ulceration, or inflammatory cancer

n

Number of affected lymph nodes (>0.2mm with metastasis).

n_ma

Number of affected macro lymph nodes (>2mm with metastasis).

n_status

Lymph node status.

0 = No affected regional lymph nodes

- 1 = Affected lymph nodes metastases in axilla ipsilateral
- 2 = N2-fixed lymph node metastases in axilla or intra mammary without axilla metastases
- 3 = N3 Lymph node metastases in fossa scl/icl ipsilateral or intra mammary in combination with axilla metastases

m

Distant metastasis.

- 0 = No known distant metastases
- 1 = Remote Metastases exists

stage

Tumor stage.

Based on TNM classification, see https://www.cancer.gov/types/breast/hp/breast-treatment-pdq#_1994_toc.

N classification: pathological nodal staging: negative (pN0), 1-3 affected lymph nodes (pN1), 4-9 affected lymph nodes (pN2), >= 10 affected lymph nodes (pN3).

- 0 = M0, N0, non-invasive, and T0
- 1 = M0, N0, (T0, T1)
- 2 = (M0, N0, (T2, T3)) OR (M0, >N0, (T0, T1, T2))
- 3 = (M0, >N0, T3) OR (M0, >N1, <T4) OR (M0, T4) OR (M0, N3)
- 4 = M1

, where

- T0 = t_cat is 0
- N0 = No affected lymph nodes
- N1 = 1-3 affected lymph nodes
- N2 = 4-9 affected lymph nodes
- N3 = 10 or more affected lymph nodes
- M0 = no observed metastasis
- M1 = metastasis
- Invasive = invasive cancer

grade

Tumor grade.

Grade (Nottingham Histologic Grade for invasive cancer and Nuclear grade for cancer in situ). Malignancy grade (highest grade) for invasive cancer and in situ according to PAD. If both invasive and in situ, grade is stated for the invasive tumor.

- 1 = Grade 1
- 2 = Grade 2
- 3 = Grade 3

er

Estrogen receptor status.

1 = Positive
0 = Negative

pr

Progesterone receptor status.

1 = Positive
0 = Negative

her2

HER2-status

1 = Amplified
0 = Not amplified

ki67

Ki-67 proliferation marker (categorization varies by lab).

1 = Low
2 = Intermediate
3 = High

Original variables, general section

REGION_NAMN

The region, where the patient was registered for cancer.

AVLIDDAT

The patient's date of death (YYYY-MM-DD), if any. Stored as a string since it is not always a valid date, both year, month and day can be 00 if the exact date is not known.

VITALSTATUS

Vitality status

0 = alive

1 = dead

2 = not registered in register anymore

VITALSTATUSDATUM

Date when vital status was set.

VITALSTATUSDATUM_ESTIMAT

Estimated vital status date, if vital status date is a non-valid date.

If it is not a valid date, estimated date is created based on the VITALSTATUSDATUM with the following rounds: year unknown (0000) gives value NULL, month and day unknown (00-00) gives the values 07-01 for month and day. Only month unknown, (00) gives the value 07 for the month. Only day unknown (00) gives the value 15 for the day

Registration Variables (name prefix a_)

a_pat_lkfdia

Code for county and municipality at diagnosis

a_inr_enh

Reporting unit (free text). Regional Cancer Center - Hospital Code - Clinic Code.

a_inr_sjhkod

Hospital code linked to a_inr_enh. Hospital Codes of code list for each region.

a_inr_klkkod

Clinic code linked to (a_inr_enh). Clinic Codes of code list for each region.

a_inr_dat

Reporting date (YYYY-MM-DD). Date when reporting is sent to RCC.

a_pat_sida_Varde

Breast with breast cancer (left, right). Bilateral cancers are registered once per laterality.

1 = Right

2 = Left

a_onk_sjhklk

Responsible hospital / unit for oncological treatment

a_onk_sjhkod

Hospital code linked to (a_onk_sjhklk)

a_onk_klkkod

Clinic code linked to (a_onk_sjhklk)

Diagnostic variables

a_diag_misscadat

The decision date for well-founded suspicion of cancer (YYYY-MM-DD).

Well-founded suspicion exists in one or more of the following findings during a clinical examination or a conversation between the patient and physician or nurse with specialized competence:

- Suspicious lump in the breast
- Suspicious lump in the armpit of women
- A changed contour of the breast
- Newly inserted retracted nipple
- Redness or swelling on the skin over the breast without any other explanation
- Bloody secretion from a single milking
- Unilateral eczema of the nipple
- Ulceration of the nipple or adjacent to the nipples
- Newly occurring orange-like skin
- Withdrawn for clinical examination after screening (BI-RADS code 3, 4 or 5)
- Findings in imaging talking about breast cancer

a_diag_kontdat

Date of the first contact at specialist unit (YYYY-MM-DD).

a_diag_dat

Sampling date (diagnosis date, YYYY-MM-DD).

Here is the date of the first test, puncture or biopsy showing cancer or suspected cancer. If no test, puncture or biopsy has been performed, the date of withdrawal from screening mammography or from a clinical examination with the date of a suspicious cancer.

a_pat_alder

Age at breast cancer diagnosis.

Automatically created by the system from the variables personnummer and sampling date.

a_diag_besdat

Date of the first visit to specialized care (YYYY-MM-DD).

Date the patient makes the first preoperative visit to the breast surgery for newly discovered primary breast cancer, regardless of whether the patient has confirmed primary breast cancer or if it is ascertained later. It refers to the first visit to a breast surgery clinic or oncology clinic that participates in the treatment of the individual case.

a_diag_screening_Varde

Screening detection. Specified when the patient is diagnosed through the national mammography-screening program, that is, only the organized screening of female breasts aged 40-74 years.

0 = No

1 = Yes

98 = No information

a_diag_preopmorf_Varde

Preoperatively determined malignancy. Established diagnosis by cytology or pathology is intended. Applies to both invasive and/or cancer in situ. Should be answered even if the patient do not have a surgery.

0 = No

1 = Yes

98 = No information

a_diag_grund_Varde

Diagnosis basis

1 = Clinical examination

2 = X-ray, scintigraphy, ultrasound, MRI or equivalent examination

3 = PAD diagnosis verified (middle sized needle, large sized needle, provexcision or surgery with histopathologic examination)

5 = Cytological examination (fine needle point)

8 = Other laboratory basis

a_pad_diagpattxt

Treating pathological / cytological department (free text).

a_pad_diagprepnr

Surgical preparation number from pathology / cytology specified as the basis for diagnosis.

a_pad_diagprepar

Year of surgical preparation from pathology / cytology specified as the basis for diagnosis.

Menstruation status variables

a_pat_mensstat_Varde

Menstrual status at diagnosis

1 = pre-menopause (< 6 months after the last menstrual period)

2 = post-menopause (>= 6 months after the last menstrual period)

4 = Uncertain (e.g. hysterectomy)

98 = No information / not applicable information (e.g. for men)

TNM classification variables

a_tnm_tklass_Varde

Breast tumor T-Classification - Primary tumor

0 = T0 Not palpable tumor

5 = Tis tumor in situ

10 = T1 tumor <20 mm

20 = T2 tumor 21-50 mm

30 = T3 tumor >50 mm

42 = T4A Fixed at the chest wall

44 = T4b skin ulceration, ipsilateral cutaneous satellite tumor or skin oedema (including peau d'orange)

45 = T4c (both T4a and T4b) from version 1.0.2

46 = T4d Inflammatory cancer

50 = TX The tumor cannot be judged

a_tnm_nklass_Varde

Breast tumor N-Classification - Regional lymph nodes

0 = N0 No regional lymph node metastases

10 = N1 Moving lymph node metastases in axilla ipsilateral

20 = N2-fixed lymph node metastases in axilla or intra mammary without axilla metastases

30 = N3 Lymph node metastases in fossa scl/icl ipsilateral or intra mammary in combination with axilla metastases

40 = NX Lymph nodes cannot be assessed

a_tnm_mklass_Varde

Breast tumor M-Classification - Remote metastases

0 = M0 No known distant metastases

10 = M1 Remote Metastases exists

20 = MX Remote Metastases cannot be assessed

a_planbeh_infopatdat

Date of the first treatment discussion (YYYY-MM-DD).

a_omv_kssk_Varde

Offered contact nurse

0 = No

1 = Yes

98 = No information

a_omv_indivplan_Varde

Has a written individualized care plan (My Care Plan XV019) been established in consultation with the patient?

0 = No

1 = Yes

98 = No information

a_mdk_Varde

Preoperative Multidisciplinary Conference (MDK)

0 = No

1 = Yes

98 = No information

a_beh_studie_Varde

The patient is included in a research study

0 = No

1 = Yes

98 = No information

a_planbeh_typ_Varde

Planned action

1 = Primary surgery

2 = Preoperative oncology or conservative treatment

3 = No surgery or remote metastasis at diagnosis

a_planbeh_ejopors_Varde

Reason for no planned surgery

1 = Locally advanced disease

2 = Remote metastases

4 = Other reason

a_planbeh_cyt_Varde

Planned chemotherapy.

0 = No

1 = Yes

98 = No information

a_planbeh_rt_Varde

Planned radiotherapy.

0 = No

1 = Yes

98 = No information

a_planbeh_endo_Varde

Planned endocrine therapy.

0 = No

1 = Yes

98 = No information

a_planbeh_antikropp_Varde

Planned immunotherapy.

0 = No

1 = Yes

98 = No information

a_planbeh_ann

Other planned treatment or targeted therapy

1 = True

a_planbeh_anntxt

If other treatment, specify which (free text)

PAD report

a_pad_invasiv_Varde

Invasiveness

1 = Invasive cancer with or without cancer in situ

2 = Only cancer in situ

98 = Assessment not possible

a_pad_ej

Only cytology or tests not performed

1 = true

a_pad_pattxt

Pathology department (free text)

a_pad_patkod

Code (Pathology Department)

a_pad_prepnr

Preparation number from biopsy

a_pad_prepar

Preparation year

a_pad_invasivsnomed_Varde

Type of invasive cancer (SNOMED classification)

10 = Only ductal cancer (85003)

20 = Both ductal and lobular cancer (85223)

30 = Ductal and other types than lobular cancer (85233)

40 = Only lobular cancer (85203)

70 = Other invasive cancer

a_pad_invasivsnomedann

Other invasive cancer (free text)

a_pad_invasivsnomedkod

SNOMED code for invasiveness

a_pad_insitusnomed_Varde

Type of cancer in situ (SNOMED classification)

10 = DCIS (85002)

20 = LCIS (85202)

40 = DCIS and LCIS (85222)

50 = Other cancer in situ

a_pad_insitusnomedann

Other cancer in situ (free text)

a_pad_insitusnomedkod

SNOMED code for cancer in situ

a_pad_erproc

Estrogen receptor (ER) percentage

a_pad_er_Varde

Estrogen Receptor status immunohistochemistry

1 = Positive

2 = Negative

97 = Not done

98 = Not assessable / No information

a_pad_prproc

Progesterone receptor percentage

a_pad_pr_Varde

Progesterone Receptor status immunohistochemistry

1 = Positive

2 = Negative

97 = Not done

98 = Not assessable / No information

a_pad_her2_Varde

HER2 status immunohistochemistry

1 = 0-1+

2 = 2+

3 = 3+

97 = Not done

98 = Not assessable / No information

a_pad_her2ish_Varde

HER2 FISH analysis

1 = Amplified

2 = Not amplified

97 = Not done

98 = Not assessable / No information

a_pad_ki67proc

Ki67 proliferation percentage

a_pad_ki67_Varde

Ki67 status (according to lab specific set cut-off)

1 = Low

2 = Intermediate

3 = High

97 = Not done

98 = Not assessable / No information

Oncological report

a_onk_rappsjhkod

Hospital code linked to (a_onk_rappsjhklk)

a_onk_rappklkkod

Clinic code linked to (a_onk_rappsjhklk)

Follow-up

a_uppf_sjhklk

Reporting responsible hospital/unit for follow-up

a_uppf_sjhkod

Hospital code linked to (a_uppf_sjhklk)

a_uppf_klkkod

Clinic code linked to (a_uppf_sjhklk)

a_uppf_sjhann

Other follow-up care providers

1 = true

a_uppf_sjhanntext

Other follow-up care providers (free text)

a_uppf_ingen

No further follow-up

Checkbox = True

a_uppf_ingenors

Cause of no follow-up (free text)

Surgery variables (name prefix op_)

op_inr_enh

Reporting unit (free text). Regional Cancer Center - Hospital Code - Clinic Code.

op_inr_sjhkod

Hospital code linked to (op_inr_sjhklk). Hospital Codes of code list for each region.

op_inr_klkkod

Clinic code linked to (op_inr_sjhklk). Clinic Codes of code list for each region.

op_inr_dat

Date of reporting (YYYY-MM-DD). Date when reporting is sent to RCC.

op_inr_monkom

Registry administrator comments (free text). Comments on the reporting and record, which the registry administrator enters as needed.

op_inr_allkom

General comments (free text). Messages from reporter to RCC.

op_pat_sida_Varde

Breast with breast cancer (left, right). Bilateral cancers are registered once per laterality.

1 = Right

2 = Left

op_kir_Varde

Surgery intent

1 = Primary surgery

2 = Surgery after started / completed preoperative oncological treatment

op_kir_dat

Date of the first surgery (YYYY-MM-DD)

op_kir_brost_Varde

Final result of breast procedures (the most comprehensive procedure)

1 = Partial mastectomy (HAB40)

2 = Mastectomy (HAC20)

3 = Not breast surgery (e.g., occult cancer, only axilla surgery)

4 = Subcutaneous mastectomy with preservation of the areola-mamilla (HAC10)

op_kir_onkoplastik_Varde

Oncoplastic surgery (reshaping, reducing plastic, direct reconstruction) in connection with the cancer surgery on the operated breast.

0 = No

1 = Yes

98 = No information

op_kir_dirrek_Varde

Direct reconstruction

0 = No

1 = Yes

98 = No information

op_kir_axill_Varde

Axillary breast surgery performed (SN and / or “utrymning”)

0 = No

1 = Yes

98 = No information

op_kir_axilltyp_Varde

Final results of axillary surgery

1 = Only SN (PJA10) including any extra Igll. Also applies to preoperative SN.

2 = Only “utrymning” (PJD42)

3 = SN and “utrymning” (PJA10 + PJD42). Also applies to preoperative SN

4 = Sampling (including SN with extra Igll removed)

98 = No information

op_kir_sekbrost_Varde

Complementary breast surgery performed in a second session - due to tumor data (PAD results)

0 = No

1 = Yes

98 = No information

op_kir_sekaxill_Varde

Complementary axillary surgery performed in a second séance - due to tumor data (PAD results)

0 = No

1 = Yes

98 = No information

op_kir_sekant

Number of additional breast and / or axillary surgeries performed, because of tumor data (excluding first surgery occasion).

Min Max value = 0 to 5

Morphology and surgery report PAD variables

op_pad_pattxt

Pathology department (free text)

op_pad_patkod

Code (Pathology / Cytology)

op_pad_preprnr

Preparation number

op_pad_prepar

Preparation year from surgery at PAD

op_pad_invasiv_Varde

Invasiveness

1 = Invasive cancer with or without cancer in situ

2 = Only cancer in situ

98 = Assessment not possible

op_pad_invasivsnomed_Varde

Type of invasive cancer (SNOMED classification)

10 = Only ductal cancer (85003)

20 = Both ductal and lobular carcinoma (85223)

30 = Ductal cancer and other types than lobular (85233)

40 = Lobular cancer (85203)

50 = Medullary cancer (85103)

60 = Phyllodes cancer (90203)

70 = Other invasive cancer

op_pad_invasivsnomedann

Other type of invasive cancer (free text)

op_pad_invasivsnomedkod

Invasiveness SNOMED code

op_pad_insitusnomed_Varde

Type of cancer in situ (SNOMED classification)

10 = DCIS (85002)

20 = LCIS (85202)

40 = DCIS and LCIS (85222)

50 = Other cancer in situ

op_pad_insitusnomedann

Other type of cancer in situ (free text)

op_pad_insitusnomedkod

Cancer in situ SNOMED code

op_pad_invant_Varde

Number of invasive tumors in the breast

0 = 0

1 = 1

2 = 2

3 = 3

4 = 4 or more

98 = No information

op_pad_invstl

Histopathological size (mm) of the main invasive cancer.

Min Max value = 0 - 999.

op_pad_invstlsakn

Size not assessable / No information

1 = True

op_pad_extentx

Extent (propagation in mm).

Min Max value = 0 – 999

op_pad_extenty

Extent 2 (propagation in mm).

Min Max value = 0 - 999

op_pad_extentsakn

Extent not assessable / No information

Checkbox = True

Tumour biology variables

op_pad_nhg_Varde

Grade (Nottingham Histologic Grade for invasive cancer and Nuclear grade for cancer in situ). Malignancy grade (highest grade) for invasive cancer and in situ according to PAD. If both invasive and in situ, then grade is stated for invasive tumor.

1 = Grade 1

2 = Grade 2

3 = Grade 3

97 = Not performed

98 = Not assessable / No information

op_pad_erproc

ER status, percent.

Min Max value = 0-100

op_pad_er_Varde

ER status immunohistochemistry

1 = Positive

2 = Negative

97 = Not done

98 = Not assessable / No information

op_pad_prproc

PR status, percent.

Min Max value = 0-100

op_pad_pr_Varde

PR status, immunohistochemistry

1 = Positive

2 = Negative

97 = Not done

98 = Not assessable / No information

op_pad_her2_Varde

HER2 status immunohistochemistry

1 = 0-1+

2 = 2+

3 = 3+

97 = Not done

98 = Not assessable / No information

op_pad_her2ish_Varde

HER2 FISH analysis

1 = Amplified

2 = Not amplified

97 = Not done

98 = Not assessable / No information

op_pad_ki67proc

Ki67 proliferation percentage

Min Max = 0-99

op_pad_ki67_Varde

Ki67 status (according to local cut-off)

1 = Low

2 = Intermediate

3 = High

97 = Not done

98 = Not assessable / No information

op_pad_snant

Number of sentinel nodes (SN) according to PAD (total number)

Min Max value = 0-9

op_pad_snet_Varde

Metastasis in SN

0 = No

1 = Yes

98 = No information

op_pad_snmakrometant

Number of SN with macro metastases (> 2 mm).

Min Max value = 0-9

op_pad_snmikrometant

Number of SN micro metastases (> 0.2 and <= 2mm / 200 cells).

Min Max value = 0-9

op_pad_snsubmikrometant

Number of SN with ITC sub micro metastases (<=0.2 mm / 200 cells).

Min Max value = 0-9

op_pad_lglusant

Total number of lymph nodes examined from all axillary surgeries (SN and / or axillary "uttrymning" and possibly intramammary lymph nodes)

Min Max value = 0-99

op_pad_lglmetant

Total number of lymph nodes with metastasis (> 0.2 mm) from all axillary surgeries (SN and / or axillary "uttrymning" and possibly intramammary lymph nodes)

Min Max value = 0-99

op_mdk_Varde

Postoperative MDK

0 = No

1 = Yes

98 = No information

op_planbeh_besdat

Date of oncological treatment recommendation (YYYY-MM-DD)

op_pad_infopatdat

Date of PAD information to the patient after surgery (at first planned follow-up visit),
YYYYMMDD

op_planbeh_onk_Varde

Planned post-operative oncology treatment

0 = No

1 = Yes

98 = No information

op_planbeh_cyt_Varde

Planned post-operative chemotherapy treatment

0 = No

1 = Yes

98 = No information

op_planbeh_rt_Varde

Planned post-operative radiotherapy treatment

0 = No

1 = Yes

98 = No information

op_planbeh_endo_Varde

Planned post-operative endocrine therapy

0 = No

1 = Yes

98 = No information

op_planbeh_antikropp_Varde

Planned post-operative immunotherapy

0 = No

1 = Yes

98 = No information

op_planbeh_bisfos_Varde

Planned post-operative treatment with bisphosphonates

0 = No

1 = Yes

98 = No information

op_onk_sjhklk

Reporting responsible hospital / unit for oncological treatment (free text)

op_onk_sjhkod

Hospital code linked to (op_onk_sjhklk)

op_onk_klkkod

Clinic code linked to (op_onk_sjhklk)

op_onk_ingen

No investigation of oncological treatment

1 = True

op_onk_ingenors

Reason why no oncological treatment should be investigated (free text)

Follow-up

op_uppf_sjhklk

Reporting responsible hospital / unit for follow-up (free text)

op_uppf_sjhkod

Hospital code linked to (op_uppf_sjhklk)

op_uppf_klkkod

Clinic code linked to (op_uppf_sjhklk)

op_uppf_sjhann

Other follow-up care providers

1 = True

op_uppf_sjhanntext

Other follow-up care providers (free text)

op_uppf_ingen

No further follow-up

1 = True

op_uppf_ingenors

Cause of no further follow-up (free text)

Pre-surgery oncological treatment variables (name prefix pre_)

pre_inr_enh

Reporting unit (free text). Regional Cancer Center - Hospital Code - Clinic Code.

pre_inr_sjhkod

Hospital code linked to (a_inr_sjhklk). Hospital Codes of code list for each region.

pre_inr_klkkod

Clinic code linked to (pre_inr_sjhklk). Clinic Codes of code list for each region.

pre_inr_dat

Reporting date (YYYY-MM-DD). Date when reporting is sent to RCC.

pre_inr_monkom

Registry administrator comments (free text). Comments on the reporting and record, which the registry administrator enters as needed.

pre_inr_allkom

General comments (free text). Messages from reporter to RCC.

pre_pat_sida_Varde

Breast with breast cancer (left, right). Bilateral cancers are registered once per laterality.

1 = Right

2 = Left

pre_diag_met

Detection of remote metastases within three months from the sampling date
(diagnosis date)

1 = True

pre_beh_studie_Varde

The patient is included in a research study

0 = No

1 = Yes

98 = No information

pre_omv_kssk_Varde

Has the patient been offered, in the medical record, a contact nurse?

0 = No

1 = Yes

98 = No information

pre_kemo_Varde

Chemotherapy

0 = No

1 = Yes

98 = No information

pre_kemo_dat

Start date first cure of cytostatic treatment (YYYY-MM-DD)

pre_kemo_antra

Anthracycline therapy.

1 = True

pre_kemo_docetax

Docetaxel therapy.

1 = True

pre_kemo_pak

Paclitaxel therapy.

1 = True

pre_kemo_ann

Other cytostatic treatment.

1 = True

pre_kemo_enlplan_Varde

Treatment completed according to plan.

0 = No

1 = Yes

98 = No information

pre_kemo_avbors_Varde

Reason for interruption / alteration of cytostatic treatment.

1 = Side effects

2 = Other

98 = No information

pre_kemo_cytokin_Varde

Cytokines primary prophylaxis (e.g. G-CSF).

0 = No

1 = Yes

98 = No information

pre_kemo_kompl_Varde

Inpatient care due to treatment complications.

0 = No

1 = Yes

98 = No information

pre_rt_Varde

Radiotherapy.

0 = No

1 = Yes

98 = No information

pre_rt_dat

Start date of first dose of radiation (YYYY-MM-DD).

pre_rt_targetbrost

Radiation of breast or chest wall.

1 box = True

pre_rt_targetaxill

Radiation target axilla.

1 = True

pre_rt_targetfscf

Radiation target fossa supraclavicularis.

1 = True

pre_rt_targetpara

Radiation target parasternal area.

1 = True

pre_rt_todos

Total dose excluding boost.

Min Max value = 0 - 99

pre_rt_boost_Varde

Boost.

0 = No

1 = Yes

98 = No information

pre_rt_boostdos

Boost dose.

Min Max value = 0 - 99

pre_endo_Varde

Endocrine therapy.

0 = No

1 = Yes

98 = No information

pre_endo_dat

Start date of endocrine therapy (YYYY-MM-DD).

pre_endo_tam

Tamoxifen.

1 = True

pre_endo_gnrh

GnRH agonist.

1 = True

pre_endo_hammare

Aromatase inhibitors.

1 = True

pre_endo_ann

Other endocrine therapy.

2 = True

pre_endo_anntxt

Other endocrine therapy (free text).

pre_antikropp_Varde

Immunotherapy.

0 = No

1 = Yes

98 = No information

pre_antikropp_dat

Start date for first antibody treatment (YYYY-MM-DD).

pre_antikropp_trast

Trastuzumab therapy.

1 = True

pre_antikropp_pert

Pertuzumab therapy.

1 = True

pre_antikropp_ann

Other immunotherapy.

1 = True

pre_antikropp_anntxt

Other immunotherapy (free text).

Post-surgery oncological treatment variables (name prefix post_)

post_inr_enh

Reporting unit (free text). Regional Cancer Center - Hospital Code - Clinic Code.

post_inr_sjhkod

Hospital code linked to (post_inr_sjhklk). Hospital Codes of code list for each region.

post_inr_klkkod

Clinic code linked to (post_inr_sjhklk). Clinic Codes of code list for each region.

post_inr_dat

Date of reporting (YYYY-MM-DD). Date when reporting is sent to RCC.

post_inr_monkom

Registry administrator comments (free text). Comments on the reporting and record, which the registry administrator enters as needed.

post_inr_allkom

General comments (free text). Messages from reporter to RCC.

post_pat_sida_Varde

Breast with breast cancer (left, right). Bilateral cancers are registered once per laterality.

1 = Right

2 = Left

post_diag_met

Remote metastasis detected within three months of sampling date (diagnostic date)

1 = True

post_omv_kssk_Varde

Has the patient been offered, in the medical record, a contact nurse?

0 = No

1 = Yes

98 = No information

post_beh_studie_Varde

The patient is included in a research study.

0 = No

1 = Yes

98 = No information

post_ingen

No post-operative oncology treatment.

Checkbox = True

post_kemo_Varde

Chemotherapy.

0 = No

1 = Yes

98 = No information

post_kemo_dat

Start date for first cure of cytostatic therapy (YYYY-MM-DD).

post_kemo_antra

Anthracycline treatment.

1 = True

post_kemo_docetax

Docetaxel treatment.

1 = True

post_kemo_pak

Paclitaxel treatment.

1 = True

post_kemo_ann

Other cytostatic therapy.

1 = True

post_kemo_enplan_Varde

Treatment completed according to plan.

0 = No

1 = Yes

98 = No information

post_kemo_avbors_Varde

Cause of interruption / change.

1 = Side effects

2 = Other

98 = No information

post_kemo_cytokin_Varde

Cytokines primary prophylaxis (e.g. G-CSF).

0 = No

1 = Yes

98 = No information

post_kemo_kompl_Varde

Inpatient care due to treatment complications.

0 = No

1 = Yes

98 = No information

post_rt_Varde

Radiotherapy.

0 = No

1 = Yes

98 = No information

post_rt_dat

Start date of the first dose of radiation (YYYY-MM-DD).

post_rt_targetbrost

Radiation of breast or chest wall.

1 box = True

post_rt_targetaxill

Radiation target axilla.

1 box = True

post_rt_targetfscl

Radiation target fossa supraclavicularis.

Check 1 = True

post_rt_targetpara

Radiation target parasternal area.

1 box = True

post_rt_totdos

Total dose excluding boost.

Min Max value = 0 - 99

post_rt_boost_Varde

Boost.

0 = No

1 = Yes

98 = No information

post_rt_boostdos

Boost dose.

Min Max value = 0 - 99

post_endo_Varde

Endocrine therapy.

0 = No

1 = Yes

98 = No information

post_endo_dat

Start date of endocrine therapy (YYYY-MM-DD).

post_endo_tam

Tamoxifen.

1 = True

post_endo_gnrh

GnRH agonist.

1 = True

post_endo_hammare

Aromatase inhibitors.

1 = True

post_endo_ann

Other endocrine therapy.

1 = True

post_endo_anttxt

Other endocrine therapy (free text).

post_antikropp_Varde

Immunotherapy.

0 = No

1 = Yes

98 = No information

post_antikropp_dat

Start date for first antibody treatment (YYYY-MM-DD).

post_antikropp_trast

Trastuzumab treatment.

1 = True

post_antikropp_pert

Pertuzumab treatment.

1 = True

post_antikropp_ann

Other immunotherapy.

1 = True

post_antikropp_anntxt

Other immunotherapy (free text).

post_bis_Varde

Bisfosfonater.

0 = No

1 = Yes

98 = No information

Post-surgery loco-regional recurrences / remote metastases variables (name prefix r_)

r_inr_enh

Reporting unit (free text). Regional Cancer Center - Hospital Code - Clinic Code.

r_inr_sjhkod

Hospital code linked to (r_inr_sjhklk). Hospital Codes of code list for each region.

r_inr_klkkod

Clinic code linked to (r_inr_sjhklk). Clinic Codes of code list for each region.

r_inr_dat

Reporting date for recidiv / remote metastases (YYYY-MM-DD). Date when reporting is sent to RCC.

r_inr_monkom

Registry administrator comments (free text). Comments on the reporting and record, which the registry administrator enters as needed.

r_inr_allkom

General comments (free text). Messages from reporter to RCC.

r_pat_sida_Varde

Breast with breast cancer (left, right). Bilateral cancers are registered once per laterality.

1 = Right

2 = Left

r_dat

Date of last contact (YYYY-MM-DD).

Variables for follow-up visit

r_recmct_rapp_Varde

Previously known and already reported loco-regional recurrence / distant metastases.

0 = No

1 = Yes

98 = No information

r_rec

Loco-regional recurrence to report.

1 = True

r_rec_sida_Varde

Side to which the recurrence refers.

1 = Right

2 = Left

r_rec_brost

Chest / chest wall on the operated side.

1 = True

r_rec_brostdat

Date of first discovery (Chest / Chest Wall) YYYY-MM-DD.

r_rec_axill

Lymph nodes in the axilla on the operated side .

1 = True

r_rec_axilldat

Date of first discovery (Lgll axilla) YYYY-MM-MM.

r_rec_fscl

Lymph nodes parasternal / supraclavicular / infraclavicular on the operated side.

1 = True

r_rec_fscldat

Date of first discovery (Lgll parasternal / supraclavicular / infraclavicular) YYYY-MM-DD.

r_met

Remote metastasis to report.

1 = True

r_met_dat

Date of discovery of first remote metastasis (YYYY-MM-DD).

r_met_hjarna

Location of first remote metastasis – brain.

1 = True

r_met_lunga

Location of first remote metastasis - lung / pleura.

1 = True

r_met_buk

Location of first remote metastasis - abdomen / abdominal wall.

1 = True

r_met_lever

Location of first remote metastasis - liver

1 = True

r_met_skelett

Location of first remote metastasis – skeleton

1 = True

r_met_ann

Other remote metastasis location.

1 = True

System variables

round_nkbc_breastcancer

Round of NKBC breast cancer registration, i.e. the order number of times the study participant were registered in the register. Used for stratifying order of registration events.

year_nkbc_breastcancer

Year of NKBC cancer diagnose registration. Used for stratifying time series data.

month_nkbc_breastcancer

Month of NKBC cancer diagnose registration. Used for stratifying time series data.

source_nkbc_breastcancer

Available NKBC breast cancer register data.