

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

<https://www.cancercentrum.se/samverkan/cancerdiagnoser/brost/kvalitetsregister/>

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](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\_targetfscf***

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.