Breast cancer variables from the INCA register (2007-2018) in Karma

The INCA register (information network for cancer treatment) was founded in 2007, 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 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 also restricted to invasive cancer and in situ cancer. Women with Phyllodes tumors, sarcoma or lymphoma are not included in the register. And the register does not include information of deceased women where and an autopsy was performed and there was a tumor finding for the first.

The register includes information on pre-surgical diagnostics, as well as 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://cancercentrum.se/stockholm-gotland/vara-uppdrag/kunskapsstyrning/kvalitetsregister/om-inca/

Versions in INCA (from date):

v1.0 (2007-05-01)
v1.0.1 (2008-02-19)
v1.0.2 (2013-01-01)

Karma holds the following INCA breast cancer variables:

Variables for first time visit (diagnosis)

Nationwide variables available from all oncological centers

LNR

Tumor sequence number.

DATEOFDEATH

Date of death, YYYYMMDD

Region

Health region oncological center affinity, i.e. one of the six RCC / OC diagnostic sites diagnosing the patient.

A000Alder

A000 Age at breast cancer diagnosis, automatic calculation.

Menstruation status variables (A020)

A020MensStat

A020 Menstrual status at time of breast cancer diagnosis.

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

2 = 0.5 - 5 years post-menopause

3 = >5 years post-menopause

4 = Uncertain (e.g. hysterectomy)

98 = No information (available from v1.0.2)

Diagnostic variables (A030)

A030ICD03Kod

A030 ICDO3 classification of breast tumor localization. (if specified location not given, then C509 is stated, as agreed in INCA steering group)

10 = C509 Breast, mammary gland, unspecified

20 = C500 Nipple and areola

30 = C501 central portion

40 = C502 Upper inner quadrant

50 = C503 lower, inner quadrant

60 = C504 The upper, outer quadrant

70 = C505 lower, outer quadrant

80 = C506 Axillar "utskott"

90 = overgrowth C508 to / from neighboring sub localized in chest although unknown origin.

A030ICD03KodTxt

A030 ICDO3 classification of breast tumor localization (free text). See above.

A030Sida

A030 side of body of breast cancer, lateral entry. (in case of bilateral cancer, two separate rows in register is created)

1 = Right

2 = Left

A030OpLasKod

A030 Treating clinic / hospital code. Hospital Codes of code list for each region.

A030OpLasTxt

A030 Treating clinic / hospital (free text).

A030BesDat

A030 Date of first visit at breast clinic for newly discovered breast cancer regardless of patient has confirmed cancer of will be confirmed later. Not relapse which is stated in follow-up part. YYYYMMDD

A030DiaForBes2

A030 Malignant diagnosis at first visit. Established by morphology (cytology/histology)

0 = No

1 = Yes

98 = Unknown

A030Screening

A030 Breast cancer detected in screening program. Stated when women participates in national screening program.

0 = No

1 = Yes

9 = Unknown

A030PreOpMorf2

A030 Malignancy determined preoperatively. In situ and/or invasive as stated by morphology (cytology/histology)

0 = No

1 = Yes

98 = Unknown

A030DiaDat

A030 Date of first diagnosis for breast cancer, YYYYMMDD. Earliest known date established by mammography, clinic or morphology.

A030DiaGrund

A030 Breast cancer diagnosis basis. If established by several methods, most reliable method is stated. Not necessarily method at diagnosis date.

1 = Clinical examination

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

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

5 = Cytological examination

8 = Other laboratory tests

A030PatTxt

A030 Treating pathological / cytological department (free text).

A030PatKod

A030 Treating pathological / cytological department (code). Pathologist or cytology codes according to the code list for each region.

A030PrepNr

A030 Surgical preparation number from PAD or cythology. Ex. T12345

A030PrepAr

A030 Year of surgical preparation, e.g. 2006

A030DiagInv

A030 Breast cancer diagnosis invasiveness at diagnosis date. (if both invasive and non-invasive, invasive is stated)

1 = invasive cancer

2 = mere non-invasive cancer

9 = Unknown

TNM classification variables (A040)

A040Tklass

A040 Breast tumor T classification. (primary tumor according to TNM-classification UICC, rev. 7)

0 = T0 Not palpable tumor

05 = Tis tumor in situ

10 = T1 Tumor <20 mm

20 = T2 tumor 21-50 mm

30 = T3 Tumour >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

A040Nklass

A040 Breast tumor N classification. (according to TNM-classification UICC, rev. 7)

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

A040Mklass

A040 Breast tumor M classification. (according to TNM-classification UICC, rev. 7) If no known distant metastases, M0 is stated although not special examination was performed to exclude possibility of distant metastases. Distant metastases discovered within 3 months from diagnosis date is noted M. Distant metastases discovered during neo-adjuvant treatment is stated M1. (There shall be no information stated about PAD or post-operative adjuvant treatment for women having distant metastases at diagnosis date)

0 = M0 No known distant metastases

10 = M1 Remote Metastases exists

20 = MX Remote Metastases cannot be assessed (in v1.0 and v1.0.1)

Neoadjuvant treatment variable (A070)

A070PreBeh

A070 planned preoperative treatment.

0 = No

1 = Yes

A070PreStrBeh

A070 planned radiotherapy.

Check box = True

A070PreEndoBeh

A070 planned endocrine theraphy.

Check box = True

A070PreCytBeh

A070 planned chemotherapy.

Check box = True

Surgery variables (A080)

A080OpDat

A080 Date of first surgery procedure (removal of tumor), YYYYMMDD

A080SlutIngrepp

A080 Final result of breast procedures.

1 = Partial mastectomy

2 = Mastectomy

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

4 = Subcutaneous mastectomy with preservation of the areola-mamilla

A080DirRek2

A080 Direct breast reconstruction performed.

0 = No

1 = Yes

98 = Unknown

A080DirRek2Txt

A080 Direct breast reconstruction (free text). See above.

A080KontrLatIng

A080 Contralateral procedures for breast symmetry performed.

0 = No

1 = Yes

A080SenNodUt2

A080 Procedure/surgerys to identify sentinel-node performed.

0 = No

1 = Yes

98 = Unknown

A080AxillOp2

A080 Axillary breast surgery performed (e.g. sampling).

0 = No

1 = Yes

98 = Unknown

A080AxillOpTyp

A080 Final results of axillary surgery.

1 = Only SN

2 = Sampling (4-5 lymph nodes in level 1)

3 = "utrymning" (extensive removal, level1 and level 2)

9 = No information available

A080SekOpBro2

A080 Additional 2nd phase breast surgery was performed, because of tumor data (PAD results), not due to breast reconstruction surgery

0 = No

1 = Yes

98 = Unknown

A080OrsKomPop

A080 Reason for additional breast surgery. (variable not available in v1.0.2)

1 = inadequate margins (invasive cancer)

2 = Multifocal invasive cancer

3 = Missed tumor

4 = Widespread CIS

5 = Diagnostic op showed cancer

6 = Other

A080SekOpLgl2

A080 Additional 2nd axilla surgery was performed, because of tumor data (PAD results)

0 = No

1 = Yes

98 = Unknown

A080OrsKompLgl2

A080 Reason for additional axilla surgery.

1 = Few lymph nodes

3 = Diagnostic surgery showed cancer

4 = Additional SN after diagnostic breast surgery

5 = Axilla "utrymning" due to pos SN

6 = Axilla "utrymning" after SN because of multi focality

7 = Axilla "utrymning" after SN because of other tumor data

8 = Other

A080AntIngrepp

A080 Number of additional breast and axillary surgeries performed, because of tumor data (excluding first surgery occasion).

MinMax value = 0 to 5

A080PadInfoDat

A080 Date of PAD information to the patient after surgery (at first planned follow-up visit), YYYYMMDD

Morphology and surgery report PAD variables (A090)

A090VpatKod

A090 Pathology / cytology department code. Codes according to the code list for each region.

A090VpatTxt

A090 Pathology / cytology department (free text).

A090VprepNr

A090 Surgical preparation number. E.g. T12345.

A090VprepAr

A090 Year of surgical preparation. E.g. 2006.

A090InvCa

A090 Breast cancer invasiveness.

1 = Only invasive cancer

2 = only carcinoma in situ

3 = Both invasive and in situ cancers

4 = Assessment not possible (v1.0.1-)

4 = Morphological assessment is not possible (v1.0)

A090SnomedInv2

A090 Type of invasive histopathology.

10 = Ductal cancer

20 = Both ductal and lobular carcinoma

30 = Ductal cancer and other types than lobular

40 = Lobular cancer

50 = Medullary cancer

60 = Phyllodes cancer (only in v1.0)

70 = Other invasive cancer

A090SnomedInvKod

A090 Invasive Snomed code. Code of Snomed as listed.

A090SnomedInvTxt

A090 Other invasive histopathology (free text).

A090SnomedTis

A090 In situ type histopathology.

10 = DCIS

20 = LCIS

40 = DCIS + LCIS

50 = Other in situ cancers

A090SnomedTisKod

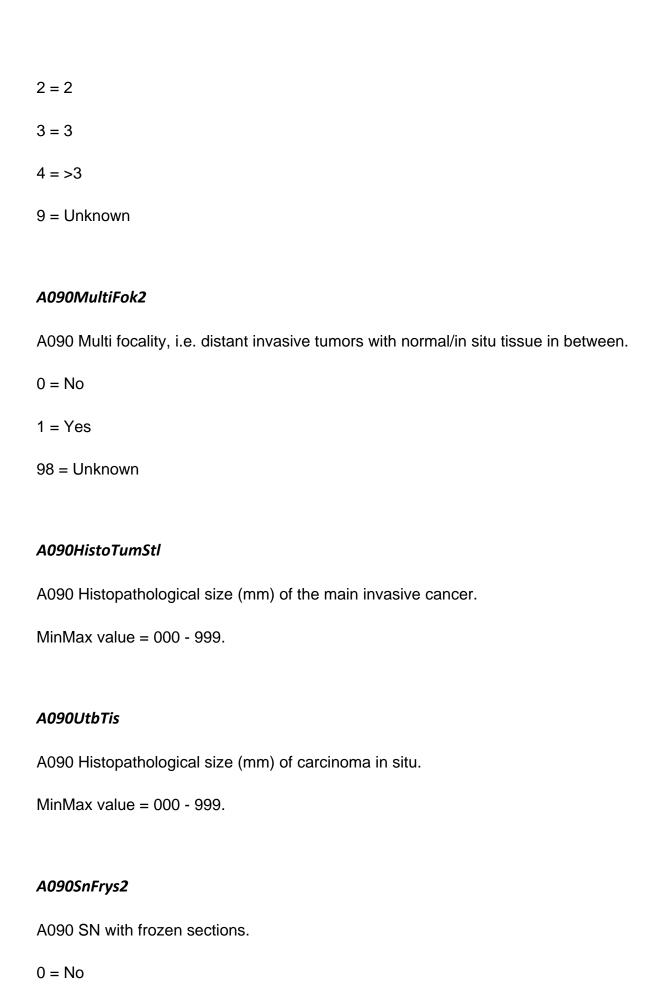A090 In situ Snomed code. Code of Snomed as listed.

A090SnomedTisTxt

A090 Other in situ histopathology. Stated in plain language.

A090AntInva

A090 Number of invasive tumors in the breast. (including satellite tumors)

0 = 0

1 = 1

2 = 2

3 = 3

4 = >3

9 = Unknown

A090MultiFok2

A090 Multi focality, i.e. distant invasive tumors with normal/in situ tissue in between.

0 = No

1 = Yes

98 = Unknown

A090HistoTumStl

A090 Histopathological size (mm) of the main invasive cancer.

MinMax value = 000 - 999.

A090UtbTis

A090 Histopathological size (mm) of carcinoma in situ.

MinMax value = 000 - 999.

A090SnFrys2

A090 SN with frozen sections.

0 = No

1 = Yes

98 = Unknown

A090SnMet2

A090 Metastasis in SN (macro, micro, sub micro).

0 = No

1 = Yes

98 = Unknown

A090SnMakroMet

A090 Number of SN with macro metastases (> 2 mm).

MinMax value = 0-9

A090SnSubMikroMet

A090 Number of SN micro metastases (> 0.2 and <= 2mm).

MinMax value = 0-9

A090SnSubMikroMet

A090 Number of SN sub micro metastases (<0.2 mm).

MinMax value = 0-9

A090AntUsLgl

A090 Total number of lymph nodes of all axilla surgeries (axilla "utrymning", sampling, SN).

MinMax value = 0-99

A090AntLglMet

A090 Total lymph nodes with metastases (> 0.2 mm) from all axilla surgeries (axilla "utrymning", sampling, SN)

MinMax value = 0-99

A090KarInv2
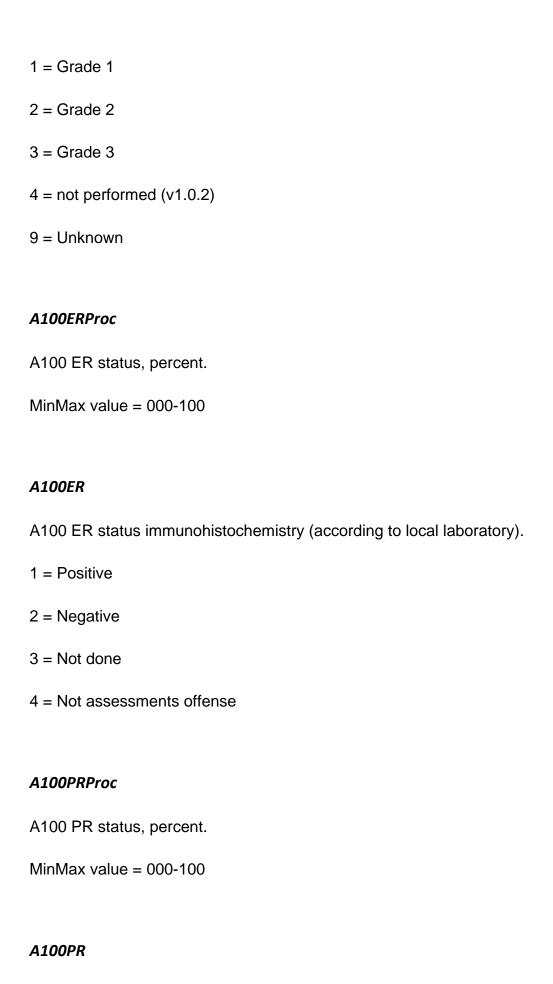
A090 The presence of vessel ingrowth.

0 = No

1 = Yes

98 = Unknown

Tumour biology variables (A100)

Variables from surgery PAD, but for women who never got surgery information is collected from biopsy prior to treatment for women who only get neo-adjuvant treatment, or from biopsy for women who have distant metastasis at diagnosis date.

A100NHG

A100 NHG (invasive) or nuclear grade (in situ). (Nottingham Histologic Grade for invasive cancer and Nuclear grade for cancer in situ) Malignancy grade (highest grade) for invasive cancer and insitu according to PAD. If both invasive and in situ, then grade stated for invasive tumor.

1 = Grade 1

2 = Grade 2

3 = Grade 3

4 = not performed (v1.0.2)

9 = Unknown

A100ERProc

A100 ER status, percent.

MinMax value = 000-100

A100ER

A100 ER status immunohistochemistry (according to local laboratory).

1 = Positive

2 = Negative

3 = Not done

4 = Not assessments offense

A100PRProc

A100 PR status, percent.

MinMax value = 000-100

A100PR

A100 PR status, immunohistochemistry (according to local laboratory).

1 = Positive

2 = Negative

3 = Not done

4 = Not assessments offense

A100HER2

A100 HER-2.

1 = Amplified (3 + or FISH analysis performed)

2 = Negative

3 = Not done

Post-surgery adjuvant treatment variables (A120)

A120PostOpBeh2

A120 postoperative treatment.

0 = No

1 = Yes

98 = Unknown

A120PostOpRt2

A120 planned radiotherapy.

0 = No

1 = Yes

98 = Unknown

If yes, specify type

A120RtBrost

A120 planned radiation of breast or chest wall.

Check box = True

A120RtLokreg

A120 planned loco regional "lymph node stations".

Check box = True

A120PostOpEndo2

A120 planned endocrine therapy.

0 = No

1 = Yes

98 = Unknown

If yes, specify type

A120PostAntiOst

A120 antiestrogen treatment.

Check box = True

A120PostAromat

A120 aromatase treatment.

Check box = True

A120PostOpCyt2

A120 planned chemotherapy.

0 = No

1 = Yes

98 = Unknown

If yes, specify type

A120PostCytAntra

A120 Anthra cycline based treatment.

Check box = True

A120PostCytCMF

A120 Chemotherapy (CMF regime).

Check box = True

A120PostCytTax

A120 Chemotherapy in combination of taxanes.

Check box = True

A120PostCytOvr

A120 Other chemotherapy.

Check box = True

A120PostKast2

A120 Castration.

0 = No

1 = Yes

98 = Unknown

A120PostImm2

A120 Immunotherapy.

0 = No

1 = Yes

98 = Unknown

A120PostImmTrast

A120 Trastuzumab therapy.

Check box = True

A120PostImmOvr

A120 Other immunotherapy.

Check box = True

A120PostImmOvrTxt

A120 Other immunotherapy (free text).

Region specific variables available in specific Swedish oncological centers

Variables prefixed by XR are regional, i.e.

XR02 is only registered at RCC Uppsala / Örebro

XR03 is only registered at RCC Linköping

XR04 is only registered at RCC Lund

XR06 is only registered at RCC Umeå

XR02Dist

XR02 Distribution, diffuse.

0 = No

1 = Yes

9 = Unknown

XR02ExtentDim1

XR02 Extent (propagation in mm).

MinMax value = 000 - 999.

XR02ExtentDim2

XR02 Extent (propagation in mm).

MinMax value = 000 - 999.

XR02KIStat

XR02 CI-status.

1 = Low (less than 10 percent)

2 = Medlhög (10-20 percent)

3 = High (greater 20 percent)

XR02KI67

XR02 Ki67 in percent. Enter the percentage of hot spots.

XR03ForstBes

XR03 Date of first visit, YYYYMMDD

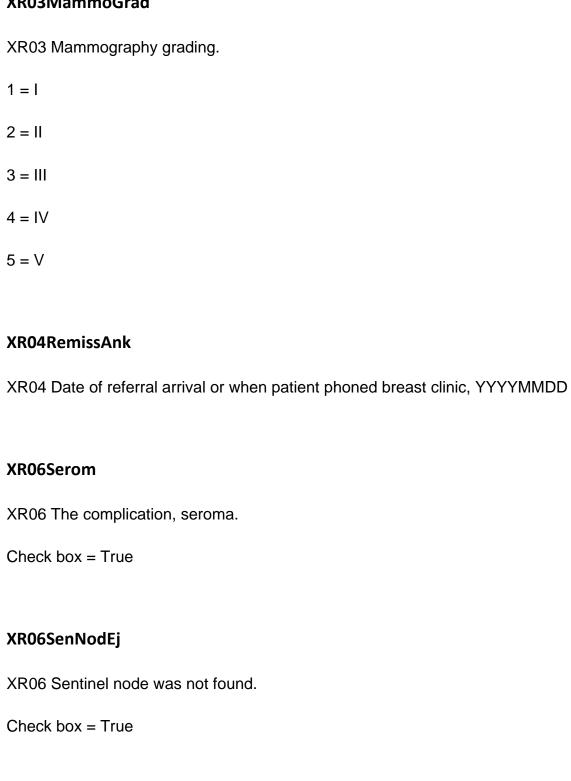**XR03Mammo**

XR03 Mammography.

1 = No

2 = Yes

9 = Unknown

XR03MammoStl

XR03 Mammography-size.

Min value = 1 mm

Maximum value = 150 mm

XR03MammoGrad

XR03 Mammography grading.

1 = I

2 = II

3 = III

4 = IV

5 = V

XR04RemissAnk

XR04 Date of referral arrival or when patient phoned breast clinic, YYYYMMDD

XR06Serom

XR06 The complication, seroma.

Check box = True

XR06SenNodEj

XR06 Sentinel node was not found.

Check box = True

Variables for follow-up visit

U040IpsiBrostKvar

U040 Local recidiv at the operated side in the remaining breast or chest wall.
Marked check box = True

U040RecBrostDat

U040 Date of 1st local recidiv in operated side in the remaining breast or chest wall.
YYYYMMDD

U040AxillRegRec

U040 Regional recidiv in axillens lymph nodes on the operated side.
Marked check box = True

U040RecAxillDat

U040 Date of 1st regional recidiv on axill operated side.
YYYYMMDD

U040RegRecFscl

U040 Newly discovered regional recidiv in the operated side in the lymph nodes "parasternalt" or "fossa supraclavikulärt" or "infraclavikulärt".
Marked check box = True

U040RecParSternDat

U040 Date of the first regional recidiv on the operated side in the lymph nodes "parasternalt" or "fossa supraclavikulärt" or "infraclavikulärt".
YYYYMMDD

U050FjerrMetFirstDat

U050 Date of patient 1st distant distant metastasis.
YYYYMMDD

U050HjarnaMet

U050 Brain metastasis, if it is the 1st "fjärrmetastasen".
Marked check box = True

U050LeverMet

U050 Liver metastasis, if it is the 1st "fjärrmetastasen".
Marked check box = True

U050LungaMet

U050 Lung metastasis, if it is the 1st "fjärrmetastasen".
Marked check box = True

U050LungSackMet

U050 Pleural metastasis, if it is the 1st "fjärrmetastasen".
Marked check box = True

U050SkelettMet

U050 Skeleton metastasis, if it is the 1st "fjärrmetastasen".
Marked check box = True

U050OvrLokMet

U050 Check box for another metastasis, if it is the 1st "fjärrmetastasen".
Marked check box = True

System variables

round_inca_breastcancer

Round of INCA 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_inca_breastcancer

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

month_inca_breastcancer

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

source_inca_breastcancer

Available INCA breast cancer register data.