Victorian Consensus Data Set
Breast Cancer

Data dictionary
Version 1.0

2010

Western & Central Melbourne Integrated Cancer Service and Cancer Council Victoria jointly fund the Victorian Consensus Data Sets Project.

Published by the Cancer Council Victoria, Melbourne, Victoria.

This document may also be downloaded from the Cancer Council Victoria website at:

cancervic.org.au/about-our-research/victorian_cancer_registry/vcds-project/

Acknowledgements

Cancer Council Victoria and Western Central Melbourne Integrated Cancer Services jointly fund the Victorian Consensus Data Sets Project.

A governance committee oversees the project with representatives from the following organisations:

- Cancer Council Victoria (CCV)
- Metropolitan Integrated Cancer Services (ICS)
- Regional Integrated Cancer Services (ICS)
- Victorian Cooperative Oncology Group (VCOG)
- BioGrid
- Victorian Department of Health
- Cancer Voices

Abbreviations

ACHI	Australian Classification Of Health Interventions
ADH	Atypical Ductal Hyperplasia
AIHW	Australian Institute of Health and Welfare
ALH	Atypical Lobular Hyperplasia
ASERNIP-S	Australian Safety & Efficacy Register of New Interventional Procedures - Surgical
CCV	Cancer Council Victoria
CDS	Consensus Data Set
CT	Computerised Tomography
DCIS	Ductal Carcinoma In Situ
ER	Oestrogen Receptor
FBE	Full Blood Examination
FNAC	Fine Needle Aspiration Cytology
GP	General Practitioner
ICD	International Classification Of Diseases
ICD-O	International Classification Of Diseases For Oncology
ICRU	International Commission On Radiation Units
ICS	Integrated Cancer Services
ISH	In Situ Hybridization
LCIS	Lobular Carcinoma In Situ
METeOR	Metadata Online Registry
MRI	Magnetic Resonance Imaging
NBCC	National Breast Cancer Centre
NBOCC	National Breast And Ovarian Cancer Centre
NHDD	National Health Data Dictionary
PD	Progressive Disease
PET	Positron Emission Tomography
PR	Progesterone Receptor
RACS	Royal Australian College of Surgeons
UICC	International Union Against Cancer
US	Ultrasound
VCDS	Victorian Consensus Data Set
VCOG	Victorian Cooperative Oncology Group
VCR	Victorian Cancer Registry
WHO	World Health Organization

Contents

About the Victorian Consensus Data Sets (VCDS)

The VCDS consist of a series of documents, initially covering 10 tumour streams and a generic data set.

The *Victorian Consensus Data Set (Cancer) – Generic Data Set* contains data elements that are common to a wide range of tumours. The *VCDS Generic Data Set* should be used in conjunction with the tumour specific items provided in the other documents.

It is important to emphasise that these are not mandatory or minimum data sets. Agreement was reached after wide ranging consultation on the items to be included and their definitions. Wherever possible, data elements are consistent with national standards (Australian Institute of Health & Welfare) and structured pathology reporting protocols for cancer (Royal College of Pathologists Australia).

For more information, users should refer to the source documents provided in the references for each data element.

The aim of developing these standard definitions is to allow the collection of consistent data in a range of IT systems. This will expand the evidence base to enhance health planning and clinical care.

Guide to the VCDS – Breast cancer data element attributes (data standards)

The VCDS have been developed to align with national health data standards. A guide to the national health data standards can be found on page 10.

Identifying and definitional attributes

Metadata item type	Data set specification
Registration status	Not registered
Scope	This cancer data specification is not mandated for collection. If items incorporated into the data set are to be collected, the application of the definition in this data dictionary is recommended. The data set allows common, consistent and high quality cancer data to be collected. These data will contribute to patient management, and help inform research, policy, planning and guideline development work in the cancer area.

Collection and usage attributes

Guide for use	Data elements in this data set may be captured more than once and in no particular order.

Source and reference attributes

Submitting organisations	Integrated Cancer Services (ICS) BioGrid Victorian Cancer Registry (VCR) Victorian Cooperative Oncology Group (VCOG)
Steward	Cancer Council Victoria (CCV) Western and Central Melbourne Integrated Cancer Services (WCMICS)
References	AIHW National Health Data Dictionary METeOR
Generic data set	CCV Victorian Clinical Cancer Registration Data Set UICC TNM Classification of Malignant Tumours, 6th Edition WHO International Classification of Diseases for Oncology, 3rd Edition National Centre for Classification in Health, International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
References Breast cancer data set	Australian Safety & Efficacy register of New Interventional Procedures – Surgical, Royal Australasian College of Surgeons (ASERNIP-S/RACS). The National Breast Cancer Audit Data Dictionary. 2006 Breast Cancer Committee, Cancer Council Victoria. Breast Cancer update. Issue 59. February 2008. Coates, A. et al. Five Years of Letrozole Compared With Tamoxifen As Initial Adjuvant Therapy for Postmenopausal Women With Endocrine-Responsive

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Guide to the national health data standards

The components described below are consistent with National Health Data Dictionary standards.

Name of the Data Element

Identifying and definitional attributes

Definition	A statement that expresses the essential nature of a data element and its differentiation from all other data elements.
Rationale	The reason for collecting this data element.

Representational attributes

Data type	The type of symbol or character, or other designation used to represent the data element. E.g. numeric, alphanumeric, alphabetic or integer.
Representational class	Describes whether the valid values for the data item take the form of a code set, free text. If the form is described as 'Code' the relevant code set or sets will be specified in the Data domain section.
Field size maximum	The number of characters allowable to represent the data element defined as a maximum.
Format	A generic example of what the data element should look like in the unit record. For example, dates should be represented in the format of DDMMYYYY where DD represents, the day, MM represents the month, and YYYY represents the four-digit numeric for the year. The Data Type indicates whether it is alphabetic or alphanumeric).
Classification scheme	The official terminology system recognised and endorsed by a national or international body, which is used to classify data.
Data domain	The set of possible values for the data item. This may take the form of a code set, or a description of the possible values. Domain values are only specified where size of the code set is small enough to be reasonably reproduced in the document. In other instances the domain may be indicated by reference to a source document.
Guide for use	These are comments designed to assist in further defining aspects of the data domain.
Validation rules	These are included to assist in reducing input error. Where validation rules are known to exist, they have been included to assist with the programming.
Related data element	Data elements that have some direct relationship with the data element being described.

Administration information

References	Documents listed here have been used as references when designing the specified item. Also listed are names of the organisations that developed the source document or provided advice on the data item.

User notes and assumptions

Dates

In this data dictionary, all dates are inter-related in some way. To avoid confusion, only those dates that have a direct relationship with a specific field (especially date fields) appear as related fields.

In some cases, there are implied relationships (even though it may not have been explicitly mentioned) between some fields (especially date fields).

For example:

DOB < Date Diagnosis, Date Diagnosis < Date of Death

This implies DOB < Date of Death

Implied relationships throughout this document are:

Assessment date < all dates (except DOB)

DOB < all dates

Date of death > all dates

Enquiries

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BREAST CANCER DATA ELEMENTS

Data element name **Pregnancy (current)**

Identifying and definitional attributes

Definition	Whether the female person is currently pregnant.
Justification	Pregnancy status can influence breast cancer treatment options and the patient may require further information, appropriate referrals or discussion with treating clinicians.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	Record whether the patient is currently pregnant (self-reported). it may not be evident whether a pregnancy test has confirmed the patient's status.
Validation rules	•
Related data element name	

Administration information

References	AIHW – Female – pregnancy indicator (current) METeOR ID: 302817 NBOCC website http://www.nbocc.org.au/breast-cancer/treatment/treatment-and-pregnancy (viewed 28 Sep 2009)

Data element name — Lactation (current)

Identifying and definitional attributes

Definition	Whether the female person is currently breastfeeding.
Justification	Lactation status can influence breast cancer treatment options and the patient may require further information, appropriate referrals or discussion with treating clinicians..

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	Record whether the patient is currently breastfeeding.
Validation rules	•
Related data element name	

Administration information

References	AIHW – Female – pregnancy indicator (current) METeOR ID: 302817 NBOCC website http://www.nbocc.org.au/breast-cancer/treatment/treatment-and-pregnancy (viewed 28 Sep 2009)

Data element name — Plans for future pregnancy

Identifying and definitional attributes

Definition	Whether the female person is planning to become pregnant in the future.
Justification	Plans for future pregnancy can influence breast cancer treatment options. It is recommended that women do not become pregnant during treatment for breast cancer. Treatments such as chemotherapy and radiotherapy can harm the unborn baby. Some treatments for breast cancer can affect a woman's fertility. Once treatment has finished there is no reliable test to determine if a woman will be able to fall pregnant in future.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
3	Unsure
4	Patient is not female
9	Not stated/inadequately described

Guide for use	This data will be self-reported and the patient may not be sure of future plans for pregnancy in the context of cancer treatment.
Validation rules	•
Related data element name	

Administration information

References

Data element name **Previous pregnancies**

Identifying and definitional attributes

Definition	Number of previous pregnancies.
Justification	Collected for demographic analyses.

Representational attributes

Data type	Number	
Representational class	Total	
Field size maximum	2	
Format	N[N]	
Data domain		
	99	Not stated/unknown
Guide for use	Self reported number of pregnancies (not including current pregnancy if relevant). Record number of pregnancies as distinct from number of live births.	
Validation rules	•	
Related data element name		

Administration information

References

Data element name — Parity (number of live births)

Identifying and definitional attributes

Definition	Number of previous pregnancies resulting in a live birth.
Justification	Collected for demographic analyses.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	N[N]
Data domain	

99	Not stated/unknown

Guide for use	Self reported number of live birth deliveries. A pregnancy resulting in multiple births should be counted as one live birth. For further details of usage and data collection refer to AIHW METeOR data element Female—number of previous pregnancies (live birth).
Validation rules	•
Related data element name	

Administration information

References	AIHW – Female – number of previous pregnancies (live birth) METeOR ID: 269931

Data element name **Age at first delivery**

Identifying and definitional attributes

Definition	The age of the person in (completed) years when first baby was born.
Justification	Collected for demographic analyses.

Representational attributes

Data type	Number	
Representational class	Total	
Field size maximum	3	
Format	{NN[N]}	
Data domain		
	999	Not stated/unknown
Guide for use	Self reported age (in completed years) at time when first baby was born.	
Validation rules	•	
Related data element name		

Administration information

References

Data element name **Menopausal status**

Identifying and definitional attributes

Definition	The menopausal status of a woman, self reported.
Justification	Menopausal status can influence breast cancer treatment options.

Representational attributes

Data type	Number	
Representational class	Code	
Field size maximum	1	
Format	N	
Data domain	**Code**	**Description**
	1	Premenopausal – has not yet experienced menopause
	2	Postmenopausal – has experienced menopause and 12 months of spontaneous amenorrhea
	3	Postmenopausal as determined by biochemical testing
	4	Perimenopausal from the onset of amenorrhea and extending across the subsequent 12 months
	9	Not stated/not adequately described
Guide for use	Responses would normally be based on self-identification of menopausal status (rather than LH/FSH concentrations which generally would be unknown). Can be collected at both initial presentation and also follow up.	
Validation rules	•	
Related data element name	Age at menopause	

Administration information

References	NBOCC – Breast cancer specific data items for clinical cancer registration, p 13

Data element name Age at menopause

Identifying and definitional attributes

Definition	Age (in completed years) of a woman at menopause, self reported.
Justification	Menopausal status can influence breast cancer treatment options.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	[NN]
Data domain	
Guide for use	Responses would normally be based on self-identification of age of menopause onset (rather than LH/FSH concentrations which generally would be unknown). Can be collected at both initial presentation and also follow up.
Validation rules	• If Menopausal status is 2 or 3, may not be null
Related data element name	Menopausal status

Administration information

References

Data element name **Hysterectomy**

Identifying and definitional attributes

Definition	Description of female patient's surgical history for hysterectomy.
Justification	Breast cancer treatment options can be influenced by whether or not the patient has had a hysterectomy as some treatments lead to an increased risk of endometrial cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Yes
2	No
9	Not stated/inadequately described

Guide for use	Previous surgical removal of the uterus for other medical reasons may have occurred.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Oral contraceptive pill use

Identifying and definitional attributes

Definition	Description of whether the female patient is currently using an oral contraceptive pill (OCP).
Justification	Required to determine patient therapy.

Representational attributes

Data type	Number	
Representational class	Code	
Field size maximum	1	
Format	N	
Data domain	**Code**	**Description**
	1	Yes
	2	No
	9	Not stated/inadequately described
Guide for use	Self reported use of OCP.	
Validation rules	•	
Related data element name		

Administration information

References

Data element name **Hormone replacement therapy**

Identifying and definitional attributes

Definition	Description of whether the patient is using Hormone Replacement Therapy (HRT) medication.
Justification	Required to determine patient therapy.

Representational attributes

Data type	Number	
Representational class	Code	
Field size maximum	1	
Format	N	
Data domain	**Code**	**Description**
	1	Yes
	2	No
	9	Not stated/inadequately described
Guide for use	Self reported use of HRT.	
Validation rules	•	
Related data element name		

Administration information

References

Data element name **Previous breast disease**

Identifying and definitional attributes

Definition	Description of any previous disease of the breast including in situ or invasive cancer.
Justification	Collected to determine duration and progress of disease.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No previous breast disease (including cancer)
1	Fibrocystic/other benign
2	ADH
3	ALH
4	LCIS
5	DCIS
6	Invasive cancer
8	Other
9	Not stated/not adequately described

Guide for use: This information should be obtained from the patient's pathology report or the patient's medical record.

Validation rules:

- Can be multiple events

Related data element name

Administration information

References

Data element name — Number of first degree relatives with breast cancer

Identifying and definitional attributes

Definition	Number of first degree relatives (mother, father, sibling or child) diagnosed with breast cancer.
Justification	Family history of cancer may indicate genetic factors to be investigated.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	N[N]
Data domain	0 – no first degree relatives with breast cancer 1 to 10 count of first degree relatives with breast cancer 88 – Unknown 99 – Not stated
Guide for use	Record self reported number of first degree relatives (mother, father, sibling or child) diagnosed with breast cancer.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Number of first degree relatives with ovarian cancer

Identifying and definitional attributes

Definition	Number of first degree relatives (mother, sister or daughter) diagnosed with ovarian cancer.
Justification	Family history of cancer may indicate genetic factors to be investigated.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	N[N]
Data domain	0 – no first degree relatives with breast cancer 1 to 10 count of first degree relatives with breast cancer 88 – Unknown 99 – Not stated
Guide for use	Record self reported number of first degree relatives (mother, sister or daughter) diagnosed with ovarian cancer.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Number of first degree relatives with other cancer

Identifying and definitional attributes

Definition	Number of first degree relatives (mother, father, sibling or child) diagnosed with cancers other than breast and ovarian cancer.
Justification	Family history of cancer may indicate genetic factors to be investigated.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	2
Format	N[N]
Data domain	0 – no first degree relatives with breast cancer 1 to 10 count of first degree relatives with breast cancer 88 – Unknown 99 – Not stated
Guide for use	Record self reported number of first degree relatives (mother, father, sibling or child) diagnosed with cancers (not including breast and ovarian cancer).
Validation rules	•
Related data element name	

Administration information

References

Data element name First degree relatives with other cancer

Identifying and definitional attributes

Definition	Description of cancers affecting first degree relatives (mother, father, sibling or child) diagnosed with cancers other than breast and ovarian cancer.
Justification	Family history of cancer may indicate genetic factors to be investigated.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	6
Format	ANN{.N[N]}
Data domain	Code: ICD-10-AM International Statistical Classification of Diseases and Related Health Problems, Australian Modification
Guide for use	Record each diagnosis of cancer in accordance with the ICD-10-AM Australian Coding Standards.
Validation rules	•
Related data element name	

Administration information

References	International Statistical Classification of Diseases and Related Health Problems, Australian Modification, Tenth Revision

Data element name — Genetic testing – breast cancer

Identifying and definitional attributes

Definition	Description of genetic testing performed on the person.
Justification	The risk of developing breast, ovarian and or other cancers is greatly increased in patients (men and women) with a genetic BRCA1 or BRCA2 mutation. Inherited variants in the TP53 tumour suppressor gene have been implicated in some families with Li-Fraumeni syndrome which is characterised by increased risk of breast cancer and a range of other cancers. Ataxia Telangiectasia (AT) is an autosomal recessive condition associated with mutations in the ATM gene. It is a syndrome characterised by a small increase in breast cancer risk.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	BRCA 1 mutation detected
2	BRCA 2 mutation detected
3	TP53 mutation detected
4	ATM mutation detected
5	Other genetic mutation detected
6	No genetic mutation detected
7	No genetic testing has been performed
9	Not stated/unknown

Guide for use: This information should be obtained from the patient's pathology report or the patient's medical record.

Validation rules:

-

Related data element name

Administration information

References: NOCC - Breast cancer risk factors a review of the evidence July 2009

Data element name — Referral source – breast cancer

Identifying and definitional attributes

Definition	The person or agency responsible for the referral of a patient to a service provider agency.
Justification	Collected to assist in the analyses of inter-service client flow and for service planning.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	General Practitioner
2	BreastScreen
3	Surgeon
4	Hospital Ward/Accident & Emergency
5	Family Cancer Centre
6	Self
7	Second opinion
8	Other
9	Not stated/inadequately described

Guide for use	The referral source should be obtained from the patient's medical record at initial presentation to identify the source of detection of cancer. The referral source should not change with subsequent assessments.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Method of detection of breast cancer

Identifying and definitional attributes

Definition	Description of the principal method by which the cancer was detected at initial presentation.
Justification	Collected to determine method by which cancer was detected and effectiveness of screening programs.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Screening – Mammography
2	Screening – Magnetic resonance imaging (MRI)
3	Screening – Other
4	Symptomatic
8	Other
9	Not stated/inadequately described

Guide for use: It is assumed that 'Screening – Mammography', ' Screening – MRI' and 'Screening – Other' are used for asymptomatic patients. Symptomatic presentation may include breast lump, nipple discharge, change in breast skin, change in nipple shape or new pain. Screening – Other may include screening through ultrasound or other clinical examination. 'Other' may include incidental detection through modalities such as ultrasound.

Validation rules:
- This data item is for both invasive cancer and in situ lesions

Related data element name

Administration information

References: NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 18

Data element name — Symptomatic presentation – breast cancer

Identifying and definitional attributes

Definition	Description of symptoms of breast cancer at initial presentation.
Justification	Collected to determine conditions in which tumour was initially detected.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
1	Breast lump
2	Axillary lump
3	Nipple discharge
4	Nipple rash
5	Nipple retraction
6	Breast skin changes
7	Breast pain
8	Other
9	Not stated/inadequately described

Guide for use: This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff.

Validation rules:

- If Initial presentation – breast cancer is 4, may not be null

Related data element name

Administration information

References

Data element name **Mammography result**

Identifying and definitional attributes

Definition	Results of mammography imaging.
Justification	Collected to determine appearance of cancer on mammographic imaging.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
1	No significant abnormality
2	Benign
3	Equivocal/atypical
4	Suspicious
5	Malignant
9	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's radiology report.
Validation rules	•
Related data element name	Mammography date

Administration information

References

Data element name **Mammography date**

Identifying and definitional attributes

Definition	Date of mammography.
Justification	Collected to determine history of breast cancer.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	[DDMMYYYY]
Data domain	Valid date
Guide for use	This information should be obtained from the patient's radiology report, the patient's medical record, or the patient's medical practitioner/nursing staff.
Validation rules	•
Related data element name	Mammography result

Administration information

References

Data element name — Ultrasound radial position of tumour

Identifying and definitional attributes

Definition	The location of an ultrasound imaging abnormality as described as a clock-face position.
Justification	Collected to determine location of breast cancer on ultrasound imaging.

Representational attributes

Data type	String
Representational class	Code
Field size maximum	3
Format	{[N]NA}
Data domain	1 to 12 followed by L or R
Guide for use	Location and laterality of the imaging abnormality is described as the position on a clock-face from 1 o'clock to 12 o'clock followed by L denoting left side of a paired organ and R denoting right side of paired organ. This information should be obtained from the patient's pathology report, the patient's medical record, or the patient's medical practitioner/nursing staff.
Validation rules	•
Related data element name	

Administration information

References	NBOCC – The pathology reporting of breast cancer: A guide for pathologists, surgeons, radiologists and oncologists

Data element name — Localisation method

Identifying and definitional attributes

Definition	Description of localisation method used during surgical biopsy or excision.
Justification	Collected to determine localisation method of surgical biopsy or excision.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
1	Hookwire
2	Carbon
3	Other
8	Not known
9	Not stated

Guide for use	If surgery is open biopsy or wide local excision, the localisation method should be recorded where indicated on patient's pathology report or medical record.
Validation rules	•
Related data element name	Surgical procedure date

Administration information

References

Data element name — Total extent of lesion (DCIS and invasive)

Identifying and definitional attributes

Definition	The maximum diameter in millimetres of the furthest points of extension of the whole lesion including any DCIS which extends beyond the invasive component.
Justification	Presence of DCIS in adjacent breast tissue can have prognostic and treatment implications. In cases where there is extensive DCIS beyond the invasive tumour component of the lesion, treatment options may be affected.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	N[NN]
Data domain	999 - Not stated/inadequately described
Guide for use	Record the total extent of lesion (DCIS + invasive carcinoma) in millimetres. For a lesion consisting only of DCIS, record the total extent of lesion in millimetres. For a single focus of invasive carcinoma associated with DCIS, the "whole-lesion size" includes any associated DCIS seen beyond the margin of the invasive carcinoma. For a lesion predominantly composed of DCIS, with multiple foci of invasive carcinoma, the whole lesion is measured. For discrete foci of invasive carcinoma arising in a background of DCIS, the size of each invasive carcinoma is measured separately (the largest of these is regarded to be the invasive tumour size). The "whole lesion size" includes the invasive foci and all associated DCIS.
Validation rules	• This data item is for combined invasive/in situ lesions.
Related data element name	

Administration information

References

Data element name — Distance from margin (invasive component) – breast cancer

Identifying and definitional attributes

Definition	The distance of invasive carcinoma from the surgical resection margin, in millimetres.
Justification	Collected to identify distance of invasive cancer from surgical margins for patient management as margin involvement is associated with risk of recurrence.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	NNN
Data domain	001 to 997 999 – Unknown
Guide for use	The distance from the nearest resection margins should be initially assessed on macroscopic examination of the specimen. The measurements should be confirmed microscopically.
Validation rules	• For invasive cancer only
Related data element name	Date of diagnosis, Margin qualifier

Administration information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 37

Data element name — Distance from margin (in situ component) – breast cancer

Identifying and definitional attributes

Definition	The distance of in situ carcinoma from the surgical resection margin, in millimetres.
Justification	Collected to identify distance of in situ cancer from surgical margins for patient management as margin involvement is associated with risk of recurrence.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	NNN
Data domain	001 to 997 999 – Unknown
Guide for use	The status of resection margins for in situ carcinoma in association with invasive carcinoma can only be assessed microscopically.
Validation rules	• For carcinoma in situ only
Related data element name	Date of diagnosis, Margin qualifier

Administration information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 39

Data element name **Margin qualifier**

Identifying and definitional attributes

Definition	The surgical resection margins (eg posterior, anterior, lateral or medial) described as involved by invasive or in situ carcinoma or where the distance to invasive or in situ carcinoma has been measured.
Justification	Collected to identify which surgical margins are involved by in situ or invasive cancer for patient management as margin involvement is associated with risk of recurrence.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	All margins are clear
2	Deep/posterior
3	Cutaneous/anterior
4	Lateral
5	Medial
6	Superior
7	Inferior
8	There is margin involvement but it is not qualified
9	Not stated/unknown

Guide for use: This information should be obtained from the patient's pathology report.

Validation rules:

-

Related data element name: Date of diagnosis

Administration information

References: NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 40

Data element name — Ductal carcinoma in situ dominant architecture

Identifying and definitional attributes

Definition	Description of ductal carcinoma in situ architecture.
Justification	Collected to identify architecture of ductal carcinoma in situ present in the tumour.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Solid
2	Cribriform
3	Micropapillary
4	Apocrine
5	Papillary
6	Other
9	Not stated/unknown

Guide for use	The dominant pattern should be recorded as many tumours show more than one type. This information should be obtained from the patient's pathology report.
Validation rules	•
Related data element name	Date of diagnosis

Administration information

References	NBOCC – The pathology reporting of breast cancer: A guide for pathologists, surgeons, radiologists and oncologists, p 31

Data element name — Ductal carcinoma in situ necrosis

Identifying and definitional attributes

Definition	Description of ductal carcinoma in situ necrosis. Necrosis is defined as the presence of ghost cells and karyorrhectic debris in the tumour.
Justification	Collected to identify type of ductal carcinoma in situ necrosis present in the tumour.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Present and associated with calcifications (comedo)
2	Present but not associated with calcifications (non comedo)
3	Present but association with calcification not stated
4	Absent/minimal
9	Not stated/unknown

Guide for use	Necrosis should be recorded as: not present or minimal, present, and whether comedo or non-comedo type. Comedocarcinoma is defined as the presence of central duct necrosis and grade 3 nuclei. It is frequently associated with coarse casting calcifications. This information should be obtained from the patient's pathology report or medical record.
Validation rules	•
Related data element name	Date of diagnosis

Administration information

References	NBOCC – The pathology reporting of breast cancer: A guide for pathologists, surgeons, radiologists and oncologists, p 31

Data element name — Ductal carcinoma in situ calcification

Identifying and definitional attributes

Definition	Description of ductal carcinoma in situ associated calcification.
Justification	Collected to identify presence of calcification with ductal carcinoma in situ. Recording the presence of histological calcification assists in correlation between radiological and pathological findings.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Present and associated with necrosis
2	Present but not associated with necrosis
3	Present but association with necrosis not stated
4	Absent
9	Not stated/unknown

Guide for use	This information should be obtained from the patient's pathology report or medical record.
Validation rules	•
Related data element name	Date of diagnosis

Administration information

References	NBOCC – The pathology reporting of breast cancer: A guide for pathologists, surgeons, radiologists and oncologists, p 33

Data element name — Extensive intraductal carcinoma component

Identifying and definitional attributes

Definition	Description of whether there is extensive intraductal carcinoma (EIC) within the the invasive tumour as well as beyond the margin of the invasive carcinoma.
Justification	Collected to determine whether there is extensive intraductal carcinoma associated with the invasive tumour. Tumours with EIC have been shown (in some studies) to have a higher rate of local recurrence following breast-conserving surgery and radiotherapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Positive > 25%
2	Negative < 25%
9	Not stated/unknown

Guide for use

This information should be obtained from the patient's pathology report or medical record.

Intraductal carcinoma is synonymous with ductal carcinoma in situ.

Validation rules

-

Related data element name: Date of diagnosis

Administration information

References: NBOCC – The pathology reporting of breast cancer: A guide for pathologists, surgeons, radiologists and oncologists, p 24

Data element name — Attempt to identify sentinel lymph nodes

Identifying and definitional attributes

Definition	Whether or not identification of sentinel lymph nodes was attempted.
Justification	Identification and removal of the sentinel lymph node is undertaken to determine nodal status in patients where there is no clinical evidence of nodal involvement. If the sentinel node biopsy shows no tumour cells, an extensive regional lymph node dissection normally would not be undertaken, reducing the potential for lymphoedema and other surgical complications.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	

Data domain

Code	Description
1	Yes
2	No
9	Not known

Guide for use	Record whether an attempt was made to locate sentinel lymph nodes.
Validation rules	• This data item is for invasive and in situ lesions.
Related data element name	

Administration information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 33

Data element name — Size of metastasis in sentinel lymph nodes

Identifying and definitional attributes

Definition	The size of the metastasis for each sentinel lymph node examined.
Justification	The number of lymph nodes with metastasis is important for cancer staging and treatment options. If no tumour cells are found, it is unnecessary to perform an extensive regional lymph node dissection.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	Not involved by tumour
1	Isolated tumour cells present (<0.2mm)
2	Micrometastasis present (0.2 to 2.0 mm)
3	Macrometastasis present (>2mm)
9	Not stated

Guide for use

Indicate the involvement of tumour in each lymph node.
Sentinel nodes are the first nodes that filter fluid draining away from the area of cancer. The presence of cancer cells in these lymph nodes indicates that the cancer has already spread outside the primary site and may have spread to another part of the body.

Validation rules

- This data item is for invasive cancer only.

Related data element name

Administration information

References

NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 35

Data element name — Number of sentinel lymph nodes examined

Identifying and definitional attributes

Definition	The number of sentinel nodes examined by the pathologist.
Justification	Collected to identify the number of sentinel lymph nodes examined. Sentinel lymph nodes are the first nodes that filter fluid draining away from the area of cancer. The number of lymph nodes with metastasis is important for cancer staging. A definitive negative result on assessment of the sentinel node may negate the need for secondary surgery.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	N[NN]
Data domain	997- Number of lymph nodes unknown
Guide for use	This information should be obtained from the patient's pathology report or medical record.
Validation rules	•
Related data element name	Date of diagnosis

Administration information

References	AIHW – Number of sentinel lymph nodes examined METeOR ID: 370558

Data element name — Number of sentinel nodes positive

Identifying and definitional attributes

Definition	The total number of sentinel lymph nodes reported as containing tumour after examination by a pathologist.
Justification	Collected to identify the number of sentinel lymph nodes with tumour present. Sentinel lymph nodes are the first nodes that filter fluid draining away from the area of cancer. The number of lymph nodes with metastasis is important for cancer staging. A definitive negative result on assessment of the sentinel node may negate the need for secondary surgery.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	3
Format	N[NN]
Data domain	997- Number of lymph nodes unknown
Guide for use	This information should be obtained from the patient's pathology report or medical record.
Validation rules	•
Related data element name	Date of diagnosis

Administration information

References	AIHW – Number of positive sentinel lymph nodes METeOR ID: 370549

Data element name — Patient referrals –breast cancer

Identifying and definitional attributes

Definition	Description of referrals for the patient to ancillary support services.
Justification	Collected to determine patient requirements for support services.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	NN

Data domain

Code	Description
1	Breast care nurse
2	Physiotherapy
3	Lymphoedema clinic
4	Social work
5	Psychologist
6	Psychiatrist
7	Dietician
8	Royal District Nursing Service (RNDS)
9	Occupational therapy
10	Support group
11	Palliative care
12	Cancer Council (local state)
13	Familial Cancer Centre/Genetic counselling
14	Pastoral care
15	Fertility services
16	Menopause clinic
88	Other
99	Not stated

Guide for use	Record whether the patient has been referred to any of these ancillary support services.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Oestrogen receptor percentage of nuclei stained

Identifying and definitional attributes

Definition	The percentage of tumour cell nuclei staining for oestrogen receptors (ER) by immunohistochemistry.
Justification	Collected to determine oestrogen receptor status. Immunochemical assay of oestrogen receptors (ER) are now routinely performed on invasive breast carcinoma because they provide independent prognostic information to predict response to hormonal therapy.

Representational attributes

Data type	Number
Representational class	Percentage
Field size maximum	3
Format	N[NN]
Data domain	Input of nuclei stained (1-100%)
Guide for use	This information should be obtained from the patient's pathology report. Only nuclear staining indicates a positive result for ER status. 0 indicates 0% or <1% staining 999 indicates not known or inadequately described
Validation rules	•
Related data element name	

Administration information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 28

Data element name — Oestrogen receptor intensity of nuclei stained

Identifying and definitional attributes

Definition	The predominant intensity of tumour cell nuclei staining for oestrogen receptors (ER) by immunohistochemistry.
Justification	Collected to determine oestrogen receptor status. Immunochemical assay of oestrogen receptors (ER) are now routinely performed on invasive breast carcinoma because they provide independent prognostic information to predict response to hormonal therapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	1+ (Low intensity)
2	2+ (Intermediate intensity)
3	3+ (High intensity)
7	Unknown (test results not available)
8	Not applicable (test not done)
9	Not stated/inadequately described

Guide for use: This information should be obtained from the patient's pathology report.

Validation rules:

- For cases with an invasive component

Related data element name:

Administration information

References: NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 29

Data element name — Oestrogen receptor status

Identifying and definitional attributes

Definition	Whether the tumour is oestrogen receptor positive (has oestrogen receptors on the tumour cells).
Justification	Collected to determine oestrogen receptor status. Immunochemical assay of oestrogen receptors (ER) are now routinely performed on invasive breast carcinoma because they provide independent prognostic information to predict response to hormonal therapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Positive ≥ 1% nuclei staining
2	Negative < 1% nuclei staining
3	Equivocal (result of test inconclusive)
7	Unknown (test results not available)
8	Not applicable (test not done)
9	Not stated

Guide for use	This information should be obtained from the patient's pathology report. Use code 7 if test results are unknown. Use code 8 to show that lack of results is due to test not being performed.
Validation rules	• For cases with an invasive component
Related data element name	

Administration information

References	AIHW – Oestrogen receptor assay result METeOR ID: 370036 NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 26

Data element name — Progesterone receptor percentage of nuclei staining

Identifying and definitional attributes

Definition	The percentage of tumour cell nuclei staining for progesterone receptors (PR) by immunohistochemistry.
Justification	Collected to determine progesterone receptor status for prognostic and therapeutic purposes.

Representational attributes

Data type	Number
Representational class	Percentage
Field size maximum	3
Format	N[NN]
Data domain	Input of nuclei stained (1-100%)
Guide for use	This information should be obtained from the patient's pathology report. Only nuclear staining indicates a positive result for ER status.
Validation rules	• For cases with an invasive component
Related data element name	

Administration information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 31

Data element name — Progesterone receptor intensity of nuclei staining

Identifying and definitional attributes

Definition	The predominant intensity of tumour cell nuclei staining for progesteron receptors (PR) by immunohistochemistry.
Justification	Collected to determine progesterone receptor status for prognostic and therapeutic purposes.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	1+ (Low intensity)
2	2+ (Intermediate intensity)
3	3+ (High intensity)
7	Unknown (test results not available)
9	Not stated/inadequately described

Guide for use: This information should be obtained from the patient's pathology report.

Validation rules:

- For cases with an invasive component

Related data element name:

Administration information

References: NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 32

Data element name — Progesterone receptor status

Identifying and definitional attributes

Definition	Whether the tumour is progesterone receptor positive (has progesterone receptors on the tumour cells).
Justification	Collected to determine progesterone receptor status for prognostic and therapeutic purposes.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Positive > = 1% nuclei staining
2	Negative < 1% nuclei staining
3	Equivocal (result of test inconclusive)
7	Unknown (test results not available)
8	Not applicable (test not done)
9	Not stated

Guide for use	This information should be obtained from the patient's pathology report. Use code 7 if test results are unknown. Use code 8 to show that lack of results is due to test not being performed.
Validation rules	• For cases with an invasive component
Related data element name	

Administration information

References	AIHW – Progesterone receptor assay result METeOR ID: 291341 NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 30

Data element name HER2 results – immunohistochemistry

Identifying and definitional attributes

Definition	The presence or absence of Human Epidermal Growth Factor receptor 2 protein overexpression (HER2) on tumour cells.
Justification	Collected to determine HER2 receptor status for prognostic and therapeutic purposes.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No staining
1	1+
2	2+
3	3+
7	Unknown (test results not available)
8	Not applicable (test not done)
9	Not stated

Guide for use

This information should be obtained from the patient's pathology report. Use code 7 if test results are unknown. Use code 8 to show that lack of results is due to test not being performed.

Code 0 No staining (HER2 status is negative)

Code 1 1+ or <10% of cancer cells show staining (HER2 status is negative)

Code 2 2+ or +++ <10% of cancer cells show strong complete membrane staining (rare) or 10–30% of cancer cells show weak to moderate complete membrane staining or strong cytoplasmic staining is present, making an assessment of membrane staining difficult (HER2 status is equivocal)

Code 3 3+ or +++ where ≥30% of cancer cells show strong, complete membrane staining without cytoplasmic staining and without staining of normal breast tissue (HER2 status is positive).

Validation rules

- For cases with an invasive component

Related data element name

Administration information

References	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 22

Data element name HER2 results – in situ hybridization

Identifying and definitional attributes

Definition	The presence or absence of amplification of Human Epidermal Growth Factor receptor 2 (HER2) oncogene in tumour cells.
Justification	Collected to determine HER2 receptor status for prognostic and therapeutic purposes.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N[N]

Data domain

Code	Description
1	Non amplified, diploid
2	Non amplified, polysomy
3	Non amplified, not otherwise specified
4	Equivocal
5	Low amplification
6	High amplification
7	Amplified, not otherwise specified
77	Unknown (test results not available)
88	Not applicable (test not done)
99	Not stated

Guide for use

This information should be obtained from the patient's pathology report. Use code 77 if test results are unknown. Use code 88 to show that lack of results is due to test not being performed.

Code 1 Non amplified, diploid (1 to 2.5 HER2 gene copies/nucleus)

Code 2 Non amplified, polysomy (>2.5 to ≤4 HER2 gene copies/nucleus)

Code 3 Non amplified (by dual probe <1.8 HER2/CHR17 ratio of gene copies/nucleus)

Code 4 Equivocal (by single probe >4 and ≤ 6 HER2 gene copies/nucleus or by dual probe 1.8 to 2.2 ratio of HER2/CHR17 gene copies/nucleus)

Code 5 Low amplification (>6 to ≤10 HER2 gene copies/nucleus)

Code 6 High amplification (>10 HER2 gene copies/nucleus)

Code 7 Amplified (by single probe >4 HER2 gene copies/nucleus or by dual probe >2.2 ratio of HER2/CHR17 gene copies/nucleus)

Validation rules

- For cases with an invasive component

Related data element name

Administration information

References

Wolff, A. et al American Society of Clinical Oncology/College of American Pathologists Guideline Recommendations for Human Epidermal Growth Factor Receptor 2 Testing in Breast Cancer, Arch Pathol Lab Med, 2007; 131:18-43

Data element name HER2 status

Identifying and definitional attributes

Definition	The presence or absence of Human Epidermal Growth Factor receptor 2 protein (HER2) on tumour cells or detection of overexpression of the HER2 oncogene in tumour cells.
Justification	Collected to determine HER2 receptor status for prognostic and therapeutic purposes. The HER2 (or c-erbB2) proto-oncogene encodes for a transmembrane receptor-like protein. HER2 gene amplification is observed in some breast cancers with an increase of HER2 protein expression on the surface of the tumour cells, a HER2 receptor. Detection of HER2 overexpression or amplification can be detected using immunohistochemistry (IHC) or In Situ Hybridisation (ISH) techniques.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Positive
2	Negative
3	Equivocal (result of test inconclusive)
7	Unknown (test results not available)
8	Not applicable (test not done)
9	Not stated

Guide for use	This information should be obtained from the patient's pathology report. Use code 7 if test results are unknown. Use code 8 to show that lack of results is due to test not being performed.
Validation rules	• For cases with an invasive component
Related data element name	

Administration information

References	AIHW – Epidermal growth factor receptor-2 test result METeOR ID: 370572 NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 22 Roche – http://www.roche-australia.com/downloads/herceptin-pi.cfm?action=get (viewed 6 Oct 2009)

Data element name HER2 test type

Identifying and definitional attributes

Definition	The type of test used to determine the results of human epidermal growth factor receptor-2 (HER2) at the time of diagnosis of the primary tumour.
Justification	Collected to determine type of HER2 testing undertaken. Detection of HER2 overexpression or amplification can be detected using an immunohistochemistry (IHC) or In Situ Hybridisation (ISH) techniques.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Fluorescence in-situ hybridisation (FISH)
2	Brightfield in-situ hybridisation
3	Immunochemistry (IHC)
8	Other
9	Test type not stated or unknown

Guide for use	This information should be obtained from the patient's pathology report. Code 2 - Brightfield in-situ hybridisation Includes Chromogenic in-situ hybridisation (CISH) and Silver in-situ hybridisation (SISH).
Validation rules	• For cases with an invasive component
Related data element name	

Administration information

References	AIHW – Human epidermal growth factor receptor-2 test type METeOR ID: 370607 NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 24

Data element name — Post operative complication(s) – breast cancer

Identifying and definitional attributes

Definition	Description of complications arising within 30 days of surgery for breast cancer.
Justification	Collected to identify acute complications arising after surgery for breast cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	2
Format	N[N]

Data domain

Code	Description
0	None
1	Haematoma
2	Seroma
3	Infection
4	Pain
5	Lymphoedema
6	DVT/PE
7	Other
99	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Chemotherapy treatment – breast cancer

Identifying and definitional attributes

Definition	Description of primary reason for patient's chemotherapy for breast cancer.
Justification	Collected to identify patient treatments for breast cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No chemotherapy
1	Neo-adjuvant (pre-operative) for primary disease
2	Adjuvant for primary disease
3	For metastatic disease
9	Not stated

Guide for use: This information should be obtained from the patient's medical record.

Validation rules:

-

Related data element name

Administration information

References

Data element name — Endocrine therapy treatment – breast cancer

Identifying and definitional attributes

Definition	Description of primary reason for patient's endocrine (hormone) therapy for breast cancer.
Justification	Collected to identify patient treatments for breast cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No endocrine (hormone) therapy
1	Neo-adjuvant (pre-operative) for primary disease
2	Adjuvant for primary disease
3	For metastatic disease
9	Not stated

Guide for use: This information should be obtained from the patient's medical record.

Validation rules

-

Related data element name

Administration information

References

Data element name — Anti HER2 treatment – breast cancer

Identifying and definitional attributes

Definition	Description of primary reason for patient's anti-HER2 for breast cancer.
Justification	Collected to identify patient treatments for breast cancer.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No anti-HER2 therapy
1	Neo-adjuvant (pre-operative) for primary disease
2	Adjuvant for primary disease
3	For metastatic disease
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	

Administration information

References

Data element name — Radiotherapy treatment – breast cancer

Identifying and definitional attributes

Definition	Description of primary reason for patient's radiotherapy for breast cancer.
Justification	Collected to determine whether radiotherapy is indicated for patient treatment.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
0	No radiotherapy
1	Neo-adjuvant (pre-operative) for primary disease
2	Adjuvant for primary disease
3	For metastatic disease
9	Not stated

Guide for use: This information should be obtained from the patient's medical record.

Validation rules

-

Related data element name

Administration information

References

Data element name Ovarian suppression

Identifying and definitional attributes

Definition	Description of suppression of ovarian function for therapeutic purposes.
Justification	Collected to determine ovarian suppression treatments used in patient therapy. Ovarian suppression is a treatment option of hormone-receptor positive breast cancer in premenopausal women.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
1	Bilateral oophorectomy
2	Gonadotropin-releasing hormone (GNrH) agonist
3	Radiotherapy
4	Not required
8	Not known
9	Not stated

Guide for use

This information should be obtained from the patient's medical record. Ovarian suppression (or ablation) can be undertaken by surgery, drug therapy or radiotherapy. Oophorectomy is the removal of an ovary. Salpingo-oophorectomy is the surgical removal of an ovary with fallopian tube. Bilateral oophorectomy is one method of ovarian ablation in the treatment of hormone-receptor positive breast cancer. Surgical removal of only one ovary (unilateral oophorectomy or salpingo-oophorectomy) for other medical reasons does not suppress ovarian hormone production and should not be recorded as oophorectomy in this context. Ovarian suppression is not required where woman is post-menopausal. GnRH agonists have a hypogonadal effect and are useful in treatment of cancers that are hormonally sensitive eg prostate cancer and breast cancer. GnRH can also be known as luteinizing hormone releasing hormone (LHRH). Some are: leuprolide (Lupron, Eligard), buserelin (Suprefact, Suprecor), nafarelin (Synarel), histrelin (Supprelin), goserelin (Zoladex), deslorelin (Suprelorin, Ovuplant).

Validation rules

-

Related data element name Date of oophorectomy or Systemic therapy protocol

Administration information

References

Data element name — Date of oophorectomy

Identifying and definitional attributes

Definition	Date when oophorectomy was performed.
Justification	Bilateral oophorectomy is an option in the treatment of hormone-receptor positive breast cancer.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	[DDMMYYYY]
Data domain	Valid date
Guide for use	If Ovarian suppression is 1, record the date of the oophorectomy. Surgical removal of only one ovary (unilateral oophorectomy or salpingo-oophorectomy) for other medical reasons does not suppress ovarian hormone production and should not be recorded as oophorectomy in this context. This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	Ovarian suppression

Administration information

References

Data element name **Menopause monitoring required**

Identifying and definitional attributes

Definition	Description of whether monitoring of menopause status/ovarian function in the patient is required.
Justification	Menopause status will affect treatment options for patients in two ways: • Return of ovarian function after chemotherapy may occur and require a change in treatment • Effects of chemotherapy on ovarian function will influence subsequent fertitlity and contraceptive advice

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
1	Yes
2	No
3	Unknown
9	Not stated/inadequately described

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	Reason for menopause monitoring

Administration information

References

Data element name — Endocrine therapy breaks in treatment

Identifying and definitional attributes

Definition	Total number of breaks in endocrine (hormone) therapy from planned treatment.
Justification	Collected to determine changes in planned hormone therapy.

Representational attributes

Data type	Number
Representational class	Total
Field size maximum	1
Format	[N]
Data domain	
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	Systemic drug therapy start date, Systemic drug therapy end date

Administration information

References

Data element name — Endocrine therapy cessation specified

Identifying and definitional attributes

Definition	Description of cause of cessation of endocrine (hormone) therapy.
Justification	To determine causes of incomplete endocrine (hormone) therapy.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
0	Endocrine (hormone) therapy completed as planned
1	Progressive disease
2	Toxicity of treatment
3	Hot flushes
4	Planned change of treatment
5	Patient request
6	Significant adverse event
8	Other
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	Systemic drug therapy start date, Systemic drug therapy end date

Administration information

References

Data element name — Anti-HER2 therapy cessation specified

Identifying and definitional attributes

Definition	Description of reason for cessation or variation in planned anti-HER2 therapy.
Justification	Collected to determine causes of variation in planned anti-HER2.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	[N]

Data domain

Code	Description
0	Anti-HER2 completed as planned (no variation)
1	Anti-HER2 ceased temporarily
2	Anti-HER2 ceased due to significant adverse effect
3	Anti-HER2 ceased on patient request
4	Anti-HER2 ceased, not otherwise specified
9	Not stated

Guide for use: This information should be obtained from the patient's medical record.

Validation rules:

-

Related data element name

Administration information

References

Data element name — Radiotherapy site –primary breast cancer

Identifying and definitional attributes

Definition	Site of radiotherapy for primary breast cancer treatment
Justification	Collected to provide the basis for a standard approach to recording and monitoring patterns of treatment for cancer patients.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Whole breast
2	Partial breast
3	Axilla
4	Supraclavicular fossa
5	Internal mammary lymph nodes
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	Radiotherapy type, Radiotherapy dose

Administration information

References

Data element name — Radiotherapy site –metastatic breast cancer

Identifying and definitional attributes

Definition	Site of radiotherapy for metastatic breast cancer treatment
Justification	Collected to provide the basis for a standard approach to recording and monitoring patterns of treatment for cancer patients.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Bone
2	Brain
8	Other
9	Not stated

Guide for use	This information should be obtained from the patient's medical record.
Validation rules	•
Related data element name	Radiotherapy type, Radiotherapy dose

Administration information

References

Data element name **Breast reconstruction date**

Identifying and definitional attributes

Definition	The date of breast reconstruction (where undertaken). Breast reconstruction is where a prosthesis or tissue from other parts of the body is used to rebuild a breast removed by mastectomy.
Justification	For patient follow-up and outcome studies.

Representational attributes

Data type	Date/Time
Representational class	Date
Field size maximum	8
Format	DDMMYYYY
Data domain	Valid date
Guide for use	This information should be obtained from the patient's medical record.
Validation rules	• This data item is for both invasive cancer and in situ lesions.
Related data element name	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009: p 47

Administration information

References

Data element name

Breast reconstruction type

Identifying and definitional attributes

Definition	The type of breast reconstruction procedure. Breast reconstruction is where a prosthesis or tissue from other parts of the body is used to rebuild a breast removed by mastectomy.
Justification	For patient follow-up and outcome studies.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	No reconstruction
2	Autologous reconstruction
3	Prosthetic reconstruction
4	Prosthetic and autologous reconstruction
5	Reconstruction done but inadequately described
9	Not known

Guide for use	This information should be obtained from the patient's pathology report or medical record. Record type of procedure where breast reconstruction was undertaken.
Validation rules	•
Related data element name	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009: p 46

Administration information

References

Data element name **Follow up arm symptom**

Identifying and definitional attributes

Definition	The nature and extent of dominant symptom such as swelling, pain or discomfort, or other symptom associated with the current treatment episode (both surgical and non-surgical) at the review appointment. Indicate whether symptom impacts on daily functioning.
Justification	Arm symptoms can be associated with axillary radiotherapy and axillary node dissection. This data item can be used to investigate the effect of conservative management and/or sentinel node dissection on the incidence of lymphoedema and other arm symptoms.

Representational attributes

Data type	Number
Representational class	Code
Field size maximum	1
Format	N

Data domain

Code	Description
1	Swelling – impacts on daily functioning
2	Swelling – does not impact on daily functioning
3	Pain – impacts on daily functioning
4	Pain – does not impact on daily functioning
5	Other symptom – impacts on daily functioning
6	Other symptom – does not impact on daily functioning
9	No symptoms reported

Guide for use	This information should be obtained from the patient's pathology report or medical record. Record self-reported dominant arm symptoms.
Validation rules	•
Related data element name	NBOCC – Breast Specific Data Item Definitions for Clinical Registrations June 2009, p 48

Administration information

References