# WELSH INFORMATION STANDARDS BOARD

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| **DSC Notice:** | DSCN 2020 / 07 |
| **Date of Issue:** | 25th June 2020 |

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| **Ministerial / Official Letter:**<br>n/a | **Subject:** National Cancer Data Standards for Wales – Site Specific - Breast[1]<br><br>[1](For the purposes of COSD v9 reference, includes Pathology v4) |
| **Sponsor:**<br>Cancer Implementation Group (CIG)<br>Welsh Government | |
| **Implementation Date:**<br><br>The Cancer Informatics Solution (CIS) MUST comply with this Standard with immediate effect.<br><br>Services/data providers, however, MUST operate to **'business as usual'** in terms of the data being collected and reported (see section Actions Required in this Notice) | |

## DATA STANDARDS CHANGE NOTICE

A Data Standards Change Notice (DSCN) is an information mandate for a new or revised information standard.

This DSCN was approved by the Welsh Information Standards Board (WISB) at its meeting on 18th June 2020

**WISB Reference:** ISRN 2020 / 006

**Summary:**

To introduce a new standard for site-specific cancer minimum reporting requirements for tumour site - Breast.

Whilst this introduces a change to an existing information standard, the immediate use of this mandate will be used as a framework for the development of the CIS, therefore services/data providers should continue with **'business as usual'** in terms of the data being collected and reported (see section Actions Required in this Notice).

**Data sets / returns affected:**

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| • All Wales Breast Cancer Minimum Reporting Requirements v5.0 including Core Reporting Items v5.0 |
| Please address enquiries about this Data Standards Change Notice to the Data Standards Team in NHS Wales Informatics Service<br><br>E-mail: data.standards@wales.nhs.uk / Tel: 02920502539 |
| The Welsh Information Standards Board is responsible for appraising information standards. Submission documents and WISB Outcomes relating to the approval of this standard can be found at:<br><br>http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&pid=24632 |

# DATA STANDARDS CHANGE NOTICE

## Introduction

The original All Wales Cancer Minimum Reporting Requirements were mandated via Data Standards Change Notices (DSCNs) in 2011 for Core and Site Specific (http://nww.nwisinformationstandards.wales.nhs.uk/empty-5)

A revision of the existing all Wales Core Cancer Minimum Reporting Requirements together with the development of new Site-Specific Cancer Minimum Reporting Requirements is necessary to ensure Wales has effective, efficient and timely world-class healthcare information to provide intelligence and the insight to drive healthcare service improvements.

A revised standard for Core was mandated through National Cancer Data Standards for Wales – Core (DSCN 2019/09) (http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20191210-DSCN%202019%2009-National%20Cancer%20Data%20Standards%20for%20Wales%20-%20Core-v1-0.pdf). **Core data items should be collected for all cancers**.

This Notice encompasses the site-specific cancer minimum reporting requirements for Breast. This should be used in conjunction with National Cancer Data Standards for Wales – Core (DSCN 2019/09).

## Description of Change

This Standard covers the data items for Breast, listed in NHS England Cancer Outcome and Services Data set (COSD) V9.0 (which includes Pathology V4.0) for comparability, and additional items to reflect NHS Wales reporting.

Whilst this introduces a change to an existing information standard, the immediate use of this mandate will be used as a framework for the development of the CIS, therefore services/data providers should continue with **'business as usual'** in terms of the data being collected and reported (see section Actions Required in this Notice).

Typically, within the DSCN we use a combination of 'strike through' and highlighted text to denote changes to the existing standard, however given that there have been a number of iterations of the COSD in England since the publication of the All Wales Cancer Minimum Reporting Requirements in Wales, for usability this practice has not been followed in this document.

## Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.10 of the NHS Wales Data Dictionary.

Given that the immediate use of this mandate will be as a framework for the development of the CIS only, the changes introduced by this DSCN will not be published to the NHS Wales Data Dictionary until such time that it applies to a wider audience and fully replaces the existing Standard.

## Actions Required

Actions for the NHS Wales Informatics Service:

- To apply this Standard with immediate effect in the development of the CIS
- Continue to make routine extracts available to the Welsh Cancer Intelligence and Surveillance Unit (WCISU) for the purpose of cancer registration via existing means.

Actions for Health Boards/Trusts:

There are no actions for health boards/trusts with regards to the changes in this Standard presently. However, health boards are expected to continue with '**business as usual'** as it pertains to the existing Standard, namely to collect and report data using existing national systems, i.e. CaNISC, PMS, WPAS, Cancer Tracking Module (Tracker 7) for the following:

- National Cancer Audits for Wales - a Tier 1 Welsh Government requirement
- Collection and reporting to the existing standards for cancer, the All Wales Core and Site-specific minimum reporting requirements (see http://howis.wales.nhs.uk/sites3/page.cfm?orgid=769&pid=19419)
- Collection and reporting of data required for Cancer Waiting Times and Single Cancer Pathway as per DSCNs issued.

In conjunction with the above points for Health Boards/Trusts, it is also important to note that:

Interim changes are currently in development for WPAS and the Cancer Tracking Module (Tracker 7) to support the single cancer pathway data collection.

That data continues to be entered into the CWT fields within CaNISC, as many standard reports rely on the completion of those data items in report logic. Such reports continue to be used for many reporting purposes including national audit submissions.

# SPECIFICATION

## Information Specification

The data items required for National Cancer Data Standards for Wales – Site Specific – Breast and their equivalent labels in COSD V9.0, where there is an equivalent, are listed below.

Where the specification cites **NHS Wales Data Dictionary**, please refer to the Dictionary for the relevant guidance i.e. definition, format or code list.

For consistency, all dates listed in the Specification are standardised as ccyymmdd.

Where *D* is denoted in Status, this indicates that the information should be derived from another data item. This typically occurs with data items that are simply text representations of their code counterparts. Other Status codes are *M* (Mandatory), *R* (Required) – the data item should be recorded where applicable and *O* (Optional).

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**Core data items should be collected for all cancers**. To reduce replication of information, Core data items have not been listed in this site-specific Standard and users should refer to National Cancer Data Standards for Wales – Core (DSCN 2019/09)( http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20191210-DSCN%202019%2009-National%20Cancer%20Data%20Standards%20for%20Wales%20-%20Core-v1-0.pdf) for a list of Core requirements. However, in some cases, the site-specific application of Core data items may differ e.g. a particular tumour site may require additional or fewer codes to those already published in Core, or perhaps have additional business rules as to how the Core data item should be coded. Where this occurs, the Core data item will be replicated in the site-specific Standard with the respective additional site-specific detail. These are flagged in the following table with an * next to the data item name.

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## National Cancer Data Standards - Breast

| Data Item | Definition | Format | Code List (Code) | Code List (Text) | Status | COSD |
|---|---|---|---|---|---|---|
| **Breast - Referral. To carry additional Referral details for breast patients. (Multiple occurrences can be added as per core referrals)** | | | | | | |
| Breast Referral Patient Status | Status of referral presentation for the patient | Code List | 1 | Screen detected | R | N/A |
| | | | 2 | Symptomatic | | |
| **Breast - Triple Diagnostic Assessment. To carry diagnostic details for Breast Cancer. (One occurrence per group)** | | | | | | |
| Triple Diagnostic Assessment | Was a triple diagnostic assessment completed for the patient in a single visit, following initial referral? | Code List | 1 | Yes | M | Triple Diagnostic Assessment |
| | | | 2 | No | | |
| | | | 9 | Not Known | | |
| **Breast - Key Investigations - Imaging. To carry additional imaging details for breast patients** | | | | | | |
| Mammogram findings | Mammogram findings | Code List | 1 | Normal | R | N/A |
| | | | 2 | Benign | | |
| | | | 3 | Probably benign | | |
| | | | 4 | Probably malignant | | |
| | | | 5 | Malignant | | |
| Ultrasound findings | Ultrasound findings | Code List | 1 | Normal | R | N/A |
| | | | 2 | Benign | | |
| | | | 3 | Probably benign | | |
| | | | 4 | Probably malignant | | |
| | | | 5 | Malignant | | |
| **Breast - Patient. To carry additional details relating to the patient. (One occurrence per group)** | | | | | | |
| Discussion of Breast Conservation or Mastectomy | Was a discussion held with the patient regarding Breast Conservation or Mastectomy | Code List | Y | Yes | R | N/A |
| | | | N | No | | |
| | | | 9 | Not known | | |
| Date Breast Conservation or Mastectomy discussed | Record the date that discussions were held with the patient regarding Breast conservation or mastectomy | ccyymmdd | N/A | N/A | R | N/A |
| Discussion on Reconstruction options | Was a discussion held with the patient regarding Reconstruction options | Code List | Y | Yes | R | N/A |
| | | | N | No | | |

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| | | | 9 | Not known | | |
| Reason for No Reconstruction Options Discussion | Specify the reason for not undertaking a discussion regarding reconstruction options with the patient | Code List | 0 | Patient Choice - Not Wanted | R | N/A |
| | | | 1 | Patient Choice - Delayed Reconstruction | | |
| | | | 2 | Patient Unsuitable - Comorbidities | | |
| | | | 3 | Patient Unsuitable - BMI | | |
| | | | 4 | Patient Unsuitable - Smoking History | | |
| | | | 5 | Patient Unsuitable - Adjuvant Oncology | | |
| | | | 7 | Other | | |
| | | | 9 | Not Known | | |
| Date Reconstruction options were discussed | Record the date that discussions were held with the patient regarding reconstruction options | ccyymmdd | N/A | N/A | R | N/A |
| Provided with written/verbal information | Was the patient provided with Breast Conservation/Mastectomy/Reconstruction information | Code List | Y | Yes | R | N/A |
| | | | N | No | | |
| | | | 9 | Not recorded | | |
| **Breast - Patient - Associated Risk Factors. To carry additional details related to the patient for breast specific risk factors. (One occurrence per group)** | | | | | | |
| Hormone Replacement Therapy (HRT) Status | Record if the patient has ever received Hormone Replacement Therapy (HRT) | Code List | 1 | Never | R | N/A |
| | | | 2 | Less than 5 Years | | |
| | | | 3 | More than 5 years | | |
| Hormone Contraceptive Status | Record if the patient has ever received and taken any form of hormone contraceptive | Code List | 1 | Never | R | N/A |
| | | | 2 | Less than 5 Years | | |
| | | | 3 | More than 5 years | | |
| Previous Breast Biopsy | Record if the patient has had any previous breast biopsies taken | Code List | Y | Yes | R | N/A |
| | | | N | No | | |
| | | | 9 | Not Known | | |
| Gravida | NHS Wales Data Dictionary | max n2 | N/A | N/A | R | N/A |
| History of Breastfeeding | Did the patient breastfeed following the birth of the baby? | Code List | Y | Yes | R | N/A |
| | | | N | No | | |
| | | | 9 | Not Known | | |
| **Clinical Nurse Specialist & Risk Factor Assessment (NABCOP). To carry assessment details for National Audit of Breast Cancer in Older Patients** | | | | | | |

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| Fitness Assessment Indicator | Indicate if there was a Fitness Assessment carried out on the patient. If yes, please complete the following five data items. These assessments and questions are for patients aged 70 and over at diagnosis | Code List | Y | Yes | R | Fitness Assessment Indicator |
| | | | N | No | | |
| Fitness Assessment Date | The date the fitness assessment was completed | ccyymmdd | N/A | N/A | R | Fitness Assessment Date |
| Clinical Frailty Scale | Record the point on the Clinical Frailty Scale, as assigned by the appropriate clinician after discussion with the patient. | Code List | 1 | Very fit | R | Clinical Frailty Scale |
| | | | 2 | Well | | |
| | | | 3 | Managing Well | | |
| | | | 4 | Vulnerable | | |
| | | | 5 | Mildly Frail | | |
| | | | 6 | Moderately Frail | | |
| | | | 7 | Severely Frail | | |
| | | | 8 | Very Severely Frail | | |
| | | | 9 | Terminally Ill | | |
| Abbreviated Mental Test Score | Record the total Abbreviated Mental Test Score, this should be a score from 0 to 10 | max n2 | (0-10) | | R | Abbreviated Mental Test Score |
| CardioRespiratory Disease | Does the patient have severe cardiorespiratory disease?<br>Severe = Less than ordinary physical activity or rest causes tiredness, palpitation or shortness of breath | Code List | Y | Yes | R | CardioRespiratory Disease |
| | | | N | No | | |
| Other Non Breast Locally Advanced/Metastatic Malignancy | Does the patient have any other Non-Breast Locally Advanced/Metastatic Malignancy | Code List | Y | Yes | R | Other Non Breast Locally Advanced/Metastatic Malignancy |
| | | | N | No | | |
| **Breast - Pathology. To carry additional pathology site specific items for breast. (One occurrence per Path Report)** | | | | | | |
| DCIS (Ductal Carcinoma in Situ) Grade | If ductal carcinoma in situ is present, record the DCIS grade. This is the cytonuclear grade. | Code List | H | High | R | DCIS (Ductal Carcinoma in Situ) Grade |
| | | | I | Intermediate | | |
| | | | L | Low | | |
| | | | X | Not Assessable (Cannot be assessed) | | |

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| Whole size of tumour (invasive + DCIS) size | Whole size of tumour (invasive + surrounding DCIS, if DCIS extends >1 mm beyond invasive) (mm). For tumours without DCIS component this will be the same as invasive lesion size | max n3.max n2 (mm) | N/A | N/A | R | Whole size of tumour (invasive + DCIS) size |
| Grade of Differentiation (Pathological) * | Grade of Differentiation (Pathological) is the definitive grade of the tumour based on the evidence from a pathological examination<br><br>**Note:** In Core there is a code of G4 (Undifferentiated/anaplastic). That code is not applicable within the Breast site-specific standard. | Code List | G1 | Well differentiated | R | Grade of Differentiation (Pathological) |
| | | | G2 | Moderately differentiated | | |
| | | | G3 | Poorly differentiated | | |
| | | | GX | Grade of differentiation is not appropriate or cannot be assessed | | |
| DCIS/Pleomorphic or DCIS like LCIS Size | The size of the non-invasive tumour in mm. This is only required if there is no invasive component | max n3.max n2 (mm) | N/A | N/A | R | DCIS/Pleomorphic or DCIS like LCIS Size |
| Multifocal Tumour indicator | Is there more than one discrete tumour identified in the same breast | Code List | Y | Yes (Multiple invasive foci) | R | Multifocal Tumour Indicator (Breast) |
| | | | N | No (Localised) | | |
| | | | 9 | Not Known (Cannot be assessed) | | |
| ER (Oestrogen Receptor) Status | Oestrogen Receptor Status<br><br>**Note:** A positive score means that oestrogen is causing the tumour to grow, and a negative score means that the tumour is not driven by oestrogen | Code List | P | Positive (> or = 1%) | R | ER Status |
| | | | N | Negative (<1%) | | |
| | | | X | Not Performed | | |
| ER Allred Score | ER Allred score | an1<br><br>Range of 0 or 2 - 8. Range does NOT include 1 | N/A | N/A | O | ER Allred Score |
| PR (Progesterone Receptor) Status | To indicate whether the pathologist identified that the lesion was progesterone receptor positive. Measure of progesterone receptor expression. | Code List | P | Positive | R | PR Status |

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| | **Note:** This information is required regardless of whether the ER (Oestrogen Receptor) Status is Positive or Negative | | N | Negative | | |
| | | | X | Not performed | | |
| PR Allred Score | Record the PR Allred score if ER Status is negative<br><br>**Note:** This information is required regardless of whether the ER (Oestrogen Receptor) Status is Positive or Negative | an1<br><br>Range of 0 or 2 - 8. Range does NOT include 1 | N/A | N/A | R | PR Allred Score |
| HER2 Status | HER2 Immunohistochemical status (Human Epidermal Growth Factor Receptor 2). Where the initial result of this test is "Borderline", a further report will follow with result of the ISH test | Code List | N1 | Negative (0) | R | HER2 Status |
| | | | N2 | Negative (1+) | | |
| | | | B | Borderline (2+) | | |
| | | | P | Positive (3+) | | |
| | | | X | Not Performed | | |
| HER2 ISH Status | Record the result of the ISH (in situ hybridization) test.<br>This is only required if the initial HER2 status is 2 +/Borderline | Code List | P | Positive (Amplified) | R | HER2 ISH Status |
| | | | N | Negative (Non-amplified) | | |
| | | | B | Borderline | | |
| | | | X | Not Performed | | |
| Metastasis Extent Code (Lymph Node) | For single node positivity, specify micrometastatic status as follows: ITC's are only classified as node negative | Code List | 2 | Micrometastasis | R | Metastasis Extent Code |
| | | | 3 | Isolated tumour cells (ITC's) | | |
| | | | 4 | Macrometastasis | | |
| | | | 9 | Not known | | |
| Distance to Margin | Distance to closest relevant margin (mm). Distance to nearest margin whether invasive or non invasive | max n2.max n1 | N/A | N/A | R | Distance to Margin |
| Cytology (Breast) | Cytology opinion (Breast) | Code List | C1 | Inadequate/unsatisfactory specimen | R | Cytology (Breast) |
| | | | C2 | Benign | | |
| | | | C3 | Uncertain | | |
| | | | C4 | Suspicious of malignancy | | |
| | | | C5 | Malignant | | |

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|---|---|---|---|---|---|---|
| Cytology (Node) | Cytology opinion on axillary lymph node | Code List | LC1 | Inadequate/unsatisfactory specimen | R | Cytology (Node) |
| | | | LC2 | Benign | | |
| | | | LC3 | Uncertain | | |
| | | | LC4 | Suspicious of malignancy | | |
| | | | LC5 | Malignant | | |
| Core Biopsy (Breast) | Needle core biopsy opinion | Code List | B1 | Unsatisfactory/normal tissue only | R | Core Biopsy (Breast) |
| | | | B2 | Benign | | |
| | | | B3a | Uncertain malignant potential without epithelial atypia | | |
| | | | B3b | Uncertain malignant potential with epithelial atypia | | |
| | | | B4 | Suspicious | | |
| | | | B5a | Malignant (In situ) | | |
| | | | B5b | Malignant (Invasive) | | |
| | | | B5c | Malignant (Not assessable) | | |
| Core Biopsy (Node) | Needle core biopsy opinion on axillary lymph node | Code List | LB1 | Inadequate/unsatisfactory | R | Core Biopsy (Node) |
| | | | LB2 | Normal/Benign | | |
| | | | LB3 | Uncertain | | |
| | | | LB4 | Suspicious | | |
| | | | LB5 | Malignant | | |
| Date of Breast/Node Biopsy/Cytology | Record the date the Biopsy/Cytology was taken | ccyymmdd | N/A | N/A | R | N/A |
| **Other - Breast. Prognostic Index** | | | | | | |
| NPI Score | Nottingham Prognostic Index Score (calculated from tumour size, grade and lymph node involvement) | max n2.max n2 | N/A | N/A | M | NPI Score |
| Oncotype DX Test Status | Record if the Oncotype DX Genomic test has been undertaken for the patient. This test analyses the genomic profiling of the tumour which can determine how a cancer is likely to behave and respond to treatment | Code List | 1 | Performed | R | N/A |
| | | | 2 | Not Performed | | |

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| Oncotype DX Recurrence Score | Record the Oncotype DX recurrence score. This is used to provide information about how likely (or unlikely) the breast cancer is to come back, and a predictive test, since it predicts the likelihood of benefit from chemotherapy or radiation therapy treatment.<br>(Range 0-100) | n3<br>Range 0-100 | N/A | N/A | O | N/A |
| Prosigna Score | Record the Prosigna Score. | n3<br>Range 0-100 | N/A | N/A | O | N/A |
| Prosigna Score Risk Score | Record the Risk Score from the Prosigna Score | Code List | 1 | Low Risk (0-40) Lymph node negative | O | N/A |
| | | | 2 | Intermediate Risk (41-60) Lymph node negative | | |
| | | | 3 | High Risk (61-100) Lymph node negative | | |
| | | | 4 | Low Risk (0-40) Lymph node positive | | |
| | | | 5 | High Risk (41-100) Lymph node positive | | |
| EndoPredict (EP clin score) | Record the EndoPredict EP clin Score | n5<br>Range 1.1-6.2<br>with up to 4 digits after decimal point (eg 3.3287) | N/A | N/A | O | N/A |