

**National Breast and
Ovarian Cancer Centre**
Breast cancer staging and treatment
Data linkage report
2010

Breast cancer staging and treatment

Data linkage report

2010

Breast cancer staging and treatment: Data linkage report 2010
was developed for National Breast and Ovarian Cancer Centre by Victorian Cancer Registry

National Breast and Ovarian Cancer Centre (NBOCC)
Level 1 Suite 103/355 Crown Street Surry Hills NSW 2010
Tel: 61 2 9357 9400 Fax: 61 2 9357 9477 Freecall: 1800 624 973
Website: www.nbocc.org.au

© National Breast and Ovarian Cancer Centre 2010

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part might be reproduced by any process without prior written permission from National Breast and Ovarian Cancer Centre. Requests and enquiries concerning reproduction and rights should be addressed to National Breast and Ovarian Cancer Centre at director@nbocc.org.au.

Copies of this booklet can be downloaded or ordered from National Breast and Ovarian Cancer Centre's website: www.nbocc.org.au.

Recommended citation

National Breast and Ovarian Cancer Centre. Breast cancer staging and treatment: Data linkage report. National Breast and Ovarian Cancer Centre, Surry Hills, NSW, 2010.

Disclaimer

National Breast and Ovarian Cancer Centre does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. National Breast and Ovarian Cancer Centre develops material based on the best available evidence, however it cannot guarantee and assumes no legal liability or responsibility for the currency or completeness of the information.

National Breast and Ovarian Cancer Centre is funded by the Australian Government Department of Health and Ageing.

Acknowledgements

Breast cancer staging and treatment: Data linkage report 2010 was prepared by Ms Helen Farrugia, Director Registry Systems, Cancer Epidemiology Centre, Victorian Cancer Registry, Cancer Council Victoria.



The development of this report was overseen by an expert working group convened by NBOCC:

| | |
|------------------------|--|
| Professor Graham Giles | Director, Cancer Epidemiology Centre, Victorian Cancer Registry |
| Ms Narelle Grayson | Manager, Central Cancer Registry, Cancer Institute NSW |
| Dr Paul Jelfs | Assistant Statistician, Health and Social Analysis Branch, Australian Bureau of Statistics |
| Dr Tim Threlfall | Principal Medical Officer & Manager, Western Australian Cancer Registry |

National Breast and Ovarian Cancer Centre staff

| | |
|-------------------------------------|--|
| Associate Professor Christine Giles | Deputy CEO and Director, Policy and Government Relations |
| Professor David Roder | Manager Population Health |
| Ms Alison Pearce | Program Manager |
| Ms Heidi Wilcoxon | Program Manager |
| Ms Trenna Morris | Senior Project Officer |
| Ms Phillipa Hastings | Project Officer |

Table of Contents

| | | |
|------|--|-----------|
| 1.0 | SUMMARY | 3 |
| 2.0 | THE RESULTING DATA | 4 |
| 2.1 | <i>TNM Staging Assumptions</i> | <i>4</i> |
| 2.2 | <i>VCR TNM Stage Data 2006-2007</i> | <i>4</i> |
| 2.3 | <i>Eligible Cases Not Staged</i> | <i>4</i> |
| 3.0 | TNM STAGE QUALITY EVALUATION..... | 5 |
| 4.0 | COMPARISON OF VCR STAGE WITH SIMILAR DATA FROM EXTERNAL ORGANISATIONS..... | 5 |
| 4.1 | <i>Comparison with data captured within a Victorian Integrated Cancer Service (ICS) region</i> | <i>5</i> |
| 4.2 | <i>Comparison with data captured within a Melbourne hospital oncology unit.....</i> | <i>6</i> |
| 4.3 | <i>Comparison of resulting TNM stage data at the population level.....</i> | <i>7</i> |
| 4.4 | <i>Comparison of VCR TNM stage data with national and international Extent of Disease data</i> | <i>8</i> |
| 5.0 | QUALITY OF TNM “T” AND TNM “N” VALUES CAPTURED BY THE VCR | 9 |
| 5.1 | <i>Incomplete nodes</i> | <i>9</i> |
| 5.2 | <i>No nodal information available</i> | <i>10</i> |
| 5.3 | <i>No regional lymph nodes removed for examination.....</i> | <i>10</i> |
| 5.4 | <i>Regional nodes sampled but no nodes were identified.....</i> | <i>10</i> |
| 5.5 | <i>Nodal information not actively chased</i> | <i>11</i> |
| 5.6 | <i>No nodal information found following investigation.....</i> | <i>11</i> |
| 6.0 | ACCURACY OF REPORTING INFORMATION ON METASTATIC DISEASE | 12 |
| 7.0 | TNM STAGE DERIVATION - ALGORITHM AND BUSINESS RULES | 13 |
| 8.0 | TNM STAGE DERIVATION ASSUMPTIONS..... | 15 |
| 9.0 | BARRIERS TO TNM STAGING BY POPULATION BASED CANCER REGISTRIES | 16 |
| 9.1 | <i>Completeness of pathology notifications</i> | <i>16</i> |
| 9.2 | <i>Completeness and accuracy of hospital notifications</i> | <i>16</i> |
| 9.3 | <i>Completeness of staging documentation in the medical record.....</i> | <i>16</i> |
| 10.0 | RECOMMENDATIONS TO IMPROVE CAPACITY FOR TNM STAGING BY POPULATION BASED CANCER REGISTRIES | 17 |
| 11.0 | REFERENCES | 18 |

1.0 SUMMARY

Population cancer registries in Australia have well developed cancer-reporting networks that include the notification of pathology reports for cancer and notifications from hospitals within the Registry jurisdiction. Information provided from these sources is consolidated to enable Registries to publish population wide cancer incidence, prevalence, mortality and survival with no information on cancer stage at diagnosis.

The Tumour, Node and Metastases (TNM) staging classification system is often referred to as the gold standard for staging. Information required to derive TNM stage comes from the same source records used for cancer registration and yet it has been outside the scope of most Australian Registries to incorporate this gold standard staging information in its data collection

The objectives of this project are:

- (1) To develop and test a means of collecting TNM stage information for breast cancer by population based cancer registries.
- (2) To evaluate the accuracy/completeness of the resulting TNM data
- (3) Commence preparatory work for Phase 2: to collect treatment data through linkage with administrative databases and ancillary means, and to demonstrate the usefulness of these data for describing broad patterns of primary course of care by stage.

The work undertaken to achieve these objectives suggests that deriving TNM stage data from routinely captured cancer notifications is very achievable. The Victorian Cancer Registry (VCR) has been able to TNM stage 96% of eligible breast cancer incident cases diagnosed in 2006 and 2007.

The resulting TNM stage data have been through an extensive quality assurance program to validate their accuracy. It has been shown that 93.1% of the stage data was derived from comprehensive information. The results of the unit record comparison with hospital based collections support the capacity of population registries to produce quality stage data. In fact it could be said that population registries are better placed to derive stage information as the hospital based collections only include information on events that occurred within the hospital which was the main reason for discordance between the data sets compared. Population registries have access to information from multiple sources that can be consolidated into a single case record, increasing the capacity to report more reliable information about a case.

Barriers to TNM stage data capture are considered briefly in this report. The biggest problem for VCR in deriving this TNM stage data for breast cancer was the time consuming task of having to chase the required missing pathology reports. Under-reporting by Victorian hospitals was also a problem but to a lesser degree.

Recommendations to improve capacity for population-based registries to capture TNM stage data have also been included. The recommendations included are thoughts based on the VCR experience in preparing this TNM stage data. Some of the suggestions may not be relevant to Registries in other jurisdictions.

The final data set produced from this project should be considered reliable for linkage to other data sets to obtain treatment information to enable analysis of broad patterns of primary care by cancer stage.

2.0 THE RESULTING DATA

The Victorian Cancer Registry (VCR) has been able to stage 96% of all eligible breast cancer incident cases in accordance with the International Union Against Cancer (UICC) Tumour Nodes and Metastases (TNM) classification system 6th edition. Ineligible breast cancer incident cases include the following categories:

- (i) Paget's Disease with or without DCIS
- (ii) Phyllodes tumour & other sarcoma
- (iii) Death certificate only notifications

The ineligible breast cancers represent 2.1% of breast cancer incident cases for 2006-2007.

2.1 TNM Staging Assumptions

The resulting TNM stage data were derived using the following assumptions:

- If MX assume M0
- If NX assume N0

Justification for this decision can be found in section 8 of this report which further describes the TNM stage derivation assumptions.

2.2 VCR TNM Stage Data 2006-2007

The resulting TNM stage data is shown in table 1 below.

Table 1 TNM Stage by year of diagnosis

| | 2006 | 2007 | TOTAL |
|--------------|--------------|--------------|--------------|
| Stage 1 | 1407 (47.3%) | 1343 (44.9%) | 2750 (46.1%) |
| Stage 2 | 1093 (36.8%) | 1123 (37.6%) | 2216 (37.2%) |
| Stage 3 | 363 (12.2%) | 391 (13.1%) | 754 (12.6%) |
| Stage 4 | 111 (3.7%) | 133 (4.4%) | 244 (4.1%) |
| Total | 2974 | 2990 | 5964 |

2.3 Eligible Cases Not Staged

The proportion of cases unable to be staged is low at 4%. It is possible that by improving the completeness of notifications submitted to the VCR and improving the completeness of staging documentation in medical records that this proportion could be reduced by a further 1 – 2%.

The profile of cases unable to be staged by VCR is shown in table 2 below.

Table 2 Breast cancers not staged 2006-07 by basis of diagnosis

| | 0-49 yrs | 50-59 yrs | 60-69 yrs | 70-79 yrs | 80-89 yrs | 90+ yrs | Total |
|--------------------------|-----------|-----------|-----------|-----------|-----------|-----------|------------|
| Microscopic confirmation | 20 | 16 | 20 | 32 | 73 | 37 | 198 |
| Clinical diagnosis only | 4 | 0 | 4 | 5 | 14 | 13 | 40 |
| Total | 24 | 16 | 24 | 37 | 87 | 50 | 238 |

3.0 TNM STAGE QUALITY EVALUATION

The quality of the resulting TNM stage data has been evaluated. There were four approaches within the evaluation process to undertake comparisons at different levels as follows:

- (1) Unit record comparison of the resulting TNM stage data with cases in data sets staged by external organizations.
- (2) Comparison of the resulting population TNM stage data with similar data in other populations.
- (3) Unit record quality of T & N values using a quality indicator developed by the VCR.
- (4) The accuracy of TNM 'M' data reporting to the VCR was measured through medical record review on approximately 10% of all cases diagnosed in 2006.

4.0 COMPARISON OF VCR STAGE WITH SIMILAR DATA FROM EXTERNAL ORGANISATIONS

The resulting TNM stage data has been compared with other data sets at two levels. Firstly a comparison of TNM stage data captured by VCR was undertaken with data from two hospital-based collections. These comparisons were undertaken at the unit record level. In addition the resulting population based TNM stage data has been compared with TNM stage data from Canada and Extent of Disease data from the NSW Cancer Registry and the US SEER program.

4.1 Comparison with data captured within a Victorian Integrated Cancer Service (ICS) region

In November 2007 the Victorian Department of Health (DOH) funded the Evaluation of Cancer Outcomes (ECO) trial, which involves the capture of the Cancer (clinical) Data Set Specification (DSS) as defined on the Meteor metadata registry. The ECO trial will capture the Cancer (clinical) DSS for 2008 and 2009 cancers diagnosed and treated within the Barwon South West Regional Integrated Cancer Service (BSWRICS). This region averages 1800 newly diagnosed cancers annually, which represents approximately 8% of cancers diagnosed in Victoria.

ECO data available for comparison with VCR TNM stage data include breast cancers diagnosed between January and August 2008 and limited to cases managed at Barwon Health, Andrew Love Radiotherapy Centre in the Barwon area and Warrnambool and Portland hospitals in the South West.

Table 3 on the following page shows the results of our TNM stage data comparison for the 60 cases available for comparison. There were 3 cases (5%) that differed, the reason for these differences are:

- (i) VCR had 2 cases with confirmed M = 1 not known to the BSWRICS ECO data team. Information about these metastases came from (a) a private hospital in the region not included in the ECO data collection and (b) a hospital outside the region. (The private hospital has recently agreed to participate in the ECO trial and data from that centre will soon be incorporated).

- (ii) BSWRICS ECO had one case staged as 2A and unable to be staged by VCR, this was a clinical stage only as this patient did not have surgery. (For this particular case VCR was able to confirm the accuracy of the clinical stage as there was sufficient information in the clinical notes section of the core biopsy report)

Table 3: Results of comparison between VCR and BSWRICS ECO data

| ECO Stage | VCR Stage | | | | | | | Total |
|--------------|-----------|-----------|----------|----------|----------|----------|----------|-----------|
| | 1 | 2A | 2B | 3A | 3C | 4 | No stage | |
| 1 | 22 | | | | | 1 | | 23 |
| 2A | | 13 | | | | 1 | 1 | 15 |
| 2B | | | 9 | | | | | 9 |
| 3A | | | | 5 | | | | 5 |
| 3C | | | | | 3 | | | 3 |
| 4 | | | | | | 5 | | 5 |
| No stage | | | | | | | 0 | 0 |
| Total | 22 | 13 | 9 | 5 | 3 | 7 | 1 | 60 |

4.2 Comparison with data captured within a Melbourne hospital oncology unit

Table 4 below shows the results of our TNM stage data comparison between a hospital-based data collection and the VCR. A total of 93 cases diagnosed between 2006 and 2007 were used for the comparison. The hospital data manager undertook the comparison and provided VCR with the results. There were 2 cases (2%) that differed, the reason for these differences are:

- (i) VCR under staged one stage 4 case recorded by the oncology unit. The stage 4 status was confirmed. Reason for error in VCR data set was that evidence of metastatic disease was not reported via the routine cancer registration process from that hospital's Health Information Unit.
- (ii) The hospital breast oncology unit dataset had under staged one case, this was a private patient treated in the public hospital and evidence of metastatic disease and hospice referral was not in the record. This patient died of their disease within 5 months of diagnosis.

Table 4: Results of comparison between VCR and Hospital oncology unit data

| Hospital stage | VCR STAGE | | | | | | Total |
|----------------|-----------|-----------|----------|----------|----------|----------|-----------|
| | 1 | 2A | 2B | 3A | 3C | 4 | |
| 1 | 43 | | | | | | 43 |
| 2A | | 22 | | | | | 22 |
| 2B | | | 7 | | | | 7 |
| 3A | | | | 6 | | | 6 |
| 3C | | | | | 8 | 1 | 9 |
| 4 | | | 1 | | | 5 | 6 |
| Total | 43 | 22 | 8 | 6 | 8 | 6 | 93 |

4.3 Comparison of resulting TNM stage data at the population level

The VCR TNM stage data has been compared with the only TNM stage data identified for comparison. This data came from Prince Edward Island and New Brunswick in Canada. The results of this comparison demonstrate similar proportions in each stage group in the two populations. Results are shown in figures 1 and 2 below.

Figure 1: Female Breast Cancer Stage Distribution

Prince Edward Island and New Brunswick (Canada), 2003-2004 and Victoria 2006 and 2007

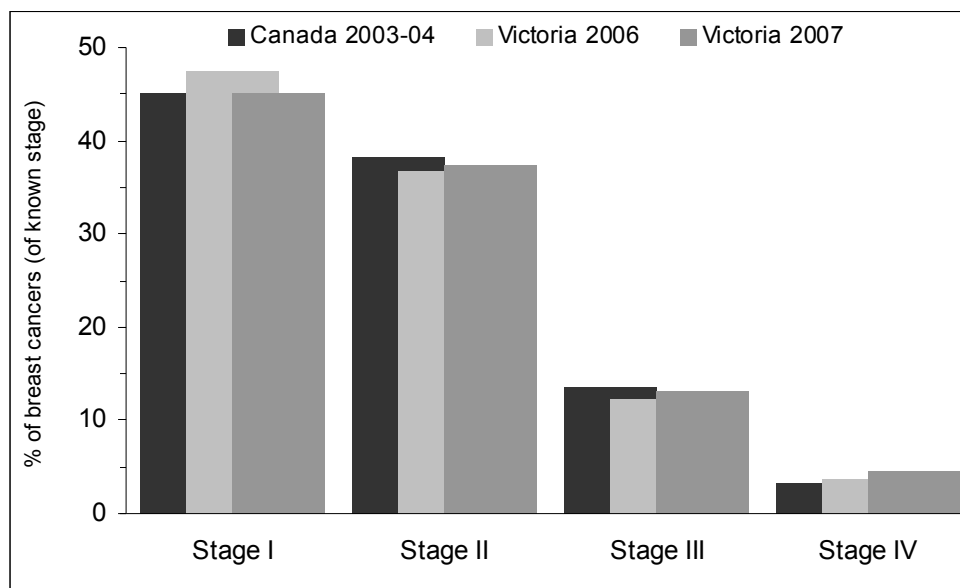
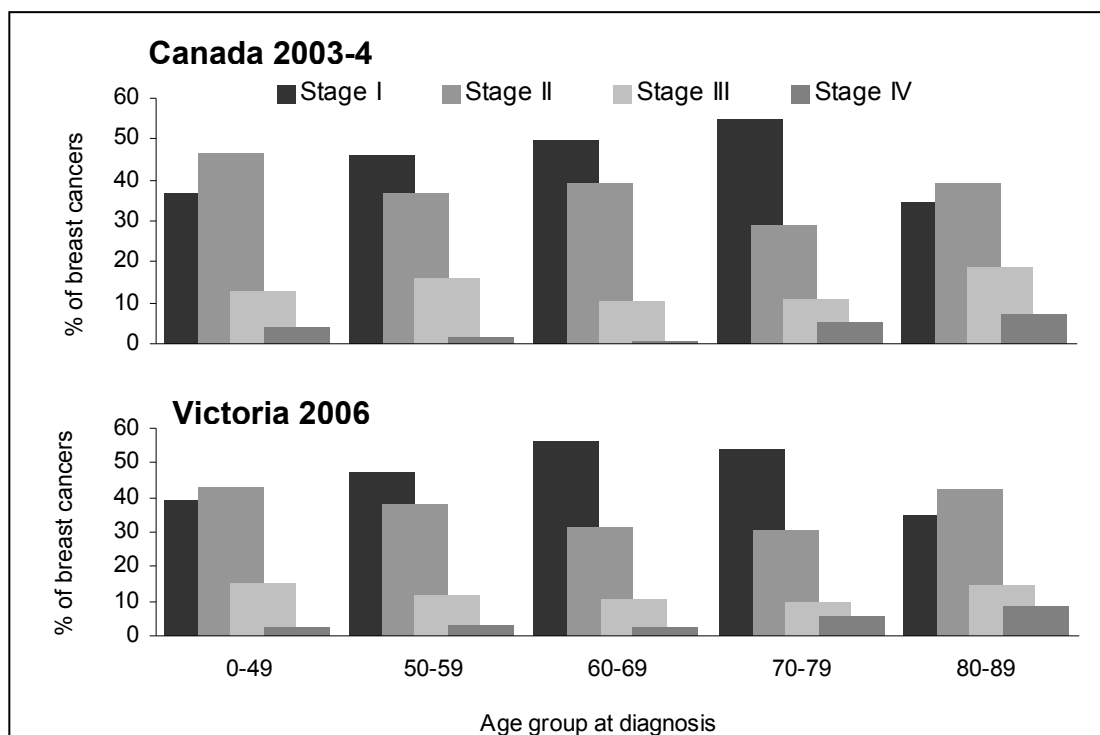


Figure 2: Female Breast Cancer Stage Distribution by age group (0-89 yrs)

Prince Edward Island and New Brunswick (Canada), 2003-2004 and Victoria 2006 and 2007



4.4 Comparison of VCR TNM stage data with national and international Extent of Disease data

The resulting TNM stage data for Victoria has been compared with breast cancer Extent Of Disease (EOD) data published by the NSW Cancer Registry and the US SEER program. All data collections included in this comparison define TNM stage or extent of disease within four months of diagnosis. Only cases with known stage have been included for comparison.

The TNM stage data for Victoria was mapped to the EOD categories in accordance with the definitions published in the NSW Incidence and Mortality Report 2004 as follows:

- TNM Stage 1 plus node negative Stage 2 cases were mapped to 'Localised' EOD
- TNM Stage 3 plus node positive Stage 2 cases were mapped to 'Regional' EOD
- TNM Stage 4 cases were mapped to 'Distant' EOD

The result of the comparison is shown in Table 5 below.

Table 5 Extent of Disease comparisons by Region for cases with known stage

| | Localised | Regional | Distant |
|--------------------|-----------|----------|---------|
| Victoria 2006-2007 | 60.2% | 35.7% | 4.1% |
| NSW 1995-2004 | 58.9% | 36.1% | 5.0% |
| SEER* 2000-2006 | 62.8% | 32.3% | 4.9% |

** SEER figures shown have been adjusted to show proportions of patients of known stage*

The accuracy of the Victorian TNM stage data is supported by the results of the quality evaluation process. It is well known that extent of disease data is less detailed than the TNM staging method but reassuring to see little difference between the two classification systems in distinguishing localized and regional disease.

A test of proportions was performed comparing the NSW EOD data and the VCR TNM stage data. To enable this comparison to be undertaken, an annual average number of cases in each EOD group were calculated for NSW and compared with data from Victoria for 2007. No significant difference was found for any of the EOD categories.

The 2007 data for Victoria was chosen for this comparison, as it is believed there was less under-reporting by Victorian hospitals in that time period and therefore more likely to be complete for information about the presence of metastases at time of diagnosis.

5.0 QUALITY OF TNM “T” AND TNM “N” VALUES CAPTURED BY THE VCR

A quality indicator has been developed to measure the completeness of pathology notifications submitted to the VCR by specimen type to enable TNM stage derivation. This indicator supports the quality assurance program for breast cancer stage information held by VCR.

Indicator definitions are:

1. **Complete** – this requires receipt of local excision and/or mastectomy specimen report with either: sentinel node sampling with 0 positive nodes OR 1 or more nodes positive from sentinel node sampling plus a subsequent axillary dissection specimen report.
2. **Incomplete nodes** – this is applied to cases with 1 or more positive nodes and where the total nodes sampled is <6. *(100% of these cases are further investigated and either re-allocated an updated completeness category or a reason qualifier is coded)*
3. **No nodal information provided** - *(these cases would have had local excision and/or mastectomy specimens submitted – not all these cases are further investigated)*
4. **Nodal information only** - *(these cases would not have had local excision and/or mastectomy specimens submitted)*

Table 6 below shows the indicator values for the 96% of data able to be staged for the 2006 and 2007 breast cancer incidence data.

Table 6

| Completeness category | Proportion |
|--------------------------------|------------|
| Complete | 93.1% |
| Incomplete nodes | 2.3% |
| No nodal information available | 4.4% |
| Nodal information only | 0.2% |

5.1 Incomplete nodes

Cases in the “Incomplete nodes” category are still allocated a TNM N value based on the known nodal information. Table 7 categorises the resulting TNM N value by the reason qualifier that was generated following investigation.

The VCR maintains a table of surgeon by hospital by usual pathology laboratory to help coders identify the relevant pathology laboratory to approach for possible missing information. Following investigation 25% of the “incomplete nodes’ category can be explained further. For the remaining 75%, the “Incomplete nodes” category remains unchanged however given the extensive pathology-chasing program it is considered more likely that no further axillary sampling was undertaken for these cases.

Table 7 on the following page shows the further completeness qualifier obtained following investigation. This information is shown by the allocated TNM-N category which shows that 55% of the cases where no further nodal pathology could be found had tumours <= 1mm in diameter.

Table 7 Incomplete nodes 'qualifier' by TNM N value

| | N = 1mic | N = 1A | N = 2A | Total |
|--|-----------|-----------|----------|------------|
| No further regional nodes removed | 1 | 1 | 0 | 2 |
| Axilla sampled with none or few nodes identified | 26 | 6 | 1 | 33 |
| No further nodal pathology found | 57 | 46 | 0 | 103 |
| Total | 84 | 53 | 1 | 138 |

5.2 No nodal information available

Cases in this category have a TNM N value of "X" (unknown) The majority (67%) of the cases in this category were investigated via approach to laboratories and/or hospitals for further information about regional lymph node status. This is a routine process undertaken by VCR and not a new procedure as a result of the TNM staging project.

Information in Table 8 provides the number and proportion of cases not actively chased for additional information due to a VCR business rule and shows the further qualifiers for those cases that were actively followed up. The VCR business rule is explained further below along with the definitions for the 'qualifier' groups shown in the table.

Table 8: Missing nodal information 'qualifier'

| Missing nodal information category | No. cases | Proportion |
|---|-----------|------------|
| No regional lymph nodes removed for examination | 18 | 6.9% |
| Regional nodes sampled but no nodes were identified | 12 | 4.6% |
| Nodal information not actively chased | 87 | 33.3% |
| No nodal information found following investigation | 144 | 55.2% |

5.3 No regional lymph nodes removed for examination

The cases in this category were confirmed by review of the hospital medical record either through a site visit by a VCR breast coder or by the hospital Health Information Manager following a request from the VCR. The number of cases in this category is small (N=18), the two common reasons recorded were (i) patient refused nodal examination and (ii) not indicated due to co-morbidity.

5.4 Regional nodes sampled but no nodes were identified

For the cases in this category, the VCR found evidence of regional lymph node surgery but the pathology report indicated no nodes were identified in the specimen.

5.5 Nodal information not actively chased

This category was developed by VCR to reduce the pathology chasing workload. Cases falling in this category include:

- (i) Cases where patient age is ≥ 90 years at diagnosis or having nursing home residential address
- (ii) Cases with tumour size ≤ 3 mm

The decision not to actively chase missing pathology for this category was based on work undertaken in processing 2005 breast cancer incidence data where greater than 90% of cases in this category did not result in the location of any nodal pathology reports, presumed to be a result of no regional lymph nodes removed for examination.

Within this group, 54 of the 87 cases had a tumour size ≤ 3 mm, of these 27% were DCIS on core biopsy with microinvasive tumour found on local excision that did not include sentinel node sampling.

5.6 No nodal information found following investigation

This is the largest group within the 'no nodal information' available to support TNM stage derivation. All cases in this group were actively chased for possible missing pathology reports. The profile of these cases can be seen in Table 9, which shows the TNM T category, by diagnosis age group.

More than half of this group are ≥ 80 years at age of diagnosis. Although the VCR pathology report-chasing program could have missed some reports for this group, it is more likely that no examination of regional lymph nodes was undertaken in the majority of cases.

Table 9

| TNM T category | 0-49 yrs | 50-69 yrs | 70-79 yrs | 80+ yrs | Total |
|-----------------------|-----------------|------------------|------------------|----------------|--------------|
| 1A | 1 | 3 | 1 | 1 | 6 |
| 1B | 0 | 15 | 8 | 8 | 31 |
| 1C | 3 | 5 | 7 | 38 | 53 |
| 2 | 0 | 6 | 8 | 35 | 49 |
| 3 | 0 | 0 | 0 | 2 | 2 |
| 4B | 0 | 1 | 1 | 1 | 3 |
| ALL | 4 | 30 | 25 | 85 | 144 |

6.0 ACCURACY OF REPORTING INFORMATION ON METASTATIC DISEASE

VCR coding staff reviewed the medical records of 317 breast cancer cases reported to the VCR in 2006 to determine:

- (1) The accuracy of metastatic disease reporting from cancer registration submissions to the VCR
- (2) The capacity to report information on the presence or absence of metastatic disease at diagnosis from hospital records.

A total of six hospitals were selected for survey, the proportion of cases reviewed represents approximately 10% of all cases diagnosed in 2006. The profile of each hospital selected for record review is shown in table 10 below.

Table 10

| | Medical Oncology Services | Radiation Oncology Services | Breast Surgery | Region | Public/Private |
|------------|---------------------------|-----------------------------|----------------|-------------|----------------|
| Hospital 1 | Y | Y | Y | Melbourne | Public |
| Hospital 2 | Y | Y | Y | Melbourne | Public |
| Hospital 3 | Y | N | Y | Regional | Private |
| Hospital 4 | Y | N | Y | Outer Metro | Public |
| Hospital 5 | N | N | Y | Outer Metro | Private |
| Hospital 6 | Y | N | Y | Melbourne | Private |

The medical record review compared the VCR TNM M value for each case with information found in the medical record about the presence or absence of metastases to determine the accuracy of information reported to the VCR.

In the sample reviewed, the proportion of cases with metastatic disease information being under reported was 0.9% while in 0.6% of cases the presence of metastatic disease at diagnosis was reported in error. The presence of metastatic disease was confirmed for 11 known cases, 3% of the sample reviewed. The results of the review are shown in table 11 below.

Table 11: Impact of TNM M value following medical record review

| Impact on TNM M value | Hospital 1 | Hospital 2 | Hospital 3 | Hospital 4 | Hospital 5 | Hospital 6 | ALL |
|-----------------------|------------|------------|------------|------------|------------|------------|------------|
| MX unchanged | 17 (28%) | 15 (32%) | 24 (48%) | 8 (18%) | 41 (68%) | 30 (53%) | 135 (43%) |
| M0 unchanged | 16 (27%) | 16 (34%) | 18 (36%) | 19 (43%) | 19 (32%) | 14 (25%) | 102 (32%) |
| M1 unchanged | 4 (7%) | 2 (4%) | 2 (4%) | 1 (2%) | 0 | 2 (2%) | 11 (3%) |
| MX to M0 | 19 (32%) | 13 (28%) | 6 (12%) | 16 (37%) | 0 | 10 (18%) | 64 (20%) |
| MX to M1 | 2 (3%) | 1 (2%) | 0 | 0 | 0 | 0 | 3 (1%) |
| M1 to M0 | 2 (3%) | 0 | 0 | 0 | 0 | 0 | 2 (1%) |
| Total | 60 | 47 | 50 | 44 | 60 | 56 | 317 |

The medical record review also captured information about the presence or absence of recorded staging information in the hospital record. The results indicate that stage is poorly documented in medical records. When stage information is recorded in the medical record it was usually found in the correspondence section. This finding was

validated by the data collection team working on the BSWRICS ECO data capture project discussed previously in this report. While this finding might be a cause of frustration for data managers looking to abstract stage information from medical records, it does not appear to have impacted on the resulting TNM stage data given the favourable comparison with other data collections. The results of this component of the medical record review are shown in table 12 below.

Table 12: Number of records containing stage information by hospital

| | Stage data present | T & N data only | No stage data |
|--------------|--------------------|-----------------|------------------|
| Hospital 1 | 8 (13%) | 16 (27%) | 36 (60%) |
| Hospital 2 | 17 (36%) | 15 (32%) | 15 (32%) |
| Hospital 3 | 5 (10%) | 3 (6%) | 42 (84%) |
| Hospital 4 | 3 (7%) | 2 (4%) | 39 (89%) |
| Hospital 5 | 0 | 0 | 60 (100%) |
| Hospital 6 | 10 (18%) | 0 | 46 (82%) |
| TOTAL | 43 (14%) | 36 (11%) | 238 (75%) |

7.0 TNM STAGE DERIVATION - ALGORITHM AND BUSINESS RULES

There is more than one method that population registries can apply to enable the capture of TNM stage data in the Registry data set. Factors that would influence choice include:

- the method of data capture i.e. electronic data or paper forms,
- work flow practice i.e. single source registration processing or case level processing,
- the capacity of existing Registry software and access to technical support to develop and maintain scripts to enable the auto derivation of stage from the individual data elements coded.

The VCR has adopted a semi automated TNM stage derivation method. New data elements were created to collect information required for TNM stage derivation algorithms, including evaluation fields.

Data elements used in TNM stage derivation and evaluation include:

Existing data elements used

Morphology code
 Tumour size in mm
 Total regional lymph nodes examined
 Total regional lymph nodes positive
 Specimen code

New data elements created for staging

Tumour extension to chest wall
 Oedema (including, peau d'orange), or skin ulceration or satellite skin nodules
 Regional lymph node micrometastasis
 Internal mammary node involvement
 Isolated Tumour cells (ITC)

Data capture rules

("Y" is captured if condition is true)
("Y" is captured if condition is true)
("Y" only captured if NO lymph node metastasis is > 0.2mm and < 2mm)
("Y" is captured if condition is true)
("Y" only captured if any lymph node has metastasis not more than 0.2mm AND no

| | |
|---|---|
| Sentinel lymph nodes examined | <i>other regional lymph node with metastasis >0.2mm)</i> <i>Number. Sentinel nodes identified is captured</i> |
| Sentinel lymph nodes positive | <i>Number of sentinel nodes positive (excluding. ITC) is captured</i> |
| Other regional lymph nodes examined | <i>Number of other regional lymph nodes identified is captured</i> |
| Other regional lymph nodes positive | <i>Number of other regional lymph nodes positive (excluding ITC) is captured</i> |
| Ipsilateral infraclavicular lymph node positive | <i>("Y" is captured if condition is true)</i> |
| Ipsilateral supraclavicular lymph node positive | <i>("Y" is captured if condition is true)</i> |

New data elements created for evaluation

| | |
|------------------------|--|
| Complete status | <i>See category definitions on P.8 of this report</i> |
| Completeness qualifier | <i>1 No <u>further</u> regional nodes removed</i> <i>2 No regional lymph nodes removed</i> <i>3 Axilla sampled – none or few nodes identified</i> <i>4 Nodal information not actively chased</i> <i>5 No further nodal pathology found following pathology chasing procedure</i> |

The complete status field is auto populated for some of the case records and uses the specimen code with other staging data fields. This auto populates for more than 50% of cases. The algorithm is not provided in this report as it is unlikely to be of use to any other Registry.

ALGORITHM used to derive TNM T category

| | |
|---|----------|
| If Morphology = 8530 (Inflammatory carcinoma) | T = 4D |
| If Extension to chest wall is true | T = 4A |
| If Oedema (inc. peau d'orange) or skin ulceration or satellite skin nodules is true | T = 4B |
| If Extension to chest wall is true AND Oedema (inc. peau d'orange) or skin ulceration or satellite skin nodules is true | T = 4C |
| For cases with no T code allocated the size field is now used | |
| If size = M (VCR category for microinvasive tumour with size not reported) | T = 1mic |
| If size <= 1mm | T = 1mic |
| If size >= 1mm and <= 5 mm | T = 1A |
| If size >= 5mm and <= 20mm | T = 1B |
| If size >= 20 mm and <= 50mm | T = 2 |
| If size >= 50mm | T = 3 |
| If size cannot be calculated based on above rules | T = X |

All cases where T = X are checked by VCR coders. The edits metafile used by VCR has been expanded to include TNM T edits to ensure any information manually updated follows TNM T derivation business rules.

ALGORITHM used to derive TNM N category

Prior to the derivation of the TNM 'N' values, a VCR developed script is run to populate the 'Total regional lymph nodes examined' and 'Total regional lymph nodes positive' fields as follows:

- The values in the fields 'sentinel lymph nodes examined' and 'other regional lymph nodes examined' are summed and the result auto populates the 'Total regional lymph nodes examined' field
- The values in the fields 'sentinel lymph nodes positive' and 'other regional lymph nodes positive' are summed and the result auto populates the 'Total regional lymph nodes examined' field

The algorithm

| | |
|--|---------|
| If 'Total regional lymph nodes positive' is 0 | N = 0 |
| If 'Ipsilateral infraclavicular lymph node positive' is true | N = 3A |
| If 'Ipsilateral supraclavicular lymph node positive' is true | N = 3C |
| If 'Regional lymph node micrometastasis' field is true | N = 1mi |
| If 'Total 'regional lymph nodes positive' is <=3 | N = 1A |
| If 'Total regional lymph nodes positive' is between 4 and 9 | N = 2A |
| If 'Total regional lymph nodes positive is >=10 | N = 3A |
| If 'Internal mammary node involvement' is true | N = X |
| If 'Specimen code' does not indicate nodal sampling or dissection has occurred | N = X |

All cases with 'internal mammary node involvement' = Y are checked and the TNM N codes are manually allocated.

All cases with missing nodal pathology specimen codes are chased according to the business rules with TNM 'N' values manually updated if further information is obtained. The edits metafile used by VCR has been expanded to include TNM 'N' edits to ensure any TNM 'N' information manually updated complies with TNM 'N' derivation business rules.

TNM M category data capture rules

The presence of metastatic disease may be provided on incidence and prevalence cancer registration submissions to the VCR. An M value of 1 is only captured if evidence of metastatic disease is reported within 4 months of diagnosis.

8.0 TNM STAGE DERIVATION ASSUMPTIONS

The TNM stage derivation is based on the UICC TNM Classification of Malignant Tumours 6th edition. For final stage derivation, the VCR has made the following assumptions:

- If TNM 'M' value is X it is assumed TNM M = 0
- If TNM 'N' value is X it is assumed TNM N = 0

These two assumptions are based on the results of the quality evaluation as follows:

MX = M0 - although the proportion of staging information documented in the medical records examined seems low at 25%, it is thought that significant events such as suspicious findings or cancer involvement in areas other than the primary site are likely to be considered more worthy of recording as opposed to the documentation of normal findings. This assumption has also been documented in the Collaborative Staging Manual and Coding Instructions used by the SEER program, the Centres for Disease Control and Prevention National Program of Cancer Registries (CDC/NPCR) and the North American Association of Central Cancer Registries (NAACCR).

Furthermore the validation of metastatic disease reporting to the VCR suggests under reporting is low and the resulting TNM Stage 4 data compared favourably with stage data in other populations.

NX=N0 – Given the comprehensive program to chase all possible missing pathology reports it is more likely that N is X as no regional lymph nodes were removed for microscopic examination. The only groups of cases excluded from the pathology-chasing program are defined on pages 10-11 of this report and these two groups represent 1% of cases with no nodal pathology available for TNM stage derivation. The favourable TNM stage data comparison with other data sets also supports this assumption.

9.0 BARRIERS TO TNM STAGING BY POPULATION BASED CANCER REGISTRIES

9.1 Completeness of pathology notifications

If mandatory pathology reporting to population-based registries is complete, the T and N values of the TNM stage classification system is easily derived. It is frustrating for coding staff to have to spend an extraordinary amount of their time chasing missed pathology notifications. The VCR undertakes TNM staging for, breast, prostate and colorectal cancers, the pathology chasing component of VCR coding staff workload is estimated to utilise between 1.0 to 1.5 EFT per year.

9.2 Completeness and accuracy of hospital notifications

Hospital notifications are the primary source of information for non-microscopically confirmed metastases at diagnosis. The cancer registration process varies from State to State and not all jurisdictions capture information about metastases at diagnosis or Extent of Disease at diagnosis. Staging cannot be undertaken from pathology reports alone. To enable staging data at the national level may require some Registries to expand the data elements captured by cancer registration.

The completeness of hospital notifications has also been identified as a problem. This has been attributed to the manual method used by more than half of Victorian hospitals to identify eligible cases for cancer reporting. This may not be an issue for Registries in other jurisdictions.

9.3 Completeness of staging documentation in the medical record

While the lack of staging information recorded in the medical record did not seem to impact on VCR's ability to derive TNM stage data, it limited our capacity to validate its accuracy.

It should be noted that as approximately 46% of cases were early stage cancers therefore staging work up is unlikely to have been undertaken which could explain the absence of information in the medical record.

10.0 RECOMMENDATIONS TO IMPROVE CAPACITY FOR TNM STAGING BY POPULATION BASED CANCER REGISTRIES

There are many strategies that could be implemented to improve both data quality and data availability to support accurate TNM stage captured by population-based registries. The implementation of any strategy to achieve this end needs to consider cancer-reporting burden for hospitals and pathology laboratories as well as costs to implement and maintain quality systems.

In terms of accurate TNM T and TNM N data, an obvious solution is to implement technology that would increase the sensitivity and the specificity of the case finding capacity to help pathology laboratories comply with their statutory cancer-reporting obligation. An example would be the **E-Path** software developed by AIM (Artificial Intelligence in Medicine). This solution would have a large one off cost, ongoing maintenance costs with no impact on cancer reporting burden.

To improve the quality of information about metastatic disease which registries would rely on to capture information on metastases not microscopically confirmed, a quality standard could be developed for statutory cancer reporting by hospitals. In addition to the development and implementation of any standard, an audit process would be required to monitor compliance to the standard.

Consideration could be given to the possibility of incorporating any standard within the "Evaluation and Quality Improvement Program (EQUIP) which is linked to the hospital accreditation process.

Another model for consideration is one used within Victoria to audit the quality of hospital morbidity data. The Funding and Information Policy Branch of the Department of Health Victoria administer this program. The audit program has a 3-year cycle during which all public hospitals would be audited for data quality at least once in each 3-year cycle. There have been some suggestions that the VCR may be able to piggyback on to this process for a fee.

11.0 REFERENCES

Canadian Cancer Society/National Cancer Institute of Canada: *Canadian Cancer Statistics 2007*, Toronto, Canada, 2007 pg 84 [<http://www.cancer.ca>]

Threll T, Wittorff J, Padabphet B: **Collection of population-based cancer staging information in Western Australia – a feasibility study.** *Population Health Metrics* 2005, 3:9: [<http://www.pophealthmetrics.com/content/3/1/9>]

National Cancer Institute, Fast Stats: An interactive tool for access to SEER cancer statistics: *Surveillance Research Program, National Cancer Institute*, [<http://seer.cancer.gov/faststats>] (Accessed on 26/08/2009)]

Link:

<http://seer.cancer.gov/faststats/selections.php?run&output=2&data=1&statistic=12&year=200903&race=1&sex=3&age=1&series=cancer&cancer=553>

Tracey EA, Chen S, Baker D, Bishop J, Jelfs P. *Cancer in New South Wales: Incidence and Mortality 2004*. Sydney: Cancer Institute NSW, November 2006 pg 25 [<http://www.cancerinstitute.org.au>]

Hopgood N **A world first in cancer data collection trial.** *Health Information Management Journal*, Vol 28 No2 2009, pg 55-57

Collaborative Staging Task Force of the American Joint Committee on Cancer. *Collaborative Staging Manual and Coding Instructions, version 1.0*. Jointly published by American Joint Committee on Cancer (Chicago, IL) and U.S. Department of Health and Human Services (Bethesda, MD), 2004. NIH Publication Number 04-5496

Barracrough H, Morrell S, Arcorace M, McElroy HJ & Baker DF. Degree of spread artefact in the New South Wales Central Cancer Registry. *Aust NZ J Public Health* 2008; 32(5) 414-416.



www.nbocc.org.au

© National Breast and Ovarian Cancer Centre 2008.
Funded by the Australian Government Department of Health and Ageing

