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MEASURING THE PERFORMANCE OF CANCER SERVICES

GUEST EDITORIAL

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How do I measure the performance of cancer services? Just answer five questions:

- what am I trying to achieve?
- what tools that work do I have for achieving it?
- how can I tell whether they are doing their job?
- what data do I need to find out?
- how will I collect them?

Your objectives tell you what you are trying to achieve. They should go beyond just 'preventing cancer' or 'increasing survival' to include less readily measurable but equally as important objectives like 'increasing quality of life', 'having satisfied patients', 'increasing the equity of cancer care', and 'increasing the efficiency of cancer care'.

Increasingly, the tools that work are detailed and supported in evidence-based guidelines, like those produced by the Australian Cancer Network (melanoma, colorectal cancer, cancer genetics services, with more in the pipeline) and the National Breast Cancer Centre (early breast cancer, breast cancer pathology reporting, psychosocial care, advanced breast cancer). Knowing whether or not they are working requires the simplest and most economical set of indicators that address:

- the process, whether the tools are in place and being used the way they should be;
- the risk factors, early indicators of a successful outcome, like a reduction in smoking prevalence or an improvement in stage distribution for colorectal cancer;
- the outcomes, like lung cancer incidence, recurrence of melanoma, survival from breast cancer, and quality of life in those who may still ultimately die from cancer.

Analysis of these indicators will tell you the data that you need to collect, and more often than not these data will already be collected routinely (death data, hospital inpatient statistics, cancer registry, the NSW Health Survey), be available by way of some simple

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enhancement (abstraction of, say, breast cancer size, grade and nodal status from pathology reports notified to the cancer registry or linking cancer registry to inpatient statistics data) or by methods for which there are already ample precedents (a clinical cancer data collection, a patterns of care survey, or a survey of patients themselves).

The papers in this special cancer issue show how easy it is. Helen Moore and colleagues outline a structured and rigorous way of arriving at a parsimonious and simple set of indicators for measuring the performance of clinical services for melanoma control. Sounds difficult? Not really. It has to be done with care, but it required only two meetings of about two hours with the expert advisory group to reach a firm consensus on what should be measured. That beats endless meetings debating 'what data we should collect' and risking an uncollectable, unmanageable and often unusable data collection in the end. In other papers, Churches and Lim show what can be achieved in measuring breast cancer services through the linkage of the cancer registry and inpatient statistics collections and Kricker shows what can be done as well when data from pathology reports are added; Taylor and colleagues report the results of linkage of BreastScreen data with cancer registry data to produce interval cancer rates, the key measure of mammographic screening performance; and Macansh shows what the Pap Test Register has to offer on performance indicators for cervical screening. In an earlier issue (*NSW Public Health Bulletin* 2001; 12 (1): 2–6), Moore and colleagues illustrated the value of the NSW Health Survey in measuring risk factors for cancer.

To move from where we are now in measuring the performance of cancer services in NSW to where, ideally, we should be still requires the introduction of standardised clinical cancer information systems in all the main cancer treatment centres in the State, which are linked to the NSW Central Cancer Registry. Requiring less development, but equally as important, in measuring and improving the performance of cancer services in NSW are:

- a regular program of surveys of cancer care 'consumers'
- a planned approach to analysis of linked cancer registry and inpatient statistics data sets
- a continued program of enhanced analysis of cancer registry data
- patterns of care surveys 'to fill the gaps' in population coverage
- continuation of full exploitation of the richness of the Cancer Registry, Pap Test Register and BreastScreen data sets.

WORKING OUT WHAT TO MEASURE: MELANOMA SERVICES

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This article reports on a process to identify a priority set of indicators to measure the performance of services for melanoma, outlined in the Australian Cancer Network's *Guidelines for the Management of Cutaneous Melanoma* published in June 1997.[1] Melanoma is a major cause of morbidity in NSW. In 1998, the year for which there is the most recently available data, it was the fourth most common cancer diagnosed in NSW residents, with 1,565 cases diagnosed in males and 1,119 in females;[2] accounting for 362 deaths, three per cent of all deaths caused by cancer. Melanoma was the most common cancer in males and females aged 15–39 years in 1998.

The importance of reducing this morbidity and associated mortality was recognised in 1994 by the Cancer Expert Working Group when they set goals and targets for NSW to reduce the incidence of, and mortality due to, melanoma.[3] To assist in achieving these goals, a health outcomes approach was applied to melanoma to identify areas for intervention across the continuum of care from prevention through to treatment and palliation or rehabilitation.[4]

HEALTH OUTCOMES APPROACH TO REDUCE MORBIDITY AND MORTALITY FROM MELANOMA IN NSW

Specific opportunities to reduce morbidity and mortality due to melanoma are presented in Figure 1. In general, the intervention points that will produce health gains for the population and for people with melanoma are:

- preventing the development of melanoma by reducing exposure to known causal agents: for example, high intensity intermittent exposure to UV radiation;
- detecting and diagnosing cutaneous melanoma as early as possible;
- giving appropriate psychosocial support to patients with suspected or confirmed melanoma and their families;
- managing primary operable melanoma in accordance with international best practice;
- managing advanced melanoma in accordance with international best practice;
- providing best practice palliative care to those who will die from melanoma.

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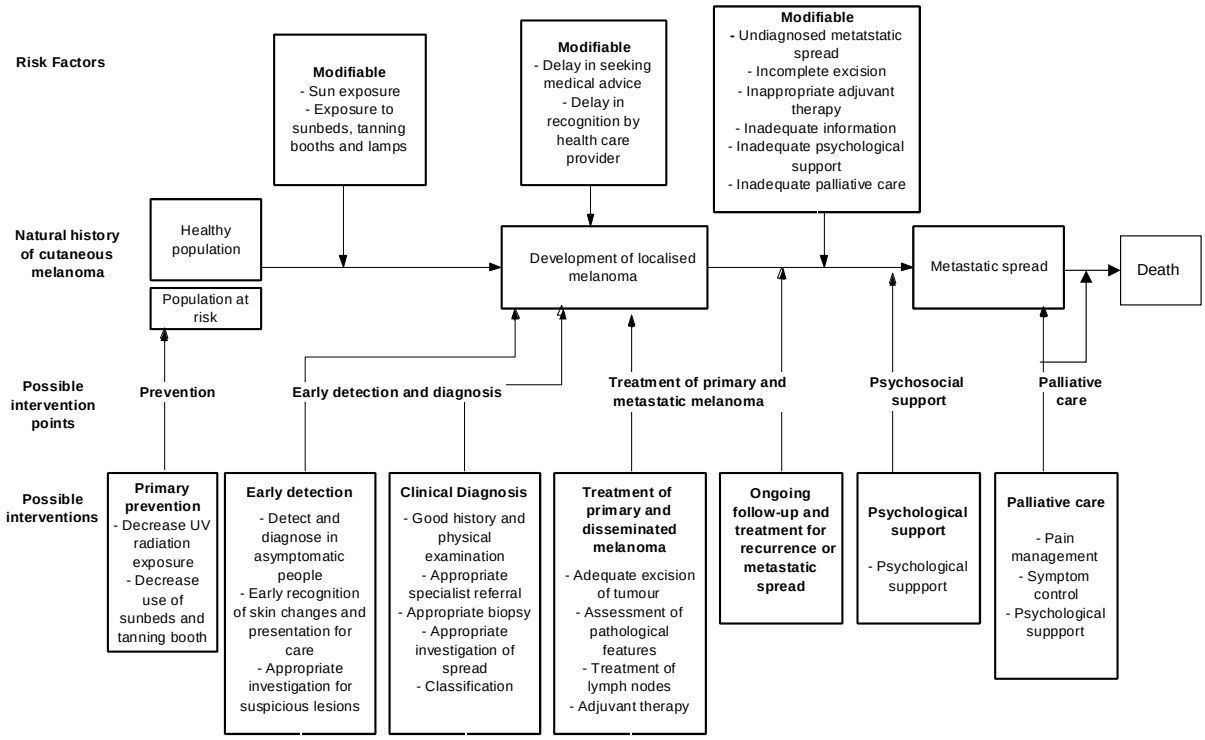
FIGURE 1

MODIFIABLE RISK FACTORS, INTERVENTION POINTS, AND INTERVENTIONS TO REDUCE THE INCIDENCE OF, AND MORBIDITY AND MORTALITY FROM, CUTANEOUS MELANOMA



The NSW Department of Health, in conjunction with the NSW Cancer Council, has implemented a range of interventions to prevent skin cancers under a series of skin cancer control strategic plans.[5,6] Recommendations on best practice in relation to the clinical intervention points are outlined in the Australian Cancer Network's *Guidelines for the Management of Cutaneous Melanoma* published in June 1997.[1] The National Health and Medical Research Council endorsed these Guidelines in December, 1999.[7] The Guidelines provide advice to a range of service providers on the principles of melanoma management based on the best evidence currently available. They cover the spectrum of care from prevention through to early detection and diagnosis, management and palliation.

Research into guideline development has shown that the way guidelines are developed, implemented and monitored determines how effective they are in changing clinical practice.[8] A critical aspect of effective guideline implementation is the integration of the guidelines into a quality improvement process. This process entails monitoring the effect of the guidelines on practice, feedback of information collected and readjustment of implementation where necessary to improve practice and ultimately outcomes.

Efficient monitoring requires the development of an efficient set of performance indicators. The development, and particularly the implementation, of performance indicators is a time consuming and expensive process. The cost-effectiveness of the information proposed for collection must be considered, and the indicators should be prioritised according to the expected benefits of their use in quality improvement. The priority set of indicators to measure the performance of services for melanoma, outlined in the Australian Cancer Network's *Guidelines for the Management of Cutaneous Melanoma*, may form the basis for the development of a melanoma module for Clinical Cancer Registries, which are currently being implemented in NSW (see article by Noworytko et al. in the February 2001 issue of the *NSW Public Health Bulletin* Volume 12, Number 2).

STEPS IN DEVELOPING A PRIORITY SET OF INDICATORS FOR MELANOMA CLINICAL SERVICES

The model used to develop an expanded set of indicators for monitoring melanoma clinical services was that proposed by the Quality and Outcomes Monitoring Working Party for the Optimising Cancer Management Initiative.[9] This process involved preparing a set of objectives for care and associated interventions; developing indicators for each objective; and assessing the benefits and costs of the indicators. Indicators were ranked in order of priority and the ranked list was further refined. The details and results of this process are as follows:

Preparing a set of general objectives and associated intervention types

These objectives described the outcomes to which melanoma services are directed and the interventions required, on either theoretical or empirical grounds, to

TABLE 1

MELANOMA CLINICAL INDICATOR FRAMEWORK: OBJECTIVES AND INTERVENTIONS FOR REDUCING MORBIDITY AND MORTALITY DUE TO CUTANEOUS MELANOMA

Objective	Description
Objective 1	**Reduce the incidence of cutaneous melanoma**
	No interventions were specified, as the focus of the indicator identification process was primarily clinical.
Objective 2	**Detect and diagnose cutaneous melanoma at the earliest possible stage**
Interventions	
2.1	Detect and diagnose melanoma in asymptomatic people;
2.2	Detect and diagnose melanoma in symptomatic people at the earliest possible stage;
2.3	Minimise the excision of benign melanocytic naevi;
2.4	Investigate symptoms and signs of melanoma in accordance with international best practice;
2.5	Report on pathology findings in accordance with international best practice.
Objective 3	**To achieve and maintain optimal psychosocial adaptation in people with suspected or confirmed melanoma and their families**
Interventions	
3.1	Promote optimism in patients in regard to their management and quality of life;
3.2	Give psychosocial support to people who have been diagnosed with melanoma and their families;
3.3	Inform people who have been diagnosed with melanoma of their diagnosis, the prognosis of their cancer, the proposed treatment and likely outcomes;
3.4	Involve people who have been diagnosed with melanoma in making decisions regarding treatment to the level they want to be involved;
3.5	Diagnose and treat psychological morbidity in accordance with best practice principles.
Objective 4	**Manage primary operable melanoma in accordance with international best practice**
Interventions	
4.1	Ensure management decisions are based on pathological features;
4.2	Ensure management of specific types and sites of melanoma is in accordance with international best practice;
4.3	Ensure patients with melanoma have appropriate follow-up organised.
Objective 5	**Manage locoregionally advanced melanoma in accordance with best practice principles**
Interventions	
5.1	Ensure management decisions are based on pathological features;
5.2	Ensure management of lymph nodes is in accordance with international best practice;
5.3	Ensure patients with locoregionally advanced melanoma have appropriate follow-up organised.
Objective 6	**Manage patients with disseminated melanoma in accordance with international best practice**
Interventions	
6.1	Ensure access to appropriate surgical, radiotherapeutic and chemotherapeutic services for patients with disseminated melanoma in whom anti-tumour therapy is judged to offer potential benefit in quality survival;
6.2	Ensure access to palliative care for people with disseminated melanoma and their carers when quality of life (including physical, social, emotional, spiritual or financial aspects), is impaired by the disease;
6.3	Ensure palliative care services are of the best quality and are in accordance with international best practice;
6.4	Improve multidisciplinary management of patients with advanced melanoma.

achieve them. Table 1 summarises the objectives and interventions used as a framework to guide development of the performance indicators.

Developing indicators for each objective

These were outcome indicators, or measures of the outcome described by the indicator (for example, death or health-related quality of life); risk indicators (determinants of the outcome); or process indicators (measures of success in implementing an intervention for which there is evidence of effectiveness in achieving the measures of outcome).

The final list contained 71 indicators that were further defined by the population and data items required for each indicator and the methods for collecting the necessary data.

Assessing the benefits and costs of the proposed indicators

This involved reviewing the available literature to assess the effectiveness of the underlying interventions and hence the quality of the evidence for the process indicators. The potential data sources for each indicator were identified as a proxy for the cost of data collection.

Of the 71 indicators, 13 were from sources which are currently available; 29 were from current sources that required further work to provide the data in a useable form (such as linking data from the NSW Central Cancer Registry with the Inpatients Statistics Collection); and 29 were from sources which required extensive developmental work (such as Clinical Cancer Registries).

When attempting to define the costs and benefits of each indicator, it became clear that there was little information available to make these estimates rigorously. Therefore opinions of an expert advisory group, the NSW Melanoma Clinical Indicators Working Party, were sought to assess the information on effectiveness and costs and provide an expert opinion on where the greatest health gain would be achieved at the least cost by monitoring the indicator. Most of the members of the Working Party were directly involved in the clinical management of melanoma and

represented a range of oncology specialties, psychiatry, pathology and epidemiology.

Ranking the indicators

To determine an order of priority for the indicators, each member of the NSW Melanoma Clinical Indicators Working Party ranked the list of indicators using the criteria listed in Table 2. Each Working Party member then scored each indicator on a 1 to 4 scale with the following importance:

- use of the indicator would be **highly** cost-effective in improving melanoma outcomes;
- use of the indicator would be **moderately** cost-effective in improving melanoma outcomes;
- use of the indicator would be **weakly** cost-effective in improving melanoma outcomes;
- use of the indicator would **not** be cost-effective in improving melanoma outcomes.

Fourteen of the 17 members of the Working Party participated in the exercise. The fourteen scores for each indicator were summed and indicators ranked in ascending order of the total scores.

Identifying priority indicators

The Working Party members reviewed the results of the ranking exercise, agreed on the order by priority of the list of indicators, and selected a minimum set of cost-effective indicators and associated data collection vehicles. This part of the process was largely based on the expert opinion of Working Party members.

A cut-off line was arbitrarily drawn in the indicator list. This included 30 indicators 'above the line', consisting of the top ranked 27 indicators and three indicators not ranked as highly, but for which data were currently available.

From this starting point, all Working Party members discussed which indicators above the cut-off line should be removed and which indicators from below the cut-off line should be included. The arguments for including an indicator that was not ranked in the top 30 were that the information provided by the indicator was unique, or there was relatively strong evidence of health gain or it was cost-effective to collect.

This process resulted in the identification of 43 priority indicators from the original list of 71 candidate indicators. These are priority indicators are listed in Table 3 with availability of their data source.

TABLE 2

MELANOMA CLINICAL INDICATORS: CRITERIA FOR RATING EACH INDICATOR

Each member of the Melanoma Clinical Indicators Working Party was asked to use the following criteria to evaluate the cost-effectiveness of each indicator:

The Intervention

- how effective the intervention underlying the indicator is in improving health or quality of life;
- the strength of evidence that the intervention does produce a beneficial outcome;
- the extent of current variation in clinical practice from best practice, as measured by the indicator.

The Indicator

- the quality of the indicator including validity, measurement accuracy, timeliness in relation to events measured, responsiveness to change in practice and stability of quality over time;
- the potential usefulness of the indicator in moving current practice towards best practice;
- the feasibility of measuring the indicator;
- the cost of measuring the indicator.

Equity

Can the indicator be used to measure and promote equity of service or outcome in relation to characteristics such as socioeconomic status, place of residence, indigenous status and country of birth?

A broad concept of equity is intended here, not just access to services. It should include:

- inequitable distribution of knowledge about health and health services;
- inequitable distribution of health and ill health;
- inequitable quality or outcome of health care.

CONCLUSION

This paper describes a process that aimed at defining a minimum set of indicators to monitor key aspects of services for melanoma in NSW. These indicators are relevant to clinicians and clinical practice; related to the most important aspects of clinical practice; could potentially assist with changing practice through feedback; and allowed the monitoring of variations in practice that may affect patient outcomes. When clinical cancer information systems begin to operate, it is hoped that subsets of these indicators may be measured—and reported on regularly—both statewide and at major cancer treatment centres.

In summary, the process involved systematically developing an extended list of indicators measuring the desired outcomes of care for melanoma, either directly or indirectly, as processes of care known or thought to be effective in producing those outcomes. These indicators were placed in order of priority through consensus of a group of experts informed by evidence of the effectiveness of interventions targeted by the indicators and the likely costs of measuring them. The process required the participation of a multidisciplinary group that met twice and was responsible for individually assessing the extended list of indicators and collectively agreeing on priority indicators.

The process was systematic, explicit and documented; it focused on areas of greatest health gain; it was evidence-based; and it involved stakeholders. It allows for the cost of implementing data collection systems to be more reliably estimated, as it assists in specifying the system outputs and functions. It also assists in generating evidence on the effectiveness of particular clinical interventions, as it provides information about the relative importance, clinically, of monitoring the outcomes of these interventions and it highlights the most important information gaps.

TABLE 3

LIST OF MELANOMA CLINICAL INDICATORS IN PRIORITY ORDER

Indicator	Data source availability*
1. Age, sex and site specific, and age-adjusted incidence of melanoma.	1
2. Proportion of newly diagnosed melanomas that are in-situ, .0.75mm, 0.76-1.50mm, 1.51-3.00mm and > 3mm thick, and median Breslow thickness.	1
3. Proportion of people with newly diagnosed melanomas with localised disease at diagnosis.	1
4. Age and sex specific and age-adjusted mortality from melanoma.	1
5. Proportion of people at high risk of melanoma who are participating in a skin surveillance program.	2
6. Proportion of high risk individuals identified as such by their self, doctor or other family member.	2
7. Proportion of people at high risk of melanoma who are undertaking monthly skin self-examination.	2
8. Proportion of adults who have been asked if they have a family history of melanoma.	2
9. Proportion of people referred to cancer genetic services for melanoma, with a genuinely higher familial risk.	1
10. Proportion of genetic tests performed that detect high-risk mutations for family history of melanoma.	1
11. Stage-specific and stage-adjusted survival after diagnosis of melanoma.	3
12. Proportion of patients with a non-facial melanoma less than 1 mm thick who have any type of closure other than a primary closure (Including those with excision margins greater than 1 cm and which result in skin grafts or flaps).	2
13. Proportion of people with locoregionally advanced or disseminated melanoma who are referred for treatment of the disease to a centre specialising in the treatment of melanoma, and where multidisciplinary care is available.	2
14. Proportion of patients with melanomas 1 to 3 mm thick on the trunk or above the elbow or knee who have a skin graft or flap repair to close the wound.	2
15. Proportion of patients with disseminated melanoma who stay 25 days or more in hospital in their last 100 days of life.	2
16. Proportion of patients with mucosal melanoma referred to a speciality clinic or clinician.	1
17. Proportion of melanoma specimens that are diagnosed with a shave or punch biopsy.	2
18. Proportion of histopathological reports on melanoma that include information on tumour thickness, Clark level and margins.	2
19. Proportion of melanomas submitted for histopathological diagnosis by total excision with margin of 2mm or more and to the upper layer of fat	2
20. Age specific rates of histopathological diagnosis of melanocytic naevi to that of melanomas.	2
21. Proportion of pathology request forms that include complete information on: patient identification; clinical details of the lesion (size, site, history of lesion etc); history of previous melanoma; and provisional clinical diagnosis.	2
22. Proportion of people with newly diagnosed melanoma who sought medical advice within four weeks of noticing skin changes.	2
23. Proportion of people with newly diagnosed melanoma who had diagnosis made within four weeks of first reporting relevant symptoms to a doctor.	2
24. Proportion of people diagnosed with melanoma who report not receiving enough information on melanoma, their diagnosis and prognosis, the treatments available and their likely outcomes.	2
25. Proportion of patients who are optimistic that they and their disease will be managed in the most effective and caring way.	2
26. Proportion of patients diagnosed with clinical levels of anxiety, depression or abnormal illness behaviour who are referred to a counselling service.	2
27. Proportion of patients who are optimistic that they will be able to maintain a good quality of life.	2
28. Proportion of people who report having unmet needs in relation to their family and carer's fears, coping and access to support.	2
29. Quality of life of people diagnosed with melanoma, and their carers by disease status at the time of measurement.	2
30. Proportion of patients with an unmet need for help with physical symptoms or emotional stress due to their melanoma.	2
31. Proportion of patients with melanoma who have undetected clinical levels of anxiety, depression or abnormal illness behaviour.	2
32. Proportion of patients who died from melanoma who were offered appropriate 24 hour nursing or medical services for palliative care in the home.	2
33. Proportion of primary melanomas correctly excised or re-excised with margins indicated by tumour thickness measurement and type (including desmoplastic melanoma with neurotropism who have excision margins 1 cm greater than the usual margins).	3
34. Proportion of patients with invasive melanoma with the margin of excision between 1cm and 3cm.	3
35. Proportion of patients with locoregionally advanced or disseminated melanoma who have multi-disciplinary care involving a surgeon, medical oncologist, radiation oncologist and palliative care specialist.	3
36. Proportion of people with disseminated melanoma who have a timely referral to a palliative care service.	3
37. Proportion of people in whom therapeutic node dissection was carried out by a surgeon with specific training in this procedure.	3
38. Proportion of people with suspicious lymph nodes who have fine needle aspiration of the suspicious nodes.	3
39. Proportion of patients who have a node dissection within two weeks of detection of nodal metastases.	3
40. Proportion of patients with melanoma less that 2mm thick who have CT, MRI or PET scans.	3
41. Proportion of patients with melanoma greater than or equal to 1 mm thick who are included in an approved clinical trial.	3
42. Proportion of primary health care workers treating a patient with locoregionally advanced or disseminated melanoma who feel they have not been given adequate information on the specialist's management of the patient.	3
43. Proportion of GPs who use surface microscopy when examining suspicious pigmented lesions.	3

* Data source availability: 1 = Currently available; 2 = Existing source but more work required; 3 = Extensive developmental work required.

Members of the Working Party contributed about six hours each, including time spent on the ranking exercise and in meetings. Preparatory work by a project officer and manager was time consuming and included the drafting of the framework and indicators, a discussion paper, and preparing and analysing the results of the ranking exercise. Despite efforts to minimise the time spent by the clinical experts, three of the 17 Working Party members did not participate in the ranking exercise.

Delays in developing clinical information systems to support indicators may undermine the processes of developing minimum data sets to monitor the quality and outcomes of patient care. Recently, health information initiatives have been given a fresh impetus by the recommendations of the NSW Health Council,[10] and the NSW Government's Action Plan for Health.[11] Consequently, the time between the development of priority sets of indicators and availability of data should be reduced.

We think that the benefits of following this process of developing indicators, if realised, would justify the costs. The process provides an assurance from the data users about what should and could be measured. Therefore, we think that it ensures that resources spent on collecting data are spent giving the best possible information about the quality of services.

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THE ROLE OF THE NSW PAP TEST REGISTER IN MONITORING THE CERVICAL SCREENING PROCESS IN NSW

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In 1993, the Steering Group on Quality Assurance in Screening for the Prevention of Cancer of the Cervix recognised that cervical cytology registers were uniquely placed to provide comprehensive information that could be used to monitor and improve the quality of cervical screening.[1] This article describes the NSW Pap Test Register, and how the data that it collects is used to monitor the performance of the NSW Cervical Screening Program. The register was established in 1996 as a central, comprehensive and confidential database of Pap test and cervical histology results for NSW women. It has a number of important functions including the collation of information that can be used to measure, monitor and improve the cervical screening process.

The Register is managed by the NSW Cancer Council and is an integral part of the NSW Cervical Screening Program. It is jointly funded by the NSW Department of Health and the Commonwealth Department of Health and Aged Care. As part of the NSW Cervical Screening Program, the Register aims to reduce the incidence of and mortality from cervical cancer by increasing participation in and improving the performance of cervical screening. The Register contributes to this aim by providing complete, accurate and timely data which can be used to measure key areas of the Program's performance.

REGISTER DATA

The Public Health Act 1991 determines that pathology laboratories must inform the NSW Pap Test Register of the results of all cervical cancer tests, Pap tests and cervical histology for NSW women. Demographic data for all

TABLE 4

DATA VARIABLES COLLECTED BY THE NSW PAP TEST REGISTER

Woman's name and address
Date of birth
Date of the test
Whether the test was for screening or diagnostic purposes
Results of the test
Provider number of the person who performed the test
Name of the laboratory and the laboratory accession number allocated to the test.

TABLE 5

CERVICAL SCREENING PATHWAY

Five inter-related steps:

1. Recruitment of women at risk,
2. Competent taking of Pap tests by health practitioner,
3. Laboratory processing of tests,
4. Notification and explanation of results,
5. Management of women with screen detected abnormalities.

these women, except those who choose not to participate, are forwarded to the Register. During the last two years the rate of non-participation in the Register was 2.2 per cent of all tests. Data variables collected by the Register under the Public Health Act are listed in Table 4.

Currently, 52 laboratories in five states and territories process cervical cancer tests for NSW women. These laboratories are electronically linked to the Register. More than 13,000 Pap test results are received by the Register each week, and more than 95 per cent are received within 15 working days of being reported.

Timely, complete and accurate data are important for all the Register's functions. Validation and quality checks are incorporated at each step of data processing to ensure that the Register's record is complete. To help ensure that the data are accurate, feedback loops return the data to laboratories as screening histories, which assist in reporting current tests and quality assurance activities.

MEASURING THE SCREENING PROCESS

Register data are used by the NSW Cervical Screening Program to measure its progress towards the goal of reducing the effect of cervical cancer in NSW. However, as the screening process involves a number of steps and different groups of stakeholders, it is important to assess a number of different performance criteria at different stages throughout the process.

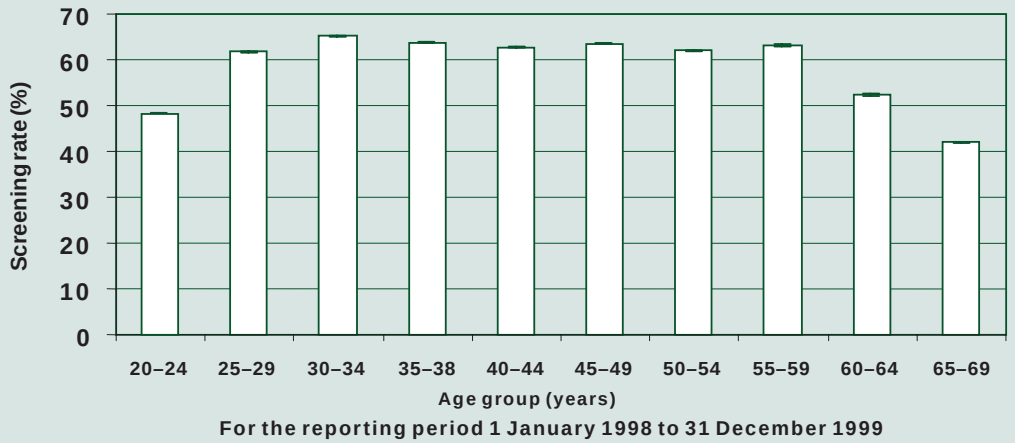
Cervical screening can be seen as a pathway of inter-related steps (Table 5). Each step is integral to the performance of the Cervical Screening Program as a whole. Register data are able to be used to measure performance at every step except that of notifying women of their results. However, performance at this step is inferred by the number of women who are lost to follow-up (Table 6). Register data is also used to assess different screening criteria, in particular to provide information in terms of both quantity and quality as illustrated in the 'indicator' column of Table 6.

Performance measures can be used to monitor progress towards the NSW Cervical Screening Program's goals by using performance standards. Performance standards are preset target values that indicate an expected level of performance. These standards may be established by the Program Manager, the NSW Department of Health or existing professional guidelines such as those of the National Health and Medical Research Council.

Variation in service performance or quality can be identified by calculating measures for the different steps in the screening process and at a range of different levels. This allows the Program to identify the most appropriate areas for improvement and resource allocation. This is

FIGURE 2

BIENNIAL SCREENING RATES BY 5-YEAR AGE GROUPS, NSW, 1998–1999



For the reporting period 1 January 1998 to 31 December 1999

TABLE 6

MEASURES OF NSW CERVICAL SCREENING PROGRAM PERFORMANCE CALCULATED USING NSW PAP TEST REGISTER DATA COMPARED TO THE EXPECTED PERFORMANCE STANDARD

Performance Measure	Indicator	NSW performance 1999	Performance Standard
Percentage of women at risk aged 20 to 69 years who have been screened once during a two year period	Recruitment of women at risk to screening	62.5%	65% *
Percentage of women who screen more than once during a two year period	Non-compliance with the recommended screening interval	39% #	40% *
Percentage of technically unsatisfactory Pap tests	Competent test taking by health practitioner (Quality of test)	2%	2% *
Percentage of technically satisfactory Pap tests with an endocervical component	Competent test taking by health practitioner (Quality, sample adequacy)	88%	75% **
Proportion of high grade cytology reports confirmed as high grade on histology	Laboratory processing and reporting (Quality)	76%	75% *
Percentage of women with high grade cytology reports who were not known to have received follow-up care within 12 months of the index Pap test	Management of women with screen detected abnormalities in a manner consistent with NHMRC Guidelines	0.5%	Negligible number *

Source of Standards:

* NSW Cervical Screening Program, *Strategic plan 2000–2004,*[2]

** NHMRC *Guidelines for the management of women with screen detected abnormalities,*[3]

\# Index period February 1998.

illustrated below for Steps 1 and 3 in the cervical screening pathway.

Step 1: Recruitment of women at risk

The demographic details of women who are recorded on the Register can be used to monitor and assess activities and projects at both a State and local level. Suburb and postcode variables of a woman's address are used to allocate women to local government and health service areas.

Demographic details also permit the monitoring of target groups: for example, those defined by age (Figure 2). Women aged 50 to 69 years of age are considered a high risk group as they have the lowest screening participation rate but the highest incidence of cancer of the cervix. As a result the recruitment rate of this group of women is specifically monitored. Currently the screening rate for women aged 50 to 69 years in NSW is 59.1 per cent with a target rate of 58 per cent for the 24 month period to June 2001.

Step 3: Laboratory Processing of Results

Laboratories often collect tests for women who live outside the laboratory's geographic location, so little may be gained from analysing the variation in laboratory performance by the distribution of the woman's area of residence. However, categorising laboratories according to the size of their cytology workload and location may be useful for monitoring laboratory performance. Variation in performance between categories potentially allows education and training activities to be targeted to the staff of laboratories most in need of improvement.

The proportion of high grade intraepithelial Pap test results that are confirmed on histology within six months is considered a measure of laboratory reporting accuracy.[4] The proportions can be calculated for laboratory

TABLE 7

PROPORTION OF HIGH GRADE CYTOLOGY REPORTS CONFIRMED AS HIGH GRADE ON HISTOLOGY BY LABORATORY WORKLOAD SIZE AND LOCATION (1 JANUARY–31 DECEMBER 1999)

	Laboratory workload size (Pap tests per year)		
	0–5000	5001–20,000	Over 20,000
Laboratory location			
Sydney	69%	74%	79%
Regional NSW	63%	81%	No laboratories

Note: The proportion of high grade intraepithial Pap Tests that are confirmed on histology is a measure of laboratory reporting accuracy. For Pap tests reporting during 1999 this proportion appears to vary between laboratories of different workload sizes and laboratories located in different areas.

categories that are determined by where the laboratory is located and the workload size in terms of numbers of Pap tests reported per year. Table 7 describes how the proportion of high grade intraepithelial Pap tests that are confirmed on histology varies between laboratories of different workload sizes and where the laboratory is located.

To measure the performance of the Cervical Screening Program as a whole, however, cervical cytology registry data must be linked to data from a central cancer registry. Linking these two data sets will allow the screening program to calculate the interval cancer rate. As the interval cancer rate is a measure of cancer incidence in women who are participating in the screening program it reflects screening failure. As a critical assessment of the ability of the Cervical Screening Program to meet its aim of reducing cancer, this is another important measure that uses Register data. The NSW Pap Test Register has been operating for four years and it is now able to calculate this measure for the first time, a process which is under way.

CONCLUSION

The NSW Pap Test Register, as a registry database, is central to the operation of a cervical screening program. A source of timely, complete and accurate data is vital to monitoring the progress of the screening program towards its aims. The data also provides the Program with measures that can be used to direct program improvement. Performance at different stages of the screening process in terms of quantity and quality as well as at the level of local activities can be assessed using Register data. This information is invaluable to direct the use of finite resources to improve the screening process in the most effective way.

ACKNOWLEDGMENT

I would like to thank the NSW Department of Health, the NSW Cervical Screening Program, and in particular the staff at the NSW Pap Test Register.

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INTERVAL BREAST CANCERS IN NEW SOUTH WALES

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This article describes a study that examined the effectiveness of mammographic screening offered to 50–69 year old women in NSW through BreastScreen NSW in 1996.

BACKGROUND

What is an interval breast cancer ?

These are cancers that are diagnosed after a woman has had a mammographic screen with a normal result and before her next scheduled screen. The interval cancer rate is an indicator of the effectiveness of mammographic screening programs. It is expressed as a proportion of the number of women screened. A consistently low interval cancer rate is correlated with a significant reduction in mortality from breast cancer in the screened population.[1–3]

Classification of interval cancers

Interval cancers can be classified by diagnosis: after the first ('prevalent') or a subsequent ('incident') screen, in the first or second year after a previous normal mammogram and by age group and period. Some screening services also classify by a woman's symptomatic status (at the previous mammogram) since those with symptoms, particularly the presence of breast a lump or nipple discharge, have a higher rate of interval cancers even though their previous mammogram showed no sign of cancer. It is preferable to use as few cross classifications as possible because of small numbers and the need for simplicity in data presentation. Interval cancer rates for small populations often must be calculated across a number of years to ensure adequate numbers.

Interval cancers during the first year after a normal mammographic screen are the most significant because they reflect cancers missed by screening. Second year interval cancers are more likely to be cancers which could not have been detected at the previous screen. Second year interval cancers are also more difficult to measure since they merge into cancers diagnosed from early return for biennial screening.

Proportional incidence

Since the underlying rate of breast cancer incidence varies between populations, interval cancer rates per woman screened are not necessarily directly comparable, especially internationally. For this reason the proportional incidence of interval cancers in the screened population can be used. This is the interval cancer incidence expressed as a proportion of the cancer incidence that would have been expected in the absence of screening in a similar but unscreened population. This statistic can be used to compare outcomes with those of major screening trials.[1,2]

Program sensitivity

Program sensitivity is defined as the proportion of invasive breast cancers diagnosed through screening compared with the total number of invasive breast cancers diagnosed in women screened (including interval cancers). This is simpler to calculate than the proportional incidence because it avoids the problem of estimating the underlying population incidence.

METHODS

The study population consists of women who attended for mammographic screening at BreastScreen NSW during 1996. BreastScreen NSW is part of BreastScreen Australia and consists of 10 screening and assessment services. Women aged 50–69 are actively recruited from the electoral roll but women 40–49 years and 70–79 years are also screened on request. This report considers only interval cancers in the target age group 50–69 years. Women who attend for screening undergo bilateral mammography and all films are read independently by two radiologists. If there is discordance in the recommendation by the first two radiologists the final recommendation is made by a third senior radiologist.

Screen detected cancers

The definition of primary breast cancer used for this study includes invasive cancer but excludes ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS). All cases of primary breast cancer diagnosed by the Screening and Assessment Service in women attending for the first time were classified as prevalent (first round) screen detected cancers. Cancers in women attending for their subsequent screens were classified as subsequent round screen detected cancers.

Interval cancers

For the purposes of this study, cases of primary cancer of the breast diagnosed up to 12 months after a screening mammogram from first or subsequent screening rounds were included.

Identification of interval cancers

Some interval cancers were reported directly to the Screening and Assessment Services, the remainder were identified by linking the BreastScreen NSW records to the NSW Central Cancer Registry. The date of diagnosis used by the cancer registry was the 'date of diagnosis (not onset of symptoms)' or date of first pathology report or first hospital admission for a particular cancer. Completeness of enumeration is difficult to determine precisely for cancer registries. The standard indicators such as the histological verification rate (0.2% of all registrations) and the death certificate only rate (0.2%) shows good completeness for breast and other cancers in NSW.[4] The data met the requirements for inclusion in *Cancer Incidence in Five Continents*.[5]

The matching of records of the screening database with the cancer registry was accomplished with the aid of probabilistic linkage using an Automatch algorithm. [6,7,8]

Underlying breast cancer rate

Whereas a previous study of interval cancer in a NSW pilot mammographic screening service was able to use the rate of breast cancer in the whole state as an underlying rate,[9] this is no longer possible because of widespread population screening. Widespread population mammographic screening initially inflates the incidence of breast cancer because of increased early detection.

Statistical analysis

The age-specific incidence of interval cancers was determined by dividing the number of interval cancers found in women screened in 1996 by the age-specific number of women screened over the same period.

These age groups are also aggregated for reporting purposes, after indirect age adjustment using the NSW age-specific rates as the standard. Program sensitivity was obtained by dividing the number of screen-detected cancers by the total number of cancers in the screened population (screen-detected plus interval).

The underlying incidence of breast cancer was obtained by APC modelling assuming a continued birth cohort trend and a constant period effect derived from pre-1991 data.[10] The age-specific incidence of breast cancer in NSW has been adjusted to discount for the 'period' effect of increased detection using age, period, cohort (APC) modeling which is described elsewhere.[10] The underlying annual incidence was 203 per 100,000 for 50–59 years and 250 for 60–69 years.

In order to express the interval cancer incidence as a proportion of the underlying breast cancer incidence rate, an indirectly age-standardised incidence ratio was calculated using the state age-specific incidences as the standard.[11] Poisson confidence limits were used for the interval cancer rate and the interval cancers as a proportion of underlying incidence. The Poisson distribution was used to calculate 95 per cent confidence intervals for the interval cancer rate and the proportional incidence,[11] and the normal approximation of the binomial was used for program sensitivity.

Comparisons

Comparisons of the interval cancer rate and program sensitivity in NSW 1996 were made using data reported from BreastScreen Victoria for the same year.[12]

Comparisons of NSW interval cancer in relation to underlying incidence were made with international studies from Sweden, Denmark, the Netherlands and the UK [2,13–15] as well as Victoria.[16] For the purposes of comparison, the 12 month interval cancer data from the first and subsequent screening rounds were used for all studies, except for the UK study for which only the first round data were available. Confidence limits for interval cancer rates from comparison populations were calculated from the published data using the Poisson distribution.

RESULTS

Figure 3 compares first year interval cancer rates in NSW and Victoria for 1996. Although rates are lower for 60–69

years compared to 50–59 years (5.9 versus 7.9 per 10,000 women screened), these differences are not statistically significant judged by overlapping 95 per cent confidence limits. There were no differences between interval cancer rates in NSW and Victoria (6.8 versus 6.5 per 10,000 women screened).

Figure 4 compares program sensitivity in NSW and Victoria for 1996. Program sensitivity is slightly higher for 60–69 years compared to 50–59 years (89.3 per cent versus 83.6 per cent), but these differences were not statistically significant as judged by overlapping 95 per cent confidence limits. There were no differences in the program sensitivity between NSW and Victoria (86.4 per cent versus 88.7 per cent).

Figure 5 provides international comparisons of interval cancer rates expressed as a proportion of underlying incidence rates. Most studies reveal proportions of 20–30 per cent, including NSW and Victoria. The upper 95 per cent CI of the Swedish two-county study extends to 20 per cent.

DISCUSSION

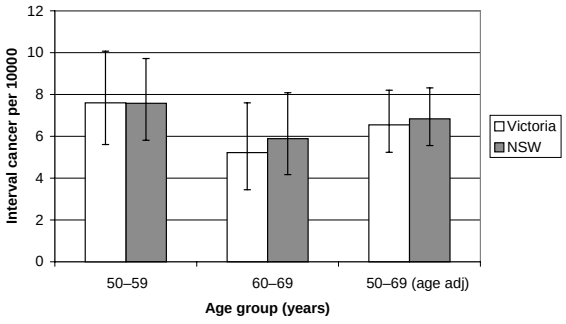
The interval cancer rates and program sensitivity in NSW and Victoria for 1996 are virtually identical. Greater numbers would be required by aggregation of years to make inferences concerning effects of age and screening rounds.

International comparisons of first year interval cancer as a proportion of underlying incidence indicates that no program has been able to replicate the Swedish two-county trial of 13 per cent.[2,13–16] However, several studies have lower 95 per cent confidence limits that overlap with the upper 95 per cent confidence limit of the Swedish two-county trial (20 per cent). Most reported data indicate first year interval cancer rates of 20–30 per cent of underlying incidence.

Consideration needs to be given to developing performance standards for mammographic screening programs that are based on assessments of achievements of programs implemented in whole populations.

FIGURE 3

FIRST YEAR INTERVAL BREAST CANCER, VICTORIA AND NSW, 1996



Note: The Poisson distribution was used to calculate 95% confidence intervals.

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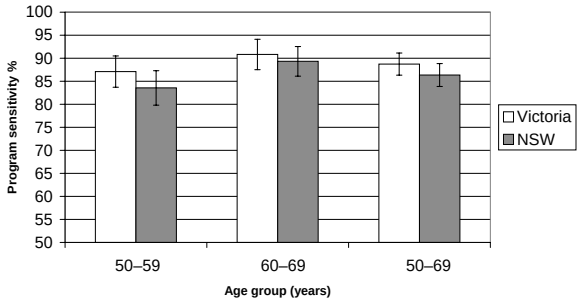
FIGURE 4

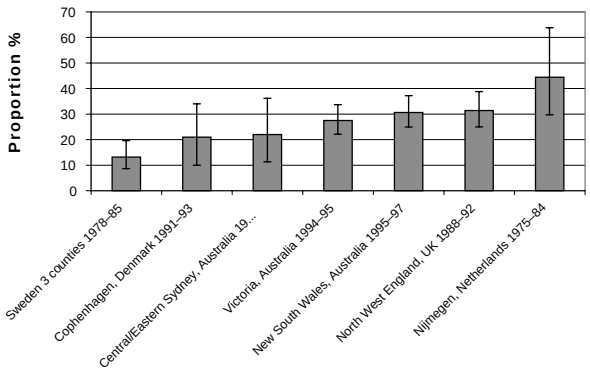
FIRST YEAR PROGRAM SENSITIVITY, VICTORIA AND NSW, 1996



Note: The Poisson distribution was used to calculate 95% confidence intervals.

FIGURE 5

FIRST YEAR INTERVAL BREAST CANCERS AS A PROPORTION OF UNDERLYING INCIDENCE, INTERNATIONAL COMPARISON



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USING RECORD LINKAGE TO MEASURE TRENDS IN BREAST CANCER SURGERY

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Since the early 1990s, there has been a growing acceptance in Australia of the efficacy of breast-conserving surgery (as defined as excision of the primary tumour and adjacent breast tissue, axillary node dissection and radiotherapy of the remaining breast) for the treatment of early breast cancer. This article describes changes in the patterns of the surgical treatment of breast cancer in NSW in the period 1991 to 1995. It follows on from an earlier study by Adelson et al,[1] which described the proportion of NSW women diagnosed with breast cancer in 1991 and 1992 who had breast-conserving therapy (BCT).

METHODS

Population-based data on the surgical treatment of breast cancer was assembled by linking two separate data collections: the NSW Central Cancer Registry data collection,[2] and the NSW Department of Health's Inpatient Statistics Collection (ISC).[3]

The NSW Central Cancer Registry (CCR) is a population-based registry to which notification of all cases of malignant neoplasm has been a statutory requirement in NSW since 1971.[4] Using data supplied by the CCR, we assembled a file of all cases of breast cancer (excepting intraductal carcinoma and Paget's disease of the nipple) diagnosed in female NSW residents between 1993 and 1995. Data items on the CCR data file used in the analysis were age at diagnosis, degree of spread, date of diagnosis, area of residence at diagnosis, and country of birth.

The NSW ISC contains records for all hospital separations (discharges, transfers and deaths) from all NSW public and private hospitals and day procedure centres. ISC records consist of demographic data items, administrative items and coded information on diagnoses related to and procedures performed during a particular admission to hospital. Records for NSW residents who were admitted to interstate hospitals were not used in this study because the partially-identifying data items used to link records, such as address and date of birth, were not available for these records. The ISC data file used for record linkage contained 6.8 million records, covering separations for the period July, 1992 to June 1996.

We used Automatch probabilistic record linkage software to create a single,[5] linked file of CCR and ISC records. Automatch software uses well established probabilistic linkage methods to link records in two data files under conditions of uncertainty,[6] such as where there is no unique identifying number common to both files. Before linking, address details from the two sources were separated into individual components (such as house number, street name and suburb or locality) and these items were standardised as far as possible using Autostan software.[7] The partially-identifying but non-unique data items common to the two sources that were used to link the files were hospital code, patients' medical record number (which, in most cases, is specific to each hospital), country of birth, full residential address, and date of birth.

These data sources and record linkage methods are essentially identical to those used in the earlier study which covered the period 1991–1992. McGeechan et al. undertook a validation study of a sample of the cohort used in the earlier study.[8] They concluded that the linked data file under-estimated the proportion of women receiving breast conserving therapy (39 per cent in the linked dataset versus an estimated true proportion of 42 per cent) but that there was no evidence that this under-estimation was biased with respect to age or geographical region.

Geographical area of residence was assigned to the cancer cases based on the boundaries of the 17 area health services defined by the NSW Department of Health in 1996. To evaluate trends in the types of surgical breast

procedures, we recoded place of residence in the 1991 and 1992 data file used in the earlier study to the current boundaries of areas health service.[1] For the purposes of this study, metropolitan area health services cover Sydney, the Central Coast, Hunter and Illawarra geographical areas. The remaining area health services cover rural areas.

Surgical breast procedures were categorised as breast-conserving (ICD-9-CM procedure codes 85.20–85.23) or mastectomy (ICD-9-CM procedure codes 85.41–85.48). Hospital admissions which included the ICD-9-CM procedure code for open breast biopsy (85.12) were not included in the main analyses for reasons discussed below.

Statistical analyses included tests for linear trend and multiple logistic regression.[9] In the logistic regression models, the outcome variable was the probability of having a mastectomy and the risk factors were age, degree of spread at diagnosis and area of residence (rural versus metropolitan). Cases with unknown degree of spread (*n*=1,062) were excluded from the data for the logistic regression. The choice of variables to include in the models was based on the *p*=0.05 criterion for main effects and *p*=0.01 for interaction terms. The base levels in the model were women aged under 60 years, localised spread, and residence in a metropolitan area.

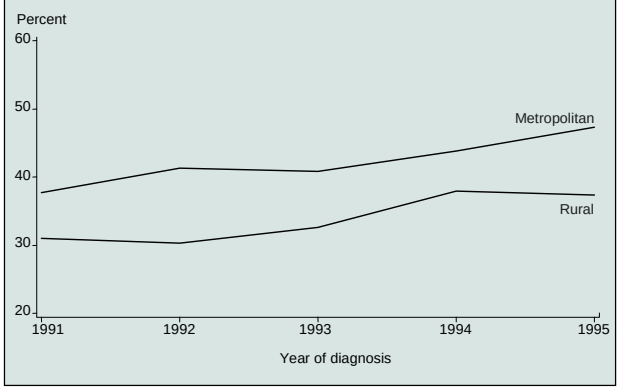
RESULTS

Record Linkage

In the period January 1993 to December 1995, there were 9849 NSW women diagnosed with breast cancer. Of these, 9417 cases were linked to ISC records, representing a match rate of 95.6 per cent. The proportion of linked cases was similar across the three years: 95.9 per cent in 1993, 95.7 per cent in 1994 and 95.2 per cent in 1995. The age distribution for the 432 cases which did not match to any ISC records was similar to those of the matched cases. The unmatched cases had a higher proportion of unknown degree of spread (38.4 per cent) compared to the same category in the linked cases (14.9 per cent). Unmatched cases were more likely to be resident in those rural area health services which share a border with other states: that is, Northern Rivers (15.3 per cent), Far West (7.4 per cent), Greater Murray (9.7 per cent) and Southern (7.4 per cent) area health services.

FIGURE 6

BREAST CONSERVING SURGERY FOR WOMEN DIAGNOSED DURING 1991 TO 1995, NSW, BY METROPOLITAN–RURAL AREA OF RESIDENCE



Hospital admissions

There were 43,254 hospital separations (that is, discharge, or transfer, or death) recorded for the linked cases of breast cancer (*n*=9,417). The hospital separations covered the period of six months before diagnosis and up to three years after diagnosis. Most of the women (77 per cent) had more than one admission to hospital. Of the women who were treated surgically, 82 per cent were admitted within one month of diagnosis and 14.6 per cent within two months of diagnosis.

Breast procedures

A small proportion of women in the linked cases (eight per cent, *n*=760) had no recorded breast procedures. As found in the earlier study, these women tended to be older: 44 per cent were aged 70 years or more compared to 25 per cent of the women who had breast procedures recorded. They were also more likely to have had metastatic disease at diagnosis (23 per cent versus two per cent of the women with recorded breast procedures) or an unknown degree of spread at diagnosis (30 per cent compared to 14 per cent of those who had breast procedures recorded). The most common procedures performed on these 760 women were administration of chemotherapy (25 per cent of admissions of the 760 women), blood transfusion, CAT scan, bone scan, thoracocentesis, pulmonary scan and bone marrow biopsy. Twenty of the 760 women were recorded as having undergone radical excision of axillary lymph nodes without mention of a breast procedure.

Table 8 shows the number of breast procedures for the remaining 8657 women. There was a small increase in the total number of breast conserving procedures over the three year period. The number of mastectomy and diagnostic breast procedures remained constant (Table 8).

Therapeutic breast procedures

The women who underwent therapeutic breast procedures (*n*=8,237) form the basis of subsequent analysis of treatment patterns. Table 9 shows that the overall proportion of women who underwent therapeutic breast surgery did not change significantly over the three year period: 2568 out of 3075 (83.5 per cent) in 1993, 2790 out of 3340 (83.5 per cent) in 1994 and 2879 out of 3434 (83.8 per cent) in 1995.

The proportion of women who underwent breast-conserving therapy (BCT) increased gradually from 39 per cent in 1993 to 45 per cent in 1995 (Table 9), with a corresponding fall in the proportion undergoing mastectomy over the same period. Forty-four per cent of women resident in metropolitan area health services underwent breast conserving therapy compared to 36 per cent of women resident in rural area health services.

Mastectomy was performed in 61 per cent of women diagnosed in 1993, 56 per cent of women diagnosed in

TABLE 8

BREAST PROCEDURES PERFORMED ON AN INPATIENT BASIS, NSW, RESIDENT WOMEN DIAGNOSED WITH BREAST CANCER IN 1993–1995

	Year of Diagnosis			Total Procedures	
	1993	1994	1995		
	n	*n*	*n*	*n*	%
Breast conserving therapy					
Local excision [85.20,85.21]	1592	1636	1722	4950	77.9
Resection of quadrant [85.22]	136	228	231	595	9.4
Subtotal mastectomy [85.23]	275	275	263	813	12.8
Subtotal	2003	2139	2216	6358	100.0
Mastectomy					
Simple unilateral [85.41]	266	236	208	710	14.6
Unilateral extended simple [85.43]	1212	1275	1278	3765	77.4
Unilateral radical mastectomy [85.45]	89	100	92	281	5.8
Unilateral extended radical [85.47]	18	11	10	39	0.8
Bilateral (simple,extended simple,radical,extended) [85.42,85.44,85.46,85.48]	24	22	25	71	1.5
Subtotal	1609	1644	1613	4866	100.0
Diagnostic procedures					
Percutaneous needle biopsy [85.11]	271	233	186	690	26.8
Other biopsy of breast,mastostomy [85.12,85.0,85.19]	617	626	643	1886	73.2
Subtotal	888	859	829	2576	100.0

1994 and 55 per cent of women diagnosed in 1995. There was considerable variation in mastectomy rates between metropolitan and rural area health services, with higher rates generally observed in the rural areas.

Figure 6 shows the change between 1991 and 1995 in the proportion of women undergoing breast-conserving therapy. Tests for linear trend indicate statistically significant increases in the proportion of women undergoing BCT in both rural and metropolitan AHSs (χ^2 statistic of 9.50 with one *df*, p=0.002 for rural areas and χ^2 statistic of 37.62 on one *df*, p <0.00001 for metropolitan areas).

The type of surgical treatment was influenced by age and degree of spread at diagnosis. Table 10 shows that, in general, women with regional spread or metastases at diagnosis were more likely to undergo mastectomy than women with local disease at diagnosis. Age and degree of spread combined do not influence the likelihood of a woman undergoing a mastectomy. There appears to be no variation in the proportion of mastectomy rates across the different age groups.

Health insurance status did not appear to influence the type of surgical treatment. Forty-three per cent of the women who underwent breast conserving surgery had private health insurance, while 42 per cent of the women were public patients.

A total of 268 women were recorded as undergoing open biopsy of the breast (ICD-9-CM procedure code 85.12) without mention of a therapeutic breast procedure in any of their other hospital admissions. There were 335 records for hospital admissions for these women: 100 of these admissions relating to 62 women included procedure codes for the dissection or clearance of the axillary lymph nodes (ICD-9-CM procedure codes 40.23, 40.3 and 40.51). A proportion of these procedures, which we have classified as diagnostic breast procedures for this study, may in fact represent therapeutic breast conserving procedures and may therefore cause the proportion of women receiving BCT to be underestimated. However, the degree of misclassification due to this cause is unlikely to exceed 1.5 per cent (up to 100 'misclassified' open biopsy procedures out of 6538 therapeutic breast-conserving procedures in the 1993–1995 period).

Place of residence and place of treatment

Of the 43,254 hospital separations for women diagnosed with breast cancer, 10,507 involved therapeutic breast surgical procedures. Of these procedures, 98 per cent were performed in hospitals located in the same area health service as that of the woman's residence. Almost all women whose usual residence was in a Sydney area health service underwent surgery within Sydney (99.8 per cent of separations). For residents of the Illawarra Area Health Service, 74 per cent of their separations involving therapeutic breast surgery were from Illawarra hospitals and 26 per cent from Sydney hospitals. Hunter Area Health Service residents had 97 per cent of their hospital separations for breast surgery from Hunter hospitals and two per cent from Sydney hospitals. Residents of rural area health services had 73.9 per cent of their surgical treatment in rural hospitals, 25.9 per cent in Sydney hospitals and 0.3 per cent in Illawarra hospitals. This is an increase in the utilisation of metropolitan hospitals compared to 1991–1992, when 90 per cent of the surgical treatment of breast cancer in women resident in rural areas was performed in rural hospitals.

Multivariate analysis

In the logistic regression models, variables found to have a significant independent association with the probability

TABLE 9

NUMBER OF NSW WOMEN DIAGNOSED WITH BREAST CANCER IN 1993,1994,1995 AND NUMBER UNDERGOING THERAPEUTIC BREAST SURGERY

NSW area health service of usual residence	BCT only			Mastectomy			Total women undergoing breast surgery			Total women diagnosed with breast cancer		
	1993 (%)	1994 (%)	1995 (%)	1993 (%)	1994 (%)	1995 (%)	1993 *n*	1994 *n*	1995 *n*	1993 *n*	1994 *n*	1995 *n*
Central Sydney	43.8	40.8	43.9	56.2	59.2	56.1	203	184	246	235	223	286
Northern Sydney	45.3	45.3	55.0	54.7	54.7	45.0	433	457	433	510	526	492
Western Sydney	48.0	52.7	52.3	52.0	47.3	47.7	229	275	262	282	315	308
Wentworth	45.7	50.8	53.5	54.3	49.2	46.5	116	130	114	136	151	137
Sth West Sydney	35.1	42.4	42.2	64.9	57.6	57.8	228	257	258	257	301	295
Central Coast	29.9	31.2	36.8	70.1	68.8	63.2	157	141	144	178	160	171
Hunter AHS	47.2	52.1	48.9	52.8	47.9	51.1	161	169	223	219	250	265
Illawarra AHS	33.8	34.2	45.4	66.2	65.8	54.6	136	190	183	149	213	198
Sth East Sydney	36.1	41.5	43.3	63.9	59.0	56.7	360	386	388	425	431	436
Northern Rivers	33.3	34.0	34.7	66.7	66.0	65.3	93	100	98	127	139	138
Mid North Coast	40.2	53.3	48.2	59.8	46.7	51.8	107	122	137	122	148	165
New England	55.4	54.5	51.3	44.6	45.5	48.8	65	77	80	80	92	104
Macquarie	24.4	24.3	30.9	75.6	75.7	69.1	45	37	55	55	47	62
Mid-Western	24.3	32.8	28.1	75.7	67.2	71.9	70	64	64	75	80	80
Far West	16.7	33.3	40.9	83.3	66.7	59.1	18	18	22	35	37	38
Greater Murray	22.2	22.4	28.7	77.8	77.6	71.3	90	116	101	115	143	144
Southern	29.8	37.3	29.6	70.2	62.7	70.4	57	67	71	75	84	115
Total	39.1	42.5	45.2	60.9	57.5	54.8	2568	2790	2879	3075	3340	3434

of undergoing mastectomy (as opposed to breast conserving treatment) were age, degree of spread, and place of residence. None of the interaction terms entered into the model were statistically significant. The final model demonstrated an adequate fit to the data (Hosmer-Lemeshow goodness of fit statistic =5.32 with five *df*, p=0.38).[10] The C statistic,[11] which provides a measure of predictive accuracy of the model, was 0.619.

Table 11 shows the likelihood of undergoing a mastectomy as opposed to breast conserving treatment while controlling for patient and tumour characteristics. Women aged 60 years and over were slightly more likely (odds ratio 1.21, 95 per cent CI 1.10, 1.34) to have a mastectomy than women under 60 years of age. Women with regional spread of disease were considerably more likely (odds ratio 2.38, 95 per cent CI 2.14, 2.65) to have a mastectomy than women with localised spread. The likelihood of a mastectomy for women with metastatic spread was not significantly different from those with localised spread (odds ratio 1.40, 95 per cent CI 0.88, 2.21). Women resident in rural area health services had a significant greater likelihood of undergoing mastectomy (odds ratio 1.50, 95 per cent CI 1.33, 1.70) than women residing in metropolitan area health services.

DISCUSSION

There are two main findings in this study. The first is that there has been a distinct increase in the utilisation of BCT in NSW, with the proportions increasing steadily from 36 per cent of all surgical treatments for breast cancer in 1991 to 45 per cent in 1995. This is an encouraging result and probably reflects both a greater acceptance of the efficacy and safety of BCT regimes by surgeons as well as the greater availability and accessibility of the radiotherapy services which are required for successful BCT.

The second finding is that the greater likelihood of undergoing mastectomy as opposed to breast conserving treatment for women resident in rural areas which was observed in 1991 and 1992 continued in the years 1993 to 1995. This difference persists after adjusting for differences in age and degree of spread at diagnosis and therefore is unlikely to be a result of earlier diagnosis in metropolitan women due to greater accessibility and uptake of mammography screening services in the cities.

Nevertheless, there has been a significant increase in the proportion of rural women who are undergoing BCT rather than mastectomy. This is reflected in the increasing number of rural women who are choosing to travel to metropolitan hospitals for the surgical treatment for their breast cancer (10 per cent in 1991–1992, 26 per cent in 1993–1995), presumably so that they can use the radiotherapy services associated with those metropolitan hospitals. Unfortunately, it is not possible to determine from currently available data what proportion of rural women are attending metropolitan radiotherapy services after undergoing breast conserving surgery in a local, rural hospital.

High quality radiotherapy services require considerable capital investment and a team of specialist staff.[12,13,] Clearly clinicians and health service administrators face policy and operational challenges in ensuring that all rural women with breast cancer have the option of choosing a form of treatment which requires radiotherapy even if there is no radiotherapy service available locally.

Like the previous study by Adelson et al.,[1] this study has used two existing data sources (a population-based cancer

TABLE 10

SURGICAL TREATMENT BY AGE AND DEGREE OF SPREAD AT DIAGNOSIS 1993–1995

Age and degree of spread	1993				1994				1995			
	Breast conserving		Mastectomy		Breast conserving		Mastectomy		Breast conserving		Mastectomy	
	n	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)
Local												
20–39 yrs	34	44.2	43	55.8	52	56.5	40	43.5	45	51.1	43	48.9
40–49 yrs	121	44.5	151	55.5	155	49.2	160	50.8	150	50.3	148	49.7
50–59 yrs	142	51.3	135	48.7	199	53.1	176	46.9	211	52.0	195	48.0
60–69 yrs	130	38.6	207	61.4	195	47.7	214	52.3	214	52.7	192	47.3
70+	126	42.1	173	57.9	173	43.7	223	56.3	223	52.3	203	47.7
Subtotal	553	43.8	709	56.2	774	48.8	813	51.2	843	51.9	781	48.1
Regional												
20–39 yrs	23	29.1	56	70.9	29	35.4	53	64.6	30	31.9	64	68.1
40–49 yrs	56	27.3	149	72.7	77	34.2	148	65.8	76	33.6	150	66.4
50–59 yrs	53	29.0	130	71.0	64	31.8	137	68.2	73	31.9	156	68.1
60–69 yrs	61	31.9	130	68.1	60	26.7	165	73.3	46	30.9	103	69.1
70+	40	21.1	150	78.9	33	20.4	129	79.6	37	20.4	144	79.6
Subtotal	233	27.5	615	72.5	263	29.4	632	70.6	262	29.8	617	70.2
Metastatic (All ages)	14	37.8	23	62.2	13	52.0	12	48.0	5	27.8	13	72.2
Unknown												
20–39 yrs	10	33.3	20	66.7	10	52.6	9	47.4	10	47.6	11	52.4
40–49 yrs	26	41.9	36	58.1	22	44.0	28	56.0	34	51.5	32	48.5
50–59 yrs	45	52.9	40	47.1	30	54.5	25	45.5	52	52.0	48	48.0
60–69 yrs	42	40.4	62	59.6	26	41.3	37	58.7	48	60.8	31	39.2
70+	82	58.6	58	41.4	49	51.0	47	49.0	47	51.1	45	48.9
Subtotal	205	48.7	216	51.3	137	48.4	146	51.6	191	53.4	167	46.6
Total	1005	39.1	1563	60.9	1187	42.5	1603	57.5	1301	45.2	1578	54.8

registry and an administrative hospital separations database) in order to provide information on the patterns and trends in the surgical treatment of breast cancer in NSW. Because neither of these data sources were designed specifically for this task, there are some inherent limitations to the accuracy of the information which can be derived from them. Possible misclassification of diagnostic open breast biopsy procedures has already been discussed. Other sources of error include under-enumeration of breast cancer cases by the NSW Central Cancer Registry, under-enumeration of therapeutic breast procedures in the Inpatient Statistics Collection, the absence of information about women who received their treatment interstate and the unquantifiable proportion of missed or false linkages between the two files.

Although the relative increase in BCT since 1991 undoubtedly represents an improvement in breast cancer care, it is still unclear whether 45 per cent of women receiving BCT is a good result in absolute terms. Furnival suggests that, based on the experience of a specialist breast clinic in Brisbane, the practical limit for BCT is between 50 and 60 per cent of all breast cancer cases treated in Australia.[14] Ideally, it should be possible to calculate the number of women with newly diagnosed breast cancer who meet the criteria for breast conserving therapy set out in the NHMRC and other guidelines, and then compare this number with the actual number receiving BCT. However, insufficient information on the degree of spread at diagnosis and tumour size was available to this study to accurately classify women into IUCC stages I and IIA, which are suitable for BCT. Future studies may be able to address this deficiency.

Published results from other Australian population-based studies report similar BCT utilisation rates to those we found in NSW. Hill et al. reported that the proportion of women diagnosed with breast cancer in Victoria who received BCT rose from 22 per cent in 1986 to 42 per cent in 1990.[15] A study of treatment patterns in women diagnosed with breast cancer in the greater western region of Sydney in 1992 found that 41 per cent received BCT.[16] Craft et al. found, in an analysis of Medicare data, that in 1993 39.9 per cent of Australian women who underwent some form of breast surgery for which a Medicare benefit was paid received BCT.[17] They also found similar urban–

TABLE 11

THE LIKELIHOOD OF HAVING MASTECTOMY, BY PATIENT AND TUMOUR CHARACTERISTICS, AS TAKEN FROM FINAL MODEL*

	No.	%	Adjusted odds ratio	95% confidence interval
Age				
<60 years	3760	52.4	1.00	
60+ years	3415	47.6	1.21	1.10, 1.34
Degree of spread				
Local	4473	62.3	1.00	
Regional	2622	36.5	2.38	2.14, 2.65
Metastatic	80	1.1	1.40	0.88, 2.21
Residence				
Metropolitan	5646	78.7	1.00	
Rural	1529	21.3	1.50	1.33, 1.70

* Final model used first-order terms for age at diagnosis, degree of spread at diagnosis and place of residence.

rural differences in the use of BCT. The largest and most comprehensive study to date, by Hill et al. collected detailed information on 4837 women through Australia diagnosed with breast cancer between April and September 1995.[18] This study found the overall utilisation of BCT to be 48 per cent. Eighty-five per cent of the 4837 women had early disease at diagnosis—of these women, 53 per cent underwent BCT compared to 32 per cent of the women who had advanced disease at diagnosis.

More recent linked hospital and cancer registry data for NSW is currently being prepared and will be reported on in the near future.

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USING LINKED DATA TO EXPLORE QUALITY OF CARE FOR BREAST CANCER

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Most women with early breast cancer have the option of surgery that conserves the breast or mastectomy. In 1990, a consensus statement of the United States National Institutes of Health concluded that breast conservation was appropriate for early breast cancer, and was preferable to total mastectomy because it provided equivalent survival while preserving the breast. This theme was taken up in Australia with the release of the *NHMRC Clinical practice guidelines for the management of early breast cancer* in October 1995. The proportion of women receiving breast conserving surgery thus became an indicator for monitoring the uptake of a new treatment option for breast cancer. This article compares patterns of breast cancer surgery in NSW in 1992 and 1995; and describes features of the women, and the breast cancers that were associated with changes in mastectomy rates.

METHODS

Routinely collected administrative data has been used for linkage studies of breast cancer surgery in NSW women.[1,2] For the present study, the NSW Department of Health used Automatch to link records of women with breast cancer in 1992 and 1995 in the NSW Cancer Registry with their treatment records in the NSW Inpatient Statistics Collection (ISC).

Some women whose records were linked had diagnostic breast procedures only (six per cent in 1992 and four per

cent in 1995) or no surgical procedures recorded (11 per cent in 1992 and nine per cent in 1995) and these women were not included in this study. Women who had any code indicating either mastectomy alone or mastectomy with breast conserving therapy were assigned to 'mastectomy'. The category of 'breast conserving therapy' (BCT) included women who had this surgery only although they may have had an additional diagnostic procedure.

We examined the relationship between type of surgery and womens' ages, places of residence and the recorded size of the breast cancer. We also grouped hospitals into categories by their 'surgical volume' (low, medium, high) based on the total number of mastectomies and BCTs in each year.

QUALITY IN BREAST CANCER MANAGEMENT

There were 2,020 women with invasive breast cancer in 1992 and 2,883 in 1995 for whom cancer registry records were successfully linked to ISC records of BCT or mastectomy.

Breast conservation and mastectomy

Breast conservation alone was the surgical treatment procedure for 39 per cent of women in 1992 and 45 per cent of women in 1995. In both years most women had mastectomy (61 per cent in 1992; 55 per cent in 1995) and rural women were more likely to have mastectomy and less likely to have breast conservation than urban women. Three-quarters of the women with breast cancer in the linked records in 1995 lived in Sydney, Newcastle and Wollongong.

While BCT increased from 1992 to 1995, it was mainly in women with the smallest breast cancers (<1cm) (Table 12). In 1992 less than half (46 per cent) the women with the smallest breast cancers had BCT compared with almost two-thirds (61 per cent) in 1995. A higher proportion of women in urban areas (64 per cent) had BCT for the smallest cancers than women in rural areas (47 per cent) (Table 12).

Mastectomy was the more common surgery for larger breast cancers, and increased steadily with increasing cancer size to around 80 per cent of urban women with 3+ cm breast cancers (Table 1). There was no similar trend in rural women, although they too had the greatest use of mastectomy (87 per cent of women) with the largest (3+ cm) cancers. Between 1992 and 1995 there was almost no change in the percentage of women who had mastectomy for the largest (3+ cm) cancers. On the other hand, mastectomy for the smallest (<1 cm) cancers fell from 50 per cent to 36 per cent in urban women and from 64 per cent to 47 per cent in rural women. Table 1 summarises the evidence that most of the shift from mastectomy to BCT occurred in the treatment of the smallest breast cancers.

As would be expected, urban hospitals performed more surgery for breast cancer in each year (up to 211 procedures in 1992 and 237 in 1995) than rural hospitals (up to 32 in 1992 and 67 in 1995) (Figure 7). Most women (65 per cent in each year) had surgery in a public hospital. While in 1992 only 10 per cent of women had surgery in urban hospitals performing the highest volume of breast cancer surgery (100+ procedures), this had increased substantially to 37 per cent in 1995. Despite this increase, more than half (55 per cent) of women in 1995 had their surgery in hospitals where no more than 60 mastectomies and BCTs were performed in the year.

Predictors of mastectomy

We examined urban or rural residence, cancer size in four categories, spread (*localised* to the breast, invading adjacent tissue or *regional* lymph nodes or *distant* metastases) and hospital volume of surgery for breast cancer (low, intermediate, high) as potential predictors of mastectomy.

The odds of mastectomy were two-fold higher in the presence of regional spread of the cancer at diagnosis than with localised cancer and higher still for the largest (3+ cm) compared with the smallest (<1 cm) cancers (Table 13). The higher mastectomy rates in rural NSW were independent of any differences in breast cancer size and spread at diagnosis (Table 13). In the multivariate models, mastectomy was, if

TABLE 12

PERCENTAGES OF URBAN AND RURAL WOMEN 40–69 YEARS OF AGE HAVING MASTECTOMY AND BCT BY BREAST CANCER SIZE, NSW, 1992 AND 1995

	1992				1995			
	Urban		Rural		Urban		Rural	
	Mastectomy %	BCT only %	Mastectomy %	BCT only %	Mastectomy %	BCT only %	Mastectomy %	BCT only %
Size:								
0–0.9 cm	50	50	70	30	36	64	53	47
1–1.9 cm	49	51	55	45	50	50	53	47
2.0–2.9 cm	62	38	63	37	64	36	50	50
3.0+ cm	81	19	87	13	79	21	87	13
All sizes	**60**	**40**	**65**	**35**	**54**	**46**	**58**	**43**

Note: Breast cancer size was recorded only for women aged 40–69 years in 1992 and for women diagnosed April–September in 1995

TABLE 13

ASSOCIATION OF MASTECTOMY WITH URBAN OR RURAL RESIDENCE, CANCER SPREAD, CANCER SIZE AND HOSPITAL VOLUME OF SURGICAL PROCEDURES IN WOMEN 40–69 YEARS OF AGE DIAGNOSED WITH INVASIVE BREAST CANCER, NSW, 1992 AND 1995

	1992 (*N*=1085)			1995 (*N*=799)		
	OR (adjusted)*	95%CI		OR (adjusted*)	95% CI	
Residence:						
Urban	1.0			1.0		
Rural	1.3	1.0	1.9	1.3	0.9	1.9
		p-value	0.09		*p*-value	0.3
Extent of cancer:						
Localised	1.0			1.0		
Regional	2.0	1.5	2.7	2.0	1.4	2.7
Metastatic	0.8	0.3	2.3	1.1	0.2	6.8
		p-value	<0.001		*p*-value	<0.001
Size (cm):						
0 to 0.9	1.0			1.0		
1.0 to 1.9	0.7	0.5	1.1	1.4	1.0	2.1
2.0 to 2.9	1.1	0.7	1.7	1.8	1.1	2.9
3 +	3.1	1.8	5.3	5.6	2.9	10.7
		p-value	<0.001		*p*-value	<0.001
Hospital volume:						
1–10 procedures	1.0			1.0		
11–20 procedures	1.5	0.9	2.6	1.3	0.6	2.5
21+ procedures	0.9	0.6	1.4	1.3	0.7	2.1
		p-value	0.04		*p*-value	0.7

* Adjusted for age, socioeconomic status of area of residence, and histopathological type of breast cancer (ductal, lobular, special types).

anything, most prevalent in hospitals in which moderate numbers of breast procedures were done rather than few or many.

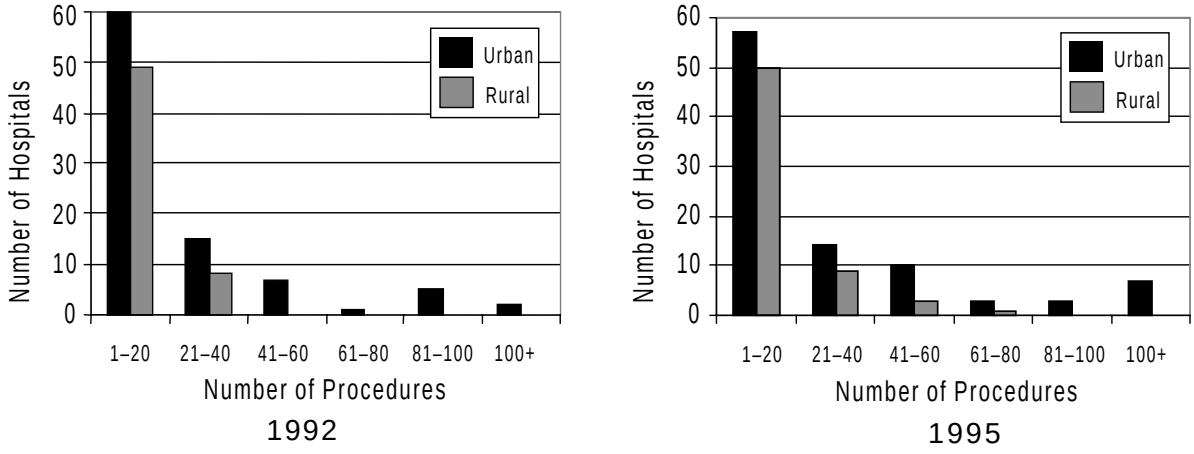
COMMENT

Our study used a linkage of two sets of routinely collected, computerised health records. The increase in NSW in BCT from 1992 (39 per cent) to 1995 (45 per cent) was consistent with increases observed in earlier periods in Australia,[3,4] and similar to the BCT rate in Victoria in 1990,[5] and Australia in 1995.[6] We concluded that BCT in NSW in 1995 was in line with current Australian practice.

Although more women had BCT in 1995 than 1992 in NSW, the increase was confined to women with small, localised breast cancers. The trend for mastectomy to increase with increasing cancer size was observed mainly in urban women. The greater use of BCT in urban women may suggest that practice had changed more in the urban setting by 1995.

FIGURE 7

NUMBERS OF MASTECTOMIES AND BREAST CONSERVATION PROCEDURES CARRIED OUT IN URBAN AND RURAL HOSPITALS, NSW, 1992 AND 1995



More than half (55 per cent) the NSW women with breast cancer in 1995 had surgery in hospitals that had a maximum of 60 mastectomies and BCTs in the year, that is, an average of less than one procedure a week. Most rural women had their surgery in lower volume hospitals; only one rural hospital had a surgical volume of 60 mastectomies and BCTs in 1995. While BCT in each of the high volume urban hospitals in 1995 was mostly close to the state average (45 per cent), rural hospitals varied substantially from 30–70 per cent. Approximately four per cent of rural women, however, had surgery in an urban hospital, a shift in place of treatment that may have contributed to low BCT rates in selected rural hospitals.

Our data tells us about the proportions of women who had BCT and mastectomy for breast cancer in NSW and some of the variations in these proportions. They do not tell us about reasons for the choice of the type of surgery. We know that screening increased the diagnosis of small cancers and that there was a greater use of BCT for the smallest cancers. In addition, rural residents are known to have less access to specialist medical care,[7] a situation perhaps reflected in the lower uptake of BCT in those rural women for whom radiotherapy would be a recommended accompaniment.

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I thank Ms Kim Lim and Dr Tim Churches of the Epidemiology and Surveillance Branch, NSW Department of Health, who prepared the linked data set and provided advice.

One factor we were unable to take into account is the womens' own choices about their surgery. About one-quarter of women with early breast cancer diagnosed in Australia in 1995 were reported by surgeons to have chosen non-conservative surgery for reasons such as concerns about recurrence or treatment by radiotherapy, which were sometimes age- or residence-related.[6]

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FACT*SHEET*

MURRAY VALLEY ENCEPHALITIS (AUSTRALIAN ENCEPHALITIS)

WHAT IS MURRAY VALLEY ENCEPHALITIS ?

- Murray Valley encephalitis (MVE) is a potentially fatal mosquito-borne disease caused by the Murray Valley encephalitis virus.
- It is also known as Australian encephalitis.

WHERE DOES THE DISEASE OCCUR?

- MVE usually occurs in remote north western Australia. It rarely occurs in eastern Australia.
- To date (May 2001), there have been no human cases in south eastern Australia—including NSW and Victoria—reported since 1974.
- In previous outbreaks, the virus affected people living in western NSW.

HOW IS THE DISEASE SPREAD?

- MVE virus is spread by the bite of a mosquito that is infected with the virus.
- Not all mosquitoes carry the virus.
- The most common species to carry the virus is *Culex annulirostris*. Only one person in about one thousand will acquire the disease after being infected through a mosquito bite.
- The virus is carried by water birds. Mosquitoes become infected by biting birds or other animals that carry the virus. Spread to south eastern Australia is thought to occur with waterbird migration that follows unusually wet conditions in inland Australia.

WHO IS MOST AT RISK?

- The disease is fatal in about 20 per cent of those who become sick, and a further 25 per cent can develop major intellectual and/or neurological complications. About 40 per cent of cases will make a complete recovery.

WHAT ARE THE SYMPTOMS?

- The disease takes about of 5–15 days to develop following the bite of an infected mosquito.
- The great majority of people infected with MVE will have no symptoms. Of those who do, symptoms may include:
  - — severe headache
  - — neck stiffness
  - — fever
  - — tremors
  - — seizures (particularly in young children)
  - — confusion
  - — vomiting
  - — nausea
  - — diarrhoea
  - — dizziness
  - — lethargy, irritability, drowsiness
  - — coma (in severe cases).
- People experiencing these symptoms should seek medical attention.

PREVENTION

There is no specific treatment or vaccine available for MVE. The **only** protection is to **avoid being bitten by mosquitoes**. This is particularly important to travellers and visitors to areas where MVE might be active.

PROTECT YOURSELF FROM MOSQUITOES

Mosquito protection during periods of MVE activity is absolutely essential:

- Avoid being outside when mosquitoes are most active, particularly early in the morning and from just before sunset to mid-evening.
- Wear loose fitting light coloured clothing with long sleeves, long trousers and socks. Mosquitoes can bite through tight fitting clothes.
- Use insect repellent when outdoors and reapply when appropriate. Lotions and gels are more effective and longer lasting than sprays.
- Make sure flyscreens and doors are in good order, if camping out sleep under a mosquito net or in a mosquito-proof tent.
- Use a 'knock down' insect spray before going to bed to kill any mosquitoes that are indoors.

For further information contact your doctor, community health care centre or your nearest Public Health Unit.

April 2001.

NSW HEALTH

Health Working as a Team The Way Forward

COMMUNICABLE DISEASES, NSW: APRIL 2001

TRENDS

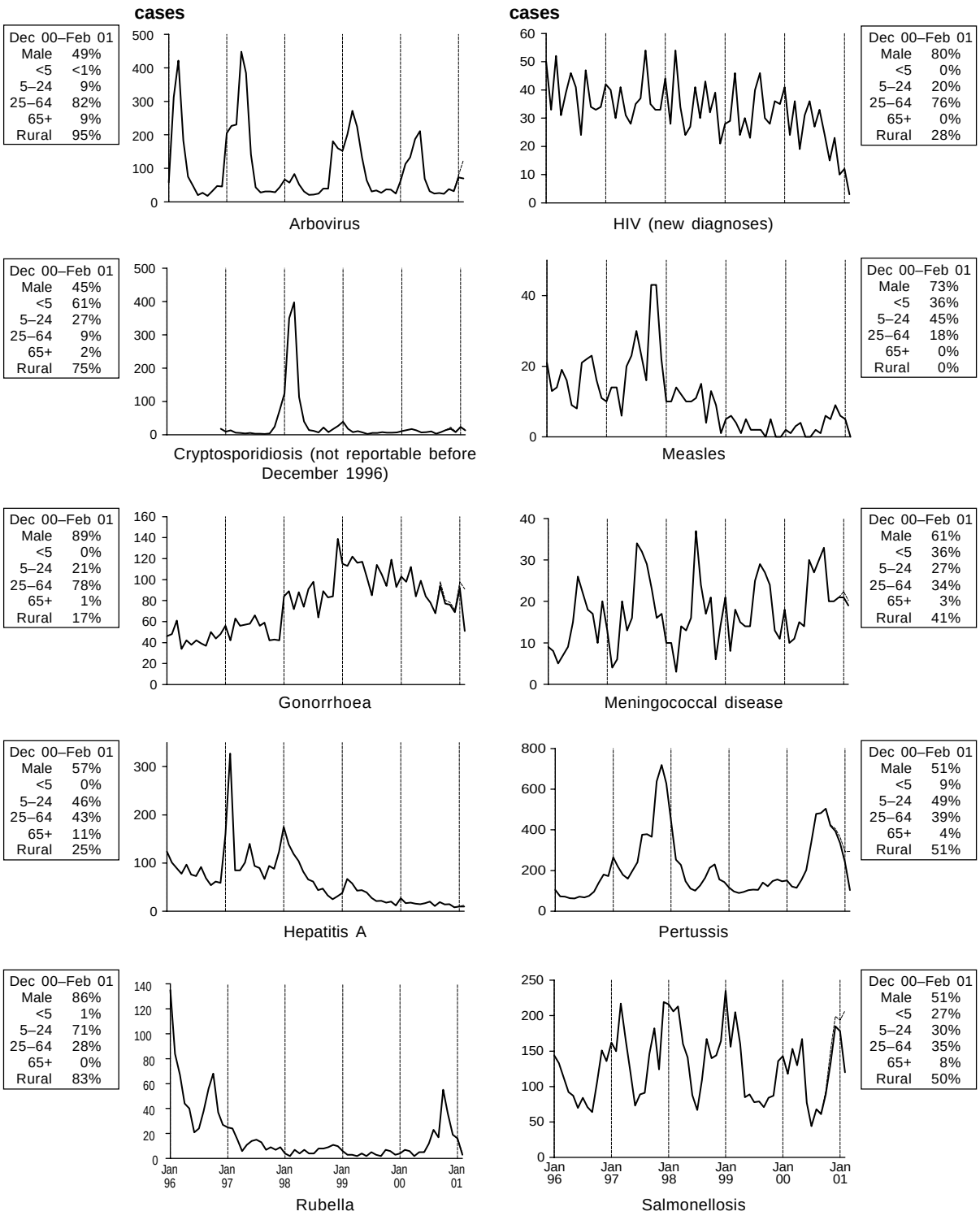
Highlights of communicable diseases notifications in NSW through to February 2001 include continuing declines in pertussis, measles and rubella, and continuation of the seasonal rise in arboviral infections, due to Ross River and Barmah Forest viruses (Figure 8, Table 14).

FIGURE 8

REPORTS OF SELECTED COMMUNICABLE DISEASES, NSW, JANUARY 1996 TO FEBRUARY 2001, BY MONTH OF ONSET

These are preliminary data: case counts for recent months may increase because of reporting delays. Laboratory-confirmed cases, except for measles, meningococcal disease and pertussis ___ actual ___ predicted after adjusting for likely reporting delays

NSW population	
Male	50%
<5	7%
5–24	28%
25–64	52%
65+	13%
Rural*	42%



* For definition, see *NSW Public Health Bulletin*, April 2000

TABLE 14 REPORTS OF NOTIFIABLE CONDITIONS RECEIVED IN FEBRUARY 2001 BY AREA HEALTH SERVICES

Condition	Area Health Service (2001) CSA	NSA	WSA	WEN	SWS	CCA	HUN	ILL	SES	NRA	MNC	NEA	MAC	MWA	FWA	GMA	SA	CHS	Total for Feb†	Total To date†
Blood-borne and sexually transmitted																				
AIDS	2	-	1	-	-	-	-	-	2	-	2	-	-	-	-	-	-	-	7	33
HIV infection*	1	-	-	-	1	-	1	-	-	-	-	-	-	-	-	-	-	-	3	15
Hepatitis B - acute viral*	-	-	-	-	1	-	-	1	2	2	-	-	6	-	-	-	1	-	13	19
Hepatitis B - other*	-	23	25	1	63	2	6	7	39	5	5	3	1	-	3	4	4	6	198	554
Hepatitis C - acute viral*	-	-	-	-	-	-	2	-	-	-	-	-	-	-	-	-	-	1	3	15
Hepatitis C - other*	-	39	45	17	61	17	38	25	66	41	31	17	5	11	1	15	16	70	518	1,304
Hepatitis D - unspecified*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Hepatitis, acute viral (not otherwise specified)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Chancroid*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Chlamydia (genital)*	-	23	14	5	20	5	20	11	86	17	15	7	6	3	9	5	11	3	264	557
Gonorrhoea*	-	5	3	3	4	2	1	1	34	3	2	1	1	2	1	-	3	2	72	177
Syphilis	1	-	4	1	3	-	-	-	17	4	-	1	2	-	-	-	-	2	36	95
Vector-borne																				
Arboviral infection (BFV)*	-	-	-	-	-	-	1	1	-	6	6	-	-	-	2	1	2	-	19	35
Arboviral infection (RRV)*	-	1	1	-	1	-	4	2	-	11	6	15	9	2	1	25	-	-	78	116
Arboviral infection (Other)*	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1
Malaria*	-	4	-	1	2	-	-	1	2	1	-	-	-	-	-	-	1	-	13	27
Zoonoses																				
Anthrax	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Brucellosis*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Leptospirosis*	-	-	-	-	-	-	3	-	-	1	1	4	-	-	-	-	-	-	9	16
Lyssavirus	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Psittacosis	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	1	5
Q fever*	-	-	-	-	-	-	1	1	-	1	4	1	1	3	-	-	-	-	12	29
Respiratory and other																				
Blood lead level*	-	-	-	-	1	-	3	5	1	-	-	-	-	-	13	1	-	-	24	48
Influenza	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	1	2
Invasive Pneumococcal Infection	-	1	-	-	-	3	-	-	-	-	-	-	-	-	-	-	-	-	4	9
Legionnaires' Longbeachae*	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	2	2
Legionnaires' Pneumophila*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	3
Legionnaires' (Other)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Leprosy	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Meningococcal infection (invasive)	1	7	3	-	3	-	-	2	-	-	1	-	-	-	-	1	-	-	19	42
Mycobacterial tuberculosis	3	4	8	-	3	1	-	-	3	1	-	-	-	-	-	-	-	-	24	60
Mycobacteria other than TB	1	-	-	-	-	-	-	-	1	1	-	-	-	-	-	2	-	-	5	18
Vaccine-preventable																				
Adverse event after immunisation	1	-	-	-	-	-	1	-	1	-	-	-	-	-	-	-	-	-	3	5
H.influenzae b infection (invasive)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Measles	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	2	6
Mumps*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	4
Pertussis	9	16	26	9	20	8	43	22	30	11	16	19	14	7	-	14	4	-	268	583
Rubella*	-	-	-	-	1	-	4	1	1	-	-	-	-	-	-	1	-	-	8	27
Tetanus	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Faecal-oral																				
Botulism	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Cholera*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Cryptosporidiosis*	-	-	1	1	1	-	-	-	5	3	1	4	-	-	-	1	-	-	17	39
Giardiasis*	-	3	7	1	4	2	6	6	12	9	1	1	2	2	-	1	1	-	58	128
Food borne illness (not otherwise specified)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Gastroenteritis (in an institution)	-	11	65	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	76	174
Haemolytic uraemic syndrome	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	4
Hepatitis A*	3	1	2	-	-	-	-	-	2	-	1	-	-	-	-	-	-	-	9	20
Hepatitis E*	-	-	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	2	3
Listeriosis*	-	-	-	-	1	-	-	-	1	-	-	-	-	-	-	1	-	-	3	5
Salmonellosis (not otherwise specified)*	1	21	12	9	15	5	14	1	14	30	18	9	3	2	2	4	1	-	161	356
Shigellosis	-	-	1	-	-	1	-	-	5	1	-	-	-	-	-	-	-	-	8	10
Typhoid and paratyphoid*	2	-	3	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	7	9
Verotoxin producing Ecoli*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

* lab-confirmed cases only

† includes cases with unknown postcode

CSA = Central Sydney Area
NSA = Northern Sydney Area
WSA = Western Sydney Area
WEN = Wentworth Area
SWS = South Western Sydney Area
CCA = Central Coast Area
HUN = Hunter Area
ILL = Illawarra Area
SES = South Eastern Sydney Area
NRA = Northern Rivers Area
MNC = North Coast Area
NEA = New England Area
MAC = Macquarie Area
MWA = Mid Western Area
FWA = Far West Area
GMA = Greater Murray Area
SA = Southern Area
CHS = Corrections Health Service