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THE FUTURE IS NOW: NEW AND BETTER CANCER INFORMATION IN NSW

GUEST EDITORIAL

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The growth of information technology in modern health service infrastructure creates opportunities for more accurate, timely, efficient and useful cancer registries. The following developments are key:

- computerised patient administration and patient care systems;
- coverage of ambulatory as well as in-patient care;
- electronic reporting of pathology and other test results;
- health data 'warehouses' that store information from these and other systems (for example, death registrations);
- the World Wide Web.

The cancer registry of the future will be:

- *more accurate*, thanks to computer-assisted coding, range and logic checks applied to input data at source, and rapid electronic feedback to the source for correction of inconsistencies or errors found in case resolution;
- *more timely*, since most of the input data will be derived directly from computerised information used for patient administration and care, which will be compiled in real or near real time;
- *more efficient*, since, ultimately, all or nearly all the data the registry needs will be extractable from a continually updated health data warehouse and will require little if any further processing before it can be analysed and reported;
- *more useful*, first because of richer population-based data collections from computerised patient-management systems and, second, because of the rapidity and richness of data and information dissemination through the World Wide Web.

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Imagine a population-based cancer registry fed continually with individually linked data from warehouses contributed to by all, or nearly all, notifiers (such as hospitals and pathology laboratories). The data include information on in-patient and ambulatory surgical, chemical, biological and radiation treatment. The few notifiers who do not use a data warehouse notify through a secure Web site or completion of a notification form through their Web browser. Sophisticated case resolution software identifies new incident cases in incoming data and there is little need for human intervention. All data are coded at source and the registry's focus is quality assurance.

A new data file is released quarterly and is complete to the end of a period six months before its release. The file is immediately accessible through an easily used, analytical 'front end' on the World Wide Web. Privacy is protected by software ensuring that disaggregation to the point of potential identifiability does not occur. Release of leading indicators of change in incidence, mortality and survival follows shortly, as does information comparing the care delivered by individual health services with best-practice care. An email alert is sent to key public health and cancer care decision-makers with a link to the new information.

Staff members spend most of their time in developing new cancer registry information products and in value-added analysis and research using cancer registry data.

This is all possible now.

This issue of the Bulletin, the second in a five-part series on cancer, contains articles and reports describing how new and better cancer information systems are being applied in New South Wales.

STATUS REPORT ON REDEVELOPING THE NSW CENTRAL CANCER REGISTRY

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Since 1972, public health legislation in NSW requires that all new cases of cancer are notified. Since 1986, the NSW Central Cancer Registry (CCR) has been based at the NSW Cancer Council and has reported on the number, rates, types and distribution of cancer cases and deaths in NSW. This information has been vital for planning cancer services, and monitoring the health of the NSW population.

Currently, the NSW Public Health Act 1991 requires that hospitals and pathology laboratories notify the NSW Central Cancer Registry of people who are treated for cancer, or who have had tests that have diagnosed cancer. These notifications contain information about the patients, the type of cancer, date of diagnosis and treatment given, and are currently received by the CCR either in electronic or paper form. A number of notifications can therefore be received for the same case of cancer from different sources, and must be matched and reconciled through the process of registration. Notification from a variety of sources ensures better capture of data on as many cancer cases as possible; and, through the process of checking and registration, better quality data on each case of cancer registered.

This article describes the progress of initiatives to improve the operational efficiency of the registration process and the quality of the data received, processed, and made available for use by, the NSW Central Cancer Registry. These initiatives include:

- automated methods to validate and check data entry in hospital patient administration systems;
- improving mechanisms to receive and process data through electronic notification, and eventually through the Health Information Exchange (HIE);
- increasing the proportion of notifications received in electronic form;
- improving the processing and storage of paper notifications through the introduction of a workflow management system;
- eliminating the backlog of unprocessed notifications;
- developing a new main database to manage the data;
- making the data available in an easily accessible format.

OVERVIEW OF THE CCR REDEVELOPMENT

The redevelopment project covers all aspects of notifying, receiving, processing, editing, extracting, analysing and reporting population-based cancer data in NSW and the ACT. The project is funded by the NSW Government and is administered by the NSW Department of Health. It aims to achieve:

- solutions that are consistent with the Department of Health Information, Management and Technology

Strategic Plan and the NSW Central Cancer Registry Business Case;[1]

- the removal of the backlog of notifications and assurance that reporting requirements take place within one year of notification;
- increased timeliness and quality of data;
- improved reporting of data.

INITIATIVES TO IMPROVE DATA QUALITY

Redevelopment initiatives in the following strategic areas should result in a major improvement in the quality of data and information produced by the CCR:

Patient Administration System

Currently, 40 per cent of all notifications are received electronically from Patient Administration Systems (PAS) in hospitals. These systems collect identifying and treatment data for all patients who are admitted to hospitals throughout the State. In the past, PAS systems have included extra fields in a cancer module, to collect data that is relevant only to patients with cancer.

With the development of new PAS systems in NSW hospitals, the CCR redevelopment process is seeking to: ensure that the cancer module is included and improved upon so that all relevant cases of cancer are notified to the CCR; and to automate data checks at the source of data entry. The business requirements of the Registry have been given to the suppliers of PAS systems to ensure that the necessary edits and validation are incorporated in the design of present and future PAS systems.[2] These specifications will require the compulsory completion of the cancer module by the expert medical coder, using relevant disease codes. Currently the completion of the module is at the discretion of these coders.

Data dictionary

Other initiatives include defining the cancer registry data items in a new cancer-specific data dictionary, which is available on the Department of Health's Web site.[3] The 11 cancer-specific data items, which are included in the cancer module of the PAS systems, are defined in this data dictionary, along with other data items notified to the CCR that are also used in other data collections such as the Inpatient Statistics Collection (ISC).

The development of the data dictionary has involved reviewing all data collected, and has provided the opportunity to address existing anomalies in data definitions used by the CCR and the Health Department in other collections, such as the ISC. For example, the codes that the CCR uses to identify institutions, and the country of birth of patients, have been changed so that they are the same as those used by the Department of Health. New codes have also been allocated for private pathology laboratories. In future, the CCR will only use codes allocated by the Department of Health. The postcode and locality tables have also been updated and an automatic coding facility (National Locality Index Grouper) has been introduced to allocate residential addresses to local government areas and area health services.

The alignment to the ISC, and the introduction of processes to ensure that data codes continue to be aligned with those of the Department of Health, will help to ensure the consistency and quality of the CCR data.

Health Information Exchange

By June 2001, cancer notifications will be received from the Health Information Exchange (HIE).[4] The HIE comprises individual data warehouses of each area health services and the Department of Health. The warehouses are repositories of historic information collected from disparate operational systems throughout the health system, including the PAS systems. The inclusion of the cancer module data will further improve the quality of the data received by the CCR in a number of ways. First, notifications that have incomplete codes on cancer type will be flagged and automatically sent back to the facilities to update. Second, output from the HIE can be presented in a consistent format that can be imported directly into the CCR database.

In time, notifications from pathology laboratories may also be incorporated into the HIE. In the short term, it is hoped that these notifications will be received in an electronic format that will allow for data from different pathology information systems to be received and used by the CCR. An Australian standard has been developed for the electronic transmission of pathology records, but further investigation is required to determine if this can be applied in practice using existing pathology systems. Preliminary discussions have been held with pathology laboratories and a pilot study is being planned.

Workflow management system

To process the remaining written notifications, and to streamline the processing of notifications by the CCR, a workflow management system is being introduced. This system will include imaging facilities that capture paper notifications in different formats as electronic images (data in the images can be read but not manipulated). This will increase the efficiency and accuracy of processing incoming paper records. The imaged records can then be read on computer screens for processing purposes, will be much more accessible than paper records, and will eliminate the need for additional, long-term storage of paper.

MAIN DATABASE DEVELOPMENT

The present database has been fully documented, including data models that describe the relationship between types of data, and the data dictionary that defines the individual data items. User requirements for the new database have been specified, and functional and technical specifications are being prepared. An audit of common reasons why records fail to load onto the current database will inform the development of the matching and code resolution algorithms for the new database. These algorithms ensure not only that people are correctly linked, but also that new notifications are correctly identified as new cancers or as re-notifications of cancers already known to the database.

PROCESSING THE BACKLOG

As at July 2000, there was a backlog of approximately 120,000 paper notifications filed alphabetically that require processing. An audit of CCR processes was undertaken to estimate average times for processing mail, sorting, coding, data entry and editing to estimate the resources required in order to eliminate the backlog in 12 months.[6] The audit results will also be used to evaluate the effect of the introduction of a workflow management system. Additional staff have been appointed and the following timetable has been set: the 1998 Cancer Registry report produced by August 2001, the 1999 report by December 2001 and the 2000 report by June 2002. Monitoring of the progress indicates that the Registry will deliver these reports on time or earlier.

REPORTING

Consultations were held to gain advice from members of the Epidemiology Special Interest Group, Directors of Health Service Development, the Central Cancer Registry, and staff of the Cancer Epidemiology Research Unit, on a set of standards for reports. An improved Statistical Analysis Software (SAS) reporting module is nearing completion, which has a user-friendly series of drop down menus that present CCR data geographically, demographically, clinically, and by time period.

Up-to-date releases of an appropriately restricted CCR database, from which data that may identify an individual has been removed, will be produced quarterly for use with the annual reporting module. The quarterly module will be made available to authorised staff of the Cancer Council's Cancer Research and Registers Division. It may also be possible to make it more widely available to public health personnel in the NSW health system, through the Health Outcomes Information and Statistical Toolkit (HOIST), which is a public health data warehouse developed and maintained by the Epidemiology and Surveillance Branch of the NSW Department of Health.

A Web-based version of the reporting module, providing access to a large number of pre-prepared tables, is also being developed for the use of the general public. Both tables and graphs of data in age-specific categories and in age-standardised and crude form will be available, as well as new measures, such as person years of life lost due to cancer.

Ultimately, the redevelopment of the NSW Central Cancer Registry will result in the provision of up-to-date data on cancer incidence, mortality, prevalence and survival in flexible formats.

REFERENCES

1. NSW Department of Health. *Central Cancer Registry business case for replacement Cancer Registry Systems*. November 1997. Unpublished report.
2. Tracey E. *Notification to the Central Cancer Registry—Outline of business requirements*. Presented to the Patient Administration System (PAS) Consortium Meeting. December 7th 1999. Unpublished report.
3. CCR Specific Data items www.health.nsw.gov.au/iasd/dm/isc/instructions/2000-2001/isc-instructions-2000-2001.html.
4. *Health Information Exchange Cancer Feed Scope*, version 1.11, October 2000.
5. Implementation of Health Level 7 (HL7) version 2.3.1 Part 4 Pathology results for registries. *AS 4700.4* October 2000.
6. Tracey E. *Resource requirements for processing the backlog of CCR notifications*. May 2000. Unpublished report.

TOWARDS A CLINICAL CANCER INFORMATION SYSTEM

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The efficient delivery of better health care depends on the availability of information on the outcomes of health care. The NSW Clinical Cancer Registries Project (ClinCRs) aims to improve—at a state level—the collection, collation and analysis of data on patterns of cancer treatment and the health outcomes of cancer patients.

The NSW ClinCRs collection system involves the 10 referral hospitals in NSW reporting a minimum data set to the NSW Central Cancer Registry (CCR). Subject to the success of the initial implementation, the system will be expanded to include all major non-metropolitan and district hospitals, both public and private. The CCR will process and analyse the data, and then return a collated state-level minimum data set to the contributing hospitals in a format of agreed indicators, together with an update on the vital statistics of patients treated by particular oncology departments. This article describes the content of the minimum data set and its relevance to improving cancer care.

The ClinCRs project is being conducted by the NSW Department of Health, and is overseen by 20 members of the Standing Committee of Directors of Cancer Services and Departments. In addition, advice from a wider group of cancer clinicians is being regularly canvassed. The objectives and processes of the ClinCRs implementation are fully compatible with the recommendations of the NSW Health Council.[1]

CANCER CARE OBJECTIVES

In 1997, the Optimising Cancer Management Expert Advisory Group defined the following objectives for cancer services:

- reduce incidence of cancer
- increase survival of cancer patients
- improve quality of life of cancer patients
- improve satisfaction with services for cancer patients and their carers
- improve equity of desirable outcomes
- increase cost-effectiveness of cancer services.[2]

TABLE 1

CORE INDICATORS FOR CLINICAL CANCER REGISTRIES IN NSW [3]

1. stage adjusted survival by time since diagnosis (absolute, relative or cause-specific).
2. distribution of patients by cancer type, stage and staging scheme used.
3. status of disease by time since diagnosis.
4. distribution of patients by performance status score.
5. status of disease at the end of definitive treatment.
6. severity adjusted treatment toxicity by toxicity type.
7. distribution of patients by treatment intent.
8. proportion of cases treated according to a local protocol based on evidence-based guidelines.
9. proportion of patients enrolled in clinical trials.
10. distribution of patients by treatment types.

The scope of the ClinCRs project is wide-ranging and includes monitoring survival, aspects of quality of life, and equity of care. Information from the ClinCRs, supported by other data, will be used to estimate changes in incidence of cancer, satisfaction with cancer services, and cost-effectiveness of those services.

CORE INDICATORS FOR THE CLINICAL CANCER REGISTRIES

Long-term and intermediate outcomes, and a vast array of interventions leading to the achievement of those outcomes, can be monitored by a number of indicators. Cancer care clinicians ranked 60 potential indicators, from which 10 were chosen on the basis of their importance and their ability to be collected. These have become the core indicators for the ClinCRs (Table 1).[3]

MINIMUM DATA SET FOR THE CLINICAL CANCER REGISTRIES

The ClinCRs system focuses on these 10 core indicators. To present them, 65 data items are required (Table 2); and these items have become the ClinCRs minimum data set. A full list of this minimum data set is included in the *NSW Clinical Cancer Registers Minimum Data Set Data Dictionary*,[4] along with other data items that are needed to present detailed information about specific cancers.

The minimum data set makes good use of existing data. Of the 65 data items, 29 are already routinely collected at the state level,[5] and 22 are collected in most local collections. A further 11 data items will be collected at the state-wide level.[6] Linkage with other already established collections in the future has been considered.[7, 8]

The ClinCRs minimum data set supports the NSW Cancer Services Model, which is a service delivery model that promotes high-quality integrated and co-ordinated cancer care.[9] Information from the ClinCRs will stimulate improvements in the quality of cancer care by providing an overview of cancer in NSW.

HOW THE MINIMUM DATA SET WILL IMPROVE CANCER CARE

Monitoring the patterns of courses of treatment by stage and other prognostic indicators

Clinicians will be able to monitor prevailing patterns of treatment. For example, it will be possible to assess what types of cancer are treated by which surgical procedure, radiotherapy, chemotherapy (including oral chemotherapy); which types are receiving multimodality treatment, and in which order. This overview of treatment patterns is not presently available in NSW. The ClinCRs will report on survival and more immediate outcomes:

TABLE 2

MINIMUM DATA SET FOR NSW CLINICAL CANCER REGISTRIES

No	Data Element	Comments
	Person characteristics	
1	Given name	Collected by ISC*
2	Family name	Collected by ISC
3	Middle name	Collected by ISC
4	Maiden name	Collected by ISC
5	Previous, Alias, AKA	Collected by ISC
6	Sex	Collected by ISC
7	Address of usual residence:	
	Street number	Collected by ISC
8	Street name	Collected by ISC
9	Locality	Collected by ISC
10	Postcode	Collected by ISC
11	Medicare number	Collected by ISC
12	Medical Record Number	Collected by ISC
13	Date of birth	Collected by ISC
14	Country of birth	Collected by ISC
15	Indigenous origin	Collected by ISC
16	Preferred language	Collected by ISC
17	Insurance status	Collected by ISC
	Death record	
18	Cause of death	Collected by RBDM* Coded by ABS* Collected by CCR*
19	Date of death	Collected by RBDM Coded by ABS Collected by CCR
	Provider characteristics	
20	Facility code	Collected by ISC
	Diagnosis	
21	Date of diagnosis of primary cancer	Collected by CCR
22	Diagnosis basis	Collected by CCR
23	Primary site	Collected by CCR
24	Laterality	Collected by CCR
25	Histological type	Collected by CCR
26	Behaviour of the tumour	Collected by CCR
27	Histopathological grade	International standard
	Stage of cancer at diagnosis	
28	Staging scheme source	For differentiating between identifiable mainstream source and Other
29	Staging scheme source edition number	For precise identification of an identifiable mainstream source
30	Staging basis	International standard
31	Stage main grouping	International standard
31a	Degree of spread of cancer at this admission	Collected by CCR
32	Stage FAB–ALL grouping	International standard
33	Stage FAB–ANLL grouping	International standard
34	Prognostic additional factors	International recommendations
35	Staging additional descriptor	International standard
36	Stage paediatric group	International standards
37	Stage of cancer: T value	International standard
38	Stage of cancer: N value	International standard
39	Stage of cancer: M value	International standard
40	Performance status at diagnosis	International standard
	Treatment types (modalities)	
41	Protocol type	Includes clinical trial protocols
42	**Surgery:** Procedure type	Collected by ISC
43	Date of Surgery	Collected by ISC
44	**Radiotherapy:** Radiotherapy Type	To be collected by RIS*
45	Date of radiotherapy start	To be collected by RIS
46	Date of radiotherapy end	To be collected by RIS
47	Radiation acute toxicity type	International standard. A high grade to be reported
48	Radiation late toxicity type	International standard. A high grade to be reported
49	Radiation toxicity severity score	High grade to be reported
50	Date of assessment of radiation late toxicity	Date recorded if late toxicity identified
51	Radiotherapy target (treatment site)	To be collected by RIS
52	Radiation dose size	To be collected by RIS
53	Radiation dose type	To be collected by RIS

TABLE 2

MINIMUM DATA SET FOR NSW CLINICAL CANCER REGISTRIES *(continued)*

No	Data Element	Comments
	Chemotherapy	
54	Date of chemotherapy start	
55	Date of chemotherapy end	
56	Chemotherapy toxicity type	International standard. A high grade to be reported
57	Chemotherapy toxicity severity score	International standard. A high grade to be reported
58	Date of assessment of chemotherapy late toxicity	Date recorded if late toxicity identified
59	Chemotherapeutic agents standard treatment protocol name (acronym)	Acronyms or a single agent name, as applicable. Approach to be tested first in NSW and later replaced by Anti-neoplastic agent name.
59a	Anti-neoplastic agent name	Common coding reference: *Antineoplastic drugs* (a manual maintained by SEER* in the United States).
60	Chemotherapeutic agent standard treatment number of cycles	The number of times that a combination of agents (protocol) was administered in the course of treatment
Intermediate outcomes		
61	Performance status at the end of treatment	International standard
62	Residual tumour	International standard
63	Date of diagnosis of recurrence	
64	Site of recurrence	To be collected by RIS
	Palliative care	
65	Palliative care status	Collected by ISC

*** Acronyms**

ABS	Australian Bureau of Statistics	ISC	NSW Inpatient Statistics Collection
ALL	Acute Lymphatic Leukaemia	RBDM	Registrar of Births, Deaths and Marriages
ANLL	Acute Non-Lymphatic Leukaemia	RIS	Radiotherapy Information System
CCR	NSW Central Cancer Registry	SEER	Surveillance, Epidemiology and End Results program
FAB	French–American–British (staging system)	TNM	Tumour Nodes Metastasis, a cancer staging system

for example, duration of remission; the burden of serious side-effects by cancer type, stage, other prognostic indicators, and treatment pattern.

Clinical cancer registries with a wide population coverage are the best option for learning about patterns of treatment for rare cancers where data on treatment patterns and risk adjusted relative survival are very scarce.

Comparing treatment results with other centres

The ClinCRs overview of cancer care will be simple. Nevertheless, valid comparisons of results between regional centres and results at the state level can be made; and it will be possible to extend these comparisons to results achieved in other states and countries. Clinicians will evaluate ClinCRs reports and assess whether outcomes meet the expectations based on the scientific literature and other sources of information.

Monitoring whether a recommended practice is being followed

Clinicians will be able to assess whether patterns of treatment are consistent with the objective of high-quality cancer care and, in many instances, be able to compare their results with recommended evidence-based guidelines. For example, the treatment pattern for early breast cancer should reveal that, as recommended, the majority of cases (but not all cases) are treated with lumpectomy followed by a course of radiotherapy. Another example is monitoring the period of time between the date of diagnosis and surgery for melanoma, where rapid response is vital. Setting benchmarks may be considered in some instances.

Improved ability to plan services and directing resources

The ClinCRs information will allow an overview of the current cancer care workload on particular hospitals by cancer site, stage and related factors. Monitoring the trends in cancer care in different hospitals will be possible, as well as an assessment of the implications for resource allocation.

The number of patients staged before the commencement of treatment should increase

Staging, or determining as precisely as possible the extent of tumour spread both at the site of origin and as metastases, is a recognised prognostic tool in cancer management.[10] Reviews of the medical records of cancer cases in the United States report significant improvements in the number of cases staged over the years. Overall increases in staging were as follows: 52.8 per cent

of cases were staged in 1985 and 1986, 65 per cent in 1988, 76.5 per cent in 1990, 84.2 per cent in 1992, 87 per cent in 1993 and 88 per cent in 1994.[10,11,12] Increased staging in hospitals was influenced by outside encouragement, and there was a continuous improvement in the quality, and percentage of cases staged.[13]

The number of local treatment protocols may increase

A treatment protocol for a condition describes the procedures, types, and doses of medication to be used for patient care. Protocols assist in the delivery of local treatment because of their accessibility, the condensed nature of their recommendations, and their portability between centres. Protocols may contain the recommendations of evidence-based guidelines, if such are available. Guidelines are considered to be 'slow' because they take a long time to develop, agree upon, ratify, and disseminate. They usually incorporate recommendations with reference to many elements in the manifestation of disease and the treatment continuum. New knowledge of evidence of effectiveness is often too fragmentary to be developed into ratified guidelines; however, it can be incorporated into local protocols, which are ideal vehicles for 'rapid response' to new information. The ClinCRs will be a convenient tool for monitoring evidence of effectiveness and adherence to local protocols.

Recruitment in clinical trials may increase

Poor recruitment to clinical trials in cancer care is a problem that is influenced by a variety of factors. The ClinCRs collection will show the levels of recruitment to trials in NSW, and may assist in developing strategies to assist with the recruitment of patients.

Communication between different providers, and between providers and patients, will improve

The ClinCRs collection offers definitions and classification systems which should assist with the development of a common cancer record for standardising and streamlining communication within cancer services, with primary care providers, and with patients.

Support for the day-to-day management of cancer patients will be gained

The NSW ClinCRs system will, with Central Cancer Registry assistance, identify patient outcomes that managing clinicians may otherwise find difficult to ascertain (such as death and long-term complications).

CONCLUSION

The ClinCRs minimum data set has a very broad application and the potential to assist in:

- providing the basis for monitoring the quality of services;
- service and resource planning;
- conducting clinical research;
- defining a common cancer record between specialities for day-to-day management of cancer patients.

REFERENCES

1. NSW Health Council. *A better health system for NSW. Report of the NSW Health Council*. Sydney: NSW Department of Health, 2000.
2. Epidemiology and Surveillance Branch. *Optimising Cancer Management. Final Report to the Expert Advisory Group*. Sydney: NSW Department of Health, April 1999.
3. Epidemiology and Surveillance Branch. *Summary of the exercise to rank indicators for Clinical Cancer Registries in NSW.* Sydney: NSW Department of Health, July 1999.
4. Epidemiology and Surveillance Branch. *NSW Clinical Cancer Registries Minimum Data Set Data Dictionary. Edition 1: Draft for Comment.* Sydney: NSW Department of Health, April 2000.
5. Information Management and Clinical Systems. *Inpatient Statistics Collection Instruction Manual*. Sydney: NSW Department of Health, 1999.
6. Radiotherapy Institutional Data Set Working Party and Radiotherapy Minimum Data Set Working Party. *Draft Radiotherapy Minimum Data Set*. Sydney: Statewide Services Development Branch, NSW Department of Health, 1998.
7. Australian Council on Healthcare Standards (ACHS) Care Evaluation Program. *Clinical Indicators in Summary*. Sydney: ACHS, 1998.
8. Centre for Health Service Development. *The NSW AN-SNAP clinical training handbook.* Sydney: NSW Department of Health, June 1999.
9. Cancer Care Model Working Party. *A Cancer Care Model for NSW.* Sydney: NSW Department of Health, 1999.
10. Fleming ID, Philips JL, Menck HR. The National Cancer Data Base report on completeness of American Joint Committee on Cancer staging in United States cancer facilities. *Cancer* 1996; 78: 1498–504.
11. Fleming ID, Philips JL, Menck HR, Murphy GP, Winchester DP. The National Cancer Data Base report on recent hospital cancer program progress towards complete American Joint Committee on Cancer–TNM staging. *Cancer* 1997; 80 (12): 2305–10.
12. Henson DE, Menck HR, Zuber-Ocweja KE. Trends in cancer patient staging. Steele GD, Winchester DP, Osteen RT, Menck HR, Murphy GP (editors). *National Cancer Data Base: Annual review of patient care, 1994*. Atlanta: American Cancer Society, 1994.
13. Smart CR, Eberle C, Simon S. An assessment of National Cancer Data Base quality control. Steele GD, Winchester DP, Menck HR, Murphy GP (editors). *National Cancer Data Base: Annual review of patient care, 1993*. Atlanta: American Cancer Society, 1993; 103–115.

BETTER INFORMATION FOR RADIATION ONCOLOGY

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The development of information management systems is vital to support integrated clinical and administrative practice in cancer management. Information on patients' disease, their treatments and treatment outcomes may affect:

- survival rates
- quality of patient care
- patient and carer satisfaction
- patient quality of life.

The NSW Department of Health recognises the importance of information management from a clinical, administrative and service-planning perspective. This article describes the rationale and development of the *Radiation Oncology Information Management and Technology Strategic Plan*, and its links to other cancer management and service planning initiatives.

RADIOTHERAPY TREATMENT MODALITY

Cancer is a major cause of mortality and morbidity in the community. It has been reported that 45–50 per cent of all cancer patients can be cured, approximately 30-40 per cent of these by radiotherapy either alone or in combination with other treatment modalities such as surgery and chemotherapy.[1] In addition, radiotherapy is an important treatment in the palliative care of cancer patients. Overall, about 50 per cent of all cancer patients need radiotherapy either as part of curative or palliative treatments.

NSW RADIATION ONCOLOGY SERVICE PROVISION

Radiation oncology services in NSW are planned at a statewide level. To meet patient demand, since 1990 the NSW Department of Health has implemented two five-year strategic plans for the expansion of radiotherapy services:

- *Radiotherapy Strategic Plan for NSW*,[2]
- *Strategic Plan for Radiotherapy Services in NSW 1995–2000*.[3]

These two plans have been developed in close consultation with professional groups involved in radiation oncology.

The Department supports the provision of radiotherapy as part of a comprehensive cancer care service. Twelve new linear accelerator machines (machines that produce beams of X-rays or high energy electrons that are focused on to a tumour within the body) have been commissioned for the public sector over a 10-year period; including the establishment of a further four centres offering comprehensive cancer care in the Illawarra, St George, Liverpool and Nepean hospitals.

Unlike other states, radiation oncology services in NSW are predominantly provided by the public sector, which deliver approximately 80 per cent of all courses of treatment. Currently there are 13 Radiation Oncology Treatment Centres—10 public and four private, with St Vincent's Hospital providing both public and private facilities. There are a total of 34 linear accelerator machines installed throughout the state (Table 3).

NSW HEALTH DEPARTMENT'S RADIOTHERAPY MANAGEMENT INFORMATION SYSTEM REPORT

Information is collected annually from all NSW Radiation Oncology Treatment Centres—both public and private—on equipment, treatment activity, staffing, source of referrals for new cases, and methods of data collection. In addition, referral data is collected for NSW residents receiving treatment at public and private services in the ACT, Queensland, South Australia and Victoria. This information is collated into the Department's *Radiotherapy Management Information System Report* (RMISR).[4] Public centres have provided data to the RMISR since 1989 and private centres since 1994. The RMISR assists the area health services to review local cancer services, and assists the networking of cancer services through the development of links with specialised radiotherapy services.

To date, information systems in NSW Radiation Oncology Treatment Centres have been developed on an ad-hoc basis, with different databases and types of information collected at each centre. A number of centres collect information for the RMISR manually, due to the limited capability of their current information systems. A cancer care database is expected to provide information for:

- conducting epidemiological studies of incidence, prevalence and survival in the community;
- providing current, quality data to support decision-making by clinicians;
- evaluating cancer treatment services, especially the cost-effective analysis of new technologies;
- planning future treatment services.

NSW HEALTH CANCER CONTROL INITIATIVES

One of the NSW Department of Health's goals for cancer control is to provide optimal cancer

TABLE 3

RADIATION ONCOLOGY TREATMENT CENTRES AND LINEAR ACCELERATORS IN NSW AT DECEMBER 2000

Area Health Service	Facility Name	Number of linear accelerators
Public facilities		
Central Sydney	Royal Prince Alfred Hospital	3
Hunter	Newcastle Mater Misericordiae Hospital	3
Illawarra	Illawarra Cancer Care Centre	2
Northern Sydney	Royal North Shore Hospital	3
South Eastern Sydney	Prince of Wales Hospital	3
	Cancer Care Centre, St George Hospital	3
	St Vincent's Hospital	2
South Western Sydney	Liverpool Cancer Therapy Centre	3
Wentworth	Nepean Cancer Care Centre	2
Western Sydney	Westmead Hospital	4
Private facilities		
Central Coast	Central Coast Radiation Oncology Centre	1
Northern Sydney	Radiation Oncology Sydney —Sydney Mater Misericordiae Hospital	2
	Sydney Adventist Hospital	2
South Eastern Sydney	St Vincent's Clinic	1

Note: Planning is advanced for a satellite centre at Campbelltown Hospital in SWSAHS.

management for all patients requiring care. The Department's Optimising Cancer Management Initiative (OCMI) is a strategy that was developed in 1995 to respond to this goal, and to consider a number of issues:

- cancer service organisation and delivery (that is, integration and coordination of care through the development of the Cancer Care Model for NSW);[5]
- promotion of consumer perspective in care management;
- implementation of evidence-based guidelines in cancer care;
- infrastructure development (that is, clinical information systems, workforce planning and treatment facilities).[6]

As part of the infrastructure development stream, a number of information management initiatives were developed, such as:

- the development of a cancer clinical data model;
- a business case for hospital-based clinical cancer registries;
- establishment of a register of existing cancer clinical data systems;
- development of a minimum data set for radiotherapy departments.

The overall success of a number of the OCMI strategies depends on timely access to accurate, relevant and current information. A review of the current available cancer management information systems identified a number of shortcomings, such as:

- a reliance on paper-based information collection processes;
- problems with accuracy, timeliness and availability of strategic, statewide and local information;
- a lack of standards in information collection and use;
- the existence of a variety of disparate information systems among the different oncology departments.

These factors, coupled with the implementation of a number of OCMI strategies, led to the development of the *NSW Radiation Oncology Information Management and Technology Strategic Plan* for public Radiation Oncology Treatment Centres in NSW.[7]

NSW RADIATION ONCOLOGY INFORMATION MANAGEMENT AND TECHNOLOGY STRATEGIC PLAN

In June 1998, the NSW Department of Health commissioned the development of a plan to develop a long-term solution for information management and technological improvements for radiation oncology treatment centres. Following an extensive consultation process with relevant cancer management stakeholders, the plan was completed in October 1998. This process was overseen by the Radiotherapy Information Strategy Steering Committee.

The primary objectives of the plan were to:

- identify the information required by radiotherapy

departments to support clinician care and patient management;

- improve the management and utilisation of this information in both the treatment of patients and the planning of services;
- establish the role of NSW radiotherapy information management within the overall framework for statewide information on cancer, cancer control and, in particular, measuring the quality of service provision and health outcomes in cancer care;
- identify appropriate management processes and information technology solutions to enable the departments to perform their information management role.

There are significant gains to be made in the better management and coordination of direct service provision (Table 4). In addition to the numerous patient, clinician and service-oriented benefits, there are other benefits at the Department of Health and area level, such as:

- improving the planning and implementation of services;
- identifying gaps in service provision;
- improving decision making and resource allocation;
- providing a framework for expansion of systems to other oncology disciplines;
- linkage with other systems, such as the Central Cancer Registry, to provide more comprehensive information regarding cancer in NSW.

Implementation of the Strategic Plan is progressing with the assistance of a Steering Committee. Following extensive consultation with stakeholders, functional specifications for ideal radiation oncology information systems and associated tasks have been finalised. These functional specifications have considered the major

TABLE 4

BENEFITS OF AN ONCOLOGY INFORMATION SYSTEM

Comprehensive Outcome Data	
Patient benefits	Increased survival rate
	Improved quality of life
Clinician benefit	Feedback on treatment results
Service benefit	Improvements in treatment methods
Provision of Good Quality Information for Patient	
Patient benefits	Improved satisfaction with service
	More involved in treatment decisions
Clinician benefit	Better response to treatment
	Better compliance with treatment
Service benefit	Patient empowered to take role in treatment decisions.
Efficient Administration	
Patient benefits	Improved service
	Better organisation of services (transport, interpreters, etc)
Clinician benefit	Improved time management
Service benefit	Time and Cost Savings
	Automated costing and billing.
Elimination of Duplication of Data Entry	
Patient benefits	Improved service
Service benefit	Time and cost savings
	Reduction in errors
Effective Scheduling of Appointments	
Patient benefits	Minimum number of visits
	Minimum wait times
Clinician benefit	Can see more patients
	Efficient use of time
	Patients and Clinicians are less stressed
Service benefit	Improved patient care
Support for Development of Evidence-Based Guidelines and Treatment Protocols	
Patient benefits	Increased survival rate
	Improved quality of life
Clinician benefit	Improvements in treatment methods
Service benefit	Optimal resource utilisation
	More consistent quality of treatment
	Reduction in costs
	Supports multi-disciplinary treatment
Effective Follow Up	
Patient benefits	Improved quality of life
Clinician benefit	Improved patient care
	Able to respond to problems quicker
Service benefit	Improved patient care
	Better outcomes data
Effective Information Exchange with GPs and other Referring Service Providers	
Patient benefits	Improved quality of life
	Continuity of (seamless) care
	Less problems in obtaining accurate data at referral
Clinician benefit	More timely referral details
	Conjoint care with other Clinicians
Service benefit	Better, more responsive after treatment care
	Day to day care handled by GP
Support for Integrated Approach to Patient Care	
Patient benefits	Increased survival rate
Clinician benefit	Improved treatment methods
Service benefit	Conducting integrated patient assessment
	Sharing of processes
Support for Clinical Trials	
Clinician benefit	Improved treatment methods
	Professional recognition
Service benefit	Support for specialisation
Improved Cancer Reporting	
Clinician benefit	Better analysis of outcomes
Service benefit	Better, more timely information to Central Cancer Registry
	Improved statewide statistical reporting

Source: *NSW Radiation Oncology Information Management and Technology Strategic Plan* [7]

information functions required for improved efficacy and efficiency of the delivery of radiotherapy services, such as:

- patient appointment scheduling and follow-up
- resource management
- tracking of patient flow
- clinical management
- clinical auditing of patterns of care
- quality assurance and treatment statistics
- patient treatment summaries
- patient accounts
- notifications to the NSW Central Cancer Registry.

As a first step towards streamlining the process of selecting suitable information systems, current potential radiation oncology information systems were reviewed through an expression-of-interest process in November 2000. This will be followed by a selective tender process for an information system that will comply with the developed functional specifications. It is envisaged there will be one or more systems available for selection by public Radiation Oncology Treatment Centres in NSW.

In order to extend this process into other areas of oncology within comprehensive cancer care centres, a business case has been submitted to the Office of Information Technology (OIT) for a similar development in medical oncology. The business case has been supported by OIT for submission to NSW Treasury.

RADIATION ONCOLOGY SERVICE PLANNING

As a result of improved information management, there will be more complete information available for planning purposes. A Radiation Oncology Planning Group was convened in early 2000 to oversee the development of a strategic plan for radiation oncology services in NSW to 2006. This group will plan for radiation oncology services and equipment needs to 2006, considering issues that affect the planning of services, such as:

- planning methodology
- potential demand for high-utiliser cancers
- treatment complexity
- future technological developments
- comprehensive cancer care provision.

It is envisaged that the third Strategic Plan will be completed in 2001.

ACKNOWLEDGEMENTS

The valuable work of Joanna Kelly and Kathy Smith, Health Informatics, is acknowledged for their continued efforts with the implementation of the NSW Radiation Oncology Information Management and Technology Strategic Plan.

REFERENCES

1. Swedish Council on Technology Assessment in Health Care. *Critical Issues in Radiotherapy.* Stockholm: SB Offset AB, 1996.
2. NSW Department of Health, Statewide Services Development Branch. *Radiotherapy Strategic Plan for New South Wales*. Sydney: NSW Department of Health, 1991; 91–12.
3. Statewide Services Development Branch. *Strategic Plan for Radiotherapy Services in New South Wales 1995–2000*. Sydney: NSW Department of Health, 1995.
4. Statewide Services Development Branch. *1998 Radiotherapy Management Information System Report.* Sydney: NSW Department of Health, 1999.
5. NSW Department of Health. *Optimising Cancer Management Initiative—A Cancer Care Model for NSW.* Sydney: NSW Department of Health, 1999.
6. NSW Department of Health. *Optimising Cancer Management Initiative – Final Report to the Expert Advisory Group.* Sydney: NSW Department of Health, 1999.
7. Deakin Consulting Pty Ltd. *NSW Radiation Oncology Information Management and Technology Plan*. Sydney: NSW Department of Health, October 1998. (Unpublished).

ESTIMATING A WOMAN'S RISK OF BREAST CANCER: THE EFFECTS OF AGE AND FAMILY HISTORY

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This article discusses the methods of estimation of cancer risk in populations and individuals from reported incidence data using breast cancer in NSW women as an example.

The use of the term 'risk' alone implies *absolute* (not *relative*) risk. The absolute risk is the chance (probability) of an event occurring over a specified time period. Absolute risks lie between zero (never) and one (certainty). One minus the absolute risk is the probability of an event not occurring. Risk is frequently calculated in public health and clinical medicine for disease occurrence (incidence), death, complications from a

TABLE 5

CUMULATIVE RISK OF BREAST CANCER TO AGE 79 YEARS IN THE POPULATION AND WITH PRESENCE OR ABSENCE OF A FAMILY HISTORY*

Exact age of woman (yrs)	Age range (yrs)	Cumulative risk of breast cancer across the specified age range: General population†		No family history		Any first degree relative age≥50†		Any first degree relative age<50†		First-degree relative (any age) and second-degree relative* (any age) †		Mother and sister (any age) †	
		%	1 in	%	1 in	%	1 in	%	1 in	%	1 in	%	1 in
20	20–79	8.6	12	7.8	13	13.1	8	16.5	6	19.5	5	25.4	4
25	25–79	8.6	12	7.8	13	13.1	8	16.5	6	19.5	5	25.4	4
30	30–79	8.6	12	7.8	13	13.1	8	16.4	6	19.4	5	25.3	4
35	35–79	8.5	12	7.7	13	12.9	8	16.1	6	19.1	5	25.0	4
40	40–79	8.3	12	7.5	13	12.6	8	15.5	6	18.6	5	24.4	4
45	45–79	7.8	13	7.1	14	11.8	8	14.3	7	17.4	6	23.1	4
50	50–79	7.0	14	6.4	16	10.7	9	12.4	8	15.6	6	21.1	5
55	55–79	6.1	16	5.6	18	9.4	11	10.5	10	13.6	7	18.7	5
60	60–79	5.1	20	4.7	21	7.8	13	8.5	12	11.3	9	15.8	6
65	65–79	4.0	25	3.6	28	6.0	17	6.4	16	8.8	11	12.4	8
70	70–79	2.7	37	2.5	40	4.2	24	4.4	23	6.1	16	8.6	12
75	75–79	1.4	72	1.3	79	2.1	47	2.3	44	3.1	32	4.5	22

*Based on 1996 NSW breast cancer incidence (adjusted for screening effect)

†Unadjusted for competing causes of death

disorder, recurrence of cancer after primary treatment, and many other events. Relative risk (RR) derives from the ratio of two incidences—usually in the unexposed, and various categories of the exposed, to putative causal factors for a disease or condition. RR does not inform us of the absolute risk of an event. For example, the RR for an event associated with all exposure with incidences of four per million per year in the exposed and two per million in the unexposed is the same as it would be if the incidences were four per 100 per year and two per 100 per year, that is: 2.0.

USES OF CANCER RISK INFORMATION

Reliable information on the occurrence of breast cancer is required for clinical and public communication concerning the risks of this disease to individuals and populations, and for informing policy for secondary prevention through regular mammographic screening. While RR is a convenient way of expressing susceptibility to cancer according to different exposure (putative causal) factors, it cannot be used on its own for population risk estimation or to provide information of the actual risk of contracting a disease over a specified period.

Public health and health promotion professionals need to know the absolute risk of breast cancer in local populations over particular age ranges so that they can convey risk meaningfully to women and encourage compliance with mammographic screening. Furthermore, health planners require data on the numbers of women with breast cancer likely to present in the future in particular populations, to ensure appropriate resources are available to treat patients. Clinicians need to know absolute risks of breast cancer over the remaining life span in women of different ages who ask for advice on their risk, particularly for those with a positive family history of breast cancer or other risk factors. Women need to understand risk of breast cancer as it applies to themselves so that they can make informed choices regarding mammographic screening and medical surveillance, and prophylactic options such as tamoxifen or even mastectomy.

ESTIMATION AND PRESENTATION OF CANCER RISK

Approaches to estimation

Two types of data can be used to estimate breast cancer risk in individuals and populations: data from large cohort studies and data from population incidence data. *Cohort data* provide a wealth of information on risk in women with a variety of risk factors, but studies generally have been on unrepresentative populations from countries with different underlying rates of breast cancer.[1] *Population incidence data* have been commonly used to estimate absolute cumulative risk using the hypothetical cohort method. The use of cumulative risks

derived from cross-sectional data is similar to actuarial life table methods, and is helpful for quantification of what would happen to a hypothetical cohort if it passed through the age-specific rates used in the calculations. The application of cumulative risks to the future is made with the caveat that this is what would be expected if contemporary, age-specific incidence rates were to continue.

Adjustment for the effect of screening

The implementation of mammographic screening in a community leads to a higher population incidence of breast cancer because of the additional diagnosis of cancers which would have presented later without screening ('borrowing cancers from the future'), particularly during the initial ('prevalent') rounds in women in the screening age groups.[2] A reasonable and responsible approach is to adjust reported incidence during the introduction of population-based mammographic screening, to provide realistic measures of breast cancer risk.[3]

Display of absolute risk

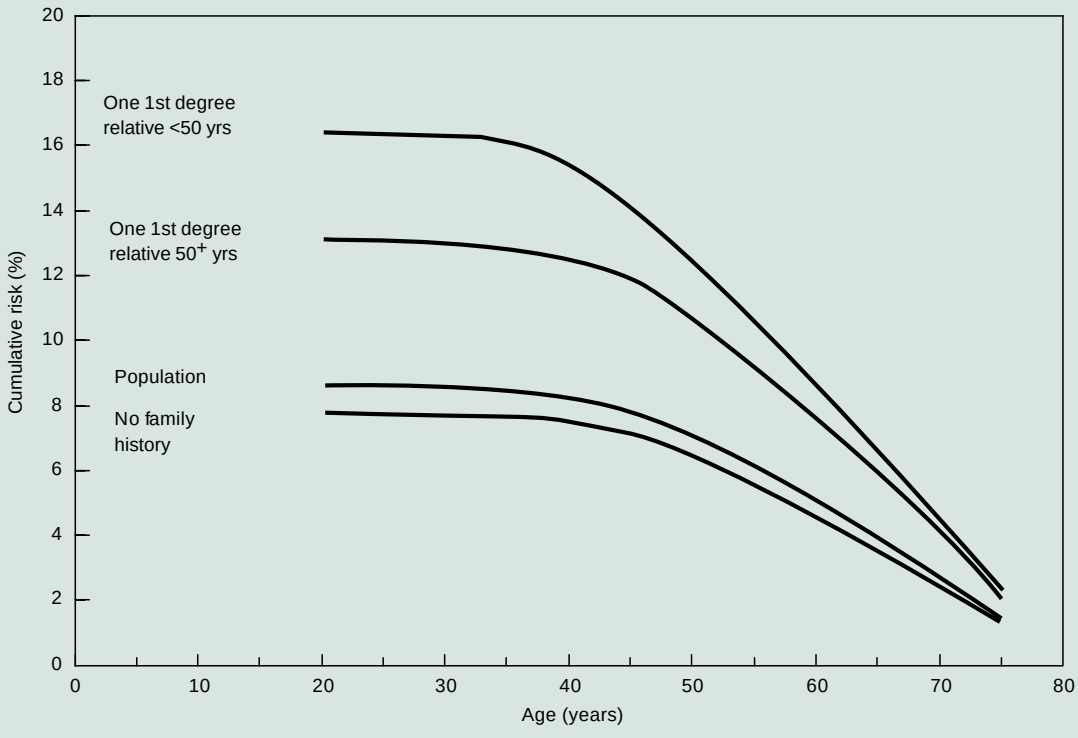
Although data are routinely available on the 'lifetime' risk (usually taken as birth to the average life expectancy), estimated from current age-specific breast cancer incidence, this information is rarely given for a variety of age ranges or for the remainder of life. Yet this is required in both the population and individual situations since the (cumulative) absolute risk for the remainder of a lifetime declines with age because women have fewer years to live as they age, even though the age-specific risks increase with age. Life expectancies at particular ages can be employed as the upper-limit for cumulation of risk. Cumulative risk can also be expressed for the target screening age ranges (50–69 years), or for the next 10 or 20 years (or other interval) from a particular age. Risk is usually given as a proportion (%), or as its reciprocal 1 in *x*, where *x* is expressed as an integer.

Estimation of absolute risk in the presence of risk factors

Most of the available information on breast cancer risk in Australian women only applies to the general population, not to women with particular risk factors. Information from cohort studies can provide data that enable the calculation of absolute risk of incidence of breast cancer in relation to risk factors. Absolute risks of breast cancer by risk factor can also be obtained by multiplying relative risks for various categories of risk factor (versus

FIGURE 1

CUMULATIVE ABSOLUTE, RESIDUAL, LIFETIME RISK TO AGE 79 YEARS FOR BREAST CANCER IN AUSTRALIAN WOMEN BY AGE AND FOR SELECTED CATEGORIES OF FAMILY HISTORY



absence of risk factor) with the risk in the general population;[4] but this relationship does not hold with higher absolute risks and a significant prevalence of the risk factor in the general population.[5] In these instances it is preferable to estimate the baseline risk of breast cancer in women with the absence of a risk factor using attributable factors.[3] Age-specific rates of breast cancer for various categories of a risk factor can then calculated by applying RRs for various categories of risk factor compared to no risk factors.

RISK OF BREAST CANCER IN NSW WOMEN

The age-specific breast cancer incidence data used in this article were derived from 1972–1996 statewide data from the NSW Central Cancer Registry. Female populations are derived from data based on successive quinquennial censuses. These data are more recent than available national data, which, in any case, could not be modelled effectively because of the relatively brief time series available.

Adjustment for screening effect

The 'underlying' incidence of breast cancer in NSW for 1996, allowing for the effects of mammographic screening, was estimated from a Poisson regression model of breast cancer incidence data, using a stable period effect derived from 1972–1989.[3,6] This method led to lower incidence of breast cancer compared to unadjusted data, particularly for the age groups 50–64 years (most of the target age range for screening), and produced lifetime risks comparable to that for NSW from the early 1990s (Table 5). The lifetime risk of breast cancer from these rates (one in 12) is similar to that calculated from NSW breast cancer incidence using data from the early 1990s.[7]

Estimation of absolute risks according to risk factors

The absolute risk of incidence of breast cancer in relation to family history can be calculated from the attributable fraction (AF), and has been described in more detail for calculation of risks of disease and mortality in smokers and non-smokers.[8,9] The method estimates breast cancer incidence rates in women with no family history from the incidence in the population and the AF; RRs are then applied to obtain incidence for various categories of family history. AFs for the Australian population for breast cancer from family history were calculated indirectly,[10] using RRs from the international meta-analysis performed by Pharoah et al.,[1] and prevalence of family history from the Queensland mammographic screening program,[11] to obtain estimates of absolute risk of breast cancer for the remainder of a lifetime for women at different ages (Table 5).[1, 11]

Data expressed as absolute risk are more intuitively understandable than RRs between women with and without a family history of breast cancer, or differences in rates of incidence between groups.[4] The risks given in this article apply to women with *average* breast cancer risk from other factors. For individual women, the risk of breast cancer is dependent on risk factors other than family history, and women with specific genetic syndromes—such as those associated with the BRCA1 and BRCA2 genes—require individualised risk assessment, as do women with a family history that includes other cancers.[12]

Calculation of cumulative risk

Age-specific incidence rates can be converted to cohort probabilities, and also summarised as cumulative risks over particular age ranges:[13]

Cumulative risk = 1 – exp (- Cumulative rate).

Cumulative risks were calculated from decade and mid-decade ages to age 79 years which is the approximate life expectancy at birth of Australian women in the 1990s. Cumulative risks of breast cancer by age (to age 79 years) in the general population, for those without family history, and for those with various categories of family history are set out in Table 5, and illustrative data are included in Figure 1. The cumulative risk of developing breast cancer to age 79 years decreases with advancing age because there are fewer years remaining to experience age-specific risks.

Compared with an average lifetime risk (to age 79 years) of around 8.5 per cent (1 in 12) for the general population and 7.8 per cent or 1 in 13 for those without a family history. Women with one first-degree relative with breast cancer ≥50 years have a higher lifetime risk of 1 in 8, with women with one first-degree relative—that is parents, siblings and children—with breast cancer < 50 having a lifetime risk of 1 in 6. First-degree women with a first- and a second-degree relative—that is uncles, aunts, nieces, nephews and grandparents on both sides of the family—or a mother and sister with breast cancer (any age), have a higher lifetime risk of 1 in 4–5 (see Table 5).

An important finding is that by age 60 years, the groups with one relative with breast cancer are well above a 90 per cent probability of *not* developing breast cancer to age 79 years, and those with a first-degree relative with breast cancer age ≥50 have a cumulative risk over the remaining years of 7.8 per cent (1 in 13), which is the same as the lifetime risk (to age 79 years) in those with no family history.

CONCLUSION

The cumulative, absolute risk of breast cancer for the remainder of a lifetime declines with age because of the diminished number of remaining years, even though the age-specific risks increase with age. Therefore, in clinical

settings, it is important to have available information about lifetime risk for various age ranges for the remainder of life, so that women can be offered advice that is specific to their personal and family circumstances.

ACKNOWLEDGEMENT

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REFERENCES

1. Pharoah P, Day N, Duffy S, Easton D, Ponder B. Family history and the risk of breast cancer: a systematic review and meta-analysis. *Int J Cancer* 1997; 71: 800–9.
2. Quinn M, Allen E. Changes in incidence of and mortality from breast cancer in England and Wales since the introduction of screening. *BMJ* 1995; 311: 1391–5.
3. Taylor R, Boyages J. Absolute risk of breast cancer for Australian women with a family history. *Aust NZ J Surgery* 2000; 70: 725–31.
4. Pharoah P, Mackay J. Absolute risk of breast cancer in women at increased risk: a more useful clinical measure than relative risk? *The Breast* 1998; **7**: 255–9.
5. Dupont WD, Plummer WD Jr. Understanding the relationship between relative and absolute risk. *Cancer* 1996; 77: 2193–9.
6. Taylor R, Rushworth RL. Hysterectomy fractions in NSW, 1971–2006. *Aust N Z J Public Health* 1998; 22: 759–64.
7. Taylor R, Smith D, Hoyer A, Coates M, McCredie M. *Breast Cancer in NSW 1972–91*. Sydney: NSW Cancer Council, September 1994.
8. Taylor R. Estimating risk for tobacco-induced mortality from readily available information. *Tobacco Control* 1993; 2: 18–23.
9. Taylor R. Risks from premature deaths from smoking in 15-year-old Australians. *Aust J Public Health* 1993; 17: 358–64.
10. Armitage P, Berry G. *Statistical Methods in Medical Research*, 3rd edition. Oxford: Blackwell Scientific Publications, 1994.
11. BreastScreen Queensland State Coordination Unit. *Annual statistical report for 1996*. Brisbane: Queensland Health, 1998.
12. Hopper JL. *Genetic testing: review of the scientific literature*. Discussion Paper. Sydney: NHMRC National Breast Cancer Centre, 1995.
13. Day N. Cumulative rate and cumulative risk. In: Muir C, Waterhouse J, Mack T, Powell J, Whelan S (editors). *Cancer Incidence in Five Continents*, Vol V. IARC Scientific publication, No. 88. Lyon: International Agency for Research on Cancer, 1987; Chapter 10.

CANCER IN NSW: INCIDENCE AND MORTALITY 1997

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This article highlights some of the information available from the latest report of cancer incidence and mortality in NSW,[1] published by the NSW Cancer Council in June 2000. A decrease in cancer mortality was confirmed for both males and females. The incidence rate of prostate cancer fell for the third successive year in 1997. This followed a dramatic increase in rates between 1988 and 1994, and is associated with widespread use of prostate specific antigen testing. Detailed information is provided for the first time for liver cancer and mesothelioma, two less common cancers that have rapidly increasing incidence and mortality rates.

THE 1997 REPORT

Cancer has been a notifiable disease since January1, 1972. Notifications are provided by patient care institutions and pathology laboratories.

The annual report of cancer incidence and mortality contains:

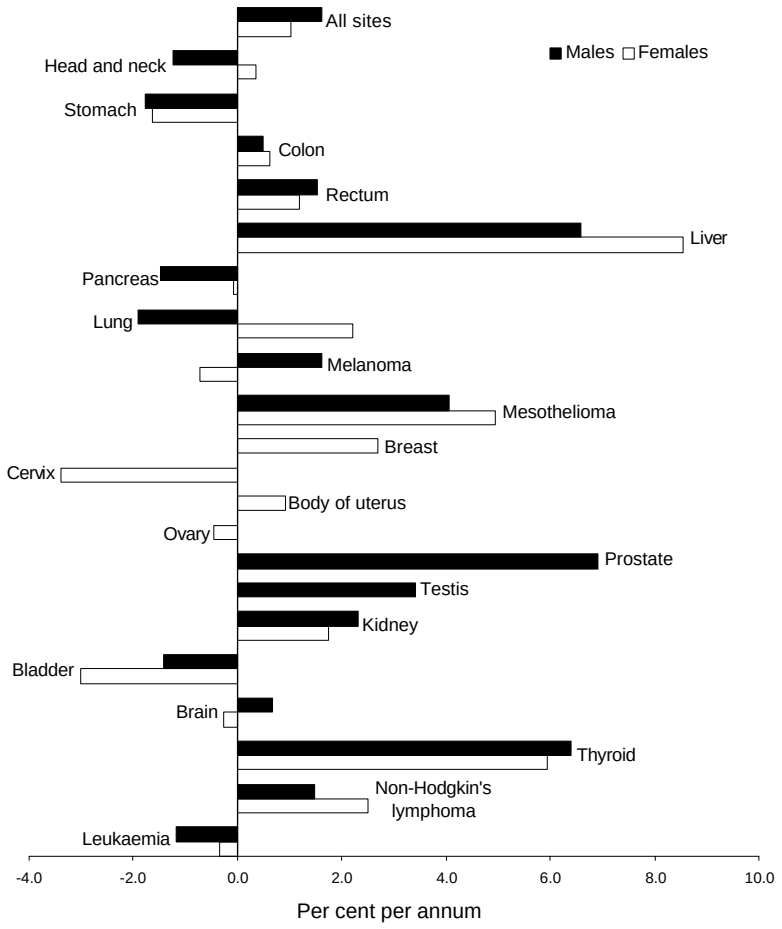
- numbers and rates
- leading cancers
- most common cancers by age
- childhood cancers
- trends and projections
- information about specific cancers including five-year survival and regional variation
- age-specific tables of incidence and mortality
- appendices describing the Central Cancer Registry, coding practices, demography of NSW, statistics and publications.

MOST COMMON CANCERS

For 1997, 27,285 new cases of cancer and 11,594 deaths attributed to cancer were registered. Prostate, lung,

FIGURE 2

ANNUAL CHANGES IN CANCER INCIDENCE RATES FOR MALES AND FEMALES, NSW, 1987 TO 1997



melanoma of skin, colon and rectum were the five most common cancers in males (accounting for 61 per cent of all cancer in males). Cancers of breast, melanoma of skin, colon, lung and rectum were the five most common in females (accounting for 59 per cent of all cancers in females).

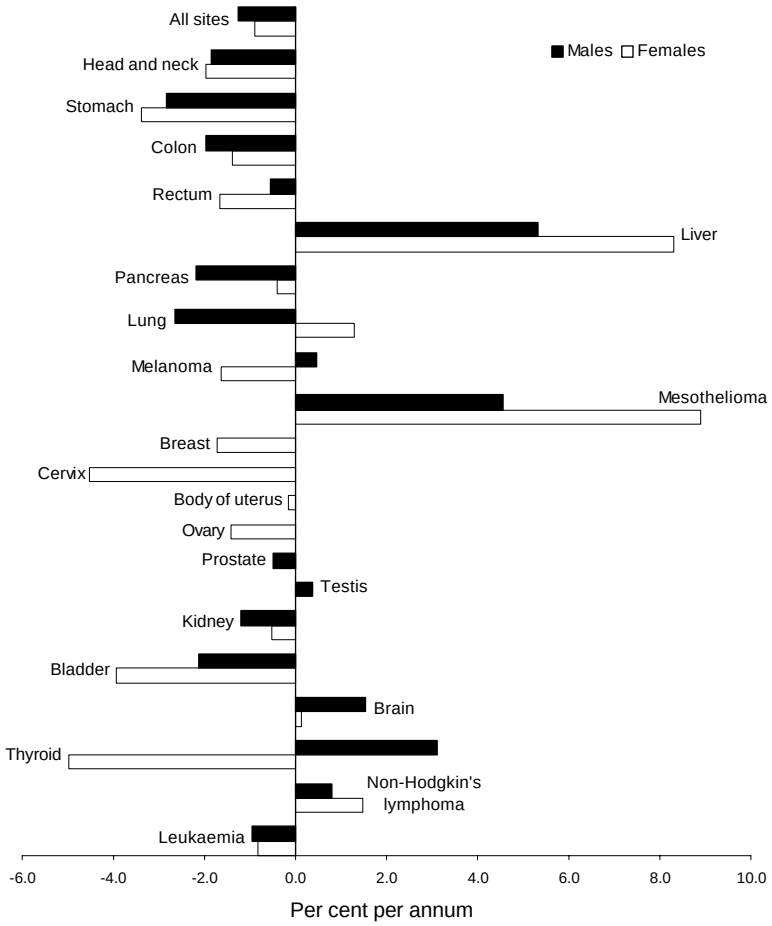
TRENDS IN INCIDENCE AND MORTALITY

Between 1987 and 1997, the incidence rates for cancer of all sites combined rose by 17 per cent for males and 11 per cent for females. The major contributors to this increase were prostate cancer and melanoma in males, and breast and lung cancer and non-Hodgkin's lymphoma in females. Notable trends described in the report included the following:

- incidence rates for prostate cancer fell in 1997 following rapid increases between 1988 and 1994;
- incidence rates continued to fall for cervical cancer, there were fewer than 300 cases in 1997;
- there were falling incidence rates of some of the more common cancers that have low survival rates such as lung cancer, head and neck, and pancreatic cancer in males and stomach and bladder cancer in both males and females;
- the rate of lung cancer in females prior to the age of 50 years is now equal to that of males. Projections indicate that lung cancer rates in males and females will continue to converge with similar rates per 100,000 expected in 2006 (30.8 in males compared to 28.7 in females);
- there was a 16 per cent fall in age standardised mortality rates from breast cancer from 1987–1997;
- the incidence and mortality rates of liver cancer and mesothelioma have increased dramatically

FIGURE 3

ANNUAL CHANGES IN CANCER MORTALITY RATES FOR MALES AND FEMALES, NSW, 1987 TO 1997



since the early 1970s, and are described in two new feature pages;

- when all cancers are considered together, mortality rates have fallen annually since 1987 by 1.3 per cent in males and 0.9 per cent in females. Age-adjusted mortality in both males and females was the lowest it has been since the Cancer Registry began operation in 1972;
- the large increases in the incidence of cancers of the prostate in males and breast in females have not been reflected in mortality rates;
- changes in mortality from stomach, pancreatic, liver, and lung cancers and mesothelioma are similar to those in incidence.

Figures 2 and 3 show the average annual changes in incidence and mortality from 1987 to 1997.

WEB SITE

Further information can be found under 'Statistics' on the NSW Cancer Council's Web site at **www.cancercouncil.com.au**. A printed copy of *Cancer in New South Wales: Incidence and Mortality 1997* can be ordered by mail from the NSW Cancer Council, Locked Mail Bag 1, Kings Cross, NSW 1340; or by telephone at (02) 9334 1902.

REFERENCE

1. Coates MS, Tracey EA. *Cancer in New South Wales: Incidence and Mortality 1997*. Sydney: NSW Cancer Council, 2000.

FACT*SHEET*
NSW HEALTH

CREUTZFELD-JAKOB DISEASE

WHAT IS CREUTZFELD-JAKOB DISEASE?

Creutzfeldt-Jakob disease (CJD) is a rare and fatal brain disease in humans. It is a type of disease known as a transmissible spongiform encephalopathy (TSE) because it causes characteristic spongy breakdown of the brain and it can be transmitted. Other animals—such as sheep, cows and cats—can also develop TSEs.

THE FOUR MAIN TYPES OF CJD.

Sporadic (classical) CJD
This is the most common form, responsible for 85 per cent of cases. The cause is unknown. It mainly affects people aged over 50 years.

Familial CJD
This is an inherited form of the disease with a younger age of onset. It causes 10–15 per cent of cases of CJD.

Iatrogenic CJD
This occurs through the inadvertent use of infectious material in medical procedures.

Variant CJD
This is a newly-recognised type that was first discovered in 1996 in the United Kingdom. It is caused by the same infectious agent that causes 'mad cow disease' (BSE or Bovine Spongiform Encephalopathy) that has affected cattle in the United Kingdom and other parts of Europe. It is different to sporadic CJD because it usually affects younger people, who have a longer duration of illness. It also has slightly different clinical features and can be distinguished from sporadic CJD by postmortem laboratory examination of brain tissue (that is, after the person has died). Evidence of the infection can also be found in lymph tissue, such as tonsils.

WHAT CAUSES CJD?

It is thought that an infectious agent, known as a prion, causes the damage to the brain. Prions are different to other infectious agents (such as bacteria and viruses) because they are made from a protein that is normally present in all cells. It is believed that the prion causes normal cell proteins to change into abnormal cell proteins, and that these build up in the brain, causing damage.

In inherited CJD the genes that tell the body how to make the protein may be faulty. In iatrogenic CJD the abnormal protein comes from contaminated tissue or instruments. Variant CJD is thought to occur when the prion is ingested in contaminated beef or beef products. It is unclear if other risk factors or predisposing factors are needed to enable the prion to cause disease. In sporadic CJD no one knows how the abnormal protein arises.

HOW COMMON IS CJD?

CJD is rare. It occurs worldwide at a rate of 0.5 to 1 case per million per year. Overall, Australia has about the same case rate as other countries. Because of the relationship with Bovine Spongiform Encephalopathy, most cases of variant CJD have occurred in the United Kingdom (a total of 85 cases as of November 2000). An additional three cases have been reported in France and one in Ireland. Because CJD can have an incubation period of many years, it is unclear how many new cases of variant CJD will occur. *As of February 2001 no cases of variant CJD or BSE have been reported in Australia.*

WHAT ARE THE SYMPTOMS OF CJD?

CJD causes progressive symptoms of difficulty with coordination, muscle jerks and memory loss with eventual dementia. Variant CJD can also cause mood disturbance and altered sensations. CJD is fatal, usually within a year of onset of symptoms. At present there is no cure. Treatments for symptoms such as pain and muscle jerks are very important in caring for people with CJD.

HOW IS CJD DIAGNOSED?

A definite diagnosis can only be made by examining brain tissue after death. There are however other tests such as CAT scans, MRI scans and EEGs that can be highly suggestive of the diagnosis and are used to rule out other diagnoses. People with variant CJD may have the prion protein present in their tonsils and other tissues.

CAN YOU CATCH CJD?

In Australia, iatrogenic CJD has been caused by the use of human growth hormone taken from the pituitary glands of cadavers that are infected with CJD. Currently, as there is no Bovine Spongiform Encephalopathy in Australian cattle, no risk is posed by eating Australian beef or beef products. Beef and beef products from countries with infected cattle have been banned from import to Australia.

There is no evidence that sporadic CJD is spread by blood transfusion. There is a theoretical possibility that variant CJD could be transmitted by blood transfusion, although this has never been reported. As a precautionary measure, people who have spent six months or more in Great Britain between 1980 and 1996 cannot donate blood. This is because beef and beef products consumed in Great Britain during this time could have come from cows harbouring BSE infection. Regular surveillance for BSE in cattle is carried out routinely in Australia.

There is no evidence that CJD can be transmitted by normal social contact.

For further information contact your doctor, community health care centre, or your nearest public health unit.

WHAT'S NEW ON THE CIAP WEB SITE

Michelle Wensley
Clinical Systems
NSW Department of Health

The Clinical Information Access Project (CIAP) Web site continues to provide a comprehensive range of peer-reviewed information 24 hours a day, seven days a week, via the Internet and Intranet. Utilisation of the Web site has steadily increased, with an average of 1.5 million 'hits' per month, and a total of over 15 million 'hits' since its inception in July 1997. Feedback from users continues to be positive and there is a high demand for education on how to effectively search the many databases linked through the Web site.

In 1998, the CIAP Web site was nominated by *PC Authority* as one of the top 10 medical Web sites in Australia, and received both the *Data Management Association Australia Achievement Award* for excellence in information management and the *Australian Library and Information Association, NSW Branch Merit Award* for services to rural and remote users and the community.

The purpose of the CIAP Web site is to:

- provide support for decision making within the public health system;
- promote evidence-based practice;
- improve communications at the point of care (that is, wherever a patient is located).

Content of the Web site has grown over the past three years in response to requests by clinicians, and the following on-line information has recently been added:

- Medweaver: for differential diagnosis and disease lookup;
- Micromedex: AltMedREAX—interactions related to herbal medicines and other dietary supplements;
- Antibiotic Guidelines (updated version 11);
- St Vincent's Hospital Nursing Monographs, 1990–2000;
- NSW Clinical Nurse Consultants Web site;
- NSW Therapeutic Assessment Group (TAG) Web site.

Other relevant Web sites can be added to this list by advising CIAP via the Feedback link available from the CIAP Web site.

The knowledge databases on the Web site are protected by password, and are accessible to any health professional employed in the NSW public health system. To obtain a password, or further information about CIAP, contact Michelle Wensley, Clinical Systems, NSW Department of Health; by telephone (02) 9391 9742; or by email mwens@doh.health.nsw.gov.au; or by visiting the CIAP Web site at **www.clininfo.health.nsw.gov.au** or **internal.health.nsw.gov.au:2001**.

COMMUNICABLE DISEASES, NSW: FEBRUARY 2001

TRENDS

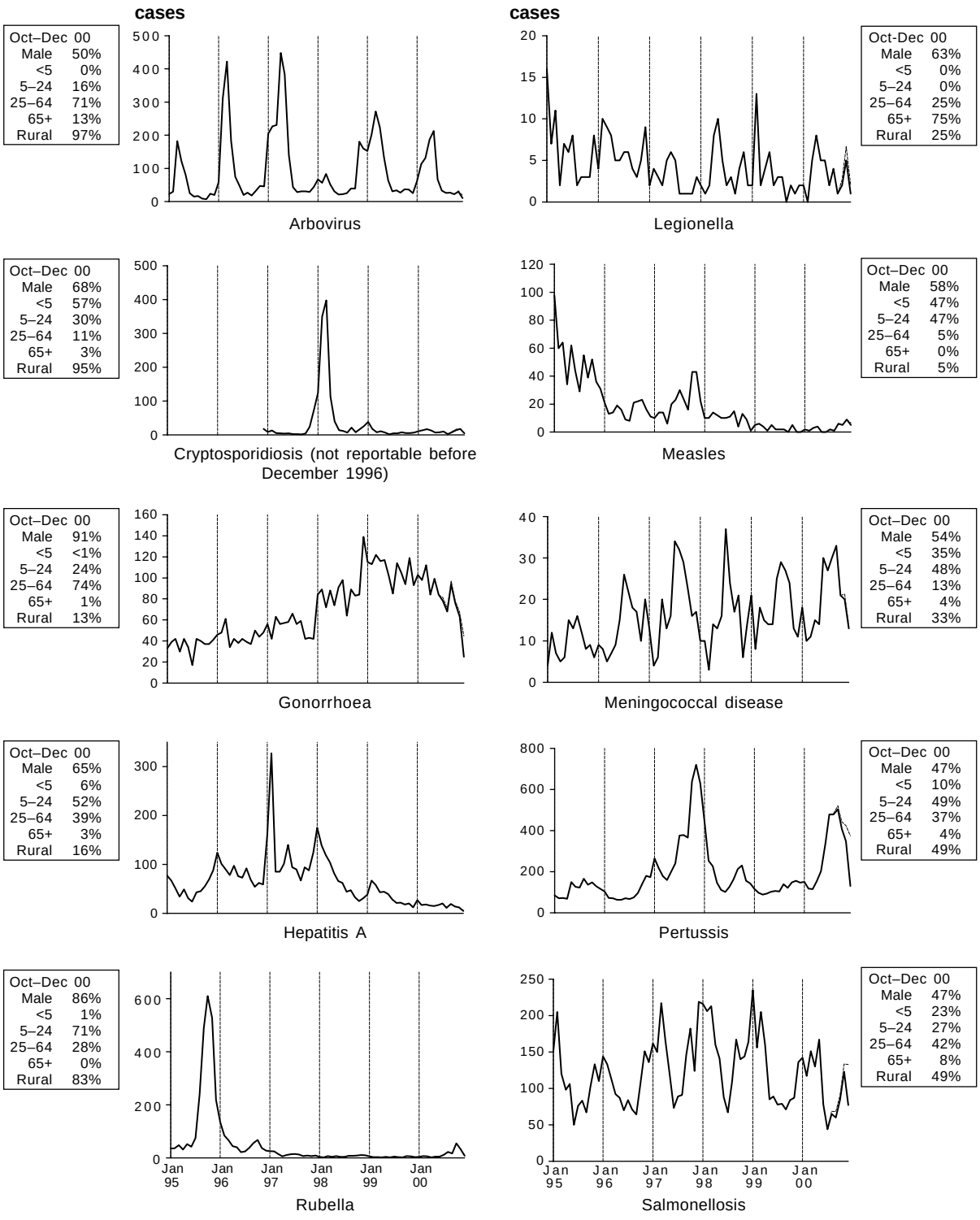
As 2000 drew to a close, there were declines in the notifications of several important infections (Figure 4). Numbers of new cases of **gonorrhoea** are beginning to decline; as are cases of **meningococcal disease** after reaching a seasonal peak (33) in September. **Pertussis** notifications also seemed to have peaked in September (504), but the epidemic may be shifting from rural areas to metropolitan Sydney. Laboratory notifications of **rubella** increased in late 2000, and peaked in October (55). Most cases notified were young men, with a large proportion residing in the Hunter Area (Table 6).

FIGURE 4

REPORTS OF SELECTED COMMUNICABLE DISEASES, NSW, JANUARY 1995 TO DECEMBER 2000, 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 6 REPORTS OF NOTIFIABLE CONDITIONS RECEIVED IN DECEMBER 2000 BY AREA HEALTH SERVICES

Condition	Area Health Service (2000) CSA	NSA	WSA	WEN	SWS	CCA	HUN	ILL	SES	NRA	MNC	NEA	MAC	MWA	FWA	GMA	SA	CHS	Total for Dec†	Total To date†
Blood-borne and sexually transmitted																				
AIDS	-	-	2	-	-	1	-	-	14	1	-	-	-	-	-	-	-	-	18	136
HIV infection*	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	2	297
Hepatitis B - acute viral*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	91
Hepatitis B - other*	15	31	-	3	11	-	8	2	58	3	3	1	3	-	2	3	6	-	150	4,294
Hepatitis C - acute viral*	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	2	125
Hepatitis C - other*	27	28	59	20	9	20	40	10	104	19	15	7	10	11	8	9	12	31	440	8,425
Hepatitis D - unspecified*	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	1	10
Hepatitis, acute viral (not otherwise specified)	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Chancroid*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Chlamydia (genital)*	1	39	26	16	2	8	32	2	88	5	9	10	3	4	6	6	5	2	267	3,380
Gonorrhoea*	1	6	8	2	1	3	1	-	25	1	1	-	-	2	1	-	-	-	55	1,054
Syphilis	-	-	6	-	2	1	-	-	14	1	1	2	1	-	-	-	-	-	29	536
Vector-borne																				
Arboviral infection (BFV)*	-	-	-	-	-	-	1	-	-	4	2	3	-	-	-	-	-	-	10	196
Arboviral infection (RRV)*	-	-	-	-	-	-	2	-	-	1	1	1	2	1	1	-	1	-	10	723
Arboviral infection (Other)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	27
Malaria*	-	-	3	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	3	226
Zoonoses																				
Brucellosis*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Leptospirosis*	-	-	-	-	-	-	-	-	-	-	-	-	1	1	-	-	-	-	2	56
Q fever*	-	-	-	-	-	-	1	-	-	1	-	-	1	2	-	-	-	-	5	117
Respiratory and other																				
Blood lead level*	-	-	-	1	-	-	2	-	4	1	1	-	1	-	22	-	1	-	33	966
Legionnaires' Longbeachae*	-	-	-	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	2	11
Legionnaires' Pneumophila*	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	1	26
Legionnaires' (Other)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	3
Leprosy	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	3
Meningococcal infection (invasive)	-	3	4	2	3	2	2	-	2	1	-	-	-	-	-	-	-	-	19	244
Mycobacterial tuberculosis	1	3	4	2	3	-	-	-	7	-	4	-	-	1	-	-	-	-	25	418
Mycobacteria other than TB	3	2	-	-	-	1	1	1	-	-	3	1	-	-	-	-	-	-	12	337
Vaccine-preventable																				
Adverse event after immunisation	-	-	1	-	-	-	-	-	2	-	-	-	-	-	-	-	-	-	3	29
H.influenzae b infection (invasive)*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	9
Measles	1	-	-	-	2	-	-	-	4	-	-	-	-	-	-	-	-	-	7	37
Mumps*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	92
Pertussis	9	59	26	15	26	5	85	3	36	5	9	13	12	17	-	12	6	-	339	3,569
Rubella*	-	-	1	-	1	-	12	-	-	-	-	-	-	-	-	-	-	-	14	179
Tetanus	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	1	2
Faecal-oral																				
Botulism	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Cholera*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Cryptosporidiosis*	-	-	-	-	-	-	-	-	-	3	-	1	3	-	-	2	1	-	10	129
Giardiasis*	-	14	6	3	-	2	5	2	12	7	-	3	-	-	1	1	-	-	56	963
Food borne illness (not otherwise specified)	-	-	-	-	-	-	-	-	3	-	-	-	-	-	-	-	-	-	3	162
Gastroenteritis (in an institution)	-	-	-	-	-	-	4	-	24	-	-	-	-	-	-	-	-	-	28	558
Haemolytic uraemic syndrome	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	5
Hepatitis A*	2	1	1	-	2	-	-	-	-	-	-	-	-	-	-	-	-	-	6	200
Hepatitis E*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	6
Listeriosis*	1	-	-	-	-	-	-	-	2	-	-	-	-	-	-	-	-	-	3	15
Salmonellosis (not otherwise specified)*	-	19	31	4	2	9	12	2	14	13	4	5	4	-	2	-	2	-	126	1,306
Typhoid and paratyphoid*	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	2	44
Verotoxin producing Ecoli*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1

* 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

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