

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