

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

| | |
|--------------------------|---|
| <i>Patient benefits</i> | Increased survival rate Improved quality of life |
| <i>Clinician benefit</i> | Feedback on treatment results |
| <i>Service benefit</i> | Improvements in treatment methods |

Provision of Good Quality Information for Patient

| | |
|--------------------------|--|
| <i>Patient benefits</i> | Improved satisfaction with service More involved in treatment decisions |
| <i>Clinician benefit</i> | Better response to treatment Better compliance with treatment |
| <i>Service benefit</i> | Patient empowered to take role in treatment decisions. |

Efficient Administration

| | |
|--------------------------|--|
| <i>Patient benefits</i> | Improved service Better organisation of services (transport, interpreters, etc) |
| <i>Clinician benefit</i> | Improved time management |
| <i>Service benefit</i> | Time and Cost Savings Automated costing and billing. |

Elimination of Duplication of Data Entry

| | |
|-------------------------|--|
| <i>Patient benefits</i> | Improved service |
| <i>Service benefit</i> | Time and cost savings Reduction in errors |

Effective Scheduling of Appointments

| | |
|--------------------------|---|
| <i>Patient benefits</i> | Minimum number of visits Minimum wait times |
| <i>Clinician benefit</i> | Can see more patients Efficient use of time Patients and Clinicians are less stressed |
| <i>Service benefit</i> | Improved patient care |

Support for Development of Evidence-Based Guidelines and Treatment Protocols

| | |
|--------------------------|---|
| <i>Patient benefits</i> | Increased survival rate Improved quality of life |
| <i>Clinician benefit</i> | Improvements in treatment methods |

| | |
|------------------------|---|
| <i>Service benefit</i> | Optimal resource utilisation More consistent quality of treatment Reduction in costs Supports multi-disciplinary treatment |
|------------------------|---|

Effective Follow Up

| | |
|--------------------------|--|
| <i>Patient benefits</i> | Improved quality of life |
| <i>Clinician benefit</i> | Improved patient care Able to respond to problems quicker |
| <i>Service benefit</i> | Improved patient care Better outcomes data |

Effective Information Exchange with GPs and other Referring Service Providers

| | |
|--------------------------|---|
| <i>Patient benefits</i> | Improved quality of life Continuity of (seamless) care Less problems in obtaining accurate data at referral |
| <i>Clinician benefit</i> | More timely referral details Conjoint care with other Clinicians |
| <i>Service benefit</i> | Better, more responsive after treatment care Day to day care handled by GP |

Support for Integrated Approach to Patient Care

| | |
|--------------------------|--|
| <i>Patient benefits</i> | Increased survival rate |
| <i>Clinician benefit</i> | Improved treatment methods |
| <i>Service benefit</i> | Conducting integrated patient assessment Sharing of processes |

Support for Clinical Trials

| | |
|--------------------------|--|
| <i>Clinician benefit</i> | Improved treatment methods Professional recognition |
| <i>Service benefit</i> | Support for specialisation |

Improved Cancer Reporting

| | |
|--------------------------|--|
| <i>Clinician benefit</i> | Better analysis of outcomes |
| <i>Service benefit</i> | Better, more timely information to Central Cancer Registry Improved statewide statistical reporting |

Source: NSW Radiation Oncology Information Management and Technology Strategic Plan⁷

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.

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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