

***Information collected on melanoma  
in NSW***

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## **Executive summary**

A prime objective of the proposed NSW Melanoma Network is to improve the quality, consistency and availability of clinical information on the detection, diagnosis and management of melanoma in the State, and on the outcomes of melanoma.

As a first step in fulfilling this objective, we examine existing information collections that contain data on melanoma in the State.

We identified a total of 14 data collections. These include institutional clinical melanoma data collections, the NSW Central Cancer Registry, the proposed NSW Clinical Cancer Registry, cause-specific data on deaths, the National Health Survey, general practice, inpatient and emergency department databases.

We conclude that all of these data collections have significant limitations with regard to the collection of comprehensive clinical data across the State.

We explore the potential for clinical services that participate in the Network to pool either aggregate data or unit-record data on individuals. We suggest that an initial analysis could focus on pooled data from high-level treatment centres on the detection, diagnosis and management of invasive melanoma, potentially invasive melanoma, melanoma with loco-regional spread, and metastatic disease.

To achieve such data pooling, it will inevitably be necessary to obtain approval under the NSW Health Records and Information Privacy Act 2002. The Act enables but does not mandate the contribution of data from different clinical institutions. Approval is likely to be conditional upon individual patient consent being obtained.

## **1 Background**

Valid and reliable data are essential for the promotion of consistent, high-quality melanoma care and the achievement of optimal patient outcomes.

In the last decade, efforts have been made to define data items that would inform improvements in melanoma management and outcomes. For example, in 1997, the NSW Department of Health established a working group to develop clinical indicators for assessing compliance with best practice in melanoma care in NSW (Lonie, Armstrong et al, 1997; Moore, Lonie, Noworytko and Armstrong, 2001). The intent was to encourage implementation of the Australian clinical practice guidelines for melanoma. As part of this process, the working group identified major existing data sources that could provide information on these melanoma indicators. Of a total of 71 melanoma indicators developed by the working group, only 13 could be measured from data sources currently available in NSW at the time. The indicators which could be measured included those relating to melanoma epidemiology (incidence, survival), skin self-examination in the general population and high-risk populations, and type of surgery carried out for melanomas of differing Breslow thickness.

Specialist melanoma units in NSW had been committed to the collection of clinical data on melanoma patients treated by affiliated clinicians. These data have been used in clinical analysis and in research that has made major contributions to melanoma management in Australia and internationally. The specialist units have expressed an intention to establish a Statewide melanoma network that would augment existing efforts to provide optimal care for melanoma patients. A major objective of this network – to be known as the NSW Melanoma Network – is to establish a Statewide framework for the collection, analysis and reporting of information on the management and outcomes of melanoma.

An important step in developing such a framework is to examine existing information collections that contain data on melanoma in the NSW, with respect to data items, data-collection methods, and links between existing databases, and to establish the potential for pooling data. In this paper we report on these data collections and draw implications for information collection within the proposed Network.

## **2 Methods**

Through internet searches and interviews with melanoma specialists, we identified 14 databases containing information on melanoma in NSW. Where possible, we interviewed, by phone or in person, a staff member responsible for each database.

### **3 General findings**

The 14 databases encompassed local, Statewide and national collections. They included collections that:

- provide information on melanoma incidence and mortality,
- support patient management, quality control and research,
- monitor services and costs, and/or
- report on regular surveys of health professionals or the general population.

The melanoma-related information contained in each database is outlined in Table 1, which lists the types of variables rather than giving detail on all the individual variables. The nomenclature for apparently similar types of data fields varies greatly. Descriptors of the variables in Table 1 are not necessarily the names of the fields used in each database.

In some databases, free text fields permit the recording of details on any aspect of a patient's treatment. For such databases, we noted the potential availability of information on surgery, chemotherapy, or other treatment modalities. As a consequence of this approach, our summary of databases may suggest that more types of information are available from some of the databases than is actually the case, particularly with regard to patient management.

In Table 2 we summarise the types of variables outlined in Table 1, listing only the major headings and subheadings of the types of information contained in each database.

Current databases are able to provide information on some of the clinical indicators developed by the NSW Department of Health working group (Moore, Lonie, Noworytko and Armstrong, 2001). However, in order to provide information on the majority of the clinical indicators, existing data collection systems must be modified or new data collection systems encouraged.

## **4 Clinical databases with information on melanoma**

### **4.1 Overview**

We identified three major clinical databases on melanoma in NSW: the Sydney Melanoma Unit (SMU) database, the Newcastle Melanoma Unit (NMU) database, and the Northern Rivers database. These three databases were developed expressly to monitor melanoma management and outcomes.

In addition, a general oncology database has been established at Westmead Hospital. This contains information on melanoma patients as well as other cancer patients. Other general oncology clinical reporting systems are likely to

exist in other hospitals in NSW, and these would also include information on melanoma patients. Clinical data collections exist in other clinical units that treat cancer patients, such as palliative care and radiotherapy, and these include information on some melanoma patients. It is also likely that individual practitioners maintain small clinical data collections for research or quality assurance purposes.

#### **4.2 Sydney Melanoma Unit clinical database**

The SMU database was established in the late 1960s and contains information on more than 20,000 melanoma patients treated by all medical practitioners associated with the SMU. It uses Clinical Reporting System (CRS) software. The CRS software is currently no longer supported, and there are plans to transfer the data into another database system.

The database is intended for both the clinical management of patients and clinical research. A variety of reports are generated from it, covering patients demographic details, clinical history, diagnosis, treatment, and follow-up. The database has also been made available for international collaborative projects (Thompson, Shaw, Stretch, McCarthy and Milton, 2003).

The SMU employs database staff to interpret and enter patient data, pursue missing data, carry out analyses and produce reports.

#### **4.3 Newcastle Melanoma Unit clinical database**

The NMU was established in 1981. The initial NMU database was a replica of the SMU database, and also used CRS software. However, it has recently been revised, condensed and transferred to a Microsoft Access database system (Microsoft Corporation 1992-2001). The database is used for both the clinical management of patients and monitoring clinical care and outcomes.

The NMU employs database staff to interpret and enter data, pursue missing data, carry out analyses and produce reports.

#### **4.4 Northern Rivers melanoma database**

The Northern Rivers melanoma database was conceived as a result of common interests among five surgeons based in Lismore, on the NSW North Coast. The database is in its infancy. At present, data are entered into the database by the surgeons themselves, registrars or medical students. It is intended that the data will be used to evaluate clinical practice and for clinical research. It is also hoped that the data may be linked with data held by the NSW Central Cancer Registry.

## **4.5 Westmead Hospital Oncology Database**

The Westmead Hospital Oncology database is currently being introduced using the Odyssey system, which is a product of the firm, Specialist Information Services. If successful, it will replace the current CRS system which contains much less information on patient management. Odyssey is designed to be an electronic medical record and patient management system. Data are entered by clinicians. The system readily generates clinical summaries. It is anticipated that the system will be used for multi-site access to clinical data on individuals, so that melanoma patients can be managed efficiently when they present to different hospitals (e.g. Westmead and Katoomba). The suitability of the database for research and evaluation purposes is unclear at this stage. Westmead Hospital employs staff to maintain the database.

## **4.6 Comments**

The SMU, NMU and Northern Rivers melanoma databases are the only three databases that concentrate exclusively on melanoma patients. They have the following characteristics.

- The information that they cover ranges from very comprehensive (SMU) to limited (Northern Rivers database).
- Most of the information contained in the databases pertain to patients and their diagnoses and management. Little information is available on the health professionals who provide care for melanoma patients.
- The data items in the three databases refer to similar core concepts, but they vary in emphasis. The ways in which information is collected and categorised also vary. The databases vary considerably with respect to overall design, data fields, and definitions of data items.
- The SMU and the NMU databases only include patients who were treated by affiliated practitioners. The Northern Rivers database includes patients treated by practitioners working in a defined geographical area. The three databases together most probably cover a significant proportion of melanoma patients in the State, particularly those with intermediate to thick melanomas.

In general, access to the information within the clinical databases is restricted to the health professionals who work in each melanoma centre or hospital.

# **5 Statewide databases with information on melanoma**

## **5.1 Overview**

The main relevant Statewide databases are the NSW Central Cancer Registry, and the NSW Clinical Cancer Registry, the NSW Inpatient Statistics

Collection and death registrations compiled by the NSW Registry of Births, Deaths and Marriages.

Linkages have been established between the NSW Central Cancer Registry and (a) the NSW Health Inpatients Statistics collection, (b) the NSW Registry of Births, Deaths and Marriages, and (c) mortality data from the Australian Bureau of Statistics (ABS), coded according to the cause of death.

Access to the data within the databases is restricted. Aggregate data are in the public domain. In general, access to data in other forms requires approval from an ethics committee.

## **5.2 NSW Central Cancer Registry**

The NSW Central Cancer Registry (CCR) was established in 1971 as a population-based register of all cancers in NSW residents. Since 2004 the Registry has been managed by and located within the Cancer Institute NSW in Redfern, Sydney.

Under the Public Health Act 1991, notification of cancers to the CCR is mandatory for pathology laboratories as well as public and private hospitals, departments of radiation oncology, nursing homes, outpatients departments and day procedure centres. Notification requires the completion of a form which is defined in the Act, and lodgement of the form with the NSW Department of Health or an agency which manages the CCR on behalf of the Department (now the Cancer Institute NSW).

Data items cover identifying and demographic information on all patients diagnosed with notifiable cancers (essentially all cancers other than non-melanomatous skin cancer), information on the tumour and a record of at least one episode of care from each notifier. The data are supplemented by information from pathology reports and death certificates that are obtained by the Registry.

A Statistical Reporting Module is available from the website of the NSW Cancer Institute. This module allows the user to generate a range of graphs on incidence or mortality for any selected cancer or group of cancers, and it can display time trends and variations by age, region of birth, cancer council regions, Area Health Services, Local Government Areas, socioeconomic status and remoteness of patients' place of residence.

Reports on incidence and mortality from cancer are published regularly by the Cancer Institute NSW. More detailed information is also made available to the NSW Department of Health, health-care institutions, health professionals and health researchers, subject to approval from the ethics committee of the Cancer Institute NSW.

### **5.3 The NSW Clinical Cancer Registry**

The Clinical Cancer Registry, as described in the NSW Cancer Plan 2004-2006, is currently under trial by the Cancer Institute NSW in five NSW Area Health Services. The Clinical Cancer Registry aims to cover more information than that collected in the CCR. Its 47 data items include tumour size and stage, treatment intention, treatments received, treatment combinations and sequencing, and patient outcomes. When the Clinical Cancer Registry is fully developed, data will be collected on these items for all cancer notifications in NSW.

The data fields in the Clinical Cancer Registry are defined in accordance with the National Data Dictionary (AIHW, 2003), and the data items reflect the scope of the Minimum Data Set for Clinical Cancer Registration (NSW Department of Health, 2001). There are plans to include a further 10 cancer-specific data items for each of the major cancers, including melanoma.

The effectiveness of the Clinical Cancer Registry will depend on an appropriate legislative or regulatory framework for its operations in compiling data. At the time of writing, options for this framework were being examined. If the Clinical Cancer Registry is recognised as part of the CCR, the Clinical Cancer Registry could compile data under the auspices of the CCR, and a change to the Schedule of the Public Health Act 1991 would mandate the collection of the additional data needed for the Clinical Cancer Registry. If this change is not acceptable to the Minister administering the Public Health Act (the NSW Minister for Health), then an alternative approach will be to seek approval for the compilation of the data under the Health Records and Information Privacy Act 2002. If neither approach is acceptable, the operations of the Clinical Cancer Registry will be confined to compilation of aggregated data voluntarily supplied by public-sector health-care institutions, and data linkage of Clinical Cancer Registry data will be impossible.

### **5.4 NSW Inpatient Statistics Collection**

The Inpatient Statistics Collection is an ongoing compilation of data on all admitted patient services provided by public hospitals, public psychiatric hospitals, public multi-purpose services, private hospitals, and private day-procedure centres in NSW. The database contains information on demographic characteristics of patients, time and type of admission and separation, diagnostic and procedural codes, items relating to cancer notification, and other specific information on neonates and psychiatric patients. Information collected from private hospitals represents only a subset of that collected for the public hospitals.

The Inpatient Statistics Collection was initiated in the early 1970s (NSW Department of Health, 2005). It was initially managed by the ABS, but since the 1980s it has been run by the NSW Department of Health. Prior to 30 June 1993 it was based on a sample of inpatients. Since 1 July 1993 it has covered all admitted patient activity for both the public and private sectors.

## **5.5 Emergency Department Information System**

The Emergency Department Information System (EDIS) records data on presentations to emergency departments in NSW public hospitals. The EDIS collection was introduced as a Statewide reporting system in 1994 by NSW Department of Health. Currently 75% of public hospitals in NSW use the EDIS. The purpose of the EDIS is twofold: to assist clinicians in the management of patients; and to enable comparisons of performance among emergency departments and over time.

The EDIS is relevant to melanoma because, in many hospitals, melanoma patients who develop acute problems related to their disease or their treatment present to emergency departments.

## **5.6 NSW Registry of Births, Deaths and Marriages**

The NSW Registry of Births, Deaths and Marriages compiles data from death certificates for all deaths that occur in NSW. Deaths of NSW residents that occur outside NSW are registered outside NSW, i.e. in the States or Territories in which the deaths occur (NSW Registry of Births, Deaths and Marriages, 2005). Delays sometimes occur in death registration. As a result, some deaths occurring in one year are not registered until the following year or even later.

Data compiled by the Registry include the date of death and the causes of death. Deaths data from all States and Territories are forwarded to the Australian Bureau of Statistics, which codes causes of death according to ICD-10 (ABS 2005), analyses data, and produces summary statistics that are published in regular reports. The Registry of Births, Deaths and Marriages also forwards details of persons who died from cancer to the NSW Central Cancer Registry, and information on cancer deaths is linked to Registry notifications.

# **6 National databases with information on melanoma in NSW**

## **6.1 Overview**

We identified four national databases that provide information on melanoma in NSW. Two of these databases obtain their data from national surveys: the ABS National Health Survey, which is a survey of the general population, and the database 'Bettering the Evaluation and Care of Health' (BEACH), which is a survey of general practitioners (GPs). A third national database collects information on services provided to patients and are the subject of a Medicare claim, and the fourth (conducted by the ABS and mentioned in section 5.5) provides information on deaths and causes of death. Many of the data and

reports from these national databases are available through the internet. Further analysis of the data can be requested on a fee-for-service basis.

## **6.2 Bettering the Evaluation and Care of Health (BEACH) database**

The 'Bettering the Evaluation and Care of Health' (BEACH) survey is an annual survey of general practice activity in Australia. It is conducted by the General Practice Statistics and Classification Unit, a collaborating unit of the Australian Institute of Health and Welfare (AIHW) and the University of Sydney, situated within the Family Medicine Research Centre at Westmead Hospital.

The BEACH survey has been conducted annually since 1998. Each year a random sample of eligible GPs is drawn. Eligible GPs are those for whom at least 375 claims for general practice Medicare items of service have been made in the preceding three months. Each participating GP records information on 100 consecutive patient encounters using a standard *pro forma* for each patient. For each encounter, the GP records the patient's presenting problem(s), symptoms, diagnosis, treatment, pathology, and referral. The GPs also provide information on themselves and their practice.

Analyses from the BEACH dataset at national and State and Territory levels are published regularly. Some of the data are available on-line through an interactive system (GPSU 2005), and can be downloaded and analysed using Microsoft Excel and other compatible software. Access to further selected data can be requested from the General Practice Statistics and Classification Unit.

## **6.3 Health Insurance Commission data**

The Health Insurance Commission (HIC) is an Australian Government statutory authority that, *inter alia*, administers the Medicare Benefits Scheme. It records data on all Medicare benefits by individual service item numbers and groups of item numbers. Aggregate data on item numbers are available in the public domain in the form of frequencies, percentages and rates (HIC 2005). They include data on service items, which can be stratified by patients' age and sex. Data relating to general practice service items can also be grouped by Division of General Practice (HIC 2002).

The HIC item numbers that are used for melanoma procedure claims are also used for other locally-aggressive skin tumours, such as appendageal carcinoma, malignant fibrous tumour of the skin, and Merkel cell carcinoma. Thus it is not possible to separate melanoma procedures from these other procedures. Consequently, at present, HIC data in themselves are of limited value in studying clinical activity relating to melanoma. However, if the HIC dataset could be linked with the NSW CCR, it would be possible to use the linked dataset to identify those procedures recorded in the HIC that were undertaken in patients registered as having a melanoma.

## **6.4 Australian Bureau of Statistics National Health Survey**

The ABS conducted Australia's first comprehensive study of Australian's health – the National Health Survey (NHS) – in 1978. The survey has since been conducted approximately every six years. The most recent survey (which was the third NHS) was carried out between February and November 2001. The 2001 NHS was in two parts – a general survey known as NHS(G), and a supplementary Indigenous survey, the NHS(I) (ABS 2003).

The NHS(G) covered a random sample of the population from 17,918 private dwellings selected through non-sparsely-settled areas of Australia. A total of 26,863 persons responded fully to the survey. Trained ABS interviewers personally interviewed the selected adult member of the household, with adult proxies answering questions for children aged <18 years. The NHS(G) interviews covered long-term medical conditions, recent injury events, consultations with health professionals, actions taken by respondents with regard to their health, lifestyle factors (e.g. smoking, alcohol consumption, exercise, and diet), and immunisation. Adult female respondents were invited to complete an additional questionnaire on women's health issues.

The NHS(I) was conducted as a supplement to the NHS(G) to improve the reliability of Indigenous estimates. The NHS(G) included 483 Indigenous Australians. The NHS(I) covered an additional sample of 3,198 Aboriginal and Torres Strait Islander adults and children, including those living in sparsely-settled areas.

With respect to melanoma, the NHS provides self-reported information on whether respondents had cancer at the time of the survey and whether they had ever had cancer; and if so, their age when the cancer was first diagnosed and the type of cancer. The survey also collected information on whether people had regular skin checks and the type of sun protection used by children (aged 17 years or less).

Access to NHS data can be obtained from reports published by the ABS, or by importing data from the ABS website (ABS 2002). The data can be downloaded and analysed using software such as Microsoft Excel.

## **6.5 Australian Bureau of Statistics mortality data**

As noted in section 5.6, death-registration data are passed from the NSW Registry of Births, Deaths and Marriages to the ABS. The ABS codes causes of death according to ICD-10 (ABS 2004). Mortality data compiled by the ABS refer to the year of registration rather than the year of death – the two may differ when there is a delay in death registration or for deaths occurring at the end of a calendar year. Unlike death registrations, published ABS mortality data refer to the State or Territory of usual residence of the deceased, regardless of the place of death. However, the ABS cross-tabulates numbers of deaths by State or Territory of death (and place of registration) against

numbers of deaths by State or Territory of usual residence. The ABS also reports on deaths registered in Australia (by State or Territory of death) of persons usually resident overseas. Some ABS mortality data are available in the public domain (e.g. in AIHW and ABS reports).

## **7 Assessment of available data sources**

Of the 14 databases that contain information on melanoma in NSW, only one – the NSW Central Cancer Registry – contains reliable population-based data on the occurrence of melanoma and melanoma outcomes (survival). Two of the databases – the NSW Registry of Births, Deaths and Marriages and the ABS mortality data compilation – contain population-based data on deaths from melanoma.

While the CCR is comprehensive in its coverage of melanoma notifications, it encompasses a limited range of data items. In particular, it omits significant detail on tumour size, stage, treatment and outcomes (other than survival). To rectify these deficiencies, a Statewide Clinical Cancer Registry is being developed under the auspices of the Cancer Institute NSW. Several problems, including the legislative or regulatory framework under which the Clinical Cancer Registry will operate and arrangements for notifications, remain to be resolved before the value of the Clinical Cancer Registry can be realised.

Clinical melanoma data collections exist at three sites. Two of the three collections (SMU and NMU) are well-established and contain substantial volumes of clinical data at a detailed level. One (the SMU) is reputed to be the largest and oldest melanoma data collection in the world. The third (Northern Rivers) has been developed only recently and has yet to establish sustainable systems for obtaining, managing and reporting upon the data (A Curtin, personal communication, July 2005). All three of the data collections are confined to patients treated by clinicians affiliated with the institutions in which they are located. That is, they are either clinician-based or institutionally-based, not population-based.

The NSW Inpatient Statistics Collection contains population-wide data on hospital admissions for melanoma, covering public and private hospitals. The utility of the Inpatient Statistics Collection for monitoring inpatient melanoma management is limited by three factors. First, only a proportion of melanomas are treated on an inpatient basis. Second, even where inpatient treatment occurs, the Inpatient Statistics Collection detects melanoma admissions only if melanoma is coded as a reason for admission; strong anecdotal evidence (including our own experience) suggests that the quality of coding is variable. Third, the Inpatient Statistics Collection contains little clinical detail, and by its nature it is confined to an index admission, so it contains no historical or follow-up data.

The NHS contains population-based data on the prevalence of melanoma (including the prevalence of a history of melanoma). It includes a special data collection of the Indigenous population. However, it relies on subjects' self-report to a trained interviewer, and is also short on clinical detail.

Two data collections focus on ambulatory care: the BEACH database, which reports on general practice encounters, and the EDIS, which reports on hospital emergency department encounters. Both are likely to be reliable where a melanoma-related clinical problem is the reason for the encounter. Neither is likely to be reliable in consistently recording melanoma patients who present for reasons that are not considered to be related to their melanomas.

Data from the CCR, the clinical melanoma databases (at present the SMU and the NMU), the Inpatient Statistics Collection and the BEACH and EDIS databases could all be used to provide information on patterns of care for melanoma. The BEACH and EDIS databases provide useful perspectives on the presentation of melanoma-related clinical problems in the community, and on the management of these problems.

## **8 Implications for the proposed NSW Melanoma Network**

### **8.1 General observations**

Our review of existing sources of melanoma data clearly shows that the State lacks detailed population-wide clinical data on melanoma. At present the State also lacks systems to obtain these data. Without the data, it is difficult to assess the extent to which the detection, diagnosis and management of melanoma comply with guidelines or standards of care; and without this knowledge, it is difficult to take rational steps to improve the quality and consistency of clinical services for melanoma. Melanoma is one of the most common cancers in NSW, and every effort must be made to ensure that melanoma patients receive the best possible care.

The overall goal of the proposed NSW Melanoma Network is to improve the quality and consistency of clinical care for melanoma, across the spectrum from detection and diagnosis, through management and follow-up, to palliation. Under this goal, information collection is a major objective.

The Network will comprise an affiliation of clinical groups that subscribe to this objective. Participants in the Network can be expected to:

- Determine the questions that should be answered using information collection systems.
- Contribute to the development and/or adoption of consistent definitions for data items relating to these questions.
- Collect and compile good-quality data within their own entities, using these definitions and consistent data-collection methods.
- Comply with information privacy legislation and ethical requirements.
- Contribute data to Network-wide collections.

Information systems managed by participants in the Network will have to be sufficiently flexible to be used in compiling data on new questions that emerge as the knowledge base on melanoma grows.

The NSW CCR already compiles population-wide epidemiological data on melanoma. If established successfully, the proposed NSW Clinical Cancer Registry will go some way towards compiling population-wide clinical data on melanoma. Clinical Registry data will help to evaluate clinical care in relation to some aspects of guidelines and standards. However, it will be insufficiently detailed to evaluate many important aspects of melanoma care.

Participants in the Network are likely to be well placed to examine the high-level management of invasive and potentially invasive melanoma, melanoma with loco-regional spread, and metastatic disease. Four major centres of clinical activity (the SMU, the NMU, Westmead Hospital and the Lismore clinicians) are likely together to manage the great majority of these serious cases. Using the CCR and possibly the Clinical Cancer Registry, it should be relatively easy to estimate the proportion of such cases not managed in these major centres. It would be valuable for these four centres to collaborate in monitoring the clinical care of patients with invasive and potentially invasive melanoma, melanoma with loco-regional spread, and metastatic disease. This could be an initial assignment of the Network, to be conducted in partnership with the CCR and (when established) the Clinical Cancer Registry.

Other projects could be developed as the Network evolves. For example, if the Network attracts the participation of dermatologists and/or general practice skin clinics, it would be possible to examine practice in relation to the detection of melanoma, initial management and referral. This might be achieved through regular random audits, using methods such as those proven in the BEACH collection, or through intermittent surveys.

New data-collection systems, and/or linkages between existing data collections, may be necessary in order to answer some of the questions defined by participants in the Network.

## **8.2 Pooling data from new or existing data collections**

In order to combine data collected in different treatment centres, it will be necessary for institutions participating in the Network to modify data-collection and data-management protocols to achieve commonality, and ensure that data definitions are compatible. Currently significant differences exist among even the major institutional melanoma collections. For example, in some settings, clinicians abstract relevant data and enter them into the local database, while in others, data-abstraction is relegated to database personnel. Rather than each centre developing an identical database, it is likely that each centre will be asked to abstract from their existing databases a defined set of information and that this information be transferred to a central

location database. The central database would be maintained and managed separately from the other four databases.

Arrangements for the pooling of data are critical. Two broad approaches exist for the combination of data from different clinical sources can be envisaged:

- The pooling of aggregate data.
- The compilation of unit-record data, i.e. data on individuals.

The pooling of aggregate data is relatively straightforward, as long as consistent definitions and data-collection methods have been used at each site. In general, there are no legislative or ethical barriers to the pooling of aggregate data, provided that the numbers of patients reported in relation to each variable is large enough to conceal the identity of individual patients. However, the information that can be obtained from the analysis of pooled aggregate data is limited.

The compilation of unit-record data is likely to lead to far more informative conclusions than the pooling of aggregate data, and much more sophisticated analyses can be undertaken. However, the transfer of unit-record data from institutions in which they are collected to a central Network repository is likely to be subject to legislative restrictions and requirements for ethics committee approval. These are discussed in the next section.

## **9 Information privacy protection and ethics**

Of the 14 databases that we examined, several had an enabling statutory base (e.g. the CCR, the NHS, the HIC, the Registry of Births, Deaths and Marriages, the ABS), some relied on individual consent from patients (e.g. the institutional clinical data collections), and some were conducted without patient consent but with ethics committee approval (e.g. BEACH).

Under current national and State privacy legislation and the NSW Public Health Act 1991, health information that is collected within an institution for clinical purposes cannot be used for research purposes without patient consent, and the information cannot be passed to a central data repository without a statutory mandate or enabling legislation. Compilation of data by the CCR is mandated by the Public Health Act 1991. Compilation of unit-record data for analysis in a central repository by the NSW Melanoma Network could be enabled by the Health Records and Information Privacy Act 2002. It is unlikely that amending the Public Health Act 1991 for this purpose would be an acceptable option for Government or the community.

In essence, approval may be given to pool unit-record data under the Health Records and Information Privacy Act 2002 if the data are to be used for certain defined purposes, which include quality assurance, research and health-services management. Approval would require the data to have been obtained with consent, and the individual from whom the data were obtained made reasonably aware of the likelihood that the data would be shared and

used for research or other purposes. An approval to pool unit-record data under the Health Records and Information Privacy Act 2002 does not mandate the centralised compilation of the data – it merely gives approval to health-care institutions to contribute the specified clinical data to a central repository, but they must do so voluntarily.

It is likely that, if the SMU, NMU and North Coast melanoma data collections were being set up today, they would be subject to the provisions of the Health Records and Information Privacy Act 2002, given that the data in these collections are derived from different clinical institutions.

When an approval under the Health Records and Information Privacy Act 2002 is sought, it is recommended that the applicant seeks advice from the NSW Privacy Commissioner.

## **10 Possible next steps**

Based on the foregoing sections of this paper, we suggest that the following initial general steps could be taken by the NSW Melanoma Network when it is established.

- 1) Through a systematic process, participants in the Network should specify the key questions that should be answered to improve melanoma care and outcomes in NSW. The selection of these questions could be based in part on previous work conducted under the auspices of the NSW Department of Health.
- 2) Through a technical process, the Network should define data items that would answer these questions. Again, the definition of these data items could draw on previous work.
- 3) Through a further technical process that uses the findings of this report, the Network should determine which of these items are covered by existing data collections, which would require linkages between existing data collections, which would require existing data collections to be modified, and which would require new information collection systems.
- 4) The Network should examine practical options for obtaining the required data, taking account of resources and the interests of and relationships among those potentially involved in obtaining or supplying data.
- 5) The Network should examine processes through which the desired data collections can be conducted in accordance with current legal and ethical requirements. This should include consultation with the NSW Privacy Commissioner.

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Table 1. Databases which include information on melanoma in NSW

DATA COLLECTED	Sydney Melanoma Unit clinical database	Newcastle Melanoma Unit clinical database	Northern Rivers melanoma database	Westmead Clinical Information System (Odyssey)	NSW Cancer Institute Central Cancer Registry	NSW Cancer Institute Clinical Cancer Registry (Pilot)	NSW Health ISC Public	NSW Health ISC Private	NSW Health Emergency Department Information System	NSW Registry of Births, Deaths & Marriages	HIC	ABS Mortality Data	BEACH GP SURVEY	National Health Survey (ABS)
							NSW Health Inpatients Statistics Collection (ISC)	NSW Health Inpatients Statistics Collection (ISC)			Health Insurance Commission (HIC) Statistical Reporting	Data from NSW Registry of Births, Deaths & Marriages	Bettering the Evaluation And Care of Health	Australian Bureau of Statistics (ABS)
<b>Coverage</b>	Clinic	Clinic	AHS(?)	Clinic	State	State	State	State	State	State	National	National	National	National
<b>1. Patient details</b>														
<b>Contacts</b>	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔			
Name	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔			
Former name(s)				✔	✔	✔					✔			
Address and phone number	✔	✔		✔	✔	✔	✔	✔	✔	✔	✔			
Next of kin		✔		✔			✔		✔	✔				
<b>Demographics</b>	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Date of birth	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Age	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Sex	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Postcode of residence	✔	✔		✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
State of residence	✔	✔		✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Marital status	✔			✔	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔
Aboriginal & Torres Strait Islander status					✔	✔	✔	✔	✔	✔	✔		✔	✔
NESB status				✔		✔	✔	✔	✔	✔	✔		✔	✔
Country of birth	✔				✔	✔	✔	✔	✔	✔	✔			✔
Preferred language				✔			✔	✔	✔	✔	✔			✔
Need for interpreter service				✔			✔	✔	✔	✔	✔			✔
Religion							✔		✔	✔	✔			
Socioeconomic status					✔				✔	✔	✔			✔
Employment status				✔					✔	✔	✔			✔
Employer details				✔					✔	✔	✔			✔
Occupation									✔	✔	✔			✔
<b>Payment information</b>	✔			✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
Government benefits status	✔			✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
DVA status				✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
Centrelink client number				✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
Workers comp	✔								✔	✔	✔		✔	✔
Pension	✔			✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
Health insurance information	✔			✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
Medicare number	✔			✔	✔	✔	✔	✔	✔	✔	✔		✔	✔
Date of requested medicare item(s) processes										✔	✔			
Cost of requested medicare item(s) processes										✔	✔			
<b>History</b>	✔	✔	✔	✔	✔	✔	✔	✔	✔	✔				✔
Details of health professionals seen for this condition (e.g. general practitioner)	✔	✔	✔	✔	✔	✔	✔	✔						✔
Allergies/alerts				✔					✔					
Previous clinical assessments														✔
Family medical history	✔		✔	✔										✔
Patient's medical history	✔	✔	✔	✔										✔
Patient's social history				✔										✔
<b>Patient status</b>	✔	✔		✔	✔	✔	✔	✔	✔	✔		✔		
Patient's status (general)	✔	✔		✔	✔	✔	✔	✔	✔	✔		✔		
Symptomatic				✔	✔	✔	✔	✔	✔	✔				
Anxiety and depression					✔	✔	✔	✔	✔	✔				
Palliative care status					✔	✔	✔	✔	✔	✔				
<b>Death information</b>					✔	✔	✔	✔	✔	✔				
Date of death				✔	✔	✔	✔	✔	✔	✔				
Place of death				✔	✔	✔	✔	✔	✔	✔				
Primary causes of death				✔	✔	✔	✔	✔	✔	✔		✔		
Antecedent causes				✔	✔	✔	✔	✔	✔	✔				
Other significant conditions										✔				



Table 1. Databases which include information on melanoma in NSW

DATA COLLECTED	Sydney Melanoma Unit clinical database	Newcastle Melanoma Unit clinical database	Northern Rivers melanoma database	Westmead Clinical Information System (Odyssey)	NSW Cancer Institute Central Cancer Registry	NSW Cancer Institute Clinical Cancer Registry (Pilot)	NSW Health ISC Public	NSW Health ISC Private	NSW Health Emergency Department Information System	NSW Registry of Births, Deaths & Marriages	HIC	ABS Mortality Data	BEACH GP SURVEY	National Health Survey (ABS)
<b>3. Diagnosis</b>														
<b>Investigations/tests</b>	Y	Y	Y	Y							Y		Y	Y
Type of test	Y													
Date of test	Y													
Location of tests	Y													
Anatomical location	Y													Y
Conclusion	Y													Y
<b>Primary melanomas</b>	Y	Y	Y	Y	Y	Y	Y	Y			Y			Y
Date of diagnosis	Y	Y		Y	Y	Y	Y	Y						
Age of patient at diagnosis	Y		Y											Y
State of residence at time of diagnosis					Y	Y	Y	Y						
Diagnosis method/best basis for diagnosis	Y				Y	Y	Y	Y						
Site	Y	Y	Y	Y	Y	Y	Y	Y			Y			
Morphology of primary cancer site					Y	Y	Y	Y						
Type	Y	Y	Y	Y										
Thickness/depth	Y	Y	Y	Y										
Exact depth														
Diameter	Y	Y	Y	Y							Y			
Degree of spread					Y		Y	Y						
Microscopic margin	Y	Y	Y	Y										
Clark level	Y	Y												
Grade				Y										
Breslow level														
Ulceration	Y	Y	Y	Y										
Lymphatic or vascular involvement	Y	Y	Y	Y										
Regression	Y	Y	Y	Y										
Microsatellites	Y	Y	Y	Y										
Growth phase	Y	Y	Y	Y										
Mitoses	Y	Y	Y	Y										
Histogenesis	Y	Y	Y	Y										
Laterality	Y	Y	Y	Y	Y	Y	Y	Y						
Staging	Y	Y	Y	Y	Y	Y	Y	Y						
<b>Lymph nodes</b>	Y	Y	Y											
Disease state & examination	Y		Y											
Lymphoscintigraphy	Y		Y											
Biopsy	Y		Y											
Excision	Y		Y											
Clearance	Y		Y											
No. of nodes taken	Y		Y											
No. of nodes positive	Y		Y											
Other details		Y												
<b>Metastases</b>	Y	Y	Y	Y			Y	Y						
Date of diagnosis	Y	Y	Y	Y										
Type		Y	Y	Y										
Site		Y	Y	Y										
Detection method		Y	Y	Y										
<b>Recurrences</b>	Y													
Date of recurrence	Y													
Site of recurrence	Y													
Recurrence type	Y													
Diagnosis made by	Y													
Further comments	Y													
<b>Pathology information</b>	Y	Y		Y	Y	Y	Y	Y					Y	
Request for pathology	Y	Y		Y	Y	Y	Y	Y						
Pathology laboratory	Y	Y		Y	Y	Y	Y	Y						
Name of pathologist	Y	Y		Y	Y	Y	Y	Y						
Date of pathology	Y	Y		Y	Y	Y	Y	Y						
Type of pathology	Y	Y		Y	Y	Y	Y	Y						
Further comments	Y	Y		Y	Y	Y	Y	Y						
Results	Y	Y		Y	Y	Y	Y	Y						
<b>Primary diagnosis</b>	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y		Y	Y
<b>Additional diagnoses</b>									Y				Y	
<b>Name and address of general practitioner</b>	Y	Y	Y	Y	Y	Y	Y	Y						

Table 1. Databases which include information on melanoma in NSW

DATA COLLECTED	Sydney Melanoma Unit clinical database	Newcastle Melanoma Unit clinical database	Northern Rivers melanoma database	Westmead Clinical Information System (Odyssey)	NSW Cancer Institute Central Cancer Registry	NSW Cancer Institute Clinical Cancer Registry (Pilot)	NSW Health ISC Public	NSW Health ISC Private	NSW Health Emergency Department Information System	NSW Registry of Births, Deaths & Marriages	HIC	ABS Mortality Data	BEACH GP SURVEY	National Health Survey (ABS)
<b>4. Management</b>														
<b>Patient education</b>														
<b>Surgery</b>	☑	☑	☑	☑		☑	☑	☑			☑			
Date of operation	☑	☑	☑	☑		☑	☑	☑						
Place of operation	☑	☑	☑	☑		☑	☑	☑						
Details of health professional	☑	☑	☑	☑		☑	☑	☑						
Type of operation	☑	☑	☑	☑		☑	☑	☑						
Site of operation	☑	☑	☑	☑		☑	☑	☑						
Complications			☑	☑										
Further comments	☑	☑	☑	☑										
<b>Chemotherapy</b>	☑	☑	☑	☑		☑	☑	☑						
Treatment type		☑		☑		☑								
Site		☑		☑										
Details of health professional		☑		☑										
Start date		☑		☑		☑								
Finish date		☑		☑		☑								
<b>Radiotherapy</b>	☑	☑	☑	☑		☑	☑	☑						
Treatment type	☑	☑	☑	☑		☑								
Site	☑	☑	☑	☑		☑								
Dose	☑	☑	☑	☑		☑								
Details of health professional	☑	☑	☑	☑		☑								
Start date	☑	☑	☑	☑		☑								
Finish date	☑	☑	☑	☑		☑								
Effect of treatment	☑													
Complications	☑													
<b>Immunotherapy</b>	☑		☑											
<b>Limb perfusion</b>	☑		☑	☑										
<b>Psychosocial support</b>						☑							☑	
<b>Palliative care</b>						☑	☑	☑						
<b>Participation in clinical trials/studies</b>	☑	☑				☑								
<b>Medications</b>				☑									☑	☑
Strength of product													☑	☑
Dose and form													☑	☑
Frequency													☑	☑
No. of repeats													☑	☑
<b>Referral</b>	☑					☑	☑	☑	☑				☑	
<b>Consultations/follow-ups</b>	☑	☑	☑	☑		☑			☑				☑	☑
Date of consultation	☑	☑	☑	☑		☑			☑				☑	☑
Place of consultation		☑	☑	☑					☑				☑	☑
Arrival time									☑				☑	☑
Departure time									☑				☑	☑
Duration of consultation									☑				☑	☑
Type of consultation (e.g. phone, interview)	☑			☑					☑				☑	☑
Primary symptom code									☑				☑	☑
Presenting problem									☑				☑	☑
Health professional conducting the consultation	☑	☑	☑	☑		☑			☑				☑	☑
Assessments (e.g. weight, temp, bp)	☑			☑					☑				☑	☑
Further comments	☑			☑					☑				☑	☑
<b>Hospital attendances</b>	☑	☑	☑	☑	☑	☑	☑	☑	☑				☑	☑
Hospital medical record number		☑	☑	☑					☑				☑	☑
Admission details					☑	☑	☑	☑	☑				☑	☑
Separation details					☑	☑	☑	☑	☑				☑	☑
Clinical coding items					☑	☑	☑	☑	☑				☑	☑
Episode of care details					☑	☑	☑	☑	☑				☑	☑
Formal discharge items					☑	☑	☑	☑	☑				☑	☑
Cancer notification items					☑	☑	☑	☑	☑				☑	☑
<b>Other information</b>	☑	☑	☑	☑	☑	☑			☑					☑

Table 2. Summary of key information collected about melanoma in NSW

DATA COLLECTED	Sydney Melanoma Unit clinical database	Newcastle Melanoma Unit clinical database	Northern Rivers melanoma database	Westmead Clinical Information System (Odyssey)	NSW Cancer Institute Central Cancer Registry	NSW Cancer Institute Clinical Cancer Registry (Pilot)	NSW Health Public	ISC	NSW Health Private	ISC	NSW Health Emergency Department Information System	NSW Registry of Births, Deaths & Marriages	HIC	ABS Mortality Data	BEACH GP SURVEY	National Health Survey (ABS)
							NSW Health Inpatients Statistics Collection (ISC)		NSW Health Inpatients Statistics Collection (ISC)				Health Insurance Commission (HIC) Statistical Reporting	Data from NSW Registry of Births, Deaths & Marriages	Bettering the Evaluation And Care of Health	Australian Bureau of Statistics (ABS)
<b>Coverage</b>	Clinic	Clinic	AHS(?)	Clinic	State	State	State		State		State	State	National	National	National	National
<b>1. Patient details</b>																
Contacts	☑	☑	☑	☑	☑	☑	☑		☑		☑	☑	☑			
Demographics	☑	☑	☑	☑	☑	☑	☑		☑		☑	☑	☑	☑	☑	☑
Payment information	☑	☑	☑	☑	☑	☑	☑		☑		☑	☑	☑		☑	☑
History	☑	☑	☑	☑	☑	☑	☑		☑		☑	☑	☑			☑
Patient status	☑	☑		☑	☑	☑	☑		☑			☑		☑		
<b>2. Health professional details</b>																
Contacts	☑	☑	☑	☑	☑		☑		☑		☑		☑		☑	
Demographics													☑		☑	
Education													☑		☑	
Registration/specialty	☑	☑			☑	☑	☑		☑				☑		☑	
Practice details													☑		☑	
<b>3. Diagnosis</b>																
Investigations/tests	☑	☑	☑	☑									☑		☑	☑
Primary melanomas	☑	☑	☑	☑		☑										
Lymph nodes	☑	☑	☑	☑												
Metastases	☑	☑	☑	☑			☑		☑							
Recurrences	☑															
Pathology information	☑	☑		☑	☑	☑	☑		☑		☑				☑	☑
Primary diagnosis	☑	☑	☑	☑	☑	☑	☑		☑		☑		☑		☑	☑
Additional diagnoses	☑	☑	☑	☑	☑	☑	☑		☑		☑				☑	
Name and address of general practitioner	☑	☑	☑	☑	☑	☑	☑		☑						☑	
<b>4. Management</b>																
Patient education		☑														
Surgery	☑	☑	☑	☑		☑	☑		☑				☑			
Chemotherapy	☑	☑	☑	☑		☑	☑		☑							
Radiotherapy	☑	☑	☑	☑		☑	☑		☑							
Immunotherapy	☑		☑	☑												
Limb perfusion	☑		☑	☑												
Psychosocial support							☑		☑						☑	
Palliative care							☑		☑							
Participation in clinical trials/studies	☑	☑				☑										
Medications				☑											☑	☑
Referral	☑					☑	☑		☑		☑				☑	☑
Consultations/follow-ups	☑	☑	☑	☑		☑	☑		☑		☑				☑	☑
Hospital attendances	☑				☑	☑	☑		☑		☑				☑	☑
Other information	☑	☑	☑	☑	☑	☑	☑		☑		☑				☑	☑