The Cancer Council NSW  
Towards a National Cancer Data Strategy for Australia

Background
The need for better access to, and consistency in, cancer data collection for the Australian community has been widely acknowledged. In response, Cancer Australia has developed *Towards a National Cancer Data Strategy: Foundation document* to identify what data already exist and cancer data needs. Cancer Australia is inviting broader comment and input until the end of March 2008. Following this period, the final foundation document will inform development of a National Cancer Data Strategy, and will remain as a companion document for future reference. Stakeholders are requested to provide input to ensure the document captures as many as possible of the potential issues, strategies and priorities for action.

The foundation document outlines assumed data needs of policy makers, planners, administrators, researchers and service providers including mention of the prevalence of social determinants of cancer and person-centred risk factors. It also provides information on currently available data sets, including their limitations (gaps, inconsistencies and implications) and offers a framework for the proposed strategic directions to improve data availability, reporting, quality, and research in data collection and use.

The Cancer Council NSW Response

Introduction
The Cancer Council NSW welcomes the opportunity to provide input into the development of a National Cancer Data Strategy and has identified the following areas as potential issues, strategies and/or priorities for action (they are not ordered on a preferential basis):

Comments on the specific content
i) For many of the proposed strategic directions listed on pages 15-19 of the foundation document, there is very little information on who is going to do the work towards fulfilling the needs and who is going to pay for it. On page 15 it is indicated “Cancer Australia will work with these bodies in a planned and coordinated manner to ensure that cancer data needs are addressed” Does this mean Cancer Australia is going to be responsible for moving most of the 18 directions forward? Without some group(s) taking responsibility for the various directions very little will happen.

ii) On Page 5, Paragraph 5: It states that “The National Cancer Data Strategy Advisory Group will advise on key needs for data in cancer control, data gaps in relation to those needs, barriers to closing those gaps, and directions that should be taken to close gaps that accord with Australia’s legal, ethical and administrative requirements.” Although it is often a difficult and lengthy process, if the case for certain data needs is strong enough, then it may be possible to make changes to the “legal, ethical and administrative requirements.” For example, privacy guidelines are often being changed. As such, moving to get changes made in the latter should be considered and not automatically dismissed. It has been said that ‘public health is threatened more by incomplete data than individual privacy is threatened by health registries’ (J. R. Ingelfinger and J. M. Drazen Registry Research and Medical Privacy. NEJM 1 Apr, 2004)

iii) In several areas of the document, mention is made of the need for outcome data. Given that the effects of cancer treatment may not be seen until many

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years later, it should be stressed that follow-up for outcomes should be long-term as well as short-term.

iv) Other databases that could be included in the list provided on page 11 of the foundation document:

- The births and midwives databases have proven to be useful in epidemiological studies (e.g. the relationship between birthweight and various childhood cancers, birthweight and breast cancer, mother’s characteristics and childhood cancer)
- Infectious disease databases (e.g. HIV, hepatitis B, C)
- The HPV vaccine registry that is currently under development.
- Although mentioned later, databases held by private health insurance companies are useful as they complement the Medicare data. There is at least one study that has linked these data to the WA Linkage System. Also, consideration should be given to developing or having access to a population registry (the electoral rolls or those covered by Medicare). They can be useful for epidemiological studies for drawing controls or for defining comparative cohorts.

Broad comments

i) Establish mechanisms to improve the reporting and collection of more detailed clinical data and patient characteristics

Quality of cancer care

We do not currently have the means to routinely monitor and track cancer care in Australia. The quality of reporting and degree to which data are collected from individual medical records varies widely. To address this deficiency, the Cancer Council NSW supports the widespread adoption of electronic patient medical records and the establishment of agreed measures to track quality of cancer care. A health care provider linked electronic medical record will provide continuous information currently unavailable but important to cancer control such as rates and types of second primary cancers, cancer recurrence, patterns of care and referral for diagnosis, treatment and survival issues. It will also provide continuous information on the effect of co-morbid conditions and variations and gaps in ongoing cancer care and support. With data acquisition as automated as possible, many errors that have been found to occur in the extraction of information from paper records will be eliminated.

Future best medical and allied health practice will increasingly depend on computer-based support tools, an electronic health record could permit effective decision support based on agreed clinical management guidelines such as the recently developed decision support system of the Haematological Society of Australia. The tool called the Lymphoma Wizard is an executable version of the Clinical Practice Guidelines for the Diagnosis and Management of Lymphoma. It includes structured data collection, and an engine to run decision support rules and automate decisions based on electronic health data.

Gains in quality of care through implementation of an electronic medical records system have been seen in large systems overseas such as the US Veterans Health Administration. Additionally, the US Department of Health and Human Services has made substantial investment in the development of a national health information infrastructure by developing a standardised medical vocabulary to facilitate the sharing of electronic information.
Cancer inequity
Cancer data are uneven in their coverage. Routinely collected data on patients' social and health characteristics will allow better identification of the complex levels of inequity experienced by different segments of the Australian population. There is inadequate information currently available to measure indicators of equity (e.g. 5-year survival rates) according to geographic location, socioeconomic status, occupation, ethnicity, aboriginal status, disability, access, risk behaviours, utilisation of healthcare, and other services. For example, community members and decision makers do not have ready access to information regarding the percentage of those traveling more than one hour to a health or cancer screening facility, which health facilities have the longest waiting times for specific services and non-surgical procedures, the percentage of rural regions offering cancer and other health screening services compared with urban regions, and variations in diagnostic and treatment practices between urban and rural health facilities etc.

Some Australians have a disproportionate exposure to hazardous occupational and environmental conditions throughout their lifecourse. A rapid ‘one-stop shop’ method of linking individual level health data with data on environmental exposures for specific geographies and occupations is needed to identify and reduce exposure in those at risk. For example, a recent epidemiological study conducted by The Cancer Council NSW on breast cancer among staff at the Australian Broadcasting Corporation is requiring ethics clearance form each State and Territory Cancer Registry ethics committee, the home institutional ethics committee and the ethics committee of the AIHW. Less than 40 women with breast cancer are anticipated to be found.

The ability to examine equity of access must be made an explicit goal in the national cancer data strategy.

Mortality data
Deaths reported on death certificates where the underlying cause was not cancer may not identify cancer as a contributing cause of death. Similarly, the accuracy of the ascertainment of the cause of death may vary according to the experience of the practitioner, the complexity of the disease process and the circumstances of the death.

As a significant contributor to mortality, history of tobacco use should be mandated to be routinely collected on all death certificates as is enforced in South Africa. (F Sitas, M Urban, D Bradshaw, D Kielkowsk, S Bah, R Peto. Tobacco attributable deaths in South Africa. Tobacco Control 2004;13:396-399) http://tobaccocontrol.bmj.com/cgi/content/abstract/13/4/396

Data and information linkage
Because of the rarity of some cancers it's often difficult for researchers to get large enough study populations that provide reliable, statistically valid conclusions about risk, treatment, survival factors etc. A larger data resource base would support research findings and associated policy and practice changes that would otherwise not be available, as well as provide greater capacity to improve statistical precision and external validity of the findings. It
would help demonstrate that particular problems are grave enough to warrant greater political attention and resource commitment.

Page 18, point 15 of the foundation document states “data linkage has been highlighted as an important methodology for increasing data capacity.” However, there is no specific point addressing directions that would lead to expanded record linkage activities in Australia.

A trial and evaluation of the feasibility of permanently integrating or linking existing data collections at individual and population levels to obtain more and/or longitudinal information is required in the strategic planning for a national cancer data strategy. Cancer registry, hospitalisation, MBS and PBS claims, census, primary care, death and other relevant public and private data collections differ in their purposes, reporting mechanisms and accuracy. There are no unique identifying codes to link records for the same individual across databases. Hospitalisation databases contain a record for each admission, which means that there are separate records for each readmission or inter-hospital transfer.

### iii) Cancer data reporting levels

There is an urgent need for small area geographical and socio-economic data. It is not currently possible to confidently extrapolate state or national cancer data to any one community. By limiting the reporting of the cancer data to broad geographies (such as national, state, urban/rural or other wide boundaries etc) assessments will be over-generalised and disguise significant differentials that exist among the Australian population. The factors affecting cancer and other chronic illness risk and survival in vulnerable population groups are not adequately measured by, or reported in, current cancer data collections. For example, a reported reduction in smoking rates by 1% each year at a state or national level allows statistical averaging to hide evidence of a real regression in smoking rates amongst the most disadvantaged.

To better understand small area differentials in cancer incidence and mortality for various cancers, cancer registration data and associated reports should routinely provide geographic coding including suburb, postcode, legal LGA, statistical subdivision, statistical division, collectors district, health service area/region and urban/rural classification for the year of incidence, and primary and secondary causes and year of death.

### iv) Make cancer registration national at the primary collection point

A national body would be best placed to act as a broker for cross-jurisdictional data linkage activities. This along with the need for ‘seamless’ data acquisition and reporting to minimise errors caused by double registration of cancer data at state and subsequently national levels necessitates cancer registration to be made national at the primary collection point.

### v) There is currently no standard reporting of incidence, mortality, mortality:incidence ratios, survival by state/territory or any other subdivision across Australia. A map of the nation highlighting these outputs would identify areas of greatest need. An example of a centralised approach would be the use of the same criteria for defining survival (eg. age ranges, socioeconomic level etc.) Currently different states and researchers use different criteria.
Epidemiology units with relevant experience could be commissioned to do this work.

vi) Cancer data access
New agreed structures and processes are needed to support efficient access to and use of linked data by researchers and policy makers including authorisation, query, search, analysis and quality control services. Robust, efficient ethics approval processes are also urgently needed. This will require strong leadership to support a change in the prevailing culture of data ownership to data stewardship.

vii) Biological samples
New infrastructure is required to coordinate access by researchers to fully characterised biological samples (standardised and detailed clinical, tissue and gene sample data) from different centres across Australia. Existing international infrastructure that could be used as a model includes PALGA, the nationwide histopathology and cytopathology data network and archive in the Netherlands. Another important new model to potentially gain broad direction on an Australian approach could be the European Biobanking and Biomolecular Resources Research Infrastructure, which was officially launched in February 2008. This ‘European Biobank’ is intended to form a central computerised system linking the records of biological samples held in different research centres and biobanks across Europe [Stafford N. BMJ 2008 Mar 1;336(7642):467]. Its aim is to facilitate pan-European research into “the association between disease subtypes and small, but systematic, variations in genotype, phenotype, and lifestyle”, which requires the study of suitably documented epidemiological, clinical and biological information and material from large numbers of individuals. It is anticipated that researchers from both public and private centres will use the resource, which seeks to have an infrastructure and legal system in place by 2010. Partners include biobanks from Finland, Denmark, Sweden, Germany, Austria, Hungary, Estonia and the UK, including the UK Biobank, the UK DNA Banking Network and Generation Scotland, as well as European groups such as the European prospective study of nutrition and cancer (EPIC) and the European Research Council. The venture is distinct from the EuroBioBank, an operating network of European biobanks from France, Italy, Spain, Germany, Hungary, Slovenia and Malta, which provides human DNA, cell and tissue samples for research into rare diseases.

viii) Communicate data
Data collection findings, including all identified differentials, and how the information gained from existing data collections are to be used to improve cancer control in Australia must be publicly available. For this to genuinely occur, data must be structured for laypersons and others not familiar with data interpretation in a logical, understandable and summarised manner.

Data detail and formats must be widely accepted by the public, health professionals, policy makers and researchers and not be selected to give only piecemeal information or to suit a particular purpose or argument. It must also allow any gaps in available statistics to be readily identified.

Community members, their representatives and relevant professionals must be regularly informed and invited to participate in data policy, development and evaluation decisions.
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