

Canstat



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Canstat: A digest of facts and figures on cancer

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A Guide to the Victorian Cancer Registry

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**The
Cancer
Council
Victoria**

The Victorian Cancer Registry has collected cancer incidence and mortality statistics on all Victorians since 1982

References:

- 1 Rankin DW. *The central cancer registry. Melbourne, 1940-1970.* Med J Aust 1971 1:750-54.
- 2 World Health Organization. WHO Handbook for Standardised Cancer Registries. WHO Geneva 1976.
- 3 Keogh EV, McCall C, Rankin DW. *Mortality from leukaemia in Victoria, 1946 to 1955: a report from the central cancer registry, Melbourne.* Med J Aust 1958 1:632-34.

Note: The Cancer Council Victoria is the new business name of the **Anti-Cancer Council of Victoria**. Both names have been used in this publication for historical reasons.

History & future directions

History

In 1937, the Medical and Scientific Committee of the Anti-Cancer Council of Victoria recommended that a cancer registry be established and, in August 1939, six Melbourne hospitals entered a voluntary cancer registration scheme. Much of the energy behind the scheme was from Dr Robert Fowler, who was made the Honorary Chief Registrar in May 1939 with the registry established on the premises of the Royal Australasian College of Surgeons. The Government Statistician made the statistical services of Mr G E Kitson available to the registry in his own time¹.

At first, six hospitals in Melbourne (Alfred, Austin, Prince Henry's, Royal Melbourne, Royal Women's and St. Vincent's) were involved and cancer registrars were appointed from among the hospitals' medical officers to abstract cancer registration data from medical records. Dr Fowler's military commitments during World War II forced the register to close from late 1941 to early 1946 when he resumed his position. By 1959 another four hospitals had joined the registration scheme (Queen Victoria, Royal Children's and the Royal Victorian Eye and Ear).

The central registry continued until it was incorporated into the present population-based registry in 1982. It was modelled on guidelines drawn up by the WHO, an exercise which was chaired by the Council's Director, Dr Nigel Gray². Its purpose was not to measure incidence but to record clinical and pathological details of cancer patients treated at public hospitals and to follow them up annually until death. It was considered important that clinicians should be encouraged to follow-up their cancer patients in order to assess the efficacy of treatments.

Through arrangements with the Registrar of Births, Deaths and Marriages and the Australian Bureau of Statistics, the registry was notified of all death certificates that mentioned cancer. The information was fed back to notifying hospitals. During this period the registry helped with many requests for information from members of the medical community and from hospitals

and published four reports³.

Work began on computerising the registry and transferring its data to punch cards in 1971. In 1975 initiatives were made to expand the registry on a voluntary basis to measure incidence in the Melbourne metropolitan area and in 1980, after extensive consultation, legislation was drafted to make cancer a notifiable disease. The legislation codified much of the practice of the original central cancer registry and incorporated the existing arrangements with the 10 teaching hospitals and the requirements of notification by all other hospitals and pathology laboratories. In December 1981, legislation was passed and 1982 became the first year in which population-based cancer incidence was measured. Since that time, the original follow-up registry has been phased out. The registry is now fully computerised, produces regular reports, and forms the basis of clinical and epidemiological research.

Future directions

The provision of accurate and timely data on incidence, disease progression and mortality outcomes is an essential prerequisite to rational planning for cancer control. State cancer registries are the main source of these data to inform strategies and to monitor and evaluate developments. The Victorian Cancer Registry is central to public health planning in this crucial area.

Currently the processing of incidence notifications in Victoria is largely a manual task, using paper recording and a resource intensive manual checking system. While reporting from hospitals and pathology laboratories via electronic media has increased, the registry still receives and processes some 60,000 paper notifications each year. The present database and associated paper-based registration system are clearly inadequate and need upgrading to cope with the increasing burden of illness, and to meet the increasing demands for data to inform service planning.

The future direction of the registry centres on the development of a new

Victorian Cancer Registry timeline

1940	<ul style="list-style-type: none"> 1939 Cancer registry established in six hospitals 1940 First cancer registrations made 1941 Registry closes—World War II
	1946 Registry reopens
1950	
	1958 Cancer Act passed “to consolidate the Law relating to the Anti-Cancer Council of Victoria and the Cancer Institute and for other purposes”
1960	1959 Four more hospitals join scheme
1970	1971 Computerisation of registry
	1975 Registry expands to cover Melbourne metropolitan area
1980	1981 Cancer Act amended make cancer notification mandatory
	1982 Registry becomes population based
1990	1988 Amendment to reporting schedule allows reporting of in-situ carcinoma
2000	1997 Reporting regulations amended to include reporting by prescribed registers
	2002 Reporting regulations amended to include details of tumour recurrence and Medicare number to enable more accurate merging of registrations from multiple sources

information technology system. The current computer system is inefficient and outdated and needs replacing with new technology that will be supportable and capable of continuing development.

The project will result in a fully functional and integrated system able to achieve the standards required of a continuing timely and quality service in an environment of technological change. The new database system, written in a modern purpose-built language, will be easier to maintain and offer greater flexibility than the existing system. It will result in increased accuracy as well as decreased paper usage.

The new system will incorporate:

- an improved database design
- replacement of the present paper-based notification system with electronic notifications
- improved functionality in terms of automating procedures such as person searching and diagnostic coding
- electronic storage of all data
- the facility to exchange data with clinic-based cancer registries, notifying hospitals and pathology laboratories.

The new system will lead to an expanded

role for the Victorian Cancer Registry. Continuing development will include:

- vital innovations to improve the quality of data
- an upgrading to enable nationally consistent reporting as per the National Cancer Data Dictionary
- expanded capacity for evaluating interventions
- expanded capacity to provide essential data to hospitals and networks to facilitate future treatment planning e.g. radiotherapy units and hospices
- expanded capacity to provide feedback to pathology laboratories on their market share, survival analysis etc.
- more accurate and timely data to inform family cancer genetic services
- expanded capacity to monitor public health interventions (e.g. for prostate cancer) and screening programs (breast, cervix and in the future colorectal cancer screening).

Operation

The Victorian Cancer Registry collects basic information on all new cases of cancer diagnosed in usual residents of Victoria. Notification is mandatory under law and is incumbent on all hospitals and pathology laboratories. Individual doctors are not obliged to notify and patients can not prevent their data being registered.

The Cancer (Reporting and Registries) Act

- made it mandatory for all persons in charge of hospitals or pathology laboratories to notify the cancer registry of the presence of cancer in patients or human tissue
- protected notifiers from possible litigation concerned with privacy and confidentiality issues.

The *Cancer (Reporting and Registries) Act 1981*, and its accompanying regulations, identified the Anti-Cancer Council of Victoria as the responsible institution and did two things. First, it made it mandatory for persons in charge of hospitals and pathology laboratories to notify the cancer registry of the presence of cancer in patients or human tissues (thus ensuring full coverage). Secondly, the Act protected notifiers from possible litigation concerned with privacy and confidentiality issues.

The following amendments have since been made to the Reporting Regulations under the Cancer Act.

- 1988—allowed for notification of in situ carcinomas and explicitly permitted pathology laboratories to notify the registry by sending copies of the pathologists' reports.
- 1997—included the prescribed registers, BreastScreen and the Victorian Cervical Cytology Service in the reporting schedule.
- 2002—allowed for the collection of data on tumour recurrence and of Medicare number to enable more accurate merging of registrations from multiple sources.

A copy of the Act, as amended, is reproduced on pages 12–15.

Notification system

Currently around 250 hospitals and 50 pathology laboratories notify cancer to the registry. Computerised death certificates are also obtained from the Registrar of Births, Deaths and Marriages on a regular basis. The duplication of notification was an important principle built into the system from its inception. Notifications from several institutions may be received for the same cancer providing a check for completeness and the collection of additional complementary information.

In preparing our latest incidence data, for 1999, over 80,000 notifications were processed relating to almost 21,000 tumours.

Ideally, a cancer registry would be based on pathology reports. In 1999, 92.5% of tumours had undergone either histological (87.5%) or cytological (5.0%) diagnosis. However, not all cancers are biopsied to obtain a pathological diagnosis. Some are so advanced that patients receive no further investigation and others are inaccessible or only detected at death. Hospital notifications identify cancer patients who are only diagnosed on clinical grounds (including biochemistry, imaging, endoscopy and exploratory surgery) with about 5% of cases in 1999 falling into this category. Hospital notifications include demographic details, such as country of birth and ethnicity that are important to the descriptive epidemiology of cancer and not usually available from pathology reports. They may also include history of previous tumours and permit valuable cross checks of important items such as the spelling of names and dates of birth.

In 1999, 1.5% of cases were identified only from a death certificate. These cases are only included after extensive follow-up to verify the date and method of diagnosis. The small proportion of cases identified this way is an indicator of the completeness of registration. Most cases occur in persons whose age, tumour stage or concomitant medical conditions preclude investigation and in those diagnosed outside Victoria or prior to population-based cancer registration. Small numbers of asymptomatic tumours are diagnosed incidentally at autopsy (0.3% in 1999).

Table 1: Minimum data set collected for each cancer

Management and personnel

The registry is housed and administered by The Cancer Council Victoria's Cancer Epidemiology Centre. It is part funded by the Department of Human Services and overseen by the Cancer Council's Executive Committee, to which the Director, Professor Graham Giles, reports annually. Research proposals to use the registry are submitted to the Cancer Council's data release and ethics committees (see pages 6–7).

The administration of the registry on a daily basis is the responsibility of the Operations Manager under the supervision of the Director of Information Systems. The staff includes a combination of clinical coders and clerks. Data requests and publications are principally the task of the Information Manager but often involve a team effort.

Data collection

The registry records the occurrence of all invasive cancers except basal cell and squamous cell carcinomas of the skin. In situ carcinomas and tumours of

uncertain behaviour of all sites and benign tumours of the brain, spinal cord and bladder are also collected. A minimum amount of information is stored about each tumour with additional information collected for certain cancers (Table 1).

Data are received by the registry in many different forms but increasingly by electronic media. The first task at the registry is to match incoming notifications against the register to see if the cancer has already been registered from another source. New notifications are entered onto the system and the data checked for completeness and consistency. Notifications concerning cancers already on the system are entered as further registrations, some details are updated and any differences are resolved by follow-up. Notifiers are not obliged to send further registrations for the same patient, unless that patient develops a new primary tumour, though some find it logistically simpler to send details of all cancers in their record system than to select only new cases.

For each person

- name
- residential address
- date of birth
- sex
- country of birth
- Aboriginal/Torres Strait Islander status
- vital status
- date of last contact
- number of primary tumours

For each primary tumour

- registry identification number
- date of diagnosis
- site of cancer
- cancer histology
- tumour laterality (if relevant)
- method of diagnosis

Extra information collected for

- breast cancer—size of tumour and nodal status
- melanoma—Clark's level and Breslow's thickness

Note: tumour site and histology are coded to ICDO-2¹ 4-digit and 6-digit rubrics respectively in line with other members of the Australasian Association of Cancer Registries and the International Association of Cancer Registries. ICDO-3² will be used from 2003. Incidence is reported in ICD-10 for compatibility with hospitals and the Australian Bureau of Statistics.

¹ Percy C, Van Holten V, Muir C eds. *International Classification of Diseases for Oncology, Second edition.* World Health Organization. Geneva. 1990.

² Fritz A, Percy C, Jack A et al. eds. *International Classification of Diseases for Oncology, Third edition.* World Health Organization. Geneva. 2000.

Data protection and privacy

The Cancer Council Victoria's Human Research Ethics Committee (HREC) must approve any research project requiring disclosure of personal details from the registry.

Proposals will only be approved if the HREC considers the public interest in the research outweighs, to a substantial degree, the public interest in privacy.

The Victorian Cancer Registry, in addition to the requirements of the Cancer Act, adheres to the Health Privacy Principles (HPPs) set by the Victorian Health Records Act (2001).

The eleven HPPs apply to personal information collected in relation to health services and to all health information held by public and private organisations in Victoria.

Data protection

All data held by the registry are kept securely and the privacy of personal details is maintained to at least the same level as the notifying institution.

The registry is housed within The Cancer Council Victoria's Cancer Control Research Institute in a separate room which is kept locked outside normal office hours and only accessible to authorised staff. Staff are trained in the handling of confidential data and are obliged to sign a declaration undertaking not to divulge or discuss information of a personal nature met within the course of their work.

The registry database resides on the Cancer Council's computer system and access is restricted to authorised personnel by password protection.

Privacy of information

The release of data from the registry is two-tiered. Statistical tabulations are routinely available from the information manager and other anonymous data are available at the discretion of the Director. The registry's 'Guidelines for the release of information' are shown on page 7.

The cancer registry is entitled under law to know the names of cancer patients and their treating doctors. It has well-established practices to ensure that any personal information that it holds is securely protected. This applies both to patients and doctors names. Names are never released to third parties without the approval of an ethics committee and the original record holder. No names are ever published in any form and data are de-identified for analysis.

Record linkage or research proposals that require disclosure of personal details require the approval of The Cancer Council Victoria's Human Research Ethics Committee (HREC). This is properly constituted according to National Health and Medical Research Council (NHMRC) guidelines and is comprised of individuals who are independent of The Cancer Council Victoria. One of the key aspects of their job is to weigh the public interest in the research against the individual interests in privacy. In doing this, they scrutinise how the proposal adheres to the

NHMRC National Statement on Ethical Conduct in Research Involving Humans, and the guidelines under the *Privacy Act 1988* (with its amendments including the *Privacy Act (Private Sector) 2000*) as required by the Cancer Act (61(a)).

Under the NHMRC guidelines (section 14.4), an HREC may approve access to identified or potentially identifiable data without consent of those the data identifies where the HREC is satisfied that:

(a) *either the procedures required to obtain consent are likely either to cause unnecessary anxiety for those whose consent would be sought or to prejudice the scientific value of the research and there will be no disadvantage to the participants or their relatives or to any collectivity involved*

or it is impossible in practice, due to the quantity, age or accessibility of the records to be studied, to obtain consent.

AND

(b) *the public interest in the research outweighs to a substantial degree the public interest in privacy.*

Where health information is sought from health service providers, the proposal must also be approved, from 1 July 2002, by the HREC under the Health Services Commissioner's Guidelines under the *Health Records Act 2001*.

Some medical practitioners may also wish to seek approval from their own hospital's ethics committee.

If researchers intend to contact individual patients, they also have to gain approval from relevant hospitals and medical personnel.

Freedom of information

As is their right under the *Victorian Freedom of Information Act 1982*, any person who can provide sufficient personal identification may be supplied with the entire dossier of information held in their file by the registry.

Guidelines for the release of information

1.0 Descriptive statistics

1.1 The registry shall prepare statistics in the form of an annual report for unrestricted release. These shall include the following items of information:

- annual numbers of new cancers by age, sex and site
- annual numbers of deaths due to cancer by sex and site
- annual crude, age–sex specific, standardised and cumulative incidence rates by site
- annual crude, sex specific, standardised and cumulative mortality rates by site

1.2 From time to time the registry shall provide descriptive statistics of its accumulated data for general release. These shall include:

- survival analyses of individual cancers by site, morphology, age and sex
- geographical analyses of individual cancer incidence by site and sex

1.3 The registry shall also, upon request and at reasonable notice, provide:

- ad hoc tabulations of incidence and mortality by ICD-10, 3-digit codes by age, sex, morphology and geographic area
- similar tabulations by notifier number for individual notifiers
- summary statistics from a cohort's nominal roll being checked against the register

2.0 Freedom of information

2.1 As is their right under State law, any person who can provide sufficient personal identification may be supplied with the entire dossier of information held by the registry in their file.

3.0 Release of patient information

3.1 Administrators or medical superintendents of notifying institutions may at any time be provided with (and may authorise the release of) information containing patient and unit record identifiers relevant to their institution. They may choose to refer to appropriate hospital committees from time to time.

3.2 Researchers requiring unit record identifiers from institutions other than their own shall be required to obtain the approval of the record holder at each institution who may choose to refer to an appropriate committee at that institution.

3.3 If suitable ethical or research review is not available at a given institution, release of identifiers shall be subject to review by the Registry's Data Release Committee and/or The Cancer Council Victoria's Human Research Ethics Committee and also the agreement of the record holder.

3.4 The Data Release Committee shall have at least three members. The present members of the committee are the Director of The Cancer Council Victoria, the Director of The Victorian Cancer Registry and the Chairperson of The Cancer Council Victoria's Human Research Ethics Committee.

3.5 Before releasing any personal information, the registry shall require that each researcher shall confirm in writing that no patient will be contacted directly, either verbally or in writing, without first approaching the institution and/or medical practitioner in charge of the patient.

3.6 The Data Release Committee may seek outside advice as to the bona fides of the research person(s), the merit of the research proposal and the ability of the researcher(s) to undertake the project.

Publications and research

Selected references:

- 1 Giles GG, Marks R, Foley P. Incidence of non-melanocytic skin cancer treated in Australia. *Br Med J (Clin Res Ed)* 1988 296(6614):13–7.
- 2 Marks R, Staples M, Giles GG. Trends in non-melanocytic skin cancer treated in Australia: the second national survey. *Int J Cancer*. 1993 53(4):585–90.
- 3 Staples M, Marks R, Giles G. Trends in the incidence of non-melanocytic skin cancer (NMSC) treated in Australia 1985–1995: are primary prevention programs starting to have an effect? *Int J Cancer* 1998 78(2):144–8.
- 4 Hill DJ, White VM, Giles GG, Collins JP, Kitchen PR. Changes in the investigation and management of primary operable breast cancer in Victoria. *Med J Aust* 1994 161(2):110–8.
- 5 Hill DJ, Giles GG, Russell IS, Collins JP, Mapperson KJ. Management of primary, operable breast cancer in Victoria. *Med J Aust* 1990 152(2):67–72.
- 6 Hill D, Jamrozik K, White V, Collins J, Boyages J et al. Surgical Management of Breast Cancer in Australia in 1995. *NHMRC National Breast Cancer Centre, Sydney* 1999.
- 7 McLeish J, Giles GG, Thursfield V. Investigation, follow-up and recurrence after resection of colorectal cancer. *Aust N Z J Surg* 1992 62: 931–40.
- 8 McLeish J, Thursfield V, Giles GG. Survival from colorectal cancer in Victoria: 10-year follow up of the 1987 management survey. *Aust NZ J Surg* 2002 72(5):352–6.
- 9 Frydenberg M, Giles G, Mameghan H, Thursfield V, et al. Prostate cancer in Victoria in 1993: Patterns of reported management. *Med J Aust* 2000 172: 270–4.
- 10 Richardson G, Thursfield V and Giles G. Reported management of lung cancer in Victoria in 1993: comparison with best practice. *Med J Aust* 2000 172:321–4.
- 11 Toner GC, Neerhut GJ, Schwarz MA, Thursfield VJ, Sandeman TF et al. The management of testicular cancer in Victoria, 1988–

Publications

The Victorian Cancer Registry has collected population-based cancer data for over twenty years and therefore holds a large and valuable research dataset. It holds information on over 400,000 cancers diagnosed in Victorians since 1982. These data are used in our publications and a growing number of internal and external research projects.

The registry produces annual statistical reports in our Canstat series that contain summary information on cancer incidence and mortality by age, sex and type of cancer. These reports contain some commentary and graphs of leading cancer sites and cancer trends as well as brief background information on the registry. As well as being available on request, Canstat is circulated to all our notifiers and a large mailing list of medical practitioners, libraries, research organisations and international cancer organisations.

The registry attempts to publish statistics in a timely manner but delays in notification and record linkage postpone publication by about 18 months after the close of a given year. Though the registry notification system is becoming faster through increasing automation, the increasing size of the database inevitably leads to more frequent linkage resolutions. Certain cancer sites, for which more recent data are needed to monitor screening programs or for research projects, are fast-tracked in the registry. These currently include cancers of the breast, prostate, cervix, bowel and melanoma.

As well as the annual reports, Canstats are produced on single cancer sites or topics. These include a collation of facts, figures and commentary on local and international incidence, mortality, and survival. Recent editions have included prostate, testicular and lung cancer and trends in cancer mortality (Australia 1910–1999). Issues are planned on breast cancer, brain and CNS cancers, gynaecological and haematopoietic cancers.

Larger monographs on topics such as survival are produced periodically.

Registry research projects

Part of the registry's raison d'être is to facilitate research. The process by which external researchers can access the register has been outlined. In addition, the registry initiates its own research projects and special interest registers. A selection of recent projects is outlined briefly below.

National skin cancer survey—The registry does not record basal or squamous cell skin cancers because these skin cancers are often treated by general practitioners, often not histologically confirmed and too numerous. Instead, the registry conducts periodic national surveys of skin cancers treated in Australia. The first survey was conducted in 1985 and was repeated in 1990 and 1995^{1–3}.

Management surveys—The registry does not routinely request treatment detail from hospitals as it would be difficult and expensive to collect accurately from medical records. Instead, periodic management surveys are conducted for selected cancers. The first survey of primary operable breast cancer was conducted in 1986, followed by two further surveys in 1990 and 1995. Management surveys have also been conducted for lung, colorectal, prostate, rectal, testicular, ovarian^{4–13} and bladder cancers. Surveys are planned for gliomas and head and neck cancers and a melanoma survey started in 2002.

As well as describing current management practices, in the context of treatment guidelines where available, the survey cohorts can be followed up for several years to compare survival by prognostic and treatment factors. The surveys provide a snapshot of management practice but are not intended as an audit of any individual clinician or treating institution.

The findings from these surveys are important to continuing professional education in Australia. The results are written up for publication in a refereed

1993. *Med J Aust* 2001
174(7):328–31.

12 Farmer KC, Penfold C, Millar JL, Zalberg J, McLeish JA et al. Rectal cancer in Victoria in 1994: patterns of reported management. *Aust NZ J Surg* 2002 72(4): 265–70.

13 Grossi M, Quinn M, Thursfield V, Francis P, Rome R et al. Ovarian cancer: patterns of care in Victoria during 1993–1995. *Med J Aust* 2002 177(1):11–6

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16 Giles GG, Ireland P. Diet in the aetiology of cancer. *Eur J Cancer* 1994 30:226–227.

17 Minami Y, Staples M, Giles GG. Cancer in Italian migrants to Victoria. *Eur J Cancer* 1993 Vol 29 (12) 1735–40.

18 Giles GG. Health 2000: a twenty-year prospective study of diet, lifestyle and health. *Today's Life Science* 1992 4:23–6.

19 Giles GG. The Melbourne Study of Diet and Cancer. *Proc Nutr Soc Aust* 1990 15:61–8.

20 McMichael AJ, Giles GG. Cancer in migrants to Australia: extending the descriptive epidemiological data. *Cancer Res* 1988 48:751–6.

Note: Only cancer-related H2000 publications have been listed here.

21 Giles GG, Severi G, McCredie MRE, English D, Johnson W, Hopper JL, Boyle P. Smoking and prostate cancer: findings from an Australian case-control study. *Ann Oncol* 2001 12:1–5.

22 Giles GG, Severi G, Sinclair R, English DR, McCredie MR, Johnson W, Boyle P, Hopper JL. Androgenetic alopecia and prostate cancer:

medical journal and usually presented at an appropriate clinical seminar.

Special interest registers

The registry also supports some special interest registers which form adjuncts to the Victorian Cancer Registry.

The Radical Prostatectomy Register

(RPR) was established to collect extra data for all men diagnosed with prostate cancer from July 1995 who underwent radical prostatectomy as their initial treatment. The register aims to

- document the population-based incidence and the clinical, surgical and pathological characteristics of radical prostatectomies in Victoria over a five-year period,
- follow up radical prostatectomy cases for recurrence, further treatments and complications,
- follow up the cohort of radical prostatectomies assembled over the five years indefinitely until death and perform survival analysis.

The In Situ and Small Invasive Breast Cancer Register¹⁴ (ISSIBCR) was established to

- document the population-based incidence and clinical, surgical and pathological characteristics of breast cancer (in situ and invasive 10 mm or less) between 1988 and 1992,
- follow up these cases for recurrence, further primary cancers and treatments,
- determine how treatment and pathological variables might affect recurrence and mortality.

The Australian Brain Tumour Register (ABTR) project collected information on all new primary central nervous system tumours diagnosed between 1986–93. This voluntary register was notified by treating surgeons. A panel of independent pathologists reviewed slides of each tumour and consensus diagnoses were recorded on the database.

The Victorian Lymphoma Register

collected data to facilitate research in tumour subtypes. Little is known of the aetiology of lymphomas which are very heterogeneous. Additional pathological data was collected resulting from slide review by an independent pathologist.

The Victorian Hepatocellular Carcinoma Register

collected data on all Victorian patients diagnosed with primary liver cancer in 1997–9. The aims of this register were to

- collect epidemiological, clinical, biochemical, radiological and pathological data on these tumours,
- record the method of management,
- document the clinical course and outcomes of patients with liver cancer,
- begin to assess which factors predict recurrence of primary liver cancer.

Collaborative research program

Part of the registry's raison d'être is to facilitate research. The process by which external researchers can access the register has been outlined on pages 6–7. Some of our current collaborative projects are outlined below.

HEALTH 2000 (Melbourne Collaborative Cohort Study)^{15–20} was established as Australia's first large-scale prospective cohort study in 1990. It is a longitudinal study, in 42,000 Melbourne residents aged 40–69 years at recruitment in 1990–4, of dietary and other lifestyle factors suspected of having a role in the development of cancer and other causes of premature death. Over a quarter of the cohort are migrants from southern Europe. Participants complete diet questionnaires, provide blood samples and have their blood pressure, glucose and cholesterol levels recorded. The cohort is now in follow-up and regular linkage is made to death and cancer registers. Non fatal, non-cancer endpoints are identified by self-report at follow up. The study will continue for up to 20 years and analysis is under way to determine what causes prostate and breast cancer, type-2 diabetes and death from cardiovascular disease.

findings from an Australian case-control study. *Cancer Epidemiol Biomarkers Prev* 2002 11(6):549-53.

- 23 Cui J, Staples MS, Hopper JL, English DR, McCredie MRE, Giles GG. Segregation Analyses of 1476 population-based Australian families affected by prostate cancer. *Am J Hum Genet* 2001 68(5):1207-18.
- 24 Cui J, Antoniou AC, Dite GS, Southey MC, Venter DJ et al. After BRCA1 and BRCA2 - what next? Multifactorial segregation analyses of three-generation, population-based Australian families affected by female breast cancer. *Am J Hum Genet* 2001 68(2): 420-31.
- 25 Marsh A, Spurdle AB, Turner AB, Fereday S, Thorne H et al. The intronic G13964C variant in p53 is not a high-risk mutation in familial breast cancer in Australia. *Breast Cancer Res* 2001;3(5):346-9.
- 26 Spurdle AB, Hopper JL, Chen X, Dite GS, McCredie MRE et al. The steroid 5 α -reductase type II TA repeat polymorphism is not associated with risk of breast or ovarian cancer in Australian women. *Cancer Epidemiol Biomarkers Prev* 2001 10(12):1287-93.
- 27 Spurdle AB, Hopper JL, Chen X, McCredie MRE, Giles GG et al. The progesterone receptor exon 4 Val660Leu G/T polymorphism and risk of breast cancer in Australian women. *Cancer Epidemiol Biomarkers Prev* 2002 11(5):439-43.
- 28 Chenevix-Trench G, Spurdle AB, Gatei M, Kelly H, Marsh A et al. Dominant negative ATM mutations in breast cancer families. *J Natl Cancer Inst* 2002 94(3):205-15.
- 29 Spurdle AB, Hopper JL, Chen X, Dite GS, Cui J et al. The BRCA2 372 HH Genotype is associated with risk of breast cancer in Australian women. *Cancer Epidemiol Biomarkers Prev* 2002 11(4):413-6.

The blood will be used to measure biomarkers of relevant exposures and to test for susceptibility genes as appropriate methods become available. In this way we will be able to look for gene-environment interactions.

Prostate program—Little is currently known about what causes prostate cancer. The **Australian prostate study**²¹⁻²² is a population-based case-control study of risk factors for prostate cancer including medical history, health and lifestyle. Its aim is to determine the extent to which the incidence of prostate cancer can be reduced by modifying diet.

The **Australian Prostate Family Study**²³ is a population-based familial study based on men aged under 70 years newly diagnosed with prostate cancer. It aims to determine the extent to which familial aggregation of cancer is due to genetic factors, to environmental factors, or to a combination or interaction of these factors. Stored DNA will allow testing of hypotheses relating susceptibility to putative and known genetic markers.

Victorian Family Cancer Genetics Services. The Cancer Epidemiology Centre has developed the **FamBIS** (Family Based Information System) software that has been successfully used for the **kConFab** breast cancer research project. FamBIS is used by hospital Family Cancer Clinics (FCCs) to ensure consistent data collection methods with common data definitions. A **Central Family Cancer Registry** has been established to carry out

- verification of self-reported family history through the Victorian Cancer Registry (with consent),
- central registration of high-risk breast, ovary and bowel cancer families to coordinate gene mutation testing of eligible family members,
- communication between FCCs,
- surveillance monitoring of registered and consenting individuals,
- regular family history update for selected moderate and all high-risk families to the FCCs.

The **Australian Melanoma Family Study** aims to help us understand how genetic and environmental factors combine to affect our risk of melanoma. The study, which began in mid-2000 and will finish recruitment during 2004, compares people aged under 40 years when diagnosed with melanoma and their relatives, with randomly-selected people and their relatives, from the same population.

The **Australasian Breast Cancer Family Registry**²⁴⁻²⁹ and **Australasian Colorectal Cancer Family Registry** are accruing breast and colorectal cancer families according to protocols that include creation of repositories of biospecimens (blood and tumour samples) and lifestyle data obtained through questionnaires. These will support collaborative research into predisposition genes, genetic fingerprints within tumours and environmental risk factors. The interactions between and within these factors will form the cornerstone of this research. A number of molecular and statistical analyses of this data have already been conducted and data have been contributed to collaborative meta-analyses.

Ad hoc information requests

In addition to these major projects, each year the registry receives over 400 information requests, often requiring more detailed statistics than are routinely published in Canstat, from researchers, health service providers, government departments and the general public. We are able to supply aggregated data for subsets of the population such as local government areas, individual hospitals, migrant groups or specific subtypes of cancer to assist in health service planning and research.

Cancer control

By virtue of its location within the Cancer Epidemiology Centre of The Cancer Council Victoria's Cancer Control Research Institute, the Victorian Cancer Registry is well placed at the heart of cancer control activity in Victoria.

Baseline cancer incidence and mortality patterns from the registry can be used to identify target groups for interventions. For example, the registry can identify groups of women (by age, country of birth, socioeconomic status, residential area) who are at particularly high risk of cervical cancer. The Centre for Behavioural Research in Cancer and the Cancer Education Unit can then design and deliver a campaign targeted specifically at women of high risk. The registry can then evaluate its impact by comparing the rates of in-situ carcinoma in the target group before and after the campaign. In the longer term, the registry's monitoring activities can also evaluate trends in the diagnosis of cancers which are amenable to early detection—

such as breast cancer and melanoma—by looking not only at total incidence but also at the proportion detected at early stage. The registry can also evaluate programs by linking with other registries set up to monitor the use of cancer screening tests such as mammography and cervical cytology.

Future trends

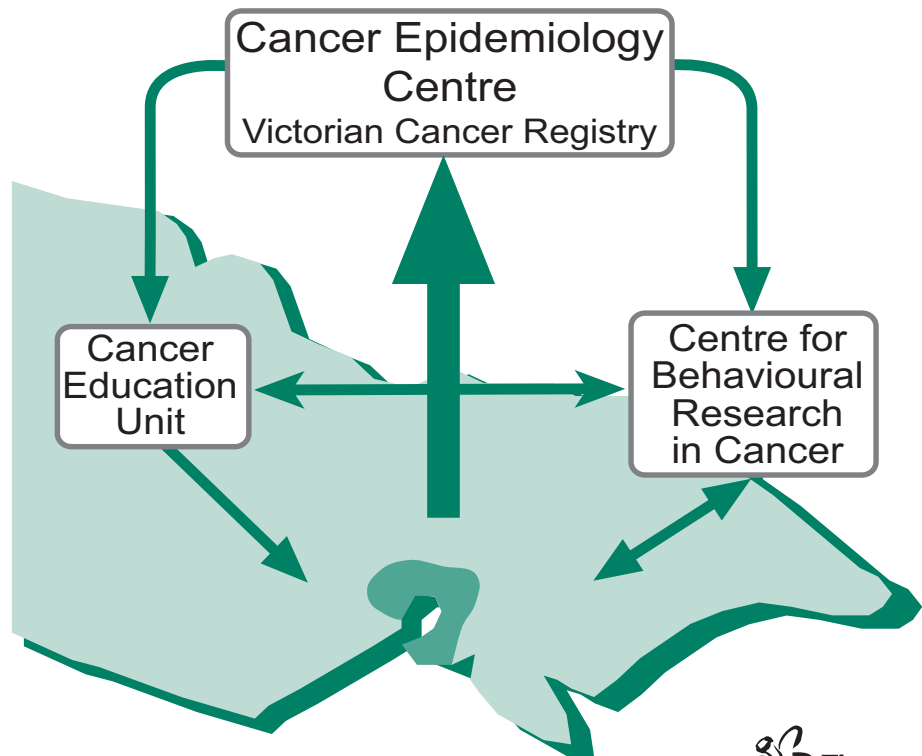
Cancer is becoming more common as the Victorian population ages. The cancer registry is therefore going to become increasingly useful in planning services such as radiotherapy units and hospices. Its utility for evaluating interventions will probably increase over the next decade as programs increase in scope and community penetration. From an epidemiological point of view, the registry will continue to be a source of descriptive research, a facility for identifying subjects for study and an essential source of follow-up for cancer endpoints in various cohort studies.

Cancer control activity within The Cancer Council Victoria

The Cancer Education Unit, the Centre for Behavioural Research in Cancer and the Cancer Epidemiology Centre, which together form the Cancer Control Research Institute, are the three units of the Cancer Council directly involved in cancer control activities.

There are also several other units which work in different areas such as patient support, clinical research coordination, administration, finance and fundraising.

The Cancer Council also funds external clinical research into cancer.



CANCER ACT

PART III - Cancer Reporting and Registers

59. (1) In this Part unless inconsistent with the context of subject-matter –

“**Cancer**” means a malignant growth of human tissue which if unchecked is likely to spread to adjacent tissue or beyond its place of origin and which has the propensity to recur, and, without limiting the generality of the foregoing, includes carcinoma, sarcoma, any mixed tumour, leukaemia, and type of lymphoma, melanoma and non-invasive, in situ carcinoma.

“**Cancer test**” means an examination or a test that is undertaken to determine whether a person is suffering from cancer and that is-

- (a) a pathological examination of a specimen from the person; or
- (b) any other examination or test whatever prescribed as a cancer test

“**Council**” means the Anti-Cancer Council of Victoria established under Part I.

“**Hospital**” means –

- (a) Health service establishment has the same meaning as in the **Health Services Act 1988**.
- (b) a public hospital or denominational hospital within the meaning of the **Health Services Act 1988**.

“**Registered medical practitioner**” means a legally qualified registered medical practitioner within the meaning of the **Medical Practice Act 1994**.

“**Patient**” in relation to a hospital or private hospital includes any person who receives relief or assistance from the hospital or private hospital, whether or not he resides in the hospital or private hospital;

“**Prescribed**” means prescribed by the regulations made under this Part.

“**Prescribed register**” means –

- (a) in relation to cancer of the cervix, the Cervical Register maintained by the Victorian Cytology (Gynaecological) Service; or
- (b) in relation to cancer of another part of the human body, the register prescribed by the regulations of results from cancer tests for that type of cancer; or
- (c) in relation to cancer of any part of the human body (including the cervix), a register prescribed by the regulations of results from cancer tests generally.

“**Private hospital**” means a private hospital within the meaning of the Health Services Act 1988.

“**Proprietor**”

- (a) in relation to a private hospital or prescribed health service establishment, has the same meaning as in the **Health Services Act 1988**; and
- (b) in relation to a hospital or prescribed registered funded agency means the committee of management or governing body (by whatever name that is) of the hospital or agency.

“**Registered funded agency**” has the same meaning as in the **Health Services Act 1988**.

60. (1) The proprietor of a hospital, private hospital, prescribed registered funded agency or prescribed health service establishment must, within the prescribed time and in the prescribed form, report to the Council on any patient, who to the knowledge of the proprietor, is suffering or commences to suffer from cancer.

(1A) The person in charge of an organization that maintains a prescribed register must, within the prescribed time and in the prescribed form, report to the Council on any person whose information is included in that prescribed register and who, to the knowledge of the person in charge, is suffering or commences to suffer from cancer.

(2) The person in charge of any place where a cancer test is undertaken shall, when the test indicates that a person is suffering from cancer, cause a report on that test to be forwarded to the Council.

(2A) A report under sub-section (2) must be –

- (a) in the prescribed form; or
- (b) if the person in charge of the place where the cancer test is undertaken has prepared for the person requesting the test a report of the test (whether or not the report also relates to any other tests undertaken) –
 - (i) a copy of that report; or
 - (ii) an extract from that report that contains the material relevant to the cancer test.

(2B) An action does not lie against a person who forwards a report in accordance with this section, by reason only that –

- (a) the report is a copy of, or extract from, a report mentioned in sub-section (2A) (b) and was forwarded to the Council without the consent of the person to whom it relates or the person for whom it was prepared; or
- (b) the report contains information identifying the person to whom it relates; or
- (c) the report is forwarded under sub-section (2A) (b) and contains information that does not relate to a cancer test; and

(3) Any person who –

- (a) when required under sub-section (1) or sub-section (1A) to report to the Council upon any person who suffers or commences to suffer from cancer, fails to so report within the prescribed time;
- (b) when required under sub-section (2) to report to the Council upon a cancer test, fails to so report in accordance with that sub-section, sub-section (2A) and the regulations made under this section; or
- (c) knowingly includes in a report under sub-section (1), sub-section (1A) or sub-section (2) any details which are false or misleading-

shall be guilty of an offence against this Act and shall be liable to a penalty of not more than \$100.

(4) The Governor in Council may make regulations for or with respect to –

- (a) prescribing the form of any report required to be made to the Council under this section;
- (b) prescribing the time within which any report required to be made to the Council under this section shall be made; and
- (c) generally prescribing any matter or thing which is by this section authorized or required to be prescribed or is necessary or expedient to be prescribed for giving effect to the provisions of this section.

61. (1) A person who is or has been a person authorized or employed by the Council to perform a function or discharge a duty with respect to reports submitted to the Council pursuant to section 60 shall not, except to the extent necessary to perform the function or discharge the duty, either directly or indirectly make a record of or divulge or communicate to any person any information that is gained by or conveyed to him by reason of the authorization or employment, or make use of the information for any purpose other than the performance of the function or the discharge of the duty.

Penalty: \$250.

(1A) Information may be released in certain circumstances

- (1) Despite section 61, a person to whom that section applies may, for the purposes of medical research or the administration of cancer related public health programs give information acquired by the Council pursuant to section 60 if –
 - (a) the use to which that information will be put and any research methodology to be used in the medical research of administration of the programs has been approved, having regard to the NHMRC guidelines, by an ethics committee established by the Council; and
 - (b) the giving of that information does not conflict with any prescribed requirements.

- (2) A person who receives information by reason of the giving of information under sub-section (1) must not give to any other person, whether directly or indirectly, any information so received unless the giving of the information –
 - (a) has been approved by the ethics committee referred to in sub-section (1); and
 - (b) does not conflict with any prescribed requirements.

Penalty: 50 penalty units

- (3) In this section “NHMRC guidelines” means the document titled “Aspects of Privacy in Medical Research: An information paper and guidelines for the protection of privacy in the conduct of medical research” endorsed by the National Health and Medical Research Council Executive Committee, June 1995 and includes and subsequent amendment to that document or any superseding document prepared or endorsed by the National Health and Medical Research Council which covers the same subject matter.

(1B) Release of information between Council and prescribed registers

- (1) Despite section 61, for the purposes of clarifying the accuracy of information provided from the Council to an organization that maintains a prescribed register under section 61A, a person to whom section 61 applies may provide information to that organization in respect of a person who, according to reports submitted to the Council pursuant to section 60, is suffering or commences to suffer from cancer.
 - (2) Despite section 62(6), for the purposes of clarifying the accuracy of information provided to the Council from an organization that maintains a prescribed register under section 60(1A), a person to whom section 62(6) applies may provide information on that register to the Council in respect of a person who, to the knowledge of the person in charge of that organization, is suffering or commences to suffer from cancer.
- (2) nothing in sub-section (1) precludes a person from –
- (a) producing a document to a court in the course of criminal proceedings or in the course of any proceedings under this or any other Act; or
 - (b) divulging or communication to a court in the course of any proceedings referred to in paragraph (a) any matter or thing coming to his knowledge in the performance of a function or the discharge of a duty referred to in sub-section (1).

Registers of results from cancer tests

62. (1) A registered medical practitioner engaged by a person who has undergone a cancer test may cause a report on the test to be forwarded to an organization that maintains a prescribed register for inclusion in that register.
- (2) A person in charge of a place where a cancer test is undertaken may cause a report on the test to be forwarded to an organization that maintains a prescribed register for inclusion in that register.
 - (3) A person who has undergone a cancer test has the right to object to a report on the test being forwarded for inclusion in that register, and if he or she so objects, a person must not, knowing of the objection forward such a report, or cause such a report to be forwarded, for inclusion in a prescribed register.

Penalty: 10 penalty units

- (4) A person who makes an examination of, or takes a specimen from, another person to determine whether that other person is suffering from cancer, before a report is forwarded to an organization under sub-section (1) or (2) –
 - (a) must ensure that other person has been informed of the right to object to the report being forwarded; and
 - (b) if aware of an objection by that other person, must ensure –
 - (i) that the report includes notice of the making of the objection; and
 - (ii) that a written acknowledgement of the objection is given to the other person.

- (5) For the purposes of this section the functions of an organization that maintains a prescribed register are –
- (a) to follow up positive results from cancer tests; and
 - (b) to send reminder notices when persons whose names appear in the register are due for cancer tests; and
 - (c) subject to and in accordance with the regulations, to give access to the register to persons studying cancer; and
 - (ca) to report to the Council in accordance with section 60(1A); and,
 - (d) to compile statistics and, if the organization considers it appropriate, to publish those statistics that do not identify the persons to whom they relate.
- (6) A person must not disclose information on a prescribed register that identifies any person except –
- (a) with that person's consent; or
 - (b) to a registered medical practitioner engaged by that person and seeking information to assist in diagnosis or treatment or to determine when the person should next have a cancer test; or
 - (c) as is necessary for the performance of the functions set out in sub-section (5) (a), (b) or (ca).

Penalty: 10 penalty units.

- (7) On the application of a person whose name appears on a prescribed register, the organization that maintains the register must remove from the register all information that identifies that person.
- (8) An organization that maintains a prescribed register is a provider of a health service for the purposes of the **Health Services (Conciliation and Review) Act 1987**.
- (9) The Governor in Council may make regulations for or with respect to –
- (a) prescribing registers or results from cancer tests by specifying in each case –
 - (i) the name of the register; and
 - (ii) whether the register is of results of tests for cancer of a particular part of the human body or of results of tests generally; and
 - (iii) the organization that maintains the register; and
 - (iv) the officer of that organization in charge of the register; and
 - (b) access to prescribed registers by persons studying cancer, including how, where, when and to whom access is to be given, and in what circumstances access is to be given or denied; and
 - (c) prescribing forms; and
 - (d) generally prescribing any other matter or thing required or permitted by this section to be prescribed or necessary to be prescribed to give effect to this section.
- (10) The regulations may confer a discretion or authority, or impose a duty, on a specified person or class of persons.
- (11) Regulations made under this section may be disallowed in whole or in part by resolution of either House of the Parliament in accordance with the requirements of section 6 (2) of the **Subordinate Legislation Act 1962**.
- (12) Disallowance under sub-section (11) is deemed to be disallowance by Parliament for the purposes of the **Subordinate Legislation Act 1962**.

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Victorian Cancer Registry publications

Canstats

A Guide to the Victorian Cancer Registry

Cancer in Victoria 1982-1987

Childhood Cancer

Cancer in Adolescents and Young Adults

Trends in Cancer Mortality, Australia 1910–1994

Trends in Cancer Mortality, Australia 1910–2000

Skin Cancer

Breast Cancer

Bowel Cancer

Prostate Cancer

Testicular Cancer

Lung cancer

Annual Victorian Cancer Registry reports were produced for the years 1982–1990.

From 1991 these annual data have been published in the Canstat series

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The Cancer Council Victoria is an independent volunteer-based charity which relies on public support to maintain vital education and patient welfare programs and to fund major scientific and behavioural research projects. This task is made possible by the generosity of Victorians, a staff of over 240 and the commitment of over 20,000 volunteers and supporters.

Canstat



**A digest of facts and figures on cancer
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Victoria's CancerEpidemiology Centre**

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