Core purpose

The National Cancer Control Initiative (NCCI) is a key expert reference body providing timely advice, identifying appropriate initiatives and making specific recommendations to the Commonwealth Government and other key groups regarding the prevention, detection, treatment and palliation of cancer for all Australians.

Core values

The work of the NCCI is based on the values of:
• scientific validity
• independence
• integrity
• relevance
• responsibility.

The NCCI gives priority to solutions which achieve:
• effectiveness
• efficiency
• equity.

The NCCI:
• works with nationally identified priorities
• works with researchers, the cancer community, the community at large, public policy makers and others to develop consensus on new methods of cancer control
• takes a leadership role by consensus.
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<tr>
<td>ACN</td>
<td>Australian Cancer Network</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>BCC</td>
<td>Basal cell carcinoma</td>
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<tr>
<td>CA125</td>
<td>Cancer antigen 125</td>
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<tr>
<td>CAN Australia</td>
<td>Cancer Alliance Network Australia</td>
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<tr>
<td>CDHFS</td>
<td>Commonwealth Department of Health and Family Services</td>
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<td>COSA</td>
<td>Clinical Oncological Society of Australia</td>
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<tr>
<td>CSG</td>
<td>Cancer Strategies Group</td>
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<tr>
<td>CT</td>
<td>Computed tomography</td>
</tr>
<tr>
<td>FOBT</td>
<td>Faecal occult blood test</td>
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<tr>
<td>GPs</td>
<td>General practitioners</td>
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<tr>
<td>HIC</td>
<td>Health Insurance Commission</td>
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<td>NBCC</td>
<td>National Breast Cancer Centre</td>
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<td>NCCI</td>
<td>National Cancer Control Initiative</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NMSC</td>
<td>Non-melanoma skin cancer</td>
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<tr>
<td>PSA</td>
<td>Prostate specific antigen</td>
</tr>
<tr>
<td>RACGP</td>
<td>Royal Australian College of General Practitioners</td>
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<tr>
<td>SCC</td>
<td>Squamous cell carcinoma</td>
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<tr>
<td>TCCA</td>
<td>The Cancer Council Australia</td>
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<tr>
<td>TNM</td>
<td>Tumour, node and metastasis</td>
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<tr>
<td>UV</td>
<td>Ultraviolet</td>
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</tbody>
</table>

Accuracy of URLs
In parts of this report, addresses (URLs) for relevant Internet material are provided. The URLs were correct when checked before publication (5 June 2003).

Names of organisations
Between 1997 and 2003, the names of several groups, organisations and government departments with whom the NCCI has collaborated changed their names. In this report, all groups, organisations and government departments are referred to by their current name.
Introduction

Associate Professor Michael Quinn  
Chair, National Cancer Control Initiative Management Committee

The NCCI is in a unique position, bridging the gap between the Commonwealth, the states and the cancer community, and holding a unique relationship with the Cancer Strategies Group (CSG) in an advisory and implementation role.

The keys to the success of the NCCI have been its consultative and inclusive national approach across all disciplines and its establishment of unique partnerships at a state, national and international level.

The Management Committee, apart from its usual governance roles, has concentrated on helping the staff set strategic goals and being a useful resource in facilitating much of the work set out in the Business Plan. We have been fortunate in having a panoply of experts from all areas on the committee and in having an excellent relationship with the Commonwealth, which have made my role and the function of the committee considerably easier.

The Cancer Council Victoria has been responsible for housing the NCCI from the start and the Management Committee is especially grateful for its support during this time.
Promoting collaboration to improve cancer care

Professor Rob Sanson-Fisher
Professor of Health Behaviour, University of Newcastle, and Director of the NCCI 1997–98

There is widespread acceptance of the need for national coordination of issues relating to cancer control, since many of these activities require collaboration between states and the Commonwealth Government. While there are many in the cancer control area who have acquired national and international reputations in the field, Australia’s limited population base encourages the need to capitalise on its intellectual capital as well as ensure that available resources are used in a collaborative and productive manner. The NCCI was established in an effort to harness the collaboration of consumers, providers, and state and federal organisations in an effort to achieve collaboration and in so doing improve outcomes associated with cancer.

The history of previous attempts to overcome traditional state, hospital and professional barriers has not always been positive. However, the early days of the NCCI were marked by the willingness of individuals and organisations to collaborate. This collaboration was reflected in people’s willingness to contribute to a consultation process designed to establish the most pressing needs in cancer control for Australia. A survey that formed part of this process canvassed a wide range of individuals and groups, asking them to indicate which areas they believed would have the greatest impact on improving cancer outcomes. The survey return rate and people’s openness to be involved in subsequent discussions were impressive and extremely helpful. Those involved indicated a willingness to accept that there was a need for groups to work together in a mission orientated way in order to lessen the burden associated with one of the most feared diseases in our society.

Such collaboration was not limited to providers working in the field, patients or organisations involved in cancer control. Strong support was also received from politicians at the state and federal level, as well as individuals working in the health departments. While there were some understandable concerns about the potential role of the NCCI, almost all of those contacted in the national consultation process shared a belief that there was a need for an organisation to take on tasks requiring national collaboration and demonstration projects. This cooperation resulted in the identification of 13 priority areas where it was believed there was a need for a national group to undertake specific tasks in order to achieve better outcomes relating to cancer control. The first year of the organisation allowed these tasks to be identified and agreed to by the Management Committee of the NCCI. The work subsequently undertaken by the organisation under the direction of Professor Mark Elwood has been able to achieve many of the objectives set by the original consultative process.
Consulting to develop cancer policy

Professor Alan Coates AM
Chief Executive Officer, The Cancer Council Australia

The mission of The Cancer Council Australia (TCCA) is to lead in the development and promotion of national cancer control policy. The NCCI represents an important and flexible bridge between government and TCCA, the peak national non-government organisation involved in cancer control. Established by contract between TCCA and the Commonwealth Department of Health and Ageing, it allows development and execution of cancer control initiatives without the need to establish new contractual relationships for each. The NCCI has a basic budget, which is supplemented as required by agreed additional funds related to particular projects. It is a pleasure to thank The Cancer Council Victoria, which has so generously provided housing and support to the NCCI over the years.

In its first year under the direction of Professor Rob Sanson-Fisher, the NCCI undertook a wide ranging consultation leading to the consensus-based set of priorities Cancer control towards 2002 (NCCI & CDHFS 1998). This proved invaluable to the later development by the CSG (2001) of Priorities for action in cancer control 2001–2003. The late Emeritus Professor Richard Lovell steered the next phase of NCCI development, establishing a sound working relationship with the staff of the organisation, and leading to the appointment of Professor Mark Elwood as Director.

The various projects completed or in progress are detailed elsewhere in this report. One important recent output has been the joint production with TCCA and the Clinical Oncological Society of Australia (COSA) of a further policy document, Optimising cancer care in Australia (COSA, TCCA & NCCI 2003), which is already proving valuable in the development of a National Service Improvement Framework for Cancer.
Working in partnership to improve cancer management

Professor Robert Burton
Chair, Cancer Strategies Group

The NCCI and the CSG provide an excellent example of the partnership and consultative mechanisms between the Commonwealth Government and its advisory bodies. Together they provide leadership to drive improvements at a national level for cancer control.

The CSG is the Commonwealth Government’s expert advisory group on cancer. The role of the CSG is to improve the prevention, detection, treatment and management of cancer in Australia. The first major task of the CSG was to build on the work of the NCCI to establish a National Cancer Control Plan. In 1997 the NCCI undertook an extensive consultation process to establish agreed priorities for national cancer control. In 2001 the CSG released Priorities for action in cancer control 2001–2003 and the NCCI has been nominated by the CSG to implement several of its key recommendations.

The CSG is a subcommittee of the National Health Priority Action Council, which was established as a subcommittee of the Australian Health Ministers’ Advisory Council in June 2000. The core business of the National Health Priority Action Council is to promote and galvanise action nationally and within jurisdictions to drive action for effective health care in the designated health priority areas.

The NCCI is one of the two outsourced organisations through which the Commonwealth Government manages its national cancer control programme. The other is the National Breast Cancer Centre (NBCC). The NCCI is represented on the CSG and from time to time is called upon to provide advice on emerging issues or manage projects on behalf of the group. Currently this work includes implementation of Australia’s cancer control plan: Priorities for action in cancer control 2001–2003 (CSG 2001), and other specific initiatives, including support for Optimising cancer care in Australia (COSA, TCCA & NCCI 2003).
Director’s report

Professor Mark Elwood
Director, National Cancer Control Initiative

Cancer control encompasses all actions to reduce the burden of cancer in the community. This includes prevention, early diagnosis, curative treatment and palliative care. Ideally, the methods used should be supported by the best scientific evidence available and the delivery of services should reach all those who can benefit. It is an exciting time to be involved in cancer control. Sir Richard Doll, arguably the world’s leading cancer epidemiologist, wrote in 1996 that the frequency of cancer could be reduced by 40% by the application of existing knowledge on prevention. At the same time, the treatment of cancer is advancing rapidly. Currently in Australia more than half of patients diagnosed with cancer are alive seven years after diagnosis, giving Australia (along with the United States) the best recorded patient outcome figures in the world. Australia is a world leader in cancer prevention through reducing smoking and sun exposure. Its research contribution is considerable, and it is the only continent with full cancer registration.

But behind such figures lies a wide gap between what is possible and what is achieved. Much of the preventive knowledge has yet to be applied. It is not unrealistic to propose that the frequency of cancer could be reduced by 20% in the next 20 years. As stated in Optimising cancer care in Australia (COSA, TCCA & NCCI 2003), ‘there is a strong conviction held by consumers and cancer care providers that Australian cancer services can be, and must be, improved substantially’. For example, patient outcomes are substantially worse in Aboriginal Australians. Australia contributes large amounts of funds to the treatment and care for cancer, and smaller but still substantial amounts to fundamental research. Relatively little is committed to ensure that the results of research are translated into better outcomes for the population as a whole.

The NCCI has some unique characteristics. It is a partnership between government and non-government sectors, and enjoys good relationships with consumers, managers, researchers and clinicians. It has a small staff and a healthy team approach to pursuing the goal of better cancer outcomes for Australians, using partnerships and collaborative work. The greatest pleasure and stimulation to me as Director, as well as the excellent staff of the NCCI, comes from the skilled, willing, and often unpaid cooperative input from consumers, government, the cancer councils, COSA, and the Australian Cancer Network (ACN) as well as a wide range of university and practice-based professionals, even if on occasion these various links may be in conflict!

The NCCI has delivered on the concepts for which it was established. It has championed new developments such as colorectal screening, applying international research to Australian practice. It has investigated some expensive practices such as skin lesion removal and unnecessarily frequent cancer screening. It has assessed new developments, such as computed tomography (CT) screening for lung cancer, and has taken on complex and controversial topics, such as the provision of radiotherapy services, and prostate cancer screening in general practice. The NCCI is developing neglected areas, such as the contribution of primary care to cancer control.

The legitimate demands on the NCCI are, perhaps inevitably, much greater than the resources available to meet them, but what has been done has been valuable, and what can be done in the future is immense.
Identifying cancer control priorities and initiating action: the NCCI from 1997

The NCCI originated from discussions between the Commonwealth Minister for Health and Ageing (the Honourable Dr Michael Wooldridge) and TCCA in 1996. Documents at that time stated that there was a conviction that it should be possible to get a better return for current expenditure on cancer than was being obtained, and that it was timely to introduce new evidence-based cancer control measures (NCCI & CDHFS 1998). The NCCI was formed in 1997, and after a call for bids from all states, the NCCI secretariat was based with The Cancer Council Victoria in Melbourne (Burton & Sanson-Fisher 1997). Robert Sanson-Fisher, Professor of Behavioural Science at the University of Newcastle, NSW, was appointed as Director, supported by two Senior Project Officers, Libby Campbell, PhD, and Paul Ireland, PhD, and by Emeritus Professor Richard Lovell as a Senior Adviser.

The first phase of the NCCI’s work was to identify national cancer control priorities. A nationwide consultation process was used (Sanson-Fisher et al. 1999). From visits with key stakeholders in each state and territory, 36 topic areas were identified. These included the six types of cancer identified in the 1996 report on the National Health Priority Areas (CDHFS & AIHW 1998) (lung and other tobacco-related cancers, colorectal cancer, skin cancers, breast cancer, cervical cancer, prostate cancer); some other cancers (uterine and ovarian cancers, leukaemia and haematological cancers); and a wide range of issues relevant to all cancers, including familial cancer, palliative care, general practice, data collection and information resources, medico-legal questions, and special considerations of Aboriginal and Torres Strait Islanders, and rural and remote areas.

For each of these 36 areas, an expert was asked to set up and chair a multidisciplinary working party of 10 to 20 people with relevant expertise, and use available evidence to propose up to 10 actions which would have the greatest potential for improving cancer control. This was defined as improving mortality and morbidity, reducing risk factors, or increasing activities such as screening which would lead to reduced mortality or morbidity. The groups were asked to focus on actions that would have an impact within the next five years. This process generated 276 proposals, which were reported in NCCI priority issues discussion papers in July 1997 (NCCI 1997a, 1997b & 1997c). To make the further work more manageable, a winnowing process involving 19 key stakeholders, including the NCCI Management Committee, was used to reduce the list to 147 actions. Actions nominated by over 50% of those asked were retained, as were all actions allocated as first or second priority by each working group.

A survey was then undertaken involving 390 stakeholders throughout Australia who were asked to rate the potential of each of the 147 actions to improve cancer control in Australia by 2002. They were asked to consider the size of the problem, the efficacy of the action within a five-year timeframe, the likelihood of successful implementation, cost and cost-effectiveness, and equity. Participants rated the potential value of each action on a standardised scale. The group surveyed represented a wide range of expertise and roles. It included:

- representatives of patients and other consumers
- practitioners in surgery, medical oncology, radiation oncology, medical imaging, palliative care, pathology, general practice, nursing and the allied health professions
- cancer councils and cancer registries
- Commonwealth, state and territory health departments
- public health, health promotion and screening programmes
- medical education, cancer research, and research funding agencies
- council members of the ACN
members of the COSA executive, chairs of COSA special interest groups and a random sample of members of each group
• members of the National Cancer Advisory Committee and the NCCI Management Committee
• chairs of the 36 working groups
• a random sample of the Heads of Divisions of General Practice.

On the basis of these questionnaire responses, 30 actions were identified which were rated as having the greatest potential for benefit. Details of these 30 proposed actions were then discussed at workshops held in each state and territory during September to November 1997, attended by 242 representatives of various organisations and interest groups. The discussions covered the evidence related to each action, the key tasks involved in implementation, feasibility, potential performance indicators, timelines and estimations of costs. Each workshop was attended by a representative of the Commonwealth Department of Health and Family Services (CDHFS) and a member of staff of the NCCI.

These discussions resulted in a list of 21 actions (Table 1), of which 13 were identified for priority attention by the NCCI Management Committee. The process resulted in the report *Cancer control towards 2002* (NCCI & CDHFS 1998), which describes approaches to each of the 13 priority actions and discusses implementation issues.

**Table 1: Actions proposed by the priority setting process**  
(reproduced from *Cancer control towards 2002: the first stage of a nationally coordinated plan for cancer control*)

<table>
<thead>
<tr>
<th>Primary prevention</th>
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<tbody>
<tr>
<td>1* Tobacco Preventing tobacco-related cancers</td>
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<tr>
<td>2 Skin cancer Reducing risk</td>
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<tr>
<th>Population-based screening and early detection</th>
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<tr>
<td>3 Breast cancer Improving BreastScreen Australia</td>
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<tr>
<td>4 Breast cancer Promoting prompt diagnosis</td>
</tr>
<tr>
<td>5 Cervical cancer Improving Pap smear programmes</td>
</tr>
<tr>
<td>6 Cervical cancer Handling Pap smear results</td>
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<tr>
<td>7* Colorectal cancer Developing faecal occult blood testing</td>
</tr>
<tr>
<td>8* Prostate cancer Rationalising PSA testing</td>
</tr>
<tr>
<td>9* Skin cancer Improving diagnostic skills</td>
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<tr>
<th>Treatment</th>
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<tr>
<td>10* Guidelines A national approach</td>
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<tr>
<td>11* Multidisciplinary care Evaluation and facilitation</td>
</tr>
<tr>
<td>12* Palliative care Filling gaps</td>
</tr>
<tr>
<td>13* Prostate cancer Dealing with treatment uncertainties</td>
</tr>
<tr>
<td>14* Psychosocial care Defining, implementing and monitoring</td>
</tr>
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</table>
General

<table>
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<tr>
<th>15*</th>
<th>General practice</th>
<th>Promoting participation in cancer control</th>
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<tbody>
<tr>
<td>16</td>
<td>Equity</td>
<td>Implementing culturally relevant cancer control measures</td>
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<td>17</td>
<td>Consumers</td>
<td>Facilitating involvement</td>
</tr>
<tr>
<td>18*</td>
<td>Research</td>
<td>Continuing the national commitment</td>
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<tr>
<td>19*</td>
<td>Familial cancers</td>
<td>Organising education and resources</td>
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<tr>
<td>20*</td>
<td>Data collection</td>
<td>Meeting urgent national needs</td>
</tr>
<tr>
<td>21</td>
<td>Clinical trials</td>
<td>Encouraging participation of doctors and patients</td>
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</table>

*The 13 out of 21 proposed actions recommended for priority implementation.

On his appointment as Dean of the Faculty of Medicine and Health Sciences at the University of Newcastle, Professor Sanson-Fisher was succeeded by Emeritus Professor Richard Lovell as Acting Director of the NCCI in February 1998. During 1998, negotiations about a further contract with the NCCI were held with the Commonwealth Department of Health and Ageing and a business plan for 1999–2001 was developed.

From 1998, the NCCI commenced projects on several of the 13 priority actions which had been identified in the consultations. The working party on colorectal screening, chaired by Associate Professor James St John, a gastroenterologist, developed a proposal which was discussed at a large workshop of key stakeholders convened by the ACN in June 1999 in Sydney. A nationally representative multidisciplinary steering committee, chaired by Professor Graeme Young, was formed to further develop the proposal for pilot studies of colorectal screening in Australia. Dr Trish Livingston was appointed as a part-time NCCI Senior Project Officer to assist with this development. The final proposal was submitted to the Commonwealth Minister for Health and Ageing in December 1999, and led to the allocation of new funding in the May 2000 Commonwealth budget.

The NCCI’s proposal for the development of a nationally coordinated approach to familial cancer was accepted by the CSG and the CSG Familial Cancer Working Party. Funds were made available for a project to prepare a proposal for national, public and professional education concentrating in the first instance on familial colorectal cancer, and for a national facility to coordinate familial cancer data nationally to support both clinical practice and research. This report was prepared by Professor Rick Kefford, Chair of the ACN Clinical Genetics Working Party, Dr Judy Kirk and Ms Sue Carrick at Westmead Hospital, NSW.

A working group was set up to develop evidence-based best practice guidelines for the management of colorectal cancer. With leadership from Professor Robert Thomas, president of COSA, Emeritus Professor Tom Reeve of the ACN, and Emeritus Professor Richard Lovell, draft clinical guidelines were developed and reviewed in two rounds of public consultation, and approved by the National Health and Medical Research Council (NHMRC). A working party chaired by Ms Dorothy Reading developed the corresponding consumer guide. A guide for general practitioners (GPs) was also developed in partnership with the Royal Australian College of General Practitioners (RACGP), and in particular Dr Ron Tomlins, RACGP Assistant Secretary General. The guidelines were launched by the Commonwealth Minister for Health and Ageing, the Honourable Dr Michael Wooldridge, at the December 1999 COSA Conference. The consumer and GP guidelines were completed and published in 2000.

A contract for the National Colorectal Cancer Patterns of Care Survey was signed in June 1999, appointing Professor Allan Spigelman and Dr David Leong of the University of Newcastle and the Hunter Area Health Service to steer the project. Ms Sandra Anderson was appointed as project manager.

Meeting urgent national needs to improve cancer data collection was one of the actions recommended for priority implementation. The NCCI commissioned Professor Alan Coates, Chief Executive Officer of TCCA, to conduct consultations across Australia to assess what data should constitute a national common clinical data set and to recommend standard definitions, classifications and codes for the data items. Professor Coates’ report was completed in December 1999.
A working group chaired by Professor Robert Burton developed a project to assess Polaroid photography to reduce the inappropriate removal of pigmented skin lesions in general practice, and funding of $400,000 was obtained in July 1998 from the Commonwealth. The proposal was for a randomised controlled trial based in Perth, and discussions with the General Practice Divisions of Western Australia in Perth led to the formation of a project team chaired by Dr Geoff Emery. Further discussions were held with pathologists in Perth, and the proposal was approved by the RACGP Research and Evaluation Ethics Committee. Recruitment of GPs commenced in August 1999. For the trial, Associate Professor Dallas English was appointed as Project Manager, Ms Chris Costa as Senior Project Officer, Ms Jade Nolan as Project Officer, and Professor Robin Marks was appointed as the independent project evaluator.

A further project was to develop an inventory of cancer control activities throughout Australia. A questionnaire was mailed to 742 organisations or individuals in 1999, in three stages, resulting in 332 responses. It was accepted that the NCCI would have no means of verifying or validating the information received, and considerable variation in the scope and detail of information was expected, but the inventory would provide useful information on a wide range of activities.

In June 1999, Emeritus Professor Richard Lovell retired as acting Director. Mark Elwood, Professor of Cancer Epidemiology at the University of Otago, New Zealand, was appointed as NCCI Director to take up the position in January 2000, and Dr Paul Ireland was appointed Acting Director from June to December 1999. At this time the other NCCI staff were Ms Josephine Ponsford as Administrative Officer, Ms Aimee Reading as Secretarial Assistant, Dr Trish Livingston as part-time Senior Project Officer, and Ms Sue Reid as casual database coordinator.

Throughout this period, the NCCI benefited from guidance from its Management Committee and the many members of staff of the Commonwealth Department of Health and Ageing who have worked with the NCCI, including Claire Caesar, David Marcus, Leslie Paton, Andrew Benson, Rosemary Knight, Monica Johns, John Primrose, Sarah Major and Paula Henriksen.

In January 2000, Professor Mark Elwood took up his position as Director of the NCCI, with Dr Paul Ireland as Deputy Director. Consideration of the expanded work plan resulted in the appointment in July-August of Dr Karen Pedersen and Ms Margaret Staples as Senior Project Officers, and Ms Cleola Anderiesz as Project Officer, with promotion to Senior Project Officer in 2001. Ms Josephine Ponsford moved overseas in December, and Ms Julie Delahunt was appointed as Administrative Officer.

In 2000, several major new developments went forward; more detail is given later in this report under the individual projects. The colorectal cancer guidelines in their specialist, general practice and consumer versions were distributed, and multidisciplinary forums were held to publicise them. The national survey of the management of colorectal cancer commenced, including all patients diagnosed during a three-month period early in 2000. A major project began, run in three states, to increase GPs’ expertise in regard to prostate specific antigen (PSA) tests. An allocation of $7.3 million in the Commonwealth budget allowed the development of pilot programmes of colorectal screening. The NCCI supported a consumer forum at the International Conference of Psycho- oncology in Melbourne. The NCCI was asked by the Commonwealth to undertake a review of the evidence-based indications for radiotherapy, to support a quantitative justification for the level of provision radiotherapy services. Tenders were sought for this work and the contract was awarded to Associate Professor Michael Barton, at the Collaboration for Cancer Outcomes Research and Evaluation in Liverpool, New South Wales.

In 2001, the first of a series of NCCI workshops was held in Fremantle on the topic of advances in screening for cervical cancer. These workshops are described later in this report; they have been characterised by the participation of key expert speakers, policy makers, and consumer representatives, independence from commercial interests, free registration, and the production of workshop reports which are made available on the NCCI website. A workshop held in Melbourne addressed the emerging issue of helical CT in screening for lung cancer, and led to a working group being set up to review the topic. An international meeting was held in Melbourne to bring together a group of experts in the primary prevention of skin cancer, which will produce a book on the topic.
In September 2001, a workshop on improving the management of ovarian cancer was run in Melbourne jointly with the NBCC, the Commonwealth Department of Health and Ageing, and OvCa Australia. This was opened by the Commonwealth Minister for Health and Ageing, the Honourable Dr Michael Wooldridge, who announced new Commonwealth funding of $500,000 for ovarian cancer developments to be coordinated by the NBCC. In conjunction with this, the NCCI sponsored a visit from Professor Ian Jacobs, Director, Gynaecological Cancer Research Unit, St Bartholomew's Hospital, London, to give presentations on developments in ovarian cancer.

From 1999, the NCCI worked extensively with the CSG. This led to the report, *Priorities for action in cancer control 2001–2003* (CSG 2001). The NCCI supported the Australian Prostate Cancer Collaboration in the development of a consumer guide to accompany the NHMRC guidelines for early prostate cancer. A consultative report by Mr Brian Wall of Oceania Health Consulting on the necessary infrastructure for clinical trials in Australia was completed, supported by COSA, the Victorian Department of Human Services, the Commonwealth Department of Health and Ageing, and the NCCI.

A strategic planning workshop involving the NCCI Management Committee, with Ms Jenny Varcoe-Cocks as facilitator, was held in April 2001 to consider the strategic direction of the NCCI in terms of the 2002–05 work plan. This led to the development of a new strategic plan.

In May 2001 Mr James McIntyre was appointed part-time as a Research Assistant in charge of library resources; in April Ms Melissa Glogolia was appointed as Secretarial Assistant; in September Ms Melissa Baxter was appointed as Administrative Officer; and in December Associate Professor James St John was appointed as Senior Clinical Consultant to the NCCI on a part-time basis.

In March 2002 Ms Jodie Williams was appointed part-time to work on the skin cancer survey, and in August Mr Greg Poynter was appointed as the part-time Research Assistant in charge of library resources following James McIntyre’s departure. In July Dr Paul Ireland resigned to take a position with the National Institute of Clinical Studies in Melbourne. Paul had been with the NCCI from its inception, and with The Cancer Council Victoria for some 13 years. His contribution to the NCCI, including a spell as Acting Director, has been greatly appreciated. After an intensive search process, Professor Brian McAvoy was appointed as Deputy Director in September 2002. Brian McAvoy’s previous experience as a Professor of General Practice in the United Kingdom and in New Zealand will bring an extra dimension to the NCCI’s skills. His appointment was made on an 80% time basis, to allow him to continue in part-time general practice. Also in September 2002, Professor Robert Burton became an honorary Senior Advisor to NCCI.

In 2002 the new contract for NCCI took effect, and the work was organised along the lines of the new strategic plan. New work included the development of projects in both Western Australia and the Northern Territory on obtaining good data on cancer staging. A large national survey of non-melanoma skin cancer (NMSC) was commenced, funded partly by NCCI, but with the major contribution coming from the cancer councils. Discussions were held with the international Concord group and the Australian Association of Cancer Registries concerning Australian involvement in the international work on cancer survival. A report on screening for ovarian cancer was prepared. The report on helical CT for lung cancer screening progressed, with discussions at the scientific meeting of the Thoracic Society of Australia and New Zealand. A survey was developed to assess the opinions of cancer researchers on strategic issues in cancer research, under a working group chaired by Professor Joe Sambrook. The randomised controlled trial of photographic aids in the management of pigmented skin lesions in general practice was completed in Perth, with the important but perhaps disappointing result that this intervention did not produce an advantageous change in the excision rate of benign lesions. A workshop was held in November, jointly with the Sydney Melanoma Unit, to discuss these findings and consider other approaches to improving the diagnosis of melanoma and the management of skin lesions in general practice. The large study of improving GPs’ skills in regard to prostate cancer continued, as did the development of pilot programmes for colorectal screening, with the first pilot programme launched in MacKay in Queensland in November. The report on The National colorectal Cancer Care Survey was completed, with information on over 2,000 patients, and the report was launched at the COSA meeting in December.
A major activity during 2002 was the development of a consultative report which became the *Optimising cancer care in Australia* report, in conjunction with TCCA and COSA. The preliminary work for this was done by Mr Brian Wall, of Oceania Health Consulting and then two workshops and much input from NCCI staff and others led to the final report which was supported by the CSG in December. At the same time, the development of a national cancer consumer organisation proceeded. The Cancer Alliance Network Australia (CAN Australia) and the report on cancer care were launched together at Sydney Town Hall on World Cancer Day, 4 February, 2003.
A national approach to cancer control

Central to the NCCI’s roles and responsibilities is the effective management of a range of projects funded by the Commonwealth. Projects managed by the NCCI are designed to demonstrate and foster evidence-based and cost-effective practices in cancer control, have a focus on issues of national interest, and be consistent with the emerging national cancer strategy. Projects managed by the NCCI often involve strategic partnerships with government, cancer councils, health care professionals and consumers, and the NCCI oversees national, state and regional projects in Australia. Moreover, the NCCI undertakes cancer control projects across the continuum of cancer care.

Figure 1: Location of NCCI managed projects

Figure 1 shows the geographic focus of NCCI projects undertaken in the period 1997–2002. National projects involve every state and territory in Australia, state projects are those that involve the entire state and regional projects involve only certain areas within a state. Furthermore, the NCCI has been involved with cancer control projects on an international level. Table 2 shows the NCCI projects undertaken in the period 1997–2002 in relation to the continuum of cancer care.

An asterisk (*) denotes projects which are undertaken in, or coordinated by, more than one state or territory.
Please refer to Table 2 for the list of NCCI projects.
Table 2: NCCI project list

<table>
<thead>
<tr>
<th>Project</th>
<th>Focus of project: international, national, state or regional</th>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A clinical cancer core data set</td>
<td>National</td>
<td>18</td>
</tr>
<tr>
<td>2. Pilot study for population-based clinical staging of major cancers in Western Australia</td>
<td>State/territory</td>
<td>20</td>
</tr>
<tr>
<td>3. Cancer stage at diagnosis and survival in the Northern Territory</td>
<td>State/territory</td>
<td>22</td>
</tr>
<tr>
<td>4. National non-melanoma skin cancer survey</td>
<td>National</td>
<td>23</td>
</tr>
<tr>
<td>5. Estimating non-melanoma skin cancer frequency</td>
<td>* State/territory and regional: all of Tasmania and 65 selected postcodes in Queensland</td>
<td>24</td>
</tr>
<tr>
<td>6. Linking of Australian survival data for cancer with international data</td>
<td>National</td>
<td>26</td>
</tr>
<tr>
<td>7. Optimising cancer care in Australia</td>
<td>National</td>
<td>27</td>
</tr>
<tr>
<td>8. International review on cancer control</td>
<td>International</td>
<td>29</td>
</tr>
<tr>
<td>9. Ovarian cancer screening</td>
<td>Regional Project conducted from the NCCI office in Melbourne</td>
<td>29</td>
</tr>
<tr>
<td>10. Lung cancer screening by helical computed tomography</td>
<td>National</td>
<td>30</td>
</tr>
<tr>
<td>11. A randomised controlled trial of population-based screening for melanoma</td>
<td>Regional 18 towns in Queensland</td>
<td>32</td>
</tr>
<tr>
<td>12. Survey of cancer researchers</td>
<td>National</td>
<td>33</td>
</tr>
<tr>
<td>13. A randomised controlled trial to encourage appropriate removal of pigmented skin lesions in general practice</td>
<td>Regional Project conducted in Perth</td>
<td>35</td>
</tr>
<tr>
<td>14. Developing national strategies for improving the use of the prostate specific antigen test in the Australian community</td>
<td>* Regional Academic detailing conducted in specific areas of Queensland, Victoria and South Australia</td>
<td>38</td>
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<tr>
<td>15. Monograph on the prevention of skin cancers</td>
<td>International</td>
<td>41</td>
</tr>
<tr>
<td>16. Bowel cancer screening pilot: implementation, evaluation and monitoring</td>
<td>* Regional Screening being conducted in three locations – Mackay, Adelaide and Melbourne – however, there is national representation on implementation, evaluation and monitoring committees</td>
<td>42</td>
</tr>
<tr>
<td>17. The primary care perspective on cancer</td>
<td>National</td>
<td>44</td>
</tr>
<tr>
<td>18. The development, dissemination and evaluation of evidenced-based practice guidelines for the management of colorectal cancer</td>
<td>National * Project coordinated from both New South Wales and Victoria</td>
<td>45</td>
</tr>
<tr>
<td>19. Guidelines for psychosocial care</td>
<td>National</td>
<td>47</td>
</tr>
<tr>
<td>21. Improving the management of lung cancer</td>
<td>National</td>
<td>50</td>
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<tr>
<td>22. The potential of a national familial cancer support facility</td>
<td>National</td>
<td>52</td>
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Table 3: NCCI projects and the continuum of cancer care

<table>
<thead>
<tr>
<th>Prevention</th>
<th>Screening and early detection</th>
<th>Clinical management and supportive care</th>
<th>Cancer care and improvement</th>
<th>Monitoring</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>30. The cancer genetics education resource directory</td>
<td>28. Review of Australian clinical management surveys and guidelines</td>
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</tbody>
</table>
NCCl key strategies

The projects managed by the NCCI fit into the NCCI’s five key strategies, which are to:

- Monitor and evaluate cancer control outcomes in Australia.
- Identify emerging issues and new strategies for cancer control.
- Develop and assess strategies to translate research outcomes into improved public health and clinical practice.
- Identify gaps between current and best practice.
- Develop and maintain the capacity to respond to issues in cancer control within the strategic priorities.
In this report, major projects undertaken by the NCCI are summarised under the relevant NCCI key strategy, but are not in any priority order. These include projects which are completed and those currently in progress up to December 2002, with some information referring to 2003 where it is relevant.
Key strategy 1: Monitor and evaluate cancer control outcomes in Australia

‘Where is the wisdom we have lost in knowledge? Where is the knowledge we have lost in information?’

T S Eliot (1888–1965), The Rock

A clinical cancer core data set

TO MAKE PROGRESS, we must know how we are doing. Ideally, we should have nationally consistent information on how each person with cancer is diagnosed, what type and extent of disease they have, how they are treated, and their subsequent progress and outcome. This priority has been highlighted by consumers and practitioners in numerous reports. In this project, we developed a ‘core data set’ of relevant clinical information for each cancer patient. This allows us to move towards producing nationally consistent information.

**Background**

One of the actions recommended for priority implementation by the NCCI in its December 1997 report was ‘meeting urgent national needs for improved cancer data collection’. An advisory group was convened to develop outlines for projects designed to address cancer data needs across all aspects of cancer care in Australia. One project, accepted by the CSG as being of high priority, involved identifying data currently collected on cancer care, and obtaining consensus on what should be collected with a view to making recommendations on a national clinical cancer core data set.

**Aims**

To identify currently collected cancer data, to obtain consensus on data items to be included, and to define the items required for a national core data set that would enable cancer survival to be assessed by stage of disease at diagnosis and by the type of treatment used.

**Methods**

Professor Alan Coates, Chief Executive Officer, TCCA was commissioned by the NCCI in April 1999 to undertake a nationwide consultation and propose a clinical cancer core data set. His report was submitted to the NCCI in December 1999 and was circulated to key stakeholders for comment. These comments were discussed at a workshop held on 12 July 2000. There was general agreement about the data items to be included and a working party was established to prepare definitions for these items in a format suitable for inclusion in the National Health Data Dictionary.

**Results**

Drafts of the core data set were circulated to council members of COSA, TCCA/COSA Medical and Scientific Committee, state and territory cancer registries, and other interested stakeholders. The definitions were submitted to the National Health Data Committee in July 2002 for consideration regarding their inclusion into the National Health Data Dictionary where they will be more widely accessible to potential users.

**Outcomes**

The clinical cancer core data set includes items on staging and treatment of primary cancers. Definitions are now complete and the dictionary is available from the NCCI website (http://www.ncci.org.au/pdf/)
The Royal Australian and New Zealand College of Radiologists – Faculty of Radiation Oncology has recommended incorporation of the NCCI core data set as standard practice in radiotherapy departments.

A report on the project has been submitted to the CSG who will consider further development along with other information systems priorities.

**Working groups**

**Clinical Cancer Registration Core Data Set Working Group**

<table>
<thead>
<tr>
<th>Representative</th>
<th>Affiliation</th>
<th>State/territory</th>
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<tbody>
<tr>
<td>Professor Bruce Armstrong</td>
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</tr>
<tr>
<td>Professor Alan Coates</td>
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<td>NSW</td>
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<tr>
<td>Professor Mark Elwood (Chair)</td>
<td>NCCI</td>
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<tr>
<td>Professor Graham Giles</td>
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<tr>
<td>Dr Julienne Grace</td>
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<tr>
<td>Dr Paul Ireland (member until July 2002)</td>
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<tr>
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<td>ACT</td>
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<tr>
<td>Dr Liz Kenny</td>
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<tr>
<td>Professor John Mathews</td>
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<tr>
<td>Associate Professor David Roder</td>
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<td>Dr Margaret Stevens</td>
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<td>WA</td>
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<tr>
<td>Dr Guy Toner</td>
<td>Peter MacCallum Cancer Centre</td>
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**Clinical Cancer Registration Data Definition Working Party**

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**Presentations**


Pilot study for population-based clinical staging of major cancers in Western Australia

THE ‘STAGE’ OF CANCER is a measure of the extent of disease at the time of diagnosis. It is the best indicator of early diagnosis, and the best predictor of the patient’s outcome, it also helps determine which treatments are appropriate. Information on stage is collected in many different ways, and is usually only available in medical records. This project is examining the logistics of obtaining good information on staging in Western Australia to identify methods which could be used for routine data collection.

Background
Information on the extent of cancer at diagnosis – cancer staging – is of vital importance in determining the patient’s prognosis and the appropriate treatment. Cancer staging information would allow us to monitor trends in early diagnosis and be helpful in understanding trends in patient survival. However collecting information on cancer staging is complex, and is not done routinely in cancer registries.

Aim
To assess the feasibility and cost of adding cancer staging data to the Western Australian Cancer Registry for the period 1995 onwards.

Methods
Staging information is being collected for 500 cancer cases retrospectively, and 100 prospectively, from a random sample of cases from the 20 cancer sites with the highest incidence. The data sources, collection methods, validity and costs of collection are being recorded, to indicate which methods would be most appropriate to achieve stage information in the future. The project started in January 2001 and is due for completion in 2003.
Working groups

Steering Group

<table>
<thead>
<tr>
<th>Representative</th>
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<tbody>
<tr>
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<tr>
<td>Dr Tim Threlfall</td>
<td>Western Australian Cancer Registry</td>
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Project Committee

<table>
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<tr>
<th>Representative</th>
<th>Affiliation</th>
<th>State/territory</th>
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<tbody>
<tr>
<td>Dr Evan Bayliss</td>
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<tr>
<td>Professor D’Arcy Holman</td>
<td>University of Western Australia</td>
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<td>Dr David Joske</td>
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<tr>
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<tr>
<td>Dr Rosemary Knight</td>
<td>Commonwealth Department of Health and Ageing</td>
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<td>Dr Bruce Latham</td>
<td>Royal College of Pathologists of Australasia</td>
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<tr>
<td>Dr Yee Leung</td>
<td>King Edward Memorial Hospital for Women</td>
<td>WA</td>
</tr>
<tr>
<td>Dr Martin Phillips</td>
<td>Western Australian Clinical Oncology Group Lung Cancer Committee</td>
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</tr>
<tr>
<td>Dr Cameron Platell</td>
<td>Western Australian Clinical Oncology Group Colorectal Cancer Committee</td>
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<td>Mr Justin Vivian</td>
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<td>Ms Jana Wittorff</td>
<td>Department of Health</td>
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<tr>
<td>Dr Liz Wylie</td>
<td>BreastScreen WA</td>
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Current state of project

The case list has been finalised and data collection through the Western Australian Cancer Registry, the Western Australian Hospital Morbidity Data System, hospital-based cancer registries and medical records has commenced.
Cancer stage at diagnosis and survival in the Northern Territory

**THIS PROJECT IS OBTAINING** information on the extent of cancer – the cancer stage – for patients in the Northern Territory. As well as clarifying the issues inherent in staging, it will show whether the extent of disease at diagnosis and the outcome for the patient differ between Aboriginal and non-Aboriginal Australian patients.

**Background**
Along with the project on staging in Western Australia, this work was funded after competitive tenders for projects to explore cancer staging. It has the additional advantage of addressing the important issue of cancer staging in Aboriginal Australian cancer patients.

**Aim**
To collect staging information for cancers of five major sites from hospital and medical records for the period 1991–2001, and compare the stage distribution and survival in Aboriginal and non-Aboriginal people in the Northern Territory.

**Methods**
The cancer staging information is being obtained from public and private hospitals for cases notified to the Northern Territory Cancer Registry (between 1991 and 2001). Cancer stage at diagnosis will be compared for Aboriginals and non-Aboriginals. Five-year relative survival rates will also be compared with and without adjustment for stage. Where suitable data are available, comparisons will also be made with survival data from other states.

**Working group**

**Steering Committee**

<table>
<thead>
<tr>
<th>Representative</th>
<th>Affiliation</th>
<th>State/territory</th>
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<tbody>
<tr>
<td>Associate Professor Ross Baillie</td>
<td>Cooperative Research Centre for Aboriginal and Tropical Health and Menzies School of Health Research</td>
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<tr>
<td>Professor Tony Barnes</td>
<td>Cooperative Research Centre for Aboriginal and Tropical Health</td>
<td>NT</td>
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<tr>
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<tr>
<td>Professor Mark Elwood</td>
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<tr>
<td>Ms Margaret Staples</td>
<td>NCCI</td>
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<tr>
<td>Dr Yuejen Zhao</td>
<td>Northern Territory Cancer Registry</td>
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</table>

**Presentations**

**Current state of project**
Data collection is complete for 87% of the 1,375 eligible cases and summary stage was available for over 99% of these. Tumour, node and metastasis (TNM) staging was available for almost 90% of the cases retrieved. A report and a journal article are in preparation.
National non-melanoma skin cancer survey

Cancers of the skin are the most common type of cancer, and account for the greatest health care costs. They are so common that, with the exception of melanoma, they are not recorded by any state or territory cancer registry, except in Tasmania. It is important to know the frequency of this disease both for health planning purposes, and to assess the effectiveness of prevention programmes. This national survey will measure the frequency of skin cancers other than melanoma in 2002, and can be compared with earlier studies as far back as 1985.

Background
Australia has the highest reported rates of NMSC in the world. It is Australia's most common cancer and its most costly in terms of dollars spent on diagnosis and treatment. Because of its high prevalence and cost, it is important to have reliable incidence figures so that trends in NMSC rates and the effectiveness of skin cancer education and prevention programmes can be monitored. The only national figures available have been obtained from household surveys conducted in 1985, 1990 and 1995, in which the frequency of treated NMSC was estimated from confirmed skin cancer diagnoses in survey respondents.

Aims
To estimate the frequency of NMSC treated in Australia by conducting a national survey in 2002 using the same methods as the previous surveys and to assess trends since 1985 by age group, sex and latitude.

Methods
People with skin cancer treated in the last 12 months were identified by a market research company as part of their weekly household survey. Those treated in the last year were asked for permission to confirm their diagnosis with the treatment provider. The NCCI coordinated the study and the confirmation of the skin cancer diagnoses. The cancer councils in each state and territory contributed to the funding of the project.

Results
Between 1 January and 31 December 2002, 57 215 people were asked if they had ever been treated for skin cancer. Of the 10 378 who had been treated, 4 098 reported treatment in the previous year and 3 157 (77%) gave sufficient information and permission to allow the diagnoses to be confirmed with their doctors. Responses were received from 80% of the doctors contacted and NMSC or melanoma was confirmed in 855 people.

Outcomes
The estimated age-standardised rates for basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) are shown in the table. There was an overall increase in NMSC rates from that found in previous surveys but the increases were predominantly in the older age groups. Rates for both BCC and SCC were higher in more northerly latitudes. Papers for peer-reviewed publication and a summary report are currently being prepared. The report will be made available on the NCCI website.

<table>
<thead>
<tr>
<th>Histological type</th>
<th>Males</th>
<th>Females</th>
<th>Persons</th>
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<tbody>
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<td>BCC</td>
<td>1040.9</td>
<td>745.2</td>
<td>883.7</td>
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<tr>
<td></td>
<td>(935.9 – 1157.6)</td>
<td>(661.7 – 839.2)</td>
<td>(816.4 – 956.6)</td>
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<tr>
<td>SCC</td>
<td>499.4</td>
<td>291.0</td>
<td>386.8</td>
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<tr>
<td></td>
<td>(429.9 – 580.2)</td>
<td>(242.4 – 349.3)</td>
<td>(344.4 – 434.3)</td>
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**Working group**

**NMSC Working Group**

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<tr>
<td>Dr Joanne Aitken</td>
<td>Queensland Cancer Registry</td>
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<td>Professor Robert Burton</td>
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<td>Professor Terry Dwyer</td>
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<td>Tas</td>
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<tr>
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<td>Professor Adele Green</td>
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<td>(member until July 2002)</td>
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<tr>
<td>Professor Brian McAvoy</td>
<td>NCCI</td>
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<td>Professor Robin Marks</td>
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**Current state of project**

Follow-up was completed at the end of March 2003 and replies not received before 30 June 2003 were counted as non-responses. Analysis has begun. The final report should be available in early October 2003.

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**Estimating non-melanoma skin cancer frequency**

**THE PREVIOUS PROJECT** described an extensive survey to measure the frequency of skin cancers, excluding melanoma, treated in one year. There is no routine recording of these cancers because they are so numerous, but there are other methods of recording which could be valuable, such as using Health Insurance Commission (HIC) information or data from pathology laboratories. This project will look at how such sources could be used to measure skin cancer frequency, and perhaps avoid the need for further complex and expensive population surveys.

**Background**

NMSC is a major public health problem in Australia but national incidence data are not routinely available. Reliable incidence figures are needed to monitor trends in NMSC rates and to assess the effectiveness of skin cancer education and prevention programmes. In the past, national figures have been obtained from household surveys conducted in 1985, 1990, 1995 and 2002 in which rates for NMSC treatment were estimated from confirmed skin cancer diagnoses in survey respondents. The increasing cost of running the survey coupled with its limitations have initiated a search for alternative methods to monitor NMSC incidence in Australia. Routine cancer registration relies on either a hospital admission for cancer or histological confirmation of a tumour, neither of which is always available for NMSC, as treatment is often carried out in doctors’ surgeries or using destructive techniques without histological confirmation. The Tasmanian Cancer Registry is the only state registry to collect and publish data on histologically confirmed NMSC. Cross-sectional studies have been carried out in defined geographical areas but they are expensive and generalisation of results to other areas may not be valid as incidence varies between latitudes. The HIC collects information on claims made through Medicare and the Department of Veterans’ Affairs for the removal of skin cancers and with suitable adjustments it may be possible to use these data to estimate NMSC ‘incidence’. Medicare data do not capture excisions done in public hospitals, hence the data require calibration against incidence estimated using other methods and in different geographical areas before generalisations about national rates can be made.
Aims
To investigate reliable, sustainable and affordable means of estimating the incidence of NMSC in Australia by examining the feasibility of using data from routinely collected administrative data sources, and to recommend improved methods for monitoring trends in NMSC frequency in Australia.

Methods
Claims to the HIC for skin cancer excisions will be compared with pathology data from Tasmania and Queensland and with results from the 2002 National Non-melanoma Skin Cancer Survey to determine whether HIC excision data can provide useful information about NMSC rates.

Results
Data have been obtained from the HIC for melanoma and NMSC claims. The data from the 2002 National Non-melanoma Skin Cancer Survey are now available and selected data from the Queensland Melanoma Screening Trial and the Tasmanian Cancer Registry will also be available.

Outcomes
The study will report on the feasibility of using routinely collected data to estimate skin cancer incidence in Australia.

Working group

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Presentations

Current state of project
The 2002 National Non-melanoma Skin Cancer Survey has been completed and analysis has commenced. Skin cancer excision data have been obtained from the HIC and summary pathology data from Queensland and Tasmania will soon be available.
Linking of Australian survival data for cancer with international data

**OUR CURRENT ROUTINE DATA** suggest that the survival of cancer patients in Australia is amongst the best in the world, but such comparisons may be affected by differences in data collection and analysis in different countries. This project links Australia with an international project to produce information on the survival of patients diagnosed with cancer across the world. Care has to be taken to ensure that the data are collected and the measurements are made in the same manner in each country. The demonstration of large differences in cancer survival between different countries has already had an enormous impact on the organisation of cancer services in Europe.

**Background**
For some 30 years, data on the incidence and mortality of cancers from many countries around the world have been collated centrally and published using standard methods, providing the well-known volumes on *Cancer incidence in five continents*. More recently, data on the survival of cancer patients from many European countries have been collected in the *Eurocare* reports. These have demonstrated considerable differences in cancer survival between countries, and have been a major stimulus to change and development of cancer services. Through an international network, the ‘Concord Project’, a worldwide collection of cancer survival data is envisaged. Already, many European countries, the United States, Canada, and Japan have become involved.

**Aim**
To facilitate links between Concord Project investigators, the Australasian Association of Cancer Registries and the AIHW, to include Australian cancer survival data within the Concord Project.

**Methods**
Australian survival data for cancer have already been published on a national basis. In principle, the same data can contribute to the international data collection.

**Working groups**
The key groups involved are the AIHW, the Australasian Association of Cancer Registries, and the individual state and territory registries.

**Presentations**

**Current state of project**
To date, data from 60 cancer registries in 18 countries have contributed to the Concord Project, representing a population base of over 220 million people. In Australia, so far, only data from the Victorian Cancer Registry have been submitted, but most of the other registries have work in progress.
Optimising cancer care in Australia

THIS REPORT, PRODUCED BY the combined efforts of TCCA, COSA, the NCCI, and an experienced independent consultant, highlights priorities for improvement in the care cancer patients receive in Australia. It has been widely accepted, and is being used by key planning groups as a blueprint for change.

Background
Many health care professionals and consumer representatives believe that the current models for health services delivery of cancer care in Australia could be substantially improved. Further, it is held that such improvements in the cancer care pathway would lead to better access to quality care and ultimately ensure better outcomes for Australians with cancer.

TCCA, COSA and the NCCI commissioned a consultative report that outlines key recommendations for improvement in cancer care in Australia.

Aims
To:
• identify systematic problems, barriers and failings of the current system of cancer care in Australia
• focus on key priorities, and be based on consultations with key organisations and individuals in the field of cancer care
• address pertinent issues to provide a framework and recommendations for policy development.

Methods
The project was overseen by a steering committee and an advisory group.

The report was developed as a result of wide consultation with a range of stakeholders, undertaken by Mr Brian Wall from Oceania Health Consulting. The key themes that were repeatedly raised during the consultations were developed into a number of key issues at a stakeholder workshop held in February 2002. Following the February workshop a draft report prepared by Mr Brian Wall was circulated for comment to relevant specialist colleges and other key stakeholder bodies. A second workshop was then held in August 2002 to discuss and incorporate the comments received.

The final report was approved by the NCCI Management Committee, and by TCCA and COSA.

Results
Optimising cancer care in Australia outlines key recommendations for improvement in cancer care in Australia. It is based on the views of the consumers, practitioners and representatives of organisations who were consulted, in addition to reviews of the published evidence and international developments.

Two versions of the report were prepared, the full version and a summary version giving simply the preface, executive summary, recommendations and action items. Both versions were made available on the NCCI website (www.ncci.org.au) as a pdf file from 4 February 2003. Printed versions of the summary version and the full text version have been disseminated widely. As of the end of May 2003, approximately 600 full text copies and 400 summary reports have been sent to individuals and organisations. In addition, the full text version of the report has received 473 hits and the summary version has received 367 hits on the NCCI website during this same time period.

Conclusions
The report provides a blueprint for the reform of cancer care in Australia and it is anticipated that both the length and quality of survival for people who are living with cancer can be greatly improved if these recommendations are implemented.

Outcomes
Optimising cancer care in Australia was publicly launched at the Sydney Town Hall on World Cancer Day, 4 February 2003 – appropriately in conjunction with the public launch of the consumer group CAN Australia. Subsequently a meeting was held with the Commonwealth Minister for Health and Ageing, Senator the Honourable Kay Patterson, attended by representatives of NCCI, COSA, TCCA, the CSG, and the Commonwealth
Department of Health and Ageing. Even prior to its public launch, the report was the focus of many useful discussions between these groups, and as a result the essential findings of the report are receiving substantial attention at both Commonwealth and state level. Responsibility for addressing the recommendations at the Commonwealth level will be undertaken by the CSG and the National Service Improvement Framework for Cancer Expert Panel, a new body with an overall aim to improve cancer services. Recent plans for cancer services, for example in New South Wales, also reflect many of the themes of the report.

**Working groups**

**Steering Committee**

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**Advisory Group**

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**Publications**


**Current state of project**

This project has been completed. The report has been widely disseminated in Australia, and there has been considerable interest from overseas. Brief articles on the report have been requested by, amongst others, *Australian Family Physician* and the *New Zealand Medical Journal*, and a news item describing the report was published in the *Journal of the National Cancer Institute* in the United States. The complete version of *Optimising cancer care in Australia* is available at [http://www.ncci.org.au/pdf/Optim_Cancer_Care.pdf](http://www.ncci.org.au/pdf/Optim_Cancer_Care.pdf)
Key strategy 2: Identify emerging issues and new strategies for cancer control

‘Data is not information, Information is not knowledge, Knowledge is not understanding, Understanding is not wisdom.’
Cliff Stoll & Gary Schubert

‘If you don’t ask the right questions, you don’t get the right answers. A question asked in the right way often points to its own answer. Asking questions is the ABC of diagnosis. Only the inquiring mind solves problems.’
Edward Hodnett

International review on cancer control

THE NCCI KEEPS a watching brief on developments in cancer control with particular reference to countries at a similar stage of development in cancer control as Australia, such as Canada and the United Kingdom. At the June 2002 meeting of the International Union Against Cancer (Union Internationale Contra le Cancer) in Oslo, it was decided to establish an information base and clearinghouse for cancer control information worldwide, with the NCCI as a member of the initial group. The NCCI will work with the International Union Against Cancer in establishing a clearinghouse to act as a network centre where information on cancer control programmes in various countries can be obtained and kept up to date.

Ovarian cancer screening

OVARIAN CANCER IS OFTEN diagnosed when it is quite advanced, and for this reason has a poor clinical outcome. There has been much research exploring possible screening tests, some of which have been subjected to randomised controlled trials that are producing clinically relevant results. This systematic review assesses the results of this research and identifies the most promising developments.

Background
Ovarian cancer has the worst prognosis of any gynaecological malignancy. Ovarian cancer is the eighth most common cancer in Australian women; each year over 1 000 Australian women are diagnosed with ovarian cancer and in 1998 over 760 Australian women died of ovarian cancer. The improved survival associated with localised disease suggests that early detection may improve survival outcomes. The goal of screening...
Aim
To review the findings of international studies on screening for ovarian cancer.

Methods
The results of randomised controlled trials, case control studies and prospective studies relating to ovarian cancer screening using different screening techniques for either general or high risk populations were identified on PubMed and Medline. The screening techniques reviewed were 1) pelvic examination, 2) ultrasound, 3) Doppler ultrasound, 4) CA125, 5) other molecular markers, and 6) multimodal and combined screening strategies. Other potential screening techniques that have appeared in the literature, such as magnetic resonance imaging, CT and the use of protein patterns, were summarised.

Results
The screening studies undertaken thus far have served to identify the efficiency with which particular techniques work, however, the studies have not been designed to evaluate the impact of screening on mortality.

Conclusions
To date, there is no definite evidence showing a reduction in mortality as a consequence of screening for ovarian cancer, although a survival advantage has been shown in two trials.

In the absence of evidence showing a reduction in mortality, screening for ovarian cancer cannot be recommended for the general population.

Publication

Current state of project
The NCCI is investigating options for publishing the complete review of international studies on screening for ovarian cancer.
screening for lung cancer using helical CT, with relevance to the problem of lung cancer in Australia. The report contains recommendations about priorities for further Australian work.

**Aim**

To produce a report on the feasibility of helical CT screening for lung cancer that would provide an update on the key issues and lead to recommendations about priorities for further Australian work on this topic.

**Methods**

The NCCI Working Group on Lung Cancer Screening was established in January 2002. The Working Group was chaired by Associate Professor Don Campbell and oversaw the development of the report. A broader advisory group was also established, which included representation from the Thoracic Society of Australia and New Zealand, the Australian Lung Foundation and the Royal Australian and New Zealand College of Radiologists, together with other interested parties. A contract was established with the Royal Melbourne Hospital for Dr Margaret de Campo and Associate Professor Don Campbell to work on the report.

**Results**

A report on the feasibility of helical CT in screening for lung cancer has been completed. The report was launched in April 2003 at a meeting held under the auspices of the NCCI in Adelaide. The report contains recommendations on further Australian work on this topic.

**Conclusions**

To date, there is no definite evidence showing a reduction in mortality as a consequence of screening for lung cancer. Randomised controlled trials investigating helical CT as a screening technique for lung cancer are in the early stages of progress or under development. None has yet produced outcome results. In the absence of evidence showing a reduction in mortality, population-based screening for lung cancer cannot be recommended.

**Outcomes**

A report on helical CT screening for lung cancer was produced that contains recommendations for further Australian work on this topic.

**Presentation**


**Publications**


**Current state of project**

This project has been completed. A report on the feasibility of helical CT screening for lung cancer that includes recommendations about priorities for further Australian work on this topic has been produced and is available at http://www.ncci.org.au/pdf/HCt_screen_report.pdf
A randomised controlled trial of population-based screening for melanoma

**Background**

The value of skin screening, either self-screening by individuals, or screening by doctors, is unknown. Despite the fact that this procedure is widely practised and recommended by some groups, particularly in the United States, there are no trials or prospective studies which assess its benefits, and as a result it is not recommended as a routine in Australia. However surveys have shown that there is a great deal of skin screening going on, with an expenditure of many millions of dollars per year in health care costs.

**Aim**

To establish, in a randomised controlled community-based trial, whether a combination of self-screening and doctor screening reduces deaths from melanoma.

**Methods**

The ‘Queensland Melanoma Trial’ was designed to include 46 communities in Queensland, to be randomised to the screening intervention or the control group. The screening intervention consists of a three-year programme of community-based activities advocating self-screening, providing assistance with self-screening, supporting local doctors in carrying out doctor screening and dealing with referrals from self-screening. The pilot phase of the trial has been funded by the Queensland Cancer Fund, and the Queensland state health department, with funding of $50 000 from the NCCI.

**Results**

The pilot phase of the programme, involving nine intervention and nine control communities, has been completed. This has demonstrated that the frequency of screening in the intervention group has increased from 20% to 60%, which was the predicted increase necessary to give the trial power to show an ultimate mortality benefit.

**Outcomes**

The trial has already provided much useful information about the implementation of skin screening, its acceptability, and its short-term impact. The definitive result in terms of mortality reduction requires completion of the full trial. Negotiations for the funding required to carry out the full trial have been difficult, and are continuing.

**Working group**

**Principal Investigators**

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**Presentations**


Publication

Current state of project
The pilot is complete and applications for further funding to both Australian and international sources have been made.

Survey of cancer researchers

AUSTRALIA HAS NO NATIONAL STRATEGY to set priorities in cancer research. This project assesses the views of cancer researchers on priorities in cancer research, and on opportunities and barriers to successful research outcomes.

Background
Australia has no national cancer research strategy. There is no formal prioritisation of research and there is limited collaboration between the funding bodies in the process of reviewing or funding grants. Cancer research is presently funded by a variety of sources including international, federal, state and territory, government and non-government, commercial and non-commercial organisations and institutional block funding.

Aims
To determine the current scope and funding of cancer research and to solicit opinions on prioritisation of research, funding of grants, strategies for reducing the frequency and impact of cancer in Australia and opportunities for change.

Methods
A questionnaire was developed and researchers on the Cancer Councils’ National Panel of Cancer Research Assessors Database, who were considered to be a representative group of people involved in cancer research, were surveyed. In March 2001 an introductory letter explaining the purpose of the questionnaire was sent prior to disseminating the questionnaire. The questionnaire was sent at the beginning of April 2001. Researchers were given four weeks to complete the questionnaire and two weeks after sending the questionnaire a follow-up letter was sent to remind people to complete and return the questionnaire.

Results
A response rate of 42% was achieved. Responses were obtained from every state and territory in Australia as well as from researchers holding a variety of positions.

Outcomes
A draft report was prepared, based on the findings of the questionnaire, and Professor Joe Sambrook, Chair of the Cancer Research Review Working Group, drafted a discussion paper on the findings of the report. The discussion paper details the recommendations and options for change and is currently being edited by the NCCI. The paper will then be circulated to the working group for comment.
**Working group**

Cancer Research Review Working Group

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**Current state of project**

The discussion paper is in preparation, and upon completion will be circulated to the Commonwealth, state and territory health and science ministers, the NHMRC, the CSG and other relevant bodies.
Key strategy 3: Develop and assess strategies to translate research outcomes into improved public health and clinical practice

‘Somewhere between 1910 and 1912 in this country a random patient with a random disease, consulting a doctor chosen at random had for the first time in the history of mankind, a better than 50:50 chance of profiting from the encounter.’

Henderson

A randomised controlled trial to encourage appropriate removal of pigmented skin lesions in general practice

BECAUSE SKIN CANCERS ARE SO COMMON in Australia, the investigation of suspicious skin lesions is a major problem for GPs. Many innocent skin lesions are removed for every malignant lesion. This project has assessed a new method which was developed to improve the management of suspicious skin lesions in general practice.

Background

Melanomas diagnosed at an early stage have a better prognosis than late stage melanomas. The ratio of benign to malignant pigmented lesions excised in general practice in Australia is approximately 30:1 and even experienced clinicians can find it difficult to distinguish between benign pigmented lesions and melanoma. A study in two towns in Queensland by Del Mar and Green (1995) showed that the use of an algorithm and skin photography in the management of patients with suspicious pigmented lesions reduced the ratio of naevi to melanomas excised in the intervention town. This project used a much larger trial to evaluate this method in urban practice.

The project was conducted on behalf of the NCCI by the Department of Public Health, University of Western Australia.

Aims

To:
• determine whether the findings of the Del Mar and Green (1995) study could be replicated in urban general practice, by a large randomised controlled trial
• compare certain variations of the Del Mar and Green algorithm in a prospective randomised controlled trial
• improve communication between GPs and pathologists in relation to the diagnosis of pigmented skin lesions
• examine the cost-effectiveness of the intervention.
Methods
All GPs in Perth were invited to take part in the group randomised controlled trial. A total of 468 GPs from 223 practices participated. Practices were randomised to one of two groups: a control group of 112 practices that continued their usual management of naevi, and an intervention group of 111 practices that was supplied with a written algorithm and instant camera. The algorithm was a simplified summary of best clinical practice and incorporated the discretionary use of the camera.

Reports of pigmented lesions excised in the 12 months prior to, and the 10 months following, randomisation were obtained from pathologists. Baseline comparisons were available for the period before randomisation, but the primary analysis was based on a comparison of the ratio of benign pigmented lesions to melanomas in the two groups in the 10 months following randomisation. GPs were also asked to describe the management details for their last three patients with pigmented skin lesions, and both GPs and pathologists were asked to report on their communication with one another.

The trial received approval from the Research and Evaluation Ethics Committee of the RACGP and the Committee for Human Rights of the University of Western Australia.

Results
During the study period, the ratio of benign pigmented lesions to melanomas was higher in the intervention group (29:1) than the control group (26:1) but the difference was not significant ($p=0.64$). During the baseline period, the ratio was higher in the control group (32:1 versus 26:1) but, again, the difference was not significant. Between the baseline and study periods, the ratio in the control group decreased while that in the intervention group increased, but the difference between these changes was also not significant ($p=0.12$).

There were, however, significant differences in the recent management of skin lesions. Fifty-four percent of GPs in the intervention group but only 1% in the control group, reported that they had photographed the last pigmented lesion they had managed ($p<0.001$). The intervention GPs were less likely to have excised this last lesion (22% versus 48%, $p<0.001$) and less likely to have referred the patient to a specialist (14% versus 27%, $p=0.013$).

Most pathologists said they wanted information about the patient’s age, past history of melanoma and anatomical site of the lesion to assist their diagnosis, while most GPs indicated they would like the pathology reports to contain evidence-based statements about management and prognosis. Neither GPs nor pathologists felt their communication with each other was improved by the trial.

Conclusions
There was no evidence of a decrease in the excision ratio of benign to malignant pigmented skin lesions following the intervention. As a result of this, there was no basis for comparing variations of the Del Mar and Green algorithm or examining the cost-effectiveness of each intervention.

Outcomes
The intervention was not found to be a useful tool to assist GPs in diagnosing melanoma. In November 2002, the NCCI and the Melanoma and Skin Cancer Research Institute convened a workshop entitled ‘Efficient and effective melanoma diagnosis’ to investigate other methods that could lead to improved diagnostic efficiency for melanoma in the primary care setting.
## Working groups

### Perth Skin Cancer Trial Project Team

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### Perth Skin Cancer Trial Project Working Party

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<td>Dr John Primrose</td>
<td>Commonwealth Department of Health and Ageing</td>
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Perth Skin Cancer Trial Project Management Group

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**Presentation**


**Publication**


**Current state of project**

This project has been completed.

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Developing national strategies for improving the use of the prostate specific antigen test in the Australian community

**THE USE OF PSA TESTING** as a screening test for prostate cancer is highly controversial because of the absence of clear evidence of its effectiveness. Despite this, it is very heavily used. This project equips GPs with knowledge and materials which help them to present balanced information to their patients to deal with questions around PSA testing.

**Background**

One of the CSG’s recommended priority actions to improve cancer prevention and care is to raise awareness of the implications of a positive PSA test. The NCCI is supporting an exploration of the ways and means to improve the use of the PSA test by GPs, which is being undertaken by the Drug and Therapeutic Information Service, an initiative of the School of Pharmacy, University of Queensland and the Repatriation General Hospital, Daw Park, South Australia.
Aim
To explore whether academic detailing, when applied on a broader scale and in different settings, has a positive effect on GP knowledge and appropriate use of the PSA test.

Methods
A systematic exploration of academic detailing methods is being undertaken in Queensland, Victoria and South Australia to demonstrate the effect of more informed use of the PSA test by GPs. Academic detailing involves one-to-one visiting of medical practitioners by trained professionals who discuss patient-management issues of concern to the doctor and provide commercially independent advice and information based on current evidence about the topic.

In the Brisbane component, the acceptability of academic detailing to GPs is being assessed. GP recruitment and drop-out rates will be determined over two series of visits, six to nine months apart. Geographically aggregated PSA test ordering rates will also be monitored.

In Melbourne, different strategies are being evaluated in a randomised controlled trial. GPs in two intervention groups receive academic detailing, with one group also receiving individualised feedback on PSA test ordering rates. Results will be compared with a control group receiving no academic detailing.

In Adelaide, outcomes for doctors who had previously participated in academic detailing visits are being compared with those for newly recruited doctors to determine whether the programme has a greater impact on GPs who have received regular visits in the past.

Evaluation
The scientific evaluation has been centred around the randomised controlled trial component in Melbourne, with a quasi-experimental design to compare effectiveness and uptake of the programme in Adelaide and Brisbane.

Participating GPs in Melbourne have agreed to complete pre- and post-intervention questionnaires assessing knowledge and self-reported practice concerning the use of the PSA test. The post-intervention questionnaire also includes a brief evaluation of the value of the service. GPs in Adelaide and Brisbane have been selected on a geographic basis, which will enable aggregated PSA testing data to be compared with similar control areas to determine any general effect of the visiting programme on PSA test ordering.

Uptake and retention rates for the geographic samples will be an important indicator of acceptability and value that GPs place on their academic detailing experiences, as will be information reported by academic detailers on post-interview review forms. The evaluation of the programme will largely focus on retention of participants in the Brisbane and Melbourne arms of the trial, and uptake of the service in areas that have not previously been visited in Adelaide and rural South Australia.

The analytical framework for the economic evaluation of the trial is presently under development. The aim of this component of the evaluation is to ensure that economic data from the trial will be analysed in a way that is consistent with the Trial of program budgeting and marginal analysis to assist cancer control planning in Australia developed by Carter et al. 2000. Data from the present trial will be analysed from a macro-economic perspective and a microeconomic evaluation will also be used to assess cost-effectiveness.

Results
Educational visits on the topic of PSA have been completed with participating GPs in Brisbane, Melbourne and Adelaide. The uptake rates for the practice visits has been about 90% for the service delivery arms of the trial in both Adelaide and Brisbane. Questionnaire and PSA data are being compiled from participants in the randomised controlled arm of the trial in Melbourne. The evaluation phase of the trial is expected to continue until June 2003, and the final report is due to the Commonwealth in late 2003.

Conclusions
Interim conclusions are that:
• The Drug and Therapeutic Information Service academic detailing programme on the topic of PSA testing has a high acceptability amongst GPs in different Australian states.
• For GPs in a given geographic area who are unfamiliar with Drug and Therapeutic Information Service services, uptake and retention in Drug and Therapeutic Information Service visiting programmes over a reasonable period can be expected to approach complete coverage for practical purposes.
• Participating GPs highly value the Drug and Therapeutic Information Service educational visits and materials.
• Academic detailing on the topic of PSA testing is effective in improving GPs’ knowledge and self-reported practice, but additional feedback of past individualised test-use profiles is not worthwhile.

**Outcomes**

Preliminary statistical analysis of the completed questionnaire data, comparing pre- and post-intervention responses, shows that 1) educational visiting is effective in increasing knowledge, but additional feedback of past individualised test-use profiles is not much more effective, and 2) the GPs highly valued the visiting programme and the materials provided.

**Working groups**

**Project Working Group**

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**Project Steering Group**

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**Presentations**


**Current state of project**

The study commenced in February 2001 and is expected to run for two and a half years, reporting in August 2003. Pre- and post-intervention PSA testing rates from both arms of the trial – GPs participating in the randomised controlled trial and geographic samples – still have to be analysed, as does the cost-effectiveness evaluation.

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**Monograph on the prevention of skin cancers**

**AUSTRALIA CAN JUSTIFIABLY CLAIM** to lead the world in the prevention of skin cancer by educational campaigns and other approaches to reduce excess sun exposure. The NCCI had the opportunity to bring together several of the leading world experts in the primary prevention of skin cancer, to contribute to a monograph which presents key scientific issues and practical options.

A book on approaches to the primary prevention of skin cancers involving many Australian and international experts, edited by Professor David Hill, Professor Mark Elwood, and Associate Professor Dallas English, has been completed and will be published by Klewer Academic Publishers in a series on cancer prevention and cancer causes coordinated by the Harvard Center for Cancer Prevention; series editor Dr Graham Colditz.
Other Australian authors are:
- Dr Peter Gies and Dr Colin Roy (Australian Radiation Protection and Nuclear Safety Agency)
- Professor Bruce Armstrong and Dr Vivienne E Reeve (University of Sydney)
- Dr David Whiteman and Dr Rachel Neale (Queensland Institute of Medical Research)
- Dr Suzanne Dobbinson (The Cancer Council Victoria)
- Associate Professor Rob Carter (Monash University).

International contributors are:
- Dr Harry Slaper and Dr Frank R de Gruijl (The Netherlands)
- Dr Gianluca Severi (Italy)
- Professor Richard P Gallagher, Dr Tim K Lee and Dr Chris D Bajdik (Canada)
- Dr Philippe Autier (Luxembourg)
- Dr Brian L Diffey (UK)
- Dr Karen Glanz, Dr Mona Saraya, Dr Peter Briss, Dr Petra Udelhofen and Dr Ronald D Ley (USA).

The book is designed to provide a scientific review relevant to the planning of skin cancer prevention programmes, with an international perspective. It covers topics including who gets skin cancer, individual risk factors, patterns and causes of sun exposure, sun protection behaviour, the effects of sunscreens and solariums, and the role of genetics in prevention. The descriptive epidemiology of skin cancers is covered along with an epidemiological perspective on how sun exposure causes skin cancer. The effects of solar and ultraviolet (UV) radiation exposure on the development of skin cancer in humans and animals are reviewed, along with molecular UV radiation targets and quantitative risk models. The impact of intervention strategies to reduce UV radiation exposure and an economic perspective of skin cancer prevention are discussed.

Bowel cancer screening pilot: implementation, evaluation and monitoring

**COLORECTAL CANCER IS THE MOST COMMON** cancer other than skin cancer in Australia. There is good evidence that screening for this disease reduces mortality, and pilot programmes of screening have been set up to assess its acceptability and feasibility in Australia.

**Background**

The NCCI prepared detailed proposals for pilot programmes of colorectal cancer screening in 1997 and 1999, and funding for pilot programmes was included in the 2000 Commonwealth budget. The Commonwealth Department of Health and Ageing Population Screening Section is responsible for development of the pilot studies of screening for colorectal cancer using faecal occult blood testing (FOBT).

The NCCI has continued to be actively involved in this programme. Professor Mark Elwood chairs the Monitoring and Evaluation Task Group and is a member of the Implementation Committee and its executive. Associate Professor James St John is a member of the Policy Task Group, chairs the Quality Task Group, is a member of the Implementation Committee and its executive and is also a member of the Advisory Committee responsible for the Melbourne pilot site. Ms Margaret Stapley is a member of the Monitoring and Evaluation Task Group. Both Professor Elwood and Associate Professor St John participated in an extensive workshop with GPs, held in Melbourne in February 2002 and Associate Professor St John participated in a similar workshop for specialists, held in Melbourne in June 2002.

**Aims**

To introduce screening for bowel cancer in three areas, to evaluate the acceptability, outcomes, costs, quality control and logistical issues in introducing a national programme, to ultimately reduce the high mortality from colorectal cancer in Australia.
Methods
Protocols for the conduct and evaluation of screening have been established and screening has started at all three pilot sites, located at Mackay, central Queensland; the southern and western parts of Adelaide; and 10 postcodes in north-eastern Melbourne. The Mackay pilot was officially launched in November 2002, the Adelaide pilot in February 2003 and the Melbourne pilot in March 2003. Screening tests are being distributed over 12–15 months to around 69,000 men and women in aggregate aged 55–74 years.

The primary evaluation for these programmes relies on the establishment of a unique data register, compatible with the HIC database. Other aspects of evaluation may include ad hoc studies to assess aspects of participation, experience of the participants, and economic evaluation.

Outcomes
The principal measures of outcome will be the FOBT participation rate, comparison of the performance of the two FOBTs selected for the pilot programme, evaluation of various feasibility issues relevant to roll-out into a nationwide screening programme and evaluation of cost-effectiveness.

Presentations


Publications


Current state of project
Screening has started at all three screening sites and distribution of tests will continue until June 2004.
The primary care perspective on cancer

**GPS AND OTHER PRIMARY CARE PROFESSIONALS** have a critical role throughout the cancer process from prevention to palliation; yet primary care has often been under-represented in cancer control activities. The NCCI will develop a primary care perspective on cancer which will inform many of its other activities, and be the focus for developments in primary care.

**Background**
The GP’s work spans the full spectrum of cancer care – prevention, detection, treatment and palliation, including psychosocial support of patients and carers. The GP practices clinical medicine in a very different setting and context from those of the hospital specialist. Problems are often undifferentiated, illness is much more common than disease, and consequently the context of clinical practice is very different from that encountered in hospitals. From a general practice perspective, patients with a new diagnosis of cancer are infrequent, but providing ongoing care for patients with an established diagnosis of cancer and their carers poses substantial issues.

Probably the largest component of a GP’s workload related to cancer involves dealing with patients who have suspicious symptoms, concerns about possible cancer or are at increased risk due to family history or lifestyle factors such as smoking, sun exposure or occupation. Moreover, GPs have a key role as ‘gatekeeper’ in determining patients’ access to specialist services, a critical factor in the burgeoning costs of medical care in developed countries.

**Aim**
To develop a primary care perspective on cancer, enabling GPs, nurses and other primary care professionals to contribute to improving the quality of cancer care for patients and carers and to promote their contribution to the full spectrum of cancer control, from prevention to palliation.

**Methods**
The project will comprise four phases:

**Phase I:** Establishment of a steering group which will:
- provide essential contacts with those involved in primary care across Australia
- act as a forum for discussion, refinement and prioritisation of issues relating to primary care and cancer control
- develop, oversee and monitor the programme of work
- liaise with and provide relevant input to the National Service Improvement Framework for Cancer Expert Panel, the CSG and other stakeholders.

**Phase II:** Scoping exercise to identify priorities, existing resources, and needs and gaps in support for primary care professionals.

**Phase III:** Development of locally relevant resources/guidelines for GPs, emphasising initial investigations and referral options for patients with cancer or suspected cancer.

**Phase IV:** Investigation and consolidation of ongoing training and professional development needs of GPs and other primary care professionals.

**Current state of project**
A steering group will be established and a proposal for funding support was submitted to the Commonwealth in July 2003. It is anticipated that this incremental programme of work will inform, complement and strengthen the development of the National Service Improvement Framework for Cancer.
Key strategy 4: Identify gaps between current and best practice

‘It ain’t what people don’t know that hurts them it’s what they know that ain’t so.’
Mark Twain

‘In theory, there is no difference between theory and practice; In practice, there is.’
Chuck Reid

The development, dissemination and evaluation of evidence-based practice guidelines for the management of colorectal cancer

EVIDENCE-BASED GUIDELINES for the clinical management of colorectal cancer were developed through COSA and the ACN, with the support of the NCCI and funding from the Commonwealth Department of Health and Ageing. Specialist, GP and consumer guidelines were developed, with an implementation plan and limited evaluation.

Background
In 1996, COSA and the ACN auspiced a process to develop evidence-based colorectal cancer guidelines. The Guidelines for the prevention, early detection and management of colorectal cancer were developed through the establishment of working groups to review available literature relating to the prevention and treatment of colorectal cancer. The guidelines were developed in accordance with the NHMRC process described in A guide to the development, implementation and evaluation of clinical practice guidelines (NHMRC 1999). Two rounds of public consultation were undertaken during the development phase in 1998.

Aims
To:
• create evidence-based best practice guidelines for the management of colorectal cancer
• satisfy the criteria of the NHMRC to have the guidelines accepted by that body and thus allow the authority of the guidelines to be recognised
• arrange dissemination of the guidelines throughout the Australian community
• arrange an initial communication and education strategy to ensure good and comprehensive use of the guidelines
• ascertain how and by whom the guidelines were being used after their dissemination.

Methods
The NCCI set up a Project Management Group and several ancillary working parties to advise on the development of the guidelines, and the evaluation of their uptake and impact, using routinely collected data.
**Results**

Guidelines for the prevention, early detection and management of colorectal cancer, endorsed by the NHMRC, were disseminated soon after their release in November 1999 to surgeons, gastroenterologists, radiation oncologists, medical oncologists and other interested health care professionals. The guidelines were the first externally developed guidelines to have received NHMRC endorsement and carry the COSA and ACN logos as well as the NHMRC logo. A consumer guide, and a concise form of the guidelines for GPs, were launched in July 2000. The consumer guide – Guidelines for the prevention, early detection and management of colorectal cancer: a guide for patients, their families and friends – is available and a copy was sent to every doctor with prescribing rights in Australia. The Guidelines for the prevention, early detection and management of colorectal cancer: a guide for general practitioners was also sent to every GP in Australia.


The evaluation of the uptake of the specialist guidelines was conducted using questionnaires sent to appropriate surgeons, radiation oncologists and medical oncologists. This work was led by Ms Annie Cooney, Professor Jeanette Ward, Professor Alan Coates, and colleagues from the University of Sydney and TCCA, and their report was reviewed by Professor Gordon Clunie of The Cancer Council Victoria.

**Conclusions**

The guidelines were widely disseminated to specialists and GPs. Dissemination was also assisted by promotion via articles in medical journals, professional newsletters and advertising at conferences.

Most surgeons (81%) and other specialists (87%) believed that the guidelines would improve outcomes to some extent. Just over half of the surgeons and almost half of the other specialists felt that their own practice had or would change because of the guidelines. Both surgeons and other specialists found the sections on ‘Screening based on family history of colorectal cancer’ and ‘High-risk familial syndromes’ particularly useful.

**Outcomes**

The original project, including the evaluation of the guidelines, was completed in September 2001.


**Presentations**


**Publications**


**Current state of project**

The development, dissemination and evaluation of the colorectal cancer guidelines has been completed and a second edition of the clinical practice guidelines is currently in preparation.
Guidelines for psychosocial care

PSYCHOSOCIAL ASPECTS HAVE BEEN CONSIDERED in various cancer-specific guidelines, but these issues extend across all types of cancer. Evidence-based guidelines for the psychosocial care of adults with cancer were developed jointly by the NBCC and NCCI. This was challenging because of the essential multidisciplinary nature of the guidelines, and the diverse groups who would make use of the guidelines.

Background
In Cancer control towards 2002: the first stage of a nationally coordinated plan for cancer control (NCCI & CDHFS 1998), the development of psychosocial care was one of 13 actions recommended for priority implementation. In February 2000, the Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer (NBCC 2000) were launched by the NHMRC. These evidence-based clinical practice guidelines were developed by the NBCC to assist health professionals in the psychosocial care of women with breast cancer. In recognising the importance of psychosocial care in the treatment of all patients with cancer, it was proposed that a generic set of psychosocial guidelines be developed for adult cancer patients.

Aim
To develop a set of evidence-based clinical practice guidelines that can assist health professionals in the psychosocial care of adult cancer patients.

Methods
The Clinical practice guidelines for the psychosocial care of adults with cancer have been developed as a partnership between the NCCI and the NBCC. The guidelines are evidence-based and were developed by a multidisciplinary team. A Steering Group was established to oversee the development of the guidelines in accordance with the NHMRC process described in A guide to the development, implementation and evaluation of clinical practice guidelines (NHMRC 1999). The Steering Group comprised members with clinical and academic expertise across a variety of cancer areas including common and priority cancers.

The guidelines were developed using the original psychosocial guidelines for women with breast cancer as a template. The Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer (NBCC 2000) were reviewed and expanded to include further information and further recommendations regarding clinical care of all adult patients with cancer. Revised chapters were drafted by members of the Steering Group and circulated for comment to other members. The Steering Group met on a number of occasions to review revised material and discuss future actions.

The project to develop the guidelines included seeking the approval of the NHMRC. As part of the NHMRC approval process the draft guidelines were made available for public comment in September 2002 and also underwent an independent review. Comments received from the public consultation and the independent reviewer were addressed and the guidelines were submitted to the NHMRC for approval in February 2003.

Results
The Clinical practice guidelines for the psychosocial care of adults with cancer were approved by the NHMRC on 10 April 2003. The guidelines were officially launched on 14 August 2003 in Canberra by Senator the Honourable Kay Patterson, Minister for Health and Ageing.

A proposal for the implementation of the guidelines is being developed by an Implementation Steering Group, as a joint effort between the NBCC and the NCCI.

Outcomes
Evidence-based clinical practice guidelines for the psychosocial care of adult cancer patients have been produced.
Working group

NBCC/NCCI Steering Group on Psychosocial Guidelines

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Current state of project

The guidelines have been approved by the NHMRC and officially launched. Plans for the implementation of the guidelines are being developed.

Publications


Radiotherapy in cancer care: estimating the optimal utilisation from a review of evidence-based clinical guidelines

THE PROVISION OF ADEQUATE SERVICES for radiotherapy has been a complex issue in Australia, as in other countries. At the request of the Commonwealth Minister for Health and Ageing, the NCCI commissioned research: to build on evidence-based guidelines for the use of radiotherapy in cancer, to develop a dynamic model of optimal utilisation, and to give an objective basis for estimates of the needs for radiotherapy services. The model developed gives a baseline against which actual utilisation is being compared, and allows the impact of future changes in the incidence and stage at diagnosis of cancer, and the evidence for the value of radiotherapy, to be assessed.
Background
For many years, planning for the provision of radiotherapy services has proceeded on the assumption that a certain proportion, often taken as 50%, of cancer patients require radiotherapy at some point in their illness. There is no scientific basis for the percentages used. At the request of the Commonwealth Minister for Health and Ageing, the NCCI commissioned research to establish an evidence-based model to estimate the ideal utilisation of radiotherapy.

Aim
To develop an evidence-based benchmark for the use of radiotherapy in cancer, and provide a dynamic model in which changes could be assessed.

Methods
After a tender process in cooperation with the Royal Australian and New Zealand College of Radiologists—Faculty of Radiation Oncology, the Collaboration for Cancer Outcomes Research and Evaluation, Liverpool, NSW, was contracted to do this project, led by Associate Professor Michael Barton. The method has been to develop a dynamic model on the basis of accepted scientific evidence-based guidelines for the use of radiotherapy, and available data on the incidence of cancer, its stage distribution, and other relevant parameters such as performance status. The evidence for both indications for radiotherapy and for the epidemiological data has been critically assessed and ranked by accepted classification systems. Decision trees using ‘TREEAGE’ data software have been developed.

Results
This project has to date yielded results for most common cancers, and the project should be completed in 2003. The project has also led to other work in which the estimated optimal utilisation is compared with actual utilisation, and this has shown considerable variations. Work to establish the reason for such variations is ongoing.

Outcomes
Regular reports on the project have been made to the Radiation Oncology Committee and to the CSG. The project is already influencing planning for radiotherapy provision.

Working groups

| Collaboration for Cancer Outcomes Research and Evaluation Working Group |
|-------------------------------------------------|-----------------|-----------|
| Representative                      | Affiliation                                                | State/territory |
| Associate Professor Michael Barton    | Collaboration for Cancer Outcomes Research and Evaluation | NSW          |
| Dr Geoff Delaney                     | Liverpool Cancer Therapy Centre                            | NSW          |
| Dr Susannah Jacob                    | Collaboration for Cancer Outcomes Research and Evaluation | NSW          |
| Associate Professor Bin Jalaludin    | Department of Epidemiology, Population Health, South Western Sydney Area Health Service | NSW          |
| Associate Professor David Roder      | The Cancer Council South Australia                         | SA          |
In addition to the working group and steering committee there is a wider court of reviewers, representing primarily experts in radiotherapy, who review draft reports as they are produced particularly in regard to the validity of the information used to assess clinical indications.

**Publications**


**Current state of project**

The major project is nearing completion. Further work to compare optimal utilisation and actual utilisation is ongoing, as is work to address possible reasons for such variations.

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**Improving the management of lung cancer**

LUNG CANCER IS THE MOST COMMON cause of cancer death in Australia, and the outcomes of treatment are poor. The NCCI has assisted the ACN in the completion of clinical practice guidelines for lung cancer. The CSG has set improvements in patient outcomes for lung cancer as a priority. In 2003 the NCCI held a national workshop on the topic, and will develop a proposal for the implementation and evaluation of the guidelines.
Background

The prognosis for patients newly diagnosed with lung cancer is poor, with five-year relative survival in Australia being only 11% for males and 14% for females. Survival figures from New South Wales have suggested that outcomes in Australia are not as good as in some other countries. A survey of the primary management of lung cancer in Victoria has shown that there is little systematic rationale in the treatment offered or the way in which different specialists contribute. As a result it is likely that a systematic approach to improving the referral system for patients suspected of having lung cancer, and improving integrated multidisciplinary care in the primary management of lung cancer, could produce benefits. An essential first step has been taken in producing the ACN’s Clinical practice guidelines for the management of lung cancer, which are currently being finalised.

Following discussions held with the Commonwealth and others about ways to approach the problem of improving the management of lung cancer, it was decided that it would be valuable to hold a workshop of key stakeholders early in 2003 to consider new approaches.

Aim

To hold a workshop of key stakeholders to consider new approaches to improving the management of lung cancer.

Methods

An organising committee that included leading figures in lung cancer in Australia was convened in October 2002 to oversee the planning for the workshop. The workshop, entitled ‘Improving the management of lung cancer’, was held on Saturday 5 April 2003 in Adelaide, South Australia, immediately prior to the Annual Scientific Meeting of the Thoracic Society of Australia and New Zealand. Invitations were sent to a broad range of key stakeholder groups including specialist clinicians, GPs and nurse practitioners, consumers, public policy makers, public health officials, cancer councils and others. Additional funding to assist with travel and accommodation support for workshop presenters, chairs and invitees was provided by the Commonwealth Department of Health and Ageing.

The NCCI has also been requested by the CSG to develop an implementation strategy for the lung cancer guidelines and a proposal to evaluate the impact of these guidelines on clinical practice. This is in the context of the National Service Improvement Framework for Cancer. This project relates to a recommendation in Priorities for action in cancer control 2001–2003 (CSG 2001): ‘Improving outcomes for ovarian and lung cancer by ensuring that all people with these cancers are assessed at a multidisciplinary specialist centre as soon as possible after diagnosis’.

Outcomes

It is intended that the workshop lead to a number of action-oriented recommendations on ways forward for improving the management of lung cancer in Australia. A proceedings book containing presentation summaries and relevant background material was produced by the NCCI and made available to registrants prior to the meeting. A summary report on the workshop and any outcomes will be produced by the NCCI and distributed to all attendees. The workshop will assist in promoting the Clinical practice guidelines for the management of lung cancer being developed by the ACN.

The NCCI is preparing a proposal, for consideration by the Commonwealth Department of Health and Ageing, for the implementation and evaluation of the lung cancer guidelines. The formulation of this proposal will involve discussions with the Lung Cancer Guidelines Working Group, the Australian Lung Foundation and prominent specialists in regard to lung cancer, and will be facilitated by the NCCI workshop on lung cancer.
Working group

Workshop Organising Committee

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<td>Emeritus Professor Tom Reeve</td>
<td>ACN</td>
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Current state of project

A summary of the workshop is being prepared and a proposal for the implementation and evaluation of the guidelines is being developed.

The potential of a national familial cancer support facility

This project looked at the issue of integration of services for familial cancer across Australia, and the development of a central data facility was proposed. Several logistic, legal and ethical issues were highlighted which would need to be addressed.

Background

One of the issues identified early in the history of the NCCI was the need for national coordination in regard to familial cancer. The advent and rapid development of genetic testing for cancers considered to have an inherited basis have led to the provision of familial cancer assessment, counselling and testing services at a state level. Because families may be geographically scattered, members of the same family often access such services in different states.

Aims

To prepare a plan for a national facility for data handling, and to consider options for coordinating familial cancer data across states in the most efficient way to aid both research and clinical practice.

Methods

The project involved very wide consultation, with interviews being held with a range of experts in genetics and oncology, as well as consumers, ethicists and health managers.

Results

A proposal for a national facility, with appropriate ethical safeguards, to collate information on individuals assessed for cancer in familial situations, and requests for DNA mutation tests, was developed. It was hoped to further progress this through the AIHW to explore in more detail the legal and ethical issues, and the detailed costing of such a proposal.
Outcomes
A plan for a national familial cancer support facility was published in March 2000.

Working group

Clinical Genetics Working Party of the ACN

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<tr>
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Publications


Current state of project
The initial part of this project is complete. At the present time the ethical and logistic issues are felt to be considerable, and further progress of this project has been deferred.

National colorectal patterns of care survey

*IN CONCERT WITH THE DEVELOPMENT* of clinical practice guidelines, a national survey was undertaken of the clinical management of patients with colorectal cancer in 2000. This survey was designed around the key issues in the guidelines, so that actual practice could be compared to the care recommended in the evidence-based guidelines.

Background
Colorectal cancer is the commonest cancer in Australia apart from skin cancer. There are over 11 000 new cases of colorectal cancer diagnosed in Australia each year, with over 4 600 deaths occurring as a result. This survey assessed the clinical management of a unique national sample of patients in 2000, allowing their care to be compared to that recommended in the evidence-based guidelines, which were released around that time.

Aim
To describe present management patterns for primary colorectal cancer in Australia.

Methods
The project was managed on behalf of the NCCI by the Hunter Area Health Service (Clinical Governance Unit) and overseen by the National Project Management Group.

This survey complemented the NHMRC publication, *Clinical practice guidelines: the prevention, early detection and management of colorectal cancer*, being undertaken at the time of their release but before they would have influenced clinical practice.

All newly reported cases of colorectal cancer to all state and territory cancer registries across Australia over a three-month period commencing 1 February, 2000 were included in the survey. All identified data were kept within state and territory cancer registers. Only de-identified data were sent to Newcastle for analysis. Detailed survey forms were sent to the treating specialists: surgeons, medical oncologists and radiation oncologists.
Results
Aspects of colorectal cancer care and its quality, in comparison with evidence-based guidelines, were described for all cases by characteristics of the patients, the tumours and the medical specialists. The surgeons, medical oncologists and radiation oncologists were classified according to the number of patients they treated in the three-month period and the location of their practice. Of the 86 guidelines listed in the NHMRC report, 46 were amenable to measurement, the questionnaires used in the study allowing detailed analysis of 23 of these.

Conclusions
There was significant variation in some aspects of patient care according to the patients’ place of residence and the clinician cohort. There was less than 50% concordance for eight of the 23 guidelines analysed.

Outcomes
The report from the investigators, led by Professor Allan Spigelman, was published by the NCCI in October 2002. The report was officially launched on 28 November 2002 at the Annual Scientific Meeting of COSA, held in Sydney. Copies of the report have been disseminated widely and the report is available through the NCCI website (http://www.ncci.org.au/pdf/Colorectal_care_survey.pdf).

Presentations


Publications


**Awards**
The NCCI would like to congratulate Professor Allan Spigelman who was awarded the HMRI/Cancer Council Prize for outstanding achievement in cancer research. Professor Spigelman was presented with the award on 28 August 2003.

**Current state of project**
An opportunity exists for the longitudinal observation of outcomes and correlation of outcomes with the multiple variables described in the survey. The CSG will consider further action to take, including the possibility of repeating the survey to see whether the NHMRC guidelines have had an impact on clinical practice in Australia.

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**Complementary and alternative medicine**

**THIS PROJECT ADDRESSED ONE ASPECT** of complementary and alternative medicine: the sources of information available to health professionals and consumers, and their completeness and reliability.

**Background**
The use of complementary and alternative medicine in Australia is increasing, with the highest reported use being amongst cancer patients.

In the NCCI's 1997 consultation on priorities on cancer control, it was clear that in terms of reducing cancer mortality or morbidity, spending resources in the area of complementary and alternative medicine was not viewed as a priority. Of the 147 actions proposed for cancer control in Australia, the three relating to complementary therapies ranked 144th, 145th and 147th.

It is possible that in the intervening period a more favourable attitude towards the role of these medicines in cancer care may have developed among traditional health care practitioners. Conversely, with the further promotion of evidence-based practice, and the Commonwealth Government's subsidisation of private health insurance, which can include complementary and alternative medicines as rebate items, there may be less tolerance of unproven practices. In 2001, the NCCI was asked to prepare a scoping paper on this topic for presentation to the NCCI Management Committee.

**Aim**
To investigate some issues surrounding complementary and alternative medicine in cancer care.

Complementary and alternative medicine is a huge subject, and NCCI's resources cannot extend to an assessment of its efficacy or utilisation. Therefore, the report was restricted to identifying key sources of useful and up-to-date information on this topic.

**Methods**
In October 2001, the NCCI undertook an investigation into some issues surrounding alternative therapies. Information was obtained through searches of the medical and scientific literature and via websites of medical research institutes and groups, both within Australia and internationally. A report on the most valuable sources of information was prepared.

**Results**
The scoping paper on sources of information on complementary and alternative medicine in cancer care was presented to the NCCI Management Committee. The paper provides evidence on complementary and alternative medicine as it relates to cancer care, and includes information on initiatives being undertaken within Australia and internationally to investigate individual therapies.
Current state of project
A paper providing information on complementary and alternative medicine as it relates to cancer care is being produced and will be submitted for publication.

Guidelines for prostate cancer, non-melanoma skin cancer and lung cancer

AN ESSENTIAL ELEMENT OF GOOD CANCER CARE is the assessment of cancer management practices in terms of evidence-based guidelines. The NCCI is working with the ACN and the NHMRC in producing guidelines for these common cancers.

Background
The ACN has produced evidence-based guidelines for several important cancers. At the request of the NHMRC and with funding from the Commonwealth Department of Health and Ageing, the NCCI agreed to facilitate the finalisation and public consultation process for the clinical practice guidelines for NMSC and for lung cancer, being developed by the ACN. The NHMRC has agreed to cover the publication cost of 6,000 copies of each of these guidelines.

The ACN has developed clinical practice guidelines for the management of localised prostate cancer. The NCCI has also provided financial support to the Australian Prostate Cancer Collaboration, to develop a consumer guide for men with localised prostate cancer based on the ACN guidelines.

Aims
To assist in finalising the clinical practice guidelines for NMSC and for lung cancer, and to assist in the production of a consumer guide for men with localised prostate cancer.

Methods
Funding was provided by the NCCI to the Australian Prostate Cancer Collaboration to support the development of a consumer guide for men with localised prostate cancer. Funding assistance was also provided to the ACN for the public consultation and finalisation of the NMSC guidelines. For the lung cancer guidelines, the NCCI was responsible for collating the submissions received from the public consultation, and supporting meetings to review these. A meeting of the Executive Review Group of the Lung Cancer Guidelines Working Party was held in Melbourne in October 2002 to consider the submissions received. A further meeting – involving the convenor of the guidelines, Emeritus Professor Tom Reeve; the Chair of the Guidelines Working Party, Associate Professor David Ball; and Dr Karen Pedersen from the NCCI – was held in December 2002.

Outcomes
Localised prostate cancer: a guide for men and their families was launched in Canberra on 4 February 2002. The major distributor for the guide is the Cancer Council in each state and territory. The Urological Society of Australasia and the Royal Australian and New Zealand College of Radiologists – Faculty of Radiation Oncology, along with the Divisions of General Practice, are providing copies to their members on request.

The public consultation process for the NMSC guidelines has been completed. A final version of the guidelines was submitted to the NHMRC and the guidelines were endorsed by the NHMRC in September 2002.

The draft lung cancer guidelines were made available for public comment in September 2002. A total of 23 submissions were received. Submissions were collated by the NCCI and considered at a meeting of the Executive Review Group of the Lung Cancer Guidelines Working Party in October 2002. The draft guidelines have been revised and they will be submitted to the NHMRC for approval in 2003.
Assessment of the need to increase the capacity of cooperative clinical trials in cancer

**Clinical Trials are the Major Method** by which improvements in cancer therapy are achieved. This project deals with the need for support of clinical trial cooperative groups, and the benefits which would arise from such support.

**Background**
Clinical trials are the main means by which improvements in the treatment of cancer occur, and the involvement of cancer patients in clinical trials needs to be encouraged. ‘Cooperative clinical trial groups’ are voluntary groups of cancer treatment specialists and others who design, carry out, and interpret such trials. While individual clinical trials may be funded from industrial or independent research sources, it is important that clinical trial groups provide continuity and assessment of the need for specific trials.

**Aims**
To review the state of cooperative clinical trial groups in Australia, and assess the need for infrastructure support and the benefits which would accrue from such support.

**Methods**
This was a joint project between COSA, the Victorian Department of Human Services and the Commonwealth Department of Health and Ageing. The project was carried out by Mr Brian Wall from Oceania Health Consulting as a consultative project, gathering information and viewpoints from a wide range of stakeholders.

**Results**
Extensive consultations were carried out, and the results reported as Cooperative clinical trials in cancer. A need for increased capacity, produced in February 2002.

**Conclusion**
The report concluded that infrastructure funding for cooperative clinical groups was important, and would be highly beneficial. Recommendations about such funding, the process by which infrastructure could be developed, and options for sources of such funding were reported.

**Outcomes**
The report was presented to the Commonwealth Minister for Health and Ageing and the Minister for Science. Funding was also sought through the research foundations. Discussions with relevant stakeholders are still continuing. The key conclusions of the consultation were reinforced by the further consultations carried out as part of the development of Optimising cancer care in Australia (COSA, TCCA & NCCI 2003).

**Working groups**

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<th>Steering Committee</th>
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Publications

Current state of project
This project has been completed. Discussions regarding the funding of infrastructure for cooperative clinical groups are continuing.

Supporting the development of a national cancer consumers’ organisation

AN EFFECTIVE CONSUMER VOICE in cancer policy is a vital and essential part of good cancer control policies. Many cancer consumer organisations are restricted to one state, or to one type of cancer. The NCCI has supported the development of a national consumer organisation relating to all cancers.

Background
Consumers bring an important perspective to cancer control. During 2001 COSA was working with a steering group of consumers to create an independent cancer advocacy network in Australia. The intention was to bring together consumer groups involved in cancer-related advocacy, to enable more effective lobbying and greater political and advocacy strength.

A consultancy, Enduring Solutions, was commissioned following a tendering process to perform some preliminary tasks necessary to facilitate the network’s formation. A workshop was held in Melbourne in July 2001, attended by people from cancer advocacy and support groups representing different states, ages and cancer types. The two main outcomes were the development of a database of potential membership of a cancer advocacy network and a report summarising the consultations and proposing a model for establishing the network. The project identified the need for a project officer and administrative support to undertake key tasks identified at the workshop.

Aim
To provide support for the development of a national cancer consumers’ organisation.

Methods
The NCCI agreed to provide $50 000 to support the development of the cancer alliance network.

Results
CAN Australia is progressing. An interim management committee has been appointed, with Mr Russell McGowan as Chair. Two project officers have been appointed, Mr John Stubbs and Ms Julie Claessens, who are working on incorporating CAN Australia, finalising a constitution, signing on members and establishing activities, including an office. CAN Australia was launched in Sydney on World Cancer Day, 4 February 2003.

Outcomes
A national consumers organisation relating to all cancers has been established in Australia.
Key strategy 5: Develop and maintain the capacity to respond to issues in cancer control within the strategic priorities

‘We are drowning in information and starved for knowledge.’

Unknown

‘In your thirst for knowledge, be sure not to drown in all the information.’

Anthony J D’Angelo, the College Blue Book

Independent evidenced-based reviews

IN ADDITION TO ADDRESSING the many issues arising from active projects, the NCCI undertakes independent evidenced-based reviews upon request from the Commonwealth and other stakeholder groups. A number of these reviews have been conducted to date and include a Commonwealth requested report on the current state of ovarian cancer screening and the evidence relating to an association between bicycle riding and testicular cancer. At the request of the Medical and Scientific Committee of TCCA/COSA, the NCCI has also reviewed the requirements to be met in regard to screening tests, which are marketed to the general public. A report on this topic is available on the NCCI website (http://www.ncci.org.au/pdf/RegulationInVitroTest.pdf)

The Australian Chronic Disease Prevention Alliance

THE AUSTRALIAN CHRONIC DISEASE PREVENTION ALLIANCE is an initiative of the leading non-government organisations concerned with cancer, heart and cardiovascular disease, diabetes and renal disease. The purpose of the alliance is to coordinate the activities of the non-government organisations, particularly in areas of primary and secondary prevention, to produce coordinated strategies, which will be more effective and efficient than current programmes.

The Commonwealth is supporting this alliance and has provided funding for some initial work. The NCCI was involved in the preliminary development and will maintain links to the alliance.
Review of Australian clinical management surveys and guidelines

MANAGEMENT SURVEYS ARE surveys of the treatment cancer patients actually receive, and indicate variations and possibilities for improvement. Australia has an excellent record of performing high quality management surveys on a national or state basis. These surveys rely on the voluntary input of specialists treating cancer patients, and are conducted with strict confidentiality.

Clinical practice guidelines are documented statements of consensus about the clinical management of cancer patients. Australian clinical practice guidelines for cancer have been mainly produced by the ACN, and use an explicit evidence based process defined by the NHMRC. In accordance with this, guidelines go through a period of public consultation and external peer review before they are finalised. For many types of cancer, guidelines for consumers and for GPs have been produced as well as guidelines for clinical specialists. Australia is a world leader in the production of national, evidence-based guidelines relating to both health care professionals and consumers.

Background
Clinical management surveys provide important information on the treatment of patients. As developments in the detection, diagnosis and treatment of disease occur, there is a need to collect accurate information on disease management so that changes in practice with time can be examined. In Australia, clinical management surveys have been conducted for a number of different cancers and in a number of different locations around the country. The NCCI was interested in identifying clinical management surveys for cancer that have been undertaken in Australia, including those that have been published, are ongoing or are planned. Compilation of a list of such surveys would provide a useful resource and allow the identification of areas and cancer types for which data from clinical management surveys are available or absent.

Guidelines that provide evidence-based recommendations regarding best practice for clinical management are an important element of good cancer care. The NCCI was also interested in identifying clinical practice guidelines for cancer that have been published, or are in development, in Australia. Compilation of a list of guidelines would again provide a useful resource and enable the identification of cancer types for which guidelines are available or absent.

Aim
To identify clinical management surveys for cancer that have been undertaken in Australia, including those that are ongoing or are planned, and to identify Australian clinical practice guidelines for cancer.

Methods
Identification of clinical management surveys in cancer was achieved by searching known publication sources and through contact with groups and individuals involved with clinical management surveys in Australia. A focus was to identify surveys with a large population base, ideally those undertaken nationally or statewide. In particular, surveys based on population registry data were sought. Cooperative or clinical oncology groups in Victoria, Western Australia, Tasmania and Queensland, the Department of Public Health at the University of Western Australia, and key individuals involved in cancer in Australia were contacted to obtain available information on surveys that were ongoing or planned. A preliminary list of surveys was circulated to the CSG for comment.

Clinical practice guidelines were identified through searching known publication sources and through contact with groups involved in guidelines development in Australia.

Results
To date, 22 published surveys have been identified. Information was obtained that a further 20 surveys were either ongoing or planned. The majority of published surveys were state-based (18 of 22 published surveys),
with the remaining four being conducted at a national level. The cancer site for which most surveys have been conducted is breast cancer (11 of 22 published surveys).

To date, 17 cancer-specific clinical guidelines have been identified (including specialist, GP and consumer versions). A further three cancer-specific guidelines are known to be in development.

**Outcomes**

Australian clinical management surveys and clinical practice guides in cancer will be identified and a list of surveys and guidelines will be produced. This list will be made available on the NCCI website as a useful resource. A report reviewing the identified surveys and guidelines will be produced.

**Current state of project**

Searches for Australian clinical management surveys in cancer and clinical practice guidelines in cancer are ongoing and a report reviewing the identified surveys and guidelines is in preparation.
OTHER ACTIVITIES

National database of cancer control activities

Background
A priority setting matrix was recommended as a means of collecting information about cancer control activities in Australia to identify gaps in knowledge and practice, options to address those gaps and optimum points for intervention. During the second half of 1999, the NCCI undertook an extensive survey of individuals and organisations known or thought likely to be involved in cancer control across Australia.

Aims
To identify:
• government and non-government bodies involved in cancer control in Australia
• cancer control activities being undertaken
• areas where needs were not being met
• areas of unnecessary duplication
• opportunities for collaboration.

It was envisaged that the National Database of Cancer Control Activities would be a useful resource for researchers, policy makers and other workers in cancer-related areas. Furthermore, it was thought that the information provided would help in the development of an ongoing national cancer control plan that would provide a framework for coordinated action across stakeholders.

Methods
Creating the database
Creating the database required:
• identifying bodies involved or likely to be involved in cancer control activities
• formulating a questionnaire that would generate information relevant to the aims
• notifying key stakeholders in cancer control across the country about the purpose of the database
• contacting individuals and organisations sent the questionnaire and requesting their assistance in the further distribution of the questionnaire
• organising and displaying the data in a way that was consistent with the aims and would fulfil the clearinghouse function envisaged for the NCCI.

Respondents were given the opportunity to nominate others for whom they felt the questionnaire would be relevant; thus a ‘snowball’ dissemination strategy was used to distribute the questionnaire.

Evaluating the database
In January 2002 the NCCI undertook an evaluation survey to gather information on the current use of the database and its perceived value.

A letter informing individuals of the evaluation survey was sent two weeks before posting the survey. The evaluation survey was sent to 349 individuals who had a cancer control activity registered on the database. The covering letter stated that the survey had been developed to gather information on the current use of the database and its value, however, it did not mention that all people receiving the evaluation survey had an activity registered on the database.

Individuals were given three weeks to complete and return the survey.
Results

Creating the database

By mid-2000, over 450 descriptions of cancer control activities were received by the NCCI and in line with our clearinghouse function, the NCCI made the data available on the Internet from July 2000.

All states and territories in Australia had activities listed on the database and 80% of activities were targeted only at the state, territory or local regional level. Fifty-nine percent of activities serviced all communities, i.e. metropolitan, rural and remote. For 31% of activities, particular steps were taken to involve specific groups within the community. Seventy-four percent of activities registered on the database were relevant to both sexes. Four hundred and thirty-five activities were relevant to all forms of cancer, and all points – from primary prevention to palliation – were represented. One-third of activities were educational, 37% were involved in programme implementation and 22% had the goal of improving quality of life.

Evaluation of the database

Three hundred and forty-nine evaluation surveys were sent out. A response rate of 47% was achieved. The evaluation survey revealed that the database had limited use following its release on the Internet. Many people were unaware of its existence. Generally, respondents believed that the database was of limited use in promoting their cancer control activity. Few people had recommended the database to their colleagues or were committed to registering new activities on the database.

It is difficult to know whether the National Database of Cancer Control Activities successfully achieved all of its aims. Evaluation survey respondents agreed that the database successfully identified government and non-government bodies involved in cancer control in Australia and identified cancer control activities being undertaken across Australia. However, there were insufficient responses and too diverse a range of opinions to determine whether the database successfully identified areas where needs were not being met, areas of unnecessary duplication and opportunities for collaboration.

Many people were unsure whether they would use the National Database of Cancer Control Activities in the future and over half the respondents indicated that the removal of the database from the Internet would not significantly limit their ability to plan and carry out cancer control activities.

Conclusions

The response to the original questionnaire, which solicited registrations for the database, indicated support for the value of a central accessible web-based database of cancer control activities. However, the database has had limited use since its release on the Internet in July 2000. The major impediment to use has been that people were unaware of its existence.

Outcomes

Given the costs associated with hosting, updating and maintaining the database and its limited use in the future, the National Database of Cancer Control Activities was removed from the NCCI website in May 2002.

Presentations


Publications


Current state of project

This project has been completed.
The cancer genetics education resource directory

Background
The National Cancer Genetics Education Group, formed in February 2000, developed the Cancer Genetics Education Resource Directory. The group recommended that the directory be developed as a means of collating quality information and resources for people with an interest in cancer genetics.

The National Cancer Genetics Education Group comprises individuals involved in cancer genetics education from various organisations in Australia. The resource directory is jointly owned by the organisations whose members comprise the National Cancer Genetics Education Group. The directory is being hosted on the NCCI website from July 2002 to July 2003.

Aim
To provide Australian health professionals and members of the public with an interest in cancer genetics with details of the cancer genetics educational resources available.

Methods
The development of the resource directory involved:
- the identification of up-to-date resources relating specifically to cancer genetics
- the identification of up-to-date general genetics resources that contained sections relating to cancer genetics
- contacting individuals and organisations to obtain information about the resources
- creating a format in which to display relevant information
- the segregation of the resources into three groups:
  - cancer genetics
  - breast/ovarian cancer
  - colorectal cancer.

The formation of a comprehensive directory was a joint responsibility and contributions were received from every member of the National Cancer Genetics Education Group.
Working group

National Cancer Genetics Education Group

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<td>Ms Liz Reeson (member until July 2001)</td>
<td>NSW Genetics Education Program</td>
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<tr>
<td>Dr Kim Summers (member until June 2003)</td>
<td>Queensland Clinical Genetics Service</td>
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<tr>
<td>Dr Kendra Sundquist</td>
<td>The Cancer Council New South Wales</td>
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<tr>
<td>Ms Shendell Surplice (member until May 2003)</td>
<td>Genetic Services of Western Australia</td>
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<tr>
<td>Ms Karen Harrop</td>
<td>Genetic Services of Western Australia</td>
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<tr>
<td>Ms Clara Tait</td>
<td>The Cancer Council South Australia</td>
<td>SA</td>
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Current state of project

The directory was hosted on the NCCI website (http://www.ncci.org.au/CGERD/index.htm) from July 2002 and received over 1,100 hits between July and December 2002. At the end of 12 months the National Cancer Genetics Education Group will report to the NCCI on the uptake of the directory as a web-based resource, its current utilisation, predicted future utilisation and potential for development. To assist in the evaluation process an online user’s survey has been made available to everyone who accesses the directory.

The findings of this survey will be made available on the NCCI website.
**NCCl representation**

**THE STAFF AT THE NCCI WORK WITH** government bodies and non-government organisations to advise on priorities in cancer control.

The NCCI is or has been represented on the bodies listed below.

<table>
<thead>
<tr>
<th>Group</th>
<th>NCCI representative</th>
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<tr>
<td>Bowel Cancer Screening Pilot Monitoring and Evaluation Task Group</td>
<td>Professor Mark Elwood, Ms Margaret Staples</td>
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<tr>
<td>Bowel Cancer Screening Pilot Quality Task Group</td>
<td>Associate Professor James St John</td>
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<td>Cancer Strategies Group</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>Cancer Strategies Group National Cancer Strategy Working Group</td>
<td>Professor Mark Elwood, Dr Paul Ireland (member until July 2002)</td>
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<tr>
<td>Clinical Oncological Society of Australia Council</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>National Service Improvement Framework for Cancer Expert Panel</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>Medical and Scientific Committee of TCCA/COSA</td>
<td>Professor Mark Elwood</td>
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<td>National Advisory Committee to BreastScreen Australia</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>National Advisory Committee to National Cervical Screening Program</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>NBCC National Multidisciplinary Care Demonstration Project Steering Committee</td>
<td>Professor Mark Elwood, Dr Karen Pedersen</td>
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<tr>
<td>NBCC National Ovarian Cancer Initiative Steering Group</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>NBCC Ovarian Cancer Expert Advisory Group</td>
<td>Professor Mark Elwood, Dr Cleola Anderiesz</td>
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<td>NBCC Program Implementation Advisory Group</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>NBCC and NCCI Psychosocial Guidelines Development Steering Group</td>
<td>Dr Karen Pedersen</td>
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<tr>
<td>NHMRC Preventive Guidelines Working Party</td>
<td>Professor Brian McAvoy</td>
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<td>National Public Health Partnership</td>
<td>Professor Mark Elwood</td>
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<td>National Public Health Partnership: National Strategies Coordination Reference Network</td>
<td>Professor Mark Elwood</td>
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<tr>
<td>Nutrition and Physical Activity Committee: The Cancer Council Australia</td>
<td>Dr Paul Ireland (member until July 2002)</td>
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<td>The Cancer Council Victoria Gastrointestinal Cancer Committee</td>
<td>Associate Professor James St John</td>
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<td>The Cancer Council Victoria Cancer Genetics Committee</td>
<td>Associate Professor James St John</td>
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<td>The Cancer Council Victoria Lung Cancer Committee</td>
<td>Associate Professor James St John</td>
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WORKSHOPS

Moving forward on cervical cytology: May 2001

‘MOVING FORWARD ON CERVICAL CYTOLOGY’ WAS co-sponsored by the NCCI and the Australian Society for Colposcopy and Cervical Pathology and was held on 9 May 2001 at the West End Convention Centre in Fremantle, WA. The workshop followed the society’s XVI scientific meeting.

Objective
To address what could and should be done in Australia to develop cervical screening both within existing programmes and in new service programmes or new research.

Structure of workshop
The workshop was chaired by Associate Professor Michael Quinn.

Five topics were identified for discussion:
• Why shouldn’t we extend the current two-year screening interval?
• Why shouldn’t we incorporate HPV testing in primary screening?
• Why shouldn’t we use HPV testing in the triage management of abnormalities?
• Why shouldn’t we use HPV testing in follow-up?
• Why shouldn’t we make changes within the current national publicly funded programme?

Two speakers were invited to introduce each topic. One speaker presented the case for change and the other speaker presented the arguments against change for each topic. The speakers were asked to present either the for or against argument whether or not it was in full accordance with their own views.

An open discussion took place at the conclusion of the presentations.

Attendance
Approximately 130 people attended the workshop. The audience comprised cytologists, histopathologists, GPs, gynaecologists, gynaecological oncologists, scientists, nurse practitioners, members of the pharmaceutical industry, state recruitment coordinators and other cervical registry staff. Members of the National Advisory Committee on Cervical Screening attended as well as members of state or territory and Commonwealth Government groups.

Workshop summary
The meeting was thought to be useful by those present, as was wider consultation and discussion on cervical screening. There was recognition of the rapid development in the field, and general agreement that Australian research and policy should be in accord with scientific advances.

A document containing the summary of the workshop proceedings can be found on the NCCI website (http://www.ncci.org.au/pdf/Cervicalworkshopreport.pdf). This document contains the main arguments raised in support of or against change for each presentation. It should be noted that the presenters were assigned the topics for discussion and the presenters did not necessarily concur with the arguments they presented. Furthermore, the presenters appeared at the workshop as individuals, not as the representatives of particular groups or on behalf of any organisation.

At the conclusion of the open discussion, Associate Professor Michael Quinn presented a summary of the main issues raised. Although no formal recommendations were solicited, several suggestions for development were presented. These included:
• Negotiating a separate research and development budget within the National Cervical Cancer Screening Program.
• Undertaking targeted policy-related research, with priorities determined by the National Advisory Committee on Cervical Screening and other stakeholders.
• Undertaking an analysis of women with many consecutive negative smears, estimating their risk of developing cervical cancer and building that into the screening programme in terms of changing screening intervals.
• Developing tests which give insight into the malignant potential of high grade lesions.
• Undertaking research around issues of over-screening and under-screening.
• Further assessing the benefits and risks of changing the screening interval.
• Developing Australian research on HPV.

Publications

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Helical computed tomography screening for lung cancer – future directions: May 2001

**‘HELICAL CT SCREENING FOR LUNG CANCER: FUTURE DIRECTIONS’ WAS** sponsored by the NCCI and was held on 22 May 2001 at the Cancer Control Research Institute, The Cancer Council Victoria, Carlton, Victoria.

**Objective**
To discuss helical CT scanning as a screening technique for lung cancer and its future directions in Australia.

**Structure of workshop**
The workshop was chaired by Professor Richard Smallwood AO and Professor Mark Elwood. The workshop comprised seven presentations and an audience discussion. Each presentation was followed by a short period of open discussion. A longer audience discussion took place at the conclusion of the presentations, to explore the issues surrounding helical CT scanning as a screening technique for lung cancer and discuss the way forward for Australia. The presentation section of the workshop was chaired by Professor Smallwood and Professor Elwood chaired the audience discussion.

The workshop programme is listed below.

**Session 1**
Chair – Professor Richard Smallwood AO

- Screening for lung cancer with helical CT: current and planned studies – Dr Renee Manser
- Aetiology of small peripheral opacities in an at-risk population – Dr David Cameron
- Proposed lung cancer screening in central Sydney: planning issues – Dr Michael Millward

**Audience discussion**
Session 2
Chair − Professor Richard Smallwood AO

Proposal for an Australian pilot study of low dose helical CT scan screening for lung cancer − Dr Renee Manser

Value adding to helical CT screening − Dr Kwun Fong

Management of scan-detected nodules − Mr Peter Cole

The economics of screening by helical CT scans − Ms Christine Stone

Audience discussion

Session 3
Open discussion

Chair − Professor Mark Elwood

Attendance
Approximately 60 people attended the workshop. The audience comprised thoracic physicians, radiologists, oncologists, thoracic surgeons, epidemiologists, scientists and radiology staff. Members of state or territory and Commonwealth Government groups also attended.

Workshop summary
A document containing the summary of the workshop proceedings can be found on the NCCI website (http://www.ncci.org.au/pdf/011101LungWorkshopSummary.pdf). For each presentation there is a short overview, a presentation abstract (as provided by the speaker) and a summary of the discussion that followed. The summary of the audience discussion includes the questions put forward for discussion and the main issues raised. Proposals arising from the workshop included that:

• a multi-centre pilot study be established in Australia to provide local information and bring together expertise
• a detailed economic analysis be undertaken to assess expected costs and benefits from helical CT screening
• a further meeting be convened to bring together representatives to review what has been discussed and move forward from there.

As a result of the workshop, a working group was established by the NCCI to produce a report on the topic of lung cancer screening using helical CT. A wider advisory group on lung cancer screening was also established and a project undertaken to conduct an economic analysis of helical CT screening.

Organising Committee

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<tr>
<th>Representative</th>
<th>Affiliation</th>
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<tr>
<td>Associate Professor David Ball</td>
<td>Peter MacCallum Cancer Centre</td>
<td>Vic</td>
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<td>Associate Professor Don Campbell</td>
<td>Royal Melbourne Hospital</td>
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<td>Mr Peter Cole</td>
<td>Monash Medical Centre</td>
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<td>Professor Mark Elwood</td>
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<td>Associate Professor Louis Irving</td>
<td>Austin &amp; Repatriation Medical Centre</td>
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<td>Dr Renee Manser</td>
<td>Royal Melbourne Hospital</td>
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<td>Dr Karen Pedersen</td>
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Publications
Challenges for sun protection in Australia: July 2001

‘CHALLENGES FOR SUN PROTECTION IN AUSTRALIA’ WAS sponsored by the NCCI and was held on 24 July at the Cancer Control Research Institute, The Cancer Council Victoria, Carlton, Victoria.

Objective
To discuss skin cancer control in Australia, including consideration of current activities and directions for the future.

Structure of workshop
The workshop was chaired by Professor Mark Elwood. The workshop comprised a number of presentations and an audience discussion. The presentations provided an overview of skin cancer control in Australia and highlighted features of skin cancer control programmes that are being undertaken in key settings within the Australian community, namely:

- mass media
- schools
- local government
- the workplace.

As part of each presentation speakers were asked to raise key issues for discussion. An open discussion took place after the presentations. This was designed to provide a forum to debate the future directions for skin cancer control in Australia, including discussion of priority and policy issues.

The workshop programme is listed below.

Session 1
Chair – Professor Mark Elwood
Overview of sun protection in Australia – Mr Craig Sinclair
Features of Australian programmes:
Mass media – Ms Jeanie McKenzie
Schools – Ms Stephanie Harper
Local government – Ms Barbara Kirke
Workplace – Mr Terry Slevin
Open discussion

Session 2
Chair – Professor Mark Elwood
Discussion of priority issues
Attendance
Approximately 50 people attended the workshop. The audience comprised epidemiologists, dermatologists, health promotion professionals, Commonwealth and state and territory health officials and other interested members of the medical and scientific community.

Workshop summary

Points highlighted in the summary include that:
- Further progress towards national coordination is needed.
- Due to the work of the CSG, there should be the opportunity to take this up at federal level to raise issues of legitimate partners and funding.
- The various components of SunSmart and similar activities could be assessed to identify the ‘best buys’.

Publications

Improving outcomes for Australian women with ovarian cancer: September 2001

‘IMPROVING OUTCOMES FOR AUSTRALIAN WOMEN WITH OVARIAN CANCER’ WAS hosted by the NCCI, the Commonwealth Department of Health and Ageing, the NBCC and OvCa Australia. The workshop was held on 28 September 2001 at the Dallas Brooks Centre in Melbourne, Victoria.

Objectives
To raise the profile of ovarian cancer in Australia, explore ways of improving outcomes for women and develop a set of action-oriented recommendations for the future.

Structure of workshop
The Honourable Dr Michael Wooldridge, Commonwealth Minister for Health and Ageing, opened the one-day workshop.

The workshop was divided into three chaired sessions with nine speakers being invited to present on a broad range of issues. Professor Ian Jacobs (Consultant Gynaecological Oncologist and Senior Lecturer, Royal London Hospital Medical School, and Director, Gynaecological Cancer Research Unit at St Bartholomew’s Hospital, London) was invited to Australia to speak about the United Kingdom’s perspective on treating and managing ovarian cancer and the future of screening.

Each session concluded with an audience discussion, which was facilitated by two discussants. The workshop programme is listed below.

Session 1 – How well are we dealing with ovarian cancer in Australia?
Chair – Professor Neville Hacker

Current management of women with ovarian cancer in NSW – Professor Bruce Armstrong
Current management of women with ovarian cancer in Vic – Associate Professor Michael Quinn

What are the problems facing rural patients and practitioners? – Dr David Goldstein

What are the needs of consumers? – Ms Denise Hynes

Open discussion – Discussants Mr Simon Lee and Dr Kelly Phillips

Session 2 – What can we do better?
Chair – Dr Greg Robertson

The United Kingdom experience. How the United Kingdom is improving outcomes for women with ovarian cancer – Professor Ian Jacobs

How can we use the ovarian cancer guidelines to improve practice? – Dr Margaret Davy

Open discussion – Discussant Professor Sally Redman

Session 3 – New approaches to improving outcomes
Chair – Associate Professor Michael Quinn

Clinical trials and ovarian cancer – Professor Michael Friedlander

Epidemiology and research – Dr Penny Webb

Laboratory research – Professor David Bowtell

The prospects for screening by 2010 – Professor Ian Jacobs

Open discussion – Discussants Dr David Purdie and Dr Danny Rischin

A distillation of key issues and recommendations raised throughout the day was presented at the conclusion of the workshop by Professor Adele Green and Dr Karen Luxford.

Attendance
Representatives from areas of consumer advocacy, epidemiology, gynaecological oncology, medical oncology and clinical research attended the workshop along with individuals from state and Commonwealth Government health organisations and cancer organisations. Approximately 89 invitees attended the workshop.

Workshop summary
The Honourable Dr Michael Wooldridge announced that the Commonwealth would provide funding of $500 000 over two years for improving the health outcomes for women affected by ovarian cancer. This initiative is being managed by the NBCC.

At the conclusion of the workshop Professor Adele Green and Dr Karen Luxford summarised the sessions and provided an overview of the proposed priority actions and issues for further exploration. Four priority action areas were identified from the presentations and subsequent discussions:

• prevention
• diagnosis and referral
• treatment
• patient support.

Several priority action recommendations were proposed in each of these priority action areas. These priority action recommendations along with opportunities for improvement can be found in the workshop report produced by the NBCC (http://www.ovariancancerprogram.org.au/pubs/workshop/workshop.pdf).
Organising Committee

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<tr>
<th>Representative</th>
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<tr>
<td>Dr Cleola Anderiesz</td>
<td>NCCI</td>
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<td>Ms Denise Hynes</td>
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<td>Dr Rosemary Knight</td>
<td>Commonwealth Department of Health and Ageing</td>
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<tr>
<td>Associate Professor Michael Quinn</td>
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<tr>
<td>Professor Sally Redman</td>
<td>NBCC</td>
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Publications

Efficient and effective melanoma diagnosis: November 2002

A workshop to discuss ‘Efficient and effective melanoma diagnosis’ was held on 20 November 2002 at the Centenary Institute of Cancer Medicine and Cell Biology, Royal Prince Alfred Hospital in Camperdown, NSW. It was jointly convened by the NCCI and the Melanoma and Skin Cancer Research Institute.

Objectives
To review past and ongoing research on the diagnosis of melanoma and to seek consensus for future studies aimed at improving the efficiency of melanoma diagnosis in the primary care setting.

Structure of workshop
The workshop was divided into three sessions as indicated:

Session 1: What’s the problem? What’s happened so far: results of trials and interventions
Chair – Professor Robert Burton
The Del Mar and Green Intervention – Professor Chris Del Mar
The Perth Skin Cancer Trial – Associate Professor Dallas English
Melanoma diagnosis and prevalence of screening in Queensland – Dr Joanne Aitken
Group discussion
Session 2: What other approaches can we use?
Chair – Professor Robin Marks
Dermoscopy – Dr Scott Menzies
Group discussion
Total body photography I – Associate Professor John Kelly
Total body photography II – Dr Pauline Hanrahan
Group discussion
Digital monitoring – Dr Scott Menzies
Group discussion

Session 3: Where to next? Future technologies, how can we proceed?
Chair – Professor Mark Elwood
Technologies in the future – Dr Scott Menzies
Discussion
Assessing the diagnostic accuracy of tests – Professor Les Irwig
What is required for a Medicare rebate? – Mr Mike McKenzie
Group discussion
Medico-legal issues – Professor Gerry Milton
Discussion
How do we proceed? Group discussion

The first session covered studies of diagnostic interventions that have been assessed in primary care. The second included approaches that have been assessed in expert settings and could be suitable for testing in general practice. The final session presented information about developments in technology that were not yet suitable for widespread use and examined issues needing consideration when designing a study for assessing a diagnostic intervention. Audience discussions followed each topic and the final discussion focused on achieving consensus for a study in general practice.

Attendance
The workshop was open to all interested participants. Forty-eight people attended including dermatologists, GPs, Commonwealth Government representatives, consumers, epidemiologists and public health professionals involved in skin cancer awareness campaigns.

Workshop summary
The Del Mar and Green intervention showed a reduction in the ratio of benign to pigmented lesions excised in general practice after doctors were trained in the use of a diagnostic algorithm and instant camera for monitoring pigmented skin lesions. The Perth Skin Cancer Trial failed to replicate this result in a randomised controlled trial, thus alternative approaches to reducing the benign excision rate while maintaining diagnostic accuracy for melanoma need to be investigated. Total body photography has been shown to be effective in reducing the number of benign excisions in high-risk patients but because of its relatively high cost may not be suitable for widespread use in primary care. Training in dermoscopy may offer a way forward as improvements in diagnostic efficiency and accuracy have been demonstrated using this technique in a specialist setting. A trial of dermoscopy in general practice was proposed and issues to be considered when
developing the proposal were discussed. Newer diagnostic technologies were not sufficiently advanced for use in primary care.

A full summary of the workshop is available from the NCCI website (http://www.ncci.org.au/pdf/Mel_Workshop03.pdf).

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<td>Ms Sarah Major</td>
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<td>Dr John Primrose</td>
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<td>Ms Margaret Staples</td>
<td>NCCI</td>
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**Publications**

PRESENTATIONS AND PUBLICATIONS

Abstracts/conference presentations

1999
Elwood M. Assessment of the effects of screening on cancer, on both stage shift and over-diagnosis of non-progressive lesions, by case-control design. COSA 26th Annual Scientific Meeting. Melbourne, 24–6 November 1999.


2000


2001


2002


Elwood M. Are we serious about evaluation in cancer screening? Screening and test evaluation program (STEP) review seminar. Sydney, 2 December 2002.

2003


Articles

1997


1999

2001


2002


2003


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### Reports

**1997**


**1998**


**1999**


**2000**


**2001**


**2002**


**2003**


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Books and book chapters


REFERENCES


