IMPROVING THE MANAGEMENT OF LUNG CANCER

Saturday 5 April 2003
Adelaide Convention Centre
North Terrace
Adelaide
South Australia

workshop summary
IMPROVING THE MANAGEMENT OF LUNG CANCER

A report of the workshop held
5 April 2003 at the
Adelaide Convention Centre
North Terrace
Adelaide SA
Improving the Management of Lung Cancer

A summary of the workshop held 5 April 2003 in Adelaide, South Australia.

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ABBREVIATIONS AND NOTES

ACN  Australian Cancer Network
CAN  Cancer Alliance Network
COPD  Chronic obstructive pulmonary disease
CT  Computed tomography
EORTC  European Organization for Research and Treatment of Cancer
FDG  Fluoro-deoxyglucose
GP  General practitioner
MIBI  Methoxy-isobutylisonitrile
MRI  Magnetic resonance imaging
MSAC  Medical Services Advisory Committee
NCCI  National Cancer Control Initiative
NHMRC  National Health and Medical Research Council
NHPAC  National Health Priority Action Council
NSCLC  Non-small cell lung cancer
NSIF  National service improvement framework
PBAC  Pharmaceutical Benefits Advisory Committee
PET  Positron emission tomography
QILCOP  Queensland Integrated Lung Cancer Outcomes Project
SCLC  Small cell lung cancer
SEER  Surveillance, Epidemiology and End Results
TSANZ  Thoracic Society of Australia and New Zealand

Accuracy of URLs

In parts of this report, addresses (URLs) for relevant Internet material are provided. The URLs were correct when checked prior to publication (December 2003).
About the National Cancer Control Initiative

The National Cancer Control Initiative (NCCI) is a key expert reference body providing timely advice, identifying appropriate initiatives and making specific recommendations to the Australian Government and other key groups regarding the prevention, detection, treatment and palliation of cancer for all Australians. The NCCI is a partnership between The Cancer Council Australia and the Australian Government Department of Health and Ageing. The Initiative works closely with other bodies including The Cancer Council Australia, state and territory governments and non-government organisations.

Central to the NCCI’s roles and responsibilities is the effective management of a range of projects funded by the Australian Government. NCCI activities take account of the National Health Priorities of the Australian Government and require evidence-based practice and systematic reviews of the literature on the various aspects of cancer control. Further information about the NCCI and its projects can be found on the NCCI website at http://www.ncci.org.au.
RECOMMENDATIONS AND KEY POINTS

Following are the recommendations and key points for improving the management of lung cancer in Australia that arose from the workshop. The recommendations and key points listed were put forward during the audience discussion in the final session (Session Four). At the commencement of the final session, it was noted that six key areas had been identified during the course of the workshop and it was proposed that a recommendation for specific action be made for each area. In addition, although the focus of the workshop was on the management of established lung cancer, a recommendation relating to tobacco control was also put forward.

Recommendations and key points are listed under the corresponding key area. The order in which recommendations appear reflects the order in which topics were discussed rather than any order of priority. Recommendations and key points also appear in the relevant section of the summary of the final session (see pages 43–52).

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Recommendations

**IMPLEMENTATION OF THE LUNG CANCER GUIDELINES**

1. That a consumer version of the ‘Clinical Practice Guidelines for the Management of Lung Cancer’ be developed.

**MULTIDISCIPLINARY CARE**

2. That a demonstration project of multidisciplinary care for lung cancer be conducted to provide leadership in this area.

**DATA COLLECTION**

3. That support be given to establish a national cooperative lung cancer group, which could promote clinical trials and facilitate data collection.

**ACCESS TO APPROPRIATE TECHNOLOGY – POSITRON EMISSION TOMOGRAPHY SCANS**

4. That one more institution receive a positron emission tomography (PET) scanner.
CONSUMER PRIORITIES

5 That psychosocial support be advanced as part of a national model for psychosocial care.

RADIATION ONCOLOGY

6 That an existing Australian radiation oncology report be implemented.

ADDITIONAL RECOMMENDATION – TOBACCO CONTROL

7 That greater support be provided for effective tobacco control strategies.

Key points

Together with the workshop recommendations, a number of other major points were raised in each of the six key areas. These are listed under the corresponding area headings.

IMPLEMENTATION OF THE LUNG CANCER GUIDELINES

I Appropriate electronic means of dissemination of the lung cancer guidelines should be developed.

II There is a need for electronic decision support tools derived from the guidelines.

III Development of clinical pathways may facilitate uptake of guideline recommendations into routine clinical practice.

MULTIDISCIPLINARY CARE

I Financial barriers to providing multidisciplinary care should be removed and incentives to providing multidisciplinary care introduced.

II Champions, including consumers, should be recruited to promote multidisciplinary care.

III Support for multidisciplinary practice as the standard of care should be sought from professional colleges, including clinical practice audits and accreditation of multidisciplinary teams.
IV Referral of lung cancer patients from general practice should be to a member of a multidisciplinary team.

DATA COLLECTION

I Clinical cancer registries and links to state cancer registries should be developed.
II Support is needed for a national audit agreed to by those working in lung cancer.
III Evidence-based benchmarks of appropriate utilisation of chemotherapy and surgery should be developed.
IV Data on lung cancer volume–outcome relationships is needed.
V Effective use should be made of existing health data relating to lung cancer.
VI Privacy issues can impact on collection of clinical data and progress is needed in this area.

ACCESS TO APPROPRIATE TECHNOLOGY – POSITRON EMISSION TOMOGRAPHY SCANS

I More PET scanners are needed.
II The Medical Services Advisory Committee review of PET was disputed.

CONSUMER PRIORITIES

I Establish lung cancer groups in all states and territories for patients and carers.
II Develop national data collection processes.
III Place on the health agenda smoking cessation programs specifically tailored for lung cancer patients who have a strong physiological dependence.
IV There is a need for community lung cancer nurses, equivalent to those for breast cancer.
V There is a need for a national clinical trials register.

RADIATION ONCOLOGY

I The Federal–State divide is seen as a major barrier for radiation oncology.
II Private health insurance should cover outpatient radiotherapy.
IMPROVING THE MANAGEMENT OF LUNG CANCER

A workshop to discuss improving the management of lung cancer was held on Saturday 5 April 2003 at the Adelaide Convention Centre in Adelaide, South Australia. The workshop was convened by the National Cancer Control Initiative (NCCI) with specific support from the Australian Government Department of Health and Ageing, and was held immediately prior to the 2003 Annual Scientific Meeting of The Thoracic Society of Australia and New Zealand (TSANZ).

Objective

The objective of the workshop was to explore ways to improve the management and outcomes for patients with lung cancer, and identify ideas and concepts that will indicate priorities for future developments.

The workshop was divided into four sessions:

- Session One: Challenges of lung cancer in Australia. Chair – Professor Alan Coates
- Session Two: Evidence-based best practice. Chair – Professor Bruce Barraclough
- Session Three: New approaches for improving care. Chair – Professor Mark Elwood
- Session Four: Discussion, summary and recommendations. Chair – Professor Brian McCaughan

The first session included a review of the priorities for lung cancer in Australia with discussions on care and outcomes for lung cancer, barriers to optimal care, national service improvement frameworks (NSIFs), Indigenous and rural / remote issues, and general practice and consumer perspectives. The second session presented information on the Australian clinical practice guidelines for the management of lung cancer, use of radiotherapy in lung cancer, new imaging techniques in the management of lung cancer and priorities for improving current practice.

The third session featured presentations on new approaches to improving care with discussions on multidisciplinary care in lung cancer and other areas, clinical trials and Breakthrough Collaboratives. In each session an open discussion followed the presentations. The final session involved an audience discussion and focussed on identifying recommendations for ways forward.
In addition to the presentation and discussion sessions, a demonstration of the minimum data set utilised by the Queensland Integrated Lung Cancer Outcomes Project (QILCOP) was held during the lunch break. The demonstration was given by Ms Jaccalyne Brady and Mr Stephen Armstrong.

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**Attendance**

The workshop was open to all interested participants. One hundred and twenty two people attended including thoracic physicians, surgeons, oncologists, radiologists, general practitioners (GPs), nurses, federal and state government representatives, consumers, epidemiologists and public health professionals. The participant list is given in the Appendix.

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**Workshop Summary**

This summary contains a synopsis of each presentation and a summary of the points raised during the audience discussion that followed. A summary of the final discussion session and the recommendations and key points put forward is also included.

Abstracts for each of the presentations were included in the Program and Proceedings for the workshop, copies of which are available on request.
SESSION ONE: CHALLENGES OF LUNG CANCER IN AUSTRALIA

Lung cancer and the national service improvement frameworks (NSIFs)

Ms Susan Garner† & Dr Rosemary Knight‡

†Director, National Chronic Disease Strategy Section, Australian Government Department of Health and Ageing, and Secretary, National Health Priority Action Council; ‡Director, Cancer and Service Frameworks, Australian Government Department of Health and Ageing

Background: The Australian Health Ministers’ Advisory Council has agreed that a major focus of the National Health Priority Action Council (NHPAC) is on service improvement in the national health priority areas, one area of which is cancer.

International and Australian models to drive service improvement across systems are being examined, including frameworks from the United Kingdom (UK). In Australia, early work has commenced on the development of the NSIFs. Challenges and underlying principles include considerations of geography, organisational arrangements and the needs of disadvantaged groups, such as Aboriginal and Torres Strait Islander people, people living in rural and remote areas, people with a mental disorder and people who are socio-economically disadvantaged.

National service improvement frameworks: National service improvement frameworks are high-level guides for service planning, design and delivery for particular national health priority areas. Respecting and positioning patients at the centre of care, the NSIFs will incorporate the best available evidence of effectiveness and will represent a national consensus about aspects of care across the care continuum. The focus will be on the critical service intervention points, which will identify where optimal improvements in health outcomes can be achieved. The way care is delivered in response to the NSIFs will reflect the arrangements and needs of local communities.

Cancer is the first NSIF to be developed, as good data and evidence of improvement are available. Lung cancer and breast cancer have been chosen as case examples. For breast cancer there is evidence that improvements have been made and how this has been achieved, while for lung cancer there is emerging evidence that improvements are needed.

Key issues in lung cancer: Key issues in lung cancer include:

- one in 28 Australians will develop lung cancer by the age of 75 years
- lung cancer survival in Australia is poor compared with international data, especially for females
- there is poor prognosis, with typically only a small proportion of patients surviving beyond one year
• there is a lack of awareness about early signs
• appropriate early diagnosis and information about available treatment choices are important as is prompt referral from diagnosis to treatment
• affordable access to medication and symptom management are important as is attention to the psychosocial needs and care of patients.

There is a need to examine the culture around lung cancer including the perception of nihilism, with recognition about what can be done to make a difference. A key lesson from breast cancer has been the importance of the multidisciplinary approach and coordinated approaches to treatment and management planning, with patients indicating that a timely coordinated approach to care and guidance through the cancer ‘journey’ is as important as survival and prognosis.

**Critical service intervention points**: Critical service intervention points are points across the continuum of care identified as having the potential for significant health gain. These will be selected according to a set of criteria developed by NHPAC. Across all conditions, critical service intervention points:

• will be based on available evidence or represent the most effective / best practice
• have the potential to result in significant health gain / improvement in patient care
• address an identified gap in current health service delivery
• limit the progression and complications of the condition
• can be translated into practical service delivery improvements.

**Preliminary examples of national service improvement frameworks**: Some very early preliminary examples of what a NSIF may look like were shown. In an example of screening to enable early detection of cancer, critical service intervention points could include access to information about signs, symptoms and benefits of early diagnosis; access to screening within a defined time period (evidence-based); and timely recall prompts. In an example of disease management, where the desired outcome is the timely commencement of treatment for persons newly diagnosed with cancer, critical service intervention points could include access to specialist practitioner(s) or treatment within defined time periods; informed consent by the patient and treatment organised in accord with the patient's treatment choices; and access to information and education to enable patients / carers to participate in the management of their condition.

**Concluding remarks**: In developing the cancer NSIF using lung cancer as one of the priority cancers, it is desired that the frameworks be developed as a collaborative exercise. Ideas and suggestions are welcome through NHPAC or the Cancer Strategies Group.
Barriers to optimal care of lung cancer in Australia

Associate Professor David Ball
Chair, Lung Service, Peter MacCallum Cancer Centre and Chair, Australian Cancer Network Management of Lung Cancer Guidelines Working Party

Summary: A personal view of the barriers to optimal care for lung cancer in Australia was presented. Identified barriers include medical and consumer nihilism, problems with evidence, lack of resources, limited access to multidisciplinary opinion and inconsistencies in patient selection.

Medical nihilism: Differences in the attitude to treatment of lung cancer exist between different countries, medical disciplines and craft groups. For example, surveys of the recommended management for a hypothetical case of lung cancer (inoperable T2N0 adenocarcinoma) have shown differences between Australian and international clinicians, with a greater proportion of international clinicians indicating they would recommend radiotherapy compared with Australian clinicians (93% and 57% respectively) (van Houtte et al. 1999). More Australian clinicians recommended a wait and see approach (25% versus 5%). In addition, a clinical management survey of Victorian practice in 1993 found that 25% of lung cancer patients received no treatment, despite a significant proportion of these patients having good performance status or stage I non-small cell carcinoma (Richardson et al. 2000).

Treatment delays: There appear to be some delays in diagnosis and referral of lung cancer patients. Information from the Combined Lung Clinic at St Vincent’s Hospital in Melbourne has shown that for patients with primary lung cancer there was a period of 47 days between onset of symptoms and first medical presentation and a further 41 days between the first medical presentation and initial visit to the Combined Lung Clinic. The end result is an almost three month period between the onset of symptoms and initiation of treatment. It would be of interest to understand what occurs in the period between first presentation and initial lung clinic visit.

Suboptimal treatment: The nihilism and poor outcomes associated with lung cancer may foster a belief that lung cancer patients do not need to be treated as rigorously as patients with other cancers, such as breast cancer or lymphoma, with poor treatment leading to poor outcomes thereby perpetuating the cycle. For example, studies involving hypothetical situations have shown considerable variation in target volumes chosen by radiation oncologists for radiation therapy of lung tumours, implying a degree of carelessness. In an Australian study involving 168 lung cancer contours and 14 radiation oncologists, in only 47% was coverage thought to be successful with miss of macroscopic tumour occurring in 34% and normal structure being mistaken for tumour in 26% (Denham et al. 1993).

Consumer nihilism: Lung cancer consumers are not as active as consumers in other cancer areas in arguing for better care. With the aetiology of lung cancer being well established, lung cancer consumers are often made to feel guilty. They also have a short life expectancy, which leaves little time to join forces and form support or advocacy groups.
Accessing the best available evidence: Problems exist with regards to accessing the best available evidence for lung cancer. There is variation in the amount of lung cancer literature appearing in different journals, with suggestions that up to two thirds of the lung cancer literature may appear in general or non-respiratory journals. Not all clinicians caring for patients with lung cancer may read the oncological literature or access the Cochrane Collaboration. The Australian Clinical Practice Guidelines for the Management of Lung Cancer being developed by the Australian Cancer Network (ACN) may assist in improving this situation.

Absent and inconclusive evidence is also an issue, although it is important to note that absence of evidence does not necessarily equate with absence of effect. Absence of available evidence raises concerns that the research questions being asked may not always be the right ones. In some instances comparative studies of different treatment strategies for lung cancer are lacking. As a result there is diversity of practice and confusion, even amongst experts, about the best treatment that might be applicable to a particular situation. Few lung cancer patients in Australia are participating in clinical trials (Richardson et al. 2000).

Lack of resources: There is a lack of resources and personnel to deal with problems that lung cancer patients encounter. Variation in the availability of imaging technologies is one issue. The lack of access to linear accelerators (geographic maldistribution) was highlighted in the recent Inquiry into Radiation Oncology chaired by Professor Peter Baume (see http://www.health.gov.au/roi/inquiry/report.htm). In addition, a recent Australian study has demonstrated that positron emission tomography (PET) staging results in improved patient selection and doubling of median survival (MacManus et al. 2001). Not all patients, however, have access to PET scanners.

Conclusion: Clinician and consumer activism is needed. There is now good evidence for a number of effective interventions in lung cancer and this information is contained in the draft Australian lung cancer guidelines. In many areas, however, much more information is required. More clinical trials and patients on clinical trials are needed, as is greater access to multidisciplinary care.
Care and outcomes for lung cancer

Associate Professor Kwun Fong
Department of Thoracic Medicine, The Prince Charles Hospital

**Lung cancer data:** Outcomes data for lung cancer are available from both international (World Health Organization) and Australian (Australian Institute of Health and Welfare; state and territory cancer registries) sources. While cancer registries provide important epidemiological information they provide limited clinical detail and data are retrospective. Other important sources of lung cancer data include clinical trials, clinical management surveys and institutional data. Clinical trials involve selected populations of patients, with older patients and those with significant comorbidities often being excluded. Management surveys and institutional data while valuable are again usually retrospective.

**Queensland Integrated Lung Cancer Outcomes Project:** In Queensland, a project (QILCOP) involving the implementation of a prospective, largely population-based clinical data set has been established. Information collected includes clinical data additional to that collected by cancer registries such as information on: presentation; diagnosis and investigations; histological type; staging; curative or palliative intent of treatment modalities; relapse and survival. The QILCOP data set is consistent with the NCCI common clinical data set and aggregate reports are provided regularly to participants to empower them to make the changes necessary to improve progress in lung cancer.

QILCOP data has been collected since the year 2000 and information is now available for over 2 000 patients. It is estimated that, at present, information is collected for around 50% of lung cancer patients in Queensland, with data collected from all Brisbane teaching hospitals and most major regional centres. Data are collected using a standard pulmonary malignancy form, which can also be used for discussing patient management at multidisciplinary team meetings.

**QILCOP data:** Information presented included:

- **Patient demographics** – For non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC) (NSCLC: n = 1 795, age range 31–93 years; SCLC: n = 244, age range 39–85 years).

- **Histological subtypes** – Compared with historical data from The Prince Charles Hospital in Brisbane (1982–1985) an increase in adenocarcinoma (38% versus 34%) and a decrease in squamous cell carcinoma (33% versus 48%) is seen. This is consistent with international data.

- **Presenting symptoms** – 84% of patients presented with symptoms and 16% were asymptomatic.

- **Smoking status** – Nearly 95% of patients are smokers (current or former smokers), with a majority of lung cancer cases occurring in former smokers. This is believed to be the first time that this has been shown in Australia and it has important implications for early detection, risk profiling, screening and public health policy.

- **Clinical prognostic indicators** – Performance status (ECOG) and comorbidities. A substantial proportion of patients have comorbidities including COPD, ischaemic heart
disease, cerebrovascular disease, diabetes and renal failure. These are factors that impact on treatment and outcome.

- **Staging** – Accurate staging is a key step for the optimum management of lung cancer. Over 95% of NSCLC patients were staged at the time of presentation to the multidisciplinary teams.

- **Treatment** – An important marker for assessing improvement in outcomes for lung cancer. Surgery and radiotherapy figures for NSCLC have not changed considerably over the past 20 years (compared with historical data from The Prince Charles Hospital, 1982–1985). An increase in chemotherapy is seen with approximately 10% of patients now receiving chemotherapy, reflecting emerging evidence from clinical trials.

- **Survival** – The data collected allow survival for all stages of lung cancer to be determined (to help ensure that best practice is being delivered).

**Patient perspective:** The patient’s perspective is important. Major issues include waiting times for diagnosis and treatment, and discrimination with respect to age. An intervention, the Rapid Access Lung Cancer Assessment Clinic, has been instigated and its effect examined. For 25 referrals to the clinic there was a mean of six days before a specialist was seen and a further mean of eight days before a histological diagnosis was reached. A diagnosis of lung cancer was made in only a proportion of patients (6/25), highlighting the importance of both early and appropriate referral. Data on treatment delays for 52 consecutive patients (both NSCLC and SCLC patients) revealed the longest treatment delays occurred in patients waiting for radiotherapy or combined radiotherapy and chemotherapy. The data indicate little evidence of discrimination in treatment with respect to age. Over 40% of patients aged over 70 years still received surgery despite a higher prevalence of comorbidities in this patient group. For those aged over 80 years the surgical rate decreases, however, this is probably quite appropriate.

**Health care quality perspective:** As early stage lung cancer is a potentially curable disease by surgery, a major aim is to ensure that early stage I or II tumours are considered for surgery as often as possible. In a cohort of 598 patients (TNM stage I or II), around 25% did not undergo surgery but received radiotherapy instead. The clinical data reveal these patients tend to have a higher incidence of comorbidities, be older in age and have a poorer performance status, with their lung function probably precluding surgery.

**Health provider perspective:** The data collected provides information relevant to the health provider. The draft Australian lung cancer guidelines and latest international guidelines suggest that in cases of early stage, asymptomatic lung cancer there is limited role for extensive staging. Examination of the QILCOP cohort (stage IA, asymptomatic patients) found that clinicians still considered there was a role for staging investigations (bone and brain scans) in some of these patients.

**Conclusion:** QILCOP is collecting important prospective population-based data to enable clinicians to learn from patient care and develop better care and outcomes. The project provides information on activities performed in routine community settings and on patients not studied in clinical trials. It can assist in the evaluation of guidelines and facilitates multidisciplinary practice. Key success factors include the need for good data standards, ensuring that the privacy framework is maintained, and obtaining adequate funding and infrastructure. It is hoped that QILCOP can be shared with others across Australia to use in capturing lung cancer outcomes.
Lung cancer in Indigenous and rural/remote Australians

Dr John Condon
Epidemiologist, Menzies School of Health Research and Director, Northern Territory Cancer Registry

**Incidence and mortality:** The pattern of cancer incidence and mortality is different in Indigenous Australians compared with other Australians. Cancer incidence and mortality statistics for Indigenous people are not available nationally, with data really only available for South Australia, Western Australia and the Northern Territory. The data presented here are summarised in a recent review (Condon et al. 2003).

Lung cancer has a greater impact in Indigenous Australians compared with non-Indigenous Australians. In the Northern Territory, incidence and mortality rates for Indigenous people are approximately twice the rates for the total Australian population (for both males and females). A higher incidence rate for lung cancer in Indigenous females has also been reported in South Australia and data from a limited study in the three western states show a higher lung cancer mortality rate in Indigenous males compared with non-Indigenous males.

**Survival:** There are no published reports of lung cancer survival for Indigenous Australians. Published information on cancer survival from South Australia (1988–1994) shows five-year cause-specific survival for all cancers in 139 Indigenous cases to be lower (37%) compared with non-Indigenous Australians (49%). Unpublished data from the Northern Territory Cancer Registry indicates that five-year survival rates for most cancer sites are 30% to 50% lower for Indigenous people compared with total Australian rates. Indigenous lung cancer survival is also lower, although the absolute difference is small and not statistically significant.

**Trends:** No national data are available on trends in lung cancer incidence for Indigenous people. Long-term mortality data from the Northern Territory indicates that since the late 1960’s lung cancer mortality has more than doubled for Indigenous males, with lung cancer mortality rates now exceeding those for total Australian males. For Indigenous females, lung cancer mortality rates have almost doubled since the late 1960’s, with most of the increase occurring since the 1980’s.

**Tobacco consumption:** There is a high prevalence of tobacco consumption by Indigenous Australians. In 1994, 54% of Indigenous males and 46% of Indigenous females reported that they currently smoked (ABS 1994). This was twice the prevalence in a comparable Australian population survey (CDHFS 1995). Smoking rates for Indigenous Australians have been reported to be even higher in the northern region of the Northern Territory, where some 70–80% of Indigenous adults currently smoke.

Indigenous Australians appear to have a different perception of smoking risks compared with other Australians. In a survey asking which of several listed substances causes death, tobacco was chosen by less than 5% of Indigenous people in urban areas compared with over 30% for other Australians. Over 60% of Indigenous people named alcohol as causing the most deaths. Campaigns to reduce smoking in the Indigenous population have had little impact.
Clinical management: There are a number of specific clinical issues that must be considered in the management of Indigenous patients with lung cancer. These include:

- Screening and treatment for scabies, strongyloides and tuberculosis in patients from remote communities and town camps who are being offered chemotherapy.
- Detection of febrile neutropenia in patients receiving chemotherapy, with family members, community nurses and Aboriginal health workers from remote areas and community health centres being trained to detect the condition. Special antibiotics are supplied to remote clinics for early administration, if clinically indicated, prior to transportation to hospital.

The specific clinical issues do not apply to all Indigenous patients in all areas and specialist cancer centres should seek advice on distinctive, particularly infections disease problems, from those referring Indigenous patients.

General issues in health care for Indigenous Australians that are equally important in lung cancer management, include:

- Serious diseases are often diagnosed very late in Indigenous people.
- There are issues of access to primary health care and access to basic investigations such as chest X-rays in some areas.
- Chronic diseases such as diabetes, heart disease and renal failure are common in Indigenous adults, particularly in younger adults, compared to the general population. These can limit treatment options for cancer and increase treatment complications.
- Health services can alienate rather than accommodate Indigenous people. Increasing the proportion of Indigenous health care workers, Aboriginal health workers, Indigenous liaison officers and trained medical interpreters can help improve the situation.
- Better communication between health professionals and patients is vital to improve understanding and compliance with treatment. All health care professionals involved in complex decisions about treatment options need to be aware of the different decision making authority in Indigenous families and the complexity of cross-cultural communication.

The issues are equally relevant in tertiary centres as in remote hospitals.

Rural Australia: Lung cancer incidence and mortality rates in rural areas are similar to those in capital cities, as is smoking prevalence. An important issue in rural regions is access to high quality lung cancer management. Many non-Indigenous residents of rural areas live near capital cities and have reasonable access to primary health care and basic specialist services. A distinctive issue for lung cancer management in rural areas is access to experienced sub-specialist medical support services, which are almost exclusively located in capital cities. While travel to and treatment in specialist tertiary centres is part of the solution, it is neither practical nor desirable for total lung cancer management.

For all Australians in rural and remote areas, an excellent collaborative regional service is of more benefit than a remote excellent centre.
No longer ‘just a GP’

Professor Brian McAvoy
Deputy Director, National Cancer Control Initiative; Adjunct / Honorary Professor, University of Melbourne, Monash University and University of Queensland; and General Practitioner, St Kilda, Victoria

Background: Changes are occurring in general practice driven by a number of factors. These include an ageing population; a shift towards more chronic disease; redirection of health care emphasis from the hospital to the community; rising public and government expectations; and advances in technology and information management. There is clear evidence that primary care oriented health services are associated with lower costs of care, higher patient satisfaction, reduced use of medications and better levels of health (Starfield 1994). The NCCI is developing a primary care perspective on cancer, to increase input and emphasis on the important contribution that primary care can make to cancer care.

Generalist practice: Generalists and specialists require different knowledge, skills and attitudes, but are complementary in their roles. General practitioners are often committed to the person rather than to a body of knowledge, group of diseases or special techniques. The spectrum of problems presenting in general practice is very different from those seen in the hospital setting and GPs have to combine scientific and humanitarian approaches to medical practice and provide holistic care to patients.

A model increasingly taken up around the world has the GP no longer working as an individual in his or her practice but as part of a generalist care team surrounded by specialist networks of services within the community (RCGP 1996). Research in different countries has shown that in terms of patients who are experiencing symptoms, only 25% consult a GP and of those patients 90% are managed within the community, with only a small proportion ending up in hospital.

Roles and activities: General practitioners and specialists have differing roles and activities. General practitioners have to accept uncertainty, explore probability, marginalise danger and exclude the presence of serious disease. Specialists have to reduce uncertainty, explore possibility, marginalise error and confirm the presence of serious disease (Marinker 1990).

Skills: General practitioners need to possess wide-ranging skills. A key skill is to solve undifferentiated problems in the context of a continuing personal relationship with individuals and families (McWhinney 1997). General practitioners also need to have preventive skills, therapeutic skills (to maximise the effectiveness of all kinds of therapy), resource management skills, and teaching and research skills.

GP workload: In Australia, there are 105 million consultations per year in general practice. Over one quarter of a million people consult a GP every day and 80% of the population consult a GP at least once a year. The average number of visits to a GP is 6.5 per year. Various surveys have shown average working times of 45–51 hours per week, with around 140 consultations per week and an average consultation time of 13.5 minutes.

Cancer workload: On average, a GP will see only four new serious cancer cases and around 1.5 cancer deaths per year. It has been estimated that at any one point in time a GP will have around 16 patients with cancer under his or her care. However, 20% of adult Australians are smokers and a large population in the practice may be at risk of breast, cervical and bowel
cancer. An even larger population may present with suspicious symptoms or possible concerns about cancer.

**Role of primary care practitioners in cancer care:** Primary care practitioners have key areas of activity in cancer care. These are:

- screening and early diagnosis
- coordination of care, involving communication and psychosocial support for patients and carers
- management of comorbidity
- delivery of palliative care services.

While hospital wards and outpatient clinics are critical sojourns on the itinerary of the cancer ‘journey’, the great majority of the cancer patient’s journey takes place in the community.

**United Kingdom experience:** Important work has been undertaken in the UK, some of which is transferable to Australia. The National Health Service Cancer Plan has redesigned cancer care, assisted by a systems approach utilising an improvement science model. The Cancer Services Collaborative has been a major step forward. Other major steps include the formation of cancer networks and tumour specific pathways, and the appointment of Primary Care Cancer Leads in all the Primary Care Cancer Trusts. The targets of the Cancer Services Collaborative program include improving access, outcomes, experiences, and certainty and choice for cancer patients.

Key strategies that have been successful in improving care in the UK involve:

- connecting the different parts of the patient journey
- developing the team around the patient’s journey
- making the patient and carer experience of care central to every stage
- making sure there is capacity to meet patient needs at every stage.

These are all key areas where primary care practitioners have a critical role to play.

**Conclusion:** General practitioners, nurses and other primary care professionals have a key role in cancer services and are major contributors to care throughout the entire cancer journey.
The consumer perspective

Mr John Stubbs
Executive Officer, Cancer Alliance Network (CAN) Australia

Needs of consumers:

1. *Access to information*
   - Access to quality information for all stages of cancer, including information on and awareness of the importance of early detection and treatment.
   - Ensure treatment or cancer care plans, including discharge plans, are provided for all patients.
   - Provide greater access to and understanding of the value of clinical trials.
   - Provide evidence-based advice for pre- and post-cancer treatment, including information about supplementary and alternate diets and other therapies. A considerable amount of information, including false and misleading information, is available on the Internet and patients need guidance in this area.

2. *Understanding the health system* – Patients need guidance in understanding the health system and how it fits together. The health system is complex and a cancer patient’s ‘journey’ can involve contact with numerous health professionals (GPs, nurses, medical specialists, other allied health professionals), institutions (private hospitals, public hospitals, palliative care services) and other organisations (cancer councils, private allied health organisations, non-government domiciliary transport services). This can be confusing for patients who may not understand where they are going.

3. *Empowerment* – It is important to give cancer patients the opportunity to become involved in their treatment. This includes understanding what the various steps involved in the cancer ‘journey’ will be and being led through that journey. Once set on this path, consumers can be a very knowledgeable group. Consumers also need a voice and skills in advocacy. Various organisations including cancer councils, TAFE colleges and some private organisations, now provide advocacy training. With these skills consumers can assist in lobbying for the cause of others, including the cause of clinicians.

4. *Access to quality care*
   - Provide access to quality care (best-practice care focused on patient needs) for all patients wherever located, including country centres.
   - Wherever possible provide treatment in accredited comprehensive cancer care centres, preferably offering multidisciplinary services from diagnosis to palliation including psychosocial care.

**Assisting the system:** Consumers can assist health care professionals in improving the health system. Ensure that consumers can participate in all levels of decision making in relation to their treatment. Develop an accreditation system in cancer care for health services throughout the country to ensure that standards are met. Address anomalies and inequities in the
Pharmaceutical Benefits Scheme, Medicare, private health insurance and other work-related insurance problems.

**Survivorship and support:** Recognise the important role support groups have in assisting many patients in dealing with psychosocial factors, including issues related to diagnosis, treatment and recurrence. Psychosocial care is most important. There are many psychosocial programs and models of psychosocial care that have been developed independently throughout Australia. These could be used to inform a national model of psychosocial care.

Cancer, post treatment, can be chronic disease and increasingly emphasis will fall onto consumers to ensure that they get the proper post-treatment care.

**Tips for health care professionals:**

- Actively involve consumers in their health care.
- Set aside time to allow patients to talk to people or have the information available to refer consumers / patients to get other advice.
- Provide information to consumers in a format that is easy for them to understand.
- Take a complete medical history including over the counter and complementary medicines.
- Provide oral and written information about medicines in plain language.
- Develop strategies to ensure that consumers get the results of their tests and investigations and provide options that they can talk through with you.

**Conclusion:** The statistics on lung cancer are poor. Establishing partnerships between consumers and health care professionals is a positive step towards improving the outcomes for patients with lung cancer. The recent *Optimising Cancer Care in Australia* report (COSA, TCCA & NCCI 2003), a consultative report released in February 2003, had input from and the support of consumer groups. It provided government health ministers (federal and states / territories) with a national model for cancer care and enabled consumers to assist in prioritising issues for cancer treatment.
The questions and discussion covered a number of issues raised in the presentations. These are summarised under the headings below.

Levels of evidence

The relationship between the NCCI, NHPAC and other government bodies such as the Medical Services Advisory Committee (MSAC) in terms of the levels of evidence required for new diagnostic or therapeutic procedures, was explained.

The Australian Government runs its cancer control programs essentially through two main outsourced organisations, one of which is the NCCI. The NCCI is funded by the Australian Government to provide the Government with up-to-date evidence and information on aspects of cancer control. The NCCI is represented on the Cancer Strategies Group, which reports directly to NHPAC.

Another principal source of evidence for those working in cancer control in the Australian Government is the National Health and Medical Research Council (NHMRC). In addition, evidence related to pharmaceuticals is obtained from the Pharmaceutical Benefits Advisory Committee (PBAC) and evidence for new diagnostic procedures and therapeutic interventions through MSAC. Both MSAC and PBAC have evidence-based frameworks.

It is the job of those within the Government cancer control area to collate the information and identify the evidence around what should be funded and importantly where we should be making a difference. The various organisations are all in line with respect to the levels of evidence considered acceptable and all communicate with each other.

Prevention

Implementation of effective prevention strategies for lung cancer is an area where consumers could assist the health system. Smoking is the largest factor responsible for lung cancer. In South Australia, legislation to restrict smoking in gaming areas and front bars of hotels is being developed, which will soon be available for consultation. Consumer networks could have a powerful say in this type of legislation, thereby assisting in reducing lung cancer through a reduction in exposure to tobacco smoking. The general practice initiative Smoking Nutrition Alcohol and Physical Activity (SNAP) is a good example of the integration of preventive interventions in a primary care setting.

It was recognised that prevention is a critical element in the total control of lung cancer. However, as the focus of the current workshop was on the management of established disease, the emphasis on prevention was not as strong as it otherwise might have been.
Smoking cessation

Evidence has recently become available that patients with head and neck cancer or lung cancer who continue to smoke whilst receiving treatment have poorer outcomes. It was suggested that given the therapeutic benefit of smoking cessation for patients diagnosed with lung cancer who still continue to smoke, more resources should be made available to assist these patients to stop smoking. Nurses can play an important role in providing advice and counseling to patients who continue to smoke.

Psychosocial support

In much of the community there is a very negative view of people who have lung cancer, including the view that they are responsible for having brought the disease upon themselves. This attitude may have affected the manner in which psychosocial support might not have been provided in the past or could be provided in the future.

New strategies to assist people with lung cancer who are fatigued by their disease and are not inspired by the traditional activities for those with cancer, are required. What has previously been tried has had difficulties in that many lung cancer patients have been too unwell to participate in traditional cancer support groups. In addition, the poor prognosis of lung cancer has meant that people with lung cancer may attend for only one or two meetings and then they “are not there anymore”. This can have a depressing effect on other participants in the group.

Performance measures

Consumers could have an important role in working together with health care providers around accountability for the performance of the health system, for example, public accountability around a data system. The need for evidence-based information is recognised by consumers. However, in many instances data on the performance of the health system are quite old and with respect to consumers much of the current focus is on information provided at an individual level. Involvement of consumers in various activities including prevention, accreditation, provision of information, data and support, can only achieve better outcomes for everybody.

Performance measures will be integral to the NSIFs. NHPAC has formed an advisory group that is looking at performance measurement across the system. Reporting at a national level on the performance of the health care system is challenging. The Australian Government is examining existing data and how useful this might be to assess change over time to provide an indication of how the system is performing.
Indigenous data

An acknowledged difficulty in the area of Indigenous data is the identification of Aboriginality and accurate definition of the population. This is a problem for those working in urban areas such as central Sydney, which has perhaps the largest Indigenous population in Australia, as well as for those working in rural areas.

It was not possible to comment on differences that may exist between Indigenous populations in urban and more remote settings in terms of lung cancer exposure, for the reasons outlined above. For urban areas on the east coast it is not known whether lung cancer incidence is similar to the western states – possibly not. The identification of Indigenous people in death statistics and cancer registries in the Eastern States is inadequate to obtain incidence or mortality rates, which may be significantly underestimated.

In Queensland, incidence and mortality information is available for a set of remote communities where the population is over 90% Indigenous. In general, this is consistent with what is available in South Australia and the Northern Territory. In Western Australia, it was thought that the cancer registry had not published incidence information for Indigenous people for more than a single year at a time. This makes it hard to form a complete picture. Rates in Western Australia may be underestimated as well.
Clinical practice guidelines for the management of lung cancer

Emeritus Professor Tom Reeve AC CBE
Senior Medical Advisor, Australian Cancer Network

**Background:** Clinical practice guidelines for the management of lung cancer are being developed by the ACN. The lung cancer guidelines follow the development by the ACN of clinical practice guidelines for breast cancer, melanoma and colorectal cancer. Among the catalysts for developing the lung cancer guidelines were the Victorian clinical management survey (Richardson et al. 2000) and a survey of Australian respiratory physicians (van Houtte et al. 1999), which revealed variations in the level of care and approaches to treatment for a single type of lung cancer case.

**Development:** The development of the *Clinical Practice Guidelines for the Management of Lung Cancer* included discussion with the TSANZ and the Australian Lung Foundation. The need for the guidelines was clearly established, with lung cancer meeting criteria for prevalence of disease, variation in treatment and high cost to the community.

**Target groups:** The guidelines are directed at clinicians and other health care professionals involved in the management of lung cancer. General practitioners are an important group, although individually they may see few lung cancer cases during their career.

**Working party:** A multidisciplinary working party was established with broad representation from various clinical disciplines. The terms of reference for the working party were:

- To inform clinicians of the incidence and special factors relating to lung cancer in Australia.
- To provide a broad picture of prevention and screening and pinpoint factors relating to the diagnosis of lung cancer.
- To provide an evidentiary basis for patient support and definitive treatment.
- To pay special attention to symptom control.
- To address SCLC and NSCLC, not adenocarcinoma or mesothelioma.
- To address cost–effectiveness, where possible, in various forms of management.
**Development process:** The development process followed the NHMRC’s *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1999). Levels of evidence were assigned as designated in the NHMRC publication (levels I–IV). While previously clinical opinion was accepted, this is no longer the case.

The process followed in developing the lung cancer guidelines included a general discussion to set the scene, allocation of topics to small multidisciplinary groups to systematically review the literature and draft chapters, and submission of draft chapters to the working party for review. The draft document was revised on a number of occasions and then made available for public consultation. All submissions received from the public consultation were considered and addressed by an executive of the working party, with an independent Chair.

**Current status:** At the time of the workshop, the draft lung cancer guidelines had been sent to the Health Advisory Committee of the NHMRC for a further independent review. Once comments are received from the independent review these will be addressed by the working party and the final version submitted to the NHMRC for accreditation.

**Dissemination:** Presentations about the guidelines have been made at annual scientific meetings of the TSANZ (2000–2002). In addition, the current workshop has provided an important opportunity to promote the guidelines to those working in the area. Following publication, there will be a wider distribution of the guidelines to clinical leaders and a multiple seminar program is planned. It is intended that an A4 laminate for GPs be produced to accompany the guidelines. The support of colleagues, speciality societies and consumers will be enlisted to assist with the dissemination process.

**Implementation:** Implementation of the guidelines will be tied to quality and safety measures. This will need support from those already involved, as well as support from the broader clinical community. Patterns of care studies over time will assist in increasing implementation and in evaluation.

**Concluding remarks:** The process followed in developing the Australian lung cancer guidelines reveals the high levels of cooperation that exist in our professional groups and broader community. Together great things can be achieved by focussing on delivering the best evidence-based care. A future step will be the revision of the current guidelines.
Use of radiotherapy in lung cancer: optimal and actual

Associate Professor Michael Barton
Research Director, The Collaboration for Cancer Outcomes Research and Evaluation, Liverpool Hospital

Background: The presentation summarised research undertaken to estimate the optimal rate of radiotherapy utilisation for lung cancer in Australia. The lung cancer study formed part of a larger project investigating radiotherapy utilisation for different cancers. The lung cancer findings have recently been published (Delaney et al. 2003).

Access to radiotherapy: In Australia, access to radiotherapy can be problematic and there is variation in utilisation rates within the country. Although the current benchmark for optimal radiotherapy utilisation is approximately 50% to 55% this is not evidence-based but rather is based on expert opinion and actual rates in well-resourced areas. Determining the optimal rate of radiotherapy utilisation is important as it (i) enables population-based resource planning and (ii) can be used in benchmarking for service delivery.

Project aims:

1. To estimate the ideal proportion of each type of cancer that should receive external beam radiotherapy at some time during the course of a patient’s illness from the best available evidence.

2. To develop a model of radiotherapy utilisation that is evidence-based and which can be altered in the future.

Methods: All cancers with an incidence in Australia of greater than 1% were identified and literature searches conducted to obtain Australian and international treatment guidelines and reviews. These were searched and levels of evidence for efficacy and epidemiology were assigned. A radiotherapy utilisation tree was constructed for each cancer, with cancers being initially divided by site, then stage, performance status and whether radiotherapy was indicated or not. For each indication for radiotherapy an incidence was given.

- Indications for radiotherapy – Defined as being where radiotherapy would produce a superior clinical outcome (improved survival, local control or lower toxicity) and the patient was suitable (sufficient performance status and lack of comorbidities).

- Incidence – Evidence was obtained from population data, hospital registries and individual series. Epidemiological data were ranked according to a quality scale.

The proportion of patients in whom radiotherapy was recommended was calculated by calculating the frequency of each indication for radiotherapy and then summing the frequencies to determine the overall optimum utilisation rate.

The robustness of the model was validated through sensitivity analyses, including Tornado (univariate) and Monte Carlo (multivariate) analyses. The process was subject to extensive peer review by both radiological experts and a wide range of non-radiation oncology experts, including Chairs of guideline committees. The project was accountable to a multidisciplinary
steering committee. A comparison was made with similar work undertaken in Canada, which identified some interesting similarities and differences.

**Optimal radiotherapy utilisation for lung cancer:** The optimal evidence-based utilisation rates for radiotherapy in lung cancer are summarised in the table below. Additional data, including comparison of optimal and actual utilisation rates, can be found in the published paper (Delaney et al. 2003).

<table>
<thead>
<tr>
<th></th>
<th>At any time</th>
<th>At first presentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small cell lung cancer</td>
<td>79%</td>
<td>68%</td>
</tr>
<tr>
<td>Non-small cell lung cancer</td>
<td>75%</td>
<td>68%</td>
</tr>
<tr>
<td>All</td>
<td>76%</td>
<td>68%</td>
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**Optimal versus actual radiotherapy:** The data available for comparing optimal versus actual rates of radiotherapy utilisation are limited and out of date. Several data sources were examined including population-based data from national surveys, patterns of care studies and the United States (US) Surveillance, Epidemiology and End Results (SEER) program, as well as data from hospital-based registries such as the South Australian Cancer Registry. Comparative rates of utilisation were presented for both NSCLC and SCLC. It was noted that overall far fewer patients receive radiotherapy than may benefit from the treatment.

There is an increasing trend towards the use of radiotherapy from the late 1980's to the year 2000, but with considerable variability in utilisation from one area to another. Data from the SEER database show radiotherapy utilisation for lung cancer falls with patient age, with a decline in use commencing at around age 50–55 years. An exception is for patients with stage I disease where utilisation increases for ages 55–64 years, presumably as a substitute for surgery. Only very limited age-specific data are available in Australia (from the South Australian Cancer Registry).

**Other treatment modalities:** The current model can be used to assess or benchmark other treatment modalities. For example, the optimum utilisation rate for surgery in lung cancer based on available evidence was estimated to be around 20%. Data from patterns of care studies show actual rates to be close to this optimum. In addition, while around 10–12% of lung cancer patients are of poor performance status and thus may not be offered treatment, in many jurisdictions in Australia the rate of no treatment is well over 20% and in some is closer to 40%.

**Further research:** Issues requiring further research include declining utilisation with age, geographic variation and ‘gatekeeping’ (ie. the concern that patients are not being referred).

**Conclusions:** Radiotherapy utilisation for lung cancer is increasing with time but a concern is that utilisation rates decrease with decreasing patient age. Radiotherapy is under utilised (reasons include old equipment, workforce shortages, gatekeeping and access issues) and the data quality are poor. The availability and timeliness of data is an issue that must be addressed urgently if we are to improve outcomes.
New imaging techniques in the management of lung cancer

Professor Ken Miles
Queensland University of Technology and The Wesley Research Institute

**Computed tomography – limitations in diagnosis and staging of lung cancer:** Computed tomography (CT) is the main technique used at present for the diagnosis and staging of lung cancer. Although CT is highly sensitive for the detection of lung nodules (sensitivity ~99%) it has limited ability to characterise nodules as benign or malignant (specificity ~61%). Computed tomography may miss endobronchial lesions and its accuracy in mediastinal staging is poor (sensitivity 56–65%, specificity 44–87%).

**Computer-based approaches for enhancing CT performance:** Computer-based developments aimed at improving the performance of CT include CT bronchoscopy (virtual bronchoscopy) and automated volume measurement. While CT bronchoscopy effectively detects stenotic lesions and can simultaneously evaluate extraluminal compression, it may miss mucosal lesions and cannot biopsy. The use of this technique is still unclear.

Automated volume measurement is emerging as an important method for evaluating CT-detected lung nodules. With repeated scans increases in nodule volume and doubling time can be determined. The accuracy of volume measurement is high but the diagnostic criteria for malignancy remains unclear. A larger series is needed to evaluate the technique.

**Contrast enhancement and tumour angiogenesis:** Contrast enhancement within lung nodules is correlated with microvessel density and is thus related to angiogenesis (Swensen et al. 1996; Tateishi et al. 2001). This approach can be used to characterise nodules that are indeterminate on conventional CT. Enhancement greater than 15 Houndsfield Units implies malignancy with high sensitivity (88–100%). However, as some inflammatory nodules can have high enhancement, the specificity is lower (36–85%).

The technique can be included in diagnostic algorithms to better characterise nodules as benign (no enhancement) and direct patients towards follow-up. This can save health care costs by avoiding additional investigations, such as PET scans, in some patients. Decision tree sensitivity analysis indicates that for solitary pulmonary nodules a management strategy that incorporates functional CT measurement is the most cost–effective.

**CT versus MRI measurement of contrast enhancement:** Measurement of contrast enhancement is also possible using magnetic resonance imaging (MRI). Use of MRI avoids ionising radiation and can assess a larger volume of tissue, so that it may be possible to characterise mediastinal nodes as well as lung nodules. Advantages of CT include that it remains the mainstay for anatomical imaging of cancer, commercial software is available for CT enhancement, and the relationship between enhancement and contrast medium concentration is more straightforward compared with MRI.

**Conventional nuclear medicine:** Developments in conventional nuclear medicine in the management lung cancer include:

- the continuing replacement of conventional radioisotope bone scans by MRI
• use of perfusion radiotracers tracers such as $^{99m}$Tc MIBI or $^{201}$Tl thallous chloride in diagnosing and staging cancer. These agents are more accurate than CT (Nosotti et al. 2002) but are less accurate than PET. In SCLC, $^{111}$In octreotide may have a role in determining somatostatin receptor status.

**Positron emission tomography:** There are now two indications for fluoro-deoxyglucose (FDG)-PET allowable under Medicare:

1. *For evaluation of a solitary pulmonary nodule where the lesion is considered unsuitable for transthoracic fine needle aspiration, or for which an attempt at pathological characterisation has failed.*

2. *For the primary staging of proven non-small cell lung cancer, where curative surgery or radiotherapy is planned.*

In Australia, PET is limited to seven locations within the country and is subject to an ongoing review of its utility. The Federal Government review concluded that PET is more accurate than conventional staging (PET: sensitivity 89–100%, specificity 58–100%; CT: sensitivity 56–65%, specificity 44–87%) but felt that more data were needed. False negatives (particularly carcinoid tumours and alveolar cell carcinoma) and false positives (associated with chronic inflammatory conditions) do occur. The Government review also concluded that with the use of PET management is changed in a high proportion of patients (32–51%), that PET is potentially cost–effective and that it may provide prognostic information on the basis that high uptake of FDG is a poor sign.

A benefit of using PET for characterising solitary pulmonary nodules is that unsuspected nodal or distant metastases may be detected. Thus, staging information is simultaneously provided and with greater accuracy. Studies have indicated that PET used in this way can be cost–effective. It is suggested that in Australia PET could save around A$750 per patient.

Data from the Peter MacCallum Cancer Centre show improved separation of survival curves for lung cancer patients stratified by FDG-PET compared with conventional staging using CT, bone scan and (where available) pathology. This highlights the importance of accurate imaging in the evaluation of therapeutic modalities, as incorrect classification of patients by stage can impact on the observed treatment response.

**Cost–effectiveness of FDG-PET in staging non-small cell lung cancer:** Cost–effectiveness studies have shown variable results. In Australia, current evidence suggests that FDG-PET is marginally cost–effective (saving A$35–$360 per patient). The cost–effectiveness is dependent on the ratio of PET costs to surgical costs, which are highly variable. Positron emission tomography is more likely to be cost–effective for patients without enlarged mediastinal nodes on CT.

**Emerging roles:** Emerging roles for FDG-PET in the management of lung cancer include (i) risk stratification, (ii) radiotherapy planning, (iii) therapy monitoring, and (iv) diagnosis of recurrent tumours. Combined PET / CT systems are also being developed, which have the potential for sophisticated characterisation of tumour biology through combining two functional images at the same time.
Priorities for improving current practice

Professor Bruce Barracough
Medical Director, Australian Cancer Network and Chair, Australian Council for Safety and Quality in Health Care

Background: Information presented was drawn from work in progress through the Australian Council for Safety and Quality in Health Care and other organisations, as well as work being conducted by the ACN.

Priorities for improving current practice: Important issues for improving current practice are:

- **A patient focused value set**
- **Accountability to management and the community** – This can be difficult to generate and requires the availability of good data. Currently, in our system support for data collection is minimal. A review of surgical services across 89 surgical units in New South Wales public hospitals reported by Professor Allan Spigelman and others, found that many units did not have enough support to conduct even simple audit programs let alone collect information for national benchmarks.
- **Leadership** – Leadership at local, state and national levels is essential to bring about the change required to improve practice.
- **Structures and processes to support best care** – In Australia, structures and processes to support best care are lacking. Work conducted by Shewart, Deming and Donabedian indicated that the greatest improvements can be gained by attention to processes. Proper accreditation is also needed. The ACN is commencing work in this area and has established a steering group to develop accreditation standards for cancer services. The ACN is also establishing a group to develop credentialing templates – initially for senior clinicians – necessary to allow organisations to put processes properly in place. At a national level work is being undertaken to encourage safe staffing.
- **Knowledge of best care (guidelines)** – Evidence-based guidelines have been produced by the ACN and associated groups, and have been disseminated. There have been limited resources put into further implementation of these guidelines because at present no pool of funding for implementation has been identified. The ACN has established a small group to look at developing a generic implementation program for evidence-based cancer guidelines.

Values: While a great deal is heard about clinical governance, if corporate governance is guided by a proper value set, we will have good clinical governance. It is important to ensure that organisations providing cancer services have a value set that is patient centred and focused on safety and quality. For example, the New South Wales Institute for Clinical Excellence, in developing its value set, listed action items in relation to the values to enable recognition that they are being met. These are as follows:

- **Respect** – through a continuing focus on the patient and collaborative team work
- **Innovation** – through producing new ideas and change for the better
• **Courage** – through challenging the existing system
• **Teamwork** – through working collaboratively, building clinical teams and communication with stakeholders
• **Professionalism** – through being skilled in all we do and being self starters
• **Equity of outcomes** – through working to reduce inequities and outcome disparities
• **Scientific method** – through using measurement and evaluation, and decisions based on evidence and reporting.

It is important to identify the activities that make the claimed values a reality.

**What does this mean in practical terms?**

• **Knowledge of patterns of care** – Knowledge of patterns of care is needed in order to make sense of the data that are collected.

• **Audit, benchmarks and reporting to the community** – There are few national benchmarks for any disease available in Australia. The Australian Council for Safety and Quality in Health Care is stimulating benchmarking, with the first action being funding for activity that will lead to a national cardiac procedures register (both medical and surgical).

• **Effective credentialing with performance agreements** – These are important, not only to identify that people have the required background skills but to make sure that they maintain competence (possibly as defined by their college or society, each year) and can improve. This may involve identifying the resources and support needed, including data collection, to ensure that performance is at the highest level.

• **Evidence-based guidelines with an implementation program** – While we have done well in producing and disseminating guidelines, more needs to be done with regards to implementation.

**Deficiencies of current data collection:** There are enormous deficiencies in our current data collection processes including that the purpose of collection can be unclear; that data collection is of limited use for clinicians and facilities; and that data collection does not lead to system improvement. There are few hospital-based cancer registries. These must be encouraged to achieve adequate data collection.

**Benchmarking:** This is vital. Without benchmarking we cannot really be accountable to the community, to management or to individual patients. However, benchmarking is complex and there are important considerations including: what is being measured and why; that there is a point of reference for comparison (eg. uniform collection); and that there are realistic data to benchmark against.

**Requirements for data collection:** The focus needs to be on data collection as the most important priority. This needs to be part, if possible, of established national systems so that data and the way in which they are collected are uniform. Data collection must not add to the burden of caring, and the data collected must be suitable for benchmarking and public reporting.

**Concluding remarks:** While in many ways the results of Australian cancer care are excellent, in other ways they can be improved. We need to know where and how we can make the changes. Support in order to answer this challenge is welcome.
Radiotherapy utilisation

In the radiotherapy utilisation project presented, a breakdown of the data for optimal radiotherapy rates into curative versus palliative in first-line treatment is possible. However, actual data on palliative or curative radiotherapy rates are not available for comparison. Cancer registries were the prime source of benchmark (denominator) data for the project and indications for radiotherapy are not registered.

The data presented gave an optimum rate for surgery for lung cancer of around 20%. It was explained that this was calculated by substituting in the model whether surgery was indicated or not, rather than whether radiotherapy was indicated or not. The program then sums the different incidences to produce the optimum rate. One way to validate the optimum rate is to examine the actual rates for surgery. As the actual and optimum rates are similar this suggests that the model is reasonable. The model does not indicate whether the patients undergoing radiotherapy or surgery are the appropriate ones because this information is not in the registry data.

Differences in the utilisation rates of radiotherapy for lung cancer were identified in different areas of Sydney, with rates in Northern Sydney where resources were greater being similar to Western Sydney and both still below the optimum. Utilisation rates for radiotherapy in the US were reported as being lower than those in Australia.

There is a certain cultural agreement, or disagreement, about the role of radiotherapy that differs from the evidence. This is not necessarily based on resources or the socio-economic status of the patient but relates to medical culture and issues of ‘gatekeeping’.

Further radiotherapy modelling

The model presented dealt with access to radiotherapy throughout the cancer ‘journey’. It was discussed that as the model is now developed it can be utilised further. There is the desire to model the effect of treatment delays, which is as large an issue as overall access, and to start adding efficacy values to the different outcomes – such as quality of life efficacy or survival efficacy. These efficacies can then be discounted based on delays.
Access to positron emission tomography scanning

There was discussion on the way forward with regards to access to PET scanning in both Australia and New Zealand. It was noted that it was difficult to answer the question in relation to New Zealand as the infrastructure is not really present in that country. One reason why access to PET scanning is currently limited in Australia is due to the requirement for data collection. This is an ongoing process. It may well be that at the end of the process there is enough evidence to lead to a broader dissemination of PET within Australia and to convince the New Zealand Government to institute a PET centre.

The UK has been through a similar process and the British report has come out favourably for PET. The situation may develop where it will be difficult to manage a patient with lung cancer without PET because it will have become the international standard of care. Use of PET has been included in the Australian lung cancer guidelines because it is backed by science.

The current workshop may assist in lobbying for the effective use of new technologies. To have identified best practice and to follow best practice is probably the most important way we have of influencing people / government to fund what is needed. If clinicians are all working to best practice and along appropriate pathways, and have agreement that this is being done in a similar fashion nationally, it will provide not only good information to lobby with but also information that funding is being well spent.

In the absence of PET, it may be reasonable to consider conventional techniques such as octreotide analogues or MIBI. Evidence indicates that MIBI is more accurate than CT for diagnosis and staging. New CT methods are also available for characterising lung nodules. However, there is a danger that this will become the accepted method and it is important to continue to lobby for PET as well.

The issue was raised that at the same time as lobbying for increased access to PET, clinicians should cease ordering other tests that duplicate information.

Lung cancer clinical practice guidelines

There is interest in producing an electronic format of the lung cancer guidelines (other than a pdf version) and potentially clinical decision support tools as well. The draft lung cancer guidelines can be accessed via a link on the ACN’s Internet page (see http://www.cancer.org.au/content.cfm?randid=236421). The task of the ACN has largely been to consult and produce the guidelines. The questions of dissemination, including electronic formats, and implementation are the next to be addressed.

The implementation team have not yet devised what the implementation strategy might be, including the cost. The ACN has limited resources but will be lobbying for funding for the implementation program once it is finalised.
Data collection

There was considerable discussion relating to data collection. It was acknowledged that good data are needed for many important issues in lung cancer to progress. In Australia, funding has not as yet been identified to implement data collection. As data collection has not been a requirement in the past, there is a need for greater support in this area from those who run institutions.

Agreement is also needed as to how data collection is best undertaken to answer multiple needs, including those of:

- clinicians and their patients
- community reporting
- feedback to management so that problems are identified and can be improved
- benchmarking for improvement.

Implementing data collection may take considerable funding. Funding issues are starting to be addressed at a national level by various states and by a number of private organisations. Organisations are being encouraged to work to an appropriate patient-centred value set, which should drive their own budget decision making towards collecting appropriate data so that patients get the care they need.

Data collection does not need to be costly in all situations. It was pointed out that we already have some good data systems but they do not collect good information. What is needed is to change some of the descriptors, including Medicare descriptors, to make them more useful for data collection. In addition, much of the information currently collected in the health area does not get fed back to the appropriate people.

The project being conducted in Queensland (QILCOP) shows that if you have tools that clinicians will use because they assist them in their daily practice (for example, in participating in multidisciplinary planning) much of the work may be done by the clinicians themselves and the actual costs can be fairly modest. The central issue is having the philosophy of wanting to change and wanting to measure to enable improvement.

Leadership in the area of data collection is vital, as is appropriate organisation and understanding of the methodology around clinical practice improvement. Once this is in place, resources that are already used for inappropriate and inefficient data collection can be used much more effectively. A positive outcome from the workshop would be to push for the development of a national model for data collection.
Data collection – privacy issues

Privacy and ethical issues create barriers for data collection and the promotion of data collection. Leadership and support in negotiating though these barriers are needed. There is different legislation in each of the states and territories as well as federal legislation, making the situation complex. The Health Ethics Committee of the NHMRC has recently produced a paper outlining how ethics processes and privacy come together in relation to quality assurance.

A health leaders group meets regularly with the Federal Privacy Commissioner, providing a forum to address issues that are important to those in working in health both at an organisational and individual practice level. The Australian Council for Safety and Quality in Health Care is working with the Privacy Commissioner and is seeking to provide support to enable work identified as being important to be conducted.
Multidisciplinary care and lung cancer

Associate Professor David Ball
Chair, Lung Service, Peter MacCallum Cancer Centre and Chair, Australian Cancer Network Management of Lung Cancer Guidelines Working Party

Aims of multidisciplinary care:

Multidisciplinary care is seen in Britain as a means of promoting communication and effective care, and checking that individual consultants are following accepted guidelines and do not work in dangerous isolation. (Illman 2002)

Integrated multidisciplinary care: Multidisciplinary care in lung cancer was discussed under a number of key headings, including:

- **The medical ‘lottery’** – The idea that traditional patterns of referral lead to a medical lottery, with a patient’s treatment being determined by the person to whom they were referred to by their GP rather than by the best available evidence.

- **The complexity of cancer management** – The notion that no one these days has an encyclopaedic knowledge of all the needs of a lung cancer patient and therefore that many experts need to be involved to provide the best level of care.

- **Does integrated multidisciplinary care work?** – There is limited evidence about the efficacy of multidisciplinary care. It is desired by patients but does it make a difference to other measurable outcomes?

- **Barriers to integrated multidisciplinary care** – If multidisciplinary care is such a good idea then why isn’t it more widely implemented? What are the barriers?

Complexity of cancer management: Lung cancer management is complex from both the clinician and patient perspective. For clinicians, various treatment approaches need to be integrated and complex treatment pathways exist. For patients, the cancer ‘journey’ involves navigation along a complex path from initial discovery to possible cure, with questions as to who will look after the various issues that may arise along the way.

The era of individual medical practitioners believing that they have an encyclopaedic knowledge of all the needs of a lung cancer patient is unfortunately not yet past. Medical nihilism with regards to lung cancer also still exists. There is evidence that the opinion of experts outside their area of expertise varies considerably. In a survey of 1 000 US clinicians who were involved in the treatment of lung cancer, significant differences were found between physicians and surgeons with respect to their belief in treatment benefits (Schroen et al. 2000).
Fifty-nine percent of physicians and 50% of surgeons believed that adjuvant chemotherapy offered benefit after total resection in patients with NSCLC, and 60% of physicians and 70% of surgeons indicated they believed chemotherapy with palliation offered benefit. It could be reasonably assumed that a patient’s pattern of referral will influence the treatment they will be offered.

**Does integrated multidisciplinary care work?** At present, there is limited evidence for the efficacy of multidisciplinary care in lung cancer. Data from Edinburgh (Price et al. 2002), indicates that in the period 1995–2002, following a redesign of services for patients with NSCLC that included an increase in the number of multidisciplinary meetings, there was an increase in number of referrals; number of patients with stage III or IV disease; and a six-fold increase in disease-modifying treatment (all for elderly patients). Comparison of survival over this same period showed a statistically significant increase of 6% (p = 0.02).

Other benefits from multidisciplinary clinics include a potential increase in recruitment into clinical trials. In a UK study, 30% of 257 lung cancer patients seen in a multidisciplinary clinic consented to participate in a clinical trial, of which 19% consented to be on a randomised trial (Magee et al. 2001). This compares with the 1993 data from Victoria where only 6% of patients were on any form of trial, randomised or otherwise (Richardson et al. 2000).

**Barriers to multidisciplinary care:** These include:

- professional resistance
- availability of team members
- no funding model – Medicare does not fund outside the public hospital system for participation in multidisciplinary processes
- critical mass – in hospitals where there are few patients to discuss, multidisciplinary meetings may be too infrequent to be of benefit for the patient.

A further issue is that of sub-specialisation within an institute, which in the Edinburgh study seemed to lead to an improvement in outcome (Price et al. 2002). Data looking at institutional experience in the delivery of complex treatment protocols (Radiation Therapy Oncology Group protocols) have shown a significant difference in outcome for patients with NSCLC who were treated in centres accruing more than five patients versus those treated in centres where five or less patients were accrued (Lee et al. 2002).

A recent survey of radiation oncologists in Australia and New Zealand has indicated that while 75% of respondents believe that they have some kind of sub-specialty interest, most were interested in breast or urology with only 7% regarding themselves as having a particular interest in lung cancer (Veness et al. 2003).

**Multidisciplinary lung cancer clinics:** Currently in Victoria, there are nine multidisciplinary lung cancer clinics, with five meeting weekly and the others meeting either fortnightly or monthly due to critical mass for patient numbers. All involve attendance by a thoracic physician, thoracic surgeon, radiation oncologist, medical oncologist and radiologist, with some involving attendance by a pathologist, GP, nurse or data manager.

**Conclusions:** Multidisciplinary care can (i) streamline the process from diagnosis to treatment, (ii) increase recruitment into clinical trials, (iii) result in improved patient satisfaction, (iv) possibly increase survival rates, and (v) improve communication between health professionals.
Multidisciplinary care and lung cancer: the nursing perspective

Ms Mary Duffy
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Nurses in the multidisciplinary team: Nurses in effective multidisciplinary teams have more contact with patients in terms of time than any other member. This contact commences from the initial appointment through staging, diagnostics, treatment and subsequent follow-up, and enables nurses to develop and consolidate a relationship with the patient and family. Ongoing communication and interaction establishes the nurse as an easily identifiable resource to the patient, providing individualised care in a continuum. In this way nurses form an integral part of the multidisciplinary team.

Nurses role: A large component of the nurse’s role is communication with the multidisciplinary team. This is not restricted to the hospital medical team. Nurses must effectively communicate with all types of allied health personnel, medical staff in the community and local support services to discuss and address issues of patient care. Communication with the patient and family is a major focus for nurses. Part of this involves the provision of information and education regarding diagnosis, treatments, potential side effects and their impact on life.

Nurses who have a good knowledge of the lung cancer process can be proactive in early detection of symptoms and appropriate referral to medical and allied health staff. Symptoms such as pain, fatigue, anxiety and breathlessness identified early and appropriately managed can improve quality of life by promoting a concept of wellness and wellbeing in this group of patients. Good palliation of symptoms need not be regarded as an end of life privilege. By engaging in collaborative decision-making, nurses in turn facilitate the patient’s participation in team decisions.

Providing information and education: An example of provision of information and education involves a new initiative suggesting that nurses can initiate health promotion strategies for patients, including those with lung cancer. Nurses in hospital and community settings who have extended periods of contact can address the issue of smoking with patients, and are effective in the provision of smoking cessation interventions.

Domains of practice: The components of the nurse’s role in multidisciplinary care have been further elaborated through a survey of cancer nurse specialists in the UK (Moore 2002). One hundred and ten nurse specialists employed in the care of patients with lung cancer nominated 13 domains of practice. Of these, the seven most commonly identified areas were:

- liaison with other members of the multidisciplinary team (100%)
- information giving (100%)
- liaison with primary care teams (98%)
- psychological support (98%)
- support at diagnosis and pre-diagnosis stage (97%)
- support during follow up (96%)
- support during treatment (94%).
Supporting patients and their carers by giving practical advice, vital information and emotional support enables patients to have greater confidence and to live better with their illness. This approach promotes the notion of learning to adapt one’s life towards living as opposed to planning only to die. For people with lung cancer this may be a novel concept.

Research: Research findings have demonstrated the positive contribution that nurses can make to patient outcomes. A randomised controlled trial in the UK that compared nurse-led follow-up in the management of patients with lung cancer to conventional medical follow-up (Moore et al. 2002), found that:

- After three months patients in the nurse-led group rated their dyspnoea as less severe than patients in the conventional follow-up arm ($p = 0.03$), although no difference was observed for physical functioning, fatigue or pain between the two groups. The score for emotional functioning was better in the nurse-led group but not until 12 months.
- On a patient satisfaction rated scale, at three months and at six months patients in the nurse-led arm rated both organisation of care, and information and advice significantly higher than the patients randomised to conventional follow-up.

Each arm consisted of a multidisciplinary team, one in which a conventional approach was taken and the other in which the nurse was given more autonomy and authority to lead follow-up care. These findings suggest that follow-up of patients by a clinical nurse specialist is safe, acceptable and probably cost-effective.

A second randomised controlled trial looked at the effectiveness of nursing intervention for breathlessness in patients with lung cancer compared with supportive care (Bredin et al. 1999). Eight weeks after entry to the study, patients randomised to receive the nursing intervention (conducted by specialist nurses) scored significantly better on scores of breathlessness at best than the control group ($p = 0.03$).

The authors suggested several key messages that challenge nurses to see their nursing care as an intervention and to structure that intervention and then measure it in terms of patient outcomes. These key messages are:

- In lung cancer high levels of distress, anxiety, and functional impairment are associated with breathlessness.
- Evidence on the use of many treatments for this common and frightening symptom is lacking.
- Interventions based on psychosocial support, breathing control, and learning coping strategies can help patients cope with the symptom of breathlessness.

Conclusion: Lung cancer nurses act as navigators. They assist patients to find their way through the complexity of the lung cancer ‘journey’ and keep a true focus on patient-centred care in the multidisciplinary team. The key is the team. Mutual respect, honesty and knowledge of the boundaries of practice are the foundation of the multidisciplinary team and the nurse’s contribution needs to develop within this context.
**Multidisciplinary care: the National Breast Cancer Centre experience**

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**Background:** Multidisciplinary care is a team approach to the provision of health care by multiple medical and allied health disciplines. It is recommended as a means of achieving best practice in that “through their combined understanding all members of the team liaise and cooperate together and with the patient to diagnose, treat and manage the condition to the highest possible standard of care”. The clinical practice guidelines for treatment of early breast cancer (NBCC 2001) recommend that women with breast cancer should be treated by specialists who have demonstrated experience in breast cancer and access to the full range of treatment options in a multidisciplinary setting.

With regards to exploring the multidisciplinary approach in cancer care, breast cancer is an area where to date more work has been conducted than has been conducted for lung cancer. The knowledge obtained from studies of multidisciplinary care in breast cancer may provide useful information for those working in other cancer areas.

**Does multidisciplinary care work?** There is some evidence from international studies of improved survival rates for women with breast cancer treated by a multidisciplinary approach. Studies have shown a 9% survival benefit at five years and 8% at 10 years, for women treated by clinicians working within centres providing a multidisciplinary approach, compared with women who were treated by clinicians working outside of these centres.

There is evidence that care is improved to be more in accord with evidence-based guidelines. Women who are managed in a multidisciplinary setting tend to have higher rates of usage of adjuvant chemotherapy and hormone therapy, increased provision of breast conserving treatment and increased entry into clinical trials. In one US study, 43% of initial treatment recommendations provided by clinicians working in isolation were inconsistent with a second opinion provided by a multidisciplinary panel, with the panel’s decision tending to be in accord with best-practice guidelines (Chang et al. 2001).

In addition, there is evidence of improved coordination of treatment and care for women with breast cancer, including improved psychosocial outcomes – increased patient satisfaction, improved provision of information and support, decreased psychological distress and improved adjustment. Recent work also shows a benefit for the treating clinicians, with increased communication with colleagues, reduced duplication, improved peer support, improved work satisfaction and improved education for clinicians participating in multidisciplinary meetings.

**Multidisciplinary care in Australia – the National Multidisciplinary Care Demonstration Project:** A national demonstration project, the National Multidisciplinary Care Demonstration Project, was established in Australia in 1999 with Federal Government funding as breast cancer was considered an appropriate model for exploring multidisciplinary care. The aims of the project were to:

1. *Examine the current status of multidisciplinary care for women with breast cancer in Australia.*
2. Evaluate the impact, acceptability and cost of the implementation of multidisciplinary care strategies for women with breast cancer in Australia.

Initially, a variety of international models were considered. However, it was recognised early on by the steering committee that local practice conditions impacted on the translation of international models to the Australian setting and that an operational definition of multidisciplinary care, which was relevant in the Australian context, was required.

The approach taken involved identifying common elements from international models found to improve outcomes for women with breast cancer. These were then used to determine a set of principles that defined the parameters within which care would be provided. Each principle aimed to achieve an outcome but it was recognised that there were a number of ways in which these outcomes could be achieved. Each outcome also had to be measurable. The common elements (with examples of outcomes) were:

- **the team** – eg. the ‘breast cancer team’ is established and known
- **communication** – eg. communication mechanisms are established to facilitate case discussions by all team members
- **the full therapeutic range** – eg. systems are established for ensuring that all women have access to all relevant services
- **standards of care** – eg. local clinician data are consistent with national benchmarks
- **involvement of the woman** – eg. women with breast cancer feel that their care is coordinated and not fragmented.

Three collaborations from across Australia were selected against competitive criteria to participate in the study. The project consisted of three phases (pre-implementation, implementation and post-implementation) and strategies implemented in the collaborations were evaluated in terms of their impact on patterns of clinical and supportive care, acceptability to clinicians and consumers, and cost.

**Results:** Preliminary results indicate that there was an increased perception of the breast cancer nurse as part of the team; improved information to women about psychosocial support; increased links with non-core specialists such as genetic counselling and occupational therapy; increased management by a psychiatrist rather than individual clinicians; and a decrease in the preoperative diagnosis by open biopsy. Almost all participating clinicians agreed that the multidisciplinary care strategies had improved communication between team members and had improved patient care.

A report is in preparation. It is anticipated that the results of this principle-based approach will inform the development of recommendations about the broader implementation of multidisciplinary care, not only for breast cancer but also potentially for other cancers and other chronic conditions that require input from a range of health care professionals.

**National Profile Study of Multidisciplinary Care:** In conjunction with the national demonstration project, a further study has been conducted to explore the current organisation of services for women with breast cancer across Australia in relation to the principles of multidisciplinary care and to examine clinicians’ views about multidisciplinary care. This study was conducted in a representative sample of 60 hospitals across Australia and is the first study to examine the extent to which multidisciplinary care was practised, prior to the implementation of the demonstration project.
Clinical trials in lung cancer

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Clinical trials in cancer: Evidence-based care relies on good quality data, with randomised controlled trials representing the gold standard in clinical studies. Significant progress has been made in the practice of medicine based on the results of well-designed, well-conducted clinical trials that have evaluated the effectiveness of promising interventions. Successful clinical trials have improved survival for childhood cancers, breast cancer, leukaemia, lymphoma, and testicular cancer; reduced the surgical morbidity of many cancers; and reduced side effects for some cancer therapies.

Cooperative cancer trials: Clinical trials can be conducted in a number of ways including both industry-sponsored trials and investigator-initiated trials. Investigator-initiated trials are often undertaken in a multicentre cooperative group setting. This increases the number of participants and thus the power of the trial to ensure that the conclusions reached are reliable and that important findings are not missed due to inadequate power. The need for adequate power in randomised controlled trials has been highlighted as the future for these types of studies.

International cooperative cancer groups: Cooperative oncology groups are established in various countries and regions. In the US, there are a number of cooperative oncology groups with collectively some 20,000 patients on treatment trials each year. The US National Cancer Institute has sponsored clinical trials in cancer since the 1950s and has recently developed the Cancer Therapy Evaluation Program (CTEP) to fast track the evaluation of new anti-cancer agents. The US cooperative groups have provided substantial evidence to advance the treatment of lung cancer.

In Canada, a national cancer cooperative group has been established – the National Cancer Institute of Canada Clinical Trials Group – with lung cancer being a subgroup. The Canadian cooperative group has published findings from numerous trials, which again have provided high quality evidence to change and shape current practice.

In Europe, the European Organization for Research and Treatment of Cancer (EORTC) is a highly coordinated group consisting of researches from many countries. EORTC has a lung group that between 1999 and 2001 enrolled nearly 1,400 patients. The lung cancer group has published over 100 peer reviewed randomised controlled trials and provided high quality evidence to advance treatment.

Australian cooperative cancer groups: Currently, there are seven cooperative cancer groups in Australia. These include a breast cancer trials group, a children’s cancer study group and the Trans-Tasman Radiation Oncology Group, with some groups being supported by the NHMRC Clinical Trials Centre. Australian cooperative groups have provided substantial evidence to advance treatment.

At present, there is no Australian cooperative lung cancer group. In a recent report by Oceania Health Consulting, which examined the feasibility of funding cooperative groups in Australia (see http://www.backingaustraliasfuture.gov.au/submissions/crossroads/pdf/239_3.pdf), it was
recommended that consideration be given to developing cooperative groups for common cancers where no such groups currently exist, with lung cancer being specifically mentioned.

**Benefits of clinical trials:** Clinical trials have benefits for participants, the community and research. Benefits for participants include:

- Early access to new treatments.
- Improved outcome – lung cancer patients enrolled in randomised controlled trials generally have a better outcome. They have an improved quality of care through the scientific demands of clinical trials including greater monitoring and follow-up.
- Patients have the chance to play an active role in deciding their own health care and to participate in advancing medical knowledge.

For the community benefits include better health outcomes for the population; reduced mortality and morbidity; improved evidence-based care; and the ability to indicate that we are practicing world’s best practice. Benefits for research include access to new therapies and that the scientific rigour of trials leads to an organisational culture that tends to provide the best patient care.

**Barriers to clinical trials:** There are, however, barriers to clinical trials. For clinicians and other health professionals these include that they may (i) be unaware of various clinical trials including difficulty in finding out what trials are going on and where to refer patients, (ii) be unwilling to lose control of a patient’s care, (iii) believe that the standard current therapy is best, (iv) believe that clinical trials are more work, and (v) worry about the patient’s care or how the person will react to the suggestion of a trial (Fallowfield et al. 1997).

From the patient’s perspective barriers to clinical trials may include a lack of awareness of the existence of clinical trials as well as a lack of access to trials – particularly for rural and remote patients; fear, distrust and suspicion of research; practical or personal obstructions; insurance or cost problems; and that they may be unwilling to go against their physician’s wishes (Slevin et al. 1995).

**Risks of participating in clinical trials:** Potential risks of participating in clinical trials include that (i) new treatments are not always better, (ii) there may be unexpected side effects, (iii) the treatment may not work for everyone, and (iv) there may be unexpected costs.

**Submission:** We can learn from clinical trials – today’s standard therapies were yesterday’s clinical trials. Many lung cancer clinical trials are being performed in Australia but most of these are in single centres or small networks. It is proposed that a national cooperative lung cancer group be established in Australia to facilitate clinical trials, as:

1. A national cooperative lung cancer group can enhance and consolidate such efforts by using well-designed studies with adequate numbers and power.
2. We can contribute to evidence-based improvements for lung cancer and answer important local questions.

Such an initiative is supported by the Australian Lung Foundation and the Lung Group of the Clinical Oncological Society of Australia.
Achieving improvements – Breakthrough Collaboratives

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Focus for improvement: In treating patients the aim is to treat the right person with the right care in the right place at the right time. Although simple, these principles can pose a significant challenge in terms of managing services to improve care. The focus for improvement in care is to:

- Move from unplanned care where patients are pushed through the system to planned care where patients are pulled through the system.
- Move away from capacity led provision to demand led provision.
- Move away from medical firms to multidisciplinary teams.
- Move away from variable quality of care to consistent care.
- Move away from an institutional focus to a network or pathway focus.
- Move away from disempowered patients to empowered patients.

These changes will require a significant cultural shift in terms of the way we think and the way we work.

Breakthrough Collaboratives: Breakthrough Collaboratives are “an improvement method that relies on the use and adaptation of existing knowledge and evidence to multiple settings to achieve a common aim”. The method was developed in the US by Don Berwick and colleagues as a means to bridge the gap between existing knowledge and evidence and actual practice.

Methodology: The Breakthrough Collaborative process involves a series of four structured learning sessions in which teams from the various institutions, health services etc that have expressed an interest in joining the Collaborative come together to be taught the methodology and address the common aim. In between each two-day learning session is an action period during which teams return to their institutions to implement improvement strategies and test change using the Plan, Do, Study, Act cycle (PDSA cycle).

During each action period data are collected to demonstrate whether or not the change is resulting in improvement. Typically, each action period is short (two to three months) with the entire process taking some 10 to 12 months. A planning group comprised of clinicians and executives meets prior to the first learning session to develop the aims, indicators and tools for change, and also acts to mentor and coach the teams during the process.

Victorian Breakthrough Collaboratives: In Victoria, Breakthrough Collaboratives have been conducted or are being conducted in a number of health areas including Emergency Departments, Adult Intensive Care Units, acute to sub-acute patient flow and blood transfusion.
The goals of the Victorian Breakthrough Collaboratives are:

1. To demonstrate measurable improvements in the timely delivery of appropriate, safe patient care whilst increasing family, patient and staff satisfaction.

2. To develop the leadership to sustain and spread the improvements and learning gained beyond the life of the Collaborative.

The US methodology has been adapted and tailored to the Australian culture and environment. In addition to the planning group, an expert panel is formed and input is sought from local and international experts. After expressions of interest are received, a visit to each team is made to identify key issues and discuss issues related to data. Orientation sessions and pre-work are also conducted. The pre-work has been identified as important in securing the right clinical and executive leadership. Prior to the first learning session, baseline data are collected around the key areas the teams have set as targets for improvement.

The whole process is supported by a ‘framework for change’ – that is, what are the aims, how will change be measured and what will be instigated to make that change? Teams are also supported by a variety of other means including e-mail, visits, coaching, publications, monthly reports, change packages and toolkits, assessments and international advisors. A dedicated website is established so that the data can be shared across the Collaborative.

Results: A ‘snap-shot’ of results from various Victorian Collaboratives provided examples of improvement in specific target areas, with importantly sustained improvement over time. A video interview provided the thoughts and views of a Collaborative participant on the process and outcomes achieved. The Emergency Department Collaborative was so successful that it has now been rolled out nationally (through the National Institute for Clinical Studies) across 40 Emergency Departments.

Breakthrough Collaboratives and cancer: In Victoria, work is being conducted in the area of cancer. Key areas for attention are (i) ensuring quality and safety of care, (ii) ensuring capacity to meet demand, (iii) ensuring services have modern, safe equipment, (iv) providing adequate resources to deliver care, and (v) to develop a Cancer Action Plan to address the issues.

In the UK, significant results have been achieved using the Breakthrough methodology in the area of cancer and cancer services. The Cancer Services Collaborative has published results showing reduced waiting times and improved patient experiences of care (Kerr et al. 2002). The National Health Service has used the methodology for implementing their National Cancer Plan, which is equivalent to the NSIFs in Australia.

Concluding remarks: A key element that we have found the methodology to provide and develop is leadership, and leadership at all levels. The methodology focuses on the patient and their journey through the system, with an ethos around creating an environment where information and ideas are shared and exchanged to achieve improvement. The measurement strategy is designed to ensure that there is action and demonstrable results from participating teams.

Some questions remain around sustainability and adoption. As a result, a national consortium is being commissioned to evaluate the Victorian Collaboratives against other methodologies for improvement, including evaluating whether Collaborative results are sustained and continually improved.
SESSION THREE DISCUSSION

Therapeutic nihilism

Several presentations identified a significant level of therapeutic nihilism. This varies within clinical sub-specialties as does enthusiasm for clinical trials. There is a need to pursue improvements in this area through professional colleges and sub-specialty groups. In addition, there are issues to do with ‘ownership’ of lung cancer patients that have had a negative influence over a long period of time.

It was indicated that it is hoped that the Australian lung cancer guidelines will be available not only to clinicians but that a consumer version will be developed as well, to enable consumers to access what is regarded as the best available evidence. The exercise of developing the guidelines would be regarded as a failure if the guidelines are not applied to clinical practice and changes in outcomes are not seen. In addition, it is hoped that following the release of the guidelines a further patterns of care survey will be conducted in Victoria to identify changes in practice.

Sustainability

There was discussion around the issue of sustainability in Breakthrough Collaboratives and the multidisciplinary care demonstration project in breast cancer.

It was explained that one of the competitive criteria on which collaborations were selected for participation in the National Multidisciplinary Care Demonstration Project was sustainability. Sites had to identify that the strategies they were going to implement would be sustainable in the longer term. An outcome from the project has been that many of the strategies implemented have been longer lasting because they have assumed a life of their own. Effects on participating clinicians and effects that they have seen on their patients have been so significant that there has been a greater impetus locally to ensure that the strategies were continued and improved.

It was commented that in the Queensland site for the demonstration project, the multidisciplinary meetings have been sustained because of the professional interest from clinicians working in the remote regions and the value they receive from attending the meetings. The project has generated a great deal of information and it is hoped that much of this will be relevant to other cancers.

Sustainability is a key element in Breakthrough Collaboratives. In developing the Collaboratives there is a specific development phase that takes place prior to seeking expressions of interest to join the Collaborative. Sustainability is an important aspect of this development phase. In addition, work is undertaken with the Collaborative teams some six months into the process to design plans on how the Collaborative will be sustained locally.
Multidisciplinary care – general practitioner involvement

There was considerable discussion around issues relating to the difficulty in getting GP participation in multidisciplinary teams. The Australian Government has an initiative with expanded primary care items for funding GPs involved in case conferences where two other clinicians participate. A problem, however, is that private specialists are not funded to attend such meetings. Further problems include that the scheduling of multidisciplinary clinics is often not appropriate for GPs and that GPs are often not informed about patients until the time of the discharge letter.

The importance of GP involvement in multidisciplinary care was recognised, with communication between GPs and specialists being considered as critical for good care. There are also issues of critical mass, with GP workloads making it difficult to attend multidisciplinary clinics for just one patient. In the breast cancer multidisciplinary care demonstration project, the important role of the GP was recognised at the outset yet in actual practice there were still difficulties in getting GP participation in multidisciplinary meetings despite a number of strategies that were implemented.

An innovative idea from New South Wales Health for how to improve GP involvement was discussed. A strategy that is being tried at the Westmead Hospital involves having a Divisional representative as part of the multidisciplinary team to support the GPs involved. In addition, as soon as the patient is admitted to the hospital the GP is contacted and invited to come into the hospital to contribute to the case notes and patient care. The GP is also contacted on patient discharge. It was recognised that this may not be possible in all cases.

It was mentioned that there are some good models of GP involvement in multidisciplinary teams and that the Australian Government is actively looking at the issue of multidisciplinary teams as part of the NSIFs.

Findings from a Queensland breast cancer project may provide some useful information. The project was developed in conjunction with the Brisbane North Division of General Practice and breast surgeons at the Royal Women’s Hospital. General practitioners indicated that due to their workload it was not possible to become involved in case conferencing but what they desired was better communication. Work was undertaken to identify what information was desired by the GPs and at what time. Case conferencing or further follow-up with specialist staff was then initiated by the GPs when they had that information. The project has been piloted and has the potential to be applied to other cancers.

Data collection

To assess changes in outcomes good data are needed. It was suggested that if the data set and data acquisition program being utilised in QILCOP could be implemented in other centres, this would provide consistent data to assess changes in practice and improvements in outcome. Means of funding would be required. It was recognised that data collection is an important point and further discussion held over to the final general discussion session.
How do we proceed?

The aim of the final session was to consider recommendations for improving the management of lung cancer in Australia. Professor McCaughan noted that six key issues had been identified during the meeting and proposed that a recommendation for specific action be made for each of these areas. It was put forward that the guiding principle should be that no matter where the patient enters the system management would be the same in all aspects, including access. This had been heard as an underlying theme in the presentations.

The six areas for which recommendations were requested were:

1. Implementation of the lung cancer clinical practice guidelines – The rollout in practical terms of the lung cancer guidelines. How will this be achieved so that the guidelines will be used and their recommendations incorporated into clinical practice?

2. Multidisciplinary management of lung cancer – What lessons for multidisciplinary care in lung cancer can be learnt from the breast cancer national demonstration project?

3. Collection of data – How can we collect data that is routine, timely and practical, and results in benchmarking across Australia? There are issues of ownership, funding and also specific privacy issues. Encompassed within this is the issue of conducting clinical trials.

4. Access for all patients to appropriate technology – How can we improve access of patients to PET scans? A practical recommendation from the meeting may be to consider how one more institution in the next six months could obtain a PET scanner.

5. Patients and carers as the focus of the cancer journey – How can consumer involvement in lung cancer management be increased?

6. Radiation oncology – How can access of patients to radiation oncology be improved? What is one step that can be recommended to improve access in this area, which despite numerous inquiries remains poor?

Professor McCaughan then invited discussion from the audience on the above topics. Recommendations for other issues where also invited.
Implementation of the lung cancer guidelines

Electronic access to the lung cancer guidelines would be useful. A plea was made that this not simply be a pdf version of the printed copy. Problems with guidelines in pdf include the lengthy time it takes to download the document and search for answers to specific questions. Electronic guidelines in html format that have a well indexed set of clinical questions can allow the user to select the question of interest and be taken straight to the relevant section. This format is also valuable when updating guidelines as only those subsections that need to be updated are modified. Guidelines in an electronic format that enable answers to questions to be rapidly distilled would be useful in multidisciplinary clinics.

There is a need for some electronic decision-making tool derived from the guidelines, either a browser version of the guidelines or a more elaborate clinical decision support tool. Significant advances in technology have been made and electronic implementation of other guidelines is in progress. In developing electronic versions of clinical practice guidelines, a challenge is to identify a technical editor who can think clinically. This helps ensure that search functions are clinically appropriate. A CD version could also be produced as not everyone has access to the Internet.

Clinical decision support tools are able to run on hand held computers. A current project is looking at the implementation of the colorectal cancer guidelines using this technology and this may be able to be utilised. Development of electronic decision-making tools is, however, expensive. It was discussed that it also assumes that we are still operating in isolated groups. If we are able to get multidisciplinary clinics to work together those clinics will by their nature want to establish normal operating procedures. Research into guideline implementation suggests that only when guidelines are locally adopted and incorporated into clinical pathways do they influence practice. This requires structure and multidisciplinary clinics would provide that.

In terms of disseminating the guidelines, college websites may be useful. For example, the website of Royal Australian College of General Practitioners can be linked to guidelines and college members informed. Use of local champions or influential peers to promote guidelines can be an effective strategy. For GPs, local champions within the Divisions of General Practice could be identified to promote the guidelines to their networks.

A consumer version of the guidelines may be produced, although it was not possible to say when this might be available. The clinical guidelines will need to be reviewed and the information distilled and put it into an appropriate language.

The guidelines could be used to identify a set of key targets for service improvement. Some eight to 10 critical points could be distilled from the guidelines and discussion from the current meeting, to provide objectives for cancer services to achieve. This may be a powerful means to communicate objectives for service improvement and assist in building energy and commitment for service improvement processes such as Breakthrough Collaboratives.

The critical points might include:

- time from diagnosis to assessment to treatment
- waiting times for radiotherapy
- use of multidisciplinary care.
**RECOMMENDATION**

That a consumer version of the Clinical Practice Guidelines for the Management of Lung Cancer be developed.

**KEY POINTS**

I Appropriate electronic means of dissemination of the lung cancer guidelines should be developed.

II There is a need for electronic decision support tools derived from the guidelines.

III Development of clinical pathways may facilitate uptake of guideline recommendations into routine clinical practice.

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**Multidisciplinary care**

The Australian Government is examining service improvement frameworks for cancer and other diseases in which multidisciplinary care is being considered. In particular, funding and structural barriers to providing multidisciplinary care are being looked at. Multidisciplinary care will have a central place in the Australian cancer NSIF. There is a need to identify good role models and determine how multidisciplinary care can best work. Multidisciplinary care is being discussed in the Radiation Oncology Jurisdictional Group and at a national level between the states and territories and the Federal Government.

Useful information for those looking at multidisciplinary care in lung cancer may arise from the breast cancer National Multidisciplinary Care Demonstration Project. Analysis of what has worked well in breast cancer could provide valuable lessons and help avoid unnecessary duplication of effort. The National Breast Cancer Centre report will identify enablers and barriers to providing multidisciplinary care. The National Breast Cancer Centre is also conducting a direct observational study that will examine what makes a good multidisciplinary team work. Much of this information should be able to be readily transferred.

It is important to identify opinion leaders who can promote multidisciplinary practice as the standard of care, especially to the non-converted. The support of professional colleges is important in this regard. The Royal Australasian College of Surgeons was pro-active in examining ways to improve care for women with breast cancer and in establishing the breast care audit. Consumers can also act as champions and play a key role in promoting guidelines and facilitating change in clinical practice.
There is a need to ensure the quality of multidisciplinary care or comprehensive cancer care at a national level, including care delivered within the private as well as public sectors. Issues raised in discussion around the provision of quality multidisciplinary care included the:

- need for accreditation of comprehensive cancer centres and multidisciplinary teams, with accreditation linked to funding
- need for a multi-faceted approach
- need for leadership from professional colleges, people of influence and government
- importance of referrals from general practice being to a member of a multidisciplinary team
- identification of a team member who is responsible for the continuity of care.

In locations where they are available, lung cancer nurses often play a central role in the coordination of patient care. Promoting a career role for lung cancer nurses is an important clinical priority.

There may need to be some central planning around multidisciplinary clinics. If a patient is to receive their definitive treatment at a particular centre, it may be preferable that they be seen at that centre from the commencement of treatment. This involves issues of patient transport and other strategic issues, which may need to be tackled centrally.

**Recommendation**

*That a demonstration project of multidisciplinary care for lung cancer be conducted to provide leadership in this area.*

**Key Points**

I Financial barriers to providing multidisciplinary care should be removed and incentives to providing multidisciplinary care introduced.

II Champions, including consumers, should be recruited to promote multidisciplinary care.

III Support for multidisciplinary practice as the standard of care should be sought from professional colleges, including clinical practice audits and accreditation of multidisciplinary teams.

IV Referral of lung cancer patients from general practice should be to a member of a multidisciplinary team.
Data collection

National clinical data set

Collection of common, clinically relevant data at a national level is important for assessing outcomes and setting benchmarks. An appropriate national clinical data set would provide an instrument for assessing current practice and measuring future changes.

Tools for collecting prospective information are now available. Many workshop attendees expressed an interest in the QILCOP database demonstrated during the workshop lunch break. The QILCOP investigators are willing to distribute the database to others to use, if desired, although it is not intended to exclude other data sets that collect comparable information. Funding to enable distribution and to support the database is required.

The importance of data sets being clinically relevant was highlighted, as was the need to work together with state cancer registries. Data sets used to collect clinical information should be sustainable and provide assistance to clinicians in their practice (to facilitate acceptance). Use of such data sets may enable savings both in terms of health resources, such as a reduction in unnecessary investigations, and intangibles.

Differences in privacy laws between states could impact on the application of a common data set. For example, in Victoria privacy laws do not allow identified patients to be easily linked to death as an outcome. For the data set to be useful, privacy and ethical restrictions would need to be overcome.

It is also essential to understand the meaning of any data collected. In this respect evidence-based benchmarks, against which data can be measured and goals determined, are critical. Comparison of collected data against evidence-based benchmarks is beginning to occur for radiotherapy, where significant variations in radiotherapy rates between some states have been identified.

Data sets are not standalone solutions and effective use should be made of existing data. Support for the incorporation of critical pieces of information in routine data collection was expressed. While cancer databases will provide a greater amount of information they tend to focus on large centres with established data systems. This can be balanced by routine data collection or patterns of care studies, to provide an idea of what is happening at the population level. Federal and state and territory governments also have significant amounts of clinically relevant information that is routinely collected by health departments.

Additional data collection issues

Two further aspects of data collection for which support is needed are:

1. The development of cancer registries in major hospitals or health areas where these do not already exist.

2. A national audit agreed to by those working in lung cancer.

The Australian Council for Safety and Quality in Health Care is working at multiple levels to identify opportunities for the ongoing funding of national audits.
Data on volume–outcome relationships is needed. It was highlighted that there is a lack of specialisation in lung cancer among oncology practitioners and surgeons, which raises questions related to volume and quality. This is an issue for the professional colleges to take up and begin to examine critically.

**National cooperative lung cancer group**

An Australian cooperative lung cancer group that could conduct appropriately powered clinical studies in Australia, promote participation in international clinical trials and improve accessibility for Australian patients to clinical trials, is needed. Such a group could also assist in facilitating collection of lung cancer data through common clinical data sets. National coordination and funding to support the group is required. There are interested and motivated parties. If these could be brought together a way forward could be planned.

**RECOMMENDATION**

That support be given to establish a national cooperative lung cancer group, which could promote clinical trials and facilitate data collection.

**KEY POINTS**

I Clinical cancer registries and links to state cancer registries should be developed.

II Support is needed for a national audit agreed to by those working in lung cancer.

III Evidence-based benchmarks of appropriate utilisation of chemotherapy and surgery should be developed.

IV Data on lung cancer volume–outcome relationships is needed.

V Effective use should be made of existing health data relating to lung cancer.

VI Privacy issues can impact on collection of clinical data and progress is needed in this area.
Access to appropriate technology – positron emission tomography scans

More PET scanners are needed. Potentially, every lung cancer patient should have access to a PET scan, although some patients will not need scans if other investigations have already shown disseminated disease. The technology is considered to have an important place in the multidisciplinary approach to the management of patients with lung cancer. At present patients may have to travel to other centres to have PET scans.

A passionate plea for the provision of a PET scanner at the Nepean Hospital, New South Wales, was made.

The issues around establishing a new PET centre are complex. Points raised in discussion included:

- Isotope supply – The Federal Government’s rollout of the PET review recommendations means that there is now good availability of radioisotopes in Australia.

- A reason why the rollout has not been larger is that MSAC did not consider the evidence to be good enough. A data collection exercise involving the existing PET centres is underway to provide that evidence.

- PET scanners are used for cancers other than lung cancer. Therefore, to sustain a PET centre an evidence-base is required for other tumours as well as lung tumours. This increases the size of the task.

- A suggested strategy for the short term is to wait for the outcome of the current data collection exercise and then press for a broader dissemination at that point.

A personal belief was expressed that the data are there and the evidence base is good enough, so that pressure should be maintained on government around the issue of PET scanners. A randomised study in the Netherlands has suggested that if lung cancer patients with operable disease on conventional staging receive a PET scan fewer thoracotomies may need to be performed (van Tinteren et al. 2002). This raises issues of cost–effectiveness, particularly if use of other investigations (for example, brain and bone scans) is reviewed concurrently.

In discussion around the appropriate use of PET and the value of diagnostic modalities in saving lives, it was noted that for patients who are over-staged by conventional investigations superior staging can direct them to curative treatment. Superior staging may also divert patients away from futile treatment, which can lead to significant morbidity and on occasion death. An important focus is on the patient and delivering appropriate patient care.

It may be important to lead with a message that outlines the value of investment in PET scanners in terms of saving lives, with the cost–benefit issues being in addition to that message.
**Recommendation**

*That one more institution receive a positron emission tomography (PET) scanner.*

**Key Points**

I More PET scanners are needed.

II The Medical Services Advisory Committee review of PET was disputed.

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**Consumer priorities**

Issues important to consumers that were raised at the workshop included: multidisciplinary care, system navigation, promotion of wellness not illness, psychosocial care, national models (evidence was given for clinical models working well in various states and we need to look at ways of raising these to a national level), leadership and empowerment.

Six priority areas from consumers were identified:

1. Establish lung cancer groups in all states and territories for patients and carers.
2. Provide support at all levels for a national model for data collection.
3. Advance psychosocial support as part of a national model for psychosocial care, and encourage the promotion of psychosocial support as a component of multidisciplinary care.
4. Place firmly on the health agenda smoking cessation programs specifically tailored for lung cancer patients who have a strong physiological dependence.
5. Support the need for lung cancer nurses in the community equivalent to those for breast cancer.

The recommendation put forward at the workshop from the members and support base of the Cancer Alliance Network (CAN) Australia was to advance psychosocial support as part of a national model for psychosocial care.

A difficulty in increasing the involvement of lung cancer consumers is the poor prognosis of the disease, with many patients being too unwell to participate for any length of time. Carers of lung cancer patients are a potential group to engage in forming lung cancer support groups. Mechanisms for accessing carers include organisations and associations (both state and national) that deal with people caring for those with chronic diseases, state cancer councils and other support groups.
A meeting of lung cancer survivors was to be held in April 2003 in Victoria, with CAN Australia taking part. This may represent a first step in Victoria towards forming a lung cancer support group. A lung cancer consumer from Queensland attending the workshop also expressed an interest in forming a support group in that state.

**RECOMMENDATION**

*That psychosocial support be advanced as part of a national model for psychosocial care.*

**KEY POINTS**

I. Establish lung cancer groups in all states and territories for patients and carers.

II. Develop national data collection processes.

III. Place on the health agenda smoking cessation programs specifically tailored for lung cancer patients who have a strong physiological dependence.

IV. There is a need for community lung cancer nurses, equivalent to those for breast cancer.

V. There is a need for a national clinical trials register.

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**Radiation oncology**

It was put to the audience that a single action to immediately improve the management of lung cancer would be to enable all lung cancer patients to have access to radiotherapy. Suggested actions to improve patient access to radiotherapy were to:

- implement any one of the existing Australian radiation oncology reports
- overcome the State–Federal divide in health care delivery, which is seen as the major barrier for radiation oncology
- have private health insurance cover outpatient radiotherapy treatment. Private health insurance does not cover outpatient radiation therapy, 95% of which is delivered in the outpatient setting. This is one area where cancer patients are particularly at a disadvantage.
It was noted that for cancer care generally our funding systems have not kept up to date with our care systems. It was suggested that jurisdictional issues between the states and territories and the Federal Government are impeding appropriate clinical care and that this is one area we should be targeting.

**Recommendation**

*That an existing Australian radiation oncology report be implemented.*

**Key Points**

I. The Federal–State divide is seen as a major barrier for radiation oncology.

II. Private health insurance should cover outpatient radiotherapy.

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**Additional recommendation**

An additional recommendation was put forward relating to tobacco control. This is complementary to the other recommendations. Although not the topic of the workshop, it was acknowledged that effective tobacco control is a major priority and a critical aspect for prevention of lung cancer.

**Recommendation**

*That greater support be provided for effective tobacco control strategies.*
REFERENCES


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