

Senate inquiry into gynaecological health in Australia

Joint submission

The Cancer Council Australia

Clinical Oncological Society of Australia

The National Aboriginal Community Controlled Health Organisation

The Cancer Council Australia is Australia's peak non-government national cancer control organisation. Its member bodies are the eight state and territory cancer councils, whose views and priorities it represents on a national level.



The **Clinical Oncological Society of Australia** is the peak multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.



The **National Aboriginal Community Controlled Health Organisation** is the peak body in Aboriginal health representing over 130 Aboriginal Community Controlled Health Services across Australia.



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Introduction

Australia's success in controlling the epidemics of the last century means that more of us than ever before are now developing and dying of cancer.

Improvements in the early detection and treatment of cancer have significantly increased cancer cure rates, but the ageing of our population and reduced impact of other diseases have positioned cancer as the major current and future health concern in Australia. Extended cancer survival also significantly increases the need to provide a comprehensive and responsive range of support services to improve quality of life for people living with cancer.

Many of the challenges of improving gynaecological cancer control in Australia also apply to all tumour and neoplasm types. A key is for governments to adopt the recommendations put forward jointly by The Cancer Council Australia, the Clinical Oncological Society of Australia, the National Aboriginal Community Controlled Health Organisation and the National Cancer Control Initiative in response to last year's Senate inquiry into treatment options for persons with cancer. Some of those have been reiterated for the benefit of the Community Affairs References Committee in this submission. We also provide a range of information and recommendations specific to gynaecological cancer.

We welcome the opportunity to respond to the inquiry and commend the Senate, and Federal Parliament more generally, for the increased interest in and commitment to cancer control in Australia. While Australia has a statistically successful record in cancer management by international comparison, in terms of gynaecological cancers Aboriginal and Torres Strait Islander women and women in remote communities do not have an equitable share in our relatively good prevention and treatment outcomes. We would hope, therefore, that a key outcome of this inquiry would be recommendations aimed at reducing these inequities in particular.

The Australian Government has recently committed to a range of cancer control reforms with the potential to make a significant contribution to reducing the burden of cancer. These include opportunities for the government and non-government sectors to work together more closely and effectively. Much work remains to be done to ensure that policies, guidelines and commitments-in-principle translate directly to outcomes, and that pre-existing investment in cancer control provides optimal returns in terms of improving the lives of all Australians touched by cancer.

Cancer in Australia

Cancer kills more Australians than any other single cause, and opinion polls have found cancer to be the nation's greatest disease concern.^{1,2}

The burden of cancer in Australia is rising, with 88,398 new cases (excluding non-melanoma skin cancers) and 36,319 cancer deaths in 2001, compared with 65,966 new cases and 30,928 deaths in 1991. Cancer currently accounts for 31 per cent of male deaths and 26 per cent of female deaths in Australia and the loss of an estimated 257,000 potential life years.³

More than 267,000 Australians are living with cancer, many with persistent and incurable forms.²

Gynaecological cancer

This submission defines 'gynaecological cancers' as ovarian cancer, uterine (endometrial) cancer, cervical cancer, vulval cancer and vaginal cancer.

In 2001, a total of 3834 Australian women were diagnosed with one of these cancers and 1506 died from a gynaecological cancer. This represents around 4.3% of overall cancer incidence and 4.1% of mortality.³ A key reason for Australia's overall low rate of gynaecological cancer mortality when compared with other countries, particularly those in the developing world, is the success of Australia's cervical cancer screening program.⁴

Of the identified gynaecological cancers discussed in this submission, ovarian cancer causes the highest number of deaths, with 837 in 2001; incidence was 1248. Uterine cancer has the highest incidence, with 1537 cases diagnosed in 2001, and 299 deaths. There were 735 new cases of cervical cancer and 271 deaths, 252 new cases of vulval cancer and 61 deaths, and 62 new cases of vaginal cancer and 38 deaths.³

¹ Australian Bureau of Statistics, Cancer in Australia: a snapshot, 2004.

² Roy Morgan Polling, Health concerns in Australia, 2001.

³ Australian Institute of Health and Welfare (AIHW) & Australasian Association of Cancer Registries (AACR) 2003. Cancer in Australia 2001.

⁴ International Association of Cancer Registries; Globocan data 2002

Table 1	Gynaecological Cancer in Australia					
Cancer	Incidence 2001 ^a	% of all new cancer cases	Mortality 2001 ^a	% of all cancer deaths	5-year relative survival females 1992-1997 ^b	Populations-based screening tests and programs
Ovarian Cancer ICD-O C56	1295	1.5	857	2.4	42%	<p>No recommended screening test</p> <p>International randomised controlled trials are investigating use of CA125 and/ or ultrasound as a screening test for ovarian cancer</p> <p>UK trial: 200,000 women http://www.ukctocs.org.uk/</p> <p>US trial: 39,115 women receive screening http://www.cancer.gov/prevention/plco/aboutplco.html</p>
Uterine Cancer Corpus Uteri and uterus unspecified ICD-O C54 & C55	1537	1.7	299	0.8	81.4%	<p>No recommended screening test</p>
Cervical Cancer Cervix Uteri ICD-O C53	735	0.8	271	0.7	74.6%	<p>Pap test – National Cervical Screening program</p> <p>Routine screening with Pap smears should be carried out every two years for women who have no symptoms or history suggestive of cervical pathology. All women who have ever been sexually active should commence having Pap smears between the ages of 18 and 20 years, or one or two years after first having sexual intercourse, whichever is later. http://www.cervicalscreen.health.gov.au/ncsp/</p>
Vaginal Cancer & Vulval Cancer ICD-O C52 & ICD-O C51	314	0.4	99	0.3	No national published data (78% 1991-1998 South Australia) ^c	<p>No recommended screening test</p>
All Cancers (males & females, excluding non-melanoma skin-cancer)	88,398		36,319		59.9%	

Recommendations

Gynaecological cancer research

- Cancer Australia explore options to better coordinate Australia's cancer research effort at the national level, providing greater insight into overall commitment and specific priority areas, e.g. ovarian cancer detection. Investigate success of integrated model used in the UK.
- Audit and evaluate cancer research in Australia to help ensure it is commensurate with the burden of cancer when compared with biomedical research in other areas.
- Support independent cancer clinical trials on a long-term recurrent basis, with ongoing review to ensure participation in trials is maximised and hospital-based trials adequately resourced.
- Explore tax breaks to attract additional community support for cancer research.

Screening for gynaecological cancers

- Support evidence- and merit-based research into effective early detection modalities for uterine and ovarian cancers (See Research section).
- Support higher standards of cancer professional education and greater public education to facilitate personal decision-making around testing for cancers that cannot be detected through screening.
- Support higher standards of cancer professional education and greater public education to assist women who may be at high risk of developing gynaecological cancers.
- Cancer Australia to consider a national quality assurance mechanism, including a framework for credentialing medical professionals involved in cancer care, to facilitate wider use of clinical practice guidelines such as those for the management of ovarian cancer.
- Support research into genetic technology for early detection of cancer; monitor genetic testing in terms of cost-effectiveness.
- Introduce measures to improve access to cervical cancer screening for under-screened populations, such as Aboriginal and Torres Strait Islander women (see separate recommendations re Indigenous women).
- Investigate feasibility of extending recommended cervical screening intervals for asymptomatic women from two to three years.
- Investigate new cervical cancer prevention modalities and technologies, such as HPV immunisation and DNA testing, and the potential for fast-tracking an HPV immunisation program for Aboriginal and Torres Strait Islander women and other high-risk population groups.

Treating gynaecological cancers

- Cancer Australia to develop an implementation plan for the National Service Improvement Framework (cancer).
- Expand the National Breast Cancer Centre's ovarian cancer role to include developing clinical practice resources for other gynaecological cancers, such as uterine cancer.
- A whole-of-government response to improving access to psychosocial support for women with gynaecological cancer, including wider application of clinical practice guidelines.
- Link the National Health Call Centre Network (see COAG Australian Better Health Initiative; 2006-07 federal budget papers) to refer calls for cancer-related support and information to The Cancer Council Helpline.

Gynaecological cancer control in Aboriginal and Torres Strait Islander women

- Identify cancer control in Indigenous Australians as a key health priority (see Attachment 1 - *Reducing the impact of cancer in Indigenous communities: conference report*).
- Explore models for the broader application of the Commonwealth's *Principles of practice, standards and guidelines for providers of cervical screening services in Indigenous women* as standard practice.
- Undertake an evaluation of the barriers faced by Aboriginal Community Controlled Health Services in claiming Medicare rebates (items 2497, 2501, 2503, 2504, 2506 and 2507) under the Practice Incentive Program/Cervical Screening Incentive (PIP/CSI).
- Formally involve NACCHO in the evaluation of, and designing any subsequent improvements to, the PIP/CSI programs.
- Conduct a targeted communications strategy to raise awareness among Aboriginal and Torres Strait Islander services and other stakeholders of the availability and objectives of PIP/CSI.
- Explore measures to extend eligibility for Practice Nurse Pap test MBS items 10998 and 10999 to all Aboriginal health workers operating out of Aboriginal Community Controlled Health Services, in recognition of the core competencies of Aboriginal health workers in all states and territories.
- Explore subsidising liquid-based cytology for cervical cancer detection in Aboriginal women through under-expended PIP/CSI program funds.
- Improve tobacco control strategies for Indigenous Australian people, who smoke at more than 2½ times the rate of non-Indigenous people.
- Explore the fast-tracking of an HPV immunisation program for Aboriginal and Torres Strait Islander women.

Gynaecological cancer control in remote communities

- Commonwealth and state/territory governments to explore a collaborative approach to reducing geographic inequities in cancer care, through the COAG process and with guidance from non-government peak bodies and Cancer Australia.
- Whole-of-government commitment to building and recurrently funding oncology centres of excellence in large regional cities, to substantially reduce distances between capital city tertiary treatment facilities and remote areas.
- Cancer Australia to establish a national quality assurance framework to facilitate regional cancer centres' use of resources such as clinical practice guidelines.
- Commonwealth, in collaboration with the states/territories and jurisdictional cancer registries, to invest in national clinical data systems to audit, monitor and plan oncology services across regions.
- Commonwealth to invest in psychosocial support services for people in rural and remote areas.
- Commonwealth to build on recent commitments in Strengthening Cancer Care (e.g. mentoring programs) to increase support for distance education, mentoring and innovative models such as telemedicine.
- Government-funded travel and accommodation schemes for cancer patients and their families in remote areas to be better coordinated across borders.

Gynaecological cancer control through medical education

- Cancer Australia to scope a mechanism to facilitate the use of clinical practice guidelines as standard practice across the healthcare system.
- Cancer Australia to scope a mechanism for accrediting/credentialing cancer treatment centres and individual professionals.
- Implement The Cancer Council Australia/COSA ideal oncology curriculum as a standard component of medical training.
- The Department of Education, Science and Training to adopt the recommendations made by The Cancer Council Australia/COSA to improve cancer competencies via vocational medical training (see Attachment 2).
- The National Breast Cancer Centre to develop and distribute a general practitioner guide to managing gynaecological cancers.

Gynaecological cancer control through community education

- Expand the National Breast Cancer Centre's role in disseminating community information to include a focus on all gynaecological cancers.
- Support primary healthcare providers through a whole-of-government approach to better inform women about gynaecological risks and treatment issues.
- Support The Cancer Council's involvement in developing primary prevention program through the COAG Better Health Initiative.
- Cancer Australia to facilitate the implementation of the National Service Improvement Framework (cancer) and the use of clinical practice guidelines.

Addressing the Terms of Reference

- (a) *level of Commonwealth and other funding for research addressing gynaecological cancers;*

Current research funding

Commonwealth funding

The National Health and Medical Research Council (NHMRC) is the chief source of Australian Government support for evidence-based cancer research. Part of the NHMRC's mission is to raise the standard of individual and public health throughout Australia; it works towards achieving this by assessing applications for Commonwealth research funds through a rigorous system, based on peer review. The Cancer Council is represented on relevant NHMRC committees and endorses the organisation's approach to evaluating proposals and allocating funds.

Last calendar year, the NHMRC allocated more than \$87 million towards cancer research. Over the past seven years, the NHMRC has funded more than \$43 million in program and project grants, scholarships and awards focused on gynaecological cancers. This includes individual project grants totalling more than \$20 million.

Another major source of Commonwealth cancer research is the Government's Strengthening Cancer Care program, which was publicly commended by The Cancer Council Australia when announced in the 2005 federal budget. The program committed an additional \$17.6 million over four years for dedicated cancer research. One of the initial priorities will be research into the early detection of ovarian cancer, which is expected to be overseen by Cancer Australia when the agency is established this year.

An additional key initiative in Strengthening Cancer Care was \$21.7 million over four years to support independent cancer clinical trials, an important boost for cancer research. This included \$440,105 in 2005-06 for the Australian New Zealand Gynaecological Oncology Group.

Cancer Council funding

Cancer Councils are the leading non-government providers of cancer research funding in Australia. As well as funding external researchers to conduct evidence-based studies, several state and territory Cancer Councils fund their own epidemiological and behavioural research units that undertake important research intended to improve cancer prevention and detection.

Research grants are made following a competitive, peer-reviewed assessment, using funds derived from fundraising, donations, bequests and merchandise sales. To help ensure transparency, accountability and rigour, the grants allocation process is managed independently on behalf of The Cancer Council by the NHMRC.

The majority of Cancer Council research funds support studies intended to reduce the burden of cancer across all tumour types. Of the \$5.5 million allocated this year by Cancer Councils to tumour type-specific research projects (i.e. studies into the prevention, detection or management of cancers primarily affecting individual body parts), \$1.34 million will contribute directly to gynaecological cancer research. This equals 24.3% of all tumour type-specific projects, an allocation well above the relative mortality (4.1%) and incidence (4.3%) of gynaecological cancers.

Ovarian cancer attracts the most research funds by site, accounting for just over half (\$681,000) of all gynaecological cancer projects. This weighting clearly demonstrates the commitment of Cancer Councils to leading the fight against gynaecological cancers, especially ovarian cancer, which causes unacceptably high death rates due to the current technological limitations around detecting the disease until it is at an advanced stage.

A full list of Cancer Council research grants is available at:
www.cancer.org.au/research

Cancer Councils have also contributed more than \$520,000 to the Australian Ovarian Cancer Study (AOCS), a national program established by scientists from the Peter MacCallum Cancer Institute, the Queensland Institute of Medical Research, Melbourne University and Westmead Hospital in collaboration with clinicians across Australia through the Australia and New Zealand Gynaecology Oncology Group. The study's national database will be a unique resource and provide Australian and international scientists with valuable information for studies on ovarian cancer for many years to come.

Opportunities for reform

Coordination

One of the challenges of improving the level of cancer research in Australia is the lack of coordination: the fragmentation of cancer research across multiple sectors, jurisdictions and organisations makes it impossible to accurately determine the overall research commitment on a national level.

While the limited available information had previously suggested that Australia's overall commitment to cancer research was substantially below the OECD average, indications are that this is no longer the case. However, with cancer claiming more Australian lives than any other cause and rising in incidence by more than 30% over the next five-to-10 years as our population ages, innovation in cancer research is urgently required.

Recent increases in government and non-government cancer research have laid a platform on which to build a better targeted and coordinated national cancer research program. While fully comprehensive integration of such broad-ranging activity is unfeasible and may even be seen as a threat to the autonomy of some funding bodies, there may be scope for Cancer Australia to provide an effective, non-intrusive level of national coordination.

Opportunities to consider might include a standardised, national approach to data collection (building on work currently being undertaken through NHMRC enabling grants and Commonwealth support for independent cancer clinical trials) and a

uniform classification system for reporting cancer research grants. Possible benefits would include better analysis of gaps and overlaps in research, thereby identifying areas where research may be insufficient in terms of relative cancer burden.

Improved coordination is particularly relevant to ovarian cancer, which has a relatively high mortality rate because of the current inability to accurately detect the disease early. Under current, fragmented research funding arrangements, it is impossible to compare the national commitment to ovarian cancer research with studies into managing other tumour types that may cause fewer deaths.

While the challenges of coordinating cancer research funding are acknowledged, it is important to note that the Cancer Research Funders' Forum in the United Kingdom is working towards a centrally coordinated model, with reports of a far more coherent approach to both fund-raising and spending on cancer research as a result.⁵

Clinical trials

The Australian Government's commitment to supporting independent cancer clinical trials is commended. This commitment will need to be supported recurrently, and scope for increased funding over time to encourage higher levels of participation in clinical trials and better management of hospital-based trials needs to be explored.

Tax incentives

Community-based contributions to Cancer Council research have increased steadily over time, indicating a high level of public commitment to fighting the nation's deadliest disease. Increasing the tax-deductibility of donations to cancer research to registered charities from 100% to 125% would encourage more contributions, build the nation's social capital and share the responsibility for improving cancer outcomes more directly with the public.

Gynaecological cancer research – recommendations

- Cancer Australia explore options to better coordinate Australia's cancer research effort at the national level, providing greater insight into overall commitment and specific priority areas, e.g. ovarian cancer detection. Investigate success of integrated model used in the UK.
- Audit and evaluate cancer research in Australia to help ensure it is commensurate with the burden of cancer when compared with biomedical research in other areas.
- Support independent cancer clinical trials on a long-term recurrent basis, with ongoing review to ensure participation in trials is maximised and hospital-based trials adequately resourced.
- Explore tax breaks to attract additional community support for cancer research.

- (b) *extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;*

Screening programs

Principles of screening

Screening refers to the application of a test to a population that has no overt signs or symptoms of the disease in question, to detect unsuspected disease while a cure is still possible. The screening test does not diagnose illness, but is used to identify people who require further investigation to determine the presence or absence of disease. The purpose of screening an apparently well individual is to detect early evidence of an abnormality or abnormalities such as a risk factor, pre-malignant changes (e.g. by Pap test) or early invasive malignancy (e.g. by mammography) in order to recommend preventive strategies or treatment that will provide a better health outcome.

To be effective, a screening test must be accurate enough to detect the condition earlier than without screening and there should be adequate evidence that early detection improves health outcomes.⁶

The accepted criteria for the assessment of evidence on the benefits, risks and costs of population-based cancer screening are the principles adopted by the World Health Organisation:⁷

- the condition should be an important health problem;
- there should be a recognisable latent or early symptomatic stage;
- the natural history of the condition, including development from latent to declared should be adequately understood;
- there should be an accepted treatment for patients with recognised disease;
- there should be a suitable test or examination;
- the test should be acceptable to the population;
- there should be an agreed policy on whom to treat as patients;
- facilities for diagnosis and treatment should be available;
- the cost of screening (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole; and
- screening should be a continuing process and not a 'once and for all' project.

Recommendations for or against population screening interventions are influenced by the relative strength of the available scientific evidence in relation to these criteria.

As well as being economically unviable, inaccurate screening carries potentially high risk for causing a number of other problems associated with false positive or false negative results. False positive results mean healthy persons will be incorrectly told they have a disease. They are likely to undergo follow-up testing that may be uncomfortable, expensive and, in some cases, potentially harmful. In rare cases, this

can lead to unnecessary treatment. Both the patient and their family are likely to experience distress and anxiety. False negative results can give rise to legal action by people whose cancers appear to have been missed.⁸

Screening for gynaecological cancers

Pap testing for cervical cancer is the only proven screening technology to reduce gynaecological cancer incidence and mortality on a population basis. There are currently no available screening tests for vulval and vaginal cancers that meet WHO criteria (see page 13). The barriers to effective population-based screening for uterine and ovarian cancers are as follows.

Uterine cancer

In Australia in 2001, 1537 women were diagnosed with uterine (predominantly endometrial) cancer and 299 died from the disease.¹ The majority of uterine cancers are diagnosed at an early stage, resulting in relatively high cure and survival rates.

A key aim of population-based screening for cancer is to detect precancerous conditions or early-stage cancers that might otherwise go undetected, thereby improving treatment outcomes and containing healthcare costs. As uterine cancers are generally detected early and have a good prognosis, population-based screening for the disease would be of very limited value.⁹

Moreover, research indicates that screening of asymptomatic women for uterine cancer using available technology would be likely to generate a high proportion of false positives – inaccurate test results leading to unnecessary distress and in some cases well women undergoing invasive exploration.^{4,10}

The most common symptom for uterine cancer is postmenopausal bleeding, which usually presents without medical observation. Effort should therefore be focused on ensuring that women and their carers are aware that postmenopausal bleeding, however slight, is abnormal and requires prompt investigation.

Ovarian cancer

In Australia in 2001, 1295 women were diagnosed with ovarian cancer and 857 died from the disease.¹ Ovarian cancer is the eighth most common cancer in Australian women and the life time risk of developing ovarian cancer before the age of 75 is 1 in 104.¹ Ovarian cancer is the sixth most common cause of cancer death in Australian women and it is the leading cause of death from gynaecological cancer. While the cause of ovarian cancer is unknown, genetic, environmental¹¹ and hereditary¹² factors may all contribute to the development of the disease.

Ovarian cancer has the worst prognosis of any gynaecological malignancy.¹³ However, five-year relative survival from ovarian cancer has increased between 1982-1986 and 1992-1997. In Australia in the period 1992-1997, the five-year relative survival from ovarian cancer was 42%.¹⁴ Data from South Australia shows a five-year survival of 79% when the ovarian cancer was diagnosed at FIGO stage I (localised disease) compared with 7% five-year survival for FIGO stage IV (evidence of spread to distant parts of the body).¹⁵ Overall, the five-year survival rates from ovarian cancer are low; the high mortality and poor survival are thought to be related, in part, to late-stage diagnosis and the associated spread of the disease by the time of

detection. It is estimated that at diagnosis, two-thirds of ovarian tumours are in advanced stages and the late presentation is thought to be attributable to the fact that early disease is asymptomatic and early symptoms are non-specific.¹⁶

The improved survival associated with localised disease has given rise to the concept that early detection will improve survival outcomes. Since a precursor lesion for ovarian cancer has not been identified, the goal of screening for ovarian cancer is to detect asymptomatic pre-clinical disease.¹⁷ A number of techniques, including bimanual pelvic exam, transabdominal and pelvic ultrasound, CA125, and the evaluation of circulating tumour markers have been investigated as possible screening modalities for ovarian cancer. Although several studies have demonstrated that it is possible to detect early-stage ovarian cancer, the screening tests investigated are not adequately sensitive (the ability to determine the presence of the disease in those who have it) or specific (the ability to exclude the disease in those who do not) to detect ovarian cancer. To date there is also no evidence to indicate a decrease in mortality as a consequence of ovarian cancer screening, although survival advantage has been found in two trials.

The benefits of any screening test should clearly outweigh any chance of physical or psychological harm. Therefore, the significant risks and interventions associated with false negative (test incorrectly gives a negative result when disease is present) or a false positive (test incorrectly gives a positive result when there is no disease) need to be considered.

Population-based screening should reduce the mortality and morbidity from a disease and it should limit the impact of the disease on the community.¹⁸ Despite preliminary studies showing that certain screening modalities can detect early stage cancer, evidence showing a definitive reduction in mortality is lacking. In the absence of evidence showing a reduction in mortality and/or morbidity from screening for ovarian cancer, population-based screening for ovarian cancer cannot be recommended.

Bimanual pelvic examination

When used alone, bimanual pelvic examination lacks both the sensitivity and specificity to be effective, and is not recommended as a screening method. Studies have concluded that it offers little value as a routine screening tool for ovarian cancer.¹⁹

Ultrasound

The use of ultrasound in ovarian cancer screening has been employed to detect ovarian enlargement and morphological abnormalities that may be suggestive of the presence of a tumour.²⁰

Research into the effectiveness of ultrasound (transvaginal, transabdominal and a combination of both) has not supported its use as a screening tool. The 'positive predictive value' (likelihood that a positive test result will be correct) of transabdominal ultrasound is consistently too low for the technique to be supported. Transvaginal ultrasound provides a better view of morphological changes and can therefore detect some ovarian disease. However, this method generates a large number of false positives due to its inability to distinguish between benign and malignant masses.^{21,22}

Studies of asymptomatic women have shown that of those who had an ultrasound test result suggestive of ovarian cancer, the proportion who actually had the disease was only between 6% and 9%.⁷ Positive predictive value is slightly improved when ultrasound is used in combination for women with a family history of ovarian cancer.⁷ Sonography may therefore best be used as a secondary test for individual women with specific concerns, due to its propensity to produce high numbers of false positives.

The benefits of ultrasound screening are safety, efficiency and acceptance by patients.²³ In contrast, the limitations of sonography as a screening technique include its low positive predictive value, inability to accurately differentiate between benign and malignant disease, and the cost of the technique.

Doppler imaging

Colour Doppler imaging techniques have been employed in screening studies to provide images of ovarian vasculature and estimates of blood flow velocity with the purpose of identifying abnormal flow patterns that may be indicative of malignancy.²⁰ The use of colour-flow techniques is based on the finding that vessels of malignant tumours have blood-flow characteristics of high velocity and low impedance. Therefore, the use of this technique was expected to improve differentiation between benign and malignant disease.²⁴

Colour Doppler ultrasound has also been used, singly or in conjunction with other techniques. Results of Doppler screening studies have been mixed. The use of colour Doppler imaging for ovarian cancer screening is limited by the low specificity, difficulties in reproducibility and subjectivity of results.²⁵ Colour Doppler imaging has not shown any advantage over transvaginal ultrasound or CA125 (see below).⁷

CA125

CA125 is an ovarian cancer antigen that can be detected in blood serum. The levels present in the blood can be affected by a number of factors such as a prior cancer diagnosis, regular smoking, caffeine consumption, age, and age at menarche, age at menopause and a previous ovarian cyst.²⁶ Elevated levels may also be associated with other malignant or benign conditions.

Overall, CA125 testing lacks the specificity and sensitivity required to be a stand-alone cancer screening tool. Importantly, fewer than 50% of women presenting with stage 1 ovarian cancer have elevated CA125 levels.⁷ Using CA125 in combination with other modalities, such as ultrasound,⁷ the utility of serial samples²⁷ and the complementary use of tumour markers²⁸ have been investigated in an attempt to increase specificity and sensitivity.

CA125 as part of a multimodal screening strategy is the focus of current large scale international clinical trials.

New technologies

Genomic and proteomic technologies have the potential to identify specific genes and novel cancer-specific markers for ovarian cancer. The development of molecular profiles for ovarian cancer and a better understanding of the genetic and molecular origins of ovarian cancer may also be used for early detection.⁷

Building the evidence base

None of the screening methods described above, either in isolation or in combination, has yet been shown to be effective in reducing ovarian cancer mortality. Three multi-centre, population-based randomised control trials are currently under way in continental Europe, the UK and the USA, using ultrasound and/or CA125. Eventually more than 320,000 women will participate in these trials.⁷ The results of these trials will help inform future decision-making about the effectiveness and scope for population-based ovarian cancer screening.

Cervical cancer

Cervical cancer is the only gynaecological cancer whose incidence and mortality can be reduced by a population-based screening tool using current technology.

It has been estimated that screening using the Pap test has the potential to reduce squamous cell carcinoma of the cervix by up to 90%. In Australia, the age-standardised incidence rate for cervical cancer declined by an average of 6.2% each year between 1991 and 2001. Mortality rates have also fallen by an average of 5.2% per year since 1991. These gains can be attributed, in part, to the success of the National Cervical Screening Program.^{29,1}

Pap test

The Pap test (named after its developer, Dr George Papanicolaou) is the most widely used cancer screening test in the world.³⁰

Typically, cervical cancer takes 10 years or more to develop. Abnormalities detected by a Pap test can be further investigated and early treatment initiated.

Cervical cancer screening with the Pap test began in British Columbia, Canada, in 1949. Studies of the effects on disease and death due to cervical cancer in Canada, the United States and several European countries have shown a 20–60% reduction in death rates following the implementation of screening programs.³¹

Past studies of the effect of screening did not include randomised controlled trials. The large body of supportive evidence has led to adoption of organised cervical cancer screening programs in many countries, making a controlled trial unlikely for ethical reasons.¹⁶

The challenge with cervical cancer screening in Australia is to ensure maximum participation of women in the target range (all sexually active women aged between 18 and 70), standardise guidelines to improve follow-up and monitoring, and continually review policy in view of changes in evidence and technology.

Other screening technologies

In the past decade, a desire to improve the Pap test has led to research into new screening technologies. One new approach involves the collection of cells in a liquid-based solution, called liquid-based cytology (LBC). With LBC, cervical cells collected on the sampling instruments are suspended in liquid, filtered to remove other materials and examined under a microscope.

An Australian Government review by the Medical Services Advisory Committee concluded that there is insufficient evidence to suggest LBC is superior to the conventional Pap test and recommended that public funding not be provided for this screening test in Australia at this time.³² The Cancer Council Australia supports this recommendation.

Emerging issues

Given the demonstrated effectiveness of population-based cervical cancer screening, it is important for policy-makers to ensure systems are in place to maximise participation and to review policy as new evidence and technologies emerge. Evidence shows that participation rates among specific population groups such as Indigenous women have been comparatively low, although there are signs of improvement (see *Term of Reference C*, page 22).

Screening intervals are also being reviewed. Australian guidelines recommend screening every two years; however, many countries have adopted a three-year interval between Pap testing of asymptomatic women, which is supported by the available evidence.³³ Two-year intervals also increase the cost of the screening program and may reduce participation rates.

HPV immunisation

One of the most significant recent breakthroughs in cancer-prevention technology is the Australian development of a vaccine shown to prevent strains of the human papilloma virus that lead to cervical cancer. Trials of two vaccines have been highly successful. One of two commercial products, Gardasil™, has already been registered for use; the other, Cervarix™, is also expected to be approved in 2006.

Developing countries that have no screening programs and high rates of cervical cancer as a result are seen as the first beneficiaries of HPV immunisation. There will also be the need to evaluate the benefits of HPV immunisation in Australia. It is important to note that the vaccine will be most effective in preventing HPV-associated cancer if delivered to women before the commencement of sexual activity. And with trials to date showing that the vaccine would not prevent all future cervical cancer cases but an estimated 60-80%, cervical cancer prevention through population-based Pap testing will be required for some years yet. The Government should, however, look at fast-tracking an immunisation program for higher-risk groups such as Aboriginal and Torres Strait Islander women (see page 26).

HPV immunisation is also expected to help prevent vulval cancer, up to 50% of which has been linked to HPV infection.

The emergence of HVP vaccines and other new technologies, such as HPV DNA testing that can identify high-risk forms of the infection, may lead to new population-based approaches to cervical cancer prevention. In the meantime, regular Pap testing, which has been shown to be the most effective population-based cancer screening in history, should be supported and measures put in place to help guarantee maximum effectiveness.

Screening for gynaecological cancers – recommendations

- Support evidence- and merit-based research into effective early detection modalities for uterine and ovarian cancers (See Research section).
- Support higher standards of cancer professional education (see following subsection) and greater public education to facilitate personal decision-making around testing for cancers that cannot be detected through screening.
- Support higher standards of cancer professional education (see following subsection) and greater public education to assist women who may be at high risk of developing gynaecological cancers. See Surveillance, page 31.
- Cancer Australia to consider a national quality assurance mechanism, including a framework for credentialing medical professionals involved in cancer care, to facilitate wider use of clinical practice guidelines such as those for the management of ovarian cancer.
- Support research into genetic technology for early detection of cancer and the use of genetic testing monitored in terms of cost-effectiveness.
- Introduce measures to improve access to cervical cancer screening for under-screened populations, such as Aboriginal and Torres Strait Islander women (see following section).
- Investigate feasibility of extending recommended cervical screening intervals for asymptomatic women from two to three years.
- Investigate new cervical cancer prevention modalities and technologies, such as HPV immunisation and DNA testing, and the potential for fast-tracking an HPV immunisation program for Indigenous Australian and other high-risk population groups.

Treatment services

The challenges of accessing optimal care for women with gynaecological cancers are in many ways consistent with those faced by all Australians living with cancer. There are also issues more specific to women living with gynaecological cancers, such as those relating to sexual and reproductive health.

A key to ensuring that Australian women with gynaecological cancers have access to optimal services is to improve the planning and provision of cancer services generally. While Australia has a generally good record by international comparison of successfully treating cancer, patients and their families consistently report difficulties in navigating through the maze of services.³⁴

Principles of optimal cancer treatment and care

Optimal cancer treatment should mean not just treating the disease, but also caring for and supporting the individual patient, their carer and family. To do so efficaciously may involve health care professionals from a number of disciplines, including the general practitioner who makes the referral; surgeons, medical and radiation oncologists; oncology and palliative care nurses; social workers, psychologists, occupational therapists and physiotherapists; pharmacists, dieticians and palliative care physicians.

There is a growing evidence base, both scientific and anecdotal, that taking a multidisciplinary team approach to caring for the individual patient is leading to improved treatment outcomes.^{20,35} Best-practice models of multidisciplinary care help to ensure that treatment and care are based on agreed national clinical practice guidelines, or the best available evidence in the absence of guidelines.^{20,36}

It is also important to note that while national standards are pivotal to best practice, flexibility is also required within a national framework. Different models of multidisciplinary care will need to be applied in different circumstances, depending on the individual patient's needs and the setting in which they are treated (see Remote communities, page 28).

The National Health Priority Action Council's National Service Improvement Framework, endorsed by all federal/state-territory jurisdictions, has identified and recommended a number of measures for optimising cancer care that should be applied as standard practice wherever possible.³⁷ These include:

- case-conferencing for agreement on options for treating each patient;
- audit systems for collecting information about the care of people with cancer, ensuring care is based on evidence and protocols. Results could be used to develop continuous quality improvement programs;
- pathways for patients to be invited to participate in clinical trials;
- protocols for exchange of information among all team members, including general practitioners;
- opportunities for patients to provide feedback about the care received from all team members;
- people living with cancer having the opportunity to contribute to the planning of cancer services;

- protocols to ensure patients can discuss their concerns openly with their treatment team or individual team members;
- access to an individualised written treatment and follow-up plan;
- provision of culturally appropriate care.
- Access to supportive care services including psychologists, psychiatrists and social workers, if needed.

Cancer Australia may be well-placed to explore ways of more rigorously applying the principles of cancer care endorsed through the National Service Improvement Framework, which currently lacks a multi-jurisdictional implementation plan.

Expanding the National Breast Cancer Centre's (NBCC's) role to develop and distribute clinical practice guidelines and other resources specifically designed to improve standards of gynaecological cancer care would support this approach. The NBCC already oversees the national ovarian cancer program; widening its remit to include all gynaecological cancers would be a logical addition to that role.

Psychosocial support

The diagnosis and treatment of a gynaecological cancer is a distressing experience and may affect a woman's sexuality, body image and/or reproductive capability. Essential to psychosocial support is the importance of addressing a patient's individual needs. Counsellors and specialist nurses who are professionally trained to support women with these health concerns are therefore an integral part of a patient-centred, multidisciplinary team approach to cancer care.

The NBCC's *Clinical practice guidelines for the psychosocial care of adults with cancer* contain well-researched, evidence-based advice on how to support a patient's psychological and emotional needs during cancer treatment. A whole-of-government response is required to ensure that these guidelines are adopted as standard practice in cancer care.

Treating gynaecological cancers – recommendations

- Cancer Australia to develop an implementation plan for the National Service Improvement Framework (cancer).
- Expand the National Breast Cancer Centre's ovarian cancer role to include developing clinical practice resources for other gynaecological cancers, such as uterine cancer.
- A whole-of-government response to improving access to psychosocial support for women with gynaecological cancer, including wider application of clinical practice guidelines.
- Link the National Health Call Centre Network (see COAG Australian Better Health Initiative; 2006-07 federal budget papers) to refer calls for cancer-related support and information to The Cancer Council Helpline.

- c) *capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions;*

Overview

Australia's success in reducing cancer mortality and improving survival has not been equitably shared by disadvantaged groups, most notably people of Indigenous background and people living in isolated regions.

There is no national dataset on cancer mortality involving the Aboriginal and Torres Strait Islander population, but from available data it is estimated that Indigenous Australians with cancer are twice as likely to die within five years of diagnosis than non-Indigenous Australians.³⁸

In regional communities generally, cancer survival is significantly poorer when compared with results in metropolitan areas. For example, a report published in the *Medical Journal of Australia* in 2004 showed that people with cancer in regional NSW were 35% more likely to die within five years of diagnosis than patients in cities. The study included a focus on cancers of the uterus and cervix, with survival deteriorating as geographical remoteness increased.³⁹

While geographical isolation are common barriers to service access for both Indigenous and non-Indigenous peoples in rural and remote locations, issues of culture and socioeconomic status vary widely between the two groups; this submission therefore addresses them separately.

Aboriginal and Torres Strait Islander women

Non-cervical gynaecological cancer

Australia is a world leader in cancer survival. It is appalling that, despite our globally enviable record in general terms, Aboriginal and Torres Strait Islander people are around twice as likely to die within five years of a cancer diagnosis as non-Indigenous Australians.³⁸

Limited available evidence shows the issue is so complex, poorly understood and population-specific that a comprehensive and dedicated whole-of-government response is required to better understand and address the unacceptable inequities in treatment outcomes. Recognising cancer control in Indigenous Australians as a public health priority would ultimately improve the management of gynaecological cancers in Aboriginal peoples and Torres Strait Islanders.

The key barriers to equitable cancer outcomes for Aboriginal and Torres Strait Islanders across tumour types generally are outlined in the joint submission to last year's Senate inquiry into treatment options for persons with cancer, available at: www.cancer.org.au/policy_submissions

Cervical cancer

In terms of specific gynaecological cancer types, cervical cancer is the subject of the most pronounced and identifiable disparity in outcomes between Aboriginal and Torres Strait Islander women and non-Indigenous women, due largely to the barriers to effective screening faced by Indigenous Australian women.

While significant gains have been made in cervical cancer prevention for non-Indigenous women, research shows that the rate of death from cervical cancer for Aboriginal and Torres Strait Islander women is much higher than for non-Indigenous women.^{40,41,42} For example, data from specific Aboriginal communities in Queensland over the 15-year period 1982-1996 indicates that the death rate from cancer of the cervix among Aboriginal women was 13.3 times higher than the state average. Data from Torres Strait indicates that the death rate was 21.5 times higher than the state average (Health Information Centre, 1999).⁴³ Other states and territories also reported a higher level of incidence and mortality from cervical cancer among Indigenous Australian women.^{27,28}

As a general guide to best practice, The Cancer Council Australia, COSA and NACCHO support in principle the Commonwealth of Australia's *Principles of Practice, Standards and Guidelines for Indigenous Women*.²⁸ There are, however, a number of practical barriers to achieving optimal effectiveness in cervical cancer screening of Indigenous Australian women.

Practice Incentive Program

The Australian Government's Practice Incentive Program/Cervical Screening Incentive (PIP/CSI) is designed to increase cervical screening participation rates in under-screened populations by providing financial incentives to GPs. It provided \$71.9 million over four years to improve cervical screening in the 2001-2002 Federal Budget. In the 2006-07 Federal Budget, the Australian Government committed continued funding of \$97.2 million over the next four years to encourage GPs to especially target under-screened women such as those in rural and remote areas, Indigenous women and women from linguistically diverse backgrounds.⁴⁴

The program is particularly significant to gynaecological cancer control among Aboriginal and Torres Strait Islander women, who represent the most under-screened population group for cervical cancer prevention in Australia on the basis of relative incidence and mortality rates.

While PIP/CSI is a potentially effective concept in principle, there are fundamental structural barriers limiting the program's capacity to significantly increase cervical screening participation rates among Aboriginal and Torres Strait Islander women.

In 2001, NACCHO outlined barriers that ACCHSs faced in accessing the program and the lack of evaluation criteria for Aboriginal and TSI women. These included:

- only a minority of ACCHSs were PIP accredited at the time (and therefore PIP-eligible), so the initiatives effectively excluded the majority of ACCHSs;
- support funds were mainly channelled through Divisions of General Practice, despite evidence that this approach was suboptimal given that relationships between Divisions of GP and ACCHSs were not uniformly established.

Independent evaluations' of other programs had demonstrated suboptimal support from Divisions for the ACCHS sector;

- services that provide Pap testing to Aboriginal women but do not use Medicare will not receive any payments.

Despite the program specifically targeting high-risk women, its effectiveness to reach under-screened Aboriginal and Torres Strait Islander women was never evaluated. The recent Department of Health and Ageing evaluation specifically excluded ACCHSs from the evaluation; the reasons for this have been unclear. Over 1.6 million episodes of care are provided to Aboriginal people and Torres Strait Islanders by ACCHSs every year, so their exclusion is a major flaw in the evaluation.

Since 2001, the number of ACCHS that are now PIP-accredited and eligible for the program has expanded to around 61 services, meaning that only around one-third of services are now locked-out of the program. Nevertheless, of those that are PIP-accredited, a substantial proportion do not claim the MBS trigger for the PIP payment, thereby receiving none of the program incentives.

The response from the Department of Health and Aging on this matter (January 2006) states:

“The PIP data shows that in 2004-05, AMSs participating in PIP screened 279 women who had not previously had a cervical smear for four years or more.”

It is unclear if this number is wholly Aboriginal women, or if these women include non-Indigenous women, as on average 10-20% of ACCHS clientele is non-Indigenous. Whatever value this data may provide, it is clear that few Aboriginal women are benefiting from the program. Moreover, the Department of Health and Ageing cannot tell what the barriers might be and appears disinclined to investigate.

It is clear that a lack of thorough consultation with NACCHO, which represents individual ACCHSs has limited the program's reach. ACCHSs target a high proportion of the Aboriginal and Torres Strait Islander population in Australia, especially patients who may not have access to mainstream services. To date ACCHSs have not been formally invited to discuss their level of participation in the program.

Awareness levels about the PIP/CSI among Aboriginal and Torres Strait Islander women and Aboriginal health workers are also inadequate, as the program has not been promoted to them through a targeted communication strategy.

Liquid-based cytology

Repeat Pap tests from Aboriginal and Torres Strait Islander women can be difficult, especially when the initial smear was the result of opportunistic screening – the usual form of screening for most Aboriginal and Torres Strait Islander women. A high proportion of smears require repeating, because of factors such as poor technique and the presence of vaginal infections. To address this problem, ACCHSs have called for government subsidisation of liquid-based cytology tests for Aboriginal and Torres Strait Islander women. There is a strong case for exploring the effectiveness of using liquid-based cytology for Aboriginal women to improve the efficiency of sample collection. The significant financial barriers that many Aboriginal people face

prevent liquid-based cytology from being a viable option for Aboriginal and Torres Strait Islander women. One option for subsidising liquid-based cytology specifically for Aboriginal and Torres Strait Islander women would be to use under-expended PIP/CSI program funds for this population group.

Medicare

Aboriginal Community Controlled Health Services have reported facing barriers to claiming a Medicare rebate (items 2497, 2501, 2503, 2504, 2506, 2507) for cervical screening of Aboriginal and Torres Strait Islander women. Claiming for these items also triggers a PIP payment, but only ACCHSs registered with the PIP will receive this additional payment. Surveys indicate that even registered ACCHSs are not claiming these rebates. The reasons are unclear and need to be investigated by the Department of Health and Ageing, if the PIP/CSI program is to be deployed to greater effect among its priority target group.

Access to cervical screening among Indigenous women is further compromised because the Medicare rebate for Practice Nurse Pap smear (items 10998 and 10999) does not apply to Aboriginal health workers. Measures to extend eligibility for these items to Aboriginal health workers nationwide, many of whom care for Aboriginal and Torres Strait Islander women seldom accessed by other services, need to be urgently explored.

Aboriginal health workers

One of the most significant health interventions put into practice, and which has the potential to counter the findings of disproportionate gynaecological cancer morbidity and mortality in Aboriginal and Torres Strait Islander women, has been the employment of Aboriginal health workers throughout Australia. Aboriginal health workers are employed within all ACCHSs and many state health services that provide cervical screening accessed by Aboriginal and Torres Strait Islander women. Anecdotal evidence over the past decade suggests that many Aboriginal health workers also practise effectively as Pap test providers, hence the need to support their efforts through Medicare (see previous subsection). Aboriginal health workers are regarded as integral team members, working alongside registered nurses in Well Women's health screening. This strategy has facilitated a steady increase in cervical screening rates for Indigenous Australian women in many areas.

The Medicare Benefits Schedule recognises AHWs as a key part of the health workforce, especially in the provision of care plans for chronic disease where it lists AHWs as part of the allied health team for these MBS rebates. However, other AHW rebates are restricted only to the Northern Territory, as this jurisdiction has a system that registers its AHWs. Other jurisdictions have alternative systems of assuring completion of training, but these are not recognised in the MBS for other rebates.

The Medicare rebate for Practice Nurse Pap testing does not apply to AHWs, an omission in need of correcting. When this is addressed, the MBS must also recognise the core competencies of AHWs in other states, not just in the Northern Territory.

Tobacco control

The evidence base linking tobacco smoking to an increasing number of cancer types is increasing. Current evidence indicates that 28% of vulval cancers and 19% of cervical cancers are associated with smoking.

Although evidence on specific cancers in Aboriginal and Torres Strait Islander people is limited, research indicates that Aboriginal and Torres Strait Islander smoking rates are more than 2½ times those of non-Indigenous peoples; it is therefore likely that smoking among Indigenous Australian women contributes to vulval and cervical cancer incidence and mortality at higher rates than in non-Indigenous women.

HPV immunisation

The availability of an HPV vaccine to prevent cervical cancer is of particular significance to Indigenous Australian women, given their higher incidence and mortality rates and poorer access to screening. The Australian Government should explore the feasibility of fast-tracking the introduction of an immunisation program for Aboriginal and Torres Strait Islander women.

Radiation therapy

More than half of all cancer patients require radiotherapy as part of their treatment.⁴⁵ Access to radiation oncology services is severely restricted in remote areas, particularly the Northern Territory where there are no radiotherapy facilities and a higher relative number of Aboriginal and Torres Strait Islander women. While there are signs that governments are addressing the issue of radiotherapy access in the Top End, with an inter-jurisdictional commitment to establish facilities in Darwin, it is important that this remains a priority.

Gynaecological cancer control in Aboriginal and Torres Strait Islander women – recommendations

- Identify cancer control in Indigenous Australians as a key health priority (see Attachment 1 - *Reducing the impact of cancer in Indigenous communities: conference report*).
- Explore models for the broader application of the Commonwealth's *Principles of practice, standards and guidelines for providers of cervical screening services in Indigenous women* as standard practice.
- Undertake an evaluation of the barriers faced by Aboriginal Community Controlled Health Services in claiming Medicare rebates (items 2497, 2501, 2503, 2504, 2506 and 2507) under the Practice Incentive Program/Cervical Screening Incentive (PIP/CSI).
- Formally involve NACCHO in the evaluation of, and designing any subsequent improvements to, the PIP/CSI programs.
- Conduct a targeted communications strategy to raise awareness among Aboriginal and Torres Strait Islander services and other stakeholders of the availability and objectives of PIP/CSI.
- Explore measures to extend eligibility for Practice Nurse Pap test MBS items 10998 and 10999 to all Aboriginal health workers operating out of Aboriginal Community Controlled Health Services, in recognition of the core competencies of Aboriginal health workers in all states and territories.
- Explore subsidising liquid-based cytology for cervical cancer detection in Aboriginal women through under-expended PIP/CSI program funds.
- Improve tobacco control strategies for Indigenous Australian people, who smoke at more than 2½ times the rate of non-Indigenous people.
- Explore the fast-tracking of an HPV immunisation program for Aboriginal and Torres Strait Islander women.

Remote communities

There is a growing body of evidence showing that Australians who live in rural and remote areas are at risk of significantly poorer survival rates following a cancer diagnosis than people with similar diagnoses in the major metropolitan centres.⁴⁶ For example, studies show that people with cancer in regional NSW are 35% more likely to die within five years of diagnosis than patients in cities. Mortality rates increase with remoteness.⁴⁷

People with cancer in rural and remote areas are diagnosed at a later stage than their urban counterparts³ and are more likely to die from cancers such as cervical and uterine cancer the further they are located from large cities.⁴⁸ The limited available evidence suggests that women with gynaecological cancers are adversely affected by the rural/metropolitan divide to a particularly high degree.

The problems of diagnosing and treating cancer in regional Australia reflect disadvantages across the healthcare spectrum experienced by all rural and remote communities. The evidence indicates that reducing inequality in cancer outcomes requires a combination of improved primary healthcare and access to specialist multidisciplinary services.⁴⁹ The disparities are so pronounced that a whole-of-government approach is urgently required to reduce inequities across the broad spectrum of cancer types. Detailed recommendations for regional cancer service reform, extracted from COSA's recent mapping of rural/remote oncology services, are set out in Attachment 2, page 42.

Psychosocial care

Psychosocial needs of women with gynaecological cancers can be particularly acute, due to concerns about sexual function, body image and reproductive capability. Access to psychosocial support has been shown to decrease with remoteness; improved access to services such as counselling for women with gynaecological cancers needs to be a priority in reforming regional cancer treatment services.

Gynaecological cancer control in remote communities - recommendations

- Commonwealth and state/territory governments to explore a collaborative approach to reducing geographic inequities in cancer care, through the COAG process and with guidance from non-government peak bodies and Cancer Australia.
- Whole-of-government commitment to building and recurrently funding oncology centres of excellence in large regional cities, to substantially reduce distances between capital city tertiary treatment facilities and remote areas.
- Cancer Australia to establish a national quality assurance framework to facilitate regional cancer centres' use of resources such as clinical practice guidelines.
- Commonwealth, in collaboration with the states/territories and jurisdictional cancer registries, to invest in national clinical data systems to audit, monitor and plan oncology services across regions.

- Commonwealth to invest in psychosocial support services for people in rural and remote areas.
- Commonwealth to build on recent commitments in Strengthening Cancer Care (e.g. mentoring programs) to increase support for distance education, mentoring and innovative models such as telemedicine.
- Government-funded travel and accommodation schemes for cancer patients and their families in remote areas to be better coordinated across borders.

Women of diverse language backgrounds

We support the quality work of the NBCC targeting women of diverse language backgrounds. Expanding the NBCC's remit to include gynaecological cancers more generally would build on the solid foundations it has laid in the area of multicultural communications and extend the organisation's reach into ethnic communities.

- d) *extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;*

Overview

As the evidence base showing the benefits of a multidisciplinary team approach to cancer care grows, along with cancer prevalence in Australia, so too does the need to improve cancer management competencies throughout the healthcare system. For example, while GPs play a pivotal role in providing primary healthcare and advice to all Australians, surveys show that most general practitioners consult very few cancer patients in a year. Elsewhere in the healthcare system, we are seeing increased specialisation, coupled with greater integration and flexibility of services.

Evidence informing best practice is also growing and changing as new data becomes available. And the full spectrum of cancer control, from primary prevention to palliation, is evolving in step with developments as wide-ranging as lifestyle prescriptions, new diagnostic and imaging technology, genetic therapy, molecular pathology and better targeted radiotherapy.

To make best use of this expanding suite of services and changing models of care, it is essential that standards and mechanisms to underwrite the quality of cancer treatment and care be built into medical education across the sector.

Clinical practice guidelines

The NBCC/Australian Cancer Network *Clinical Practice Guidelines for the Management of Women with Epithelial Ovarian Cancer*, released in 2004, have been widely distributed to healthcare professionals. We would also support the allocation of Australian Government funds for the development and distribution of clinical practice guidelines for cervical, uterine (endometrial), vaginal and vulval cancers – and, moreover, a mechanism for their wider application.

Clinical practice guidelines are comprehensive, peer-reviewed guidelines covering all facets of managing particular disease. They include advice on how to involve non-clinical allied health services, such as counsellors, and on enhancing communication skills and other elements of care based on a patient-centred approach. They are a good example of excellence in evidence-based policy that does not automatically translate to standard practice nationally, as there is currently no quality assurance framework to facilitate their use.

Accreditation/credentialing

The Australian Cancer Network (a resource of The Cancer Council Australia) and the NBCC have been developing national policy for accrediting cancer services and credentialing individual practitioners. Cancer Australia may be well placed to work across jurisdictions to develop a mechanism for formally adopting clinical practice guidelines through the accreditation/credentialing process. Accreditation and credentialing would also help to ensure cancer care professionals are applying the principles of optimal cancer care endorsed by all jurisdictions through the National Service Improvement Framework.

Vocational education

Cancer's high prevalence (estimated at 267,000 by the Australian Bureau of Statistics in 2004) and increasing incidence demonstrate a growing need for minimum national standards in medical competency. The volume of cancer patients should also mean that both undergraduates and hospital interns have adequate access to appropriate clinical practice-based training in managing the many potentially fatal forms of the disease. However, there are no minimum national standards in place. Moreover, evidence shows that cancer competency in graduates is below the level cancer specialists recommend for optimal care and efficiency, and that cancer knowledge and skills in relative terms are deteriorating in Australia.

A comparative study published in the *Medical Journal of Australia* in 2003 indicated that recent medical graduates had less exposure to cancer patients than those who had been trained 11 years earlier.⁵⁰ This is of serious concern, as previous studies had in any case demonstrated that training standards in cancer management were not high.^{51,52}

These studies show, for example, that many medical students graduate without having examined people with the most common forms of cancer or knowing the ages of greatest risk of developing the most common cancers. Graduates have also been unable to confirm whether five-year survival rates are higher or lower than 50% for some of the most common cancers in Australia. It is likely that this decline in competency standards also applies to the management of gynaecological cancers.

The Department of Education, Science and Training (DEST) is currently studying undergraduate and graduate medical competencies with a view to fostering a culture of excellence in medical care nationwide. Attachment 3 – *COSA/Cancer Council submission to DEST medical education study*, includes a number of recommendations from leaders in oncology education in Australia aimed at improving overall cancer competency in the wide medical profession. Central to these recommendations is the application of an 'ideal oncology curriculum', developed by The Cancer Council Australia/COSA's Oncology Education Committee.

GP education and support

As the symptoms of some gynaecological cancers are difficult to detect, GPs may miss early diagnoses. Education programs for GPs are conducted by various groups on an ad-hoc basis. We support the development of a nationally coordinated GP education program on gynaecological cancer. The NBCC guide *The investigation of a new breast symptom – a guide for General Practitioners* (February 2006) is highly commended; a similar resource for GPs would be beneficial in identification, investigation and appropriate referral of women with a suspected gynaecological cancer. As an extension of managing the National Ovarian Cancer Program, the NBCC could oversee the development and implementation of such a resource.

Surveillance

Factors such as heredity and coexisting medical conditions can place a number of women at higher risk of developing a gynaecological cancer. For example, up to 10% of all cases of ovarian cancer are thought to be due to the inheritance of a small genetic mutation.⁵³ Carriers have an increased risk of epithelial ovarian cancer of at least 10-fold. Women at increased risk of ovarian cancer due to genetic mutations may in some cases also benefit from pre-emptive, risk-reducing surgery.⁵⁴

The risk of developing uterine cancer increases for women taking tamoxifen to prevent or treat breast cancer, women with a genetic disorder and women carrying a proven DNA mismatch repair gene. Other potentially identifiable risk factors apply to cervical, vulval and vaginal cancers.

Advancements in genetic technology are increasing the significance of family history to cancer control. Governments will need to invest increasingly in familial cancer clinics, which can make a thorough assessment of a family's cancer history and determine the likelihood that an gynaecological cancer-related genes may be present. Improving the level of cancer professional awareness across the healthcare spectrum would lead to better use of such services.

Non-medical health professionals

It is important to note that non-medical health professionals (nurses, psychologists, social workers etc.) also have a significant role in treating and caring for gynaecological cancer patients. A recent study shows that many nurses (across a variety of settings) caring for women with gynaecological cancer report a lack of confidence in their ability to manage commonly experienced issues, in particular infertility, genetic susceptibility, menopause, lymphoedema and psychosexual dysfunction.⁵⁵

Allied health professional education programs should include a focus on cancer management, particularly as incidence rates rise and as the trend towards multidisciplinary care creates increased opportunities for a wider range of healthcare professionals to participate in patient care.

Gynaecological cancer control through medical education – recommendations

- Cancer Australia to scope a mechanism to facilitate the use of clinical practice guidelines as standard practice across the healthcare system.
- Cancer Australia to scope a mechanism for accrediting/credentialing cancer treatment centres and individual professionals.
- Implement The Cancer Council Australia/COSA ideal oncology curriculum as a standard component of medical training.
- The Department of Education, Science and Training to adopt the recommendations made by The Cancer Council Australia/COSA to improve cancer competencies via vocational medical training (see Attachment 2).
- The National Breast Cancer Centre to develop and distribute a general practitioner guide to managing gynaecological cancers.

- (e) *extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers;*

Overview

Community education is essential to individuals adopting lifestyles that promote good health, being aware of warning signs that may indicate the presence of disease, and making informed choices about the management of their particular health and medical concerns.

Gynaecological health is a complex area. Women at risk need to be fully supported across the health spectrum. Better coordination of and building on existing resources is a key to ensuring Australian women are better supported in reducing their risk of gynaecological cancer and making optimal use of early detection, treatment and care services to improve their treatment outcomes.

Risk factors

Some risk factors associated with gynaecological cancers are well-known and avoidable. Others, such as ageing or heredity, are unavoidable but can be factored into surveillance and the management of an individual woman's concerns. (See Attachment 3 – *Gynaecological cancer risk factors*.) All women should have access to available information about risk factors and specialised services, such as familial cancer centres (See Surveillance, page 31).

We support the NBCC's management of the Ovarian Cancer Program, which includes the development and distribution of a range of resources aimed at raising community awareness about ovarian cancer risk. Commonwealth funding for an expansion of the NBCC's role to manage all gynaecological cancers would not only improve community understanding of these cancers generally, it may also extend the community reach of the ovarian cancer program, which targets the gynaecological cancer responsible for the most deaths in Australia.

As maintaining a healthy weight and not smoking have been shown to reduce the risk of some gynaecological cancers, government support for primary prevention measures, such as those outlined in the Council of Australian Governments' Better Health Initiative, may also help to reduce the impact of these cancers.

Symptoms

Symptoms for gynaecological cancers vary widely. Women are advised to discuss their gynaecological health with healthcare professionals.

An extension of the NBCC's role to raise community awareness about all gynaecological cancers would have the potential to alert women at risk to possible early warning signs.

The Australian Government should fund the NBCC to develop GP guidelines for the detection of gynaecological cancers, similar to its GP guide to investigating breast

cancer symptoms. This would help to ensure that women in the broader community have access to optimal advice from their family doctor.

Cancer Councils disseminate a range of resources aimed at raising women's awareness of gynaecological cancer symptoms or indications of precancerous conditions. The Cancer Council Help Line (13 11 20) also provides telephone counselling and referral to appropriate professionals. Aboriginal Community Controlled Health Services seek to raise awareness of the signs of gynaecological cancers among Indigenous women.

By maintaining formal links, such as the relationship between The Cancer Council Australia's Australian Cancer Network and the NBCC, and the Cancer Council and NACCHO's proposal for a memorandum of understanding, these organisations may be able to better coordinate their gynaecological awareness raising activities. Governments in Australia need to consult more thoroughly with these peak bodies to ensure community stakeholders are better represented in the development of educational resources.

Treatment

A key principle of multidisciplinary cancer care is a patient-centred approach: the patient is a core member of the team and is consulted about all aspects of the care plan to ensure informed decision-making.

Implementing the recommendations in the National Service Improvement Framework for cancer would help to ensure that women being treated for gynaecological cancers had a clear understanding of their individual treatment regimen. This would include bringing allied health service providers, such as counsellors who could address some of the specific concerns of women with gynaecological cancers, into the multidisciplinary team as standard practice.

The wider application of clinical practice guidelines, such as those for ovarian cancer and for the psychosocial care of adults with cancer, would also help to ensure that women with gynaecological cancers are fully informed about treatment issues. These guidelines include advice on the importance of discussing with the patient any interest they may have in areas such as complementary and alternative medicine.

Gynaecological cancer control through community education - recommendations

- Expand the NBCC's role in disseminating community information to include a focus on all gynaecological cancers.
- Support primary healthcare providers through a whole-of-government approach to better informing women about gynaecological risks and treatment issues.
- Support The Cancer Council's involvement in developing primary prevention programs through the COAG Australian Better Health Initiative.
- Cancer Australia to facilitate the implementation of the National Service Improvement Framework (cancer) and the use of clinical practice guidelines.

- (f) *extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently established Cancer Australia.*

Gynaecological cancer representation

Diverse representation on policy-making and service planning bodies is critical to providing equity in the development and implementation of cancer prevention, treatment and care services.

The Cancer Council Australia, COSA and NACCHO do not support a quota-system approach to representation on policy-making bodies based on tumour type. If such an approach were taken, efforts to systematically reform cancer services would be fragmented; and people with cancers that cause relatively low incidence and mortality might struggle to find a voice. Instead, we support broad representation from groups with a wide range of cancer experience and skills, including oncologists, population health experts, consumers and allied health professionals. These groups would include people with personal experience of gynaecological cancer – as service providers, advocates and/or consumers.

We support specific representation of people from population groups that face demonstrated barriers to equitable service provision, such as Indigenous people and people in remote communities. Indigenous and rural/remote community representatives would be expected to support the needs of women at risk of or living with gynaecological cancers, particularly as the evidence shows such cancers impose a considerable burden on these population groups.

The Cancer Council Australia and COSA have strong links with the NBCC and support the organisation's efforts to reduce the impact of ovarian cancer. Expanding the NBCC's role to include the management of other gynaecological cancers would bring additional expertise to the organisation and, by extension, to its joint activities with The Cancer Council and COSA.

Cancer Australia

The Cancer Council Australia and COSA advocated for the establishment of Cancer Australia. We therefore look forward to its establishment and opportunities to work closely with the agency, while maintaining our independence as community- and clinical-based cancer control advocates.

Australian cancer agencies, in the government and non-government sectors, have produced a wealth of evidence-based guidelines and policy documents to underpin best practice in cancer prevention, early detection and care. This effort is expected to continue. Translation from theory into practice, however, is limited by the absence of a national agency that can bring governments together across jurisdictions to develop practicable implementation plans for standardising best practice nationally. It is our hope that Cancer Australia is able to provide that link.

A key way to improve cancer services for women at risk of or affected by gynaecological cancers is to implement the National Service Improvement

Framework for cancer. The framework is based on a patient-centred approach, which, by definition, would address the individual needs of women with gynaecological cancers. It is hoped that Cancer Australia identifies implementation of the National Service Improvement Framework as an urgent priority.

The Cancer Council Australia and COSA are strongly committed to reducing the impact of gynaecological cancers. Our representatives on Cancer Australia's advisory committee will convey the concerns of our gynaecological cancer stakeholders and work to help ensure that relevant issues receive due prominence in discussion around the agency's strategic directions.

Representation of a number of professionals involved with the NBCC on the advisory committee would also help to ensure that gynaecological cancer became an appropriate priority issue for Cancer Australia, particularly if the NBCC's role were to be extended to oversee gynaecological cancer control measures at the national level.

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Attachment 1 – article from *Medical Journal of Australia*

Reducing the impact of cancer in Indigenous communities: ways forward

Ray M Lowenthal Paul B Grogan Ellen T Kerrins

Indigenous Australians with cancer are twice as likely to die from the disease than non-Indigenous Australians. Because of this stark imbalance, the Cancer Council Australia recently convened the first ever national discussion forum to address the issue.

Around 120 people from around Australia gathered in Darwin in August 2004 for the forum, “Reducing the impact of cancer in Indigenous communities: ways forward”.

Originally conceived by the Cancer Council Australia as an internal event, planning for the forum tapped into a groundswell of concern about the poor outcomes for Indigenous Australians with cancer. This interest, combined with financial support from the Australian and Northern Territory governments, the National Cancer Control Initiative and the Cancer Council Northern Territory, turned the meeting into a major national event.

Why a discussion forum?

The past two decades have seen a 30% reduction in cancer mortality rates in Australia. However, at a meeting in late 2003, the board of the Cancer Council Australia reflected on the fact that recent successes in cancer control were not shared by Indigenous Australians and that we did not fully understand why.

We were familiar with the rhetoric about limited access to services, cultural barriers and coexisting health problems, but, before we could work towards improving Indigenous cancer outcomes, the problems needed to be better understood.

To this end, we invited Australia’s leading oncologists and epidemiologists with an Indigenous focus, academics, Aboriginal health workers and Indigenous cancer survivors to the forum. Organisational support from the National Aboriginal Community Controlled Health Organisation (NACCHO) helped us reach Aboriginal health workers from Australia’s most remote communities. The result was an unprecedented sharing of epidemiological, cultural and anecdotal Indigenous cancer data, with consensus on ways in which stakeholders could work together to effect measurable improvements.

Epidemiology

There is no simple answer to the question of why Indigenous people with cancer die at twice the rate of other Australians with cancer, nor is there a national dataset from which to draw. The inadequacy of data itself demonstrates the extent to which the problem has been overlooked.

However, information gathering on a state and territory basis is improving significantly, particularly in South Australia and the Northern Territory. David Roder (Head of Epidemiology, Cancer Council South Australia) and John Condon (Senior Research Fellow, Menzies School of Health Research) explained that the comparatively high mortality rate is partly the result of Indigenous Australians getting “more than their share” of cancers with poorer survival outcomes, such as cancers of the lung, oropharynx, oesophagus, liver, gallbladder and pancreas. Conversely, Indigenous Australians have lower rates of some of the more curable cancers, such as breast, prostate, bowel and skin cancers.

Delayed diagnoses in Indigenous people also contribute to poor survival rates, along with a reduced likelihood of completing treatment. These problems may explain why Indigenous Australians die at higher rates than other Australians, even when afflicted with the same cancer type. However, the forum also revealed other, less apparent factors.

Penetrating insights

Ngiare Brown (an Aboriginal medical educator and child health specialist with the NT Government) cited institutionalised racism, bureaucratic inaction, and a disconnect between

Indigenous and non-Indigenous Australians as the underlying reasons behind the so-called “double burden” of disease suffered by Indigenous people. Brown also reminded the forum of other statistical inequities: twice the rate of low birthweight, and an overall life expectancy 20 years lower than that of non-Indigenous Australians.

A penetrating cultural insight came from Jeremy Baker Balung (an Indigenous man who works as a counsellor for Aboriginal and Torres Strait Islander cancer patients at the Royal Darwin Hospital). Among Baker Balung’s Yolgnu people, each part of the body represents a spiritual link to individual members of the extended family; to have a cancer in a certain organ may be the result of offending the relative whom that part of the body represents. He emphasised the need to respect such beliefs, which are underscored by a deep regard for kin. A person who believes his or her cancer is “payback” for offending a family member may not pursue treatment. Respect and understanding must be reciprocal for people with such strong spiritual convictions; medical practitioners dismissive of time-honoured traditions may be unable to gain their patients’ trust.

Cultural differences go hand in hand with communication barriers. For many Indigenous people, English is the second, third or fourth language, with multiple native dialects predominating in more remote communities. NT epidemiological data show that treatment outcomes are consistently poorer for all cancers in people whose first language is an Indigenous language.

Access and distance

Cancer is a difficult disease to treat remotely, and many Indigenous people live vast distances from urban centres. Sid Selva (Oncologist, Royal Darwin Hospital) described treating patients for whom arduous travel exacerbated the disorientation already induced by their diagnosis. The fact that Selva is the only resident medical oncologist in the Top End underscores a general problem with service provision in regional Australia.

Michael Barton (Deputy Director of Radiation Oncology, Liverpool Hospital), who is author of a study of radiation services in the Northern Territory, expanded on the problems of distance with a reminder about the immobile and high-maintenance nature of radiotherapy hardware.

Such problems reflect overall challenges for healthcare delivery in rural and remote Australia, which are compounded by the cultural, linguistic and socioeconomic barriers unique to Indigenous communities.

Jacinta Elston (Associate Professor of Indigenous Health, James Cook University), herself an Aboriginal woman undergoing cancer chemotherapy, described the practical hurdles for anyone on the cancer journey and explained how they are considerably higher for most Indigenous people: no health insurance or income protection, limited understanding of prognosis and treatment options, the absence of an informed community, unfamiliarity with a hospital environment — all of it bewildering, particular for people already at the margins of Australian society.

Ways forward

The forum sought “ways forward”, and the discussions and workshops mapped out paths towards improving the poor cancer outcomes for Indigenous people.

Consistent throughout was the need for allied health agencies to form collaborative partnerships with Indigenous organisations and individuals. Our ignorance of complex yet imperative cultural and linguistic issues was laid bare at the forum and supported by the latest data. Only by engaging with people like Jacinta Elston and Jeremy Baker Balung in interface roles will we be able to break down these barriers.

In response, the Cancer Council Australia is inviting Indigenous representatives to join its principal committees, is seeking to co-opt an Indigenous Australian onto its board, and is discussing a memorandum of understanding with NACCHO.

Options will be examined to boost research on cancer in Indigenous people, ensuring it is undertaken with liaison officers and developed in ways that will give ownership of the data to Indigenous people, many of whom have reason to be sceptical about research, given the history of European paternalism.

Increased collaboration should be enhanced by efforts to build the capacity of the Aboriginal health workforce. Much will depend on government funding, and improved cancer control in Indigenous communities has now become a key cancer council advocacy goal. The signs are encouraging: the Coalition’s pre-election cancer policy included a national bowel cancer screening program, targeting Australians aged from 55 and Indigenous Australians aged from

45, indicating a shift towards policy adjustments consistent with the poorer health outcomes of Indigenous people.

Cancer councils and their allies will also work towards factoring Indigenous issues into policy development and promotion at every step in the cancer journey, from prevention to palliation.

There is no better example of the challenges of cancer prevention than smoking prevalence: 50% of the Indigenous population smokes, compared with about 20% of non-Indigenous Australians. To reduce this figure, again we must connect with Indigenous people and involve their organisations and communities in spreading the public health messages.

The need to formally involve Indigenous people in service design and delivery also applies to cancer screening programs. Already there are signs of improvement, with targeted Pap smears contributing to a 50% fall in Indigenous cervical cancer mortality in the late 1990s.

Palliation is also critical, particularly among people with such high rates of mortality and premature death. The Cancer Council Australia will look at educational tools to assist in the management of pain, dying and death among Indigenous communities.

Our commitment is already well supported at state and territory level. The Cancer Council New South Wales' recent funding of an indigenous health supportive care strategy, in partnership with the University of New South Wales, and the release of a cancer information kit for Aboriginal health workers are excellent initiatives that could be applied nationally.

These are all small steps towards a distant destination. But only through setting and achieving shorter-term goals will we be able to make an impact on the appallingly poor state of cancer outcomes for Indigenous Australians.

The discussion forum reiterated the overarching themes of dispossession, hopelessness, grieving, racism, paternalism and abject socioeconomic status — seemingly insurmountable problems, but not when addressed with the sense of purpose, cooperation and strategic thinking evident at the recent national forum.

Attachment 2 – Recommendations for improving cancer service provision to remote communities

The existence of some regional cancer-care capacity and a range of guidelines, studies and recommendations, provide a strong foundation on which to expand services in a cost-effective, strategic way.

The immediate challenge for governments – both national and state – is to pull these many strands together and invest in improved coordination and an expansion of existing resources to deliver much needed improvements in cancer-care services for Australia's substantial rural and remote population.

The findings in a recent mapping of oncology services by the Clinical Oncological Society of Australia, and ongoing investigation into the problem by professionals at the frontline, indicate that the next steps towards equity should be:

- formal recognition of the problem and a collaborative government response;
- building regional oncology centres of excellence;
- establishing a national quality assurance framework; and
- short-term capacity-building measures while the reforms above roll out.

Formal recognition, collaborative response

There are encouraging signs that governments are becoming increasingly focused on the problems of cancer care in regional Australia and are working more strategically to improve outcomes.

Initiatives such as the Australian Government's rural mentoring program, commitments in state government cancer plans and the emergence of both federal and state cancer control agencies present opportunities to begin building now to reduce the imbalance between rural/remote and city patients over the longer term.

The Council of Australian Governments (COAG) is scheduled to meet in June 2006 and expected to discuss a number of healthcare reforms, including improved coordination of chronic disease management and Medicare support for case-conferencing of cancer specialists. The Australian Health Ministers' Advisory Council has also agreed to a rural health reform agenda, aimed at addressing high-priority issues as a matter of urgency.

This may be an ideal time for governments at both levels to consider and agree to actions to address specific areas of cancer care for people in rural and remote areas. Proposed solutions, which would require commitment and collaborative approach, are outlined as follows.

Regional oncology centres of excellence

Based on the evidence and the experience of cancer care professionals working in regional areas, the establishment of "regional oncology centres of excellence" would be the most cost-effective and efficient way to roll out a sustainable framework for reducing disparities in treatment outcomes between urban and rural Australia.

Moreover, regional oncology centres have the potential to yield wide-ranging benefits in other areas of clinical practice and contribute to overall improvements in rural/regional life. The problems of attracting GPs and allied health professionals would potentially be reduced in centres that offer services such as multidisciplinary cancer care. The logical starting point for building regional oncology centres of excellence would be treatment facilities that already have radiotherapy capacity.

Rationale

Around half of all cancer patients require radiotherapy. Radiation oncology is therefore essential to the provision of multidisciplinary cancer care. While it is the most expensive treatment modality in capital outlays and maintenance, and the least mobile due to hardware requirements, in terms of cost versus efficacy radiotherapy is the most cost-effective treatment to administer once the infrastructure is in place.⁵⁶

There is, therefore, a strong case for building multidisciplinary cancer centres in the 10 non-metropolitan centres that already have radiotherapy infrastructure. These are:

Coffs Harbour, Port Macquarie, Wagga, Wollongong (NSW); Albury-Wodonga, Ballarat, Bendigo, Geelong, Latrobe Valley (Vic); and Townsville (Qld).

There is commitment from the Northern Territory Government to fund radiation oncology services in Darwin, which could form the basis of a multidisciplinary centre to service the Top End. At the time of writing there were signs that additional services were also being considered for the NSW North Coast. (In Newcastle, a multidisciplinary cancer treatment service already operates at the Newcastle Mater Hospital, servicing people in the NSW Hunter region.)

The combined population of these 11 centres is more than 1.5 million people. It is estimated that an additional 700,000 people live within 150km of these centres. Based on current cancer prevalence rates, this equates to around 630,000 people living in or relatively near these centres who are likely to be diagnosed with cancer by age 75 and who, under current arrangements, would in many cases need to travel considerable distances to access multidisciplinary care in a state capital city.

Attracting two medical oncologists and a range of allied health service providers to each centre where radiation services exist is the most cost-effective way to introduce multidisciplinary cancer care into the regions. It would also be consistent with the Australian Medical Workforce Advisory Committee's recommendations around practitioner-to-patient numbers according to critical population mass. In addition to treating substantial local populations, these centres would operate as relay points for supporting remote services and communities, providing mentoring and referral links for rarer cancers. They would also serve as a template for setting up future centres in regional areas with similar populations that currently have no radiotherapy capacity.

In the opinion of experienced rural/regional cancer care professionals, regional cancer centres would also attract GPs and other practitioners to regions where there are current shortfalls, by contributing to an overall culture of local best-practice.

An informative example of the potential of regional oncology centres of excellence is the centre at Albury-Wodonga, a former outreach facility that now features five resident oncologists, a clinical trials unit, oncology pharmacist and a two-machine radiotherapy service. Outreach clinics are performed within the region from Albury-Wodonga. Reported benefits include an increase in the number of new patients able

to be treated locally from 150 to 750 a year, an eight-fold increase in chemotherapy day treatments performed locally, the establishment of multidisciplinary clinics and more than 10% of new patients participating in a clinical trial.⁵⁷

A national quality assurance framework

Medical groups have done considerable work developing guidelines to underpin best practice in cancer care in Australia, yet there is no national framework for ensuring such guidelines are universally adopted.

The Australian Medical Workforce Advisory Committee has released a number of recommendations on infrastructure requirements for cancer services; the Australian Cancer Network is developing a model for accrediting cancer services and credentialing individual practitioners and has produced (with NHMRC endorsement) clinical practice guidelines; and the Medical Oncology Group of Australia has scoped minimum standards for medical oncology services for rural and remote Australia.

There may be a role for Cancer Australia to endorse these and other similar documents and negotiate, with appropriate federal and state/territory government agencies, a framework for their adoption as standard practice.

The application of evidence-based guidelines would be particularly helpful in regional centres, which currently lack the economies of scale to develop their own mechanisms for quality assurance.

Shorter-term capacity building

There are a number of shorter-term measures that would help reduce inequities in treatment outcomes while longer-term reforms are being developed. These include:

- investment in clinical data systems to audit, monitor and plan oncology services;
- investment in psychosocial support services for people in rural and remote areas, who have been shown to have significantly inequitable access to such services;
- support for distance education, mentoring and innovative models such as telemedicine in remote areas; and
- improved coordination of government-funded travel and accommodation schemes for cancer patients and their families in remote areas. This is particularly relevant to women with gynaecological cancers, as the schemes generally allow referral to the nearest 'specialist' – in most cases a generalist gynaecologist, when women with gynaecological cancers would benefit from supported access to the nearest multidisciplinary care team.

By formally identifying improved cancer care in rural and remote Australia as a policy priority in the context of existing government reform frameworks, formal structures can be put in place to develop targeted solutions to the stark geographical inequities in cancer treatment outcomes.

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Attachment 3 – Known gynaecological cancer risk factors

Uterine cancer

Known risk factors for uterine cancer include obesity, type 2 diabetes, hypertension, anovulation (particularly in the presence of polycystic ovarian syndrome) and long-term use of some hormone replacement therapies. Taking the breast cancer drug tamoxifen may also increase the risk of uterine cancer.⁵⁸ There is some evidence of a genetic link, although this is rare and associated with coexisting conditions such as age and the presence of colon cancer.⁵⁹

Ovarian cancer

Increasing age is a well-established risk factor for ovarian cancer, with around 80% of cases occurring in women aged 50 years and over. Women with a family history of ovarian cancer are at increased risk according to the number of first degree relatives affected. However, the number of women in this category is small, as hereditary links only appear to account for about 5-10% of all cases. Other factors that may cause ovarian cancer are unclear.⁶⁰

Cervical cancer

The clearest link between a precancerous condition and cancer across all tumour types is the relationship between cervical cancer and the human papilloma virus, which is directly associated with virtually all cases.⁶¹ Smoking has also been linked to increased cervical cancer morbidity and mortality.⁶²

Vulval cancer

Risk factors associated with vulval cancer include age, sexually transmitted infections, never having children, vulvar intraepithelial neoplasia (a precancerous condition), prior incidence of squamous cell cancer of the cervix or vagina and other genital conditions such as HPV and pruritis (chronic itching).⁶³ Vulval cancer has also been linked to smoking.⁶⁴

Vaginal cancer

A hormone called diethylstilboestrol (DES) has been shown to cause vaginal cancer in daughters of women who took the drug between 1940 and 1970. The risk is very low, with only one in 1000 daughters developing vaginal cancer. HPV infection has also been linked to vaginal cancer, as is cervical or pre-cervical cancer. Radiotherapy to the pelvic area has also been shown to increase risk, but it is very slight.⁶⁵

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