

Senate Community Affairs References Committee
Inquiry into gynaecological health in Australia

Response from



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Background

Gynaecological cancer

Gynaecological cancers are a group of different malignancies of the female reproductive system. The most common types of gynaecological malignancies are cervical cancer, ovarian cancer, and endometrial (uterus) cancer. There are other less common gynaecological malignancies including cancer of the vagina and cancer of the vulva.

For the purposes of this submission, 'gynaecological cancers' are defined as ovarian cancer, uterine cancer, cervical cancer, vulval cancer and vaginal cancer.

In 2001, 3834 Australian women were diagnosed with one of these cancers and 1506 died from an identified gynaecological cancer. This represents around 4.3% of overall cancer incidence and 4.1% of mortality [1]. In Western Australia the lifetime risk of a woman developing one of the gynaecological cancers is currently approximately 1 in 40 [2].

Table 1. Incidence and mortality of gynecological cancers in Western Australia, 2003 [2].

Cancer type	Incidence	Mortality
Cervical	82	24
Ovarian	120	71
Uterine	114	24
Vulva & Vagina	34	7

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.

According to cancer incidence projections for Australia 2002-2011 [3], the incidence of uterine cancer, ovarian cancer and cancers of the vulva and vagina is projected to remain stable. Incidence of cancer of the cervix has been steadily decreasing and this decrease is projected to continue, largely due to the success of the national Pap smear screening program.

Uterine, cervical, vulval and vaginal cancer

In Western Australia in 2003, there were 114 new cases of uterine cancer, and 24 deaths. Uterine cancer is the most common gynecological cancer in Australian women. There has been little change in the number of cases of uterine cancer in Western Australia in the last ten years. In Australia, the current lifetime risk of a woman being diagnosed with uterine cancer is 1 in 77. In comparative terms this is similar to cervical cancer and ovarian cancer, but quite different to the lifetime risk for breast cancer, which is currently 1 in 11.

Cervical cancer is one of the most preventable cancers, due to the Pap smear. In Western Australia in 2003, there were 82 new cases of cervical cancer, and 24 deaths. In Australia, the current lifetime risk of a woman being diagnosed with cervical cancer is 1 in 183, with both incidence and mortality rates decreasing in Western Australia since 1983.

Vulval and vaginal cancers are very rare in Australia, accounting for approximately 5 per cent and 2 per cent respectively of all gynecological cancers. In Western Australia there were 34 cases of vulval or vaginal cancer in 2003, and 7 deaths.

Symptoms of gynecological cancers in general include:

- *Abnormal vaginal bleeding* –
 - For postmenopausal women this means vaginal bleeding which occurs six months or more after menopause.
 - For peri-menopausal women this means persistent bleeding between periods.
 - For women who are still menstruating this means bleeding or spotting not associated with a period.
 - Bleeding after sexual intercourse is abnormal at any age and should be investigated promptly.
- *Abnormal vaginal discharge.*
- *Lower abdominal swelling or discomfort.*
- *Pain associated with urination or pain during sexual intercourse.*
- *Changes in bowel and/or bladder function, including constipation, diarrhea, or the urge to pass urine more frequently.*
- *Severe itchiness or changes to the vulva.*

The exact cause of each gynecological cancer is not known, but factors that play a role in the development of these cancers have been identified. Having one or more of these risk factors does not mean that a woman will develop a gynecological cancer, and only a small portion of women with any of these risk factors will do so.

- *Age* – gynecological cancers are more common in postmenopausal women over 50 years of age.
- *Family history* – of ovarian or uterine cancer increases the risk of these occurring. There is no family history link for cervical, vaginal or vulval cancers.
- *Personal history* – a personal history of cancer may increase the risk of cancer in the future.
- *Human Papilloma Virus* – is a necessary but not sufficient cause of cervical cancer.
- *Reproductive and hormonal factors* – include early menarche, nulliparous, late menopause, hormone replacement therapy use and use of the oral contraceptive pill.
- *Lifestyle* – smoking, being overweight or obese, diet low in fruit, vegetables and grains and high in saturated fat, sexual history.

Ovarian cancer

Ovarian cancer is the eight most common cancer in Australian women. In Western Australia in 2003, there were 120 new cases of ovarian cancer and 71 deaths. As is the case with uterine cancer, there has been little change in the number of cases of ovarian cancer in Western Australia in the past 10 years. In Australia, the current lifetime risk of a woman being diagnosed with ovarian cancer before the age of 75 years is 1 in 104.

Ovarian cancer has by far the worst prognosis of all gynaecological cancers. Ovarian cancer is the leading cause of death from a gynecological malignancy, as over 70 per cent of all women with ovarian cancer have advanced disease at the time of diagnosis.

In many cases, ovarian cancer is curable if detected early. The mortality rate is around 40 percent, but is much better for stage I – II tumours.

Table 2. Five year survival – ovarian cancer

Stage	Five year survival estimate
I	60 – 100 per cent
II	About 60 per cent
III	About 20 per cent
IV	About 10 per cent

The most commonly reported symptoms of ovarian cancer are often vague and non-specific and not gynecological in nature. Often the symptoms can be related to many other common medical conditions. The symptoms can include:

- Abdominal bloating
- Abdominal and/or pelvic pain
- Feeling of pressure in the abdomen
- Increased abdominal girth
- Weight gain or weight loss
- Change in bowel habits/constipation
- Urinary frequency
- Fatigue
- Heartburn/Indigestion
- Appetite loss
- Feeling full after only a small amount of food
- Back pain

Distinguishing these symptoms from those that normally occur in women remains problematic. In the absence of effective screening for early disease the initial management of symptoms by the general practitioner is crucial.

According to the Ovarian Cancer Program at the National Breast Cancer Centre, the main risk factors for ovarian cancer are:

- *Increasing age* - more than 80% of cases occurring in women aged 50 and over. The median age at diagnosis is 64 years.
- *Hereditary links* - around 5-10% of all cases. Women with a family history of ovarian cancer are also at increased risk, with the risk increasing the more first degree relatives are affected, but the numbers of women in this category are small. Women with a family history should consider increased surveillance/referral to a familial cancer clinic.

Being physically active, use of the oral contraceptive pill, pregnancy and breastfeeding have all been found to provide some protective effect for ovarian cancer.

The Cancer Council WA acknowledges that our submission contains information provided from The Cancer Council Australia's submission to the Senate Inquiry.

(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 National NHMRC allocated more than \$87 million towards cancer research.

Another key 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 cancers, which is expected to be overseen by Cancer Australia when it is established this year.

Another 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

The Cancer Council WA provides research funding through an investigator led competitive research grants process. Some recent examples of relevant Cancer Council WA research funding in this area are:

- **2006** Dr Anthony McCartney – Multi-state grant
Project title: Total Laparoscopic Hysterectomy (TLH) versus Total Abdominal Hysterectomy (TAH) for the treatment of endometrial cancer – Qld, WA, Vic, NSW.
- **2004** Prof David Bowtell (Dr Nik Zeps) – Multi-state grant
Project Title: Molecular epidemiology of ovarian cancer: The Australian ovarian cancer study - WA, Tas and a national clinical follow-up core.
- **2003** Prof David Bowtell (Dr Nik Zeps) – Multi-state grant
Project Title: Molecular epidemiology of ovarian cancer: The Australian Ovarian Cancer Study - WA, Tas and a national clinical follow-up core.

Regarding local clinical trials and research, we would be welcoming of greater availability of research support staff.

Due to the paucity of data guiding policy on issues ranging from best practice implementation of HPV vaccine policy through to early detection of ovarian cancer policy, there is good justification for increased funding into gynaecological cancers. Further funding needs to be allocated as an addition to existing cancer research priorities; funding should not be taken to the detriment of existing cancer research priorities.

Research on screening for ovarian cancer

Attempts have been made at finding an appropriate screening tool for ovarian cancer, including CA125, ultrasound, trans-vaginal ultrasound and bimanual pelvic examination. It would be a significant breakthrough if we could find an effective way to screen women for ovarian cancer and be able to detect the disease before it spreads beyond the ovary.

A number of screening tests are currently being evaluated. Three multi-centre, population-based randomised control trials are currently under way in continental Europe, the UK and the USA, using all available testing modalities in varying combinations; eventually more than 320,000 women will participate in these trials [4]. The results of these trials will help inform future decision-making about the effectiveness and scope for population-based ovarian cancer screening.

Human Papilloma Virus Vaccine Research

The development of prophylactic HPV vaccines offers new hope for primary prevention of cervical cancer. The vaccines are based upon the Australian discovery that the major HPV capsid protein L1 can self assemble into virus-like particles (VLP) when independently expressed in cultured cells, and induce high titres of type-specific and protective neutralising antibodies in animals. These VLP lack any viral genetic information and are not infectious [6].

The particles in the vaccines are immunogenic and safe and data from proof-of-principle efficacy trials strongly suggest that they conferred high levels of protection against incident and persistent infections and type-specific cervical intraepithelial neoplasia (CIN) [7]. However the duration of protection provided by these vaccines is not known and immunisation must occur prior to exposure to the virus, highlighting the importance of targeting vaccination campaigns towards presexually active children and adolescents [7, 8].

Brotherton and McIntyre [6] discuss that vaccinating against HPV 16 and HPV 18 could potentially prevent over 70 per cent of cervical cancers worldwide. Franco and Harper [9] report that vaccines against HPV types 16, 18, 45, 31 and 33 would potentially prevent 83% of all cervical cancers, and a vaccine that also includes HPV types 52 and 58 could potentially prevent 87% of the overall cervical cancer burden internationally. These figures are shown visually below:

HPV Type	Prevention
16 & 18	70%
16, 18, 45, 31 & 33	83%
16, 18, 45, 31, 33, 52 & 58	87%

Plummer and Franceschi [10] outline optimistic projections on the effectiveness of the vaccine targeting HPV types 16 and 18. If the vaccine aimed at preventing 70% of cancer, 100% population coverage and 90% efficacy would prevent 63% of cancer deaths. Plummer and Franceschi [10] state that '*200 vaccinations would be required to prevent a single case of cervical cancer in developing countries and 350 vaccinations will be required in developed countries*'.

Expanding on these figures using 2001 Australian data where the incidence of cervical cancer was 735 and mortality 271. If 63% of these cases were prevented then the incidence of cervical cancer in Australia would likely be reduced to 272 cases, with approximately 98 deaths per year.

HPV trials currently underway

HPV vaccine research is advancing at a rapid pace. Clinical trials of the two first generation vaccines are underway – one for HPV types 16 and 18 and the other for HPV types 16, 18, 6 and 11. GlaxoSmithKline (GSK) and Merck & Co., Inc. have each developed first generation prophylactic vaccines (Cervarix™ and Gardasil™ respectively), and it is anticipated that a vaccine will be registered for use in 2006. GSK currently has Phase 3 clinical trials underway and Merck has completed some of its phase 3 clinical trials with others underway [5].

Trials on girls aged 10-14 years have reportedly been completed with data yet to be published. Currently in Australia data is being collected on girls aged 17-25 years as part

of a worldwide trial of 18,800 women using Cervarix. Research into the therapeutic use of a HPV vaccine is also underway. A worldwide study has just commenced targeting women aged 26 and over also using Cervarix. The aim of this research is to look at whether a vaccine can act as a chain breaker in the natural history of HPV infection, thus preventing development of cervical cell abnormalities in older women.

HPV research questions

Many questions regarding the implementation of a HPV vaccine strategy in Australia remain unanswered. Some of the identified priority areas for further research include:

- HPV knowledge: Knowledge of HPV is low (general public and health professionals); knowledge of the link between HPV, abnormal Pap smear results and cervical cancer is low.
- Education of health professionals and the general community should be considered a priority, especially: relationship between persistent genital oncogenic (high risk) HPV infections, cervical dysplasia and cancer; HPV and abnormal pap smears.
- What information do GPs and other health professionals currently provide to their patients about HPV and cervical cancer?
- Presentation of the prophylactic vaccine as an STI/HPV vaccine versus cervical cancer vaccine. What is the impact on acceptance?
- What factors increase vaccine acceptability? What factors reduce vaccine acceptability? Are there gender differences?
- Mothers versus Fathers: are there differences in acceptance for their daughters? Who controls the decision making? Will the child be involved in the decision to vaccinate? Would parents agree to their child's vaccination? Are parents willing to acknowledge their child's STI risk? Are parents concerned about how to describe an HPV vaccine to children? What are the rights of the child to request vaccination without parental consent?
- Is there an uneasiness around the sexually transmitted nature of HPV? Issues of anxiety about vaccination encouraging promiscuity or encouraging unsafe sexual behaviour are potential attitudinal barriers to implementation of a vaccination program – how much of an issue is this within the community? How is it best constructively addressed as an issue?
- What are the perceptions and attitudes towards HPV vaccination in Western Australia? How does the general public view vaccinating adolescents against HPV? What is the impact of different religious, ethnic and cultural views?
- Is there a lack of understanding of the importance of vaccination prior to onset of sexual activity? How will this impact on vaccine implementation?
- Informed consent – what are the issues? What are the information needs? Is there scope for sexual health information to accompany vaccination? How do we adequately communicate vaccine safety, possible adverse outcomes and efficacy?
- Physician recommendation: are GPs willing and able to recommend HPV vaccination to their patients? Are health professionals adequately informed about HPV and HPV vaccination to be able to advise their patients? What communication skills will be required for health professionals to effectively communicate the advantages (and disadvantages) of vaccination to adolescents and their parents? Will physicians be reluctant to recommend vaccination for younger people?
- What kinds of information do health care providers give to women with abnormal Pap smears in regards to HPV, if anything? What kinds of HPV information is given to women with cervical cancer, if any?

- What will be the likely impact of the introduction of a vaccine on cervical screening programs? Perceptions regarding the need for continued cervical screening after the introduction of a vaccine? Has there already been an impact on the perception of need for cervical screening, due to the media coverage of the newly developed cervical cancer vaccine? Incomplete and misleading media coverage?
- Does the term 'cervical cancer vaccine' imply a treatment effect in women with cervical cancer? Will there be confusion/anxiety/false hope for women who develop, or who are already experiencing cervical cancer?

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 [11].

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.

(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 is used to identify people who require further investigation to determine the presence or absence of disease; it does not diagnose illness. 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 [12].

The accepted criteria for the assessment of evidence on the benefits, risks and costs of cancer screening are the principles adopted by the World Health Organisation [13]:

- 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)
- 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. A false negative means a missed opportunity to successfully intervene when disease is present, and the individual is falsely reassured, which can have devastating consequences. False negative results can give rise to legal action by people whose cancers appear to have been missed. 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 [14].

Screening for gynaecological cancers

Based on the World Health Organisation principles and available technology, cervical cancer is the only gynaecological cancer that can be effectively detected through population-based screening of apparently well women.

For very rare tumors, such as vulval and vaginal cancer there is no effectiveness in the development of a screening program as a primary requirement for the introduction of a population based screening program is that the condition being screened for is a relatively common health problem [13]. A major reason for this is that the process of undertaking a mass population screening program is intrusive and has a variety costs which are not just financial. Screening programs raise anxiety, are prone to imperfections and draw otherwise healthy individuals into the health system. To justify such an intervention into healthy people's lives a clearly quantified benefit to the community must be proven. It is unlikely that an adequate quantum of benefit would be achieved in programs seeking to identify very rare conditions.

It is important to acknowledge and empathize with the enormous impact a diagnosis of a gynaecological cancer has not only on the woman herself, but also her partner, her family and her friends, however we must recognise the limitations of screening for rare conditions.

Uterine cancer is the most common gynaecological cancer in Australia and ovarian cancer is the cause of the most gynaecological cancer deaths; effective screening for these cancers would therefore be clearly beneficial. However, the evidence shows that population-based screening for uterine and ovarian cancers cannot be supported using currently available technology and applying WHO principles.

Cervical Cancer Screening

Cervical cancer is one of the most preventable and curable of all cancers. WHO [15] recognizes that the Pap smear for cervical cancer is the single best cancer screening procedure. Research suggests that up to 90 per cent of the most common type of cervical cancer could be prevented if all women had regular Pap smears every two years [16]. Cervical cancer is the only gynaecological cancer that can be reduced in terms of incidence and mortality by a population-based screening tool using current technology.

In Australia, the incidence of cervical cancer has dropped markedly since the beginning of the National Cervical Screening Program (NCSP) in 1991. The Australian Institute of Health and Welfare [17] explains that the NCSP was implemented in Australia to reduce morbidity and deaths from cervical cancer by detecting treatable pre-cancerous lesions before their progression to cancer. The program targets women between 20-69 years of age, with a recommended screening interval of 2 years following a negative smear.

In 2002-2003 the participation rate in the NCSP for Australian women aged 20-69 years was 60.7% [17].

In Australia, 735 new cases of cervical cancer occurred in 2001, accounting for 1.8% of all female cancer cases. The incidence rate among the cervical screening target age range of 20-69 years in 2001 was 9.5 per 100,000. This is a sharp decline from the incidence rate of 17.1 per 100,000 in 1991 (1,089 cases), when organised screening programs started in Australia [18].

In Australia in 2003 there were 238 deaths due to cervical cancer, equating to 2.2 deaths per 100,000 women. Mortality has declined from 3.8 per 100,000 women in 1993 [18].

The age-standardised incidence rate for cervical cancer has declined by an average of 6.2% per annum between 1991 and 2001. Mortality rates have fallen by an average of 5.2% per year since 1991. These gains are due, in part, to the success of the National Cervical Screening Program in both detecting precancerous abnormalities and in detecting cervical cancer at an early stage [19, 20].

Pap test

The Pap test (named after its developer, Dr George Papanicolaou) is the most widely used cancer screening test in the world [21].

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 [22].

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 [21].

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.

New 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 [23]. 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.

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 [24]. Two-year intervals also increase the cost of the screening program and may reduce participation rates.

Ovarian cancer screening

The poor prognosis for women diagnosed with ovarian cancer is related to the fact that the disease is often diagnosed at a late stage. By the time the patient is investigated for often generalised symptoms, the disease has usually progressed and chances of a cure are reduced. Early-stage ovarian cancer, where the disease is confined to the ovaries, is associated with a five-year survival rate of more than 80% [25]. Unfortunately there is currently no screening test for ovarian cancer, unlike the Pap test for pre-cancerous cervical cell changes, and the mammogram to help detect breast cancer.

The link between inability for early diagnosis and relatively high mortality has generated significant global interest in developing an early detection tool for ovarian cancer. However, the feasibility to screen for ovarian cancer is presently limited. No true precursor lesion for ovarian cancer has been identified; and to date there is no evidence to indicate a decrease in mortality as a consequence of ovarian cancer screening, although survival advantage has been found in two trials. Available technology does not provide adequate sensitivity (the ability to determine the presence of the disease in those who have it) and specificity (the ability to exclude the disease in those who do not) [26].

The benefits of any screening test should clearly outweigh any chance of physical or psychological harm. Therefore, the significant risks associated with false positive and false negative results mean screening for ovarian cancer with existing technologies cannot be supported. A number of early-detection techniques for ovarian cancer are being explored, none of which has been shown to be effective on a population basis.

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 [27].

Ultrasound

Research into the effectiveness of ultrasound (transvaginal, transabdominal and a combination of both) has not supported its use as a screening tool. Transabdominal ultrasound has been used to detect changes in the ovaries that may suggest the presence of a tumour, such as enlargement. However, the 'positive predictive value' (likelihood that screening identifies a person with a particular condition) 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, it generates a large number of false positives due to its inability to distinguish between benign and malignant masses [28, 29].

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%. Positive predictive value is slightly improved when ultrasound is used in combination for women with a family history of ovarian cancer [26].

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.

Colour Doppler ultrasound has also been used, singly or in conjunction with other techniques, to better differentiate between benign and malignant disease through blood flow imaging. Results have been mixed and it has not shown any advantage over transvaginal ultrasound or CA125 (see below) [26].

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 [30]. Elevated levels may also be associated with other malignant or benign conditions. It is most often raised in serous and less frequently in mucinous cancer and is found in over 80% of non-mucinous epithelial ovarian cancers.

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. Using CA125 in combination with other modalities, such as ultrasound, has been investigated in an attempt to increase specificity and sensitivity [26].

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 [26].

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. The link between the inability to detect ovarian cancer early and the high mortality rate has led to wide-ranging research into whether or not existing technologies can be used in a way that would make screening feasible and effective. Three multi-centre, population-based randomised control trials are currently under way in continental Europe, the UK and the USA, using all available testing modalities in varying combinations; eventually more than 320,000 women will participate in these trials [26]. The results of these trials will help inform future decision-making about the effectiveness and scope for population-based ovarian cancer screening.

Should evidence emerge of a successful ovarian cancer screening program from large international studies currently underway, it would be important to ensure a rapid and adequately funded implementation program, to provide benefit to women within the community as soon as possible.

Women at high-risk

Up to 10% of all cases of ovarian cancer are thought to be due to the inheritance of mutations in one of a small number of ovarian cancer-related genes [31].

Carriers of mutations in such genes have an increased risk of epithelial ovarian cancer of at least 10-fold. These genetic factors are the strongest known risks for ovarian cancer, although they are rare and do not inevitably lead to disease. There may be many other genes, as yet undiscovered, which are associated with an increased risk of ovarian cancer.

Women who are concerned about having a possible genetic risk of developing ovarian cancer should discuss the issue with their GP or gynaecologist. Familial Cancer Clinics can make a thorough assessment of the family's cancer history and determine the likelihood that an ovarian cancer-related gene may be present. Genetic testing should only be offered with pre and post-test counselling, conducted in conjunction with a specialist genetics service for breast/ovarian cancer. The potential harms, benefits and limitations of genetic testing need to be considered. The Australian Cancer Network and National Breast Cancer Centre's *Clinical practice guidelines for the management of women with epithelial ovarian cancer* contains evidence-based advice on the care of patients with a concern about genetic risk of developing ovarian cancer. The widespread application of the guidelines in frontline clinical practice would help to ensure Australian women at risk of or concerned about ovarian guidelines had access to optimal treatment and professional support.

Uterine cancer screening

The majority of uterine cancers in Australia 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 [32].

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 [13, 26].

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.

Psychosocial services for women with gynecological cancers

Psychosocial services for women with gynaecological cancers is a significant concern in Western Australia, with lack of specialised psychosocial support identified as a significant issue for women facing a diagnosis of gynaecological cancer. For example, services such as sexual health counselors and psychologists are often lacking. Shortcomings in aftercare have been recognized and need to be addressed.

The Cancer Council WA dedicates considerable funding for provision of a range of professional support and information services for cancer patients and their families, which can be accessed by women with gynaecological cancers. These services aim to help alleviate the burden of cancer across Western Australian communities, through partnerships with other agencies and equitable distribution of support, targeting remote communities and those without support networks. Services provided through the Statewide Supportive Care Network include:

- *The Cancer Council Helpline* – A ‘one-stop-shop’ for access to information about cancer related issues and support services for individuals, families and communities affected by cancer. Services provided through The Cancer Council Helpline include; information on specific cancers; information on chemotherapy, surgery and radiotherapy; information on new treatments and clinical trials; information on prevention, screening and risk factors for cancer; written materials and publications both online and in hard copy; information on The Cancer Council WA’s support services, including counseling, financial assistance and accommodation for country people accessing health services in the metro area; information about services in the community; information about how to best navigate the health care system; and someone confidential and professional to talk to.
- *Cancer Counselling* – Statewide provision of subsidised face-to-face and telephone counseling for cancer patients and their families provided by practitioners who have professional accreditation.
- *Cancer Support Service* – Coordinated local provision of emotional and practical support for cancer patients and their families provided by hand-picked volunteers and Cancer Council Support Coordinators.
- *AH Crawford Lodge* – Accommodation for country patients, including transport to treatment centres, information library, financial assistance, lymphoedema management service, complementary therapies, wig library, on-site social and recreational activities.

The Cancer Council WA also facilitates an ovarian and gynaecological cancer informal peer support group, held on a monthly basis. The group allows women experiencing gynecological cancers to meet with others finding themselves in a similar situation. The Cancer Council WA also provides support and works in partnership with organisations such as the Gynaecological Awareness and Information Network (GAIN).

Clinical Practice

The NHMRC has endorsed the *Clinical practice guidelines for the psychosocial care of adults with cancer*, prepared by the National Breast Cancer Centre and the National Cancer Control Initiative. According to the Executive Summary of these guidelines:

- Many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical treatment. These psychosocial needs are significant and frequently go undetected and unmet.
- Up to 66% of people with cancer experience long term psychological distress: up to 30% experience clinically significant anxiety problems, and prevalence rates for depression range from 20% – 35%.

- Many people report inadequate information to guide decision making, and others are disadvantaged because of a lack of knowledge about practical support, even when such services are available.

The guidelines are based on comprehensive and systematic reviews of the research and an extensive consultative process to ensure their clinical relevance.

This review of the treatment services and management of newly diagnosed ovarian cancer patients was undertaken in Victoria. The aim was to describe the management of and outcomes in patients with newly diagnosed ovarian cancer during 1993 – 1995 in Victoria, and found that [34]:

- Only 79 per cent of women underwent primary surgery, with less than half having their operation performed by a gynaecological oncologist.
- A relatively low number of women had adequate preoperative assessment including CA125.
- There was often failure to perform adequate debulking procedures and staging, even by the gynaecological oncologist, but even more so by general gynecologists, and never by the general surgeons who performed 15 percent of the primary surgery.
- In early disease prognosis was worse if treated primarily by a general surgeon.
- Rural women fared no worse than urban women.

We believe a similar review in WA is likely to uncover similar issues.

Western Australia currently has three gynecological oncologists. Gynaecological oncology services in Western Australia are provided through King Edward Memorial Hospital, St John of God Healthcare Murdoch and Subiaco and Hollywood Private Hospital. These services include gynaecological oncology consultation, gynaecological oncology surgery, chemotherapy, radiotherapy, specialist nurse, palliative care, psychosocial care, multidisciplinary meetings and opportunities to participate in clinical trials. The level of services provided by each of these hospitals is summarized in the table below.

Table 3. Summary of gynaecological oncology services in Western Australia.

Key

☑ - Available

☒ - Not available

Hospital name	Gynae oncology consultation	Gynae oncology surgery	Chemotherapy	Radiotherapy	Specialist nurse	Palliative care	Psychosocial care	Multidisciplinary meetings	Opportunity for clinical trial participation
Hollywood Private Hospital	☒	☑	☑	☒	☒	☑	☑	☒	Referral
King Edward Memorial Hospital	☑	☑	☑	☑ (referral to Royal Perth Hospital)	☑	☑	☑ (Pastoral Care)	☑	Onsite
St John of God Healthcare Murdoch	☑	☑	☑	☑ (referral to Royal Perth Hospital or Perth Radiation Oncology Centre)	☒	☑	☑ (Pastoral Care)	Some	Referral
St John of God Healthcare Subiaco	☒	☑	☑	☑ (referral to Royal Perth Hospital)	☒	☑	☑ (Pastoral care, clinical psychologist, massage and reflexology)	☑	Referral

Lymphoedema and gynaecological cancers

Lymphoedema can be a significant complication of treatment of Gynaecological cancers and yet is poorly recognised by the medical and wider communities. There has been very little research into the incidence of secondary lymphoedema following gynaecological cancer treatment, and prediction of which patients may be at risk in relation to surgical or radiotherapy interventions is rarely even considered.

Lymphoedema is not life threatening, however the impact of untreated lymphoedema on the patients is life long. Without correct management there can be a range of issues that the patient has to deal with including: lower limb swelling (either unilateral or bilateral), quality of life issues including reduced mobility, increased risk of falls, postural changes, loss of self esteem related to change of physical appearance, depression and stress related to trying to cope with the chronic nature of this condition, and often frustration at the lack of services available for treatment.

A unique, dedicated service for those affected by lymphoedema is provided by The Cancer Council WA. The Lymphoedema Management Service operates on subsidised fee for service basis and is located at AH Crawford Lodge. The service offers comprehensive initial assessment, tailored treatment programs, self management advice, education sessions, manual lymph drainage, complex lymphatic therapy and manages to accommodate over 2000 patient appointments annually. The number of gynaecological cancer patients seen by the Lymphoedema Management Service is estimated as approximately 30 patients per year, with most of these patients likely to be seen on at least a monthly basis.

Apart from this, the services available for people with lymphoedema in Australia are few and far between with very limited services available in the public hospitals within the major cities, and often no service available in remote and rural areas. The number of trained lymphoedema therapists working in the private sector is also extremely limited. This frequently leaves patients with few options for what can often be a time consuming and extremely expensive treatment of a lifelong condition.

Even after the primary and adjunctive treatment of the gynaecological cancer has been completed it may be several years before any symptoms of lymphoedema become apparent. The secondary implications of a chronic condition such as lymphoedema need to be carefully considered and adequate support given. This is certainly not the case in WA at present.

(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

According to an unpublished Cancer Council WA report (May 2006) health concerns with regard to Aboriginal population and cancer are increasing, with Aboriginal Australians being twice as likely to die from cancer as non-Aboriginal Australians. Cancer was one of the three prioritised chronic diseases referred to in the National Aboriginal and Torres Strait Islander Health Strategy in 2001.

The Cancer Council WA report recognised that psychosocial support was based on westernised models and it was unclear what impact or meaning this has for Aboriginal clients. There has been limited research regarding the cultural context that influences decision-making about cancer treatment and support services. The recommendations of the report include education and training of mainstream health services providers on Aboriginal perspectives on cancer, health service delivery and traditional healing, and improving cancer services for Aboriginal people.

Unfortunately, information regarding cancer among the Australian Aboriginal population is very limited, and is only just beginning to be comprehensively documented. The dearth of information indicated a need for more in-depth epidemiological study of cancer in Aboriginal people across Australia.

A disproportionate burden of cervical cancer is borne by Indigenous women and some ethnic groups within Australia. While significant gains have been made in cervical cancer prevention for non-Indigenous women, research shows that cervical cancer is responsible for mortality rates in Indigenous women that are almost five times higher than that for other Australian women, likely as a result of poorer access to services [6, 18]. The high incidence of cervical cancer may be related to lower Pap test coverage or to a higher prevalence of infection with HPV. Aboriginal people are diagnosed later and at a more advanced stage than their non-Aboriginal counterparts.

Table 4. Age standardized mortality rate attributable to cervical cancer, 2000 – 2003 [20].

	Indigenous	Other Australians
AS rate	12.0	2.5

The National Cervical Screening Program identifies and addresses the barriers in facilitating the cervical screening process among Aboriginal women. This includes enhancing knowledge about the screening process, addressing the issue of 'fear' of pain during screening, concerns about lack of confidentiality, feelings of shame and embarrassment, and fear of having an abnormality detected. Addressing these issues, as well as highlighting the potential benefits of screening, aims to create an environment that enables delivery of a service that is Aboriginal-specific, culturally safe and comfortable for the participants (The Cancer Council WA, 2006 unpublished report).

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 [35].

Patient travel and accommodation

Gynaecological cancer patients from rural and remote Western Australia face the added burden of having to travel to Perth for assessment and treatment. Travel assistance funds for rural and remote women in Western Australia needing to travel to Perth for cancer treatment are currently limited.

Patients needing to travel to Perth for cancer treatment who live 100kms or more from the city may be eligible for funding through the government's Patient Assisted Travel Scheme (PATS) scheme. Applications for assistance with travel and accommodation costs are made via the PATS Clerk at the local hospital or through the treating doctor before commencement of travel.

PATS provides a subsidy only, it does not cover all of the costs associated with travel to a specialist appointment. A standard fuel subsidy of 13 cents per kilometer is available for travel by private car. When two or more patients are traveling in a minibus or a similar group transporter owned by a community or organisation, the fuel subsidy is 25 cents per kilometer payable to the relevant organisation. Only one subsidy per vehicle is provided. Air travel costs will only be met where it is required because of a medical condition or the journey is over 16 hours (one way) by road and prior approval has been granted. Accommodation assistance is provided where the specialist certifies it is necessary for follow-up treatment, for long journeys by private car, or where transport schedules necessitate an overnight stay. Assistance towards accommodation costs are paid on a per night basis at up to \$35 per night for commercial accommodation and \$10 per night for private accommodation.

Subsidised accommodation facilities are also limited for these patients having to traveling to Perth for cancer treatment.

For more than 20 years, The Cancer Council WA has been assisting country people by providing a range of services including subsidised accommodation in a supportive environment through its AH Crawford Lodge facility located at Nedlands, Perth.

The subsidized accommodation amounts to \$35.00 per person per night which helps to relieve the financial burden of visiting Perth for treatment. The cost of accommodation may be claimed through the PATS scheme, if the patient is eligible. Patients must contact the PATS Clerk at their local hospital before coming to Perth. If the patient is provided cover through PATS, the Cancer Council WA will invoice PATS direct for the cost of the accommodation. The Lodge provides much needed accommodation to around 2500 country cancer patients and their loved ones, every year.

While The Cancer Council WA provides practical support for cancer patients from the country, a close review of the functioning of PATS needs to be undertaken with the following questions to be considered:

- Does the PATS subsidy provide adequate assistance to country cancer patients for their travel to Perth?

- Is there scope to reconsider the eligibility criteria from the current 100km radius, to a reduced 50km radius (as is the case in QLD)?
- What percentage of their travels costs does the subsidy represent? How much of a financial burden is being experience by country cancer patients having to travel to Perth? What out of pocket costs are being placed on country cancer patients?
- Is the PATS Scheme adequately promoted to country cancer patients needing to travel to Perth for treatment?
- How can the PATS scheme be improved to increase the assistance currently provided to country cancer patients having to travel to Perth for treatment?

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

The Cancer Council WA is committed to ensuring that ongoing cancer education is available to those working in general practice statewide. The GP Education Project has been in operation since September 2000. Over the past five years, the following GP education events and initiatives relating to gynaecological cancers have been conducted:

Table 5. GP Cancer Education Program events held in Western Australia since 2001 with a gynaecological focus.

Date	Topic
September 2005	Women's Health Day for GPs Topics covered included: <ul style="list-style-type: none"> • The sex virus jab, what is it? HPV Vaccine • The Cervical Cytology Registry of WA • Sorting out vaginal discharge • How to do a better Pap smear • Ovarian cancer: using the assessment guidelines • Screening for STIs • Contraception update • Managing the menopause: a hypothetical
August 2004	A seminar for health professionals: Epithelial ovarian cancer – encouraging best practice (A promotion of clinical practice guidelines presented by NBCC in association with CAN, TCCWA, WACOG and RANZCOG)
November 2003	Cervical and ovarian cancer screening issues: HPV testing The link between HPV and cervical cancer Guidelines for ovarian cancer (Presented by Dr Kirsty Milward)
August 2003	Ovarian cancer update: Diagnosis and treatment case study discussion; and Adjuvant treatment for ovarian cancer (Presented by Dr Yee Leung and Dr Simon Troon)
June 2003	Cervical cancer workshop (Presented by Dr Yee Leung)
June 2002	Update on cervical cancer screening (Presented by Dr Yee Leung)
August 2001	RPH Postgraduate seminar for GPs: Genetic screening Promotion of clinical guidelines on Advice About Familial Aspects of Breast and Ovarian Cancer (Presented by Dr Jack Goldblatt)

The latest GP Cancer Education Program 'Woman's Health Day for GPs' attracted over 200 local attendees, and was evaluated favorably with almost all participants, acknowledging that the workshop provided information that was practical and useful. Following on from the success of the first Women's Health Day for GPs in 2005, the collaboration between The Cancer Council WA, BreastScreen WA, Family Planning

WA, and King Edward Memorial Hospital will be continuing annually, to optimize reach to general practitioners in Western Australia. A half day event is being planned for 2006, with another full day event booked for 2007. The event is scheduled for September to correspond with National Gynaecological Awareness Day.

Lack of awareness of the symptoms of ovarian cancer, delayed or inappropriate referral, and inadequate preoperative assessment have all been identified as barriers for women diagnosed with ovarian cancer.

To tackle the issue of delays between symptom presentation and definitive treatment, we welcome the implementation of demonstration projects incorporating rapid access clinics for women with symptoms suspicious of being gynecological cancers.

The Cancer Council WA is also supportive of Western Australian Department of Health state initiative to appoint cancer nurse coordinators to address gynaecological malignancies.

In addition to WA based programs outlined above, The Ovarian Cancer Program of the National Breast Cancer Centre produces a number of resources for clinicians and consumers. These include:

- The National Health and Medical Research Council approved *Clinical practice guidelines for the management of women with epithelial ovarian cancer* According to their Executive Summary:
 - Cancer of the ovary is a significant malignancy in Australian women, being the eighth most common cancer and the sixth most common cause of death. It is the most common cause of death from gynecological malignancy.
 - In Australia in 1999 the age-standardised incidence rate was 10.6 per 100,000 female population. There has been a decline in mortality since 1983, most notable for women less than 55 years of age. Possible explanations for the trend include differences in histological types and prognosis of tumours occurring in the younger age groups, protective effects of oral contraceptive use and improvements in treatment.
 - The established risk factors for ovarian cancer are strongly related to family history and increasing age, neither of which is readily modifiable through prevention strategies.
 - Specific strategies may be considered to reduce the risk of ovarian cancer for women with one of the familial cancer syndromes.
 - Protective factors for ovarian cancer include increasing parity, hysterectomy, tubal ligation and oral contraceptive use.
 - The issues around screening for ovarian cancer are not yet resolved and the results of three large randomized, controlled trials are awaited.
 - The vagueness of initial symptoms of ovarian cancer requires that clinicians be alert to their significance during examination and investigation.
 - The surgical approach is the cornerstone of all subsequent treatment and management of ovarian cancers, as the careful and accurate surgical procedure will determine the true stage. Optimal benefits result when all gross malignancy can be excised safely. Chemotherapy is available for the treatment of any residual disease.
 - Radiation therapy may be used in certain circumstances.

- Accurate histopathological and clinical staging provide prognostic indices for gynecological oncologists and women.
- To achieve best outcomes for women with ovarian cancer the ideal is that they be treated by a multidisciplinary team that includes a gynecological oncologist.
- Attention to psychosocial issues, quality of life and palliative care is an essential part of multidisciplinary care.
- Better outcomes have been reported for those cancer patients taking part in clinical trials.
- Emphasis must be placed on optimal use of available resources and the collection of comprehensive and consistent data to plan future strategies in prevention and to achieve a reduction in mortality.

- *Assessment of symptoms that may be Ovarian cancer: a guide for GPs*

The information in this guide is intended to assist general practitioners assess if a woman with persistent, unexplained symptoms may have ovarian cancer. The guide is based on the *Clinical practice guidelines for the management of women with epithelial ovarian cancer*. It instructs General Practitioners that if vague abdominal symptoms persist for more than one month consider ovarian cancer and undertake further assessment. The guide provides a checklist for assessing patient symptoms, and situations for referral for a combination of transvaginal ultrasound, abdominal ultrasound, CA125 and CT.

- *Advice about familial aspects of breast cancer and ovarian cancer: A guide for health professionals*

These guidelines contain three parts: 1) information for health professionals; 2) tables which describe three categories of women according to their family history of breast or ovarian cancer, their risk of cancer, and the current suggested management for each category; and 3) information for consumers. The guidelines cover familial aspects of both breast and ovarian cancer, because of the recent discovery of two genes, BRCA1 and BRCA2. Women born with mutation in either of these genes are at high risk of both breast cancer and ovarian cancer. The families in which these women are most likely to be found are those with multiple cases of breast and/or ovarian cancer, in different generations on the same side of the family. The information in this guide can be used by health professionals to determine a woman's risk of ovarian cancer, based on her family history. The guide is based on the best information in terms of evidence where it exists otherwise consensus expert opinion.

The Cancer Council WA wishes to emphasise the importance of good referral pathways and multidisciplinary care. This is best done where settings and resources are adequate, as currently exists in multidisciplinary teams dealing with breast cancer. This implies the availability of administrative support to deal with referrals in a timely manner, reducing the likelihood of long, unnecessary patient delays. We believe an additional two gynaecological oncologists need to be established in the public sector service delivery in WA. Lack of access to multidisciplinary care from the onset of management has been identified as a barrier for women diagnosed with ovarian cancer.

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists recommend one gynaecological oncologist per 400,000 population. This leaves Western Australia two specialists short, with a current population of about 2 million, and three gynaecological oncologists.

Also required are two to three extra radiation and medical oncologist sessions, particularly in the private sector.

Inequity with regards to dedicated gynaecological oncology specific supportive care such as social work and clinical psychology also needs to be addressed locally, especially within the private sector.

Regarding high risk women and surveillance, we need to ensure that all 'at high risk' families are being identified and monitored, in particular BRCA II and HNPCC probable cohorts.

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

Generally, the symptoms of ovarian cancer are vague, non-specific and not gynecological in nature. Often the symptoms are similar to those experienced by women every month, as a result of hormonal changes in the menstrual cycle. They can also be related to many other common medical conditions. Distinguishing the symptoms of ovarian cancer from those that normally occur in women remains problematic, both for health professionals and for women.

The promotion of such generalised symptoms in relation to gynecological cancer has significant potential to generate high levels of anxiety, and potentially promoting significant increase in health service seeking, with little evidence to suggest that such anxiety and further investigation will result in improved detection or ultimately better health outcomes. Further research to identify more specific early detection options and more effective primary care responses is urgently needed.

Every woman diagnosed with a gynecological cancer has the right to accurate information about the disease. The Ovarian Cancer Program of the National Breast Cancer Centre produces a number of resources for both clinicians and consumers.

The National Breast Cancer Centre, through their Ovarian Cancer Program produce a consumers booklet based on the NHMRC endorsed '*Clinical Practice Guidelines for the Management of Women with Epithelial Ovarian Cancer*'. The booklet aims to assist women in understanding their diagnosis and making decisions about treatment and care. The booklet is also useful for partners, family and friends. The Ovarian Cancer Program also produces an information fact sheet on ovarian cancer for all women, and information on CA125 for women.

The Cancer Council WA produces a women's cancers speaker's kit, covering all women's specific cancers (breast, cervical, ovarian, uterine, vulval and vaginal), a DL brochure on gynaecological cancer, an A5 booklet on uterine cancer, an A5 booklet on cervical cancer and provides public and health professional talks on gynaecological cancers.

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

It is understood that some groups submitting to the inquiry will argue for the development of a national gynaecological cancer organisation to act as a peak national body. It is the view of The Cancer Council WA that this could represent an inefficient use of resources, likely resulting in duplication of infrastructure.

We recognise the ability of the recently established Cancer Australia to include a gynaecological cancers component, providing the opportunity for work in this area to be undertaken under the one entity and in concert with other developments in cancer control. At this stage, duplication of infrastructure is not likely to be a cost effective means of addressing gynaecological cancers effectively and adequately.

The Cancer Council WA emphasises the importance of appropriate consumer representation on bodies such as Cancer Australia.

Summary and conclusions

Assistance for country cancer patient travel and accommodation

- Travel assistance funds for rural and remote women in Western Australia needing to travel to Perth for cancer treatment are currently limited. A review of The Patient Assisted Travel Scheme (PATs) scheme functioning needs to be undertaken.

Research funding

- There is good justification for increased funding into gynaecological cancer research. Further funding needs to be allocated as an addition to existing cancer research priorities; funding should not be taken to the detriment of existing cancer research priorities.

Cancer screening

- There is currently no screening test available for ovarian cancer, however, should a successful ovarian cancer screening program be identified, we support a rapid and adequately funded implementation program. Until such a time as a screening test is identified, it is not responsible to implement any ovarian cancer screening programs within the community.

Multidisciplinary care and resources

- We emphasise the importance of good referral pathways and multidisciplinary care. We believe an additional two gynaecological oncologists need to be established in the public sector service delivery in WA.

Cancer Australia

- The recently established Cancer Australia has the ability to include a gynaecological cancers component, providing the opportunity for work in this area to be undertaken under the one entity and in concert with other developments in cancer control.

Glossary

asymptomatic

Without symptoms.

BRCA1 (BR for breast, CA for cancer)

A gene which is defective in about two per cent of women with breast/ovarian cancer.

BRCA2 (BR for breast, CA for cancer)

Another gene implicated in familial breast/ovarian cancer.

cancer

A malignant tumour that is a growth of abnormal cells that have the potential to spread to other parts of the body.

cervical

Of either the neck or the cervix. Cervical cancer refers to cancer of the cervix.

cervical intra-epithelial neoplasia (CIN)

Cervical cell abnormalities. Also called dysplasia.

cervix

The narrow passage that connects the uterus with the vagina. Sometimes called the neck of the womb.

chemotherapy

Treatment of cancer with powerful cytotoxic drugs to destroy cancer cells, prevent or slow down their growth.

clinical trial

Clinical trials test new cancer treatments or may compare existing treatments to determine the best way of improving health outcomes. The research is called a trial because it is uncertain whether a new treatment is better than existing ones.

detection

The discovery of an abnormality or disease in the body. Early detection is the discovery of an abnormality at an early stage when it is readily treated and, in the case of cancer, much more likely to be curable.

false negative

A test result that indicates a person does not have the disease, when in fact they do.

false positive

A test result that indicates a person has the disease, when in fact they do not.

gynaecological oncologist

A doctor who specialises in treating women diagnosed with cancer of the reproductive tract.

hereditary

Passed on through generations from parents to children.

hereditary non-polyposis colorectal cancer (HNPCC)

An inherited form of colorectal cancer accounting for between 2.5 - 5 per cent of all colorectal cancers. Endometrial cancer may also be part of this syndrome.

human papilloma virus (HPV)

A common viral infection of which there are more than 100 types, some of which cause genital warts and some of which are related to cervical cancer.

incidence

The number of new cases of a disease occurring during a given period (usually one year) in a specific population.

lymphoedema

Swelling in one or more limbs due to poor drainage of lymphatic fluid.

malignant

Harmful. A malignant tumour is a cancer which may spread and metastasise.

menarche

The onset of menstruation.

menopause

The period marked by the natural and permanent cessation of menstruation, usually occurring between the ages of 45 and 55.

- **Pre-menopause**
The whole of the reproductive period prior to menopause.
- **Per-imenopause**
The three to five year period prior to menopause during which oestrogen levels begin to drop. Also known as the change of life.
- **Post-menopause**
The physiological period following menopause.

NBCC

National Breast Cancer Centre.

NHMRC

National Health and Medical Research Council.

nulliparous

Never having given birth to a child.

ovarian cancer

Cancer which begins in an ovary or fallopian tube.

ovary

A woman has two ovaries, which produce the female sex hormone oestrogen and, once a month, release an ovum (egg). The ovaries are found in the lower abdomen either side of the uterus, and are about the size of an almond.

parity

Number of babies a woman has given birth to.

pelvic examination

When a doctor examines the organs of the pelvis by feeling them with fingers inserted into the vagina and/or rectum.

radiotherapy

Treatment with high energy x-rays to destroy cancer cells.

referral

The process of one doctor directing a patient to another doctor, usually a specialist, for further information or medical care.

risk

The probability or likelihood that a person will develop a disease. Being at risk does not mean that you will develop the disease.

screening

Examining and/or testing a large number of people who have no symptoms of a particular disease, to identify anyone who may have that disease. This enables the disease to be treated at an early state, when cure is more likely. Examples include Pap smears to detect precancerous changes of the cervix, and mammography, to screen women for early breast cancer.

surveillance

Close observation of individuals at high risk.

tumour

A growth of cells resulting from uncontrolled and disorderly cell replacement. Tumours are either benign or malignant.

ultrasound

An [imaging technique](#) which [uses high-frequency sound waves](#) to find changes in tissues. A gel is put on the skin to make it slippery and a small transducer or microphone is moved along the skin. The sound waves make an image of the body tissues and organs.

uterus

The womb; the hollow, muscular organ which, during pregnancy, holds and nourishes the developing child.

References

1. Australian Institute of Health and Welfare and Australasian Association of Cancer Registries, *Cancer in Australia 2001*, in *Cancer Series no. 28*. 2004, AIHW cat. no. CAN 23.: Canberra: AIHW.
2. Threlfall, T.J.a.T., J.R and Olsen N., *Cancer in Western Australia: Incidence and mortality 2003 and Mesothelioma 1960-2003.*, in *Statistical Series Number 74*, T.W.A.C. Registry, Editor. 2005, Department of Health: Perth.
3. Australian Institute of Health and Welfare, Australasian Association of Cancer Registries, and National Cancer Strategies Group, *Cancer incidence projections Australia 2002 to 2011*. 2005: Canberra: AIHW cat no CAN 25.
4. Langer RD, P.J., O'Hanlan KA, et al, *Transvaginal ultrasonography compared with endometrial biopsy for the detection of endometrial disease: Postmenopausal Estrogen/Progestin Interventions Trial*. N Engl J Med, 1997. **337**: p. 1792-1798.
5. Herdman, C., *A Status Report on Human Papillomavirus Vaccines*. 2005, Program for Appropriate Technology in Health: Seattle. p. 2.
6. Brotherton, J.M. and P.B. McIntyre, *Planning for human papillomavirus vaccines in Australia; report of a research group meeting*. Commun Dis Intell, 2004. **28**(2): p. 249-54.
7. Stanley, M., *HPV vaccines*. Best Practice & Research Clinical Obstetrics & Gynaecology, 2006. **In Press, Corrected Proof**.
8. Moscicki, A.-B., *Impact of HPV infection in adolescent populations*. Journal of Adolescent Health, 2005. **37**(6, Supplement 1): p. S3.
9. Franco, E.L. and D.M. Harper, *Vaccination against human papillomavirus infection: a new paradigm in cervical cancer control*. Vaccine, 2005. **23**(17-18): p. 2388-94.
10. Plummer, M. and S. Franceschi, *Strategies for HPV prevention*. Virus Research, 2002. **89**(2): p. 285.
11. NCCI Cancer Research Review Working Group, *Cancer Research in Australia - A Survey of Cancer Researchers*, E.b.C. Anderiesz, Editor, National Cancer Control Initiative: Melbourne.
12. Miller, A. *Fundamental issues in screening for cancer*. Second edition ed. Cancer epidemiology and prevention, ed. D Schottenfeld. and J Fraumeni. 1996, New York: Oxford University Press.
13. Wilson, J. and G. Jungner, *Principles and practices of screening for disease*. Public health paper. 1968, World Health Organisation: Geneva.
14. The Cancer Council Australia, *National Cancer Prevention Policy 2004-06*. 2004, The Cancer Council Australia: NSW.
15. WHO. *Global cancer rates could increase by 50% to 15 million by 2020*. 2003 [cited 2006 01/02]; Available from: <http://www.who.int/mediacentre/news/releases/2003/pr27/en/>.
16. Commonwealth Department of Health and Family Services, *Screening for the prevention of cervical cancer*. 1998, Commonwealth Department of Health and Family Services: Canberra.
17. Australian Institute of Health and Welfare, Department of Health and Ageing, and National Cervical Screening Program, *Cervical Screening in Australia 2002-*

- 2003, in *Cancer Series*. 2005, Australian Institute of Health and Welfare: Canberra.
18. AIHW, *Cervical Screening in Australia 2002-2003*, in *Cancer Series*. 2005, Australian Institute of Health and Welfare and the Australian Government Department of Health and Ageing for the National Cervical Screening Program: Canberra.
 19. Australian Institute of Health and Welfare, *Cancer in Australia 2001*, in *Cancer Series no. 28*. 2004, Australian Institute of Health and Welfare and Australasian Association of Cancer Registries: Canberra.
 20. AIHW and AACR, *Cancer in Australia 2001*, in *Cancer Series no. 28*. 2004, Australian Institute of Health and Welfare and Australasian Association of Cancer Registries: Canberra.
 21. EUROGIN France, *Conclusions: cervical cancer control, priorities and new directions: international charter*. 2003.
 22. US Preventive Services Task Force (USPSTF), *Guide to clinical preventive services*. Second edition ed. 1996, Washington, DC: US Department of Health and Human Services, Office of Disease Prevention and Health Promotion.
 23. Medical Services Advisory Committee (MSAC), *Liquid based cytology for cervical screening: August 2002 assessment report.*, M.r. 12a, Editor. 2003, Commonwealth Department of Health and Ageing: Canberra.
 24. Sawaya, G.F., et al., *Risk of cervical cancer associated with extending the interval between cervical-cancer screenings*. *New Engl J Med*, 2003. **349**(16): p. 1501-9.
 25. The Australian Cancer Network and National Breast Cancer Centre, *Clinical practice guidelines for the management of women with epithelial ovarian cancer*. 2004, National Breast Cancer Centre: Camperdown, NSW.
 26. Langer, R., et al., *Transvaginal ultrasonography compared with endometrial biopsy for the detection of endometrial disease: Postmenopausal Estrogen/Progestin Interventions Trial*. *N Engl J Med*, 1997. **337**: p. 1792-1798.
 27. Grover, S. and Q. MA., *Is there any value in bimanual pelvic examination as a screening test*. *Med J Aust.*, 1995. **162**: p. 408-410.
 28. Bell, R., M. Petticrew, and T. Sheldon, *The performance of screening tests for ovarian cancer: results of a systematic review*. *Br.J.Obstet.Gynaecol.*, 1998. **26**: p. 109-114.
 29. Karlan, B., *The status of ultrasound and color Doppler imaging for the early detection of ovarian carcinoma*. *Cancer Invest*, 1997(15): p. 265-269.
 30. Pauler, D., et al., *Factors influencing serum CA125II levels in healthy postmenopausal women*. *Cancer Epidemiol.Biomarkers Prev*, 2001. **10**: p. 489-493.
 31. Stratton, J.F., et al., *Contribution of BRCA1 mutations to ovarian cancer*. *N Engl J Med*, 1997. **336**: p. 1125-30.
 32. Robertson, G., *Screening for endometrial cancer*. *MJA*, 2003. **78**(12): p. 657-659.
 33. Ng, A., et al., *Significance of endometrial cells in the detection of endometrial carcinoma and its precursors*. *Acta Cytol*, 1974. **18**: p. 356-361.
 34. Grossi, M., et al., *Ovarian cancer: patterns of care in Victoria during 1993-1995*. *MJA*, 2002. **177**(1): p. 11-16.

35. Jong, K.E., et al., *Remoteness of residence and survival from cancer in New South Wales*. Med J Aust, 2004. **180**: p. 618-622.