

SENATE ENQUIRY INTO GYNAECOLOGICAL CANCER SERVICES

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EXECUTIVE SUMMARY

INCIDENCE & MORTALITY OF CANCER IN SOUTH AUSTRALIA

In South Australia, the data from the Annual report of the Cancer Registry shows that for 2003 the incidence and mortality rates for cervix, uterine, ovarian and vulvar cancer were as follows:

- **CERVIX CANCER**
46 new cases and 24 deaths were in women aged between 25-85+ years.
- **UTERINE CANCER**
166 new cases and 35 deaths were in women aged between 40-85+ years
- **OVARIAN CANCER**
81 new cases and 64 deaths were in women aged between 35-85+ years
- **VULVAR CANCER**
17 new cases and 5 deaths were in women aged between 40-85+ years

This therefore represents a considerable burden of care for this State. Each State will be able to present similar data, as Cancer Registration is nationally mandated, but the responsibility of the States to maintain the data.

There is a comprehensive Gynaecological Oncology Unit based at the Royal Adelaide Hospital, offering a Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) accredited training program for the subspecialty of Gynaecological Oncology, leading, after a 3 year training program to examination for the CGO (Certified Gynaecological Oncologist) qualification, recognised by NASQAC.

There are two CGOs in South Australia.

This Unit offers care for any woman in South Australia suffering from a gynaecological malignancy. It also has an outreach function which encompasses The Northern Territory, where the Director makes 4-5 trips annually, Broken Hill, NSW and Mildura, Victoria. Until February 2006, it also provided services to Flinders Medical Centre. Adelaide has been the natural "drainage" for people living in these more remote areas unless they have family in other major centres. Thus, this Unit "speaks" for many country people from NT, NSW, VIC, as well as country SA, all of whom need uniform services for their illnesses.

Best practice, world-wide is that women with gynaecological malignancies are treated in a dedicated gynaecological oncology unit, offering multidisciplinary care to obtain the optimal outcome. In practical terms, this means specialists educated in all aspects of the various diseases;

- specialist gynaecological oncologists
- radiation oncologists
- medical oncologists

- radiologists
- pathologists
- palliative care physicians
- specialist gynaecological oncology nurses
- psycho-social-sexual specialist social workers and or psychologists
- genetic counselling services
- data management
- clinical trials coordinators.

These disciplines must either be represented as part of the team or readily available.

AREAS THAT NEED TO IMPROVE OUTCOMES & CARE DELIVERY

A) Screening

It is vital that the currently successful Cervical Screening Program must continue to be adequately funded. This must include funding for:

- Backup Registration
- Monitoring of Ongoing Programs
- Education
- Innovation to recruit those not currently screened
- Surveillance to ensure timeliness of the guidelines.

Currently, some 30% of the target population do not participate in the screening program, despite the current efforts with education, media campaigns etc. Whilst we need to ensure that women currently screened continue to return for ongoing surveillance, the greatest health benefit dollar for dollar spent will be on recruitment of the unscreened woman.

B) Education

- (i)** For the medical fraternity about risk factors, epidemiology, presentation, natural history, treatment options, BEST PRACTICE and prognosis of each disease entity.

Some education is provided through the Divisions of General Practice and Rural and Remote Telelinks, but more could and should be done in an organised manner across the country so that there are no gaps. Centralised education programs, with laminated *aides memoires* such as produced by the National Breast Cancer Centre (NBCC) for breast cancer is an invaluable and excellent use of resources by coordinating effort.

- (ii)** The university-based nursing degree currently offers limited education on general gynaecology, and none, specifically about gynaecological oncology. There is no post-graduate course which nurses may pursue. A nurse practitioner course would be an ideal way to fill this gap and also provide another level of support to women and their carers.
- (iii)** For the women. Just as there are many different organisations providing support, so are there a plethora of education pamphlets. It would be valuable to have a central clearing house for information which is reliable including web-based sites.

(iv) For the health administrators. Provision of services for women with gynaecological cancers does need to be special. There has been a tendency to dispense with gynaecological wards, and lump all patients regardless of any special need together. I refer to the situation where all patients undergoing surgery are in the same ward, nursed by the same nurses. In some cases, this includes male and female patients sharing the same facilities. This is not appropriate for women with gynaecological malignancy. There are instances where intimate dressings are performed in an open ward, etc. Provision must be made for the peculiar circumstances of these women during stressful periods of the treatment time. Even placing women with a newly operated cancer in a ward with women who have just given birth is totally inappropriate.

(v) **HPV Vaccination**

With the imminent approval of the HPV vaccine against high risk viruses implicated in the development of cervical cancer and its precursors, there is an urgent need to have organised records to check the outcomes for those who have been vaccinated. Ideally this should be linked to the already existing Cervical Screening Backup Register, to check that these women do not develop abnormalities of the cervix. If so much money is to be expended on the vaccine, it is a major public health issue to glean information about its efficacy. There also needs to be an advocacy to remove the “pseudo” stigma currently given by some ill-informed moralist lobby groups to HPV and its vaccination. The vaccine is a long term investment in the health of our female children.

C) Data Collection

Accurate data collection and timely analysis of the epidemiological factors of the diseases, outcomes of patterns of care and projections of manpower and resource allocations, based on numbers of women requiring care, are essential for Government, both Federal and State, to plan adequately for future health care requirements.

Such data collections are also vital for clinical research into all aspects of the disease.

(i) **Cancer Registration**

This is a State function. Unfortunately, there is not uniform data collection across the States. This leads to lack of timely reporting which in turn, means that Health Initiatives are not monitored. South Australia used to lead the way with timely reports, but the government has not seen fit to maintain this advantage by recruitment of personnel of prime value after vacancies have occurred. Other States also suffer under the similar lack of vision, funding and support.

(ii) **Hospital-based Registration**

In South Australia, there has been a Gynaecological Oncology Hospital-based registry since 1984. A hospital-based registry serves quite a different role from the State and Commonwealth ones. In this registry, we record individual cancers by stage, treatment type, outcomes including complications and death. Thus, this unique repository of information is invaluable both for quality control of our

treatments, research and also helping to plan for future requirements of manpower and other service delivery projections. Other Units situated in each State of Australia also have such registries, and it is vital that the Government recognises what an asset they are and supports them with data management and backup.

D) Special Needs Groups

i) Aboriginal Health

There was a Commonwealth-funded initiative for an Outreach gynaecologist for the indigenous people in Northern Territory "Top End". This has proven extremely successful in increasing the coverage of screening programs for cervix cancer, as well as managing any screen- detected abnormalities. It has also identified special groups of women who might be at an even higher than average risk of developing vulvar cancers. Unfortunately, this position has been allowed to flounder and is not currently filled by a dedicated gynaecologist. This has occurred because the local hospital did not value this service highly enough, and the incumbent had to consider her own health, and moved to Far North Queensland, where she has been given better support to perform a similar task.

There is an urgent need that the Commonwealth revisit this initiative and re-establish its importance to Indigenous health initiatives.

There should be provision for such positions of Outreach gynaecologist in all parts of the country where there are concentrations of aboriginal people in remote areas. This facilitates their access to specialist gynaecological care.

A further area that a National Gynaecological Cancer Centre could prove a lead would therefore be in the governance and selection of such positions, taking them away from State government controls, as we have first hand evidence from NT that this does not work.

ii) Rural and Remote Women

Unfortunately, these will always be disadvantaged by the tyrannies of distance, but much can be done to help.

Government-funded travel schemes are inconsistent around Australia. For example, one must travel at least 200km in NSW, 100km in VIC and SA, and 0km for Tasmania.

It is difficult to gain approval for escorts to travel with the patient for support. (e.g. NT will not permit an escort for a patient unless they are aboriginal, whereas, SA and NSW will permit an escort to attend.)

The travel cost schemes will only help with costs for one trip per treatment. There is no provision for travel home during any break in treatment or for a weekend, when no treatment is undertaken.

Long distance patients have inadequate accommodation availability. This applies equally to the rural women as well as the indigenous women who are often very badly and inappropriately housed.

There is a strong need for the Multidisciplinary Group approach to gynaecological cancer care, so that it is not possible, nor even desirable that women are offered a poorer standard of care, just to make it closer to home.

Government has to appreciate that time and money must be set aside to ensure that OUTREACH clinics are appreciated and properly funded. This will include:

Sufficient numbers of trained gynaecological and other oncologists to travel to centres. The implication is that there is funding for training positions and also for salaries after they are trained.

Appreciation from funding sources that Outreach clinics take much more time and resources per patient to perform. This is because time must be set aside for travel itself, where the doctor can not see other patients or perform other tasks. There must also be adequate and experienced support staff, to collect and collate notes, letters, laboratory results etc, and nursing staff to ensure that the treatment plans are followed through and that the woman is adequately supported. The usual model is that of the hub and spoke, where management decisions and treatment are carried out centrally, but as far as possible, ongoing surveillance and support occur locally. Some of these functions can be facilitated by Telemedicine links between visits from the specialists. This obviously has funding implications for the States and federally.

E) Research

Our Unit pursues clinical and basic research programs. Our research programs are vital to sustain our long-term commitment to expanding our knowledge base and permit us to continue to advance in the prevention, control and cure of gynaecological cancers. With properly formulated treatment and research protocols, and our Tumour Register as a rich resource, we aim for steady progress in understanding the molecular, cellular, and genetic mechanisms involved in gynaecological cancer, and continued advances in patient care.

Our Unit, like all others around the nation, is heavily committed to, and involved in clinical studies – specifically, randomised clinical trials, predominantly sponsored and supported financially by the Pharmaceutical Industry.

We are also part of the national ANZGOG (Australian and New Zealand Gynaecological Oncology Group) trials consortium. There is some (minor) funding for group-agreed studies, but this is not sufficient to cover the costs of data management and study costs.

We collaborate extensively with our local basic scientists in the University for more laboratory-based research. Here, funding is non-existent, and we are reliant upon local departmental funding for all pilot projects. This is seemly and reasonable, but there is currently no mechanism where there is any translational funding to progress research to the next stage – namely, collaborative activities across the gynaecological units in each State.

Specific laboratory-based or clinical research funding for gynaecological cancer is not available. All research is in competition for NHMRC or other

funding. In fact, the major collaborative study nationally is funded by U.S.A Department of Defence. (Australian Ovarian Cancer Study - OVCA).

It is appreciated and accepted that funding must be competitive and based on merit through a peer review process, but there are some studies which are of great importance, but not seen as “sexy” which are not going to be picked up by alternative funding from industry or other sources. Examples of this are studies asking surgical questions.

Breast cancer has specific funding through the NBCC. A similar model would be advantageous for gynaecological cancers. A National Gynaecological Cancer Centre with some discretionary funds would be the ideal vehicle to auspice such studies.

F) CONSUMER SUPPORT

The availability of support systems varies widely around the country and from city to rural and remote areas. Each State has one or a series of supports, varying from The Cancer Councils, through special interest groups to general cancer groups. With such a variety of groups, it is inevitable that there will be duplication of efforts which under a national system could be avoided, leaving energies to be directed to more initiatives.

Most councils have:

- **Government-funded home assistance** schemes which may offer help in the short term, but only for those over 60 years, and on a pension. There is no assistance for younger patients.
- **Domiciliary Services** for Cancer Patients only occur for Palliative Care patients due to the long waiting list. Those less critically ill never get to the top of the list.
- Younger patients (less than 60 years) are not eligible for **Home Community Nursing** care unless they are palliative; they are required to attend a clinic.
- **Centre-Link assistance.** It is extremely difficult for cancer patients to be eligible for a disability pension, or for a family member to get carer payments. In many cases, a family member may be required to stop work to help care for a patient undergoing treatment. It is only when a patient has been certified as terminal, with a specific life span, only then that Centre-Link is willing to pay. Younger women, still in the workforce, with a currently-working partner have difficulty in accessing Health Care Cards and sickness benefits.

Palliative Care Provision

It is well known that the major providers of end of life care are the women family members. Thus, many men are cared for at home. When a woman is ill, the family structures are often insufficient to easily adapt to the carer's role. There is an urgent need to fund to an adequate level the provision of Palliative Care services throughout the country, especially in rural and remote areas; including physicians, nurses and ancillary carers, and sufficient places.

Hospice eligibility is only available in the last few weeks of life. There are no other options other than residential aged care. Increased funding for longer term placement in hospice would reduce stress and anxiety for the patient and her carers, and also reduce the burden of disease on the acute care facilities.

Psycho-social-sexual Supports

The diagnosis of a gynaecological malignancy hits at many levels.

- a. Life threatening situation.
- b. Possible mutilation and loss of body image or physical function.
- c. Loss of home coordinator of the family.
- d. Brings out need for refined coping skills.

Throughout the country, there has been insignificant attention to this aspect of the diagnosis and management and (hopefully) rehabilitation of gynaecological cancer sufferers.

Acknowledgement of the strong psychological input must be made by government in a positive manner by setting aside funding for the provision of these support services by trained professionals. Obviously, these services must be fully accountable and data will be able to show that timely interventions decrease the need for extra hospitalisation as well as aid in the more rapid and smoother rehabilitation back to a normal life style.

Genetic Services

There is not equity of availability of genetic counselling and testing for uterine and ovarian cancer across the country. There are major differences regarding what is offered. Even where there is a service, funding is not adequate for all who would undergo the testing. There must be a nationally coordinated program encompassing clinicians (geneticists, counsellors), genetic testing, genetic education and data management across the country. One must remember that families cross State boundaries, so this service does require consistency.

G) National Health & Medical Research Council (NHMRC) Guidelines

Gynaecological cancers have been the subject of two NHMRC endorsed set of guidelines for management in the last decade.

1. ***GUIDELINES FOR THE MANAGEMENT OF EPITHELIAL OVARIAN CANCER***, endorsed in 2005, but there are still major gaps in the execution of these guidelines, including equity for all Australians regardless of place of domicile. Not all women suffering from a gynaecological malignancy are referred for care to a gynaecological oncologist, as has been recommended in these Guidelines.
2. Revision of the 1994 document ***GUIDELINES FOR THE MANAGEMENT OF SCREEN-DETECTED ABNORMALITIES OF THE CERVIX*** was accepted in 2005 and will be implemented on July 3 2006.

For the most part, these Guideline reviews were performed by individual specialists in their spare time, with no support for research or recompense for time spent in reviewing all the literature. A small amount of funding, but not adequate for the task, was made available from Cancer Councils and Screening programs.

Infrastructure for monitoring and support of evaluation

If these Guidelines, and subsequent ones, are to be implemented, there needs to be an infrastructure with adequate support to provide incentives, as well as monitoring outcomes.

There is absolutely no value for any Government to support any initiative if the outcomes are not monitored carefully by defining Best Practice and then developing and utilising tools to measure outcome.

H) REPRESENTATION ON NATIONAL ADVISORY COMMITTEES

50% of the population are women, but there is no government policy to ensure that their needs and ideas are equally represented, especially on committees where their wellbeing is an issue.

There is a notional mandate that on the major Government committees, there is lip service to State representation, and some gender representation. There is, however, no appreciation that women's cancers should have a voice in this new **Cancer Australia** organisation.

This is inequitable.

BACKGROUND INFORMATION ABOUT INDIVIDUAL GYNAECOLOGICAL CANCERS

1. CERVIX CANCER

Before the organised Pap Smear Screening Program, this was the most prevalent gynaecological cancer.

In 1987, in S.A. 101 women were diagnosed and subsequently treated for cervix cancer.

A decade later, after the introduction of the Population-based Screening Program (as opposed to opportunistic screening), where we now have >60% coverage of eligible women, the incidence has fallen to 48 women. The Screening Program has made significant inroads into the incidence of invasive cervical cancer, but there are still major obstacles to tackle. The main reason for women developing cervical cancer is because their smear test is not up to date. These women also have more advanced cancers, so are at a greater risk of dying from the disease, regardless of treatment given.

CHALLENGE

How to encourage more women to take part in routine screening. Non-English speakers, Aboriginal, and lower socio-economic groups are over-represented in this group of women.

2. UTERINE CANCER

This is now the most common occurring gynaecological cancer. It occurs predominantly the post-menopausal woman.

Known risk factors include obesity.

There about 120 new cases each year in South Australia, and increasing. Abnormal vaginal bleeding is the commonest presenting symptom. Three quarters of cases are early stage, and thus, the prognosis is good for most women.

CHALLENGE

Public education that obesity is a major health hazard, and that weight reduction can prevent this disease.

3. OVARIAN CANCER

There are about 100 new cases annually in South Australia. It occurs in the peri- and post-menopausal woman.

Symptoms are usually vague, so that the majority are in an advanced stage before presenting for treatment. Overall survival for the 75% who present with advanced disease is one of remission with treatment and then, relapse. This cycle may recur several times. For the early stage women, (25% approximately), the prognosis is good, with 85-90% surviving. The major problem is that there is no effective screening test or early warning symptoms. Medical effort is into treatment, and with recurrent episodes so that a strong component is needed for supportive services.

CHALLENGE

Educate the profession and the public about the signs and symptoms of ovarian cancer, which usually are insidious.

Ensure that all women with suspected ovarian cancer are adequately investigated and appropriately referred to a gynaecological oncology unit for treatment.

Development of a screening test that enables the detection of ovarian cancer at an early stage when treatment is more likely to be successful and a complete cure is possible.

4. VULVAR CANCER

There are two modal ages of incidence.

- a. 30-40 years, with a strong association with HPV (Human Papilloma Virus) infection, with precursor lesions analogous to those on the cervix from the same aetiological factors.
- b. Older age group – 70 years or nearer in association with Lichen Sclerosis, and bearing no relation to HPV.

We see approximately 25-30 new cases annually.

Usually, they are treated surgically; often requiring a combined approach with the Plastic Surgeons.

CHALLENGE

There is a great propensity for local recurrence, even greater when the surgical margins of excision are not clear histologically. This results in an ongoing burden for surveillance and further surgery and other measures to manage these recurrences.

There is therefore, evidence of progress in the management and care of the woman with a gynaecological malignancy, but, as highlighted, there are still major areas requiring further effort, and deserving special attention.

Not all women have benefited equally from the improvements already at hand.

The Gynaecological Oncology Unit is situated in the major teaching hospital in Adelaide, centrally, with outreach services where they can be safely and satisfactorily managed. Women are referred for investigation and management plan, and any surgery is performed centrally. Radiation also needs to be undertaken centrally.

There is accommodation provided at a reasonable price through The Cancer Council SA at Greenhill Lodge, for those with no local family or friends.

For women who live in larger country areas, where there is adequate support and backup, some chemotherapy may be delivered more locally, to save the often long journey every several weeks. Still, the majority of county women will need to travel long distances for their treatment.

This places a severe psychological and monetary handicap on them and their families who will usually need to travel with them. To be entitled for any Government assistance, they must travel in excess of 100km. The recompense is then meagre.

A National Gynaecological Cancer Centre specific for women with gynaecological cancer would go a long way to redress many of these issues.

This would need to be separate from the NBCC, as, despite some commonalities, gynaecological cancer needs are not currently met adequately.

The diseases behave differently and are managed by a different set of doctors.

Research directions also differ.

ASGO (The Australian Society of Gynaecological Oncologists) aims to support all aspects of care for the woman with a gynaecological malignancy. This includes education of subspecialists and research also. All subspecialist gynaecological oncologists belong to ASGO, but all work is done in an honorary capacity and there is no infrastructure. Obviously, therefore, there are no funds for ongoing initiatives.

There needs therefore to be a well funded and supported National Unit which will have a high profile to:

- *Coordinate the current individual local initiatives.*
- *Ensure new initiatives continue.*
- *Provide a focus for lobby groups.*
- *Inject a high profile for women's cancers.*
- *It needs funding and goodwill from Government, and committed staff to ensure its success.*
- *There must be provision for equity of care and availability of specialists.*
- *A reinstatement of the Outreach Gynaecology Service across all areas where there is a concentration of Indigenous people in remote areas with poor access to mainstream care.*
- *Genetic services must be nationally managed.*
- *Access and equity for financial, psychosocial supports and palliative care will require more financial help.*

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