Queensland Centre for Gynaecological Cancer (QCGC)
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The Secretary
Senate Community Affairs Reference Committee
Parliament House
Canberra ACT 2600
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Dear Sir/Madam,

RE: SENATE INQUIRY INTO GYNAECOLOGICAL CANCER SERVICES

About QCGC
The Queensland Centre for Gynaecological Cancer (QCGC) was established in 1994. It is not only the largest tertiary referral centres for gynaecological cancer in Australia but also in the Southern hemisphere. At QCGC we will see more than 600 new patients with gynaecological cancer every year. Many more patients will have continuing follow-up.

QCGC operates from two hubs. The main hub is located at the Royal Brisbane and Women's Hospital in Herston. It shares the Herston Campus with the Royal Children's Hospital and the Queensland Institute of Medical Research. The Royal Brisbane and Women's Hospital Health Service District currently has an operating budget of approximately $400 million and has recently undergone a major redevelopment program. The second hub is located at the Mater Misericordiae Hospital in South Brisbane.

In this submission to the Senate we wish to outline that there is a disparity between what is achievable if adequate funding is provided and what is currently achieved. In addition, we would like to focus on the needs of gynaecological cancer patients in Queensland but also in Australia. The main areas of need are:

1. Research
2. Clinical shortages
3. Information needs
4. Aboriginal and Torres Strait Islanders
5. Representation of gynaecological cancer

1. RESEARCH NEEDS

Since the implementation of the position of a Director of Research in 2003, the Queensland Centre for Gynaecological Cancer (QCGC) has taken a lead role in conducting research in gynaecological oncology in Australia.

Considering that basic research is highly successfully performed at the Queensland Institute of Medical Research (QIMR), the Mater Medical Research Institute (MMRI) and a number of other institutions there was no point orienting QCGC's research towards basic research. Therefore we have put our research focus strongly on clinical research, such as clinical trials and translational research. Since 2003 we have established and completed a number of clinical trials, including the following:

1. **Prospective non randomised phase 2 clinical trial on Uterine Papillary Serous Carcinoma (UPSC) -** UPSC is a very uncommon but aggressive form of uterine cancer. Treatment of patients with UPSC varied hugely over time and no treatment standard exists to date. Therefore we treated prospective patients in a uniform way as part of a clinical phase 2 trial. Patients receive radical surgery, combination chemotherapy (Carboplatinum and Taxol) and radical radiotherapy to the whole pelvis. Outcomes are tolerability and morbidity of this aggressive regimen. Twenty-four patients have been enrolled so far and the aim was to enrol 30 patients by the end of 2006.

2. **Randomised pahse 3 clinical trial on Skin Closure -** While wound problems are very common after surgery and extremely troubling for gynaecological cancer patients, very little evidence exists to recommend the best wound closure method. A phase 3, prospective randomised trial comparing titanium staples, Monocryl subcuticular suture and Caprosyn subcuticular suture in patients who had a laparotomy for gynaecological cancer has been completed in June 2006. Outcomes include cosmesis, pain and wound healing.

3. **Laparoscopic Approach to Carcinoma of the Endometrium (LACE) -** Every year more than 2,000 women require a hysterectomy for uterine cancer in Australia and some 30,000 women will have a hysterectomy for benign conditions. Laparoscopic techniques have been shown to be equally effective but less traumatic than open surgery for patients with endometrial cancer. The prognosis of endometrial cancer is extremely good but the risks of adverse events from open surgery are significant (especially in obese patients). Currently we enrol patients for a phase 3 clinical trial "Laparoscopic Approach to Carcinoma of the Endometrium – LACE". We plan to enrol 640 patients in Australia, Europe and England until 2009. Outcomes are disease-free survival and quality of life. 71 patients have been enrolled to date and recruitment is above expectations. This is the first surgical trial in gynaecological cancer ever performed in

Australia. Funding has been obtained from industry sponsors and from the Cancer Councils Australia.

In addition, a number of other research projects are currently carried out at QCGC, which address research needs. Examples are:

a. Malnutrition in patients with ovarian cancer - Our preliminary findings on 145 patients indicate that ovarian cancer patients are at particular risk of malnutrition at the time of diagnosis. Compared to patients with other types of gynaecological cancer and to benign pelvic masses, patients with ovarian cancer carry a 19-fold increased risk of being malnourished.

b. Genetic risk of endometrial cancer - Patients with mismatch repair gene defects have a 50%+ risk to develop endometrial and colon cancers. We diagnose mismatch repair gene defects on histopathological specimen after hysterectomy for endometrial cancer. We have been granted access to the Queensland Cancer Registry to match our data with population data. Patients with endometrial cancer who carry the gene defect might benefit from screening for colon cancer and female patients diagnosed with colon cancer might prevent endometrial cancer by screening. We plan to analyse data of 146 patients in the second half of 2006

c. CA-125 tumour marker - Preoperative serum CA125 levels might be of significant prognostic value in patients with surgical Stage I ovarian cancer. An Australian-wide collaborative study showed that stage 1 ovarian cancer patients with a CA125 of < 30 carry an extremely good prognosis with an overall survival rate of 95%. In contrast, patients with CA-125 levels > 30 have a 12% less overall survival rate at five years. Subsequent study involved collaboration with 7 gynaecological cancer centres from Australia and 4 from the U.S. and Europe. Based on these data, a new staging system for ovarian cancer has been proposed. The data suggest that one third of all patients with stage 1 ovarian cancer could be spared toxic chemotherapy.

d. Elderly patients with ovarian cancer – Thirty per cent of all patients with advanced ovarian cancer are 80 years of age or older. Older age is also associated with a greater number and severity of medical co-morbidities. Decisions to limit treatment and to exclude elderly patients from clinical trials are often made under the assumption that 1. Treatment-associated morbidity and perioperative mortality would be unacceptably high in elderly patients with advanced ovarian cancer and 2. The benefit of radical treatment in elderly patients presenting with advanced ovarian cancer would be very low. We have established a risk score which will estimate the risk of perioperative mortality and the expected outcomes of patients 80 years of age or older.

In the last 12 months, our centre was offered to participate in two large, multi-institutional and international important research projects on the prevention of ovarian and uterine cancer. Unfortunately, we were not able to participate because of lack of funding. We could have contributed significantly to those two studies but we did not have the funds available to participate in this important research.

Cost effectiveness: In the past it has been shown many times that research is cost effective. One of our trials, "Laparoscopic Approach to Carcinoma of the Endometrium" will hopefully demonstrate that laparoscopic treatment of patients with uterine cancer is as safe as an open operation. The risk of complications through laparoscopy is reduced to one third according to previous research carried out by our group. Hence, the savings of this new operation demonstrated by the LACE trial (see above) would be enormous. In another project on malnutrition in ovarian cancer, we provide evidence that malnutrition is not only extremely inconvenient to patients, but also very costly to the health system. Overall, investment in research would enable the Federal Government to achieve not only significant savings in treatment costs, but also increase and promote Australian women's health.

The current contributions of the Royal Brisbane and Women's Hospital and the Mater Hospital are in the provision of office space, but everything else including computers, internet access, personnel, equipment and staff travel is not supported by Queensland Health. The University of Queensland also provides in kind support by administering our funds, and providing an on-line accounting system. While all this in-kind support is important and many of the projects could not have been carried out without it, this level of support is clearly not enough to drive research in gynaecological oncology.

We propose a clinical research scheme supporting personnel for clinical research (clinical trials, translational research) by the Federal Government. The Federal Government shall provide the funds to employ clinical trial nurses, project managers, statisticians, and data managers for proven clinical research activity. Currently we employ four full-time clinical trial nurses, and we are seeking funds to employ a PTE business manager, FTE statistician, and a FTE data manager.

2. Clinical Needs

For many years there had been inadequate funding for gynaecological cancer services in Queensland. From 1994 onwards, on a yearly basis, enhancement application went to Queensland Health with little positive outcome. The enhancement application from 1994 showed a costed funding shortfall of approximately $1.25 million for the state-wide service.

In 1999 Queensland Health assembled a multidisciplinary committee, including Gynaecological Oncologists, Medical Oncologists and Radiation

Oncologists to undertake a detailed review of the States Gynaecological Cancer Service. That Committee met on a regular basis throughout 1999 and in November of that year Queensland Health produced a "Report on State-wide Gynaecological Cancer services for Queensland". This report contained 43 recommendations which when costed demonstrated an annual funding shortfall of over $2 million per annum. Nothing happened with respect to the Reports recommendations with the Report then disappearing within Queensland Health's Corporate Office. While in the last two years a couple of these issues have been addressed, the majority of Queensland Health's own recommendation for its State-wide Gynaecological Cancer Services remain unaddressed.

The following Spread sheet is based on those aspects of this Report that still remain relevant and need to be funded:

Queensland Present and Required Service Levels - These requirements and numbers are based on a Queensland Health Review of Statewide Gyn Cancer services in 1999.

Services	Current staffing	Required staffing	Extra staff	Costings with on-costs (approx)
Gynaecological Oncologists	5.0	7.0	2	$ 600,000.00
Trainee Fellows	3.0	4.0	1	$ 85,000.00
Secretarial staff	2.0	2.0		
Clerical staff	2.0	3.0	1	$ 40,000.00
Clinical psychologist	1.0	2.0	1	$ 75,000.00
Dedicated Social workers	1.5	3.5	2	$ 140,000.00
Physiotherapists	2.0	4.0	2	$ 140,000.00
Case Managers	2.0	2.0		
Research Nurse	0.0	2.0	2	$ 120,000.00
Data Manager	1.0	1.0		
Medical coder	1.0	2.0	1	$ 70,000.00
Data entry person	1.0	2.0	1	$ 40,000.00
PO5 Statistician / Network Manager	0.0	1.0	1	$ 85,000.00
Dedicated Acute Care Monitored beds with 1:2 nurse:patient ratio	0.0	7.0		$ 1,000,000.00
R&D Oncology laboratory set-up (one off)				$ 300,000.00
PO5 Post Doc. Enior Scientific Officer	0.0	1.0	1	$ 80,000.00
R&D Oncology laboratory running expenses				$ 80,000.00
Project Officer	0.0	1.0	1	$ 75,000.00
TOTAL				**$ 2,930,000.00**

3. Requirements for Indigenous Women in Queensland

Indigenous people make up 2.2% of the Australian population, but 3.1% of the Queensland population. The majority of this population group lives in the division of Brisbane ~ 27,000, the Northern Division ~ 11,600 and the Far Northern Division ~ 29,000. The remainder are scattered in much smaller numbers, roughly equally through the rest of the state. Forty-three percent of indigenous people live in the areas designated the most disadvantaged 20% of the state. These areas are largely in the rural and remote category. This demographic profile has implications for health care requirements and provision of services.

From available data, it is apparent that Torres Strait women have an incidence of cervical cancer five times greater than the state average and a site-specific mortality rate 13 times greater than the state average. Indigenous women do not have a statistically worse incidence or mortality rate than non-indigenous women for any of the other gynaecological cancers.

As with non-indigenous women, indigenous women with gynaecological cancers have improved outcomes when managed in a tertiary centre, by a multi-disciplinary team including a sub-specialty trained gynaecologic oncologist. Gynaecologic cancer services are largely provided through Brisbane and Townsville and this reflects the distribution of the indigenous and the non-indigenous population. It is uneconomic, impractical and implausible to provide a comprehensive tertiary level gynaecologic cancer service to a population base smaller than Townsville. Therefore the provision of these services to people in more remote areas necessarily involves the transfer of patients to major centres.

The transfer of indigenous women to the major centres for treatment entails identification of the gynaecologic cancer by the primary and secondary health care provider (general gynaecologist), the physical transfer of the patient, and provision of culturally specific and sensitive services within the tertiary centre.

At both the Royal Women’s and Brisbane Hospital and The Townsville Hospital a full time Indigenous Women’s Liaison Officer has been appointed funded by Women’s Cancer Screening Services, Queensland Health under the title of Program Coordinator, Indigenous Women’s Cancer Prevention and Support . These officers have access to an office and a vehicle and perform the following roles.

1. Increase awareness of screening services in breast and cervix cancer.
2. Advocacy and support for women and their families through treatment.
3. Provide a cultural link with health care providers and management.
4. Provide culturally specific information to patients, family and staff.
5. Facilitate transfer of patients and escorts.
6. Provide follow-up contact.
7. Reinforce recommendations of health care providers.
8. Assist with education of local health care providers.

Our recommendations are:

1. Greater promotion of and provision of cervical cancer screening services for women in rural and remote areas, particularly indigenous women.

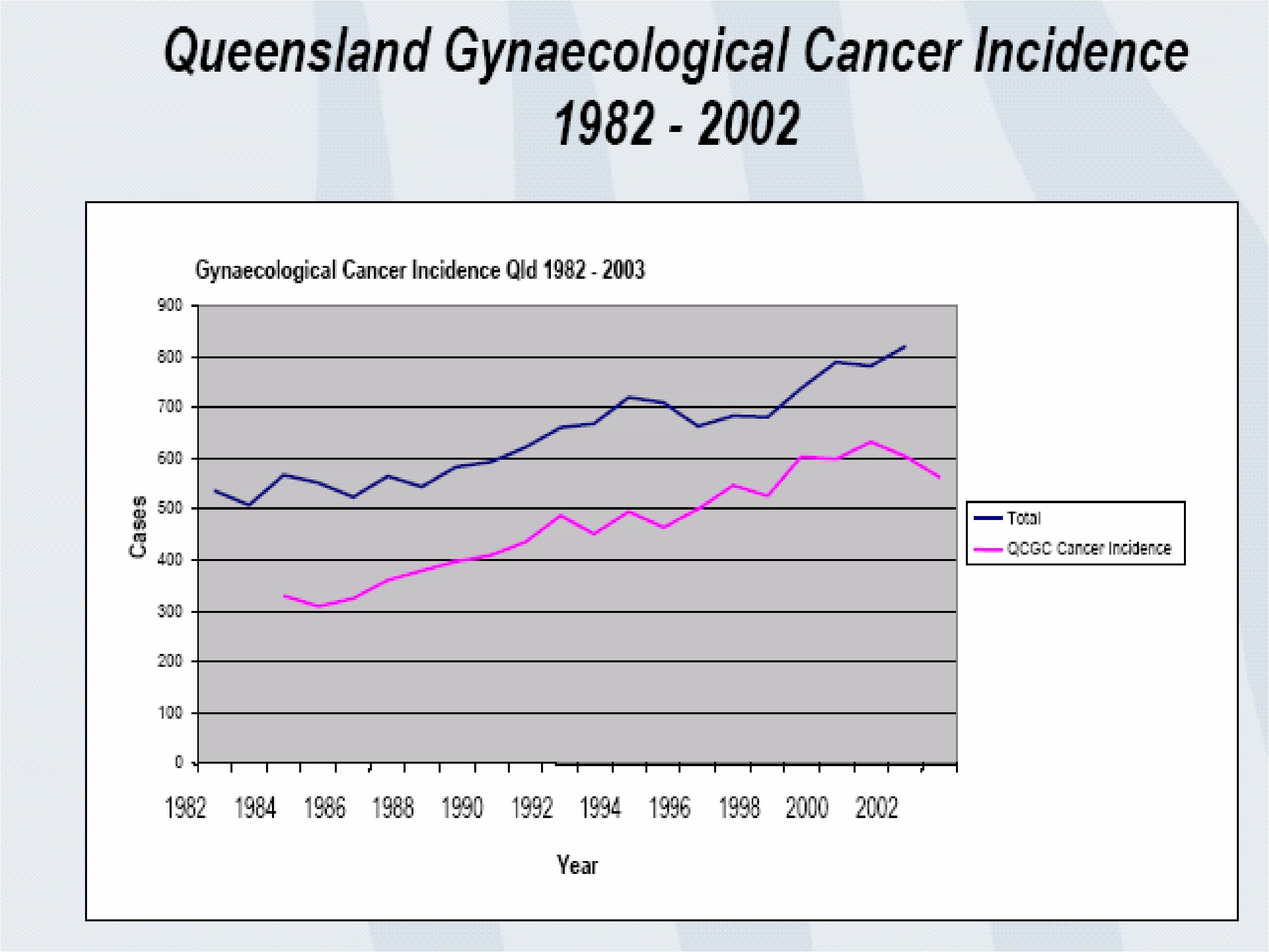
2. Fast track the provision of the HPV vaccine to indigenous communities along guidelines currently being developed.

3. There does not need to be an increase in tertiary level gynaecologic oncology services specific to indigenous women, however the need for increased services to the state as a whole is emphasized.

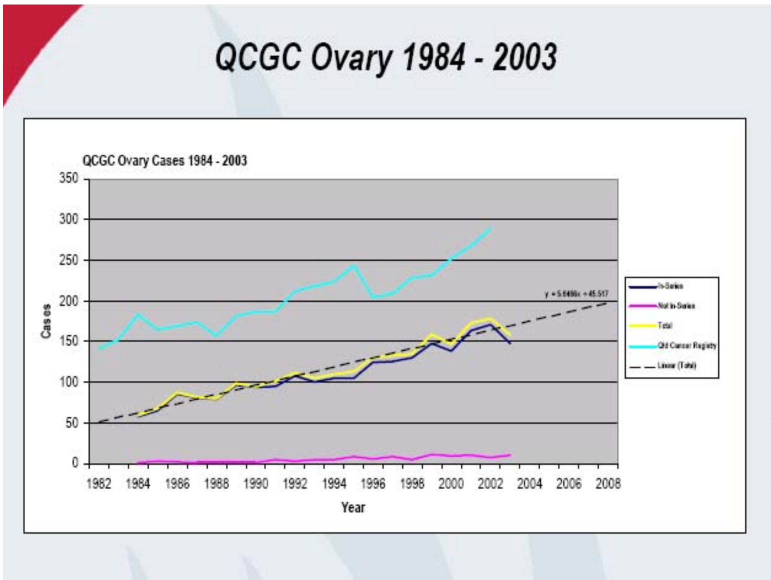
4. The general need for improved access to high quality housing, hygiene, education, and law and order is apparent. The suboptimal utilization of available gynaecological cancer services is in large part a reflection of deficiency of the basic necessities of life rather than a deficiency of specific services.

4. Information needs

In 2002 just over 800 new gynaecological cancers were diagnosed in Queensland and just under 600 new cases were treated by QCGC, which is the only gynaecological oncology unit in the state. Therefore 25% of cases are not being treated in a gynaecological unit. According to current NHMRC guidelines, ovarian cancer is best treated in a multidisciplinary team, guided by a gynaecological oncologist. However, for ovarian cancer only 50% of cases are treated by the QCGC unit as demonstrated in the graph below. The NHMRC guidelines from 2005 are based on the understanding that the incidence of treatment-related adverse events is less in a tertiary referral



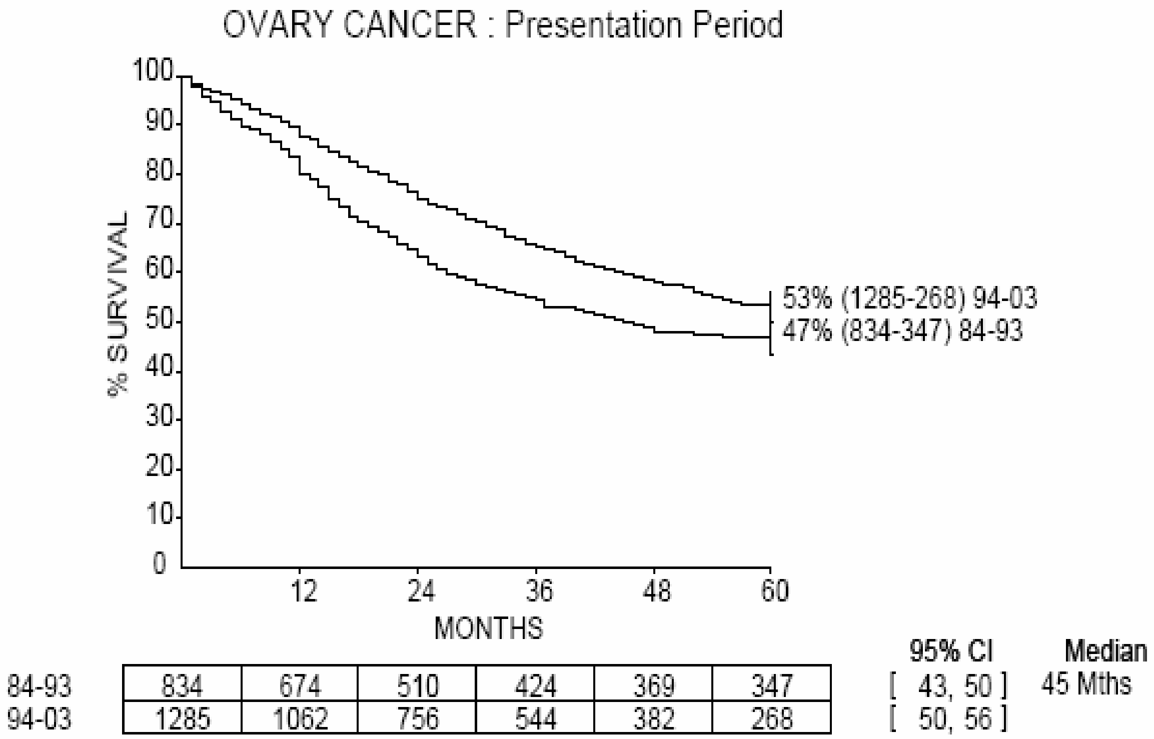
centre but also that the outcomes are better in regards to prognosis and survival.



Relative survival of ovarian cancer nationally was published in the Australian Institute of Health and Welfare to be 42% at 5yrs in the years between 1992 and 1997 (AIHW 1999). This compares poorly with the results from QCGC annual report with relative survival of 53% in 1984-2003. With the large disparity of survival it demonstrates the need for medical community education on the treatment of gynaecological cancers.

The graph above illustrates that only 50% of ovarian cancers in Queensland are treated by QCGC. If it is assumed that the relative 5 year survival in Queensland is the same as that nationally at 42% , then as approximately 50% of patients treated by gynaecologic oncologists at the Queensland Centre for gynaecological Cancer have a relative 5 year survival of 53%, those not treated by our unit must have a survival of 31% to bring the relative survival down to 42%.

Similar to improved survival with time (see QCGC data below), the same advantages are available for patients Australia-wide. With the substantially improved survival when treated in gynaecological oncology units, this a major area where education of the medical community would have an impact on patient survival and welfare. The majority of these patients who were not treated by the gynaecological oncology units were treated by other practitioners without the recognized subspeciality expertise, it is important that the broader community is made aware of the expertise that is available and the improved results possible.



							95% CI	Median
84-93	834	674	510	424	369	347	[43, 50]	45 Mths
94-03	1285	1062	756	544	382	268	[50, 56]	

5. Representation of Gynaecological Cancer

Gynaecological cancer is grossly underrepresented in the public domain and on national health agencies. This under representation seems to be a continuing theme involving the setting of health priorities and the distribution of (research) funds. One of the more recent examples is the constitution of the recently formed Cancer Australia. While breast cancer is represented with at least three members in the 12 member committee, gynaecological cancer is not represented at all.

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