Queensland Government
Queensland Health

Submission to the Senate Community Affairs References Committee

Inquiry into Gynaecological Cancer in Australia

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Introduction

Gynaecological cancers relate to cancer of the vulva and vagina, cervix, uterus, ovary and some other specific sites (female genital organs). Of the range of gynaecological cancers ovarian is the most lethal and accounts for greater than 50% of deaths due to gynaecological cancers. Australian Institute of Health and Welfare data for 2001 show that 3,881 Australian women were diagnosed with incident gynaecological cancers and 1,526 women died.

The most recent data for Queensland shows the incidence and mortality for the range of gynaecological cancers (Table below).

Table: Cancer Incidence and Mortality Gynaecological Sites, Queensland 2002

Cancer Site	Incidence	Rate/ 100,000	Mortality	Rate/100,000
Vulva	42	2.3	11	0.6
Cervix Uteri	148	7.9	36	1.9
Corpus Uteri	309	16.6	60	3.2
Ovary	289	15.5	134	7.2
Other	32	1.2	8	0.4

Source: QCR, Cancer in Queensland Incidence and Mortality 1982 - 2002

This data clearly indicates that ovarian cancer has the worst outcome (mortality rate) compared to the other gynaecological cancers for Queensland women.

Earlier this year Queensland Health released its *Cancer Control Strategic Directions 2005-2010* (Copy attached). This strategy outlines how Queensland Health will address the National Service Improvement Framework for Cancer Control. The emphasis for Queensland Health planning will be the spectrum for cancer control from prevention, screening, early detection, treatment and management, rehabilitation, supportive care and palliation. The focus and significant investment by Queensland Health in implementing these strategic directions will benefit all Queenslanders with cancer including women with gynaecological cancer.

This submission provides Queensland Health's responses to/comments on each of the Senate Inquiry Terms of Reference in relation to gynaecological cancer in Australia.

Level of Commonwealth and other funding for research addressing gynaecological cancers

It is noted that NHMRC have increased their funding for ovarian cancer research in recent years and this is of benefit. However, more needs to be done in the provision of research infrastructure support to bolster capacity for research of this type. There is also a need for increased support for clinical trials and other translational research. This support includes the development of expertise in study design, data management and data monitoring.

Extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer

As noted above, ovarian cancer has the worst outcome (mortality rate) compared to the other gynaecological cancers for Queensland women. The improvements experienced in the other gynaecological cancers partly reflects existing screening programs leading to early detection and effective treatment. We need to continue to monitor advancements made in investigating possible screening strategies for ovarian (The NHS currently have two studies underway screening for ovarian cancer) and other gynaecological cancers with a view to adoption if and when research demonstrates that screening is appropriate and cost effective.

Screening Programs

More can be done to promote participation in relevant cancer screening programs. The introduction of Medicare Item Numbers 10998/9 for Practice Nurse cervical screening consultations for general practitioners in RRMA 3-7 is anticipated to increase rural and remote women's access to cervical screening services. However, poor participation rates in Queensland are evident in low socio-economic areas on the outskirts of Brisbane and other metropolitan areas which are not included in RRMA 3-7. Reduced participation in these locations has been attributed to high population growth relative to the number of general practitioners and limited access to female and/or bulk-billing general practitioners. Expansion of the Medicare rebate for cervical screening consultations provided by Practice Nurses across the whole of Queensland will enhance women's access to female Pap smear providers and increase women's participation in cervical screening.

Gynaecological Cancer and Genetics

- Gynaecological cancers may occur as a result of an inherited gene mutation
- Women who have inherited a mutation in one of the causative genes have a significantly increased risk of gynaecological cancers
- The cancers may occur at younger ages than in the general population

Examples: BRCA1 gene mutation carriers; ovarian cancer risk around 40-60%
BRCA2 gene mutation carriers; ovarian cancer risk around 40%
Woman with the condition hereditary non-polyposis colorectal cancer (HNPCC) have a risk of between 25-70% of endometrial cancer (depending upon which gene is involved) and an increased risk of ovarian cancer

Funding

- There is no commonwealth funding for gene testing in high risk families
- There is no specific funding for screening in these high risk women
- There is no specific funding for prophylactic surgery to minimise the chance of high risk women developing cancer
- We are not aware of specific research funding to look at the needs of Indigenous women with an inherited cancer predisposition

Access

- There is limited access to appropriate genetic screening through the public health system for a number of women because of availability (particularly in remote areas)
- There is very little information about the specific needs of Indigenous women

Education

- There is a lack of knowledge about the importance of relevant family history
- There is a subsequent issue with women accessing appropriate testing and screening
- A better awareness in the community, both broader and medical, would ensure appropriate referral and management of women at potentially high risk

Treatment Services

Queensland Health has recently announced significant funding increases for cancer care and treatment services within the public sector. In October 2005 the Government released its *Action Plan: Building a better health service for Queensland*. Increased funding in 2005-06 included an immediate injection of $24.1 million for cancer services growing to some $70 million from 2006-07. Overall, the *Action Plan* provides an additional $463.7 million over five years in funding for cancer care including new services and the maintenance of existing services.

Also Queensland Health has a comprehensive model for cancer care under development based on the hub and spoke model of cancer centres, cancer units and networks. This model will involve Area Health Service Clinical Networks in state-wide implementation of clearly defined service networks that encompass the public and private sector and that are based on a framework of underlying principles of cancer care. The model will promote service integration, coordination, a multidisciplinary team approach, evidence-based care and support for people on their cancer journey. Issues relating to communication across these networks, clinical governance, standardisation of care, coordination, timeliness of service provision and the need for people with cancer to travel to receive highly specialised treatments will be addressed. This approach will benefit women with gynaecological cancer as well as all Queenslanders with cancer.

Psychosocial Support

In terms of wider support programs for women with gynaecological cancer, psychosocial support is extremely important and an area where more could be done.

The “Queensland Indigenous Women’s Cervical Screening Strategy 2000-2004” has guided Aboriginal and Torres Strait Islander women’s cervical screening initiatives. The 2006-2010 strategy is in press and includes strategies to progress the key action areas from the previous strategy. There are two key action areas that relate to psychosocial and psychosexual care for patients and families affected by cervical cancer, namely, cancer support services for Aboriginal and Torres Strait Islander women and recognising and supporting the role of men.

Also more generally there is a need to support men in their supporting roles and in coping with a life limiting disease as experienced by their partner.

Queensland Health provides part-funding to the Gynaecological Cancer Society (GCS) for three state-wide programs aimed at providing support for women with gynaecological cancer. The programs include:

1. Emotional Support – a peer-based support program with special groups for male partners and children of women with gynaecological cancer.
2. Information and Education Program – where specific materials relating to gynaecological cancers and related issues are developed in-house and provided freely through the GCS website.
3. Patients Partners Program – is a pilot project where the focus is on providing support and teaching male partners of women with gynaecological cancer to cope with the stress of living with someone with a life limiting illness. The program was developed to address the evidence that relationship breakdown is higher among couples where the woman has gynaecological cancer and breakdowns are initiated more frequently by the male partners (this is in contrast to the trend in the general population for women to more frequently initiate separations). The program consists of materials (CD-ROMs and literature) provided to men as a 'kit'.

Whilst the Ovarian Cancer Program, hosted by the National Breast Cancer Centre (NBCC), is a valuable program educating and supporting women with ovarian cancer the higher incident cancers such as uterine are neglected at the National level. The work of the NBCC in collaborating with the Australian Cancer Network to develop clinical practice guidelines for the management of women with ovarian cancer, website and fact sheets and their educative literature for general practitioners on symptoms of ovarian cancer show clearly what can be achieved with dedicated resources.

Capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds, and those living in remote regions

Cervical cancer is currently the *second* most common cause of cancer death for Aboriginal women and Torres Strait Islander women is also one of the most preventable cancers (Homewood, Coory & Dinh, 2005). Geographical disparities exist in terms of survival outcomes for those living in regional and remote areas.

There needs to be specific and targeted efforts made by health and medical services if we are going to be able to meet the needs of our indigenous populations and other cultural backgrounds and those living in remote regions. Queensland Health has been working to ensure that the needs of these groups are responded to.

- The Queensland Cervical Screening Program has developed health promotion resources to increase participation in cervical screening for Aboriginal and Torres Strait Islander women. These resources feature culturally appropriate messages and artwork and include brochures, posters, prompt and reminder cards, videos and a culturally effective resource kit that provides Aboriginal and Torres Strait Islander Health Workers with health promoting information to use when providing workshops for women.
- The Queensland Cervical Screening Program has conducted specific projects for women from culturally and linguistically diverse backgrounds to increase their participation in cervical screening. These projects proved difficult to sustain due

to limited access to interpreter services and therefore alternative strategies will need to be developed to target these specific groups in the community.

- Queensland Health is also implementing a new program, the Healthy Women's Initiative, to promote and encourage Aboriginal and Torres Strait Islander women's participation in cervical screening and sexual health services over the next three years. This initiative will be delivered by eight Indigenous Women's Health Workers employed specifically for this project, who will work directly with local Aboriginal and Torres Strait Islander women and the community to ensure that cervical screening and sexual health services are coordinated and culturally appropriate and culturally safe. In addition, the Mobile Women's Health Service has been enhanced by the addition of two new Mobile Women's Health Nurse positions. The Mobile Women's Health Service (MWHS) provides an important outreach health service to women in rural and remote communities, including Aboriginal and Torres Strait Islander women and women from culturally and linguistically diverse backgrounds, who may be geographically or socially isolated.

Extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers

As noted above there is a need for greater medical education regarding genetic screening of at risk women.

The Queensland Cervical Screening Program is implementing a number of initiatives for general practitioners (GP) and other health providers including registered nurses and Aboriginal and Torres Strait Islander health workers. GP-related initiatives include:

- GP cervical screening clinical updates
- cervical screening education for international medical graduates
- the development of a handbook for providers of cervical screening medical education.

These education strategies focus on cervical screening but are undertaken with a focus on holistic women's health.

Within services providing treatment and management there is an increasing emphasis on multidisciplinary care and this combined with the implementation of information technology tools (including some currently under development) will support the sharing of information with GPs.

In a more general sense though, more education of GPs could usefully undertaken to raise awareness of risk factors, symptoms and treatment options for women with gynaecological cancer. It should be acknowledged that given the relatively low incidence rates for gynaecological cancers (compared to breast, bowel and prostate in men) most GPs are unlikely to be confronted with a patient with this potential diagnosis in any given year. There is recent research (NSW Cancer Institute) that suggests that GPs also favour a broad and diverse range of approaches to on-going education making the development and targeting of education programs difficult.

Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers

There is a significant need to improve the level of awareness of the risk factors, symptoms and treatment of gynaecological cancers among women and the broader community. Part of the reason for the poor survival of women diagnosed with ovarian cancer is late presentation due to a lack of awareness about symptoms and risk factors. Research into early detection diagnostic tests for ovarian cancer could lead to significant gains for women who develop this cancer. As noted above the dedicated efforts of the Ovarian Cancer Program (through NBCC) indicates the level of commitment that is needed to begin to raise community awareness. Other gynaecological cancers could usefully be included in an expanded program or have similar programs implemented.

Also as noted above, there is a lack of knowledge about the importance of relevant family history which means that at risk women do not seek genetic testing and GPs do not promote it.

Extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently establish Cancer Australia

It is intended that Cancer Australia will provide national leadership in cancer care. Cancer Australia has somewhat restricted representation presumably for the practical reason of limiting numbers. It is noted though that there is significant membership drawn from organisations targeting Breast Cancer and a relatively heavy focus on members drawn from NSW. Gynaecological and/or other cancer care groups could usefully be represented as could state jurisdictions.