SUBMISSION TO THE SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY
into
GYNAECOLOGICAL CANCER SERVICES
in
AUSTRALIA

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Background

- Gynaecological cancers are a significant health problem. Data from the Australian Institute of Health and Welfare (AIHW) shows that 3881 women were diagnosed with a gynaecological cancer in 2001, representing almost 10% of all female cancers.
- Gynaecological cancers are the fourth most common cancer site in women, behind skin, breast, colorectal and ahead of melanoma and lung cancer.
- The overall mortality rate from gynaecological cancer (50%) is disproportionately high compared with breast cancer (22%), and much of this mortality arises from the 66% mortality rate from ovarian cancer.
- It is estimated that there will be 4488 new cases of gynaecological cancer in 2011, which is an increase of 14% since 2001 (AIHW. Cancer Series 30). Ovarian, uterine and vulvovaginal cancers are each expected to increase by 25%, while the number of cervical cancers are expected to further decrease by 34%.
- There are 34 certified gynaecologic oncologists (CGO) in clinical practice in Australia. The RANZCOG have recently revised their projected manpower needs, suggesting that there should be one CGO per 400,000 population.
- We need 48 CGOs to adequately meet the health care needs of Australian women.
- International and national best practice supports a Multi-Disciplinary Care Team approach for all women with gynaecological cancer. While this is usually available in metropolitan tertiary medical facilities, it is lacking in rural and remote areas.
- In Western Australia, the Western Australian Gynaecologic Cancer Service, located at King Edward Memorial Hospital for Women in Perth, provides tertiary level sub specialist multidisciplinary care for women with gynaecological cancer.
- The population of Western Australia is approx. 2 million with 1.5 million living in the Perth metropolitan area.
- Visiting Medical Oncology services exist in Bunbury, Geraldton, Mandurah and Kalgoorlie. There are no radiation oncology treatment facilities outside of Perth.

Main Recommendation

The Commonwealth should establish a new government agency, the National Gynaecological Cancer Centre (NGCC). This agency should be independent and responsible for coordinating and improving gynaecological cancer services and research in Australia. This agency should have significant representation from clinicians involved in treating gynaecologic cancer.

Summary of Recommendations to the Senate Inquiry

- The Commonwealth and associated funding agencies (such as NHMRC) should show increased interest and financial support for high quality research into the prevention and treatment of gynaecological cancer in Australian women.
- The Commonwealth should establish a new government agency, the National Gynaecological Cancer Centre (NGCC). This agency should be independent from other cancer related agencies and be responsible for coordinating and improving gynaecological cancer services in Australia. The NGCC should be independent of the National Breast Cancer Centre in terms of funding.
- The NGCC could have a major role in the coordination of gynaecological cancer research in collaboration with ANZGOG (Australia & New Zealand Gynaecological Oncology Group), COSA (Clinical Oncology Society of Australia) and ASGO (Australian Society of Gynaecologic Oncologists).
- Maintenance of funding for the current National Cervical Screening Program with encouragement of Australian research into improved prevention of cervical cancer
- Increased funding for research into prevention and early detection of ovarian cancer, and the other gynaecological cancers.
- Funding should be specifically set aside for the implementation and support of a possible ovarian cancer screening program.
- Increased funding for adequate staffing of multi-disciplinary care teams and centres in each state and territory for gynaecological cancer treatment.
- Funding for improved health education programs for the community and health professionals, both rural and metropolitan.
- Increased funding to facilitate adequate staffing for allied health support services, both rural and metropolitan.
- Improved funding for the WA gynaecological cancer database and coordination of the many interstate hospital based databases with a centralized collation of data and national reporting capacity.
- Increased funding to support improved travel and accommodation for women, especially those from rural and in WA, very remote, areas.
- Increased funding to support staff increases to assist Indigenous and other women who require assistance coping with relocation, separation or cultural differences. This would

lead to an increase in Aboriginal liaison officers and appropriate translation facilities.

- Improved funding to support Telemedicine facilities which may allow doctors in rural and remote areas to access a sub specialist consultation without the burden of travel and family separation for the patient in question.
- Increased funding for personnel to provide visiting medical oncology and radiation oncology services to larger rural towns and cities.
- Increased funding to provide adequate ‘support services’ such as psychosocial, psychosexual etc to women in rural and remote areas, possibly by the establishment of regular visiting services in these disciplines, if the population size will not support a resident person.
- Establishment of a Coordinating Gynaecologic Oncology Nurse Specialist position, based in Perth (and similarly for other major treatment centres throughout the country). This nurse could coordinate for both public and private patients.
- Increased funding to develop educational materials regarding the risk factors, symptoms, signs, treatment and referral pathways for women with gynaecological cancer for general practitioners, through the proposed NGCC.
- The government should increase funding to provide adequate staffing for Familial cancer services to enable genetic testing and counselling to occur in a timely fashion.
- The government should increase funding to provide coordinated educational resources to the community at large, which should translate in reduced anxiety, earlier presentation to general practitioners and improved outcomes for the women who do have gynaecological cancer.
- Education regarding gynaecological cancers should be included in school health education programs.
- Establishment of a central website, with appropriate educational resources which are culturally sensitive, developed by the NGCC.
- The establishment of a NGCC would allow this body to coordinate and implement all of these strategies without duplication and improved efficiency.
- There should be representation of people with experience and expertise in gynaecological cancer on peak national bodies such as Cancer Australia (& it’s advisory council).

The terms of reference for the inquiry have been addressed below:

(a) Level of Commonwealth and other funding for research addressing gynaecological cancers

- There has been some government funding for gynaecological cancer programs, such as the National ovarian cancer program conducted under the auspices of the National Breast Cancer Centre (NBCC).
- There has been very little, if any, support for specific research in gynaecological cancer treatment and prevention, when compared with other cancer sites.
- Breast cancer research has enjoyed a high level of government interest and funding, commensurate with the high incidence of this cancer in women.
- Gynaecological cancer research deserves a similar level of government support and interest, as the overall death rate from gynaecological cancer is significant.

Recommendations (a):

- The Commonwealth and associated funding agencies (such as NHMRC) should show increased interest and financial support for high quality research into the prevention and treatment of gynaecological cancer in Australian women.
- The Commonwealth should establish a new government agency, the National Gynaecological Cancer Centre (NGCC). This agency should be independent from other cancer related agencies and be responsible for coordinating and improving gynaecological cancer services in Australia. The NGCC should be independent of the National Breast Cancer Centre in terms of funding.
- The NGCC could have a major role in the coordination of gynaecological cancer research in collaboration with ANZGOG (Australia & New Zealand Gynaecological Oncology Group), COSA (Clinical Oncology Society of Australia) and ASGO (Australian Society of Gynaecologic Oncologists).
- The NGCC could have a role as a funding agency.

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

Screening programs

- The Commonwealth funded National Cervical Screening Program (NCSP) has been an outstanding success with a reduction in incidence of cervical cancer of 48%, and of mortality of 49%, over the past 15 years. Australia has the second lowest incidence and mortality rate from cervical cancer in the world. The success of this coordinated approach to cervical cancer prevention is laudable.

- The anticipated introduction of a Cervical Cancer Vaccine in Australia within the next 12 months should not lead to any complacency in regard to the NCSP. This program, based on the Pap smear test detection and subsequent eradication of precursors of cervical cancer, will still be required. The vaccines, even if there is 100% uptake and efficacy, will only prevent 70% of cervical cancer, requiring an ongoing screening program for the foreseeable future.
- Unfortunately, there is no proven evidence based screening strategy for the other gynaecological cancers.
- There is considerable current international research activity into the efficacy of existing tests, such as the serum tumour marker CA125 and pelvic ultrasound, in the early detection of ovarian cancer. The results of this research will not be available until 2008 at the earliest.
- There is Australian research in progress (Sydney and Melbourne) into improved and innovative screening tests to aid in the early detection of ovarian cancer, the number one killer due to gynaecological cancer in Australian women. Funding for this research is limited and should be increased.
- If a suitable screening test/strategy is identified, there will be need for significant government funding to implement a National Ovarian Cancer Screening Program.

Treatment

- Multi-disciplinary care (MDC) for gynaecological cancer is available at the dedicated tertiary gynaecological cancer centres, which are present in all of the state and territory capital cities throughout Australia.
- MDC teams comprise specialist gynaecological, radiation and medical oncologists, pathologists, specialised nursing staff, psychologists, social workers, physiotherapists, pharmacists, palliative care services and general practitioners.
- These MDC teams are not available in rural and remote areas, denying rural patients local access to high quality care. Unfortunately, the tyranny of distance is compounded by small populations in rural towns and cities, which makes the establishment of ‘MDC facilities’ a difficult proposition economically. This is particularly relevant in Western Australia.
- Some aspects of ‘treatment’ can and should be improved in metropolitan areas (capital cities). There is a lack of access to allied health facilities, particularly physiotherapy, psychosocial and psychosexual support and palliative care services.

- Improved access to medical oncology and prescribed chemotherapy in the larger rural towns and centres should be encouraged.
- Increased understanding of the role of radiation therapy in gynaecological (and other) cancers requires education of the community and health professions.
- A local (WA) gynaecological cancer treatment and outcome data base is maintained at King Edward Memorial Hospital for Women. This hospital based gynaecological cancer registry is poorly supported both financially and in regard to data entry and analysis. It is unable to provide reliable outcome data, on which the performance of the hospital can be assessed. Currently in Australia, all major centres maintain their own database with no central coordination of results and outcomes.

Health support programs

- This should encompass access to supportive care, both physical, social, financial and psychological. This is woefully inadequate in rural and remote areas. It is often deficient in major population centres, particularly for privately insured patients. This is true for Western Australia, where private patients are limited in access to supportive facilities, most of which are located in a coordinated fashion in the public hospital system.
- Educational support regarding gynaecological (and other cancers) for patients & health professionals should and can be improved.
- Improved assistance with travel and accommodation for rural and remote patients, enabling easy access to major treatment centres is essential.

Recommendations (b):

- Maintenance of funding for the current NCSP with encouragement of Australian research into improved prevention of cervical cancer
- Increased funding for research into prevention and early detection of ovarian cancer, and the other gynaecological cancers.
- Funding should be specifically set aside for the implementation and support of a possible ovarian cancer screening program.
- Increased funding for adequate staffing of multi-disciplinary care teams and centres for gynaecological cancer treatment.

- Funding for improved health education programs for the community and health professionals, both rural and metropolitan.
- Increased funding to facilitate adequate staffing for allied health support services, both rural and metropolitan.
- Improved funding for the WA gynaecological cancer database and coordination of the many interstate hospital based databases with a centralized collation of data and national reporting capacity.
- All of the above could be facilitated and coordinated by the establishment of a National Gynaecological Cancer Centre.

(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**

- A recent report, “ Mapping rural and regional oncology services in Australia” was released in March 2006 and is available at www.cosa.org.au/publications. Deficiencies in cancer services outside of major cities have been highlighted and the need for government commitment to the rural and remote community has been reiterated.
- Nearly 500.000 people in WA live outside of the Perth metropolitan area, and need to travel to Perth for specialised gynaecological cancer treatment. A significant number live in very distant rural remote areas, and for these people, travel, accommodation and separation from established family and community support systems are a significant burden.
- Women who relocate to Perth for assessment and treatment would benefit from a highly coordinated and timely ‘diagnostic and investigatory process’, which may be difficult to organise at short notice, given the ongoing pressure on the public health system. As this involves attending other health campuses in Perth, a coordinating oncology nurse would be helpful to these women and their welfare.
- In Western Australia, there is an inequity of access to tertiary care in gynaecological cancer for women who live in rural and remote areas, including women of indigenous and other cultural backgrounds.
- The PATS (Patient Assisted Travel Scheme) is of help to women who have to travel for health care. The gatekeepers of this system are usually clerical officers in

regional hospitals, who appear to apply rigid bureaucracy to the process, which can be very difficult for women in distress. On occasions, granting of PATS appears to be idiosyncratic.

- Indigenous women are often distressed by the relocation to Perth for assessment and treatment, which in many cases requires prolonged stay away from their family and community. At King Edward Memorial Hospital for Women we do have an Aboriginal liaison worker who is of great help to these women.
- Women from non English speaking cultures require special consideration particularly in regard to easy access to female personnel and to translators.
- It is not feasible in WA to provide sub specialist gynaecological surgical services to rural towns and cities. The population of these towns and cities range from 5-60,000, and will not sustain a resident or visiting service. However, visiting services in medical oncology do exist in WA and could be improved with appropriate funding.
- It is not feasible to have radiation treatment facilities outside of Perth until the size of the rural cities has increased to a critical mass to support the infrastructure required for such a service. However, a visiting consultation service does exist in Bunbury, but could be extended to other centres if funding for staff were increased.

Recommendations (c):

- Increased funding to support improved travel and accommodation for women, especially those from rural and in WA, very remote, areas.
- Increased funding to support staff increases to assist Indigenous and other women who require assistance coping with relocation, separation or cultural differences. This would lead to an increase in Aboriginal liaison officers and appropriate translation facilities.
- Improved funding to support Telemedicine facilities which may allow doctors in rural and remote areas to access a sub specialist consultation without the burden of travel and family separation for the patient in question.
- Increased funding for personnel to provide visiting medical oncology and radiation oncology services to larger rural towns and cities.
- Increased funding to provide adequate ‘support services’ such as psychosocial, psychosexual etc to women in

rural and remote areas, possibly by the establishment of regular visiting services in these disciplines, if the population size will not support a resident person.

- Establishment of a Coordinating Gynaecologic Oncology Nurse Specialist position, based in Perth (and similarly for other major treatment centres throughout the country). This nurse could coordinate for both public and private patients.
- Establishment of a NGCC which could coordinate infrastructure support for all of these recommendations.

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

- At present varying educational materials and strategies are employed in the States and Territories of Australia. This is wasteful and leads to unnecessary duplication of effort and actual materials.
- There is a varying degree of knowledge about gynaecological cancers in the medical community.
- The late presentation of women with advanced ovarian cancer is often due to misdiagnosis by the local doctor, due to the vagueness of presenting symptoms in this condition.
- A recent initiative by the National Ovarian Cancer Program has been successful in developing materials which will inform and educate general medical practitioners about the early symptoms of ovarian cancer and the relevance of the serum CA125 test. This was a government funded initiative which demonstrates what can be achieved using a coordinated centralised approach to a specific problem.
- There is a lack of understanding regarding the role of inherited genetic abnormalities and the development of gynaecological cancer, particularly ovarian and endometrial cancers.
- The role of Familial Cancer clinics and of genetic testing is poorly understood.
- There is a lack of knowledge among general practitioners regarding the optimal treatment for gynaecological cancers. It has been demonstrated that the best outcomes for women with gynaecological cancer occurs when they are treated by certified gynaecologic oncologists (CGO) in a multi-disciplinary gynaecological cancer treatment centre.

- The National Ovarian Cancer Program has developed a website with appropriate information regarding sub specialist care for ovarian cancer.

Recommendations (d):

- The government should provide increased funding to develop educational materials regarding the risk factors, symptoms and signs of gynaecological cancer for general practitioners.
- The government should actively promote educational materials regarding the optimal referral and treatment pathways for women with gynaecological cancer.
- The government should increase funding to provide adequate staffing for Familial cancer services to enable genetic testing and counselling to occur in a timely fashion.
- The government should establish a NGCC to oversee and coordinate these activities.

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

- Symptoms of gynaecological cancer may be vague or easily confused with variations in normal function, and lead to significant delay in presentation to a medical practitioner for evaluation.
- Early presentation will usually lead to early diagnosis and the cancer will *usually* be at an earlier stage and more amenable to curative treatment.
- There is a paucity of knowledge in the general community regarding the risk factors, symptoms, signs and treatment of gynaecological cancers.
- Currently there are fragmented approaches to community education, often precipitated by media publicity regarding specific medical ‘breakthroughs’ or medico-legal disasters.

Recommendations (e):

- The government should increase funding to provide coordinated educational resources to the community at large, which should translate in reduced anxiety, earlier presentation to general practitioners and improved outcomes for the women who do have gynaecological cancer.

- Education regarding gynaecological cancers should be included in school health education programs.
- Establishment of a central website with appropriate educational resources which are culturally sensitive.
- The establishment of a NGCC would allow this body to coordinate these educational activities without duplication and improved efficiency.

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

- The Cancer Australia advisory council has no gynaecological oncologists among its members.
- Gynaecologic Oncologists have been represented on the Australian Screening Advisory Committee (ASAC) and other national committees, *all of which are no longer in existence.*
- There is a lack of representation of people with expertise in gynaecological cancer on national health agencies and the recently established Cancer Australia.

Recommendations (f):

- There should be representation of people with experience and expertise in gynaecological cancer on peak national bodies such as Cancer Australia (& it's advisory council).
- Such representation will ensure that women who suffer from gynaecological cancer will have a national voice and receive appropriate consideration.
- Appropriate representation could be drawn from the membership of the Australian Society of Gynaecologic Oncologists following recommendation from the Executive of that organisation.
- Further representation could be drawn from those gynaecologic oncologists who serve on the proposed National Gynaecological Cancer Centre.