SUBMISSION FOR SENATE INQUIRY

INTO

GYNAECOLOGIC CANCER SERVICES

FROM

SYDNEY GYNAECOLOGICAL ONCOLOGY GROUP,
SYDNEY SOUTH WEST AREA HEALTH SERVICE, NSW.

Summary

The Group believes that the priorities (in order) required to improve delivery of timely and effective care to women with gynaecological cancer are:-

1. Establishment of an independent National Gynaecological Cancer Centre (NGCC) to oversee care improvements and education.

2. Establish a national database within NGCC of gynaecological cancers occurring within Australia so that accurate data on these diseases become available to allow monitoring of management improvements.

3. Recognition and funding for psychosocial and psychosexual support in all centres. Continuing research into appropriate methods of dysfunction recognition and effective intervention is vital.

4. Education/information material and programmes for patients with disease; similar material available for patients' families and carers; similar information for the general public to increase awareness of all gynaecological cancers.

5. Improved education/information to primary health care providers to facilitate earlier diagnosis of gynaecological cancers. Continuing education for all health providers involved with gynaecological cancer patients

6. Improved health care delivery for women in remote areas, indigenous women and those from socially and culturally diverse backgrounds including appropriate interpreter services.

7. Increased staffing levels within recognized units, particularly clinical nurse consultants/cancer nurse co-ordinators and appropriate allied health specialists relevant to ongoing patient support during and following treatment.

8. Increased support and funding for research into screening and management for all gynaecological cancers in association with the Australia & New Zealand Gynaecological Oncology Group.

Preamble

Women with gynaecological cancers as a group represent a significant number of patients in Australia annually but there is disproportionately smaller funding and public recognition for these women compared to more “fashionable” diagnoses eg breast cancer.

From AIHW figures for 2001, in Australia 3,886 women developed gynaecological cancers in 2001 making them as a group the fourth most common cancer site behind skin, breast and colorectal cancer and ahead of melanoma and lung cancer. However the number of women dying from gynaecological cancers is disproportionately high compared to breast cancer which only had a comparative 22% mortality rate in 2001. Much of this effect is from ovarian carcinoma with a 66% death rate in the same period. (Cancer in Australia 2001)

In the original petition the low level of overall spending on female cancers was shown to be lower than that for male cancers and spending directed to gynaecological cancers is but a small proportion of this total despite the incidence.

In Australia, clinicians dealing with gynaecological cancers recognized more that 20 years ago that management outcomes can be improved with a multispecialty approach. The first Australian multidisciplinary Dept of Gynaecological Oncology was established at Royal Prince Alfred Hospital in 1979 under Prof. Malcolm Coppleson and this model has been emulated nationally and internationally. In 1984 the Australian Society for Gynaecological Oncology (ASGO) was established and it is the premier body in Australia for scientific review and training guidelines. In 1992 the Royal Australian & New Zealand College of Obstetricians and Gynaecologists (RANZCOG) implemented a formal training process for specialists in Gynaecological Oncology in consultation with ASGO and all subspecialists in Australia now are credentialled and fulfil continuing medical education within the degree of Certified Gynaecological Oncology (CGO). The CGO training process is now recognized as a premier training degree worldwide within this specialty. The Clinical Oncological Society of Australia (COSA) gynaecological oncology subgroup has been the multidisciplinary forum for scientific review and research and two years ago the Australia New Zealand Gynaecologic Oncology Group (ANZGOG) was formed from interested clinicians within this to co-ordinate and oversee Australian participation in multicentre international studies. ANZGOG has already been successful in doing so in a number of studies to date despite minimal funding.

The Priorities

1. Establishment of a National Gynaecological Cancer Centre.

Currently there is no recognizable body for patients or clinicians to approach for advice on gynaecological cancer. There is currently no co-ordinated development of resources which are now developed on an ad hoc basis within every State. Guidelines of management have been developed on a national level for ovarian cancer but all other guidelines are institutional or at State level. Specialists working in this field strongly feel that it is inappropriate for such a Centre to be overseen by any other disease grouping (eg breast cancer). The administration and funding for this Centre should be independent but could be colocated with a similar body. While familial disease represents only a small proportion of patients overall, they are a group, when identified, who may benefit from early intervention. As the numbers are small, national guidelines for recommendations and management may improve their survival but this must be in accordance with the latest international developments. A co-ordinated approach nationally could provide comprehensive, multidisciplinary management for individuals at high risk of breast and/or ovarian cancer, standardise screening protocols in line with national and international guidelines, improve access to breast and ovarian cancer prevention strategies, improve access to research protocols and investigate the role of new screening modalities in high-risk women.

2. Establishment of a national database of gynaecological cancer.

Currently most States have independent State Cancer Registries where basic data is collected and some survival statistics can be generated. There is some sharing of data between States to allow updating of survival given our mobile population. Pooling of data nationally is used for AIHW statistics but these results give minimal information and cannot be used for outcome management. There is some doubt about whether all patient data are captured by the current system. All Depts. Of Gynaecological Oncology in Australia have databases with varying levels of data and support. These have been largely self-funded or run by clinicians with no government funding until recently. It is now recognized that it is not possible to measure any improvements in outcome from any clinical measure without this data. To this end the NSW Cancer Institute has begun a process of improving data collected. The Greater Metropolitan Clinical Taskforce (GMCT) has Gynaecological Oncology as a recognized subgroup and it is the first clinical group to develop a subspecialty minimum data set in association with the Institute. This will allow State data to be accurately collected with relevant clinical details. GMCT special funding has allowed appointment of data managers to the four recognized oncology units within the State short term. This process should be instituted nationally with the NGCC as the appropriate body. Appropriate funding for long term data managers nationally needs to be instituted. Appropriate hardware and software would need to be assessed. The data set developed by the clinicians and the Cancer Institute promises effective review of outcomes and demonstrates that those working in this field can co-operate to produce a useful management tool. This should include a register of the rare gynaecological cancers where therapeutic options are often poorly represented in the literature.

3. Psychosocial/psychosexual support

There have now been many publications on the psychosocial and psychosexual dysfunction that arises after a diagnosis of cancer. Sexual dysfunction rates after treatment for gynaecological cancer range from 20% to 100% (Lutgendorf et al. 2000). 85% of women with cervix cancer report low or no sexual interest, with 55% reporting dyspareunia and 30% dissatisfied with their sex life (Jensen et al. 2003). 62% of women with ovarian cancer report dyspareunia with 47% reporting little or no desire and 57% reporting deterioration (Stewart et al. 2001; Carmack Taylor et al. 2004). In assessing quality of life in survivors of gynaecological cancers problems with sexuality had a significant negative impact on quality of life (Molassiotis et al. 2000). Despite its obvious importance sexuality within gynaecological cancer is under-recognised and professional knowledge and communication about this aspect of care is inadequate (Stead et al. 2001). Even a diagnosis of preinvasive disease is accompanied by a significant rate of psychological disturbance. Some smaller reviews have indicated significant rates of marital failure and psychological difficulties in children of patients during and after treatment. While these are well recognized problems with great morbidity to the patients and their families, very few centres are provided with any resources to allow them to help these patients. All units should have access to a clinical psychologist and psychosexual counsellor and have appropriate social support mechanisms in place. These need to be both within treatment centres and available to patients for on-going support after discharge. While some units are undertaking research to identify factors in patients with psychosocial and psychosexual dysfunction, this should be expanded nationally so that all patients are assessed and can be helped as necessary. Many patients are not receiving any support at all at the moment. A NGCC could co-ordinate resources and direct patients to appropriate care for this major neglected problem.

4. Education/information resources.

To date there is no national strategy to increase womens' awareness or knowledge of gynaecological cancers. Many individual units have produced their own patient information material representing great duplication of work around the country by involved clinicians. There is information available to patients on-line at some centres within Australia (www.gynaecancer.org.au) and at some overseas cancer centres. Centring such resources within the NGCC would provide efficient production of up to date material and be a well publicised site for both patients and the general public to approach for information as they need it. While some printed resources would need to be available, increasing use of electronic media would allow on-line access to these materials at the patients' convenience. A NGCC would be the appropriate place for production and dissemination of these resources removing the current duplication. Our failure to distribute the message is demonstrated by the screening programme where it is estimated that only 60% of women in NSW avail themselves of cytological screening despite the most intensive advertising campaign of any gynaecological disease.

5. Improved education for primary health care providers.

While all medical practitioners are aware of gynaecological cancers, many of these tumours present with nondescript symptoms and there is an element of delayed diagnosis in a proportion of cases. Educational meetings to update clinicians about advances in patient care have proved extremely successful at a unit and State level. GMCT provides funding for the units to hold an annual education meeting. That held by SGOG annually attracts over 100 delegates at no charge and covers varying aspects of care from diagnosis to palliation. The GMCT recently held a successful forum on palliative care with emphasis on care and support in regional areas which was very well supported and is likely to be a continuing event. A NGCC would be an appropriate site to publicise these meetings to increase knowledge in health care providers. Disseminating data about improved survival rates when patients are treated primarily in gynaecological oncology centres should be a prime concern as a significant percentage are still currently treated outside these centres. There is now such extensive data from within Australia and overseas about survival advantage and appropriate primary treatment that this is a high priority issue. A NGCC would be the main co-ordinator of educational resources and activities around the country.

6. Women in remote areas, indigenous women and those from socially and culturally diverse backgrounds.

It has long been recognized that women in remote areas and our indigenous communities have significantly worse outcomes because of poorer diagnosis and later presentations. The difficulties that they face with removal from their surroundings to have treatment that may entail an absence of months further worsens their plight. This is well demonstrated by the high incidence of cervical cancer in the Northern Territory compared to all other States. This has been addressed to some extent by the Australian Society for Colposcopy and Cervical Pathology who have supported an outreach service in the Northern Territory. A similar service is running in northern Western Australia as well. It is essential that we cater for the particular needs of the diverse cultural groups in Australia and this problem needs to be addressed and remedied to increase the rate of screening, education and access to optimal services. Addressing the needs of women in regional/remote areas needs to be improved, particularly those having palliative care. These women often have complex multisystem disease and require specialist management to control their symptoms and optimise their quality of life. Ensuring they have appropriate and timely access for symptom control locally is essential and their health care providers need to have ready access to metropolitan services for advice and transfer as required. A NGCC would be the appropriate venue to co-ordinate such efforts.

7. Staffing levels

In the last 5 years many of the major services have improved the quality of patient care with the appointment of clinical nurse consultants/cancer nurse co-ordinators who play a vital role in ensuring the patients' smooth passage through multidisciplinary care and can identify potential/possible problems that patients may encounter medically and socially during management. These team members have become an essential part of the service and need to be increased in number given the rising patient load. All services should have at least two such co-ordinators in every institution. In addition all services should have an appropriate number of clinical nurse specialists working in the surgical areas. Research reveals that by focussing on broader aspects of the health care experience specialist nursing improves quality of cancer care (Ambler et al. 1999; Campbell et al. 2000; Faithful et al. 2001; Corner et al. 2002). Women with gynaecological cancer who receive support from a specialist nurse experience reduced psychosexual dysfunction and a clinically significant reduction in their level of psychological distress (Maughan & Clarke 2001; Booth et al. 2005). Training opportunities should be ensured for interested staff. All major centres should have access to facilities such as lymphoedema care and occupational assessment for ongoing patient support. In conjunction with the RANZCOG and ASGO, appropriate numbers of Fellows need to be appointed to ensure continuing staffing levels to cover retirement in future years.

8. Research

Australian medical research has an enviable reputation worldwide despite proportionately small funding, much of which comes from the private sector. Increased funding, possible as directed funding through NHMRC, should be addressed. Direct support to ANZGOG to participate in international management trials will increase the rate of improvement in patient outcomes.

References available on request

Feasibility

While the priorities above constitute a significant workload and commitment, the clinicians from all disciplines dealing with gynaecological cancers are highly motivated and supportive. NSW Health has provided them with an opportunity to undertake a number of these priorities per GMCT. This body has achieved State management guideline for all gynaecological cancers, the first subspecialty cancer dataset for the Cancer Institute, educational seminars for health providers and an on-line patient information/support resource and psychosocial support project (www.gynaecancersupport.org.au). This energy is reflected nationally and all of the above priorities are achievable given appropriate funding and support.

Inequity of Funding

There is current major inequity between funding for male and female cancers and within female cancers, funding for gynaecological cancers is further disadvantaged as it has not been considered "fashionable" to support despite being the fourth most common female cancer group. Review of funding and arguments for funding improvement have been presented in "Response to petition on gynaecological health issues" Heffernan 10/2/06. This group believes that funding needs to be urgently reviewed and adjusted to take into account the prevalence and high morbidity, both physical and psychological, of these diseases.

Representation

Gynaecological cancers have had little recognition as reflected in many of the overseeing bodies. In particular there is no appropriate clinician appointed to Cancer Australia despite the prevalence of these diseases. Clinicians involved with these diseases feel that representatives for other disease groupings do not adequately consider the importance of gynaecological cancers.

Sydney Gynaecological Oncology Group

Surgical Oncology	Prof Jonathan Carter (RPA)
	Prof Roger Houghton (RPA/Liverpool)
	Dr Ken Atkinson (RPA)
	Dr Felix Chan (Liverpool)
	Dr Chris Dalrymple (RPA)
	Dr Selvan Pather (RPA)
Medical Oncology	Dr Diana Adams (Liverpool)
	Dr Philip Beale (RPA)
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	Dr Amanda Goldrick (Liverpool)
	Dr Anne Hamilton (RPA)
Radiation Oncology	Prof Chris Milross (RPA)
	Dr Allan Fowler (Liverpool)
	Dr Michael Jackson (RPA)
	Dr Shalini Vinod (Liverpool)
Palliative Medicine	Dr Katherine Clark (RPA)
Genetics	Dr Lesley Andrews (RPA)
Histopathology	Prof Peter Russell (RPA)
Clinical Nurse Consultants	Sr Rosemary Craft (Liverpool)
	Sr Kathryn Nattress (RPA)
Patient Advocates	Ms Mercia Bush
	Ms Jennifer Herrera
Data Manager	Dr Stephen Cotterell (RPA)

Sydney Gynaecological Oncology Group

The following is a summary of achievements of the SGOG to illustrate what a dedicated co-operative clinician grouping can achieve:

Establishment of first Australian multidisciplinary gynaecological oncology department including multidisciplinary outpatient clinics 1979
Establishment of departmental database for all gynaecological malignancies (from 1979) 1987
Guidelines for the Management of Gynaecological Malignancies 1988
Appointment of Professor of Gynaecological Oncology, Sydney University 1992
Guidelines for the Management of Gynaecological Malignancies 1997
Formation of SGOG from Departments at Liverpool and RPA 2001
Appointment of Clinical Nurse Consultant 2002 (Sydney Cancer Foundation funded)
Patient Information Resource (covering all gynaecological cancers) 2003 (printed and subsequently on-line) (Sydney Cancer Foundation funded) [www.gynaecancer.org.au]
Establishment of multidisciplinary Familial Cancer Clinic (Genetics, Gynaecological Oncology, Breast Oncology, Medical Oncology) 2003
Establishment of SGOG website 2003 [www.gynaecancer.org.au]
Clinical Practice and Management Guidelines 2003 (printed and on-line) (Sydney Cancer Foundation funded)
Appointment of part-time data manager 2004 (GMCT funded)
1st Annual Gynaecological Oncology Advances Seminar 2004 (GMCT funded)
Appointment of Psychosexual Research Psychologist 2005 (Sydney Cancer Foundation funded)
Establishment of SGOG Research Group co-ordinating involvement of in-house and national/international studies 2005

Members of SGOG

- have produced over 200 original research papers, chapters and text books
- have and continue to undertake research including acting as Principal Investigators for international studies
- are actively involved in ANZGOG
- participated in the production of NSW Guidelines for the Management of Gynaecological Malignancies 2004 (GMCT funded)
- participating in the establishment of NSW Gynaecological Oncology dataset for uniform State data collection for gynaecological malignancies (GMCT/Cancer Institute funded)
- have and/or continue to serve on executive boards of GMCT, COSA, ASGO, ASCCP, ANZGOG, NSW Pap Test Register
- are actively involved in teaching/lecturing at state, national and international level.
- are a recognized RANZCOG CGO training unit for advanced oncology trainees (2 positions)
- attend weekly Tumour Board meetings to review the management plan and progress of all patients currently having treatment and monthly Morbidity Review meetings to maintain standards and patient care