SUBMISSION
TO

SENATE COMMUNITY AFFAIRS

REFERENCE COMMITTEE

From
Gynaecological Cancer Society

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(General Submission)

Whilst the vast knowledge and direct experience of our members into all aspects of gynaecological cancer provides the Society with insight into the six (6) aspects being considered by this Committee, we believe that we are best qualified to address two (2) items in the terms of reference; item (b) and item (e). We have chosen these items as they pertain directly to the Society's considerable knowledge and experience derived from our day to day activities over the last eight years.

We have taken the liberty of commenting on items (a), (c), (d) and (f) from our patient oriented perspective, although we understand that you will receive detailed submissions from those more closely associated with these areas. For convenience we will comment on these items first.

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

It is an anomaly that Australia, unlike the rest of the world, chooses to consider breast cancer as a separate disease and medical discipline to gynaecological cancer.

The 'upside' of this division is that both disciplines (gynaecological cancer and breast cancer) have developed specialist clinical skills and practises that are second to none in the world. Indeed, many of the worlds leading specialists in both fields are Australian or Australian trained clinicians.

The 'downside' of the division is that the large sums of research funding invested into breast cancer are not mirrored in gynaecological cancer. It is unfortunate that breast cancer funding is often passed off as gynaecological cancer funding – this is incorrect and misleading.

There is demonstrably no doubt that Australia possesses the research talent required to make significant, life-saving advances in gynaecological cancer. The will and drive is there; it just takes better funding.

We understand that this investment will take millions of dollars; however offsetting this is the significant downstream savings to be made by not having to fund long-term cancer treatment regimens.

Although it is not common practise in any form of research, we would like to see mandated closer dialog and collaboration between gynaecological cancer researchers to avoid costly duplication. Due to the competitive and commercial nature of modern research this can only be achieved effectively through a ‘condition clause’ in government funding.

(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

Given that, in particular cases, we can always do better, in general we believe that the capability exists to treat all gynaecological cancer patients no matter where they live.

The effective treatment of gynaecological cancer, in the vast majority of cases, involves not only a highly specialised regimen involving surgery, radiotherapy, chemotherapy, but also physiotherapy and emotional/psychological support.

The current practise of transporting patients to and from specialist treatment centres is the only practical approach given our geographically diverse rural and remote communities; this applies particularly when considering indigenous communities.

Our experience suggests that the effective treatment of indigenous patients has more to do with breaking down traditional ‘taboos’ at a tribal level that the capability and capacity of the medical system.

Pap smear screening for cervical cancer would serve as an example. In many indigenous communities husbands dissuade their wives and daughters from any form of sexual examination. Women who do present for examination risk potential punishment and ostracism. It is little wonder that those women subsequently diagnosed with cancer or pre-cancerous conditions often do not present for treatment.

The very real need is to break down the traditional ‘taboos’ first. This applies to many more cultures than just the indigenous community. If patients present for treatment the system has the capability and capacity to assist.

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

The gynaecological cancer journey for most patients will begin at their general practitioner (GP). If the diagnosis is unclear the patient is referred to a gynaecologist and subsequently, in many cases, referred on to a gynaecological oncologist.

Whilst it is true that, in some cases, the definite cancer diagnosis can only be made during surgery, patients are generally well served by their gynaecologists and gynaecological oncologists.

The weakest link in the chain, by necessity, is the general practitioner. Gynaecologists and, in particular gynaecological oncologists, see cancer patients on a regular basis. They are cancer specialists familiar with the disease; the way it presents in its many forms and its differing stages. Even so, some may only see the rarer cancers once or twice a year making diagnosis for even these specialists difficult.

Remembering that many gynaecological cancers present with symptoms that could represent a multitude of other illnesses and diseases, it is little wonder that many busy GP's who individually see very little instantly recognisable gynaecological cancer opt for more obvious diagnoses.

There are GP's who misdiagnose due to work pressure, laziness or incompetence and where identified these doctors should be sanctioned and retrained. We believe, however, that in most cases of misdiagnosis it is simply that gynaecological cancer is not 'front of mind'. The Society addresses this issue later in our submission.

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

The Society has difficulty commenting on Cancer Australia as we have absolutely no first-hand knowledge regarding the organisation, its intended function or its membership. Certainly the Society has never been approached to participate nor offered any information regarding the activities of Cancer Australia.

As a matter of principle the Society strongly endorses a policy of inclusiveness for any organisation that purports to represent the interests of cancer stakeholders in Australia.

We can only hope that other organisations representing a patient's perspective are included in a meaningful way. Certainly, with regard to gynaecological cancer, we would have thought that our experience in this area and particularly our patient orientation may have been of some value.

Having said this, the Society recognises the valuable work that has been done by the National Breast Cancer Centre. It seems axiomatic that the establishment of a National Gynaecological Cancer Centre (NGCC) should be a major priority.

The establishment of the NGCC can only benefit all gynaecological cancer stakeholders. It is important to note that all the necessary elements for an effective and efficient NGCC already exist within State based organisations. Incorporating the best elements of each under the umbrella of the NGCC would quickly, cheaply and efficiently address the problem areas represented by communication, duplication and statistical gathering and analysis.

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From

Gynaecological Cancer Society

(Detailed Submission)

We propose to deal with the two remaining items in more detail and offer action and implementation plans including proposed 5 year operational budgets.

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

Screening Programs

Australia currently has only one screening programme applicable to gynaecological cancer; the Pap smear for cervical cancer. In general this program is well funded and supported and has proved effective and efficient in reducing the number and severity of cervical cancer in Australia.

There are, however, some worrying trends that require attention for the program to continue to deliver its desired results.

Trend One –Dropping Participation Rate

The participation rate in cervical cancer screening has been dropping for some years from a high of 67% to the current rate of 57%. The main factors responsible appear to be the following:

- Familiarity – a series of negative results promotes apathy
- Fear – of a positive result
- Lack of knowledge – migrant or non-English speaking background
- Availability – few mobile services

With the exception of ‘Availability’, a reenergised information campaign as an element of a general public awareness campaign discussed later in this submission should produce the desired reversal in this trend.

Furthermore, the importance of preventative health issues such as screening and vaccination should be a mandatory part of any school’s (both primary and secondary) curriculum.

Adequate education cannot start too early and experience from Scandinavian countries shows that when these principles are taught at school it translates into higher screening rates in later life.

Trend Two – Cultural Factors

As discussed previously, there are traditional ‘taboos’ within many cultural groups with regard to any form of sexual examination. Often these groups are amongst our most isolated, both culturally and geographically.

It is difficult to see how any real change in attitude or behaviour in these groups can be achieved unless and until we address the cultural problem with an effective cultural solution.

It is likely that these groups will represent an ever increasing proportion of our population and therefore to ensure their participation in screening programs we need to determine what is culturally acceptable to each group and develop and implement an educational plan based upon that information.

Treatment Services

Although gynaecological cancer treatment services nationally are adequate there are some geographical anomalies in service delivery that cause significant and unacceptable delays in treatment.

The greatest delays occur in the public sector due to the disproportionate spread of specialist gynaecological oncologists between the states and territories. Against a national waiting list average of two (2) weeks for surgical treatment Queensland performs worst with usual waiting lists of up to six (6) weeks.

As it is difficult to tell doctors where to practise, and considering that service provision is a State issue, there may not be a lot that this inquiry can accomplish in this area.

Health Support Programs

Emotional support for gynaecological cancer patients is the most neglected area in the treatment regimen. The nation’s major public treatment centres usually employ social workers; however they are usually understaffed and consequently overworked. Public patients can expect only one visit from a social worker during their management and often only upon specific request.

In the private sector the situation is even worse. Many private treatment centres do not employ social workers and these patients, who account for approximately 50% of all gynaecological cancer patients, are left to fend for themselves. Whist private social workers do exist they are very few in number and extremely expensive to consult.

To address the issue of a lack of emotional support the society established its Emotional Support Programme with Queensland wide and quasi-national coverage six (6) years ago.

The emotional Support Programme consists of two elements:

- A 24 hour/7 day emotional support free-call help-line
  (Since its inception this help-line has processed over 5,000 calls)
- A supporting partner assistance kit
  (Since its inception over 2,500 kits have been distributed)

We propose a federally funded National rollout of this programme. Attachment One looks at the Emotional Support Programme in detail and includes a proposed rollout budget.

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

Most medical practitioners will agree that an informed patient is a more receptive and retentive patient. Once cancer is suspected the diagnosis and treatment can proceed at a pace that can be both confusing and frightening to many patients.

In a perfect word specialist practitioners would have the time to discuss and ensure understanding of each detail of the treatment process. As this is not a perfect world, patients are most often left with unanswered questions that can lead to irrational fears. This situation, if left unchecked, can interfere with good treatment outcomes.

To address the issue of improving knowledge of gynaecological cancer in general and individual cancers and related issues in the specific, the society established its Information & Education Programme with Queensland wide and quasi-national coverage seven (7) years ago.

The Information & Education Programme consists of three elements:

- A gynaecological specific web site – www.gcsau.org
  (Believed to be the world's largest at 40,000 pages of information and receiving over 49,000 hits per month)
- Subject specific printed literature and CD-Roms
  (We currently produce in-house 13 booklet titles, 20 leaflet titles and 3 CD-ROMs)
- Computer based information and education kiosks
  (A computer driven centre containing all web site information for patient, family and staff use)

We propose a federally funded National rollout of this Programme. Attachment Two looks at the Information & Education Programme in detail and includes a proposed rollout budget.

Following the rollout of the Information & Education Programme material we propose a national public awareness campaign focusing, in a non-alarmist manner, on symptom identification promoting better gynaecological health. A supplemental budget is attached (attachment 3).

Summary

The Gynaecological Cancer Society proposes a fully costed, federally funded campaign, in three parts, to nationally address the joint issues of general information and education on gynaecological cancer and emotional support for patients and families.

The Information & Education Programme is tried, tested and proven and is ready for immediate rollout.

Similarly, the Emotional Support Programme is tried, tested and proven and is also ready for immediate rollout

The national media campaign to follow these rollouts will complete the circle. The Society has available a 30 second television commercial promoting the free-call help-line.

Establishing the NGCC using the best existing elements of State based organisations will be effective, efficient, quick and inexpensive. For the benefit of all gynaecological cancer stakeholders the Society would support establishing a working party to make this happen.