

Mr Elton Humphery
The Secretary
Senate Community Affairs References Committee
Parliament House
CANBERRA ACT 2600

Dear Mr Humphery

Thank you for the opportunity to comment on the issues being considered by the Senate Community Affairs References Committee within the Inquiry into Gynaecological Cancer in Australia. My response to the Terms of Reference for the Inquiry are as follows:

**1. LEVEL OF COMMONWEALTH AND OTHER FUNDING FOR RESEARCH ADDRESSING
GYNAECOLOGICAL CANCERS**

Research plays a vital role in cancer control, from prevention through to end-of-life care. Research is critical to improving the quality of services and must be a core element of all health services.

The increasing numbers of people with cancer, the broad range of cancer types and increasing treatment options drive the ongoing quest for research funding. Clinical trials are a major component of cancer care, particularly in driving improvements in treatment protocols and, ultimately, better health outcomes for those affected by cancer. There is a need for improved coordination of clinical trials across Australia, in particular to support access to clinical research trials for people from rural and remote areas and those being treated outside of the public health system who are often marginalised in relation to participation in trials.

The current level of competition for research dollars by the various cancer research centres splits the available research funding. The need for a more collaborative approach to researching cancer control exists in relation to gynaecological cancers as with other cancers.

The amount of research being undertaken in South Australia is unknown at present. The South Australian Statewide Cancer Control Plan adopted in 2006 recommended a review of cancer research currently being undertaken in South Australia, to establish the range of research and identify gaps, areas of overlap and areas of strength, and monitor cancer research to assist in planning and co-ordination of research.

The valuable role of community initiated and driven research funding should be acknowledged, but not considered as an alternative to Commonwealth and/or State funding of research opportunities.

2. EXTENT, ADEQUACY AND FUNDING FOR SCREENING PROGRAMS, TREATMENT SERVICES, AND FOR WIDER HEALTH SUPPORT PROGRAMS FOR WOMEN WITH GYNAECOLOGICAL CANCER

The Statewide Cancer Control Plan recommends coordination of gynaecological cancer services, which treat a range of cancers detected in the female reproductive system, would be best managed on a statewide basis, with greater outcomes and benefits to women in the local community. The Plan recommends strengthened data collection monitoring and evaluation to promote development of evidence-based strategies to reduce risk.

At present, there is a focus in South Australia on improving the coordination of services across the continuum of health care, including gynaecological services. The Women's and Children's Hospital in Adelaide provides women with a colposcopy clinic. This is a diagnostic service only and women are referred to the adult acute hospital system for further treatment as necessary. Work currently being undertaken on 'patient journey' is designed to improve services to these women.

On a National level, there is also a need to consider clear clinical protocols, in a similar way to paediatric cancer, so that there is an ability to be confident about outcomes achieved.

Figures on maintenance of funding per capita (women only) in real terms in line with population changes and inflation are not available.

There is a perception amongst some women that the physical process used in undertaking pap smears, vaginal examinations and vaginal ultrasounds are invasive and intrusive. We are concerned that these perceptions can act as a deterrent for women to undergo screening, and are working to address these issues and increase the rate of screening amongst South Australian women

Screening

Comprehensive screening programs for gynaecological cancers are limited to cervical cancer. The lack of an effective screening tool to detect ovarian cancers is a significant barrier to a comprehensive screening program for all gynaecological cancers.

Improved screening programs have made a significant impact on death rates for some forms of cancer, in particular cervical screening programs.

The National Cervical Screening Program (NCSP), a joint Australian, State and Territory Government initiative, is a highly effective program. The incidence rate of cervical cancer amongst women 20-69 years has fallen from 17.1 per 100,000 women in 1991 to 9.5 in 2001. Mortality from cervical cancer has declined from 3.8 per 100,000 in 1993 to 2.2 in 2003. International Agency for Research on Cancer data demonstrates that Australia now has the lowest rate of cervical cancer mortality in the world.

Strengths of the program include jurisdictional collaboration, a focus on clear and tangible goals, a systematic approach to all aspects of the program and strong relationships with clinicians and other stakeholders.

However, despite the program's success to date, there is a need to remain vigilant to ensure the future continued success of the program. Some issues are:

- State and Territory cervical cytology registers were established more than a decade ago, thus, in many jurisdictions registers are using obsolete technology. The source of funding to address the capital and recurrent costs of replacing registers has not been addressed.
- The coordination of the NCSP is in a state of flux. In the last two years the National Advisory Committee to the NCSP was replaced by the Australian Screening Advisory Committee (ASAC). It is also proposed that two new principal committees - NPHDC (National Population Health Development Committee) and the NHPC (National Health Protection Committee) will take over the program advisory role. The role of ASAC will be separated into two committees - a screening committee reporting to NPHDC, made up of jurisdictional reps, and a separate technical (expert) advisory committee. It is important that these committee structures efficiently support the NCSP by:
 - clear, effective two way communication mechanisms between the State/Territory cervical screening programs and these committees;
 - mechanisms to ensure issues are fully discussed with stakeholders before decisions are made by these committees; and
 - adequate resources for the secretariat for these committees.The ASAC lacked adequate resources and did not have appropriate communication mechanisms for consumers or State/Territory committees
- Implementation of the new NHMRC (National Health and Medical Research Council) Guidelines *Screening to Prevent Cervical Cancer: Guidelines for the Management of Asymptomatic Women with Screen Detected Abnormalities* requires the NCSP to incorporate into all aspects of the Program the current knowledge about the relationship between cervical cancer and Human Papilloma Virus (HPV), which is essentially a sexually transmitted infection. This incorporates changes to information systems by both State/Territory cervical cytology registers and laboratories, and entails extensive education of both health professionals and the general public. It is anticipated that the public education campaign and evaluation measures required by the NCSP will be resource intensive.

3. CAPABILITY OF EXISTING HEALTH AND MEDICAL SERVICES TO MEET THE NEEDS OF INDIGENOUS POPULATIONS AND OTHER CULTURAL BACKGROUNDS; AND THOSE LIVING IN REMOTE REGIONS

The limited data available on the extent to which Aboriginal women access gynaecological services makes it difficult to determine whether all needs are being met.

In 2003 Aboriginal medical services (Nunukuwaarin Yunti) launched Aboriginal and Torres Strait Islander Primary Health Care Initiatives. Preventative health care was a high priority of that program.

Within this program, the No Pulgi program provides an outreach program for homeless Aboriginal and non Aboriginal people which includes providing PAP smears. A Women's and Children's Health worker attached to the program also supports the gynaecological needs of women using the service and ensures that women are referred for ongoing care to Nunkawaarin Yunti and other health care services.

NACCHO (National Aboriginal Community Controlled Health Organisations) is the national peak Aboriginal health body representing Aboriginal Community Controlled Health Services throughout Australia. Both NACCHO and State Aboriginal Health Council of SA Inc (AHCSA) have employment strategies - AHCSA run certificate training programs for Aboriginal Health workers. South Australian experience demonstrates that Aboriginal people are more likely to seek health care from Aboriginal Health Care Workers.

The data quality issues relating to identifying race/ethnicity are well recognised. An optimal mechanism for identifying women's ethnicity (preferably by persons self-identifying) is required, as well as a mechanism for linking ethnicity data to other cancer registry data. For example, the rate of participation in the NCSP by Aboriginal women is unknown as no information regarding ethnicity is collected by cervical cytology registers. The need for this information has been expressed by many service providers working with both Aboriginal women, women from culturally and linguistic diverse communities and bodies such as ASAC.

Of those women identified as Aboriginal, Australian Cancer Registry data demonstrates a rate of cervical cancer which is approximately six times that of other women. Cancer registry data has also identified the incidence of cervical cancer in women born in some overseas countries as being higher than that in Australian born women. This indicates that more needs to be done in relation to improving management of cancers in both populations.

South Australia's Statewide cervical screening program incorporates a specific *Well Women's Program* for Aboriginal women and a specific program for women from culturally and linguistically diverse communities. The effectiveness of these programs is directly related to their culturally appropriate operation and engaging the relevant communities.

Workforce development strategies need to target increasing employment opportunities for both Aboriginal and Torres Strait Islander and culturally and linguistic diverse people in both Government and community controlled health services, across the spectrum of agencies that deliver cancer control programs. It is well known that Aboriginal people prefer working with their own people to address health issues that affect local communities.

It is important to enable community inclusion and participation in the development of programs and resources for Aboriginal and Torres Strait Islander and culturally and linguistic diverse women. It is recognised that within some communities, women's gynaecological issues are not discussed openly, providing additional challenges for public awareness campaigns to reach these groups.

Services such as the *Aboriginal Well Women's Program* have used this model of community participation very successfully to achieve effective health care programs over the last eight years.

4. EXTENT TO WHICH THE MEDICAL COMMUNITY NEEDS TO BE EDUCATED ON THE RISK FACTORS, SYMPTOMS AND TREATMENT OF GYNAECOLOGICAL CANCERS;

Improving access to information for primary health care providers about risk factors, symptoms and treatment options was identified as a priority during the development of the South Australian Statewide Cancer Control Plan. The plan also includes development and implementation of a strategy to incorporate multidisciplinary care as an essential component of cancer services. It recommends the principles of multidisciplinary care be incorporated in the undergraduate and postgraduate training of all disciplines. It also notes the Medicare Benefits Schedule may require change to facilitate multidisciplinary care delivery in the private sector.

It is recognised that health care practitioners need training in issues pertaining to culture on women's interactions with the health care system, particularly in relation to gynaecological procedures. SA was a key contributor to the development of the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009. This framework is being promoted throughout SA and has been taken up by the various health units.

More flexible use of the clinical workforce, particularly in screening and case management could benefit both rural and indigenous populations and reduce impact of shortage of medical practitioners.

5. EXTENT TO WHICH WOMEN AND THE BROADER COMMUNITY REQUIRE EDUCATION OF THE RISK FACTORS, SYMPTOMS AND TREATMENT OF GYNAECOLOGICAL CANCERS.

There is an ongoing need to focus on health promoting programs addressing risk factors associated with gynaecological cancers.

International studies show women have low levels of existing knowledge about the relationship between Human Papilloma Virus and cervical cancer. It is anticipated that this is likely to also be the case in Australia. Given this evidence, South Australia recognises the vital role that community education must play in addressing gynaecological cancer in Australia. South Australia notes the benefits of ensuring educational materials are translated into community languages, and to provide a range of non-written educational messages, including community outreach, public talks and radio announcements.

National health promotion strategies, such as the one coordinated by the National Cervical Screening Program to educate the general public relating to the July 2006 implementation of the new NHMRC Guidelines "Screening to Prevent Cervical Cancer: Guidelines for the Management of Asymptomatic Women with Screen Detected Abnormalities", are supported.

6. EXTENT TO WHICH EXPERIENCE AND EXPERTISE IN GYNAECOLOGICAL CANCER IS APPROPRIATELY REPRESENTED ON NATIONAL HEALTH AGENCIES, ESPECIALLY THE RECENTLY ESTABLISHED CANCER AUSTRALIA.

I am unable to comment at this point, given the limited time that Cancer Australia has been in existence.

I trust that this information is of help to the References Committee.

Yours sincerely

JOHN HILL

Date: