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The Secretary
Senate Community Affairs References Committee
Parliament House
Canberra ACT 2600

Dear Sir,

Please find enclosed our submission to the Senate References Committee inquiry into gynaecological cancer in Australia.

Yours sincerely,

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SUBMISSION TO THE SENATE INQUIRY INTO GYNAECOLOGICAL CANCER IN AUSTRALIA

There are no national statistics on cancer incidence, diagnosis, treatment, mortality or survival for Indigenous Australians. The most comprehensive and reliable information available is for Indigenous people in the Northern Territory (NT), from the statistics reported by the NT Cancer Registry (NTCR) and the research undertaken by the Menzies School of Health Research.

This submission therefore focuses on the impact of cancer on NT Indigenous people. The limited information available from elsewhere in Australia suggests that the cancer control issues that are most important for Indigenous people in the NT – high incidence of some cancers, low screening participation, late diagnosis, deficiencies in cancer treatment and low survival – are equally applicable throughout Australia.

Incidence, mortality and survival.

Cancers of the cervix and vulva occur more frequently in NT Indigenous women than in Australian women generally (1). Compared to the total Australian rate, the incidence rate for NT Indigenous women in 1991-2001 was higher for cancer of the cervix (35 c/w 9 per 100,000) and vulva cancer (13 compared with 2 per 100,000), but similar for cancer of the uterus (14 c/w 15 per 100,000) and lower for cancer of the ovary (6 c/w 13 per 100,000).¹

Mortality rates are much higher for Indigenous women than would be expected from these incidence rates because Indigenous women have very low survival rates from these cancers. For example, compared to total Australian women, cervical cancer incidence is four times higher for NT Indigenous women but mortality is nine times higher (28 c/w 3 per 100,000) because their five-year survival rate is much lower; NT Indigenous women with cervical cancer are three times more likely to die from their cancer than other Australian women (2).

Cervical cytology screening

Following the introduction of the NT Pap Test Register in 1994, the Women's Cancer Prevention Program in 1996 and the Gynaecology Outreach Service in 1997, there was a large improvement in participation in cervical screening rates for Indigenous women in remote areas of the NT that commenced in the late 1990s and has been sustained since then. The Gynaecology Outreach Service has also achieved and maintained a very high level of follow-up of Indigenous women with high-grade abnormal Pap smears since its inception; over 80% of Indigenous women from remote communities have been treated within six months. Unfortunately, these improvements have been largely confined to the Top End of the NT; similar improvements have not yet occurred in Central Australia (3).

However, these improvements in screening and treatment services have coincided with (and probably been responsible for) a large reduction in cervical cancer incidence and mortality for NT Indigenous women. In the late 1990s their cervical cancer mortality rate declined by 50% compared to the very high levels of the previous two decades (4), and their cervical cancer incidence rate also decline by 25% between 1991 and 2001 (2) and has declined further since then (NTCR unpublished).

Cancer diagnosis and treatment

Research into the effectiveness of cancer care in the NT has focused on diagnosis and treatment for all cancer patients rather than gynaecological cancers in particular, but the main findings (late diagnosis and deficiencies in cancer treatment for Indigenous patients) probably apply equally to gynaecological as to other cancers. An investigation of cancer treatment for Indigenous compared to non-Indigenous patients with five cancers (lung, bowel, breast, cervix and non-Hodgkin lymphoma) found that Indigenous people were more likely to be diagnosed late, with

¹ The NT incidence rate for cancer of the vulva is unpublished data from the NT Cancer Registry.

more advanced disease, and that they were less likely to receive appropriate medical treatment for their cancer once it has been diagnosed (5;6).

These deficiencies in cancer treatment were restricted to Indigenous people who spoke an Indigenous language as their first language, while late diagnosis affected all Indigenous people with cancer (5;6). For Indigenous people who spoke English as their first language, cancer survival rates were lower than for non-Indigenous patients because they had more advanced disease by the time they were diagnosed but, once diagnosed, cancer treatment services appeared to be as effective for them as for non-Indigenous patients. However, cancer survival was much worse for Indigenous first-language speakers because, as well as being diagnosed with more advanced disease, they were less likely to be offered curative treatment, less likely to choose curative treatment if it was offered, less likely to complete curative treatment if they chose it, and less likely to travel interstate for radiotherapy and other specialised treatment if it was recommended.

Human Papillomavirus (HPV), gynaecological cancers and Indigenous women

There is a high incidence of several ano-genital cancers in NT Indigenous people, including cancer of the cervix, vulva, penis and anus. HPV infection is implicated in the majority of cases of cervical cancer, and vulvar cancer occurring in younger women; HPV infection has also been associated with other ano-genital cancers including cancer of the vagina and anus, and for men, cancer of the penis. Indeed, over sixty percent of the NT Indigenous women diagnosed with vulvar cancer or high-grade VIN between 1996 and 2005 were also diagnosed with invasive disease or intraepithelial neoplasia of the cervix, vagina or anus. The high burden of HPV-related ano-genital cancer seen in these communities highlights the need for adequate primary prevention, including an investigation of the potential effectiveness of an HPV vaccine in these communities.

Cancer control

For cervical cancer, priorities for cancer control in Indigenous women include continuing to improve cervical cytology screening participation rates, maintaining the very timely treatment of women with high-grade abnormal smears, and improving cancer treatment services, particularly for Indigenous first-language speakers. Improved prevention, early detection and effective follow-up has already had a major impact on cervical cancer incidence and mortality; continuing improvement in these areas, and improvements in cancer treatment, can further reduce the gap between Indigenous and other Australian women. These priorities are relevant to Indigenous women throughout Australia.

The imminent introduction of the HPV vaccine is of major importance for all Australian women, but even more so for Indigenous women. Cervical cancer has a much greater impact on Indigenous than other Australian women, and in the NT at least other HPV-related cancers also have a much greater impact on Indigenous women. While screening and follow-up services have reduced cervical cancer incidence and mortality in recent years, vaccination against HPV is expected to reduce these even further, and may also prevent other ano-genital cancers that are more common in Indigenous women.

However, the cause of the vulvar cancer epidemic is as yet unknown. While the HPV vaccine may be an effective control measure if HPV is the cause of the epidemic, this is not yet clear; identifying the cause of this epidemic and implementing an immediate program of early detection and treatment are urgent priorities.

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