Submission to the Senate Community Affairs References Committee Inquiry into gynaecological cancer in Australia

Organisation: Federation of Ethnic Communities' Councils of Australia (FECCA)

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Federation of Ethnic Communities' Councils of Australia

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

FECCA welcomes the opportunity to lodge a submission to the Senate Community Affairs References Committee Inquiry into gynaecological cancer in Australia.

This information in the submission was generated through consultations with community and service provider stakeholders who are familiar with particular women's needs and experiences.

Terms of reference for the current Inquiry

The terms of reference for the Inquiry were seen to capture a very reasonable scope within which this inquiry is taking place, as it encompasses stakeholders at various levels: community, healthcare providers, the medical community, etc. Comments were made that this approach augurs well for maintaining a holist understanding of women's needs.

Level of Commonwealth and other funding for research addressing gynaecological cancers

There is a clear need for additional funding for research addressing gynaecological cancers in Australia. There are many gaps in our current knowledge about the impact of gynaecological cancer in communities from culturally and linguistically diverse backgrounds (CLDB). The collection of data relating to population demographics is patchy and widely variant between different states and territories. For example, in Western Australia, hospitals collect statistics on Aboriginality, but not on cultural and linguistic diversity. This means that tracking gynaecological cancer rates for multicultural communities is very difficult because statistical frameworks do not reflect important questions about changing demographics, and how various groups rate in relation to certain areas of ill health.

This inability to effectively track health issues for women from culturally and linguistically diverse backgrounds is likely to have a long term impact on women's health. For example, little is understood about the connection between gynaecological cancers and Female Genital Mutilation (FGM). Service providers are seeing more and more young women, often who have come to Australia as humanitarian entrants, who are now entering relationships and struggling with the impacts of FGM. There is a lack of understanding both amongst the women themselves, and amongst service providers about how to effectively deal with the ongoing effects of FGM, and how any potential risk of gynaecological cancers can be minimised.

Likewise, we have little understanding of potential health issues for women from Middle Eastern backgrounds who may be vulnerable to developing cancer through being exposed to nuclear weaponry during war. Without available hospital statistics, it's very difficult to tell how these women are faring and what long-term health impacts may be.

FECCA advocates for research that focuses on developing a broad understanding of women's gynaecological health in general, including an understanding of community needs and ways of sustaining support across the lifespan for women, including those whose reproductive health has already been impacted (e.g. as a result of FGM). Investments in research of this sort is likely to have positive benefits for many women including young women exposed to FGM. It will enhance women's knowledge and ability to manage their health and relationships into the future. As one worker put it: *'some of the girls we see feel lost because they've formed relationships with people* *from other cultures, and they really need help – but we have to look at doing social and medical research which is beneficial for the longer term'.*

The extent, adequacy and funding for screening programs, treatment services and for wider health support programs for women with gynaecological cancer

There is a lack of understanding in multicultural communities about what screening and treatment services are available for women with gynaecological cancer. FECCA believes that outreach work would help to overcome this. Forming partnerships with ethno-specific community organisations would provide one model for outreach work and would be a valuable way of informing women in a familiar, non-threatening environment. To be effective, funding for such outreach programs must be sufficient to cover child care, transport costs and provide support for key community members involved in bringing women together.

Funding for screening programs, treatment services and wider health support programs for women with gynaecological cancer must be sufficient to provide effective services for women from culturally and linguistically diverse backgrounds. Information including posters, fact sheets and other written material must be available in a range of community languages, including languages of new and emerging communities.

A culturally competent health workforce is also essential to provide effective services for our diverse population. Cultural competence is not knowing everything about every culture, but recognising and respecting difference and having the attitudes, skills and knowledge that support individuals and organisations to work effectively in cross cultural situations. The ability to work effectively with interpreters is one indicator of cultural competency. Without adequate funding to support services to work in this way, the needs of women from CLDB with gynaecological cancer are at risk of being overlooked.

The capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds; and those living in remote regions

Our consultations indicate that whilst a number of services do their utmost to respond to women's health needs, Australia's social demographic changes require certain programmatic shifts in response to the new emerging needs of a diverse and changing community. For example, whereas a mainstream service may still have some useful knowledge to support women in building preventative and early intervention knowledge about gynaecological cancers, the agency's budget can be almost devoid of interpreter considerations and outreach budgeting.

Contributors strongly felt this lack of capacity is not because current providers are not doing their job adequately, instead, they felt these gaps are best seen as part of the historical development of services that may have been adequate at one time, but requiring more changes in the current climate. Such changes though were seen as possible if supported through a broad funding incentive structure, in recognition of the additional responsibilities expected of existing providers.

People involved in our consultation wondered whether organisations such as the Cancer Council and their like had facilities for interpreters:

> *Yet, this is a great service and we would want women to benefit – so they are inaccessible because of lack of funding for interpreters, through no fault of their own. It is a historical thing and changing demography….it is the same with other mainstream foundations catering for other health support needs, so language is a barrier.*

(comments from a community-based healthcare practitioner).

Some community groups appear to be missing out on information and support. As shared by one speaker from a community based agency supporting migrant women:

> *“women’s groups come and use my services, we get some referrals from torture and trauma services, but there are lot more people who have been here for a while who may be active in the community through their own associations – who is accessing them? Who pays for their interpreters? Who provides outreach services? They tend to miss out. So really this is a question of funding frameworks recognising significant changes in the demographics of groups that have come to* (in this case) *Western Australia. On the other hand, we should not assume that the rest of the population is as informed about these issues either – it is a matter of degree’.*

Women who have come to Australia as humanitarian entrants, after surviving war and civil unrest often have additional health issues that impact on their ability to access mainstream services that meet their needs. For example, most single women who come to Western Australia as humanitarian entrants from African countries were raped and/or witnessed others being raped - one of the key reasons they were accepted as refugees. Not surprisingly, women in this situation can be rather tentative in telling their stories. Access to female practitioners and community health providers is vital for these women as they are often still vulnerable and find it very difficult to broach issues of reproductive health/sexuality with their doctors. Doctors must therefore learn more to work proactively and sensitively check some of these issues with women.

As social demographics are changing, medical doctors need to gain greater exposure to training on contemporary content on multicultural needs. One lecture is not enough. A thorough and systematic curriculum, designed to build the cultural competence of the health workforce – including doctors, nurses and allied health progressions is essential to good practice as our population profile changes.

Many of the health issues women are grappling with are lifelong issues. A point was repeatedly made by a couple of service providers and a representative from a group of women who entered the country under the 'at risk' criteria that *"we are always sick since we've come. We're middle aged and there are struggles around sexuality"*. These struggles can make it very difficult for women to openly discuss health issues, with implications for prevention, screening and early detection of gynaecological cancers.

Understandings about health are culturally bound. Barriers to effective service provision and communication can occur when there is a lack of understanding by health professionals about the cultural meanings of diseases like cancer, or there is an incompatibility between Western and traditional beliefs. In some cultures, discussions about prognosis are taboo. Unless health providers have an understanding of these issues, they will not be able to provide services that meet the needs of women with gynaecological cancer.

The lack of appropriate health services to support women living in the rural and regional areas is well documented. Women from CLDB living in these areas are further disadvantaged, as they are less likely to be able to access services and personnel who can effectively meet their needs for culturally and linguistically appropriate services.

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

There are some examples of good practice where committed and knowledgeable individuals are working effectively with women from CLDB with gynaecological cancers. However, there is a strong sense of concern about what will happen when the few committed doctors who are working with these issues move on. It is vital that these practice understandings are extended beyond the very few doctors working in these areas.

There is still a lack of understanding in the health workforce about some the risk factors, symptoms and treatment of gynaecological cancers. For example, one community based nurse who was part of our consultation reported that a woman had visited almost five GPs; none of them were concerned enough to further investigate symptoms, so it was not picked up that the women had ovarian cancer. When it became apparent, at a later date, it was too late and the only solution was radical surgery.

The extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers

Despite good progress in some areas, there are still many gaps in women's knowledge about the risk factors, symptoms and treatment of gynaecological cancers, particularly for women whose first language is one other than English. These women may not be effectively reached by existing mainstream health promotion and public education campaigns, and remain unaware of important information that may enable them to seek medical advice and assistance. In these circumstances, women may have symptoms, but may not know the significance of mentioning this to their doctor.

Women need opportunities to develop further knowledge about how their body works; this has a lot of relevance especially in minimising the chance of diagnosing ovarian cancer late.

Community education campaigns that are delivered through community radio, partnerships with ethno-specific and other community based organisations, and in culturally and linguistically appropriate ways must be funded to ensure that women are able to build their knowledge about gynaecological cancers.

The extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently established Cancer Australia

There are many barriers to CLDB women having the opportunity to participate in key decision making bodies at local, community, state and national levels. This includes representation on national health agencies. Migrant women have a small public profile. In corporate management and governance structures, women continue to be represented in much smaller numbers than men. This is particularly true for women from CLDB backgrounds.

We believe that ensuring the inclusion of women from CLDB on governance structures, like the Board of Cancer Australia, will help to make certain that national health agencies are able to meet the needs of our diverse and continually changing community.