CHAPTER 7

EXPERIENCE, EXPERTISE AND REPRESENTATION OF GYNAECOLOGICAL CANCER ISSUES

Introduction

7.1 There are a multitude of individuals and organisations in Australia with experience and expertise in gynaecological cancer that strive to improve all aspects of care and support for women.[1]

7.2 This chapter examines where the expertise and experience is found and the extent to which it is represented in the priorities and directions of:

- national health agencies, including Cancer Australia; and
- key advisory bodies and Commonwealth government forums that shape health priorities.

7.3 This chapter considers the appropriateness of the level of representation and the extent to which initiatives, programs and services address gynaecological cancers and related issues.

Experience and expertise in gynaecological cancers

7.4 The Committee heard that there was a considerable amount of expertise and experience in gynaecological cancer matters in Australia.[2] This resides with gynaecological oncologists and other members of the medical and allied health communities, the women who have, or have survived, gynaecological cancers and with the professional bodies, organisations and community-based groups that represent and promote matters relating to women with these types of cancers.

7.5 The extent to which this knowledge and 'know-how' has been successfully utilised by, and incorporated into the decision-making of, national health agencies was a matter of some contention, with some arguing that gynaecological cancers were often over-shadowed by other tumour types with a higher public profile, particularly breast cancer.

Medical community and allied health community

7.6 Members of the medical community and allied health professionals have close relationships with women who have, or are at risk of, gynaecological cancers. Professionals that form multidisciplinary care teams include (but are not limited to)

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[1] *Committee Hansard* 16.8.06, pp.1-2 (United States National Cancer Institute).

[2] *Committee Hansard* 1.8.06, p.2 (Royal Hospital for Women).

gynaecological oncologists, medical oncologists, radiation oncologists, palliative care specialists, specialist gynaecological cancer nurses, dedicated physiotherapists, clinical psychologists, dieticians, social workers, supportive care and pastoral care workers.

7.7 With gynaecological cancer care moving to a more patient-centred approach, professionals are uniquely placed to provide their perspectives on issues relating to the adequacy of treatment, care and support systems and future priorities in gynaecological oncology. It was argued that representation of their views would help to better address the individual physical and emotional needs of women and better shape policies and strategies designed to improve care for women.

Gynaecological cancer organisations

7.8 There are many established and emerging professional and consumer non-government organisations that advocate for improvements in all aspects of gynaecological cancer care. These organisations operate on a national, as well as a state and local level.

7.9 The existence of many organisations is indicative of the high level of enthusiasm and importance that individuals and professionals place on working collaboratively to promote and advance gynaecological cancer care.

Professional bodies

7.10 A number of organisations represent and support the work of gynaecological oncology professionals, including the Australian Society of Gynaecological Oncologists (ASGO) and the Australia New Zealand Gynaecological Oncology Group (ANZGOG).

7.11 ASGO was founded in 1985 and is an organisation of Australian and New Zealand gynaecological oncologists. Its role is to promote 'improvement in the service delivery' in Australia, including in the area of patient care.[3]

7.12 ASGO is the closest organisation to a national body representing gynaecological cancer issues in Australia. By virtue of its national status, ASGO has assumed a limited coordination role, but it said its ability to perform effectively was hampered by resource (human and financial) constraints.[4]

7.13 The ANZGOG has a narrower remit than ASGO. It was established in 2000 to facilitate a collaborative and coordinated approach to gynaecological cancer clinical trials in Australia and New Zealand.[5] Professor Michael Friedlander, Chairman of

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[3] *Committee Hansard* 2.8.06, p.50 (ASGO).

[4] *Submission* 24, p.7 (ASGO).

[5] *Submission* 55, p.1 (ANZGOG).

ANZGOG, stated that it has developed a viable and effective clinical trials group because it has 'very close working relationships' with all of the Australian gynaecological cancer units and international gynaecological cancer groups.[6]

7.14 ANZGOG commented that its most critical issue was the lack of recurrent funding to support infrastructure and specific clinical trials. To date, it has received 'limited' financial support from the Commonwealth government, through the Strengthening Cancer Care initiative and a grant form the Cancer Institute of New South Wales.[7]

Community organisations

7.15 Australia has a large number of community-based organisations that work on gynaecological cancer issues. Depending on their size, and geographical region, the Committee heard that some organisations tended to focus on a broad range of issues associated with gynaecological cancers, whereas others narrowed their activities to specific tumour types. Evidence received during the inquiry indicated that more groups focused on ovarian cancer than for any other gynaecological cancer.

7.16 Many of these organisations coordinate, conduct or provide a broad range of activities, support and other services often on a volunteer basis with minimal funding. These include (but are not limited to):

- to act as a clearinghouse for information on gynaecological cancer issues for women, carers, professionals, government, community organisations and those who support women;
- to be a 'voice' for patients;
- to raise awareness of gynaecological cancers amongst women and the medical community;
- to consult with identified interest groups and stakeholders; and
- to raise funds to support gynaecological cancer control.

7.17 There is a vast amount of expertise that these groups bring, or could potentially bring, to national health agencies and other government decision-making bodies. Many past and present gynaecological cancer patients work actively in these organisations and bring their personal experiences and expertise to their work.

The Cancer Councils

7.18 The Cancer Council Australia is Australia's national non-government cancer control organisation. It has eight State and Territory cancer organisations that work

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[6] *Committee Hansard* 1.8.06, p.43 (ANZGOG).

[7] *Committee Hansard* 1.8.06, p.43 (ANZGOG).

together to undertake and fund cancer research, to prevent and control cancer and to provide information and support for people affected by cancer.[8]

7.19 The Cancer Council Australia acts nationally to advise governments and other bodies on appropriate practice and policies for the prevention, detection and treatment of cancer and is an advocate for the rights of cancer patients to best treatment and supportive care.

7.20 Although the Cancer Councils do not specifically focus on gynaecological cancers, those tumours fit within their broad remit.

National health agencies, bodies and initiatives

7.21 In Australia, a mix of government, non-government and community sectors shape health priorities and deliver and fund health services.

7.22 The Commonwealth Government – through the Commonwealth Department of Health and Ageing (the Department), Cancer Australia, the National Breast Cancer Centre (NBCC) and other bodies and initiatives – is responsible for setting national health policies and service delivery for those with gynaecological cancers through funding for research, policy and program implementation. The Department also has responsibility for building strong partnerships with stakeholders.[9]

7.23 Although the Government's various bodies, policy forums and initiatives focused on gynaecological cancers, it appeared that gynaecological cancers were only a sub-set of a wider focus on cancer. The extent to which representative and community groups, and the experience and expertise they represent, had access to government decision-making bodies was often difficult to gauge. The level of involvement of 'experts' and those with experience, particularly consumers, remained somewhat vague and uncertain to many witnesses and submitters.

Commonwealth Department of Health and Ageing

7.24 The broad role of the Department is to:

- provide expert policy advice and analysis to the Commonwealth Government;
- manage the Commonwealth Government's health programs to ensure the provision of quality, cost effective care to Australians; and
- promote healthy living and communicate information about health services to Australians.

7.25 In providing leadership for gynaecological cancer matters, the Department works with consumers, communities, health providers, peak bodies, industry groups,

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[8] The Cancer Council of Australia, *About Us*, (http://www.cancer.org.au/content.cfm?randid=325412).

[9] *Submission* 52, p.5 (Commonwealth Department of Health and Ageing).

professional organisations, State and Territory governments and portfolio agencies. The NBCC's Ovarian Cancer Program is largely funded by the Commonwealth Government to undertake activities in relation to ovarian cancer.

7.26 The Department also administers the ongoing funding provided for initiatives aimed at improving the prevention, detection, treatment and management of cancer more generally for the Australian community. Whilst the Department funds and oversees many initiatives, the few that focus on gynaecological cancers appear largely limited to ovarian cancer control (through the NBCC) or cervical cancer screening programs. It was unknown whether this lack of focus was due to little gynaecological cancer representation on decision-making bodies or whether other tumour types warranted greater priority.

7.27 To help reduce the burden of cancer the Commonwealth Government allocated $189.4 million over the five years to 2008-09 through the Strengthening Cancer Care initiative.[10] The initiative aims to ensure:

- better coordination of the national cancer effort;
- more research funding for cancer care;
- enhanced cancer prevention and screening programs; and
- better support and treatment for those living with cancer.

7.28 One of the most significant elements in this initiative is the establishment of a new national cancer agency, Cancer Australia.

Cancer Australia

7.29 The Commonwealth Government announced its intention to establish Cancer Australia as part of its Strengthening Cancer Care initiative. According to the Government's 2004 Federal election policy, a body such as Cancer Australia was needed to ensure that 'the entire spectrum of cancer care services throughout Australia are evidence based and consumer focused'.[11]

7.30 Cancer Australia's role is to:

- provide national leadership in cancer control;
- make recommendations to the Commonwealth Government about cancer policy and priorities;
- guide scientific improvements to cancer prevention, treatment and care;
- coordinate and liaise between the wide range of groups and providers with an interest in cancer; and

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[10] Commonwealth Department of Health and Ageing, *Budget 2005-06* (www.health.gov.au/budget2005).

[11] Dr Angela Pratt, *Bills Digest – Cancer Australia Bill 2006*, 1.3.06, p.2.

- oversee a dedicated budget for research into cancer.[12]

7.31 The Committee understands that Cancer Australia will have four priority areas in which it will take leadership: research and clinical trials; quality; consumers; and policy. Each of these areas will have a national reference group to support it and consumers and cancer experts to inform and drive priorities.

7.32 Cancer Australia is expected to spend $16.663 million in grants in 2006-07 to support the following Strengthening Cancer Care measures:

- clinical trials;
- cancer research;
- cancer support networks;
- mentoring for regional hospitals and cancer professionals; and
- developing training courses for cancer nurses.[13]

7.33 Cancer Australia will comprise of a Chief Executive Officer (CEO), an Advisory Council and support staff. The CEO, medical oncologist Professor David Currow, will head the agency and will report to the Minister for Health and Ageing.[14] The Advisory Council, chaired by former Australian Medical Association president Dr Bill Glasson, will be advisory to the CEO and will consist of a Chair and a maximum of 12 other members.[15]

Issues regarding the operation of Cancer Australia

7.34 The establishment of Cancer Australia appears to be supported by cancer groups and others in the gynaecological cancer community.[16]

7.35 Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia, was a strong advocate of Cancer Australia's formation and saw the organisation as having the potential to make a significant impact on controlling cancer, including gynaecological cancers, in Australia.[17] The Cancer Council Western Australia and Professor Christobel Saunders, Acting Director of the Cancer and Palliative Care Network, also welcomed its establishment and argued it provided a

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[12] Portfolio Budget Statements 2006-07 – Health and Ageing Portfolio, p.299.

[13] Portfolio Budget Statements 2006-07 – Health and Ageing Portfolio, p.303.

[14] Minister for Health and Ageing, the Hon. Tony Abbott MP, *Media Release* (ABB124/06), 25.8.06.

[15] Minister for Health and Ageing, the Hon. Tony Abbott MP, *Media Release* (ABB025/06), 7.3.06.

[16] *Submission* 56, p.35 (The Cancer Council Australia, COSA and NACCHO).

[17] *Committee Hansard* 2.8.06, pp.3-4 (The Cancer Council Australia).

good opportunity for gynaecological cancer work to be undertaken by one entity and in concert with other more general developments in cancer control.[18]

7.36 Professor Olver said the following about Cancer Australia's formation:

> …one of the difficulties in Australia is there are little bits of organisations and people doing things all over the place, and not only in organisational things—supportive things and research. Something that could focus that in would be a good idea. We see Cancer Australia as a portal of entry into government—into the minister's office, if you like—and the exit portal of government communicating with the community.[19]

7.37 A number of witnesses and submitters expressed uncertainty about Cancer Australia's operation in practice and questioned its capacity to address issues specific to gynaecological cancers.[20]

7.38 First, there was concern about the low profile gynaecological cancer issues might receive once Cancer Australia was operational. Associate Professor David Allen, representing The Cancer Council Victoria's Gynaecological Cancer Committee and Victorian Cooperative Oncology Group, argued that gynaecological cancer representation on decision-making and policy development bodies was important. Associate Professor Allen said that this representation was lacking on Cancer Australia's Advisory Council.

> But if you look at that committee…it has no real gynaecological representation. I do not know if the idea is to try to represent most of the cancer entities on that committee or not. It seems to have a lot of breast input and interests. Certainly we believe, and I know that ASGO, the Australian Society of Gynaecologic Oncologists, believes as well that we should have some sort of voice or connection with that, even if it is in the form of a subcommittee, or whether some national gynaecological body should be aligned to the Cancer Australia. But we believe that sitting in or around councils like that is very important.[21]

7.39 The Queensland Centre for Gynaecological Cancer highlighted that breast cancer was represented on the Advisory Council with 'at least three members', whereas gynaecological cancer was not represented at all.[22]

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[18] *Submission* 51, p.31 (The Cancer Council Western Australia); *Committee Hansard* 4.8.06, p.26 (Cancer and Palliative Care Network).

[19] *Committee Hansard* 2.8.06, p.3 (The Cancer Council Australia).

[20] *Committee Hansard* 4.8.06, p.58 (Health Consumers Council Western Australia); *Committee Hansard* 2.8.06, p.26 (Cancer Voices Australia).

[21] *Committee Hansard* 3.8.06, p.85 (The Cancer Council Victoria and Victoria Cooperative Oncology Group).

[22] *Submission* 11, p.9 (Queensland Centre for Gynaecological Cancer).

7.40 In response, the Department maintained that Cancer Australia's formation would mean that 'all cancers, including gynaecological cancers, continue to be a focus for the Commonwealth Government'.[23] In addition, The Cancer Council Australia, the Clinical Oncological Society of Australia (COSA) and the NBCC all emphasised that through their representatives on Cancer Australia's Advisory Council there would be a strong commitment to ensuring that gynaecological cancer issues were afforded appropriate priority. They argued that they would:

> …convey the concerns of our gynaecological cancer stakeholders and work to help ensure that relevant issues receive due prominence in discussion around the agency's strategic directions.[24]

7.41 Second, some witnesses had difficulty commenting on the role Cancer Australia would play, or the difference it could make, to gynaecological cancer control because of the lack of information or communication about its operations.[25] At the time of writing its submission, the Gynaecological Cancer Society stated:

> …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.[26]

7.42 Third, there were concerns about the lack of direct representation of experts in gynaecological cancers and consumers on the Advisory Council and its impact on the ability of professionals and women to access Cancer Australia.[27]

7.43 The Sydney Gynaecological Oncology Group felt that there was no appropriate clinician appointed to Cancer Australia despite the prevalence of gynaecological cancers in Australia.[28]

> Clinicians involved with these diseases feel that representatives for other disease groupings do not adequately consider the importance of gynaecological cancers.[29]

7.44 Cancer Voices Australia, a body representing the views of consumers, said it was involved in some consultation with Cancer Australia during its developmental phases, but that contact was a 'one-off'.[30] Although Cancer Voices Australia was

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[23] *Submission* 52, p.5 (Commonwealth Department of Health and Ageing).

[24] *Submission* 56, p.36 (The Cancer Council Australia, COSA and NACCHO).

[25] *Committee Hansard* 3.8.06, p.85 (The Cancer Council Victoria and Victoria Cooperative Oncology Group).

[26] *Submission* 7, p.3 (Gynaecological Cancer Society).

[27] *Committee Hansard* 2.8.06, pp26-27 (Cancer Voices Australia).

[28] *Submission* 10, p.11 (Sydney Gynaecological Oncology Group).

[29] *Submission* 10, p.11 (Sydney Gynaecological Oncology Group).

[30] *Committee Hansard* 2.8.06, p.26 (Cancer Voices Australia).

advised that one or two of the members of the Advisory Council would be a conduit for consumers into the organisation, it stressed that representation of women's views would be more meaningful if consumer representatives were directly appointed to the Council.

7.45 The Gynaecological Cancer Society also argued for meaningful commitment to consumer involvement.

> 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.[31]

7.46 In relation to the composition of Cancer Australia's Advisory Council, Professor Olver argued that the membership included a wide range of expertise and experience in cancer control and that the lack of direct representation would not necessarily preclude gynaecological oncology interests being put forward:

> …all of us who were approached to sit on that council were not approached with any designation at all. I wear a number of hats, I guess, in the cancer community and I have no idea which of them, if any of them, I was specifically appointed to that council for. I think the idea was to develop a body of expertise that covered quite a wide spectrum.
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> …
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> So it is highly unlikely that there can be a representative of particular tumour types—lung cancer, breast cancer and so on, although breast cancer is represented, as it happens.[32]

7.47 Despite the concerns put forward by some witnesses about Cancer Australia's ability to focus on, and address, gynaecological cancer issues, the establishment of a national government agency was widely agreed to be essential.

7.48 Dr Robert Rome, a Melbourne gynaecological oncologist, argued:

> There certainly needs to be a more coordinated effort to improve gynaecological cancer and this would best be done through a Federal initiative rather than at a state level.[33]

7.49 The suggestion by many to establish a national body with a national approach and focus for gynaecological cancers, such as the National Gynaecological Cancer Centre (NGCC), is considered in further detail in Chapter 2.

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[31] *Submission* 7, p.3 (Gynaecological Cancer Society).

[32] *Committee Hansard* 2.8.06, p.3 (The Cancer Council Australia).

[33] *Submission* 32, p.2 (Dr Robert Rome).

National Breast Cancer Centre

7.50 The NBCC is currently Australia's peak body for breast and ovarian cancer control.[34] It was established in 1995 by the Commonwealth Government in response to community concerns about the human cost of breast cancer. In September 2001, in recognition of the impact of ovarian cancer on Australian women, the Commonwealth Government provided funding to the NBCC to manage the Ovarian Cancer Program.[35]

7.51 The work of the Ovarian Cancer Program covers many aspects of ovarian cancer control, from risk factors, symptoms and diagnosis to the multidisciplinary treatment of women with ovarian cancer.

7.52 The NBCC told the Committee its Ovarian Cancer Program works in partnership with women, health professionals, cancer organisations, researchers and governments to improve the ovarian cancer outcomes for women.[36]

7.53 The NBCC stated it has ensured clinical and consumer representation of ovarian cancer issues on its relevant Advisory and Working Groups.[37] For example:

- a clinical advisor in ovarian cancer is a member of the NBCC’s Clinical Expert Advisory Panel providing advice to the NBCC on emerging and current issues in research and treatment; and
- the NBCC works closely with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and with ANZGOG involving them in development and implementation of initiatives in ovarian cancer control.

7.54 It is acknowledged that there is only one clinical advisor in ovarian cancer and none in other gynaecological cancers and the Committee considers this gives good reason for a separate focus through a stand-alone body.

7.55 The NBCC works closely with women who have ovarian cancer and it argued that their insights and understanding of the disease and its impact on women and their families enriched the overall approach taken in its ovarian cancer activities.

> The involvement of both clinical and consumer experts is vital to the way NBCC develops and delivers on a relevant and informed business plan in ovarian cancer.[38]

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[34] *Submission* 52, p.5 (Commonwealth Department of Health and Ageing).

[35] *Submission* 44, p.12 (NBCC).

[36] *Submission* 44, p.3 (NBCC).

[37] *Submission* 44, p.13 (NBCC).

[38] *Submission* 44, p.13 (NBCC).

7.56 In turn, the NBCC incorporates the expertise, views and interests it gathers through consultative processes at the National Cancer Strategies Group and the Australian Screening Advisory Committee (ASAC).[39]

7.57 The NBCC addresses ovarian cancer through its Ovarian Cancer Program, but it does not address education, research and management issues pertaining to other gynaecological cancers.[40] The Committee noted that although the NBCC utilised much gynaecological oncology expertise, its remit is limited to ovarian cancer.

Roles and responsibilities in advising the Commonwealth Government

7.58 At the Canberra hearing, the Committee sought clarification from the Department about how it, Cancer Australia and the NBCC worked together in practice to provide advice to Government. The Department was questioned about the responsibility of each organisation in the development of new initiatives, such as a national awareness campaign. The Committee was concerned that the Department did not provide a clear answer about the delineation of the respective roles between the three organisations.

7.59 The Department commented that each agency was responsible for making recommendations to the Commonwealth Government about cancer policy and priorities and that Government would take into account the views of each body, but that 'there is no neat formula' and that ideas could be initiated by any of the three.[41]

7.60 As key advisers to Government, this has the potential to cause gaps and to send mixed messages.

Policy advisory structures

7.61 As cancer was established as a National Health Priority area in 1996 by Commonwealth, State and Territory health ministers, the Commonwealth Government established a number of health advisory committees to inform policy development (in addition to the Department, Cancer Australia and the NBCC). Some are discussed below.

7.62 Many of the national health agencies and policy advisory structures have gynaecological cancer expertise in their membership or committee membership – such as the ASAC – but due to the terms of reference of such committees, this has largely involved expertise related to cervical cancer.

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[39] NBCC, *Annual Report 2004-05*, p.4.

[40] *Submission* 40, p.6 (Professor Neville Hacker).

[41] *Committee Hansard* 23.6.06, pp.56-57 (Commonwealth Department of Health and Ageing).

Australian Health Ministers' Conference and Australian Health Ministers' Advisory Council

7.63 The Australian Health Ministers' Conference (AHMC) and its Australian Health Ministers' Advisory Council (AHMAC) are the key coordinating bodies comprising all Australian and New Zealand Ministers with direct responsibility for health matters.

7.64 The AHMC examines matters concerning health policy, health services and programs with the aim of promoting a consistent and coordinated national approach to health policy development and implementation.[42] The AHMAC advises the AHMC on strategic issues relating to the coordination of health services across Australia and operates as a national forum for planning, information sharing and innovation.

7.65 In 2002, the AHMAC agreed to the development of a National Service Improvement Framework for cancer. The content of this Framework was drawn from existing cancer plans and policies, including those developed at the State and Territory level. It also drew on a number of other documents developed including *Optimising Cancer Care in Australia* and the *Priority Actions for Cancer Control*. Examination of the Framework did not show specific policies for, or references to, gynaecological cancers but it addressed the general issues of detection, treatment and cancer management that are important across the cancer spectrum.

National Cancer Strategies Group and National Health Priority Action Council

7.66 The National Cancer Strategies Group was established in 1998 to provide expert advice to the Commonwealth Government on strategies to improve the prevention, detection, treatment and management of its National Health Priority Areas.[43] Its membership includes clinicians, consumers, epidemiologists, general practitioners, peak cancer bodies, Aboriginal and Torres Strait Islander representatives, and government representatives.

7.67 The National Cancer Strategies Group was formed under the auspices of the National Health Priority Action Council (a sub-committee of the AHMAC). The purpose of the Council is to drive health service improvements to achieve better health outcomes for all Australians for the national health priority chronic conditions.[44] This Council is chair by the Commonwealth Government's Chief Medical Officer and comprises representatives from each jurisdiction, as well as consumer representatives and an Aboriginal and Torres Strait Islander representative.

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[42] AHMAC, *The Australian Health Ministers' Advisory Council*, (http://www.ahmac.gov.au/site/home.asp).

[43] Commonwealth Department of Health and Ageing, *National Cancer Strategies Group*, http://www.health.gov.au/internet/wcms/publishing.nsf/Content/pq-cancer-ncsg

[44] The National Health Priority chronic conditions are cancer, diabetes, asthma, cardiovascular disease and stroke, and arthritis and musculoskeletal conditions.

The Australian Screening Advisory Committee

7.68 The Australian Screening Advisory Committee was established in 2004 as a national body to provide advice to the Commonwealth, State and Territory governments on national screening programs, including existing programs, those under consideration and emerging screening issues.[45] ASAC replaced a number of previous advisory committees including the National Advisory Committee to the National Cervical Screening Program. Members of ASAC are drawn from Commonwealth government agencies, State and Territory health departments, and epidemiology, population health, gastroenterology, gynaecological oncology, general practice, consumer and Aboriginal and Torres Strait Islander groups.[46] The NBCC is also represented.

National Cancer Control Initiative

7.69 As mentioned above, many submitters and witnesses from the health and medical sector welcomed Cancer Australia's formation, however the announcement in 2004 caused a lot of uncertainty over the future of the Commonwealth's previous expert advisory body on cancer, the National Cancer Control Initiative (NCCI). The NCCI was established in 1997 to advise the Commonwealth government on all aspects of cancer control including prevention, early detection, treatment and palliative care.[47] A comparison of the terms of reference of NCCI and those of Cancer Australia show a great deal of similarity.

7.70 Following the announcement of the formation of Cancer Australia, many assumed that the NCCI would be subsumed into Cancer Australia, given the similarities between the advisory work of the NCCI, and the roles and functions of Cancer Australia.[48] However, because of the uncertainty over the NCCI's future in the Cancer Australia structure (as well as uncertainty over the NCCI's short term Commonwealth funding), the NCCI ceased to operate on 31 May 2006.[49]

7.71 Whilst operational, the NCCI managed a range of Commonwealth-funded projects focusing on cancer. Of the projects that focused on specific cancer types (approximately half by number), none focussed on gynaecological cancers (though the Committee acknowledged that many other tumour types were also not included).[50] Of the remaining projects, more general health topics were covered including screening

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[45] AIHW, *Cancer Committees*, (http://www.aihw.gov.au/cancer/committees.cfm).

[46] AIHW, *Cancer Committees*, (http://www.aihw.gov.au/cancer/committees.cfm).

[47] Commonwealth Department of Health and Ageing, *Initiatives*, (http://www.health.gov.au/internet/wcms/publishing.nsf/content/pq-cancer-init).

[48] Dr Angela Pratt*, Bills Digest – Cancer Australia Bill 2006*, 1.3.06, p.4.

[49] Dr Angela Pratt*, Bills Digest – Cancer Australia Bill 2006*, 1.3.06, p.4.

[50] The NCCI's projects focussed on colorectal (bowel) cancer, lung cancer, melanoma and non-melanoma skin cancer, prostate cancer and familial cancers.

and early detection, supportive care, service improvement and research. The Committee noted that these are areas of great importance to women with gynaecological cancers. By way of example the NCCI worked with the NBCC to develop the first guidelines about psychosocial care for adults with cancer.[51]

Representation of gynaecological oncology issues

The need for greater representation

7.72 The NBCC noted that although many aspects of care were generic, there were also important aspects which were specific to individual cancers.[52]

7.73 The Cancer Council Australia, COSA and NACCHO agreed and emphasised that representation was critical in order to raise the profile of tumour types.[53]

> Diverse representation on policy-making and service planning bodies is critical to providing equity in the development and implementation of cancer prevention, treatment and care services.[54]

7.74 Evidence from submitters and witnesses presented an overwhelming view to the Committee that experience and expertise in gynaecological cancers was not appropriately represented on national health agencies (and their initiatives) and in other policy development bodies.[55] The Queensland Centre for Gynaecological Cancer strongly argued that the issues were 'grossly underrepresented' and that this under representation seemed to be a 'continuing theme involving the setting of health priorities and the distribution of (research) funds'.[56]

7.75 Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women, argued that the incidence of gynaecological cancers justified direct representation.

> Gynaecological cancers represent 9.6% of cancers in women, which should be sufficient justification for representation on national cancer agencies.[57]

7.76 The Cancer Council Australia, COSA and NACCHO did not support a quota-system approach to representation on national health agencies and in other policy-making bodies based on particular tumour types.

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[51] *Submission* 44, p.10 (NBCC).

[52] *Submission* 44, p.12 (NBCC).

[53] *Committee Hansard* 2.8.06, p.14 (The Cancer Council Australia).

[54] *Submission* 56, p.35 (The Cancer Council Australia, COSA and NACCHO).

[55] *Submission* 28, p.12 (Western Australia Gynaecologic Cancer Service); *Submission* 10, p.11 (Sydney Gynaecological Oncology Group).

[56] *Submission* 11, p.9 (Queensland Centre for Gynaecological Cancer).

[57] *Submission* 40, p.6 (Professor Neville Hacker).

> If such an approach were taken, efforts to systematically reform cancer services would be fragmented; and people with cancers that cause relatively low incidence and mortality might struggle to find a voice.[58]

7.77 Professor Olver from The Cancer Council Australia cautioned against a tumour-specific approach because it would not be practical for rarer malignancies to have their own national organisation. Where no direct gynaecological cancer expertise was present, he argued that it was still expected that those professionals would consider, represent and support the needs of women at risk or living with gynaecological cancers.

7.78 The Cancer Council Australia, COSA and NACCHO supported broad representation from groups with a wide range of cancer experience and skills, including oncologists, population health experts, consumers and allied health professionals. Specific representation was thought to be necessary though for population groups that face barriers to equitable service provision, such as Indigenous people and people in remote communities.[59]

Improved coordination and leadership

7.79 Evidence to the Committee suggested that the existence of a large number of organisations meant there was no unified voice coming from the gynaecological oncology profession or consumers. A lack of coordination was described at many levels, including at the policy level, and within professional and community organisations.

7.80 Professor Michael Quinn, Director of Oncology/Dysplasia at The Royal Women's Hospital stressed the need for better cooperation within the gynaecological oncology community.

> We have got a bigger picture about what is important in gynaecological cancer as opposed to the small, local issues that we all face on a day to day basis. I think there is a commitment from gynaecological cancer specialists to talk to each other, to talk to the community, and therefore they are an excellent model. The value-add, from my point of view, is the cooperation that we can all give together because we are a subspecialty that is very well organised. That is the way I would answer that question.[60]

7.81 Professor Quinn made the following remarks to the Committee about the present state of cancer leadership in Australia:

> …there is a feeling amongst the cancer community in Australia that there is a vacuum in cancer leadership. I think the reasons for this—and we can observe this—are that the Cancer Strategies Group has not met for two

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[58] *Submission* 56, p.35 (The Cancer Council Australia, COSA and NACCHO).

[59] *Submission* 56, p.35 (The Cancer Council Australia, COSA and NACCHO).

[60] *Committee Hansard* 3.8.06, p.36 (The Royal Women's Hospital).

> years, the National Cancer Control Initiative has been disbanded, the Australian Cancer Society has just appointed a new CEO, who is obviously trying to find his feet, and there has been an inordinate delay in the formation of Cancer Australia. That was part of the present government's election platform in 2004 and so far more than $5 million of budgeted funds have not been used.[61]

7.82 Professor Quinn's views were echoed by others and many agreed with the need for a central body to ensure collaboration and a unified voice for policy development and funding allocation.[62] There was a difference of opinion amongst witnesses as to the means by which this is to be achieved. Some witnesses – notably the Cancer Council Australia – argued that Cancer Australia was the appropriate body, whilst the vast majority recommended the formation of a separate national gynaecological cancer centre.[63]

Conclusion

7.83 The incidence of gynaecological cancers in women is growing and so are the flow-on impacts for others in the community. Evidence to the Committee questioned the extent to which expertise and experience in gynaecological cancers is being utilised effectively by national health agencies in Australia. Particular concerns were expressed about the extent to which Cancer Australia would successfully incorporate the concerns and needs of those in the gynaecological cancer community with experience and expertise.

7.84 Experience and expertise in gynaecological cancers is found in many different individuals and organisations. From individual gynaecological oncologists and other medical and allied health professionals and researchers, to consumers and community-based organisations – all bring unique and valuable perspectives, knowledge and experiences to the table. It is vital that these are utilised and that information flows to the national agencies, particularly the Department, Cancer Australia and the NBCC, which advise the Government and other decision-making bodies to ensure that gynaecological cancer interests are taken into account.

7.85 The key challenges for guaranteeing an appropriate level of representation were a lack of cooperation between the players and the lack of a unified approach to representational activities in the gynaecological cancer sector. As a result, there were high expectations about the unifying role Cancer Australia was expected to play, but also doubts about whether its stated objectives would be achieved in practice for gynaecological cancer issues.

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[61] *Committee Hansard* 3.8.06, p.2 (The Royal Women's Hospital).

[62] *Committee Hansard* 3.8.06, p.5 (Monash Medical Centre).

[63] *Submission* 40, p.6 (Professor Neville Hacker); *Submission* 24, p.3 (ASGO); *Submission* 27, p.20 (Ms Margaret Heffernan).

7.86 As a result, many submitters and witnesses suggested that a national centre focusing on gynaecological cancers be established to provide a strategic framework, to increase efficiencies through coordinated action and to develop a better understanding of gynaecological cancer issues at the political and policy level.

7.87 The Committee acknowledges the complexity of the health system and the delineation of responsibility across all levels of government and other organisations have posed challenges to identifying activities and directions that would deliver better outcomes for the future.

Recommendation 32

7.88 The Committee recommends that Cancer Australia collaborate with individuals and groups to identify the best ways to ensure that expertise and experience in gynaecological cancer is represented on national health agencies, particularly Cancer Australia.

7.89 The Committee further recommends that consumer and community representatives have greater involvement in the decision-making of national health agencies.

7.90 The Committee further recommends that when membership of Cancer Australia's Advisory Council is due for review, one or more consumer representatives from the reproductive cancer sector be appointed to maintain the confidence of groups within those areas.

Recommendation 33

7.91 The Committee recommends that the Commonwealth Department of Health and Ageing, Cancer Australia and the Centre for Gynaecological Cancers communicate with each other about the content of future work plans in order to avoid confusion over responsibility for the development of initiatives and program delivery.

Recommendation 34

7.92 The Committee recommends that the Centre for Gynaecological Cancers put arrangements in place to ensure continuity between the work of the now defunct National Cancer Control Initiative and Cancer Australia, particularly in relation to gynaecological cancers.

Senator Gary Humphries
Chair
October 2006