

CHAPTER 6

GYNAECOLOGICAL CANCERS EDUCATION FOR WOMEN AND THE COMMUNITY

Introduction

6.1 The Committee heard that information and education were critical for women with, or at risk of, gynaecological cancers. It was emphasised that women who were well-informed on issues relating to gynaecological cancers generally had better health outcomes than those who were poorly informed. Specifically, they:

- had a better understanding of their choices and what may happen to them;
- were more satisfied with their care, psychosocial wellbeing and compliance with their treatment; and
- experienced less anxiety and had better coping skills.

6.2 Information about gynaecological cancers, treatment and prognosis should be timely, reliable and accessible. The Committee heard that a commonly unmet need of women was the lack of appropriate information. As such, strong concern was expressed about the low levels of awareness and its flow on effects for the care of women.

6.3 The level of awareness of gynaecological cancers in the broader community, particularly of family members and carers, was also critical to the health outcomes of women. Evidence to the Committee indicated it was not only important to ensure that women themselves were adequately informed because the effect of a gynaecological cancer does not finish there – it was vital that the people around them received appropriate information as well.

The importance of education

6.4 Education is a wide-ranging term that encompasses a wide range of activities. This inquiry focused on education in the context of the provision of information for the purpose of raising awareness and understanding of gynaecological cancers. Currently, responsibility for educational initiatives and implementation is multi-layered and rests with government, non-government organisations and community-based organisations. The delivery of education about gynaecological cancers is done primarily through printed material, online resources, electronic media as well as face-to-face interaction.

6.5 At present, there is no national education strategy designed to increase the awareness and knowledge of the full range of gynaecological cancers. Some of the strategies for specific tumour types are discussed later in this chapter.

6.6 The Committee heard that education was important because many women with gynaecological cancers frequently seemed to know nothing about their condition, even though some considered themselves to be well-informed consumers and well-informed about their own health. The Committee heard that it was often distressing for women to discover that there was much they did not know about their condition, treatment and other services.

6.7 The Gynaecological Cancer Society argued:

In a perfect world 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.¹

Awareness leads to empowerment

6.8 Education and information empower women and those in the broader community (such as family and friends) faced with uncertainty about decisions that need to be made in physically and emotionally-demanding situations.

6.9 Evidence suggested that women with gynaecological cancers seemed to go through a journey from starting to feel ill, to some form of medical intervention and then medical treatment. The Committee heard that access to appropriate treatment by a gynaecological oncologist (as part of a multidisciplinary team) sometimes had more to do with a woman's insistence that something was wrong rather than medical knowledge that something was wrong.

6.10 Mr John Gower, Chief Executive of the Gynaecological Cancer Society agreed with the need for showing assertiveness:

There is a lot of evidence where women have presented with symptoms and in truth the only reason that a final diagnosis of gynae cancer was made was because the patient sat there and said: 'That's not good enough. I don't have a cold.' ...There are a lot of women alive today who would not be if they had not been assertive about their symptoms.²

6.11 The Committee heard that awareness of the sub-speciality of gynaecological oncology and assertiveness were linked to earlier diagnosis of gynaecological cancers, which was particularly important in the case of ovarian cancer.³ It was argued that if women knew of the existence of gynaecological cancer centres and gynaecological oncologists there would be more consumer awareness, and therefore demand, to get the best treatment.

1 *Submission 7*, p.6 (Gynaecological Cancer Society).

2 *Committee Hansard 2.8.06*, p.42 (Gynaecological Cancer Society).

3 *Submission 33*, p.6 (National Ovarian Cancer Network).

Improving awareness of the sub-specialty of gynaecological oncology

6.12 Education is needed to inform women about the sub-specialty of gynaecological oncology which is generally not understood well by women. Professor Neville Hacker, Director of the Gynaecological Cancer Centre at the Royal Hospital for Women argued:

If you asked the average woman on the street whether she had ever heard of a gynaecological oncologist, she would say no.⁴

Eliminating the stigma associated with gynaecological cancers

6.13 The Committee also heard that gynaecological cancers and conditions were a sensitive issue for the great majority of Australians and that education was the key to overcoming some of the feelings of embarrassment, guilt and fear about the conditions.⁵ Ms Natalie Jenkins, Chairperson of the Gynaecological Awareness Information Network (GAIN) said:

GAIN continues to be surprised and dismayed at the lack of knowledge and awareness of gynae conditions amongst the general populace. We believe this is the result of the social taboo surrounding the subject.⁶

6.14 Ms Sally Crossing from Cancer Voices Australia agreed and cautioned that 'loneliness, embarrassment and stigma may hinder women from taking action' in relation to their health.⁷

6.15 Professor Barbara Andersen, a Professor at the Department of Psychology and the Department of Obstetrics and Gynecology at The Ohio State University, told the Committee that information for women was particularly important at the time of diagnosis because:

...everybody has very high levels of stress and anxiety, and interventions at that time would probably be best focused on delivering understandable information to patients.⁸

Women and the broader community

Women

6.16 Women affected by gynaecological cancers not only experience impacts to their physical health, but also to their social, psychological and economic wellbeing. It

4 *Committee Hansard* 1.8.06, p.11 (Royal Hospital for Women).

5 *Committee Hansard* 4.8.06, p.36 (GAIN).

6 *Committee Hansard* 4.8.06, p.37 (GAIN).

7 *Committee Hansard* 2.8.06, p.24 (Cancer Voices Australia).

8 *Committee Hansard* 12.9.06, p.2 (Professor Barbara Andersen).

is therefore important that women are educated about the risk factors, symptoms and treatment options available. This information needs to be easily available and visible.

6.17 In relation to education, witnesses and submitters told the Committee that women wanted information to:

- better understand the risks of developing gynaecological cancers and to know how to reduce their risk of gynaecological cancers;
- be able to access highly credible and nationally consistent evidence-based information about the symptoms of gynaecological cancers; and
- if they are diagnosed with a gynaecological cancer, to:
 - be told appropriately and provided with supportive care services and information about their treatment;
 - know who is coordinating their care and who can answer their questions;
 - have information about and help to minimise any uncertainty following the completion of treatment;
 - have information about prevention and the ongoing side effects of treatment; and
 - know how to take care of themselves and to maintain optimal health.

6.18 The Committee heard from women and representative groups that the current approach to health education needed to be improved in order to provide better support through the provision of information to women.

Broader community

6.19 Education and awareness about gynaecological cancer issues are not only important for women.⁹ Evidence to the Committee suggested that education is important for members of the broader community – which could include family members, friends, carers or colleagues – so they can better understand the physical and emotional journey that women with gynaecological cancers are experiencing in order to provide the necessary support. To illustrate this point, GAIN noted that if partners are unable to discuss matters of concern, such as sexual dysfunction, women can become isolated emotionally.¹⁰

It can have devastating effects on whole families, which means men too need to have awareness, so they can develop understanding and cope with the unforeseen side effects. Most medical practitioners and support services do not acknowledge this and there are very few support services available for partners and families.¹¹

9 *Submission* 14, p.6 (GAIN).

10 *Submission* 14, p.6 (GAIN).

11 *Submission* 14, p.6 (GAIN).

6.20 Gynaecological cancers are physically and emotionally debilitating for women, their partners and families. Mr John Stubbs, Executive Officer of Cancer Voices Australia argued that partners of women with gynaecological cancers should be encouraged to be more involved and should be provided with evidence-based information.¹²

Current education strategies

Current activities

6.21 A range of communication and education resources are available for women for gynaecological cancers. Many organisations produce material for women.

Commonwealth Department of Health and Ageing

6.22 Information links for women on gynaecological cancers are available through the Commonwealth Government's information portal, HealthInsite.

6.23 The Commonwealth Department of Health and Ageing (the Department) said that HealthInsite is designed to provide all consumers with easy access to reliable, high quality and relevant information about health and wellbeing.¹³ It works by linking users to specific information on the websites of approved information partners. It links to a number of resources about cancer and includes information about diagnosis, treatment options, support services, latest research and statistical information. The Committee noted that the only gynaecological cancers listed were cancer of the uterus, cervical cancer and ovarian cancer.

National Breast Cancer Centre's Ovarian Cancer Program

6.24 The National Breast Cancer Centre's (NBCC) Ovarian Cancer Program produces a number of resources designed to provide information to women and the wider community.¹⁴

6.25 Products developed by the NBCC include:

- a web-based national directory of gynaecological oncology services;
- a guide titled *Epithelial ovarian cancer: understanding your diagnosis and treatment* to provide information to women diagnosed with ovarian cancer, their family, partners and friends;
- a web-based fact sheet about the tumour marker CA125 for women who have been referred for a blood test during the diagnostic process; and
- a fact sheet for the general public about ovarian cancer.¹⁵

12 *Committee Hansard* 2.8.06, p.35 (Cancer Voices Australia).

13 *Submission* 52, p.12 (Commonwealth Department of Health and Ageing).

14 *Submission* 44, pp.11-12 (NBCC).

6.26 The NBCC also raises awareness of ovarian cancer through national forums, an electronic bi-monthly newsletter *Ovarian e-upd@te* and through working with the National Ovarian Cancer Network in promoting Ovarian Cancer Awareness Week.¹⁶

Cancer Councils

6.27 The Cancer Council Australia told the Committee that the State and Territory Cancer Councils disseminate a range of resources aimed at raising women's awareness of gynaecological cancer symptoms or indications of precancerous conditions.¹⁷

6.28 For example, The Cancer Council Western Australia produces a women's cancers speaker's kit covering gynaecological cancers (including cervical, ovarian, uterine, vulval and vaginal). It also produces a brochure on gynaecological cancers, booklets on uterine cancer and cervical cancer and provides public and health professional talks on gynaecological cancers.¹⁸

6.29 The Cancer Council Australia also highlighted that its Help Line provides telephone counselling and referral to appropriate professionals and that its work with National Aboriginal Community Controlled Organisation (NACCHO) helps to promote and raise awareness of the signs of gynaecological cancers amongst Indigenous women.¹⁹

Community Organisations

6.30 A number of community organisations also provide education to women and the broader community. In commenting on the role that they played, Australian Society of Gynaecologic Oncologists (ASGO) said that 'these organisations admirably perform a much-needed function with little or no support'.²⁰

6.31 Many of these organisations develop pamphlets, information packages and websites to inform and support women and their families with their experience with gynaecological cancers.²¹ Many also endeavour to gain a media profile and involve themselves in media events to increase the community awareness of gynaecological cancers.²²

15 *Submission 44*, p.11 (NBCC); *Committee Hansard 1.8.06*, p.59 (NBCC).

16 *Submission 44*, p.12 (NBCC); *Submission 52*, p.13 (Commonwealth Department of Health and Ageing).

17 *Submission 56*, p.34 (The Cancer Council Australia, COSA and NACCHO).

18 *Submission 51*, p.29 (The Cancer Council Western Australia).

19 *Submission 56*, p.34 (The Cancer Council Australia, COSA and NACCHO).

20 *Submission 24*, p.12 (ASGO).

21 *Submission 7*, p.6 (Gynaecological Cancer Society); *Submission 6*, p.1 (NSW Psychosocial Support Project); *Submission 14*, p.8 (GAIN).

22 *Submission 24*, p.12 (ASGO).

6.32 Some examples include:

- the development of the *Directory of gynaecological oncology treatment and support services* (NSW Psychosocial Support Project, NSW Health and Life Force Foundation);²³
- the establishment a national gynaecological awareness day in Perth on 10 September 2006 (GAIN);²⁴
- the launch of an online patients' forum to encourage interaction between women with gynaecological cancers (National Ovarian Cancer Network);²⁵
- the adaptation of the Breast Cancer Network of Australia's *My Journey Kit* for gynaecological cancers (Ms Margaret Heffernan);²⁶ and
- the development of a supporting partners program focusing on women with gynaecological cancers (Gynaecological Cancer Society).²⁷

Success of current activities

6.33 The Committee heard from witnesses that despite the efforts and enthusiasm of governmental and other organisations in developing and disseminating education nationally and locally, the level of awareness and understanding of gynaecological cancers remained low in Australia. The Western Australian Gynaecologic Cancer Service said:

There is a paucity of knowledge in the general community regarding the risk factors, symptoms, signs and treatment of gynaecological cancers.²⁸

6.34 Ms Carmen Duncan, Fundraising Manager for the GO Fund, commented that when she approached the corporate sector for donations, she found there was 'widespread ignorance about ovarian cancer in particular and gynaecological cancer in general'.²⁹

6.35 Gynaecological cancer control can be measured by success in prevention, reduction in incidence, increasing survival and improving quality of life. These factors are all linked to the level of education and awareness that women and the broader community have about these cancers.

23 *Submission 6*, p.1 (NSW Psychosocial Support Project).

24 *Committee Hansard* 4.8.06, p.40 (GAIN).

25 *Committee Hansard* 3.8.06, p.103 (National Ovarian Cancer Network).

26 *Committee Hansard* 3.8.06, p.51 (Ms Margaret Heffernan).

27 *Submission 7*, Attachment 1 B (Gynaecological Cancer Society).

28 *Submission 28*, p.11 (Western Australian Gynaecologic Cancer Service).

29 *Committee Hansard* 1.8.06, p.4 (GO Fund).

6.36 In examining current educational activities, it was hard to measure the success of the activities themselves without mechanisms for review and feedback from women and the community. Whilst this occurred on an informal and ad hoc basis, no detailed national studies on the adequacy of current approaches to education in Australia have been undertaken to date.

6.37 The Committee considers the following issues raised throughout the inquiry are important and must be considered in further detail.

Vagueness of symptoms

6.38 As noted many times throughout the inquiry, symptoms of some gynaecological cancers are vague.³⁰ This is particularly the case for ovarian cancer as its symptoms can be easily confused with variation in normal function, leading to delay in presentation to a medical practitioner for evaluation.³¹

6.39 The Cancer Council Western Australia stressed that distinguishing the symptoms of ovarian cancer from those that normally occur was problematic, for women and also health professionals. Ms Crossing from Cancer Voices Australia agreed that women were largely ignorant of the connection between known risk factors and the symptoms of some gynaecological cancers. She argued 'there is less than easy access to reliable information for women'.³²

Disproportionate focus on other cancers

6.40 The extent to which women currently received and retained appropriate information and education on gynaecological cancers was thought to be influenced by the focus on other types of cancer. The Committee heard that information was generally more accessible for some cancers than others and that women with breast cancer could access much more information about aspects of their disease and its management than women with gynaecological cancers. The clear message from submitters and witnesses was that a strategy to increase women's awareness and knowledge of gynaecological cancers was required to ensure it was 'higher on the radar'.³³

6.41 The Committee also noted that a large proportion of the information and awareness raising efforts in Australia have tended to focus on cervical cancer screening programs and ovarian cancer (through the NBCC's Ovarian Cancer Program). It is important to raise the profile of all gynaecological cancers.

30 *Submission 24*, p.12 (ASGO).

31 *Submission 28*, p.11 (Western Australian Gynaecologic Cancer Service).

32 *Committee Hansard 2.8.06*, p.24 (Cancer Voices Australia).

33 *Committee Hansard 1.8.06*, p.62 (NBCC).

Fragmented approach

6.42 Many witnesses and submitters commented on the fragmented and uncoordinated approach to education, particularly at the community level.³⁴ This influenced the ability of women and the broader community to receive and retain educational messages. The following were identified as the consequences of this fragmentation:

- duplication of resources and effort, often by people and professionals working in a volunteer capacity;³⁵
- increased potential for confusion over responsibility for initiatives;³⁶ and
- untargeted dissemination of large volumes of information and other products, leading to gaps in delivery and lack of readily available information.³⁷

Personal experiences needed

6.43 The Committee heard that women generally seemed to be poorly informed about gynaecological cancers until they were touched by it in one way or another, either personally or through someone close to them.³⁸

6.44 Dr Helen Zorbas, Director of the NBCC, agreed that most people were not interested in something until it came close to home. She argued that because breast cancer affected a greater number of women it was higher on the radar than ovarian cancer 'which touches relatively fewer people in the community'.³⁹

6.45 Ms Tish Lancaster from the Cancer Nurses Society of Australia (CNSA) also acknowledged that gynaecological cancers were not high on women's radar.

We have also heard several times today about knowledge of gynaecological cancer and women saying that they had never heard of ovarian cancer until they got it or until they know somebody who gets it. I think that is not particular only to ovarian cancer; I actually think it is particular to many cancers.⁴⁰

34 *Submission 28*, p.11 (Western Australian Gynaecologic Cancer Service); *Submission 24*, p.12 (ASGO).

35 *Submission 10*, p.7 (Sydney Gynaecological Oncology Group).

36 *Committee Hansard 23.6.06*, p.55 (Senator Jeannie Ferris).

37 *Committee Hansard 2.8.06*, p.8 (The Cancer Council Australia).

38 *Committee Hansard 1.8.06*, p.62 (NBCC).

39 *Committee Hansard 1.8.06*, p.62 (NBCC).

40 *Committee Hansard 1.8.06*, p.73 (CNSA).

Misunderstanding about what Pap smears screen for (ie, only cervical cancer).

6.46 The Committee was told that women were getting the message about having Pap tests and that the current cervical cancer screening program was very successful, however it was evident that women commonly misunderstood that Pap smear testing did not screen for the full range of gynaecological cancers. Mrs Erica Harriss from the National Ovarian Cancer Network (ACT and region) made the following comment about the misunderstanding.

Senator FERRIS—Do you think there might be some confusion in the general umbrella of gynaecological cancer between pap smears and the protection that they might offer?

Mrs Harriss—Yes, I have actually had it said to me, ‘You don’t need to worry about that. You have had a pap smear.’ And you have to say to that, ‘A pap smear does not detect ovarian cancer.’⁴¹

Lack of media profile

6.47 The media is a popular source of information for many Australians. The Committee heard that gynaecological cancers did not have a high media profile relative to other cancers, despite the efforts of many organisations.

Despite the efforts of established ovarian cancer organisations that are attempting to get this information out it does not get high media profile, and if it is available it is not being communicated effectively.⁴²

6.48 Ms Anne Mellon, a clinical nurse consultant from the Hunter New England Centre for Gynaecological Cancer, commented that breast cancer was in the public eye, whereas gynaecological cancers were not talked about as much in the media or by women publicly 'because it is stuff that happens "down there" and people do not want to bring it up'.⁴³

6.49 The Committee also noted that much of the media interest in gynaecological cancers was generally ad hoc and triggered by publicity regarding specific media 'breakthroughs' such as the recent release of a vaccine for the human papilloma virus.⁴⁴

Strategies for change

6.50 The provision of information on gynaecological cancers and support to the women and community should be a priority. In supporting this argument, Professor David Allen from The Cancer Council Victoria's Gynaecological Cancer

41 *Committee Hansard* 23.6.06, p.24 (National Ovarian Cancer Network – ACT and region).

42 *Committee Hansard* 3.8.06, p.74 (Ms Connie Nikolovski).

43 *Committee Hansard* 2.8.06, p.64 (Hunter New England Centre for Gynaecological Cancer).

44 *Submission* 28, p.11 (Western Australian Gynaecologic Cancer Service).

Committee and Victorian Cooperative Oncology Group argued that education of the public should be 'carefully considered and messages and advice must always be properly formulated and tested prior to being disseminated'.⁴⁵

6.51 In commenting on public education and cancer more generally, Mr Terry Slevin, Director of Education and Research at The Cancer Council Western Australia, said that a balance must be reached between getting a profile and getting the attention.

The notions of cut-through, as you will know from your own careers as politicians, of reaching your target audience, is an immediate challenge. Sometimes the way some organisations can achieve that is through hyperbole, if you like, so that it is a clear and dramatic statement of a problem. We have a clear and dramatic statement of a problem, but what we do not have is a clear and constructive solution to that problem.⁴⁶

Areas of focus

6.52 Witnesses called for new educational strategies to focus on all aspects of gynaecological cancer issues, ranging from identification of symptoms to the location of treatment facilities. Organisations such as GAIN said that issues must not be considered in isolation; rather they must be integrated with the larger, more challenging issues of gynaecological cancer care across the board. GAIN argued that education 'must also extend beyond the narrow realm of cancer education to education regarding the full range of gynaecological issues facing women in today's society'.⁴⁷

Education needs to focus on the holistic nature of risk factors, symptoms and treatment, in order that it is relevant to communities; accommodate the individual's preference for a range of treatment options (ranging from conventional to alternative); and be extended to include non-cancerous gynaecological conditions/issues.⁴⁸

6.53 It was noted that the need for information and the depth of information being sought would vary between women and would change throughout their cancer journeys. Commonly identified areas in need of greater attention included: psychosocial and psychosexual support; physical and daily living; patient care and support; services and resources; and complementary and alternative therapies and medicines.

Too much education?

6.54 It was suggested to the Committee that too much awareness generation and education could be counter-productive as it had the potential to unnecessarily scare

45 *Committee Hansard* 3.8.06, p.83 (The Cancer Council Victoria and Victorian Cooperative Oncology Group).

46 *Committee Hansard* 4.8.06, p.5 (The Cancer Council Western Australia).

47 *Submission* 14, p.8 (GAIN).

48 *Submission* 14, p.8 (GAIN).

women. GAIN refuted this argument saying this underestimated the ability of women to use knowledge in a way that is beneficial for them. Ms Jenkins from GAIN argued:

Our experience as a support organisation, from people that contact us on a daily basis, is that their lack of knowledge and awareness has contributed to whatever problem they have had, in that they often do not know how to describe their symptoms or indeed their gynaecological parts correctly; that they did not know that these things existed and how they could prevent transmission of them or how they could look after themselves; and that they feel ignorant when they go to their GP or gynaecologist, which no woman needs to feel about her body.⁴⁹

6.55 Ms Carolyn Walker, Director of the National Ovarian Cancer Network, also stressed that 'knowledge is power' and that it was important that organisations work together to 'get this vital and life-saving information out into the community'.⁵⁰

A new, coordinated approach

6.56 Many groups, such as the Sydney Gynaecological Oncology Group at the Royal Prince Alfred Hospital, did not make specific recommendations about the need for particular activities, but instead simply argued for a more coordinated approach and increased funding.

6.57 As such, the Committee has focused its attention on the key recommendation made during the inquiry – the need for a national public awareness campaign.

National Awareness Campaign

6.58 There was support for the development of a national awareness campaign to raise the profile of gynaecological cancers and to encourage women to present to general practitioners with symptoms earlier. It was also argued that a campaign would raise the level of awareness about gynaecological cancers in the community more generally.⁵¹

6.59 Mrs Lisle Fortescue, an ovarian cancer survivor, argued that because gynaecological cancers were a mystery to Australians, funding for an awareness campaign was needed.⁵² GAIN also recommended that awareness and education campaigns would enable women to take better control of their own gynaecological health.⁵³

49 *Committee Hansard* 4.8.06, pp.38-39 (GAIN).

50 *Committee Hansard* 3.8.06, p.94 (National Ovarian Cancer Network).

51 *Committee Hansard* 2.8.06, p.63 (ASGO).

52 *Committee Hansard* 1.8.06, p.28 (Mrs Lisle Fortescue).

53 *Committee Hansard* 4.8.06, p.37 (GAIN).

6.60 Of all the gynaecological cancers, a particular need to raise awareness about ovarian cancer was identified. Associate Professor Anthony Proietto, Chairman of ASGO, stated:

If we look at some of the other cancer sites, cervical cancer has a reasonable public profile, breast cancer certainly has an excellent public awareness profile and the profile of prostate cancer is getting better and better. We see this with our own patients. They often say: 'We didn't know anything about ovarian cancer. We didn't know it could exist. We didn't know that there were symptoms. We didn't know anything about it.' It is not talked about by the media, it is not talked about among women themselves and there is an awful lot of ignorance about some of the other sites, like ovary endometrial, vulval et cetera.⁵⁴

Whilst there was broad agreement about the need for a greater awareness, the detail of how a campaign would be executed or the cost were not examined in any depth by many.

6.61 In evidence, Dr Edward Trimble, Head of Gynecologic Therapeutics at the National Cancer Institute in the United States mentioned that the Centers for Disease Control and Prevention had conducted a public education that targeted ovarian cancer in the United States.

One of our sister agencies, the Centers for Disease Control and Prevention, has a public education campaign targeting ovarian cancer and the vague symptoms that you have mentioned. They have worked with the society of oncologists and several of the ovarian cancer advocacy groups in helping to identify these symptoms and to develop a broad based educational campaign.⁵⁵

6.62 Professor Philip Di Saia, a gynaecological oncologist from the United States, also referred to a number of public education initiatives that had been successful in the United States. These included an ovarian cancer month (each September), marathons to raise funds and awareness and the development of brochures, guidelines and cervical cancer screening programs.⁵⁶

6.63 The Gynaecological Cancer Society presented the Committee with a detailed proposal for a national public awareness campaign and argued that an 'effective and efficient' example could be found by looking at the NBCC's approach to breast cancer.⁵⁷

54 *Committee Hansard* 2.8.06, p.63 (ASGO).

55 *Committee Hansard* 16.8.06, p.4 (United States National Cancer Institute).

56 *Committee Hansard* 10.8.06, p.4 (Professor Philip Di Saia).

57 *Submission* 7, Attachment 3 (Gynaecological Cancer Society).

Over the years many millions of dollars have been spent informing and educating the public on relevant breast cancer issues and we must be prepared to do the same if we expect to see similar results.⁵⁸

6.64 For an efficient and effective campaign, the Gynaecological Cancer Society stressed that all stakeholders needed to participate in a coordinated fashion, that it needed to be a long campaign and that all media streams should be involved. The Society estimated that their proposal would cost around \$19 million over five years.⁵⁹

6.65 Ms Connie Nikolovski, an ovarian cancer survivor, suggested that television would be the best medium to convey messages to a large number of people.

Definitely more television, because everybody watches TV—and communicating. And radio, in people’s own language—not just in the Australian language. We are a multicultural society, so we should cater for that. I know that people stick in their own little groups. As soon as you have a representative of one community, that flourishes throughout that whole community.⁶⁰

6.66 In agreeing that raising awareness was a positive step, witnesses cautioned that education needed to be carefully tailored so as not to create a scare campaign and to overload general practitioners.⁶¹ Mr Gower from the Gynaecological Cancer Society stated:

My only fear with a national campaign is that it has to be done sympathetically so that we do not have all of our GPs and our treatment centres totally overwhelmed by six million women who are sure they have one of the six gynaecological cancers, but that can be done.⁶²

6.67 The Committee heard that because of the vague nature of the symptoms for gynaecological cancers, in particular ovarian cancer, effort was needed to strike an appropriate balance between providing women with useful and timely information (from a more medical perspective), and not scaring them into confusing a gynaecological cancer with, for example, their normal monthly menstrual cycle.⁶³ Mr Slevin from The Cancer Council Western Australia argued that greater investment in research was needed to better shape the messages provided to women.⁶⁴

58 *Submission 7*, Attachment 3 (Gynaecological Cancer Society).

59 *Submission 7*, Attachment 3 (Gynaecological Cancer Society).

60 *Committee Hansard* 3.8.06, p.76 (Ms Connie Nikolovski).

61 *Committee Hansard* 1.8.06, p.75 (CNSA).

62 *Committee Hansard* 2.8.06, p.43 (Gynaecological Cancer Society).

63 *Committee Hansard* 4.8.06, p.5 (The Cancer Council Western Australia).

64 *Committee Hansard* 4.8.06, p.6 (The Cancer Council Western Australia).

6.68 Not all witnesses supported a campaign, nor saw it as a priority, instead choosing to direct resources and funding on more focused educational activities. The main reason cited was summed up by The Cancer Council Western Australia.

The promotion of such generalised symptoms in relation to gynaecological cancer has significant potential to generate high levels of anxiety, and potentially promoting significant increase in health service seeking, with little evidence to suggest that such anxiety and further investigation will result in improved detection or ultimately better health outcomes.⁶⁵

6.69 The Department and the NBCC agreed with the position of The Cancer Council Western Australia.

6.70 Dr Zorbas from the NBCC argued that the lack of a clear, simple message about ovarian cancer symptoms meant that there was not a strong evidence base present for a viable campaign and as such it had 'not been identified as a priority area' by the NBCC's stakeholders.⁶⁶ Dr Zorbas stated:

If we could find a particular group of symptoms, for example, that were more significant when pooled together, that could give us an important key message. The message around early detection is around symptoms that are vague and common, and it is not a simple, clear message about awareness or screening or anything that you could put into a clean package for women. Unfortunately, that is the case at the moment.⁶⁷

6.71 The Department also agreed that the lack of a simple message or slogan similar to those developed for breast cancer and for cervical cancer (such as 'have a Pap smear'), prevented the viability of a public awareness campaign.

6.72 On this point, Professor Ian Olver, Chief Executive Officer of The Cancer Council Australia, said that the 'one thing that ovarian cancer shares with other cancers is that the symptoms are persistent'. He argued that a message about persistency of symptoms should be investigated further and could also be given to the community and reinforced without creating 'public panic'.⁶⁸

6.73 The NBCC highlighted its work with the National Ovarian Cancer Network, particularly around Ovarian Cancer Awareness Week and an upcoming awareness road-show focusing on regional centres, were effective avenues for spreading some of its key messages in both breast cancer and ovarian cancer.⁶⁹

65 *Submission 51*, p.29 (The Cancer Council Western Australia).

66 *Committee Hansard 1.8.06*, p.62 (NBCC).

67 *Committee Hansard 1.8.06*, p.63 (NBCC).

68 *Committee Hansard 2.8.06*, pp.8-9 (The Cancer Council Australia).

69 *Committee Hansard 1.8.06*, p.62 (NBCC).

6.74 The NBCC and the Department emphasised that they had instead focused their attention on working with general practitioners to raise awareness on ovarian cancer issues.

We have put a lot of energy into that because we want them to have it on their radar, to think, 'Maybe this woman could have ovarian cancer and we should be appropriately investigating her.'⁷⁰

Broader education about cancer

6.75 Witnesses suggested that improvements to gynaecological cancer awareness could be made as part of a broader strategy to increasing education about cancer. Professor Olver considered that the whole cancer community, including the sub-specialty of gynaecological cancer, would benefit from information and awareness about all cancers, with priority put on disseminating messages about seeking advice on persistent symptoms.⁷¹

Factors to consider

One size does not fit all

6.76 When developing new initiatives, the Committee heard that it was important to recognise that women and the broader community have different information needs and different ways of absorbing information.

6.77 In considering the merits of particular educational strategies, Dr Sarah Pickstock, a Palliative Care Physician from the King Edward Memorial Hospital argued that 'we are all unique with our decisions in life and health decisions' and that the challenge for health care workers was to 'pick the right style for the right person'.⁷² The Committee heard that for some people, it was deleterious to give too much information, whereas this was not the case for others.

6.78 As a practical way of addressing this issue, Mr Michael Powell, Vice Chair of Cancer Voices Victoria suggested that setting a minimum information standard would be a positive step to overcoming inconsistencies in the amount of information given to women and the timing of it. Mr Powell argued:

Set a minimum, set a protocol and everyone has to be given this minimum information, which gives them the guidelines of where to go and is structured in such a way that country people have the phone numbers, toll free numbers, to talk to somebody, because they cannot go down to the corner and find someone. It has to be structured to suit all Australians.⁷³

70 *Committee Hansard* 1.8.06, p.63 (NBCC).

71 *Committee Hansard* 2.8.06, p.9 (The Cancer Council Australia).

72 *Committee Hansard* 4.8.06, p.76 (King Edward Memorial Hospital).

73 *Committee Hansard* 3.8.06, p.89 (Cancer Voices Victoria).

Overcome stigma and use terminology correctly

6.79 It was evident throughout the inquiry that in discussions about gynaecological cancers it was important to overcome any taboos that might exist.

6.80 Witnesses emphasised that women were more comfortable talking about breast cancer than ever before and that the same needed to occur for gynaecological cancers, particularly for women from culturally and linguistically diverse backgrounds. Ms Jenkins from GAIN said that if discussions about gynaecological cancers were more public and women became more comfortable with the language of gynaecological cancer, its profile would grow.

The terminology is not even being used correctly...Using 'gynae cancers' in itself as a catch-all is not providing the right levels of education. The media has to be on to it. We have to be talking about it in public forums and again at all levels—community, clinical and also government.⁷⁴

6.81 It was argued that education should aim to facilitate more open discussion about gynaecological cancers in order to overcome some of the stigma attached to the terminology and related issues. Ms Nikolovski argued that people should learn 'that cancer is a word that should not be avoided but must be discussed'.⁷⁵

6.82 Ms Michele Kosky, Executive Director of the Health Consumers Council Western Australia, argued that gynaecological health deserved more attention within Australia's sexual health framework in order to give it a higher profile alongside breast cancer.⁷⁶

Written information

6.83 There is a large amount of written information produced for women with gynaecological cancers and the broader community, including pamphlets, booklets and fact sheets. The Committee heard that high quality information should include evidence-based statements and be easily accessible. Also important is that information should be presented in a balanced way using concise, jargon-free language.

6.84 Traditionally, sources of written information have been medical and allied health professionals, family and friends and the publicly available media.

6.85 It was evident that many organisations produced well-written and appropriate information to assist women with gynaecological cancers, however the Committee heard that many women were not able to access the full range of information available necessary to make fully informed decisions about different treatment options.

74 *Committee Hansard* 4.8.06, p.40 (GAIN).

75 *Committee Hansard* 3.8.06, pp.74-75 (Ms Connie Nikolovski).

76 *Committee Hansard* 4.8.06, p.60 (Health Consumers Council Western Australia).

Online information and e-medicine

6.86 Some women have become more active managers of their health since the introduction of the Internet. The Internet has meant women can access information about gynaecological cancers and their specific conditions online in addition to information supplied by medical and other health professionals.

6.87 The Committee heard that women used information on the Internet as an educational tool to:

- obtain a range of opinions regarding gynaecological cancers, for themselves, family or friends;
- search directly for health information, health organisations or providers;
- participate in support groups; and
- consult with health professionals.

6.88 The Internet, particularly in the context of psychosocial support, can be helpful for women in many respects as it is a convenient, anonymous and cost effective source of information.

6.89 For health providers and government, the Internet can be a very effective tool for disseminating health information, health education and services.

6.90 Though the Internet is highly visible and accessible to many Australians, there is an enormous volume of information online meaning that it is potentially confusing to navigate through. Often individuals might not get to the right website or get conflicting information. A coordinated and visible approach is needed.

6.91 Although many organisations provide high quality information, there is no comprehensive site which details information on types of gynaecological cancers as well as treatment options, treatment facilities and Government assistance (for example, patient travel schemes) in Australia. In New South Wales there is a directory of gynaecological oncology treatment and support services that is available online, but a national approach is needed with a broad focus that includes all aspects of gynaecological cancer care.

Face-to-face contact important.

6.92 Despite the prevalence of health information on the Internet, women still value face-to-face interaction.⁷⁷

6.93 Ms Jenkins from GAIN pointed out that the Internet 'is not the be-all and end-all'.⁷⁸ It is used a lot because it is accessible, cheap and gives immediate access, but

77 *Committee Hansard* 1.8.06, p.33 (Mrs Lisle Fortescue).

78 *Committee Hansard* 4.8.06, p.43 (GAIN).

any coordinated approach to information provision must include human interaction, particularly for those that are not computer literate.

Consideration of population differences

6.94 As the incidence of gynaecological cancers as a group continues to rise, with a disproportionate rate in disadvantaged groups including Aboriginal and Torres Strait Island populations and those in rural and remote areas, special consideration of women from culturally and linguistically diverse backgrounds must be taken into account by decision-makers.

6.95 Furthermore, given the ageing of the population and the fact that gynaecological cancers are mainly a disease of older people, incidence is expected to continue to rise in the future. This trend will pose an ongoing challenge in the delivery of optimal gynaecological cancer education – both about prevention and detection and also throughout the cancer journey.

Roles and responsibilities

6.96 The need for a better coordinated approach to promoting awareness and conducting education about gynaecological cancers was thought to be a high priority by many witnesses and submitters. It was argued that a powerful voice was required to implement a national campaign and associated programs along similar lines to that of the successful breast cancer movement, which achieved a great deal for the Australian community.⁷⁹

6.97 Many suggested that the establishment of a national body to provide this coordination and to centralise resources would represent a significant advance for women and an important strategic investment for Australia as a whole.⁸⁰ A national body would provide efficient and timely mechanisms to produce up-to-date educational material and to consolidate and integrate the current ad hoc development and delivery of support and information resources.⁸¹ The proposal for a national centre is discussed further in Chapter 2.

6.98 The Australian Society of Gynaecologic Oncologists (ASGO) indicated its support for such a national approach. It argued that the formation of a National Gynaecological Cancer Centre (NGCC) would mean that education was better coordinated, diversity catered for, a higher audience reach achieved and better support for existing organisations already providing education.⁸²

79 *Submission 7*, Attachment 3 (Gynaecological Cancer Society).

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

81 *Submission 27*, p.26 (Ms Margaret Heffernan); *Submission 10*, p.6 (Sydney Gynaecological Oncology Group); *Submission 48*, p.3 (The Cancer Council Victoria).

82 *Submission 24*, p.12 (ASGO).

6.99 Others, such as The Cancer Council Australia, recommended that the NBCC's existing role in disseminating community information should be expanded beyond ovarian cancer to focus on all gynaecological cancers.⁸³

6.100 It was also thought that Cancer Australia was an authoritative body that could coordinate educational strategies to ensure that information is available and visible.

Conclusion

6.101 Gynaecological health is a complex area and education is essential to ensure that women and the broader community:

- are aware of the risk factors and symptoms that may indicate the presence of gynaecological cancers; and
- make informed choices about the treatment and management of their particular health and medical issues.

6.102 The Committee heard that through education, women with gynaecological cancers are generally better informed about all aspects of their health and care. Information based on quality evidence led to improved referrals, better knowledge of treatment options and more realistic outcome expectations. The key is reliable information that is available and accessible to women and the broader community. It is also important that health providers (for example, general practitioners) play a role in encouraging women to take full advantage of the information available to them.

6.103 Better coordination of existing resources and providing the necessary support to organisations and primary healthcare providers were important pre-conditions to ensuring that women and the community were supported and educated about gynaecological cancers.

6.104 It was argued that responsibility for coordination and strategic planning of educational initiatives could lie with one of a number of bodies, including the newly established Cancer Australia, the NBCC, the proposed NGCC or another national body (under the umbrella of Cancer Australia). Whilst witnesses and submitters diverged on the appropriate body to take responsibility, an overwhelming number considered that a national approach would ensure a suitable body provided leadership and a nationally consistent source of information on services, treatment options, government assistance and links to appropriate support groups which can be made readily available in different forms.

83 *Submission 56*, p.34 (The Cancer Council Australia, COSA and NACCHO).

Recommendation 28

6.105 The Committee recommends that Cancer Australia, in conjunction with the Centre for Gynaecological Cancers, be given wide-ranging responsibility for the management of coordinated national education strategies targeting women and their families, friends, carers and the broader community about gynaecological cancers.

6.106 The Committee further recommends that a review of all existing gynaecological cancer educational material targeting women and the broader community be undertaken by Cancer Australia, in conjunction with a Centre for Gynaecological Cancers, to review the currency of the content and the appropriateness for the audience.

Recommendation 29

6.107 The Committee recommends that Cancer Australia and the Centre for Gynaecological Cancers work together to develop a resource pack be developed and disseminated to give women and the broader community consolidated and consistent information about gynaecological cancers, treatment options, support groups and other services.

Recommendation 30

6.108 The Committee recommends that Cancer Australia and the Centre for Gynaecological Cancers work together to ensure that medical facilities and support organisations have visible and current information on-site in the form of posters and pamphlets about gynaecological cancers and related services.

Recommendation 31

6.109 The Committee recommends that Cancer Australia analyse and assess the approach taken in the United States in the following areas:

- public education (for example, the strategies of the Centres for Disease Control in relation to ovarian cancer);
- advocacy by gynaecological cancer groups; and
- service provision by support groups.

