

**AUSTRALIA'S FIRST
NATIONAL BREAST CANCER CONFERENCE FOR
WOMEN**

MAKING A DIFFERENCE

**A report from the conference:
Actions recommended by women with breast cancer for the
benefit of the Australian community**

Canberra, Australia. October 16-18 1998



Making a difference

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Making a difference

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Preamble

Australian women affected by breast cancer met at their first national conference in October 1998. They exchanged views on many different topics and agreed that it was necessary to *make a difference* to the way in which breast cancer is managed in Australia.

Breast cancer affects the whole community, not just women with the disease. Every year, 10,000 Australian women are diagnosed with breast cancer and 2,600 die from the disease. The number of women diagnosed with breast cancer is still increasing. A small reduction in the mortality of the disease is now evident. Thus at least 100,000 women are living with the disease at any one time and this number will increase with time.

Any change to the prevention and treatment of the disease will affect the whole Australian community. The priority actions proposed by the conference are aimed at *making a difference* to the whole community as well as women living with the disease.

Because breast cancer has such far reaching affects, the priority actions identified at the conference require various groups within the community to make changes to their current practices. These include:

- * government policy makers, both State and Commonwealth and the public servants who implement these policies;
- * the research community;
- * the medical and nursing communities, both current practitioners and those educating the practitioners of tomorrow;
- * the cancer organisations in each state and territory which have responsibility for research, public education, support groups and volunteer services: these organisations are described generically in this report as 'cancer councils';
- * the general community who need to understand more about breast cancer in order to help women and their families to deal with the disease in a humane way; and most importantly,
- * the women directly concerned, those living with breast cancer. They need to take a proactive role to ensure that their voices are heard loudly and clearly.

The national conference built on issues raised at state and territory forums which were held during 1998, involving about 1,500 women. These issues formed the basis of discussion in the conference workshops.

Each workshop was lead and facilitated by a consumer, who introduced a panel of speakers representing various stakeholders relevant to each topic, including: clinicians, researchers, industry representatives, bureaucrats, health care workers and administrators, and women with breast cancer. Workshop panelists acted as 'triggers' for discussion.

The issues raised were subsequently brainstormed by workshop participants and developed into an agenda for priority actions that could be undertaken on an 'individual and group' basis, on a 'state and territory' basis and on a 'national' level.

These actions were endorsed by the conference as a whole and publicly released, as a Priority Action Plan, at the end of the conference on 18 October.

This report from the conference provides a valuable resource for all those interested in *making a difference*.

Comments are welcome and should be directed to the Breast Cancer Network Australia, PO Box 4082, AUBURN SOUTH VIC 3122.

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Acknowledgments

Women from every state and territory worked hard to ensure that as many women as possible from across the nation were represented at this conference. We thank them all for their work.

The large number of women who attended the state and territory forums held during 1998, eloquently expressed their views, fears and concerns to help deliver better services for women in the future. They were the backbone of this conference.

Women who attended this conference came with enthusiasm and ideas for action. This action plan is a result of their voices which were clearly expressed and heard.

The steering committee listened and contributed through numerous teleconferences to develop and implement the organisation of, and the concepts behind, this conference. Most of the steering committee members also chaired the workshops which developed the actions listed here. This was a difficult but most important task. International and local speakers and participants in workshop panels and the hypothetical provided an important and varied frame of reference for the discussions. The identified priority actions came from the women themselves.

The NHMRC National Breast Cancer Centre provided most of the funding and the conference organisation skills to ensure that this conference worked so well. The staff of the NHMRC National Breast Cancer Centre, in particular Sally Redman, deserve the heartfelt thanks of the women of Australia living with breast cancer. Without this vital support, the conference would not have taken place.

Finally, women living with breast cancer are the inspiration for all those involved with this conference. They fight their individual battles, quietly, patiently, but with the utmost determination and courage and the support of their families and friends. May their voices continue to be heard.

Priority Action Plan

Context

This Priority Action Plan was publicly released at the end of the conference on 18 October 1998. It has been distributed by individual women and consumer groups to stakeholders at both state and national levels.

The following major actions were identified by Australia's First National Breast Cancer Conference for Women:

Actions

- * Breast Cancer Network Australia to lobby for breast care nurses to follow women from diagnosis throughout treatment.
- * Ensure that all women are provided with information at the time of diagnosis and before treatment, in particular the consumer guidelines and relevant local information.
- * Breast Cancer Network Australia to lobby the Australian Medical Council and Professional Colleges that communication skills must be made an essential component in initial and continuing medical education and training.
- * Consumers to promote consumer representation in all areas and at all levels of decision-making related to breast cancer research including the development and coordination of clinical trials.
- * Undertake to ensure funding is increased and maintained through grassroots approaches (e.g. letter writing, lobbying) for medical, scientific and policy research.
- * State and territory groups and Breast Cancer Network Australia to lobby government for the continued funding of the NHMRC National Breast Cancer Centre.
- * Develop a mechanism for linking young women nationally.
- * Lobby the medical profession to ensure that all women are told about the risk of developing lymphoedema following axillary clearance or radiotherapy prior to the procedure to ensure informed consent.

Special Needs

The conference recognised that there are many women with special needs who may not have been represented in large numbers, therefore the following additional actions are recommended:

Aboriginal and Torres Strait Islander women

- * Lobby to develop resources for indigenous women about information, education, counselling, support and training of aboriginal health workers.

Women with recurrent and advanced disease

- * Promote access to clinical trials and ensure equitable access to therapies and drugs.
- * Lobby Breast Cancer Support Services and other appropriate bodies to be inclusive of women with advanced breast cancer.

Rural and regional women

- * Lobby to improve access to information for rural and regional women, e.g. raise awareness of the National Information Hot Line and develop information packages with local and regional specifics.

The future

Australian women are now ready to push for the actions outlined in this report to become realities. These actions, which arose from discussions within the framework of specific workshop sessions at the national conference, will need to be progressed in conjunction with relevant organisations.

As women living with breast cancer, our task ahead is to communicate these priority actions to health service providers; state, territory and commonwealth governments; medical, nursing and research communities; cancer councils; support providers, and the general community. This task is being taken up by individual women and groups of women across Australia.

We want to work in partnership with others to *make a difference* to breast cancer treatment, research and care.

During 1998, some 1,500 women from all over Australia, of all ages and backgrounds and stages of the disease, came together in local forums to identify the issues of importance to them. Some of these women have joined advocacy groups which have now been set up in all states and territories. Other women have taken the ideas and issues back to their support groups for local action. Women who attended the national conference in Canberra returned to their communities with renewed enthusiasm and determination to make a change.

The voices of all of these women will now be heard clearly across Australia.

Following the national conference an umbrella group, the Breast Cancer Network Australia, was set up to represent the views of all women and others in the community with an interest in breast cancer. This network will ensure that the voices of women are heard in national forums.

This plan of action is the first time the voices of those living with breast cancer have been expressed nationally. There are now mechanisms by which their voices can be heard in local, state and national forums. Australian women hope to meet again in two years time to consider the extent to which change has been made.

With these actions, determination and dedication, the future must become brighter for Australian women living with breast cancer and the many thousands who will follow them.

Making a difference

Detailed reports from the workshops:

The following section includes a detailed report from each of the workshop sessions held at Australia's First National Breast Cancer Conference for Women:

- Influencing breast cancer research
- Women with recurrent or advanced disease - improving care
- 'Replace a breast' - improving access to prostheses and breast reconstruction
- Young women - improving care
- Rural and regional women - improving access to services and information
- A team approach - improving the quality of care
- Improving supportive care
- Doctor/patient relationship - improving communication
- Other issues
- Aboriginal and Torres Strait Islander women - improving care
- Lymphoedema

Influencing breast cancer research

Context

Consumer participation in the direction of breast cancer research has been a major issue at state and territory forums held during 1998. Australian women have expressed interest in research into the causes, prevention and optimal treatment and care of breast cancer. Women's priorities have frequently been found to be different from those of researchers. Women bring a special and essential perspective to research which could be shared with those determining research directions. Consumers are part of the research process in the UK, USA and Canada and the outcomes of these partnerships have been very positive.

This workshop identified the following actions as priorities for ensuring consumer participation in breast cancer research:

Individual and group actions

- * Participate in science and advocacy training programs to develop the skills needed to participate in decision-making about research and clinical trials.
- * Be prepared to become a member of committees which are making decisions about research and clinical trials.

State and territory level actions

- * Consumer groups to promote and ensure consumer representation at all levels of decision-making related to breast cancer research, including the development and co-ordination of clinical trials.
- * Consumer groups to establish a list of consumer representatives available to participate in local decision-making forums.
- * Consumer groups to approach organisers of medical and research conferences to allow free or reduced registration fees for consumers.

National level actions

- * Consumer groups to work for the finalisation of the National Action Plan for Breast Cancer Research, as recommended in the report by the NHMRC National Breast Cancer Centre / Kathleen Cuningham Foundation, with consumer input at all stages.
- * Consumer groups to work with organisations, such as the NHMRC National Breast Cancer Centre, to maintain and develop training and education programs for consumers who will participate in decision-making forums.

- * Consumer groups to lobby for representation on national research organisations through nomination by the Breast Cancer Network Australia.
- * Consumer groups to work with clinicians and the research community to promote the awareness of, and participation in, clinical trials and the dissemination of the results of these trials.
- * Consumer groups, in co-operation with the Breast Cancer Network Australia, to lobby for the continued funding of the NHMRC National Breast Cancer Centre.
- * Consumer groups to work with the research community to lobby for increased funding by state and commonwealth governments for research, including funding for alternative/complementary therapies.
- * Breast Cancer Network Australia to work with the National Breast Cancer Foundation (formerly the Kathleen Cuninghame Foundation) to fund research which reflects the priorities of consumers.
- * Breast Cancer Network Australia to establish a list of consumer representatives available to participate in national decision-making forums.
- * Breast Cancer Network Australia to approach organisers of medical, nursing, research and other relevant conferences to allow free or reduced registration fees for consumers.

Women with recurrent or advanced disease - improving care

Context

Women with advanced breast cancer face many challenges including living with a life threatening or chronic illness. They have frequent contact with the medical profession but to date have not received adequate acknowledgment of the quality of life issues which are important to them.

This workshop identified the following actions as priorities for improving the care of women with recurrent or advanced breast cancer:

Individual and group actions

- * Ensure that information relating to advanced disease is used by the medical profession, hospitals, cancer councils and women's groups.
- * Individuals to be encouraged by consumers and clinicians to keep a patient held record containing test results, reports etc.

State and territory level actions

- * Consumer groups to work with cancer councils to ensure that women with advanced disease have access to trained support volunteers who also have advanced disease.
- * Consumer groups to work with cancer councils to develop a training module for counsellors to provide one on one support for women with advanced disease.
- * Consumer groups to work with cancer councils and the medical profession to increase awareness of the value and availability of palliative care to women with advanced disease and their families.
- * Consumer groups to lobby governments, hospitals and the medical profession for the adoption of patient held records.
- * Consumer groups to work with state and commonwealth governments and the medical profession to ensure that women with advanced disease have equitable access to therapies and drugs.
- * Consumer groups to lobby governments for increased funding for home care services.
- * Consumer groups to develop appropriate links with allied organisations.
- * Governments and hospitals to ensure that the needs of women with advanced disease are specifically considered when resource allocation decisions are made.
- * Governments, hospitals and community care services to improve the continuity of care for women with advanced disease by designating a breast care nurse responsible for the care of an individual.

National level actions

- * Consumer groups, in co-operation with the NHMRC National Breast Cancer Centre and the Breast Cancer Network Australia, to develop a resource directory which can be disseminated through mechanisms such as *The Beacon* and *Breast News* to community groups, helplines, local governments and libraries.
- * Breast Cancer Network Australia to work with the National Breast Cancer Foundation to fund research that reflects the priorities of consumers.
- * Breast Cancer Network Australia and state consumer groups to work with the research community to increase the number of women with advanced breast cancer participating in clinical trials.
- * Breast Cancer Network Australia to develop appropriate links with allied organisations.
- * Breast Cancer Network Australia to work with state and commonwealth governments and the medical profession to ensure that women with advanced disease have equitable access to therapies and drugs.
- * Australian Cancer Society to promote awareness of the National Cancer Help Line and extend it to a 24 hours service.

'Replace a breast' - improving access to prostheses and breast reconstruction

Context

Each year 10,000 Australian women are diagnosed with breast cancer.[▲] Approximately 60% of women will have one, or in some cases both, breasts removed as part of their treatment.[✦] The loss of a breast may cause physical and psychological problems. To overcome these problems, women may choose to use an external prosthesis, to use an internal prosthesis such as a saline implant, to have a breast reconstruction, or to do nothing. Most women choose an external prosthesis.

This workshop identified the following actions as priorities for improving access to prostheses and breast reconstruction:

Individual and group actions

- * Women who experience difficulties in obtaining a prosthesis to document their experience for use by consumer groups to influence change.
- * Women be prepared to set up an informal network of women who have had a breast reconstruction to provide advice to women trying to decide what course of action is suitable for them.

State and territory level actions

- * Consumer groups work with the Breast Cancer Network Australia to influence governments to implement a nationally standardised policy on breast prostheses.
- * Consumer groups to lobby governments to improve access to breast reconstruction surgery, e.g. change the priority status of this surgery from elective to urgent and / or modify systems to reduce time delays.
- * Governments and cancer councils to provide support volunteers and breast care nurses with information on reconstruction which can be used in discussion with women.

[▲] Australian Institute of Health and Welfare. *Breast and cervical screening in Australia 1996-1997*. Canberra: Australian

Institute of Health and Welfare. 1998.

[✦] Craft PS et al. Surgical management of breast cancer in Australian women in 1993: analysis of medicare statistics. *Medical Journal of Australia* 1997;166:626-9.

National level actions

- * The NHMRC National Breast Cancer Centre be asked to continue its work in developing a national policy for the provision of breast prostheses and to work with the Breast Cancer Network Australia to ensure that such a policy is implemented.
- * NHMRC National Breast Cancer Centre to provide accurate and high quality information on breast reconstruction on the Internet as part of their overall package of information for women.
- * Breast Cancer Network Australia to lobby private health insurance funds to ensure that every insured woman who has a mastectomy is able to obtain a prosthesis without 'extras cover'.
- * Breast Cancer Network Australia to lobby distributors of prostheses to increase the life of and decrease the cost of prostheses.
- * Breast Cancer Network Australia to work with clinicians and the Australian Society of Plastic Surgeons to ensure that surgeons with expertise in breast reconstruction are included in the multidisciplinary treatment team.
- * Breast Cancer Network Australia to work with clinicians and the NHMRC National Breast Cancer Centre to ensure that women are advised of the option of reconstruction and ensure that sufficient time is made available for making informed decisions.

Young women - improving care

Context

While breast cancer is more often associated with older women, and resources are targeted at women over 50 years of age, significant numbers of young women are diagnosed, or in some cases misdiagnosed, with the disease. Studies have shown the experience of breast cancer can be more psychologically demanding for younger women as they face unique needs as part of their earlier stage of life.

Issues such as fertility, raising young children, achieving career goals, treatment induced menopause, body image, sexuality and relationship concerns may cause additional distress at diagnosis as well as during and after treatment. Young women want effective strategies put in place to fulfil their unmet needs.

This workshop identified the following priority actions to meet these needs:

Individual and group actions

- * Participate in a network/action group to specifically meet the needs of young women.
- * Discuss strategies to overcome community and clinical misconceptions e.g. 'Too young to have breast cancer'.
- * Consumers to encourage young women to become informed and take responsibility for their own health care specifically relating to breast cancer, to become assertive and to have the confidence to seek a second opinion.
- * Consumers, as volunteers, to help to work with young women to overcome issues such as body image and sexuality problems.

State and territory level actions

- * Cancer councils to provide support volunteers who are similar in age and stage of life to speak to young women.
- * Consumer groups to lobby governments to provide access to home based child and respite care for young women before, during and after treatment.
- * Consumer groups to work with Divisions of General Practice to ensure that General Practitioners use the NHMRC National Breast Cancer Centre recommended 'triple test' for the diagnosis of young women.
- * Consumer groups to nominate young women for positions on decision-making committees and as speakers, for example in medical and nursing education and at conferences and workshops.

National level actions

- * Consumer groups to establish a national network for young women under the auspices of the Breast Cancer Network Australia.
- * NHMRC National Breast Cancer Centre to develop specific information leaflets for young women dealing with issues such as sexuality, fertility, access to support groups, support for partners and other family members, strategies for coping with young children and breaking bad news to young children.
- * NHMRC National Breast Cancer Centre to develop educational materials and national advertising campaigns aimed at educating young women regarding breast health care.
- * National network for young women to distribute information and advice specifically designed for young women.
- * Breast Cancer Network Australia to work with research community and clinicians to encourage more research and clinical trials into improving the diagnostic tools, as well as the incidence, course and treatments for breast cancer in young women.

Rural and regional women - improving access to services and information

Context

Women in rural and regional Australia face many difficulties as a result of their relative isolation from city centres and major medical facilities. Amongst the most common obstacles are lack of access to the full range of treatment options, lack of availability of appropriate medical expertise, the need to travel long distances for certain treatments, separation from families and support systems during treatment, increased costs due to travel and accommodation, and difficulty accessing information and support services.

This workshop identified the following priority actions to overcome these obstacles:

Individual and group actions

- * Consumers to have access to, and be involved in choosing, the most appropriate treatment team including their primary care manager.
- * Consumers to identify local organisations (e.g. schools and libraries) as a means of gaining Internet access to breast information services such as the NHMRC National Breast Cancer Centre Web site.

State and territory level actions

- * In co-operation with rural women, governments to develop region-specific information kits on breast cancer which will then be disseminated to the specialists, general practitioners, breast care nurses, support services and community health centres.
- * Cancer councils to develop a system of breast cancer 'buddies' to support women from rural and regional areas who are being treated away from home.
- * Governments to improve access to, and increase the level of subsidies for, travel and accommodation for women and their children whilst undergoing treatment.
- * Governments, hospitals and private practitioners to provide breast care nurses for women in rural and regional areas.

National level actions

- * Breast Cancer Network Australia, in conjunction with the NHMRC National Breast Cancer Centre, to develop a model travel assistance scheme and together with state consumer groups, to lobby for national implementation.
- * Commonwealth government to encourage the national use of telemedicine for rural women; telemedicine consultations should allow a patient advocate to participate if requested by the woman concerned.

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- * Commonwealth government and relevant professional colleges to improve the availability of medical practitioners suitably qualified in the diagnosis and treatment of breast cancer in rural areas.
- * NHMRC National Breast Cancer Centre to review the level of adherence to the clinical practice guidelines by general practitioners and other clinicians in rural areas.
- * NHMRC National Breast Cancer Centre to develop strategies for the comprehensive dissemination of the consumer guidelines to all who need them in rural areas.

A team approach - improving the quality of treatment

Context

Women with breast cancer need excellent treatment which includes not only physical care, but attention to their psychological, social and information needs. A team approach, incorporating all the necessary medical specialists and other services such as physiotherapy, social services and long term care, is a key way to ensure that all of a woman's needs are met. Women with advanced breast cancer have special needs such as the integration of their treatment into the work of the palliative care team. We need quality treatment for the whole woman.

This workshop identified the following priority actions to improve the quality of treatment for women with breast cancer, using a multidisciplinary approach:

Individual and group actions

- * All women diagnosed with breast cancer to ask how, in general, their treating clinicians communicate with each other and, specifically, which one will oversee her long term care.
- * Women in advocacy and support groups to identify which hospitals and clinics use multidisciplinary teams and then share this information amongst the groups.
- * The woman, in co-operation with her treatment team, to decide who will co-ordinate her care.

State and territory level actions

- * Breast care nurses are a vital part of any multidisciplinary team, thus governments and hospitals must ensure the utilisation of breast care nurses.
- * Governments, hospitals and private practitioners to provide a written treatment plan to all women.
- * Governments, hospitals and private practitioners to ensure that women can obtain copies of important information such as pathology reports and correspondence between doctors.
- * Governments and hospitals to provide multidisciplinary services which are accessible to all women.

National level actions

- * The Breast Cancer Network Australia to discuss with health insurance funds and state and commonwealth governments the composition, availability and development of multidisciplinary teams.

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- * NHMRC National Breast Cancer Centre to continue to develop its pilot project on the provision of multidisciplinary teams for the benefit of all women no matter where they are treated.

Improving supportive care

Context

Throughout the state and territory forums, women have expressed concerns regarding supportive care for women with breast cancer and their families. Most concerns arise from the following identified challenges and problems:

- ◆ Lack of recognition of the value of supportive care to the woman. Treatment and care is focused purely on 'the tumour' at the expense of the woman's psychosocial needs.
- ◆ Support needs vary between individual women and according to their circumstances, which may change over time. Consequently there exists a need for a wide range of services to be available and accessible.
- ◆ There is a lack of information on what supportive care is available; women often hear of services after they have need of them.
- ◆ There is a concern that well organised services offered by Breast Cancer Support Services and support groups are compromised through a lack of adequate funding.
- ◆ There is often a lack of integration and co-ordination between existing support services, causing unnecessary competition, duplication and gaps in services.

This workshop identified the following priority actions to improve supportive care:

Individual and group actions

- * Consumer groups and individual women to request copies of their treatment plans.
- * Support groups to advertise themselves within their community.

State and territory level actions

- * Consumer groups to work with the cancer councils and the Australian Cancer Society to ensure that adequate funding and recognition is given to the Breast Cancer Support Service volunteer program. The aim is to ensure that every woman diagnosed with breast cancer has access to a trained survivor at her request.
- * Consumer groups to work to ensure that every woman with a breast cancer diagnosis is given access to a breast care nurse from the time of diagnosis through treatment and on a continuing basis and that adequate funds are available for the provision and training of these nurses.
- * Consumer groups to work with cancer councils and the Australian Cancer Society for the provision of volunteer services to women with advanced disease.

- * Consumer groups to work with the cancer councils and the Australian Cancer Society to train and ensure the use of trained facilitators to lead support groups; ideally these facilitators would be survivors.
- * Consumer groups to work with the Breast Cancer Network Australia to ensure that, in each phone book, there is an entry for breast cancer information and support services under 'B'.

National level actions

- * Breast Cancer Network Australia to work with other groups to develop a media campaign highlighting the psychosocial and emotional issues around breast cancer.
- * NHMRC National Breast Cancer Centre to change clinical practice guidelines to include the need for clinicians to ask for and record the psychosocial needs of a woman, including those of her family.
- * NHMRC National Breast Cancer Centre to develop a kit for general practitioners to be made available to women diagnosed with breast cancer, similar to BreastScreen Victoria's positive diagnosis information kit. The kit would contain a listing of all the support services available to a woman in her own community.
- * NHMRC National Breast Cancer Centre to actively promote and disseminate the Psychosocial clinical practice guidelines: providing information, support and counselling to women with breast cancer (in press) to the medical community.
- * NHMRC National Breast Cancer Centre to trial a model, or series of models, demonstrating the integration of all support services within a community, e.g. the integration of public and private services provided by a breast care nurse, Breast Cancer Support Service, local support groups, counsellors etc.

Doctor / patient relationship - improving communication

Context

Doctors are the first contact and main source of health care for most women with breast cancer. As a result, a woman's relationship with her doctors has a significant impact on the quality of her care, the extent of co-ordination of services, and the nature and amount of information she receives. It can also affect her feelings about herself and her treatment, whether she receives timely and appropriate support and her more general emotional and personal responses to having cancer.

Consequently it is of concern that many patients, in the state and territory forums, expressed dissatisfaction with the way doctors interacted with them. Some women remain deeply distressed long after the events in question. In response, the forums recommended communication skills training for medical students and doctors.

It is also worrying that some women are not taking responsibility for their care by telling doctors what their needs are, and by changing doctors if these needs are not adequately met. Doctors are a primary source of information and women should feel that they can ask their doctor a question and receive an answer that they can understand and with which they are satisfied.

This workshop identified the following priority actions to improve communication in doctor/patient relationships:

Individual and group actions

- * Individual women to advise consumer groups about their willingness to speak to medical students about their experiences related to diagnosis and treatment.
- * Individual women to take responsibility for making their own treatment decisions, ask for test results and if necessary a second opinion and when appropriate to use the health complaints procedures available in each state.
- * Support groups to encourage women to ask for tape recordings of their consultations.

State and territory level actions

- * Consumer groups to work with Breast Cancer Network Australia and governments to ensure that breast care nurses are available to all women and that they be present at consultations at the request of the woman concerned.
- * Consumer groups to set up a panel of women prepared to speak with medical students about their experiences.

- * Consumer groups to work with cancer councils to encourage all medical practitioners and nurses to offer to refer women to the Breast Cancer Support Service.
- * Consumer groups and the Breast Cancer Network Australia to work with the media, particularly women's magazines, to develop stories on the human side of breast cancer.
- * Breast Cancer Network Australia and state consumer groups to work with state governments to ensure that sufficient trainee specialist positions are available within their health systems.
- * Cancer councils or other relevant organisations to supply information on advocacy and support groups and other appropriate support services which will be made available in doctors' surgeries.

National level actions

- * Breast Cancer Network Australia and state and territory consumer groups to lobby for continued funding for the NHMRC National Breast Cancer Centre, with particular emphasis on the work they have done on communication skills for medical practitioners.
- * Breast Cancer Network Australia to work with the Australian Medical Council and professional colleges to ensure that communication skills training is included as an essential part of initial and continuing medical education.
- * NHMRC National Breast Cancer Centre to add to guidelines the necessity for all doctors to assess the psychosocial needs of all women and to develop a question prompt sheet for doctors.
- * NHMRC National Breast Cancer Centre to ensure that supplies of consumer information guidelines are available to the medical and other professionals at all times, so that they can be made available to women at the time of diagnosis.

Other issues

Context

This workshop dealt with issues raised at state and territory forums and not covered in other workshops. It provided women with an opportunity to raise issues of importance to them and to identify actions which needed to be taken. These priority actions include:

Private health insurance

- * Consumers need to be represented on the boards of private health insurance funds to ensure that these organisations can be shown to be accountable and transparent. This issue could be taken up by the Breast Cancer Network Australia in co-operation with state and territory consumer groups.

Hormone replacement therapy

- * Breast Cancer Network Australia and state consumer groups to work together to lobby pharmaceutical companies and others to provide money for research into the effects of hormone replacement therapy in women with breast cancer.

Home help support

- * During the treatment process many women need assistance with practical matters such as shopping, driving, cleaning, cooking etc. These women are often ineligible for government assistance. This matter can best be addressed by the Breast Cancer Network Australia and state and territory consumer groups working with governments to change the eligibility criteria for these services.

Alternative/complementary therapies

- * Alternative/complementary therapies have a role to play in the treatment of breast cancer. Women need information about the nature, value and costs of these therapies. A leaflet with reliable information needs to be distributed to women.

Aboriginal and Torres Strait Islander women - improving care

Context

The needs of Aboriginal and Torres Strait Islander (ATSI) women were discussed as part of the 'Other Issues' workshop. Because in many ways their needs are different from those of other women, the actions relating to these women are detailed here.

Non-indigenous women participating in the 'Other Issues' workshop strongly supported the special health needs and issues raised by Aboriginal and Torres Strait Islander women with breast cancer and their families.

The 'Other issues' workshop identified the following priority actions to improve care for Aboriginal and Torres Strait Islander women with breast cancer:

Individual and group actions

- * Indigenous women to participate in the development and ongoing running of breast cancer support groups
- * Indigenous health workers and women with breast cancer to participate in the development of training materials for cross-cultural training and information, education and counselling resources.
- * Non aboriginal health workers to be provided with culturally sensitive training on the needs of Aboriginal and Torres Strait Islander women.

State and territory level actions

- * Cancer councils and health services for indigenous women to review their organisation and policies to determine to what extent indigenous women are being employed to assist indigenous women diagnosed with breast cancer, e.g. to what extent are indigenous women being recruited as volunteers.
- * Consumer groups to lobby for the provision of support groups for Aboriginal and Torres Strait Islander women; this may involve discussions with state governments and hospitals, health professionals, community leaders, cancer councils, indigenous health services and other professional groups.
- * Governments, hospitals and community health services to involve indigenous and/or women's health workers in multidisciplinary teams for the treatment of indigenous women with breast cancer.
- * Governments, hospitals and community health services to provide services which provide flexibility in service delivery and acknowledge cultural issues such as the use of traditional medicines and the need for 'sorry business'.

National level actions

- * Commonwealth government to provide the funding necessary for the NHMRC National Breast Cancer Centre to provide a full-time, permanent project officer to support the work of its Aboriginal and Torres Strait Islander Advisory Group and the needs of indigenous women.
- * Indigenous health workers and indigenous women with breast cancer and health promotion officers, together with the Breast Cancer Network Australia and the NHMRC National Breast Cancer Centre, to develop resources for indigenous women covering information, education and counselling.
- * Conference organisers and those funding the attendance of consumers at conferences, to encourage the participation of indigenous women at breast cancer conferences.
- * Breast Cancer Network Australia, in co-operation with other bodies such as the NHMRC National Breast Cancer Centre, cancer councils and indigenous health services, to investigate the need for further training in breast cancer for indigenous health workers.
- * Consumer groups to jointly lobby for research into the needs of Aboriginal and Torres Strait Islander women with an emphasis on genetics and advanced breast cancer.

Making a difference

Lymphoedema

Context

About 80% of women undergoing treatment for breast cancer have an axillary dissection (D. Hill, Centre for Behavioural Research in Cancer, Anti-Cancer Council of Victoria, personal communication). As a consequence, about 8,000 women each year have the potential to develop lymphoedema at any time in their lives.

In the view of workshop participants, the prevalence of lymphoedema has been underestimated by the medical profession. However there is little evidence available to accurately determine the prevalence and treatment options for lymphoedema. Women are not having the disease diagnosed promptly, as a consequence the problems are exacerbated. This increases costs to public and private health providers, the community and the women themselves.

The 'Other issues' workshop identified the following priority actions for lymphoedema:

Individual and group actions

- * Consumer groups in conjunction with other professional organisations such as the Australasian Lymphology Association and the Lymphoedema Associations in each state, to arrange information and education meetings to allow women to identify the early signs of lymphoedema and to enable them to gain a sensible perspective on the problem.
- * Consumer groups, in conjunction with other professional organisations such as the Australasian Lymphology Association and the self help Lymphoedema Associations in each state, to take a lead in assessing and if necessary, re-writing the guidelines for consumers on avoiding lymphoedema.

State and territory level actions

- * Governments to establish mechanisms for easier access to lymphoedema treatment services and garments; access means geographic, financial and timely provision of services.
- * In conjunction with other organisations, training facilities to set up training courses for carers to assist women with lymphoedema, particularly in the use of massage therapy.

National level actions

- * Breast Cancer Network Australia and NHMRC National Breast Cancer Centre to work together with the Royal Australasian College of Surgeons to ensure that surgeons gain fully informed consent to axillary clearance or radiation to the axilla by giving women accurate information about the risk of lymphoedema.

- * Breast Cancer Network Australia to set up a working relationship with professional organisations interested in lymphoedema.
- * Consumer groups to encourage other professional organisations, the NHMRC National Breast Cancer Centre and the research community to collect evidence relating to the prevalence of lymphoedema, the effectiveness of different treatment options, alternatives to axillary dissection, surgical techniques to minimise damage to the axilla, and the role of radiotherapy to the breast in causing lymphoedema. This evidence to be publicly reported.
- * Consumers and state lymphoedema associations to work with health insurance funds to improve access to lymphoedema garments and complex massage therapies for women with private health insurance.
- * Commonwealth and state and territory governments, in conjunction with state lymphoedema associations, consumers and other professional organisations, set up a working party to develop a set of national benchmarks for the delivery of lymphoedema services.
- * Royal Australasian College of Surgeons and Royal Australian College of General Practitioners to work with professional organisations and consumers to alert their members to the prevalence of and risk factors associated with lymphoedema. This information must be made available to consumers at time of diagnosis.

Conference Contributors

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Influencing breast cancer research

Convenor: Sally Crossing

Panelists: Christine Clarke, Christine Brunswick, Avis Macphee

Women with recurrent or advanced disease – improving care

Convenor: Carol Bishop

Panelists: Fran Boyle, Jane Turner, Liz Libregts, Des Threllfall

'Replace a breast' – improving access to prostheses and breast reconstruction

Convenor: Sue Lockwood

Panelists: David Marcus, Owen Ung, Robyn Wicks

Young women – improving care

Convenor: Leonie Young

Panelists: Fran Boyle, Helen Zorbas, Jane Poynts

Rural and regional women – improving access to service and information

Convenor: Anne Fletcher

Panelists: Cherrell Hirst, David Marcus, Susan Tulley

A team approach – improving the quality of treatment

Convenor: Sue Lockwood

Panelists: Alan Rodger, Helen Zorbas, Jenny James

Improving supportive care

Convenor: Lyn Swinburne

Panelists: Christine Gray, Jane Turner, Robyn Wicks, Paulette Calabro

Doctor/patient relationship – improving communication

Convenor: Dorothy Broom

Panelists: Phyllis Butow, Sharon Batt, Alan Rodger, Raelene Boyle

Other issues

Convenor: Vivianne de Vahl Davis

Hypothetical: Lymphoedema

Convenor: Margaret Beazley

Panelists: Owen Ung, Trish Allen, Nick Stephkovitch, Karen Finch, Gavin Frost