



National Breast Cancer Centre
incorporating the Ovarian Cancer Program

Strategic Directions
2004–2007





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NATIONAL
LEADERSHIP



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ISBN Print: 1 74127 067 7 Online: 1 74127 073 1

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MISSION STATEMENT

To strive to reduce mortality from breast and ovarian cancer and improve the wellbeing of women diagnosed with breast or ovarian cancer and to further the Objects of the Company.

OVERVIEW

Since its establishment in 1995, the National Breast Cancer Centre (NBCC) has demonstrated the value of a national, integrated approach to cancer control. The NBCC has played a key role in the translation of research into evidence-based information, best practice recommendations and changes in health service delivery.

The NBCC has developed and fostered collaborative partnerships with diverse groups, including federal and state governments, professional colleges, researchers, consumer organisations and cancer organisations. These partnerships have underpinned the success of the NBCC over the past nine years.

During 2004–2007, the NBCC will continue to foster a collaborative approach and to maintain its role as an independent source of up-to-date, quality information on which to guide best practice and empower consumers and the community.

This next phase of the NBCC's growth will see greater emphasis on providing national leadership in improving cancer control. The NBCC will stay at the forefront of change by developing and implementing programs designed to improve the delivery of care and inform policy. The NBCC will continue to focus on its core objective of improving outcomes in breast and ovarian cancer. Where applicable and synergistic with this core objective, the NBCC will also engage with opportunities to improve other cancers. To better support these roles, the NBCC will develop new partnerships and strategic alliances and make representation to government and policy makers.

CONSTITUTION

OBJECTS OF THE NATIONAL BREAST CANCER CENTRE

The NBCC is established to work directly in partnership with women, health professionals, cancer organisations, researchers and governments, to improve breast and ovarian cancer outcomes for women.

The NBCC will strive to reduce mortality from breast and ovarian cancer and to improve the wellbeing of women who are diagnosed with the disease.

For this purpose the NBCC may undertake, but is not limited to undertaking, the following:

- i to act as a clearing house for information about breast and ovarian cancer
- ii to undertake evidence-based analyses of relevant breast and ovarian cancer research and inform researchers, governments, policy makers, service providers and members of the public on these matters
- iii in conjunction with key stakeholders in breast and ovarian cancer control, to develop guidelines relating to the diagnosis, treatment and care of people with breast and/or ovarian cancer, and design and execute strategies for their implementation
- iv to develop, implement and evaluate educational strategies and programs relating to breast and ovarian cancer on a national basis for service providers across the health spectrum and the public in particular women with breast and ovarian cancer and their families
- v to support and fund the development, provision and evaluation of innovative models of direct services for women with breast and/or ovarian cancer
- vi to work collaboratively with, and provide advice on specific aspects of the operation of the Company which may be of relevance to, other organisations and stakeholders in breast and ovarian cancer care, early detection and prevention area
- vii to encourage the making of gifts and testamentary dispositions by the public to the Company to enable the Company to further its Objects; in particular to improve breast and ovarian cancer outcomes for women
- viii to develop and maintain a national monitoring system for breast and ovarian cancer, and
- ix to do all such acts as are incidental and conducive to the furtherance of the above Objects.

IMPROVING CARE IN BREAST AND OVARIAN CANCER

Breast cancer is the leading cause of cancer mortality among Australian women, accounting for 16% of total annual cancer deaths. It is also the second most common cancer among Australian women (after non-melanoma skin cancer), affecting one in 11 women before the age of 75. In 2001, more than 11,700 women were diagnosed with breast cancer and more than 2,500 died from the disease. From 1991 to 2001, the incidence of breast cancer increased by 1.7% per year while mortality rates declined by an average of 2.2% per year.

While less common, ovarian cancer is the leading cause of death from gynaecological cancers in women in Australia. About one in 100 women will experience the disease before the age of 75. Each year over 1,200 women are diagnosed with ovarian cancer and more than 800 women die from this cancer. Survival outcomes for women diagnosed with ovarian cancer are often poor due to the high proportion of women who have advanced disease at the time of diagnosis. On average, incidence and mortality have declined by 0.4% and 0.7% per year respectively from 1991 to 2001.

The NBCC is Australia's peak body for breast and ovarian cancer control. It was established in 1995 by the Commonwealth Government in response to community concerns about the impact of breast cancer. In 2001 the Government provided additional funding to the NBCC for a national ovarian cancer initiative to improve health outcomes for women with ovarian cancer.

The NBCC works with women, health professionals, cancer organisations, researchers and governments to improve the management of breast and ovarian cancer and the wellbeing of women with these diseases. It aims to improve health outcomes for Australian women with breast and ovarian cancer by ensuring that wherever they live, they receive the best possible care.

The NBCC plays a vital role in providing women and health professionals with reliable information based on research findings to improve the systems through which cancer treatment and supportive care are delivered.

The work of the NBCC is based on the belief that mortality and morbidity from breast and ovarian cancer can be improved significantly if knowledge gained from research is better translated into practice.

BREAST CANCER IN AUSTRALIA

- One in 11 women will be diagnosed with breast cancer before the age of 75.
- Breast cancer is the most common cause of cancer-related death in women in Australia.
- More than 2,500 women died from breast cancer in Australia in 2001.
- Breast cancer is the second most common cancer among Australian women, after non-melanoma skin cancer.
- In Australia in 2001 more than 11,700 women and 95 men were diagnosed with breast cancer.
- In the 10 years from 1991 to 2001, the incidence of breast cancer in women rose from 100.4 cases per 100,000 women to 117.2 cases per 100,000 women (most likely due to the introduction of the national breast cancer screening program). In the same period, the breast cancer mortality rate declined by an average of 2.2% per year.
- The five-year relative survival rate for Australian women with breast cancer during the period 1992-97 was 84%, compared with 72.3% in 1982-86.

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Australian Institute of Health and Welfare and Australasian Association of Cancer Registries. Cancer survival in Australia, 2001. Part 1: National summary statistics. Canberra: Australian Institute of Health and Welfare, 2001.

OVARIAN CANCER IN AUSTRALIA

- Ovarian cancer is the leading cause of death from gynaecological cancers in women.
- Each year over 1,200 women are diagnosed with ovarian cancer and more than 800 women die of ovarian cancer.
- The median age for diagnosis of ovarian cancer is 64 years of age, and the incidence increases with age. However, about 20% of women diagnosed with ovarian cancer are younger than 50 years of age.
- In the 10 years from 1991 to 2001, the incidence and mortality rates declined by an average of 0.4% and 0.7% respectively.
- The five-year survival rate after diagnosis of ovarian cancer, compared with survival in women who do not have the disease, is about 42%.

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National Breast Cancer Centre. Ovarian cancer in Australian women. Woolloomoolloo: National Breast Cancer Centre, 2002.

NATIONAL LEADERSHIP IN CANCER CONTROL

Over the past nine years, the NBCC has demonstrated the value of a national, integrated approach to cancer control.

The NBCC was a new model in cancer control in Australia – a national centre, committed to collaboration, innovation and the translation of evidence into better practice. The NBCC's collaborative and evidence-driven approach was significantly different from prevailing approaches in 1995, and differs from that of other cancers.

The NBCC has successfully demonstrated that an integrated approach, delivered by a national centre, avoids duplication of effort by providing a central base for the major and costly tasks of review and guideline development. The NBCC has pioneered processes for involving the broad range of stakeholders in the development and support of evidence-based practice in breast cancer and, since September 2001, in ovarian cancer.

The NBCC has led the way in its commitment to a collaborative approach, forming partnerships with all organisations, governments and professional and consumer groups with an interest in improving cancer control. Through these partnerships, the NBCC has clearly identified, and focused resources on, priorities in improving breast and ovarian cancer control in Australia.

The NBCC has established an international reputation for its achievements in the development and implementation of clinical practice guidelines and resources for consumers. Over 20 sets of clinical practice guidelines and recommendations provide a framework for best practice in all aspects of breast cancer care, from diagnosis and treatment of pre-invasive, early and advanced disease to world-first guidelines for the psychosocial care of adults with cancer produced in collaboration with the National Cancer Control Initiative. These evidence-based guidelines have contributed to improvements in the diagnosis, treatment and supportive care of women with breast cancer in Australia. In collaboration with the Australian Cancer Network, the NBCC has also launched guidelines for the management of women with epithelial ovarian cancer – a first for Australia.

Over 20 high quality resources for consumers, including books, CDs, and websites, have been produced to support the information needs of women with breast cancer and their partners and families.

The NBCC has also been a driving force in influencing national health policy and practice, through innovative and pioneering projects. The NBCC's work in identifying evidence for the benefits of specialist breast nurses in ensuring coordination of care and psychosocial support for women with breast cancer has led to wider recognition of and support for this role at a national level.

The NBCC has developed and trialled tools to assist quality assurance processes in health services, providing evidence of improved care for women with breast cancer. A groundbreaking national study by the NBCC has contributed to evidence around the processes and benefits of implementing a multidisciplinary approach to care for women with breast cancer in Australia. Policy recommendations based on outcomes from this study are already informing future work around the implementation of multidisciplinary cancer care.

In the coming years the focus will be on consolidating this work in the implementation of innovative cancer care delivery and policy development, in order to further improve health outcomes for women with breast and ovarian cancer.

Much of the NBCC's work also has broader application to other cancers. Our patient-centred approach aims to foster a richer, more holistic approach to health service delivery. The NBCC's reach has already expanded to include ovarian cancer and to the development of guidelines to enhance psychosocial support of people affected by all cancers, and innovative models of multidisciplinary care. Our communications skills training program has positively enhanced clinicians' views about the value of good communication, and several professional colleges now include communications skills training in their continuing education strategies.

As an internationally renowned and nationally respected leader in breast and ovarian cancer control, the NBCC can look forward to applying its expertise and approach to further enhancing cancer care in Australia.

STRUCTURE

The NBCC was established in 1995. It is a company limited by guarantee, and governed by a Board of Directors appointed by the Federal Minister for Health and Ageing. Its primary source of funding is the Australian Commonwealth Government.

The NBCC has established a Clinical Expert Advisory Panel, a number of advisory groups, and project teams comprising individuals from various disciplines and consumers who provide expert advice to inform the work of the NBCC and ensure its relevance.

The Ovarian Cancer Program is based on the priorities outlined in Priority actions for ovarian cancer control: a framework for a national approach.

The NBCC functions as a 'centre without walls' operating at a national level. As well as supporting projects throughout Australia dependent upon local expertise and needs, the NBCC has direct representation on key national committees.

The NBCC is responsible to its shareholders:

- Federal Minister for Health and Commonwealth Department of Health and Ageing
- Corporate sponsors and also to its key stakeholders:
- Women with breast or ovarian cancer, well women and the community
- State Health Ministers and government bodies including BreastScreen
- Clinicians, allied health professionals, and specialist colleges
- General practitioners
- Cancer organisations/charities
- Researchers.

APPROACH

The NBCC has developed a systematic and evidence-based approach to improving care. Its programs are based on demonstration of a need for change, careful analysis of where programs can best be targeted, and trialling of strategies to improve information, practice or policy. The NBCC's achievements are testimony to the effectiveness of this integrated model for improving cancer control.

OUR APPROACH

Identify needs

The first step is to identify gaps in current care where there is an opportunity to impact on breast or ovarian cancer control by improving prevention, early detection, treatment or support. Information is gathered from the views of women and health professionals, from surveys and from published research.

Review the evidence

Systematic reviews and meta-analyses of the evidence form the basis for developing recommendations.

Develop and disseminate recommendations

The evidence reviews are used by multi-disciplinary groups to develop recommendations, position statements and clinical guidelines.

Initiate implementation strategies

Implementation programs seek to encourage change in clinical practice through quality improvement or training programs or providing women with better information. Encouraging the adoption of recommendations might require the trialling of new models of service delivery, perhaps through demonstration projects or advocating for policy change.

Monitor impact

The impact of these strategies is evaluated by monitoring the process and outcome of breast and ovarian cancer care.

VALUES

The following values guide the NBCC to achieve its mission:

LEADERSHIP

The NBCC will maintain and expand its role as an independent, authoritative and credible body for providing high-quality information, improving practice and informing national policy.

ENGAGEMENT

The NBCC will use an integrated, inclusive and collaborative approach through consultation and partnerships with a broad range of organisations and individuals to harness resources and expertise, promote ownership and avoid duplication.

EVIDENCE-BASED

All aspects of the NBCC's work will be informed by, and based on, the best available evidence.

EQUITY OF CARE

The NBCC will promote best care for women irrespective of their geographic location, cultural, ethnic or indigenous background or socio-economic status.

INFORMED BY CONSUMERS

The NBCC will ensure that its work will be informed by, and responsive to, consumer needs.

MULTIDISCIPLINARY

The NBCC will use a multidisciplinary approach, bringing together individuals with different expertise to achieve common goals, ensure relevance and promote uptake of products or programs.

INNOVATIVE AND OUTCOMES-ORIENTED

The NBCC will stay at the forefront of innovation by trialling, evaluating and fostering new approaches to improving care and responding to challenges in clinical, research and health service environments.

STRATEGIC GOAL

The NBCC will position itself through its work in breast and ovarian cancer to take a leading role nationally in cancer control.

The NBCC has seven Key Result Areas, all directed towards achieving its Mission.

KEY RESULT AREAS

These Key Result Areas are considered to be of equal importance, and their numbering does not indicate a priority ranking.

1. LEADERSHIP

The NBCC will collaborate with key stakeholders, government and key agencies, such as National Cancer Control Initiative, The Cancer Council Australia, National Breast Cancer Foundation, Breast Cancer Network Australia and National Institute of Clinical Studies, to contribute to national policy and set strategic priorities in cancer control.

2. INFORMATION

The NBCC will ensure that research findings are translated and disseminated in a timely manner to support clinical practice, and proactively and reactively inform policy, the media and the community.

3. QUALITY ASSURANCE AND STANDARDS OF CARE

The NBCC will collaborate with relevant stakeholders to develop, implement and evaluate, as appropriate, evidence-based training and standards of best practice to support current and emerging paradigms of care.

4. INNOVATION AND BEST PRACTICE

The NBCC will develop, trial, implement and evaluate selected innovative approaches in order to improve practice and health service delivery, to impact on cancer policy and ensure that the work of the NBCC informs other cancer control initiatives.

5. EMPOWERMENT OF CONSUMERS

In collaboration with Breast Cancer Network Australia, OvCa Australia and other key consumer groups and individuals, the NBCC will ensure that its work and planning reflects and supports the needs of consumers to make informed decisions about their care and to advocate for improved cancer services based on evidence of best practice.

6. MONITORING

In collaboration with Cancer Strategies Group, Australian Institute of Health and Welfare, Australian Association of Cancer Registries, National Cancer Control Initiative and other relevant national and state/territory stakeholders, the NBCC will promote standardised approaches to data collection and timely reporting, and identify, monitor and independently report on key indicators of cancer control.

7. SUSTAINABILITY OF THE NBCC

The NBCC will seek to ensure its sustainability through best governance, management and staff development, and will seek to secure additional funding sources as appropriate.

MAJOR ACHIEVEMENTS

In the nine years since the NBCC was established, much has been achieved.

Since its establishment, the NBCC has

- published over 70 reviews and reports
- developed 20 sets of guidelines and recommendations covering all aspects of breast cancer and the management of ovarian cancer
- published resources for women and their families about familial aspects of breast cancer, early detection, treatment and supportive care
- trialled many innovative approaches to improving care and changing policy and practice.

The achievements of the NBCC have been recognised in the two international and independent reviews, in 1997 and 2003, which noted that several programs were world-leading. Many of the NBCC's best practice guidelines are considered 'world firsts'.

The NBCC is also recognised by other national cancer organisations and agencies for its promotion of, and contribution to, improving health policy and practice, particularly in the areas of supportive and multidisciplinary care.

1. LEADERSHIP

The NBCC has contributed to and facilitated national policy development in many ways:

- Provided expert advice about all aspects of breast and ovarian cancer control, including detection and treatment, in order to inform governments and peak health bodies that plan health service delivery for women with breast or ovarian cancer.
- Membership of key national policy and priority-setting committees, including: the Commonwealth Cancer Strategies Group; Australian Screening Advisory Committee; BreastScreen Australia's National Advisory Committee and Policy Working Group; National Cancer Control Initiative Management Committee; National Health and Medical Research Council Research Committee; National Health and Medical Research Council Health Advisory Committee; National Health and Medical Research Council HRT Working Party; NSW Clinical Service Framework for Cancer Expert Reference Group; National Breast Cancer Foundation's Research Priorities Steering Committee; and the Royal Australasian College of General Practitioner's Prevention and Management of Breast and Cervical Cancer in Aboriginal and Torres Strait Islander Women Steering Committee.
- Facilitated collaborations with many individuals, groups and organisations across Australia, and encouraged health professionals, researchers, cancer organisations, consumers, health departments and policy makers to work together towards a shared understanding of the needs of women with breast or ovarian cancer and those who manage their care.
- Co-convened the first national workshop, Improving outcomes for Australian women with ovarian cancer, with the Commonwealth Government, National Cancer Control Initiative and OvCa Australia. The workshop brought together key organisations to consider priorities in ovarian cancer control.
- Developed and disseminated the report, Priority actions in ovarian cancer control: A framework for a national approach.
- Enhanced understanding of how to implement evidence-based care. The NBCC, in association with National Institute of Clinical Studies, published a report from a joint workshop held in 2001: Clinical practice guidelines – where to from here? The report summarises some of the lessons learned about fostering evidence-based care through clinical practice guidelines in Australia and makes recommendations about the next challenges.

2. INFORMATION

The NBCC is renowned for its achievements in the development of evidence-based reviews, guidelines and information for health professionals, policy-makers, consumers and the community. (See Empowerment of Consumers (page 23) for information about consumer resources).

Information for health professionals

The NBCC has produced a comprehensive range of clinical practice guidelines and recommendations, based on the latest national and international evidence, to guide the work of health professionals in the Australian practice setting.

The NBCC has developed and disseminated:

- Twenty clinical practice guidelines, including guidelines for the management of early breast cancer, advanced breast cancer, management and support of younger women with breast cancer, psychosocial care of women with breast cancer and the management of epithelial ovarian cancer (the latter in collaboration with the Australian Cancer Network).
- Recommendations about the clinical management of ductal carcinoma in situ, lobular carcinoma in situ and atypical hyperplasia of the breast.
- The world's first clinical practice guidelines for the psychosocial care of adults with cancer, in collaboration with the National Cancer Control Initiative. The World Health Organization has expressed interest in these guidelines.
- Evidence-based guides for general practitioners, tailored to the needs of general practice in dealing with patient needs and care.
- A summary card for radiologists, based on reporting recommendations in the NBCC's publication Breast imaging: a guide for practice, produced in association with the Royal Australian and New Zealand College of Radiologists.
- Evidence-based reviews and reports on aspects of breast cancer control, including the use of high-dose chemotherapy, axillary dissection and irradiation, and radiation oncology issues including postmastectomy radiotherapy.
- Reviews of new diagnostic technologies, including computer-aided detection, magnetic resonance imaging, breast thermography and positron emission tomography.
- Comprehensive reviews of evidence about risk factors for breast cancer and ovarian cancer.
- Advice for health professionals about familial aspects of breast cancer and ovarian cancer.
- Regular news bulletins and electronic newsletters providing concise summaries of the latest evidence as well as updates on NBCC programs, including BreastFax, Clinical Update and Ovarian e-Update.

Community information

The NBCC has developed a comprehensive range of resources and conducted community education campaigns to provide information to women, their partners and families and to enhance community understanding of breast and ovarian cancer, including:

- A public health campaign about the early detection of breast changes (2001). Two-thirds of women in targeted towns were aware of messages about the importance of prompt investigation of breast symptoms promoted as part of this campaign. An innovative partnership approach was used to reach women across regional Australia.
- The Boys Do Cry national campaign (2003) raised awareness of the needs of partners. A community kit and a dedicated website were developed to support this campaign.
- A national series of forums for women, promoted the message that 'Any change is worth talking about' (2004). The forums were extremely well attended and were conducted in collaboration with Breast Cancer Network Australia, BreastScreen and local clinicians and community groups. Mrs Janette Howard was the patron of the national campaign.
- The first National directory of hospital-based services for women with breast cancer, a web-based directory of services to assist women in deciding about and accessing care.
- A web portal (www.nbcc.org.au) providing a one-stop shop for comprehensive information about breast and ovarian cancer.
- Proactive and reactive media strategies to help promote key health information and to translate research into meaningful messages for the public.

Guidelines improve general practitioners' approaches to breast cancer

- In a pilot of a general practitioner summary of the Clinical practice guidelines for the management of advanced breast cancer, 91% of general practitioners stated that the guide provided them with new information.
- A survey of general practitioners in Victoria found that over one-third used the relevant NBCC guidelines when investigating breast symptoms and in managing women with early breast cancer.
- Following the launch of the Advice about familial aspects of breast cancer guidelines, there was a significant increase in the proportion of appropriate referrals to family cancer clinics (from 76% to 95%).

3. QUALITY ASSURANCE AND STANDARDS OF CARE

While much remains to be done to ensure that all women receive the best possible care, there has been considerable progress over the past nine years.

A gradual but consistent decrease in mortality from breast cancer is evident. This decrease is undoubtedly due to many factors, including the national mammographic screening program, and improvements in early detection, treatment and the organisation of breast cancer services.

Although it is not possible to assess the independent contribution of the NBCC to changes in mortality, the NBCC's work in coordinating breast cancer programs and in fostering collaboration and an evidence-based approach has been credited with contributing to change.

Improving cancer management and care

The NBCC works to encourage best practice in order to improve the early detection, treatment and management of breast and ovarian cancer.

Achievements include:

- The 2003 Breast Health Survey was conducted, with a sample of 3,000 women nationally, to gauge knowledge, attitudes and behaviour in relation to the early detection of breast cancer. Information gathered from this survey can also be compared with the results of a previous survey, conducted in 1996, to monitor changes in awareness, behaviour and attitudes and to guide future work.
- A major program in general practice was implemented, including: guidelines and resources for general practitioners, seminars in Divisions of General Practice, training programs in clinical breast examination, a continuing medical education program, a Breast Resource General Practitioner Project, information in general practice publications and development of breast-specific modules as part of continuing education programs.

- A workshop program with rural practitioners to improve the use of chemotherapy and other adjuvant therapies. A kit based on the program has been made available to over 200 individuals and organisations. The model developed for these workshops has been used by the Medical Oncology Group of Australia to conduct workshops about the use of chemotherapy for patients with colorectal cancer.
- Investigation of a new breast symptom: a guide for general practitioners improved the diagnosis of breast symptoms, with general practitioners being more likely to refer women with suspicious breast changes and to use the triple test approach after the release of the guidelines and an associated workshop and feedback program.
- The effective diagnosis of breast abnormalities is supported by the development of a standardised reporting and classification system for breast imaging, in collaboration with the Australian and New Zealand College of Radiologists. This will provide better communication between managing clinicians about their levels of concern with imaging findings in the investigation of breast abnormalities.
- A range of programs addressing familial aspects of breast cancer, including: guidelines for general practitioners, guidelines for family cancer clinics, resources for women and support for national meetings to foster a consistent approach among those working in the area.
- Programs to improve care in relation to ductal carcinoma in situ, including: conduct of reviews and development of evidence-based recommendations, studies of the needs of women and development of consumer resources, analyses of patterns and reporting of ductal carcinoma in situ.
- A range of implementation programs to encourage adoption of the clinical practice guidelines, including feedback mechanisms for clinicians and a Quality Improvement Kit to encourage organisational change in hospitals.

- Conducted a national series of educational seminars for health professionals to promote best practice recommendations in breast and ovarian cancer.
- Implemented programs to encourage multidisciplinary care and care coordination, including initiatives with rural surgeons, telemedicine, a national survey about coordination of breast cancer care, and a major National Multidisciplinary Care Demonstration Project.

Evidence-based training for health professionals

The NBCC has developed specialised training programs, educational workshops and resources designed to improve the skills and knowledge of the many health professionals who manage the care of women with breast and ovarian cancer. The NBCC encourages the inclusion of practice recommendations into the curriculum for clinician training.

Achievements include:

- A National Communications Skills Training Program has been conducted over six years to improve communications and supportive care skills of clinicians. Communication skills training has been provided to over 430 clinicians across Australia, through workshops and competitive grants schemes, and 80 new communication skills trainers have been trained. The Medical Oncology Group of Australia and the Royal Australasian College of Surgeons have made communication skills training integral for trainees.
- An innovative training program for radiologists working in BreastScreen was developed and implemented across NSW. The program was evaluated highly by radiologists of varying levels of expertise. It is anticipated that this program will be implemented more broadly.
- Interactive satellite education broadcasts were conducted for general practitioners and allied health professionals in rural and remote regions of Australia.
- A model curriculum for breast cancer and an associated interactive CD ROM program was developed for undergraduate medical students.
- A training scholarship program for nurses to improve the care of women with breast cancer in rural areas.

Enhancing quality assurance

The NBCC plays a key role in developing and maintaining standards and quality assurance in breast cancer.

Achievements include:

- The NBCC has provided ongoing support for BreastScreen Australia's quality improvement program, including secretariat support for the National Quality Management Committee.
- The revision of the National Accreditation Standards for BreastScreen Australia was undertaken to support BreastScreen's quality improvement program and to provide standards for accreditation based on international evidence for best practice and applicable to the Australian practice setting. Current initiatives include the development of a site visitor training package and forms for documenting accreditation processes.
- Developing standards around best practice in breast cancer in association with Australian Safety and Efficacy Register of New Interventional Procedures - Surgical and the Royal Australasian College of Surgeons.

Improvements in the diagnosis and treatment of breast cancer

- State-based data indicate that there have been improvements in breast-conserving surgery and the provision of radiotherapy, endocrine therapy and chemotherapy since 1995.
- A survey of radiation oncology departments has shown improvement in the planning and provision of radiotherapy.
- Changes in line with recommendations in pathology reporting of invasive cancer and of ductal carcinoma in situ have been noted since 1995.

4. INNOVATION AND BEST PRACTICE

The NBCC has contributed to health service and policy change through the establishment and evaluation of groundbreaking practice models.

Although it is difficult to demonstrate the ways in which policy change occurs, examples of NBCC's contributions include:

- The Specialist Breast Nurse Demonstration Project reviewed the role of breast nurses in Australia. This information was used in an analysis undertaken by the Cancer Strategies Group and resulted in a recommendation to establish specialist breast nurse positions as a cancer control priority action.
- The NBCC conducted a three-year National Multidisciplinary Care Demonstration Project to examine sustainable and locally relevant strategies to improve multidisciplinary cancer care. Strategies trialled were found to be acceptable to clinicians, who felt that this approach encouraged more appropriate care for women and better communication between clinicians.
- Recommendations for improving multidisciplinary care were made to the Commonwealth Government, and outcomes from the National Multidisciplinary Care Demonstration Project are being used to inform the development of practical kits to assist health services in implementing a multidisciplinary approach.
- The Principles of Multidisciplinary Care developed as part of this project have already been adopted in the treatment of other diseases. For example, in North Queensland the principles have been used to establish multidisciplinary meetings for colorectal cancer, melanoma and respiratory medicine.
- The Quality Improvement Kit for hospitals demonstrated that service delivery could be improved in hospitals with collaboration from senior service administrators and clinicians.
- Following the development in 1998 of Australia's first guide for General Practitioners on investigating a new breast symptom, Breast Resource General Practitioners were appointed in 19 regions to promote the use of guidelines and consumer resources.

5. EMPOWERMENT OF CONSUMERS

The NBCC aims to ensure that all women with breast and ovarian cancer are provided with optimal care regardless of where they live in Australia and have access to accurate, timely and appropriate information.

The NBCC produces comprehensive and accessible information to help women with breast or ovarian cancer understand their diagnosis and their treatment and support options.

The NBCC's resources and support for consumers include:

- Evidence-based consumer guides and other resources relating to breast and ovarian cancer, including information about particular issues such as the needs of partners and children of women with breast cancer, breast reconstruction, body image, fertility and sexuality.
- Programs and resources for women from non-English-speaking backgrounds and indigenous women, including development of a video and work to improve training of Indigenous health workers in breast and cervical cancer issues.
- Support for the first national conference for women affected by breast cancer, 'Making a Difference', in 1998, and participation in 'Still Making a Difference' in 2004.
- Convening two series of consumer meetings around Australia, to inform women with breast cancer about new initiatives in breast cancer control and to invite consumers to contribute their views about NBCC priorities, programs and consumer information.
- Two new consumer-friendly websites providing the latest information about breast cancer and support for families and carers, including an innovative site for the teenage children of people with cancer (www.breasthealth.org.au and www.myparentscancer.com.au).
- A regular newsletter, From the Source, providing updates about NBCC initiatives to women affected by breast cancer including Breast Cancer Network Australia members.

Development of relevant and user-friendly consumer information

The NBCC's consumer survey found that in 1998, two-thirds of women received the NBCC's consumer guide at the time they were diagnosed with early breast cancer.

Of the women who received the booklet *All about early breast cancer*, 90% thought it was 'very helpful', 98% thought it was 'very easy' or 'quite easy' to understand, 90% thought it contained 'just the right amount of information', and 65% also reported their family and friends read the booklet. A new version of the consumer guide for women with early breast cancer, based on the latest evidence, was completed in 2003.

6. MONITORING

The NBCC collects data to monitor trends in breast and ovarian cancer outcomes and care.

Achievements include:

- Publication of a series of reports about key aspects of breast cancer control, including: trends in incidence and mortality; detailed analyses of survival; completeness of pathology reporting; patterns of treatment; and quality of life following treatment.
- Conducted national survey of women aged 30–69 about their knowledge attitudes and behaviour with regard to early detection and risk of breast and ovarian cancer.
- Produced detailed reports in special areas, including: ductal carcinoma in situ, tumour size and nodal status.
- Reviewed incidence, mortality and other data about ovarian cancer, leading to publication of the national report *Ovarian cancer in Australian women in 2002*. This was the first compilation of data on incidence and mortality Australia-wide, and demonstrated that there was considerable variation in the way that data about ovarian cancer were collected.
- Contributed to the establishment of the Royal Australasian College of Surgeons' Breast Audit which, over time, will provide a national system for providing prompt information about changes in breast cancer management.

7. SUSTAINABILITY OF THE NBCC

The NBCC is an efficient and successful organisation through a commitment to effective governance, management and staff development. The development of corporate partnerships provides funding that enables the NBCC to develop additional programs, and to deliver programs more quickly than would otherwise be possible.

Achievements include:

- Successful applications for grants from National Health and Medical Research Council, Rural Health Support, Education and Training, and BreastScreen NSW.
- Gaining additional funding from the Commonwealth Government for significant programs – such as the Strengthening Support for Women with Breast Cancer Program and the National Multidisciplinary Care Demonstration Project – in addition to core activities.
- Establishment of partnerships with corporate sponsors with an interest in supporting breast and ovarian cancer programs, including the AMP Foundation and Polo Ralph Lauren (Pink Pony campaign), Estée Lauder Companies, Macquarie Bank Foundation and Woolworths.
- NBCC staff members are invited members of key national policy and priority-setting committees (see Leadership (page 15)), contribute to many other external programs, organisations and professional associations, and represent the NBCC at national and international conferences.
- Staff skill mix reflects the needs of the organisation, and continuing education and staff development initiatives that support the work of the NBCC are fostered.



STRATEGIC DIRECTIONS 2004-2007

This section outlines the Strategic Directions for the NBCC for 2004–2007. The Strategic Directions will guide the work of the NBCC to June 2007, recognising the need to remain responsive to changes in social, medical and research environments.

A broad range of stakeholder input has been utilised in the development of the new Strategic Directions. To guide its strategic planning process and canvass stakeholder needs, the NBCC commissioned a survey in mid-2002 of relevant organisations in cancer control and individuals who had worked with the NBCC.

Another important source of information about stakeholders' needs has been the Independent Review of the NBCC, commissioned by the Australian Government Department of Health and Ageing in 2003. Over 40 individuals were interviewed by an Independent Review Panel that included international expertise, with a further 17 submissions received from stakeholder organisations.

In reviewing the NBCC's work to date, the Independent Review Panel noted the NBCC's reputation for excellence, effectiveness and productivity. The Panel recommended that the NBCC enhance its leadership role by continuing to contribute to cancer control policy, promoting the implementation of best practice, encouraging innovative cancer service delivery and exploring opportunities to build national data monitoring capacity.

The views of the NBCC Board and Clinical Expert Advisory Panel were sought to identify program priority areas for future work. The NBCC has also considered the direction of national cancer control strategies as outlined in the significant Australian Government publications, *Priorities for Action in Cancer Control* and the *National Service Improvement Framework for Cancer*.

Each year the work of the NBCC will be guided by a Business Plan. The Strategic Directions 2004–2007 will provide overall guidance to ensure that our work will further improve health outcomes for women with breast or ovarian cancer.

The strategies outlined are based on servicing the NBCC's mission and key result areas. They include the deliverables that the NBCC can achieve within the scope of work possible with the core Government contract funding of \$2.1 m per year. The NBCC will prioritise the workplan, and identify additional sources of funding, in order to undertake some of the strategies to better serve its mission.

1. LEADERSHIP

The NBCC will collaborate with key stakeholders, government and key agencies, such as National Cancer Control Initiative, The Cancer Council Australia, National Institute of Clinical Studies, Breast Cancer Network Australia and the National Breast Cancer Foundation to contribute to national policy and set strategic priorities in cancer control.

Strategy

- 1.1 Identify, through research and analysis, gaps in quality service provision to inform governments, policy makers and service providers in relevant forums.
- 1.2 Inform the Minister and the Department of gaps in evidence relevant to service improvement within the National Service Improvement Frameworks.
- 1.3 Contribute to relevant policy-making through representation on key committees and to Federal and State Ministers and health departments.
- 1.4 Extend effective consultative process with key stakeholders in breast and ovarian cancer control.
- 1.5 Participate purposefully in collaborations with other relevant agencies, such as National Cancer Control Initiative, The Cancer Council Australia, National Institute of Clinical Studies, Breast Cancer Network Australia and the National Breast Cancer Foundation to identify and fulfil respective roles in the context of the National Cancer Control Plan.

2. INFORMATION

The NBCC will ensure that research findings are translated and disseminated in a timely manner, to support clinical practice and to proactively and reactively inform policy, the media and the community.

Dissemination strategies will be tailored to the needs of specific target groups and depend upon budgetary considerations.

Strategy

- 2.1 Undertake and publish, in appropriate format for the target groups, evidence-based reviews or updates of relevant breast and/or ovarian cancer research.
- 2.2 Develop and maintain current best practice guideline recommendations relating to the risk, diagnosis, treatment and care of breast and ovarian cancer.
- 2.3 Service requests from the Department and the Minister for information on breast and ovarian cancer.
- 2.4 Regular review of communication methods to ensure their relevance eg BreastFax and Ovarian e-Update.
- 2.5 Maintain an authoritative website about breast and ovarian cancer for consumers, service providers, policy makers and researchers.
- 2.6 Conduct public information campaigns to communicate key messages.

3. QUALITY ASSURANCE AND STANDARDS OF CARE

The NBCC will collaborate with relevant stakeholders to develop, implement and evaluate, as appropriate, evidence-based training and standards of best practice to support current and emerging paradigms of care.

Strategy

- 3.1 Partnerships with relevant training agencies for the delivery of education and training programs.
- 3.2 Contracts and/or service agreements with relevant agencies for the development of standards and/or accreditation processes.
- 3.3 Provision of secretariat support for National Quality Management Committee of BreastScreen Australia.

4. INNOVATION AND BEST PRACTICE

The NBCC will develop, trial, implement and evaluate selected innovative approaches to improve practice and health service delivery, to impact on policy and ensure that the work of the NBCC informs other cancer control initiatives.

Strategy

- 4.1 Undertake and evaluate strategies for the implementation of evidence-based practice in priority areas.
- 4.2 Develop proposals for the provision and evaluation of innovative models of service improvement for women with breast and/ or ovarian cancer.
- 4.3 Develop and pilot strategies in information technology for dissemination and adoption of information in clinical practice.
- 4.4 Identify potential national and international partners for developing innovative strategies for service delivery.

5. EMPOWERMENT OF CONSUMERS

In collaboration with Breast Cancer Network Australia, OvCa Australia, and other key consumer groups and individuals, the NBCC will ensure that its work and planning reflects and supports the needs of consumers to make informed decisions about their care and to advocate for improved cancer services based on evidence of best practice.

Strategy

- 5.1 Implement the NBCC consumer representation policy.
- 5.2 Maintain, routinely update and evaluate the NBCC's consumer websites: www.breasthealth.com.au; myparentscancer.com.au.
- 5.3 Publish key printed resources for consumers, based on identified need.
- 5.4 Explore partnerships to increase capacity to publish, reprint and distribute selected print resources for consumers.
- 5.5 Collaborate with all relevant consumer advocacy groups to provide information suitable for inclusion in newsletters, etc.
- 5.6 Attend and provide information to support relevant consumer meetings and forums.
- 5.7 Research into resources to support women in making decisions about their care.

6. MONITORING

In collaboration with Cancer Strategies Group, Australian Institute of Health and Welfare, Australian Association of Cancer Registries, National Cancer Control Initiative and other relevant national and state/territory stakeholders, the NBCC will promote standardised approaches to data collection and timely reporting, and identify, monitor and independently report on key indicators of cancer control.

Strategy

- 6.1 In conjunction with Cancer Strategies Group, Australian Association of Cancer Registries, Australian Institute of Health and Welfare and other relevant groups identify national needs in relation to monitoring breast and ovarian cancer.
- 6.2 Maintain up-to-date information (dependent on availability) about status of breast or ovarian cancer control.
- 6.3 Develop and maintain a system of regular reports on priority parameters, such as cancer control outcomes and treatment trends, and promote comprehensive data collection.

7. SUSTAINABILITY OF THE NBCC

The NBCC will seek to ensure sustainability through best governance, management and staff development, and will seek to secure additional funding sources as appropriate.

Strategy

- 7.1 Establish best practice governance and management procedures for the organisation.
- 7.2 Operate within a sustainable business plan with satisfactory audit reports.
- 7.3 Recruit and retain high-calibre staff with appropriate skills mix within available budget, provide staff development and develop relationships with other providers to fill any skill gaps.
- 7.4 Establish a network of formal relationships with relevant agencies, such as Australian Cancer Network, Australian Council for Safety and Quality in Health Care, Breast Cancer Network Australia, The Cancer Council Australia, Cancer Institute NSW, National Breast Cancer Foundation and National Cancer Control Initiative, to leverage capacity.
- 7.5 Pursue externally funded grants, contracts and sponsorships that support the Mission of the NBCC.



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