

A national cancer control program: the ‘Down Under’ experience with breast cancer

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Abstract The use of national, coordinated and comprehensive strategies supported by evidence and focused on a specific cancer is one model for improving cancer control. The National Breast Cancer Centre (NBCC) was established in Australia in 1995 to coordinate breast cancer control initiatives across the country and has successfully achieved a number of world-firsts in this thirteen year period. Crucial elements of the initiative have included broad consultation with key stakeholders, evidence-based focus, addressing recognized gaps in care, multidisciplinary input including consumer involvement, innovative approaches, and independent operation notwithstanding government funding. The NBCC’s experience has been extended to ovarian cancer control and may be useful for others intending to establish national programs in cancer control.

Keywords MeSH descriptor · Neoplasms · Prevention and control · National Health Program · Breast neoplasms · Models, organization

Background

Internationally, over 10 million people are diagnosed with cancer each year with this rate potentially increasing by 50% by 2020 [1]. In May 2005, the World Health Assembly recommended that all governments develop and

implement comprehensive cancer-control programs utilizing evidence-based strategies [2].

To alleviate this burden of disease, different countries have adopted varying approaches across the globe to implementing programs and policies to improve cancer control. In England, for example, the National Institute for Clinical Excellence (NICE) focuses on establishing disease management guidelines, and auditing practice against these recommendations to monitor improvements in care in cancer and other diseases.

One challenge in state or province-based countries with health systems containing both public and private sectors has been to undertake a national program that can affect change across jurisdictions. In America, the approach taken by the National Comprehensive Cancer Control Program of the Centers for Disease Control and Prevention is to provide a focus for existing cancer programs to collaborate and pool resources [3]. In Canada, the Canadian Strategy for Cancer Control has provided a collaborative forum for key cancer groups and government to plan cancer control strategies.

Given the global impact of cancer and the similarity of some health care systems, there may be lessons learnt from the conduct of such programs that would be worth sharing with those establishing or managing national programs in cancer control. For example, in 1985 The Europe Against Cancer program was launched and set the ambitious target of reducing the expected number of deaths due to cancer by 15% by the year 2000. A program of activities and research was developed focussing on three major themes: prevention (particularly tobacco control), screening, and education and training. Whilst the 15% reduction target was not met across the European Union, some countries hit the reduction target (Austria and Finland), while others (Portugal and Greece) actually had an increase in cancer deaths [4].

National Breast Cancer Centre officially changed its name to the National Breast and Ovarian Cancer Centre in February 2008.

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The ‘Down Under’ experience

Another approach to cancer programs is to focus on the control of high incidence cancers in a comprehensive manner, using strategies to improve awareness and early detection, lower risk, improve diagnosis, treatment, and supportive care whilst monitoring disease trends and outcomes.

In Australia in the early 1990s breast cancer was one such high incidence cancer, the impact of which was starting to receive community attention. In 1995, the Australian Government released the findings of a Parliamentary Inquiry that identified significant issues and variations in the care of women with breast cancer, such as the extent to which women were treated by multidisciplinary teams and received adequate supportive care and information [5]. In that year, 10,048 Australian women were diagnosed with breast cancer and 2,629 women died from breast cancer [6]. The age-standardized breast cancer incidence rate was 111.3 per 100,000 population (1997 data) and the age-standardized mortality rate was 27.8 per 100,000 population (1997 data) [6]. A population mammographic screening program was introduced in Australia in 1991 and was fully implemented by the end of 1995 [7]. The establishment of the BreastScreen Australia program emphasized a national commitment to the early detection of breast cancer.

In 1995, the National Breast Cancer Centre (NBCC) was established in response to the Parliamentary Inquiry as the first national cancer center with initial start-up funding of AUD \$5 million per annum from the Australian Government and recurrent funding of AUD \$3 million per annum. The NBCC has received ongoing bipartisan support since this time.

Using approaches that were unique in Australia at this time, the NBCC program used an evidence-based approach combined with the ‘Plan-Do-Check-Act’ Deming Cycle of continuous quality improvement to address all aspects of the breast cancer journey. Input from a wide range of stakeholders and data monitoring enabled the identification of priority areas of need or gaps in care, in which systematic reviews of international research were conducted to establish a current evidence-base. The development of information resources (e.g., clinical practice guidelines/position statements/consumer guides/information campaigns) were supported by the follow through conduct of tailored strategies to action improvements. Evaluation of the effectiveness of interventions and the monitoring of change provided a feedback loop to initiate new programs of work.

The establishment of a national organization for breast cancer control provided a focus for a number of efforts in a range of areas and the opportunity to translate research into clinical practice. Necessary conditions for broad support of

a new national initiative at the time included key environmental issues, such as the growth of the consumer advocacy movement, evidence-based medicine increasingly gaining acceptance amongst clinicians, and increasing frequency of litigation for missed or delayed diagnoses of breast cancer.

In the initial years, the NBCC conducted the first national audit of practice in breast cancer care [8] identifying areas, where practice was not in accord with guideline recommendations and, therefore needed improvement. In 1995, the audit of the management of over 4,200 breast cancer cases found that hormone receptor status was not measured in 20% of cases although this was known to be important information for determining appropriate endocrine therapy [8]. Despite the known benefits of radiotherapy following breast conserving surgery, only 41% of women with early disease received adjuvant radiotherapy [8]. Subsequently, areas selected for national program strategies included promoting a multidisciplinary approach to treatment planning, reporting of tumor hormone receptor status, and use of radiotherapy following breast conserving surgery.

There has been a significant improvement in breast cancer outcomes in Australia in the past decade. In 2004, the age-standardized mortality rate had fallen to 23.4 per 100,000 population from 29.4 per 100,000 in 1992 [6]. Between 1982–1986 and 1998–2002, five-year survival following a diagnosis of breast cancer increased from 70.9% to 86.6% [6]. In 2006, the 5-year relative survival was 98% for women with tumors 10 mm in size or less [9].

It is not possible to determine the independent contribution of the NBCC’s work in breast cancer control. There are, however, areas where the organization’s work has had a measurable effect on knowledge, practice, and outcomes. These areas include providing accurate information to the public about risk and early detection, improved investigation of breast symptoms by primary care practitioners, contributing to improvements in pathology and radiology reporting, providing evidence-based information about treatment options to clinicians and women with breast cancer, improving monitoring of breast cancer control, and contributing to health service and policy change through innovative practice models.

The approach used by the NBCC has been acknowledged by government as beneficial and in 2001 the remit was extended to also improve ovarian cancer control. Although principally Government funded, the NBCC operates as an independent company governed by a Board, staffed by 30 people (primarily located in Sydney) using a matrix work style within an organizational structure focused around Executive Management, Programs, Communications and Public Relations, and Administration. Stakeholder engagement and communications throughout the country are facilitated by regular face-to-face and

teleconference meetings, newsletters, email alerts and updates, and a comprehensive website.

This article intends to summarize the key features of this Australian program undertaken in a ‘mixed’ public and private health care system, in a country with urban and rural regions and within a limited budget. Case studies are used to further explore possible models for cancer control strategies and to illustrate how the program has affected impact across a broad range of areas. Lessons learnt will be explored to illustrate some of the potential pit falls that can be experienced when implementing such programs.

Key program attributes

At the outset of the NBCC program, principles and values were established, many of which have subsequently been mirrored in the 2002 World Health Organization’s principles for managing cancer control programs: [10].

Consultative and collaborative

Broad consultation with key stakeholders across the country including specialists, allied health professionals, primary care practitioners, people affected by cancer (consumers), epidemiologists, geneticists, policy makers, academics, and researchers provides a ‘voice for all’, national expertise, engages ‘buy-in’, and overcomes perceptions of threat to professional practices. Annual advisory group meetings, regular fora and working group meetings facilitate consultation.

Partnerships

Program uptake in a ‘mixed’ health system can be a challenge. Working with the state health authorities and state cancer charities provides leverage to action service-based initiatives and local level activities. Engaging the private sector (through national associations, individual services, and clinicians) facilitates the uptake of program strategies. Engaging rural groups in programs having a special focus on rural and remote regions (e.g., rural satellite broadcasts, training workshops for Aboriginal community health workers, scholarships for rural and remote nurses) ensures that programs reach regional communities. Working with corporate partners with an aligned mission can provide leverage to deliver or expand costly programs (e.g., communication skills training for doctors).

Comprehensive and patient-focused

This inclusive approach described above can be used to establish work program priorities which cover all aspects

of the patient journey from prevention/risk factors, detection, diagnosis, treatment, supportive care, follow-up, and end-of-life issues. Other integral components focus on national data monitoring (to determine care gaps and benchmark care improvements) and a communications stream (to raise public awareness of cancer issues).

Multidisciplinary input

Program capacity can be leveraged through the honorary commitment of time and expertise of advisors, committee and working group members from a range of disciplines, from organizations and individuals, who can subsequently champion the program work. The inclusion of consumer representation (see below) was considered ‘novel’ at the commencement of the program, but is now wide spread internationally. High level secretariat and administrative support provided for the organization of meetings significantly contributes to the willingness of busy members to participate.

Informed by consumers

Consumer involvement at a range of levels, from representation on the Board of Directors through to representation on working groups, is integral to establishing priorities and strategic directions and gaining organizational support from advocates. The program has been formative in the establishment and close working relations with Australia’s first national cancer-specific consumer organization (Breast Cancer Network Australia, est. 1998), from the organization of the first national consumer conference to the conduct of science and advocacy training for consumers. This crucial relationship ensures appropriate consumer representation in all aspects of work which informs the direction of projects to ensure outcomes support the needs of women.

Evidence-based

Surveillance of emerging research and systematic reviews of peer-reviewed published literature is used to support the development of clinical practice recommendations and accompanying consumer information. The development of more than twenty evidence-based guidelines and recommendations covers all stages of the disease continuum from identification of those at high risk, early detection, diagnosis, treatment for in situ, early and advanced disease, psychosocial care, and the special considerations of younger women with breast cancer [11–18]. Consumer input ensures that the psychosocial care as well as the medical needs of patients are addressed.

Innovation and continual improvement

Implementation strategies used for improving outcomes include behavioral, educational, organizational, and policy approaches determined effective in the research literature [19–23]. Interventions are evaluated, using methods ranging from questionnaires to randomized controlled trials, to contribute further to the international body of knowledge about effective implementation strategies. Strategies are tailored to target a particular area of need identified through gap analysis. Strategies implemented can include audit and feedback, interactive educational workshops, organizational change in health services, and joint policy statements. New approaches to care based on emerging evidence can be trialed and models developed suited to the local health care environment.

Strategies

In addition to general principles, a number of specific strategic approaches have been applied.

Public information campaigns

Annual public information campaigns promote key messages to the general public typically targeting women without breast cancer. Using a multi-faceted communications strategy, campaigns can include advertising (television, printed press, radio), brochures, supermarket advertising, and local community forums for women across the country especially in rural areas. Pro-bono placement of advertising and partnerships formed with other cancer organizations and corporate groups, such as supermarket chains and women's magazines, can help promote the message given limited financial resources [24]. Strategies involving primary care practitioners are the key, when promoting early detection messages. Campaigns for women of culturally and linguistically diverse backgrounds target major non-English speaking background communities using ethnic media, ethnic community groups and health professionals.

Informing current issues

With the continuous emergence of new research findings, it is important to inform public debate and improve knowledge about cancer issues with independent comment through the media. Supporting the popular media by providing timely comment to TV, radio, and newspaper journalists about new developments supports the objective translation of research into meaningful messages.

Opinion leaders and endorsement

Targeting the inclusion of opinion leaders in their respective fields for membership on committees and working groups as well as gaining endorsement from key organizations for products or undertakings results in 'buy-in' and ensures long-term ownership of resultant outcomes. Without a mandate to work at a local level within services, this strategy helps with gaining 'grass roots' support particularly within the clinical professionals.

Supporting policy development

Providing the federal health minister and the national government with information about emerging issues, such as new treatments, is an avenue for facilitating evidence-based policy development. Whilst not a lobbying or advocacy group, the NBCC program fulfils an advisory role through membership on key national government strategy groups and committees informing policy about national cancer control programs (e.g., population screening). Recommendations can be made to Government about areas where changes in reimbursement systems may promote best practice such as in multidisciplinary care. Similarly, work with state governments and local service initiatives promotes the uptake of national recommendations.

Informing the research agenda

Based on broad national consultation, the development of national research priorities provides guidance for investigators and assists research foundations with prioritizing the allocation of fundraising monies. Collaborative research initiatives engage individual groups with the national research agenda. Gap analysis and evidence reviews also identify outstanding research questions to be provided as feedback to clinical trials groups. Championing emerging areas of research, such as health services research, promotes the role of action research in investigating cancer control.

A number of the above approaches have been recently identified by the Breast Health Global Initiative as being feasible for use globally by non-government organizations including those in limited-resource countries, where interventions promoting improved outcomes can be introduced in an incremental manner [25].

Case studies

Case studies are used below to illustrate the application of the above principles to areas of identified need in the Australian national program for breast cancer control.

Case study 1

Improving symptom investigation and referral in primary care [26]

- *Evidence*—Clinical practice guidelines recommend that the ‘triple test approach’ (ie clinical breast examination, imaging, fine needle aspiration and/or core biopsy) be used in the investigation of breast symptoms.
- *Gap analysis*—In Australia, primary care practitioners are the first ‘port of call’ for women with breast symptoms. Over half of all breast cancer diagnoses resulted from the identification of a breast change. Investigation of breast symptoms in primary care was inconsistent, leading to delays in diagnosis of breast cancer [27]. Inconsistency included not ordering all recommended imaging tests, not conducting diagnostic tests in the recommended order or simply taking a ‘wait-and-see’ approach. Breast cancer was the most common cancer to be involved in medical malpractice with delay in diagnosis being the most frequent reason for litigation [28].
- *Aim*—To improve the investigation of women with breast symptoms by primary care practitioners in line with evidence-based recommendations.
- *Information*—A guide is developed specifically for primary care practitioners providing a step-by-step process for investigating breast symptoms [13].
- *Implementation strategy*—Guideline dissemination followed by multifaceted strategy including practice audit, data feedback, and educational interventions.
- *Setting*—A total of 112 primary care practitioners randomly selected from across Australia, including urban and rural practices.
- *Evaluation*—Pre/post design examining the approaches used by primary care practitioners to investigating new breast symptoms before, and five months after receiving guidelines and implementation program.
- *Outcomes*—Statistically significant improvements at the post-test phase for investigation of breast lumps and for appropriate referral. For example, at pre-intervention, only 57% of women with suspicious clinical or ultrasound findings were referred for mammography. At post-intervention, referral had increased to 83% [26].

Case study 2

Promoting multidisciplinary care (MDC) model

- *Evidence*—International studies indicate that breast cancer outcomes are improved for patients treated in multidisciplinary settings [29, 30]. Clinical practice guidelines recommend MDC as optimal care [12, 13].

- *Gap analysis*—1995 National patterns of care study indicates 41% of women with breast cancer were treated by a surgeon who treats less than 20 breast cancer cases per year [8]. National profile study indicates lack of MDC in hospitals with a range of caseloads [31].
- *Tailor model to local health care system*—International models of MDC unsuitable for Australian ‘mixed’ health care setting including public/private and urban/rural sectors. NBCC developed ‘Principles of MDC’ to provide a framework for a flexible approach to implement across the Australian health care system [32].
- *Innovative implementation*—In 2000, a three-year National demonstration project commenced with three large collaborative hospital sites across the country to implement MDC for women with breast cancer [31].
- *Evaluation*—Included clinician survey, consumer survey, clinical audit, log of planning meetings and cost analysis; Sustainability—demonstration sites followed-up 18 months later; Observational study—anthropological investigation of established MDC meetings generally considered by medical community to be ‘successful’ to determine key characteristics for sites starting de novo. [31] Barriers identified to MDC implementation in the demonstration project included practitioner reimbursement and legal liability of ‘collective’ decision making.
- *Information resources*—A guide to establishing and sustaining MDC case planning meetings was developed using ‘lessons learnt’ from implementation studies. Guide sent to clinicians and senior hospital service administrators. A communication skills training module was developed to assist clinicians with interdisciplinary team work.
- *Broad promotion*—A national forum series conducted with local key clinicians, policy makers, and service administrators to promote the benefits of MDC and to workshop strategies to implement MDC in their settings. Communication skills training component included. Stakeholder workshops held with medico-legal experts to establish legal status of team-based case management planning meetings.
- *Public information*—Use of annual breast cancer awareness day to promote message to the public of the benefits of a ‘care team’.
- *Policy impact*—Report to federal government about national demonstration project outcomes recommends the inclusion of a national reimbursement item to cover clinicians attending MDC case planning meetings.
- *Outcomes*—A national audit of MDC in cancer care conducted in 2006 found that MDC teams existed more frequently for breast cancer than for other cancers (*report in preparation*). Routine attendance by all

relevant team members at case planning meetings was inconsistent across the country, however, higher levels of routine specialist attendance was found in the breast cancer teams than other cancers. The audit identified further areas for improvement in implementing this care model.

- *Clinician re-imburement*—Funding item announced by federal government for case conferencing re-imburement for cancer specialists from November 2006.

Case study 3

Raising awareness about early detection

- *Evidence*—International and Australian studies emphasize the importance of early detection for improving survival for women diagnosed with breast cancer. The most commonly detected symptom of breast cancer is a lump in the breast. More than 50% of breast cancers are detected by a woman or her doctor as a result of a change to the look or feel of the breast [8].
- *Gap analysis*—A national survey of 3,000 ‘well-women’ in 2003 indicated that Australian women had a lack of knowledge about breast cancer symptoms [33]. Only 57% of women identified a breast lump as their first response when asked about symptoms of breast cancer and 10% could not name any potential symptom of breast cancer [33]. Additionally, after discovering a new breast symptom, 23% of women reported that they did not see a doctor about the symptom at all [33]. International and national studies highlight specific issues for women of culturally and linguistically diverse backgrounds (CALD) in relation to breast cancer ‘myths’ which could impact on early detection [34, 35].
- *Public information*—Survey results released to mass media in lead up to Breast Cancer Awareness Month (October 2005) to create interest about common myths, misconceptions, and lack of knowledge. Public information campaign conducted over nine months to promote breast awareness was launched by campaign patron, the Prime Minister’s wife, on Australia’s Breast Cancer Day (24 October 2005). Extensive campaign with three main components: (1) Advertising campaign (TV, radio, print, posters and web) promoting campaign message “Breast cancer - Finding it early could save your life”, highlighting breast changes to look for and to see a primary care practitioner if unusual changes are found [36]. Free advertising placements with a value of over AU \$800,000 were negotiated; (2) Breast Health Forums held in eleven state capitals and regional and rural centers around the country. Free public forums

targeted local women who had not had breast cancer to hear talks by local survivors, local primary care practitioners, and celebrity guests (e.g., national women’s magazine editor, best-selling female novelist, female TV news presenter); and (3) Campaign for CALD women targeting key messages in five key language groups for Australia (Arabic, Italian, Chinese, Vietnamese, and Greek) [37]. Campaign developed with specialist multi-cultural communications consultant including language translations of information resources, non-English speaking TV, radio, and print advertising campaign, dissemination of resources to community groups and primary care practices, and free-call phone numbers for women to bi-lingual health consultants.

The public information campaign was run in parallel with the promotion of breast screening attendance for asymptomatic women to the national population mammographic screening program.

- *Evaluation*—Includes online national survey of 2,200 women regarding the awareness advertising campaign, a survey of 1,047 women attending Breast Health Forums, reports on dissemination quantities of CALD resources and inquiries to free-call line, and national survey of 3,000 ‘well women’ repeated in late 2007 to investigate knowledge changes.
- *Outcomes*—Evaluation outcomes indicate wide penetration of campaign messages to women without breast cancer. Breast Health Forum attendees were in the target audience with 92% of survey respondents indicating they were women without breast cancer and 80% were over 40 years old. About 95% of forum respondents stated that they had gained new information about breast changes that could be breast cancer and the importance of early detection. About 75% of forum attendees reported having seen the TV advertisement. Two years after the TV campaign was commenced, 50% of the respondents to the online women’s survey remembered the campaign and 64% of these women could recall the advertisement having a breast cancer message. The CALD campaign resulted in the dissemination of over 33,000 translated resources and over 100 calls to the free-call line. The results of the national survey of well-women conducted in late 2007 are yet to be released.

Case study 4

Promoting the role of specialist breast care nurses (BCNs)

- *Evidence*—Trials from the United Kingdom indicate that specialist breast care nurses (SBN) have a

beneficial impact on the care of women with breast cancer by reducing psychological morbidity, increasing understanding, recall, patient support, and improving continuity of care [38, 39]. Women in these studies received a systematic program of care which included repeated contact with a SBN during diagnosis and treatment.

- *Gap analysis*—A national survey of 544 women with breast cancer in 1997 indicates that only 25% of Australian women saw a breast nurse on more than one occasion during diagnosis and treatment. [40] At Australia's first National Breast Cancer Conference for Women in 1998, coordinated by NBCC, consumers identify the provision of SBNs as a top priority [41]. Consumers identify that SBNs could be in a unique position to offer women information, emotional and practical support at crucial time for women [41].
- *Tailor model to local health care system*—An evidence-based SBN model of care was developed for the Australian setting based on national treatment and psychosocial clinical practice guidelines developed by the NBCC. The model focused on assessing and responding to women's needs and providing continuity of care.
- *Innovative implementation*—In 1999, the SBN model was tested at four hospital-based treatment centers throughout the country with senior nurses trained to deliver care in accord with the SBN model. The model was operationalized in a "5 in 12"-clinical pathway which included five pre-scheduled consultations at key treatment phases (diagnosis, pre-operative, post-operative, and two follow-up appointments) across a 12-week period [42].
- *Evaluation*—Includes consumer survey (intervention versus control sample), acceptability and feasibility study, observational study, and economic feasibility. Findings indicated that SBN model could be successfully implemented across a range of settings and that the SBNs integrated well into the multidisciplinary team and played a key role in facilitating women's understanding of the MDC team [42]. Women who had consultations with an SBN were more likely to report receiving information and emotional support with 88% of women believing that the SBN had made a significant contribution to their care [42].
- *Professional standards*—NBCC developed standards to define the core competencies of SBN positions to promote national consistency in the new clinical role [43]. Educational requirements also established to ensure consistency of training requirements. Annual training grant program implemented for rural and remote nurses to gain exposure to breast cancer courses and clinical placements.

- *Policy impact*—There are now over 250 specialist breast care nurse positions in Australia. In May 2008, the federal government announced funding of AU \$12 million over four years to create 30 new SBN positions throughout the country.

With the benefit of hindsight

Over the 13 years of undertaking cancer control programs, there have been a range of lessons learnt about barriers and enablers. As a federally funded organization, the NBCC has had to work closely with state jurisdictions, which administer and fund hospitals within the states. Partnering with state health authorities and cancer organizations has provided leverage for programs conducted within these jurisdictions.

Wanting to run a comprehensive program covering all aspects of the patient's cancer journey saw NBCC initially work in areas in which we now recognize we had little capacity to effect change. For example, aiming to improve clinical trial participation rates for women diagnosed with cancer which in 1995 was at about 3% for early disease [8]. Based on clinical practice guidelines recommending trial participation [15, 16], the NBCC promoted awareness of trials through a website for newly diagnosed women and a discussion paper about women's participation in trials. Over the years, it became apparent that the real barrier to trial participation was in fact more about local infrastructure in the form of availability and employment of data managers within local services to support service trial participation. NBCC realized that whilst, we could inform women we had limited ability to break down the real barrier existing around local resourcing.

Whilst NBCC's guidelines have been well received and adopted across a range of cancer areas, development and revision has been resource intensive and time consuming. Comprehensive guideline sets covering all aspects of the management of stages of disease formed a solid foundation to evidence-based cancer control programs. Maintaining guideline currency has proven to be a challenge as new research emerges rapidly particularly in the field of breast cancer with numerous large international trials underway. In recent years, we have adopted a 'topic-specific' approach to guidelines to ensure that recommendations can be developed more rapidly whilst still maintaining a rigorous evidence-base [44]. The internet has become a major platform for releasing regular research summaries and clinical updates to support information currency.

Another barrier to progress has been identified as the lack of consistency within cancer data collections across the country. Using the continuous quality improvement

approach to our program delivery necessitates, having access to national data to benchmark and monitor progress in breast cancer control. A barrier to this monitoring function was identified in the lack of consistency of items collected in state-based cancer registries and clinical registries. To improve data collection and reporting, NBCC has undertaken a number of initiatives to promote cancer registry consistency throughout the country and agreed minimum data sets for hospital-based collections.

Summary table

A national cancer control program

- Informed by and responsive to consumer needs—*patient-centered*
- Systematic process for research analysis and review—*evidence-based*
- Engagement of all key stakeholder groups and opinion leaders—*collaborative approach*
- Investigating new models of care—*innovative*
- Transparent processes—*open and representative*
- Translation of evidence into clinical practice, service delivery and policy—*outcomes orientated*

The result

Through the approach and work outlined above, the NBCC has earned a reputation as a trusted and authoritative body for independent evidence-based information for consumers and health professionals. Government and other funders regard NBCC as a reliable organization which delivers high quality outcomes on time, within budget and provides exceptional value for money. Through the approach described here, NBCC is now considered a national leadership organization in cancer control which can make a difference through a comprehensive and effective work program. The NBCC's mandate is viewed broadly as 'translating evidence into information, promoting best practice and informing policy'.

Building on the experience of breast cancer control

In recognition of successes achieved in breast cancer, the Australian Government extended the NBCC's mandate in 2001 to coordinate the first National Ovarian Cancer Program. Using the same approach, the Program has conducted evidence reviews, disseminated new clinical practice guidelines and consumer information, developed information about familial risk, undertaken educational

initiatives, held conferences for stakeholders and the first national consumer forum for women with ovarian cancer and their families. In acknowledgement of the incorporation of this ovarian cancer initiative, NBCC officially changed its name to the National Breast and Ovarian Cancer Centre (NBOCC) in February 2008.

Given the leadership role of the NBCC in breast and ovarian cancer, and the transferability of this approach to other cancers, there are many gains which can readily be made through the wider adoption of this model. Recent programs undertaken by the NBCC have had a broader cancer focus; including the development of *Clinical practice guidelines for the psychosocial care of adults with cancer* [45], initiatives to promote psychosocial care and MDC for cancer patients in general and communication skills training for medical and allied health practitioners.

Where to from here?

In looking forward and in response to stakeholder consultation, the NBOCC will be giving greater focus in its programs influencing improvements in service delivery and health policy. Areas planned for future programs include standards of care for services, exploring new models of post-surgical care and follow-up, 'living' electronic guidelines, survivorship information needs, promoting early detection for indigenous women, and supporting ongoing education for primary care professionals. Whilst not an advocacy group, the NBOCC has recently established a Policy Unit to better inform and respond to government policy issues including the development of submissions to parliamentary inquiries and commissions.

The evolution of the NBOCC in response to new research, changes in cancer outcomes and in the cancer and health care landscape in Australia provides an opportunity for other cancer programs to benefit from the experience of a cancer control initiative conducted 'Down Under'.

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