



**NATIONAL BREAST
CANCER CENTRE**
Incorporating the
Ovarian Cancer Program

**BREAST CANCER –
KNOWLEDGE TO SUPPORT
WOMEN IN YOUR COMMUNITIES**

**TRAINING WORKSHOP FOR
ABORIGINAL AND TORRES STRAIT
ISLANDER HEALTH WORKERS**

SUMMARY REPORT

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EXECUTIVE SUMMARY

Breast cancer is a major health issue for Indigenous women. It is the most common cancer and the third leading cause of cancer death in Indigenous women. The disease is diagnosed at a more advanced stage, and outcomes are generally poorer than in non-Indigenous women with breast cancer. A number of factors may contribute to the lower rate of early detection and the lower rate of participation in treatment by Indigenous women, including a strong fear of cancer, insufficient culturally appropriate information about breast cancer and its treatments, and negative community attitudes about cancer.

Indigenous health workers play a pivotal role in the provision of culturally appropriate information and support to the Indigenous community, and are thus in an important position to assist in ameliorating the imbalance in outcomes for Indigenous women with breast cancer. However, there is no training program in breast cancer for Indigenous health workers to support them in their role. Indigenous education and breast cancer support initiatives by the National Breast Cancer Centre revealed a need amongst Indigenous health workers for a comprehensive introduction to breast cancer, including information about incidence in Indigenous women, symptoms, early detection, treatment, and supportive care.

The National Breast Cancer Centre held Australia's first national workshop for Aboriginal and Torres Strait Islander health workers to address the identified gaps in breast cancer training. The workshop aimed to increase Indigenous health workers' knowledge and skills in improving early detection of breast cancer, and in providing information, care and support to women in their communities affected by breast cancer.

The workshop was attended by 60 Indigenous health workers from across Australia, the majority coming from Queensland, New South Wales, Western Australia and the Northern Territory. In an evaluation survey provided at the end of the workshop, 100% of health workers reported that they had gained knowledge that would assist them in their work in their communities, with more than two thirds indicating that their knowledge had improved significantly in each of six key learning areas. All agreed that the workshop had been "very valuable".

Workshop discussions identified some key areas of need, including:

- the development of culturally appropriate breast cancer information and support resources for Indigenous women
- the development of culturally appropriate breast cancer information resources for Indigenous health workers
- support for the wider dissemination of existing breast cancer resources for Indigenous women
- conduct of future breast cancer education initiatives for Indigenous health workers
- exploration of partnerships with organisations ideally placed to deliver further training.

The information will help to inform the future work of the National Breast Cancer Centre in Indigenous breast cancer initiatives.

BACKGROUND

Breast cancer is the most common cancer in Indigenous women,¹ with 27.7 Indigenous women per 100,000 diagnosed annually between 1997 and 2001.² It is the second leading cause of cancer deaths in Indigenous women after lung cancer.¹

While the incidence of breast cancer appears to be lower than that in non-Indigenous women (with an annual rate of 117 per 100,000 women reported across Australia between 1997 and 2001),² the survival rate for Indigenous women is lower (56% five-year relative survival for Indigenous women from the Northern Territory compared with 87% across Australia)³ and the mortality rate is approximately 9% higher than that observed across Australia.¹ Indigenous women are diagnosed at a later stage of disease,⁴ and amongst women aged 50-69 years have a lower rate of participation in the BreastScreen Program than non-Indigenous women (36% compared with 55% for the period 2002-2003).⁵

A number of factors may influence the poorer breast cancer-related outcomes observed in Indigenous women. Research suggests Indigenous women and their communities commonly regard cancer with a high level of fear and associate the disease with a fatal prognosis.^{6,7} This can result in delay or failure to participate in screening or seek medical attention for breast symptoms, scepticism regarding treatment efficacy, and insufficient community communication about the disease.^{6,7} Embarrassment associated with examination and screening may further hinder early detection, while reduced treatment compliance may in part be due to a shortage of culturally appropriate information concerning treatment options and efficacy.⁶ The potentially profound negative impact of losing a breast for a woman on her standing in her family and community may also affect treatment compliance.^{6,7}

Indigenous health workers (IHWs) play a crucial role in cultural brokerage between the Indigenous community and mainstream healthcare providers, and are key providers of culturally appropriate health information and support to the community.^{7,8} As one researcher notes, "Aboriginal Health Workers are in an ideal position to take a lead role in encouraging women to talk more openly about their fears and concerns related to cancer, and to dispel some of the myths and misinformation that prevent people from getting appropriate cancer health care".⁷

The importance of ensuring an appropriately skilled Indigenous health workforce,⁹ and the need for ongoing, culturally appropriate training for IHWs, as well as training in women's health issues for female IHWs¹⁰ has been recognised. The outcomes of several Indigenous breast cancer initiatives funded by the National Breast Cancer Centre (NBCC) in 2005 and 2006 revealed a need for breast cancer education for IHWs, including a comprehensive introduction to breast cancer and the issues relevant specifically to Indigenous women.

In response to this need, the NBCC held Australia's first national breast cancer training workshop for IHWs. The workshop was developed to improve knowledge and skills related to breast cancer in Indigenous women using culturally appropriate content and format. In addition, the workshop aimed to explore the scope for improvement in key areas of information and care for Indigenous women with breast cancer and for IHWs.

OBJECTIVES

The objective of the workshop was to bring together IHWs from across Australia in order to:

- Improve the knowledge and skills of health workers in several key areas:
 - breast cancer incidence in Indigenous women
 - symptoms of breast cancer
 - early detection and mammographic screening
 - clinical breast examination
 - treatment for breast cancer
 - psychosocial care for women with breast cancer.
- Provide an opportunity to share experiences and build networks.
- Identify future breast cancer training and resource needs of IHWs and Indigenous women.

METHODOLOGY

LOCATION

Cairns was selected as the venue for the workshop. Queensland has the second largest Indigenous population of all states, and far north Queensland is relatively close to other areas of Australia with a large Indigenous population.¹¹ While Cairns is easily accessible from different parts of Australia, it is also a relatively small urban centre. Unlike the larger state capitals, it is easy to navigate and has a large and visible Indigenous population.

The workshop room was set up to promote interactive discussion both within the audience and between audience and presenters.

TRAVEL GRANTS

Financial constraints were recognised as a major potential barrier to attendance for many health workers.¹⁰ To support the attendance of IHWs from across Australia, the NBCC made funds available to supplement expenses related to accommodation and travel.

WORKSHOP PROMOTION

The workshop was widely promoted by the NBCC through direct emails, faxes, and the Indigenous media. Previous experience publicising NBCC initiatives for IHWs indicated that effective promotional strategies should include the following:

- Publicising through a variety of local and national Indigenous media.
- Publicising through the online notice boards, newsletters and emailing lists of:
 - Indigenous health organisations
 - Government health departments
 - Local Indigenous community organisations
 - Rural and remote health organisations
 - Women's health organisations
 - Professional bodies representing Aboriginal Community Controlled Health Organisations.
- Allocating significant time to follow up initial enquiries.

Four months before the workshop, a diary alert was emailed to relevant Indigenous and health organisations and government health departments, who distributed the notice through their emailing lists or advertised the workshop on their websites.

An insert advertising the workshop was distributed with the March issue of the *Aboriginal and Islander Health Worker Journal*, which also mentioned the workshop in the Editorial of the May issue. Two months before the workshop a second round of emails were sent to relevant Indigenous and health organisations, government health departments, and Aboriginal Community Controlled Health Organisations. Faxes were sent to Aboriginal Community Controlled Health Organisations without email facilities. The workshop was promoted in numerous editions of national and local Indigenous journals and newspapers and on several Indigenous radio stations.

The workshop was also promoted to a wide audience through *BreastFax*, the NBCC's monthly newsletter.

A record was kept of all expressions of interest, and these were periodically followed up to encourage registration.

WORKSHOP PROGRAM DEVELOPMENT

Following a review of the literature regarding IHW training, breast cancer in Indigenous women, and Indigenous women's perceptions of cancer, a program was developed in consultation with IHWs and educators, and others involved in cancer training for IHWs.

Issues taken into consideration in developing the program included:

Format

- Presentations should be brief and straight forward.
- Presentations should be tied to real life situations.
- The program should integrate regular audience participation.
- Breast cancer is a women's health issue, and as such should be respected as Women's Business. The workshop should be 'female only'.

Content

- Health workers require basic information about breast cancer and its implications for the individual woman and her community.
- Participation in screening and treatment influence outcomes for Indigenous women with breast cancer. Barriers to screening and treatment compliance in many Indigenous women include myths about cancer generally and breast cancer specifically. Presentations should address these myths.
- The community plays an important role in a woman's wellbeing after treatment.

PROCEEDINGS

The workshop was delivered in four sessions that were divided by morning tea, lunch and afternoon tea. The workshop opened with a traditional welcome to country by an elder of the Yirriganydji people, the traditional owners of the land.

Each presentation was given by an Indigenous woman who had expertise or experience in a particular area of breast cancer, or by a non-Indigenous presenter recognised as an expert in her field.

The opening presentation was given by an Indigenous academic with expertise in Indigenous women's health and cancer, who is also a breast cancer survivor. She spoke about breast cancer and how it affects Indigenous women at a population and at the individual level, with personal insights into her own cancer journey. The second presenter had worked as an IHW, and in Indigenous health promotion and cancer screening. She spoke about the barriers to cervical cancer screening in Indigenous women that are also of relevance to breast cancer. The third presentation concerned the importance of breast awareness and finding breast cancer early, and was delivered by the director of the NBCC.

The second session opened with two concurrent presentations on clinical breast examination. One presentation used a video demonstration of a clinical breast examination performed by an IHW, while the other used only still images to cater for those attendees who indicated that they would prefer not to see the video. Both groups discussed barriers to awareness of breast cancer, and the appropriate assessment of women with breast symptoms. The presentation that followed focussed on IHWs and GPs working together, and was given by a female GP with considerable experience working in remote Indigenous communities. This was followed by a role play in which a female breast surgeon and an Indigenous woman, whom she had treated for breast cancer, explored the issues facing Indigenous women undergoing treatment for the disease.

Session three began with a presentation by a female psychiatrist with expertise in the psychosocial care of women with breast cancer. She spoke about the supportive care needs of women with breast cancer and their families, exploring the various challenges they might face along the treatment pathway. This was followed by the screening of a DVD titled *My Story*,¹² depicting several Indigenous survivors of breast cancer and their families discussing their experiences with the disease. The DVD was introduced by its producer, who discussed the experience of interviewing the women and the intended purpose of the DVD. After watching the DVD, the audience split into small groups to discuss the issues raised in the women's stories. This was followed by a large group discussion in which points of interest that arose during the small group work were discussed.

The closing session of the workshop synthesised the themes that arose during the day, and opened the floor to discussion of future directions. Attendees were invited to raise issues around breast cancer training and resources for IHWs and for Indigenous women.

AVAILABLE MATERIALS

All attendees received folders with the workshop program, copies of PowerPoint presentation slides, an evaluation form, a copy of an Aboriginal woman's account of her experience with breast cancer, and an NBCC resource order form.

Materials produced by the NBCC were available free of charge for participants at each seminar. At the end of the workshop all displayed materials had been distributed. The Queensland Health resource, *Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women* was also available.

OUTCOMES

ATTENDANCE

Attendance at the workshop was strong, with participation by 60 IHWs from across Australia. The majority of attendees came from Queensland (47%), while New South Wales (23%), Western Australia (15%) and the Northern Territory (10%) were also well represented. One delegate came from Victoria (2%), one from South Australia (2%), and one from Tasmania (2%). There were no delegates from the ACT.

The proportional distribution of attendance across states/territories reflects the spread of the Indigenous population across Australia,¹¹ suggesting that the workshop approximated the national mix that was intended.

All attendees received certificates of attendance.

EVALUATION

At the conclusion of the workshop, participants were invited to complete an evaluation form. The evaluation form was designed to be simple to understand and answer to encourage completion. The form was returned by 54 (90%) attendees.

The evaluation form assessed the perceived extent of learning in the six key learning areas covered in the presentations:

- Breast cancer and how it affects the Indigenous population
- The signs and symptoms of breast cancer
- The importance of early detection of breast cancer
- Performing a clinical breast examination
- Treatments for breast cancer
- Psychosocial support for women with breast cancer.

The extent to which the workshop would assist attendees in their roles and the overall value of the workshop were assessed. Space for comment was provided, and attendees were asked to indicate if there was anything not covered in the workshop that would have been useful.

RESULTS

Participants

Results of the evaluation form showed that respondents ranged in age from 21 to 65 years, with an average age of 42 years. The majority of respondents (72%) worked as IHWs. Several were employed in the capacity of several roles (eg one woman was an Aboriginal community worker/Indigenous health worker). A breakdown of respondents by area of specialisation is presented in Table 1.

Table 1. Role of respondents	
Indigenous health worker	39 (72%)
Registered nurse	5 (9%)
Aboriginal community worker	4 (7%)
Education/liaison officer	5 (9%)
Women's health support worker	3 (6%)
Enrolled nurse	2 (4%)
Program co-ordinator	2 (4%)
Midwife	1 (2%)
Sexual assault counsellor	1 (2%)
Sexual health worker	1 (2%)
Women's health coordinator	1 (2%)

Workshop

All respondents indicated that they found the workshop very valuable, with none indicating that it had been only "a little valuable" or "not valuable".

All respondents stated that what they had learnt at the workshop would assist them in their work (see Table 2). The majority (56%) indicated that all of what they had learnt from the workshop would assist them in their work, while 85% said that "all" or "most" of what they had learnt would assist them in their work.

Table 2. Impact of workshop on work	
All of the information learnt will assist in work	30 (56%)
Most of the information learnt will assist in work	16 (30%)
Some of the information learnt will assist in work	5 (9%)
None of the information learnt will assist in work	0 (0%)
Missing	3 (6%)

Key learning areas

Respondents were asked to rate their level of learning (“a lot”, “quite a bit”, “a little bit” or “nothing”) in each of six key knowledge areas. Between 91% and 67% of respondents indicated that they had learnt either “quite a bit” or “a lot” in each key knowledge area: how breast cancer affects Indigenous women in Australia (91%), the symptoms and signs of breast cancer (83%), the importance of early detection (89%), how to perform a clinical breast examination (81%), treatments for breast cancer (67%) and psychosocial support for women with breast cancer (79%) (see Table 3).

The majority of respondents indicated that they had “learnt a lot” about how breast cancer affects Indigenous women in Australia (61%), the symptoms and signs of breast cancer (59%) and the importance of early detection (65%). No respondents said that they had learnt “nothing” about how breast cancer affects Indigenous women in Australia.

Table 3. Learning achieved in six key knowledge areas						
	Breast cancer in Indigenous women	Symptoms and signs of breast cancer	Importance of early detection	Performing a clinical breast examination	Treatments for breast cancer	Psychosocial support for women with breast cancer
Learnt a lot	33 (61%)	32 (59%)	35 (65%)	23 (43%)	23 (43%)	26 (48%)
Learnt quite a bit	16 (30%)	13 (24%)	13 (24%)	21 (39%)	13 (24%)	17 (31%)
Learnt a little bit	4 (7%)	5 (9%)	1 (2%)	4 (7%)	11 (20%)	8 (15%)
Learnt nothing	0 (0%)	2 (4%)	3 (6%)	2 (4%)	3 (6%)	1 (2%)
Missing	1 (2%)	2 (4%)	2 (4%)	4 (7%)	4 (7%)	2 (4%)

Comments

Respondents expressed their appreciation for the opportunity to network with other IHWs. This was seen as a way forward to sustainably improve the care they give women with breast cancer in their communities. A list with contact details of attendees and presenters was distributed to all who participated in the workshop. Several comments expressed appreciation for the women's stories that were incorporated into the presentations, and for the *My Story* DVD.

Topics that respondents would have liked to have seen covered in greater depth in the workshop included:

- information about treatments for breast cancer and the potential side-effects
- clinical information about breast cancer
- referral systems
- relaxation techniques
- debriefing for work that involves dealing with life and death issues
- the sharing of resources
- issues related to living and working in remote areas
- support and education for partners and children of women affected by breast cancer
- places that offer screening.

Many respondents stated that they would have liked the workshop to have been spread out over several days, while several comments suggested making such workshops a regular occurrence.

Three-Month evaluation

A second evaluation form was sent to attendees to assess the impact of the workshop on their practice after three months. Data from the three-month evaluation is currently being collated. Results will be released on the NBCC website and included as an addendum in ensuing versions of the report.

KEY ISSUES

Overall, feedback from participants was very positive, and everyone felt that the workshop would improve their ability to provide care for women in their community with breast cancer. A number of key issues emerged from the afternoon discussion session of the workshop concerning the needs of Indigenous women with breast cancer and of IHWs.

INDIGENOUS WOMEN WITH BREAST CANCER

SUPPORTIVE CARE NEEDS

A number of factors important in supporting Indigenous women with breast cancer were discussed. These included:

- The important role of family and friends in providing support.
- The need for education and support for the partners of Indigenous women with breast cancer.
- The need for support for the children of Indigenous women with breast cancer.
- The need for education and support for the friends and communities of Indigenous women with breast cancer.
- The need to support the children of women who do not survive breast cancer.
- The role of palliative care.
- The need for financial support to reduce the burden of additional costs related to travel expenses etc faced by Indigenous women with breast cancer and their families.

RESOURCE NEEDS

The importance of culturally relevant information and support resources was emphasised. Areas of need identified by health workers were:

- Information resources that addressed the particular needs of Indigenous women.
- Resources and support programs tailored to the needs of Indigenous women, eg prostheses and cosmetics.
- Possible roles for Indigenous survivors of breast cancer providing peer support through community based programs.

Elements noted as contributing to the cultural relevance of resources for Indigenous women included:

- The use of personal stories to provide context to information.
- The use of Indigenous images.

SCREENING

Possible approaches suggested to make screening mammograms less intimidating for Indigenous women and encourage uptake were:

- Elders and health workers having regular mammograms so that they can share their knowledge of the process and the experience with other Indigenous women.
- The presence of female elders during mammograms to provide comfort and support.
- Health workers visiting screening services to familiarise themselves with the screening process, enabling them to share this information with their communities.
- Creating partnerships between BreastScreen and IHWs to collaborate in raising awareness and encouraging attendance, eg through block bookings.
- Supporting local 'champions' of breast awareness to promote messages.

ACCESS

Access to health care was identified as a factor influencing outcomes for Indigenous women with breast cancer. Key issues included:

- An undersupply Aboriginal Medical Services and IHWs in some areas.
- The challenges of implementing broad screening and health promotion in rural and remote areas.
- Difficulties in locating women requiring follow up in rural and remote areas.
- The availability of bulk billed services and women's awareness of these.

INDIGENOUS HEALTH WORKERS

TRAINING NEEDS

As the first national workshop of its kind, the learning objectives covered a comprehensive range of key areas. The resulting program attempted to accommodate a large amount of information in a series of closely scheduled segments. Speakers and audience alike agreed that a more flexible program, with ample time for presentations and discussion would enable topics of particular relevance to be explored in greater depth. There was consensus about the value of further training in breast cancer for IHWs. It was suggested that training:

- be available locally, in order to
 - build on information learned through the national training
 - minimise the travel required
 - develop local networks and the sharing of resources
- be held regularly
- be comprehensive
- enable topics to be covered thoroughly

- allow sufficient time for questions, clarification and discussion – this may mean that training is spread over more than one day
- include personal stories to give context to the clinical content
- also be conducted within workplaces and include other relevant staff.

A number of topics were suggested that require greater depth in training:

- Screening and its rationale.
- Supportive care for women.
- Supportive care for the families of women with breast cancer.
- Communication skills.
- Treatments for breast cancer.

Methods for promoting health worker training in breast cancer were put forward. Suggested strategies were:

- Advocating the importance of training locally, both within workplaces and within larger professional bodies.
- Including breast cancer in the programs of national meetings and conferences for IHWs.

WORKFORCE ISSUES

The nature of the health worker role requires the ability to respond to a wide range of health care and support needs.^{8,10} Attendees identified a need to balance awareness of breast cancer with other pressing health conditions. Several approaches to negotiating this balance were suggested:

- The development of specialist oncology/breast cancer IHW roles.
- Networking with other IHWs to support each other's learning and promote awareness of resources available to their clients.
- Raising awareness within medical services of the particular breast cancer related needs of Indigenous women and the associated duties of IHWs.
- Supporting IHWs in their role by making available funding, counselling and information.
- Collaboration with the professional bodies (eg professional colleges) of other specialisations involved in the care of Indigenous women with breast cancer to encourage cultural awareness and communication skills training.

AWARENESS RAISING

The health workers discussed approaches towards raising the awareness of breast cancer in Indigenous women. Possible strategies noted were:

- Educating younger women, raising their understanding of the importance of early detection through breast awareness, and through screening later in life.
- Holding annual awareness events, such as a breast cancer breakfast during breast cancer awareness month every October.
- Promoting breast awareness when Indigenous women come in for a Pap smear.

RESOURCE NEEDS

Outcomes of the discussion suggested both a paucity of resources for Indigenous women concerning breast cancer awareness and information, as well as variable knowledge amongst health workers about the resources that are available. Early breast cancer and advanced breast cancer were mentioned as priority topics for clinical resources for IHWs, and a need for resources to use in a local context was identified. A national clearinghouse for Indigenous resources was one suggested approach to facilitating the sharing of available information.

The response to the *My Story* DVD was very positive. Attendees were enthusiastic about the idea of being able to use such a DVD in their practice, and many indicated that it would be a valuable resource in educating other health professionals and Indigenous women with breast cancer and their communities.

AFTER THE WORKSHOP

A number of attendees and presenters contacted the NBCC to express their appreciation for the opportunities provided by the workshop, and positive feedback was also received from managers commenting on the benefits for staff who attended. The NBCC has also received several requests from attendees for resources to be used in local awareness raising and education initiatives.

CONCLUSION

The first national breast cancer training workshop for Indigenous health workers, *Breast cancer: Knowledge to support women in your communities*, enabled all 60 attendees to improve their ability to raise awareness of breast cancer and provide breast cancer-related care to Indigenous women. Many new directions for future initiatives in Indigenous breast cancer care emerged from workshop discussions. The NBCC has identified a number of key priorities to consider in its future initiatives for IHWs:

Resources

- The development of culturally appropriate information for Indigenous women about early detection, symptoms, early and advanced breast cancer, and treatment.
- Existing NBCC resources for partners and children of women with breast cancer could be adapted to produce appropriate Indigenous resources.
- The development of culturally appropriate information for IHWs about performing a clinical breast examination.
- Incorporating a focus on women's stories to provide a context for information.
- Exploring the possibility of supporting wider dissemination of the *My Story* DVD.

Workforce issues

- Engaging in further analysis of the issues identified.

Training

- Support of education initiatives for IHWs.

Partnerships

- Investigation of the possibility of creating partnerships with appropriate local organisations to support implementation of future initiatives.

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