Strengthening Support for Women with Breast Cancer:

National Process Evaluation Report

March 2005

Prepared by the National Breast Cancer Centre

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Project teams

The project teams involved in the Strengthening Support for Women with Breast Cancer program are (listed in alphabetical order):

ACT: ACT Health

NSW: NSW Breast Cancer Institute

NT: The Cancer Council Northern Territory

QLD: Women’s Cancer Screening Services of the Queensland Department of Health

SA: Country and Disability Services Division of the South Australian Department of Human Services

TAS: The Cancer Council Tasmania

VIC: The Cancer Coordination Unit, Victorian Department of Human Services

WA: The Cancer Council Western Australia
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Over the course of the Strengthening Support for Women with Breast Cancer program, the following people were involved as staff members in the conduct of the Project(s) and/or the preparation of this report:

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EXECUTIVE SUMMARY

The special needs of women with breast cancer living in rural and remote areas of Australia were highlighted in 1994 in the House of Representatives Standing Committee on Community Affairs on the Management and Treatment of Breast Cancer. In response to this report, the Australian Government provided funding for the Strengthening Support for Women with Breast Cancer (SSWBC) program in the 1999/2000 Federal budget.

The SSWBC program was a 4-year initiative in which the Australian Government funded each State and Territory to develop and implement locally relevant strategies to improve supportive care for women with breast cancer in rural and remote regions. In 1999, at the project outset, the National Breast Cancer Centre (NBCC) convened a national summit on behalf of the Australian Government to facilitate the development of appropriate supportive care models for inclusion as part of the program. The summit involved approximately 40 participants representing various Government bodies, cancer organisations, rural health care providers, clinical groups, breast cancer and rural health consumer groups. The four models developed from the summit were:

- establishment of new specialist breast nurse (SBN)/cancer supportive care coordinator roles with the aim of improving support and care coordination for women with breast cancer

- upgrading existing services through audit, training, coordination and promotion, recognising that most rural and remote areas had existing professional services that provided support for women with breast cancer

- extending the role of an existing healthcare worker to include the tasks of a SBN to overcome difficulties in establishing dedicated breast care nurse positions in rural areas

- strengthening access to tertiary referral support services through the development of a referral framework, implementation of satellite clinics, or provision of psychiatric services via tele-health.
**Process evaluation**

The NBCC was commissioned by the Australian Government to oversee a national process evaluation of the program initiatives and to provide a clearinghouse function. It was recognised and agreed from the outset that an assessment of the impact on supportive care of the SSWBC program would not be possible in isolation of other existing strategies aimed at improving outcomes for women with breast cancer. A comparison of the impact of strategies from different States and Territories would also not be possible because of the range of strategies used. It was agreed that the national evaluation should focus instead on supportive care delivery structures (process) and acceptability of strategies rather than measurable outcomes such as quality of life (impact). In addition to the national process evaluation, each State and Territory has or is in the process of undertaking a local evaluation of the strategies implemented. These results have been summarised in State and Territory reports to the Australian Government Department of Health and Ageing.

In order to guide the national process evaluation, and in recognition of the diverse range of strategies implemented, five theme areas were developed. These were:

- **Theme 1: Models that improve approaches to supportive care**

- **Theme 2: Providing information to women and health care providers**

- **Theme 3: Improving communication between health care providers**

- **Theme 4: Improving continuity of care**

- **Theme 5: Health care or supportive care provider needs in relation to training and support.**

The process evaluation drew upon a range of information sources:

- baseline and follow-up surveys with three key health professionals (breast care nurse, specialist and supportive care worker) at a minimum of two sites in each State and Territory
• an acceptability survey with key project stakeholders towards the end of the project

• quarterly discussions between State/Territory project coordinator and a Senior Project Officer at the NBCC to discuss project progress

• quarterly workshops with all State and Territory project coordinators to discuss key issues and share ideas

• State and Territory progress and evaluation reports.

**Strategies**

The States and Territories implemented a range of diverse strategies to improve supportive care for women with breast cancer in rural and remote areas. These included:

• employment of an SBN to improve supportive care and care coordination for women with breast cancer in rural areas

• development of multidisciplinary care (MDC) strategies to increase awareness of and communication about supportive care issues among health professionals

• capacity building with existing health professionals to take on the roles managed by the SBN

• use of information technology to enhance information provision and communication

• development of locally relevant information resources for use by health professionals and women with breast cancer

• strategies to improve communication between health professionals such as communication skills training workshops and MDC meetings.

A criterion for all strategies was that they should be sustainable. Transferability to other cancers was also considered.
Key results

The national process evaluation of the program provides a valuable insight into the process, successes, barriers and enablers of the strategies implemented by the States and Territories. Despite the variation in approaches, common themes have emerged from the process evaluation that will be beneficial for health services and facilities wishing to improve the level of supportive care for women with breast cancer in rural areas. Many of the strategies implemented have broader application beyond breast cancer and will be transferable to other cancers and chronic diseases. Some of the key lessons learned from the project are outlined below.

Successes

Theme 1: models that improve approaches to supportive care

Key successes reported included:

- implementation of the SBN role in rural areas and perceived improvements in supportive care and care coordination for women with breast cancer in these areas

- increased awareness and recognition of the SBN role by other health professionals

- recognition of the SBN as an MDC team member

- implementation of MDC as a strategy to improve supportive care

- reductions in inequalities and improved care coordination for women in rural areas through a capacity building approach in which existing health workers took on the roles of the SBN.
Theme 2: Providing information to women and health care providers

Key successes reported included:

- increased awareness amongst health professionals of services and resources to provide information and support for women with breast cancer
- implementation of a range of strategies to provide information to women and health care providers in rural and remote areas, including service directories and consumer forums.

Theme 3: Improving communication between health care providers

Key successes reported included:

- increase in protocols to ensure communication about supportive care needs and in perceived levels of communication between health professionals
- use of information technology to improve communication links between health professionals working in rural areas and to provide information, e.g. SBN online chat room
- increased awareness of the importance of SBNs in providing information about supportive care issues to other health professionals
- increased confidence by SBNs in their ability to provide information about supportive care issues to other health professionals
- development of tailored resource packages to improve supportive care for Aboriginal and Torres Strait Islander women and for women from non-English-speaking backgrounds.
Theme 4: Improving continuity of care

Key successes reported included:

- increase in MDC meetings to coordinate treatment planning
- recognition of the critical role played by the SBN in ensuring continuity of care for women with breast cancer
- increases in the level of supportive care planning undertaken for women with breast cancer
- increase in consultations between SBNs and women with breast cancer, particularly for women travelling between rural and urban areas for treatment.

Theme 5: Health care or supportive care provider needs in relation to training and support

Key successes reported included:

- training in e-health technologies to support the implementation of technology-based strategies
- increased reports of regular supervision for SBNs
- innovative strategies to provide support for SBNs in rural areas such as regular debriefs by telephone with a psychologist.

Overall acceptability

Overall there was a high level of agreement that the strategies implemented through the SSWBC program had impacted positively on supportive care for women with breast cancer in rural areas. A high level of sustainability was reported with over 90% of
respondents indicating that either additional funding had been secured or was being sought to sustain strategies. Some flow-on effects to other cancers were also reported.

**Challenges and barriers**

Challenges encountered during the implementation of SSWBC strategies related to:

- role delineation for the SBN
- lack of support or infrastructure at an organisational or State/Territory government level for the strategies
- difficulties in managing all program tasks within the timeframe
- issues of change management
- issues of geographic isolation.

**Enablers**

Mechanisms identified through the program to facilitate the implementation of new strategies related to the need for ensuring stakeholder buy-in and ownership of strategies through consultation and ongoing demonstration of benefits, managing expectations and provision of infrastructure and administrative support.

**Lessons learnt**

Key lessons from the SSWBC program relate to specific issues associated with developing and implementing strategies for improving supportive care across a range of health service delivery settings.
Some of the key lessons learnt include:

- the need for new roles, such as the SBN position, to be defined and for implementation to be responsive to the local region’s health care structures, systems and needs

- the need for community consultation and engagement from the outset, particularly with women with breast cancer, to ensure buy-in and to help define priorities

- the importance of high-level stakeholder engagement to ensure sustainability

- the need for flexibility and innovation in approaches to improving supportive care

- the importance of networking and communication between health professionals

- the need for adequate resourcing

- the importance of strategies to ensure sustainability.

**Conclusion**

The SSWBC program has demonstrated that supportive care for women with breast cancer in rural areas of Australia can be improved through a range of strategies. Implementation of new strategies is dependent on adequate resourcing and on ongoing support and buy-in from key stakeholders. Many of these strategies have broader application to other cancers.
1. BACKGROUND

The Strengthening Support for Women with Breast Cancer (SSWBC) program

Every year in Australia over 11,000 women are diagnosed with breast cancer.\(^1\) Of these, around 30% live in rural or regional areas.\(^2\) The disease has an enormous impact on the women, their families and communities to which they belong. Women living in regional and rural areas face particular barriers to accessing treatment options and support services due to geographic isolation and limited contact with specialist health care workers.

The special needs of rural women diagnosed with breast cancer were highlighted in 1994 by the House of Representatives Standing Committee on Community Affairs on the Management and Treatment of Breast Cancer,\(^3\) which recommended that priority be given to addressing the problems faced by women from rural and remote Australia. The Committee recommended that:

"Commonwealth and State/Territory governments, along with practitioners, professional bodies and all other service providers, give urgent priority to addressing the problems faced by women from rural and remote areas in accessing multidisciplinary teams, adjuvant therapy, clinical trials, counselling, support groups, and information." (p14)

In response to these recommendations, the Australian Government announced the SSWBC initiative in the 1999/2000 Federal budget.

Funding of $4.1 million dollars over 4 years was provided to States and Territories to fund initiatives to improve support for women diagnosed with breast cancer, particularly women living in rural and remote areas. Funding was allocated on the basis of the proportion of the population in each State and Territory living in rural and remote areas, using the Rural and Remote Areas Classification (RRMA) as the basis for calculations.
**Guiding principles for the SSWBC program**

Projects in each jurisdiction were based on locally identified needs and priorities, and guided by the following principles, identified at the outset of the project:\(^4\)

- The project should result in feasible and sustainable improvements in supportive care for rural women with breast cancer
- In achieving sustainable benefits, the models adopted should take into account the funds available; specifically that the funds are limited to approximately $1 million per annum and will only be available for four years
- Where possible, and acknowledging the paucity of data, the project should be based on evidence of need
- Where possible, and acknowledging the paucity of data, the strategies adopted should be based on evidence of benefit (efficacy)
- Where possible approaches should aim to reduce inequity of support services for rural women
- All of the approaches adopted as part of this project should be evaluated to develop our understanding of effective strategies in increasing support for rural women
- Opportunities for developing partnerships with other organisations and between States and Territories should be considered, particularly with reference to cross-border areas
- Wherever possible, the development of resources should be undertaken collaboratively to reduce duplication and encourage consistency in information.
Developing approaches to strengthen supportive care: the 1999 summit

In November 1999, the National Breast Cancer Centre (NBCC) convened a national summit on behalf of the Australian Government to facilitate the development of appropriate supportive care models for inclusion as part of the program. The summit involved approximately 40 participants representing various Government bodies, cancer organisations, rural health care providers, clinical groups, breast cancer and rural health consumer groups. The summit aimed to:

- review existing data about the supportive care needs of rural women with breast cancer
- canvas the views of key stakeholders about options for strengthening supportive care services
- reach a consensus about optimal approaches to strengthening supportive care services for rural women with breast cancer within the context of the funding announced in the federal budget.

To support the summit, the NBCC summarised available data about the supportive care needs of rural women with breast cancer and examined the effectiveness of different strategies for improving support. The main findings of this review are summarised below and have been published in the *Strengthening Support for Women with Breast Cancer: Background paper*.

Breast cancer and rural women

The review found no evidence to suggest that breast cancer incidence or mortality differed for women living in rural versus urban areas in Australia. There was also no evidence that rural women received significantly different treatment for breast cancer compared with their urban counterparts. Data from a national patterns of care study in 1995 indicated that women living in rural areas were just as likely as women in urban
areas to be diagnosed by the national screening program, receive the same investigations, have the hormone status of their tumour assessed and to participate in clinical trials. One exception was that the proportion of women undergoing mastectomy for both early and advanced breast cancer was higher in rural areas compared with urban areas.

Supportive care needs of women with breast cancer in rural and remote Australia

Much of the data about the supportive care needs of women from rural areas was drawn from qualitative rather than quantitative information. Data from a national survey of 544 women with early breast cancer conducted by the NBCC in 1996 demonstrated that women from rural areas (n=204) were satisfied with the care they received in the following areas:

- how they were told their diagnosis of breast cancer
- their involvement in treatment decisions
- information about many aspects of their care
- amount of emotional support received
- understanding who was in charge of their care and information sharing within the team.

The survey showed that women from rural and remote areas experienced problems in the following areas:

- Receiving full information about treatment: few women received written (22%) or audio taped (4%) information about their care; only 25% of all women (and 24% of rural women) received a written follow-up plan.
- Receiving information about support: 25% of rural women wanted more information about financial support for travel and accommodation; 17% wanted more information about practical and emotional support available near treatment centres,
and 12% wanted more information about accommodation; 30% believed that living in a rural area had limited their access to information or services.

- Continuity of care: although the women surveyed appeared to understand who was in charge of their care and felt that communication among the treatment team was adequate, 42% of rural women would have liked one person identified as the main contact during treatment.

- Information about financial support for travel and accommodation: the survey found that substantial numbers of rural women travelled more than 100 kilometres for: surgery (15%); radiation therapy (63% of those who received radiation therapy); and chemotherapy (36% of those who received chemotherapy). Only 44% of the women who travelled for treatment received financial assistance and, while 24% were unaware of its availability. In addition, specific family concerns for rural women, focused on how the family would manage during their absences for treatment and the added financial strain brought about by the costs associated with travel for treatment.

Other issues of relevance for women in rural areas include:

- Detection and treatment for depression and other serious psychological problems: key factors associated with an increased risk of psychosocial problems include: marital status, economic adversity, perceived poor social support, poor martial functioning, cumulative stressful events and mental health history. Given the socio-economic decline in many Australian rural and remote communities, these factors needed to be considered when exploring the psychosocial needs of rural women.

- Access to services for lymphoedema: Poor access to physiotherapy and other treatments may exacerbate the needs of rural women with lymphoedema.

- Special issues for women from Indigenous and non-English speaking backgrounds: Research identifying the support needs of non-English speaking or indigenous women living in rural and remote areas is limited. A range of consultative processes have indicated that these women require more information about all aspects of breast cancer and access to culturally appropriate support and health care.
Treatment also has the potential to isolate these women from support provided by their family units.

Evidence about the effectiveness of supportive care strategies

The NHMRC Psychosocial Clinical Practice Guidelines: information, support and counselling for women with breast cancer published in 20007 provide recommendations about psychosocial aspects of the management of breast cancer, focusing on the following areas:

- general interactional skills
- discussing prognosis
- providing information and choice
- preparing women for potentially threatening procedures and treatment
- providing emotional and social support
- providing psychological care
- ensuring continuity of care.

Strategies identified by the NBCC as having particular benefit to women living in rural and remote areas include the importance of specialist breast nurses (SBNs) in providing information and support, and increasing awareness of psychosocial issues and use of e-health to improve access to specialist services for consumers from rural and remote areas and to improve communication between clinicians.

Summit outcomes

Drawing on information in the background paper, stakeholders of the 1999 summit considered potential models for improving supportive care needs of women with breast
cancer in rural and remote regions of Australia, focusing on the merits of various models and issues associated with implementing and evaluating each model in the rural context. The importance of achieving sustainable improvements was emphasised. Four models for implementing the SSWBC program were proposed:

- Establishment of new SBN / cancer supportive care coordinator roles with the aim of improving support and care coordination for women with breast cancer

- Upgrading existing services through audit, training, coordination and promotion, recognising that most rural and remote areas had existing professional services that provided support for women with breast cancer

- Extending the role of an existing healthcare worker to include the tasks of a SBN to overcome difficulties in establishing dedicated breast care nurse positions in rural areas

- Strengthening access to tertiary referral support services through the development of a referral framework, implementation of satellite clinics, or provision of psychiatric services via tele-health.

These models were used as a basis for locally appropriate strategies developed by each State and Territory. Further information on these models was summarised in a paper developed by the NBCC following the workshop.8
2. EVALUATION PROCESS AND CLEARINGHOUSE FRAMEWORK

The role of the National Breast Cancer Centre

In 2000, the Australian Government Department of Health and Ageing (DOHA) contracted the NBCC to conduct a national evaluation of the SSWBC program and provide a clearinghouse function. It was recognised and agreed from the outset that an assessment of the impact on supportive care of the SSWBC program would not be possible in isolation of other existing strategies aimed at improving outcomes for women with breast cancer. A comparison of the impact of strategies from different States and Territories would also not be possible because of the range of strategies used. It was agreed that the national evaluation should focus instead on supportive care delivery structures (process) rather than measurable outcomes such as quality of life or mortality (impact).

Five themes were identified to guide evaluation of the strategies implemented:

- Theme 1: Models that improve approaches to supportive care
- Theme 2: Providing information to women and health care providers
- Theme 3: Improving communication between health care providers
- Theme 4: Improving continuity of care
- Theme 5: Health care or supportive care provider needs in relation to training and support.

Specifically, the evaluation aimed to answer the following questions:

- How was supportive care provided to rural women with breast cancer in Australia?
• How were strategies for improving supportive care developed and implemented as part of the SSWBC program?

• What changes were there to the provision of supportive care services during the SSWBC program?

The objectives of the evaluations were therefore to:

• provide a detailed description of the SSWBC program in each State and Territory

• analyse the successes, barriers and enablers of strategies adopted, including a description of the acceptability of the implemented strategies in each State and Territory

• describe supportive care at the outset and end of the program, relative to the five main themes of the program, with regard to:

  o changes in each theme area across the program

  o changes in the theme areas targeted by individual strategies.

The evaluation would not:

• make comparisons between States/Territories

• establish whether the SSWBC program was specifically responsible for any changes.

**Project timeframe**

The SSWBC program timeframe was 2000–2004. However, contracts with each State and Territory were signed at different times so there were some differences in start dates and completion dates. Key dates within the project timeframe are listed in Figure 2.1.
Information sources

A range of methods for gathering information were proposed by the NBCC in order to ensure the evaluation resulted in a comprehensive description of the nominated strategies undertaken in each State and Territory. This included the benefits, outcomes, successes, and barriers to implementing strategies. Development of the evaluation methodology was a collaborative process, with feedback about the proposed methods sought from States and Territories through individual discussions and at regular program meetings. Figure 2.2 describes the reporting relationships between each of the key stakeholders of the SSWBC program. Further details on the strategies used to gather information are discussed in the following sections.

Baseline and follow-up evaluation

The baseline and follow-up evaluation is described in detail in Chapter 4, and results are discussed in Chapter 5. Interviews were conducted with three health professionals (a surgeon or oncologist, a breast or oncology nurse, and a supportive care worker) at a minimum of two sites in each State and Territory at the outset and at the end of the program. Participants were asked about supportive care systems and structures relative to the five theme areas.

Acceptability survey

The acceptability survey is described in detail in Chapter 6. Interviews were conducted with key stakeholders involved in developing and implementing the State and Territory initiatives, primarily members of Steering and Advisory committees and in some cases, consumers. The survey aimed to examine stakeholders’ perceptions about the strategies implemented in each State and Territory with a view to identifying the successes, barriers and enablers of strategy implementation.
Interviews with program co-ordinators

Semi-structured interviews were held every 3 months between State/Territory program coordinators and the NBCC project officer responsible for the SSWBC program. These discussions provided a detailed description of project progress and helped to provide information about the successes, barriers and enablers to implementation of the strategies.

An example of the types of questions asked at these interviews is included at Appendix I.

Workshops

A series of quarterly one-day workshops involving the program coordinators from each State and Territory were held throughout the duration of the program. In all, 12 workshops were held. Workshop content was developed through a consultative approach with States and Territories and provided an opportunity for each of the States and Territories to network and share ideas on the progress of their strategies. Evidence-based information on agreed topics would also be presented by guest speakers to support the work of the program coordinators. Appendix II provides a list of workshop topics presented as part of the SSWBC program.

State and Territory evaluation activities

In addition to the national evaluation, all States and Territories undertook their own evaluation of their strategies (see State and Territory evaluation reports). The NBCC provided support by assisting with the development and implementation of individual evaluation plans as requested. Where acceptable to States and Territories, information collected from local evaluations has been included in this national evaluation report.
Functions of the clearinghouse

The aim of the clearinghouse component was to support the States and Territories by providing a mechanism for reviewing and sharing information relevant to the SSWBC program and providing access to recent relevant data and research. The NBCC provided support through the initiatives outlined below. Further detail about the resources developed is provided in Chapter 7.

Supporting initiatives and local evaluations

Some State and Territory project coordinators and project officers requested assistance in developing evaluation measures. In an effort to provide further training in this area, some of the SSWBC workshop topics focused on evaluation strategies.

Electronic newsletters and bulletin board

An electronic ‘e-list’ newsletter was distributed to program participants and other interested stakeholders at regular intervals. In total 17 e-lists were sent out. Each newsletter had a different theme with information drawn from Internet searches, circulars, organisational newsletters and journal articles. The newsletter was divided into two sections: News and Events (which would include information on upcoming conferences, relevant research underway in Australia) and New Research (which included summaries of relevant recent publications). A list of e-list topics and sample newsletter is provided in Appendix III.

An electronic bulletin board for use by SSWBC project team members was launched in July 2001. Users could access the board through a password-protected entry point. The aim of the bulletin board was to provide a forum for sharing experiences progress updates. However, due to limited uptake of this initiative, its use was discontinued.
Resources

The NBCC collated a comprehensive list of resources developed under the SSWBC program from each State and Territory with the aim of assisting health care professionals, service providers and consumer organisations to access resources that would help in establishing similar programs or services in their local area. The list was made available on the NBCC website in order to promote access to the information resources developed. Further information on the type of resources produced under the SSWBC is outlined in Chapter 7.
### Figure 2.1 Key project dates

- **May 1999**  
  Funding for project announced

- **Nov 1999**  
  National summit held

- **Oct 2000–Feb 2001**  
  State and Territory funding agreements signed

- **Apr 2001**  
  First workshop held

- **Jul 2001**  
  First e-list newsletter sent

- **May–Sep 2002**  
  Baseline surveys

- **Aug 2003**  
  Follow-up surveys

- **Mar 2004**  
  Acceptability surveys

- **Mar 2004**  
  Final workshop

- **Apr–Sep 2004**  
  National evaluation data analysis

- **Oct–Nov 2004**  
  National evaluation report writing

- **Dec 2004**  
  Final national evaluation report submitted to DOHA

- **Mar 2005**  
  Final report released
Figure 2.2 Relationships between States and Territories, DOHA and the NBCC

*States and Territories were not required to provide reports about their local evaluation to the NBCC. However, they were encouraged to send copies of their final reports to the NBCC so that data from local evaluation could supplement information in the final national process evaluation report*
3. STATE AND TERRITORY STRATEGIES

Funding to develop and implement the SSWBC program was distributed by the Australian Government to Health Departments in each State and Territory. In some cases, the project was subcontracted to another organisation, such as the State/Territory Cancer Council or other group. A project coordinator was identified for each State and Territory. States and Territories were encouraged to use combinations of several models identified at the summit or explore variants of different models to suit local circumstances. Collaboration within and between States, Territories and other organisations was also encouraged. A key factor in the development of strategies was that they were to be sustainable.

An overview of the strategies is provided below. Appendix IV summarises the range of strategies implemented and anticipated outcomes at the outset for each of the SSWBC projects. Further information on specific initiatives is provided in the evaluation reports submitted by individual State/Territories to the Australian Government Department of Health and Ageing. At the time of preparing this national report, five State/Territory evaluations were available.

The intended outcomes of strategies implemented related to five key theme areas:

- Models that seek to improve approaches to supportive care, such as creating SBN positions or multidisciplinary care (MDC)
- Providing information to women and health care providers
- Improving communication between health care providers
- Improving continuity of care
- Health care or supportive care provider needs in relation to training and support.
Australian Capital Territory

Project management

ACT Health was responsible for the overall management of the SSWBC program. A Steering Committee was established to oversee the development, implementation and evaluation of strategies developed under the initiative.

Project aims

The project aimed to improve the coordination of information and preliminary support to women receiving treatment for breast cancer in the ACT through the creation of an SBN position.

Strategies

The limited geographic and population distribution of the ACT indicated that the maximum benefit of the SSWBC program would be gained by creating an SBN position. This position was located within Calvary Hospital in Canberra but had wide-ranging responsibility across six public and private sites in the ACT and Queanbeyan.

The SBN was responsible for seeing newly diagnosed women with breast cancer; however time constraints meant that the SBN did not see women who presented for day surgery and lumpectomy. The SBN also visited patients while they were attending the Departments of Radiation Oncology and Medical Oncology for treatment. Follow-up telephone calls and home visits on discharge were also seen as vital to convey information and provide necessary support at such a vulnerable time. In total it was estimated that 325 cases were referred each year to the SBN.
A number of other strategies were implemented under the project:

- In an effort to identify the information and support needs of women during their treatment for breast cancer in the ACT, a needs assessment survey of 150 women who had completed multi-modality therapy for breast cancer during the previous 12 months was undertaken at the beginning of the project. The information gathered from the survey was then used to develop an information and support package that was delivered to all women newly diagnosed with early breast cancer in the ACT.

- Fortnightly multidisciplinary breast care meetings were established. The SBN was responsible for arranging and co-ordinating these meetings. They were attended by principal surgeons, medical oncologists, radiation oncologists, histopathologists from the two principal pathology services and nursing staff from the different hospital sites in the ACT. Allied health professionals were invited but did not attend on a regular basis. The aim of these meetings was to discuss new cases of breast cancer and cases awaiting treatment in a multidisciplinary setting.

- The SBN worked with Community Nursing and the Oncology Units within all hospitals of the ACT to establish a uniform cancer care pathway.

- The SBN attended a monthly multidisciplinary clinic arranged by the Lymphoedema Service for the ACT and South East NSW.

- The SBN conducted information seminars on breast cancer for nursing staff and consumers. Issues covered screening, axillary surgery and adjuvant treatments.

**State evaluation plan**

The ACT evaluation plan sought to measure the following outcomes of the project:

- increased support and information for women diagnosed with breast cancer including the development of a support plan for all women

- contact with a woman by the SBN with breast cancer at the time or near as possible to the time of diagnosis
• early detection of depression and anxiety and appropriate referral

• increased access for women to information about financial support for items such as travel, prosthesis and accommodation

• an increased sense of continuity for the woman and her family through the episodes of care

• more involvement of women and families in treatment decisions, understanding who was coordinating their care and information sharing with the treatment team

• increased understanding by the treatment team of issues related to Indigenous and non-English speaking women

• overall patient satisfaction.

These outcomes were measured through local surveys of women and health professionals in the region.

State evaluation results

To establish satisfaction with the information and support provided by the SBN, 150 women who underwent surgery for breast cancer in the ACT were surveyed towards the end of the program. Seventy three women responded (49% response) and the results showed that women found the emotional and practical support provided by the SBN to be of considerable value and would recommend the service to friends or relatives if they required breast cancer treatment.

A survey of 100 health professionals involved in the care of women with breast cancer in the ACT and South East region of NSW was also undertaken at the end of the program to establish how satisfied health professionals were with the SBN model of care for supporting women with breast cancer. Sixty five per cent of the health professionals responded and again the analysis showed that they valued the services of the SBN.
In recognition of the important role played by the SBN, the ACT Government has provided recurrent funding for the initial position developed under the SSWBC program and two additional SBN positions.

**New South Wales**

**Project management**

NSW Health contracted the NSW Breast Cancer Institute (NSW BCI) to co-ordinate the SSWBC program within NSW. The NSW BCI worked in collaboration with established groups including the consumer advocacy group Breast Cancer Action Group NSW, The Cancer Council NSW and rural Area Health Services through Women’s Health coordinators. An Advisory Committee was established to:

- provide specialised advice on issues related to the SSWBC program objectives
- provide communication and network links between the SSWBC project team and key stakeholders in NSW
- review progress reports prior to submission to the Australian Government.

**Project aims**

The NSW project aimed to cover three main areas: consumer education; health professional education; and web-based technology and resourcing. A number of strategies were implemented in each of these areas.
**Strategies**

**Consumer education**

- Patient fact sheets were developed on topics such as *Breast Self Examination, Lymphoedema, Ductal Carcinoma in Situ, Breast Reconstruction* and *Tamoxifen*. These were distributed to rural women’s health co-ordinators for use in their local communities and placed on the website of the NSW BCI.

- The NSW BCI worked in collaboration with Breast Cancer Action Group NSW to develop a paper and online directory of State-wide breast cancer treatment services. Clinicians across the State were asked to complete details on their area of expertise, research interests, location of service provision and whether they delivered care in a multidisciplinary setting. The aim of the directory was to help women, through their general practitioners (GPs), find treatment and other breast cancer services that were most appropriate for their particular needs.

- The NSW BCI co-ordinated satellite broadcasts from an annual public forum on breast cancer targeting consumers and health care professionals. The broadcasts not only transmitted to sites within NSW, but to over 500 rural and remote locations across Australia including public hospitals, Divisions of General Practice and RSL clubs. Forum topics included *Delivering best practice multidisciplinary care for patients with breast cancer, Breast cancer and beyond* and *If breast cancer comes back*. Educational CD-ROMs containing information from the forums were distributed to GPs in NSW.

**Health professional education**

The project team worked with NSW Divisions of General Practice to organise GP workshops and support in the area of breast cancer through email information updates.
For example, multidisciplinary workshops held in Orange and Port Macquarie aimed to:

- document the current pathways of care
- identify gaps in rural breast care services
- identify and prioritise potential solutions.

Participants included representatives from consumer and support groups, women’s health services, occupational therapy, breast screening, GPs, oncology and palliative care.

Issues raised during these workshops were gathered into workshop reports that were then distributed to participants and respective Area Health Services to help inform possible future funding opportunities.

The NSW BCI also worked with The Cancer Council NSW to develop and implement a training program for Cancer Information Helpline consultants. The learning and development needs of Helpline staff were identified and then staff undertook a clinical placement program, involving attendance at a multidisciplinary case conference and ‘shadowing’ of specialist staff at the NSW BCI. These structured learning activities provided staff with greater knowledge on how best to respond to difficult questions asked on the Helpline.

**Web-based technology**

BreastNet, the website of the NSW BCI provided the platform for the development of on-line strategies for information, education and access in rural and remote areas. This included the establishment of a State-wide network of over 170 clinicians.

**State evaluation plan**

Local evaluations were undertaken of specific strategies in the NSW project. For example, the forums were evaluated through participant surveys. Four hundred and
thirty attendees completed evaluation surveys for the Public Forum in 2002, a response rate of 47%.

**Northern Territory**

**Project management**

Initiatives under the SSWBC program were managed by The Cancer Council Northern Territory.

**Project aims**

The project aimed to improve supportive care and care coordination for women receiving treatment for breast cancer in the Northern Territory through the creation of an SBN position.

**Strategies**

Two SBNs, one in Darwin from the project outset (full time) and one in Alice Springs 18 months later (0.4 FTE), were employed to care for women, including those in regional and rural areas.

The establishment of these positions aimed to:

- improve communication between health care professionals (ie, the SBNs would network and act as a link between health care professionals)
- improve links between health care professionals based in a hospital setting and community organisations
- lead to the establishment or improvement in multidisciplinary approaches to providing supportive care for women
• provide training and professional development for women’s health educators and remote area health workers.

Under the initiative, a referral pad was also developed to encourage referrals to the SBNs and these were distributed to outpatient clinics and surgeries. A client database was also developed and trialled in an effort to streamline the discharge process. Details on the database included a client’s profile, medical history and psychosocial status.

The establishment of the SBNs also led to the development of a referral system between Royal Darwin Hospital and treatment services offered at interstate centres, such as Royal Adelaide Hospital.

Visits to remote centres such as Katherine, Tiwi Islands, Tennant Creeks and Nhulunbuy also meant that the SBNs were able to meet and liaise with health professionals in the region. While in these locations the SBNs held public forums, provided in-house training to health professionals such as Aboriginal Health Workers and saw women individually as required.

**State evaluation plan**

The evaluation of the Northern Territory SSWBC program had not been reported at the time of preparation of the national report.

**Queensland**

**Project management**

The Women’s Cancer Screening Services of the Queensland Department of Health was responsible for implementing initiatives in Queensland under the SSWBC program. Five Zonal Project Teams and an overarching advisory committee structure were also established to guide project planning and implementation.
Project aims

The aim of the project in Queensland was to improve access to information and to develop and implement a sustainable model of improved service delivery for the provision of information and supportive care for Queensland women with breast cancer and their families, especially those residing in rural and remote areas.

Strategies

State-wide mapping exercise

Initially, a State-wide mapping exercise was undertaken to identify the strengths and weaknesses in the current provision of supportive care in the public, private and community sectors and to identify the current level of care coordination that was occurring in the State.

State-wide workshops were held in Brisbane and Cairns with representation from each of the three Queensland Health Zones. Consumers, health professionals and planners/managers of support services were invited to discuss gaps in service delivery, identify priorities for action, and to explore models and alternative approaches to improving support services for women with breast cancer. Following these consultations, Zonal Project Teams were established to develop formal project plans and to decide on appropriate strategies to address priority action areas. These teams then reported to an Advisory Committee.

Zonal strategies

For the Central Zone, a project officer was employed to examine communication and information links between services and providers, and how this impacted on women with breast cancer. Focus groups with consumers were conducted to document their
experiences. Existing care pathways were mapped with a view to identifying gaps and developing recommendations for service improvement.

The establishment of a network of SBN positions was identified as a high priority by the Southern and Northern Zone Project Teams. In an effort to ensure that all women diagnosed with breast cancer received a coordinated approach to supportive care regardless of locality, the Queensland project established six part-time SBN positions in Cairns (30% FTE), Mackay (20% FTE), Townsville (50% FTE), Toowoomba (25% FTE), the Gold Coast (25% FTE) and the Princess Alexandra Hospital in Brisbane (50% FTE).

The Northern Zone SBNs were all co-located within BreastScreen Queensland Services. This community based-approach was chosen as sites were already well accepted by women in the community as a user-friendly environment, had strong multidisciplinary approaches and well-developed communication networks.

For the Southern Zone, a hospital-based approach was chosen with the SBN located within the Division of Surgery since each of the three centres functioned as a referral hospital for surrounding Health Service Districts (HSD). As such, women had access to specialist staff and either on-site or visiting oncology services.

The purpose of the positions was to improve continuity of care and to provide psychosocial support to women diagnosed with breast cancer and their families. The SBNs at all sites provided women with a co-ordinated approach to supportive care from the point of diagnosis, through to treatment and follow up phases in accordance with recognised clinical practice guidelines.

An orientation program for the SBN’s was developed under the SSWBC initiative. Continuing support for these positions was provided by monthly teleconferences providing an opportunity for discussion of project implementation and clinical issues, peer support, data collection issues and evaluation methodologies.
State evaluation plan

A State evaluation plan was developed in consultation with the SBNs, Zonal Project Teams, Advisory Committee, consumers and District Managers at each of the sites. The purpose of the evaluation was to determine the impact of the SBNs on provision of supportive care in a variety of settings, both hospital and community-based. More specifically it sought to explore the following themes:

- the SBN role was established as an essential component of MDC
- recognition by the multidisciplinary treatment team of the integral role of the SBN in coordinating care to achieve optimal clinical outcomes for each woman
- establishment or enhancement of effective communication networks between service providers to ensure consistent access to psychosocial support services appropriate to the needs of each woman
- increased awareness of the role of the SBN among service providers.

The evaluation focused on qualitative rather than quantitative data due to an emphasis on process description rather than clinical outcomes. Whilst some quantitative data were collected, the focus was on analysing perceptions, particularly among consumers and members of the treatment team. Data were collected from daily client records, activity dairies, client satisfaction surveys, and surveys of SBNs and members of the multidisciplinary treatment team at each site. Further details on the evaluation process are contained in the Queensland State Evaluation Reports.
South Australia

Project management

In South Australia, the SSWBC program was undertaken by the Country and Disability Services Division of the Department of Human Services. A Steering Committee was established and met bi-monthly to support the project. An Evaluation Advisory Group was also established to actively support the State evaluation process.

Project aims

In an effort to achieve sustainable models of care, beyond the funding made available by the SSWBC program, this State project was based on building capacity to improve access to information and rural breast cancer support services.

The three main aims of the project were to:

- establish mechanisms to enhance communication between health service providers
- develop and implement information initiatives for women who have experienced breast cancer, their families and significant others, and service providers
- facilitate the implementation of workforce development initiatives for service providers.

Strategies

South Australia's strategies accordingly focused on the three areas outlined below.
Communication between health care professionals and peer support workers

One of the main strategies was to upskill existing rural health professionals to the role of Local Breast Cancer Contact Worker (BCCW). These health professionals included clinical and community nurses; palliative care and women’s health workers; and enrolled nurses. Approximately 100 health professionals across rural South Australia were trained. These workers were supported by the regional health services and hospital system, providing a continuum of care for rural women seeking treatment to and from Adelaide. Their main roles included:

- provision of information
- provision of community education and health promotion activities
- care coordination and continuity of care
- assessment of supportive needs.

Information

In order to identify gaps in information provision, regional audits of supportive care services and community consultations with rural women were undertaken. Information resources developed as a result of these consultations included:

- a Resource Kit for Women with Breast Cancer, located in all major health and hospital services
- information on the role of the BCCW and a list of names and contact details, provided to all treatment centres and hospitals to ensure that referrals occurred
- information resources and a workshop for health workers who work with women from culturally and linguistically diverse (CALD) backgrounds
- a web-based directory of services and referral system (options explored).
Strong linkages were developed with key partners that included The Cancer Council South Australia, who agreed to monitor and update resources as appropriate.

**Workforce development**

A BCCW Orientation and Professional Development Program was developed, comprising:

- a one-week orientation program
- BCCW Practice Guidelines, which outlined processes for engaging women diagnosed with breast cancer, assessing their needs and referring them onto appropriate care
- a list of organisations and key contacts that BCCWs could approach in order to arrange clinical visits as part of their professional development process.

**Other strategies**

Regional funding grants were provided to improve rural support systems for women in local areas. Priorities were identified from the regional audit process with input from the Regional Breast Care Network. Initiatives included:

- the purchase of resources for services and local libraries
- information displays in shopping centres and field days to promote the role of the BCCW
- a range of workforce development opportunities for health professionals
- liaison with the rural Divisions of General Practice to develop collaborative initiatives promoting breast cancer information and support
- facilitation of health and well-being days for women.
State evaluation plan

A range of evaluation methodologies was initiated at the State level. Focus group meetings were held with community women in three country regions, along with the SSWBC Steering Committee, metropolitan breast care nurses and BCCWs. Surveys were also sent to metropolitan centres.

State evaluation results

Overall the majority of respondents to the surveys reported that the BCCW model had improved access to information for women with breast cancer in rural areas of South Australia. More information is provided in the South Australia State Evaluation Report.

Tasmania

Project management

In Tasmania, the SSWBC program was tendered to The Cancer Council Tasmania (TCCT) through a service agreement with the Department of Health and Human Services Tasmania. A project team was formed to implement the initiative with a Reference Group later established to help develop appropriate strategies. The Reference Group included representation from a wide range of professional and consumer stakeholders.

Project aims

The project team used information collected from community consultations and an audit of service provision to identify the following five key implementation objectives for the project:
to evaluate project strategies for the improvement of Tasmanian service provision and inclusion in national evaluations

to develop and implement appropriate and readily accessible information service initiatives for women with breast cancer, their families and service providers

to facilitate the further development of peer and group emotional support services for women with breast cancer, and for their families and carers

to establish and/or strengthen communication networks between service providers and consumers

to develop opportunities for coordinating the care of a woman with breast cancer, including the potential for breast cancer, or specialist cancer nurses.

From the outset it was recognised that a broad range of support services already existed for Tasmanian women with breast cancer, including local support groups and services. However, these services were often poorly co-ordinated. Furthermore, many support services were under-utilised, indicating a need to raise awareness of clinicians and consumers about existing services.

The project team proposed a three-phased approach to the SSWBC program:

• an audit of current service provision

• development and implementation strategies to improve service provision

• project evaluation.

Audit

The aims of the audit were to identify:

• issues and concerns for women from rural communities regarding diagnosis and treatment of breast cancer
• existing resources and possible gaps or difficulties in current service provision

• best practice, and ideas that could be transferable to other areas or developed further

• gaps in the current skills base and the potential for training and development.

As part of the audit process, an extensive consultation was undertaken involving over 20 State and National stakeholder groups. Consumer focus groups were held in all regions, and four cancer support groups. Data were collected through group discussions with Breast Cancer Support Service Volunteers and Breast Cancer Network Australia representatives (Tasmania group), and three one-on-one in depth interviews with representatives from these groups. Consultations were also conducted with clinical and organisational stakeholders with an interest in breast cancer, including surgeons, medical and radiation oncologists, physiotherapists, nurses, social workers, community nurses, GPs, and breast cancer screening staff.

Strategies

A range of strategies were developed in response to the consultation results and these are summarised below:

**State-wide breast cancer information strategy**

A State-wide breast cancer information strategy was developed, which included three information kits targeting both consumers and health professionals.

• A Consumer Pack – containing a covering letter, general breast cancer booklet and information on the availability of regional services (specifically lists of information, support, and practical services)

• A Provider Kit – designed to remain at the site for reference by health care providers. The provider kit included clinical practice guidelines, patient information
sheets, health care provider resource list, resource order forms, and a copy of the Consumer Pack.

- A Patient Kit – designed to remain at the site for reference by women with breast cancer, their families and health care providers. The aim was to have the kit on display in an appropriate location such as a waiting room or library. The patient kit included material from the Consumer Pack, a Consumer Pack order form, patient information sheets, resource order forms, and a selection of State-wide brochures from organisations such as the Cancer Helpline, Breast Cancer Support Service and TCCT.

A 3-month pilot of the information strategy was undertaken and adaptations to the strategy were made before State-wide dissemination. In an effort to ensure sustainability, agreement was sought from TCCT to coordinate the breast cancer information strategy as part of their ongoing Support & Information Program. TCCT took on responsibility for disseminating and updating information contained in the kits. Over 100 kits were distributed to health care providers State-wide. Health sites and TCCT were both disseminating Consumer Packs. Posting of this information onto TCCT’s website was being pursued.

**Public forums**

Three regional Advanced Breast Cancer Forums were convened targeting GPs, hospital and community nurses, support volunteers, and interested members of the public. All forums linked in with the satellite broadcasts from the NSW BCI as part of the SSWBC program in NSW, and were followed by local panel discussions involving a local breast care nurse and representatives from TCCT, palliative care, and oncology. Overall approximately 100 people attended the Forums.

**Establishment of breast care nurse positions**

In the South of Tasmania, a partnership between the Department of Health and Human Services and the SSWBC project team led to the employment of a community breast
care nurse role for 1 year (two positions at 0.4 FTE). The nurses were available to both public and private patients.

In North Tasmania, an SBN position was established and made available to all private patients through St Vincent’s and St Luke’s Private Hospitals. The SBN duties were added to two appointed roles for each St Vincent and St Lukes and while the roles were supported through the SSWBC program, the salaries were not funded through the project.

**Tasmanian Breast Nurse Network**

Tasmania established the *Tasmanian Breast Nurse Network* for professional development, education and support. TCCT agreed to support the Network on an ongoing basis.

The Network aimed to:

- develop an ongoing professional support network for breast care nurses
- inform members of activities across the State
- provide ongoing educational opportunities
- identify opportunities to address barriers to breast nursing.

Educational sessions of the *Tasmanian Breast Nurse Network* meetings were also expanded to include interested health care providers across the State.

Communication skills training workshops, facilitated by health care providers, were also held across the state for hospital, community and palliative care nurses.
State evaluations

TCCT is working in collaboration with the University Department of Rural Health in Tasmania to assess the effectiveness of specific SSWBC strategies undertaken in the State.

Specific evaluation reports on some strategies had been produced at the time of preparing the national evaluation report. Copies of the evaluation reports for the Communication Skills Training Workshops and the Advanced Breast Cancer Forums are available by contacting TCCT.

Victoria

Project management

BreastCare Victoria, which has since become the Cancer Coordination Unit of the Department of Human Services, managed the SSWBC program in Victoria.

To maximise available resources and opportunities, SSWBC strategies were designed to complement existing rural and regional initiatives undertaken through the Breast Services Enhancement Program (BSEP), another initiative of BreastCare Victoria. Established networks and existing committee structures through all five BSEP teams in rural Victoria (including Lodden Mallee, Barwon South Western, Gippsland, Grampians and Hume regions) were responsible for the implementation of SSWBC strategies.

Project aims

The Victorian project aimed to investigate and trial e-health technologies, such as videoconferencing and teleconferencing, to improve supportive care and service delivery to women with breast cancer. The project also aimed to use information
technology to link isolated clinicians into treatment planning and professional development opportunities elsewhere in the State by:

- broadening the scope of the established multidisciplinary team and enabling input from the whole health care team
- improving the profile of breast care nurses in MDC meetings
- enabling the linkage of GPs in distant centres to local clinicians / practitioners to discuss recommendations regarding the care of women diagnosed with breast cancer within a multidisciplinary setting
- linking physicians and GPs from remote sites with medical oncologists at urban sites to allow discussion of treatment planning
- exposing health care professionals to current management guidelines, techniques and trials
- providing opportunities for practice improvements through the educative component of the multidisciplinary team meetings.

**Strategies**

**Training and consultation**

At the start of the SSWBC program in Victoria, a workshop was planned to introduce participants to the concept of e-health and the SSWBC program. Participants included BreastCare Victoria representatives, BSEP staff and hospital and technical staff throughout rural and regional Victoria. The workshop was followed by a series of training and consultative processes:

- The Regional Leader e-Health Training initiative was held in May 2001 to educate project teams and key stakeholders on the practical and theoretical aspects of e-
health and videoconferencing. The training included presentations on e-health, and hands-on training in the use of videoconferencing.

- Information sessions commenced in July 2001 to provide project teams with guidance on the development of project proposals. Presenters from South Australia, Queensland, Victoria and the United States provided information in the form of case studies highlighting potential uses and issues in e-health. An e-health information package was also developed by BreastCare Victoria to complement the information sessions.

- A series of local consultations assisted regions with identifying priority issues and options for implementation. A professional facilitator was made available to guide meetings and assist in the preparation of preliminary submission documentation.

**e-health strategies**


- **Grampians**

  The Grampians Region Breast Cancer Information and Services Website was designed for use by health professionals and people affected by breast cancer. It brought together general information relating to breast cancer and local area service information by linking with other information websites, including ConnectingCare, the region’s electronic service directory and referral system.

- **Gippsland**

  In Gippsland, multidisciplinary meetings were videoconferenced between three sites. There was representation from a number of disciplines including surgeons, pathologists, radiologists, breast care nurses, social workers, physiotherapists, surgical registrars, interns and medical students. GPs were also invited.
• Loddon Mallee

In the Loddon Mallee region, MDC meetings were expanded via videoconference to include up to four sites across the region. Cases were discussed retrospectively so meetings were primarily used as an educational and peer networking forum. Evaluation results from meetings were used to inform future meetings. Videoconferencing guidelines were also drafted as part of the project.

• Barwon

The Barwon region aimed to link medical and radiation oncologists through on-line clinics. Video-conferencing between hospital sites was implemented to enable input from a medical and radiation oncologist in treatment planning at regional sites.

• Hume

In the Hume regions there were six strategies implemented:

- an information technology and training needs analysis to determine the existing and future IT skill level needs of key stakeholders across the Hume region

- an Information technology educational voucher scheme (ITEVS) developed to enable stakeholders to undertake training and education tailored to their needs

- education for migrant women from non-English speaking backgrounds to convey culturally appropriate information and literature on breast health

- a breast care nurse on-line chat room and clinical support/peer support online needs analysis to facilitate communication and resource sharing for breast care nurses working in isolation

- electronic release and availability of research results and other breast cancer related publications and presentations which allowed Hume research data to be presented simultaneously around the region by key researchers

- research and development of a plan for the expansion of MDC clinics using e-health technology.
State evaluation plan

Local level evaluations, tailored to specific initiatives, were undertaken in each region. State-wide progress across all regions was monitored by two-monthly project team teleconferences, providing an opportunity for regional progress updates, and identification of project support requirements.

Reflective Learning Workshops for program coordinators and staff participating in the SSWBC program in Victoria also played an important role in sharing information on progress.

Western Australia

Project management

The Cancer Council Western Australia (TCCWA) won a competitive tender from the Western Australian Health Department to implement the SSWBC program in Western Australia.

Project aim

The aim of the Western Australian initiative was to improve resources and support for rural women with breast cancer by providing SBNs in three rural locations: Albany, Bunbury and Geraldton.
Strategies

Mapping care pathways

An important first step in the planning phase of the project in WA was to undertake a thorough mapping process of care pathways in an effort to identify service gaps. Relevant stakeholders were identified and regional working parties were established to sign off on project strategies.

SBN positions

Three rural SBN positions were created in Albany (0.4 FTE), Bunbury (0.6 FTE) and Geraldton (0.4FTE), based on the numbers of women in the region aged over forty and the incidence of breast cancer.

Each SBN was a registered nurse who was provided with training in breast cancer nursing. The role of the SBN was to provide:

- a readily accessible contact for women throughout their diagnosis and treatment for breast cancer
- information on multiple occasions and at appropriate times
- emotional and counselling support
- practical support and information
- a point of contact for ongoing liaison and referral to other health professionals and services.

Care provided by the SBNs was based on the NBCC report Specialist Breast Nurses: an evidence-based model for Australian practice. The clinical pathway was adapted to provide a model of six interventions over a 6-month period.
**Other strategies**

A number of strategies were developed to support the role of the SBNs. These included:

- appointment of an SBN Co-ordinator to provide ongoing clinical supervision and mentoring for the three SBNs through weekly individual telephone contact and monthly team teleconferences, in addition to scheduled site visits

- creation of a Breast Cancer Clinical Psychology Service to provide regular confidential support and debriefings for each SBN

- development of an SBN Orientation Program comprised of:
  
  o a pre-reading package
  
  o a 1-week orientation course with supervised visits to: BreastScreen WA; Breast Assessment Clinics at public and private hospitals; chemotherapy units; radiotherapy clinics; and oncology clinics; The Breast Cancer Clinical Psychology Service and relevant TCCWA services, namely the Lymphoedema Management Service, Professional Counselling Service, Cancer Helpline, Wig Library, Cancer Support Centre and an accommodation facility for country cancer patients
  
  o a regional orientation program designed to initiate contact with health care professionals identified in the mapping process.

- a core professional development program involving the SBN Unit at Edith Cowan University, in-house media training, a psychosocial support and skills training day and counselling skills training

- an annual program for professional development incorporating an in-house study day, team meetings and opportunistic events such as the Royal Perth Hospital Breast Cancer Study Day and relevant conferences (e.g. BreastScreen WA, TCCWA, National breast care nurses, Clinical Oncological Society of Australia, Cancer Nurses Society of Australia)
• development of administrative processes to support caseload management and project evaluation that included referral pathway summaries, process guidelines and a patient database.

State evaluation plan

Due to delays in establishing the SSWBC program in WA, the final evaluation report for this project is not due to the Australian Government until 30 September 2005.

In the meantime, the project team has contracted Edith Cowan University to conduct the State-level evaluation of the program. It is anticipated that the evaluation will focus on three aspects: client satisfaction, acceptability and perceptions of health professionals and SBN groups. It will do this through a variety of survey methodologies.
4. Baseline and follow-up evaluations

Analysis of theme-based outcomes

The national process evaluation of the SSWBC strategies uses a theme-based approach. A direct comparison of the impact of strategies from different States and Territories was not possible because of the range of strategies used. Instead, the national evaluation focused on the processes used within each of the five theme areas:

- Theme 1: Models that improve approaches to supportive care
- Theme 2: Providing information to women and health care providers
- Theme 3: Improving communication between health care providers
- Theme 4: Improving continuity of care
- Theme 5: Health care or supportive care provider needs in relation to training and support.

These common theme areas were used to inform the development of the national evaluation.

Case studies

In addition to reporting outcomes from surveys conducted with program participants, case studies are used to illustrate some of the challenges associated with developing and implementing strategies for enhancing supportive care to suit local health care services. The case studies highlighted here do not cover all of the initiatives implemented in every State and Territory. Some initiatives were implemented in more than one State and Territory and the case studies are provided as examples.
Methodology: baseline and follow-up questionnaires

Aim

The aim of the baseline (Time One) and follow-up (Time Two) surveys was to provide a description of supportive care at the outset and the end of the program.

Design overview

To provide a description of supportive care at the outset and the end of the program, two rounds of surveys were conducted using semi-structured interviews with a range of health professionals at two or more nominated sites in each State and Territory. Baseline surveys were conducted between May and September 2002 and follow-up surveys were conducted in August 2003 (with the exception of two sites in Queensland in which surveys were conducted in April and July 2003).

The survey instrument was developed by the NBCC based on supportive care elements from the National Consumer Survey. Questions were tailored to investigate the five common themes that were identified across the States and Territories. The survey was trialled by an independent interviewer, with revisions made as appropriate.

Structured interviews were conducted with specialist clinicians, breast or oncology nurses, and supportive care staff about supportive care systems and structures. Follow-up interviews included additional items about the acceptability to health professionals of the strategies that were implemented in each State and Territory (see Chapter 6). An example of the survey instrument used is available in Appendix V.

Recruitment and consent procedures

At each of the nominated sites, structured interviews were conducted with three health professionals nominated by State and Territory program teams. Specialist clinician
surveys were conducted with a surgeon, radiation oncologist or medical oncologist. Breast care nurse or oncology nurse surveys were conducted with a nurse currently working in the chosen site. Supportive care worker surveys were conducted with a health care provider such as a GP, community health nurse or social worker.

State and Territory coordinators or project officers contacted each proposed participant to discuss participation in the survey, outlining basic information to the participant including the aims and thematic focus of the interviews, many specific to the strategies developed in their region. Participants were informed that involvement was voluntary and that withdrawal of consent was allowed at any time, either before or during the interview.

Following the receipt of verbal consent, a standard consent form and information letter was sent to all participants together with a reply-paid envelope. All participants were asked to return the signed consent form to the NBCC within seven working days. Telephone reminders were used after 10 days of non-response in order to ascertain willingness to participate.

Completed consent forms were collated by the NBCC project officer and participant details were entered into a database. Contact details were forwarded to independent consultants recruited to undertake the interviews.

Prior to all interviews, consenting participants were contacted to organise a convenient interview date and time. Interviews took approximately 30 minutes to complete and all responses were de-identified prior to entry into databases and subsequent analyses.

**Interviews**

Interviews were conducted by an independent consultant. In total 66 people were surveyed at baseline (22 clinicians, 21 breast care nurses and 23 supportive care workers) and 59 people were surveyed at follow up (18 clinicians, 18 breast care nurses and 23 supportive care workers). Every effort was made to interview the same individuals at each time point. However, in some cases this was not possible due to changes in staff positions.
Development of the coding framework and analysis plan

Responses to closed, multiple-choice questions were recoded in the form of categorical variables. Depending on the question, these variables were either dichotomously or multichotomously coded. Coding was performed by constructing variable maps that provided a broad-based overview of inter-relationships between and among questions and their variables.

Once recoded, conventional descriptive statistical summaries were prepared. These consisted of absolute and relative frequency distributions using single variable tabulations or contingency tables consisting of two or more variables.

All analyses were conducted using SPSS version 11 (SPSS Inc, Chicago, IL USA) and Stata SE version 8.2 (StataCorp Inc, College Station, TX, USA). Graphs were prepared using SigmaPlot 2003 (SPSS Inc, Chicago, IL, USA), Excel XP (Microsoft Inc, Redmond, WA, USA) and Kaleidagraph 3.2.4 (Synergy Software, Reading, PA, USA).
5. Baseline and follow-up evaluation results

Note: States and Territories identified employment of an SBN as a key strategy during the program. However, the survey questionnaire refers to a ‘breast care nurse’. Where the term ‘breast care nurse’ is used in this chapter it is assumed to relate to the SBN positions recruited through the program.

Theme 1: Models that improve approaches to supportive care

Models under theme 1 included the development of the SBN role, implementation of MDC meetings to improve supportive care and use of e-health strategies to support MDC.

Approaches to care involving breast care nurses

Five States and Territories nominated strategies that involved appointing one or more SBN. Awareness by all health professionals of breast care nurses appointed through the SSWBC program increased by around 25% between baseline and follow-up. There was a corresponding decrease in awareness of breast care nurses employed through other means (Table 5.1). Lack of funds was a common explanation for why a breast care nurse was not appointed.

The States and Territories appointed SBNs to improve supportive care and care coordination for women with breast cancer in the region. It is evident from the survey responses that the breast care nurses were perceived to be fulfilling this role (Table 5.2). The most common roles described by all groups surveyed were provision of information directly to women and provision of supportive care to individual women (88%–100% at follow-up). A considerable increase was seen in the percentage of health professionals identifying care coordination during treatment and coordination of supportive care needs as roles for the breast care nurses between baseline and follow-up, signifying that the role of the breast care nurses was better understood by the time
the follow-up survey was conducted. Other roles described for breast care nurses included organising MDC meetings, coordinating volunteers and providing support for family members of women with breast cancer.

Case study A: Implementing the breast care nurse role in the Territories

Aim

To improve the coordination of information and support for women receiving treatment for breast cancer through the creation of SBN positions.

Strategy

Two SBNs were employed in the Northern Territory one in Darwin (full time) and another in Alice Springs (0.4 FTE). Referral to the SBNs was through the woman’s surgeon, BreastScreen and local GPs. A referral pad developed to encourage referral to the SBNs was distributed to outpatient clinics and surgeries. There was some variation in the number of consultations with each patient due to the absence of a defined clinical pathway. In general the SBNs saw patients pre-operatively, after surgery and at follow-up. However, some patients were seen only once. The SBNs also had an educative role, visiting community groups and organisations. Visits to remote centres enabled the NT SBNs to meet and build links with local health workers and establish trust with Indigenous women. The SBNs also convened public forums and provided training to health professionals including Aboriginal Health Workers.

In the ACT, one SBN position was located within Calvary Hospital in Canberra with wide-ranging responsibility across six public and private sites in Canberra and Queanbeyan. It was intended that the ACT SBN would see all women newly diagnosed with breast cancer, but time constraints meant the SBN did not see women who presented for day surgery or lumpectomy. In general the SBN saw about 30 patients per month. Referrals to the SBN were mainly through the four surgeons in the region. The SBN saw patients five times (pre-operatively, on the day of surgery, after surgery,
and after 1 week and 1 month of follow-up). The SBN also visited patients while they were attending the Departments of Radiation Oncology and Medical Oncology for treatment, and conducted follow-up telephone calls and home visits on discharge to convey information and provide necessary support. In addition, the SBN provided training and professional development for nurses, maintained links to support groups in the region and provided administrative support and coordination of MDC meetings.

**Key outcomes – Territory evaluation**

- In a survey conducted in April 2004 of 150 women who underwent surgery for breast cancer in the ACT, almost half of the women (49%) responded. These women reported that the emotional and practical support provided by the SBN was of considerable value and that they would recommend the service to friends or relatives if they required breast cancer treatment.

- In a survey of 100 health professionals involved in the care of women with breast cancer in the ACT and South-East region of NSW 65% responded and the analysis showed that they valued the services of the breast care nurse.

- The NT evaluation was not available at the time of preparing this national evaluation report.

**Key issues**

- The SBNs in both Territories managed a large caseload and the administrative burden was high. Support for this aspect of the role would have been valuable.

- Large distances between sites meant that travel was time-consuming, reducing the amount of available time to spend with patients. Telephone contact overcame this issue in some cases.

- Employment of more than one SBN in the NT provided an opportunity to discuss ideas and management plans for patients. However, the SBN in the ACT felt
• overburdened and isolated at times. The ACT Government has since successfully obtained recurrent funding for two additional SBN positions, which will reduce these issues of isolation and burden.

• The success of these roles was dependent on appropriate referral. In the NT, surgeons phoned the SBNs directly to refer newly diagnosed women. Formal, documented referral and liaison processes were developed to ensure that no woman was ‘lost’ in the system and/or returned home without follow-up and support.

• Networking was seen as an important part of the role. In both Territories, the high turnover of nursing and hospital staff necessitated ongoing and repeated networking and training of staff in the role of the SBN.

• Collaborative gestures, such as in-kind support for accommodation, were a way of reducing expenses incurred from the project.

**Multidisciplinary care models**

The use of MDC meetings to improve supportive care was nominated as a strategy by two States and Territories. Awareness of face-to-face MDC meetings increased between baseline and follow-up for all health professionals surveyed (breast care nurses 28%; specialists 23%; supportive care 18%), with overall awareness highest for the specialists surveyed (Table 5.3). There was a corresponding decrease in the number of all health professionals reporting that no meetings occurred. Interestingly, although tele- and videoconferencing were identified as strategies to increase attendance at MDC meetings by rural health professionals, only 10% of respondents at baseline and 5% of respondents at follow-up indicated that teleconferencing or videoconferencing was used.
Attendance patterns by supportive care workers

Responses from the health professionals who stated that MDC meetings occurred in their region indicated that supportive care workers were almost always in attendance at the meetings (Table 5.4).

Case study B: e-health at work – supporting MDC in regional and rural Victoria

**Aim**

To improve and expand the multidisciplinary approach to care in regional Victoria through the use of e-health technologies such as videoconferencing and teleconferencing and the internet.

**Strategy**

Videoconferencing of multidisciplinary meetings was supported in four rural regions: Gippsland, Loddon Mallee, Barwon South Western and Hume. In some regions, meetings were newly established while in others, the program built on established multidisciplinary meetings with the aim of increasing attendance by breast care nurses and GPs, increasing attendance at remote sites, and providing further professional education opportunities.

A scoping study and needs analysis was undertaken to identify available technology and skills in each region. An e-health information package was developed and e-health training was provided to upskill personnel in each region.

Meetings in each region involved linking several sites by videoconference and included representation from a range of disciplines, including surgery, oncology, pathology, radiology, supportive care and allied health. GPs were invited to attend but were not present in all meetings. Preparation for meetings was either the responsibility of an
administrative officer or the breast care nurse. In general, meetings were either treatment planning or retrospective case review meetings, with some educational components included. In one region, ‘real time’ transmission of histopathology and X-ray images was used as opposed to the static presentation of slide and PowerPoint presentations used elsewhere. This allowed flexibility to address questions in regard to the pathology imagery during presentations. A proposed on-line clinic, where the clinicians and the patient at a distant site would be able to consult with a medical/radiation oncologist was proposed in one region but not developed during the project timeframe.

**Key outcomes – State evaluation**

- Videoconferencing provided the opportunity for interactive discussion amongst clinicians across the region, improving communication and continuity of care for the women in these regions.

- Meetings were perceived to have enhanced professional development and support for clinicians, through exposure to additional disciplines, and to have achieved practice improvements, through the educative component offered by the meetings.

- The use of videoconferencing to improve and expand the multidisciplinary team approach was perceived to have achieved practice change through peer review, further education and networking.

- Videoconferencing also provided the opportunity to involve GPs who would otherwise not have attended multidisciplinary meetings, giving GPs the opportunity to contribute to patient care plans.

- Videoconferencing also enabled health care providers to ‘connect a face to a name’ and establish contacts for routine referral or atypical queries.
Key issues

Key factors important for the success of videoconferencing included:

- having a nominated meeting coordinator to prepare the meetings
- IT support available locally and at remote locations
- access to an adequate number of remote videoconference facilities
- checking and testing of equipment prior to the meeting to avoid wasting time during meetings
- ensuring that the quality of equipment meets the needs of participants (e.g., if the meeting aims to discuss diagnostic issues, the microscope and digital camera specifications must be of high quality)
- identification of an ‘e-health champion’ to drive initiatives and encourage uptake of technology
- awareness by the Chair of ‘videoconference etiquette’ including ensuring that speakers can be heard across all sites and that all sites remain on-line for the duration of the meeting
- implementing ‘back up’ strategies such as emailing agenda papers and overheads to each site in advance in case of technology failure.

Barriers to implementation of e-health strategies included:

- technology complications/failures
- lack of IT support
- cost
• additional time needed to set up strategies.

The need to include videoconferencing meeting and equipment purchasing costs when setting a project budget was identified. Costs include equipment purchase, room hire, phone line, bridging facility and personnel.

Other models to improve supportive care: cancer contact workers

South Australia implemented a strategy that involved upskilling health professionals to the role of BCCW. However, no respondents indicated awareness of a cancer contact or cancer coordinator appointed through the SSWBC program in their region (Table 5.5). Around one-quarter of respondents indicated that a cancer contact or cancer coordinator had been appointed in their region through other means with no noticeable difference between baseline and follow-up. These outcomes suggest there may have been some confusion over the distinction between cancer contact workers and the breast care nurse role, or that health professionals were unaware that the incorporation of this role into existing roles had occurred through the SSWBC program.

Case study C: Upskilling the workforce – cancer contact workers in South Australia

Aim

To build on and improve supportive care, reduce inequities in care and improve continuity of care arrangements for rural women with breast cancer by upskilling existing rural health professionals (clinical and community nurses, palliative care and women’s health workers, and enrolled nurses) to the role of local Breast Cancer Contact Worker (BCCW).
### Strategy

Each health region nominated health professionals to take on the role of rural BCCW. Eighty health professionals attended an initial 1.5-day breast cancer seminar providing information on clinical services, treatment options and support services for women with breast cancer. Not all attendees went on to become BCCWs. Around 4 BCCWs were identified per region. Training involved a one-week orientation program, provision of BCCW Practice Guidelines and a list of organisations and key contacts for professional development. A professional development program was created for ongoing skills development for rural BCCWs and regional training initiatives were developed in partnership with other organisations, such as The Cancer Council SA, the Lymphoedema Assessment Clinic and Relationships Australia.

The role of BCCWs included the provision of information, provision of community education and health promotion activities, coordinating care, ensuring continuity of care and assessment of psychological and supportive needs. The role also involved liaison with a broad range of supportive services from the tertiary sector to primary care services in local, regional and metropolitan areas.

Information on the role of the BCCW and a list of names and contact details was sent to all treatment centres and hospitals to encourage referrals.

### Key outcomes – State evaluation

The local evaluation in South Australia included focus group meetings with community women (18) in three country regions, rural Breast Cancer Contact Workers (12), metropolitan breast care nurses (6) and members of the project Steering Committee (9 of the 16 provided feedback).

Surveys were sent to service providers and other stakeholders, including rural Directors of Nursing and Managers of Community Health Services (90 surveyed; 27% return rate) and medical specialists, including breast surgeons, radiation and medical
oncologists and rural general surgeons who perform breast surgery (16 surveyed, 60% return).

- Overall most respondents in all groups reported that the model for the project in South Australia had improved outcomes for rural and remote women diagnosed with breast cancer and their families. In rural areas with limited resources and staff, the BCCW model provides an innovative approach to increasing supportive care to women with breast cancer.

- It was perceived that the development of the role of BCCW had reduced inequalities for rural women diagnosed with breast cancer through increased access to information and supportive care in their local areas. Increased communication between the local BCCW and Breast Cancer Support Groups and improved systems between local surgeons and the BCCWs had improved continuity of care for women.

- More than 90% of Directors of Nursing and Community Health Managers surveyed felt that the implementation of Breast Cancer Contact Workers had had ‘great’ or ‘some’ improvement for women diagnosed with breast cancer.

- BCCWs reported feeling part of an important initiative to provide necessary support for rural and remote women and their families. They had been provided with appropriate, up-to-date information on breast cancer issues and knew where to get additional information.

**Key issues**

- In most cases the role of BCCW was an additional ‘hat’ for a rural health professional with an already demanding workload. While most BCCWs felt supported by their management, particularly in community settings, demands on general nursing positions led to difficulties within acute services. Some BCCWs were fulfilling the role in their own time.
Different regions experienced different levels of communication between BCCWs, the broader health system and the community. In some regions, particularly where BCCWs were able to make breast cancer support a high priority in their work commitments, communication was improved significantly through strategies such as websites, pamphlets and advertisements in local papers. BCCWs in these regions believe that women in the community are now better informed about what services are available to them.

There were differences in referral systems and discharge planning between metropolitan and regional-based treatment centres. In some areas there had been a lack of networking between the rural sector and metropolitan treatment services resulting in few referrals of women back to their rural areas.

There was a need for ongoing support and training for the role. The focus on workforce development had significant benefits in increasing the information, knowledge and skills needed by BCCWs to fulfil their role effectively.

Some BCCWs were unaware of training opportunities due to poor communication within regions or unable to attend due to lack of financial support, and were not able to attend network meetings in work time.

Valuable peer support for the role was gained by the availability of a breast/cancer support group or Cancer Council South Australia volunteer in the area.

There is a need for contact lists of rural BCCWs to be updated and readily available and easily accessible to surgeons, breast care nurses and other health professionals.

Ongoing promotion of the role of BCCW, particularly to local GPs and metropolitan treatment centres is essential to increase referrals and improve continuity of care for women.
Theme 2: Providing information to women and health care providers

Improving communication between healthcare professionals and women with breast cancer

All States and Territories implemented strategies to improve communication between health professionals and women with breast cancer. While there was some variation in the proportion of different health professionals indicating that communication skills training had been encouraged (Table 5.6), the percentage of breast care nurses and supportive care workers encouraged to attend communication skills training workshops increased between the two surveys (by 18% and 6%, respectively).

In terms of attendance at communications skills workshops, survey responses indicated that State-/Territory-based or national communication skills workshops were more commonly attended than local workshops. (Table 5.7). Courses cited by respondents included those run by the NBCC and by State and Territory Cancer Councils. The percentage of breast care nurses who attended such training programs increased considerably between baseline and follow-up (from 14% to 61%) but remained reasonably constant for the other health professionals surveyed. Furthermore, even at follow-up, more than half of the clinicians and supportive care workers surveyed indicated that they had not attended a training workshop. Reasons given for non-attendance included lack of time and the fact that workshops were often held at some distance from the respondent's place of work.

When asked to estimate the proportion of other health professionals who had attended communication skills training workshops in their local area (Table 5.8), respondents either did not know or thought that 'very few' local health professionals had attended such workshops.
Information for women and their families

Many of the strategies implemented during the SSWBC program aimed to improve the level of information provided to women with breast cancer and their families. Information was provided in a number of formats but in broad terms fell into two main categories – personalised information tailored specifically to the woman’s case, and more general information for the woman and her family.

**Personalised information**

Personalised information sources for women with breast cancer include individual pathology reports, patient-held records and the ‘My Journey Kit’, an information resource and personal record produced by the Breast Cancer Network Australia. Overall, there was an increase in reports of available information sources between baseline and follow-up. Pathology reports and ‘My Journey’ folders were the personalised resource cited most frequently by all health professional groups (Table 5.9). It is interesting to note that even at follow-up, 35% of the supportive care workers surveyed were unaware of personalised resources available for women with breast cancer.

Survey responses indicate that personalised information was more likely to be provided to women by either the specialists or the breast care nurse (Table 5.10). However, despite an overall increase in the proportion of health professionals indicating that they gave women personalised information, at follow-up, 40% of breast care nurses, 26% of clinicians and 44% of supportive care workers indicated that no personalised information was provided to women with breast cancer. Some health professionals indicated that personalised information was given only if the patient requested it, while others indicated that plans were being made to introduce a system to provide information in this way. The use of drawings was mentioned by some respondents. However, in the case of the breast care nurses and supportive care workers, 13% and 32%, respectively, indicated at follow-up that they did not see it as their role to provide personalised information to women.
It is noteworthy that despite some increase in awareness between baseline and follow-up, the specialists surveyed were more likely than the breast care nurses or supportive care workers to indicate that all or some health professionals provide personalised information to women (Table 5.11).

**Informing women and their families about breast cancer issues and services**

This section relates to the role of health professionals in providing written and/or verbal information to women with breast cancer and their families about services available to them and issues surrounding breast cancer. A separate section (Continuity of Care, page 81) describes respondents’ roles in provision of supportive care to individual women.

The majority of respondents (89%) at baseline reported that they provided written information resources to women and their families, increasing to 93% at follow-up. The most common resources cited were printed resources such as booklets, pamphlets and facts sheets, and brochures from local organisations (Figure 5.1). Increases were seen between baseline and follow-up in reported provision of written information from consultations (12%), brochures from local organisations (11%), resources for families (13%) and copies of the NBCC’s booklets (11%).

Reported provision by all health professionals of electronic or e-health information increased between time points (Figure 5.2). Increases of 15% were reported for the provision of Internet-based information and 14% in the case of other electronic media such as a CD-ROMs. The number of health professionals who reported providing the contact numbers of telephone help-lines such as the Cancer Information Service increased by 15%, while the proportion of respondents who stated that they did not provide this type of information had reduced from 13% to 5% (Figure 5.2).

The degree to which health professionals agreed that it was possible to access information to provide to women and their families on a local level is shown in Figure 5.3. Following the program, twice as many respondents agreed that health professionals in the local area were always able to access as much information as needed compared with baseline (67% compared with 32%), and far fewer (16% reduction) considered that only a limited amount of information was actually available
to be accessed. Some respondents indicated that information was accessible but that it was not always accessed due to lack of time.

Respondents were asked whether supportive care services were modified in any way to provide assistance to women of non-English speaking or Indigenous backgrounds. Overall the responses before and after implementation of the SSWBC program were similar. The majority of respondents stated either that they did not have contact with women from non-English-speaking or Indigenous backgrounds (41%), that interpreter services were provided (53%), or that they liaised with local Indigenous health services or community workers (47%). There was little change between baseline and follow-up although reported use of interpreter services and liaison with indigenous health services increased. Less than 5% of respondents at baseline and follow-up reported that written information developed specifically for women of non-English-speaking or Indigenous backgrounds was available with no difference between the two surveys (Figure 5.4). Other strategies for ensuring that the needs of non-English speaking and Indigenous women were met included the use of volunteers or family members to act as an interpreter during consultations. In one State, respondents described a service in which Indigenous women travelling interstate for treatment were provided with an escort to provide assistance.

Case study D: A state-wide information initiative in Tasmania

**Aim**

To develop and implement appropriate and readily accessible information service initiatives for women with breast cancer, their families and service providers.

**Strategy**

An analysis of existing information for women with breast cancer in Tasmania identified that while a broad range of support services existed for Tasmanian women with breast cancer.
cancer, including local support groups and services, they were often poorly coordinated and under-utilised.

The Cancer Council Tasmania developed a State-wide breast cancer information strategy, including information kits targeting both consumers and health professionals:

- Patient Information Packets were provided to women with breast cancer and their families through health care providers (including lists of regional support and practical services, state-wide information available, ‘Questions for your Doctor’ and the NBCC guides for women with early or advanced breast cancer).

- Breast Cancer Information Kits (Health Care Provider Kits and Patient Kits) were provided to health care sites as an on-site resource for referencing and photocopying as needed.

The Health Care Provider Kits included a sample Patient Information Packet and Clinical Practice Guidelines along with resource order forms and other patient information sheets. The Patient Kits include a sample Patient Information Packet, information on how to order your own Packet, and patient pamphlets and information sheets.

Over 100 kits were disseminated by The Cancer Council Tasmania to health care providers across Tasmania (including public and private hospitals, community health centres, BreastScreen, palliative care services, women’s health centres and specialists’ rooms). The kits were also promoted at relevant workshops and events and via consumer, GP and mass media. Patient Information Packets were disseminated by both health sites and The Cancer Council Tasmania.

In order to limit the costs involved in developing and maintaining materials, NBCC consumer booklets were included as the source of general breast cancer information. Tasmanian regional service information was compiled on A4 pages that could be easily photocopied for distribution. The cost of compiling and producing the information was less than $10 per kit. A three-month pilot was undertaken in 2002 at 15 health care sites to evaluate information materials and the distribution strategy approach. The materials and the strategy were adjusted to reflect the experiences and recommendations of pilot participants and sites.
**Key outcomes – State evaluation**

- Pilot respondents found the Patient Information Packet:
  - appropriate (100% agreed/strongly agreed)
  - practical (100% agreed/strongly agreed)
  - timely for women’s needs (78% agreed/strongly agreed)
  - simple and easy to use (96% agreed/strongly agreed)
  - of a high quality (93% agreed/strongly agreed; 7% did not respond).

**Key issues**

- While information resources were highly accessible, the timing of the distribution of the packet to breast cancer patients was an issue. For example, counsellors at screening and diagnostic services felt the information was overwhelming for women at this early stage. However, consumer consultations revealed that women preferred to have control over whether they accepted information offered to them, rather than a health professional deciding whether the information was useful or relevant. The importance of encouraging health care providers to offer the consumer packet at multiple points in a woman’s journey was identified.

- Distribution of patient information from The Cancer Council Tasmania to health care sites presented an opportunity to provide health care providers with Clinical Practice Guidelines in an organised and accessible folder or ‘kit’ and facilitated the establishment of new communication networks.

- Educating ward staff about the material contained in each of the kits was seen as an essential task, to ensure that the material was incorporated into everyday practice.
• Finding a location for the resource materials to be stored at hospital or clinic sites where staff might see and remember them proved difficult.

• Involvement of consumer and professional groups in the initial audit process meant these groups continued to provide interest, support and active participation in the project. This initiated a spirit of shared ownership and problem solving.

• Ongoing updating was viewed as essential to the usefulness of a locally-specific information resource.

• Providers reported using the newly developed materials to support other cancer patients. It is envisaged that generic kits will be developed using this template and strategy.

Case study E: Public forums via satellite in NSW

Aim

To coordinate satellite broadcasts of an annual public forum on breast cancer providing information for consumers and health care professionals.

Strategy

In 2001–2003 the NSW Breast Cancer Institute broadcast annual public forums to around 30 sites within NSW and other States. The forums involved a multidisciplinary expert panel participating in case study discussions and question and answer sessions. The interactive nature of the broadcasts meant that viewers could phone or fax in questions to the panel for discussion. Forum topics included ‘Delivering best practice MDC for patients with breast cancer’, ‘Breast cancer and beyond’ and ‘If breast cancer comes back’.

Educational CD-ROMs and videos containing information from the public forums were produced and distributed to all GPs in NSW (approximately 7,600) and
to Strengthening Support project coordinators across the country. The CDs included case study discussions, along with question and answer information presented at the forums, supplementary information about topics that were not covered in full at the forum and relevant extracts from BCI treatment protocols.

**Key outcomes – State evaluation**

The forums were evaluated through participant surveys. Almost half of the participants (430 attendees; 47%) completed evaluation surveys of the public forum in 2002. Overall they rated the programs highly (9.4–9.6 out of 10, over the period 2001–03) and 94% of attendees indicated that they were interested in attending further forums.

**Key issues**

- New technologies (such as satellite broadcasts, CD ROMs and websites) enable health messages to be transmitted to a large audience on a national basis. However, there is a cost involved.

- The participation and support of a multidisciplinary team of experts contributed to the success of the forums.

- Production of CD-ROMs and educational videos from the public forums provided an ongoing educational resource for rural and remote practitioners not only in NSW but in other States and Territories.
Theme 3: Improving communication between health care providers

Improving communication between health care providers about supportive care

A range of strategies was implemented to facilitate communication between health professionals about the supportive care needs of individual women with breast cancer. Awareness of multidisciplinary team meetings as a method to improve communication increased between baseline and follow-up for all health professionals surveyed (Table 5.12). There was also an increase in specialists and supportive care workers indicating that other communication protocols were in place and a corresponding decrease in these health professionals indicating that no protocols were in place. Interestingly, over 50% of the breast care nurses surveyed at both baseline and follow-up stated that no communication protocols were in place, often describing the process as ‘ad-hoc’.

In each health professional group surveyed, the majority of respondents indicated that communication about supportive care in their local areas was ‘fairly good’ or ‘very good’ (Table 5.13). The percentage of breast care nurses and clinicians who believed that communication in their local areas was ‘very good’ increased between baseline and follow-up (from 11% to 28% for breast care nurses and from 19% to 33% for clinicians). No change in the response rate for this level of communication was noted in supportive care workers. However, there was an increase in the proportion of supportive care workers who indicated that the level of communication was ‘fairly good’ (from 50% to 75%) and a corresponding decrease in the proportion indicating that communication was poor (from 27% to 2%).

Informing health care providers about breast cancer issues and services

At both timepoints health professionals indicated awareness of written information about breast cancer issues, services and local supportive care services available locally (Figure 5.5). The most commonly cited written information for local health professionals took the form of regular research updates from local, state or national
organisations, newsletters and the NBCC guidelines *Psychosocial Clinical Practice Guidelines: Providing Information, Support And Counselling for Women with Breast Cancer*. There was a modest increase in awareness of research updates and newsletters at follow-up compared to baseline (69% at baseline compared with 80% at follow-up).

In terms of other educational resources, there was an increase at follow-up in the proportion of respondents who were aware of face-to-face seminars on supportive care issues that had taken place in the previous 12 months specifically for the benefit of local health professionals (45% at baseline vs 57% at follow-up; Figure 5.6). There was little difference in awareness of other educational initiatives such as seminars (around 23% at both timepoints), workshops and education sessions presented via e-health technologies, electronic or email newsletters (21% at baseline compared with 15% at follow-up) or online discussion groups and bulletin boards (around 6% at both timepoints). Over 30% of respondents at both time points were not aware of any of the above resources for local health professionals provided over the previous 12 months. Overall, the proportion of respondents able to identify e-health and other electronic media initiatives about breast cancer issues and services did not change greatly between baseline and follow-up.

**Case study F: NESB/ATSI worker resource packages South Australia**

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<th><strong>Aim</strong></th>
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<tr>
<td>To improve supportive care, reduce inequities in care and improve continuity of care arrangements for rural women from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander women with breast cancer.</td>
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<table>
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<tr>
<th><strong>Strategy</strong></th>
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<tr>
<td>Information gathered from regional audits and community consultations in South Australia led to the development of a range of resources for women and service</td>
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providers, including two resources to assist health service providers in mapping the breast cancer journey for women from culturally and linguistically diverse backgrounds, and for Aboriginal and Torres Strait Islander women, in a culturally appropriate manner.

‘Mapping a Breast Cancer Journey after diagnosis: A Service Provider’s Information Resource for working with Aboriginal and Torres Strait Islander Women’ was developed in consultation with Aboriginal Health Workers across rural SA, Indigenous women and workers from the Anangu Pitjantjatjara Lands in the north west of SA, breast care nurses, The Cancer Council Northern Territory and Aboriginal and Torres Strait Islander women and workers in Northern Territory.

‘Mapping a Breast Cancer Journey after diagnosis: A Service Provider’s Information Resource for working with Women from Culturally and Linguistically Diverse Backgrounds’ included basic information about the breast cancer pathway, and was aimed at Multicultural Workers / Ethnic Link Workers. The resource was launched at a regional multicultural conference.

In addition to these resources, The Royal Adelaide Hospital facilitated a training day for Aboriginal Health Workers on breast cancer issues. Presentations were also given to the Aboriginal, Home and Community Care workers and Aboriginal Primary Health Care Network. A training day was also held for rural Ethnic Link workers to increase awareness of cancer support services available for women with breast cancer from culturally and linguistically diverse backgrounds.

**Key outcomes – State evaluation**

The training of a diverse workforce, including multicultural workers and Aboriginal Health Workers, and the development of appropriate resources was required to ensure specific population groups of women had access to information on supportive care.
Involvement of the breast care nurse or cancer contact worker in providing information to health professionals about supportive care

The survey outcomes indicated an increase in awareness of the breast care nurse or cancer contact worker role in providing information and education to local health professionals between baseline and follow-up. While the majority of breast care nurses considered that providing information and education to local health professionals about supportive care issues for women with breast cancer was a component of their role at both time points, there was an increase between baseline and follow-up (76% at baseline, 84% at follow-up) (Table 5.14).

All breast care nurses stated that they were either very or somewhat confident of the quality of the information they could provide (Table 5.15). Importantly, the proportion of breast care nurses who felt very confident increased from 41% at baseline to 60% at follow-up. While the involvement of the breast care nurses in provision of information to clinicians had clearly improved over the course of the program, some breast care nurses surveyed indicated that they would still like to do more in this area but were unable to do so due to time constraints.

The proportion of clinicians and supportive care workers who were aware of a breast care nurse or cancer contact person whose role it was to provide information to local health professionals about supportive care issues for women with breast cancer also increased between time points (specialists: 45% to 72%; supportive care workers: 68% to 87%; Table 5.16).

Finally, overall satisfaction of clinicians and supportive care workers in the quality of supportive care information provided to them by either breast care nurses or cancer contact persons increased during the program (very satisfied: clinicians 56% to 85%; supportive care workers 46% to 60%) (Table 5.17).
Improving communication through innovative approaches

Some innovative approaches to improve communication between health care professionals were seen throughout the SSWBC program. These included an online chat room to improve communication and support for breast care nurses.

Case study G: An on-line chat room for breast cancer nurses in Victoria

**Aim**

To provide accessible further education, supervision and debriefing, support and networking opportunities for breast care nurses in Victoria.

**Strategy**

Breast care nurse website forums were developed in the Loddon Mallee and Hume regions to facilitate communication and support for breast care nurses in remote and rural areas and other nurses working in isolation throughout the region and beyond.

In the Loddon Mallee region, a dedicated forum software package was adapted and customised to meet the needs of the region. Breast care nurses had access through the forums to a broad range of medical experts, including a surgeon, pathologist, radiation oncologist, lymphoedema management representative, psychologist, counsellor and further education representative, together with representatives from The Cancer Council Victoria, BreastScreen Victoria and the National Breast Cancer Centre.

The Loddon Mallee project team used the free Government IT training program, VicNet, to enable training sessions for breast care nurses throughout the region.

In the Hume region, a chat room within the Hume website was used as a means for breast care nurses to communicate with each other and upload information as
required. The website was developed as part of an umbrella website for the region using a content management system purchased specifically for the purposes of the project.

**Key outcomes – State evaluation**

- In both regions, the forum areas provided an informal method of contact for breast care nurses working in isolated areas to communicate with peers and exchange ideas and information regarding strategies to improve support to breast cancer patients.

- In the Hume region, the breast care nurse chat room was seen as fundamental to the communications and information strategies employed within the region.

- More than 150 registrations to the Loddon Mallee breast care nurse discussion forum were received from state and national levels.

**Key issues**

- Customisation of software packages, such as those used in these initiatives, requires specialised technical skills.

- The ongoing administration and maintenance of a website and breast care nurse discussion forum/chat room requires support from staff with the appropriate communication and technical skills. This is an ongoing expense and planning for ways to address this issue should take place early in the project.

- Training was critical to support this initiative. breast care nurses’ lack of computer and Internet skills would limit their access to the website and training was necessary to ensure use of the forum/chat room.
Theme 4: Continuity of care

Multidisciplinary care models

Respondents indicated that supportive care planning was established as part of MDC meetings for at least some or all women (Table 5.18). The proportion of breast care nurses stating that supportive care was considered for all women increased from 0% to 30% between baseline and follow-up, while more modest increases were seen for specialists and supportive care workers. The proportion of specialists who indicated that supportive care was considered for some women increased by 27% for clinicians and by 9% for supportive care workers between baseline and follow-up. Importantly, there was a corresponding decrease in the proportion of breast care nurses and specialists who stated that supportive care planning was not included in MDC meetings (Table 5.19). However, further discussion with survey respondents indicated that in many cases, meetings were still clinically focused.

The proportion of supportive care workers who indicated that supportive care planning was used throughout all stages of care increased from 8% to 31% between baseline and follow-up (Table 5.19). However, fewer breast care nurses and clinicians at follow-up than at baseline stated that supportive care planning was used throughout all stages of care.
Case study H: Establishment of multidisciplinary team meetings in ACT

**Aim**

To develop a multidisciplinary approach to treatment planning for women with breast cancer.

**Strategy**

As part of the ACT SSWBC initiative, fortnightly multidisciplinary team meetings were established. The meetings were attended by 12–15 participants, including principal surgeons, medical oncologists, radiation oncologists, histopathologists from the two principal pathology services and nursing staff from the various hospital sites in the ACT. Psychologists and other allied health professionals were invited to attend the meetings but did not attend on a regular basis.

The meetings provided a forum to discuss specific cases. The SBN circulated a case list to surgeons in advance of the meetings and they selected around three patients to discuss; usually these were more difficult cases or reflected a particular theme (eg ductal carcinoma in situ). The meetings were used as a forum to discuss the management of specific cases, including psychosocial issues, and as an educational forum.

The SBN also attended a monthly multidisciplinary clinic arranged by the Lymphoedema Service for the ACT and South-East NSW.

**Key outcomes – State evaluation**

- The multidisciplinary meetings were viewed as a great success, generating discussion and involving a range of participants.
• An unexpected function of the meetings is their role in providing quality assurance for the histopathology laboratories, which previously had no reporting standard.

**Key issues**

• It was noted that the group proved to be quite difficult to establish; surgeons in particular were initially quite reluctant to be involved.

• Establishing the meetings involved considerable work from the SBN and medical oncologist.

**Approaches involving breast care nurses**

A high proportion of respondents indicated that consultations with a breast care nurse occurred pre- and post-operatively and during treatment. There was a marked increase in the percentage of responses by all health professionals for all categories between baseline and follow-up (Table 5.20). By follow-up, over 90% of health professionals stated that a breast care nurse consultation occurred pre- and post-operatively; about 90% stated that a consultation occurred during chemotherapy or hormonal therapy.

Over 60% of specialists surveyed at both time points indicated that all local surgeons and oncologists refer all or most women (Table 5.21). The proportion of breast care nurses and supportive care workers who indicated that all local surgeons and oncologists refer all or most women increased between baseline and follow-up. Responses indicated that referral was more likely to occur from the public sector than from the private sector. Some respondents also indicated that referrals to a breast care nurse came through the State and Territory Cancer Councils.

There was an increase in the proportion of all respondents who indicated that supportive care was provided by a breast care nurse or cancer contact worker for women travelling between rural and urban areas for treatment (Table 5.22). This was most noticeable for the breast care nurses (50% at baseline vs 89% at follow-up). Some respondents indicated that information about travel and accommodation was supplied by the local Breast Cancer Support Service or other voluntary groups. There
was a marked increase between baseline and follow-up of respondents indicating that the breast care nurse or cancer contact worker coordinated access to support for women within rural settings (Table 5.23) (breast care nurses 40% at baseline vs 94% at follow-up; clinicians 42% at baseline vs 90% at follow-up).

Methods to inform and involve GPs in the supportive care of women with breast cancer were also investigated (Table 5.24). The proportion of respondents who indicated that no protocols to involve GPs were in place or that they did not know about protocols decreased between baseline and follow-up. The most frequent reported method of informing GPs was use of referral letters or faxes that contain supportive care information. A number of respondents indicated that efforts were made to include GPs in MDC meetings but that this had not been successful.

**Case study I: The Breast Cancer Nurse model in Queensland**

**Aim**

To improve access to information and psychosocial support for women with breast cancer and their families residing in rural areas by providing SBN positions in six regional centres in Queensland.

**Strategy**

In an effort to ensure that all women diagnosed with breast cancer received a coordinated approach to supportive care regardless of locality, the Queensland project established six part-time SBN positions: in Cairns (30% FTE), Townsville (50% FTE), Mackay (20% FTE), Toowoomba (25% FTE), the Gold Coast (25% FTE) and at the Princess Alexandra Hospital in Brisbane (50% FTE). The SBNs were located in different sites, reflecting local practice and acceptance. Northern Zone SBNs (Cairns, Townsville, Mackay) were co-located within BreastScreen Queensland Services. This community-based approach was chosen as sites were already well accepted by women in the community as a user-friendly
environment, had strong multidisciplinary approaches and well-developed communication networks. In the Southern Zone, there was a hospital-based approach, with SBNs located within the Division of Surgery, since each of the three centres (Toowoomba, Gold Coast and Princess Alexandra Hospital) functioned as a referral hospital for surrounding Health Service Districts.

Key functions of the SBNs included the coordination of supportive care across the care continuum, the provision of information and psychosocial care and referral to specialised services and support agencies. Training and support comprised an orientation program and continuing support by monthly teleconferences where SBNs could discuss project implementation and clinical issues, provide peer support and discuss data collection issues and evaluation methodologies. The NBCC's evidence-based clinical pathway was used as a guide to clinical practice; contacts with clients were spread across key points along the clinical pathway.

**Key outcomes – State evaluation**

A State evaluation plan determined the impact of the SBNs on the provision of supportive care in a variety of settings, both hospital and community based, with a focus on analysing perceptions, particularly among consumers and members of the treatment team, rather than clinical outcomes. Data were collected from daily client records, activity diaries, client satisfaction surveys and surveys of SBNs and members of the multidisciplinary treatment team at each site.

The State evaluation found that:

- the SBNs’ ability to liaise between individual clinicians as well as surgical and oncology units was seen as a critical component in the coordination of care
- the SBNs’ coordinating role ensured vital patient information was transferred to the relevant clinician in a timely way and discussed within a team context
- patients were less likely to be 'lost' in the system since they were captured at diagnosis or prior to surgery
women's coping ability was considered to be enhanced by the availability of the one contact person for any issue that might arise

women rated positively the availability of the one constant contact person throughout their care.

**Key outcomes – other**

- The SBN was seen as a valuable source of information, emotional support, compassionate care and optimism by women. Her liaison role was seen as valuable and her presence was important for assisting women in the recovery process.

- Nursing staff valued the SBNs' ability to provide the emotional support they found difficult to provide because of time constraints.

- Women attending surgical and oncology clinics were perceived as more relaxed and knowledgeable about their treatment leading to smoother functioning of these clinics.

- Nearly all health professionals interviewed felt that the appointment of a SBN had a very positive impact on the quality of care provided to the women. Women were seen as being able to make better treatment decisions such as conservative surgery because of the information and practical support offered by the SBN.

- SBNs were perceived as integral members of the multidisciplinary treatment team and provided a valuable linkage or conduit of information between individual team members, the team itself and individual patients.

- A lack of acceptance and understanding of the SBN role in one particular location meant that there was limited clinical and managerial support for the position. This hampered the effective implementation of the role at this site and created additional stresses for the nurse.
The SBN was integral to the coordination of care, the timely transfer of patient information between clinicians and reduced likelihood of patients being ‘lost’ in the system. Women rated positively the availability of the one constant contact person throughout their care.

**Key issues**

- The project established the need for full time or upgraded roles to enable the full range of support services to be offered to all women diagnosed with breast cancer, and a need for dedicated administrative support.

- The limited hours funded compromised the ability of SBNs to provide support and follow up to women. Most SBNs in part-time positions worked additional hours in their own time on a regular basis to meet the demand for support and/or were unable to follow a patient through the whole continuum of care.

- While in most areas about 60% of the SBN’s time was spent in clinical activities such as patient support, in two centres the SBN spent more than half her time on non-clinical activities. This was due to the limited hours allocated to the position, the high administrative burden on the SBN in the absence of administrative support and the difficulties of juggling several roles simultaneously.

- It was essential to secure support from clinical teams for the effective implementation of the SBN’s coordinating role. Lead clinicians played a key role in advocating for establishment and maintenance of SBN positions.

- About 75% of women surveyed in Queensland would have preferred more regular scheduled appointments rather than the less structured approach taken in this project.

- There was a high level of awareness of the SBN role among clinicians in the public sector, Nurse Practice Coordinators and Clinical Nurse Consultants, but a need to educate generalist nursing staff from surgical wards about the role and to provide regular updates due to staff turnover. Clinicians in the private sector also were not
necessarily aware of the SBN role if they were not involved in multidisciplinary team meetings.

- Caseloads varied depending on type of women seen, location of breast care nurse and throughput of centre. In some cases, large case loads and competing time pressures reduced the capacity of SBNs to follow a patient through the whole continuum of care.

**Breast care nurse models in other regions**

Breast care nurse positions also were established in Western Australia, Tasmania, Northern Territory and the ACT (see case study A) as part of the Strengthening Support for Women with Breast Cancer program. The development and implementation of the SBN role needs to be responsive to the region’s health care structures, systems and needs. The setting, training and professional development and support structures all may differ in response to local needs.

In Western Australia, three rural SBN positions were created – in Albany (0.4 FTE), Bunbury (0.6 FTE) and Geraldton (0.4 FTE) – based on the numbers of women in the region aged over 40 and the incidence of breast cancer. Each SBN was a RN who was provided with training in breast cancer nursing. Their role was to provide a readily accessible contact for women throughout their diagnosis and treatment for breast cancer; information on multiple occasions and at appropriate times; emotional and counselling support; practical support and information; and a point of contact for ongoing liaison and referral to other health professionals and services. The NBCC’s clinical pathway was adapted to provide a model of six interventions over a six month period.

In addition to an orientation program and monthly teleconferences, WA SBNs were supported by the creation of an SBN Coordinator position (providing ongoing clinical supervision and a mentoring function through weekly individual telephone contact and scheduled site visits); appointment of the Breast Cancer Clinical Psychology Service to provide regular confidential support and debriefings for each rural SBN; (see case study M); a core professional development program; and development of administrative
processes to support caseload management and project evaluation (including referral pathway summaries, process guidelines and a patient database).

Evaluation of the WA project is not due until 2005, but early successes include:

- Integration of the role of the SBN into local pathways. Acceptance of the SBN role has been highlighted by the number of referrals originating from local health care professionals.

- Identification and addressing of existing problems for women with breast cancer in the local areas, such as access to information about and treatment for lymphoedema, which probably would not have been recognised otherwise.

- Clinical supervision, teleconferences, phone calls and confidential debriefing services have been established as effective means of overcoming rural SBNs’ sense of isolation and helping them operate as a team even though geographically and professionally separated.

**Theme 5: Health care provider needs in relation to training and support**

**Training and development**

Before the SSWBC program, 15% of breast care nurses stated that no opportunities for training and education were available for breast care nurses or that they had not participated in training in the previous 12 months (Table 5.25). This proportion was reduced to 6% in the follow-up survey. Most breast care nurses took part in education or training workshops (65% at baseline and 78% at follow-up), with a smaller proportion participating in other initiatives such as university courses and e-health initiatives.

Prior to the SSWBC program, 5% of specialists and 14% of supportive care workers stated that they were unaware of any local training and education programs (Table 5.26). A further 23% of specialists and 18% of supportive care workers stated that no
opportunities for such training or education had been available during the previous 12 months. This proportion did not change substantially in the follow-up survey. Similar to breast care nurses, most specialists and supportive care workers (around 60%) took part in education or training workshops with a smaller proportion participating in other initiatives.

Of the specialists interviewed, 70% indicated that they had participated in training programs about the supportive care for women with breast cancer at baseline compared with 76% at follow-up. A smaller proportion of supportive care workers stated they had participated in training programs at baseline (52%) although this proportion increased by 9% at follow-up (Table 5.27).

**Case study J: Integrating supportive care – a training resource for NSW Cancer Information Service workers**

The Breast Cancer Institute worked with The Cancer Council NSW to develop and implement a training program for Cancer Information Helpline Consultants to assist them in supporting women with breast cancer, including those from rural areas of NSW.

The first phase of this project was to identify the learning and development needs of Helpline staff. This was then followed by a clinical placement program, where staff would attend a multidisciplinary case conference and ‘shadow’ specialist staff at the NSW BCI. These structured learning activities provided staff with greater knowledge on how best to respond to difficult questions asked on the Helpline.

**Support and supervision**

There was a 13% increase between baseline and follow-up in the proportion of breast care nurses reporting regular weekly professional supervision sessions in which clinical and supportive care aspects were discussed (Figure 5.7). While this represented a substantial increase from baseline (in which no weekly sessions were reported), the majority of supervisory opportunities were still reported as ‘opportunistic’ or ‘informal’.
Moreover, one in four respondents reported that no opportunities were available at follow-up.

Despite the irregularity of supervisory opportunities, breast care nurses reported numerous opportunities to network with other breast care nurses (Table 5.28). In particular, a substantial increase was noted in regular teleconferences or videoconferences (5% at baseline versus 35% at follow-up). At follow-up, no breast care nurses reported a lack of opportunity to liaise with other colleagues.

Overall, breast care nurses reported increases in opportunities to support improvements in the knowledge and skills (Figure 5.8), with the greatest increases described in the areas of peer-to-peer contact, educational and training activities, and other opportunities. The proportion responding that no opportunities existed decreased fourfold from baseline (24% to 6%).

A high proportion of breast care nurses and supportive care workers thought that local education programs were very useful in improving skills and knowledge, with no change between baseline and follow-up (Table 5.29). However, an increase of 20% in the number of specialists who thought the programs were ‘very useful’ was noted at follow-up.

Over 80% of all respondents reported that the supportive care education programs increased their confidence in the care for women with breast cancer (Table 5.30) with an increase of around 10% seen between baseline and follow-up.

The majority of specialists reported that they felt ‘very confident’ about supportive care after participating in education programs whereas breast care nurses and supportive care workers were more likely to indicate that they were ‘confident’ (Table 5.31). Generally, few health professionals claimed that they were only ‘somewhat confident’ about supportive care after participating in education programs. The percentage of clinicians indicating that they were ‘very confident’ about the supportive care of women increased from 80% to 92% between the two surveys. However, the percentage of breast care nurses and supportive care workers who claimed to be ‘very confident’ about supportive care decreased from 35% to 24% and from 45% to 25%, respectively. The majority of respondents who no longer felt they were ‘very confident’ about supportive care, classified themselves as being ‘confident’ during the follow-up survey.
No respondents during either time survey reported to be ‘not very confident’ about the supportive care of women with breast cancer.

Case study K: Linking health professionals – an innovative model of professional supervision for breast care nurses as provided by psychologists in Western Australia

**Aim**

To provide professional support for rural SBNs.

**Strategy**

In Western Australia, a number of strategies were implemented to support the rural SBN positions created as part of the project. One component was the appointment of the Breast Cancer Clinical Psychology Service to provide regular confidential support and debriefings for each rural SBN. This service was set up to provide support for cancer patients and their families, but the two psychologists who job-shared the position agreed to provide supervision to SBNs as part of the program. Fortnightly telephone calls between a clinical psychologist and each rural SBN provided an opportunity to debrief and discuss supportive strategies that may be offered in challenging situations.

**Key outcomes – State evaluation**

Due to delays in establishing the project in Western Australia the final evaluation report is not due until 30 September 2005. However, preliminary evaluations indicate that confidential debriefing services with a psychologist have assisted in overcoming rural SBNs’ isolation and managing professional stress.
Knowledge and attitudes

Respondents reported limited opportunities in the past 12 months for local or visiting clinicians to learn about new technologies in their area (Table 5.32). Around 60% of respondents indicated that they were unaware of opportunities at baseline. At follow-up, the proportion of breast care nurses and specialists who were aware of opportunities had decreased, while there was a small (8%) increase in awareness by supportive care workers.

The majority of health professionals surveyed rated their personal knowledge of the locally available supportive care services and resources for women with breast cancer as either ‘very high’ or ‘high’ (Table 5.33). For specialists and supportive care workers there was an increase in the proportion rating their knowledge as very high between baseline and follow-up.

A larger percentage of specialists claimed to have a ‘very high’ level of knowledge about resources that are available to them than respondents in the other health professional groups (Table 5.34). The proportion of specialists and supportive care workers who rated their level of knowledge of resources about supportive care for health professionals as ‘very high’ increased between baseline and follow-up.

When asked whether opportunities existed for leaders of breast cancer support groups to network with other groups, almost one third of breast care nurses and supportive care workers reported not knowing about the existence of such opportunities (Table 5.35). There was an increase in awareness for both groups between baseline and follow-up (breast care nurses: 40% vs 47%; supportive care workers: 27% vs 48%).

The majority of respondents from all health professional groups were ‘very’ or ‘somewhat’ aware of the SSWBC program (Table 5.36). An increase in the percentage of respondents who were ‘very aware’ of the program was noted for all three groups between baseline and follow-up (breast care nurses: from 50% to 72%; clinicians: from 59% to 74%; supportive care workers: from 43% to 54%).
Case study L: Upskilling healthcare professionals in the use of e-health technologies: The educational voucher scheme in Victoria

**Aim**

To encourage health professionals and consumers to increase their skills in the use of e-health equipment and operations by providing a financial contribution towards training tailored to their needs.

**Strategy**

In an information technology needs analysis (ITNA) to determine the existing and future IT skill level needs in the Hume Region, surveys were distributed to 63 stakeholders including consumers, breast care nurses, surgeons, GPs, medical and radiation oncologists, radiologists, pathologists and allied health professionals. Of the 42 respondents, 64% indicated that they had barriers that currently restricted their use of IT or its components; 40.5% lacked skills and 38% lacked time. Most respondents reported need for improved IT skills in the future.

In line with the ITNA recommendations, this project aimed to up-skill Hume Region stakeholders in the use of e-health equipment and operations pertinent to their needs and abilities, thus increasing workforce productivity and consumer empowerment. Rather than provide generic training, an Information Technology Educational Voucher Scheme (ITEVS) was developed to enable stakeholders to undertake training and education tailored to their needs. This scheme involved creating customised packages of training information for stakeholders (depending on their location) so that they were able to choose their type (for example, word processing) and mode (group or self-paced) of training, within their local communities. Upon completing their training, the stakeholders were able to redeem up to $125 towards the original cost of the training.

Initially the ITEVS was trialled with eight stakeholders to test usability and ensure that the paperwork system to administer the scheme was adequate. The ITEVS was
released (with refinements following the trial) to 74 stakeholders, who were given a five-month time frame to use their education voucher. A marketing program advertising the Hume Breast Services Enhancement Program website ran alongside the voucher scheme to entice stakeholders to take up the training opportunity, become more computer literate and advertise the website.

**Key outcomes – State evaluation**

As part of the redemption process, stakeholders needed to complete financial data requirements and a short evaluation regarding the suitability/usability of the ITEVS and their training. For those stakeholders who agreed, 19 qualitative telephone interviews were also conducted to extend the evaluation data gathered.

- A total of 46 vouchers (including seven trial vouchers and 10 second round vouchers) were used and reimbursed to a maximum of $125.00 (plus GST). The total dollar value of training spent by the participants was $5,235.98, an average of $113.83 per training experience.

- The minimum amount claimed on a voucher was $25.00 for an Internet course at a local community house, and the most expensive training undertaken was a self-paced CD-ROM computer course for $250.00 obtained from a local adult education centre, of which the participant paid the balance beyond his voucher entitlement.

- Consumers, breast care nurses and community/district nurses represented the highest intake of the voucher scheme, accounting for 26%, 19% and 10% of participants respectively.

- The type of training providers used ranged from Technical and Further Education (TAFE) institutes, colleagues and IT retail stores through to community houses and private accredited providers. The mode of delivery of this training was mainly one-to-one, self-paced manuals or software, and attendance at group sessions. The most popular content of training was Internet, email and word processing.
**Key issues**

- By providing links and funding incentives for training within local areas of the region, stakeholders have been given an opportunity to undertake training that they otherwise may not have been able to undertake.

- This concept is very relevant for clinicians and consumers living and working in rural communities. Being unlimited in the type, mode, time and location of training, it provides flexibility to those wanting to up-skill without the need, in most instances, to leave their community.

- The training supported both consumers and clinicians to improve their IT skills which will allow them to more easily access information electronically and, at the same time, increase their awareness of available information on breast health and breast cancer.
Table 5.1  Presence of breast care nurse in local area*

<table>
<thead>
<tr>
<th>Has a breast care nurse been appointed?</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care Workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
<td>1 (6)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Appointed through SSWBC†</td>
<td>5 (24)</td>
<td>9 (50)</td>
<td>5 (23)</td>
</tr>
<tr>
<td>Appointed through other means</td>
<td>9 (43)</td>
<td>5 (28)</td>
<td>8 (36)</td>
</tr>
<tr>
<td>General oncology nurse</td>
<td>0</td>
<td>1 (6)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Other nursing position</td>
<td>1 (5)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No, but is soon to be appointed</td>
<td>1 (5)</td>
<td>0</td>
<td>4 (18)</td>
</tr>
<tr>
<td>No, there is no breast care nurse</td>
<td>5 (24)</td>
<td>1 (6)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Don't know</td>
<td>0</td>
<td>1 (6)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>18 (100)</td>
<td>22 (100)</td>
</tr>
</tbody>
</table>

*Results are given as frequency (%) and may not sum to 100% due to rounding

†Strengthening Support for Women with Breast Cancer
<table>
<thead>
<tr>
<th>Role of breast care nurses</th>
<th>Breast care nurses Baseline</th>
<th>Breast care nurses Follow-up</th>
<th>Specialists Baseline</th>
<th>Specialists Follow-up</th>
<th>Supportive care workers Baseline</th>
<th>Supportive care workers Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing supportive care to individual women</td>
<td>20 (95)</td>
<td>18 (100)</td>
<td>17 (81)</td>
<td>19 (100)</td>
<td>18 (82)</td>
<td>21 (88)</td>
</tr>
<tr>
<td>Coordinating role to ensure supportive care is addressed</td>
<td>19 (91)</td>
<td>17 (94)</td>
<td>15 (71)</td>
<td>19 (100)</td>
<td>16 (73)</td>
<td>21 (88)</td>
</tr>
<tr>
<td>Coordinating care while the women are receiving treatment</td>
<td>12 (57)</td>
<td>15 (83)</td>
<td>11 (52)</td>
<td>16 (84)</td>
<td>9 (41)</td>
<td>16 (67)</td>
</tr>
<tr>
<td>Providing information directly</td>
<td>19 (91)</td>
<td>17 (94)</td>
<td>18 (86)</td>
<td>19 (100)</td>
<td>20 (91)</td>
<td>21 (88)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (29)</td>
<td>3 (17)</td>
<td>5 (24)</td>
<td>5 (24)</td>
<td>9 (41)</td>
<td>5 (21)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (4)</td>
</tr>
</tbody>
</table>

*Results are given as frequency (%) and are not to be summed as multiple responses were allowed.*
### Table 5.3 Awareness of MDC meetings in the local area*

<table>
<thead>
<tr>
<th>Type of meeting</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Face to face meetings</td>
<td>7 (33)</td>
<td>11 (61)</td>
<td>12 (55)</td>
</tr>
<tr>
<td>Local meetings with teleconferencing/videoconferencing</td>
<td>1 (5)</td>
<td>0</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Local face to face meetings being planned</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Local meetings linking professionals being planned</td>
<td>0</td>
<td>1 (6)</td>
<td>0</td>
</tr>
<tr>
<td>No meetings</td>
<td>12 (57)</td>
<td>5 (28)</td>
<td>7 (32)</td>
</tr>
<tr>
<td>Don't know</td>
<td>1 (5)</td>
<td>1 (6)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>18 (100)</td>
<td>22 (100)</td>
</tr>
</tbody>
</table>

*Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.4  Awareness of attendance by supportive care workers at MDC meetings*†

<table>
<thead>
<tr>
<th>Attendance</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Always</td>
<td>7 (88)</td>
<td>10 (91)</td>
<td>10 (71)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>0</td>
<td>1 (9)</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Rarely</td>
<td>0</td>
<td>0</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Not in the past but plan to include in the future</td>
<td>0</td>
<td>0</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Never</td>
<td>1 (12)</td>
<td>0</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>8 (100)</td>
<td>11 (100)</td>
<td>14 (100)</td>
</tr>
</tbody>
</table>

*Results are given as frequency (%) and may not sum to 100% due to rounding

†Question only asked of respondents who indicated that MDC meetings occurred
### Table 5.5  Appointment of cancer contacts or cancer coordinators to a local area*

<table>
<thead>
<tr>
<th>Has a cancer contact/cancer coordinator been appointed?</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes</td>
<td>2 (10)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Appointed through SSWBC†</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Appointed through other means</td>
<td>5 (24)</td>
<td>6 (22)</td>
<td>8 (29)</td>
</tr>
<tr>
<td>No, but is soon to be appointed</td>
<td>1 (5)</td>
<td>0</td>
<td>1 (5)</td>
</tr>
<tr>
<td>No, there is no cancer contact person</td>
<td>13 (62)</td>
<td>14 (78)</td>
<td>13 (62)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0</td>
<td>0</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>17 (100)</td>
<td>21 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
† SSWBC, Strengthening Support for Women with Breast Cancer
### Table 5.6  Health professionals encouraged to attend communication skills training workshops in the past 12 months*

<table>
<thead>
<tr>
<th>Response</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes, encouraged</td>
<td>8 (38)</td>
<td>10 (56)</td>
<td>14 (64)</td>
</tr>
<tr>
<td>No, not encouraged</td>
<td>8 (38)</td>
<td>4 (22)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5 (24)</td>
<td>4 (22)</td>
<td>6 (27)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>18 (100)</td>
<td>29 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.

### Table 5.7  Communication skills training workshops attended by health professionals during the past 12 months*

<table>
<thead>
<tr>
<th>Participation</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes, local workshop</td>
<td>1 (5)</td>
<td>1 (6)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Yes, State-based or national workshop</td>
<td>3 (14)</td>
<td>12 (61)</td>
<td>8 (38)</td>
</tr>
<tr>
<td>No, have not participated</td>
<td>16 (76)</td>
<td>5 (28)</td>
<td>12 (51)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
Table 5.8  Estimates of attendance by local health professionals at communication skills training workshops*

<table>
<thead>
<tr>
<th>Impression</th>
<th>Breast care nurses</th>
<th></th>
<th>Specialists</th>
<th></th>
<th>Supportive care workers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>All or most local health professionals have attended</td>
<td>2 (10)</td>
<td>1 (6)</td>
<td>2 (10)</td>
<td>2 (11)</td>
<td>1 (5)</td>
<td>3 (13)</td>
</tr>
<tr>
<td>Some local health professionals have attended</td>
<td>3 (15)</td>
<td>2 (11)</td>
<td>7 (33)</td>
<td>8 (42)</td>
<td>6 (27)</td>
<td>6 (25)</td>
</tr>
<tr>
<td>Very few local health professionals have attended</td>
<td>7 (35)</td>
<td>11 (61)</td>
<td>6 (29)</td>
<td>2 (11)</td>
<td>6 (27)</td>
<td>8 (33)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>8 (40)</td>
<td>4 (22)</td>
<td>6 (29)</td>
<td>7 (37)</td>
<td>9 (41)</td>
<td>7 (29)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100)</td>
<td>18 (100)</td>
<td>21 (100)</td>
<td>19 (100)</td>
<td>22 (100)</td>
<td>24 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.9  Personalised forms of information or resources for women available for health professionals to use during consultations*

<table>
<thead>
<tr>
<th>Resource available</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>‘My Journey’ folder</td>
<td>3 (14)</td>
<td>4 (24)</td>
<td>8 (38)</td>
</tr>
<tr>
<td>Patient held record</td>
<td>3 (14)</td>
<td>4 (24)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Tape recordings of consultations</td>
<td>2 (10)</td>
<td>0</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Pathology reports</td>
<td>6 (29)</td>
<td>5 (29)</td>
<td>7 (33)</td>
</tr>
<tr>
<td>Other information resources</td>
<td>5 (24)</td>
<td>3 (18)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0</td>
<td>1 (6)</td>
<td>5 (24)</td>
</tr>
<tr>
<td>None</td>
<td>5 (24)</td>
<td>5 (39)</td>
<td>2 (10)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
Table 5.10  Health professionals providing personalised forms of information or resources to women with breast cancer*

<table>
<thead>
<tr>
<th>Provision of personalised information</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline Follow-up</td>
<td>Baseline Follow-up</td>
<td>Baseline Follow-up</td>
</tr>
<tr>
<td>Yes, personalised information provided to all women</td>
<td>5 (28) 7 (47)</td>
<td>8 (50) 9 (47)</td>
<td>2 (13) 3 (16)</td>
</tr>
<tr>
<td>Yes, personalised information provided to some women</td>
<td>1 (6) 0</td>
<td>3 (18) 5 (26)</td>
<td>0 2 (11)</td>
</tr>
<tr>
<td>No personalised resources provided to women</td>
<td>8 (44) 8 (40)</td>
<td>4 (25) 5 (26)</td>
<td>9 (56) 8 (42)</td>
</tr>
<tr>
<td>Not my role to provide personalised information to women</td>
<td>4 (22) 2 (13) 1 (6) 0</td>
<td>5 (31) 6 (32)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>18 (100) 17 (100) 16 (100)</td>
<td>19 (100) 16 (100) 19 (100)</td>
<td></td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.11 Impressions of respondents regarding whether or not personalised forms of information are actually provided to women by other local health professionals

<table>
<thead>
<tr>
<th>Impression</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>All/most local health professionals provide personalised information</td>
<td>0</td>
<td>3 (18)</td>
<td>5 (24)</td>
</tr>
<tr>
<td>Some local health professionals provide personalised information</td>
<td>4 (19)</td>
<td>2 (12)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Very few local health professionals provide personalised information</td>
<td>12 (57)</td>
<td>7 (41)</td>
<td>10 (48)</td>
</tr>
<tr>
<td>Don't Know</td>
<td>5 (24)</td>
<td>5 (29)</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>17 (100)</td>
<td>21 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.12  Awareness of protocols developed within a local area to facilitate communication between health professionals about the supportive care of individual women with breast cancer*

<table>
<thead>
<tr>
<th>Protocol</th>
<th>Breast care nurses</th>
<th></th>
<th>Specialists</th>
<th></th>
<th>Supportive care workers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Multidisciplinary team meetings</td>
<td>5 (24)</td>
<td>7 (39)</td>
<td>8 (31)</td>
<td>14 (48)</td>
<td>4 (18)</td>
<td>13 (54)</td>
</tr>
<tr>
<td>Communication protocol between cancer contact person and local health professionals</td>
<td>0</td>
<td>1 (6)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Communication protocol between GPs and local health professionals</td>
<td>0</td>
<td>1 (6)</td>
<td>3 (12)</td>
<td>1 (3)</td>
<td>1 (5)</td>
<td>0</td>
</tr>
<tr>
<td>Another type of communication protocol is in place</td>
<td>5 (24)</td>
<td>3 (17)</td>
<td>2 (8)</td>
<td>10 (34)</td>
<td>3 (14)</td>
<td>8 (33)</td>
</tr>
<tr>
<td>Communication protocols are currently being developed</td>
<td>1 (5)</td>
<td>0</td>
<td>1 (4)</td>
<td>0</td>
<td>2 (9)</td>
<td>0</td>
</tr>
<tr>
<td>No protocols currently in place</td>
<td>12 (57)</td>
<td>10 (56)</td>
<td>12 (46)</td>
<td>3 (10)</td>
<td>13 (59)</td>
<td>7 (29)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (5)</td>
<td>0</td>
<td>0</td>
<td>1 (3)</td>
<td>3 (14)</td>
<td>1 (4)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
Table 5.13  Assessment of the level of communication in the local area by health professionals*

<table>
<thead>
<tr>
<th>Level of communication</th>
<th>Breast care nurses</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Very Good</td>
<td>2 (11)</td>
<td>5 (28)</td>
<td>4 (19)</td>
<td>6 (33)</td>
<td>3 (14)</td>
<td>3 (13)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fairly Good</td>
<td>12 (63)</td>
<td>11 (61)</td>
<td>14 (67)</td>
<td>8 (44)</td>
<td>11 (50)</td>
<td>18 (75)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fairly Poor</td>
<td>5 (26)</td>
<td>2 (11)</td>
<td>3 (14)</td>
<td>3 (17)</td>
<td>6 (27)</td>
<td>2 (8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Poor</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (5)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (6%)</td>
<td>1 (5)</td>
<td>1 (4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>19 (100)</td>
<td>18 (100)</td>
<td>21 (100)</td>
<td>18 (100)</td>
<td>22 (100)</td>
<td>24 (100)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.

Table 5.14  Responses by breast care nurses about responsibility for provision of information and education to local health professionals about supportive care issues for women with breast cancer*

<table>
<thead>
<tr>
<th>Response</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, significant component</td>
<td>3 (14)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Yes, small component</td>
<td>13 (62)</td>
<td>12 (67)</td>
</tr>
<tr>
<td>Not currently</td>
<td>0</td>
<td>1 (6)</td>
</tr>
<tr>
<td>No</td>
<td>5 (24)</td>
<td>2 (11)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>18 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.15  Responses by breast care nurses concerning their confidence in providing quality information to local health professionals about supportive care issues for women with breast cancer*

<table>
<thead>
<tr>
<th>Response</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very confident</td>
<td>7 (41)</td>
<td>9 (60)</td>
</tr>
<tr>
<td>Somewhat confident</td>
<td>9 (53)</td>
<td>6 (40)</td>
</tr>
<tr>
<td>Not very confident</td>
<td>1 (6)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>17 (100)</td>
<td>15 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding.

Table 5.16  Responses by specialists and supportive care workers about awareness of breast care nurses or cancer contact workers providing information about supportive care issues for women with breast cancer*

<table>
<thead>
<tr>
<th>Response</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Yes</td>
<td>10 (45)</td>
<td>13 (72)</td>
</tr>
<tr>
<td>No</td>
<td>10 (45)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>9 (9)</td>
<td>9 (11)</td>
</tr>
<tr>
<td>Total</td>
<td>22 (100)</td>
<td>18 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.17  Satisfaction of specialists and supportive care workers with the quality of supportive care information provided by local breast care nurses or cancer contact workers*

<table>
<thead>
<tr>
<th>Response</th>
<th>Specialists</th>
<th></th>
<th>Supportive care workers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>5 (56)</td>
<td>11 (85)</td>
<td>6 (46)</td>
<td>9 (60)</td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td>3 (33)</td>
<td>2 (15)</td>
<td>5 (38)</td>
<td>5 (27)</td>
</tr>
<tr>
<td>Not very satisfied</td>
<td>0</td>
<td>0</td>
<td>1 (8)</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Not at all satisfied</td>
<td>0</td>
<td>0</td>
<td>1 (8)</td>
<td>0</td>
</tr>
<tr>
<td>Don't know</td>
<td>1 (11)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>9 (100)</td>
<td>13 (100)</td>
<td>13 (100)</td>
<td>16 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.18  Distribution of responses from health professionals regarding the establishment of supportive care planning as part of MDC meetings*

<table>
<thead>
<tr>
<th>Supportive care planning as part of MDC meetings</th>
<th>Breast care nurses</th>
<th></th>
<th>Specialists</th>
<th></th>
<th>Supportive care workers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Yes, supportive care planning is considered for all women</td>
<td>0</td>
<td>3 (30)</td>
<td>4 (33)</td>
<td>6 (38)</td>
<td>3 (25)</td>
<td>4 (29)</td>
</tr>
<tr>
<td>Yes, supportive care planning is considered during case conferencing about some women</td>
<td>3 (38)</td>
<td>4 (40)</td>
<td>2 (17)</td>
<td>7 (44)</td>
<td>5 (42)</td>
<td>3 (31)</td>
</tr>
<tr>
<td>No, but in the process of being established</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No, not established</td>
<td>3 (38)</td>
<td>2 (20)</td>
<td>5 (42)</td>
<td>3 (19)</td>
<td>1 (8)</td>
<td>2 (14)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (25)</td>
<td>1 (10)</td>
<td>1 (8)</td>
<td>0</td>
<td>0</td>
<td>2 (14)</td>
</tr>
<tr>
<td>Don't Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3 (25)</td>
<td>3 (21)</td>
</tr>
<tr>
<td>Total</td>
<td>8 (100)</td>
<td>10 (100)</td>
<td>12 (100)</td>
<td>16 (100)</td>
<td>12 (100)</td>
<td>14 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.19  Responses outlining the stages of care in which supportive care planning is used*

<table>
<thead>
<tr>
<th>Stage of care</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>All stages of care</td>
<td>2 (25)</td>
<td>2 (18)</td>
<td>3 (25)</td>
</tr>
<tr>
<td>Some stages only</td>
<td>1 (13)</td>
<td>2 (18)</td>
<td>3 (25)</td>
</tr>
<tr>
<td>At one stage only</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not consistently used</td>
<td>2 (25)</td>
<td>4 (36)</td>
<td>3 (25)</td>
</tr>
<tr>
<td>throughout all stages of care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At no stage at all</td>
<td>0</td>
<td>0</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Is done informally</td>
<td>3 (38)</td>
<td>3 (27)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Don't Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>8 (100)</td>
<td>11 (100)</td>
<td>12 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding.
### Table 5.20 Stages in a patient's management in which breast care nurses or cancer contact workers establish routine consultations*

<table>
<thead>
<tr>
<th>Time of consultation</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>12 (57)</td>
<td>16 (89)</td>
<td>11 (55)</td>
</tr>
<tr>
<td>Pre-operatively</td>
<td>14 (67)</td>
<td>17 (94)</td>
<td>17 (85)</td>
</tr>
<tr>
<td>Post-operatively</td>
<td>17 (81)</td>
<td>18 (100)</td>
<td>17 (85)</td>
</tr>
<tr>
<td>At the time of chemotherapy or hormone therapy</td>
<td>17 (81)</td>
<td>16 (89)</td>
<td>13 (65)</td>
</tr>
<tr>
<td>At the time of radiation therapy</td>
<td>10 (48)</td>
<td>13 (72)</td>
<td>5 (25)</td>
</tr>
<tr>
<td>After treatments have been completed</td>
<td>13 (62)</td>
<td>16 (89)</td>
<td>9 (45)</td>
</tr>
<tr>
<td>Other times</td>
<td>2 (10)</td>
<td>3 (17)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Don't Know</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*Results are given as frequency (%) and are not to be summed as multiple responses were allowed.*
### Table 5.21  Referral source to breast care nurses or cancer contact workers*

<table>
<thead>
<tr>
<th>Source of referral</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>All local surgeons and oncologists refer all or most women</td>
<td>7 (35)</td>
<td>9 (50)</td>
<td>12 (67)</td>
</tr>
<tr>
<td>All local surgeons and oncologists refer some women</td>
<td>1 (5)</td>
<td>2 (11)</td>
<td>0</td>
</tr>
<tr>
<td>Some surgeons and oncologists refer all or most women</td>
<td>9 (45)</td>
<td>6 (33)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Only some surgeons and oncologists refer some women</td>
<td>1 (5)</td>
<td>0</td>
<td>2 (11)</td>
</tr>
<tr>
<td>Non of the local surgeons or oncologists refer women</td>
<td>2 (10)</td>
<td>0</td>
<td>1 (6)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>0</td>
<td>1 (6)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>20 (100)</td>
<td>18 (100)</td>
<td>18 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.22  Coordination activities by breast care nurses and cancer contact workers of supportive care for women who are travelling between rural areas and urban centres for treatment*

<table>
<thead>
<tr>
<th>Supportive care coordinated?</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes</td>
<td>10 (50)</td>
<td>16 (89)</td>
<td>9 (50)</td>
</tr>
<tr>
<td>No</td>
<td>6 (30)</td>
<td>1 (6)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (15)</td>
<td>1 (6)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (5)</td>
<td>0</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100)</td>
<td>18 (100)</td>
<td>18 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.

Table 5.23  Coordination activities by breast care nurses and cancer contact workers of supportive care for women in rural areas to access support in their rural settings*

<table>
<thead>
<tr>
<th>Local supportive care coordinated?</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes</td>
<td>8 (40)</td>
<td>16 (94)</td>
<td>8 (42)</td>
</tr>
<tr>
<td>No</td>
<td>4 (20)</td>
<td>1 (6)</td>
<td>3 (16)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (35)</td>
<td>0</td>
<td>4 (21)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (5)</td>
<td>0</td>
<td>4 (21)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100)</td>
<td>17 (100)</td>
<td>19 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.24  Methods to inform and involve GPs in the supportive care of women with breast cancer*

<table>
<thead>
<tr>
<th>Method of Involvement</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Referral letters or faxes</td>
<td>11 (52)</td>
<td>10 (56)</td>
<td>13 (59)</td>
</tr>
<tr>
<td>Telephone calls</td>
<td>7 (33)</td>
<td>7 (39)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Involvement in MDC meetings</td>
<td>4 (19)</td>
<td>4 (22)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Other systems or strategies</td>
<td>3 (14)</td>
<td>1 (6)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Other strategies currently being</td>
<td>1 (5)</td>
<td>0</td>
<td>1 (5)</td>
</tr>
<tr>
<td>No planned strategies</td>
<td>3 (14)</td>
<td>2 (11)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Not sure if any strategies are in place</td>
<td>3 (14)</td>
<td>1 (6)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Don't know</td>
<td>1 (5)</td>
<td>2 (11)</td>
<td>1 (5)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
<table>
<thead>
<tr>
<th>Mode of training/education</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education or training workshop/programs/seminars about breast cancer (except communication skills)</td>
<td>13 (65)</td>
<td>14 (78)</td>
</tr>
<tr>
<td>A specific university based educational course about breast cancer nursing</td>
<td>5 (25)</td>
<td>4 (22)</td>
</tr>
<tr>
<td>Another activity held specifically for breast care nurses (e.g. breast care nurse conference)</td>
<td>6 (30)</td>
<td>6 (33)</td>
</tr>
<tr>
<td>A clinical placement or mentorship program, visiting another breast care nurse</td>
<td>1 (5)</td>
<td>0</td>
</tr>
<tr>
<td>e-health training about video-conferencing facilities</td>
<td>5 (25)</td>
<td>3 (17)</td>
</tr>
<tr>
<td>e-health workshops held via video-link</td>
<td>2 (10)</td>
<td>4 (22)</td>
</tr>
<tr>
<td>Public forums or meetings held via satellite</td>
<td>5 (25)</td>
<td>4 (22)</td>
</tr>
<tr>
<td>Training in e-health technologies</td>
<td>2 (10)</td>
<td>0</td>
</tr>
<tr>
<td>Training has not yet taken place, but is planned for during the next six months</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Another type of activity</td>
<td>3 (15)</td>
<td>0</td>
</tr>
<tr>
<td>No opportunities have been available in the past 12 months</td>
<td>2 (10)</td>
<td>0</td>
</tr>
<tr>
<td>Have not participated in any programs or initiatives in the past 12 months</td>
<td>1 (5)</td>
<td>1 (6)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
Table 5.26  Availability of local training and education programs or initiatives for specialists and supportive care workers during previous 12 months*

<table>
<thead>
<tr>
<th>Mode of training/education</th>
<th>Specialists Baseline</th>
<th>Specialists Follow-up</th>
<th>Supportive care workers Baseline</th>
<th>Supportive care workers Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education or training workshop/programs/seminars about breast cancer (except communication skills)</td>
<td>14 (64)</td>
<td>13 (68)</td>
<td>14 (64)</td>
<td>14 (58)</td>
</tr>
<tr>
<td>Workshops/programs/seminars specifically about supportive care issues</td>
<td>5 (23)</td>
<td>3 (16)</td>
<td>4 (18)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>e-health training about video-conferencing facilities</td>
<td>2 (9)</td>
<td>2 (11)</td>
<td>0</td>
<td>2 (8)</td>
</tr>
<tr>
<td>e-health workshops held via video-link</td>
<td>4 (18)</td>
<td>3 (16)</td>
<td>1 (5)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Public forums or meetings held via satellite</td>
<td>6 (27)</td>
<td>4 (21)</td>
<td>2 (9)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Another type of activity</td>
<td>0</td>
<td>3 (16)</td>
<td>2 (9)</td>
<td>0</td>
</tr>
<tr>
<td>No opportunities have been available in the past 12 months</td>
<td>5 (23)</td>
<td>4 (21)</td>
<td>4 (18)</td>
<td>7 (29)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1 (5)</td>
<td>0</td>
<td>3 (14)</td>
<td>4 (17)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
Table 5.27  Distribution of overall participation in local training and education programs or initiatives by specialists and supportive care workers*

<table>
<thead>
<tr>
<th>Participation in local training program</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Yes</td>
<td>14 (70)</td>
<td>13 (76)</td>
</tr>
<tr>
<td></td>
<td>12 (52)</td>
<td>14 (61)</td>
</tr>
<tr>
<td>No</td>
<td>6 (30)</td>
<td>2 (24)</td>
</tr>
<tr>
<td></td>
<td>11 (48)</td>
<td>9 (39)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100)</td>
<td>15 (100)</td>
</tr>
<tr>
<td></td>
<td>23 (100)</td>
<td>23 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%).

Table 5.28  Types and regularity of opportunities to network with other breast care nurses*

<table>
<thead>
<tr>
<th>Type of opportunity and regularity of participation</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face meetings with other breast care nurses held weekly/fortnightly/monthly/every 2-3 months</td>
<td>9 (45)</td>
<td>7 (41)</td>
</tr>
<tr>
<td>Face-to-face meetings with other breast care nurses held opportunistically</td>
<td>4 (20)</td>
<td>3 (18%)</td>
</tr>
<tr>
<td>Teleconferences or videoconferences held weekly/fortnightly/monthly/every 2-3 months</td>
<td>1 (5)</td>
<td>6 (35)</td>
</tr>
<tr>
<td>Teleconferences or videoconferences held opportunistically</td>
<td>3 (15)</td>
<td>2 (12)</td>
</tr>
<tr>
<td>On-line support groups or breast care nurse chat rooms</td>
<td>1 (5)</td>
<td>3 (18)</td>
</tr>
<tr>
<td>Other networking opportunities that include a range of health professionals, not only breast care nurses</td>
<td>6 (30)</td>
<td>4 (24)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (35)</td>
<td>5 (29)</td>
</tr>
<tr>
<td>None available</td>
<td>1 (5)</td>
<td>0</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and are not to be summed as multiple responses were allowed.
Table 5.29  Usefulness of local training and education programs in improving the skills and knowledge of health professionals*

<table>
<thead>
<tr>
<th>Usefulness of program in improving skills and knowledge</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Very</td>
<td>15 (88)</td>
<td>15 (88)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Somewhat useful</td>
<td>2 (12)</td>
<td>2 (12)</td>
<td>5 (50)</td>
</tr>
<tr>
<td>Not very useful</td>
<td>0</td>
<td>0</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Not at all useful</td>
<td>0</td>
<td>0</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Total</td>
<td>17 (100)</td>
<td>17 (100)</td>
<td>10 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.30  Changes in confidence in health professionals in the supportive care of women with breast cancer as a result of participation in local training and education programs*

<table>
<thead>
<tr>
<th>Confidence increased</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes</td>
<td>15 (88)</td>
<td>15 (94)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>No</td>
<td>2 (12)</td>
<td>1 (6)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Total</td>
<td>17 (100)</td>
<td>16 (100)</td>
<td>10 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.

Table 5.31  Degree of confidence in skills and knowledge associated with supportive care gained as a result of education programs reported by health professionals*

<table>
<thead>
<tr>
<th>Confidence level</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Very confident</td>
<td>6 (35)</td>
<td>4 (24)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Confident</td>
<td>10 (59)</td>
<td>13 (76)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Somewhat confident</td>
<td>1 (6)</td>
<td>0</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Total</td>
<td>17 (100)</td>
<td>17 (100)</td>
<td>10 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.32  **Awareness of opportunities during the previous 12 months for local or visiting clinicians to find out about new technologies available in the local area**

<table>
<thead>
<tr>
<th>Opportunities available</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Yes</td>
<td>5 (26)</td>
<td>3 (18)</td>
<td>6 (27)</td>
</tr>
<tr>
<td>No</td>
<td>12 (63)</td>
<td>14 (82)</td>
<td>14 (64)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2 (11)</td>
<td>0</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Total</td>
<td>19 (100)</td>
<td>17 (100)</td>
<td>22 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding.

Table 5.33  **Rating of personal knowledge by health care professionals of locally available supportive care services and resources for women with breast cancer***

<table>
<thead>
<tr>
<th>Level of knowledge</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Very high</td>
<td>7 (33)</td>
<td>6 (33)</td>
<td>9 (41)</td>
</tr>
<tr>
<td>High</td>
<td>12 (57)</td>
<td>12 (67)</td>
<td>11 (50)</td>
</tr>
<tr>
<td>Not very high</td>
<td>2 (10)</td>
<td>0</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>18 (100)</td>
<td>22 (100)</td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.34  Rating of personal knowledge of locally available resources for health professionals about supportive care for women with breast cancer*

<table>
<thead>
<tr>
<th>Level of knowledge</th>
<th>Breast care nurses</th>
<th>Specialists</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
</tr>
<tr>
<td>Very high</td>
<td>6 (29)</td>
<td>4 (22)</td>
<td>8 (38)</td>
</tr>
<tr>
<td>High</td>
<td>12 (57)</td>
<td>8 (44)</td>
<td>9 (43)</td>
</tr>
<tr>
<td>Not very high</td>
<td>3 (14)</td>
<td>6 (33)</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Not at all high</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>21 (100)</td>
<td>18 (100)</td>
<td>21 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.

Table 5.35  Responses by breast care nurses and supportive care workers regarding whether or not opportunities exist for leaders of breast cancer groups to network*

<table>
<thead>
<tr>
<th>Do opportunities exist?</th>
<th>Breast care nurses</th>
<th>Supportive care workers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
</tr>
<tr>
<td>Yes</td>
<td>8 (40)</td>
<td>7 (47)</td>
</tr>
<tr>
<td>No</td>
<td>5 (25)</td>
<td>4 (27)</td>
</tr>
<tr>
<td>Don't know</td>
<td>7 (35)</td>
<td>4 (27)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100)</td>
<td>15 (100)</td>
</tr>
</tbody>
</table>

* Results are given as frequency (%) and may not sum to 100% due to rounding.
Table 5.36  Awareness of health professionals about the SSWBC program*

<table>
<thead>
<tr>
<th>Level of awareness</th>
<th>Breast care nurses</th>
<th></th>
<th></th>
<th></th>
<th>Supportive care workers</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td>Baseline</td>
<td>Follow-up</td>
<td></td>
</tr>
<tr>
<td>Very aware</td>
<td>10 (50)</td>
<td>13 (72)</td>
<td>13 (59)</td>
<td>14 (74)</td>
<td>10 (43)</td>
<td>13 (54)</td>
<td></td>
</tr>
<tr>
<td>Somewhat aware</td>
<td>7 (35)</td>
<td>3 (17)</td>
<td>5 (23)</td>
<td>4 (21)</td>
<td>8 (35)</td>
<td>9 (38)</td>
<td></td>
</tr>
<tr>
<td>Not very aware</td>
<td>3 (15)</td>
<td>2 (11)</td>
<td>4 (18)</td>
<td>0</td>
<td>5 (22)</td>
<td>2 (8)</td>
<td></td>
</tr>
<tr>
<td>Not at all aware</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (5)</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>20 (100)</td>
<td>18 (100)</td>
<td>22 (100)</td>
<td>19 (100)</td>
<td>23 (100)</td>
<td>24 (100)</td>
<td></td>
</tr>
</tbody>
</table>

Results are given as frequency (%) and may not sum to 100% due to rounding
Figure 5.1 Health professionals providing various written information resources to women with breast cancer and their families at baseline (left) and follow-up (right)
Figure 5.2  Types of electronic resources provided to women and their families at baseline (left) and follow-up (right)
Figure 5.3  Perception of whether health professionals in the local area can access as much information as they need to provide to women and their families about breast cancer about supportive care issues at baseline (left) and follow-up (right)
Figure 5.4 Health professionals reporting provision of supportive care resources to assist women of non-English speaking or Indigenous backgrounds

The chart shows the percentage of health professionals reporting the provision of various resources for women of Indigenous or non-English speaking backgrounds. The resources include:

- Community Languages
- Information for Indigenous Women
- Interpreter Services
- Liaison with Indigenous Health Services
- Other Information
- No Contact
- Don’t Know How
- Don’t Know

The chart compares baseline and follow-up data, with follow-up data generally showing a higher percentage of reported resources.
Figure 5.5 Availability of generic resources (left) and those focusing on local supportive care services (right) accessible to local health professionals.
Figure 5.6  Availability of educational resources accessible to local health professionals

[Bar chart showing the availability of educational resources over baseline and follow-up, with categories including None, E-Newsletter, E-Health, Online Discussion, Seminar, and Face-to-face Seminar.]

Educational Resources Available to Local Health Professionals

Type of Resource

- None
- E-Newsletter
- E-Health Seminar
- Face-to-face Seminar
- Online Discussion
- Don't Know

Percentage

Baseline
Follow-up

0 20 40 60 80 100

0 2 0 4 0 8 1 0 0

Face-to-face Seminar

0 20 40 60 80 100

0 2 0 4 0 8 1 0 0

Educational Resources Available to Local Health Professionals
Figure 5.7  Frequency of professional supervision sessions for the discussion of clinical and supportive care aspects of the breast nurse role

Strengthening support for women with breast cancer: national process evaluation report
Figure 5.8  Responses from breast care nurses concerning the availability of opportunities over the previous 12 months to support improvements in knowledge and skills in the area of supportive care for women with breast cancer.
6. Acceptability of the Strengthening Support for Women with Breast Cancer program

Aim

As part of the national evaluation of the SSWBC program, interviews were conducted with people who were involved in the development and implementation of strategies in each State and Territory. The purpose of the interviews was to examine perceptions of programs implemented as part of the SSWBC program in individual regions.

Methods

Surveys were administered by semi-structured interviews at the time of the follow-up theme-based surveys described in the previous section. Separate consent procedures were instituted and, following the procedures outlined in the theme-based surveys, consisted of preliminary telephone contact with final written confirmation of consent received after supporting documentation was forwarded by potential participants. Interviews took approximately 30 minutes to complete and all responses were de-identified prior to entry into databases and subsequent analyses.

Instrument and Sample

Participants were asked about a range of issues related to the strategies implemented, including the planning stages, successes and barriers encountered during implementation, unanticipated benefits and sustainability. A sample of the survey instrument is included in Appendix VI.

Survey participants were required to have been involved in the development and implementation of State and Territory initiatives under the SSWBC program. Of particular interest were the insights and comments provided by members of Steering
and Advisory Committees including consumer representatives. A target of seven stakeholders per State and Territory was chosen. In total, 49 respondents were interviewed.

Analysis

Responses to closed, multiple-choice questions were recoded in the form of categorical variables. Depending on the question, these variables were either dichotomously or multichotomously coded. Coding was performed by constructing variable maps that provided a broad-based overview of inter-relationships between and among questions and their variables.

Once recoded, conventional descriptive statistical summaries were prepared. These consisted of absolute and relative frequency distributions using single variable tabulations or contingency tables consisting of two or more variables.

All analyses were conducted using SPSS version 11 (SPSS Inc, Chicago, IL USA) and Stata SE version 8.2 (StataCorp Inc, College Station, TX, USA). Graphs were prepared using SigmaPlot 2003 (SPSS Inc, Chicago, IL, USA), Excel XP (Microsoft Inc, Redmond, WA, USA) and Kaleidagraph 3.2.4 (Synergy Software, Reading, PA, USA).

Results

Participation in the SSWBC program

The various roles of the respondents to the acceptability survey in relation to the SSWBC program are shown in Table 6.1. Thirty five percent of respondents were directly associated with the program as members of a State or Territory Committee, Program Team, or Advisory or Reference Group.

The capacity in which respondents were involved in the program and the extent of their participation is shown in Figure 6.1. Over half of the respondents (51%) provided advice, feedback and expertise in relation to proposed strategies, 45% participated in
strategies implemented as part of the program, 41% were actively involved in the implementation of strategies and 39% were involved in the design and development of these strategies. Overall, 8% of respondents stated that they were involved in an audit of supportive care services in their local area, zone, State or Territory, and 10% were involved in other capacities.

Overall, a high proportion of respondents were ‘very aware’ (55%) or ‘somewhat aware’ of the strategies implemented across the relevant State or Territory. Another 11% reported they were somewhat unaware and 2% not at all aware of the strategies implemented at state or territory level (Figure 6.2). Strategies that respondents were predominantly aware of were the appointment of breast care nurses to provide counselling and information to women with breast cancer and e-health strategies to facilitate MDC. However, some respondents highlighted confusion about where the funding for the program was coming from and whether or not strategies implemented at State/national level were part of the SSWBC program.

Awareness of local strategies was higher than for State/Territory level strategies, with 82% of respondents very aware of strategies implemented. Appointment of a breast care nurse and use of information technology were the most common strategies referred to. Other strategies mentioned by respondents included developing a document for health professionals to help the management of breast cancer in women, the establishment of MDC meetings and the development of multicultural booklets.

**Planning phase of strategies**

A range of activities were undertaken during the planning and development stage of the SSWBC program (Table 6.2). The two most frequently employed strategies were consultation with consumer groups and individuals (67%), consultation with existing organisations (60%) and the creation of an advisory group such as a Steering Committee (48%). Another 19% of respondents highlighted other activities undertaken in the planning and development stages such as consultation with the indigenous community, the use of electronic discussions of local research programs, using already established steering committees to help in the planning stages, an audit of information needs for health professionals and consumers and an audit of information technology needs for health professionals.
The needs and views of breast cancer consumers were considered and incorporated into planning and development through active collaboration and representation of consumers on a Steering Committee, Program Team, Advisory or Reference Group according to 72% of respondents. Active consultation with consumers through focus groups, interviews, consumer surveys or audit of supportive care services was employed in 49% of cases. Another 28% of respondents involved consumers through other methods such as holding ongoing meetings with consumer representatives and ensuring input into any consumer information that was produced as a result of the SSWBC program. However, 17% didn’t know whether consumer needs had been addressed during planning and development stages.

Similarly, 67% of respondents highlighted that the needs and views of health professionals were sought through membership on Steering Committee, Program Team, Advisory or Reference Group and 48% of respondents incorporated the needs and views of health professionals through consultation such as focus groups, interviews, surveys or audits of supportive care services. Another 19% of respondents stated that they involved health professionals through other means such as discussions with health professionals directly and involving health professionals in workshops in using information technology and 23% of respondents did not know.

Overall themes

Respondents were asked to rate whether they agreed that the strategies used in the SSWBC program impacted on the way supportive care was organised and provided in their respective State or Territory (Table 6.3). There was a high level of general agreement (‘strongly agree’ or ‘somewhat agree’) that the SSWBC program had impacted on a range of issues. The respondents reported that the areas in which the SSWBC strategies had the greatest impact were in providing opportunities for health professionals to enhance their knowledge and awareness of supportive care issues for women with breast cancer (90%), enhancing the availability of quality information for women with breast cancer (76%) and encouraging a consistent approach to information provision (75%). Improvements in MDC and continuity of care for women living in rural areas were also highlighted (70%). The lowest level of agreement was
around the establishment of cancer contact workers – however this is not necessarily surprising as these positions were only established in one State.

**Successes, enablers, barriers and unanticipated benefits**

Overall, respondents felt that the SSWBC program was successful with 71% indicating that the program had been ‘very successful’ and 21% ‘moderately successful’. Key to the success of the program was the appointment of a breast care nurse and the importance of this within the multidisciplinary team. Respondents highlighted that the breast care nurse improved liaison and ensured continuity of care, reduced the likelihood of duplication between health professionals through clearer role definition and enhanced communication between health professionals. Breast care nurses also distributed current, high-quality information to women, provided essential support in the initial stages of care, reduced stress due to early detection and referral of psychological issues, facilitated greater access to expertise and provided supportive care for rural women with breast cancer.

Other successful aspects of the program included the implementation of MDC and increased access to information technology. Respondents stated that MDC in some cases resulted in changes in management of breast cancer, improved teamwork and created a less competitive environment which resulted in a more holistic approach to care. Technology provided opportunities for training that otherwise would not have been available and, through the use of teleconference and videoconference facilities, enabled efficient functioning of MDC meetings.

Respondents nominated a variety of factors that facilitated the successful implementation of SSWBC strategies (Figure 6.3). Factors rated most highly were the skills and abilities of the people employed for and directly involved in implementing the program (89%), support from health professionals (79%), collaboration and/or commitment from other organisations (74%), support from consumers (74%), existing infrastructure (66%) and established communication networks between health professionals (66%). An example of existing infrastructure highlighted by respondents was the Breast Services Enhancement Program (BSEP) in Victoria. Through the BSEP program, key stakeholders had already been identified and the key structure to support the SSWBC program was already in place.
Twenty one percent of respondents mentioned that stakeholder, executive and also information technology support were also factors that facilitated the success of the program. Twenty six percent considered that collaboration with other States/Territories facilitated successful implementation of the strategies used in the SSWBC program.

The majority of respondents experienced at least some difficulties implementing strategies (72%) with only 21% stating they experienced no difficulties at all. Difficulties highlighted by respondents included initial resistance to the breast care nurse by the multidisciplinary team especially in consultations due to unclear role definition, increased workload of the breast care nurse and issues of communication between team members. Resistance to new technology and lack of time for training was also highlighted as a reason for difficulties implementing the strategies.

Respondents suggested that educating members of the multidisciplinary team in the early stages of implementation about the role of the breast care nurse could improve role definition and help to minimise resistance to the role by other members of the multidisciplinary team.

The particular barriers encountered during the implementation of SSWBC strategies are described in Figure 6.4. Time constraints (60%) and limited funds (35%) were cited as the main barriers to implementation. Comments from respondents highlighted that these two barriers were related because limited funding was available for the extra hours needed to fulfil the role of breast care nurse. Extra hours were needed to travel to and take part in consultations especially by nurses responsible for providing supportive care over large geographical regions. In one case ongoing funding for a breast care nurse was an issue.

Technological constraints were also mentioned as a barrier, eg scanning mammograms for use in videoconferencing, difficulties keeping website information updated, resistance to new technologies due to a lack of time for training and a lack of technological support and expertise.

Thirty seven per cent of respondents believed that their programs and strategies had yielded unanticipated benefits. Such changes included raised awareness of the services available to members of the multidisciplinary team, gaps identified in support services, improved communication and networking skills and broadened skill base of
team members. This maximised resources available to team members and in some cases provided additional resources or services such as provision of supportive care for women with advanced breast cancer and services for Aboriginal and Torres Strait Islander women and women from non-English speaking backgrounds.

One respondent highlighted gaining further funds and setting up a lymphoedema clinic as a result of participation in the SSWBC program.

Some of the respondents (22%) believed that the program and/or implementation strategies had flow-on effects to other programs for patients with other cancers or diseases. In many cases, the model provided by the SSWBC program raised awareness about similar needs in other cancers. For example, a service directory used in one region was adopted as the basis of a model in other States and Regions.

**Sustainability of SSWBC Strategies**

The importance of sustainable strategies was highlighted from the outset of the SSWBC program. When asked about methods to ensure the sustainability of strategies developed as part of the SSWBC program, 44% of respondents indicated that an agreement had been secured from a health organisation, service or government body for on-going maintenance of strategies, while a further 53% indicated that such an agreement was currently being sought (Table 6.4).

Although efforts were made to ensure sustainability, there were some barriers experienced by respondents. The major perceived barrier to sustainability was lack of funding or unwillingness to continue the strategies (83%). Other issues included an inability to incorporate strategies into local health policy and planning (21%) and a lack of leaders (12%) or infrastructure (10%) to support implemented strategies (Table 6.5).

However, one respondent pointed out that while there were barriers to sustaining the program, the benefits were recognised by all team members, which would make it difficult to discontinue the program.
Summary of findings

Eighty one per cent of respondents indicated that their involvement in the SSWBC program was ‘very acceptable’, while 18% indicated their involvement was ‘moderately’ or ‘somewhat’ acceptable. Only 2% said their involvement was ‘a little’ acceptable.

The appointment of breast care nurses, provision of information and the multidisciplinary meetings were perceived as the most useful strategies in providing supportive care for women with breast cancer in a rural setting.

According to respondents, breast care nurses improved supportive care for women by providing support early in the diagnosis, acted as a single access point to answer all queries and also providing greater access to local expertise, improved communication between all multidisciplinary team members which resulted in better care for women with breast cancer. Also, the appointment of a breast care nurse raised awareness about gaps in supportive care to rural women with breast cancer.

Improved access and better provision of information for women with breast cancer was also seen as a useful strategy in improving supportive care by respondents. Information deemed as useful included a directory of local resources and information kits for women and health professionals.

Multidisciplinary team meetings were also highlighted by respondents as a strategy useful in improving supportive care for women. It was felt that each team member benefited from the meetings and that the breast care nurse were a key player in facilitating the process.

In terms of giving advice to others wanting to implement similar strategies, respondents highlighted the need for thorough planning in the first instance. In the initial stages, mapping the needs, understanding what resources are available and identifying the major stakeholders were perceived as crucial to the success of the SSWBC program.
The breast care nurse was seen by respondents as integral to the success of the program. However, respondents suggested there was a need to ensure that roles and responsibilities were clearly defined between the breast care nurse and members of the multidisciplinary team early in the implementation of the program. The importance of support and training for the role was highlighted to ensure continuity and stability.

While technology played an important role in the success of the SSWBC program, respondents highlighted that careful consideration needs to be given to the types of technology that are available and that sufficient on-going support is available once technology has been implemented. The importance of training for members of the multidisciplinary team in new technologies was emphasised. Frustrations that were apparent in the program came from lack of support when technology failed or when insufficient training was given to members of the program.

Finally, the need for senior level executive support to ensure sustainability was highlighted.

Overall, comments from respondents about the SSWBC program were very positive. The program was perceived to have filled gaps in the support services available for women with breast cancer and ensured a smoother transition for women from the community to the hospital and back into the community. This was in sharp contrast to the services experienced by women before the program was implemented. Respondents proposed that the model used in the SSWBC program be broadened to other clinical areas.
Table 6.1  Roles of respondents to the acceptability survey

<table>
<thead>
<tr>
<th>Role</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member of a State or Territory Committee, Program Team, Advisory or Reference Group</td>
<td>17</td>
<td>35</td>
</tr>
<tr>
<td>Member of a regional or local Steering Committee, Program Team, Advisory of Reference Group</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Program Manager</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Program Coordinator</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Program Officer</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Breast care nurse</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Breast Cancer Contact Person</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 6.2  Activities undertaken during the planning and development stage of the SSWBC program

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The creation of a State/Territory Steering Committee, Program Team, Advisory/Reference Group</td>
<td>23 (48)</td>
</tr>
<tr>
<td>The creation of zonal/regional/local Steering Committees, Program Teams, Advisory/Reference Groups</td>
<td>14 (29)</td>
</tr>
<tr>
<td>The conduct of an audit of supportive care services or supportive care services mapping exercise</td>
<td>16 (33)</td>
</tr>
<tr>
<td>Consultation with existing organisations that could assist with the planning of strategies including:</td>
<td></td>
</tr>
<tr>
<td>Local area or zone health services</td>
<td>21 (44)</td>
</tr>
<tr>
<td>Existing breast cancer organisation</td>
<td>14 (29)</td>
</tr>
<tr>
<td>State or Territory Cancer Councils</td>
<td>18 (38)</td>
</tr>
<tr>
<td>State or Territory health departments</td>
<td>11 (30)</td>
</tr>
<tr>
<td>Consultation with representatives of local services including:</td>
<td></td>
</tr>
<tr>
<td>Clinicians and other health professionals based at local hospitals</td>
<td>25 (52)</td>
</tr>
<tr>
<td>Community health services</td>
<td>20 (42)</td>
</tr>
<tr>
<td>Other organisations directly linked to services</td>
<td>16 (34)</td>
</tr>
<tr>
<td>Consultation with consumer groups or individuals</td>
<td>32 (67)</td>
</tr>
<tr>
<td>Lobbying of clinical leaders to encourage participation and interest from health professionals</td>
<td>9 (19)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (19)</td>
</tr>
<tr>
<td>Don’t know/not involved in planning</td>
<td>9 (19)</td>
</tr>
</tbody>
</table>

* Multiple responses were allowed.
Table 6.3  Distribution of responses concerned with strategies used in the SSWBC program

<table>
<thead>
<tr>
<th>Statement: ‘The Strengthening Support program has...’</th>
<th>Frequency (%) in general agreement*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provided opportunities for health professionals to enhance their knowledge and awareness of supportive care issues for women with breast cancer (including services and resources available for women with breast cancer, resources available for health professionals)</td>
<td>43 (90)</td>
</tr>
<tr>
<td>Enhanced the availability of quality information for women with breast cancer through the development of information kits or new resources specifically designed for women</td>
<td>35 (76)</td>
</tr>
<tr>
<td>Encouraged a consistent approach to ensuring all women receive information about breast cancer, through coordinated efforts by health professionals such as breast care nurses, cancer contact workers and GPs</td>
<td>36 (75)</td>
</tr>
<tr>
<td>Established or encouraged further implementation of a MDC approach between health services in urban and regional/rural locations</td>
<td>33 (70)</td>
</tr>
<tr>
<td>Enabled continuity of care for women living in rural areas when returning home after receiving their treatment in urban areas</td>
<td>33 (70)</td>
</tr>
<tr>
<td>Enabled continuity of care for women living in rural areas within their own community of region</td>
<td>32 (70)</td>
</tr>
<tr>
<td>Established or improved professional support and supervision for breast care nurses or cancer contact workers</td>
<td>33 (69)</td>
</tr>
<tr>
<td>Provided training and development opportunities for health professionals (such as e-health initiatives, public forums, communication skills training programs, training for GPs)</td>
<td>32 (67)</td>
</tr>
<tr>
<td>Established breast care nurse positions in regional rural or remotes locations</td>
<td>29 (60)</td>
</tr>
<tr>
<td>Increased acceptance of and improved attitudes towards e-health resources and infrastructure from health professionals</td>
<td>27 (57)</td>
</tr>
<tr>
<td>Established cancer contact persons in rural areas</td>
<td>8 (17)</td>
</tr>
</tbody>
</table>

*Either ‘strongly’ or ‘somewhat’ agree
Table 6.4  Efforts undertaken to sustain strategies implemented in the SSWBC program*

<table>
<thead>
<tr>
<th>Efforts to sustain strategies</th>
<th>Frequency (% in agreement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have secured agreement from health organisation/service/government body for on-going maintenance of strategies</td>
<td>15 (44)</td>
</tr>
<tr>
<td>Currently seeking agreement from health organisation/service/government body for on-going maintenance of strategies</td>
<td>18 (53)</td>
</tr>
<tr>
<td>Have secured key stakeholders (including consumers) or clinicians to lobby in support of strategies</td>
<td>3 (9)</td>
</tr>
<tr>
<td>Currently seeking key stakeholders (including consumers) or clinicians to lobby in support of strategies</td>
<td>0</td>
</tr>
<tr>
<td>Currently undertaking/completed the collection of local or state-based evaluation data to assist in demonstrating the value of strategies</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Have undertaken other efforts</td>
<td>3 (9)</td>
</tr>
</tbody>
</table>

* Multiple responses were allowed.
Table 6.5 Barriers to sustaining strategies implemented in the SSWBC program

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Frequency (%) in agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of funding or unwillingness to allocate funds to continue strategies</td>
<td>35 (83)</td>
</tr>
<tr>
<td>Other</td>
<td>12 (29)</td>
</tr>
<tr>
<td>Inability to incorporate strategies into local health policy and planning</td>
<td>9 (21)</td>
</tr>
<tr>
<td>Lack of influential clinicians/health professionals/consumers/other leaders to lobby for continuation of strategies</td>
<td>5 (12)</td>
</tr>
<tr>
<td>Lack of local infrastructure or systems to support implemented strategies</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Lack of human resources to dedicate to continue strategies</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Insufficient data or evidence to demonstrate the value of SSWBC strategies</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>
Figure 6.1 Extent of respondents' involvement in the SSWBC program subdivided by role
Figure 6.2  Awareness of strategies used in the SSWBC program implemented across States and Territories (left) or local areas (right)
Figure 6.3  Factors facilitating the successful implementation of SSWBC strategies and the percentage of respondents who agreed that these factors had an impact
Figure 6.4 Barriers encountered during implementation of strategies used in the SSWBC program
7. Clearinghouse

The resources developed by all States and Territories numbered 116 in total, and included a range of printed and electronic material. For a full list of the resources developed see Appendix VII. These were grouped into one of five focus areas:

- Workforce/Training, eg position descriptions, course outlines
- Service delivery, eg referral forms, professional information kits
- Consumer information, eg brochures and kits
- Directory of services, eg web-based material
- Research/Discussion papers/Workshop findings.

Focus areas

Workforce/training

Resources in this area consisted mainly of position descriptions, training videos, meeting guides and orientation and information packages. For example, Victoria developed online training resources such as the Breast Care Nurse Forum Area and the ITEVS. South Australia and the Northern Territory collaborated to develop training resources for Aboriginal and Torres Strait Islander health workers and for those working with culturally and linguistically diverse women. The supportive care required of these workers was found to involve a greater emphasis on the practical aspects of treatment, including the need for strategies to address communication barriers. Affiliations with educational institutions such as universities or tertiary hospitals provided health professionals working under the SSWBC program with training opportunities. In South Australia, collaboration with the Royal Adelaide Hospital allowed the implementation of education modules for local breast cancer contact...
workers. Tasmania ran a communication skills training workshop for health care providers, as well as developing a communication template to facilitate the exchange of information most relevant to providing optimal care between multidisciplinary health professionals. CD-ROMs based on public breast-cancer-care forums were distributed to every GP in New South Wales.

Service delivery

Resources relating to service delivery comprised mainly information kits, referral forms, templates and guidelines. For example, Western Australia developed a range of templates and forms that could be used for both administrative and service delivery purposes, as well as guidelines and referral pathways. The ACT developed a breast cancer surgery clinical and patient pathway. To address the distinct supportive care needs of Aboriginal and Torres Strait Islander women and those from culturally and linguistically diverse backgrounds, the Northern Territory and South Australia collaboratively developed culturally appropriate communication aids for health professionals. These used pictures to describe a woman’s journey through breast cancer from screening to treatment.

Consumer information

Consumer information resources consisted mainly of patient brochures, fact sheets, information kits, web-based information and CD-ROM material. For example, NSW planned and co-ordinated annual public forums on breast cancer care that were broadcast nationally via satellite. CD-ROMs and booklets based on these forums were widely distributed to consumers.

Directory of services

Almost every State and Territory produced a service directory. For example, in Tasmania an audit of service provision was undertaken through community consultations. Provider and consumer kits were developed that included a list of health
providers and services. Partnership arrangements with the The Cancer Council Tasmania ensured the sustainability of the service directory.

Research/discussion papers and workshop findings

These resources consisted mainly of workshop reports, conference presentations and project plans. All States and Territories have produced or are in the process of producing final evaluation reports about the SSWBC program initiatives.

Dissemination

Many of the resources, such as contact lists, service directories and clinical practice guidelines were distributed to health professionals during the induction and orientation programs for the SSWBC program. Information technology such as web-based technology, CD-ROMs and videos provided a valuable means of resource development and distribution. This was especially useful for rural health professionals. Newsletters distributed through local networks or by a related cancer organisation helped to keep health professionals in the program up to date on government and community initiatives and training opportunities. Community newsletters provided an opportunity to promote the SSWBC program initiatives to women in the local regions. Dissemination efficacy was affected by the availability of resources. Materials also needed to be reviewed regularly and updated as required. The forging of partnerships between the States and Territories helped to ensure the sustainability of resource dissemination.
8. Conclusions and discussion

Around 30% of women with breast cancer in Australia live in remote and rural areas of the country. The need to improve supportive care for these women has been identified. The SSWBC program provided an opportunity for each State and Territory to implement locally relevant strategies to improve supportive care for women with breast cancer in rural and remote areas. This national process evaluation provides a valuable insight into the process, successes, barriers and enablers of these strategies. Despite some variation in approaches, common themes and lessons learned have emerged that will be beneficial for health services and facilities wishing to improve the level of supportive care provided for women with breast cancer in rural areas. Many of the strategies implemented have broader application beyond breast cancer and will be transferable to other cancers and chronic diseases. Key lessons learned are outlined below. Further information regarding specific strategies can be found in the State and Territory local evaluation reports submitted to the Australian Government Department of Health and Ageing.

Successes

Theme 1: models that improve approaches to supportive care

Key successes reported included:

- implementation of the SBN role in rural areas and perceived improvements in supportive care and care coordination for women with breast cancer in these areas
- increased awareness and recognition of the SBN role by other health professionals
- recognition of the SBN as an MDC team member
- implementation of MDC as a strategy to improve supportive care
• reductions in inequalities and improved care coordination for women in rural areas through a capacity building approach in which existing health workers took on the roles of the SBN.

Theme 2: Providing information to women and health care providers

Key successes reported included:

• increased awareness amongst health professionals of services and resources to provide information and support for women with breast cancer

• implementation of a range of strategies to provide information to women and health care providers in rural and remote areas, including service directories and consumer forums.

Theme 3: Improving communication between health care providers

Key successes reported included:

• increase in protocols to ensure communication about supportive care needs and in perceived levels of communication between health professionals

• use of information technology to improve communication links between health professionals working in rural areas and to provide information, eg SBN online chat room

• increased awareness of the importance of SBNs in providing information about supportive care issues to other health professionals

• increased confidence by SBNs in their ability to provide information about supportive care issues to other health professionals
• development of tailored resource packages to improve supportive care for Aboriginal and Torres Strait Islander women and for women from non-English-speaking backgrounds.

Theme 4: Improving continuity of care

Key successes reported included:

• increase in MDC meetings to coordinate treatment planning

• recognition of the critical role played by the SBN in ensuring continuity of care for women with breast cancer

• increases in the level of supportive care planning undertaken for women with breast cancer

• increase in consultations between SBNs and women with breast cancer, particularly for women travelling between rural and urban areas for treatment.

Theme 5: Health care or supportive care provider needs in relation to training and support

Key successes reported included:

• training in e-health technologies to support the implementation of technology-based strategies

• increased reports of regular supervision for SBNs

• innovative strategies to provide support for SBNs in rural areas such as regular debriefs by telephone with a psychologist.
**Overall acceptability**

Overall there was a high level of agreement that the strategies implemented through the SSWBC program had impacted positively on supportive care for women with breast cancer in rural areas. A high level of sustainability was reported with over 90% of respondents indicating that either additional funding had been secured or was being sought to sustain strategies. Some flow-on effects to other cancers were also reported.

**Challenges and barriers**

Challenges encountered during the implementation of SSWBC strategies included:

- difficulties in delineating the role of the SBN, combining clinical, supportive care, educational and information provision roles
- lack of support at an organisational or government level for the strategies
- lack of adequate infrastructure or administrative support
- difficulties in managing all program tasks within the timeframe
- issues of change management – including managing individual perceptions about changing or expanding roles, and system-level change to incorporate new strategies, such as MDC
- issues of geographic isolation for SBNs working in rural areas
- the challenge of supporting time away from local service for health professionals to undertake training.
Enablers

Mechanisms identified through the program to facilitate the implementation of new strategies included:

- the need for all stakeholders to have realistic expectations of what is achievable and a clear understanding of the project aims from the outset
- the need for adequate infrastructure and administrative support
- the importance of gaining cooperation and participation from health professionals through shared understanding of the value of implemented initiatives
- creating stakeholder ownership of initiatives.

Unanticipated benefits

A number of unanticipated benefits were reported to have resulted from the implementation of SSWBC initiatives.

- The initial audit of services undertaken at the outset identified unexpected issues for a number of States and Territories and was viewed as beneficial for generating stakeholder interest in the proposed initiatives.
- In seeking to update information across organisations there was an opportunity to identify under-utilised information resources and gaps.
- The program fostered collaboration between State and Territory groups (eg New South Wales public forum broadcast to other States and Territories; Northern Territory and South Australia working together on indigenous programs; e-health links within and between States and Territories).
- The increased communication between health professionals provided opportunities for different health professionals to learn about each other’s roles.
• The need for additional initiatives was identified, such as a lymphoedema clinic for women in rural areas.

Lessons learnt

Key lessons from the SSWBC program have been highlighted at program workshops and in State and Territory evaluation reports. These lessons relate to specific issues associated with developing and implementing strategies for improving supportive care across a range of health service delivery settings and are described below.

Role adaptation: the SBN

• Where new roles were established, it was important to have clear definition of these roles and for their implementation to be responsive to the local region’s health care structures, systems and needs.

• Tasks that were undertaken by an SBN role were successfully adapted in some cases to other rural positions (eg Women's Health Nurse, Palliative Care Worker, Community Health Worker/Nurse and Acute Nurse). However, the importance of clearly defining these roles with adequate guidelines, training and support was highlighted.

• The setting of the SBN role varied. SBNs provided service in a variety of locations, including specialist’s rooms, hospital units and wards or in a community-based non-clinic setting.

• Where SBNs were community-based, it was important to establish strong lines of communication with local and regional health professionals to assist in referrals. Close communication with BreastScreen services helped to connect with women at the earliest possible time in the cancer journey. Referral pads were useful in assisting health professionals to refer women with breast cancer to an SBN.

• While the NBCC Specialist Breast Nurse Demonstration Project advocates a five-in 12-week intervention model for SBNs, some States and Territories tailored this
model to suit local needs. For example, in Western Australia a model of six SBN interventions over a six-month period was used.

Community consultation and engagement

- Community consultation and engagement was critical to the success of the program and helped to determine State- and Territory-specific program objectives.

- Attendance by project staff at community and service group meetings helped to ensure ongoing community engagement and liaison. Events such as these were used to ensure stakeholder buy-in, kept the lines of communication open, and were used as a feedback loop on issues of implementation.

- A mapping or audit process, performed in the first phase of the program helped to identify and initiate contact with key stakeholders in each region/State/Territory.

- Consumers were good advocates for identifying gaps in services and highlighting the needs of local women newly diagnosed with breast cancer. Consumer representation on local Steering Committees involved in program planning and implementation facilitated consumer knowledge and support for initiatives.

High-level stakeholder buy-in

- It was important to identify an exhaustive list of key stakeholders in the early stages of the program; consultation processes proved an effective means of engaging stakeholders.

- The importance of a shared vision was identified, ensuring that stakeholders had a shared idea of the aims of the strategies and the benefits of implementing them.

- Collaboration with key agencies through a broadly represented Steering Committee/Reference Group provided commitment from other sectors to ensure the program succeeded with improved outcomes for rural women.
• Stakeholder buy-in was maintained through strategies such as ongoing communication with consumer groups and widely disseminated program bulletins; such strategies were time-intensive but were viewed as important to ensure ongoing buy-in from stakeholders.

Emphasis on different approaches to implementation

Some of the innovative approaches to improving supportive care are outlined below.

• Information technology was used to improve access to timely information by both consumers and health professionals, to facilitate attendance at MDC meetings by rural health professionals and to provide methods for networking by SBNs and other health professionals in rural areas. An information technology skills and technology audit was critical for identifying relevant approaches and unexpected issues. The importance of having realistic expectations of what was achievable with information technology was identified, as was the need for adequate information technology support.

• Educational aids were developed with messages for Aboriginal and Torres Strait Islander women, in recognition of the fact that cultural traditions and beliefs may be barriers to accessing treatment for these women. Facilitation of face-to-face discussion of breast cancer treatment for Aboriginal women also allowed time for family participation and consultation.

• A ‘capacity building approach’ for service development was used in rural South Australia to overcome workforce issues and to ensure that the outcomes of the program for rural women could be maintained within the existing health care structure.

• The SBN roles tended to reflect local needs and service structures. For example, hospital-based positions tended to become more involved in care of women during treatment, while community-based positions focused more on follow-up after initial surgery and liaison with community-based services.
• A SBN co-ordinator role was useful for providing clinical supervision and a mentoring function.

• A Breast Cancer Clinical Psychology Service was a valuable means of providing regular confidential support and debriefings for SBNs in rural areas by telephone.

• Poor clinician referral rates were overcome by SBN personal letters of introduction to newly diagnosed women.

Local relevance and appropriateness

It was important for strategies to be flexible and based on identified local, regional and state level needs and capabilities. Some of the lessons learned in this regard are outlined below.

• A community-based approach to breast care nursing, rather than the traditional hospital-based approach, was developed in recognition that the majority of a woman’s journey with breast cancer occurs at home, rather than in the confines of the hospital.

• The need for strategies to take account of existing structures or systems was identified. For example, in Tasmania, information kits were distributed through the Support and Information Program of The Cancer Council Tasmania.

• Established departmental infrastructure was utilised to communicate with women from remote regions (eg Community Care Centres and District hospitals).

• Local networks with Aboriginal and multicultural groups were established to assist in identifying and dealing appropriately with issues and special needs.

• The training of a diverse workforce, including multicultural workers and Aboriginal Health Workers, and the development of appropriate resources was required to ensure specific population groups had access to information on supportive care.
**Networking between health professionals**

Networking between health professionals was seen as an important strategy to ensure the implementation and sustainability of strategies. Some of the approaches to networking and the benefits of this approach are outlined below.

- Networking was seen as an important tool to help identify opportunities for collaborative work, thereby reducing duplication of effort and maximising utilisation of resources (e.g., National broadcasts of the NSW Public Forums on Breast Cancer were accessed by health professionals across Australia).

- Networking took place both formally and informally through the establishment of professional support networks, interagency communication and informal links to key groups such as Council Councils and BreastScreen services.

- Training opportunities such as orientation programs and workshops provided opportunities for networking of health care providers with different roles and from different services. These interactions improved understanding of women’s experiences and aided communication between rural and metropolitan-based health care professionals.

- It was important for SBNs to develop relationships with pre-admission clinics at local hospitals as well as discharge planners at hospitals to aid referrals.

- The development of referral processes and tools such as referral pads assisted in maintaining relationships between the SBN, specialists, tertiary treatment services and local GPs.

- SBNs working in rural areas valued the opportunity to learn from their peers and debrief with others in similar roles, particularly as the role was often isolated. An online SBN chat room established in Victoria provided the opportunity for SBNs in rural areas to contact each other.
Sustainability

One of the criteria for strategies implemented through the SSWBC program was that they should be sustainable. Some of the key factors contributing to sustainability are outlined below.

- The need to take a strategic approach to ensuring sustainability was identified. Planning to ensure stakeholder buy-in and ongoing communication were critical components to ensure sustainability of strategies.

- It was viewed as important to source appropriate funding with realistic expectations. The need to lobby for funding at multiple levels was identified (eg regional stakeholders were lobbied to include monies for local SBN positions in their budget proposals).

- Evaluation and regular reporting was an important component of sustainability, providing evidence of the effectiveness and need for an initiative. For example, data collection processes and the development of a computerised patient management system facilitated analysis of the program.

- Ensuring the ‘fit’ of program initiatives into current local practice and health system structures supported their acceptability and long-term sustainability.

- Gaining strong support from senior executive management & key clinicians was vital. Organisational support was also important to ensure a readiness for system change.

- There were benefits to enlisting the assistance of positive consumer advocacy to support program outcomes.
Transferability to other cancers

Many of the strategies implemented in the SSWBC program have broader application to other cancers. Models such as the BCCWs in South Australia were designed with the aim of transferring and adapting these for use with other cancers or chronic illnesses. The SBN model also has broader application for other cancers through a cancer care coordinator/supportive care role. Key lessons from the SSWBC program will be useful in informing State/Territory reviews of cancer treatment services. However, in planning for the transferability of strategies, a number of factors should be considered:

- consultative processes with key stakeholder groups, tailored resources, and in some cases a wider evidence base, will be required to extend program initiatives to other cancers

- it may be difficult to pursue breast cancer-specific initiatives in an environment where providers are typically generalists, as is the case in rural areas.

Concluding remarks

The SSWBC program has demonstrated that supportive care for women with breast cancer in rural areas of Australia can be improved through a range of strategies. The importance of the SBN role in this process was apparent, as were strategies such as MDC, referral networks and innovative use of information technology. Implementation of new strategies is dependent on adequate resourcing and on ongoing support and buy-in from key stakeholders. Additional funding provided by the Australian Government under a new initiative Supportive Care for Women in Rural Areas with Breast Cancer will provide an opportunity to further develop some of the strategies described here and for new strategies to be explored.
REFERENCES


APPENDICES

Appendix I: Program coordinator interview questions

Semi-structured interviews were held every three months between State/Territory program coordinators and the NBCC project officer responsible for the SSWBC program. An example of the types of questions asked at these interviews is listed below.

Overview of progress

1. How has/have the project(s) been progressing over the past 3 months?

2. What has happened since last time we spoke?

3. Have there been any changes to your plans or strategies in the last 3 months?

What has been working well, what barriers have been encountered

4. In the past three months, what has been working well?

5. Have there been any problems that you’ve encountered?

6. Have you noted any unanticipated benefits as a result of the project?

Sustainability

7. Are you thinking about any issues regarding the sustainability of your project(s) at the moment?
Resources

8. Are there any resources that you have developed in the past 3 months? If you think these resources are suitable for inclusion in the resource book, would you mind if sending us copies?

Case studies (optional if any good examples have come up during the call)

9. We’d also like to collect some case studies to include in the final evaluation report. You mentioned earlier about (..........) I think this would be really interesting to write up as an example of a success story from the project. Would you mind if I typed something up and then sent it to you check that I have enough detail?
## Appendix II: Topics for program coordinator workshops held over the course of the SSWBC program

<table>
<thead>
<tr>
<th>Topic</th>
<th>Date</th>
<th>Venue</th>
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</thead>
<tbody>
<tr>
<td>Preliminary one-day meeting</td>
<td>April 2001</td>
<td>Melbourne</td>
</tr>
<tr>
<td>Introductory workshop</td>
<td>July 2001</td>
<td>Sydney</td>
</tr>
<tr>
<td>Consumer participation</td>
<td>November 2001</td>
<td>Adelaide</td>
</tr>
<tr>
<td>Communication skills training and information provision</td>
<td>March 2002</td>
<td>Sydney</td>
</tr>
<tr>
<td>Specialist breast nurses</td>
<td>June 2002</td>
<td>Canberra</td>
</tr>
<tr>
<td>Sustainability and evaluation</td>
<td>September 2002</td>
<td>Sydney</td>
</tr>
<tr>
<td>Practical support</td>
<td>December 2002</td>
<td>Brisbane</td>
</tr>
<tr>
<td>Local evaluation</td>
<td>March 2003</td>
<td>Sydney</td>
</tr>
<tr>
<td>Multidisciplinary care</td>
<td>June 2003</td>
<td>Hobart</td>
</tr>
<tr>
<td>Social Marketing</td>
<td>September 2003</td>
<td>Sydney</td>
</tr>
<tr>
<td>Gestational breast cancer, advanced breast cancer and palliative care, and the role of the breast care nurse and maintaining professional boundaries</td>
<td>November 2003</td>
<td>Perth</td>
</tr>
<tr>
<td>Final workshop</td>
<td>March 2004</td>
<td>Brisbane</td>
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### Appendix III: List of e-list topics and sample e-list newsletter

<table>
<thead>
<tr>
<th>Topic</th>
<th>E-list</th>
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<tbody>
<tr>
<td>Information needs / information provision</td>
<td>August 2001</td>
</tr>
<tr>
<td>Needs of women’s partners</td>
<td>October 2001</td>
</tr>
<tr>
<td>Consumer participation</td>
<td>October 2001</td>
</tr>
<tr>
<td>Breast nurses</td>
<td>December 2001</td>
</tr>
<tr>
<td>E-health / information technology</td>
<td>February 2002</td>
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<tr>
<td>Communication skills</td>
<td>April 2002</td>
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<tr>
<td>Multidisciplinary care</td>
<td>June 2002</td>
</tr>
<tr>
<td>Support service utilisation</td>
<td>August 2002</td>
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<tr>
<td>Support in palliative care</td>
<td>October 2002</td>
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<tr>
<td>Prostheses</td>
<td>December 2002</td>
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<tr>
<td>Travel and accommodation assistance</td>
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<tr>
<td>Lymphoedema</td>
<td>February 2003</td>
</tr>
<tr>
<td>Support for rural women</td>
<td>April 2003</td>
</tr>
<tr>
<td>Depression and anxiety</td>
<td>June 2003</td>
</tr>
<tr>
<td>Survival issues</td>
<td>August 2003</td>
</tr>
<tr>
<td>Multidisciplinary care</td>
<td>November 2003</td>
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<tr>
<td>Supportive care</td>
<td>February 2004</td>
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<tr>
<td>Final newsletter</td>
<td>June 2004</td>
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Strengthening support for women with breast cancer

Multidisciplinary care is increasingly being adopted as best practice for the management of the woman with breast cancer. Evidence indicates that a multidisciplinary approach to the care of women with breast cancer can reduce mortality and improve quality of life for women with this disease. Without a multidisciplinary team, women with breast cancer may not be offered the full range of potential treatments and psychosocial issues may not be considered. The NHMRC Clinical Practice Guidelines for the Management of Early Breast Cancer (2nd edition) also recommend that ‘women with breast cancer should be treated by specialists who have a demonstrated expertise in breast cancer and have access to the full range of multidisciplinary treatment options.’

This edition of Strengthening Support e-list newsletter outlines the latest studies and research currently underway in Australia and internationally relating to multidisciplinary care. We also take the opportunity to provide an overview on the National Breast Cancer Centre’s (NBCC) new website including two exciting new sites for consumers.

NEWS AND EVENTS

News

www.breasthealth.com.au is the NBCC’s new consumer website which contains readily-available and comprehensive breast cancer information for Australian women. This website is a joint venture with the Macquarie Bank Foundation.

www.myparentscancer.com.au is Australia’s first website for teenagers who have a parent with cancer. The interactive website developed by the NBCC in conjunction with CanTeen, aims to help families communicate about cancer by giving teenagers information and advice, and telling them ‘You are not alone’.

www.breasthealth.com.au/boysdocry is a dedicated section of the NBCC new consumer website information on how men can cope and offer better support when a woman they love has breast cancer.

www.nbcc.org.au The National Breast Cancer clinical best-practice website has been redesigned to provide health professionals with better access to evidence-based information on breast and ovarian cancer.

Multidisciplinary care demonstration study completed

The NBCC has completed a three-year study to examine the process, impact, acceptability and cost of implementing strategies to increase multidisciplinary care in Australia. The Centre submitted a comprehensive report on the study findings to the Commonwealth Department of Health Ageing in August 2003. A report summarising the main study outcomes will be released by the National Breast Cancer Centre in December 2003.
A paper that considers the benefits of a multidisciplinary approach to the care of women with breast cancer within the Australian setting has recently been published. The paper provides an operational definition of multidisciplinary care as well as outlining the development of the five principles of multidisciplinary care on which the NBCC’s demonstration project is based.


Where did they get the term multidisciplinary?
A project to determine the consumers’ understanding of a multidisciplinary meeting was conducted by the Victorian Breast Services Enhancement Program in collaboration with the Breast Unit at Mercy Private, Melbourne. Both women with and without breast cancer viewed a video of a multidisciplinary team meeting and were asked to explain their understanding of what they had seen, and to make suggestions about how clinicians could best explain the meeting and share treatment plans with patients. Results indicated the term ‘multidisciplinary’ was not generally understood or accepted by the women and it conveyed negative associations of childhood discipline. They described the meeting as being ‘formalised’, ‘bringing together a group of experts for a round table discussion’, ‘all the information about the patient is in the one place’ and ‘they (the clinicians) are suggesting the best possible treatment for the patient’. Results of the study have implications for how clinicians deliver feedback to their patients to optimise understanding and retention.


A framework for measuring best practice in multidisciplinary meetings
Maroondah Hospital Melbourne has developed a multidisciplinary audit tool to both guide and audit their performance on an ongoing basis. The performance of the team has so far been audited three times at 12 monthly intervals and results have proved the tool to be an effective means of measuring performance and reflecting on current practice.


NEW RESEARCH

Breast cancer nurses effective members of multidisciplinary teams
This study examined the effectiveness of 72 randomly selected multidisciplinary breast cancer teams from across England, with each team minimally including a surgeon, a breast nurse, and either a radiologist, oncologist or pathologist. In multivariate analyses, better clinical performance was predicted by the proportion of breast care nurses in the team and higher breast cancer caseload.

Surgeon workload and survival from breast cancer

The formation of multidisciplinary breast teams across the UK is intended to concentrate the assessment and treatment of breast cancer into the hands of high volume specialists. A retrospective population based study of 11,329 women in Yorkshire was undertaken to determine the trends in surgeon breast cancer workload and to investigate whether workload affected the patients’ survival. Five-year survival was 60% in the lowest workload category compared to 68% in the highest category. The relative risk of death was increased by 15% and by 10% for patients managed by surgeons with workloads <10 and 10-29 cases respectively per annum in comparison to patients managed by surgeons with workloads of >50. The results of this study suggest increasing site specialisation in breast cancer among general surgeons. It also provides further evidence that the management of patients by surgeons with low workloads decreases overall survival.


Visit the Strengthening support for women with breast cancer bulletin board at www.nbcc.org.au/sswboard
### Appendix IV: Overview of strategies implemented and anticipated outcomes at project outset

<table>
<thead>
<tr>
<th>State/Territory strategies</th>
<th>Nominated strategies</th>
<th>Anticipated outcomes</th>
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<tr>
<td><strong>ACT</strong></td>
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</table>
| SBNs / breast care nurses employed to care for women, including those in regional/rural areas | One SBN covering 4 Canberra hospitals | **Outcomes for health professionals:**
- Improved communication between health professionals (SBN to network and act as link between health professionals)
- Improved links between health professionals based in hospital setting and community organisations
- Establishment or improvement in multidisciplinary approach to providing supportive care for women
- Training and professional development for nurses
  
  **Outcomes for women:**
  - Improvement in continuity of care for women
  - Better access to information resources for women & families
  - Better access to support through the SBN being available to women and families
  - Improved referral systems for women – including psychological services and practical support |
| **NT**                     |                      |                      |
| SBNs / breast care nurses employed to care for women, including those in | Two part time SBN positions:  
Darwin: Full timr FTE  
Alice Springs: 0.4 FTE | **Outcomes for health professionals:**
- Improved communication between health professionals (SBN to network and act as link between health professionals)
- Improved links between health professionals based in hospital setting and community organisations |

174  Strengthening support for women with breast cancer: national process evaluation report
<table>
<thead>
<tr>
<th>State/Territory strategies</th>
<th>Nominated strategies</th>
<th>Anticipated outcomes</th>
</tr>
</thead>
</table>
| regional/rural areas      |                      | Establishment or improvement in multidisciplinary approach to providing supportive care for women  
Training and professional development for nurses  
*Outcomes for women:*  
Improvement in continuity of care for women  
Better access to information resources for women & families  
Better access to support through the SBN being available to women and families  
Improved referral systems for women – including psychological services and practical support |
| WA                        | Appointment of 3 part-time nurses in Geraldton (0.4 FTE), Bunbury (0.6 FTE) and Albany (0.4 FTE) | *Outcomes for health professionals:*  
Improved communication between health professionals (SBN to network and act as link between health professionals)  
Improved links between health professionals based in hospital setting and community organisations  
Establishment or improvement in multidisciplinary approach to providing supportive care for women  
Training and professional development for nurses  
*Outcomes for women:*  
Improvement in continuity of care for women  
Better access to information resources for women & families  
Better access to support through the SBN being available to women and families  
Improved referral systems for women – including psychological services and practical support |
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<tr>
<th>State/Territory strategies</th>
<th>Nominated strategies</th>
<th>Anticipated outcomes</th>
</tr>
</thead>
</table>
| QLD: Southern and Northern Zones  
SBNs / breast care nurses employed to care for women, including those in regional/rural areas | **Southern Zone:**  
3 part-time nurses based at:  
Princess Alexandra Hospital (50%),  
Gold Coast Hospital (25%),  
Toowoomba Hospital (25%)  

**Northern Zone:**  
3 part-time nurses based at:  
Townsville (50%),  
Cairns (30%),  
Mackay (20%) | **Outcomes for health professionals:**  
Improved communication between health professionals (SBN to network and act as link between health professionals)  
Improved links between health professionals based in hospital setting and community organisations  
Establishment or improvement in multidisciplinary approach to providing supportive care for women  
Training and professional development for nurses  

**Outcomes for women:**  
Improved in continuity of care for women  
Better access to information resources for women & families  
Better access to support through the SBN being available to women and families  
Improved referral systems for women – including psychological services and practical support |
| QLD Central Zone: One full-time Project Officer based at Royal Women’s Hospital in Brisbane | Project officer will examine issues including:  
access to information,  
building networks between the public and community sectors and training packages (eg lymphoedema management training for carers and families). | Improved links between health professionals based in hospital setting and community organisations  
Increased support for the upskilling and training of health professionals  
Enhanced communication about/ dissemination of available training materials  
Increased knowledge about available training materials  
Better access to information resources for women & families |
<table>
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<tr>
<th>State/Territory strategies</th>
<th>Nominated strategies</th>
<th>Anticipated outcomes</th>
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</table>
| QLD                        | Project coordinator will:  
Project Coordinator to undertake State level initiatives  
review breast prosthesis policy, its implementation, and administrative processes  
review Patient Travel Subsidy Scheme  
establish an Indigenous Women’s Reference Group to advise on and support strategies for ATSI women | Appropriate and sensitive administration processes and policy regarding access to prostheses  
Enhanced eligibility and availability of prostheses in the public hospital system  
Better understanding/ awareness of PTSS guidelines  
Enhanced sensitivity in administration of PTSS guidelines  
Increased consistency in application of PTSS guidelines  
Increased awareness/ knowledge about support services for women of ATSI backgrounds |
| SA                         | Development of information initiatives for women and families | Improved access to information for women and their families  
Improved access to information for paid and unpaid workers that will enable them to do their role well  
Improved access to information for paid and unpaid workers to provide to women and their families  
Systems in place to ensure the ongoing distribution of information |
| SA                         | Development and implementation of a workforce development plan for key service providers and peers in relation to psychosocial support | Development and implementation of workforce development plans  
Range of workforce development activities conducted  
Improved communication skills for health care providers, for example, establishment of a train-the-trainer approach to educating service providers about communication skills  
Systems in place to ensure the ongoing sustainability of workforce development initiatives |
| SA                         | Enhancing communication between health care professionals and peer support workers | Improved continuity of care for women with breast cancer  
Improved communication between health professionals |
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<th>State/Territory strategies</th>
<th>Nominated strategies</th>
<th>Anticipated outcomes</th>
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<td>Improvement in links/ networks of health professionals</td>
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<td>Systems in place to ensure ongoing sustainability</td>
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<tr>
<td>SA</td>
<td>Methods to integrate sustainability into all project strategies</td>
<td>Establish systems so that key implemented strategies can continue after SSWBC funding ceases</td>
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<td>Establish partnerships so that collaborative regional action plans become part of the regional planning process</td>
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<td>NSW SBNs</td>
<td>Development of a multidisciplinary support services model with the involvement of a rural breast care nurse</td>
<td>Outcomes for health professionals:</td>
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<td>Improved communication between health professionals (SBN to network and act as link between health professionals)</td>
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<td>Improved links between health professionals based in hospital setting and community organisations</td>
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<td>Establishment or improvement in multidisciplinary approach to providing supportive care for women</td>
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<td>Training and professional development for nurses</td>
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<td>Outcomes for women:</td>
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<td></td>
<td>Improvement in continuity of care for women</td>
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<td>Better access to information resources for women &amp; families</td>
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<td>Better access to support through the SBN being available to women and families</td>
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<td>Improved referral systems for women – including psychological services and practical support (eg, lymphoedema)</td>
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<td>Documented critical care pathway which identifies the points of potential intervention by a breast care nurse.</td>
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<td>Better supported breast care nurses</td>
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<td>Enhanced access for breast care nurses to education and training</td>
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<td>State/Territory strategies</td>
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| **NSW**
Breast Cancer Support Service | Needs assessment for CCNSW help-line information consultants | Development of/ increased access to standardised information and responses for CIS workers
Enhanced knowledge, confidence of CIS workers
Address workforce issues including morale, turnover
Greater opportunities for CIS workers to participate in debriefing sessions, professional supervision, and MDC case conferencing as a result of needs assessment |
| **NSW**
Public forums | Public forums via satellite to rural towns, using a multidisciplinary approach to breast cancer care | Better knowledge about breast cancer for participating consumers and their families
Increased opportunities for health care professionals to discuss/learn about MDC approach to care
Enhanced GP education |
| **NSW**
Consideration of the relevance of breast care nurses in NSW | Sustainable MD support services model appropriate for regional area(s)
Professional development and workforce issues for SBNs
Potential State-wide breast nurse interest group or online breast care nurse chat room | |
| **VIC Barwon:**
e-health | Using e-health initiatives to establish/improve the multidisciplinary approach | Greater opportunities for regional health professionals to participate in multidisciplinary meetings through using e-health technologies
Improved communication and continuity of care for women throughout the region, in particular for those in distant areas
Improved coordination of care and support for women through increased opportunities for consultation and information sharing to |
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<th>State/Territory strategies</th>
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<td>occur without distant travel</td>
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<td>Professional development and support for clinicians, through videoconferencing and exposure to additional disciplines</td>
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<td>VIC Loddon Mallee: MDC</td>
<td>Development of a regional multidisciplinary approach to services, education and supports, utilising information and communications technologies</td>
<td>Improved infrastructure to allow facilitation of multidisciplinary approach to care</td>
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<td>Improved awareness and skill level for health professionals and consumers in e-health technology</td>
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<td>Improved continuity of care for women through the use of case conferencing</td>
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<td>Improved communication between GPs (community), hospital staff (breast care nurses, surgeons) and consumers</td>
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<td>Improved support for women through greater contact between support groups and increased health professionals knowledge of support groups available</td>
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<tr>
<td>VIC Hume: IT</td>
<td>Use of technology to enhance clinical and psychosocial outcomes for breast cancer services in Hume</td>
<td>Increased skills and confidence for health professionals in using e-health technologies</td>
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<td>Improved access to e-health technology through education and promotion, to facilitate multidisciplinary approach to care, continuity of care and communication between health professionals and consumers</td>
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<td>Education and increased access to relevant information for non English-speaking women and health professionals</td>
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<td>Greater opportunities for breast care nurses to access support and information from peers, and to access clinical supervision</td>
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<td>Increased consumer and health professionals awareness of issues identified in region through electronic dissemination</td>
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<td>State/Territory</td>
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<td>Anticipated outcomes</td>
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| **TAS SBNs**    | Specialist breast nurses / breast care nurses employed to care for women, including those in regional/rural areas | Outcomes for health professionals:  
Improved communication between health professionals (SBN to network and act as link between health professionals)  
Improved links between health professionals based in hospital setting and community organisations  
Establishment or improvement in multidisciplinary approach to providing supportive care for women  
Training and professional development for nurses  
Outcomes for women:  
Improvement in continuity of care for women  
Better access to information resources for women & families  
Better access to support through the SBN being available to women and families  
Improved referral systems for women – including psychological services and practical support (eg, lymphoedema) |
| **TAS Information** | State-wide information strategy                                                                                      | To improve information provision for women with breast cancer and clinicians  
Linkage with NSW public forums |
| **TAS Networking** | To develop a breast nurse network                                                                                      | To develop an ongoing professional support network for breast care nurses  
To inform members of activities across the State  
To provide ongoing educational opportunities  
To identify opportunities to address barriers to breast nursing. |
Appendix V: Sample survey instrument used for baseline and follow-up evaluations

BREAST NURSE SURVEY

STRENGTHENING SUPPORT FOR WOMEN WITH BREAST CANCER

NATIONAL EVALUATION

ID: [Blank]
Specialty: [Blank]

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Background statement for interviewer to read aloud:
The Strengthening Support for Women with Breast Cancer program is a Commonwealth funded initiative to improve supportive care for Australian women. The National Breast Cancer Centre has been commissioned to conduct a national evaluation of the program. I am conducting the interview on behalf of the Centre. Some of the questions asked will be directly relevant to the strategies being used in your state/territory. Other questions may cover strategies not specifically being used in your state/territory. However, we would like to find out about supportive care in your area. (A definition of supportive care: ‘Supportive care can be broadly defined as providing care that attempts to meet the psychological, emotional and practical needs of the person living with cancer, with an emphasis on person-centred care, rather than disease-centred care.’)

1. Are there multidisciplinary care meetings held for planning the management of women with breast cancer? – Prompt: Don’t read response options, but elicit details after establishing whether meetings are held or planned.
   - Yes, face-to-face meetings are held locally
   - Yes, local meetings are held, with some health professionals linking in via teleconference videoconferencing facilities
   - Yes, meetings are held that link urban and regional/rural sites using videoconferencing facilities
   - Local face-to-face meetings are being established or planned
   - Local meetings that link in health professionals are being established or planned
   - Meetings linking urban and regional/rural sites via new technologies are being established or planned
   - New infrastructure (such as new technologies) is currently being established to enable meetings
   - No, there are no multidisciplinary care meetings – Prompt: go to q5
   - Don’t know – Prompt: go to q5

Comments
2. **Do supportive care health professionals participate in multidisciplinary team meetings?**

*Prompt:* read out response options – only one should be selected.

- □ Always – *Prompt:* go to Q2a
- □ Sometimes – *Prompt:* go to Q2a
- □ Rarely – *Prompt:* go to Q2a
- □ Not in the past, but plan to include – *Prompt:* go to Q2a and ask who will participate in future
- □ Never – *Prompt:* go to Q3
- □ Don’t know – *Prompt:* don’t read aloud, go to Q3

Comments

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2a. **Which supportive care health professionals members participate?**

*Prompt:* provide examples if requested – breast nurse, social worker, psychologist, discharge planner, oncology nurse, etc. **Note** if the person says that all health professionals raise supportive care issues.

________________________________________________________________________

________________________________________________________________________

3. **Has supportive care planning been established as part of the multidisciplinary meetings?**

*Prompt:* read out response options – only one should be selected. **Note** any comments about whether supportive care planning is viewed as a standard part of the meetings.

- □ Yes, supportive care planning is considered for all women
- □ Yes, supportive care planning is considered during case conferencing about some women
- □ No, but in the process of being established – *Prompt:* go to q5
- □ No, not established – *Prompt:* go to q5
- □ Not applicable – *Prompt:* go to q5
4. **Is supportive care planning used throughout all the stages of managing a woman’s care?**

*Prompt:* read out response options – only one should be selected.

- [ ] Supportive care planning is used throughout all stages of care, including after active treatment finishes
- [ ] Some stages only (eg. diagnosis and treatment, but not after treatment has finished)
- [ ] At one stage only (eg. diagnosis or initial planning only – *Prompt:* list which stage below)
- [ ] Not consistently used throughout all stages of care
- [ ] At no stage at all
- [ ] Supportive care planning is done informally – *Prompt:* elicit any details and describe below
- [ ] Don’t know – *Prompt:* don’t read aloud
- [ ] Other – describe below

5. **Is there a breast nurse in your local area?** *Prompt: don’t read aloud options aloud unless requested. If there is a breast nurse, elicit detail about whether they are employed as part of Strengthening Support.*

- [ ] Yes – a breast nurse has been appointed – *Prompt:* specify from list below
  - [ ] Breast nurse employed as part of Strengthening Support program
  - [ ] Breast nurse employed through other means
  - [ ] General oncology nurse
  - [ ] Other nursing position
- [ ] No – but is soon to be appointed
No – there is no breast nurse – **Prompt:** Ask respondent to clarify what their role is, since they are answering the survey in the capacity of a “breast nurse”. Write in comments below.

Don’t know – **Prompt:** don’t read aloud

Comments ________________________________

6. Is there a cancer contact or cancer coordinator position in your local area? **Prompt:** don’t read aloud options aloud unless requested. **Note:** This is a general oncology supportive care role, not breast cancer specific. It is unlikely that there will be both a breast nurse and a cancer contact/coordinator in place. If there is a contact person, elicit detail about whether they are employed as part of Strengthening Support.

Yes – a cancer contact position or cancer coordinator has been appointed – **Prompt:** specify below

- Employed as part of Strengthening Support program
- Employed through other means

No – but is soon to be appointed

No – there is no cancer contact position or cancer coordinator

Don’t know – **Prompt:** don’t read aloud

Comments ________________________________

7. **Does your role include the following responsibilities…?** **Prompt:** read each option aloud - more than one option can be selected. **Note:** It is unlikely that both a breast nurse and a cancer contact person will both be present.

- Providing supportive care to individual women?
- Playing a coordinating role within the local area to ensure supportive care is addressed?
- Coordinating care during the time when women are receiving treatment?
- Providing written and/or verbal information directly to women?
- Other roles?
8. Do you routinely offer to have consultations with women at the following times? *Prompt: read each option aloud - more than one can be selected.*

- [ ] Diagnosis
- [ ] Pre-operatively
- [ ] Post-operatively
- [ ] At the time of chemotherapy or hormone therapy
- [ ] At the time of radiation therapy
- [ ] After treatments have been completed
- [ ] At other times? *Prompt: describe below*

Comments


9. Do the local (and any visiting) clinicians refer women with breast cancer to you? *Would you say… Prompt: read out response options – only one should be selected.*

- [ ] All local surgeons and oncologists refer all or most women
- [ ] All local surgeons and oncologists refer some women
- [ ] Only some local surgeons and oncologists refer all or most women
- [ ] Only some local surgeons and oncologists refer some women
- [ ] None of the local surgeons or oncologists refers women
- [ ] Don’t know – *Prompt: don’t read aloud*

Comments
10. Does your role involve coordinating supportive care for women who are travelling between rural or remote areas to urban centres where they receive their treatment? –

**Prompt**: Don’t read aloud out response options. **Probe**: Elicit as much detail as possible.

- [ ] Yes
- [ ] No
- [ ] Don’t know
- [ ] Other

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11. Does your role involve coordinating supportive care for women from rural areas, so that women know where to access support within their rural setting? **Prompt**: This part of the person’s role might be particularly relevant at the times when women are first diagnosed and need local support or when active treatment has finished. **Probe**: Elicit as much detail as possible.

- [ ] Yes
- [ ] No
- [ ] Don’t know
- [ ] Other

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12. In what ways are general practitioners in the local area informed and involved in the supportive care of women with breast cancer? **Prompt**: read each option aloud - more than one can be selected.

- [ ] Referral letters or faxes are provided to general practitioners, which include supportive care information
- [ ] Phone calls are made to the general practitioner, which include discussing supportive care
- [ ] General practitioners are regularly involved in multidisciplinary meetings
- [ ] Other systems or strategies are in place that involve general practitioners – **Prompt**: describe below
☐ Other systems or strategies are currently being developed – **Prompt**: describe below

☐ There are no planned systems or strategies involving general practitioners – **Prompt**: don’t read aloud

☐ Not sure if any systems or strategies are in place or are being planned – **Prompt**: don’t read aloud

☐ Not applicable – **Prompt**: don’t read aloud. **Prove**: elicit why this is not applicable

☐ Don’t know – **Prompt**: don’t read aloud

Comments

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**Communication**

The next set of questions asks about communication in the local area. The first questions examine whether any strategies are in place to facilitate good communication between health care professionals about supportive care. The second set of questions explores issues about communication between health care professionals and women with breast cancer.

13. Within your local area, are there any protocols in place to facilitate communication between health professionals about the supportive care of individual women with breast cancer?

**Prompt**: don’t read aloud options aloud unless prompted.

☐ Multidisciplinary team meetings facilitate communication

☐ A communication protocol between a cancer contact person and local health professionals is in place

☐ A communication protocol between general practitioners and local health professionals is in place

☐ Another type of communication protocol/strategy is in place – **Prompt**: describe below

☐ Communication protocols/strategies are currently being developed – **Prompt**: describe what is planned

☐ There are no protocols or initiatives in place

☐ Don’t know – **Prompt**: don’t read aloud
14. Would you say that communication in the local area amongst health professionals about supportive care is ...? *Prompt:* read out response options – only one should be selected.

- [ ] Very good
- [ ] Fairly good
- [ ] Fairly poor
- [ ] Very poor
- [ ] Don’t know – *Prompt:* don’t read aloud

Comments

________________________________________________________________________
________________________________________________________________________

15. Have local health professionals been encouraged to attend any communication skills training workshops in the past 12 months? *Prompt:* don’t read response options aloud unless requested.

- [ ] Yes, they have been encouraged to attend workshops
- [ ] No, they have not been encouraged to attend workshops
- [ ] Don’t know – *Prompt:* don’t read aloud

Comments:

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16. Have you participated in any communication skills training workshops in the past 12 months? *Prompt:* don’t read response options aloud unless requested. *Probe:* Elicit whether this was a workshop held especially for people from the local area, or whether it was state or nationally based.

- [ ] Yes, local workshop
- [ ] Yes, state-based or national workshop

Comments:
17. Is it your impression that local health professionals have attended communication skills training workshops? Would you say… Prompt: read out response options – only one should be selected.

- All or most local health professionals have attended
- Some local health professionals have attended
- Very few local health professionals have attended
- Don’t know – Prompt: don’t read aloud

Comments

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18. Which of the following personalised forms of information or resources for individual women are available for health professionals to use during consultations? These may include…

Prompt: Read out response options – more than one can be selected.

- A “my journey” folder that the woman has for keeping her notes
- A patient held record
- Tape recordings of consultations
- Pathology reports
- Other information resources – Prompt: specify below

- Don’t know of any personalised resources – Prompt: don’t read aloud, and then go to q20
- No, don’t provide any personalised resources – Prompt: don’t read aloud, and then go to q20

Comments

________________________________________________________________________
________________________________________________________________________
19. Do you provide any personalised forms of information or resources to women with breast cancer?

*Prompt:* Read out response options – only one option to be selected.

- □ Yes, provide personalised information to all women
- □ Yes, provide personalised information to some women
- □ No, I don't provide these personalised resources
- □ Not my role to provide these personalised resources – *Prompt:* don’t read aloud this aloud

Comments
________________________________________________________________________
________________________________________________________________________

20. Is it your impression that other local health professionals provide these personalised forms of information or resources? Would you say…

*Prompt:* Read out response options – only one option to be selected.

- □ All or most local health professionals provide personalised information or resources
- □ Some local health professionals provide personalised information or resources
- □ Very few local health professionals provide personalised information or resources
- □ Don’t know – *Prompt:* don’t read aloud

Comments
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*Information provision*

The next set of questions is about the provision of information to women and for health care providers.

21. What types of general written information do you provide to women with breast cancer and their families? Do you provide most women with… *Prompt:* Read out response options – more than one can be selected.

- □ Printed resources (such as booklets, pamphlets, fact sheets)
- □ Written information from consultations, such as written treatment plans, drawings, or diagrams
- □ Brochures from local organisations or services
22. **What types of electronic or e-health information do you provide to women and their families?** Do you provide… **Prompt:** Read out response options – more than one can be selected.  

- Information that is Internet based, such as relevant web-sites  
- Information that is of another electronic media type, such as CD-ROM  
- Contact numbers of telephone help-lines such as the Cancer Information Service  
- Do not provide these types of information – **Prompt:** don’t read aloud aloud.  
- Other: please list below in comments

Comments:  

__________________________________________________________________________  

__________________________________________________________________________

23. **Do you think health professionals in the local area can access as much information as they need to provide to women and their families about breast cancer, including supportive care issues?**  

- Always able to access as much information as needed  
- Usually able to access as much information as needed  
- Only a limited amount of information can be accessed  
- A very limited amount of information can be accessed  
- Don’t know – **Prompt:** don’t read aloud
24. Are supportive care services modified in any way to provide assistance to women of Non-English Speaking (NES) or Indigenous backgrounds? *Prompt:* Read out response options – more than one can be selected. Please note down any comments made.

- [ ] Yes, provide written information about breast cancer in common community languages
- [ ] Yes, provide written information about breast cancer specifically developed for Indigenous women
- [ ] Yes, provide interpreter services (either face-to-face or telephone)
- [ ] Yes, liaise with local Indigenous health services or community workers
- [ ] Yes, other types or information or resources – *Prompt:* list below
- [ ] No, supportive care services are not modified in any way
- [ ] No, don’t know how to access specific information or resources – *Prompt:* don’t read aloud aloud.
- [ ] Don’t have contact with women from NES/Indigenous backgrounds – *Prompt:* don’t read aloud aloud.
- [ ] Don’t know – *Prompt:* don’t read aloud aloud.

Comments

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*(Informing health care providers)*

25. What written information about supportive care is accessible to local health professionals?
   
a). First, please could you tell me what general resources are available from the following list?  
   
   *Prompt:* Read out response options – more than one can be selected.
a. Which of the following other resources specifically for local health professionals about supportive care issues have been available in the past 12 months? Have there been...

- Regular research updates from local, state or national organisations
- Newsletters (eg. printed newsletters, regularly faxed newsletters or updates)
- the Psychosocial Clinical Practice Guidelines: providing information support and counselling for women with breast cancer from the National Breast Cancer Centre
- Other clinical practice guidelines – Prompt: please list in comments below
- Other written resources – Prompt: please list in comments below
- Not aware of any resources – Prompt: don’t read aloud
- Don’t know – Prompt: don’t read aloud

Comments
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b). Second, could you tell me what information about local supportive care services and resources is available to health professionals? Prompt: Read out response options if requested.

- Locally produced resources, such as information kits
- Local directory of services
- Another strategy or system to provide information to health professionals – Prompt: please specify
- Nothing specific is available – Prompt: don’t read aloud
- Don’t know – Prompt: don’t read aloud

Comments
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26. Which of the following other resources specifically for local health professionals about supportive care issues have been available in the past 12 months? Have there been...

- Face-to-face seminars, workshops and/or education sessions
- Seminars, workshops and/or education sessions, presented via e-health technologies
- Electronic or email newsletters
- On-line bulletin boards or on-line discussion groups
27. Does your role include being responsible for providing information and education to local health professionals about supportive care issues for women with breast cancer? Prompt: Don’t read aloud options aloud unless requested.

- Yes, this is a significant component of the role
- Yes, this is a smaller component of the role in relation to other responsibilities
- Not currently part of the role, but will become a role in near future
- No, this is not part of the role

Comments

28. Are you confident that you can provide quality information to local health professionals about supportive care? Would you say you are…? Prompt: read out response options – only one should be selected.

- Very confident
- Somewhat confident
- Not very confident
- Not at all confident
- Neither confident or not confident – Prompt: don’t read aloud.
- Don’t know – Prompt: don’t read aloud.

Comments

Health care or supportive care providers needs

The focus of the final section of the survey is about the needs of health care professionals for professional support and supervision, education, training and professional development.
29. Do you have professional supervision sessions to discuss the clinical and supportive care aspects of your role? Would you say... **Prompt:** Read out response options – only one should be selected.

- [ ] Weekly supervision is provided by another health professional – **Prompt:** specify this person’s role
- [ ] Fortnightly supervision is provided by another health professional – **Prompt:** specify this person’s role
- [ ] Monthly supervision is provided by another health professional – **Prompt:** specify this person’s role
- [ ] Regular supervision is provided by another health professional – **Prompt:** specify this person’s role and specify how frequently these sessions occur
- [ ] Supervision is provided by a health professional – but it is opportunistic, not regular
- [ ] You have informal debriefing with a colleague or another health professional, but not “supervision”
- [ ] No regular supervision is available

Comments
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___________________________________________________________________________

30. Are there any opportunities for you to network or talk with other breast nurses? Would you say you participate in... **Prompt:** Read out response options – more than one can be selected.

- [ ] Face-to-face meetings with other breast nurses held weekly/fortnightly/monthly/every 2-3 months
- [ ] Face-to-face meetings with other breast nurses held opportunistically
- [ ] Teleconferences or videoconferences held weekly/fortnightly/monthly/every 2-3 months
- [ ] Teleconferences or videoconferences held opportunistically
- [ ] On-line support groups or breast nurse chat rooms
31. Have there been any opportunities in the past 12 months for you to improve your knowledge and skills specifically in the area of supportive care for women with breast cancer? Prompt: Read out response options – more than one can be selected.

☐ By receiving regular information or research updates from a local, state or national organisation

☐ Through contact with other specialist breast nurses

☐ Through education and training workshops, programs or seminars

☐ Through other methods Prompt: elicit examples and list below

☐ No opportunities have been available in the past 12 months

Comments

_________________________________________________________________________
_________________________________________________________________________

32. Are you aware of any opportunities for health professionals who are responsible for leading breast cancer support groups to network, so that these groups can be linked in some way? Prompt: Don’t read aloud options aloud unless requested.

☐ Yes

☐ No

☐ Don’t know

Comments

_________________________________________________________________________
_________________________________________________________________________
33. In the past 12 months, have you participated in any training and education activities that been of benefit to your role as a breast nurse? Prompt: Read out response options – more than one can be selected.

☐ Education or training workshops/programs/seminars about breast cancer (except communication skills) Prompt: elicit whether this was a local activity.

☐ A specific university based educational course about breast cancer nursing (e.g. La Trobe University, Queensland University of Technology, or Edith Cowan University breast nurse courses)

☐ Another activity held specifically for breast nurses (e.g. breast nurse conference)

☐ A clinical placement or mentorship program, visiting another breast nurse

☐ E-health training about video-conferencing facilities

☐ E-health workshops held via video-link

☐ Public forums or meetings held via satellite

☐ Training in e-health technologies (e.g. using videoconference facilities or tele-medicine initiatives)

☐ Training has not yet taken place, but is planned for during the next six months – Prompt: don’t read this option aloud.

☐ Another type of activity – Prompt: list below

☐ No opportunities have been available in the past 12 months – Prompt: go to q34

☐ Have not participated in any programs or initiatives in the past 12 months – Prompt: go to q34

Comments

_________________________________________________________________________
_________________________________________________________________________

33a. Was the program a useful way by which to improve your skills and knowledge in this area? Would you say it was...?  Prompt: read out response options – only one should be selected. If more than one activity was nominated above, ask the respondent to choose one activity and answer Q33a,b&c on that basis.

☐ Very useful ☐ Somewhat useful

☐ Not very useful ☐ Not at all useful
33b. Has the program increased your confidence in this area? *Prompt:* Go to 33c regardless of whether response is yes or no.

☐ Yes
☐ No

33c. Would you say you are...? *Prompt:* read out response options – only one should be selected.

☐ Very confident  ☐ Confident
☐ Some what confident  ☐ Not very confident

34. In the past 12 months, have there been any opportunities for local or visiting clinicians to find out about new technologies, such as video-conferencing facilities, that are available in the local area? *Prompt:* Elicit as much detail as possible about how they were informed of these new technologies.

☐ Yes
☐ No
☐ Don’t know

35. Overall, how would you rate your knowledge of the locally available supportive care services and resources for women with breast cancer? Would you say it was... (read options aloud) *Prompt:* note any comments made.

☐ Very high  ☐ High
☐ Not very high  ☐ Not at all high
☐ Don’t know – *Prompt:* don’t read aloud
36. Overall, how would you rate your knowledge of the **locally available resources for health professionals about supportive care for women with breast cancer**? Would you say it was… (read options aloud) **Prompt:** note any comments made.

- □ Very high
- □ High
- □ Not very high
- □ Not at all high
- □ Don’t know – **Prompt:** don’t read aloud

__________________________________________________________________________

__________________________________________________________________________

37. How aware are you of the Strengthening Support for Women with Breast Cancer program?

- □ Very aware
- □ Somewhat aware
- □ Not very aware
- □ Not at all aware

__________________________________________________________________________

__________________________________________________________________________

*Thank you very much for your time today. We greatly appreciate your participation in this interview.*
Appendix VI: Acceptability survey

NATIONAL BREAST CANCER CENTRE

ACCEPTABILITY SURVEY

STRENGTHENING SUPPORT FOR WOMEN

WITH BREAST CANCER

ID: [ deserved name or ID number here]
STRENGTHENING SUPPORT FOR WOMEN WITH BREAST CANCER

The following questions relate to the Strengthening Support for Women with Breast Cancer project that has been implemented in your local area/zone/region/State or Territory. The project has involved the implementation of strategies to improve supportive care for women with breast cancer, particularly those living in regional, rural and remote areas. The aim of this survey is to investigate the acceptability of the process to key individuals involved in strategy implementation. Your responses will contribute to the national evaluation. There may also be some questions specific to your state (QLD, NSW, SA, NT, TAS only). (Interviewer note: try to keep responses focused on relevant aspect of the project, i.e. implementation of strategies - not the evaluation process)

Participation in the Strengthening Support Program

1. Which of the following best describes your role in the Strengthening Support program?

☐ Member of a State or Territory Steering Committee, Project Team, Advisory or Reference Group (please note respondent’s role in the group, eg consumer representative, breast nurse, surgeon etc.)

   Role: __________________________________________________________

☐ Member of a regional or local Steering Committee, Project Team, Advisory or Reference Group

☐ Project manager (eg Health Department manager overseeing State/Territory project)

☐ Project coordinator

☐ Project officer employed for the Strengthening Support program

☐ Breast nurse employed for the Strengthening Support program

☐ Breast Cancer Contact worker employed through the Strengthening Support program

☐ Staff member specifically responsible for implementing Strengthening Support strategies (eg BSEP staff member in one of five regions in Victoria)

☐ Other (please specify)

   __________________________________________________________

   __________________________________________________________

   __________________________________________________________
2. **Which of the following best describes your involvement in the Strengthening Support program?**

(Interviewer note: can answer more than one; please record any details provided)

- [ ] Involved in an audit of supportive care services in the local area/zone/state/territory
- [ ] Involved in designing and developing Strengthening Support strategies
- [ ] Provided advice / feedback / expertise in relation to proposed strategies
- [ ] Actively involved in the implementation of the Strengthening Support strategies (note: this may be the person’s actual role, i.e. breast nurse is the strategy being implemented)
- [ ] Participated in strategies implemented as part of the Strengthening Support project (note: this may include participation in a multidisciplinary meeting, public forum, education seminar etc.)
- [ ] No involvement (note: end interview here)
- [ ] Other (please specify)

___________________________________________________________________________

Comments:_________________________________________________________________

___________________________________________________________________________

3. **How would you rate your awareness of the Strengthening Support strategies that have been implemented across your State or Territory?** (Interviewer note: not all respondents will be aware of statewide implementation strategies so please note which aspects of the project are know to respondent)

- [ ] Very aware
- [ ] Somewhat aware
- [ ] Not very aware
- [ ] Not at all aware

Which strategies?:_________________________________________________________________

____________________________________________________________________________
4. **How would you rate your awareness of the Strengthening Support strategies that have been implemented in your zone/district/local area?** (Interviewer note: not all respondents will be aware of specific local strategies so please note which aspects of the project are known to respondent)

- [ ] Very aware
- [ ] Somewhat aware
- [ ] Not very aware
- [ ] Not at all aware
- [ ] N/A, unaware of/not familiar with any strategies implemented in my local area (note: this response intended for those participant from metropolitan regions where local level strategies not implemented)

*Which strategies?: ________________________________

5. **What activities were undertaken during the planning and development stage of the Strengthening Support Program in your State/Territory?** (Interviewer note: this is not an exhaustive list so probe and note any other activities nominated – top of next page)

- [ ] The creation of a State/Territory Steering Committee, Project Team, Advisory/Reference Group
- [ ] The creation of zonal/regional/local Steering Committees, Project Teams, Advisory/Reference Groups
- [ ] The conduct of an audit of supportive care services or supportive care services mapping exercise
- [ ] Consultation with existing organisations that could assist with the planning of strategies, including
  - [ ] (tick all relevant) local area or zone health services
  - [ ] existing breast cancer organisation (eg BSEP in Victoria)
  - [ ] state or territory Cancer Councils
  - [ ] state or territory health departments
- [ ] Consultation with representatives of local services, including
  - [ ] (tick all relevant) clinicians and other health professionals based at local hospitals
6. **How were the needs and/or views of breast cancer consumers considered and incorporated during the planning and development phases of the program?** Would you say there was… (Interviewer note: can select more than one option)
- Active collaboration and representation through consumer membership on a Steering Committee, Project Team, Advisory or Reference Group
- Active consultation with consumers through focus groups, interviews, consumer surveys or an audit of supportive care services
- Consumer involvement through another mechanism (describe)
- No active collaboration or consultation with consumers (probe: why/why not?_)
- Don’t know

Comments

7. **How were the needs and/or views of health professionals considered and incorporated during the planning and development phases of the program?** Would you say there was… (Interviewer note: can select more than one option)
Active collaboration and consultation through membership on Steering Committee, Project Team, Advisory or Reference Group

Active consultation through focus groups, interviews, surveys or audit of supportive care services

Health professional involvement through another mechanism (describe)

No active collaboration or consultation with health professionals (probe: why/why)

Don’t know

Comments

Overall themes

8. The following statements ask you to rate whether you agree that Strengthening Support strategies have impacted on the way supportive care is organised and provided in your State or Territory. Please rate each item according to whether you strongly agree, agree, disagree, strongly disagree or not applicable. (Interviewer note: respondents must answer all items, although not all responses will be applicable in all jurisdictions)

Would you say that the Strengthening Support project has…

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree somewhat</th>
<th>Disagree somewhat</th>
<th>Strongly disagree</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>...provided training and development opportunities for health professionals (such as e-health initiatives, public forums, communication skills training programs, training for general practitioners)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>...established or improved professional support and supervision for breast nurses or cancer contact workers</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>...provided opportunities for health professionals to enhance their knowledge and awareness of supportive care issues for women with breast cancer (including services and resources available for women with breast cancer, resources available for health professionals)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
... increased acceptance of and improved attitudes towards e-health resources and infrastructure from health professionals

...established or encouraged further implementation of a multidisciplinary care approach between health services in urban and regional/rural locations

...established breast nurse positions in regional, rural or remote locations

...established cancer ‘contact’ positions in rural areas

...enabled continuity of care for women living in rural areas when returning home after receiving their treatment in urban areas

...enabled continuity of care for women living in rural areas within their own community or region

...enhanced the availability of quality information for women with breast cancer through the development of information kits or new resources specifically designed for women

...encouraged a consistent approach to ensuring all women receive information about breast cancer, through coordinated efforts by health professionals such as breast nurses, cancer contact workers, and general practitioners

### Successes, enablers, barriers and unanticipated benefits

9. **In your opinion, how successful was the Strengthening Support for Women with Breast Cancer project in your State/Territory or region?**

   - [ ] Very successful
   - [ ] Moderately successful
   - [ ] Somewhat successful
   - [ ] Not very successful
   - [ ] Not at all successful

10. **What do you consider to be the most successful aspects of the project?**

    __________________________________________________________
    __________________________________________________________
    __________________________________________________________
11. In your opinion, which of the following factors facilitated the successful implementation of the Strengthening Support strategies? (Interviewer note: can select more than one option)

- [ ] Existing infrastructure (eg access to e-health technology)
- [ ] Established communication networks between health professionals
- [ ] Skills and abilities of the people employed for, or directly involved in, implementing the project
- [ ] Support for the project from consumers
- [ ] Support for the project from health professionals
- [ ] Collaboration/commitment from other organisations (eg Cancer Councils, private hospitals)
- [ ] Collaboration/sharing from other States/Territories as part of the Strengthening Support project
- [ ] Other (describe):

 Comments:

12. In your opinion, how difficult was it to implement strategies within your local area?

- [ ] Very (probe – see below)
- [ ] Moderately (probe – see below)
- [ ] Somewhat (probe – see below)
- [ ] A little (probe – see below)
- [ ] Not at all (Go to Q14)
- [ ] N/A, unaware of/not familiar with any strategies implemented in my local area

If difficult, what difficulties were encountered?

 What was done to overcome difficulties?
13. *In your opinion, were there any particular barriers encountered during the implementation of strategies?* Would you say there was… (Interviewer note: can select more than one option)

- ☐ Time constraints
- ☐ Limited funds available
- ☐ Inadequate infrastructure to support specific strategies
- ☐ Poor support from State/Territory level administrators/funders
- ☐ Poor support from local/regional/zonal level administrators/funders
- ☐ Poor support from local/regional/zonal level health professionals
- ☐ Lack of collaboration from existing organisations
- ☐ Others *(describe)*:

  ________________________________________________________________

Comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14. *Were there any unanticipated benefits of the project and/or strategy implementation?*

- ☐ No  ☐ Yes *(If yes, describe:)*

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

15. *Has the project and/or implementation of any strategies had any flow-on effects? (eg to other programs or care for patients with other cancers/diseases?)*

- ☐ No
- ☐ Yes *(If yes, describe:)*

________________________________________________________________________
________________________________________________________________________
Sustainability of Strengthening Support strategies

16. Are you aware of any efforts that have been or are currently being made to sustain the strategies developed as part of the Strengthening Support program? Would you say you...

☐ Have secured agreement from health organisation/service/government body for ongoing maintenance of strategies (eg funding staff positions, commitment to maintain/distribute resources)

☐ Currently seeking agreement from health organisation/service/government body for ongoing maintenance of strategies (eg funding staff positions, commitment to maintain/distribute resources)

☐ Have secured key stakeholders (including consumers) or clinicians to lobby in support of strategies

☐ Currently seeking key stakeholders (including consumers) or clinicians to lobby in support of strategies

☐ Currently undertaking/completed the collection of local or state-based evaluation data to assist in demonstrating the value of strategies

☐ Have undertaken other efforts ((describe):

______________________________________________

Comments

_____________________________________________________________________
________________________________________________________________________

17. In your opinion, do you think there are any barriers that will prevent strategies from being sustained beyond the implementation period of the project? If so, are these related to... (Interviewer note: can select more than one)

☐ Lack of local infrastructure or systems to support implemented strategies

☐ Lack of influential clinicians/health professionals/consumers/other leaders to lobby for continuation of strategies

☐ Lack of funding or unwillingness to allocate funds to continue strategies

☐ Lack of human resources to dedicate to continue strategies

☐ Inability to incorporate strategies into local health policy and planning

☐ Insufficient data or evidence to demonstrate the value of Strengthening Support strategies
Other (describe):

________________________________________________________________

Comments

________________________________________________________________________

________________________________________________________________________

Change

18. Please list below any significant changes in supportive care provision in the local area or across the State/Territory as a direct result of the Strengthening Support strategies. How successful do you think these changes have been? (Interviewer note: Please briefly list each change and indicate level of success on scale opposite)

<table>
<thead>
<tr>
<th>Change</th>
<th>Very</th>
<th>Moderately</th>
<th>Somewhat</th>
<th>A Little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
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<td>2)</td>
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<td>3)</td>
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<td>5)</td>
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<td>6)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Overall opinions

19. How acceptable have you personally found being involved in the Strengthening Support Program?

<table>
<thead>
<tr>
<th></th>
<th>Very</th>
<th>Moderately</th>
<th>Somewhat</th>
<th>A Little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

20. Which of the strategies implemented in your area or State/Territory do you think are the most useful in improving supportive care for women with breast cancer, and why? (Interviewer note: can be more than one. Prompt: what were they? Probe: Why do you think they will be useful?)
21. Do you have any suggestions or advice from your involvement in the program that you would give to others who plan to implement similar strategies?

☐ No

☐ Yes

Comment (Probe: what advice?)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

22. Do you have any other comments you would like to make about the project and/or implementation of the Strengthening Support strategies?

☐ No

☐ Yes

Comment (Probe: what advice?)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

State/Territory specific questions to be asked now, participating States/Territories:

- New South Wales
- South Australia
- Queensland
- Tasmania
- Northern
For Western Australia, Australian Capitol Territory and Victorian participants:

Thank-you

We appreciate the time you have given us.
## New South Wales questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not at all</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you participated as a speaker in any of the NSW Breast Cancer Institute’s Public Forums?</td>
<td>☐</td>
<td>☐</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
| If Yes:  
Please rank the usefulness of these forums for consumers out of five, with 1 ranking as ‘not at all’ and five ‘extremely’. |     |    | 4          | 5          |           |
| Have you participated as a member of the audience in the NSW Breast Cancer Institute’s Public Forums? | ☐   | ☐  | 1          | 2          | 3         |
| If Yes:  
Using the one to five scale how useful do you think these forums were? |     |    | 4          | 5          |           |
| Have you seen any of the NSW Breast Cancer Institutes Fact Sheets?        | ☐   | ☐  | 1          | 2          | 3         |
| If Yes:  
Using the one to five scale please rank the usefulness of this strategy. |     |    | 4          | 5          |           |
| Have you seen any of the NSW Breast Cancer Institutes Fact Sheets?        | ☐   | ☐  | 1          | 2          | 3         |
| If Yes:  
Please rank the usefulness of this strategy using the one to five scale. |     |    | 4          | 5          |           |
| Have you seen any of the Breast Cancer Institute’s CDs, (Ask the Specialist & Understanding Breast Cancer). | ☐   | ☐  | 1          | 2          | 3         |
| If Yes:  
Please rank the usefulness of these CDs using the 1 to 5 scale. |     |    | 4          | 5          |           |
| Have you ever accessed the Breast Cancer Institute’s website www.bci.org.au? | ☐   | ☐  | 1          | 2          | 3         |
| If Yes:  
Please rank the usefulness of the website using the 1 to 5 scale. |     |    | 4          | 5          |           |
<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>29</td>
<td>Have you used the Breast Cancer Institute’s electronic Directory of Breast Cancer Treatment and Services, which has been funded by the Strengthening Support for Rural Women with Breast Cancer Program?</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

**If Yes:**

*Please rank the usefulness of the electronic Directory using the 1 to 5 scale.*

<table>
<thead>
<tr>
<th>Rank</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>
Queensland questions

23. *Do you think the strategies implemented by the Strengthening Support for Women with Breast Cancer Project in your zone or district have improved coordination and continuity of care for women with breast cancer?*

☐ Yes ➔  Can you give examples of any improvements?

________________________________________________________________________________________

________________________________________________________________________________________

☐ No ➔  *What have been the main barriers to such improvements?*

________________________________________________________________________________________

________________________________________________________________________________________

24. *How would you rate awareness of the strategies implemented among consumers and service providers in your zone or district?* (Interviewer note: this is similar to question four however this question specifically relates to consumers and service providers)

☐ Very aware

☐ Somewhat aware

☐ Not very aware

☐ Not at all aware

*What steps do you think could be undertaken to increase awareness?*

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

25. *Is there any evidence of improvements or enhancements to the flow of information between members of the multidisciplinary treatment team and other service providers?*
☐ Yes ➔  Please describe:

........................................................................................................................................

........................................................................................................................................

........................................................................................................................................

☐ No

........................................................................................................................................

........................................................................................................................................

........................................................................................................................................

26  Do you think access to information has improved for women with breast cancer?

☐ Yes ➔  In what ways?

........................................................................................................................................

........................................................................................................................................

........................................................................................................................................

☐ No ➔  What do you think could be done to improve this access?

........................................................................................................................................

........................................................................................................................................

........................................................................................................................................

Thank-you

We appreciate the time you have given us.
South Australia

23 How has the Strengthening support project addressed issues for Aboriginal women.

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

24 How has the strengthening support project addressed issues for women with a culturally or linguistically diverse background? (Note: interviewer shouldn’t list response options unless respondent doesn’t answer and requires prompting)

- membership on Steering/other committees or working groups
- training opportunities for workers
- community &/or worker consultations & presentations
- development of information resources
- other:

_____________________________________________________________________

25 How have the Breast Cancer Support Service (BCSS) Volunteers from The Cancer Council SA been included and linked to the Project? (Note: interviewer shouldn’t list response options unless respondent doesn’t answer and requires prompting)

- membership on Steering/other committees or working groups
- consultations
- presentations
- newsletters/updates
- local Breast Cancer Support Project meetings
- planning of local initiatives
- other:

_____________________________________________________________________

Strengthening support for women with breast cancer: national process evaluation report 219
26 **How well do you think local health professionals working with women diagnosed with breast cancer (eg, GPs, hospitals) are aware of the Local Breast Cancer Contact Workers role?**

- [ ] very aware
- [ ] somewhat
- [ ] not very
- [ ] not at all

27 **What mechanisms have been used to create community awareness of the Local Breast Cancer Contact Workers role?** *(Note: interviewer shouldn’t list response options unless respondent doesn’t answer and requires prompting)*

- [ ] local media releases
- [ ] local radio
- [ ] pamphlets in local libraries/GPs
- [ ] women’s health displays ie field days, luncheons, women’s groups. Shopping centre stalls
- [ ] ABC day events
- [ ] other;

---

**Thank-you**

*We appreciate the time you have given us.*
For the following statements please rate each item according to whether you strongly agree, agree, disagree, strongly disagree or not applicable.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree somewhat</th>
<th>Disagree somewhat</th>
<th>Strongly disagree</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>The establishment of the Breast Care Nurse position has assisted in addressing gaps in service provided to remote communities by coordinating care pathways.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>24</td>
<td>The Strengthening Support Initiative has assisted aboriginal women from remote communities with breast cancer to feel comfortable in accessing services relating to treatment and ongoing care.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>25</td>
<td>The SS Initiative has assisted in coordinating the clinical pathway for aboriginal patients and has increased sensitivity in meeting their cultural and linguistic needs through the Breast Care Nurse</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Thank-you

We appreciate the time you have given us.
Appendix VII: Resources

See following pages for lists of resources produced by each State and Territory.
<table>
<thead>
<tr>
<th>Title of resource</th>
<th>Format</th>
<th>Focus Area *</th>
<th>Contacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT BREAST CARE PACKAGE- a resource package for consumers diagnosed with early breast cancer</td>
<td>Yes</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Unmet needs survey of women who have undergone multi-modality treatment for early breast cancer</td>
<td>Yes</td>
<td>Yes</td>
<td>x</td>
</tr>
<tr>
<td>Multidisciplinary Breast Meeting Flow Sheet</td>
<td>Yes</td>
<td>Yes</td>
<td>x</td>
</tr>
<tr>
<td>Multidisciplinary Lymphoedema Clinic Flow Sheet</td>
<td>Yes</td>
<td>Yes</td>
<td>x</td>
</tr>
<tr>
<td>Information leaflets on types of breast surgery</td>
<td>Yes</td>
<td>No</td>
<td>x</td>
</tr>
<tr>
<td>Breast cancer surgery clinical pathway</td>
<td>Yes</td>
<td>Yes</td>
<td>x</td>
</tr>
<tr>
<td>Breast cancer surgery patient pathway</td>
<td>Yes</td>
<td>Yes</td>
<td>x</td>
</tr>
</tbody>
</table>

Explanation notes:

*Publications that concentrate on:
- Workforce and training issues include positions descriptions, course outlines etc.
- Service delivery includes referral forms, patient information forms and professional information kits etc
- Consumer information include brochures, information kits etc
- Service directories include any website or printed material
- Research/ Discussion paper/ Workshop findings include any reports or publications that may be disseminated

** Electronic copy - please note what format this product comes in e.g. CR-Rom, pdf file, word doc, video, web material etc
## SUMMARY OF RESOURCES DEVELOPED FROM THE STRENGTHENING SUPPORT FOR WOMEN WITH BREAST CANCER INITIATIVE

**STATE:** New South Wales  
**DATE OF UPDATE:** May 2004

<table>
<thead>
<tr>
<th>RESOURCES</th>
<th>FORMAT</th>
<th>FOCUS AREA *</th>
<th>CONTACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Paper copy available (Yes/No)</td>
<td>Electronic copy available ** (Yes/No)</td>
<td>Workforce / Training</td>
</tr>
</tbody>
</table>
| Breast Conservation - Patient brochure                               | Yes                     | Yes          | x                                                                                       | Marketing and Promotions NSW Breast Cancer Institute  
PO Box 143 Westmead NSW 2145. Phone (02)9845 45 68; Facsimile (02)9845 8468; email: maps@bci.org.au |
|                                                                      |                         |              |                                                                      |                                                                      |
| Breast Reconstruction - Patient brochure                              | Yes                     | Yes          | x                                                                                       | Marketing and Promotions NSW Breast Cancer Institute  
PO Box 143 Westmead NSW 2145. Phone (02)9845 45 68; Facsimile (02)9845 8468; email: maps@bci.org.au |
|                                                                      |                         |              |                                                                      |                                                                      |
| Directory of Treatment and Services NSW                              | Yes-web                 | x            | x                                                                                       | www.bci.org.au/BreastCancerDirectory/home.htm |
|                                                                      |                         |              |                                                                      |                                                                      |
| Public Forum 2001 - A multidisciplinary approach to the diagnosis, treatment and management of early and advanced breast cancer | CD-ROM or Video (VHS) | x            |                                                                      | Marketing and Promotions NSW Breast Cancer Institute  
PO Box 143 Westmead NSW 2145. Phone (02)9845 45 68; Facsimile (02)9845 8468; email: maps@bci.org.au |

The Breast Conservation patient brochure is designed to enable women to discuss and understand Breast Conservation in an informed way.

The Breast Reconstruction patient brochure is designed to enable women to discuss and understand breast reconstruction in an informed way. Please note that it is not a substitute for advice.

The online directory will help women and their families, through their general practitioners, to find the treatment and other breast cancer services which are most appropriate for their particular needs.


The NSW Breast Cancer Institute co-ordinates an annual public forum on breast cancer. The Public Forum 2001 covers treatment issues surrounding a multidisciplinary approach to care.
<table>
<thead>
<tr>
<th>Public Forum 2002 - Breast cancer and beyond</th>
<th>CD-ROM or Video (VHS)</th>
<th>x</th>
</tr>
</thead>
<tbody>
<tr>
<td>The NSW Breast Cancer Institute co-ordinates an annual public forum on breast cancer. The Public Forum 2002 covers issues such as: I'm still tired doctor; I've gained too much weight; DCIS in a young woman; Understanding options for DCIS; Breast reconstruction - understanding your options; Communicating with your doctor</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Public Forum 2003 - If breast cancer comes back ...</th>
<th>CD-ROM or Video (VHS)</th>
<th>x</th>
</tr>
</thead>
<tbody>
<tr>
<td>The NSW Breast Cancer Institute co-ordinates an annual public forum on breast cancer. The Public Forum 2003 covers issues on understanding how and why breast cancer comes back; treating breast cancer if it comes back; fighting metastatic disease - a personal journey; keeping pain under control; and maintaining hope</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Explanation notes:**

*Publications that concentrate on:
- Workforce and training issues include positions descriptions, course outlines etc.
- Service delivery includes referral forms, patient information forms and professional information kits etc.
- Consumer information include brochures, information kits etc.
- Service directories include any website or printed material
- Research/Discussion paper/Workshop findings include any reports or publications that may be disseminated*

**Electronic copy - please note what format this product comes in e.g. CR-Rom, pdf file, word doc, video, web material etc**
<table>
<thead>
<tr>
<th>RESOURCES</th>
<th>FORMAT</th>
<th>FOCUS AREA</th>
<th>CONTACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brochure: The Specialist Breast Care Nurse</td>
<td>Paper copy available (Yes/No): Y</td>
<td>Electronic copy available ** (Yes/No): x</td>
<td>Workforce/ Training: x</td>
</tr>
<tr>
<td>A consumer brochure describing the role of the Specialist Breast Care Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral Pad</td>
<td>Paper copy available (Yes/No): Y</td>
<td>Electronic copy available ** (Yes/No): x</td>
<td>Workforce/ Training: x</td>
</tr>
<tr>
<td>A set of forms for medical specialists to refer women to a Specialist Breast Care Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Position Description - Specialist Breast Care Nurse</td>
<td>Paper copy available (Yes/No): Y</td>
<td>Electronic copy available ** (Yes/No): Y</td>
<td>Workforce/ Training: x</td>
</tr>
<tr>
<td>Standard position description for a Specialist Breast Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Draft only: Aboriginal Clients Resource</td>
<td>Paper copy available (Yes/No): Y (draft only)</td>
<td>Electronic copy available ** (Yes/No): x</td>
<td>Workforce/ Training: x</td>
</tr>
<tr>
<td>A pictorial guide that can be used by Aboriginal Health Workers and health professionals to show Aboriginal women what they can expect during their treatment journey for breast cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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## SUMMARY OF RESOURCES DEVELOPED FROM THE STRENGTHENING SUPPORT FOR WOMEN WITH BREAST CANCER INITIATIVE

**STATE:** Queensland  
**DATE OF UPDATE:** May 2004

### RESOURCES

<table>
<thead>
<tr>
<th>Title of resource</th>
<th>FORMAT</th>
<th>FOCUS AREA *</th>
<th>CONTACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Breast Nurse (SBN) Brochure - information to consumers on role of SBN</td>
<td>Paper</td>
<td>Workforce</td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>locations in Qld</td>
<td>copy</td>
<td>Training</td>
<td>Yes No x</td>
</tr>
<tr>
<td>Generic Position Description Specialist Breast Nurse - standard position description</td>
<td>Electronic</td>
<td>Service</td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>used for advertising positions in Qld</td>
<td>copy available **</td>
<td>Delivery</td>
<td>Yes Yes - Word x</td>
</tr>
<tr>
<td>State Evaluation Report Southern Zone Implementation: Gold Coast and Princess</td>
<td>Yes No</td>
<td>Consumer</td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>Alexandra Hospitals Sites - results of implementation process of SBN position at</td>
<td>Directory of</td>
<td>Services</td>
<td>Yes No x</td>
</tr>
<tr>
<td>these sites</td>
<td>Research/ Discussion paper/ Workshop findings</td>
<td></td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>State Evaluation Report Southern Zone Implementation: Toowoomba Hospital Site -</td>
<td>Yes No</td>
<td>x</td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>results of implementation process of SBN position at this site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Evaluation Report Northern Zone Implementation: Mackay and Townsville Sites</td>
<td>Yes No</td>
<td>x</td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>- results of implementation process of SBN position at these sites</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Evaluation Report Northern Zone Implementation: Cairns Site - results of</td>
<td>Yes No</td>
<td>x</td>
<td>Ms Kay Murray, Women’s Cancer Screening Services, Qld Health Ph: (07) 3234 0903 <a href="mailto:KMurray@health.qld.gov.au">KMurray@health.qld.gov.au</a></td>
</tr>
<tr>
<td>implementation process of SBN position at this site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please note: limited copies of evaluation reports available</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Explanation notes:**

*Publications that concentrate on:*  
- Workforce and training issues include positions descriptions, course outlines etc.
- Service delivery includes referral forms, patient information forms and professional information kits etc
- Consumer information include brochures, information kits etc
- Service directories include any website or printed material
- Research/ Discussion paper/ Workshop findings include any reports or publications that may be disseminated

**Electronic copy** - please note what format this product comes in e.g. CR-Rom, pdf file, word doc, video, web material etc

---

Strengthening support for women with breast cancer: national process evaluation report 227
<table>
<thead>
<tr>
<th>Title of resource</th>
<th>Paper copy available</th>
<th>Electronic copy available</th>
<th>Workforce Training</th>
<th>Service Delivery</th>
<th>Consumer Information</th>
<th>Directory of Services</th>
<th>Research/ Discussion paper/ Workshop findings</th>
<th>CONTACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Draft) Orientation Resource for Breast Cancer Contact Workers</td>
<td>Yes</td>
<td>No</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Department of Human Services (SA), Social Justice Division Ph: (08) 82266466 or website <a href="http://www.dhs.sa.gov.au">www.dhs.sa.gov.au</a></td>
</tr>
<tr>
<td>(An orientation resource for newly nominated BC contact workers.)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Mapping a breast cancer journey after diagnosis: A service provider's information resource for working with women from culturally and linguistically diverse backgrounds</td>
<td>Yes</td>
<td>Yes - PDF &amp; web</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Department of Human Services (SA), Social Justice Division Ph: (08) 82266466 or website <a href="http://www.dhs.sa.gov.au">www.dhs.sa.gov.au</a></td>
</tr>
<tr>
<td>(A resource which maps the journey for CALD women from rural areas to city based treatment services for BC.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast Cancer Information: Supporting women with breast cancer in rural and remote South Australia</td>
<td>Yes</td>
<td>Yes-PDF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>Department of Human Services (SA), Country Health Division Ph: (08) 82266466</td>
</tr>
<tr>
<td>(A pamphlet describing the role of the Breast Cancer Contact Worker in SA &amp; the services they offer)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning a trip for medical care</td>
<td>Yes</td>
<td>Yes-PDF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>Department of Human Services (SA), Country Health Division Ph: (08) 82266466</td>
</tr>
<tr>
<td>(A checklist of tasks for country people planning a trip to Adelaide for medical care)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resource Kit for Women with Breast Cancer</td>
<td>No</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>Department of Human Services (SA), Country Health Division Ph: (08) 82266466</td>
</tr>
<tr>
<td>(A resource folder of BC information for hospitals and community health services)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mapping a breast cancer journey after diagnosis: A service providers information resource for working with Aboriginal and Torres Strait Islander women</td>
<td>Yes</td>
<td>Yes- PDF &amp; Web</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>Department of Human Services (SA), Country Health Division Ph: (08) 82266466 or website when available <a href="http://www.dhs.sa.gov.au">www.dhs.sa.gov.au</a></td>
</tr>
<tr>
<td>(Resource which maps the journey to be experienced by ATSI women when travelling to Adelaide for BC treatment)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral form</td>
<td>Yes</td>
<td>Yes - web</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>Department of Human Services (SA), Country Health Division Ph: (08) 82266466 or website when available <a href="http://www.dhs.sa.gov.au">www.dhs.sa.gov.au</a></td>
</tr>
<tr>
<td>(Web based form for medical specialists to refer rural patients to a Breast Cancer Contact Worker in their local area.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(The final State Evaluation Report)

| | Yes | Yes - web | | x | |

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## SUMMARY OF RESOURCES DEVELOPED FROM THE STRENGTHENING SUPPORT FOR WOMEN WITH BREAST CANCER INITIATIVE

### STATE: Tasmania  
**DATE OF UPDATE:** 10-May-04

<table>
<thead>
<tr>
<th>RESOURCES</th>
<th>FORMAT</th>
<th>FOCUS AREA</th>
<th>CONTACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of resource</td>
<td>Paper copy available (Yes/No)</td>
<td>Electronic copy available ** (Yes/No)</td>
<td>Workforce Training</td>
</tr>
<tr>
<td><strong>RESOURCES</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report: Tasmanian Strengthening Support for Women with Breast Cancer Phase One Report - describes initial project approach and results to define areas of need and project objectives</td>
<td>yes</td>
<td>yes</td>
<td></td>
</tr>
<tr>
<td>Project Planning Materials 1) Project Management Plan: SSWBC Tasmania 2) Terms of Reference: Project Reference Group 3) Visual Tasmanian Project Approach 4) Evaluation Strategy</td>
<td>no</td>
<td>yes</td>
<td></td>
</tr>
<tr>
<td>Referral Form: Community Breast Care Nurse - form to be completed by health care providers when referring a patient to the Community Breast Care Nursing Service</td>
<td>yes</td>
<td>yes</td>
<td></td>
</tr>
<tr>
<td>Brochure: Community Breast Care Nursing Service - promotional and information tool for the community and health care sites</td>
<td>yes</td>
<td>yes</td>
<td></td>
</tr>
<tr>
<td>Promoting the Breast Nurse: Introduction to the Breast Nurse (generic PowerPoint Presentation) - designed for use by Breast Nurses to describe and promote their role at in services</td>
<td>no</td>
<td>yes</td>
<td></td>
</tr>
<tr>
<td>Letter Template: Breast Nurse Communication - template used by breast nurses to communicate important information to other health care professionals involved in a woman’s care</td>
<td>yes</td>
<td>yes</td>
<td></td>
</tr>
<tr>
<td>Report: Tasmanian Breast Cancer Pilot Information Strategy - details information strategy and evaluation results of pilot strategy</td>
<td>Yes</td>
<td>yes</td>
<td></td>
</tr>
</tbody>
</table>

Please indicate a contact for each resource to distribute copies if requested. Please include name, phone and fax number and/or email address. Also include any relevant website details.
**Consumer Information:**
1) Tasmanian Breast Cancer Information Packet - details support, practical, and informational services available to regional Tasmanians
2) Breast Cancer Information - Consumer Kit for Health Care Sites - details support, practical, and informational services available to regional Tasmanians including key brochures for the community to view at health care sites

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Workforce Information:**
Breast Cancer Information - Health Service Provider Kit - brings together information about relevant local Tasmanian services and clinical practice guidelines

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Report:**
Satellite Breast Cancer Forums in Tasmania - describes experience and evaluation of 2003 satellite forums and provides recommendations for future forums

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Initiating Discussions about New Co-ordination of Care Roles:**

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Position Description:**
Specialist Breast Nurse - hospital

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper phone 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Position Description:**
Community Breast Care Nurse

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Reports:**
Communication Skills Training Workshop Evaluation - details experience and evaluation from three Tasmanian workshops

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |

**Project Bulletin (Numbers 1 - 4) SSWBC TAS:**
4 - 6 monthly bulletins utilised to communicate with stakeholders about project developments during implementation stage

| yes | no  | x  | The Cancer Council Tasmania, Lesley Cooper ph 03 6336 2030 fax 03 6336 2789 or lcooper@cancertas.org.au |
**Conference Presentations:**
1) Poster: Public Health Association of Australia 2003 - "Potentials in supportive cancer care: specialist breast nurse development, implementation and research"  
2) Poster: Clinical Oncological Society of Australia 2003 - "Addressing supportive care needs in rural areas: The Tasmanian Experience"  
3) PowerPoint Presentation: National Breast Care Nurses Conference 2004 - "Developing Information: Local Resources for Consumers and Health Care Sites"  
4) PowerPoint Presentation: National Breast Care Nurses Conference 2004 - "Initiating Rural Breast Nurse Positions: The Tasmanian Experience"

**Final Report:** Strengthening Support for Women with Breast Cancer - overall activity and evaluation report including recommendations (anticipated availability September 04)

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<th>CONTACTS</th>
</tr>
</thead>
</table>
| **Rural Specialist Breast Nurse Project (RSBN) - Referral forms (13x 20cm, pads of 30 forms)** | Paper copy available (Yes/No): Yes, Electronic copy available ** (Yes/No): Yes | Workforce Training (Please mark with an "x") Service Delivery, Consumer Information "x" the focus | Directory of Services area that most appropriately summarizes | Julia Fallon-Ferguson  
Manager, Women’s Cancer  
The Cancer Council Western Australia  
Tel: 08 9212 4348  
Email julia@cancerwa.asn.au |
| **Rural Specialist Breast Nurse - orientation and training program** | Yes | x | Julia Fallon-Ferguson  
Manager, Women’s Cancer  
The Cancer Council Western Australia  
Tel: 08 9212 4348  
Email julia@cancerwa.asn.au |
| **Brochure - Rural Specialist Breast Nurse Project** | Paper copy available (Yes/No): Yes, Electronic copy available ** (Yes/No): Yes - PDF | Workforce Training (Please mark with an "x") Service Delivery, Consumer Information "x" the focus | Directory of Services area that most appropriately summarizes | Julia Fallon-Ferguson  
Manager, Women’s Cancer  
The Cancer Council Western Australia  
Tel: 08 9212 4348  
Email julia@cancerwa.asn.au |
| **Poster (A3 size)- Rural Specialist Breast Nurse Project** | Yes | x | Julia Fallon-Ferguson  
Manager, Women’s Cancer  
The Cancer Council Western Australia  
Tel: 08 9212 4348  
Email julia@cancerwa.asn.au |
| **Administrative Templates** | Paper copy available (Yes/No): Yes | Workforce Training (Please mark with an "x") Service Delivery, Consumer Information "x" the focus | Directory of Services area that most appropriately summarizes | Julia Fallon-Ferguson  
Manager, Women’s Cancer  
The Cancer Council Western Australia  
Tel: 08 9212 4348  
Email julia@cancerwa.asn.au |
Explanation notes:

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</thead>
<tbody>
<tr>
<td>Title of resource</td>
<td>Paper copy available (Yes/No)</td>
<td>Electronic copy available ** (Yes/No)</td>
</tr>
<tr>
<td>LESSONS LEARNED - SSWBC VICTORIA</td>
<td><a href="#">Use of E-health to Improve Supportive Care for Women with Breast Cancer</a> - this resource includes a selection of ehealth initiatives implemented through the SSWBC Program in Victoria and outlines the lessons learned</td>
<td>Yes-PDF</td>
</tr>
<tr>
<td>Grampians Region Breast Cancer Information and Services Website - also includes links to the Connectingcare Electronic Service Directory &amp; Referral System, a referral mechanism to all health and community services within different municipalities around Victoria</td>
<td><a href="http://www.whg.org.au/breastcancer">www.whg.org.au/breastcancer</a></td>
<td>Yes - web</td>
</tr>
<tr>
<td>Hume Region Breast Cancer Information Website - this site has general information on breast related topics, including breast cancer, and a detailed directory of services for the Hume Region</td>
<td><a href="http://www.breastservices.humehealth.com.au">www.breastservices.humehealth.com.au</a></td>
<td>Yes - web</td>
</tr>
</tbody>
</table>

**Notes:**
- Please mark with an "x" the focus area that most appropriately summaries the publication.
- Please indicate a contact for each resource to distribute copies if requested. Please include name, phone and fax number and/or email address. Also include any relevant website details.

---

*Strengthening support for women with breast cancer: national process evaluation report*
<table>
<thead>
<tr>
<th>BCN SUPPORT WEBSITE FORUM</th>
<th>Yes - web</th>
<th>x</th>
<th>Julie Harris, Loddon Mallee Region, Ph: (03) 5441 6850 <a href="http://www.breastservices.lmha.com.au">www.breastservices.lmha.com.au</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Loddon Mallee Region Breast Care Nurse Forum Area - an education and support forum area for breast care nurses available through the Loddon Website. A promotional flyer is also available which briefly describes the forum area and provides contact details for further information <a href="http://www.breastservices.lmha.com.au">www.breastservices.lmha.com.au</a></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hume Region Breast Care Nurse Forum Area - accessible via Hume Website. The forum area is open to Breast Care Nurses nationally. Instructions on how to register for access to the forum area are also available <a href="http://www.breastservices.humehealth.com.au">www.breastservices.humehealth.com.au</a></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IT AUDIT / SURVEY TOOLS</th>
<th>Yes - web</th>
<th>x</th>
<th>Philippa Hartney, Loddon Mallee Region, Ph: (03) 5441 6850</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loddon Mallee Information Technology &amp; Skills Audit Report - audit of current skills and available technology in the Loddon Mallee region.</td>
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<tr>
<td>Hume Region Information Technology Needs Analysis - survey tool developed to determine the information technology skills and needs of key stakeholders across Hume Breast Services Enhancement Program</td>
<td>Yes-PDF</td>
<td>x</td>
<td>Kate Cuss, Hume Region, Ph: (03) 5832 2740</td>
</tr>
<tr>
<td>Grampians Region Website Usability Testing - describes the approach adopted to test the usability of the Grampians Breast Cancer Services website with a small sample of participants</td>
<td>Yes</td>
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<tr>
<td>Barwon South Western Region Videoconference Evaluation Tool - proforma in excel format used for evaluating meetings held via videoconference. The videoconference technology is the focus of the evaluation questions</td>
<td>Yes-Excel</td>
<td>x</td>
<td>Jane Jones, Barwon South Western Region, Ph: (03) 5246 5159</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>VIDEOCONFERENCE GUIDELINES / FACILITATION SKILLS</th>
<th>Yes-PDF</th>
<th>x</th>
<th>Catuscia Bluso, Victorian Department of Human Services, Ph: (03) 9616 2132</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workshop Notes for Facilitating Videoconferences - provides tips for facilitating meetings held via videoconference</td>
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<tr>
<td>Loddon Mallee Region Guidelines for Videoconferencing - guidelines developed to assist with the preparation and coordination of meetings held via videoconference</td>
<td>Yes-PDF</td>
<td>x</td>
<td>Philippa Hartney, Loddon Mallee Region, Ph: (03) 5441 6850</td>
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### E-Health Information / Presentations

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<tr>
<td>Oncology via Telemedicine</td>
<td>Yes -video</td>
<td>x</td>
<td>Catuscia Buoso, Victorian Department of Human Services, Ph: (03) 9616 2132</td>
</tr>
<tr>
<td>Video</td>
<td>Yes-video</td>
<td>x</td>
<td>Catuscia Buoso, Victorian Department of Human Services, Ph: (03) 9616 2132</td>
</tr>
<tr>
<td>E Health Presentations - Loddon Mallee Breast Services Enhancement Program</td>
<td>Yes</td>
<td>x</td>
<td>Philippa Hartney, Loddon Mallee Region, Ph: (03) 5441 6850</td>
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</table>

### IT Training Program

<table>
<thead>
<tr>
<th>Information Technology Education Voucher Scheme (ITEVS)</th>
<th>Yes</th>
<th>x</th>
<th>Kate Cuss, Hume Region, Ph: (03) 5832 2740</th>
</tr>
</thead>
<tbody>
<tr>
<td>ITEVS Final Evaluation Report</td>
<td>Yes</td>
<td>x</td>
<td>Kate Cuss, Hume Region, Ph: (03) 5832 2740</td>
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### Promotional Material

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<tbody>
<tr>
<td>Hume Region Website Promotional Materials</td>
<td>Yes</td>
<td>x</td>
<td>Nerida Woodcock, Hume Region, Ph: (03) 5832 2740</td>
</tr>
<tr>
<td>Loddon Mallee Website Promotional Material</td>
<td>Yes</td>
<td>x</td>
<td>Julie Harris, Loddon Mallee Region, Ph: (03) 5441 6850</td>
</tr>
</tbody>
</table>
Explanation notes:

*Publications that concentrate on:
- Workforce and training issues include positions descriptions, course outlines etc.
- Service delivery includes referral forms, patient information forms and professional information kits etc
- Consumer information include brochures, information kits etc
- Service directories include any website or printed material
- Research/ Discussion paper/ Workshop findings include any reports or publications that may be disseminated

** Electronic copy - please note what format this product comes in e.g. CR-Rom, pdf file, word doc, video, web material etc