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Strengthening support for women with breast cancer: background paper

I. National Breast Cancer Centre (Australia)

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NHMRC National Breast Cancer Centre
PO Box 572
Kings Cross NSW 1340
Australia

Ph: +61 2 9334 1700
Fax: +61 2 9326 9329
Email: directorate@nbcc.org.au

Website for publications:

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Executive summary

In the May 1999 Australian Federal budget, funding of $4.1 million over four years was announced for a new program, *Strengthening support for women with breast cancer*. The funding will focus on improving support for women diagnosed with breast cancer, particularly women living in rural and remote areas.

Two papers have been developed to support this project. This background paper summarises the available data on rural women with breast cancer and is designed to present contextual information relating to the project. The other paper, *Strengthening support for women with breast cancer: principles, outcomes and models*, outlines the project’s direction, which as decided upon in consultation with stakeholders at a national workshop held in November 1999, on the basis of the data presented in the background paper.

This background paper is divided into three sections, as outlined below.

1. Breast cancer in women in rural and remote communities

There is no evidence to suggest that incidence or mortality from breast cancer differs for women living in rural versus urban areas in Australia.

There is no evidence that rural women receive significantly different treatment for breast cancer compared with their urban counterparts. With one exception: a greater proportion of rural women undergo mastectomy for both early and advanced breast cancer.

2. Support needs of rural women with breast cancer

While there are limited data about the experience of rural women diagnosed with breast cancer, there is evidence to suggest that women from rural areas are satisfied with the care they receive 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;
- the amount of emotional support they received; and
- understanding who was in charge of their care and information sharing within the team.

Research data and consultation with rural consumers and health care providers highlights that women from rural and remote areas experience problems in the following areas:

- receiving full information about treatment, and particularly about their own management;
- receiving information about support;
- detection and treatment for depression and other serious psychological problems;
- continuity of care;
- access to services for lymphoedema;
- information about financial support for travel and accommodation; and
- special issues for women from indigenous and non-English speaking backgrounds.

3. Evidence about the effectiveness of different strategies

The *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* summarise existing data about the effectiveness of different strategies in increasing supportive care for women with breast cancer. Two additional strategies may be of special benefit to women living in rural and remote areas:

- Specialist breast nurses have been shown to increase the provision of information and, level of support for women, and are more likely to detect psychological distress. Research has shown that women and members of the treatment team give positive evaluation of the specialist breast nurse role.
- Strategies using E-health have been shown to improve access to specialist services for consumers from rural and remote areas.
1 Breast cancer in women in rural and remote communities

1.1 Defining “rural and remote”

For health care planning purposes, definitions of rural or remote residence are usually based on population size and density. The Rural, Remote and Metropolitan Areas (RRMA) classification takes into account both population size and remoteness. This classification system, developed by the Department of Primary Industries and Energy and the then Department of Human Services and Health, has been increasingly adopted by organisations such as the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) (see Appendix 1 for a full description and, Appendix 2 for State and Territory Population Distributions using the RRMA).

However, in the context of providing supportive care to women with breast cancer, when defining whether a woman lives in a rural or remote area there are other issues which must be taken into account. Isolation from other communities and access to services may be the most important of these issues. Although the availability of local radiotherapy services is often used as a marker for access to services for cancer patients; limited local access to chemotherapy, psychiatry and genetic counselling services may also indicate that a woman is living in an area with poorer access to services.
1.2 Rural population

In the 1996 Australian census, 26% of the Australian population (approximately 4.6 million people) lived in rural zones, and 3% (0.5 million people) in a remote zone, as shown in Figure 1. While the population in rural areas continues to decline overall, there are pockets of growth in rural coastal communities that reflect the growing trend towards coastal living. Of women aged 40 and over, approximately 30% live in rural and remote areas (see Table 1 for a breakdown of the distribution of women aged 40 and over in each State and Territory).

1.3 Breast cancer and rural women

Breast cancer remains the most common cause of cancer deaths in women from urban, rural and remote areas in Australia.

Incidence

It is estimated that one in 12 women will develop breast cancer if they live to 75 years of age. The incidence of breast cancer does not differ between women living in urban, rural and remote parts of Australia. Figure 2 shows the incidence rates of breast cancer by place of residence. Breast cancer incidence increases with age. Of women aged 55 years and older, more than 50% reside outside capital cities or other metropolitan centres.

The Surgical Management of Breast Cancer in Australia in 1995 explored the treatment of women with breast cancer by studying a sample of 5000 women – nearly all women diagnosed with breast cancer during a six-month period. The survey used the ABS 1991 categories to define rural/urban, with “capital city” and “metropolitan centre” defined as urban and all other categories defined as rural.
Table 2 shows the number of women diagnosed with breast cancer during the six-month period of the survey in each State and Territory and the number and percentage of these women who lived in rural areas. It also shows the proportion of women from rural areas diagnosed with breast cancer residing in each State. Overall, 71% of women resided in urban locations. However, there were differences in Queensland (fewer urban), Western Australia (WA) (more urban), Tasmania (fewer urban) and the Northern Territory (NT) (fewer urban). Table 3 shows the proportion of women diagnosed with early and advanced disease living in rural and urban locations.

**Mortality and survival**

Likewise, there is no evidence for differences in mortality from breast cancer between urban, rural and remote locations. Figure 3 shows mortality rates by geographical classification.

The small amount of available data suggest that survival from breast cancer is similar in rural and urban areas of Australia. The only existing data come from New South Wales (NSW), as shown in Figure 4. It is evident that there is no difference in the five-year survival for women residing in urban NSW (77.1% : 95%. CI 76.6 – 77.6) and rural NSW (76.5% : 95%. CI 75.5 – 77.5).7

**1.4 Treatment of rural women**

Based on data from the *Surgical Management of Breast Cancer in Australia in 1995*, there was little evidence that in relation to most aspects of care, women in rural areas received significantly different treatment from women living in urban areas. Women living in rural areas were just as likely as urban women to be diagnosed by the screening program, to receive the same investigations, to have the hormone status of their tumour assessed and to participate in clinical trials.

However, as shown in Table 4, rural patients were less likely to be treated by surgeons who treat many women with breast cancer and were less likely to have breast conserving surgery for early disease. Rural women with advanced disease were also relatively more likely to have mastectomy.
2 Support needs of rural women with breast cancer

2.1 Data sources

A detailed review was undertaken of research about the needs of women with breast cancer in rural areas in Australia. Details of the search are shown in Appendix 3a. A number of sources of information were located and used in compiling this chapter (see Appendix 3b).

Interviews with State and Territory health departments and Breast Cancer Support Service (BCSS) State coordinators were also used in compiling this chapter.

2.2 Support needs of women with breast cancer in rural areas: existing evidence

Data about the support needs of women from rural areas are limited, and often qualitative rather than quantitative. One of the major sources of data drawn on for this report was the National Consumer Survey. This survey interviewed 544 women randomly selected from cancer registries 6-12 months post diagnosis. Although this report is not yet available, data from the survey were presented at the November 1999 workshop. The perceptions of women and healthcare providers about the needs of women are not always substantiated by the small amount of quantitative data. Therefore, in considering outcomes for the project, there may be a need to go beyond the data reported here.

Nonetheless, the small amount of existing data demonstrate that while women are satisfied with many aspects of their care, there are other aspects where women clearly need improved supportive care. These aspects are outlined below.
2.3 Aspects of care that appear to be appropriate

Based on the National Consumer Survey, most women were satisfied with the care that they received in the areas shown below:

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

There was no evidence that women in rural areas were more dissatisfied with these aspects of their care than women in urban areas.

2.4 Aspects of care where there appear to be opportunities for improvement

Based on these data, there were a number of areas where supportive care could be improved as part of this project.

2.4.1 Information about treatment

Better access to information about treatment for women in rural and regional areas has been identified in many of the consultative reports. The potential role of tele-health in improving access to information has also been identified, and is discussed in Section 4 of this report.
NHMRC Consumer Guides

The NHMRC recommends that all women be as involved in their treatment decisions as they wish. For this to happen, women need adequate information based on the clinical guidelines. There is a version of the NHMRC Clinical practice guidelines for the management of early breast cancer available for women. However, the National Consumer Survey found that only 61% of all women (and 59% of rural women) received a copy of this information.8

Information about their own care

Few women in the National Consumer Survey received written (22%) or audiotaped (4%) information about their care 8. Only 25% of all women (and 24% of rural women) received a written follow-up plan.8

2.4.2 Information about support

Better access to information about support services has been identified in many of the consultative reports.9,10

Support overall

The National Consumer Survey found that fewer women were satisfied with the information they received about access to emotional support or counselling (69% of all women; 66% of rural women); treatment costs (59% of all women; 59% of rural women); or specific resources for their partners (26% of all women; 23% of rural women).8 The lack of information about support has also been identified as an issue during consultations.9,10
Special issues for rural women

The National Consumer Survey found that 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. Thirty per cent believed living in a rural area had limited their access to information or services. Similarly, Davis et al. found that 76% of rural women who travelled for breast cancer treatment identified problems related to “being rural”, and that obtaining information about travel and accommodation was also problematic for the women surveyed.

2.4.3 Depression and serious psychological problems

In general, women in the National Consumer Survey were satisfied with the extent of supportive care that they received. However, data from the Specialist Breast Nurse Demonstration Project show that 34% of women were highly distressed or had a high level of psychological disturbance (based on a score of 4 or greater on the General Health Questionnaire) at the time of diagnosis, 35.4% at two months post-diagnosis and 26.3% at six months post-diagnosis. Forty-six per cent of the women in this study were high scorers at either time point. Among these women, few were referred to a psychiatrist or other tertiary referral point.

This is consistent with international data that indicate that up to 29% of women experience a major depression at three months post-diagnosis, and up to 20% at 12 months post diagnosis. The incidence of psychological disturbance increases at stressful times in the course of the illness, with studies indicating that 40% of women with advanced disease and in the palliative care phase are clinically depressed, and that 50% of women at time of the diagnosis of recurrence experience psychiatric disturbance.
In a review of research about the psychosocial impact of breast cancer, Turner, Wooding and Neil\textsuperscript{15}, identified key factors associated with an increased risk of psychosocial problems as including: marital status, economic adversity, perceived poor social support, poor marital functioning, cumulative stressful events and mental health history. Given the clearly identified decline in the socio-economic wellbeing of Australia’s rural and remote communities, these factors need to be considered when exploring the psychosocial needs of rural women. Similarly, specific times within the course of a breast cancer illness were also associated with increased risk—including at the time of diagnosis and recurrence, in the advanced stage of the disease, and in women experiencing lymphoedema or chronic pain.\textsuperscript{15}

### 2.4.4 Continuity of care

Although women in the *National Consumer Survey* appeared to understand who was in charge of their care and felt that communication among the treatment team was adequate, 42% of women (46% of rural women) would have liked one person identified as the main contact during treatment.

McGrath et al\textsuperscript{16} reported that rural health practitioners described a lack of continuity of care as problematic for women diagnosed with breast cancer. Consultative reports have also identified continuity of care as an issue. For example, the report from *Making a difference—Australia’s first national breast cancer conference for women*\textsuperscript{9} noted the need for women from rural and regional areas to feel able to choose the most appropriate treatment team. The National Breast Cancer Centre’s *Consultative report volume 1: summary and outcomes*\textsuperscript{10} flagged the importance of developing stronger professional links between metropolitan centres and rural teams.
2.4.5 Lymphoedema

In the National Consumer Survey, 38% of women reported that they had experienced or were experiencing swelling of the arm. It is unclear how much of this swelling was caused by lymphoedema. However, international data suggest that between 25% and 30% of women who receive both axillary surgery and axillary irradiation will develop lymphoedema.17

Although a recent review17 has highlighted the need for better research about all aspects of lymphoedema, the needs of women with lymphoedema living in rural areas may be exacerbated by poor access to physiotherapy and other treatments.

2.4.6 Travel and accommodation

The National Consumer Survey provides some data about travel among rural women with breast cancer. Among rural women, 15% travelled more than 100 kilometres for surgery.8 Of those rural women who had radiotherapy, 63% travelled more than 100kms. Among rural women who had chemotherapy, 36% travelled more than 100kms.8 Only 47% of those travelling for treatment received financial assistance, and 13% of these women had difficulty in organising this assistance.8 Of the women who indicated that they stayed away from home for treatment, 24% were not aware of available financial assistance.8

These data are consistent with those of Davis et al.11 who reported that only 39% of women travelling to urban areas for their treatment received financial assistance, and that 19% of these women reported difficulties in obtaining financial assistance.11 Twenty nine per cent of those who did not receive financial assistance were not aware of its availability. Davis et al. found that 89% of the women reported experiencing problems specific to living in a rural location; these problems were primarily related to practical and social concerns, such as the need to travel and disruptions to family life and work.11
Butler and Howarth\textsuperscript{18} estimated that for a woman who is required to travel 450kms (return trip), the extra expenses required for travel and accommodation range from $900 for primary surgical treatment to $3600 for radiotherapy, and from $9000 to $10,200 for women with advanced disease.

Other needs identified by women from rural and remote areas have focused on: their partner and family; meeting financial costs; and maintaining productivity and income on the farm.\textsuperscript{19} Specific family concerns centred on how the family would manage during the woman’s absence, and the increased burden that this absence would place on the family in relation to running and maintaining the farm.\textsuperscript{19}

Consultative reports stress the consequences of travelling for treatment for women from rural and remote areas and their families. For example, the National Breast Cancer Centre’s \textit{Consultative report volume 1: summary and outcomes}\textsuperscript{20} noted the need to examine financial assistance schemes and the difficulty in accessing rural cancer specialists, especially for radiotherapy. The need to improve travel assistance schemes was also highlighted in the report \textit{Making a difference – Australia’s first national breast cancer conference for women}\textsuperscript{9}.

A recent report has explored the costs to women of travel and accommodation and the adequacy of existing support schemes. Table 5 provides a summary of the support provided by different States and Territories for travel. The \textit{Marcus Report}\textsuperscript{20} identified a number of problems with existing schemes:

- As shown in Table 5, there are considerable variations between States and Territories in their provision of travel and accommodation subsidies.
- Women have difficulty accessing information about the schemes for these subsidies, and about how they might apply for support.
- Some schemes require women to access the nearest available specialist. This limits choice and may prevent a woman being treated by a multidisciplinary team.
- There are often limited opportunities for women to apply for support for an accompanying spouse or friend, despite the length of time away from home and the life-threatening nature of the disease.
Eligibility for support usually depends on the distance that the woman has to travel for treatment. Although distance criteria are easy to administer, they often take little account of transport infrastructure or the lengthy nature of treatments such as radiotherapy. A woman may incur considerable travel and accommodation costs while still living within the 200km radius, which is the criterion for eligibility for support in some States. The limited availability of local public transport and/or the condition of the woman's health may make it impossible for her to return home each day during the six weeks of radiotherapy treatment.

Women who live near State borders may find it easier to travel to the adjoining State for treatment. For example, women in the north of NSW may find seeking treatment in Queensland easier than in NSW. This affects their eligibility for support.

In many cases, the available subsidy covers only a proportion of the woman's travel and accommodation costs.

2.4.7 Access to high quality treatment and treatment choice

Many of the consultative reports and interviews with women identify a concern that women in rural areas are not able to access the same quality of treatment, or treatment choice, as women in urban areas. However, this is not well supported by the data. As discussed in Section 1 of this report, the study *Surgical management of breast cancer in Australia in 1995* did not find many differences in treatment between rural and urban women, and there was little evidence of differences in survival or mortality rates.
However the *Surgical management of breast cancer in Australia in 1995* did identify two differences in the care provided based on place of residence: women in rural areas are more likely to receive a mastectomy, and are less likely to receive care from a surgeon who treats many women with breast cancer. This report did not provide any evidence that women treated by surgeons who see less than 40 cases of breast surgery annually are managed overall in a different manner from women seen by surgeons with a higher caseload.6 Likewise, a survey of surgeons about their knowledge and use of the NHMRC *Clinical practice guidelines for the management of early breast cancer* did not demonstrate significant differences between rural and urban surgeons.21

The reasons for higher rates of mastectomy in rural women are unclear, although there is an association between caseload and rates of mastectomy. It is often argued that rural women choose mastectomy because they do not wish to travel for treatment, but the data provide little support for this hypothesis. Data from the *National Consumer Survey* showed that when women who had had a mastectomy were asked the reason for this choice, only 7% of rural women said that they chose mastectomy because they did not wish to travel for treatment.8 Surgeons participating in the *Surgical management of breast cancer in Australia in 1995* study reported that 25% of women had mastectomy entirely from their own choice; reason would include a preference for not travelling.6 This was only slightly more likely to be the case for rural women (30%) than urban women (22%).6

### 2.4.8 Special groups: indigenous women and women from non-English speaking backgrounds

It seems likely that the unmet needs of women living in rural and remote areas may be greater for those who are also from non-English speaking or indigenous backgrounds.

Research identifying the support needs of rural women from indigenous or non-English speaking backgrounds has been difficult to find. Two reports commissioned by the National Breast Cancer Centre have explored the needs of these groups of women.10,22
**Indigenous women**

While the indigenous population comprises only 2% of the overall population in Australia, the proportion is significantly higher in rural and remote Australia (see Figure 5).

The incidence of breast cancer in indigenous women is not fully known, as not all cancer registries routinely record whether patients are of an indigenous background. Based on the limited data available, Carrick et al.\(^2\), reported that indigenous women have similar mortality rates from breast cancer, slightly lower incidence rates and, lower rates of participation in screening and are less likely to be hospitalised for breast cancer. Lower rates of hospitalisation for breast cancer may mean that indigenous women do not present for treatment or are not continuing with treatment.\(^2\) The Northern Territory Cancer Registry data identified similar age-adjusted risk for breast cancer between Aboriginal and non-Aboriginal women, with 36 of the 401 breast cancer cases diagnosed between 1987–1997 occurring in Aboriginal or Torres Strait Islander women.\(^2\) Consumer information about breast cancer and support needs for indigenous women was described as “lacking”.\(^2\)

Consultations with Aboriginal and Torres Strait Islander women across Australia\(^10,2\) have identified several key areas that are important to providing support for indigenous women:

- education resources and information needs to be culturally appropriate;
- it is important to maintain confidentiality about women’s health business;
- support needs to be accessible from within the immediate community; and
- breast cancer education and training are needed for Aboriginal health workers;
- healthcare should be sensitive to the cultural beliefs of indigenous women-for example medical and nursing staff should be female.

When receiving treatment from home, indigenous women need to be able to access culturally appropriate support.
While there are no data about the support needs of indigenous women, it is recognised that family and kinship are extremely significant in providing support. For this reason it is important that the needs of indigenous women are explored within the context of events within the family and indigenous communities. Given that a higher percentage of indigenous women live in the more remote areas of Australia and that most treatment for breast cancer requires women from remote areas to travel, treatment thus potentially isolates indigenous women from the support provided by their family units. The impact of this isolation has not yet been explored.

**Women from non-English speaking backgrounds**

The National Breast Cancer Centre’s *Consultative report volume 1: summary and outcomes* highlights potential differences in the needs of women from non-English speaking backgrounds in rural and remote areas compared with those of their urban counterparts, given the differences in access to interpreter services and community support. This report also highlights the support needs of women from non-English speaking backgrounds: for information about all aspects of breast cancer, for access to services (including support groups) and for culturally appropriate healthcare.

**2.4.9 Support for partner and family**

Families are a significant source of support for women with breast cancer. Women with limited or no support from family or partners have been shown to have poorer emotional adjustment to their diagnosis. The partners of women with breast cancer require access to support, with up to 38% of partners experiencing psychological distress. Emotional concerns experienced by partners include adjustment to role changes, fear that their partner may die, and the provision of adequate support. The support needs of partners and family may increase if there are young children involved, or if the woman has advanced disease. No studies have explored the specific support needs of the partners or families of rural women diagnosed with breast cancer.
2.4.10 Palliative care for women with advanced breast cancer

There are no data that specifically document the needs of rural women with advanced breast cancer. However, data from studies exploring advanced disease show that women may experience many physical and psychological symptoms. There is evidence that women experience significant depression and anxiety when diagnosed with a recurrent breast cancer, and that diagnosis of recurrence is more devastating than the original diagnosis. Physical symptoms can range in severity and include pain, dyspnoea, fatigue, nausea and vomiting. Physical symptoms can impact on the social function and quality of life for women with advanced breast cancer. Access to services such as counselling, pastoral care and specialist palliative care services can improve women's quality of life. Access to specialist palliative care services in rural areas has improved in the past decade due to Commonwealth and State initiatives to establish regional/area specialist palliative care services. It should be noted that palliative care is provided by both generalist and specialist services and that research has highlighted that rural populations have access to high quality palliative care services. Support needs for women with advanced cancer include those previously identified – information, counselling and practical support.
3 Evidence about the effectiveness of different strategies

There is a growing body of evidence about the effectiveness of different strategies in providing supportive care to women with breast cancer.

3.1 Reviews of evidence and the Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer

The National Breast Cancer Centre (NBCC) has recently completed several detailed reviews of the evidence supporting different strategies to improve supportive care for women with breast cancer. These reviews are available from the NBCC and have been used to develop the Psychosocial clinical practice guidelines: providing information, support and counselling to women with breast cancer. These guidelines have been endorsed by the National Health and Medical Research Council. Table 2 summarises their main recommendations.
Summary statements with Level I and II evidence from the *Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer*

### General interactional skills

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<td>Women’s understanding, recall and satisfaction increases when techniques such as the following are used:</td>
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<td>• taping the consultation;</td>
<td>II</td>
</tr>
<tr>
<td>• a general information tape;</td>
<td>II</td>
</tr>
<tr>
<td>• a summary letter as a “follow-up” to the consultation; and</td>
<td>II</td>
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<tr>
<td>• the presence of a specialist breast nurse (SBN).</td>
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### Discussing prognosis

Factors such as the amount of information, mode of expression (descriptive versus probabilistic), framing (negative or positive) and doctor’s communication style influences a woman’s decision about treatment. | II

### Providing information and choice

Appropriate, detailed information promotes understanding and increases the psychological well-being of women with breast cancer. | I

Discussions with an SBN reduce psychological morbidity for women with breast cancer and increase their understanding of breast cancer, their recall of information and perceptions of support. | II

Women’s recall of information increases when they are provided with individualised information. | II

### Preparing women for potentially threatening procedures and treatment

Providing women with information about the procedure they are about to undergo reduces emotional distress and improves psychological and physical recovery. | I

Providing women with procedural information from a clinician, allied health professional or SBN, a booklet and/or videotape decreases anxiety and psychological distress. | II

Providing women with psychosocial support before undergoing surgery reduces psychological distress. | I

### Providing emotional and social support

Appropriate counselling improves the wellbeing of women with breast cancer. | I

The opportunity to discuss feelings with a member of the treatment team or counsellor decreases psychosocial distress. | I

SBNs enhance early recognition of social support needs and decrease psychological distress. | I

### Providing psychological care

A variety of psychological interventions, including involvement in group support, reduce psychological distress. However, greater beneficial effects are observed when therapies are longer and conducted by more highly trained therapists. | I

Depression in women with breast cancer can be managed by incorporating a combination of supportive psychotherapy, cognitive and behavioural techniques and pharmacotherapy. | I

In cases of anxiety, cognitive and behavioural techniques (eg muscle relaxation and imagery) are effective treatment options. However, when anxiety or panic impedes or complicates treatment, prompt assessment from a psychiatrist or clinical psychologist may be required. | I

### Ensuring continuity of care

SBNs improve understanding and continuity of care throughout the treatment process. | II

Patient-held records improve continuity of care. | II
There are several strategies for providing support that are of particular interest or importance to women living in rural areas. These are described below.

3.2 Specialist Breast Nurses

3.2.1 Type of Model

As shown in the summary of recommendations from the *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*, there is evidence (both Level I and Level II) that specialist breast nurses (SBNs) improve supportive care for women with breast cancer.

However, this evidence comes primarily from the United Kingdom, where the model of care by SBNs includes repeated opportunities for women to spend time with such nurses and a primary focus in the job description is on the provision of information and counselling rather than on clinical care. The SBN is a full member of the treatment team and attends multidisciplinary team meetings. It is this UK model which has shown to be effective in improving outcomes for women. Appendix 5 shows a potential protocol for such positions developed by the National Breast Cancer Centre as part of the Specialist Breast Nurse Demonstration Project.

There is also some evidence within the Australian context that women who have access to breast nurses will also report better care. Figures 6 and 7 compare women in the *National Consumer Survey* who received no access to breast nurses with those who had three or more such visits. It is evident that a greater proportion of women who were able to access SBNs (on three or more occasions) reported receiving enough support compared with those women who had not seen an SBN (93% versus 76%). Women who had seen a breast nurse on three or more occasions were also significantly more likely to report receiving enough support for their family (85% versus 61%) and receiving enough information about clinical trials (24% versus 10%). However, it should be noted these comparisons do not control for other differences between centres which have SBN positions and those that do not.
It should also be noted that like the limited Australian data, the international data are based on women receiving reasonably intensive input from an SBN. There is no evidence that limited access to an SBN (on say, only one occasion) will have any impact on care.

3.2.2 Information from the Specialist Breast Nurse Demonstration Project: overall findings

The National Breast Cancer Centre is in the process of completing a major demonstration project examining SBN positions. It provides a detailed overview of the role of an SBN in four sites. Preliminary data from the study have some implications for the present project.

Activities of specialist breast nurses

Table 6 provides a breakdown of the time spent by the SBNs on different activities. It is evident that they spent most of their time with women with breast cancer. Table 7 shows that the SBN provided information in most consultations; counselling was also frequently provided. Direct clinical care was infrequent. On average, SBN spent about an hour with each woman per visit.

Caseload issues

Caseload was dependent upon a range of local issues including whether the SBN saw women with breast disease only, the extent of additional activities, and the centre’s throughput. It appeared that the maximum number of new cases per month was 8-12.

Needs of women identified by specialist breast nurses

Table 8 shows the needs of women that emerged during the consultations with SBNs. It is apparent that these needs changed with time and that the most common discussions related to information about treatment and psychological symptoms.
Figure 8 shows the number of women initiating consultations with the SBN at each of the follow-up periods. Women were most likely to initiate contact at the first follow-up period, demonstrating the importance of continuing contact after the period of surgical treatment.12

**Psychological issues**

Thirty-four per cent of women were highly distressed or had a high level of psychological disturbance (based on a score of 4 or greater on the *General Health Questionnaire 12* (GHQ-12) at the time of diagnosis, 35% at two months post-diagnosis and 26% at six months post-diagnosis.12 Forty-six per cent of the women in this study were high scorers at either time point. The SBN detected the psychological needs for 59%-72% of those with high scores on the GHQ-12 at 12 months. However, few of these women were referred to a psychiatrist or a psychologist.12

**Acceptability of the specialist breast nurse to women with breast cancer, the treatment team and others**

All members of the treatment team and other healthcare providers were positive about the role of the SBN. Table 9 shows the perceptions of different groups about the key components of the SBN role.12

Women were also very positive about the care provided by the SBN, as highlighted below:

- “I found the role of the breast care nurse very important as the link between me and ‘the system’-between me and the surgeon. [The breast care nurse] was the human link providing personal attention and care that doctors are often not able to give. She was the one constant throughout the whole process.”12
3.2.3 Information from the Specialist Breast Nurse Project: a rural case study

The Specialist Breast Nurses demonstration project included an SBN in a rural centre.12 There were some differences in the role of the rural SBN compared with urban SBN,12 and some limitations.

While the rural SBN provided support for women in the rural area, compared with urban SBNs the overall number of women treated was significantly lower (average 16 women per month at the rural site, versus 27-49 at the other sites), as was the amount of time spent on clinical activities (34% compared versus an average of 54% for all sites).12 The rural SBN had a larger role in educating the wider healthcare community across the Area Health Service. As women still travelled from more rural and remote areas, education programs and resource folders were developed for healthcare workers in other rural centres, to improve the care of women when they returned home.12

The SBN in an urban setting was part of a larger multidisciplinary team, primarily located in a tertiary referral centre. This provided the urban SBN with a clear role and system from within which to work. The rural SBN position differed in that there was no formalised multidisciplinary team, and no “breast clinic” to facilitate the coordination of women’s care. While breast surgeons were available on site at all times, medical and radiation oncology services were provided through satellite clinics by a large urban hospital. Women were still required to travel for radiotherapy, and at times for chemotherapy treatments. The surgeons saw newly-diagnosed women in private rooms, making it difficult for the SBN to be present during the interview. The absence of team meetings, and of a clinic that facilitated the SBN being able to coordinate care from diagnosis, hindered some aspects of the role. This project highlighted the need for close liaison in rural settings with existing screening, cancer specific and surgical services.
3.2.4 Part-time rural specialist breast nurses: experience from the National Breast Cancer Centre’s rural pilot

It is likely that SBNs in rural areas will have an outreach role in training and support of other staff, and direct clinical contact with women with breast cancer. The SBN may also play a role in community education and provide support for general practitioners.

The issue of caseload needs to be considered carefully. The Specialist Breast Nurse Demonstration Project concluded that a total caseload of between 36-44 was appropriate within an urban area, using the five-session (12 week) protocol. Few rural centres would have sufficient workload to fully occupy a breast nurse, even given the outreach role outlined above. Part-time positions may therefore be preferable.

However the development of part-time SBN positions in rural areas appears to be far from straightforward. The National Breast Cancer Centre sought to establish three rural pilot projects to explore the impact of a part-time breast nurse in rural areas. At this time, it has not been possible to establish any positions. Some of the difficulties experienced in establishing these positions have been:

- limited availability of sufficiently skilled nursing staff able to take up new positions in rural areas;
- concern about investing additional resources in breast cancer at a time when rural services are already stretched;
- concerns about whether the positions might best be established as community or hospital-based; and
- concerns about being able to continue the position after the end of the funding phase.
3.3 E-health opportunities

Developments in telecommunications have provided an avenue for overcoming the barriers of geographical isolation and distance. Initially called telemedicine, e-health combines “electronic communication and information technology in the health sector … for clinical, educational and administrative purposes” (p11). There are now many examples of successful programs for providing education, accessing specialist services, and disseminating information. The Federal Government has made a commitment to increase access to information technology for Australians in rural and remote areas. Opportunities provided by information technology are considerable, particularly in areas where the technology is already in place. Listed below are some examples of established initiatives.

Adelaide and Darwin: facilitating cancer management through telemedicine

A telemedicine link was established between the Royal Adelaide Cancer Centre and the Royal Darwin Hospital in order to provide isolated clinicians with multidisciplinary oncology meetings. Breast cancer patients are case-managed using this system. Specialists involved include medical and radiation oncologists, palliative care and allied health staff. In a recent study, this service has recently been highly evaluated from the perspective of consumers and healthcare.

Med-E-Serv Internet health

This is an Internet site for health professionals, which supports best practice through the delivery of education, the establishment of clinical project teams, and virtual conferences. Projects developed by Med-E-Serv include the National Asthma Project, where GPs submitted patient data, viewed results and discussed management in real-time. In conjunction with the Australasian Faculty of Public Health Medicine, Med-E-Serv has also developed a Rural Health Training Project covering mental health, counselling and health promotion. This project accessed Aboriginal health workers, community nurses, general practitioners and the Royal Flying Doctor Service.
Mental health information for rural and remote Australia

This service aims to ensure prompt access to information and referral to mental health services through a telephone service.

Model e-health in a rural hospital community

Optus and the Victorian Department of Human Services are undertaking a project to determine the information and communication needs of health providers servicing rural communities. Among the many areas being investigated are remote patient audiovisual conferencing and education.

Renal videoconferencing

The renal unit of Queen Elizabeth Hospital, Adelaide, conducts live videoconferences with staff from Alice Springs, Darwin and the Flinders Medical Centre to discuss patients. Medical images—from scans to pathology results—are all viewed in real-time.

CMENet

This is a consortium established in Queensland to improve access to continuing medical education for rural and remote health professionals. This website has been designated for the delivery of education for the Australian College of Rural and Remote Medicine, and has received recognition for its innovation from several bodies.

Child and adolescent mental health services, Adelaide

This service provides a range of services to mental health staff in remote and rural areas in the NT, South Australia (SA) and parts of Western Australia (WA). Case conferences are provided each week via videoconferencing and education sessions.
Peer support via audio-teleconferencing

Canadian women living in rural areas participated in a pilot project to examine whether self-help peer support for breast cancer survivors could be effectively facilitated through the use of an audio-teleconferencing network. The opportunity to participate in such meetings twice a week was found to be very helpful in overcoming the isolation experienced by such women.26

There are several areas where this technology could benefit women from rural and remote areas diagnosed with breast cancer—such as to access specialist services which are not available locally, and to make contact with other women in similar circumstances.
## Tables

### Table 1  
Distribution of women aged 40 and older across Rural, Remote and Metropolitan Classifications within each State and Territory: raw scores and percentage of women 40 and older in each region

<table>
<thead>
<tr>
<th>Region</th>
<th>NSW  (N)</th>
<th>NSW  %</th>
<th>VIC  (N)</th>
<th>VIC  %</th>
<th>QLD  (N)</th>
<th>QLD  %</th>
<th>SA   (N)</th>
<th>SA   %</th>
<th>WA   (N)</th>
<th>WA   %</th>
<th>TAS  (N)</th>
<th>TAS  %</th>
<th>NT   (N)</th>
<th>NT  %</th>
<th>ACT  (N)</th>
<th>ACT  %</th>
<th>Total  (N)</th>
<th>Total  %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capital City</td>
<td>77,8176</td>
<td>60.6</td>
<td>654,177</td>
<td>71.0</td>
<td>300,241</td>
<td>43.7</td>
<td>238,213</td>
<td>74.5</td>
<td>254,639</td>
<td>74.9</td>
<td>40,816</td>
<td>41.9</td>
<td>12,799</td>
<td>46.9</td>
<td>53,981</td>
<td>99.1</td>
<td>2,333,042</td>
<td>62.5</td>
</tr>
<tr>
<td>Other Metropolitan Centres</td>
<td>16,8072</td>
<td>13.1</td>
<td>32,031</td>
<td>3.5</td>
<td>100,783</td>
<td>14.7</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>N/A</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>300,886</td>
<td>8.1</td>
</tr>
<tr>
<td>Large Rural Centres</td>
<td>65,430</td>
<td>5.1</td>
<td>44,550</td>
<td>4.8</td>
<td>132,520</td>
<td>19.3</td>
<td>4,392</td>
<td>1.4</td>
<td>–</td>
<td>–</td>
<td>18,117</td>
<td>18.6</td>
<td>N/A</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>265,009</td>
<td>7.1</td>
</tr>
<tr>
<td>Small Rural Centres</td>
<td>102,445</td>
<td>8.0</td>
<td>56,943</td>
<td>6.2</td>
<td>11,751</td>
<td>1.7</td>
<td>16,141</td>
<td>5.0</td>
<td>25,406</td>
<td>7.5</td>
<td>11,367</td>
<td>11.7</td>
<td>N/A</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>224,053</td>
<td>6.0</td>
</tr>
<tr>
<td>Other Rural Centres</td>
<td>158,369</td>
<td>12.3</td>
<td>130,790</td>
<td>14.2</td>
<td>108,024</td>
<td>15.7</td>
<td>56,315</td>
<td>17.6</td>
<td>31,756</td>
<td>9.3</td>
<td>25,535</td>
<td>26.2</td>
<td>2,442</td>
<td>8.9</td>
<td>46</td>
<td>0.9</td>
<td>513,277</td>
<td>13.8</td>
</tr>
<tr>
<td>Remote Centres</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>15,343</td>
<td>2.2</td>
<td>–</td>
<td>–</td>
<td>14,589</td>
<td>4.3</td>
<td>–</td>
<td>–</td>
<td>5,588</td>
<td>20.5</td>
<td>–</td>
<td>–</td>
<td>35,520</td>
<td>1.0</td>
</tr>
<tr>
<td>Other Remote Areas</td>
<td>10,656</td>
<td>0.8</td>
<td>2,799</td>
<td>0.3</td>
<td>18,204</td>
<td>2.7</td>
<td>4,634</td>
<td>1.4</td>
<td>13,427</td>
<td>4.0</td>
<td>1,473</td>
<td>1.5</td>
<td>6,468</td>
<td>23.7</td>
<td>–</td>
<td>–</td>
<td>57,661</td>
<td>1.5</td>
</tr>
<tr>
<td>Total number of women by region</td>
<td>1,283,148</td>
<td>100</td>
<td>921,290</td>
<td>100</td>
<td>686,866</td>
<td>100</td>
<td>319,695</td>
<td>100</td>
<td>339,817</td>
<td>100</td>
<td>97,308</td>
<td>100</td>
<td>27,297</td>
<td>100</td>
<td>54,027</td>
<td>100</td>
<td>3,729,448</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 2  Number of women diagnosed with breast cancer in each State and Territory over the six-month period of the survey

<table>
<thead>
<tr>
<th>State</th>
<th>Total number of women diagnosed with breast cancer</th>
<th>Percentage of women diagnosed with breast cancer living in a rural area %</th>
<th>Number of women diagnosed with breast cancer living in a rural area</th>
<th>Percentage of rural women with breast cancer living in each State %</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>1,363</td>
<td>24</td>
<td>327</td>
<td>27</td>
</tr>
<tr>
<td>Victoria</td>
<td>1,263</td>
<td>27</td>
<td>341</td>
<td>28</td>
</tr>
<tr>
<td>Queensland</td>
<td>617</td>
<td>41</td>
<td>253</td>
<td>21</td>
</tr>
<tr>
<td>WA</td>
<td>387</td>
<td>20</td>
<td>77</td>
<td>6</td>
</tr>
<tr>
<td>SA</td>
<td>391</td>
<td>30</td>
<td>117</td>
<td>10</td>
</tr>
<tr>
<td>Tasmania</td>
<td>115</td>
<td>59</td>
<td>68</td>
<td>6</td>
</tr>
<tr>
<td>NT</td>
<td>8</td>
<td>62</td>
<td>5</td>
<td>0.5</td>
</tr>
<tr>
<td>ACT</td>
<td>73</td>
<td>26</td>
<td>19</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>4,217</strong></td>
<td>–</td>
<td><strong>1207</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>


Table 3  Number of women diagnosed in a six-month period with early and advanced disease, by geographic location

<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Rural</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early disease</td>
<td>2556</td>
<td>1043</td>
<td>3599</td>
</tr>
<tr>
<td>Advanced disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Operable</td>
<td>263</td>
<td>119</td>
<td>382</td>
</tr>
<tr>
<td>Non-operable</td>
<td>194</td>
<td>56</td>
<td>250</td>
</tr>
</tbody>
</table>

# Table 4 Surgical treatment across geographic locations: percentage receiving treatment

<table>
<thead>
<tr>
<th></th>
<th>Urban %</th>
<th>Rural %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Surgery for early disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td>44</td>
<td>54</td>
</tr>
<tr>
<td>Breast conserving therapy</td>
<td>56</td>
<td>46</td>
</tr>
<tr>
<td><strong>Surgery for advanced disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td>64</td>
<td>77</td>
</tr>
<tr>
<td>Breast conserving surgery</td>
<td>37</td>
<td>23</td>
</tr>
<tr>
<td><strong>Surgeon case load</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 40 new patients</td>
<td>47</td>
<td>17</td>
</tr>
</tbody>
</table>

Table 5  State and Territory patient travel assistance schemes

<table>
<thead>
<tr>
<th>Criteria</th>
<th>NSW</th>
<th>Victoria</th>
<th>SA</th>
<th>NT</th>
<th>WA</th>
<th>Queensland</th>
<th>ACT</th>
<th>Tasmania</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum distance (return trip)</td>
<td>200km</td>
<td>200km</td>
<td>400km</td>
<td>400km</td>
<td>200km</td>
<td>TBA</td>
<td>400km</td>
<td>350km</td>
</tr>
<tr>
<td>Bus/train</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Airfare</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Minimum distance (return trip)</td>
<td>200km</td>
<td>200km</td>
<td>400km</td>
<td>400km</td>
<td>200km</td>
<td>TBA</td>
<td>400km</td>
<td>350km</td>
</tr>
<tr>
<td>Private car allowance</td>
<td>Equal to cheapest public transport</td>
<td>10c/km</td>
<td>10c/km</td>
<td>10c/km</td>
<td>10c/km</td>
<td>$40 per trip</td>
<td>10c/km</td>
<td>$40 per trip</td>
</tr>
<tr>
<td>Interstate assistance?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>HCC contribution</td>
<td>Nil</td>
<td>$20 per trip</td>
<td>?</td>
<td>II</td>
<td>Nil</td>
<td>Nil</td>
<td>Nil</td>
<td>$15/trip up to $120.</td>
</tr>
<tr>
<td>Accommodation subsidy</td>
<td>$30/night</td>
<td>Patient pays first night, then $30/night</td>
<td>Patient pays first night, then $30/night</td>
<td>$25/night ($30 with HCC)</td>
<td>$35/night</td>
<td>Patient pays first 4 nights, then $30/night</td>
<td>Variable</td>
<td>$30/night up to $420 per annum</td>
</tr>
<tr>
<td>Subsidy if staying with friends</td>
<td>Nil</td>
<td>Nil</td>
<td>Nil</td>
<td>$10/night</td>
<td>$10/night</td>
<td>$10/night</td>
<td>$10/night</td>
<td>$10/night</td>
</tr>
<tr>
<td>Choice of specialist?</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
</tr>
<tr>
<td>Criteria</td>
<td>NSW</td>
<td>VIC</td>
<td>SA</td>
<td>NT</td>
<td>WA</td>
<td>QLD</td>
<td>ACT</td>
<td>TAS</td>
</tr>
<tr>
<td>Companion allowed?</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
<td>✓*</td>
</tr>
<tr>
<td>Retrospective claims</td>
<td>Yes, within three months</td>
<td>Yes, within three months</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes, within three months</td>
<td>Yes, within three months</td>
<td></td>
</tr>
<tr>
<td>Cost per night</td>
<td>$11-30</td>
<td>$10-70</td>
<td>$1.5</td>
<td>$21-$60</td>
<td>$13.50-$30</td>
<td>$30</td>
<td>$12-$20</td>
<td></td>
</tr>
<tr>
<td>Funding/administration source</td>
<td>Health regional office</td>
<td>Health regional office</td>
<td>Health regional office</td>
<td>Health regional office</td>
<td>Health regional office</td>
<td>Health regional office</td>
<td>Canberra Hospital</td>
<td>Health regional office</td>
</tr>
</tbody>
</table>

Source: Marcus D. Patient travel programs and women with breast cancer. Unpublished report from the National Breast Cancer Centre
### Table 6  Specialist breast nurses time spent per day

<table>
<thead>
<tr>
<th>Clinical activities</th>
<th>Hours : Minutes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct</td>
<td>2:35</td>
<td>34</td>
</tr>
<tr>
<td>Face-to-face consultation</td>
<td>1:31</td>
<td>20</td>
</tr>
<tr>
<td>Telephone consultation</td>
<td>0:20</td>
<td>4</td>
</tr>
<tr>
<td>Supporting patients during doctors’ consultation</td>
<td>0:16</td>
<td>4</td>
</tr>
<tr>
<td>Activities related to non-breast cancer patients</td>
<td>0:15</td>
<td>3</td>
</tr>
<tr>
<td>Clinical duties (eg wound dressing)</td>
<td>0:13</td>
<td>3</td>
</tr>
<tr>
<td><strong>Indirect</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Documentation</td>
<td>0:31</td>
<td>7</td>
</tr>
<tr>
<td>Verbal hand over to other health professionals</td>
<td>0:13</td>
<td>3</td>
</tr>
<tr>
<td>Referring patients to various practitioners</td>
<td>0:11</td>
<td>2</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multi-disciplinary meetings</td>
<td>0:17</td>
<td>4</td>
</tr>
<tr>
<td>Leading support groups</td>
<td>0:08</td>
<td>2</td>
</tr>
<tr>
<td>Informal patient contacts</td>
<td>0:08</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total clinical activities</strong></td>
<td><strong>4:03</strong></td>
<td><strong>54</strong></td>
</tr>
<tr>
<td><strong>Non-clinical activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Project</td>
<td>0:58</td>
<td>13</td>
</tr>
<tr>
<td>SBN project</td>
<td>0:48</td>
<td>11</td>
</tr>
<tr>
<td>Other concurrent projects</td>
<td>0:10</td>
<td>2</td>
</tr>
<tr>
<td><strong>Meetings</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff meeting</td>
<td>0:20</td>
<td>4</td>
</tr>
<tr>
<td>Staff contact</td>
<td>0:17</td>
<td>4</td>
</tr>
<tr>
<td>General meeting</td>
<td>0:09</td>
<td>2</td>
</tr>
<tr>
<td>Debriefing of SBNs</td>
<td>0:05</td>
<td>1</td>
</tr>
<tr>
<td>Administration</td>
<td>0:45</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total non-clinical activities</strong></td>
<td><strong>3:27</strong></td>
<td><strong>46</strong></td>
</tr>
</tbody>
</table>

Total number of days 195. Total time per day: 7.5 hours (450 minutes) per day.

## Table 7 Proportion of women receiving different interventions, by phase

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Diagnosis %</th>
<th>Pre-op %</th>
<th>Post-op %</th>
<th>FU 1 %</th>
<th>FU 2 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>57</td>
<td>79</td>
<td>84</td>
<td>86</td>
<td>59</td>
</tr>
<tr>
<td>Counselling</td>
<td>33</td>
<td>66</td>
<td>73</td>
<td>73</td>
<td>65</td>
</tr>
<tr>
<td>Treatment</td>
<td>0</td>
<td>1</td>
<td>12</td>
<td>19</td>
<td>5</td>
</tr>
<tr>
<td>Liaison</td>
<td>18</td>
<td>32</td>
<td>42</td>
<td>49</td>
<td>33</td>
</tr>
</tbody>
</table>

### Table 8  Proportion of identified needs of women, by phase

<table>
<thead>
<tr>
<th></th>
<th>Diagnosis</th>
<th>Pre-op</th>
<th>Post-op</th>
<th>FU 1</th>
<th>FU 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experience of having cancer</td>
<td>7</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Understanding a diagnosis of cancer</td>
<td>23</td>
<td>21</td>
<td>14</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Prognosis</td>
<td>8</td>
<td>16</td>
<td>35</td>
<td>30</td>
<td>5</td>
</tr>
<tr>
<td>Experience of cancer in others</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td><strong>Health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>2</td>
<td>2</td>
<td>14</td>
<td>31</td>
<td>21</td>
</tr>
<tr>
<td>General health / background</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>10</td>
<td>13</td>
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<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Surgery</td>
<td>30</td>
<td>53</td>
<td>19</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>6</td>
<td>6</td>
<td>15</td>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td>Adjuvant therapy</td>
<td>4</td>
<td>4</td>
<td>17</td>
<td>44</td>
<td>14</td>
</tr>
<tr>
<td>Breast reconstruction</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>General</td>
<td>18</td>
<td>30</td>
<td>45</td>
<td>33</td>
<td>18</td>
</tr>
<tr>
<td>Problems after treatment</td>
<td>2</td>
<td>3</td>
<td>15</td>
<td>34</td>
<td>22</td>
</tr>
<tr>
<td><strong>Psychological needs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological symptoms</td>
<td>25</td>
<td>51</td>
<td>52</td>
<td>49</td>
<td>40</td>
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<tr>
<td>Psychosexual needs</td>
<td>2</td>
<td>6</td>
<td>6</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Family concerns/ relationship</td>
<td>17</td>
<td>17</td>
<td>19</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td><strong>Social and practical needs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Finance</td>
<td>5</td>
<td>8</td>
<td>6</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Experience of/ feelings about health care</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Practical problems</td>
<td>9</td>
<td>9</td>
<td>18</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Support</td>
<td>10</td>
<td>14</td>
<td>11</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>Other needs</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

Total number of patients: 237.

### Table 9  Perceptions of key components of the specialist breast nurse role: ranking of response by occupation

<table>
<thead>
<tr>
<th>Rank</th>
<th>Specialist medical</th>
<th>Nursing</th>
<th>SBN</th>
<th>Allied health</th>
<th>Community health</th>
<th>BCSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>Information Support</td>
<td>Information Support</td>
<td>Information</td>
<td>Information</td>
<td>Information Support Liaise/refer</td>
<td>Information</td>
</tr>
<tr>
<td>Second</td>
<td>Continuity</td>
<td>Staff education</td>
<td>Support</td>
<td>Support</td>
<td>Support Filtering Advocacy Staff education</td>
<td></td>
</tr>
<tr>
<td>Third</td>
<td>Liaise/refer</td>
<td>Liaise/refer</td>
<td>Filtering</td>
<td>Liaise/refer</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figures

Figure 1  Australian population densities by geographic location


Density (pers/km sq)

- Less than 1 person
- Between 1 and 30 people
- More than 30 people

Figure 2  Incidence of breast cancer in females, 1986-1994: new cases per 10,000 population


Figure 3  Death rates for breast cancer in females, 1992-1996: deaths per 100,000 population

Figure 4  Five year relative survival (%) from breast cancer by place of residence in NSW women, 1973–1995

Figure 5  Distribution of the indigenous population 1996


Figure 6  Proportion of women who received either no access to a breast nurse or had three or more visits with a breast nurse, who reported receiving enough information

Figure 7  Proportion of women who had either no access to a breast nurse, or had three or more visits with a breast nurse and who reported receiving enough support for themselves and their family


Figure 8  Proportion of women initiating consultation at each phase

Appendix 1

Rural, Remote and Metropolitan Classification

<table>
<thead>
<tr>
<th>Zone</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metropolitan zone</td>
<td>Capital cities</td>
</tr>
<tr>
<td></td>
<td>Other metropolitan (centres urban centre population $\geq$100,000)</td>
</tr>
<tr>
<td></td>
<td>Large rural centres (urban centre population 25,000-99,000)</td>
</tr>
<tr>
<td>Rural zone</td>
<td>Small rural centres (urban centre population 10,000-24,999)</td>
</tr>
<tr>
<td></td>
<td>Other rural centres (urban centre population &lt;10,000)</td>
</tr>
<tr>
<td>Remote Zone</td>
<td>Remote areas (urban centre population $\geq$ 5,000)</td>
</tr>
<tr>
<td></td>
<td>Other remote areas (urban centre population &lt;5,000)</td>
</tr>
</tbody>
</table>

RRMA classification areas are determined on Statistical Local Areas based on Australian Standard Geographical Classification (Australian Bureau of Statistics, 1995). The Index of Remoteness is used to classify areas as rural or remote, determined by distance factors from urban centres (population 10,000 or more) and personal distance (remoteness and average distance from each other residents).

(Source: Department of Primary Industries and Energy and Department of Human Services and Health *Rural, Remote and Metropolitan Classification*. Canberra: Australian Government Publishing Services, 1994.)

The Commonwealth Department of Health and Aged Care has been refining the classification for “remote”, in order to develop a standard index of remoteness. In an Occasional paper released in August 1999 the Department outlines the “Accessibility/Remoteness Index of Australia (ARIA)”. This classification system is based on geographical remoteness, and excludes socioeconomic, urban/rural and population size factors. The Department proposes that this new model replaces the Rural, Remote and Metropolitan Classification identified above. This has not yet been agreed.

Appendix 2

State and territory distributions of Rural, Remote and Metropolitan Zones (Australian Bureau of Statistics, 1995)

- 2a Queensland distribution
- 2b New South Wales distribution
- 2c Victoria distribution
- 2d Tasmania distribution
- 2e South Australia distribution
- 2f Western Australia distribution
- 2g Northern Territory Distribution
- 2h Australian Capital Territory distribution
Appendix 2a

Qld distribution

[Map showing Qld distribution with various centers and areas marked]
Appendix 2b

NSW distribution
Appendix 2c

Victorian distribution

[Map of Victoria showing distribution of areas with different types of health centers and distance scale in kilometers]
Appendix 2d

Tasmanian distribution
Appendix 2e

SA distribution
Appendix 2f

WA distribution
Appendix 2g

NT distribution

Map of NT distribution showing locations such as Darwin, Katherine, Tennant Creek, Alice Springs, and Mt Olga.
Appendix 2h

ACT distribution
Appendix 3a

Literature search – electronic database search strategy


Breast neoplasms (all subheadings): 94,343 results
Rural health (all subheadings): 13,340 results
Combined: 53 results

Australia (all subheadings): 41,185 results
Combined with breast neoplasms: 323 results
Combined with breast neoplasms and rural health: 10 results

Depression (all subheadings): 115,777 results
Combined with breast neoplasms: 570 results
Combined with breast neoplasms and rural health: 0 results
Combined with breast neoplasms and Australia: 1 result

Support (all subheadings): 2,620,642 results
Combined with breast neoplasms: 28,864 results
Combined with breast neoplasms and rural health: 25 results
Combined with breast neoplasms and rural health and Australia: 4 results

Medline / Psychlit / Nursing Collection searched using similar strategy attached (three abstracts)

Four relevant abstracts and one article
Appendix 3b

Data Sources


- National Consumer Survey. Unpublished data collected by the NHMRC National Breast Cancer Centre. The survey was undertaken with 544 women with early breast cancer randomly selected from cancer registries across Australia. Women completed the survey between 6-12 months after diagnosis.

- Specialist breast nurses: an evidence-based model for Australian practice. National Breast Cancer Centre. This report includes data collected from women, health professionals and SBNs in rural and metropolitan settings.


- McGrath P, Patterson C, Yates P, Treloar S, Oldenburg B, Loos C. A study of post-diagnosis breast cancer concerns for women living in rural and remote Queensland. Part 2: Support issues. *Aust. J. Rural Health* 1999, 7:43-52. This research provided preliminary indications of the support needs of post-diagnosis women with breast cancer in remote and isolated areas of Queensland. It focussed on their support needs in particular, from the perspective of both the women experiencing breast cancer and their health service providers.
• National Breast Cancer Centre consultations with rural women and rural health professionals, undertaken as part of the consultations for the establishment of the Centre. Consultative report volume 1: summary and outcomes. Sydney: NHMRC National Breast Cancer Centre 1996. (See Appendix 4a)

• Report from Making a difference: Australia’s first national breast cancer conference for women. Held in Canberra 16-18 October 1998. (See Appendix 4b.)

• Submission, from NSW Breast Cancer Action Group. Difficulty in accessing optimal treatment in own area: needs of women travelling to urban centres for treatment. (See Appendix 4c.)


• Carrick S, Clapham K, Paul C, Plant A, Redman S. Breast cancer and Aboriginal and Torres Strait Islander women. Sydney: NHMRC National Breast Cancer Centre, 1996. This report sought to summarise all available information about Aboriginal and Torres Strait Islander women and breast cancer on a national basis for the first time.
Appendix 4a

Priorities from the special workshops, excerpt from the National Breast Cancer Centre’s Consultative report volume 1: summary and outcomes (National Breast Cancer Centre 1996 pp18-19)

Priorities from the special workshops

Volume 2 provides a report from each of the special workshop held, each of which provided unique insights into the needs of these priority groups. After the conclusion of the workshops, the report from each of the special workshops was reviewed to identify the issues that were raised in these workshops that had not been mentioned in the state workshops and these are summarised below.

Some of the issues raised in the rural and remote workshop which were not included in the state/territory workshops

The NBCC should:

- Foster information programs and services that address the needs of women from non-English speaking backgrounds who live in isolated communities
- Promote existing information, referrals and support services such as the Cancer Information Services (CIS) and the Breast Cancer Support Services (BCSS) more widely in rural and remote areas.
- Disseminate information about all aspects of breast cancer control for health care providers through regional conferences and local professional associations.
• Foster the use of communication technologies such as audio-visual teleconferences and satellite meetings to deliver continuing education programs to health professionals.

• Provide screening to rural and remote women as part of other health checks and in association with other major community events.

• Explore the most effective timing of assessment clinics in rural areas to ensure that women can attend in a timely fashion after screening.

• Utilise existing rural services to provide a comprehensive screening assessment and diagnostic service.

• Foster the development of stronger professional links between metropolitan and major multidisciplinary cancer centres, treating specialists, breast cancer support services and rural and remote general practitioners.

• Advocate for the development of facilities to enable local general practitioners to gain the appropriate training to provide chemotherapy for remote and rural women.

• Support the rural incentive training programs to address the shortfall of rural cancer specialists, radiologists and surgeons.

• Increase the number of radiation therapy centres in major regional centres.

• Ensure health professionals have an adequate understanding of the full impact of family separation during a woman’s treatment period in major centres.

• Undertake an access audit of existing financial assistant schemes for each state and territory, for travel and accommodation for rural and remote women and their families when travelling for treatment and promote national equitable schemes.

• Support potential rural researchers by directing them to appropriate funding bodies and provide advise on submission writing.

• Explore modifying the state cancer councils’ ethic’s committees to enable them to review research applications from those rural health professionals who may not have access to established ethics committees.
• Explore the viability of training rural and remote general practitioners to perform fine needle biopsy.

**Some of the issues raised in the Urban and Rural Aboriginal workshops which were not included in the state/territory workshops**

The NBCC should:

• Ensure that programs address beliefs about Aboriginal women and breast cancer including that cancer is a white man’s disease and will only effect old women.

• Ensure that programs acknowledge that Aboriginal women do not find it culturally acceptable to have health services provided by men; that Aboriginal communities are heterogenous with many different languages and cultural groups; that for Aboriginal women breasts signify links to family and nurturing rather than sexuality; that confidentiality must be assured; and that care should be holistic including all aspects of women’s health business rather than focusing on just breast cancer.

• Seek local community ownership of programs and/or resource production.

• Provide programs which address the lack of support for Aboriginal women from rural and remote communities travelling to treatment centres.

• Provide appropriate screening and treatment for Aboriginal women in rural and remote areas.

• Increase the number of trained female Aboriginal health workers.

• Promote sharing of information and resources among Aboriginal health workers across Australia.

• Ensure that educational materials are culturally appropriate and use visual imagery where possible.

• Use existing Aboriginal networks such as Imparja, Tanami and the Broadcasting for Remote Aboriginal Communities Scheme.
• Provide education about Aboriginal culture and values to health professionals.
• Ensure that mammographic screening is acceptable to Aboriginal people, including consideration of involving Aboriginal health workers, no appointment times, access, and clarification of the NPEDBC policy of not offering screening to women aged less than 40 years.
• Encourage the establishment of more Aboriginal liaison positions within screening, cancer care centres and palliative care.
• Develop Aboriginal Breast Cancer Support Service Groups.
• Ensure that information about the incidence of and mortality from breast cancer among Aboriginal women is collected.
• Collate existing information and encourage further research into environmental risk factors for breast cancer, particularly pesticides.

Some of the issues raised in the non-English speaking background workshops which were not included in the state/territory workshops

The NBCC should:

• Foster the development of programs which recognise that the non-English speaking background community is a heterogenous group.
• Foster the development of culturally relevant and linguistically appropriate services for women from non-English speaking background diagnosed with breast cancer.
• Increase the understanding among health professionals of different cultural views of breast cancer.
• Ensure confidentially of NESB women in relation to interpreter and clinical services.
• Establish ongoing links with all national bodies of the ethnic communities.
• Non-English speaking women from rural and remote areas may have different information and service needs to those in urban communities.

• Provide balanced information about breast cancer and services for women from non-English speaking backgrounds.

• Establish partnerships with different ethnic communities to develop culturally appropriate training programs for ethnic health workers.

• Increase access to appropriate training programs for interpreters and translating services that address issues that include health education, medical terminology, cultural awareness, gender issues and working with women.

• Increase access to appropriate information about mammographic screening for women from non-English speaking backgrounds.

• Support the development of ethnic breast cancer support groups.

The rural/remote workshops nominated a number of issues or strategies that had not been mentioned elsewhere in the process, as shown in Table 5, and gave a special insight into rural and remote needs. For example, the rural and remote workshops identified the need for the NBCC to promote support and information services such as the Cancer Information Service and the Breast Cancer Support Service in rural and remote areas; to foster the use of communication technologies such as audio-visual teleconferences and satellite meetings to deliver continuing education programs to health professionals; to foster the development of stronger professional links between metropolitan and major multidisciplinary cancer centres, treating specialists, breast cancer support services and rural and remote general practitioners; and to undertake an access audit of existing financial assistance schemes for each state and territory for travel and accommodation for rural and remote women and their families when travelling for treatment and promote national equitable schemes. Similarly, the urban and rural Aboriginal workshops identified unique issues and priorities for the NBCC. A number of priorities were identified, as shown in Table 6, that had not been mentioned in any of the others workshops, and included the need to ensure that Aboriginal women were aware that they could develop breast cancer; to foster culturally acceptable health care for breast
cancer including a recognition that Aboriginal women do not find it culturally acceptable to have health services provided by men especially for women’s business; to develop programs that recognise Aboriginal communities are heterogenous with many different languages and cultural groups, that care should be holistic and that community ownership of programs and resource development is vital. There is a need also to provide programs which address the lack of support for Aboriginal women from rural and remote communities travelling to treatment centres and that provide education about Aboriginal culture and values to non-Aboriginal health professionals.

It should also be a priority to ensure that information about the incidence of and mortality from breast cancer among Aboriginal women is collected.

Finally, the workshop for women from non-English speaking background identified a number of priorities which had not been mentioned in any other workshops, as shown in Table 8. The workshop identified a number of issues including the need for programs which recognise that there are many heterogenous groups within the non-English speaking background community; for services that are culturally relevant and linguistically appropriate; to increase understanding among health professionals of different cultural views of breast cancer; to ensure the development of culturally appropriate training programs for ethnic health workers and for interpreters and translators. The workshop also emphasised that women from non-English speaking backgrounds from rural and remote areas may have special difficulties in obtaining and support because of their isolation from other community members.
Appendix 4b

Rural and regional women – improving access to services and information, excerpt from *Making a difference – Australia’s first national breast cancer conference for women* (National Breast Cancer Centre and Breast Cancer Network Australia 1998 pp21-22)

Rural and regional women - improving access to services and information

**Context**

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

This workshop identified the following priority actions to overcome these obstacles:
**Individual and group actions**

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

**State and territory level actions**

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

**National level actions**

- Breast Cancer Network Australia, in conjunction with the NHMRC National Breast Cancer Centre, to develop a model travel assistance scheme and together with state consumer groups, to lobby for national implementation.
- Commonwealth government to encourage the national use of telemedicine for rural women; telemedicine consultations should allow a patient advocate to participate if requested by the woman concerned.
- Commonwealth government and relevant professional colleges to improve the availability of medical practitioners suitably qualified in the diagnosis and treatment of breast cancer in rural areas.
• NHMRC National Breast Cancer Centre to review the level of adherence to the clinical practice guidelines by general practitioners and other clinicians in rural areas.

• NHMRC National Breast Cancer Centre to develop strategies for the comprehensive dissemination of the consumer guidelines to all who need them in rural areas.
Appendix 4c

Correspondence from NSW Breast Cancer Action Group

Difficulty in accessing optimal treatment in own area needs of women travelling to urban centres for treatment

One possible source of assistance is the potential role of community service clubs. In particular women’s service clubs. As a member of such organisation, ‘ZONTA’ I have recently undertaken a survey of health related projects supported by Zontians in District 23 consisting of NSW and Queensland. Of the 63 surveyed, 32 clubs responded revealing a total of 83 projects in all relating to the provision of health services. Several of these were directly related to the breast cancer cause ie the provision Mastectomy Pillows (following lumpectomy or mastectomy), donation of wigs to patients suffering to hair loss, fundraising for Breast Cancer Awareness Day by the sale of pink ribbons and even donations of funds for the purchase of an Ultrasound for the purpose of conducting breast screening at regional centre.

A model in which service club members assist rural women with accommodation during Radiotherapy treatment is a possibility. The service club sector is particular interested in projects of this nature, in many cases preferring service to the community in preference to straight fundraising. A list of Clubs in each of the nine local areas is readily available. Contact with the women’s service club sector may also throw up potential breast cancer buddies ie members who themselves have undergone treatment for disease and who can offer telephone support to their rural counterparts.

Other forms of support could be forthcoming from other women’s organisations eg The Older Women’s Network. The CWA, which has accommodation venues, may be approached in an effort to secure cheap (or subsidised) accommodation.
Regarding travel costs, regional airlines may be prevailed upon to make available unused seats at substantial discounts enabling women to access treatment programs. This scheme would possibly require assistance in the form of government subsidies but these may now more readily forthcoming after recent Victorian election results! (Rural Australians have voting power)

**IPTAAS** is a huge issue and certainly requires an injection of flexibility into the scheme. It is nonsensical that rural women should be denied access to travel subsidy simply because they are a few kilometres short of the required distance. Similarly it is denying rural women freedom of choice if they are disqualified because they do not choose to attend the nearest regional centre on account of their support system is situated elsewhere.

**Prosthesis provision** is another major issue facing rural women with breast cancer. Problems exist in the areas of cost, lack of skilled fitters and again difficulties with transport. Possible solutions include subsidising the cost of training fitters in regional areas or subsidising their travel costs to facilitate their regular attendance at nominated areas. The cost involved would be negated by the reduction in complications requiring expensive physiotherapy treatment.

**Provision of specialist breast nurse in regional centres**

While this is an excellent suggestion there are other alternatives for consideration. Women would still have to travel long distances and the breast nurse, with no replacement provided could eventually suffer burnout, common phenomenon amongst rural health professionals. A possible solution could be the provision of short skill-based courses (as mounted by the College of Nursing) for Women’s Health Nurses. Alternatively Distance Education courses are offered by many University based Department of Nursing.
Difficulty in obtaining information about breast cancer access to communication technology

These two issues appear to have common components ie Models incorporating the use of teleconference facilities offered by regional university and tele education facilities utilised by rural medical practitioners may be utilised to enable telemedicine consultants. Similarly these facilities may also utilised for information purposes ie information evening on the complementary treatments, types of breast reconstruction available, prosthesis etc.

In reality the issue concerning information is not that there is a lack of it but that it is not readily accessible to rural women. This is often due to the fact that rural health practitioners are not aware of its availability. There is an urgent need for the facilitation of existing information networks, eg perhaps the position of State coordinators may need to be re-introduced or alternatively the nomination of a person who can advise the different groups of health professionals with direct patients care contact. Certainly more publicity is required regarding already existing resources of information.
Appendix 5 (see overleaf)

Specialist breast nurse study –
specialist breast nurse protocol
Specialist Breast Nurse

Diagnosis
(during or immediately after)

Multidisciplinary Meeting

Pre Operatively

Information
- Discuss: surgical intervention and procedures
  - possible complications/side effects
  - prosthesis

Support
- Check psychological risk factors
- Discuss: response to diagnosis
  - support networks
  - offer: discussions with family
    - referral to BCSS

Possible patient initiated consultation

Multidisciplinary Meeting

Post Operatively

Information
- Discuss: results/prognosis
  - new treatment decisions
  - adjuvant therapy options
  - breast reconstruction/prosthesis
  - clinical trials
  - wound and drain care
  - discharge plan
  - what happens next
- Introduce treatment team

Support
- Discuss feelings, problems, solutions
- offer: family discussion
- Check practical support on discharge
- Discuss family issues/needs

Possible patient initiated consultation

Multidisciplinary Meeting

Follow up 1
1-6 weeks
Post Operatively

Information
- Discuss: treatment plan
  - adjuvant therapy
  - possible side effects
  - clinical trials
  - breast reconstruction
  - what happens next

Support
- Discuss feelings, problems, solutions, effects on intimacy/relationships
- Check: major psychological problems
  - support networks

Possible patient initiated consultation

Follow up 2
6-10 weeks
Post Operatively

Information
- Discuss: treatment plan
  - adjuvant therapy
  - side effects
  - clinical trials
  - breast reconstruction
  - what happens next
- Discuss clinical trials

Support
- Discuss: feelings, problems, solutions
  - support groups
- Check: for psychological problems

Possible patient initiated consultation
Appendix 6

Other initiatives for improving access to healthcare services for rural Australians

Rural liaison nurse consultant
Royal Adelaide Hospital

Having recognised that a large percentage of patients travels in from areas outside Adelaide, staff at Royal Adelaide Hospital, have explored avenues to improve care for rural patients. One approach was to establish a rural liaison nurse to improve the coordination of care between treatment centres for rural patients. The aims of establishing this position are to ensure that patients are linked with appropriate healthcare services on returning to their local area, and to provide support for rural patients while they are away from home. The position has been positively received. As recognition of the role grows in rural areas, patients are increasingly linked with the rural liaison nurse before their arrival in Adelaide.

Mobile women's health nurses

To improve access to women’s health services in rural Queensland, 13 mobile women’s health nurse positions have been established. These nurses cover a radius of 500-1000kms and are based in regional centres such as Mt Isa, Townsville, Roma and Longreach. The mobile women’s health nurses work closely with existing local health services to provide primary health care for women in rural and remote areas.
Rural nurse practitioners

The role of the nurse practitioner in Australia is being increasingly explored, particularly in rural and remote areas. While the shortage of medical services is perceived as a major impetus for these positions, they remain strongly focused on nursing care and working within a team structure as opposed to being independent health practitioners. These nurses are health practitioners with extended skills and expertise. Recognition of these positions is currently occurring across Australia, with legislation passed or being developed in many States. There are many examples of rural nurse practitioners across Australia. These positions are developed to meet the specific needs of a local area, so the job description varies.

Rural women’s health days

Women’s Health Days are run in remote areas of WA. These are coordinated to include the mobile screening vans and Aboriginal and community health programs. The aim is to focus on all aspects of women’s health, using a primary health model.

“Fly In-Fly Out” Women’s Health Program

This program has been running in Queensland for 10 years, and in 1999 became a joint project between Federal and State Governments and the Division of General Practitioners. The aim of this program is to provide women in rural and remote areas with access to female general practitioners, who visit rural and remote areas by air.
Specialist cardiac nurse educator/coordinator

Since most NT patients travel interstate for cardiac surgery, a position was established to coordinate patient care pre- and post- cardiac treatment. The specialist cardiac nurse educator/coordinator is responsible for educating health care teams in local areas and for coordinating patient care, follow-up and support for patients and their families. The role of the nurse includes acting as a resource for the local health care team, and providing education or practical advice—either by visiting the local area or by telephone. As the number of patients per year is not high, one cardiac specialist nurse educator coordinates all patients in the NT. This has improved continuity of care, as well as access to support for patients, family and staff.
References


27 Sach J and Associates. *Palliative care in rural Australia: a project of the National Palliative Care Program*. Melbourne, Australian Government Printing

