National survey of women with early breast cancer: their perceptions of care (1997)
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April 2004

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It is the first time a survey of this type has been conducted in Australia and we are particularly grateful for the willingness of the women who participated in this study and gave generously of their time in sharing their experiences. A great many people also contributed to the development and implementation of the survey, including:

- The Centre’s Consumer Advisory Group who contributed to the development of the survey items
- The Centre’s Psychosocial and Monitoring Working Groups who reviewed the survey items and the methodology
- Members of the Breast Section of the Royal Australasian College of Surgeons who reviewed the survey and who encouraged participation in the survey among their membership
- The New South Wales Central Cancer Registry who trialled the recruitment procedures
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• Ms Danielle Campbell from the National Breast Cancer Centre who assisted in the preparation of the final report

We are very grateful for the assistance of these individuals and organisations.

Last, but not least, this study would not have been possible without the contribution of the clinicians who were caring for women participating in the study.

It is hoped that the information obtained from this study will be used to further improve the care for women diagnosed with and treated for early breast cancer in Australia.
PUBLICATIONS FROM THE NATIONAL SURVEY OF WOMEN WITH EARLY BREAST CANCER

Data from the National survey of women has been published in several peer reviewed journal articles and reports. Different sampling frameworks for the purposes of data analysis have been utilised in each instance; hence, the figures reported for particular variables are different across publications.

The publications resulting from the National survey of women include:


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EXECUTIVE SUMMARY

Care in relation to the NHMRC Clinical practice guidelines for the management of early breast cancer

Ninety-five per cent of women were told their diagnosis by a senior doctor or their general practitioner.

Ninety per cent of women felt that the style used to tell them their diagnosis was honest, open and frank.

Eighty-six per cent of women were told their diagnosis face-to-face; while 13% were told their diagnosis by telephone. Of the total sample, 3% thought the way they were told their diagnosis of breast cancer was inappropriate.

Eighty-one per cent of women felt that they had received enough information about their treatment.

Eighty-three per cent of women felt that they had received enough support during diagnosis and treatment.

Only 13% of women reported being told about clinical trials and only 6% reported taking part in a trial.

Sixty-one per cent of women were offered either of the consumer guides produced from the NHMRC Clinical practice guidelines for the management of early breast cancer.

Very few women were offered an audio tape of any of their consultations (4%) and only 22% were offered written information about their own diagnoses.

Twenty-two per cent of women reported that their families needed better support.

Women reported not receiving enough information about the psychosocial impact of breast cancer including availability of support or counselling (22%) and costs of treatment (24%).

Twenty-one per cent of women who had a mastectomy would have liked more information about breast reconstruction.

Twenty-four per cent of women would have liked more information about lymphoedema and how to prevent it.

Although 73% of women reported that they were as involved as they wanted to be in their treatment decision, 22% reported that they were told there was only one treatment choice. Women who reported being told that there was only one choice were no more likely to receive mastectomy than breast conserving surgery.
Fifty-six per cent of women reported that they had time to think about treatment options. Although 41% of women reported being told that they had to make their decision about treatment straight away, most of these women (75%) still felt that they had sufficient time to decide.

Although 79% of women reported that they were given a follow up plan, only 20% reported receiving this in writing.

Overall, there were very few differences in women’s judgements about the care received according to their age, whether they were private or public patients or whether they lived in urban or rural areas. This suggests that most women with breast cancer are given a similar standard of care along the dimensions measured in this survey.

However, there were a few exceptions where differences were apparent:

- Younger women, women with higher levels of education and private patients were more likely to be given a greater range of information about their treatment
- While many women indicated that their families would have appreciated more support, this was particularly the case for younger women
- Younger women and those living in urban areas were more likely to be given information about clinical trials
- Among women who had had mastectomies, younger women were more likely to have had breast reconstruction. Younger women were also more likely to report that they had not received enough information about breast reconstruction
- Public patients were more likely to receive a written follow up plan
- Public patients were more likely to report that they had seen too many people during their treatment and to want to have one person identified as a contact point
Special issues

Care overall

Eighty-two per cent of women reported being highly satisfied with their care and 10% were somewhat satisfied.

Side effects

Fifty-two per cent of women receiving radiotherapy and 64% receiving chemotherapy reported that they had experienced side effects sufficient to delay their return to normal activities.

Thirty-eight per cent of women reported that they had experienced swelling in their arm following their treatment.

Early discharge

Seventeen per cent of women were discharged from hospital within 48 hours. Women who were discharged within 48 hours were significantly more likely to have had a lumpectomy compared to women who had stayed in hospital for more than two days.

Support services

About one third of women reported using the BCSS for support. Women who used the service were very satisfied.

Fourteen per cent reported seeing a breast nurse on three or more occasions. There is evidence that these women were more likely to: be informed about clinical trials; have enough information about the side effects of treatment; know about follow-up care; and have received enough support both for themselves and their families.

Continuity of care

Ninety-four per cent of women felt that they understood who was in charge of their care and that the information given to other members of their treatment team and general practitioner was
adequate. However, 42% of women would have liked to have had one person identified as the main contact point during treatment.

**Rural women**

Rural women were more likely to have a mastectomy than urban women. Sixty-three per cent of rural women who had radiotherapy travelled more than 100 kilometres to receive radiotherapy and the average time away from home was 43 days. Less than half of the women who travelled for treatment received any financial assistance.

**IMPLICATIONS FOR CARE**

The findings of the National survey of women with early breast cancer have several implications for care:

1. By and large women reported that they were receiving care in accord with the NHMRC Clinical practice guidelines for the management of early breast cancer and that they were satisfied with this care. In comparison with other women, women living in rural areas and public patients were just as likely to report receiving care which is in accord with the guidelines and with which they were satisfied. The community should be made aware that most women report receiving high quality care as this knowledge may reassure women newly diagnosed with breast cancer.

2. Efforts should be directed to improving care in several areas to ensure the full implementation of the NHMRC Clinical practice guidelines for the management of early breast cancer including:

   - **Information:** There is a need to increase the proportion of women who receive copies of the consumer guides based on the guidelines and to provide access to a greater range of resources such as written information about women’s diagnoses and audiotapes of the consultation. In particular, more information about lymphoedema, options for supportive care, and breast reconstruction is needed. Few women received a written follow up plan. Clinicians should be made aware that most women want high quality information about all aspects of their disease; special efforts should be made to inform women with lower education levels and older women who currently appear to be more likely to miss out
- **Clinical trials:** Few women are offered the opportunity to participate in clinical trials. The evidence suggests that women will take part if they are offered the chance; strategies to encourage clinicians to take part in clinical trials are needed.

- **Breast reconstruction:** Only 8% of women who had a mastectomy underwent breast reconstruction. Some women also felt they did not receive enough information about breast reconstruction. An analysis of the reasons for the low rates of breast reconstruction in Australia should be undertaken.

- **Supportive care:** Although women felt they received appropriate supportive care in the main, there is a need to improve support for families and to improve information about the psychosocial impact of breast cancer, including availability of support or counselling and costs of treatment.

3 In some areas, a better understanding of women's needs would enable the development of more appropriate recommendations in future editions of the guidelines. For example, women's views about their involvement in decision making and about whether treatment should be delayed for a week or two do not necessarily reflect clinical opinion. Additional research in these areas may assist in better framing guideline recommendations to meet women's needs.

4 Special strategies are needed to ensure that rural women have adequate support for travel for treatment. There was no evidence that rural women received poorer care in relation to most of the guidelines, but better information about financial support for travel and accommodation was needed.

5 Many women reported experiencing side effects of surgery, radiation therapy and chemotherapy which were in many cases sufficient to delay their return to normal activities. Thirty-eight per cent of women also reported that they had experienced swelling in their arm following their treatment. Information resources for women with breast cancer should include accurate information about the likelihood of experiencing treatment side effects.

6 Relatively few women reported that they saw a specialist breast nurse on three or more occasions, despite evidence of the value of these nurses in improving care. Women also reported that they would have liked one person who they could contact about their care. In many cases, breast nurses fulfil this role. There is a need to improve access to specialist breast nurses.
About one third of women used the Breast Cancer Support Service (BCSS) for support. Those who used the Service found it very helpful. Women need access to a range of support options; better information about the availability of the BCSS volunteers may improve access.

A INTRODUCTION, AIMS AND METHODS

A.1 Introduction

Approximately 10,000 Australian women are newly diagnosed with breast cancer each year; breast cancer remains the most common cause of cancer deaths among women in Australia, accounting for 2,558 deaths in 1994. Of these, approximately 85% are early breast cancer.

In 1995, the National Health and Medical Research Council (NHMRC) published the NHMRC Clinical practice guidelines for the management of early breast cancer. These guidelines were part of a national program to promote the development of evidence based clinical practice guidelines. The guidelines are designed to assist in decision making by women and their doctors and to inform all involved in the care of women with breast cancer about the most recent evidence.

The NHMRC Clinical practice guidelines for the management of early breast cancer include evidence and recommendations about the benefits of surgery, radiotherapy and medical oncology in treating women with breast cancer. They also make recommendations about information and support for women and the overall approach to care.

Guidelines will only be effective in improving care if efforts are made to encourage their adoption. Audit is a key component in encouraging adoption of an evidence based approach to care as it highlights areas where care is in accord with guidelines and where it differs.

Patterns of care studies provide information about the extent to which the clinical aspects of care are in accord with the guidelines. However, many of the recommendations in the guidelines can only be evaluated by asking women about their experiences during the diagnosis and treatment of their breast cancer. For example, the most accurate record of whether women received information about all aspects of their care or adequate emotional support will be obtained by asking women themselves.

Research about the needs of women with breast cancer have been summarised in the recently published Psychosocial clinical practice guidelines: information, support and counselling for women with breast cancer. Several recent studies have examined women’s needs following the diagnosis of breast cancer within the Australian context. These studies have been designed to explore the needs of
women with breast cancer and focus on a particular group of women recruited, most usually, through hospitals.

However, to estimate the extent to which care is in accord with the recommendations in the NHMRC *Clinical practice guidelines for the management of early breast cancer*, a different approach is required. The women surveyed must be a population sample representative of all women diagnosed with early breast cancer in Australia. The survey itself must be a patterns of care study focusing on the recommendations in the guidelines; it must measure both women's report of the way care was provided and their perceptions of this care in respect of the recommendations in the guidelines. No population based study of women's perceptions of their care was located either in Australia or internationally.

The primary purpose of the *National survey of women with early breast cancer* was therefore to determine the extent to which women with early breast cancer perceived their care to be in accord with the recommendations in the NHMRC *Clinical practice guidelines for the management of early breast cancer*. It was intended that the survey provide parallel data to the patterns of treatment surveys by exploring the views of a large, representative sample of women diagnosed with early breast cancer in 1997 across all States in Australia. This information would enable the identification of those areas of care where there may be a need for implementation programs to encourage full adoption of the guidelines. The data from the survey would also provide a benchmark against which the impact of future programs can be assessed.

A secondary purpose was to take the opportunity offered by a unique large scale population study to explore some special issues for women with early breast cancer which are critical to the development of policy and practice.

### A.2 Aims

The aims of the *National survey of women with early breast cancer* were to:

1. Describe the perceptions of a representative sample of women with early breast cancer about their care in relation to the recommendations from the *NHMRC clinical practice guidelines for the management of early breast cancer*.

2. Explore the relationship between women's perceptions of their care and the following:
   - treatment in public versus private facilities
   - living in urban versus rural location
   - age of the women
Explore a range of special issues important for planning service delivery or providing information to women diagnosed with breast cancer, including:

- the experience of side effects of surgery, radiotherapy and adjuvant therapy
- early discharge following breast surgery
- Breast Cancer Support Services
- specialist breast care nurses
- continuity of care
- travel and accommodation needs for rural women

A.3 Method

The method and characteristics of the sample are described in detail in the document *National survey of women with early breast cancer: Technical paper*. The *Technical paper* is available from the Centre as a printed document on request, or from the website www.nbcc.org.au.

A.3.1 Survey instrument

The aims were used to develop the items for the survey. Survey items were extensively reviewed during the development phase by consumers and by surgeons. Two rounds of pilot testing were undertaken and the survey was modified based on the results. A copy of the final survey instrument is included in the *Technical paper*.

The survey was assessed for test-retest reliability and found to be reliable. It was not possible to explore the validity of all items in the survey, particularly the items asking about women's perceptions. However, two items that asked about the type of surgery women had (mastectomy or lumpectomy) and whether women had chemotherapy were compared with other independent records and there was an acceptable level of agreement. Further details about the reliability and validity of the survey instrument can be found in the *Technical paper*.

The final survey consisted of 83 questions addressing the three aims as well as some items about patient demographics. It was designed to be administered as a telephone interview and took an average of 40 minutes to complete.
The survey was administered between six and 12 months after diagnosis. At this point, most women would have completed or almost completed treatment, but should still have been able to recall salient details of their diagnosis and care.

A.3.2 Sample

The women to be approached were identified from women newly diagnosed with breast cancer and reported to the population-based cancer registries in each State and Territory to ensure that the sample was as representative as possible.

Women were considered eligible to participate in the survey if: they had a new histological or cytological diagnosis of invasive primary breast cancer; they received their diagnosis within the preceding six to 12 months; they were not known to have distant metastases at time of diagnosis; they were aged over 18 years; they were not known to have died; they spoke and understood English sufficiently well to complete the survey; and they were not considered by their surgeon to be too ill or too psychologically or emotionally distressed to complete the survey.

A.3.3 Recruitment and response rate

State and Territory cancer registries were approached with details of the proposed study and approval was sought from each of the relevant ethics committees. All States and Territories except Tasmania agreed to take part in the project.

The participating State and Territory cancer registries were asked to randomly select 25% of women diagnosed in the six month period 1 March 1997 to 31 August 1997. Based on 1992 incidence figures, it was estimated that this would be more than sufficient to provide the required sample size of 400. In total, the 25% sample resulted in 1184 women being selected as shown in Figure 1.

Figure 1 shows the three phase consent procedure and the number of women consenting and responding after each phase. A total of 405 clinicians were the treating practitioners for women selected from the cancer registries; 104 women were excluded as a result of their clinicians not agreeing to approach any of their patients.

The clinicians who agreed to participate were asked to indicate whether the identified women were eligible to participate. As shown in Figure 1, 37 of these women had not been diagnosed with early breast cancer and 7 had died. In total, 19.6% of women in the initial sample were classified as ineligible by their clinicians. Of the 868 women who were eligible to participate, a randomly
selected sub-sample of 36 women were not invited to take part as the recruitment target was reached before all letters of invitation had been sent.

Of the 832 women who were invited by mail to participate in the study, 134 refused to participate and 83 could not be contacted. Of the 615 women who were then approached by telephone, 38 refused to complete the interview and 33 could not be contacted. A total of 544 women completed the survey (65% of the 832 women who were personally invited to participate). Overall, the participation rate was established at 49% when only women who were ineligible because they did not have early breast cancer or were randomly selected out of the source at Stage 3 were excluded from the denominator (N=1111), and the response rate was 76% when only women who were contacted themselves were included in the denominator (N=716).
Figure 1  Recruitment process, consent, and response rates

Stage 1  Clinicians consent on behalf of women

- Women selected from the registries to participate  n=1184
- Clinicians identified and contacted  n=405
  - Clinicians not responding  n=34
    - Clinicians responding  n=351
      - Clinicians agreeing  n=331
        - Women therefore not given an opportunity to participate  n=104
          - Excluded by clinician:
            - Too disturbed  n=42
            - Too ill  n=18
            - Unstated reason  n=54
            - Other reason  n=29
          - Judged by clinicians to be unsuitable to participate
          - Ineligible; should not have been included in the original sample

Stage 2  Women consent to an approach for the survey

- Total number of women identified who were managed by consenting clinicians  n=1080
  - Total number of eligible women  n=868
    - Total number of women sent a letter inviting participation  n=832
      - Women refused to participate  n=134
        - Women not contactable by mail or follow-up calls  n=83
  - Total number of ineligible women:
    - Poor English  n=25
    - Not early breast cancer  n=37
    - Deceased  n=7
  - Women who did not complete the survey:
    - Refused  n=15
    - Terminated calls  n=23
    - Women not contactable by phone after 5 attempts  n=33

Stage 3  Women contacted for and participate in survey

- Total number of women approached by telephone  n=615
  - Total number of women completing survey  n=544
A.3.4 Recruitment and response rate

There are no population data about the education status of women with early breast cancer and therefore comparisons were made between New South Wales women from the National survey of women sample, the Australian Census, and the NSW Health Survey; these comparisons are shown in Table 1.

**Table 1** Comparison of the National survey of women sample and population samples in regard to post school qualifications

<table>
<thead>
<tr>
<th></th>
<th>National survey of women: NSW cohort</th>
<th>NSW Health Survey 1997*</th>
<th>Australian Census 1996: NSW women**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-school qualifications</td>
<td>29%</td>
<td>32%</td>
<td>39%</td>
</tr>
</tbody>
</table>


While there is insufficient age-adjusted data on which to make accurate comparisons, the differences between the proportion of women with post school education from the National survey of women sample and the two population samples are relatively small.

Table 2 shows a comparison between the place of residence of participants in the National survey of women and NSW Cancer Registry data.

**Table 2** Comparison of National survey of women sample with data from the NSW Cancer Registry: ARIA Index

<table>
<thead>
<tr>
<th></th>
<th>National survey of women: NSW cohort</th>
<th>NSW Cancer Registry 1995: Women with breast cancer†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highly accessible</td>
<td>85%</td>
<td>83%</td>
</tr>
<tr>
<td>Accessible</td>
<td>12%</td>
<td>14%</td>
</tr>
<tr>
<td>Moderately accessible, remote and very</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

† NSW Health Department, *Cancer Registry and Inpatient Statistics Collection linked data file*, 1995.
The sample was also compared with data from the *Surgical management of breast cancer in Australia in 1995* survey, which included all Australian women diagnosed with breast cancer during a defined six month period. This survey provides the most comprehensive set of breast cancer data currently available in Australia. It shows that early breast cancer accounted for 85% of all breast cancer cases diagnosed in 1995. Comparisons are shown in Table 3.

**Table 3 Comparison of National survey of women sample with Surgical management of breast cancer sample**

<table>
<thead>
<tr>
<th></th>
<th>National survey of women</th>
<th>Surgical management of breast cancer survey</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>24%</td>
<td>22%</td>
</tr>
<tr>
<td>50-59</td>
<td>32%</td>
<td>26%</td>
</tr>
<tr>
<td>60-69</td>
<td>24%</td>
<td>23%</td>
</tr>
<tr>
<td>70+</td>
<td>20%</td>
<td>29%</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>63%</td>
<td>71%</td>
</tr>
<tr>
<td>Rural</td>
<td>37%</td>
<td>29%</td>
</tr>
<tr>
<td><strong>Surgical treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative</td>
<td>60%</td>
<td>53%</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>37%</td>
<td>47%</td>
</tr>
</tbody>
</table>

**Is the sample representative of women with early breast cancer?**

The extent to which the sample is representative is of considerable importance because of the loss of women at each step in the recruitment process. Overall, it appears that:

- The sample is representative by State and Territory with the exception of Tasmania, which did not participate

- The sample is probably representative in terms of sampling of urban and rural women. It approximates the distribution reported by the NSW Central Cancer Registry based on the
ARIA index. The ARIA index was selected as most appropriate for classification of urban/rural status since it reflects the accessibility of services. The differences between the sample in the National survey of women and that of the Surgical management of breast cancer survey may be attributable to categorisation differences. In the National survey of women, respondents were asked to indicate whether they lived in a rural or remote area, a country town or country centre, or a major city. Women who indicated that they lived in ‘a major city’ were categorised as urban dwellers, with the remaining women categorised as living in rural areas. This method of categorisation is somewhat different to the Surgical management of breast cancer survey, which used the Australian Bureau of Statistics’ 1991 postcode/SLA/Rural, Remote and Metropolitan category concordance, where Category 1 (Capital City) and Category 2 (Other Metropolitan Centre), were classified as urban and the remaining categories as rural.

Although it is difficult to judge the representativeness of the sample in terms of demographic and treatment characteristics, there does not appear to be a systematic bias. The National survey of women sample is similar to that of the Surgical management of breast cancer survey in terms of age distribution. It appears that the NSW cohort at least is representative in terms of education. Women in the National survey of women sample were more likely than those in the Surgical management of breast cancer survey to receive breast conserving therapy and chemotherapy. Given that this effect does not appear to be due to differences in the women themselves, this result may be attributable to the time difference between the two surveys. The National survey of women interviewed women diagnosed two years after the release of the NHMRC Clinical practice guidelines for the management of early breast cancer while the Surgical management of breast cancer survey explored the records of women diagnosed prior to the release of the guidelines. An alternate explanation is that surgeons who did not participate in the survey provided care less in accord with the guidelines.

A.3.5 Data analysis

Frequencies were calculated for each survey question.

For each of the major questions in the survey, chi-square and t-test analyses were used to compare the responses of:

- women living in urban versus rural locations
- younger women (younger than 50 years) versus older women (50 years and older)
- women treated in private versus public facilities
When the expected frequencies were less than the minimum requirement for chi Square analysis, Yates correction for continuity ($\chi^2_c$) was used for bivariate analyses and cells were collapsed for larger analyses.\textsuperscript{13} In all analyses, the Bonferroni correction for multiple comparisons was used, so that differences were considered significant when $p<0.01$, rather than $p<0.05$, owing to the large number of comparisons.\textsuperscript{14}

Only differences that were statistically significant are mentioned in the text.

### A.4 Interpretation of the results

In interpreting the results of the survey, several potential sources of bias should be considered.

**Participants**

Of the initial sample selected from the cancer registries, a proportion of women were not contacted because their clinicians did not wish to participate or categorised them as ineligible. The non-participation of these clinicians and women may have introduced some bias into the sample, as it is possible that some of these clinicians provided care which was not in accordance with the guidelines, or that the women excluded by clinicians were less satisfied with their care. Some women also declined to participate in the survey. It is unlikely that these women were particularly dissatisfied with their care; if this were the case, they would probably have welcomed the opportunity to comment. However, some of these women may have been too distressed to participate in the study, or concerned that any negative comments might influence their treatment.

It should also be noted that women with limited English language were not eligible to participate in the study. Future research should address the specific needs of women from non-English speaking backgrounds.

The representativeness of the sample was explored in some detail. These comparisons are described in section A.3.4 above and in more detail in the *Technical paper*.\textsuperscript{12}

These comparisons are necessarily limited because there are no previous national population samples of women with breast cancer for which demographic data are available. However, the sample was representative by State and Territory with the exception of Tasmania and in terms of urban or rural residence, using the ARIA classification. Within the limits of the available data, it appeared that the sample was representative in terms of age distribution and education.
While it appears unlikely that there is a systematic bias towards either underestimating or overestimating compliance with the recommendations, the difficulties in achieving a representative sample should be borne in mind in interpreting the results.

**Time since diagnosis**

Women were interviewed between six and 12 months after diagnosis. There has been no investigation of how women’s recall of diagnostic and treatment events change over time; however, a study comparing self-reported treatment for prostate cancer with medical records six months after treatment reported excellent patient recall of invasive treatments such as surgery and radiation therapy, and moderate to substantial recall of hormone therapy.\(^{15}\)

**Interview questions**

As described, the items have demonstrated reliability. They were designed to assess whether care was in accord with the guidelines rather than to explore unmet needs. It is recognised that women may respond positively to generic questions about their views of care in part because ‘nothing bad’ happened, rather than because care was as good as it might be. Nonetheless, the survey included specific questions asking whether key aspects of care were given in a particular manner; such questions are less open to bias. Further, women expressed dissatisfaction with a number of specific aspects of care suggesting that there was no consistent bias towards favourable opinions.

**B. Comparison of reported psychosocial care with the NHMRC Clinical practice guidelines for the management of early breast cancer**

The first aim of the *National survey of women with early breast cancer* was to determine the degree to which women’s perceptions of their care were consistent with recommendations made in the *NHMRC Clinical practice guidelines for the management of early breast cancer*.

**B.1 Overall**

The twelve recommendations from the guidelines examined as part of this survey are shown in Table 4 along with a summary of results.
The majority of women reported receiving care in accord with most aspects of the guidelines. The extent to which the same women were reporting care not in accord with different recommendations was explored. Seven recommendations which were relevant to all women were examined, including whether: women were told their diagnosis of cancer by a senior doctor or a general practitioner; the method of being told their diagnosis was appropriate; the style of being told the diagnosis was open/honest/frank; women were given the opportunity to have someone with them if told their diagnosis face-to-face; women thought they had enough time to decide about treatment; women received an appropriate amount of information; women received enough support.

Figure 2 shows the proportion of women who reported care not in accord with the guidelines in respect to different numbers of recommendations. Twenty-nine per cent of women indicated care not in accord with recommendations on none of the key questions, 37% indicated care not in accord with recommendations on one key question, 19% on two questions, 10% on three questions, 4% on four questions, 1% on five questions and no women reported care discordant with recommendations on 6 or 7 questions.

Chi square analyses were undertaken to explore the association between reporting care not in accord with the guidelines on two or more items and age, residence, public/private treatment and education. No significant associations were found.

**Table 4: Recommendations from the NHMRC Clinical practice guidelines for the management of early breast cancer**

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Per cent reporting receiving care in accord with recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Diagnosis should be given by a senior doctor</td>
<td>95%</td>
</tr>
<tr>
<td>2. Diagnosis should be given to women face-to-face</td>
<td>86%</td>
</tr>
<tr>
<td>3. Diagnosis should be given in an open manner</td>
<td>90%</td>
</tr>
<tr>
<td>4. Women should be encouraged to have a second person present when being given a diagnosis</td>
<td>59%</td>
</tr>
<tr>
<td>5. Women should be reassured that there is no reason to believe that waiting a week or two to decide on treatment will make any difference</td>
<td>56%</td>
</tr>
<tr>
<td>6. Treatment decisions should be made by the woman after discussing with her doctor and any others she may care to consult</td>
<td>73%</td>
</tr>
<tr>
<td></td>
<td>Statement</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>7</td>
<td>Women are entitled to make their own decisions about treatments or procedures and should be given adequate information on which to base those decisions</td>
</tr>
<tr>
<td>8</td>
<td>While information about the disease and its treatment is critical, women also need information about the psychosocial impact of breast cancer and the material and practical resources required to adjust to and cope with the disease</td>
</tr>
<tr>
<td>9</td>
<td>Appropriate counselling has the potential to improve quality of life</td>
</tr>
<tr>
<td>10</td>
<td>Doctors should encourage women with breast cancer to consider participating in appropriate clinical trials for which they are eligible</td>
</tr>
<tr>
<td>11</td>
<td>Women should be given the opportunity to consider breast reconstruction, so they can balance the advantages and disadvantages of reconstruction after mastectomy</td>
</tr>
<tr>
<td>12</td>
<td>Clinicians should provide women with a management plan and follow-up plan</td>
</tr>
</tbody>
</table>

**Figure 2** Dissatisfaction with different numbers of key guideline items

![Figure 2](image-url)
B.2 Diagnosis should be given by a senior doctor

Women were asked: *Who first told you that you definitely had breast cancer? This person may be different from the doctor that you first went to with symptoms.* (Table B.2.1)

Seventy-eight per cent of all respondents were told their diagnosis by a senior doctor such as a surgeon or consultant, 17% were told their diagnosis by their general practitioner, 3% were told by a junior doctor, nurse or technician, and 3% were told by another person. Overall 95% of women were given their diagnosis by an appropriate doctor such as a specialist or a general practitioner.

B.3 Diagnosis should be given to women face-to-face

Women were asked: *Some women get told their diagnosis over the telephone, others are told face-to-face. How were you told your diagnosis? Did you find the way that you were told of your diagnosis was appropriate?* (Table B.3.1)

Eighty-six per cent of women were told their diagnosis face-to-face, and all but one woman felt this was an appropriate way to be told.

Thirteen per cent of women were told their diagnosis by telephone, 1% by letter and 1% by another method. Of the women who were told their diagnosis by a method other than face-to-face (N=78):

- 76% thought it was an appropriate method; and
- 24% would have preferred being told face-to-face.

Of the total sample, 3% thought the way they were told their diagnosis of breast cancer was inappropriate.

B.4 Diagnosis should be given in an open manner

Women were asked: *Which of the following best describes the style used to tell you that you had breast cancer? That is, how clearly was it explained? The words the person used, the way the person spoke and so on. Was it: too abrupt/matter of fact/business like; honest/open/frank; not very direct or clear.*

Women were also asked: *Did you feel that the person telling you your diagnosis was: supportive and understanding, or not very supportive or understanding?* (Tables B.4.1, B.4.2)

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1 Table numbers refer to tables in the Technical Paper
2 Total does not equal 100% due to rounding
3 Comparisons of women who received care in accord with the guidelines and those who did not in terms of age, residence and public versus private care were undertaken for each recommendation. Only differences that were statistically significant are reported. Further details are available in the Technical Paper
4 Total does not equal 100% due to rounding
Ninety per cent of respondents felt that the style used to tell them their diagnosis was honest, open and frank; 7% that the style was too abrupt and 1% that it was not very direct or clear. One per cent gave an ‘other’ response.4

Eighty-nine per cent of women said the person was supportive and understanding, while 8% said the person was not supportive and understanding and 4% could not say.4

**B.5 Women should be encouraged to have a second person present when being given a diagnosis**

If women were told their diagnosis face-to-face, they were asked: *Were you given the opportunity or encouraged to have people you wanted with you when you were being told your diagnosis?* Women were asked if they: had a family member or friend with them, had a health professional such as a nurse or counsellor with them, chose not to have someone with them, or wanted someone but couldn’t arrange for someone to come. If women were not given the opportunity, they were asked: *Would you have liked to have had the opportunity or have been encouraged to have people with you when you were being told you diagnosis?* (Tables B.5.1, B.5.2)

Of the 466 women told their diagnosis face-to-face, 59% were given the opportunity or encouraged to have someone with them at the time, 39% were not given the opportunity or encouraged and 2% could not say.

Of the 59% who were given the opportunity or encouraged, most were accompanied by a family member or friend (81%), while 2% had a health professional (eg counsellor or nurse) with them, and 15% chose not to have someone with them. One per cent wanted to have someone with them but could not arrange for someone to come, and 1% could not say.

Of the 466 women told their diagnosis face-to-face, 39% were not given the opportunity to have someone with them at the time of diagnosis. Thirty two per cent of these women reported that they would have liked this opportunity and 6% could not say.

Overall, 12% of the 466 women told their diagnosis face-to-face were not given the opportunity to have someone present when being told their diagnosis and would have liked this opportunity.
B.6 Women should be reassured that there is no reason to believe that waiting a week or two to decide on treatment will make any difference

Women were asked: *When your treatment options were being discussed, were you given the impression that: you needed to decide about treatment straight away; or you had some time to think about it. Was the time you had too short, as much time as you needed, or too long to think about your treatment options?* (Tables B.6.1, B.6.2)

Fifty-six per cent of women reported that they were given the impression that they had some time to think about treatment decisions and 41% indicated that they were given the impression that they needed to decide about treatment straight away. Three per cent of women could not say.

Eighty-three per cent of the sample reported having as much time as they needed to think about treatment options, however, 7% had too short a time, 8% had too long a time, and 2% could not say. Fifteen per cent of the total sample was dissatisfied with the amount of time that they had to think about treatment decisions.

B.7 Treatment decisions should be made by the woman after discussing with her doctor and any others she may care to consult

Women were asked: *How involved would you say you were in the process of deciding about your treatment? Would you say you: were as involved as you wanted to be in the decision and happy about the degree of your involvement; would have preferred to be more involved; would have preferred to be less involved; were told that there was only one treatment which was appropriate, so there was no choice about it. If women reported being as involved as they wanted to be, they were also asked whether they: chose to leave it completely to the doctor to decide, made the decision jointly with your doctor; made the decision completely on your own or with family and friends.* (Tables B.7.1, B.7.2)

Seventy-three per cent of women reported being as involved as they wanted to be in treatment decisions, while 22% of women reported that they were told there was only one appropriate treatment and so there was no choice about it. Four per cent reported that they would have preferred to have been more involved and only one woman reported wanting to be less involved. One per cent could not say.

No demographic comparisons were significant; there was also no significant difference between the proportion of women who had a mastectomy reporting being told there was no choice of
treatment (22%) and the proportion of women who had breast conserving therapy (21%) ($\chi^2=0.01, p=0.93$).

Of the 73% of women (N=398) who reported being as involved in the decision process as they wanted to be, 16% chose to leave it completely to the doctor to decide, 58% made the decision jointly with their doctor and 24% made the decision completely on their own or with family or friends. Two per cent gave ‘other’ responses.

Seventy-four per cent of women reported that their family was encouraged to be as involved as they wanted to be, 10% would have preferred more family involvement, 1% wanted less family involvement and 15% could not say.

**B.8 Women are entitled to make their own decisions about treatments or procedures and should be given adequate information on which to base those decisions**

Women were asked: *Thinking about the amount of information you needed about different aspects of treatment and support, would you say you received: the right amount of information; too much information; too little information. Were you offered any of the following information resources by a member of your treating team to help you to understand more clearly what you were told about your breast cancer (from a list): NHMRC Consumers guide or the book or tape of All about early breast cancer; a BCSS booklet; other printed resources; audio or video tapes about breast cancer; a hospital fact sheet; written information about own diagnosis; audio tape of any of your consultations; specific resources for rural women; specific resources for partners; specific resources for children; treatment choices; surgery; side effects of different treatments; follow-up care; prognosis. Women were asked to indicate whether they: received as much information as they needed, would have liked more information, or would have liked less information in relation to each of a number of different aspects of care. (Tables B.8.1, B.8.2, B.8.3, B.8.4)*

Eighty-one per cent of women reported receiving the right amount of information about different aspects of treatment and support, 14% reported receiving too little and 4% reported receiving too much. One per cent could not say. No demographic comparisons were significant.

Sixty-one per cent of women were offered the NHMRC Consumer Guide to Early Breast Cancer (orange book) and/or All about Early Breast Cancer (either the pink book or tape). Younger women were significantly more likely to be offered one of the resources than older women (72% vs 59%);
Only small numbers of women were offered other information resources. For example, only 4% of women were offered an audio tape of any of their consultations and 22% were offered written information about their own diagnoses.

Younger women were significantly more likely than older women to be offered written information about their own diagnosis (32% vs 19%; \( \chi^2=9.32, p<0.005 \)) and information about the Breast Cancer Support Service (65% vs 51%; \( \chi^2=7.17, p<0.01 \)). Private patients were significantly more likely than public patients to be offered written information about their own diagnosis (27% vs 15%; \( \chi^2=11.18, p<0.001 \)).

Most women surveyed received enough information about: treatment choices (80%), surgery in general (79%), side effects of different treatments (72%), prognosis (82%) and follow-up care (77%).

Older women were significantly more likely than younger women to report having received enough information about surgery (82% vs 68%; \( \chi^2=14.7, p<0.001 \)). Similarly, women without tertiary education were significantly more likely to report having received enough information about surgery than women with tertiary education (81% vs 70%; \( \chi^2=8.8, p<0.01 \)). Older women were significantly more likely to report having received enough information than younger women about follow-up (79% vs 69%; \( \chi^2=8.7, p<0.01 \)). There was a trend towards women without tertiary education being more likely to report having received enough information about follow-up care than women with tertiary education (79% vs 68%; \( \chi^2=6.4, p=0.01 \)). Older women were significantly more likely to report having received enough information than younger women about prognosis (85% vs 75%; \( \chi^2=10.3, p<0.001 \)) and women without tertiary level of education were significantly more likely to report having received enough information about prognosis than women with tertiary education (85% vs 74%; \( \chi^2=6.85, p<0.01 \)).

Of the 293 women who had radiotherapy, 82% reported receiving enough information about radiotherapy in general. Of the 424 women who had additional treatments (chemotherapy, tamoxifen, ovarian treatment), 74% reported receiving enough information about these additional treatments.
B.9 While information about the disease and its treatment is critical, women also need information about the psychosocial impact of breast cancer and the material and practical resources required to adjust to and cope with the disease.

Women were asked a series of questions about information in relation to supportive care as follows: Considering the amount of information you received about each one would you say that you: received as much information as you needed; would have liked more information; would have liked less information. They were asked this question in relation to: where to get support/counselling if you or your family needed it and the likely costs of treatment. Women were also asked whether their family had enough information about breast cancer and issues related to having a family member with breast cancer by choosing between three options: they had access to as much information as they needed; they may have liked more information; they may have liked less information. (Tables B.9.1, B.9.2)

Of all women surveyed, 69% reported receiving enough information about where to get support or counselling and 59% received enough information about treatment costs; 22% and 24% respectively wanted more information.

Sixty-eight per cent of women reported being given enough information about how to prevent or minimise lymphoedema, 24% would have liked more information, 4% could not say, and 4% reported that it was not applicable.

Seventy-three per cent of women reported that their family had access to as much information as they needed, 17% said they may have liked more information and 10% could not say. When asked about being offered information for their families, few women reported being offered resources specifically for their partners (29% of the 389 women who were married or living with a partner) or for their children (11% of the 472 women who had children).

B.10 Appropriate counselling has the potential to improve quality of life

Women were asked five questions about support and counselling as follows: We are interested in finding out how satisfied you were with the level of support you received during the diagnosis and treatment periods. By support, we mean someone to talk with about the problems or difficulties you were experiencing or about personal
issues such as emotional or relationship difficulties, how you and your family were coping and so on. First, women were asked: In general do you feel you have received enough support during the diagnosis and treatment of your breast cancer? In general, do you feel your family received enough support during the diagnosis and treatment of your breast cancer? Which of the following groups or people did you use for support during the period since you were diagnosed with breast cancer? Women were also asked a similarly phrased question about the groups or people their family used for support. The response options for both questions included a list of 13 possible sources of support. Women were asked: How do you feel about the level of support you received from the people who were treating you, such as the specialist doctors and nurses? The following responses options were used: you were given as much support as you needed at the time, you felt you needed a little more support than you received, you felt that you needed much more support than you received. Women were also asked: How do you feel about the level of support your family received from the people who were treating you such as the specialist doctors and nurses? Response options were similar to those listed above. (Tables B.10.1; B.10.2; B.10.3; B.10.4; B.10.5)

Eighty-three per cent of women felt that in general they received enough support, and 16% felt they did not receive enough support. Two per cent of women could not say. Sixty-five per cent of women reported that their families received enough support, 22% felt their family did not receive enough support, and 13% could not say.

The most commonly reported source of support for women was their surgeon (58%), followed by their general practitioner (53%), some other group or person (53%), their oncologist (37%) and the Breast Cancer Support Service (36%).

The most commonly reported source of support for families was the surgeon (34%), some other group or person (34%), the general practitioner (20%) and the oncologist (17%).

Eighty-two per cent of women felt that the level of support they received was as much as they needed, 11% said they needed a little more support than they received and a further 7% reported they needed much more support.

Sixty-five per cent of women felt that the level of support their family received was as much as they needed, 14% said they needed a little more support than they received and a further 9% reported their families needed much more support. Thirteen per cent of women responded that they couldn’t say if their family received enough support.5

Younger women were significantly more likely than older women to say that they needed a little or a lot more support for their families than they received (34% vs 20%, \( \chi^2 = 7.39, p<0.01 \)).

5 Total does not equal 100% due to rounding
**B.11 Doctors should encourage women with breast cancer to consider participating in appropriate clinical trials for which they are eligible**

Women were asked: *Clinical trials are large research projects to find better treatments for breast cancer. For example comparisons may be made about the effectiveness of different types or doses of drugs in treating breast cancer. Did anyone from your treating team talk to you about clinical trials?* The following response options were used: yes I was told about them but told that I was not eligible; yes I was told about them and told that I could go in one; no I was not told about them. Women were asked: *Did you participate in a clinical trial when you were receiving your treatment?* If yes, women were asked: *What was your main reason for participating in a clinical trial?* If no, women were asked: *What was your main reason for not participating in a clinical trial?* (Table B.11.1)

In total, 13% of women were told about clinical trials with 11% told they were eligible and 2% that they were ineligible. Six per cent of the total sample reported participating in a clinical trial.

Of those women who did participate in a clinical trial, 70% stated their main reason for participation was because they knew it would be helping women in the future, 20% thought they would end up having better treatment, and 3% reported participating because of clinicians’ recommendations. The remaining 7% gave other responses.

Of those women who reported being told about clinical trials but not participating, 13% were not eligible, 16% did not want to be a guinea pig, 7% wanted to know exactly which treatment they were going to get, 3% lived too far from the research centre, and 3% reported that it would not help them get better treatment. The remaining 58% gave other responses.

Women living in urban areas were significantly more likely to be informed about clinical trials than women living in rural areas (17% vs 8%, $\chi^2=8.56$, $p<0.01$) and younger women were significantly more likely than older women to be informed about clinical trials (24% vs 10%; $\chi^2=15.26$, $p<0.001$).
B.12 Women should be given the opportunity to consider breast reconstruction, so they can balance the advantages and disadvantages of reconstruction after mastectomy

Breast reconstruction

Women who had had a mastectomy were asked: Considering the amount of information you received about breast reconstruction would you say you received as much information as you needed, would have liked more information, would have liked less information. Women were also asked: Please tell me whether you have had breast reconstruction or are you considering having it done. If they had not had breast reconstruction, they were asked: What was your main reason for not having a breast reconstruction. (Tables B.12.1, B.12.2)

Of the women who had a mastectomy (N=204), 78% did not have a reconstruction, 8% had had a reconstruction, a further 10% indicated that they were considering having breast reconstruction and 5% could not say or gave another response. Younger women were significantly more likely to have had a breast reconstruction than older women (20% vs 4%, $\chi^2=15.9$, p<0.001).

Forty-nine per cent of women who had a mastectomy reported receiving enough information about breast reconstruction; 21% of women said they would have liked more information, 29% said this information was not applicable to them and 2% could not say. Among the women who had had a mastectomy, older women were significantly more likely than younger women to have received as much information as they needed about breast reconstruction (77% vs 51%, $\chi^2=8.66$, p<0.01).

Among those women who had a mastectomy but did not have reconstruction (n=188), 50% thought it was unnecessary, 27% did not want to have more surgery, 5% were concerned about complications or side effects, 5% were unaware of breast reconstruction as an option, 4% were concerned about the costs, while 9% gave an ‘other’ response.

Breast prostheses

Women who had had a mastectomy but not a reconstruction were asked: Considering the amount of information you received about breast prostheses, would you say you received as much information as you needed, would have liked more information, would have liked less information. Women were also asked: Did you get an external breast prosthesis? I don’t mean the temporary bra insert you received when you left the hospital. Women who did not obtain an external prosthesis were also asked: Why did you decide not to have an external breast prosthesis? Women
were asked if they agreed or disagreed with the following statements: you felt that you had enough information about breast prostheses; you were aware that there were different types of prostheses available, including different colours, shapes and fillings; you had a range of prostheses that you were able to choose from; you were able to get access to a prosthesis fitter; you had to travel a long way from where you live to get a prosthesis. Women who had a prosthesis were also asked: Did you receive any financial help to buy the breast prosthesis? If so, they were asked: Who provided funds to buy the breast prosthesis? (Tables B.12.3, B.12.4)

Responses were analysed from the sub-sample of 188 women who had had a mastectomy (N=204) and who did not have a breast reconstruction (N=16).

Seventy-nine per cent of the sub-sample reported that overall, they received as much information as they needed about breast prostheses; 87% of the sub-sample obtained an external breast prosthesis.

Thirteen per cent of the sub-sample did not use a breast prosthesis; the most common reasons for deciding not to get a prosthesis were not feeling the need to have one (n=14) and being unable to find one with which they felt comfortable (n=2).

When asked if they agreed or disagreed with a range of statements, 71% of the sub-sample felt they had enough information about breast prostheses; 63% of women reported that they were aware that there were different types of prostheses available; 59% had a range of prostheses to choose from; 96% were able to get access to a prosthesis fitter; and 15% agreed that they had to travel a long way from where they lived to get a prosthesis.

Women from urban areas were significantly more likely to be aware that different types of prostheses were available than rural women (73% vs 53%, $\chi^2=7.10, p<0.01$) and to have a range of prostheses to choose from (72% vs 43%, $\chi^2=14.10, p<0.001$).

Of the 188 women who had a mastectomy but who did not have a breast reconstruction, 164 women had an external prosthesis. Eighty one per cent of these 164 women reported that they received financial assistance to help buy the prosthesis. The women who received financial assistance did so from: public hospitals (43%); private health insurance (26%); Medicare (16%); private hospitals (1%); or another source (14%). Sixty four per cent of these women said that the amount they received was adequate to get the prosthesis they thought was best suited to them, 30% said the prosthesis they wanted cost more, and 6% could not say.
**B.13 Clinicians should provide women with a follow-up plan**

Women were asked: *At the end of your treatment, were you given a follow up plan? This may have included a schedule of how often you need to come back to see the surgeon or other people involved in your treatment.* If they reported receiving a follow plan they were asked: *Was the follow up plan written, verbal, both written and verbal.* (Tables B.13.1, B.13.2)

Seventy-nine per cent of women reported that they were given a follow up plan, 16% were not, 3% could not say and 2% said they had not yet completed their treatment.

Of the women who did receive a plan, 319 women (or 59% of the total sample) were given a verbal follow up plan, 29 women (or 5% of the total sample) received a written follow up plan, and 79 women (or 15% of the total sample) received both a written and verbal plan.

Public patients were significantly more likely than private patients to receive a written follow-up plan, either alone or in combination with a verbal plan (32% vs 21%, $\chi^2=6.87$, p<0.01).

**Comment: Was care in accord with the guidelines?**

Overall, most women reported that their care was in accord with the twelve aspects of the *NHMRC Clinical practice guidelines for the management of early breast cancer* explored in the survey.

For example: most women were told their diagnosis by a senior doctor or their general practitioner (95%); most women (90%) felt that the style used to tell them their diagnosis was honest, open and frank; most women (81%) reported receiving the right amount of information about different aspects of treatment; and most women (83%) felt that they had received enough support. Likewise, most women (86%) were told their diagnosis face-to-face and were satisfied with the way in which they were told their diagnosis (97%). Of the 13% of women who were told their diagnosis over the telephone, most (76%) felt this was appropriate. While it is often argued that the telephone is used in rural areas to prevent the need for women to travel to receive their diagnosis, there was no evidence from the survey that telling women by telephone was more common in rural than urban areas.

Few of the demographic comparisons were significant, indicating that, by and large, the psychosocial care provided for women does not differ on the basis of their age, health insurance status or their residence in rural or urban areas.
Recommendations where care could be improved

However, the survey did identify several areas where care could be improved:

Clinical trial participation

First, the guidelines recommend that doctors should encourage women with breast cancer to consider participating in clinical trials for which they are eligible. However, only 13% of women reported being informed about clinical trials and only 6% reported taking part in a trial. This is consistent with the findings from the Surgical management of breast cancer survey where 5% of women with early breast cancer were reported by their surgeons to be taking part in clinical trials, despite their estimate that at least half the women taking part in the survey would have been eligible for inclusion in a clinical trial.2

The reasons for the low rates of participation are not clear. It appears that, if women are invited to participate in a clinical trial, 50% will agree; this suggests that reluctance among women is not a major barrier to participation in clinical trials. It has been proposed that many Australian clinicians do not feel fully informed about clinical trials and/or lack the infrastructure support such as data managers to take part in such trials.16 Support for this hypothesis comes from the Surgical management of breast cancer survey finding that larger surgical caseloads are associated with increased rates of clinical trial participation2 and from the results of the present study that younger women and those living in urban areas were more likely to be provided with information about clinical trials.

Information and treatment decisions

Second, the guidelines recommend that women be given adequate information to assist them in contributing to decisions about their treatment. At the time of this survey, the best available information was contained in the two editions of the consumer guides about early breast cancer (Early Breast Cancer: A Consumer's Guide17 and All About Early Breast Cancer18) since they represent evidence based information in line with the clinical guidelines.

However, only 61% of women reported being offered one of the consumer guides. Younger women are significantly more likely to receive such guides than older women, and tertiary educated women were more likely than those with less education. Clinicians may differentially offer the resources based on their perceptions of the woman's information needs. While these were relatively new resources at the time of the survey, it is clear that strategies are needed to ensure that all women are offered a copy of these guides.
Likewise, although there is level II evidence that an audiotape of the consultation can improve outcomes, only 4% of women reported receiving this type of information. Twenty-two percent of women received written information about their own diagnosis and this was more likely among younger and privately insured women. Similarly, while most women (79%) reported that they were given a follow-up plan, only 21% received this in writing and this was more likely in the public sector. The value of written and alternate sources of information should be recognised in clinical practice and the development of an easy to complete form, perhaps for inclusion in the consumer guides, may assist in providing the written advice that women will find most useful.

**Psychosocial support**

Third, although 83% of women felt that they had received enough support, there were some areas in which psychosocial support could be improved. In particular, many women felt that they had not received enough information about the psychosocial impact of breast cancer including support or counselling (31%) and treatment costs (41%). In addition, 22% of women reported that their families needed better support; the need for improved support was particularly highlighted by younger women. The *Psychosocial Clinical Practice Guidelines: information, support and counselling for women with breast cancer* note that diagnosis and recurrence of breast cancer impacts negatively on marital and other relationships. These guidelines suggest that families may benefit from information about support services and groups that can provide practical assistance, support and counselling.

**Diagnosis**

Fourth, the guidelines recommend that women should be encouraged to have a second person present when being given a diagnosis. Fifty-nine per cent of women told their diagnosis face-to-face were given the opportunity to have someone present with them at the time of the diagnosis. Of those women who were not given the opportunity, 30% (or 11% of the total sample) would have liked to have someone with them.

There are many reasons why it may not be possible to have someone present at diagnosis: some women may not have a close relative or friend to accompany them, and there may be a need to balance giving information as soon as possible against waiting until someone is available. Nonetheless, it may be relatively easy to address the needs of the 11% of women who would have liked someone with them by providing better advice about when key information will be given. It may be, for example, that general practitioners could consider reminding women that the clinician would prefer that they took someone with them even though their diagnosis may not be
breast cancer. Similarly, women might be advised to take someone with them to BreastScreen Assessment Clinics.

**Breast reconstruction**

Finally, care in relation to breast reconstruction could be improved. Twenty-one per cent of women who had had a mastectomy felt that they had not received enough information about breast reconstruction and young women were more likely to feel that information was inadequate.

Only 8% of women had had a reconstruction and younger women were more likely to have had this surgery despite research findings that body image and sexuality are equally as important for older and younger women. This rate is considerably lower than those in some comparable countries. For example, up to 40% of women who have a mastectomy in Sweden have breast reconstruction. The low rate of reconstruction in this survey might be due in part to proximity to surgery, as some women may begin to consider reconstruction years after initial treatment. Costs associated with reconstruction in Australia may also be a prohibitive factor.

**Recommendations where better understanding of women’s needs are required**

The results of the survey have contributed to an increased understanding of women’s needs in several areas and therefore of how best to form guideline recommendations.

**Involvement in treatment decisions**

First, the guidelines recommend that women are entitled to make their own decisions about treatments or procedures.

Most women (73%) reported that they were as involved as they wanted to be in their treatment decision; only 4% would have liked greater involvement. Overall this reflects a very high degree of patient involvement in decisions about their care in comparison to previously reported Australian and international data. Of the 73% of women who reported being as involved as they wanted to be in the decision making process, 82% reported that they made the decision jointly with their doctor or on their own. Most women wanted a collaborative approach; clinicians should be aware of the desire among most women to be involved in their treatment decisions.

6 Kerstin Sandelin, specialist surgeon, personal communication
However, 22% of women reported that they were told that there was only one appropriate treatment indicating that there was no choice. Interpretation of these findings are difficult; in fact, there are some situations in early breast cancer where mastectomy may be the only real option because, for example, breast conservation treatment would produce an unacceptable cosmetic result or there is evidence of more than one focus of cancer in the breast. There is a need for the guidelines and patient information materials to indicate that in some cases mastectomy may be the only appropriate approach.

However, in this survey, women who had had a mastectomy were not more likely to report being told that there was no treatment choice than women who had a lumpectomy (22% vs 21%, \( \chi^2 = 0.10, p=0.92 \)). This is surprising and suggests that non-clinical reasons are responsible for whether or not the woman feels involved in decision making. It seems most likely that the communication skills of the clinician may play a key role in presenting choice to women; there is evidence that communication skills training can improve skills among clinicians.

Making treatment decisions

Second, the guidelines recommend that women should be reassured that there is no reason that waiting a week or two to decide about treatment will make any difference to the outcomes of treatment. About half of the sample (56%) reported having time to think about treatment options, and these women were largely satisfied with this approach. However, 41% felt they were told that they should decide about their treatment options immediately; most of these women (75%) also felt that they had sufficient time.

There is a need for greater understanding of women's responses at this time; some women may feel that a quick decision and treatment constitutes best care and is most likely to prevent any further spread of the cancer. However, unnecessary rush to treatment may increase anxiety by generating a sense of urgency; it may also result in decisions about treatment which the woman later regrets. There may be a need for clinicians to more clearly explain the value in delaying an immediate decision.

Counselling

Third, there is level I evidence that appropriate counselling has the potential to improve quality of life. Most women (83%) were satisfied with the level of support that they received. However, despite women's positive judgements about the support they received, it seems likely that there remain high levels of unmet need. For example, recent evidence suggests that up to 42% of women may be clinically depressed following a diagnosis of breast cancer. If these women were being detected and
referred, the rates of use of other support services such as psychologists and psychiatrists might be expected to be somewhat higher than was reported here. There is a need for further research but it seems likely that in commenting that they were satisfied with the support received from their treatment team, women were making a judgement about appropriate care from the team treating their breast cancer. There remains a need to more carefully explore the services available to those women who experience psychiatric illness following the diagnosis of their breast cancer.

C SPECIAL ISSUES

C.1 Perceptions of overall care

The House of Representatives Standing Committee on Community Affairs Report on the management and treatment of breast cancer in Australia included submissions from women with breast cancer. Many of these submissions described care which would be categorised as unacceptable by many clinicians and by the community. However, it is difficult to gauge the extent to which unacceptable care is widespread or occurs as isolated instances. It was therefore of interest to explore the extent to which women are satisfied overall with their care and to explore whether some groups of women are less satisfied than others.

There may be other factors which are linked to satisfaction with care. For example, research suggests that women who feel better informed and more involved in decision making about their care will be more satisfied. The survey presented the opportunity to explore these associations within a population based sample.

Women were asked: In general, would you say the overall standard of your care was highly satisfactory, somewhat satisfactory, neither satisfactory nor unsatisfactory, somewhat unsatisfactory, or highly unsatisfactory. Women were also asked: What kind of services do you think would have made it easier for you and your family during and/or after your treatment? (Tables C.1.1, C.1.2)

Eighty-two per cent of women rated the overall standard of their care as highly satisfactory, 10% rated their care as somewhat satisfactory, 1% rated their care as neither satisfactory nor unsatisfactory, 2% reported somewhat unsatisfactory care, 3% reported highly unsatisfactory care, and 2% could not say. There were no demographic differences between those who found their care highly or somewhat satisfactory and the others.

Sixty per cent of women reported that they did not need any additional services during or after treatment. However, 15% would have liked more emotional support or counselling for themselves
and 9% for their partner or children. Eleven per cent would have liked more practical support with house and family. Younger women were significantly more likely than older women to report needing additional services (50% vs 29%, $\chi^2=11.67, p<0.001$).

Women who were highly satisfied with their overall care were also significantly more likely to be satisfied with their involvement in treatment decisions ($\chi^2=27.86, p<0.001$) and whether they thought their family was encouraged to take part in decisions ($\chi^2=62.93, p<0.001$).

The level of satisfaction with overall care was also significantly related to which State women lived in, with 90% of Victorian women saying that they were highly satisfied with their care compared to 79% of women from other States ($\chi^2=8.11, p<0.01$).

**Comment**

Overall, most women were satisfied with the care that they received. There was no evidence that care was poorer among groups of women based on their age, place of residence or insurance status.

Nonetheless, 8% were not satisfied with their care and a further 10% did not feel that their care was fully satisfactory. It may be that qualitative studies of women who report dissatisfaction with their care may be very helpful in establishing the basis of this dissatisfaction and in determining strategies for the future. Women who are not satisfied with their care can make substantial contributions to determining community perceptions of the management of women with breast cancer. In turn, this may discourage women with symptoms from seeking treatment and create an environment which is not conducive to establishing trust between women and their doctors. Exploring the reasons for dissatisfaction among this subset of women is therefore of considerable importance.

In responding to questions about satisfaction with care, women are commenting without full knowledge of what might be possible – that is, to say that one is satisfied with the care that one received often means no major problems were apparent that could readily have been resolved. It is therefore significant that 40% of women felt that they needed additional services at some point – these responses likely represent unmet needs and when considered in conjunction with other data reported in this report suggest that psychosocial care can still be improved for women with breast cancer. This survey is consistent with recent work that demonstrates a positive relationship between overall satisfaction with care and achieving the desired level of involvement in decision making. It suggests the need for clinicians to take extra care in ensuring that women feel fully informed about and able to participate in decisions about their care.
C.2 The experience of treatment side effects

There have been relatively few population based studies of treatment side effects. The majority of information about treatment side effects comes from clinical trials of treatment efficacy – these studies describe side effects among often highly selected groups of women attending treatment centres and participating in clinical trials under controlled conditions. They may not reflect the occurrence of side effects among all women receiving the treatment in routine practice.

Data about the occurrence of treatment side effects will help inform women about their likely experiences.

Surgery

Women were asked: Thinking about the side effects that you might have experienced with different types of treatments that you had, I would appreciate it if you could tell me what side effects or complications, if any, you experienced or were told you had, after your surgery. (Tables C.2.1, C.2.2, C.2.3)

Sixty-seven per cent of women reported experiencing one or more side effects following surgery. The most commonly reported side effects were numbness in the armpit (33%) and pain in the upper arm (20%).

Thirty-eight per cent of women reported that they did or still do suffer from swelling of the arm on the side of their breast surgery. Women who underwent radiotherapy as part of their treatment were significantly more likely to experience swelling in the arm (44% vs 31%; $\chi^2=9.81, p<0.01$).

Radiotherapy

Women were asked: Could you please tell me what complications you had, if any, following radiotherapy? Could you tell me whether you experienced any significant complications after radiotherapy that delayed your return to normal activity? (Table C.2.4, C.2.5)

Fifty-two per cent of women who had radiotherapy reported experiencing significant complications that delayed their return to normal activity. Skin problems (34% of those receiving radiotherapy) and tiredness (32% of those receiving radiotherapy) were the most commonly reported side effects which delayed return to normal activity.
Chemotherapy

Women were asked: Could you please tell me what complications you had, if any, as a result of chemotherapy. Could you tell me whether or not you experienced any significant complications that delayed your return to normal activity? (Table C.2.6, C.2.7)

Sixty-four per cent of women who had chemotherapy reported experiencing significant complications that delayed their return to normal activity. The most commonly reported side effects which delayed return to normal activity were fatigue (43% of those receiving chemotherapy), nausea (42% of those receiving chemotherapy) and hair loss (34% of those receiving chemotherapy).

Comment

The survey provides the first contemporary Australian data documenting rates of side effects in a representative sample of women.

Overall, many women reported side effects of each aspect of treatment. While many of these may be transitory, women should be informed about the possibility of developing these side effects prior to treatment. Information should indicate that between one third and a half of all women will report numbness in the armpit following surgery, skin problems and tiredness after radiotherapy, and fatigue, nausea and hair loss following chemotherapy. For about half of the women receiving radiotherapy and over 60% of those receiving chemotherapy, the side effects will be sufficiently debilitating to delay their return to normal activity.

There is considerable concern amongst women about lymphoedema and relatively little information in Australia about the prevalence or impact on daily living of this condition. In this survey, it was not possible to undertake a detailed examination of rates of the prevalence of lymphoedema, partly because a valid and reliable self report measure does not exist. Further, many women will experience swelling of the arm following surgery which is not necessarily lymphoedema and the most common time for lymphoedema to occur appears to be around three years after surgery; the present survey interviewed women only 6-12 months after treatment.

Bearing in mind these reservations, 38% of women in the present survey reported that they had experienced or still do suffer from swelling of the arm. It is likely that most women received axillary dissection and in this survey women were more likely to experience swelling if they also received radiotherapy. The findings are therefore consistent with the established association between axillary dissection with radiotherapy and lymphoedema.
The findings are also consistent with preliminary findings from another recent Australian study which explored reported prevalence of arm swelling; in this study of a population sample of 805 women, 40% reported at least one symptom associated with arm swelling.

These findings highlight the importance of additional research about arm morbidity in women following treatment for breast cancer.

C.3 Early discharge following breast surgery

There is an increasing move towards discharging women from hospital within 48 hours of their surgery. The consequences of early discharge for the woman are not well understood.

Women were asked: How long did you stay in hospital after your surgery? Were you discharged from hospital with a drain still in place? By drain, I mean a tube which drains fluid from the wound. (Table C.3.1, Figure C.3.1)

Women reported staying in hospital between 0 and 25 days with an average length of stay in hospital of 5.75 days (SD=3.450) and a median length of 5 days, as shown in Figure 3. The median length of stay for women discharged without a drain was 6 days, compared with 3 days for women discharged with a drain.

Seventeen per cent of women were discharged from hospital within 48 hours (SD=0.62). Women who were discharged within 48 hours were more likely to have had a lumpectomy than a mastectomy compared to women who stayed in hospital for more than two days (92% vs. 56%, \( \chi^2=40.21, p<0.001 \)) and were more likely to be discharged with a drain still in place (53% vs. 24%, \( \chi^2=32.01, p<0.001 \)).

Younger women were significantly more likely than older women to be discharged with a drain still in place following their surgery (39% vs 25%; \( \chi^2=9.55, p<0.005 \)) as were employed women compared to women who didn’t work outside of the home (37% vs 23%, \( \chi^2=11.19, p<0.001 \)) and women who were married or living in a de facto relationship compared with others (32% vs 20%, \( \chi^2=8.00, p<0.005 \)).

Women who were discharged from hospital with a drain still in place reported similar levels of satisfaction with care as other women (94% vs 95%; \( \chi^2=0.17, p=0.68 \)). Women who were discharged within 2 days of surgery reported similar levels of satisfaction with care as other women (91% vs. 93%, \( \chi^2=0.27, p=0.60 \)).
Comment

There is a trend in Australia to offer women the option of early discharge following surgery for breast cancer; women who are discharged early will go home when their wound still requires some care and in many cases with the axillary drain still in place. This is standard practice in the US and there appears to be some randomised trial evidence that early discharge is not associated with more adverse physiological or psychological outcomes.31,32

Early discharge appears to be relatively common in Australia. Fifty-three per cent of women were discharged within 5 days of surgery and 17% within 48 hours.

Early discharge appears to be an acceptable approach to women, since those who were discharged early were no less likely to be satisfied with their care than those who stayed longer in hospital.

It appears that early discharge is based to some extent on the likelihood of women coping at home. For example, women with less severe surgery, younger women and those who were married or in de facto relationships were more likely to be discharged early.33

Figure 3 Number of days spent in hospital following surgery

![Bar chart showing number of days spent in hospital following surgery](chart.png)
C.4 Breast Cancer Support Services

Each State and Territory cancer organisation operates a Breast Cancer Support Service (BCSS) which provides practical and emotional support to women with breast cancer on a one to one basis by women who have had breast cancer themselves. There is some evidence (level III) that volunteer led groups can improve adjustment.34-36 While there is no evidence about the impact of the BCSS on quality of life or other outcomes, many women anecdotally report the Service to be helpful.

Women who used the BCSS

Women were asked: Did you use the Breast Cancer Support Service (BCSS) for support during the period since you were diagnosed with breast cancer? Women who had used the BCSS were asked the following questions: Could you please tell me how you first heard about this service? When did you have a visit or phone call from a Breast Cancer Support Service volunteer? What was the most beneficial part of the Breast Cancer Support Service for you? To what extent would you recommend the Breast Cancer Support Service to other women diagnosed with breast cancer? (Table C.4.1)

Thirty-six per cent of women indicated that they had used the Service for support. None of the demographic comparisons between women who used the Service and those who did not were significant although the number of women who reported using the BCSS for support varied widely across States: New South Wales/Australian Capital Territory (39%); Victoria (21%); Queensland (51%); South Australia (28%); Western Australia (58%) and Northern Territory (83%).

The women who used the BCSS were most likely to hear about it from hospital staff (36%) or a clinician (16%). Most women were visited after surgery (82%); however, some women reported being visited by a volunteer before surgery (21%) or at diagnosis (6%).

The women who used the BCSS reported the most beneficial aspects to be: talking to women with similar experiences (53%); emotional support (15%); practical advice (12%); and information (10%). Eight per cent of women who used the BCSS reported that it was not beneficial, and 2% were unsure.

Of those women who used the service, 85% reported they would definitely recommend the BCSS to other women diagnosed with breast cancer, 10% would probably recommend it, 3% would probably not recommend it, 1% would definitely not recommend it, while 2% could not say.7

7 Total does not equal 100% due to rounding
**Women who did not use the BCSS**

Women who did not use the BCSS were asked: *Earlier you said that you had not used the Breast Cancer Support Service. Just briefly, the service offers practical and emotional support on a one-to-one basis, using volunteers who have previously had breast cancer. What was your main reason for not using this service?*

The majority of women (64%) did not use the BCSS for support. The main reasons given for not using the Service were: they had enough support from family/friends (43%); they did not know about the BCSS (23%); and they did not think it would be useful (20%).

**Comment**

In this survey, only about one third of women reported using the BCSS for support. It is possible that the BCSS volunteers contacted other women who did not choose to use this service.

Most women who did use the BCSS for support reported that they were very satisfied and commented on the value of the opportunity to talk to another woman who had been through the same experience.

Most women who did not use the Service did not think they needed it or did not think it would be useful (63% of non-users). However, 23% (15% of the total sample) were unaware of the existence of the Service. Therefore, while it appears that the BCSS is a useful part of the supportive care network for some women, there may be a need to improve information to ensure that all women know about the availability of volunteers.

It is of interest that there were considerable variations between States and Territories in the proportion of women accessing the BCSS. It may be of value to explore the approaches used in States such as the Northern Territory, Western Australia and Queensland in ensuring women know about and have access to the volunteers.

Nonetheless, the findings illustrate the need to provide diverse opportunities for support in the recognition that different approaches will be most appropriate for different women.
C.5 Specialist breast nurses

Specialist breast nurses can improve psychological well being among women with breast cancer. There is evidence from randomised trials and systematic reviews that specialist breast nurses: reduce psychological morbidity; increase understanding of breast cancer, recall of information and perceptions of support for women with breast cancer; improve recognition of social support needs; and provide continuity of care. In these trials, women received a systematic program of care including repeated contact with the breast nurse during the course of treatment and diagnosis.

Women were asked: "Now I am going to ask you a question about the breast care nurse. A breast care nurse is a nurse who specialises in breast cancer and gives information and support to women throughout diagnosis, treatment and follow-up. Were you seen by the breast care nurse on any of the following occasions? Were you seen by the breast care nurse at the time of diagnosis; before surgery; immediately after surgery; within 2 months of surgery; approximately 2 to 4 months following surgery; or at some other time?" (Tables C.5.1, C.5.2; Figure C.5.1)

Forty-eight per cent of women reported seeing a breast care nurse at some stage, 25% on more than one occasion, and 14% of women saw a breast nurse three or more times.

The women who were seen by a breast care nurse were most commonly seen before surgery (22%), immediately after surgery (30%) and within 2 months of surgery (22%); fewer women were seen at diagnosis (14%), 2 to 4 months post surgery (12%) and other times (4%).

There were no significant demographic differences between women who saw a breast nurse at all compared with those who never saw one.

Further analyses compared women who had seen a breast nurse on three or more occasions (n=58) with those who had not seen a breast nurse at all (n=244). Responses are shown in Figure 4.

Women who saw a breast nurse on three or more occasions were more likely than those who did not see a breast nurse at all to: have sufficient information about side effects (81% vs 66%, \( \chi^2=4.7, p=0.03 \)); have been given verbal information about clinical trials (24% vs 9%, \( \chi^2=8.7, p<0.01 \)); and report being given as much support as needed, both for the woman herself (93% vs 76%, \( \chi^2=8.5, p<0.01 \)) and her family (85% vs 61%, \( \chi^2=11.4, p<0.01 \)). There was a trend for women who saw a breast nurse on three or more occasions to be more likely to have sufficient information about follow-up care than those who did not see a breast nurse (86% vs 73%, \( \chi^2=4.5, p=0.04 \)).
Figure 4  Comparison of responses of women who did not see a breast nurse and those who saw a breast nurse on three or more occasions

Comment

Despite level I and II evidence of benefit, in Australia there is no coordinated approach to the provision of specialist breast nurse services. Some breast nurses provide mainly clinical care while others are volunteers who have had breast cancer themselves. In the specialist breast nurse model developed in the United Kingdom and which formed the basis of the randomised trials, the nurse provides primarily information and supportive care and sees the woman on repeated occasions from diagnosis through treatment and follow-up.

Although 57% of women reported seeing a breast nurse at some stage, only 14% reported seeing such a nurse on three or more occasions. The 14% of women who saw a specialist breast nurse more often would be more likely to benefit from the continuity of breast nurse care in ways described in the randomised trials.

The survey provided some evidence that women receiving care from a specialist breast nurse received similar benefits to those reported from overseas trials. For example, women seeing a breast
nurse on three or more occasions were more likely to receive information about a range of issues and support for their families.

However, it is likely that women receiving care from a specialist breast nurse were treated at centres with an organised approach to breast cancer care and a moderate to large case load in breast cancer. The treatment of these women may be different to that of most women with early breast cancer in a number of ways other than access to a specialist breast nurse and this may account for the differences between the groups.

Nonetheless, a recent report from a demonstration project comparing the care provided to women before and after the introduction of a specialist breast nurse found similar benefits to those reported here. In addition, the specialist breast nurses were perceived positively by the treatment team and 98% of women in the demonstration project would recommend that their friends attended hospitals which had a breast nurse.

Taken together, the overseas trials, the Australian demonstration project and the results reported here, indicate that specialist breast nurses are of benefit to women with early breast cancer. The findings from the National survey of women illustrate the need to offer more women the opportunity of receiving care from a specialist breast nurse.

### C.6 Continuity of care

Women sometimes report that they experience their care as lacking in continuity. The *House of Representatives Standing Committee on Community Affairs Report on the management and treatment of breast cancer in Australia* commented that “there are indications that for many women the treatment process is fragmented and uncoordinated……” (pp. xviii).

Women were asked a range of questions about the continuity of their care. Women were asked to agree or disagree on a 4 point scale with the following seven statements about their continuity of care: 

- You felt that you understood who was in charge of your overall care and treatment; 
- You felt that you had to see too many people in the process of your treatment; 
- You would have liked to have one person identified as your main contact during your treatment; 
- You would have liked more access to your surgeon and treatment team; 
- You felt that the information given to your local GP from other members of your treatment team such as the surgeon, the radiation oncologist or the medical oncologist was not adequate for his/her needs; 
- You felt that the information given to your surgeon from other members of your treatment team such as the radiation oncologist or the medical oncologist was not adequate for his/her needs; 
- Once you had returned home after treatment you were not sure who you should contact when you had concerns related to treatment. (Table C.6.1)
Ninety-four per cent of the sample said they understood who was in charge of their care.

Nine per cent agreed that they had seen too many people. Public patients were significantly more likely than private patients to say that they had to see too many people in the course of their treatment (14% vs 6%; $\chi^2=11.93$, $p<0.001$).

Forty-two per cent of women agreed that they would have liked one main contact person. Public patients were more likely to say that they would have liked to have one person identified as their main contact during treatment (48% vs 38%; $\chi^2=5.93$, $p<0.01$).

Eighteen per cent of women agreed that they would have liked more access to their surgeon and treatment team.

One hundred and one women (19%) felt that they did not know whether the information provided to their general practitioner from other members of the treatment team was adequate. Of those women who could answer the question, 75% agreed that the information provided was adequate.

Ninety-two women (17%) felt that they did not know whether the information given to the surgeon from other members of the treatment team was adequate. Eighty-one per cent of women who could answer this question agreed that the information given to the surgeon was adequate.

Nineteen per cent of women surveyed felt that once they had returned home after treatment they were not sure whom they should contact.

**Comment**

Women expressed mixed views about whether they had received a coordinated approach to care. Most women reported being satisfied with their continuity of care, believing that they understood who was in charge of their care and that the information given to other members of their treatment team and their general practitioner was adequate.

However, 42% of women felt that they would have liked to have had one person identified as the main contact during treatment. This may reflect a different aspect of continuity of care; women may believe, for example, that the surgeon is overall in charge of their care but that it is inappropriate to contact him or her, particularly during the radiotherapy or systemic adjuvant phases of treatment. This may be where a specialist breast nurse can do much to improve the woman’s perception that her care is being provided by an accessible team.
It is of interest that public patients were more likely to feel that they had seen too many people in the course of their treatment and to want one person identified as their main contact during treatment. It may be that in the private sector the surgeon takes a greater responsibility for coordinating referrals to other treatment specialists. It may also be that women experience a team approach to management or a public clinic as less clearly identifying those responsible for her care.

### C.7 Travel and accommodation needs for rural women

The House of Representatives Standing Committee on Community Affairs Report on the management and treatment of breast cancer in Australia noted that women diagnosed with breast cancer living in rural and remote areas of Australia have special needs and may require special support when undergoing treatment for breast cancer. Women living in rural or remote areas experience considerable social and financial costs when travelling for adjuvant therapy. The Committee recommended that urgent priority be given to addressing the problems faced by women from rural and remote areas in accessing multidisciplinary teams, adjuvant therapy, clinical trials, counselling, support groups and information. It recommended that governments should standardise and broaden travel assistance schemes.

Women were asked: Could you please describe whether you live in a rural or remote area, a country town or country centre, or a major city? Women who described themselves as rural dwellers were asked: Do you believe that living outside a major city has limited your access to information or services? At the time you were being treated how far away did you live from where you had your surgery/chemotherapy/radiotherapy/other treatment? Where did you stay while away from home for treatment? Has travel and staying away from home disrupted your life? If women responded yes, they were also asked: Thinking about different aspects of your life that might have been disrupted because of travel and staying away from home, which, if any of the following would you say were moderately or highly disrupted because of travel and staying away from home? In total, how long were you away from home for your radiotherapy/chemotherapy?

Thirty-seven per cent of women (N=204) said they lived in a rural/remote area or a country town/country centre. These women were classified as rural dwellers.

Thirty per cent of rural women stated that living outside a major city had limited their access to information or services.

Forty-nine per cent of rural women had a mastectomy, compared with 32% of urban women ($\chi^2=14.36$, $p<0.001$). Thirty-two per cent of rural women had to travel 100kms or more for their surgery; 63% of the 95 rural women who had radiotherapy had to travel 100kms or more for
radiotherapy treatment and 36% of the 53 rural women who had chemotherapy had to travel 100kms or more for chemotherapy treatment.

Of the rural women who travelled for adjuvant therapy, 34% stayed with family/friends, 25% in cancer patient accommodation, 15% in hospital residential accommodation, 10% in a hotel/motel, 8% stayed in the hospital ward and 8% used other types of accommodation.

Fifty-eight per cent of women who stayed away from home for treatment said that travelling and staying away from home disrupted their lives. Sixty-one per cent of these women reported that family and/or children were disrupted, 46% said work was disrupted, 7% said caring for parents was disrupted and 38% said some other aspect of their life was disrupted.

Of the 21% who travelled for radiotherapy, the average number of days away from home was 42.98 days (SD=21.54); of the 12% who travelled for chemotherapy, the average number of days away from home was 19.95 (SD=26.53).

**Financial assistance**

Rural women who had to travel away from home for treatment were asked: *Did you receive any financial assistance to travel or stay away from home for treatment?* If they did receive assistance, they were also asked: *Did you have any difficulties organising or claiming this financial assistance?* Women were asked: *When thinking about practical assistance when organising travel and/or accommodation during your treatment, did you: need support and get it, need support but did not know where to get it, or you did not need support. It was specified that this practical assistance may have been given in the form of information, or someone may have organised transport and accommodation during treatment. (Tables C.7.1, C.7.2)*

Forty-five per cent of rural women stayed away from home at least one night for some type of treatment.

Of rural women who stayed away overnight for treatment, 44% received financial assistance, 18% believed they were not entitled to assistance, 24% were not aware they could get assistance, and 10% gave an ‘other’ response.8

Of the 44% of women who received financial assistance, 14% had difficulty organising or obtaining financial assistance.

8 Total does not equal 100% due to rounding
Of the women who travelled for adjuvant therapy, 79% reported they did not need practical assistance in organising travel and/or accommodation, 15% needed and received assistance and 6% needed assistance but did not know where to get it.

**Information**

Women were asked a series of questions about information in relation to supportive care as follows: *Considering the amount of information you received about each one would you say that you: received as much information as you needed; would have liked more information; would have liked less information.* They were asked this question in relation to: *emotional and practical support services near treatment centre for women staying away from home; financial support available for women travelling for treatment; where to get information about accommodation if staying away from home.*

Thirty-four per cent of rural women reported that they received enough information about practical and emotional support near treatment centres, 30% received enough information about financial support available for travelling for treatment; and 30% received enough information about where to get information about accommodation.

Eighteen per cent of all women surveyed reported that they had to travel a distance of over 100kms from home for their treatment (either surgery, radiotherapy, or adjuvant therapy). Of these women, 40% indicated that they would have liked more information about financial support available, 37% about the likely costs of treatment, and 32% about emotional and practical support services near treatment.

**Comment**

Previous studies have explored care for breast cancer and needs among women living in rural areas and these findings have been recently summarised. For example, among Australian women who travel for their treatment, few receive financial support and most identified special problems for rural women. Women in rural areas diagnosed with breast cancer may be more likely to have a mastectomy than those in urban areas; however, they otherwise receive similar care.

This survey confirmed and extended previous findings in several ways. First, it confirmed the special needs of rural women. One third of rural women felt that living outside a major city had limited their access to information or services. Sixty-three per cent of rural women had travelled more than 100 kilometres to receive radiotherapy and the average time away from home was 43 days. This represents a major social and economic cost.
Second, this survey found that women in rural areas are more likely to have mastectomy than those living in urban areas. This finding is in accord with some previous data, although conflicting reports exist. The main reason for rural women choosing mastectomy was that they believed this was the best type of surgery for the size and location of their cancer. It is of interest that women did not cite the need to travel for radiotherapy as the major reason for deciding against breast conserving therapy.

Third, the support received by rural women appears to remain limited. Less than half of the women who had to travel for treatment received financial assistance and some of the women who did receive help had difficulty in accessing support. Of those women who did not receive financial assistance, one quarter were unaware that assistance was available. When these difficulties are considered in the light of the complex schemes operating in different States, the need to improve support for rural women in travelling for treatment becomes very evident. However, it is of interest, that 25% of women who travelled for treatment reported receiving accommodation in specially designated cancer patient services – these are run by cancer organisations and/or hospitals and are clearly an important component of support for rural women.

Finally, despite women’s concerns, there was little evidence that women in rural areas received poorer care than those in urban areas in relation to the twelve aspects of the guidelines examined in this survey. The only issue where there was a difference between rural and urban women was in whether clinical trials was discussed – this is most likely to be associated with the size of the treatment centre where women were managed rather than a simple urban rural difference. It is of interest that women who lived in rural areas were not more likely than urban women to be told their diagnosis over the telephone.
REFERENCES


